



**Report on selected questions from  
the NHS England Accessible  
Information Surveys: May 2014**

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# **Report on selected questions from the NHS England Accessible Information Surveys:**

**May 2014**

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## 1 Summary

This report contains the results of selected questions from the NHS England Accessible Information Surveys, which closed in February 2014, plus 'free text' responses.

There were three surveys – one for patients, one for health and care staff, and one for support organisations / patient groups.

In total there were 1,144 surveys completed – 675 people completed the patient survey, 299 completed the health and care staff survey, and 173 completed the support organisations survey. The surveys could be completed and submitted in a variety of different ways; online, posted, or emailed. There was also an "Easy Read" version of the surveys which could be emailed or posted. A breakdown showing the method of collection for all the surveys completed is shown in Table 1.

**Table 1: Method of collection for each survey**

Method of collection	Patient Survey	Health and care staff survey	Support Organisations survey
Online	478	292	164
Posted	6	3	3
Posted (Easy Read)	161	0	0
Emailed	29	4	6
Emailed (Easy Read)	1	0	0
<b>Grand Total</b>	<b>675</b>	<b>299</b>	<b>173</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

The charts and tables within this report contain the results of all surveys completed, including online, posted, emailed, and those in "Easy Read" format.

### Note on 'free text responses'

Note that appendices contain 'free text' responses. In the interest of transparency, the free text responses are published verbatim and do not therefore represent the view of NHS England. Responses are unedited except:

- where information identifies, or may identify, an individual or organisation;
- references to brand, company, trade or product names;
- details of websites / blogs;
- text copied from other documents in full;
- language or opinion which may cause offence; and
- comments which are irrelevant to accessibility in health and social care.

Wherever text has been removed for one or more of these reasons, this is indicated by way of square brackets [...] Obvious spelling errors have also been corrected for ease of reading. In the interests of document length, in longer responses, text which

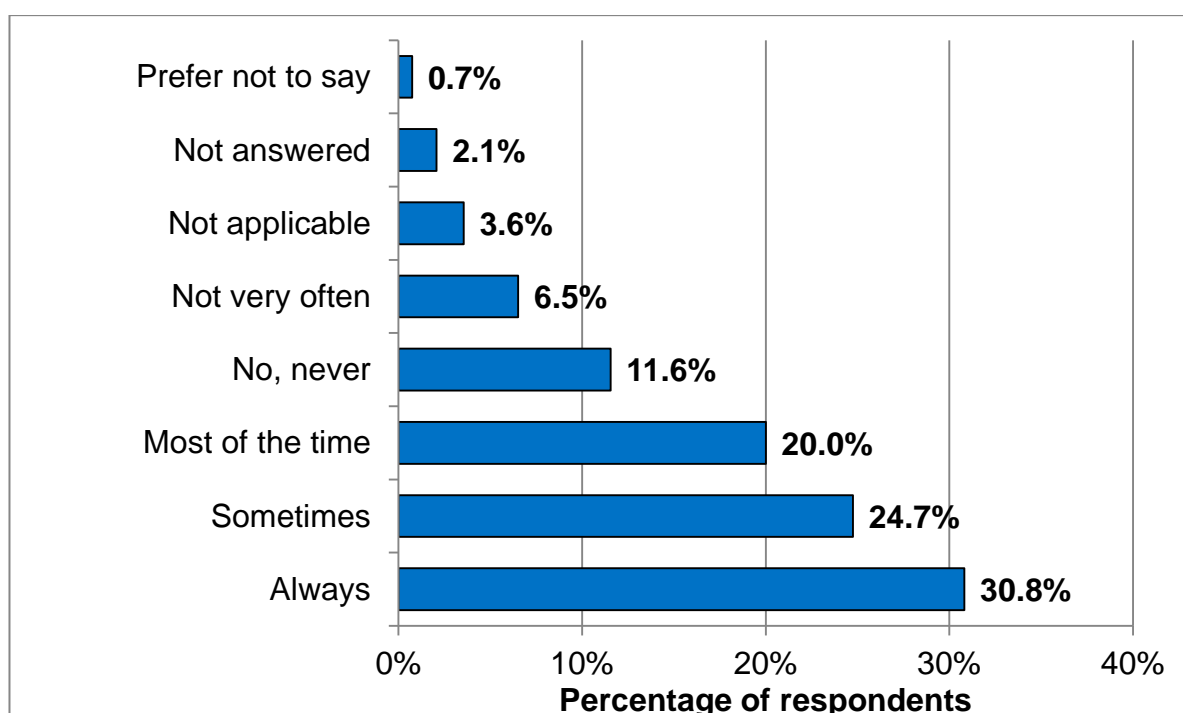
has been separated by spaces is listed as part of a paragraph, with appropriate punctuation.

## 2 Patients, carers and service users survey

### 2.1 Part 1 – Your experiences

#### 2.1.1 Question 1

**Figure 1: Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said? For example, if you are deaf, blind, have some hearing or visual loss or have a learning disability**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 2: Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said? For example, if you are deaf, blind, have some hearing or visual loss or have a learning disability**

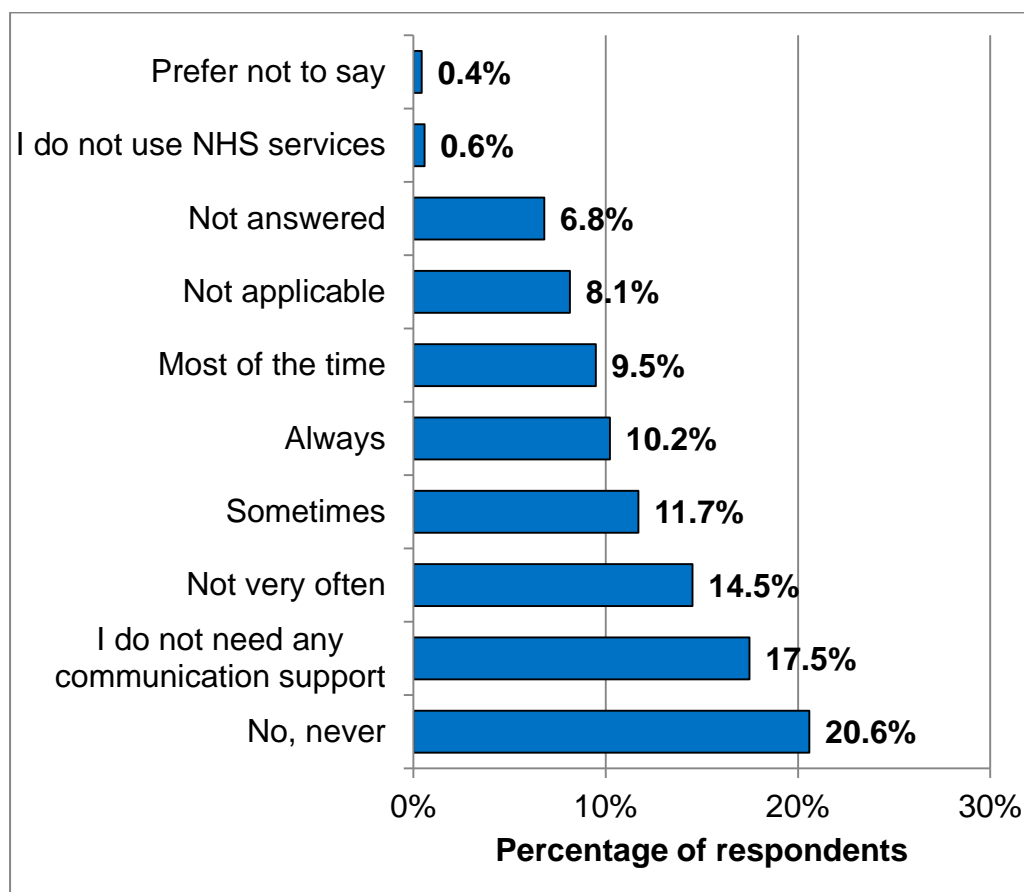
Response	Total	Percentage of respondents
Always	208	30.8%
Sometimes	167	24.7%
Most of the time	135	20.0%
No, never	78	11.6%
Not very often	44	6.5%
Not applicable	24	3.6%
Not answered	14	2.1%
Prefer not to say	5	0.7%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

The highest proportion of respondents (30.8%) stated they always find it difficult or need support to see, hear, speak, read, or understand what is being said. 24.7% stated they sometimes find it difficult or need support to see, hear, speak, read, or understand what is being said.

### 2.1.2 Question 2

**Figure 2: Do you usually get the communication support you need when you use NHS services? For example, if you need a British Sign Language interpreter or communication support at your appointment**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 3: Do you usually get the communication support you need when you use NHS services? For example, if you need a British Sign Language interpreter or communication support at your appointment**

Response	Total	Percentage of respondents
No, never	139	20.6%
I do not need any communication support	118	17.5%
Not very often	98	14.5%
Sometimes	79	11.7%
Always	69	10.2%
Most of the time	64	9.5%
Not applicable	55	8.1%
Not answered	46	6.8%

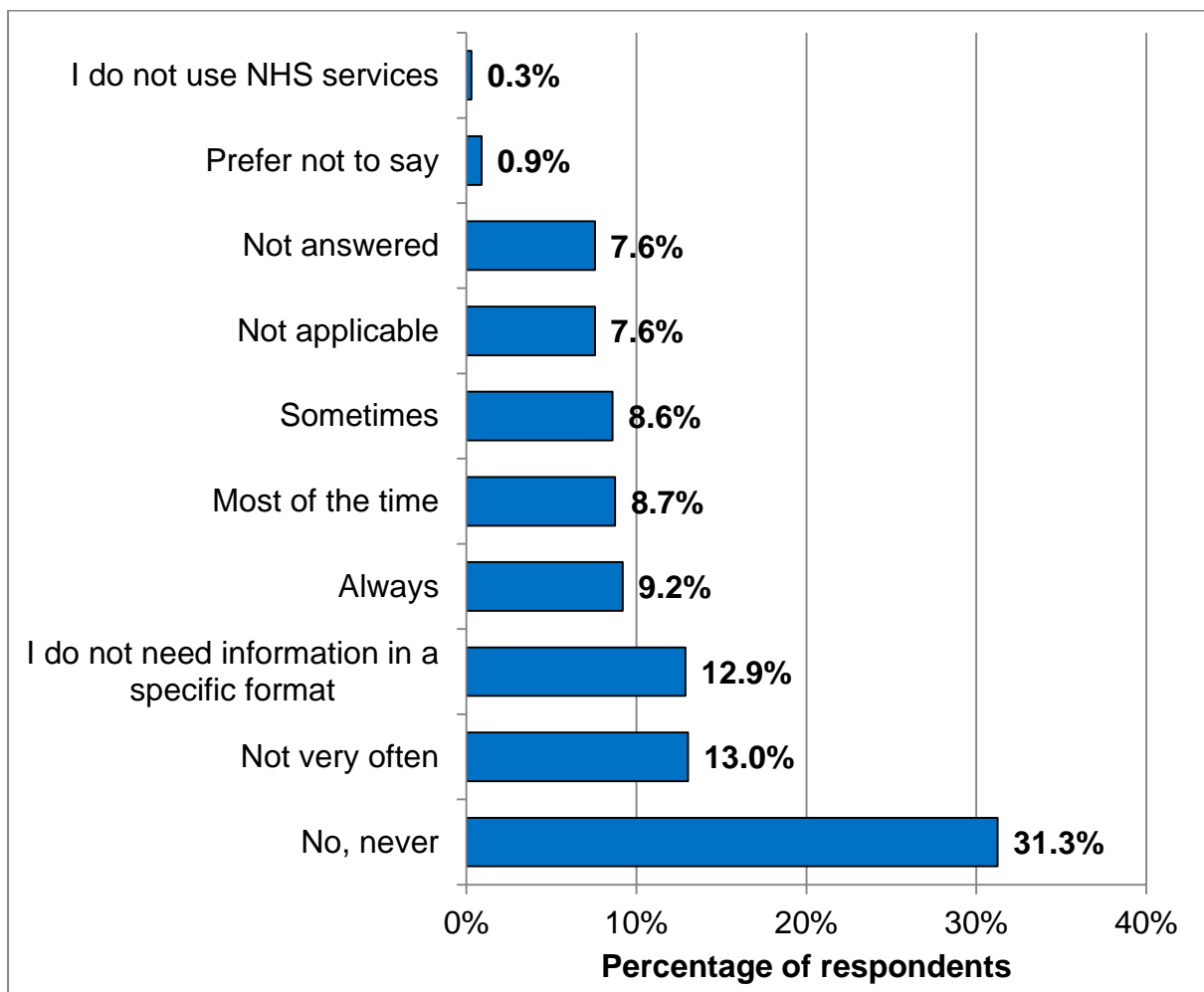
I do not use NHS services	4	0.6%
Prefer not to say	3	0.4%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

The highest proportion of respondents (20.6%) stated they never get the communication support they need when they use NHS services, whereas 10.2% of respondents stated they always got the communication support they needed when they use NHS services.

### 2.1.3 Question 3

**Figure 3: Do you usually get information in a format you can understand when you use NHS services? For example, information in Easy Read, Braille or audio**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 4: Do you usually get information in a format you can understand when you use NHS services? For example, information in Easy Read, Braille or audio**

Response	Total	Percentage of respondents
No, never	211	31.3%

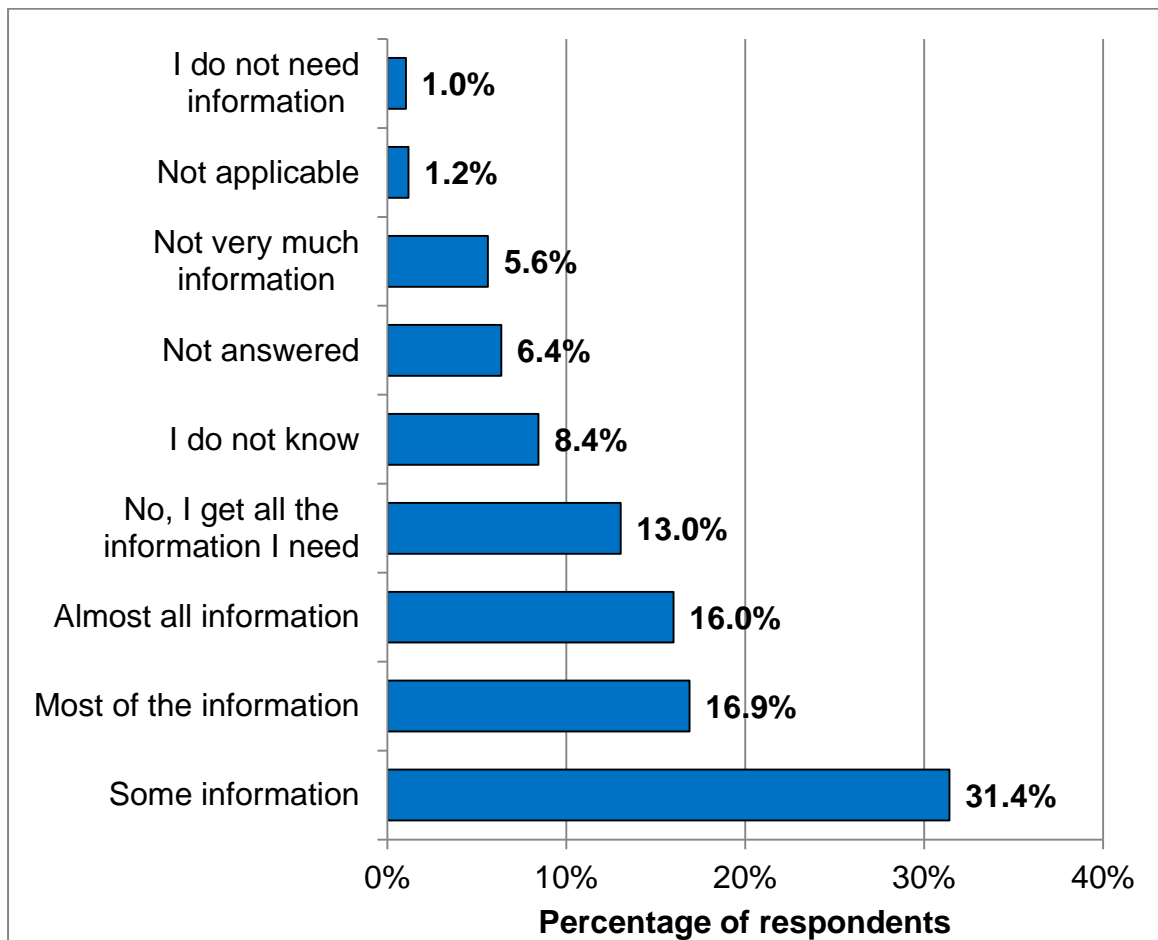
Not very often	88	13.0%
I do not need information in a specific format	87	12.9%
Always	62	9.2%
Most of the time	59	8.7%
Sometimes	58	8.6%
Not applicable	51	7.6%
Not answered	51	7.6%
Prefer not to say	6	0.9%
I do not use NHS services	2	0.3%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

31.3% of respondents stated they never get information in a format they can understand when they use NHS services, whereas 9.2% of respondents stated they always got information in a format they could understand when they use NHS services.

#### 2.1.4 Question 4

**Figure 4: Do you think there is any information you are missing out on when you use NHS services?**



Source: Accessible Information Survey Consultation, NHS England, 2014



**Table 5: Do you think there is any information you are missing out on when you use NHS services?**

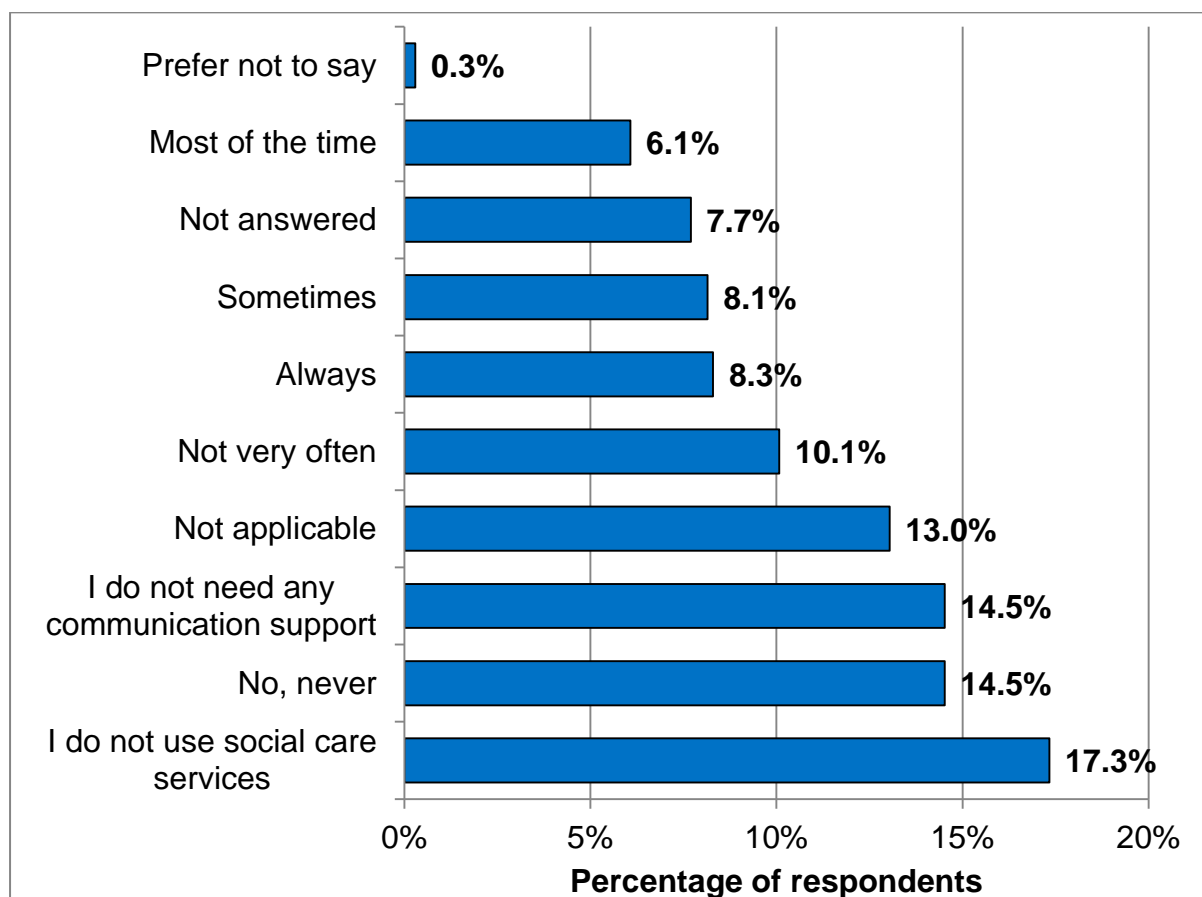
Response	Total	Percentage of respondents
Some information	212	31.4%
Most of the information	114	16.9%
Almost all information	108	16.0%
No, I get all the information I need	88	13.0%
I do not know	57	8.4%
Not answered	43	6.4%
Not very much information	38	5.6%
Not applicable	8	1.2%
I do not need information	7	1.0%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

31.4% of respondents stated they are missing out on some information when they use NHS services, whilst 16.9% of respondents stated they are missing out on most of the information when they use NHS services.

### 2.1.5 Question 5

**Figure 5: Do you usually get the communication support you need when you use social care services? For example, if you need a British Sign Language interpreter or a communication support worker at your appointment**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 6: Do you usually get the communication support you need when you use social care services? For example, if you need a British Sign Language interpreter or a communication support worker at your appointment**

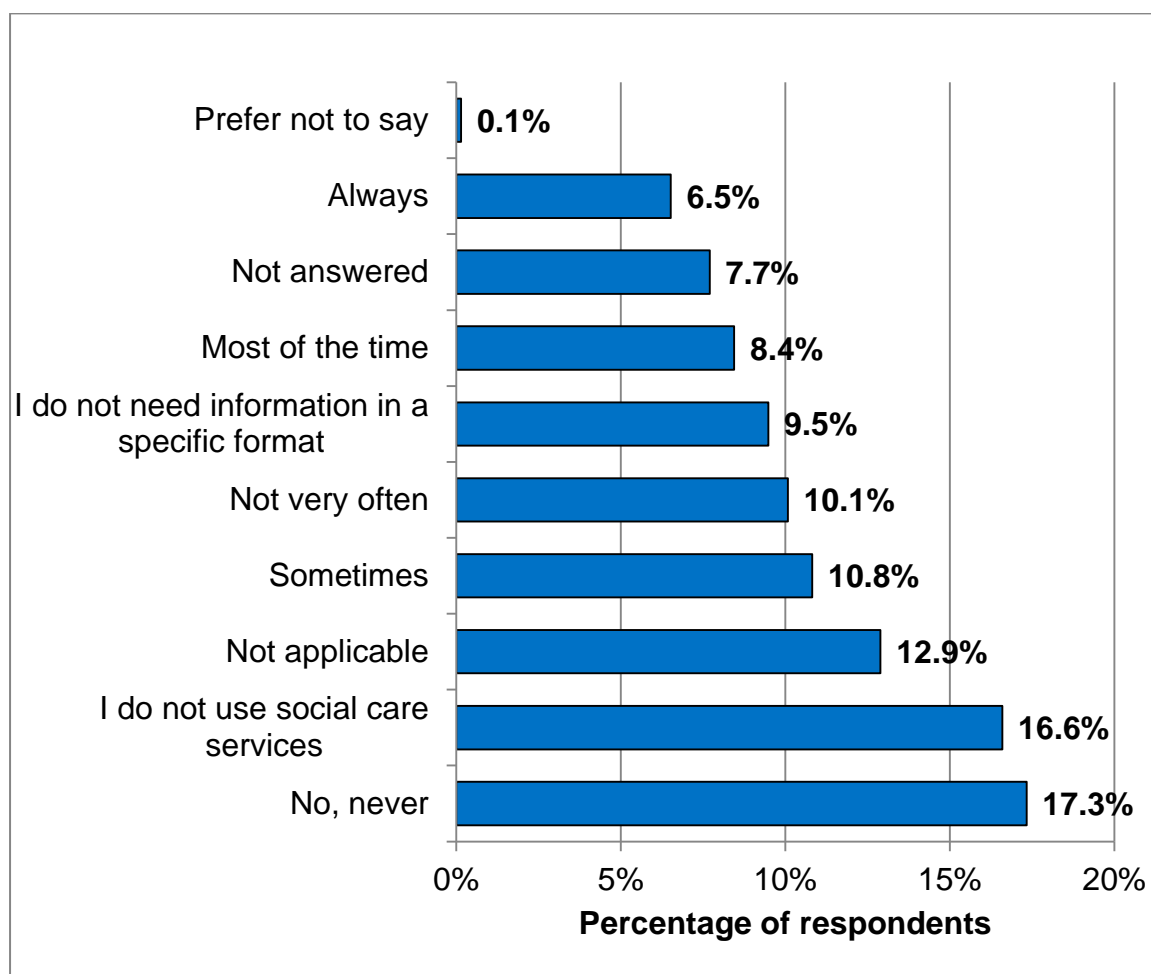
<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
I do not use social care services	117	17.3%
No, never	98	14.5%
I do not need any communication support	98	14.5%
Not applicable	88	13.0%
Not very often	68	10.1%
Always	56	8.3%
Sometimes	55	8.1%
Not answered	52	7.7%
Most of the time	41	6.1%
Prefer not to say	2	0.3%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

14.5% of respondents stated they never get the communication support they needed when using social care services, whereas 8.3% stated that they always got the communication support they needed.

## 2.1.6 Question 6

**Figure 6: Do you usually get information in a format you can understand when you use social care services? For example, information in Easy Read, Braille or audio**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 7: Do you usually get information in a format you can understand when you use social care services? For example, information in Easy Read, Braille or audio**

Response	Total	Percentage of respondents
No, never	117	17.3%
I do not use social care services	112	16.6%
Not applicable	87	12.9%
Sometimes	73	10.8%
Not very often	68	10.1%
I do not need information in a specific format	64	9.5%
Most of the time	57	8.4%
Not answered	52	7.7%
Always	44	6.5%

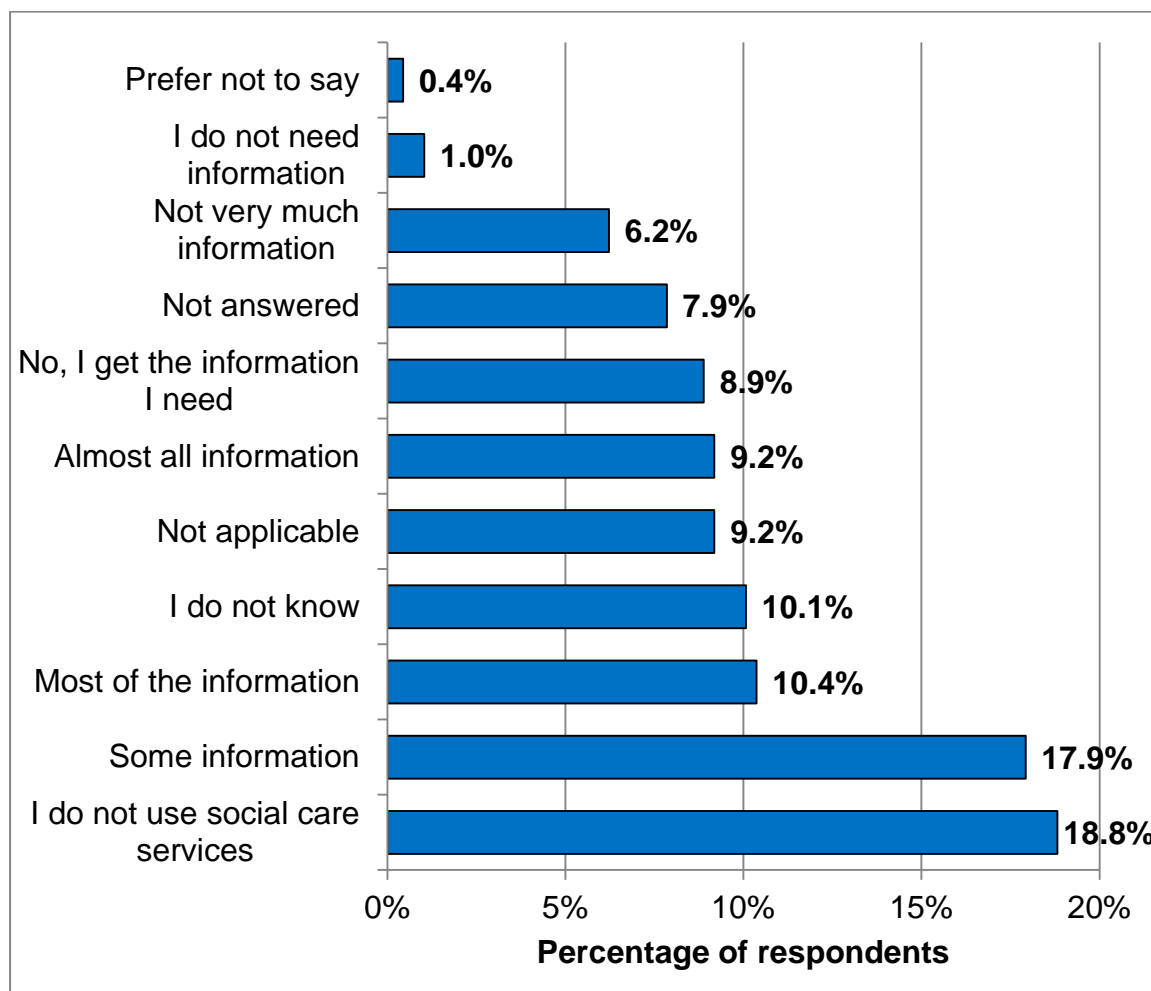
Prefer not to say	1	0.1%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

17.3% of respondents stated they never get the information in a format they can understand when using social care services, and 6.5% stated they always get the information in a format they can understand when using social care services.

## 2.1.7 Question 7

**Figure 7: Do you think there is any information you are missing out on when you use social care services?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 8: Do you think there is any information you are missing out on when you use social care services?**

Response	Total	Percentage of respondents
I do not use social care services	127	18.8%
Some information	121	17.9%
Most of the information	70	10.4%
I do not know	68	10.1%
Not applicable	62	9.2%
Almost all information	62	9.2%
No, I get the information I need	60	8.9%
Not answered	53	7.9%
Not very much information	42	6.2%
I do not need information	7	1.0%
Prefer not to say	3	0.4%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

28.3% of respondents stated they thought they were missing out on some or most of the information when using social care services, whereas 6.2% stated they thought they were not missing out on very much information when they use social care services.

#### **2.1.8 Question 8**

Please see Appendix 1 for the free text responses to this question.

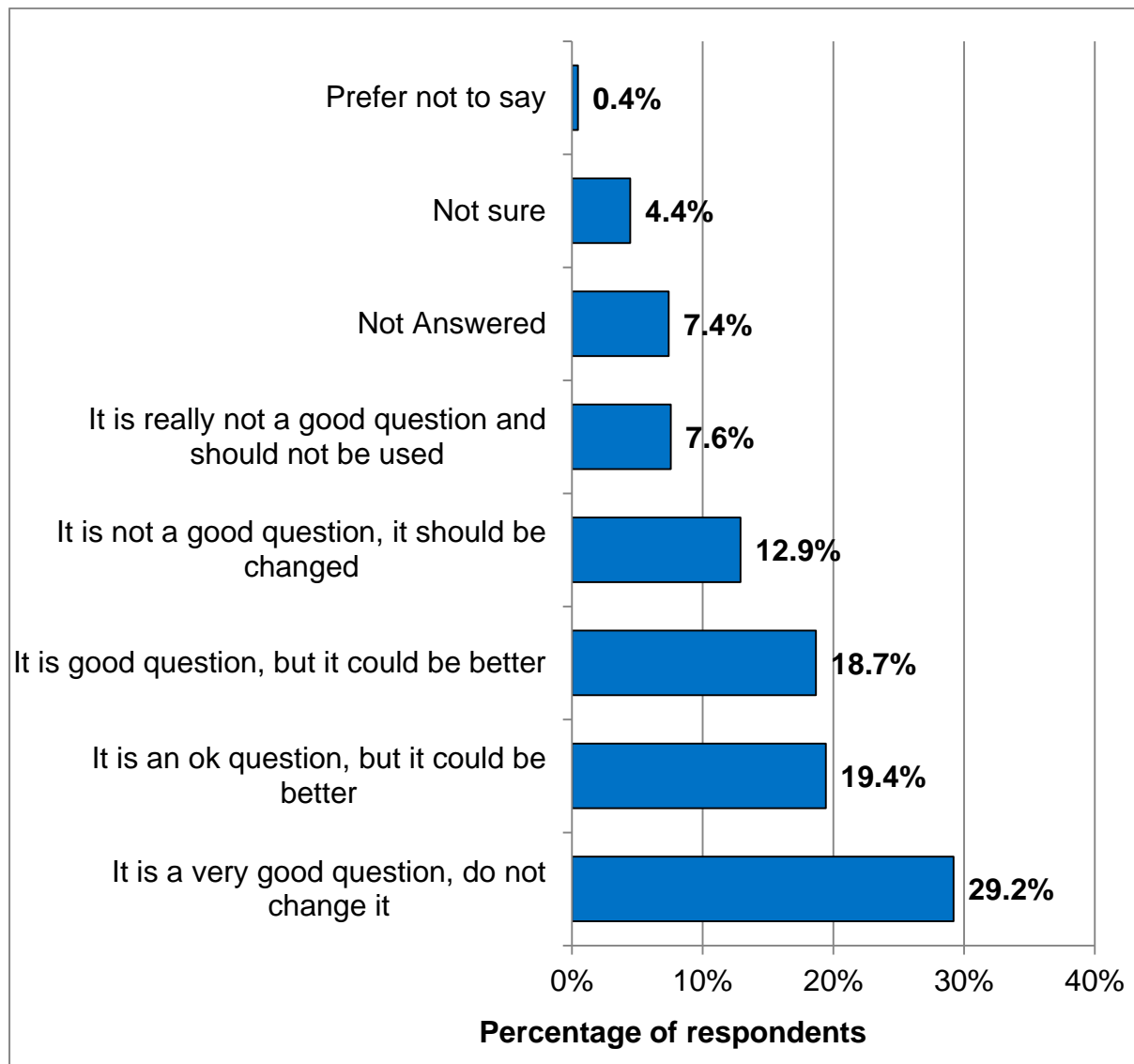
#### **2.1.9 Question 9**

Please see Appendix 2 for the free text responses to this question.

## 2.2 Part 2 – Getting the right information and the right communication support

### 2.2.1 Question 10

**Figure 8: We think that your doctor, care worker or a receptionist at a hospital should ask everyone if they need any support. We want to write a question for them to ask, so that everyone is asked the same. What do you think about the following question: “Do you find it difficult or do you need support to see, to hear, to speak, to read or understand what is being said?”**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 9: We think that your doctor, care worker or a receptionist at a hospital should ask everyone if they need any support. We want to write a question for them to ask, so that everyone is asked the same. What do you think about the following question: “Do you find it difficult or do you need support to see, to hear, to speak, to read or understand what is being said?”**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
It is a very good question, do not change it	197	29.2%
It is an ok question, but it could be better	131	19.4%
It is good question, but it could be better	126	18.7%
It is not a good question, it should be changed	87	12.9%
It is really not a good question and should not be used	51	7.6%
Not answered	50	7.4%
Not sure	30	4.4%
Prefer not to say	3	0.4%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

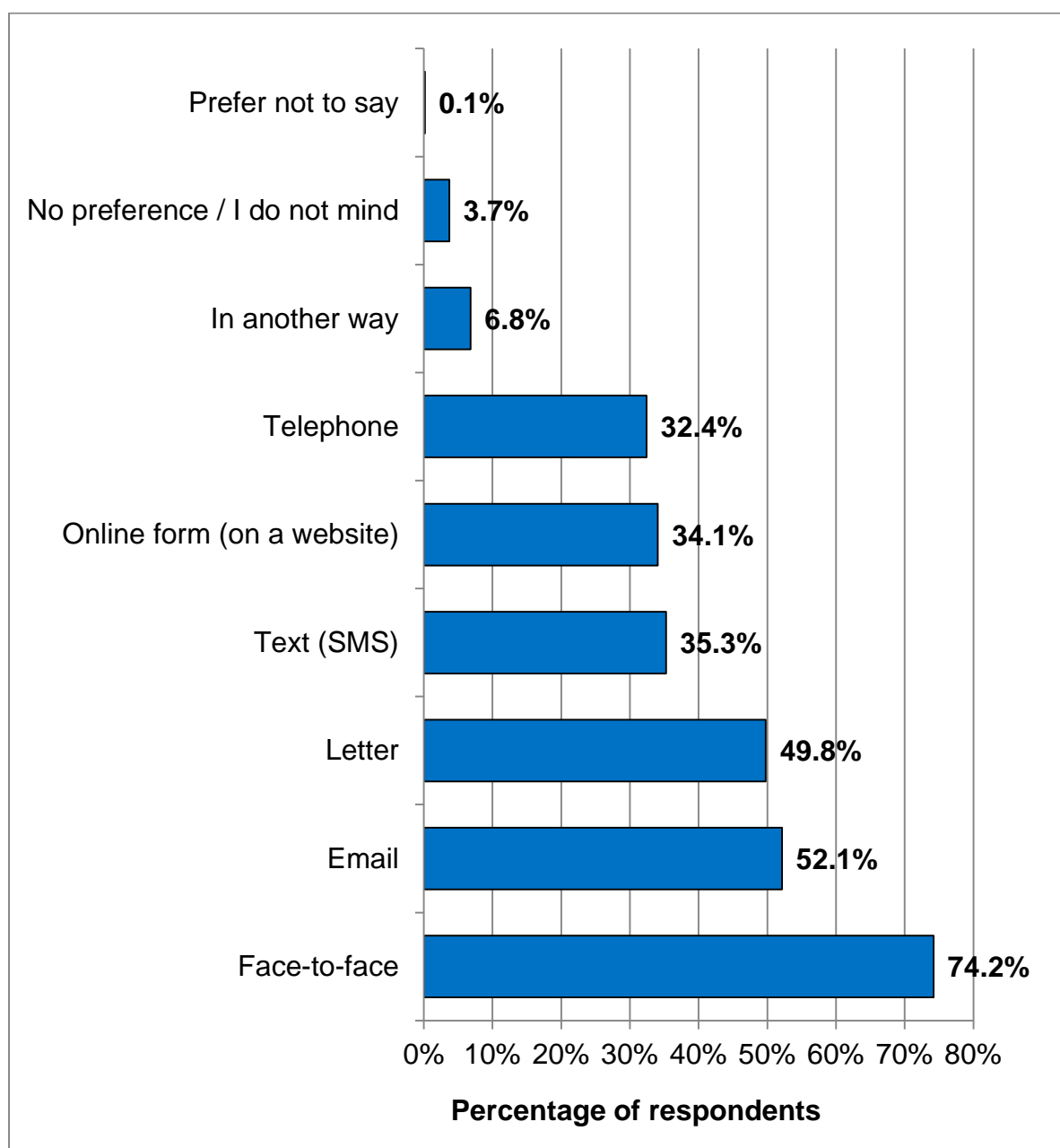
Source: Accessible Information Survey Consultation, NHS England, 2014

Please see Appendix 3 for explanations on the reason given for these answers.



## 2.2.2 Question 11

**Figure 9: How do you think we should ask people about their information and communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 10: How do you think we should ask people about their information and communication support needs?**

Response	Total	Percentage of respondents
Face-to-face	501	74.2%
Email	352	52.1%
Letter	336	49.8%
Text (SMS)	238	35.3%
Online form (on a website)	230	34.1%

Telephone	219	32.4%
In another way	46	6.8%
No preference / I do not mind	25	3.7%
Prefer not to say	1	0.1%
<b>Total respondents</b>	<b>675</b>	

Source: Accessible Information Survey Consultation, NHS England, 2014

Please note that due to an error in the online survey, some respondents were unable to select more than one answer to this question, and so some wrote their additional answers in the “in another way please tell us” option. These answers have been included in the chart and table above in the appropriate category. In addition, please note that as respondents were asked to select all the answers that applied, the analysis is a reflection of the percentage of respondents selecting each communication method, and therefore the percentages do not add up to 100%. Please see Table 11 for a summary of the main suggestions and Appendix 4 for all the free text answers in response to the option “in another way, please tell us”.

**Table 11: How do you think we should ask people about their information and communication support needs? In another way, please tell us. This is a summary of the main suggestions**

<b>Response</b>
Audio
Braille
BSL video on website
Deafblind manual interpreter
Easy read / text supported by pictures
Email
Fax
Hospital passport
Large print
Lip-reading
Minicom / Text Relay / Typetalk
Moon
Social media
Telephone
Video
Video call
Webcam

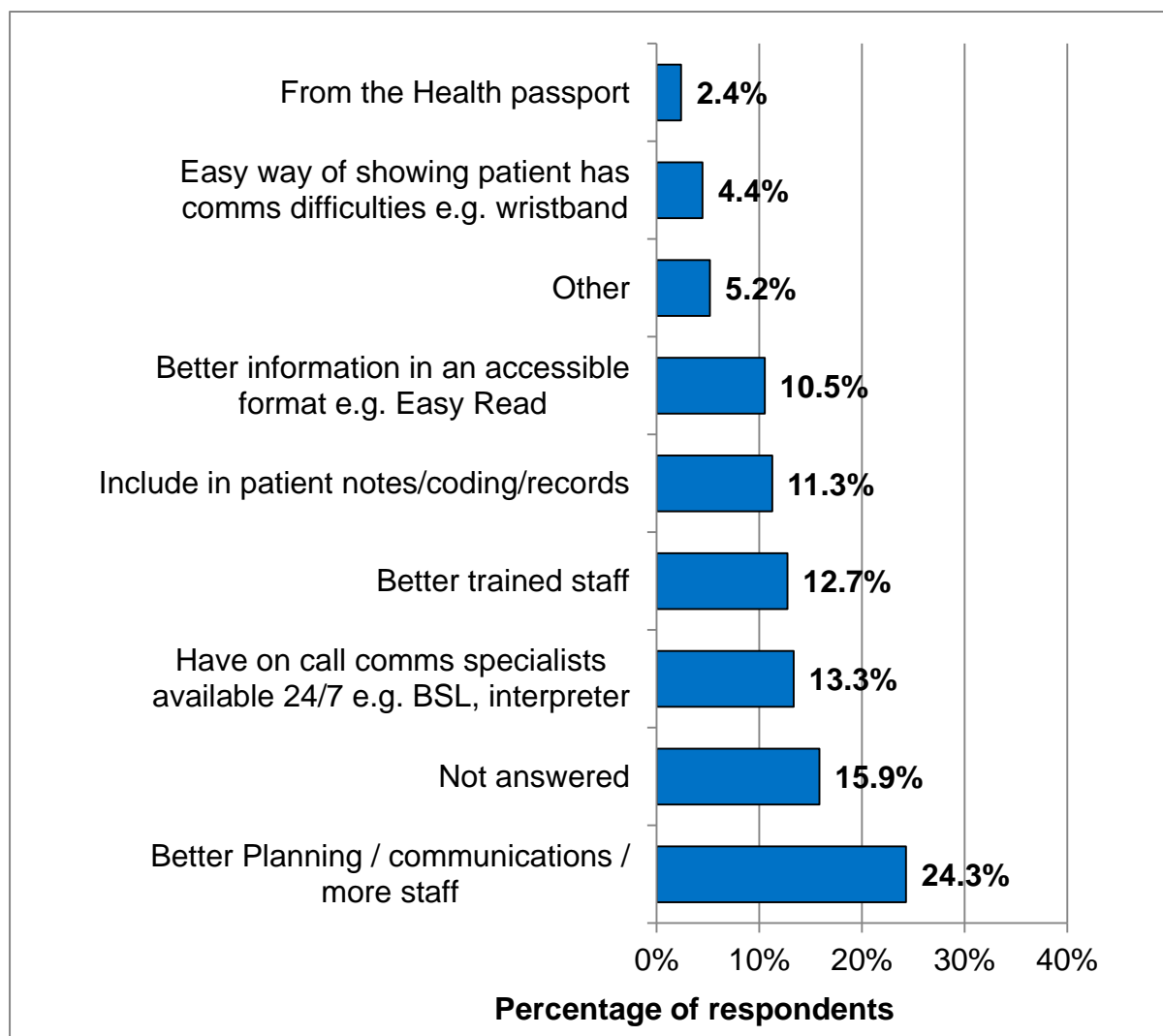
Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.2.3 Question 12

It can take time for organisations to get information in different formats or to find communication support workers. Sometimes things can be planned in advance, for example if you have an appointment in a few days’ time or if you live in a care home and always use the same support. Sometimes, you need treatment or support in an emergency and there is no warning, or it might be late at night.

The answers to this question were “free text”, and have been analysed and disseminated into nine broad categories, shown in Figure 10 and Table 12.

**Figure 10: What should organisations do to make sure that you can get communication support and information in the right format quickly?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 12: What should organisations do to make sure that you can get communication support and information in the right format quickly?**

Response	Total	Percentage of respondents
Better planning / communications / more staff	164	24.3%
Not answered	107	15.9%
Have on call communications specialists available 24/7 e.g. BSL interpreter	90	13.3%

Better trained staff	86	12.7%
Include in patient notes / coding / records	76	11.3%
Better information in an accessible format e.g. easy read	71	10.5%
Other	35	5.2%
Easy way of showing patient has communication difficulties e.g. wristband / sticker on file	30	4.4%
From the Health Passport	16	2.4%
<b>Total respondents</b>	<b>675</b>	<b>100%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

Please see Appendix 5 for all the “free text” answers to this question.

#### **2.2.4 Question 13**

Please see Appendix 6 for the “free text” answers to this question.

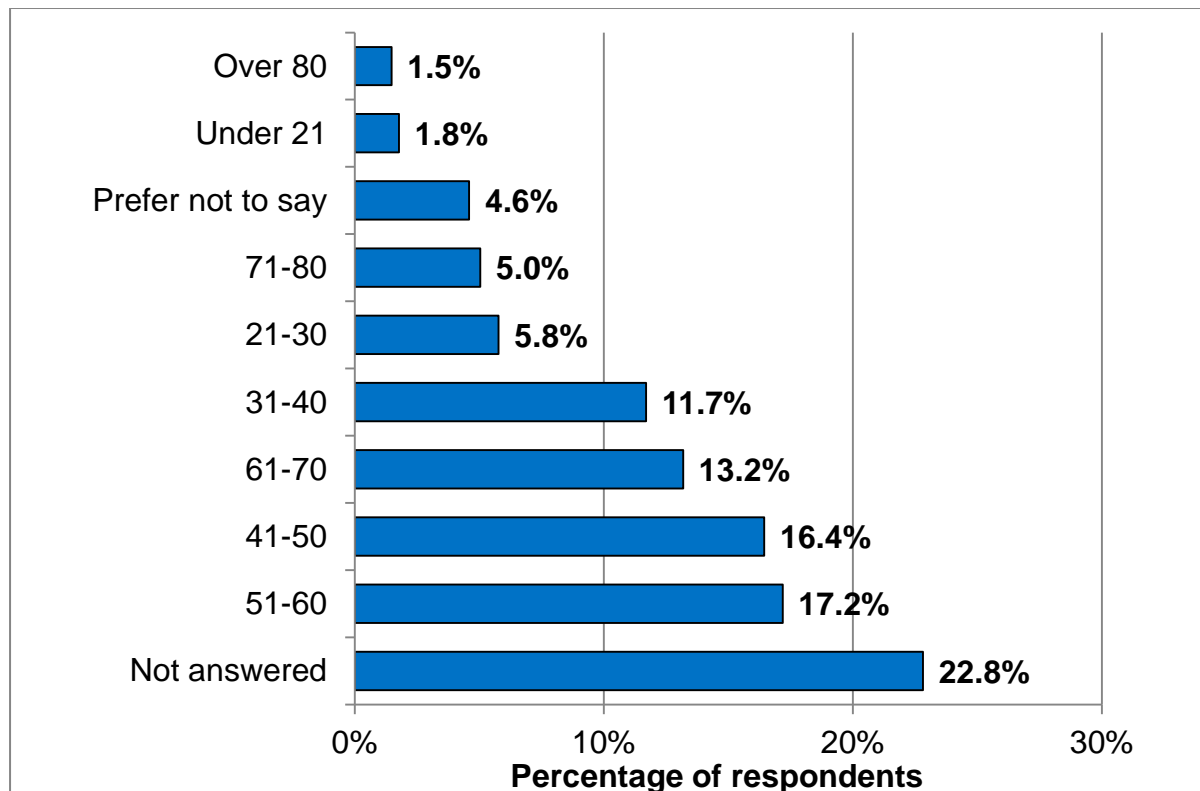
#### **2.2.5 Question 14**

Please see Appendix 7 for the “free text” answers to this question.

## 2.3 Part 3 – Diversity monitoring questions

### 2.3.1 Question 15

Figure 11: What was your age at your last birthday?



Source: Accessible Information Survey Consultation, NHS England, 2014

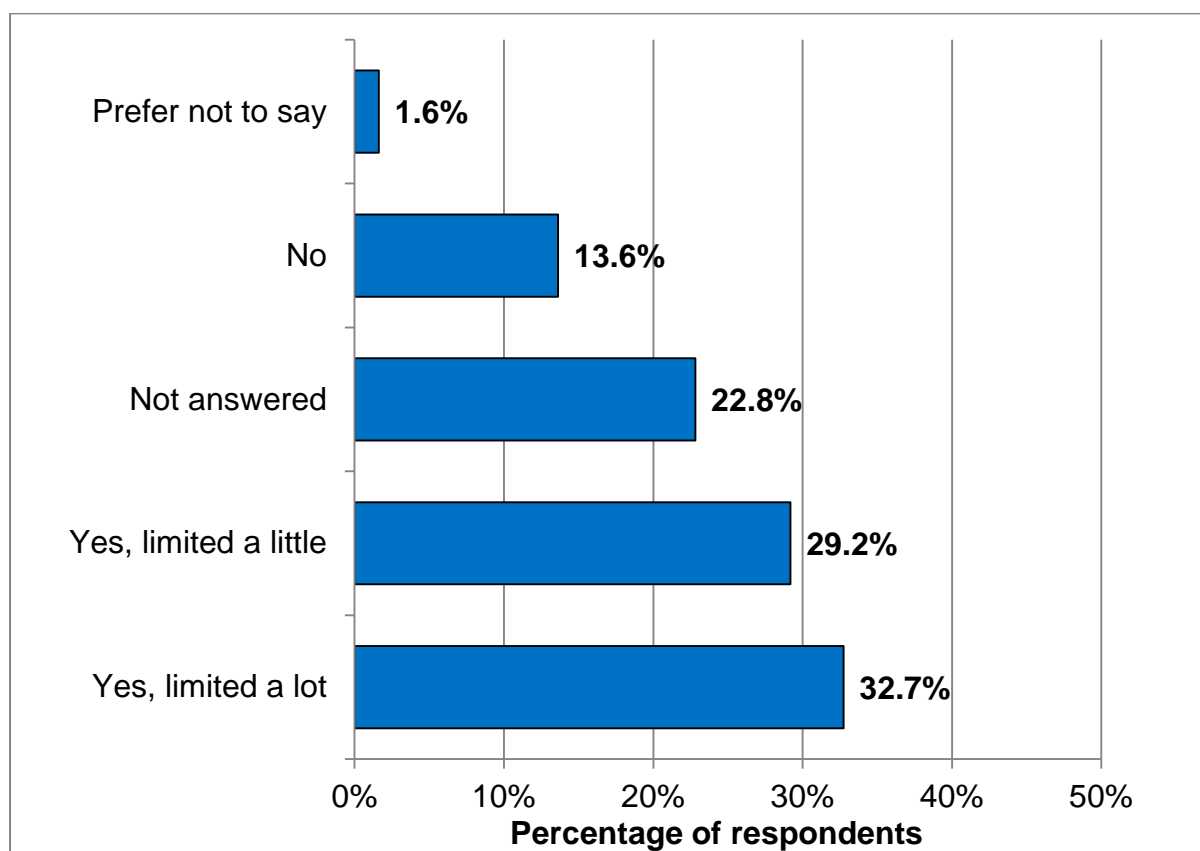
Table 13: What was your age at your last birthday?

Response	Total	Percentage of respondents
Not answered	154	22.8%
51-60	116	17.2%
41-50	111	16.4%
61-70	89	13.2%
31-40	79	11.7%
21-30	39	5.8%
71-80	34	5.0%
Prefer not to say	31	4.6%
Under 21	12	1.8%
Over 80	10	1.5%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.3.2 Question 16

**Figure 12: Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? This includes any issues or problems related to old age.**



Source: Accessible Information Survey Consultation, NHS England, 2014

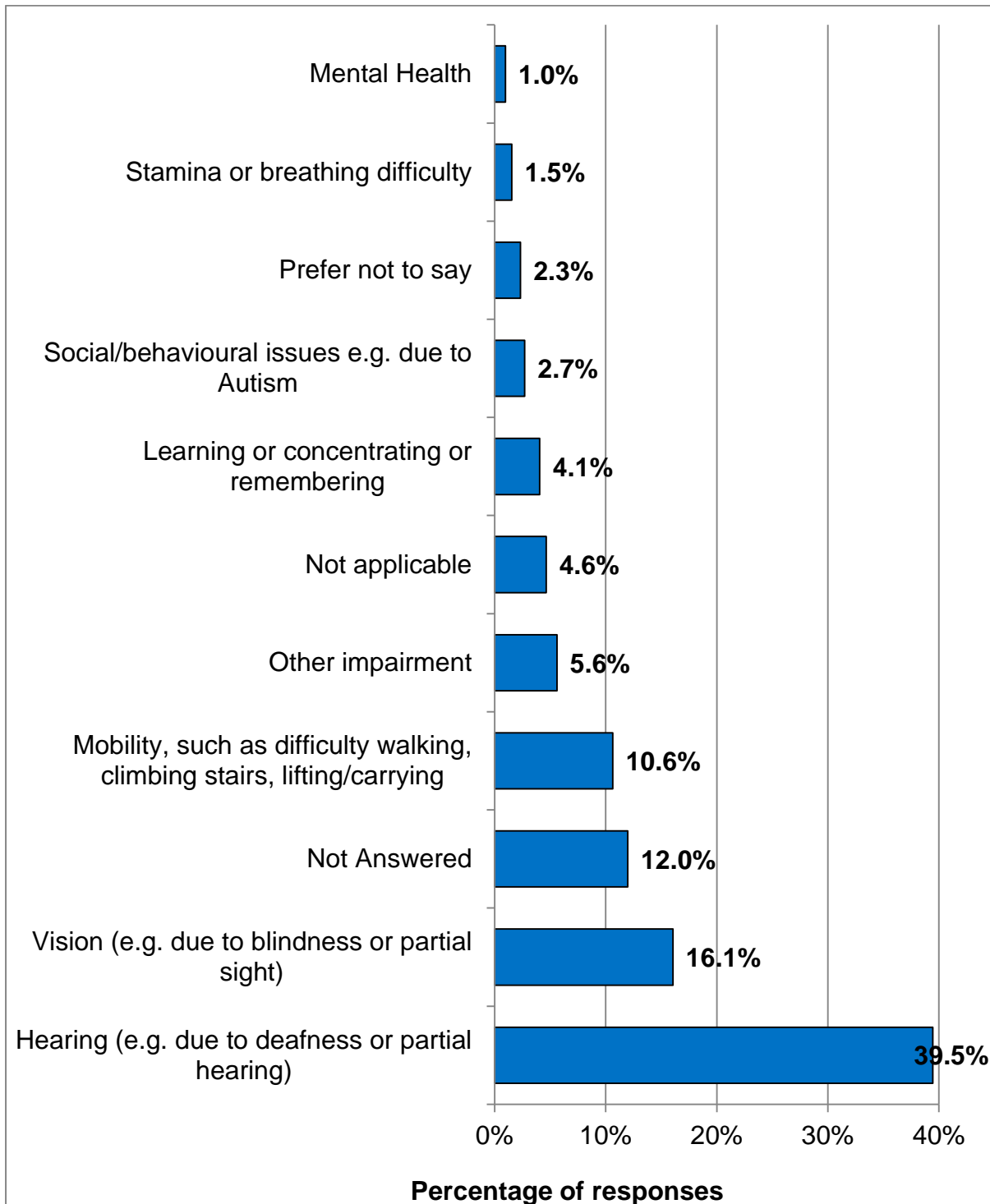
**Table 14: Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? This includes any issues or problems related to old age.**

Response	Total	Percentage of respondents
Yes, limited a lot	221	32.7%
Yes, limited a little	197	29.2%
Not answered	154	22.8%
No	92	13.6%
Prefer not to say	11	1.6%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.3.3 Question 17

Figure 13: If you answered “yes” to question 16, please indicate why?



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 15: If you answered “yes” to question 16, please indicate why?**

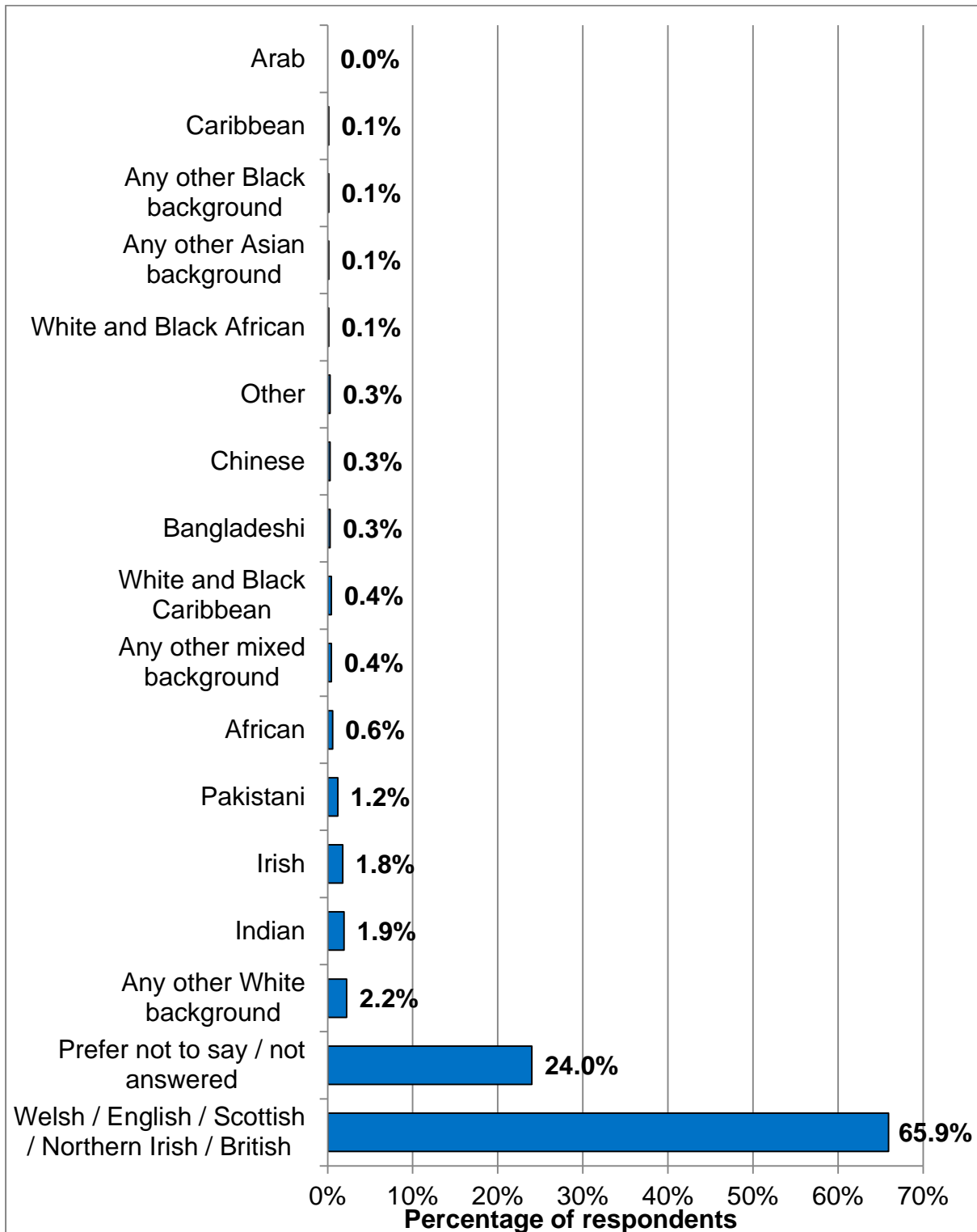
<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Hearing (e.g. due to deafness or partial hearing)	204	39.5%
Vision (e.g. due to blindness or partial sight)	83	16.1%
Not answered	62	12.0%
Mobility, such as difficulty walking, climbing stairs, lifting/carrying	55	10.6%
Other impairment	29	5.6%
Not applicable	24	4.6%
Learning or concentrating or remembering	21	4.1%
Social/behavioural issues e.g. due to Autism	14	2.7%
Prefer not to say	12	2.3%
Stamina or breathing difficulty	8	1.5%
Mental Health	5	1.0%
<b>Total respondents</b>	<b>517</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014



### 2.3.4 Question 18

Figure 14: What is your ethnic group?



Source: Accessible Information Survey Consultation, NHS England, 2014

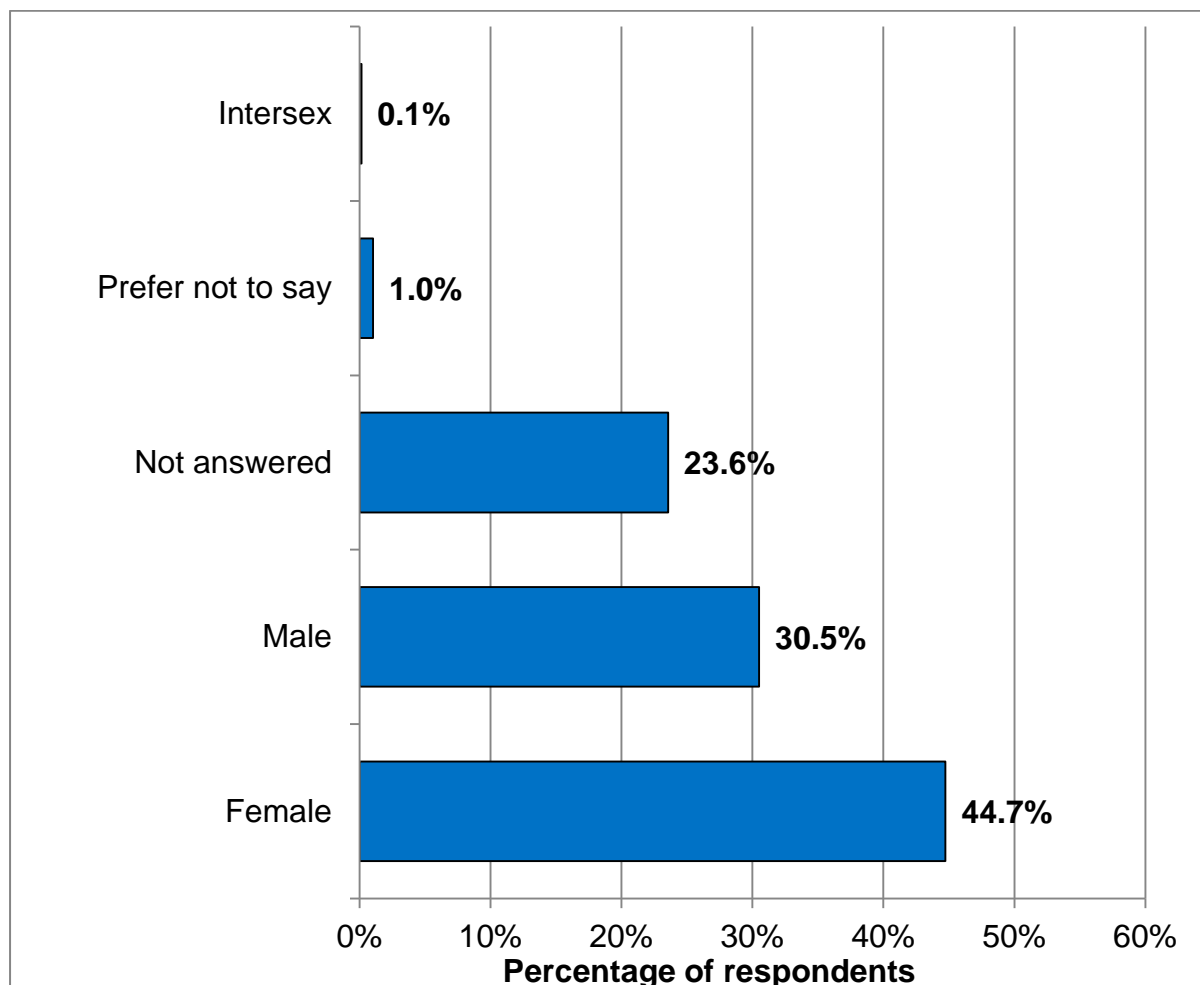
**Table 16: What is your ethnic group?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Welsh / English / Scottish / Northern Irish / British	445	65.9%
Prefer not to say / not answered	162	24.0%
Any other White background	15	2.2%
Indian	13	1.9%
Irish	12	1.8%
Pakistani	8	1.2%
African	4	0.6%
Any other mixed background	3	0.4%
White and Black Caribbean	3	0.4%
Bangladeshi	2	0.3%
Chinese	2	0.3%
Other	2	0.3%
White and Black African	1	0.1%
Any other Asian background	1	0.1%
Any other Black background	1	0.1%
Caribbean	1	0.1%
Arab	0	0.0%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.3.5 Question 19

Figure 15: What is your sex?



Source: Accessible Information Survey Consultation, NHS England, 2014

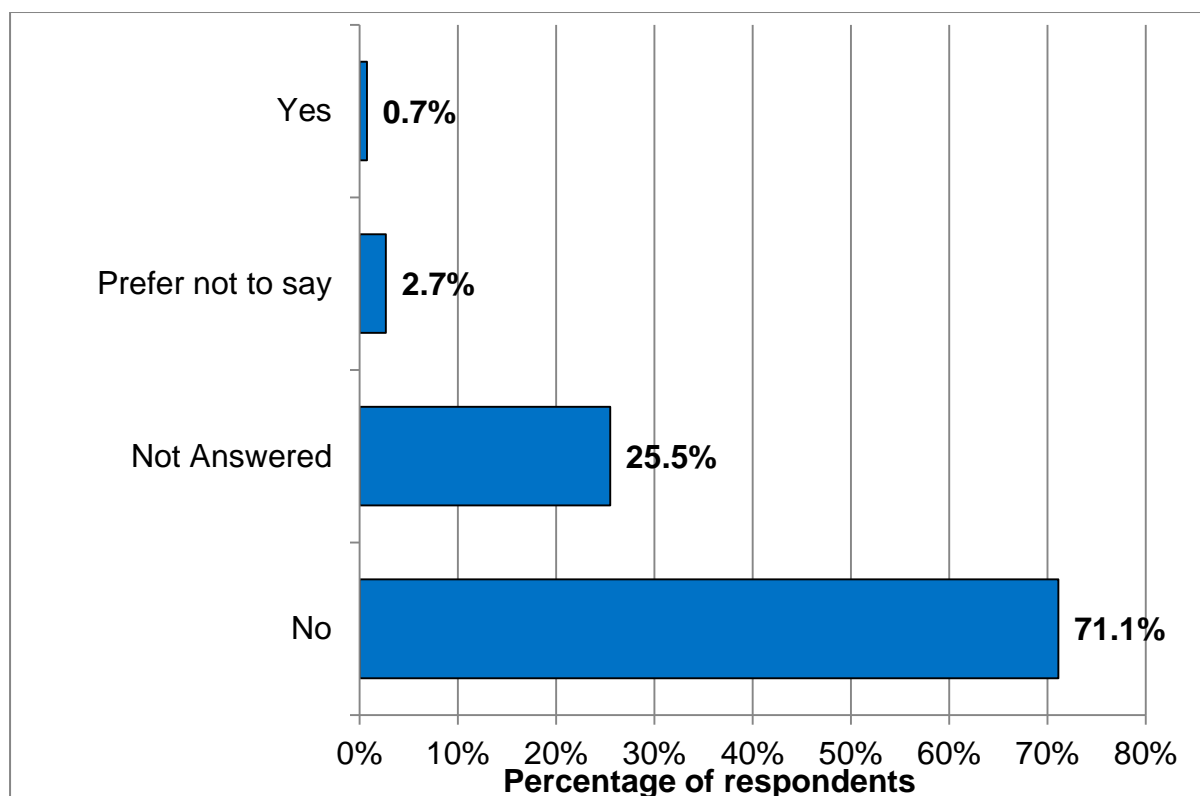
Table 17: What is your sex?

Response	Total	Percentage of respondents
Female	302	44.7%
Male	206	30.5%
Not answered	159	23.6%
Prefer not to say	7	1.0%
Intersex	1	0.1%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.3.6 Question 20

**Figure 16: Have you gone through any part of a process, or do you intend to (including thoughts or actions) to change from the physical sexual appearance you had at birth to the gender you now identify with? This could include changing your name, your appearance and the way you dress, taking hormones or having gender confirming surgery**



Source: Accessible Information Survey Consultation, NHS England, 2014

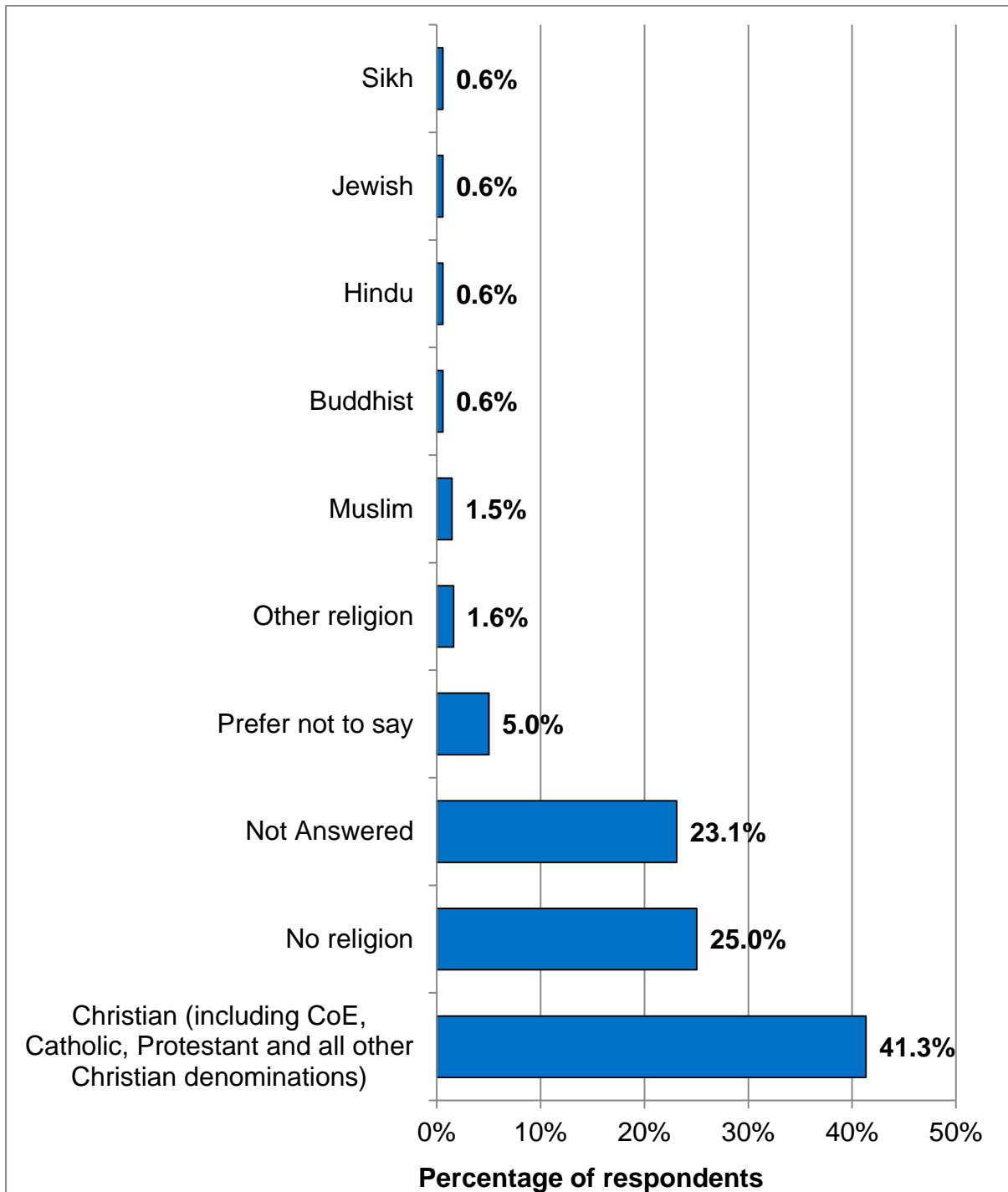
**Table 18: Have you gone through any part of a process, or do you intend to (including thoughts or actions) to change from the physical sexual appearance you had at birth to the gender you identify with now? This could include changing your name, your appearance and the way you dress, taking hormones or having gender confirming surgery**

Response	Total	Percentage of respondents
No	480	71.1%
Not answered	172	25.5%
Prefer not to say	18	2.7%
Yes	5	0.7%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.3.7 Question 21

Figure 17: What is your religion?



Source: Accessible Information Survey Consultation, NHS England, 2014

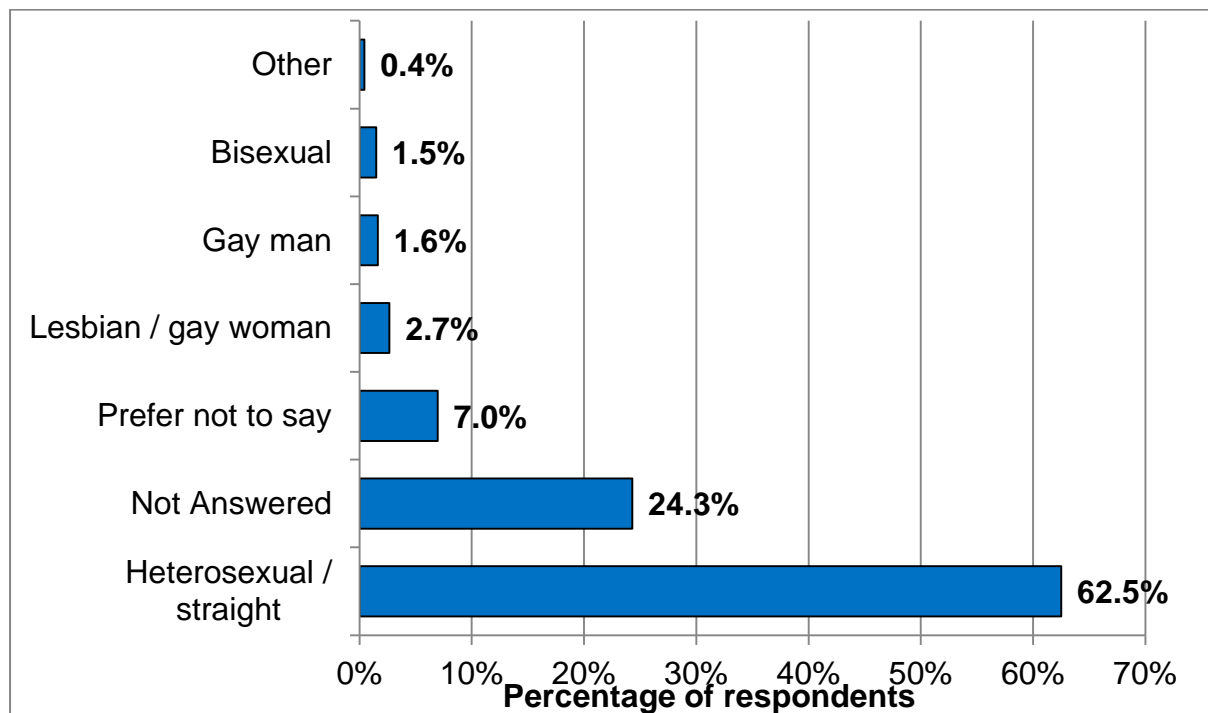
**Table 19: What is your religion?**

Response	Total	Percentage of respondents
Christian (including CoE, Catholic, Protestant and all other Christian denominations)	279	41.3%
No religion	169	25.0%
Not Answered	156	23.1%
Prefer not to say	34	5.0%
Other religion	11	1.6%
Muslim	10	1.5%
Buddhist	4	0.6%
Hindu	4	0.6%
Jewish	4	0.6%
Sikh	4	0.6%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

**2.3.8 Question 22**

**Figure 18: Which of the following best describes your sexual orientation?**



Source: Accessible Information Survey Consultation, NHS England, 2014

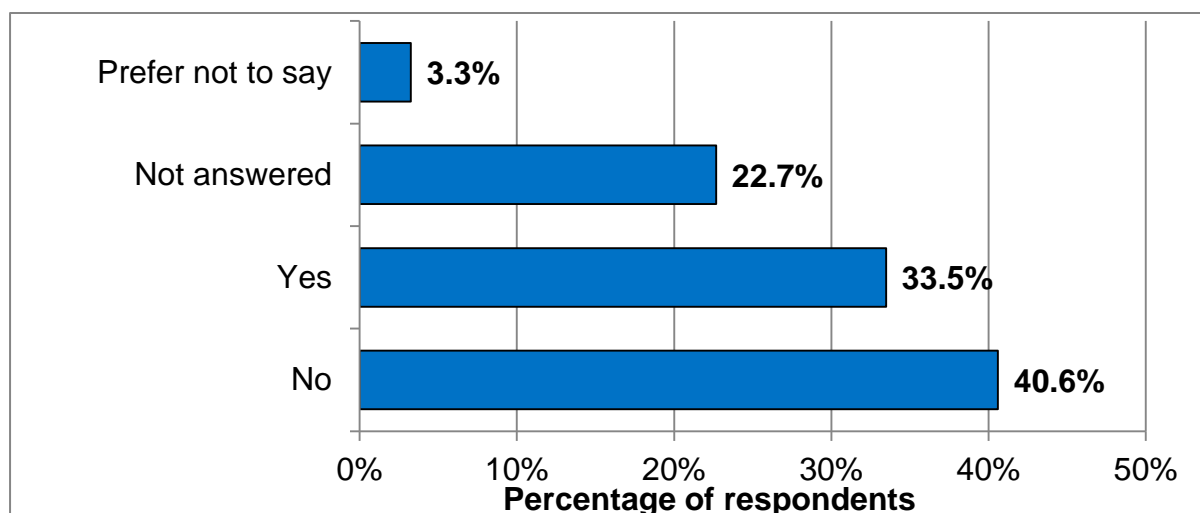
**Table 20: Which of the following best describes your sexual orientation?**

Response	Total	Percentage of respondents
Heterosexual / straight	422	62.5%
Not Answered	164	24.3%
Prefer not to say	47	7.0%
Lesbian / gay woman	18	2.7%
Gay man	11	1.6%
Bisexual	10	1.5%
Other	3	0.4%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 2.3.9 Question 23

**Figure 19: Do you look after, or give any help or support to family members, friends, neighbours or others because of either long-term physical or mental ill-health / disability, or problems related to old age?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 21: Do you look after, or give any help or support to family members, friends, neighbours or others because of either long-term physical or mental ill-health / disability, or problems related to old age?**

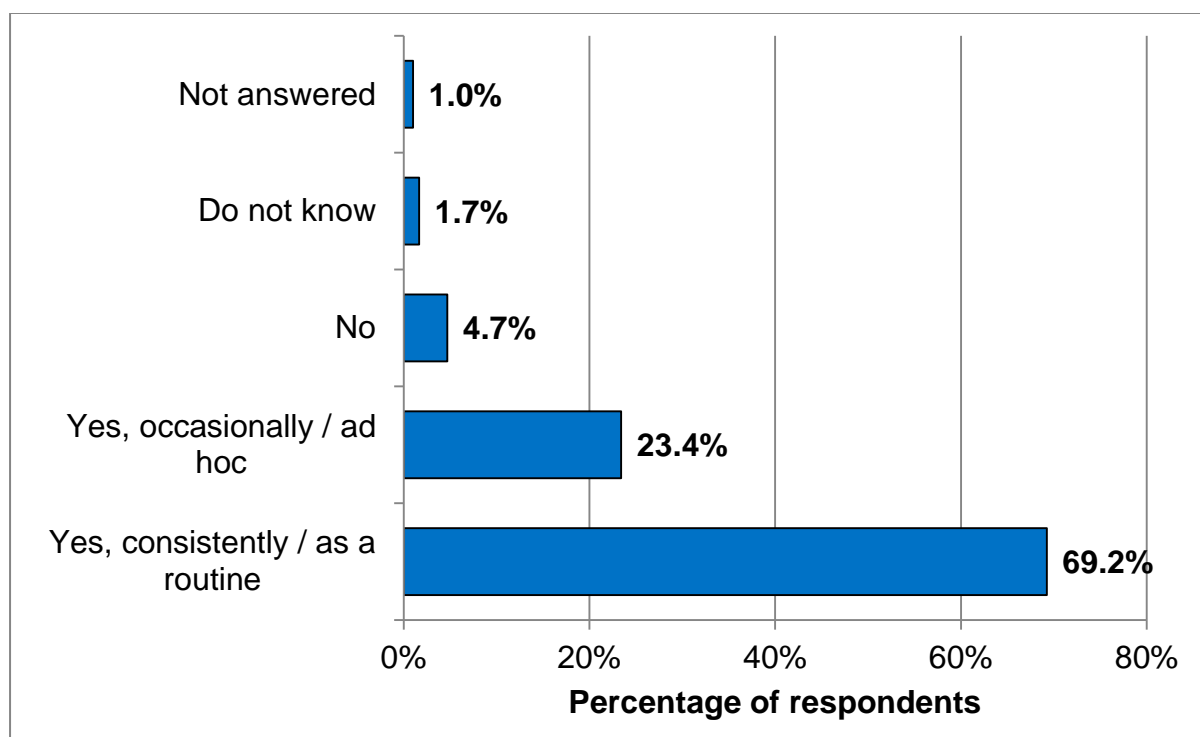
Response	Total	Percentage of respondents
No	274	40.6%
Yes	226	33.5%
Not answered	153	22.7%
Prefer not to say	22	3.3%
<b>Total respondents</b>	<b>675</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 3 Health and social care professionals and organisations survey

#### 3.1.1 Question 1

**Figure 20: Do you / your organisation currently record information about your patients,' service users' or customers' information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 22: Do you / your organisation currently record information about your patients,' service users' or customers' information or communication support needs?**

Response	Total	Percentage of respondents
Yes, consistently / as a routine	207	69.2%
Yes, occasionally / ad hoc	70	23.4%
No	14	4.7%
Do not know	5	1.7%
Not answered	3	1.0%
<b>Grand Total</b>	<b>299</b>	<b>100.0%</b>

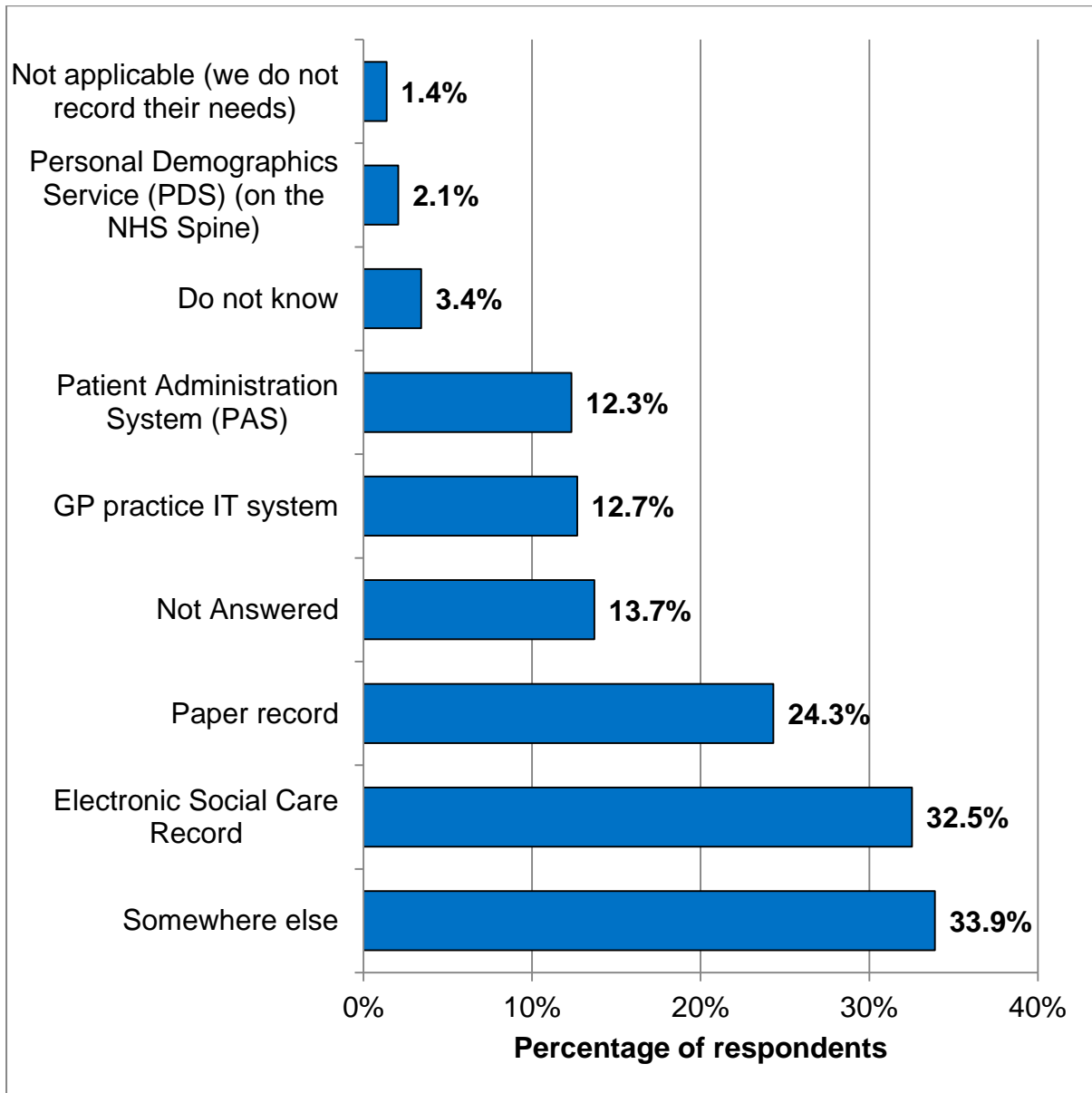
Source: Accessible Information Survey Consultation, NHS England, 2014

69.2% of respondents stated they consistently / as a routine record information about their patients,' service users' or customers' information or communication support needs, whereas 4.7% of respondents stated they do not record this information



### 3.1.2 Question 2

**Figure 21: Where do you / your organisation currently record patients', service users' or customers' information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 23: Where do you / your organisation currently record patients', service users' or customers' information or communication support needs?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Somewhere else	99	33.9%
Electronic Social Care Record	95	32.5%
Paper record	71	24.3%
Not Answered	40	13.7%
GP practice IT system	37	12.7%
Patient Administration System (PAS)	36	12.3%
Do not know	10	3.4%
Personal Demographics Service (PDS) (on the NHS Spine)	6	2.1%
Not applicable (we do not record their needs)	4	1.4%
<b>Total respondents</b>	<b>299</b>	<b>100%</b>

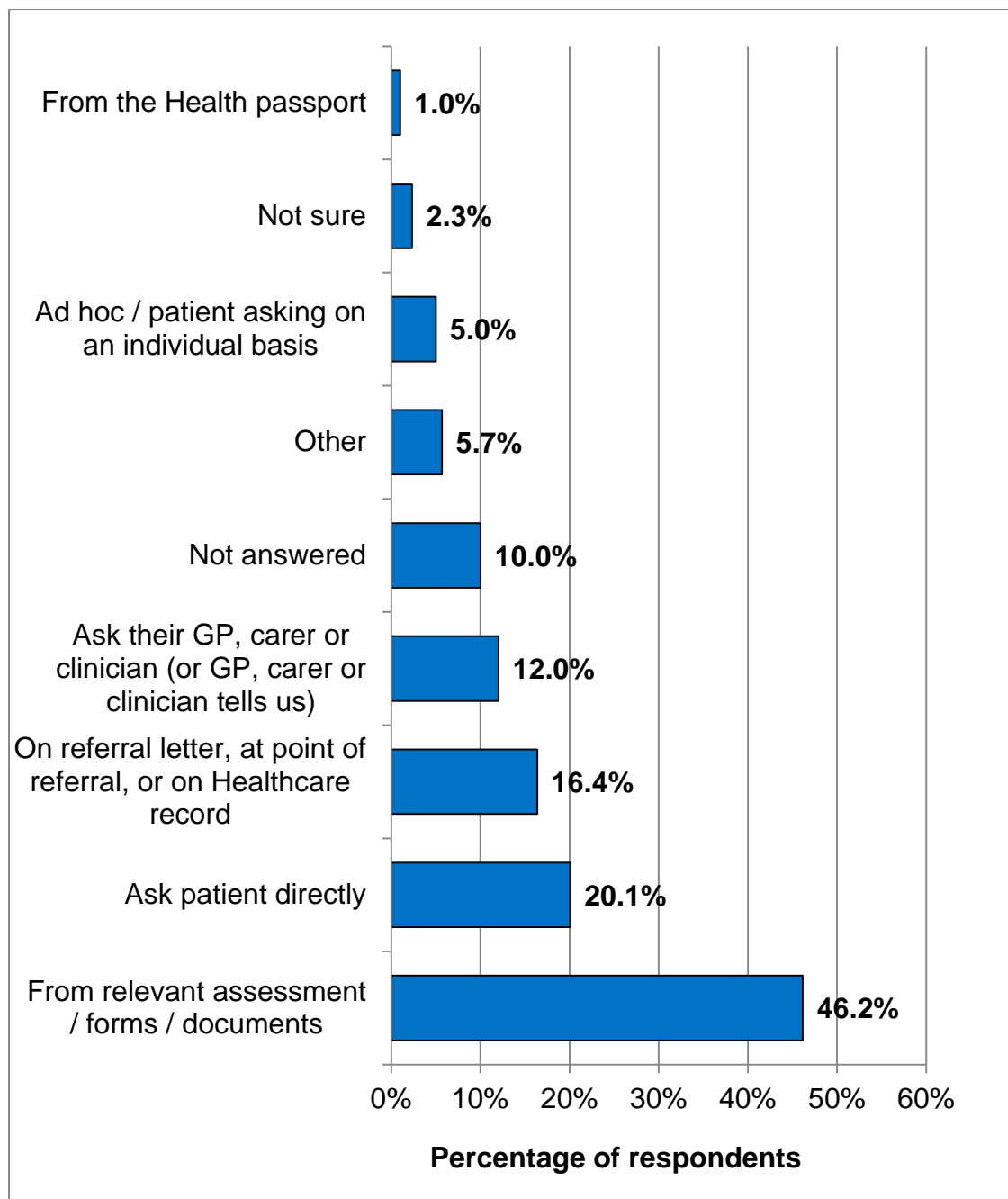
Source: Accessible Information Survey Consultation, NHS England, 2014

Please see Appendix 8 for a breakdown of the answers for category "somewhere else".

### 3.1.3 Question 3

The answers to this question were “free text”, and have been analysed and disseminated into eight broad categories, shown in Figure 22 and Table 24.

**Figure 22: How do you / your organisation currently find out about patients', service users' or customers' information or communication support needs? For example, do you have a standard question which is asked?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 24: How do you / your organisation currently find out about patients', service users' or customers' information or communication support needs? For example, do you have a standard question which is asked?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
From relevant assessment / forms / documents (usually as part of the assessment process)	138	46.2%
Ask patient directly	60	20.1%
On referral letter, at point of referral, or on healthcare record	49	16.4%
Ask their GP, carer or clinician (or GP, carer or clinician tells us)	36	12.0%
Not answered	30	10.0%
Other	17	5.7%
Ad hoc / patient asking on an individual basis	15	5.0%
Not sure	7	2.3%
From the Health Passport	3	1.0%
<b>Total respondents</b>	<b>299</b>	

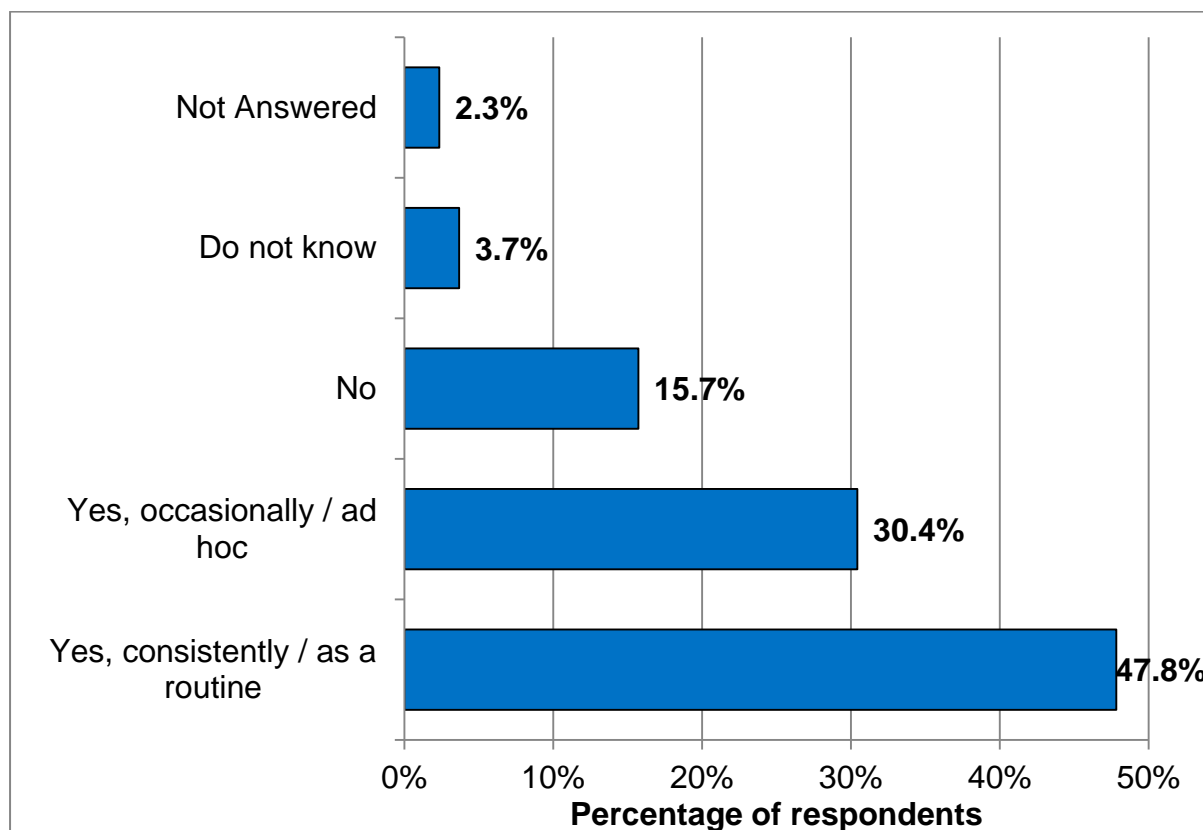
Source: Accessible Information Survey Consultation, NHS England, 2014

Please note as respondents sometimes gave answers for more than one category, the analysis is a reflection of the percentage of respondents selecting each category, and therefore the percentages do not add up to 100%.

46.2% of respondents stated they / their organisation find out about patients', service users' or customers' information or communication support needs from relevant assessment, forms and documents.

### 3.1.4 Question 4

**Figure 23: Do you / your organisation currently record information about carers' information or communication needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

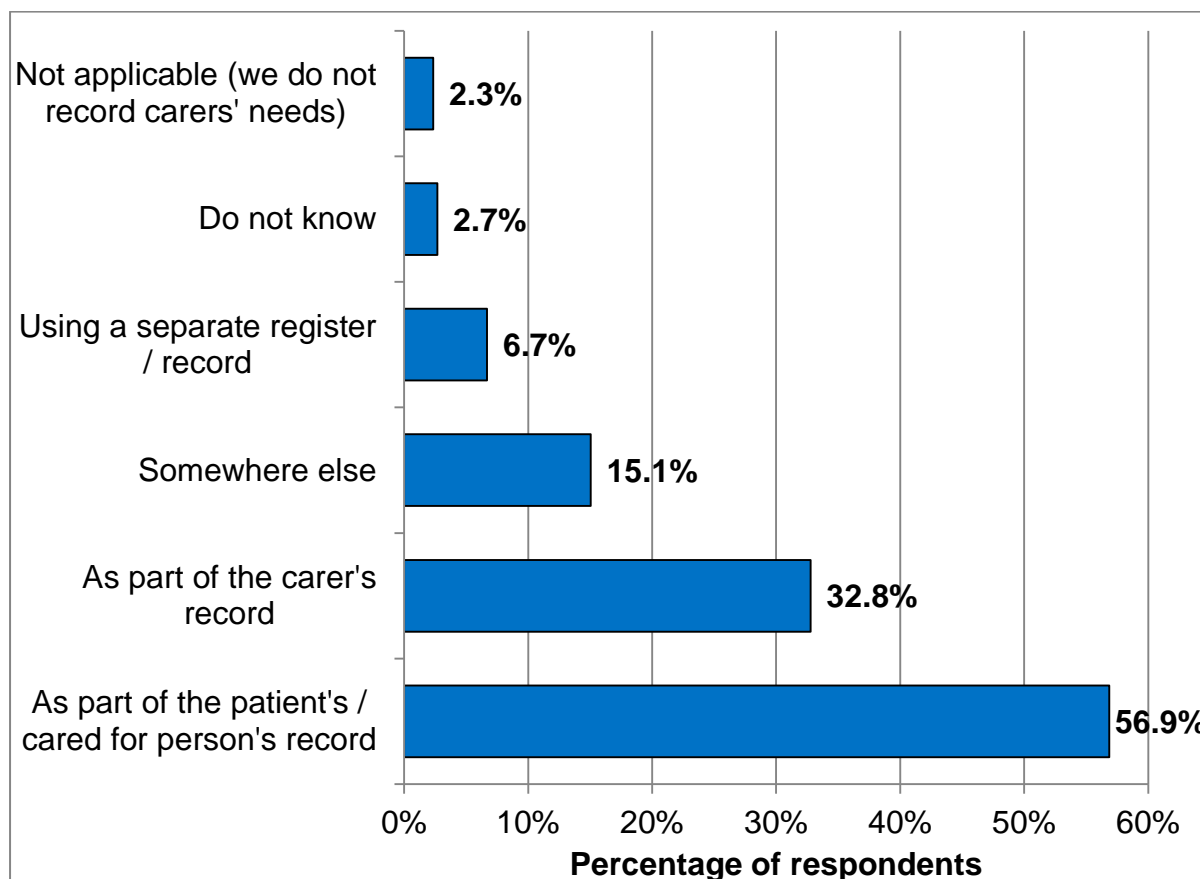
**Table 25: Do you / your organisation currently record information about carers' information or communication needs?**

Response	Total	Percentage of respondents
Yes, consistently / as a routine	143	47.8%
Yes, occasionally / ad hoc	91	30.4%
No	47	15.7%
Do not know	11	3.7%
Not answered	7	2.3%
<b>Total respondents</b>	<b>299</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 3.1.5 Question 5

**Figure 24: Where do you / your organisation currently record carers' information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 26: Where do you / your organisation currently record carers' information or communication support needs?**

Response	Total	Percentage of respondents
As part of the patient's / cared for person's record	170	56.9%
As part of the carer's record	98	32.8%
Somewhere else	45	15.1%
Using a separate register / record	20	6.7%
Do not know	8	2.7%
Not applicable (we do not record carers' needs)	7	2.3%
<b>Total respondents</b>	<b>299</b>	

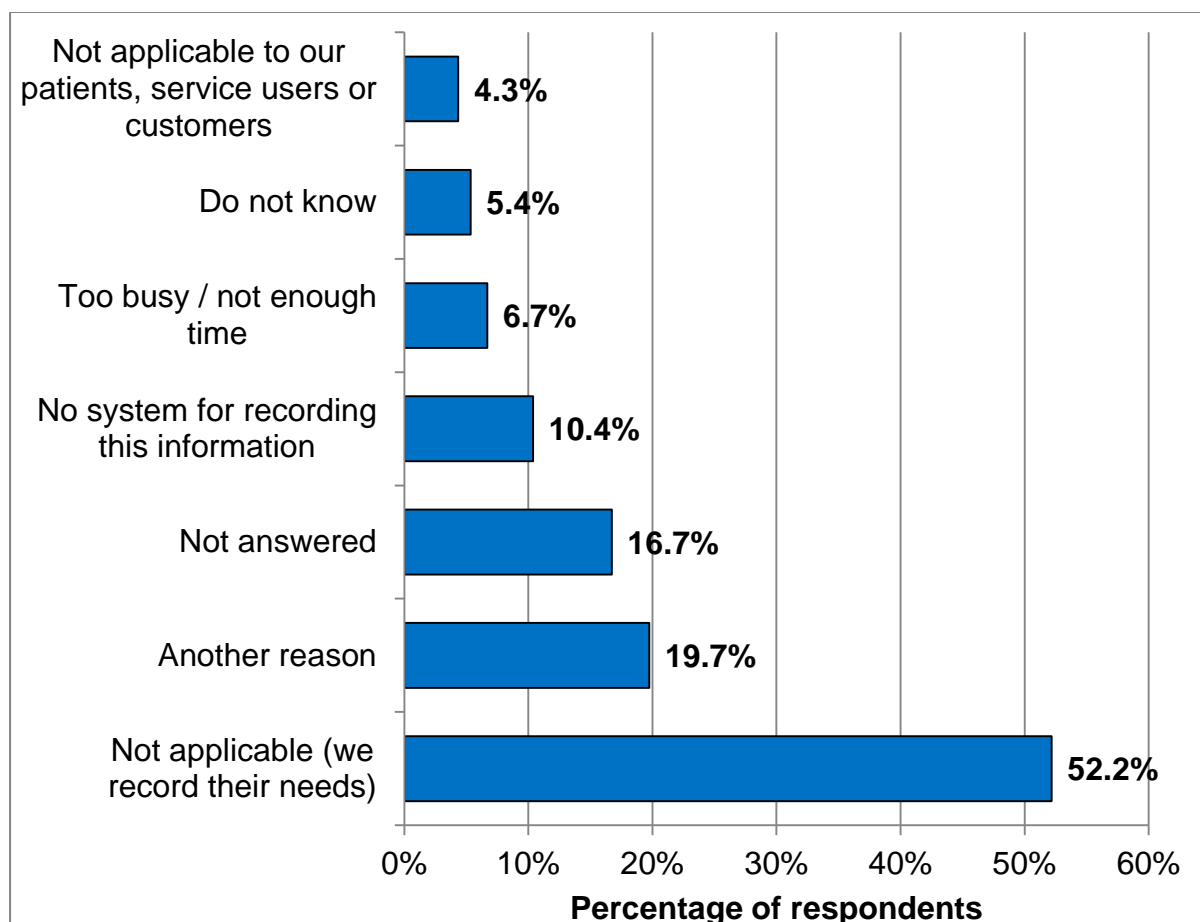
Source: Accessible Information Survey Consultation, NHS England, 2014

Please note as respondents were asked to select all the answers that applied, the analysis is a reflection of the percentage of respondents selecting each method, and therefore the percentages do not add up to 100%.

Please see Appendix 9 for a breakdown of the answers for category “somewhere else”.

### 3.1.6 Question 6

**Figure 25: What is the main reason for not recording patients’, service users’ or customers’ information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 27: What is the main reason for not recording patients’, service users’ or customers’ information or communication support needs?**

Response	Total	Percentage of respondents
Not applicable (we record their needs)	156	52.2%
Another reason	59	19.7%
Not answered	50	16.7%
No system for recording this information	31	10.4%
Too busy / not enough time	20	6.7%
Do not know	16	5.4%
Not applicable to our patients, service users or customers	13	4.3%
No system for acting upon this information	10	3.3%
<b>Total respondents</b>	<b>299</b>	

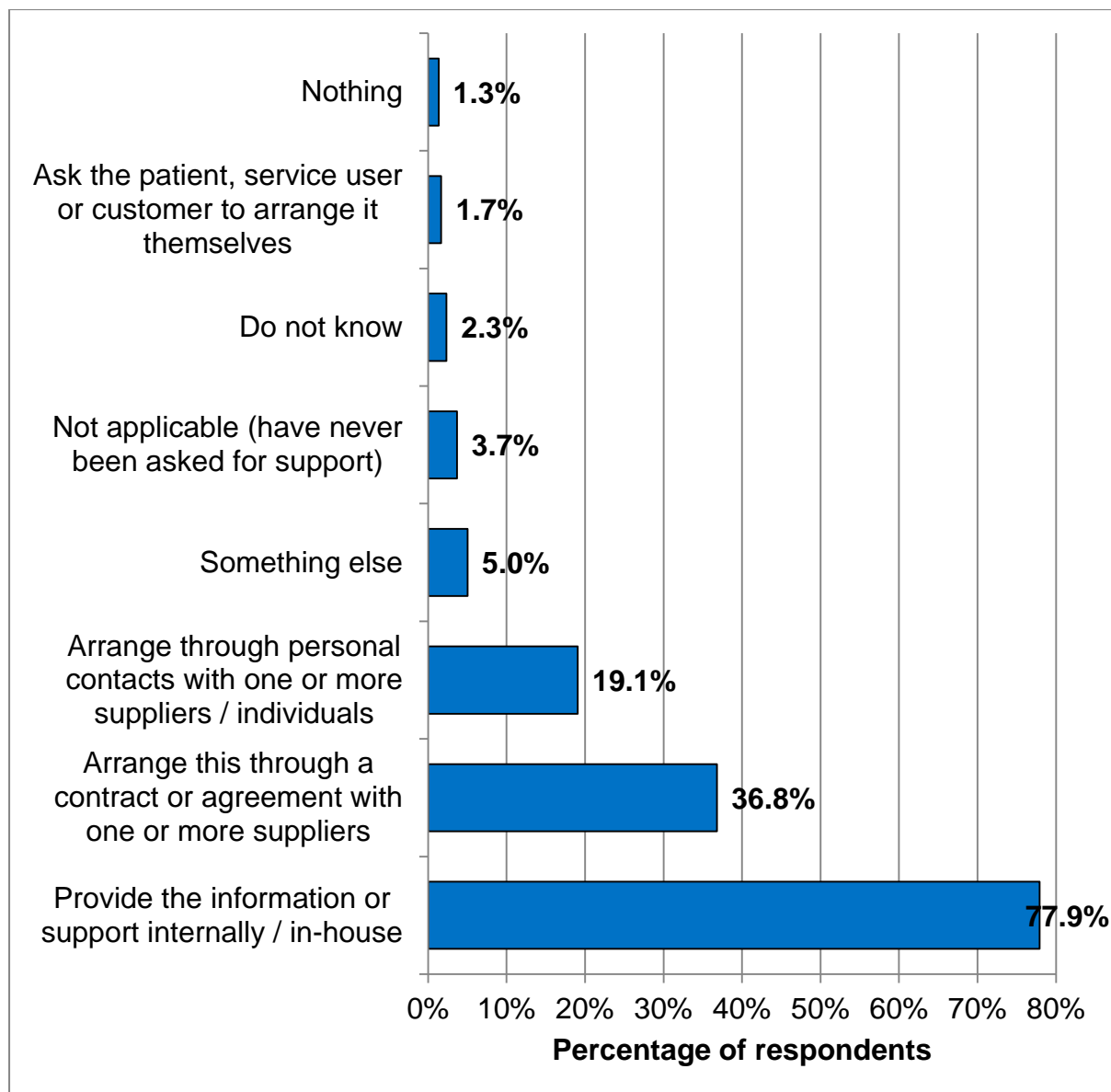
Source: Accessible Information Survey Consultation, NHS England, 2014

Please note as some respondents have selected more than one reason, the analysis is a reflection of the percentage of respondents selecting each reason, and therefore the percentages do not add up to 100%.

Please see Appendix 10 for a breakdown of the answers for category “another reason”.

### 3.1.7 Question 7

**Figure 26: If your patients, service users or customers need information in an alternative format or communication support, what do you currently do about this?**



Source: Accessible Information Survey Consultation, NHS England, 2014



**Table 28: If your patients, service users or customers need information in an alternative format or communication support, what do you currently do about this?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Provide the information or support internally / in-house	233	77.9%
Arrange this through a contract or agreement with one or more suppliers	110	36.8%
Arrange through personal contacts with one or more suppliers / individuals	57	19.1%
Something else	15	5.0%
Not applicable (have never been asked for support)	11	3.7%
Do not know	7	2.3%
Ask the patient, service user or customer to arrange it themselves	5	1.7%
Nothing	4	1.3%
<b>Total respondents</b>	<b>299</b>	

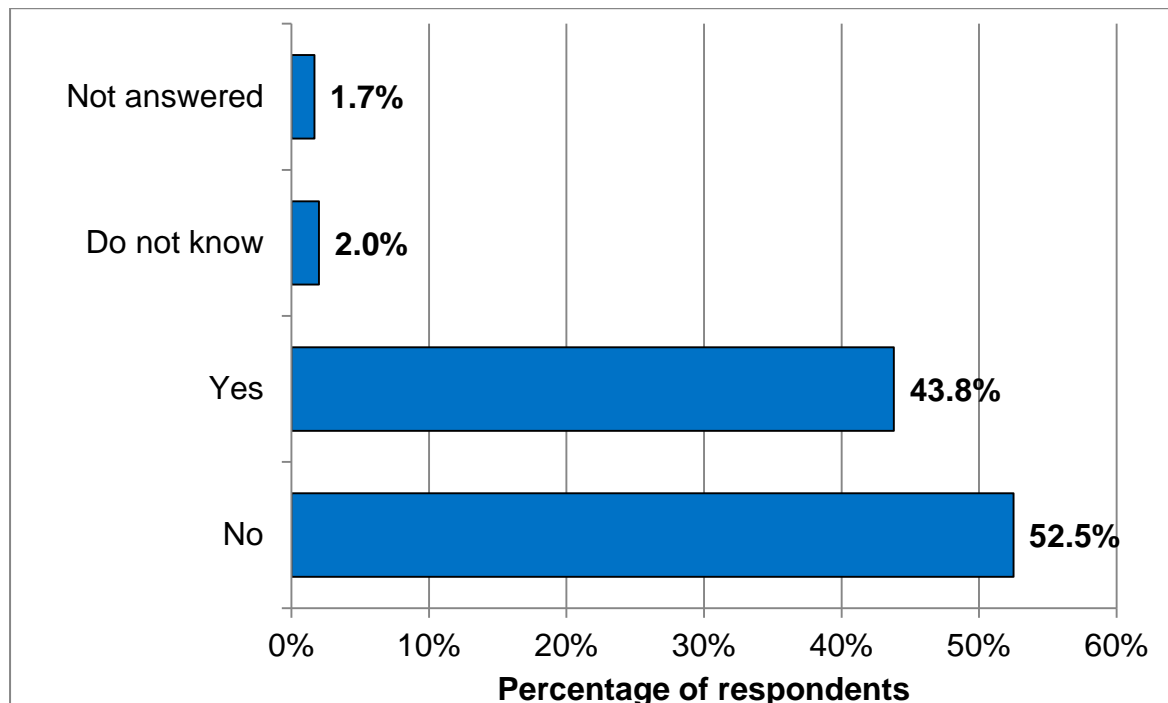
Source: Accessible Information Survey Consultation, NHS England, 2014

Please note that due to an error in the online survey, some respondents were unable to select more than one answer to this question, which they should have been able to. Some respondents have therefore written these answers in the free text area, and these have also been counted in the analysis. In addition, as respondents were asked to select all the answers that applied, the analysis is a reflection of the percentage of respondents selecting each category, and therefore the percentages do not add up to 100%.

77.9% of respondents stated that they would provide the information or support internally / in house if their patients, service users or customers need information in an alternative format or communication support. 36.8% of respondents stated they would arrange this through a contract or agreement with one or more suppliers. Please see Appendix 11 for a breakdown of the answers for category “something else”.

### 3.1.8 Question 8

**Figure 27: Have you experienced / do you experience any difficulties in recording or responding to patients,' service users' or customers' information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 29: Have you experienced / do you experience any difficulties in recording or responding to patients,' service users' or customers' information or communication support needs?**

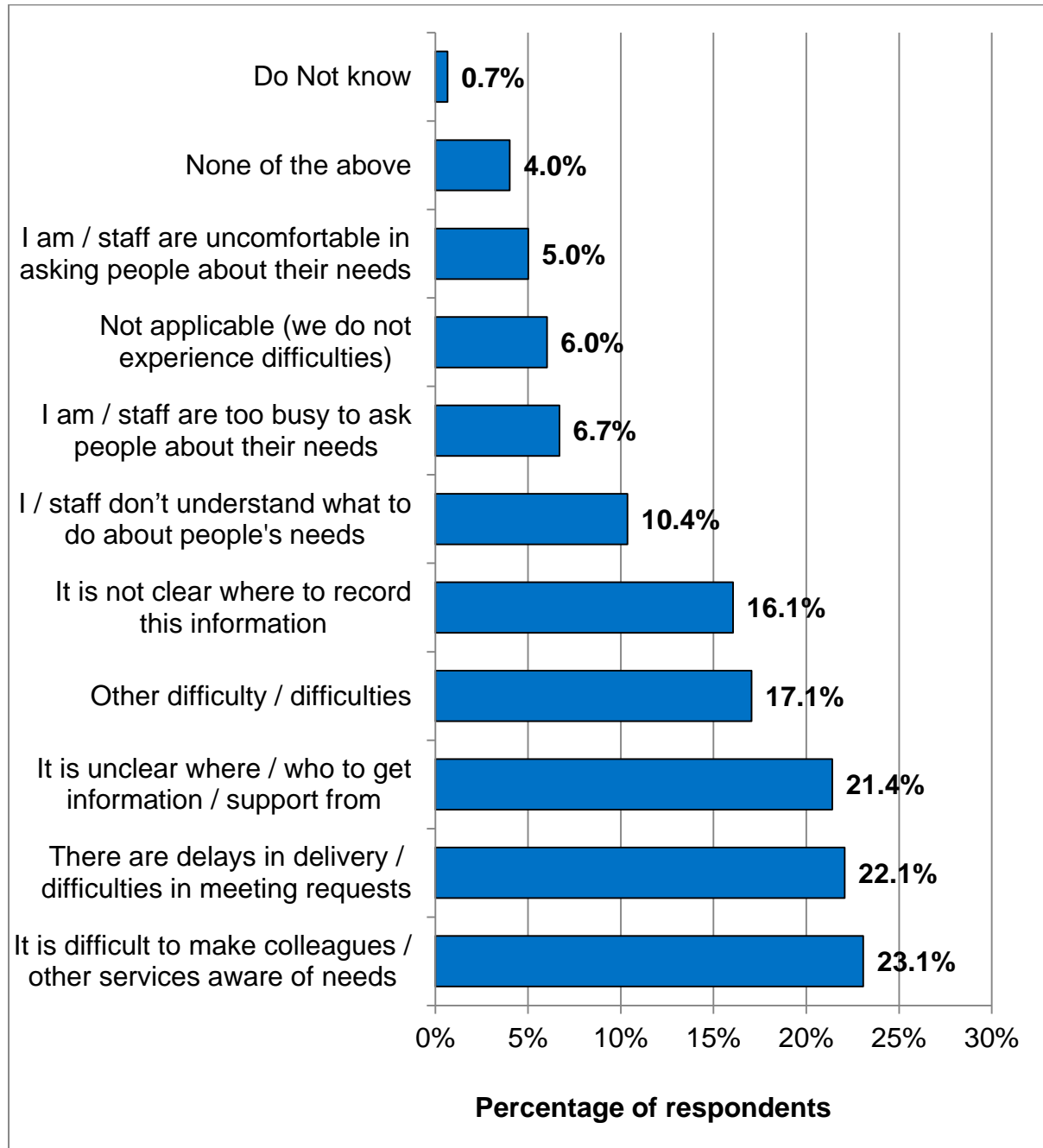
Response	Total	Percentage of respondents
No	157	52.5%
Yes	131	43.8%
Do not know	6	2.0%
Not answered	5	1.7%
<b>Total respondents</b>	<b>299</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

52.5% of respondents stated they do not experience any difficulties in recording or responding to patients,' service users' or customers' information or communication support needs, whereas 43.8% of respondents stated they do.

### 3.1.9 Question 9

**Figure 28: What difficulties do you experience in recording and / or responding to patients', service users' or customers' information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 30: What difficulties do you experience in recording and / or responding to patients', service users' or customers' information or communication support needs?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
It is difficult to make colleagues / other services aware of needs	69	23.1%
There are delays in delivery / difficulties in meeting requests	66	22.1%
It is unclear where / who to get information / support from	64	21.4%
Other difficulty / difficulties	51	17.1%
It is not clear where to record this information	48	16.1%
I / staff don't understand what to do about people's needs	31	10.4%
I am / staff are too busy to ask people about their needs	20	6.7%
Not applicable (we do not experience difficulties)	18	6.0%
I am / staff are uncomfortable asking people about their needs	15	5.0%
None of the above	12	4.0%
Do not know	2	0.7%
<b>Total respondents</b>	<b>299</b>	

Source: Accessible Information Survey Consultation, NHS England, 2014

Please note that as respondents were asked to select all the answers that applied, the analysis is a reflection of the percentage of respondents selecting each category, and therefore the percentages do not add up to 100%.

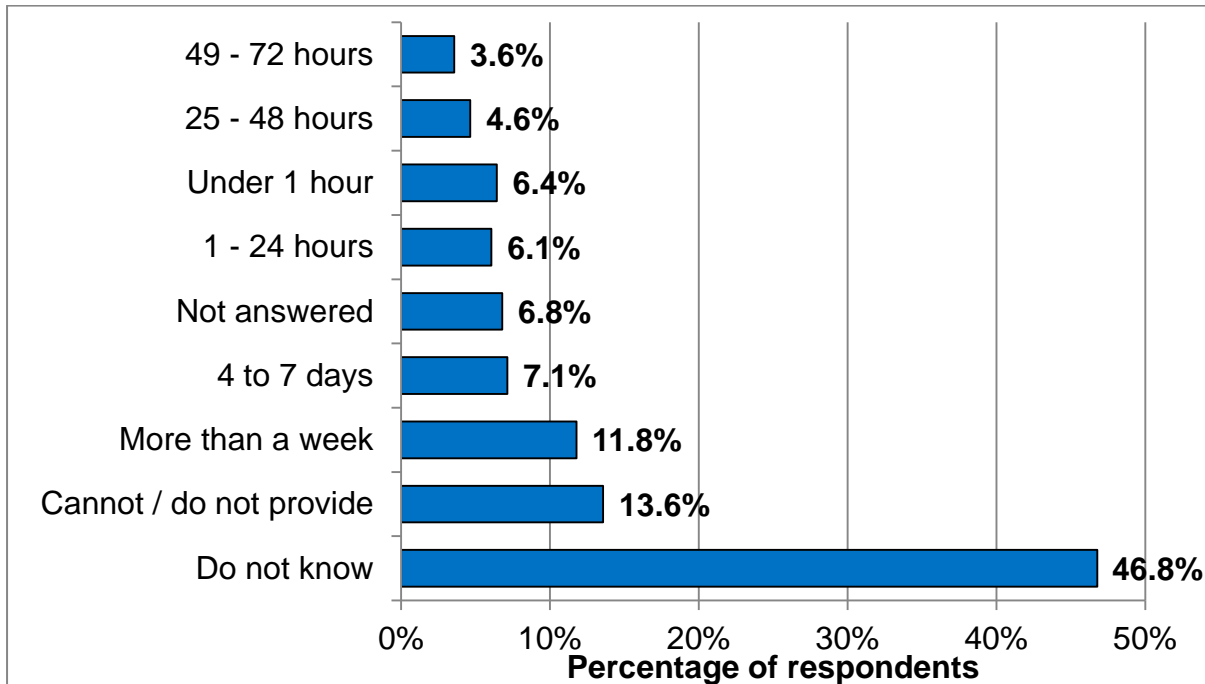
23.1% of respondents stated it is difficult to make colleagues / other services aware of patients', service users' or customers' information or communication support needs. 22.1% of respondents stated there are delays in delivery / difficulties in meeting requests.

### **3.1.10 Question 10**

Please see Appendix 12 for the "free text" responses to this question.

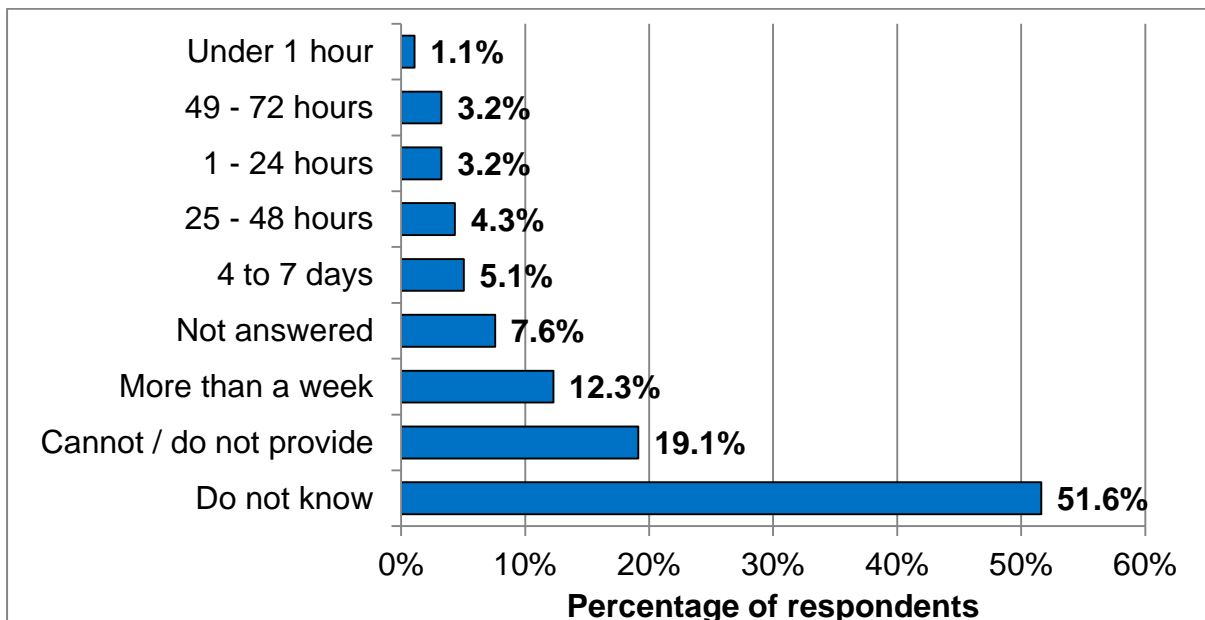
### 3.1.11 Question 11

**Figure 29: How long does it usually take you / your organisation to provide information to patients, service users or carers in audio format?**



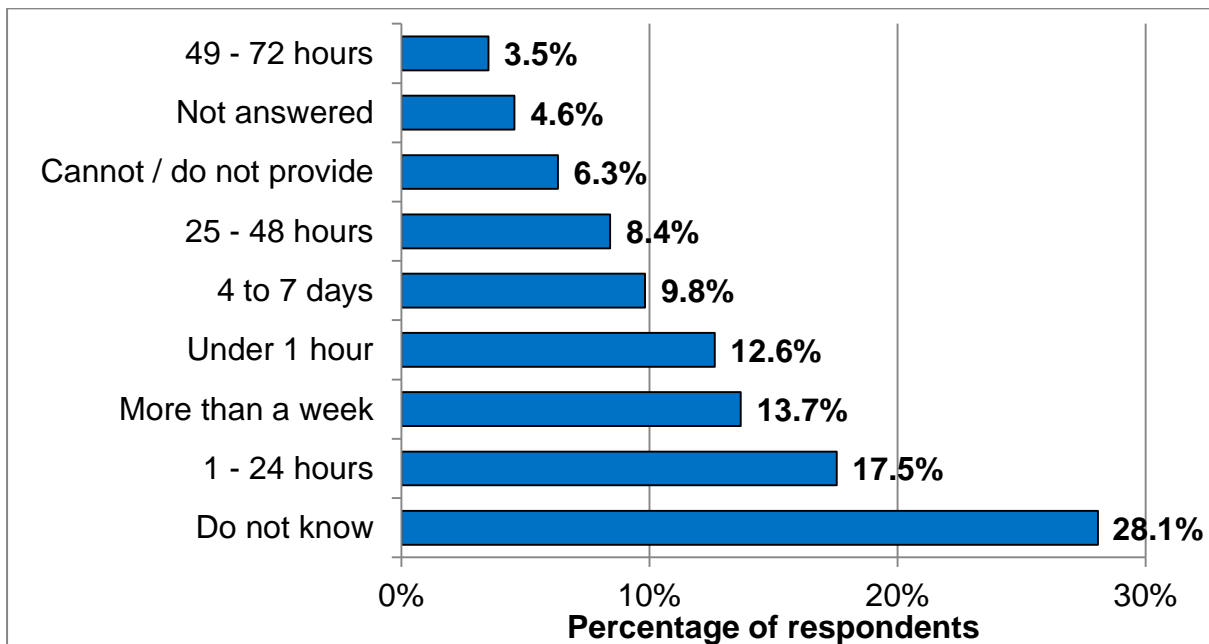
Source: Accessible Information Survey Consultation, NHS England, 2014

**Figure 30: How long does it usually take you / your organisation to provide information to patients, service users or carers in Braille format?**



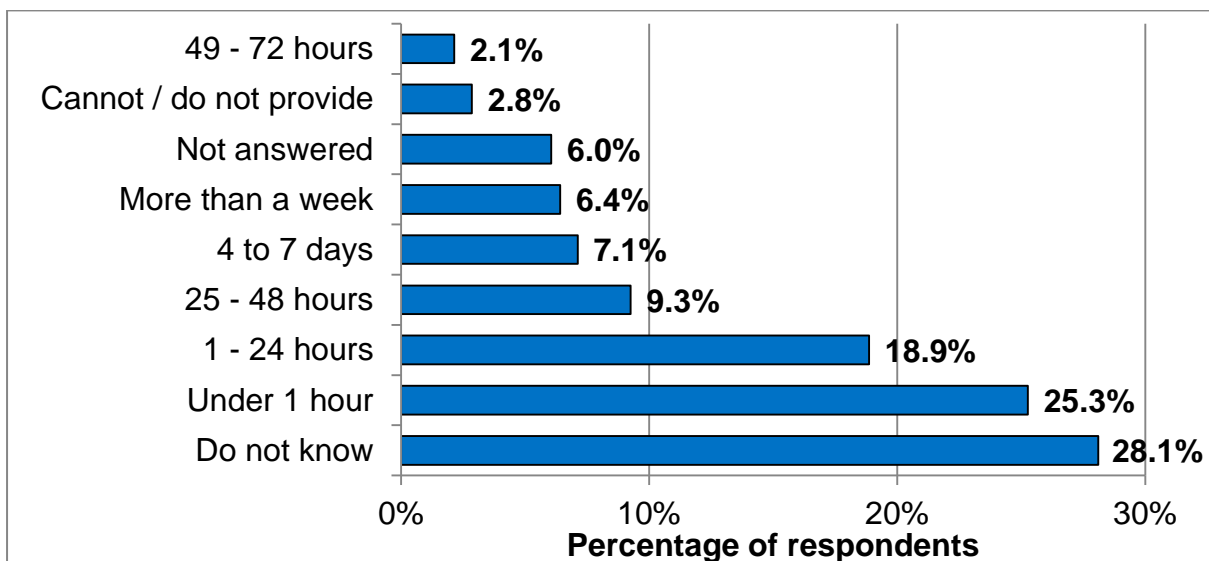
Source: Accessible Information Survey Consultation, NHS England, 2014

**Figure 31: How long does it usually take you / your organisation to provide information to patients, service users or carers in Easy Read format?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Figure 32: How long does it usually take you / your organisation to provide information to patients, service users or carers in Large Print format?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 31: How long does it usually take you / your organisation to provide information to patients, service users or carers in the following alternative formats?**

Format	Time Taken									Grand Total
	Under 1 hour	1 - 24 hours	25 - 48 hours	49 - 72 hours	4 to 7 days	More than a week	Cannot / do not provide	Do not know	Not answered	
Audio	6.0%	5.7%	4.3%	3.3%	6.7%	11.0%	12.7%	43.8%	6.4%	100.0%
Braille	1.0%	3.0%	4.0%	3.0%	4.7%	11.4%	17.7%	47.8%	7.4%	100.0%
Easy Read	12.0%	16.7%	8.0%	3.3%	9.4%	13.0%	6.0%	26.8%	4.7%	100.0%
Large Print	23.7%	17.7%	8.7%	2.0%	6.7%	6.0%	2.7%	26.4%	6.0%	100.0%
Grand Total	10.7%	10.8%	6.3%	2.9%	6.9%	10.4%	9.8%	36.2%	6.1%	100.0%

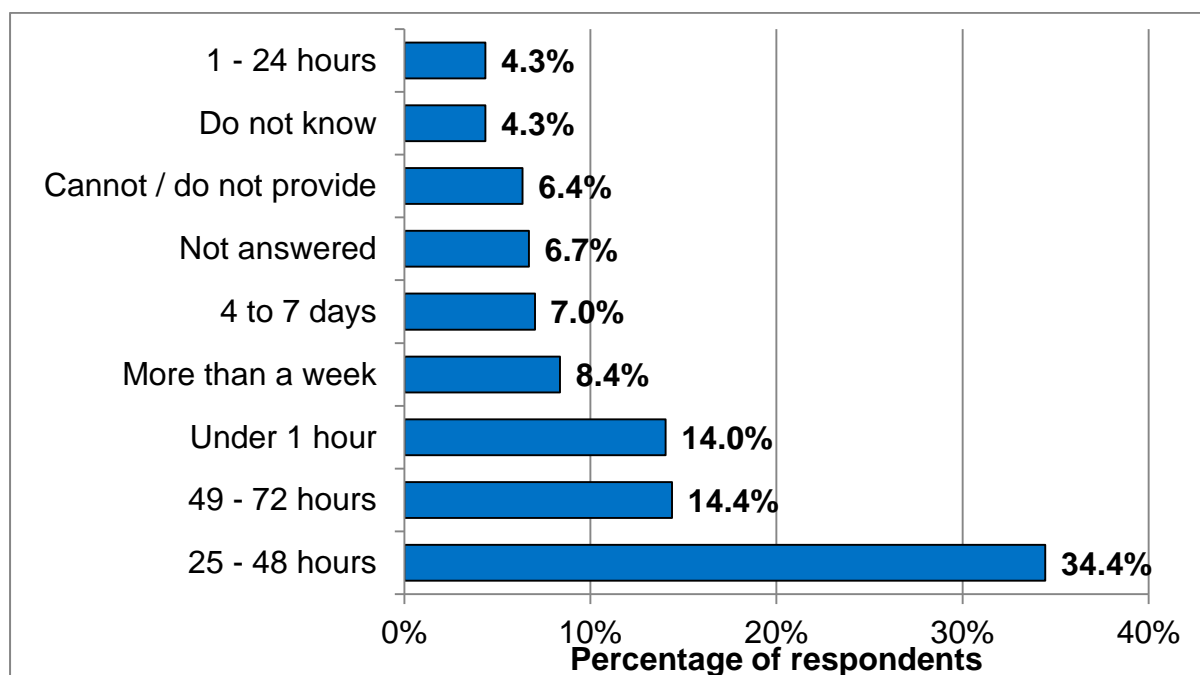
Source: Accessible Information Survey Consultation, NHS England, 2014

### 3.1.12 Question 12

Please see Appendix 13 for the “free text” responses to this question.

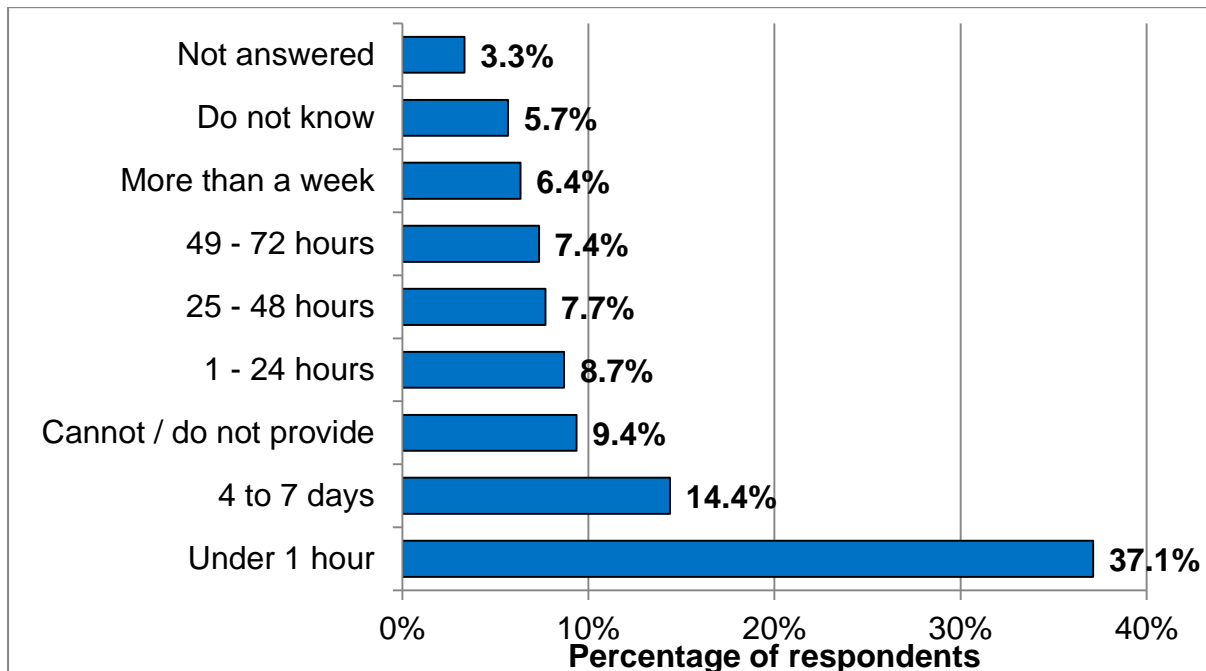
### 3.1.13 Question 13

**Figure 33: How long does it usually take you / your organisation to arrange or provide an Advocate for a face-to-face appointment?**



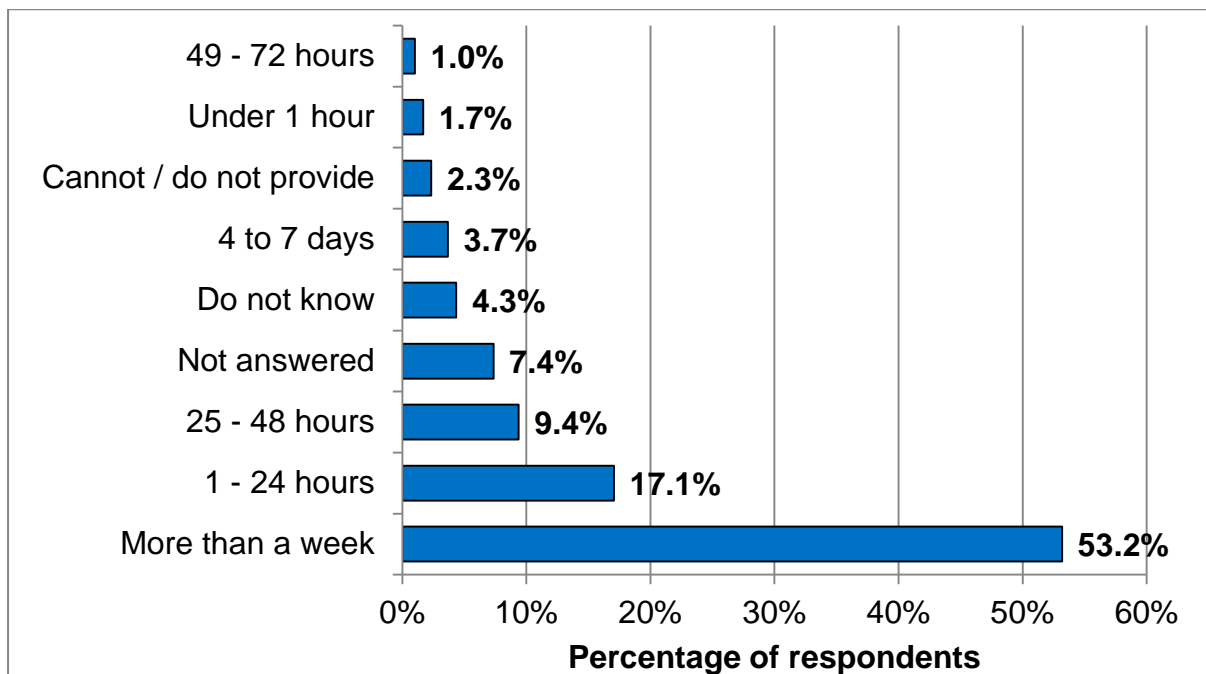
Source: Accessible Information Survey Consultation, NHS England, 2014

**Figure 34: How long does it usually take you / your organisation to arrange or provide a British Sign Language Interpreter (BSL) for a face-to-face appointment?**



Source: Accessible Information Survey Consultation, NHS England, 2014

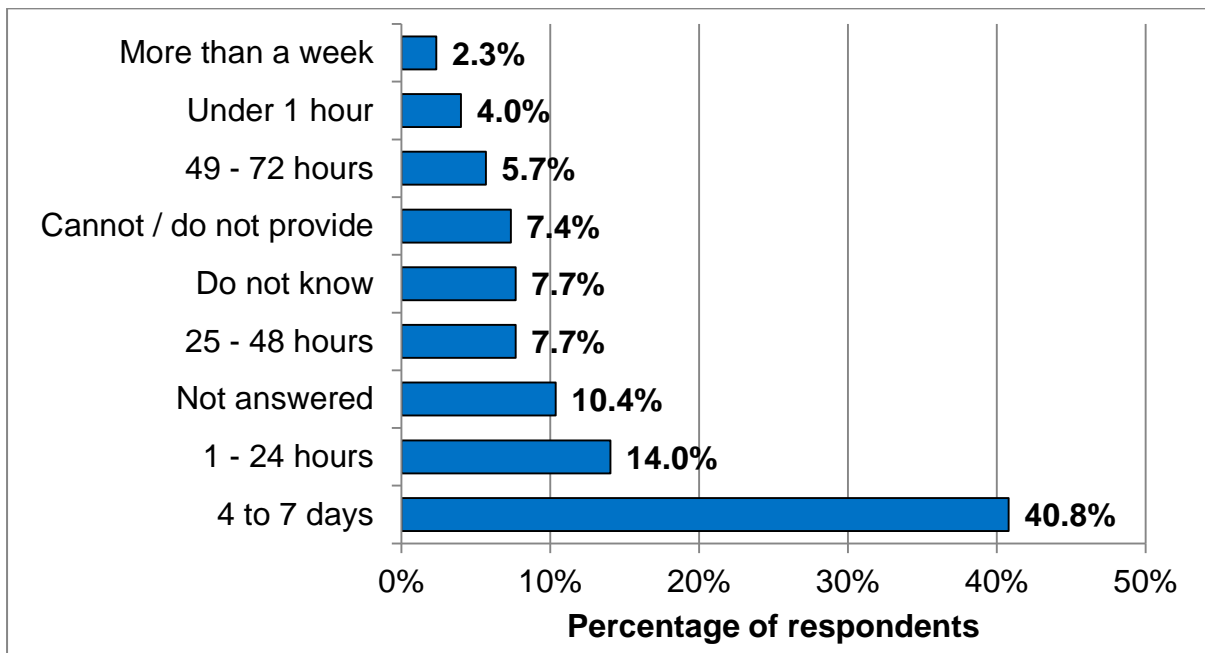
**Figure 35: How long does it usually take you / your organisation to arrange or provide a BSL interpreter online for a face-to-face appointment?**



Source: Accessible Information Survey Consultation, NHS England, 2014

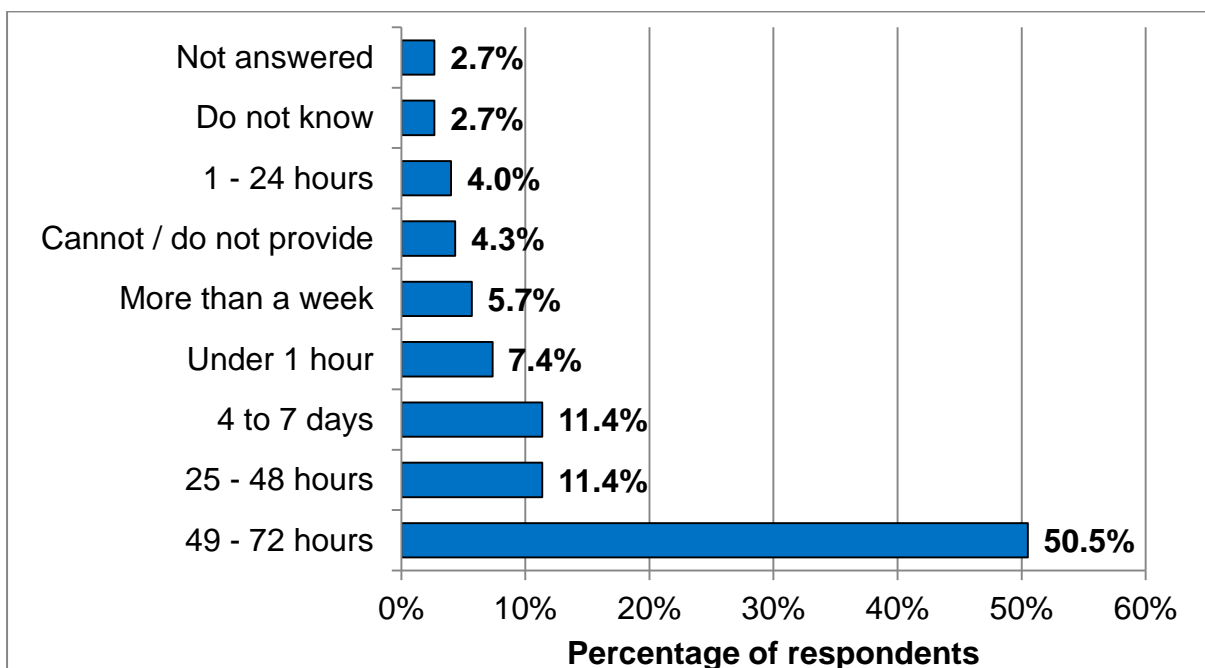


**Figure 36: How long does it usually take you / your organisation to arrange or provide a communication support worker for a face-to-face appointment?**



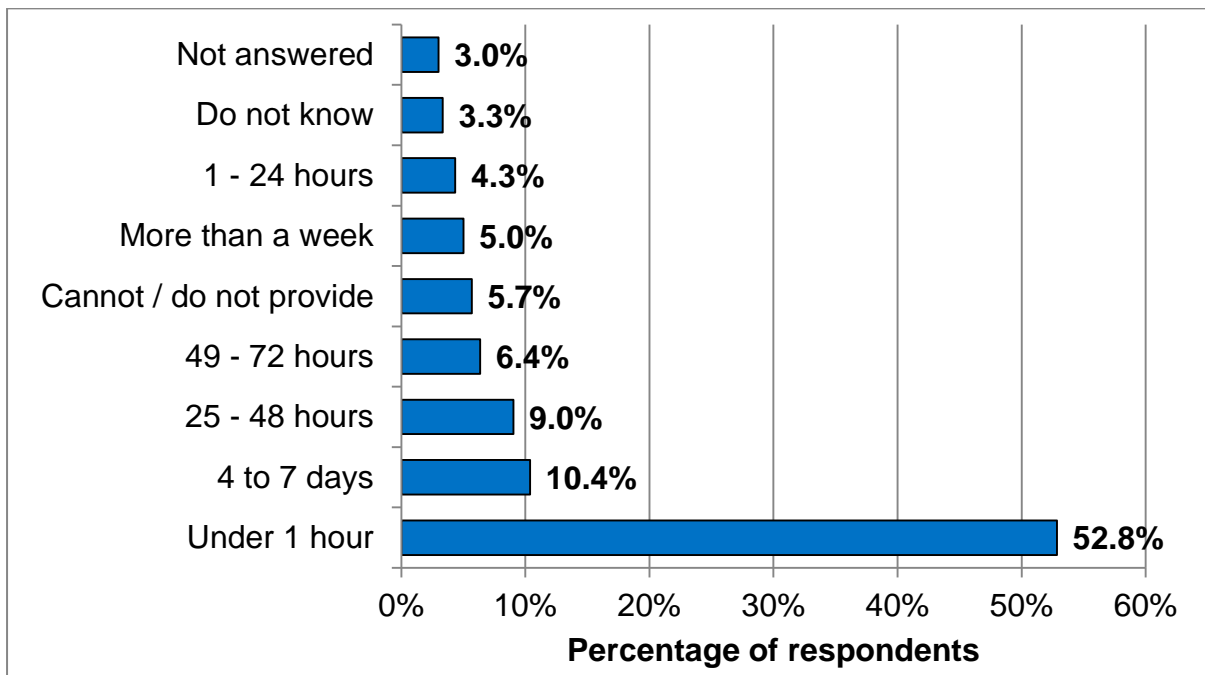
Source: Accessible Information Survey Consultation, NHS England, 2014 **Figure 37:**

**How long does it usually take you / your organisation to arrange or provide a deafblind manual interpreter for a face-to-face appointment?**



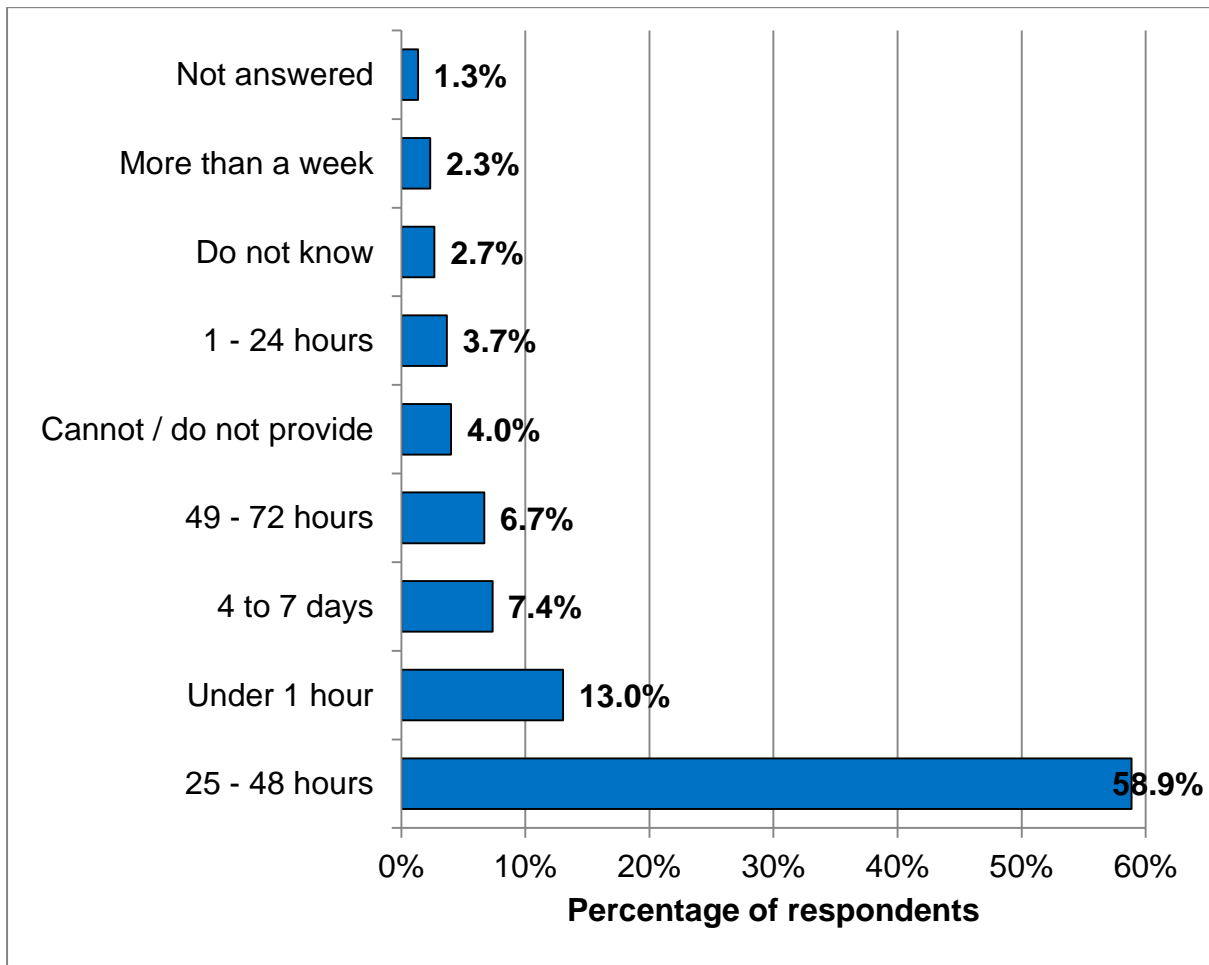
Source: Accessible Information Survey Consultation, NHS England, 2014

**Figure 38: How long does it usually take you / your organisation to arrange or provide a Lip speaker for a face-to-face appointment?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Figure 39: How long does it usually take you / your organisation to arrange or provide a speech to text reporter (e.g. Palantypist) for a face-to-face appointment?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 32: How long does it usually take for you / your organisation to arrange or provide communication support for a face-to-face appointment?**

Format	Time Taken									Grand Total
	Under 1 hour	1 - 24 hours	25 - 48 hours	49 - 72 hours	4 to 7 days	More than a week	Cannot / do not provide	Do not know	Not answered	
Advocate	6.4%	14.0%	8.4%	4.3%	7.0%	14.4%	4.3%	34.4%	6.7%	100.0%
British Sign Language (BSL) interpreter	3.3%	14.4%	8.7%	6.4%	7.4%	9.4%	7.7%	37.1%	5.7%	100.0%
BSL Interpreter online	3.7%	9.4%	2.3%	1.0%	1.7%	4.3%	17.1%	53.2%	7.4%	100.0%
Communication support worker	7.7%	14.0%	7.4%	2.3%	4.0%	7.7%	10.4%	40.8%	5.7%	100.0%
Deafblind manual interpreter	2.7%	5.7%	4.3%	2.7%	4.0%	11.4%	11.4%	50.5%	7.4%	100.0%
Lip speaker	3.3%	5.7%	5.0%	3.0%	4.3%	9.0%	10.4%	52.8%	6.4%	100.0%
Speech to text reporter (e.g. Palantypist)	2.7%	4.0%	2.3%	1.3%	3.7%	7.4%	13.0%	58.9%	6.7%	100.0%

Source: Accessible Information Survey Consultation, NHS England, 2014

### 3.1.14 Question 14

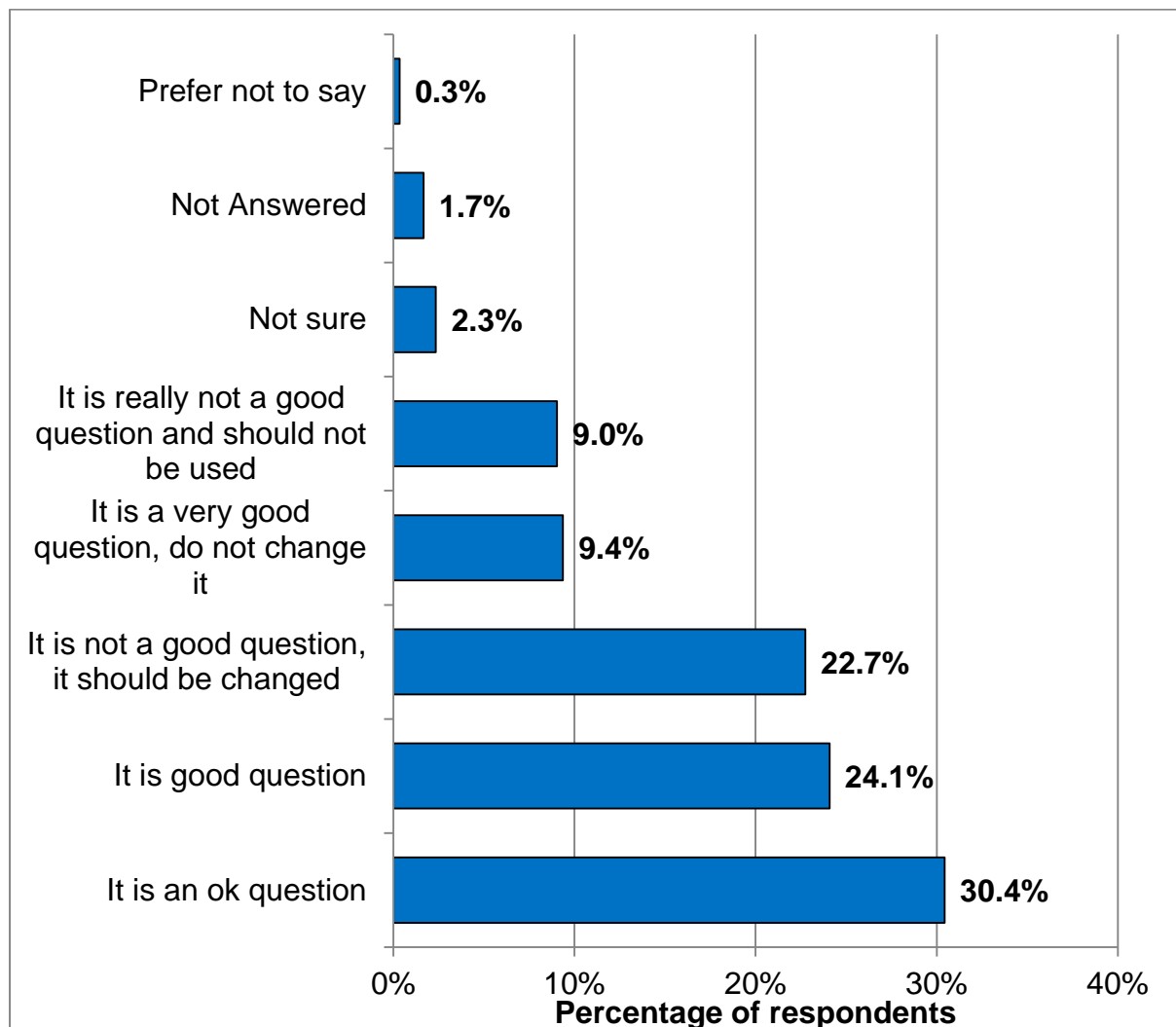
Please see Appendix 14 for the “free text” responses to this question.

### 3.1.15 Question 15

Please see Appendix 15 for the “free text” responses to this question.

### 3.1.16 Question 16

**Figure 40: We are looking to develop a standard question which can be used so that patients', service users' or customers' information or communication support needs are recorded consistently. We are currently considering the following question, with a prompt for recording specific details where appropriate, and would welcome your opinion of this. "Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?"**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 33: We are looking to develop a standard question which can be used so that patients', service users' or customers' information or communication support needs are recorded consistently. We are currently considering the following question, with a prompt for recording specific details where appropriate, and would welcome your opinion of this. "Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?"**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
It is an ok question	91	30.4%
It is good question	72	24.1%
It is not a good question, it should be changed	68	22.7%
It is a very good question, do not change it	28	9.4%
It is really not a good question and should not be used	27	9.0%
Not sure	7	2.3%
Not answered	5	1.7%
Prefer not to say	1	0.3%
<b>Total respondents</b>	<b>299</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 3.1.17 Question 17

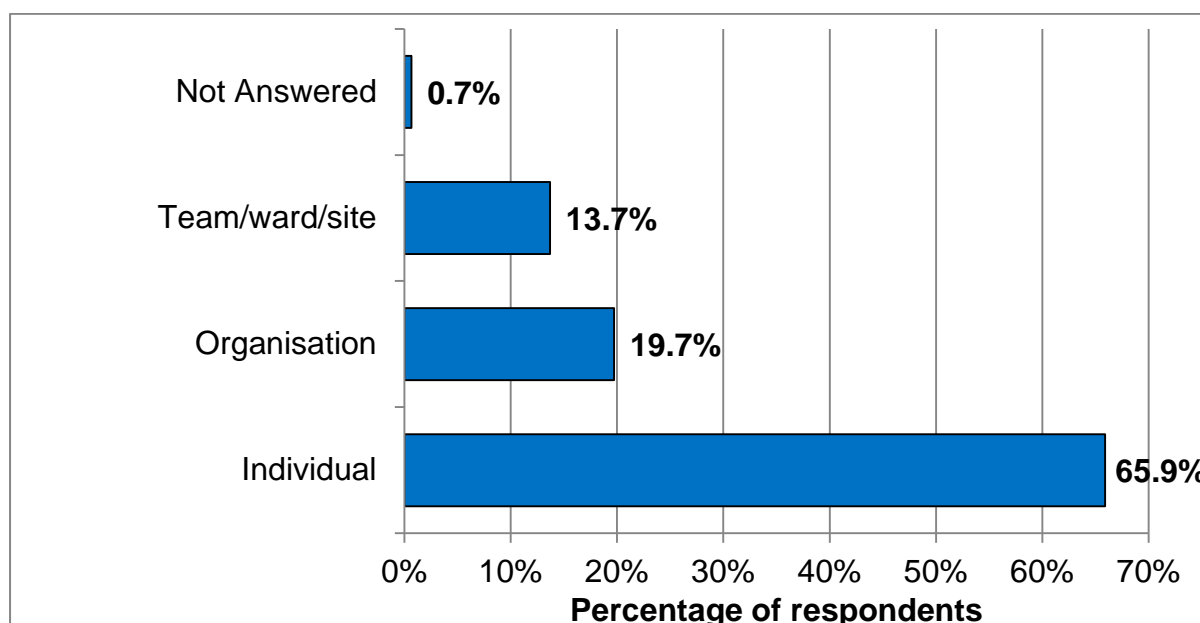
Please see Appendix 16 for the "free text" responses to this question.

### 3.1.18 Question 18

Please see Appendix 17 for the "free text" responses to this question.

### 3.1.19 Question 19

**Figure 41: Are you responding as an individual member of staff, on behalf of a team or on behalf of an organisation?**



Source: Accessible Information Survey Consultation, NHS England, 2014

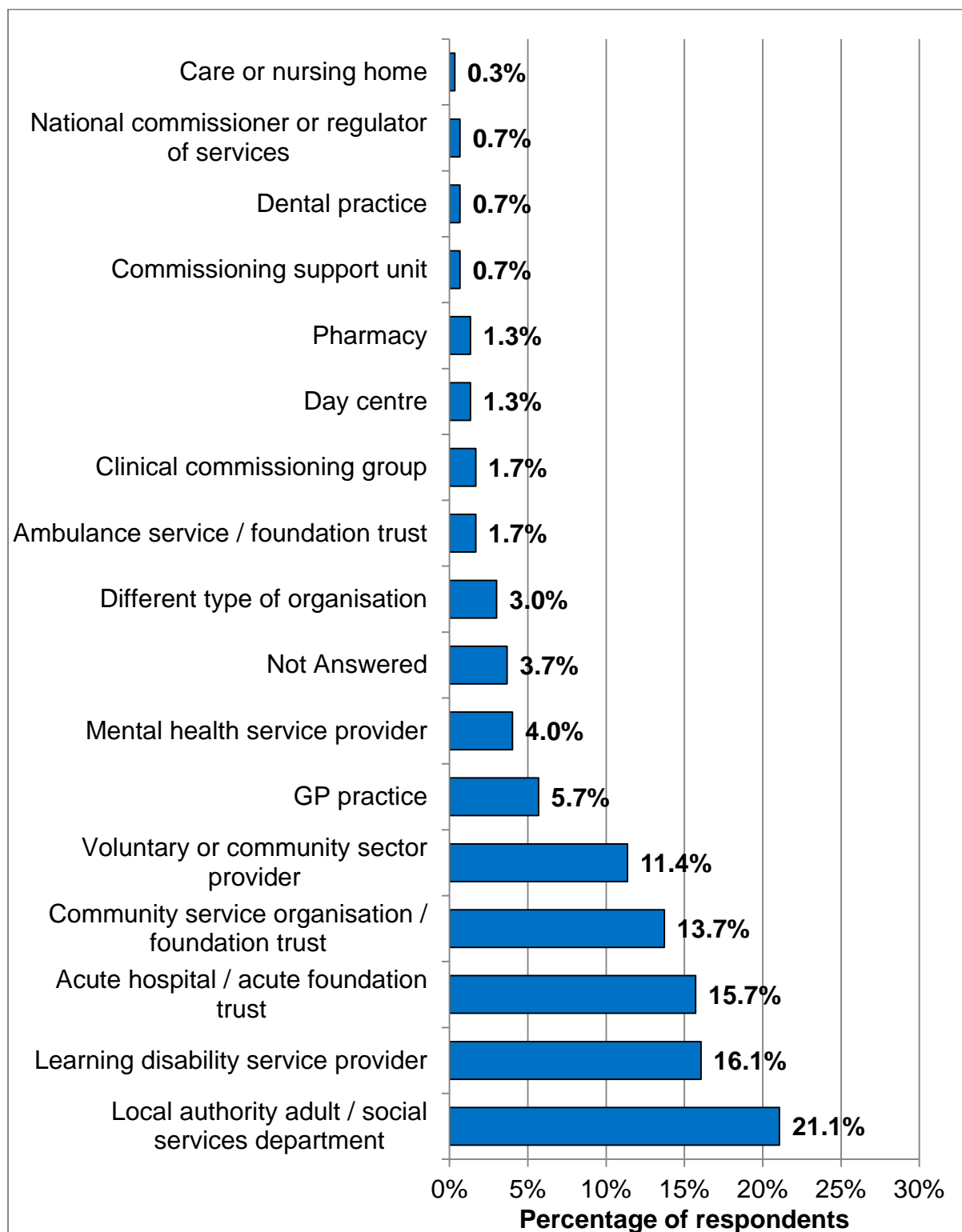
**Table 34: Are you responding as an individual member of staff, on behalf of a team or on behalf of an organisation?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Individual	197	65.9%
Organisation	59	19.7%
Team/ward/site	41	13.7%
Not answered	2	0.7%
<b>Total respondents</b>	<b>299</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

### 3.1.20 Question 20

**Figure 42: Which of the following best describes the organisation you work for / are responding on behalf of?**



Source: Accessible Information Survey Consultation, NHS England, 2014



**Table 35: Which of the following best describes the organisation you work for / are responding on behalf of?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Local authority adult / social services department	63	21.1%
Learning disability service provider	48	16.1%
Acute hospital / acute foundation trust	47	15.7%
Community service organisation / foundation trust	41	13.7%
Voluntary or community sector provider	34	11.4%
GP practice	17	5.7%
Mental health service provider	12	4.0%
Not answered	11	3.7%
Different type of organisation	9	3.0%
Ambulance service / foundation trust	5	1.7%
Clinical commissioning group	5	1.7%
Day centre	4	1.3%
Pharmacy	4	1.3%
Commissioning support unit	2	0.7%
Dental practice	2	0.7%
National commissioner or regulator of services	2	0.7%
Care or nursing home	1	0.3%
Minor injuries unit / walk-in centre	1	0.3%
<b>Total respondents</b>	<b>299</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 36: Which of the following best describes the organisation you work for / are responding on behalf of? Breakdown of answers for a different type of organisation.**

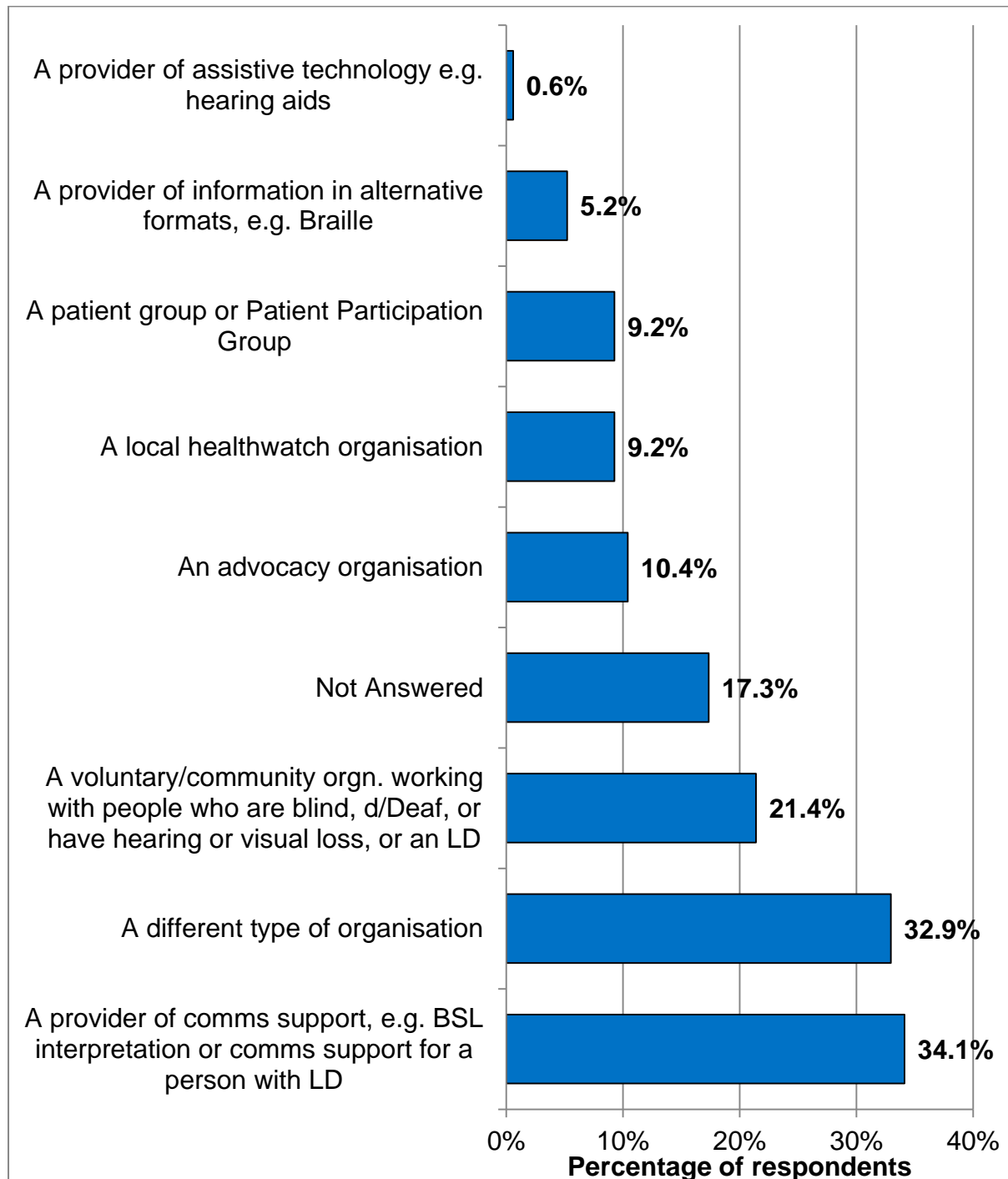
<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Charity	3	33.3%
Police service	2	22.2%
An organisation led by people with learning difficulties	1	11.1%
Public sector	1	11.1%
Sheltered Housing	1	11.1%
The Chartered Institute of Linguists Working Group	1	11.1%
<b>Total respondents</b>	<b>9</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

## 4 Support and supplier organisations survey

### 4.1.1 Question 1

**Figure 43: How would you define your organisation or group, or the organisation you work for?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 37: How would you define your organisation or group, or the organisation you work for?**

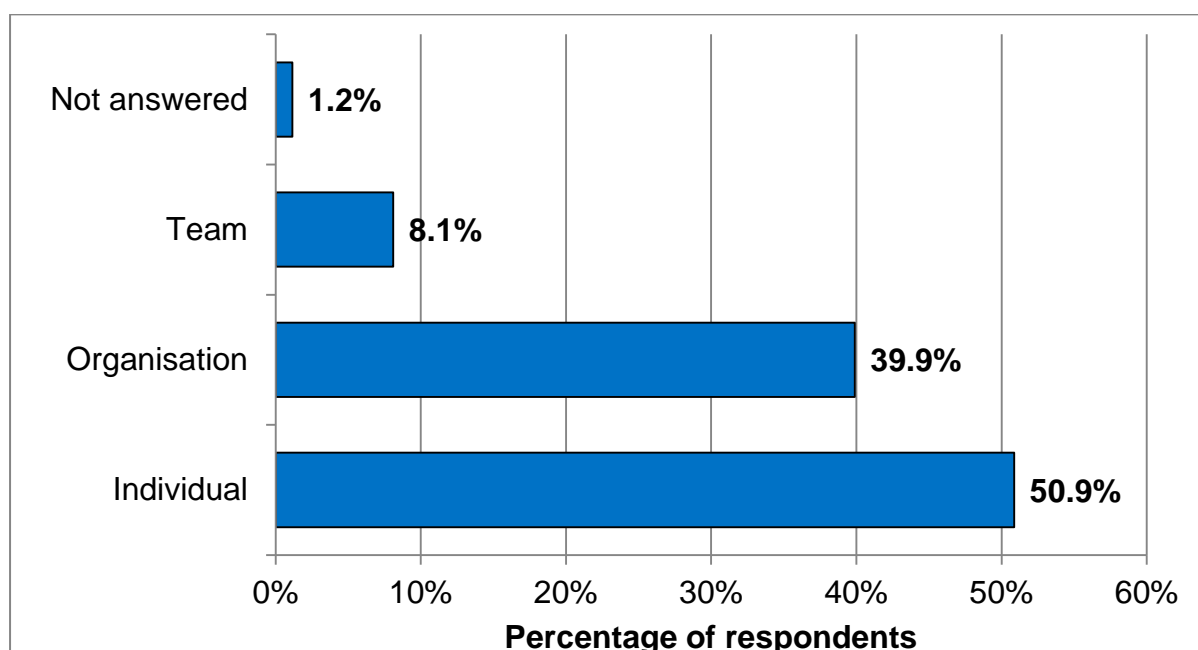
Response	Total	Percentage of respondents
A provider of communication support, for example British Sign Language interpretation or communication support for a person with learning disabilities	59	34.1%
A different type of organisation	57	32.9%
A voluntary or community organisation working with people who are blind, d/Deaf, have some hearing or visual loss, or a learning disability	37	21.4%
Not answered	30	17.3%
An advocacy organisation	18	10.4%
A local healthwatch organisation	16	9.2%
A patient group or Patient Participation Group	16	9.2%
A provider of information in alternative formats, for example Braille	9	5.2%
A provider of assistive technology e.g. hearing aids	1	0.6%
<b>Total respondents</b>	<b>173</b>	

Source: Accessible Information Survey Consultation, NHS England, 2014

Please note as respondents were asked to select all the answers that applied, the analysis is a reflection of the percentage of respondents selecting each organisation type, and therefore the percentages do not add up to 100%.

#### 4.1.2 Question 2

**Figure 44: Are you responding as an individual, on behalf of a team or on behalf of an organisation?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 38: Are you responding as an individual, on behalf of a team or on behalf of an organisation?**

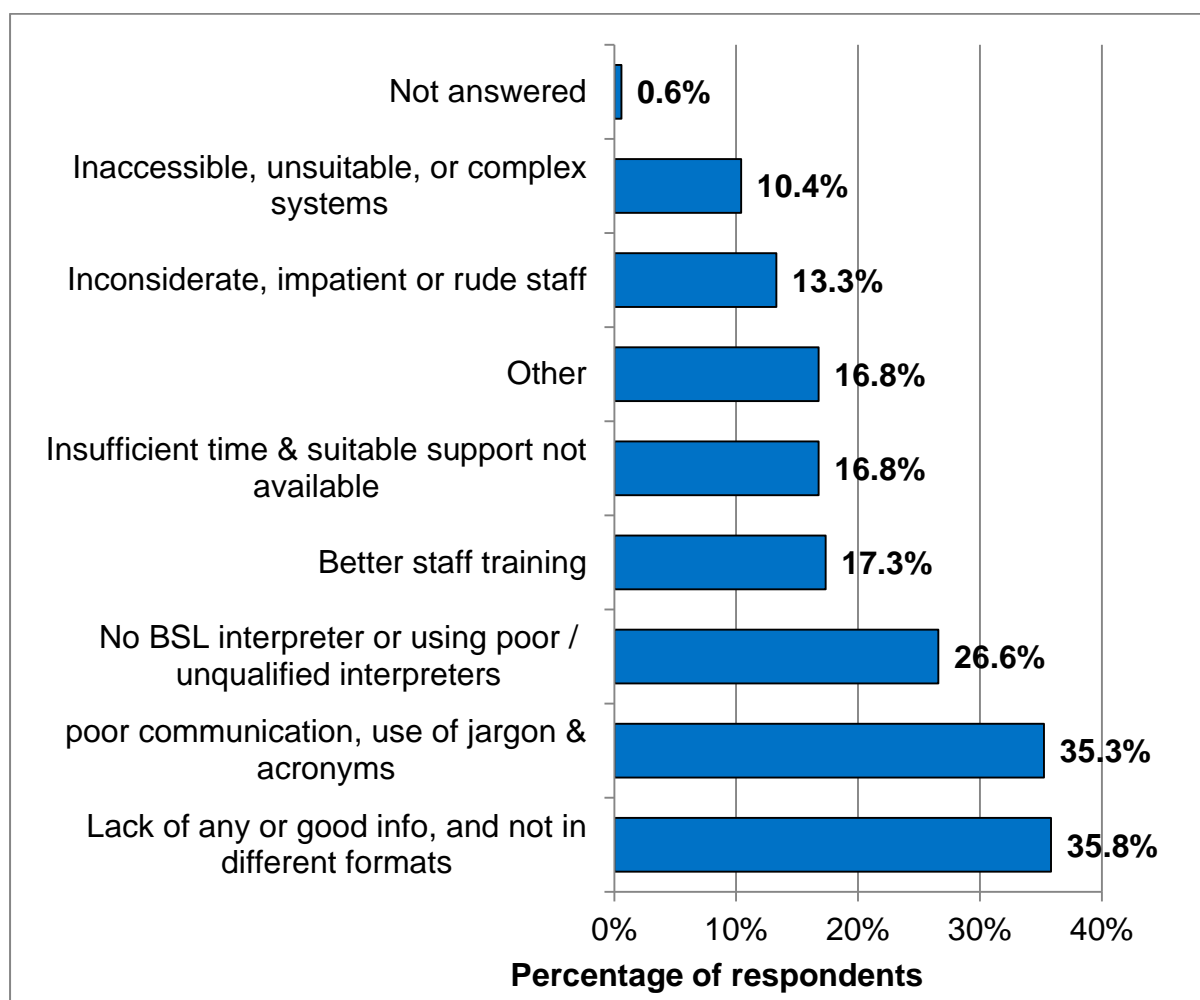
Response	Total	Percentage of respondents
Individual	88	50.9%
Organisation	69	39.9%
Team	14	8.1%
Not answered	2	1.2%
<b>Total respondents</b>	<b>173</b>	<b>100.0%</b>

Source: Accessible Information Survey Consultation, NHS England, 2014

#### 4.1.3 Question 3

The answers to this question were “free text”, and have been analysed and disseminated into nine broad categories, shown in Figure 45 and Table 39

**Figure 45: Based on your experience, what are the key challenges faced by patients, carers and service users who have information or communication support needs when accessing NHS or social care services?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 39: Based on your experience, what are the key challenges faced by patients, carers and service users who have information or communication support needs when accessing NHS or social care services?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Lack of any or good information, and not in different formats	62	35.8%
Poor communication, use of jargon and acronyms	61	35.3%
No BSL interpreter or using poor / unqualified interpreters	46	26.6%
Better staff training	30	17.3%
Insufficient time and suitable support not available	29	16.8%
Other	29	16.8%
Inconsiderate, impatient or rude staff	23	13.3%
Inaccessible, unsuitable, or complex systems (e.g. insisting deaf people must phone to re-arrange appts)	18	10.4%
Not answered	1	0.6%
<b>Total respondents</b>	<b>173</b>	

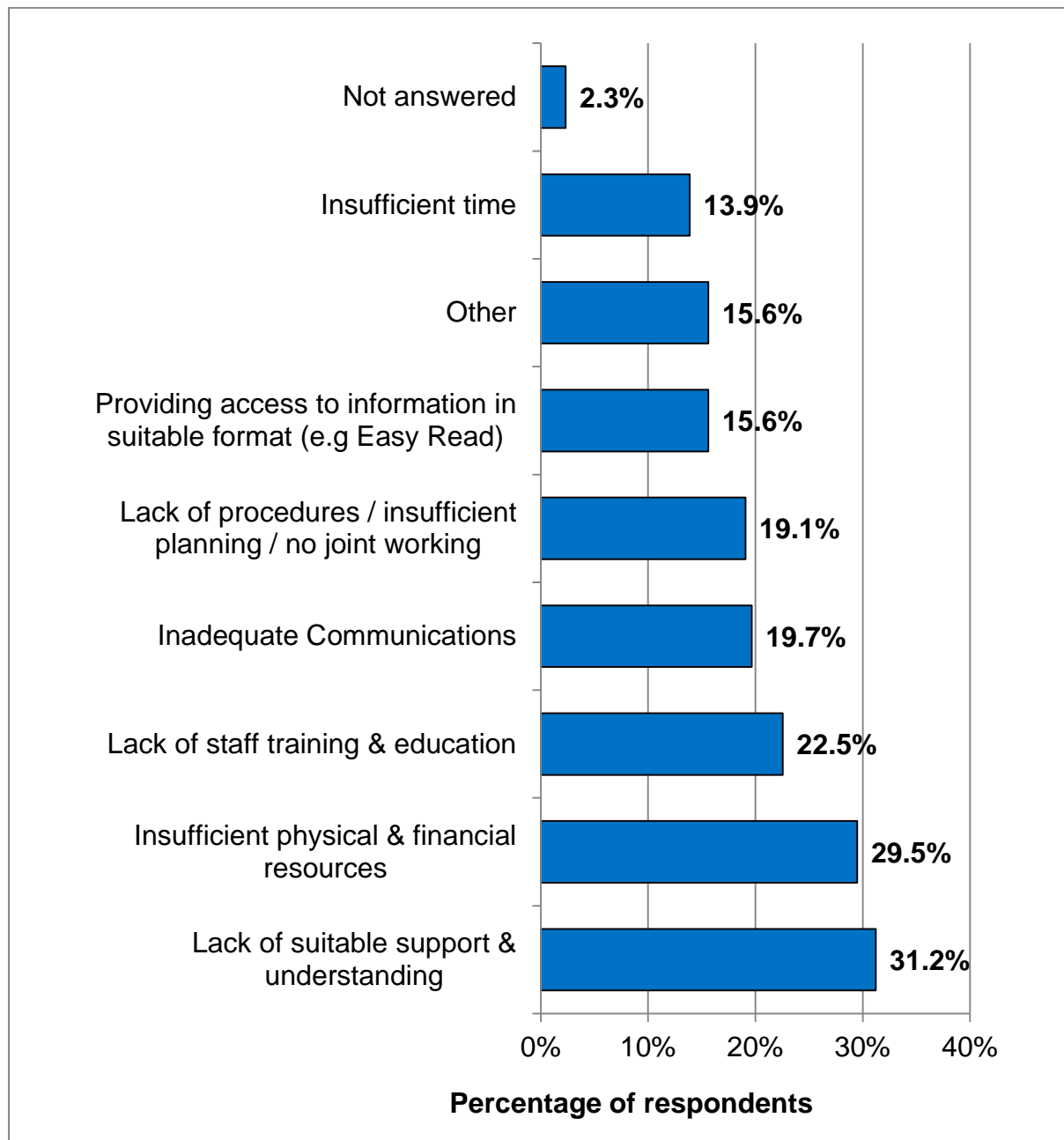
Source: Accessible Information Survey Consultation, NHS England, 2014

35.8% of respondents stated the key challenges faced by patients, carers and service users who have information or communication support needs when accessing NHS or social care services is a lack of any or good information / it is not in different formats.

#### 4.1.4 Question 4

The answers to this question were “free text”, and have been analysed and disseminated into eight broad categories, shown in Figure 46 and Table 40.

**Figure 46: Based on your experience, what are the key challenges faced by NHS and social care organisations in meeting, or trying to meet, the needs of patients, service users or carers with information or communication support needs?**



Source: Accessible Information Survey Consultation, NHS England, 2014

**Table 40: Based on your experience, what are the key challenges faced by NHS and social care organisations in meeting, or trying to meet, the needs of patients, service users or carers with information or communication support needs?**

<b>Response</b>	<b>Total</b>	<b>Percentage of respondents</b>
Lack of suitable support and understanding	54	31.2%
Insufficient physical and financial resources	51	29.5%
Lack of staff training and education	39	22.5%
Inadequate Communications	34	19.7%
Lack of procedures / insufficient planning / no joint working	33	19.1%
Providing access to information in suitable format (e.g. easy read)	27	15.6%
Other	27	15.6%
Insufficient time	24	13.9%
Not answered	4	2.3%
<b>Total respondents</b>	<b>173</b>	

Source: Accessible Information Survey Consultation, NHS England, 2014

Please note as respondents sometimes gave answers for more than one category, the analysis is a reflection of the percentage of respondents selecting each category, and therefore the percentages do not add up to 100%.

31.2% of respondents stated that a lack of suitable support and understanding are the key challenges faced by NHS and social care organisations in meeting, or trying to meet, the needs of patients, service users or carers with information or communication support needs.

#### 4.1.5 Question 5

The answers to this question were “free text”, and have been analysed and disseminated into ten broad categories, shown in Table 41.

**Table 41: Do you have any suggestions as to how the experience of patients, carers and service users who have information or communication support needs could be improved, either generally or in particular settings? Please include any examples of good practice you are aware of.**

Number of responses	Responses
53	<b>Deaf awareness and customer service training including BSL / d/Deaf awareness for all staff</b> (GP's, consultants, nurses, receptionists etc.) as part of their induction, including their legal obligations under the Equality Act 2010 – training via e-learning and led by disabled people. Administrative / reception staff should contact patients using the communication method which works best for them, recognising that this varies between individuals, and should include email, text, telephone, text relay, and include reminders / appointments / test results. Videos shown on televisions in waiting areas and wards should have subtitles / include BSL. NHS to employ more deaf BSL users. Keep continuity of staff. All staff should know how to operate assistive technology. GP and hospital waiting rooms better designed.
31	<b>Easy Read material available nationally in different formats</b> online and from GP practices, hospitals, libraries etc. Posters in hospitals should have good contrast and be easy to understand. Need for a national sensory strategy and public awareness sessions, and nationally agreed standards. Braille on ward doors and signs.
29	<b>Use local, NRCPD registered interpreters</b> / specialist agencies that are long established - they are more cost effective and better quality. Alternatively all Trusts should have their own “in-house” interpreters - easier to find and more cost effective - they could specialise in medical interpreting and be seen as one of the team. Have an NHS and council BSL supported “drop-in” centre. Use specific deaf tailored services and voluntary and community sector organisations.
27	<b>Efficient sharing of information</b> Keep records up-to-date, disability passport, disability flag on systems e.g. for aphasia, systems should prompt GP's and nurses for disability and communications requirements for patients, integrated care records/central repository
20	<b>All hospital and GP surgery staff should know how to book a BSL interpreter</b> - some good examples of Trusts with arrangements and systems in place particularly for BSL interpretation. Specialist / dedicated nurses to support people with learning disabilities on unplanned admissions
17	<b>Use different methods - one size doesn't fit all</b> - e.g. Better use of assistive digital technology e.g. using text, sending letters by email. Provision of Speech to Text Reporters, Lipspeakers and online interpreting as standard (as well as face-to-face interpreting where



	appropriate). Good practice examples of partnership working between NHS Trusts and voluntary organisations, including outreach services / services in people's own homes. Allowing patients to contact their GP by SMS, use of smartphone / tablet with speech recognition facility
15	<b>More involvement with patient groups for all disabilities and self-advocacy organisations</b> , for example to help in designing communications systems, and to check Easy Read documents prior to publication, in design of service delivery, also use for peer support.
14	<b>Ensure all NHS appointments with a d/Deaf BSL user have a NRCPD registered sign language interpreter present</b> - this should be included in all NHS policies. The interpreter should be automatically booked when the appointment is made and the patient given the choice of male or female interpreter, and an early confirmation sent to the patient confirming this to stop them worrying about it.
10	<b>Longer time for appointments</b> (Inpatient, outpatient and A&E) for people with communications difficulties - these take longer when an interpreter is needed for translation. Also enable complaints / feedback process suitable for deaf people, and one to one communication
3	<b>A small team to take responsibility for quality and standardised information</b> - The Information Standard mark is a sign of good practice. Explain what all acronyms mean in all NHS and Social Care documents, and put more public service information in BSL.

#### 4.1.6 Question 6

Please see Appendix 18 for the “free text” responses to this question.

## 5 Appendices

### Note on 'free text responses'

Note that appendices contain 'free text' responses. In the interest of transparency, the free text responses are published verbatim and do not therefore represent the view of NHS England. Responses are unedited except:

- where information identifies, or may identify, an individual or organisation;
- references to brand, company, trade or product names;
- details of websites / blogs;
- text copied from other documents in full;
- language or opinion which may cause offence; and
- comments which are irrelevant to accessibility in health and social care.

Wherever text has been removed for one or more of these reasons, this is indicated by way of square brackets [...] Obvious spelling errors have also been corrected for ease of reading. In the interests of document length, in longer responses, text which has been separated by spaces is listed as part of a paragraph, with appropriate punctuation.

### **Appendix 1 – Patients, carers and service users survey, Q8.**

**“If health and social care organisations always gave you information in a format you could understand and if you always got the support you needed to communicate, what difference would this make to you?”**

I can see pictures. The writing would be in large print and not small letters. There would be no jargon words. I can read it properly. I can understand it properly. It makes you feel better about it when it is easy to read. There would be no difficult words because we would understand it better. We would not have to rely on anyone else to understand what is being said to us.

BSL Interpreting support is vital for me as out-patient and in-patient in all NHS hospitals as I miss too much important information. Only when this support is in place I shall feel safer. Presently NHS hospitals are DANGEROUS places for all deaf patients!

A huge difference. I could be totally independent re health and social care instead of having my privacy violated almost for every communication about my health and social care. BTW, if there were categories to choose here, I couldn't find them in this version of the form. A bit ironic, that.

I would find it very helpful. I am totally blind and my wife/carer usually accompanies me on these visits

This would be amazing! I would feel less disabled. I would feel more independent and less reliant on others.

It would make it a lot easier with BSL video clip and or Subtitle video clip and also have BSL interpreter at the appointment to ensure clear communication and not to miss out anything that I don't understand.

It would make me independent as I would not need to ask anyone else to read the information for me. I would then be able to make informed decisions about my health care.

I didn't realise that it wasn't clear so I didn't understand any of it; it just went over my head. It was poor; I did not understand any of it. It would be better if it was formal BSL conversation; with the interpreter it is not clear at all. I don't understand the interpreter. It is not clear at all. A hearing person to another hearing person talking about/for a deaf person; I feel it is not right. I feel left out of the conversation.

It makes me feel better or confident so I can understand it

It would help me understand better about my health conditions. It would also reduce the stress having to understand the information and enable me to focus on my health to get better.

If NHS and social care give the suitable provision that matches my needs it will change my life. It is a better quality and standard of living. Better health and social knowledge. It is better and you can influence your friends around you as well. For better quality you need to listen to what we want and need.

If they made information in our format (BSL, visual) then it would make a big difference to our lives because we will understand everything clearly. What happened? Why? Everything could be better understood.

I am more confident and happy that I am being included.

Makes me feel more confident about things.

I feel happy if I have understood what has been said, my staff are good at communicating to me in an easier format.

I live with my mum and dad. When I need to make a phone call to the doctor or nurse my mum phones them for me.

It makes me feel happy!

I feel better when I have things explained to me.

I do not read or write so I need support to be told what information is in letters and to fill in forms etc.

I do not worry because I feel I get help when I need it.

When I speak to doctors they give very long descriptions. It would be easier to get things written down so I don't have to rely on memory.

It's very good when I get all of the information I need and I get very good communication support and all of the information is very good all of the time.

Makes me at ease as I know what they are talking about.

It makes things easier for me to understand things.

It makes it a lot easier to understand.

The person I support would be more informed and empowered to make choices.

It helps me a lot.

It makes me happy!

Relaxed!

It helps me to live my life.

Good and included.

This helps my support workers to look after me properly as they organise all my appointments and daily routines along with my parents.

The doctor always relies on written information that is passed between us. I am trying to explain the problem with my ear and I constantly have to write everything down. I do not have very good English. They only ask questions, but never explain what is going on. I ask my mother why, she told me they need to check my blood levels and if there is a problem they will send a letter, but I waited a long time, it never arrived. I asked my mother to phone because I can't communicate by phone, they said it was alright. I am healthy.

I would not be reliant on friends and family

With the services, such as hospitals, social services, and interpreters, I would like to know more about interpreter services structure, such as complaint procedures, regulations and so on. I hardly use Social Services as I feel they are more focused on more vulnerable types of people. I would love to know more information about health issues and social issues so I could share it with the Deaf community, and point them in the right direction to appropriate bodies. I would like to have some knowledge, as knowledge is important.

Visual graphics on DVD in private - easier and protect my name (anyone don't know what my health issue)

If I ever get full information from NHS and social services, then I will be more comfortable. This would mean not just interpreter, I mean very accessible resources, such as easy to read, visual aids, and so on. Not just an interpreter! Then I would be really comfortable and going home feeling safer. I can share with my family the sense of security and so on instead of being in doubt and not knowing what to do. But this is wishful thinking.

If you help me feel more confident and understand more

When there is information, and no interpreter, it is more difficult. Sometimes they are [...] so I have no chance of understanding them. I can sign to them, but they do not fully understand me.

If I get full information from the NHS and social services, then I will be more confident and understand a lot more. I will feel good and it will be good for me.

Makes life easier

It varies, I understand information from Social Services, but with NHS I only understand some of it. It varies.

If the hospital provides interpreters, or deaf friendly resources, I would certainly understand what's going on. I believe that every hospital should be Deaf aware. When I am in a waiting room at hospital, I often miss out my name being called out, so I had staff approaching me. This can be embarrassing, unless they come for me without calling my name. Sometimes I just sit there and wait for an "awkward silence" where everyone starts to wonder who the person is, and then I check if it is me or someone who hasn't turned up.

The difference with interpreters is that they help me understand English because BSL is my first language

Yes I find I do get the right communication from doctors and NHS

I am able to understand

Able to understand

Feel happy and at ease

Makes things better for me

If I understand what has been said I feel much better and understandably it helps me understand things better

It helps me do the right thing

It would be helpful to me

It does help you to get the right information

Makes me feel happier about getting there

I feel happy

Support stops me worrying

I feel happy

Makes me happy

When I am given information in a way I can understand it makes me feel good, it makes me feel safe and I feel better about myself

It makes a big difference

I am happy when I get the information, but sometimes I don't understand what people are saying, so I get confused

Have a choice. Understand what's happening

I am able to understand more when the communication support is correct

Understand instruction better

A lot when we do ask we invariably do not understand what is being said

Understanding

All the difference

Reassurance. Gives me choice

Helps to be more independent and mix with others

It's important to get right info

Understand more, feel happier, helpful

Very helpful

I have aphasia and find it hard to follow information and need people to go slow and make eye contact and gesture to help me understand

It helps to understand and not get confused

Yes but understand some info when I received communication support

Yes but I understand some

Help understand

I've seen lots of different doctors; I don't always understand what they say

Helps me with good health and I'm able to make the right choices

I feel scared if I don't understand all the information. I feel better if I understand what people are telling me

It makes me feel happy when I get all the info I need and communication support

Get worried, don't understand, confused. Decisions will be made which I don't understand, hard to take part. Good how they know you, makes me feel better, less worried, and happy

Feel good

If I get the right info I feel better, and if I get the wrong info it makes me angry

Considerable

It helps doctors if they know you have a learning disability

I go to my [...]. I makes me think about things?

It is good and makes life easier

Happy

It makes me happy that I am getting support

To date all the info I receive I have no problems in understanding

A big difference! Ps I don't see the need for this question

To help you make decisions for yourself

You feel you know what's going on. To help you make decisions for yourself. It gives you confidence to say what you need to say.

It gives you confidence to say what you need to say.

You can change your life

You rely on less people

I ignore info that is too difficult

I would ask my carer for help if it was difficult

Makes me feel happier

When I get the right info it helps me because then I know what I'm doing

Its better for me when I understand more it makes me feel better

Makes life easier

It makes a lot of difference as know what is happening. If it comes in braille or audio I can read info myself and understand it a lot more

I understand better; it is clearer, help me better with info that is sometimes difficult to understand

It's upsetting when I don't understand. I feel lonely. It makes me nervous to ask people to repeat something when I don't understand. I feel better when I know what is going on.

When I don't get right support it's not helpful. It makes me feel bad when people talk to my carers. If the person asks me first I can say what I need, it's about me not other people. After talking to me they can talk to my carer.

Suffers from multiple downs

My mum explains everything to me, but I still don't understand everything

I can understand better

Makes life a lot easier

I get anxious and upset when I don't understand. Also don't understand [...]

Less frustrated and happier, I don't understand [...]

It makes it a lot easier if they give you proper info. Word large enough so you can read it. Pictures to go with writing. Picture on left writing on right. Font 18 plus.

It makes me happier if I can understand it

I feel cross and don't understand the letter

Good

You can understand it better; otherwise you might miss out on appointments and things

It gives me confidence

It is really helpful

I can understand everybody

I am deaf and blind. A lot of info is given to me in paper and it is very difficult to read as they are too small. Prescriptions are worse. It would help to have a card that I can show to the pharmacist to identify my medication and benefits. I cannot read the prescription part 1 relating to criteria for non-payment. It would help me to show a "credit card" to show my criteria rather than having to answer the pharmacist because most of the time I don't understand them especially when they ask for my name and address. Another proof would be id through a photo or thumb print

Make my life easier. I need a companion, carer or parent/relative to accompany me on any visit to GP or hospital to assist me in simplifying what they are telling me (have learning difficulties)

Feel more relaxed and re-assured

I don't lose my temper I feel happy

I am not getting good info. I am not getting support from social care, and I'm a carer (unpaid) and get very confused and mixed messages - I'm deaf



I need an interpreter because I can't speak or hear what the GP is saying but need GP to explain. Someone missing out as I was in bed with flu

Feel more confident and less anxious

Same equal as hearing peers

I feel valued and that I am a person not just another name on a page

Speaking to me is good, written communication is not good

Helpful

Big difference

A lot

To know everything I need to know

Info needs to be shared with the individual in a way which they can understand - an individual may need a carer or a second person to help interpret some info

Helps understand what is going on and helps me to deal with it

I feel safe and secure in what is going to happen

It helps me in my choices

Helps me to understand things

A big difference if get large print

It makes me feel happy and safe

It makes me happy, and feel safe, it's helpful

It makes me happy, feel safe, helpful

Good and included

This helps my support workers to look after me properly as they organise all my appointments and daily routines along with my parents

More confident and happy to be included

Makes me feel more confident

All right

I feel happy if I have understood what has been said - my staff are good at communicating to me in an easy format

I live with mum and dad when I need to make a phone call to the GP or nurse my mum phones them for me.

It makes me feel happier

I feel better when I have things explained to me

I do not read or write so I need support to be told what info is in letters and to fill in forms etc.

I do not worry because I get help when I need it

When I speak to doctors they give me long descriptions - it would be easier to get things written so I don't have to rely on memory

It helps me to plan ahead. If there is any info about which I can't read I still want to know

Its v good when I get all the info I need and get very good communication support and all of the info is v good all of the time

Makes me feel at ease

It makes things easier to understand

Makes it easier to understand

They would be more informed and empowered to make choices

It helps me a lot

Makes me happy

Relaxed

Helps me to live my life

By receiving the support I need to communicate would put me at ease, lessen the frustration I would otherwise experience and I would be able to express my concerns more freely. If I don't receive the communication support i.e. a BSL interpreter, I would rely on pen and paper which isn't always very effective

My husband and I both rely on accessible formats. I can read standard print provided the lighting is at the right level and my reading glasses are in one piece – currently they are not. As a renal patient my results are on an accessible website, but the IOU's that come with the drugs home delivery service, are not. Consequently, as I write I am waiting for the remainder of a delivery, which took 10 days to sort out because I could not read the IOU. For both of us we would be certain of attending appointments and missing them due to the inability to read the letter. My husband could keep his medical results/appointment more private. When I am unable to read our mail in standard print there is less need to rely on my elderly Mother-In-Law to

read or complete forms. In summary the important thing is greater privacy and less cost to the NHS and GPs in missed appointment

I understand better when I get the information

If it was in Easy Read I could understand it better. Most of the booklets are too hard to understand

It might prevent an early death

[...] of a difference.

Better understanding

[...]

Social Care personal don't do assessment right and in case of recommendation being made by a qualified person who understands the needs of deaf blind person. Social worker tries to ignore recommendation but is not qualified and does not understand deaf blind person.

I believe if all the information made available by health and Social care organisations in a British Sign Language Format, then I would have access to full information from these services.

Easy Read English, is not applicable to myself as a BSL user, as I understand the English Vocabulary quite well, and would like to receive this information as stated in the right "English" context, not simplified English, which is appropriate for others. Also, having this information in a BSL context means I can refer back to the BSL translation if I become unsure or need to revisit guidelines.

If I got the support I required, it would mean I have greater independence and confidence away from family members who try to assist, and if I have any worries or concerns, then I don't have to inform a family member about it, giving me the right to privacy with issues concerning myself. This would put me in "Power" to make my own decisions regarding my health and welfare.

I am profoundly deaf and rely heavily on lip-reading or BSL but I always have to take my mother with me when I attend hospital appointments because a BSL interpreter is never provided for me. It would mean more independence for me if I have the support that I need, and do not need to rely on my mother anymore as I am 23 years old which is pathetic.

I am a carer of a person with learning disabilities. I believe all publications/communications in health and social care should be in EasyRead as a matter of course at the same time as mainstream publications. We should not have to request or it should not weeks after mainstream messages.

I would as a blind person: 1) Feel involved. 2) Feel empowered. 3) Get the information I need for my care. 4) Not feel so insulted in that I am not the first to read a letter from my consultant - my carer is and that is not right

Written format and needing the person who is speaking to me to repeat or write it down would help me greatly. If I requested a support worker as well as using one or all of the above, it would help me to keep my independence.

I would leave the doctors or health care knowing everything I need to know and what happens next.

I would be equal with everyone else

It would ensure that I could maximise my independence, exercising meaningful choice and control over my life. I would be better informed about health and social care options and services, especially those which are directly relevant to my health and medical conditions.

A great difference. I wouldn't feel like a nuisance ( because sometimes your made to feel like that) hearing people have no idea what the deaf or hard of hearing have to put up with if you have to ask someone to repeat what they have said or signed!

It would be first point of contact!

It's would make my life so much easier, its gets very frustrating and upsetting not being aware of services that can make life easier

I would not be so stressed or reluctant to go to my GP (I have to book appointments in person and despite complaining they have never sorted out my access needs so I gave up.

NHS appointments hospitals lack of deaf awareness means I spend considerable time on alert waiting to lip read my name bring called and why are staff so lacking awareness they then patronise you?!

[...]

It would make a huge difference to the access to care I need, the communication and of course obviously I'd be less stressed and anxious as not just having to deal with the issues at hand but communication could be so easily sorted.

Would clarify and be inclusive and not speak down to me/cause me to feel less than anyone else. I am not stupid just because I cannot hear.

It would allow me to understand my health better, and get advice from professional trained medical staff potentially help me to live longer and perhaps save my life. Accessible information mean I can learn about any health conditions and make sure that I will manage prescriptions or diet, exercise correctly.

I would be confident that I had all the information I would need

Appointments via email I am blind screen reader user.

All information available either via download in word format or in audio

it would make me feel more valued, and would allow me to be more informed, and not miss appointments etc. and not get anxious about trying to work out appointments with my support workers etc. as I would know what was going on and when.

A massive difference

I would feel included and informed, and on a level playing field with everyone else. I would feel safe

I would not have to rely on others in order to access information. I would be able to attend appointments independently. I would be able to make informed choices after reading literature myself, rather than hearing someone else's interpretation of the information provided.

I would be better informed both as a patient and as a Carer. I would be able to make informed choices rather than relying on someone else either making the decision for me or giving me the information they think I need.

I need larger print information not just about my appointments as a disabled person but also my daughter who has disabilities.

I would not have to rely on finding help to understand communications.

I wouldn't have to rely on others to ask questions about me on my behalf or to read sensitive private and confidential documents and information (such as my health records) that sighted people take for granted that could be spread around leading to embarrassment

I would not have to rely on carers and friends.

It would mean I could manage my own private information for health and social integration. Currently I am completely dependent upon others to read it to me. There is no privacy or independence.

Makes me more independent, not having to get others to read and check the information for me.

Better understanding of services available

It would make understanding situations quicker and easier and make me feel I was included in the "normal" range.

I would understand it better and not have to depend on my wife or children to read small typeface to me

I could be more in control of my life, it would build my confidence and if wouldn't sit in every day waiting for friends to have time to take me out and help me do things. I can go 6 weeks without going out.

My finances are in a mess as is all my post because I just can't cope with it all.

I do not have a social worker in fact I had one for two days in October 2010

It would benefit me in several ways, examples included: (i) able to understand the information fully without difficulty; (ii) reduce the feelings of stress and anxiety when trying to understand the information in English; (iii) it will save me feeling embarrassed of having to ask hearing people to translate the information for me; (iv) by having BSL information made available, it will make me and other Deaf people feel valued as member of community; (v) having information in BSL will save me from having to disclose about, for example, the health issues to hearing people that I would not want them to know (e.g. family members or friends).

It would make a lot of difference to my life e.g. save me time and frustration. I would also not be anxious about missing out on important information.

They should have visual information and some kind of training in Makaton sign Language.

This would be very helpful. Otherwise I have to rely on someone else explaining or remembering what I am told.

I would have a good understanding of personal choices for myself, my children and my elderly disabled father whom I care for.

This would make me able to understand what the doctor/nurse is saying to me in a much clearer and in finely graded steps.

It would give me confidence and enable me to manage my needs independently.

I have Asperger's and find it hard to understand a lot of written information. When I was diagnosed the NHS autism service in [.....], [.....] sent me a huge list of services which could help me. This was pages long. I am unable to use the information without support to summarise and identify the most useful parts of it to me, thus I cannot access the help available, if any. Support from a care worker or OT or anyone like that does not seem to be available to high functioning autistic individuals.

I would be able to self-manage my problems better. I would understand exactly what was wrong with me and what treatment was being considered and how to do my wound care.

The biggest problem is [...] who speak too fast!

It is also very frustrating if you are laying in a low bed with the care staff, doctor/nurse/ carer towering over you! Why don't they sit down and talk to us at eye level!

I would be able to manage any health conditions I have more effectively and to understand more about my own health.

This would greatly alleviate my son's anxiety, as he has problems with communication. They seem to think I as a mother should interpret, or worse of all, they talk over and above him as if he is not there. [...] can understand some things, but not all, and as a result he rocks or makes noises. He is trying to join in.

I need coloured paper as I have severe dyslexia and [...] I'm never asked even writing this there are no choices for coloured background etc.

I always receive letters on white paper no one asked me ever if I need the letter in a different format.

More informed and more empowered to make right decisions

It would give me back my independence and prevent me from being excluded.

It would enable me to make choices that I cannot do at the moment

We would be up to date with all current information, we would be able to make the same judgements as the sighted world, have greater independence and privacy.

Equality of access to information, services and choices.

Yes a big difference as it would help to improve the quality of life and have access to information that can help to prevent deterioration of physical and mental health.

My treatment and support would make more sense. I could have a plan which would support me and other people involved in my care and support.

It would ensure that I am able to understand what the plans are for my future care. It would help me understand what my options are. It would help with communications with my family and carers in the future. I would have the opportunity to express what I would like to happen and more importantly, what I do not want to happen.

It would mean that I did not need to always rely on my wife or a third party to summarise the information provided or give me the help through the application process. It would mean independence.

It would make it easier to understand. No long words and it would explain things better.

It would make a difference and make it easier to understand things.

It would make a significant difference at times of great stress. Cancer patients have the support of [.....]. Their support is excellent and they understand the whole system from health care to social care and rehab.

Much more engagement in the process and much better outcomes as a result.

Online access to my own records, and the person for whom I am the carer, would help tremendously!

A lot because it would enable to discuss any issues properly.

This survey itself only mentions BSL provision, something used by a tiny number of the UK population. As a deaf person I need lip speaker or speech to text support for some appointments. The health service does not have a clue about this but offers BSL which I do not use!

It would make these aspects of life less frustrating and confusing, when you have to keep asking and explaining why you need something in a different format, it is very demoralising and sometimes you feel like not bothering even though it is in your best interest to do so. It is often difficult enough dealing with health and social care needs without this added burden. It would remove an additional unnecessary layer of difficulty.

If THESE questions were easier to understand I could answer them better

I would fully understand my condition(s) and treatment / management options without having to rely on communication support provided by my mother - which compromises my patient confidentiality and dignity.

It will make my life more easy as I do not like to ask but if it was very clear what I am entitled to and how I can get help that will be a big change to me

Massive difference having lost a large percentage of my hearing I find it difficult when attending hospitals to hear my name called out. Laughably the ENT clinic I use have an announcement system installed it would seem but never use it for the hearing clinics! Illuminated scrolling signs similar to those used in some doctors surgeries would be a great help for starters. I would regain some independence too giving a feel good factor.

I will fully understand what are available for me, more clearly about the options and the side effects, so that, I can choose the best treatment myself.

I would like hospital appointments either via text, email or in braille so I could read them myself and results via the same way so that I had total privacy. Also when information is in a print format missing an appointment becomes a concern as people aren't always on hand to read the post. Blind people and other people who can't read should have privacy and independence like anyone else.

LOTS. Have already spent 4 months worrying I would be diagnosed with breast cancer due to misunderstanding consultant!

Psychologically it is amazing not having to ask for help and just having information available in a format I understand. It makes me feel more independent and less of a burden on people.

Just some information would be useful I have lost my hearing and other than hearing aids I have never been offered any more information or support

Give me access to get best of the services available.

A huge difference; it would take any stress out of the process of health appointments and struggle out of reading any NHS communication sent to me.

An early check-up would be appreciated, but then I don't get them anymore for skin cancer, so I don't suppose they will ever come back for deafness or checks on hearing aids. It seems you have to go private now and be expected to pay up to £2000 for a hearing aid



Will prevent from worse like mental health problems

More confidence to know and how to cope the problems

Booking appointments online is not always possible. Sometimes I have been advised that I have to phone and I am unable to do so.

It would enable me to fully understand what is being discussed. Because a lot of the time I only half understand.

I could actually use the service instead of taking up time and resources trying to obtain the minimum of help

My privacy would be respected and I would be able to handle my health issues in a confidential way, as I am entitled to it by law. I could make my appointments earlier if I got the right information on time and I could read it, therefore I would avoid many health problems to myself. I would feel much more confident using the NHS Services because I would have equal opportunities.

To understand why decisions have been made and what alternatives have been rejected or not considered.

I would be able to understand what is happening better and what staff are planning to do. It would also help me to be involved in decisions rather than someone else always making them for me.

Accessibility via online resource would be very beneficial. There is no online access to my health or social care records/data

It would make it easier to self-manage LTCs

Huge.

I speak as parent of a man with learning disabilities and am answering questions on his behalf. Some professionals are really good at making sure people understand as best they can, and check with carer about what language etc. is appropriate and how best to communicate with them. Training and empathy are as important (if not more so) as materials, visual aids etc.

I would be able to understand all the options that are available and make clear informed choices.

It would mean increased independence.

This would mean that I will be able to access NHS services with more confidence. At the moment I avoid them if possible as I have had many negative experiences as I get fobbed off with excuses why they haven't booked a BSL interpreter despite making the request for one at the time of booking the NHS appointment. I am silently suffering repetitive ear infections; severe problems with my ear moulds and one digital hearing aid needs retuning. I am profoundly deaf since birth and on the point of giving up wearing hearing aids altogether as the NHS simply don't care.....

Because of problems communicating, I haven't been to my GP for months, despite having complex health problems. Not going to my GP has also meant I've had to stop taking some medications. I have also in the past lost out on the opportunity for hospital treatment because the hospital wouldn't arrange an interpreter and I couldn't find one for the appointment date. I have also discharged myself from hospital against medical advice because I couldn't tolerate the communication problems. If I always had accessible information and support to communicate it would mean I could get the healthcare I need. Having accessible social care information would mean that I had more control over the services I receive.

I would be able to take control, know where and when I needed to be, have contact information, know about additional details for pre-visit and post visit etc.

I am Deaf so do not always understand what is being said to me. I am not a sign Language user but do feel I would benefit from a communication support worker who could explain to me what is happening. My reading skills are not very good and I always need the information explaining.

Would feel more included

Not applicable. I simply need NHS staff to remember that a minor hearing loss can prevent patients hearing their name being called or information announced to a group.

If it was applicable to me then it would make an important difference as I may understand what is happening

I can't get information from letters and written - I have learning difficulties - and my sister supports me reading all my letters and dealing with my personal business. If I could understand the information I would feel more in control and more secure - not knowing what a letter is about and what it means makes me nervous and stressed.

I could be more independent and not have to rely on my Mum to interpret for me. I have a varied profile of understanding so I can understand some of what is said and can respond to specific questions. I struggle with open questions and also with retaining information and instructions after an appointment is over. I rely on my Mum to help me prepare for all appointments and act as interpreter because people think I am more able than I am.

I would not miss my appointments at the hospital or the GP's

It is crucial to be able to understand what is being said by health professional, to understand health issues and answer questions correctly. Also to get correct information on what to do. It is easy for people like me with hearing impairment to misunderstand what is being said if key words are not heard correctly. Some staff are not always sensitive to these problems (or you are just regarded as [...!]).

[...]

I would access the support

Obviously, if I ever found myself needing extra support in the form which you describe, it would make a real difference.

It would make things so much easier and less stressful.

A world of difference! Simple things like being aware in advance of my hearing loss, speaking clearly, looking at me when speaking, and having someone else actively listening, advising and ensuring I understand what's being said. I don't sign but I do lip read!

I have to arrange all appointment so that my husband can attend with me because I would miss important information.

It would help me make the right decisions with regards to my health instead of me having to look it up on the internet.

I nearly always have to have someone with me so I don't miss the important stuff i.e. consultants that don't look at me when talking...

It would be easier for everyone to understand what people were talking about if organisations used straight forward language. I have a mild learning disability, but sometimes don't understand what people mean. It would make a lot of difference.

It would make appointments less stressful and it would mean that I had a better understanding of my diagnosis, treatment and care plan

It would help greatly, and give me the confidence to tackle issues independently and without having to ask a friend/relative to attend with me.

I am deaf and lip read only, upon telling this to NHS staff they still do not understand what I need from them in terms of help - deaf awareness training should be compulsory for all staff.

It would make appointments so much less stressful and I would be confident I understood what my health issues were and how I need to act to ensure I get better. At the moment I often feel patronised, or that I am causing a fuss, and hate going to see doctors and so often am unsure what the problem actually is?

I could be more independent. I would not have to rely on my carers to help me in making choices. I would feel in control of my life. I would feel that my needs were respected and understood.

If health and social care services used email instead of the phone all the time life would smell of roses instead of being constantly frustrated and humiliated by being told info is insecure or wanting me to rely on someone else to phone for me. How is it more confidential for someone to phone for me than for me to email myself!!

I have only used Social Services twice once in [.....] and once in [.....] both were ok Numerous really.

I would spend less time wandering around the hospital [...]

I would be more likely to attend an interview or appt.

I would not feel so stupid and have to keep asking what has been said.

Hitherto I have not encountered any problems

Although I always take a family member with me on appointments, I always find I leave the appointment wondering what I have missed. And not having been able to ask a question which I would have done if I had understood all that was said in the appointment.

It would allow me to fully weigh up options if I need to choose a certain treatment. It would also allow me to fully understand and look back at a later date. I would feel empowered

Normality !!

Increase confidence and feel I had all the information I needed.

I would be far more aware of the wide variety of services, I can make better choices, it could save me time, money, energy etc.

A significant difference

I need something like a loop system to be able to get verbal information but these aren't available at most health and social care places, it would make a very big difference to be able to hear what is being said properly instead of just guessing some of it, I'm lucky that I can lip read which helps although the lighting and room placement isn't always conducive to being able to see the persons face properly

A great deal. For instance in Hospital when staff [...] or speak too quietly I am often unable to understand my treatments.

My son would be able to understand what is about to happen to him at appointments and would be more able to co-operate with examinations.

It would relieve anxiety and give me the confidence to go to appointments by myself.

It would help me understand easier and make me less isolated.

An amazing difference

Much better informed decision making and keeping up with the plethora of changes in our health provision

It would enable me to be more independent and not have to rely on others to read my mail so protecting my privacy

Information to be accessible in plain English without too much jargon.

I need an easier format. More information in 'layman's terms'

I can read but some forms used in the NHS use complicated terminology.

Just need doctor to be hearing impaired aware

It would improve my life. Understand more about my condition- stroke. It would give me more options to make choices about my treatment.

It would mean I don't have to struggle with my magnifier or copying it onto coloured paper

I would be able to feel confident going to appointments knowing that I can hear and understand what is being said to me. I have missed appointments because I couldn't hear the doctor shouting my name despite telling the receptionist I am deaf. Also I have never been able to make an appointment online or by text message to my local GP or Dentist when I need an appointment, I have to rely on finding a hearing relative or friend to make the appointment for me, or waste a day by walking to the surgery which causes me to take time off work for no reason!

When I do visit a doctor or when I went to A&E once the doctor didn't acknowledge me, they spoke to my partner who is hearing, and it was me that needed to be seen by the Doctor not my partner. It was very patronising and belittling, it highlights the need for disability awareness training in the NHS.

A lot.

A huge difference.

I find this frustrating, [...]

Less time would be wasted trying to obtain information. Less time would be wasted getting help I need.

It would keep me up to date with what is going on and would let me know if there is anything new I should be aware of.

It would enable me to make informed choices about my care. It would help me to understand possible side effects of medications, how to store things, having Braille would help me to be independent and safe.

It would mean I do not miss out on services available to me - for example I was not aware until recently that being blind I can claim Disability Living Allowance. There should have been pro-active steps taken to make all blind people aware of this when DLA was introduced.

Better information equals better knowledge and ability to learn. "Learn" can be as simple as knowing when an appointment is, right through to complex details of medical conditions and therapies. Without it, there's a real possibility that I simply might not turn up to an appointment because I do not know about it, because the information was not accessible.

I am visually impaired (registered blind)

Large text would be beneficial to me but is never forthcoming and I find that the information supplied is always written in "technical speak"

In many cases you need to be a high level academic to understand all the jargon that fills any written paperwork from adult social services or the DWP ..... and why is everything referenced to another document ??????

It would give me the choice and control over the decision making process and to obtain important information about my condition or illness

If they understood that deaf is not automatically meaning sign language, which would be a good start.

The most important issue is good deaf awareness and understanding how to accommodate the needs of people who don't use BSL which is massive majority.

I could make better decisions, given more simple and complete information.

I would feel at ease and not worry about hearing my name called out in a hospital.

I would not be afraid to go to an appointment.

I would be able to access everything said to me if using a BSL interpreter instead of a third party explaining it to me in brief sentences.

Give me an option to voice how I feel in BSL to a consultant / doctors round etc.

It would remove stress which is bad for my health

This would help me understand the information if I could read myself

It would provide me with the same info that others have, and ensure that accidents caused by lack of info were avoided.

I would be able to participate more fully than I can right now. I would be able to better digest any information that I get concerning any aftercare.

I would be more confident, know what was happening, know about any dangers, know about the pluses and minuses of medication and when to medication and what dosage to take, who was in the medical centre, what departments were in the medical centre and how to get to them, how to communicate and who to communicate to and their communication details

It would enable me to access warnings, instructions and other important information in braille.

Choice awareness, side-effects awareness, dosage awareness, lifestyle changes awareness, the more information is available the better able I would be to make proper and informed decisions.

I would be able to read all health booklets necessary for procedures I require. At present I fail to use this information and therefore remain ill-informed of the procedure I am receiving

I would be able to examine my medical records, which have all sorts of errors in them that I already know about, know when and where appointments are without somebody else having to read things to me as there is "no way" of telling them I need information in braille or by email in their systems, not have to rely on others when I get information about up-coming surgery and be much less likely to miss appointments. Information in a format I can access is required by law and it is not possible with current systems so NHS England, at least all parts I've ever dealt with, are breaking the law with regards to blind people

Improve service accessible using British Sign Language format, not written documents.

It would mean that I wouldn't have to rely on other people to be able to read/view the information given and could access the information independently.

It would mean that I know I have understood CORRECTLY all the information given to me, rather than just hoping or thinking I have got it right. I know I have often got it totally wrong.

Explains in British Sign language (BSL) in face to face to make sure I receive full information that I understand before go home and pace in time no hurry. Then will help me reduce worry and anxiety if not knowing what is had been going on or what will happen. Also Basic Friendly English written with visual resource / leaflets to take home for remind me or help me to read if I forget.

I would be better informed

Be clearer about what was happening and outcomes. Be more able to ask pertinent questions about care.

Greater ease of access to information and independence

It would help me to be more in control

I would understand my choices. I wouldn't feel isolated at times.

Makes life easier and stress free

Increased Independence. Doctors always use parents as interpreters and this is unfair as no privacy and they might not sign well. They talk to parents rather than you as the Deaf person because it's easier for them. If there were better services I could go to hospital appointments on my own or not need to rely on others which is harder now I'm at university. It's about independence and confidence and having a voice

I would feel in control of my situation, and that I was being treated as an equal citizen.

Would understand more

British Sign Language full qualified interpreter in NHS services and all the staff in UK hospitals should have basic deaf awareness with sign language level 1 to 6

For a start I would be better able to interact with health services, I would be more informed before the consultation by being able to read through the literature that accompanies the appointment letter.

This would make a huge difference. It would allow me to be a lot more independent without having to be dependent on other people and it also maintains privacy and confidentiality.

So I could understand fully about my own body and I would know what to do next and where to go for the right type of support. I will be fully confident if I get the full information.

No BSL translation - we want to understand what GP, dentist, social worker or professional try to tell us. For example, why I have high blood pressure, how to manage it. I prefer information in BSL. Problem is that GP surgery is not prepared to book BSL interpreters, always said no money!! If I get wrong information, I could be killed by taking too much pills, or maybe I could die if I don't follow instructions properly. Need full BSL that stops me to get wrong instruction or information. [...]

I would know and fully aware of what's happening. This would change my life if it does happen.

I have no special communications needs

It would give me a confidence boost knowing now I got information I need to know and wouldn't worry anymore. To give me peace of mind instead of thinking have I got all the information, or feeling stupid to ask to repeat the information in case I miss out.

Information relating to entitlements is sadly lacking, particularly with Social Services.

I understand what I am told.

I use BSL and there are not many, if any, materials in sign language. Even this questionnaire overlooks this: "Do you usually get information in a format you can understand when you use NHS services? For example, information in Easy Read, Braille or audio" - There is no mention of BSL although this is very important.

I really need British sign language video as there has no access for me that is breach of equality act 2010

It would be most helpful.

It would help to make better informed choices.

It would take away some of the fear of visiting hospital



I would be able to access services and support that I often do not know about until it is mentioned by other carers etc.

I would be clear that I was not missing out on anything

Able to access health care independently understand what is going on and what is going to happen next. Feel less scared as not being able to communicate is very isolating and makes me feel like a second class citizen.

It would ease the pathway to obtaining care

Reduce duplication

Save time

Ease frustration

Reduce stress

Health Professionals could help older people by writing a summary of what's been discussed to benefit understanding by the patient and those around them also trying to support and understand.

Huge difference, will make informed consent better and recovery/adherence to treatment better

I would understand the information much more clearly if I could have better access to the health and social care

It is really hard to get the services initially and always feel I have to just make do

Seeing the same person throughout would assist as having to explain my communication needs to different staff is daunting and makes it very stressful speaking to different staff and also repeating what was done before - hoping that I had understood properly what happened before

This would make a huge difference, I would be receiving the same service that most people do. I currently do not receive the same level of service as other people because I am not getting the information I need in the right format.

I just want to talk to someone who will listen to me then answer my basic questions.

If I get the right information then I would understand better and get full support instead getting error letter or late payment or late notice of information. If given the right information in the first place then I would not have any difficulty and be equal same as other people

Not all Health & Social Care organisations have information on their services available. It is sometimes assumed that you somehow should already know.....

Being aware in advance of services being offered or started has obvious benefits.....

It would save me time, stress and missed appointments

It would be easier to keep appointments, know what services are available to me locally including immunisations/screening, I could manage my health more efficiently

It would hugely reduce the anxiety and stress caused by not being able to hear properly and worrying you are missing vital information.

Not required as lip-read as Deafened and read English

I do not need support other than to wear my hearing aids and patience from the workers.

Would make life easier and more relaxed, if I've missed anything (or misheard information)

Information needs to be available for all, even those who do not qualify for free social care. Many abbreviations and terms are not known to those outside the NHS so outsiders do not know what they do not understand. e.g. 'Care package' is that the same as a 'first aid kit' from [...]? If jargon were to be avoided, more people would understand.

Yes obviously it would.

My main issue is that the Audiology clinic is only contactable by telephone which is to be honest quite ridiculous considering the nature of their business.

Email would so much benefit all of the patients.

Huge convenience with getting hearing aid paraphernalia and regular hearing checks

Being profoundly deaf because of having meningitis I have two cochlear implants. Providing people face me and speak slowly using a pen and paper if needs be I don't have any problems with communication. People need to be patient as I also have tinnitus which makes the skill of listening even harder.

I am almost profoundly deaf and a better understanding by the care services and indeed the public in general, would improve my quality of life.

Make me more comfortable and would relieve my anxiety and would allow me to fully understand

SOMETIMES PEOPLE TALK TOO LOW AND DON'T ALWAYS UNDERSTAND THAT I NEED THEM TO SPEAK UP THEY MORE OFTEN COME UP WITH THE SAME LAME EXCUSE. THAT'S HOW I TALK OR THEY TURN THEIR HEADS TO LOOK ROUND WHEN I NEED THEM TO FACE ME. MOST ANNOYING. IT'S ALRIGHT FOR THEM THEIR EARS WORK.

I would feel less isolated

It would make getting appointments etc. easier

Ownership...better quality of life...make right informed choices. ..Be able to trust professionals better.

With hearing aids I usually do not need extra help

I suppose written information would be a good thing; obviously as I am severely deaf fast speech is not the ideal way to give me information particularly if the professional is at the same time looking at a computer!

It would make a huge difference. It would remove a lot of fear.

Save time and effort on both sides. Avoid frustration and mistakes

This would give me all information it is my right to know. Now I always feel I do not know and not safe.

I'd be happier!

None at all

Amazing difference. If the services were 'joined up' then information would flow. For example there is no induction loop in the audiology dept., visual display board for appointments. The mini com phone system is rarely answered.

I am severely deaf but otherwise enjoy good health so seldom need NHS input. If I do, a medical appointment can be very stressful, especially in a hospital environment, where, for example, it is impossible to hear one's name called. Even in an Audiology department little effort seems to be made to help patients. My doctor has a note on my records, of course, but I struggle to hear and understand.

It would be amazing

I find it very stressful waiting for appointments. I am deaf and either I sit alert for any announcement, which means I am a nervous wreck by the time I am finally called, or I take a book and read like other people and can miss the call altogether.

I really badly need the NHS to mark all deaf patients' files so that staff are aware they have to make a little effort to speak to me and all the other deaf patients

I would receive the same service and help sighted, people without hearing difficulties and able bodied that don't have physical problems take for granted and won't need help that at the moment impinges upon my personal and private information and my personal difficulties and problems which I don't want others to know about

I wouldn't worry that I might have missed something really important.

A great deal

Less stressful when attending appointments

Everything

If GPs will listen and refer you instead of playing with their pc and pretending you are not in the room it may help

Please give me BSL video of all information. FED UP ALL HAVE AUDIO< BRAILLE< WHERE BSL???

I CONFUSED AND ALL DEAF DIFFERNT INFORMATION DEAF CLUB>

A great help and saving time trying to find information elsewhere.

I do not use social care work so cannot comment on this

It would make things a lot easier and also help to promote my independence and stop the isolation.

Being able to read papers right through would be easier for me to understand

Less worried and bit more confident to make decision quickly.

I would not feel as anxious, wondering if I have heard correctly

I would feel a lot happier and more confident with my treatment if I was certain that I had heard and understood what was said to me.

My local council won't put me on their social care list without a letter from My GP My GP won't give me a letter unless asked by social services. As regards social care, all I want is for my deafness to be included in the local statistics (not extra money). I think deafness/hearing loss is an invisible disability and hard of hearing people are largely ignored - people just assume you are [...].

Greatly. I am hard of hearing, so often cannot hear when my appointment is due. My GP surgery has no visual aid to telling patients when their appointment is due. The receptionists say it is not their job to tell me when to go in, even though they know I am very hard of hearing. My normal GP does usually come to get me. A major problem with my hearing condition (otosclerosis) is excess wax; and my GP practice refuse to syringe ears. They have to be ordered to do this by hospital audiologists. This policy is stressing me, because I can't use my hearing aid simply because of wax build up.

It means I can make right decisions. It means I understand what going on. Very important. Most of time I feel frustrated and confused. Makes my health worse.

Need BSL

Would reduce any anxiety or sense of isolation

I need BSL to understand. BSL is a different language with own grammar.

Would become more knowledge and aware. And can ask lot of questions that worries me

In writing would be preferable.

Need a BSL Interpreter when appointment

Pleasseeeeeeeeeee have DVDs or Video clips in BSL not subtitles!

I would like easy read pictures to help me read my own letters and appointments.

A lot of difference. I would be more confident that I had understood, therefore less anxious that I had missed something. With regard to answers to the above I take my husband with me whenever possible as he has good hearing.

Reassured and independent

Communication needs to be in a simple format.

If communication support was provided to a person who didn't speak English very well then they are able to make choices of their health & social care treatments.

It would help us when we leave to make the right decision about any after care needed or what to do next, rather than coming away sometimes saying what they said and what have I got to do next!

We need to book BSL interpreters and have information relayed from BSL to English and vice versa

I do not need help or support

I would feel better informed

Better understanding to make a more informed choice

It would make it easier for me to understand and follow what is happening around me. Because sometimes individuals like me who have sensory impairment are unlikely to know what is happening around them and misunderstand following procedures that are required. I'm sure people get happy when they're guided properly via the communication they find easier to follow up.

I would be able to make informed decisions

I would be able to make a fully informed decision. Quite often they will not write things down, and if they had a plain English version handy of specific instructions then that would be helpful. I needed this when I went through a termination recently.

I would be more independent and able to make decisions on my own. I would also be able to take a greater interest in my health and wellbeing because more information is available in my language and can request for additional information/clarification more easily.

It would reduce the stress and frustration of understanding the info. This will help me to understand more about your service and how to make a good use of it. It would improve the quality of my life and I would have the same access as hearing people. It would improve my health greatly and I would be able to focus on my health issues

rather than having to worry about the info that I don't understand. This would upset me greatly.

I do not have a problem

It would make a massive difference to me. I would feel as though my health needs were as important as other peoples. I would be aware of so much more vital health information and as a consequence be able to take more ownership of my own wellbeing and general health. I would feel like a real proactive participant in my health care rather than a reactive individual, waiting to be informed or told information by others. I would feel a degree of equality with fellow patients and/or service users. I would have access to knowledge and information to make me aware of different services and support offered by organisations that may benefit, not only me, but other family members, friends or acquaintances.

I could access the information in BSL

I have sensory processing disorder, this means that I am often overwhelmed by the situation I am in, especially if it is out of my usual routine like a medical appointment. I also have dyspraxia and a higher level speech and language disorder. My organisation skills are poor, if I am feeling overwhelmed information doesn't sink in or I think I have understood but haven't and have got things out of context. I have often missed valuable information cos of this. I worry that I appear rude, I am poor at reading people, I over compensate by asking again and again and often receptionists [...]. My mum comes to all appointments with me and makes sure I understand it all, clear concise written information is best for me

I would be able to make better use of it, e.g. remember what I had been told or apply my physio exercises properly rather than a half remembered blur.

I always get the help I need from [...] but only during the hours of work of my helper there. At other times I just have to get by and if I write everything down so as not to forget it, things usually work out.

I am very lucky and do not require any communication assistance or need information in a special format. However I work with Deaf, Deafened and HoH people who struggle greatly in receiving the specialist assistance they require when accessing these services.

My life would be much easier and more equal to other sections of the community.

Feel equal as a deaf person like other hearing people giving me a human right to access to information!

Total

As I often have difficulty reading smaller print it would make it easier if I was asked if I needed information in large print

Without feeling stressed, or confused - This will make me a big different by understand the information I need, for example the access to my health issues, preventing to be in a bad health, and improving health well-being.

Give confidence to discuss and understand medical issues without being reluctant to visit Health and Social Care personnel.

So I can access with the communication support and I will definitely have all the information that I need to know rather just hardly can understand some information or the most when I don't have the communicate support. It's important to know all the information I need from the health and social care.

Immediate understanding. Less stress and anxiety about not having all available facts. Save time.

This would make a huge difference to me because I would feel more empowered and less reliant. I get very frustrated at not being able to read my NHS letters because they are in such a horrible, small and unreadable font and I have to ask my husband to read them for me, most of the time. This is very annoying for me and it also frustrates my husband that the letters are so unreadable for me. He gets frustrated at something that could be so simply resolved.

There is little excuse that letters these days cannot be sent in a readable font - Arial or Comic Sans, size 12. The script I get letters in from the NHS is a horrible small, Time New Roman-like print and it is very difficult to read.

Access to information

More aware of what is going on

I could be independent

It would make me feel a lot more confident. At the moment I prefer not to use the organisations unless my husband is with me because I feel very upset if I can't understand what is being said.

More independent making my own decisions and treated like a human being.

If I get an appointment see my GP before I ask to the receptionist for a booked BSL Interpreter, then I booked it.

When I see the doctor and with BSL Interpreter, and a doctor referred me I go to hospital and a doctor needs to contact for BSL Interpreter for an appointment to go to hospital or also NHS hospital should a booked BSL Interpreter when a patient should receive a letter from NHS.

I would be able to make informed choices and decisions, the pros and cons can be explained to me in a way I understand and it means something.

More at ease

I may have a better understanding as my sister is filling this in on my behalf as I have Autism and Down Syndrome. Most information is given to my parents as I live with them and they are my carers. Most information is in written format, my reading level is probably the same age as a 3 year old, and I struggle with written English. If I had

visual information I'd be able to understand certain things, I may then ask questions about what's happening.

I would have the confidence to say whatever I want rather than relying on family/friend member to translates as they're are not qualified. For an example they might not be able to translate medical terminology to British Sign Language.

DVD or with signer to tell me

Layman English please

The NHS does not have loop systems in place to help Hearing Aid wearers. This would help a great deal in hospital outpatient appointment desks, doctors surgeries etc.

Would improve my confidence and make me feel better knowing what was going on

Informed decisions, reduce anxiety, able to ask questions

If I got BSL interpreters, it would mean I understand all the information I am being told. If I got English format information in BSL, it would mean I would understand the information.

I would have a better understanding about my health and the health service

Because I have hearing loss, I have difficulty in understanding what some medical staff (doctors and nurses), [...], are saying to me. It would be helpful if these individuals recognised this and took trouble to ensure that I understood them fully.

It would be great to see all NHS staff learning Deaf Awareness and BSL course

Able to understand more and be able to make decisions. you could discuss with peers and not always have to get staff or professionals to explain.

It would mean I could be independent and not have to rely on family or other people for support.

I would not rely on my wife or children to read things and tell me what it says.

Sometimes I get letters, I don't understand them, get stressed and text my social worker to come and see me to sort it out

It would help me to understand what help I need with my health and with social care services.

I would then have exactly the same information that non-disabled people have available to them and which they take for granted, as a result of having this information made available to them. So if I had this same information made available to me in an accessible format, I would then be on the same level playing field as non-disabled people and would no longer be at a disadvantage to them.



Although I do not currently use Social Care Services, if I did need to use them at any point in the future, I would also benefit from having fully-accessible information made available to me for exactly the same reasons as set out above.

I could make informed decisions and take control without delays

would know whether treatment was average or abnormal

It would make so much easier and not an ordeal

Nursing staff seem always rushed so appear not to have the time to explain things. Patients don't know if they are missing out if they don't know what they are missing out. Circular argument

None

This would make me feel less frustrated and save our time in writing to each other...also I will be able to understand information clearly before I leave them.

Immense difference which would reduce my anxiety and stress brought about by worrying that I have misunderstood

It would allow me to be independent and not have to rely on others to have access to my private and personal information. I would also be able to make informed decisions about my health and social care.

IT IS IMPORTANT THAT ALL INFORMATION IS GIVEN IN 'LAY MAN' TERMS WITHOUT THE JARGON OFTEN USED BY HEALTH PROFESSIONALS

Clearly the person would understand what is expected of them and health issues. They could make considered decisions

I would know more about the types of service available to me.

When information about a particular service is provided, I would understand the jargon, and understand the implications of what was being told.

I would know the right questions to ask and would be able to give the correct information about myself.

I would know what kind of services are available to me and understand what the service is offering.

Also, the service provider understand me what I need from them about my health.

I would feel more engaged, and I would make more use of the NHS and social care services

short clear and concise

I would feel more confident that I am understanding, and being understood.

I would like to be treated like a person and be spoken to face to face even after lots of visits to my doctors he still refuses to [...] come and get me for an appointment

That I have instant access in my language BSL - I can read English text fluently but when it comes to communication, I would want interpreters not communication support workers as they have only one or two years of BSL learning - no skill in translating/interpreting - very dangerous for NHS situations.

feel information given better. feel doctor understand me. feel me understand doctors.

I would manage my life better with the right access to information and I'd feel more included

To me, not hugely significant, as I tend to keep digging until I have all the information I need.

No-one as answered the question I am continually raising concerning the Privacy and Confidentiality of my personal medical Records. I have repeatedly stated that I do not wish to allow any aspect of my personal medical records to be accessed by any person or Organisation without my Express Approval. I cannot make this decision any PLAINER but you are all ignoring my responses

It would make a fantastic difference.

I am a carer for my daughter who is a rare cancer patient. There is little or no information available from the NHS about her condition and any that exists has been produced by the charity [...]

This would make my life a lot easier. Often I am reluctant to ask for information in a larger print because I know it isn't available - so why make a fuss when everyone is so busy? I then have to try to find the information on the internet, struggle with a magnifier, ask someone to read it or just remember what I have been told etc. However, if it was a standard choice to have information in large print then I would be much more inclined to use it and ask for it. For example, large print captions are usually available in museums, and I always ask for them.

The Format I would require is British Sign Language Interpretation by way of DVD in a BSL format. This is not offered by most hospitals, and is incredibly frustrating.

English does not make sense, so I am expected to try and read simple English reserved for people with learning disabilities, but I don't have a learning Disability, I would like to receive it in BSL.

If I received the full support, it would mean I would be able 100% understand what is being stated and would mean I have autonomous decision choice over the support I receive and be able to receive my information and choices in a private respectful manner.

I could be a bit more independent and understand the information. Would give everyone a chance to understand what is happening.

I would be healthier

It would enable me to have much clarity in understanding and it would assist me in making better decisions about my future treatment and care when it may be required in the future. Having the various options for treatment and carefully explained to me would be most helpful. Hospital, doctor, social and community nursing services should be fully integrated with clear pathways for patient support and treatment.

As a carer of a daughter with learning disabilities it is more vital that the information aimed at her meets her needs. The key issue is jargon filled letters addressed to her. There is a need to let carers know that information has been sent to the person they care for. Having information in a simple consistent form would make it easier to discuss with my daughter.

Empower to make decisions

Stop things getting worse

Improved mental health as not so frustrated

Less relying on family

I wouldn't have to rely on wife

My mental health would improve as I would feel understood and more accepted to be me

I would feel less daunted by the idea of seeking advice / support. It would not feel like such a big deal. It would save me time if I knew I could just pick up the information I need easily

It would be clearer

To be an active citizen, to be able to play a role in my own life - I am the individual I can say if I want sugar.

Make me feel 100% full understand

I am profoundly deafened and rely upon lip-reading as a means of communication so the timely provision of a professional lip-speaker (for communication support) to facilitate understanding of the spoken word would make an enormous difference... It would ease the anxiety and strain of having to lip-read staff who are not deaf aware (particularly doctors) and who may not have good, visible lip patterns or clear speech.

I am well educated so understanding written English isn't a problem but understanding speech can be very difficult... Providing a lip-speaker would also help re acquiring more 'Equality' (i.e. bringing me more in line with other service users re accessible information) - at present I am disadvantaged in relation to the spoken word. Note that foreign language users are often treated more fairly than deaf / deafened people re language support – they are usually offered a language interpreter automatically and relatively quickly.

As a stroke survivor information needs to be short & to the point. Found this form difficult to fill in from a carers point. Has communication is difficult and if as the carer explains the problems if am relied on by patient AND professional. Not aware of any help with communication support worker for any appointments

I would feel more confident in my healthcare, and my health care needs would be met with far less appointments. About a 1/3 to 1/2 are cancelled because of no interpreter being booked or arriving in some Trusts. Using unregistered interpreters has also led to incorrect information being given to me.

Because they so often get it wrong, I always phone and chase them, until they confirm an interpreter has been booked. Even given this, it's often not true!

## Appendix 2 – Patients, carers and service users survey, Q9.

**“If you have any other comments you would like to make about your experiences of getting the support you need from health and social care organisations, please write or type them here.”**

I have supplied two pages feedback on outcomes during my stay at hospital for cochlear implantation surgery. I was exposed to carelessness by a specified nurse who did not bother to check my medical notes. I became aware that it is a continued practice being swept aside – dismissed as not serious etc. etc. Dangerous again

Most health services refuse to send me information by email or if they do, can't do it with word documents. They send PDF picture files which are not accessible to screen reader users. I am forced to ask a third party to read me health communications which violates my privacy. I don't get instruction on how to use medications in accessible forms so have to try to remember this. I should be allowed to sign a disclaimer saying I give permission for communication via email and word attachment and for the privacy issues to be my risk if I accept email and accessible electronic document communication. As far as I am concerned, sending me print letters violates my privacy anyway so what difference does it make to do it accessibly and possibly have the communication go astray from time to time

I find if I request information via email from an individual, this usually happens. Obviously before I make contact with the appropriate person I do not receive information that I can access. My wife has to read this information to me

I recently went for a routine mammogram. All the info was in small print. I couldn't read it. I would appreciate an email; my phone would read it to me then. All the staff were helpful except one. A receptionist kept telling me to, "go along there" I explained I couldn't see where "there" was or where she was pointing to. I had my white cane fully extended in my hand. The woman just kept repeating "go over there". Then I heard someone hurry toward me, it was a nurse who apologised for the woman's behaviour. The nurse took me down a corridor to where I needed to go. I felt humiliated.

The excuse is often made that providing information by email, for example, is insecure and would breach patient confidentiality. Printed letters may get lost in the post, so email is a much faster and more effective way to communicate now for such things as appointments.

I never go to a social worker or interpreter to show them information I do not understand because I do not trust them. It is not clear and often their explanations are wrong. They say to go to hospital but how do I communicate with them? That's the NHS. That's life. Stressful! But that's life.

I usually use my mother but she has a health problem I don't use her as much I end up stuck because I don't have access to interpreters. I rarely use my sister-in-law

I find the prescription note difficult to read when I had to complete one part of it relating to which benefits I am in receiving. It would be useful to have a credit card

style with all of my details including my address, disability, communication methods, etc. This would save communication difficulties with receptionists and pharmacists.

For the past 20 years, I have noticed that NHS, as well as social care, is very negative because they say they will make changes, but nothing has happened. My experience for the past 30 years is that it is all talk no action.

When I go to doctors' appointments I am with support staff or parents.

When visiting doctors or other NHS places I will always have support staff with me.

I have support from my family on matters with my health and they will explain to me if I don't understand.

I am supported to go to hospital and doctors' appointments by my family and they will explain things to me in an easier way. I would like to see my advocate more.

I get very good support when I get communication and support is very helpful for me.

When I get very good support from my doctors and they are both very helpful all of the time.

Doctor always asks questions, never explains anything. They never have an interpreter. If I have a blood test, they never explain the reason to have a blood test. Also same answer to 8, if I have an illness I try to get doctor to explain.

All information seems to be sent without consideration of the individual's medical history or communication preferences

About my personal experience, I never had an interpreter in medical services at all, usually just me with a notepad and write things down. There was one occasion I had used a friend of mine to assist me in language support. I had visited hospital for a private matter, and had relied on pen and paper from walking in to the operation and to the recovery, I did it all by myself, and had learnt a lot about their procedures. About social services, I distrust them as I am aware of their unprofessional conduct in the past, as well, that they had too many roles, one day they're social worker, and next they're the interpreters. Same person doing the different roles, I don't have faith or trust in them as they often bring their personal feelings and opinions into their line of work rather than being professional. Hospitals should arrange and provide ALL information in British Sign Language as it is my language and I have a right to access to the information. They have produced many leaflets, pamphlets, radio information and so on; where are the resources for the Deaf? I would like to see that happen. As for social services, in the past, we had patronizing ministers and then social services took over, still patronizing us Deaf people, but what information should they provide us? There are NO interpreters skilled in medical translation, and we need more of that. It's embarrassing to have a well-known interpreter, because if I wanted something private in the hospital, and suddenly, an interpreter turns up, and we know each other, so after that, any social events wouldn't be the same if that particular interpreter is there, so awkward silence would be present

I had a difficult experience in communication with the doctors. My husband had a problem for years and years, and then he was diagnosed with ADHD. So, at the doctors, we had great difficulty understanding, even though we had an interpreter, and some leaflets. It's all just words and words. Where was the visual aid? It took my husband and me three months to figure out how to use the tablets. As for myself, I am pregnant, thinking in hindsight, I am worried that, touch wood, if I ever get a problem, would they provide interpreters on the spot or must I wait a long while before I can find anything out? There are two major concerns, my age and my weight, and supposing I had a problem during my visit at the doctors, will they immediately obtain an interpreter? That's my worry

I never go to doctors by myself because my English is not that good so I ask my family to come. I ask the receptionist to book an interpreter, but that means I have to wait for 2 weeks so I don't bother because I don't want to have wait and I need it now. It should be automatically provided.

They never ask how I feel, if I am okay or if I understand what is going on

There are some good things and some bad things. One of the bad things is that once when I was trying to make a cup of tea, my arm dropped, I was confused as to why was it weak? I went to see my doctor. I explained what had happened and she asked me to walk around and to sign as normal. I thought they were very strange questions because how does walking link to my arm issue? They sent me off for some tests and they mentioned the word 'stroke'. They sent me home and sent a letter to my GP. They couldn't find the cause of my arm dropping. About 48 hours later I actually did have a stroke. They could have caught it earlier on, but I am okay now and getting on with life. Another problem I had was with my knee, so I went to a walk in centre. I was in pain and limping, because my knee had an inflammation issue. I waited until finally they called for me. There was no interpreter because it was last minute so I had to write everything down. The lady pressed down on the perfect spot which caused me to call out in pain and she straightaway realised what the problem was. When they had written down what the problem was, I didn't understand what was it, then I asked them to provide me pictures and visuals, and they did. I realised it was inflammation and, to my surprise, it was on other side of the leg and was instructed to inform the GP. The GP had referred me to a scan, and it was quicker than expected, then with all that experiences, I had realised that I need to ask a lot of questions in order to obtain more understanding.

All information should be in Easy Read and Font 16

I had a bad experience when I had a problem with my appendix. I took my mother to the doctor and they said to take some tablets, but I didn't have an interpreter. I was so ill I didn't know what I was taking or doing. It got worse a few days later and I ended up in hospital after GP said it was an emergency. Again there was no interpreter so my mum came with me. My sister came down from London to interpret for me as well. It was a bad experience because there was no interpreter at all. There must be an interpreter available 24 hours a day

Let's imagine you're going to study French, and go to college, and no one speaks French, except German. Isn't that strange? That's what it is like in the Hearing Aid Dept.: The staff do not sign, they just speak. Zero Sign Language, except for lip

reading! None of the staff even know the vowels of BSL! Every department should study BSL for the Deaf patients. Yes, there may be deafened people, and so on, but newsflash, some people are born deaf and are fluent in sign language, aren't they important too?

There are social workers and interpreters but I don't have any idea what they have available for my benefit.

The health service is very good you are happy with the NHS

Would like more pictures and easy read information

The correct support helps me understand

I didn't understand the menus when I was in hospital. I don't understand big or long complicated words and need someone to explain

We don't like waiting for a long time. We are happy with our doctors

Use more pictures and more time would be helpful

My communication needs are quite specific and it can take someone some time to understand my needs

Following stroke [...] needs some help to understand medication or instructions

There is not enough

I always need support as my speech is very poor. More people need to find out about services which are available to help in the area

We think that the letters and info could be much better - we think it would be easy to make our letters in an Easy read version, so we would find them easier to understand

People get the info they need

I could not fill in my response on line - couldn't see if there was any way to fill in the boxes in earlier questions

Information often gets to the carer / support worker and not to the individual at the GP / hospital

The writing on the labels for my medication is tiny. It would be better if it was in bigger writing

One time my [...] was in a different colour box. I wondered what it was.

Once the chemist put my medication in the wrong box, it was a different strength medication

Helps me to cope with everyday tasks having the info



The lack of social care workers in Britain

Need more support for deaf people

A lot of the info is too hard to understand. My support worker helps me.

When I get info the writing is too small and I can't read it. Sometimes people don't listen to what I say

There is a need to be examined by a healthcare professional with regard to the stated condition

Make sure writing is large and there are pictures - my GP is so fast I tell him to slow down and he forgets. I don't understand [...]

I used to call my care manager directly

More in easyread

Without carer / parent strong support I would not have received adequate support / help in these particular areas: dental care, optician and ophthalmic care, dietary assistance/advice by proper NHS dietician

When giving any info easy read should be available immediately

NHS queues make it worse

How do you help people who don't get social care support?

I want info about social care service - what's care service mean? Because I'm deaf without help BSL

I complain if I don't understand info and this makes me angry and can upset other people

I have receptive and expressive aphasia

Oral communications for me

Some medical staff are not aware that individuals have more than 1 illness e.g. stroke victims may have communications problems which may impact on other areas e.g. heart care

Some people are ignorant and don't help

When I go to GP appointment I am with support staff/parents

When visiting GPs or other NHS places I will always have support staff with me

I have support from my family on, matters with my health and they will explain to me if I don't understand

I am supported to go to hospital and GPs appointment by my family, and they will explain things to me in an easier way

I would like to see my advocate more

I get v good support when I get good communications, it is v helpful. When I get v good support from my GP they are helpful all the time

I think in order to receive support effortlessly, the staff at the GP surgeries or hospitals need to be deaf aware and possess a good knowledge of the booking system to book qualified interpreters and ensuring that they turn up for appointments.

It would be helpful if greater use was made of email, non-PDF format, for appointments, results, etc. Hiding behind the Data Protection Act does not wash. Where is data protection if, as was my case for several years, you do not live close to a trusted family member and have to ask your neighbour or visitor?

NHS direct and or 111 service is phone only how can deaf people use these?

Recently, I have been experiencing a decline in the quality of Communication Support given at medical appointments.

Unfortunately, there are some Language organisations who have started to offer BSL interpreting as part of their remit, these organisations have no specialist knowledge of British Sign Language.

A lot of the NHS trusts are commissioning [...] providers to provide foreign languages as well as British Sign Language Users, due to costs. The organisations who hire these [...] to translate highly confidential and possibly emotional declarations about health or care to the "Patient" are incredibly inept at delivering the translation in the correct medical way. Also these organisations do not have any vetting or policies in place to check that the people they hire can actually translate the correct information to patients, leading to a rise in the patient being more confused. I know I have had experience, of a BSL interpreter participating in the conversation with medical health professionals and myself, which is highly unprofessional and that a registered qualified, highly experienced Sign Language Interpreter would not do. In essence, these [...] agencies are springing up all over the place, and I have had to fight to get the right appropriate support given to me. In another instance, another [...] agency that was contracted by NHS providers to provide BSL sent a male interpreter to a medical appointment for me, a female, which was highly inappropriate. Another example is, a BSL interpreter tried to cancel a medical appointment directly with myself, because they had booked a medical appointment for themselves, even though my appointment was booked 2 months previously. IF the organisation who had hired this interpreter, read the code of conduct for communication professionals they would in fact see that this person was unprofessionally contacted the patient personally.

I would hope that when this guideline goes through, that it includes making language service providers responsible for the quality of service that they deliver, and encourage the patient to make choices with regards to how they receive

communication support, whether it would be a request from the patient that a specific interpreter is booked because the interpreter knows their medical history, or they are comfortable with that interpreter, rather than booking sub-standard interpreters who are wholly unprofessional during appointments and are not proficient enough to understand medical jargon and are lacking the skills in a medical setting.

This is an issue that is not limited to myself, and have seen numerous other BSL users who are friends; complain the same thing is happening to them. This is a serious medical time bomb, as one day, someone will get a diagnosis and not understand the translation from an incompetent BSL interpreter, you would have to ask, if that medical issue was life-threatening, who would be responsible for booking that Interpreter, the NHS. Leading the way, for medical negligence claims.

BSL Interpreters should always be provided for deaf people or at least give them the choice of support when booking appointments so that they will get the required support without relying on their relative/partner etc.

I am a carer of a person with learning disabilities. I believe all publications/communications in health and social care should be in EasyRead as a matter of course at the same time as mainstream publications. We should not have to request or it should not weeks after mainstream messages.

Generally staff are kind and caring but need more training and/or more time

It would good to exploit modern means of communication e.g. emails

Please think about signage etc. - there is a team at [.....] who can help under Professor [.....]

Organisations' providing deaf people emails. Sign boards that show a person's name being called; all help me as a deaf person to keep my independence and knowing when it is my turn. It can also be used by everybody else too.

My GP is usually contactable by Text Relay and I can make appointments but it offers other patients an automated booking service by phone which I can't access. There is no online alternative so sometimes I wait a long time 4 my call to be answered. My GP has 2 locations one has a digital display but its not used to call patients, the other has a tannoy. I usually have to tell the receptionist that the doctor or nurse will have to come out and call me. I have been to other places where visual displays tell you where to go and this is really helpful.

GP needs to inform Choose and Book and hospital of my communication needs --- in advance!!!!

I was disappointed with this survey. It appears superficial and doesn't reflect the current needs of many Disabled People to have information in an electronic format, e.g. via email. This is despite the irony that the survey is conducted primarily via the Internet! The inadequate level of PPI evident in the compilation of this survey (as opposed to PPE) is perhaps an indication of the level of genuine user participation in survey and research design. I can only hope that this will be remedied when it

comes to drawing up, designing and disseminating the booklet to be published as a result of this activity.

A better understanding of difficulties we face day to day.

More details of mental health addiction services in my area of [...] & on the website!

I find it very upsetting when my GP gives me a prescription and I'm asked to fill it in I'm blind and on my own so something as simple as completing a prescription is extremely difficult even visiting the Eye Hospital and having various eye drops in before my vision was as bad as it is now then to be handed a prescription and asked my chemist to fill it in have people no idea how hard and upsetting this is??????

Never offered communication support by NHS in [.....] Assumed cos I have speech I'm not deaf.

Had MRI scan cos I complained about the way staff member treated me re my deafness (I should have brought someone with me he said) despite my reply why I'm an adult why would I? he deliberately put the headphones on my head wrong didn't tell me how to alert him and I spent 20 minutes holding the headphones to my ears to protect what little hearing I had. I was in tears after at being treated like that. That was last year and is one of many incidents over the years. I was struck off by my dentist for complaining about lack of email communication to make appointments and how I couldn't alert them that I was going to be late for appointments. The receptionist deliberately whispered it to me in reception in front of everyone. It took 4 months to find a new dentist who had email for me to make appointments etc.

Health and social care agencies should know about access and support and guess what they don't they don't consider basic respect or dignity. I have so many horror experiences at hands of NHS where communication in a basic level has failed and it has impacted on my treatment and trust. An audiology consultant at [.....] in [.....] was a total [.....]. Having got new hearing aids for first time in 4 years and wearing them he yelled at me for not wearing them refused to look at me so I could lip-reading and told me to stop signing. That was humiliating and totally out of order.

I appreciate the drive with this initiative but I'm not inspired with confidence that anything will change properly until NHS is sued under Equalities Act maybe then the issues will be taken seriously.

Ongoing problems in the 'calling name out' in any services no one listens to the fact highlighted on notes and reiterated on arrival at appointments - please do not call my name as I cannot hear you! They still call and it's the "hearing" that are just not listening!!

Need all visual information on videos/dvds on any web site or any screens showing information whilst waiting in waiting rooms etc. to be captioned and embed BSL - even TV screens in some hospital waiting rooms need to have the subtitled functions switched on.

Biggest issue with the health service is that virtually no health information is made available in BSL for example NHS Choice, NHS 111, and any other health topics. By

making them available in BSL, deaf people will have some access to health information that has been denied to them for decades.

I very rarely get information in an accessible format, and when I have it has been down to the health professional themselves who have chosen to take the time to email me documents electronically

Sensitive information is never sent in an accessible format, i.e. Braille, so I always have to disclose health issues to family members or friends. During pregnancy my wife was given a lot of literature to read, none of which was available in an alternative format which left me feeling at times isolated from the wonderful journey we were having together. My wife had to read everything to me which felt more of a burden.

My experience both as a patient or a carer has been similar, although the staff on the whole are very nice and try and help the support is totally inadequate. The assumption is always that information will be read to me or forms filled in for me and this is thought to be acceptable information, letters or appointments are sent in print although I request emails or a phone call. Staff have no idea on how to communicate with a visually impaired person, simple things like which way to get onto a bed so your head is on the pillow or where the step is to make it easy to get onto the bed. All staff are in desperate need of vision awareness training.

It is becoming harder and harder to get help since the austerity measures came in , even when you are not ready they want to discharge you from their lists it is very frustrating especially when my daughter is going through such a difficult time transferring to secondary school

The most logical and easiest way for me to receive information is not exemplified here, that is by email or text which I can use on my accessible technology using text to speech software.

I'm totally blind (although I did have good vision until 15 years of age) and now use digital hearing aids in both ears and am also a wheelchair user - the doctors and nurses at my GP's practice [.....] send me information via email which I read on my PDA which has a braille display, but the hospital and Chiropodists always send me print which I need a third party to read which as I live alone isn't always possible meaning I unavoidably miss some appointments leading to anger and frustration. Fortunately the boxes of medication from the Chemist always have braille on them telling you the dose and what they are but they neglect to tell you what's on the warning sheet accompanying it which it's necessary to know about. I'm supposed to be allowed access to my medical records which is especially necessary when I'm in hospital which occurs from time to time, but these are bulky and in print and often in jargon my reader cannot understand what he/she is reading about and in this 21st century, technology is available cheaply to allow me to be as independent as every other Tom, Dick or Harry who isn't disabled!

Any change will be better than nothing!

I just feel that the organisation links outside the NHS should be made more known at the first point of consultation instead of having to find them for ourselves.

I am dyslexic not with limited knowledge or ability to retain information. I don't want to read pictures and words [...], I want the same detailed information given to patient with no disabilities, if just want all web pages leaflets and other media available on various coloured paper rather than white paper!!

Although health professional may be aware of my visual impairment any information is always presented in a small font which is very difficult to access - need magnifiers and a lot more time to read. If they could just acknowledge and print off or provide in a much larger font this would be a lot better. Even information by email is good because I can access via my computer with my own accessibility settings.

All if require is 16 point font. Dr's surgery and [.....] are unwilling to provide this even when requested. Their researchers and nurses and doctors wave their hands in my face and ask if can see them (I'm partially sighted), post-graduate level educated and Director of my own company.

Please understand not all disabilities can be solved with a ramp! Training and awareness are needed urgently to understand a visual impairment

There is a serious shortage of sign language interpreters using languages other than BSL. I know of only one college offering an overseas sign language [.....] which teaches ASL. As far as I am aware, there are no sign language interpreters in my home town that offer languages from other EU countries.

I have had several examples of unable to get the support that I need. One of them, once I went to see a GP (the practice are fully aware that I am Deaf and would need a BSL interpreter). However, when I arrived there was no BSL interpreter available for me so I had no choice but to ask the GP to write down what she was trying to say. Her response to my request was appalling - her face expression was saying that I was the one who is not making effort with communicating with her.

One example of poor information is that I am regularly not told whether my transport to hospital has been arranged. I end up having to make three or four phone calls to get it confirmed.

I am a parent and care for my two severely non-verbal children, I have had training in Makaton signing and [...] communication system and also structured teach approach. All of the above are very sufficient and vital for communication in non-verbal autistics and should be introduced to Health professionals.

People do not generally listen and professionals have annoying habit off walking away when things get tough. Has this happen on countless occasions in [.....]

I have a diagnosis of high function autism. I find informal language very difficult to follow. Clear instructions with few words are best. Email is good as reminders for appointments, asking how I am getting on etc. I need people to give me time to understand the information and write it down.

My child has glaucoma and receiving or being able to pick up a leaflet about treatment etc. would be helpful. A leaflet concerning contraceptive advice for older and younger women would have been useful too. Equally, accessible information

regarding older people's health issues would be useful now as my father has many health complaints.

I am often asked if I would like documents and booklets in an accessible form, but it hardly ever comes.

As someone on the autistic spectrum, it is important that health care professional does take time to check what they communicate is understood and there are no time pressures preventing this taking place.

When an adult is current diagnosed with Autism there is no help. I certainly haven't had any autism specific support from anyone in the NHS and as a result have mental health problems (which I am getting marginal support for as there is a mental health service). There needs to be an 'autism health service' as it [...] requires very different support, knowledge and understanding from the professional.

The main problem I experience is when doctors talk to each other about me, rather than discussing things with me. It's very hard to interrupt them and ask them to include me and to explain in non-medical terms. Sometimes they talk about outside the consulting room and their decision on treatment is made by the time they come back to me. Also after surgery the surgeon often doesn't come and see you before you get sent home these days, as everything is so rushed in day surgery. The nurses can't always answer my questions about how to look after the wounds and what I can and can't do while they're healing, so I have to guess, which sometimes has caused problems with the wounds getting infected or not healing properly. This is particularly a problem in mixed day surgery wards where patients attend from different specialities and the nurse left at discharge time may know nothing about the type of surgery you've had as she's from another speciality.

[...]

This survey has set me thinking as to what I might be missing in terms of information, particularly at the GP surgery. For example, I don't have access to my records, to information leaflets or to posters on the wall.

One more point is that I often find it hard to find the building, entrance, desk or door that I am meant to be going to. This is not communicated to me in advance in an accessible way and it is often difficult to find help when I get there. One final point is that when I get to the reception desk, it is often difficult to work out whether I am being spoken to - there is often a silence while the person looks at me expectantly - but I can't see this and so don't know whether there is anyone there. Any training or systems that could resolve this would be appreciated.

There is a lack of communication between health and social care, which I believe increases the risk to his safety, as I often have to act as go between. I have also had to fight for the needs of my autistic child and his siblings, as there are so few resources available. The system is reactive, and not proactive, and often only makes suitable provision available retrospectively, after a crisis. How many more tragedies have to occur? We, as families deserve better, and I would thoroughly endorse a system of care that encompassed a multi-disciplinary approach, from the point of diagnosis.

Before sending letters out ask service users if they are dyslexic as many people are. It doesn't mean [...] or can't read or spell, it just means it is more difficult to learn the way the majority of people do

Sometimes a simple coloured background would be a massive help

Need to have qualified BSL interpreters or BSL advocates ...not someone who can sign a little bit as their vocabulary is not good enough

I don't see why a consultation is required this access is my right to receive not a privilege for you to grant.

Difficult to obtain information as our experience has proved that the personnel we deal with are reluctant to provide information in a format accessible to us as a blind couple.

NHS should start with making sure appointment letters for health consultations are provided in a format suitable for the individual. This should include the option of telephone call, email or text.

BSL access for BSL users please. Simple as that!

A bit more time and patience would help me to understand. Writing information down so that I can keep a record would be helpful. Professionals usually tell me something, ask me if I understand and then say 'goodbye, see you at the next appointment'. I walk away and then forget what's been said.

The time is not available for the health and social carers to spend trying to communicate with me. I have a digital readers which scans onto my TV screen and I can read, however, there isn't time for them to write everything down and then wait for me to read it. My sight is almost entirely gone and I have become more and more isolated, with no hearing either.

Sometimes all options are not fully explained.

It seems that everybody else within the NHS is allowed access to my records but they are kept secret from me.

When will the power of information be implemented so that I & other patients have equitable transparency?

When will NHS England and the CCGs start to begin looking after the interests of Patients and care about what they think?

My Doctor is helpful and listens to me.

I have excellent support from my Occupational Therapist, who is employed by the [.....].

Within the health service, I have to ask every single department separately for my preferred format and the result is patchy. Sometimes I have to ask more than once or even at each contact. This is often despite promises to the contrary. Surely once



it is noted that a certain format is required, this should be flagged up across the board and not left up to the individual to obtain from every department or at every visit. This should happen in the background with the client being aware only of getting their information in their required format rather than the fuss it seems to cause these days making one feel a conspicuous nuisance. Often staff don't know how to meet your request. Some make more effort than others. Some just say it isn't possible. Where does that leave you? Especially when you know that it is not only possible but you're right.

I have never once been offered lip speaker support as a profoundly deaf person with no residual hearing, and the general expectation is that my mother will provide communication support - despite me being in my late 30s. In the consultation room the healthcare professionals will usually talk direct to my mother and have no qualms about asking me the most personal questions in front of my parents. That said, as there are only a small number of lip speakers in the country, I feel my confidentiality would be further compromised if a lip speaker was used because I use them frequently in my professional life. It would be more helpful in this respect if another healthcare professional was trained to provide some degree of communication support (e.g. simply repeating things more clearly, or spending time with me after the appointment to explain anything missed) for patients like myself who are able to lip-read well.

As an inpatient, I am talked about at ward rounds etc., and rarely talked to - I would like to know how I am doing in terms of progress and ongoing management.

You always make it feels that you are a nuisance more that it is not your fault if you do get things understood or misunderstood.

Not all people with hearing impairment need sign language, especially for those hearing lose in their later life. Few organisations aware the needs and support for people with hard of hearing.

Cannot make appointment by phone as I cannot use one any longer, have to ask my husband to do it for me. When he was ill after being discharged from hospital, I had to walk to surgery to ask for advice and someone to see him. By the time I got home, due to illness and medication, he had nearly set our home on fire!

Cannot make appointment at Walk in Centre due to no suitable contact details available.

If my husband ends up in hospital, I need support in communicating with staff as I have no one suitable to support me. I have equipped myself with [.....] in the hope that staff would use [...] to communicate with me via text.

If my husband is ill and unable to make phone calls for me, I have no way of communicating with NHS, other than by asking a neighbour, IF I can find one at home who is willing to do so! In the meantime, the situation could have deteriorated

Staff just keep talking to me and expecting me to understand, I may understand a few words here and there but never the complete situation. Full instructions should always be available in text to give patients and their carers.

Too tired to continue

The NHS has always been good to me personally, the staff communicate well and I'm glad for that.

more back up after going deaf. Once hearing aide supplied you are then forgotten about, tinnitus no help or support.

Communication is one of the barrier hold people from getting best out of any opportunity or services in life and if people help each other by supporting others with less able to communicate & I believe , life will be a bit fairer to everyone.

I would appreciate having letters sent to me in larger print than that which is current.

Information is not always passed on, sometimes what is not clear enough

waste of time

too many health staff are not deaf awareness !! so many are very naive how to communicate with deaf people ! everyone are different need of communicate, some can lip-reading, some can't write, some can't BSL, foreign sign languages, some can't hear, some can hear with hearing aid, some can speaking well, some can't speak at all, some can tell what to do, some are difficult engagement with staff due low self-esteem, or ignore their need communicate

There should be more online support, and via text by mobile (not minicom service), and by email.

During hospital appointments although advised I was deaf I misunderstood a lot of what was said during my appt and left feeling embarrassed.

I would like all organisations to be fully aware that booking interpreters can be difficult and must be done in advance. If they know the patient is deaf, they should automatically book a BSL interpreter rather than the deaf patient having to chase the organisation if they have booked or not. This can be stressful not knowing if an interpreter has been booked or not. Also another thing - when organisations book interpreters, they must make sure they are registered and have ID to show that they are qualified because there has been cases when interpreters have turned up but they were not qualified enough or simply a [...] interpreter!!

Right now I have to get people to read my personal NHS letters because they are not accessible to me. This affects my privacy and my confidence, because many of these issues are extremely personal. More than three times I have had missed appointments because I have not been able to read the letters they give. I have asked repeatedly to get the information either by a phone call, text or e-mail, both of which I can read perfectly, but, even in the era of technology, this seems to be a big problem for the NHS. Please work to improve this because it will make many people's lives better. Thanks for your concern it is much appreciated!!!

People very rarely ask or assess disability needs.

All organisations need to recognise that they are merely the current keeper of the individual's information. Only one person has the absolute right to see / process / manage the information - the individual themselves.

I think more use could be made from texting appointment times out so that when booking over the phone, I could be confident of getting the time right!

Although I have not come across any within the health and social care organisations, if there were videos giving information, they should always have subtitles or a subtitle option.

I am a bit deaf and staff speak too quietly. Often I can't hear them. This has been a particular problem with doctors in hospital and GP

Very poor - I do not have any online access to any of my health or social care records

What would help me cope with long term conditions and comorbidities would be electronic access to all medical information because: speech is at times very difficult for me as I suffer from sudden drop of oxygen saturation due to chronic lung diseases; visually and practically the best medium for me is a tablet because I can easily swipe the screen to make the font bigger and easier to read or a laptop screen for the same reasons

Having autism, I communicate best by written word (e.g. through email or fax) and I need reasonable adjustments for this. I can have a delay processing verbal information and formulating a response and tend to realise things after the event, which may be too late. No service I have encountered is even aware of the fact that they are legally obliged to provide reasonable adjustments for people like myself.

Care with people who have hearing/understanding difficulty. Staff will sometimes talk loudly (or even shout) about person's health information, which can lead to serious breaches in confidentiality. While as a patient myself in a day surgery unit I recently overheard an older patient being given a diagnosis of stomach cancer, which she clearly found difficult to hear and understand. The doctor ploughed on through discussion on type of cancer, options re treatment, what team the patient would see next etc. for all to hear, and the patient herself was hardly considered at all.

Health and Social care professionals need to understand how to communicate correctly to people with learning difficulties including the importance of correct body language.

Stay clear of TLA,s (three letter abbreviations) and medical jargon

Information provided is usually clear. The problem is that there is potentially appropriate information around that I am not aware of and therefore cannot be assured that I have all pertinent information to hand when making a decision

I have found a lot of variation in the way services do or don't meet my needs. Mostly it is left to me to arrange and pay for an interpreter and to convert printed information to a format I can read. There are two notable exceptions. My old GP suggested that

he could do home visits and communicate with me by typing on my computer, rather than us having to arrange an interpreter. This worked really well for me and for him. There is one hospital that did arrange an interpreter, including to stay overnight when I had to be there as an inpatient.

Much more opportunity for communication through electronic means should be utilised so that people can receive details on mobile electronic devices.

you rely on post too much, spout the Caldicott principles then post 1st class not even recorded

I have to take my daughter with me as I have had problems with consultants not talking clear and keeping hands away from their mouths

I am profoundly deaf & have worn an aid for 50 years. The [.....] has been brilliant for me. However now I am expected to wear a digital. To me it is not the same or anywhere near as good as the analogue. I am told I can no longer obtain one on the NHS. Cannot hear indicator on the car. Traffic on the roads. Myself Speaking, many things I am missing out on. Why? please can you tell me is it at all possible to get an analogue on the NHS?

If say during a long term rehab a condition is mentioned and you pass that information onwards there should be some help in being able to get a diagnosis rather than the guess route that if am going down!!!

There is no point trying anymore to get the help I need from social services - they do not understand my hidden cognitive problems, and are very unskilled at any level of empathy or understanding. I have asked and asked for someone to help me fill in forms, or read things to me to help me extract the information and it never NEVER happens. If am penalised if I miss an appointment but I never knew it was happening as it came in a letter that made no sense to me.....

The big problem that I have is when my Mum is no longer around. I have complex health issues which need a lot of understanding and knowledge and the only person who has that is my Mum. Care providers just don't want to know and assume that my Mum will always fill in the gaps. Even the so-called professional community nurses don't understand the problems I face with my own understanding. I don't want people to think they have to take over all the decisions or discussions about my health; what I want is people to take a genuine interest, gain sufficient knowledge so that they can help me when I need it. But there is no training for care providers so my Mum has to step in and ensure that I stay away from GP surgery and out of hospital. Talking about it is great, but until a layer of support people is created who can carry out maintenance level of support for people like me, nothing will change. Either my Mum will continue or I will be left to just get on with things which I will find very difficult.

If letters could be sent to me in large print that would help. A sighted guide at the hospital would help too.

He is a vulnerable adult and [...] Communication and help is still desperately needed. For the past year I have tried to be present with every appointment especially [...] and yes there are serious matters.

Hospital visit and stay no hearing help, very poor understanding of my hearing needs

Nurses and doctors need training on how to deal with and support people with severe/profound hearing loss that may for example need to take them out (at night) so therefore need time to wake and put aids in before they give drugs or go to take blood sample

Being a carer for my wife, I am fortunate in being able to access information without any problems at the moment. I would like to think that any information and/or help which I needed in the future, should my position change, would be there for me to access with the help of the appropriate healthcare professionals.

It would mean such a lot if staff at hospitals were made deaf aware, I find it so stressful having appointments and straining to hear my name even though I have already notified staff of my hearing problem, I have missed my app several times through not hearing my name being called.

Most people, not just health professionals, are in need of educating. Hearing loss is a hidden disability but no less of one. It is frustrating when your needs are simply ignored. I am not stupid far from it - I just can't hear! Speak up please!

The issues I have are with the NHS. I am aware that my hospital offers other services for hard of hearing/tinnitus sufferers - but I have had to find this out myself after 4 months and 2 ENT appointments and 1 audiology appointment. I have not been given any support info or assistance and this would have supported and assisted me through difficult times. The only person who has actually supported me has been my GP who actually understood how my deafness and tinnitus affected my job and life. I am now having to go to my next ENT appointment in Feb asking again for info that I know I should have been given. I have been left with no answers or back up from the hospital at all - I was not even given a number or told what to do if I had issues with my hearing aid(using and personal issues - I do have a number for broken). I chose this hospital out of my district as if thought this would benefit me and am now regretting my choice as it seems they cannot wait to get me out of the door. I don't even know if I should be having social or work support?

Where do I start? The list is so long: need to be able to book and alter appointments online or by text; need visual displays in waiting rooms or vibrating pagers to alert you of your turn; hearing loops at reception AND in consulting rooms (portable loops should always be available); STAFF TRAINING on how to communicate effectively with the 10 million people in UK with hearing loss. (Face us, write things down, don't speak to us when hearing devices are removed, etc.)

Recently my 9yr old daughter broke her thumb, and I was unable to deal with it on my own, I luckily had the assistance of my husband. This causes me great concern that if something more serious were to happen to my children I would not be able to deal with it independently.

GP now less likely to book BSL interpreter as PCT do not pay for this now. GP says can't afford to pay for interpreter.

In a single consultation I had to ask a consultant 5 times (FIVE) to face me and speak more slowly so I could understand her. This consultation lasted less than 10mins in total, including an examination. I felt stupid, and came away not fully understanding what was wrong with me. I also felt angry that a professional wouldn't make the effort to communicate properly with me.

I asked for some sensory support as I am deaf was given an web page only to find that when it went to the web page if had to contact the support by phone not much good when you cannot hear

I have Asperger's Syndrome (A.S.). Most of the services I have contact with do not seem to recognise that A.S. is a disability that affects my ability to communicate. They do not make reasonable adjustments to what they say and how they say things. They do not ask questions in ways that I can cope with e.g. giving me time to process what has been said to me.

BSL is not the only communication used by deaf people. People should be asked what their communication needs are? Assumptions should not be made. Use of lip-readers, STTR operators etc. should be available too if required.

It is not always obvious until arriving at sites whether communication support is required. e.g. Is it in a noisy venue? How many people will be in the room? Will they be wearing surgical masks? Have they [...]? People should be asked how well they are managing and if any further support is needed. Deaf awareness training is required by staff.

The future will cause me to use Social Services so only experience will tell

There are numerous guides about how to provide information more accessibly for disabled people. The question is enforcing its adoption. The NHS is a medical organisation and so see disabled people as a "bag" of medical needs and not as a customer or patient with information rights. You will need a complete culture change to drive this programme. you will need to see information as part of making your organisation accountable and seeing design as following on from function and not as something which can detract from the attractiveness of a document. You need to look at accessible information from within mainstream budgets and not as an addition. Looking at it this way will mainstream the issue or support this ambition and go some way to reducing disparities in treatments across different groups of people. All desirable things I would think

Email or even a pen and paper would make my visits to doctor or hospitals easier as i wear two hearing aids. I would like my hospital notes to have written on the front if am deaf, as i never hear my name being called.

I have not encountered any problems but have heard of others having so.

I am a member of my local health care and at the last meeting I told them when it came to deaf people NEVER assume anything. What might apply to one deaf person may not apply to another.

I don't think this description in your question above 'if you need a British Sign Language interpreter or a communication support worker at your appointment' is acceptable simply because it leads to BSL and the rest of the sentence is meaningless as it doesn't indicate what other support is available. If one sees BSL they will very likely stop at that and not bother to find out about other support. It would be best if the sentence was changed to 'if you need a British Sign Language interpreter, speech to text reporter or lip speaker at your appointment' as this would give a clear distinction on what other support is available and whoever reads this will know what to ask for.

In this technology age the use of computers and [...] can be a help to those who can understand English [...] Use of [...] and computers to type things down will also save the NHS the cost of interpreter fees. However all this depends on the patient. As I have said before NEVER assume anything. Assess the patient first. If they request a particular communication support then that should be fine it is after all 'their' request. There have been quite a few instances when the NHS arranged a BSL interpreter when the patient was not a BSL user.

NHS staff need to be more deaf aware!

Being able to contact the hospital/doctor etc. via email instead of struggling with the phone would be a massive help.

Receptionists talking slower, they are normally really busy and this comes out in hurried speech which is difficult to understand.

Staff need to be aware that not all d/Deaf people can lip-read or sign, especially recently deafened people, and they need to be prepared to write things down to ensure they are understood, instead of relying on family members to fill in the gaps later. They also need to check that they are being understood instead of assuming that they are.

More visual aids in audiology departments, calling out names is not acceptable.

I rely heavily on my hearing aids and hear nothing without them. As I went deaf aged 34 I was never offered sign language lessons so loop systems are my only aid. In NHS and other places loops seldom work and staff either know nothing about them or how to access them i.e. don't even know how to turn them on! Why aren't they on permanently and serviced regularly?

Also deaf children learn BSL free but adults have to pay several hundreds of pounds to learn! WHY ???

Good quality front line customer services is also a great support

I am consistently misunderstood, due to my speech and sight difficulties. This dictates a lack of appropriate/useful response, in many instances.

I find that all the health organisations are pretty useless in communicating with deaf and hard of hearing people even in the audiology dept. sometimes! It should really be compulsory to have a loop system in the Drs surgery or Drs consulting rooms

They should make sure that I understand and not make it difficult if I need to have someone accompany me.

I'm constantly amazed that GPs and ENT hospital doctors do not speak at a volume I can hear, though they know I am deaf.

I have waited over 1 year just to get a hearing aid and then now have it, but need to get replacement parts for it and have found that I have to be referred back to my doctor who in turn will refer me back to the hospital from where I had the initial appointment. Nothing seems to be straight forward and it very frustrating and stressful.

I also need my ears micro suctioned and had a very long wait to get an appointment sorted out and then gave up with the doctors who would not refer me to my local hospital so had it done in [...] hospital and went there for my appointment.

Most of the staff from Audiology appear without compassion uncaring & arrogant. Am made to feel am just a nuisance when asking for advice

NHS uses interpreting agencies to book BSL interpreters, not all are competent. I had to stop interpreters communicating at consulting rooms as they did not understand me as I use high level BSL skills and they miss-interpreted me when I was trying to explain to the consultants so I had to use pen and paper to communicate with them.

We had to find out and fight for support ourselves after my stroke. The hospital did not pass on information to agencies -social services. We had to follow this ourselves.

We did get information from [...].

I would like more feedback. I asked-questions at an Expert Patient programme but I have not been given the answers. Another example is a survey I completed following physiotherapy, although I was promised feedback this never happened.

Why do NHS organisations use such complicated language? Would it not be better to use plain English/language and please stop using capital letters for headings.

All I need is for staff to have had Deaf Awareness Training so they know how to deal with profoundly deaf lip-readers like me - the lack of awareness within the NHS and Social Care is SHOCKING to say the least. My biggest problem is speaking to people on the phone, if I tell them I am deaf they simply start shouting, which does not help at all - I already use an amplified phone at home. My type of deafness means sometimes I am unable to process sounds, rather than not hear them at all.

Never had any support given to me.

I dislike the excuses people come up with for not having the information in the correct format. I am blind and need everything in large print yet, even the eye



hospital that registered me as blind say they are unable to send appointment letters in large print as they do not have a large-print printer! Theirs is one of the few buildings I visit that does not have braille numbers in their lift or speech to tell you which floor you have reached.

GP practices and hospitals should not provide information or services, without making all information and services properly and fully accessible to blind and partially sighted patients.

It would be helpful if things are explained in plain simple English that can be easily understood rather than medical jargon being used.

I recently had discussions about having a PEG feeding tube. the dietician said he would get the information leaflet in Braille which would enable to read it independently and to make an informed choice. My best friend said to me one day "are you waiting for a Braille leaflet about getting a PEG Feeding Tube?" "yes, I am" this now meant that all of my visually impaired friends now know my business, and yes it isn't that important but it bothers me.

It is very common for NHS and other sites to be difficult / impossible to access using a screen reader such as [...]. Even this survey does not follow accessibility standards so that, for example, the questions are not read out when tabbing from one field to the next, Edit boxes like this one do not have a heading which [...] can detect.

I am visually impaired and over the last couple of years have been a patient at [...] Hospital. Being visually impaired, standard print letters are not good for me. Worse still is when a standard print form is completed by hospital staff or doctor's surgery by handwriting. Printed forms may be electronically scanned (OCR) (at my own inconvenience) but handwriting is totally inaccessible. So, worse case, if I try and scan a letter, I might get something like the following: Your appointment is at /:p\_, on the \_/\_\. It is important that you attend this appointment ...When I have asked about receiving letters in Braille, I have repeatedly been told that there is no provision available. This is unlawful (Equality Act). The same is true for my doctor's surgery. If I compare NHS with say, my bank or telephone company, the NHS comes out in a very poor light. My bank has provided me with braille information for the best part of 30 years. Why is it so lacking in the NHS? I will commend the [...] that they do now have a mobile phone texting service, this is a lot of help, but the information in the text messages is a little incomplete and the reminder only comes a few days before the appointment - if the secretary has remembered to tick the box.

As well as providing accessible services and information, I feel a significant part of the job will be promoting the services to NHS staff and providing training on the systems in place and being put in place.

Keep it simple so the ordinary citizen can understand it

I feel that they should listen more to the service user

My son is under care of [...] and diagnosed with [...]. One of recommendations was for me and my husband to attend support group. We received a letter which only

asked if we need BSL, no space any other request. We made it clear that we don't, we need electronic notetaker or speech to text reporter. Staff had no clue what we are asking about, and we missed out on support groups meetings. They finally arranged the support for next group session 6 months later. This was unacceptable as we already had to find our ways to support our son. Staff, during assessment show total lack of deaf awareness and that was not helping with assessment process.

Most of the consultants [...]. You are left with not knowing what is wrong with you.

Lack of general awareness of deafness within the NHS at a whole however my GP surgery is very aware.

I can read, so information that is written is not a problem for me however I do know of many deaf friends who do not know what to do when they get a letter.

A strange issue formed when I get letters - a question on a letter states – “If you need an BSL interpreter please phone..... I'm deaf how do I do that???” Alternative methods should be provided texting and emailing.

I would be terrified if I ever had to stay in a hospital with nurses and doctors talking to me and I would not understand. Ward managers DO NOT book interpreters everyday especially for doctors rounds in the morning. The situation would make me very ill and could prolong my stay in hospital. Many of my deaf friends have horror stories of they stay in hospital or when in AE. - Asking for a BSL interpreter is OFTEN ignored by staff in general.

Communication is a two way process - staff need to understand what the patient have to say as well.

Saying that a BSL user can Lip-read is offensive and a poor excuse to not book an interpreter.

COST is always the excuse when an interpreter is not booked making the deaf patient feel so devalued. It is often said into their faces. 'We can't book an interpreter, it is too expensive' is a common saying among staff to deaf people and family.

Out of hours doctors always use mobile phones and therefore can't use Text Relay services. They and health centres, hospital departments and all doctors and health and social care workers need either to be able to use Text Relay or be prepared to send text messages or converse by email. Audiology departments in particular should know when a patient needs this.

All organisations should have information in alternative formats so you don't have to rely on other people and be independent.

I have a severe-to-profound hearing loss in both ears and rely on hearing with lip-reading to communicate. I find I have to be more assertive when visiting my GP to slow down, face me when talking and explain terms in more simply as it takes me longer to hear and understand new terms that I am unfamiliar with.

Visits to my GP (often different GP each time) is stressful even before I see them as I know I have to but in a lot to make sure I have heard and understood them. More time should be allowed for those in my case to allow for time to hear and understand everything correctly. Also I have missed my name being called even though I inform reception of my deafness and that the GP needs to know that first when calling for me. This is more unnecessary stress and I'm sure there are loads more hearing impaired people who don't inform reception therefore missing more appointments.

A numbering system where you obtain a ticket with a number may be useful and it will appear on a screen.

My GP and district nurse are very good at sending me info via email but the Chiropodists and both [...] and [...] hospitals never provide information in accessible formats and this is against ones private, personal and confidentiality

The first time I visited my doctor for a number of years, I was unaware that I needed to book myself in using a touch screen. I waited for a long time without being called and a member of the public who had arrived after me and been attended to, drew my attention to this fact and booked me in to the system. I now know to wait at reception for this to be done for me but hadn't been made aware of this beforehand the other year.

I have never been asked if I need the information for a procedure in another format

I have to use patient transport for all appointments as there is no service that would meet me at the hospital bus stop and take me from there, an awful waste of money and everyone's time. There is no awareness that most blind people need guiding, not wheelchairs, and I have been humiliated by the production of chairs many times, no disability training at all, and some of the most discriminatory and ignorant staff I've ever met at the [.....]. Access for blind people needs planning at all levels from clinic location and processes onwards, it's more than just sending out information and even that doesn't happen

Should be able to book doctor or appointment on online or email and when visit GP or A& E need able to book an interpreter straight away not wait for 2 weeks' time for available.

It is a shame that most if not all communication from NHS is only in print. As a blind person this means that whenever I receive any sort of communication like a letter I am forced to rely on someone else in order to be aware what is presented. This means that at times I have no one to read such information for me and therefore I have no access to the information in timely manner. If the information was presented in accessible format this could be avoided and I would have no delay in receiving the information and acting upon it if needed.

I have never been asked if I need any communication support. When I have asked for support my request has been met with disbelief. Even when I have offered a tablet for text this has not been used.

To ensure Qualify BSL Interpreter for appointment as it is important to receive the correct full information. Do not use trainee BSL interpreter or Communication

Support worker as it is not appropriate for hospital appointment / doctor appointment etc.

I am severely sight impaired/registered blind.

In [...], I was taken to A and E with stomach pains. When they were ready to discharge me, I was still in a great deal of pain and was told that I could use their telephone to call my husband to come and fetch me. I could not see where it was so I did not move. I felt they got a bit uppity with me. However, someone did take me to the phone, but left me to find my own way back to the bed to wait for my husband. They were informed that I had a sight problem, and I found this experience most upsetting.

I'm hard of hearing - one side is very deaf - the other severe to profound. This questionnaire is talking about very Deaf / Blind, but this issues affects hard of hearing too.

English language, also terms you can understand instead of "medicaleese".

I think that Doctors need to understand more about blindness and what information is out there. For example renewing

More use of loop systems within the support services please

I find it frustrating being able to communicate directly with right departments via email/online chat as I cannot use the phone.

A lot of letters say if you need an interpreter please call us. or please use text phone. Most deaf young people don't have access to text phones. An email address would be better.

Often when you need an interpreter they ask you to bring a family member, this is unfair and causes issues and tension.

Lots of times I've been told an interpreter has been booked and arrived and there isn't one. Also the biggest issue is doctors and nurses lack of deaf awareness.

If documents are to be provided as PDFs, these must be authored with proper mark-up to make them fully accessible to the visually impaired.

Doctors, nurses and health care professionals take a lot of time to make sure I am involved in my consultations

The main method of getting in touch with NHS services is through phone. However, this is not ideal for a large majority of deaf people who then have to rely on others to relay information when it comes to appointments or health issues. There must be another alternative such as email or text, in order to improve access to services as well as maintaining independence and privacy for deaf individuals.

We are not happy to hear so many real stories that hospitals avoid to find and book BSL interpreters. Not fair! We heard foreign language translators provided, no problem, why nurses and doctors ignored deaf asking for BSL interpreters, they want

to write notes, and English is not our language. Respect our language BSL! They cannot mess us around, hope to save time and money! Our health in their hands - where safe?

For years, I would not make the appt if I can because I can end up feeling hurtful because I attempt to make them aware that I need BSL signer but always have let me down. It is much better to suffer from the health issues that I have than to tried to and arrange signer because I end up in more pain, heartache because of what I am trying to do, I don't want to bring in my family member or friend because I can't say what is the problem fully, and it's not fair on my family/friends because I may want to keep it private until I got the results, it's not right for them to worrying about it, if I had a signer, they won't know anything, if results is clear, I won't need to tell them anything but if results show some problems, then I will tell them. I believed that not having this have make me feel depression that could otherwise could do without.

It is too easy for organisations to make it unclear as to who takes responsibility for providing services and facilities.

[...]

It is sometimes very hard to get a BSL interpreter because receptionists and other staff just don't understand how important it is for a deaf patient to be fully aware of what is happening to them, and what treatment they are getting, including medication. Some staff don't know how to book an interpreter or have no idea if they are allowed to book or not. Some ask me if I have a hearing friend who could come with me, or even my mother. It is appalling, and many less assertive deaf people actually accept this and bring their own underage children to interpret for them. This is not acceptable and needs to stop.

Please provide British sign language video so I can access fully

At my local surgery there are touch screens which are not accessible to myself being a totally blind person. Plus the fact when ones name comes up on the screen it is visual only with a bell ringing to go for appointments. Plus the fact the staff have not had the relevant training through no fault of their own. They are always short of time and rush you into and out of appointments without time to repeat information or clarify what they mean.

I have a language and communication difficulty which means that I cannot always express myself as clearly as I would like. My GP is very good at getting all the information she needs from me to make informed decisions however most of the specialists I see do not give me sufficient time to give them all the information which has led to poor treatment and delays in accessing the treatments that I actually need.

physical help for blind people is excellent but availability of information is poor.

Deaf awareness in the NHS is nil, from booking appointments where they insist on me using the phone, I cannot use the phone I am deaf.

Staff do not understand deafness even in audiology and ENT, they try speaking to me when my hearing aids are out, and they don't even have the manners to face me when speaking being able to see a person's face while they are speaking is so important for deaf people.

While in the waiting rooms there is nothing visual to let you know it is your turn, calling my name out in a busy waiting room is not going to work even worse is when they shout your name from the consultation room.

Health and Social Care organisations need to be giving the same information and working together

Information is often complicated and has to be obtained from multiple sources. I am a carer to both of my elderly parents and they are often left confused when they have been given information by a health professional so I either have to be there or have to follow up afterwards.

Lots of negative experience, appt cancelled due to no interpreter whilst undergoing tests, hearing people never experience that! also assumption from nursing staff that I need help understanding information and when I challenged that they said been before with other deaf. they would not make the same assumption with hearing people

I get the support I need if I go to health services as the health service refuse to do it for me. They will not take on the responsibility of getting the interpreter. The GP is harder to get support - they say pen and paper will do.

One of my biggest frustrations is not being able to receive emails from the NHS. Email is the best way for me to receive information. Even at [...] Hospital they only send out letters in 14 or 16 font. One of my consultants does encourage me to email him if I have an urgent query and by doing this he was able to give me advice which meant I avoided a trip to A&E saving everyone time and money. I also find that many health professionals are unsure of very basic things when providing treatment or a service to me as a visually impaired person. After eye surgery once I was given a pot of tea and cup and saucer for a drink after surgery. I was groggy had my eye patched and found it difficult but was able to pour out my tea as I am used to being partially sighted. The patient opposite me had both eyes patched and was given the same. No one even told her it was a pot of tea and not just a cup that had been put in front of her. no one asked if she needed any assistance. I think this shows where just basic communication fails. If someone has a visual impairment then verbal communication from staff is vital such as announcing your arrival and when you leave, asking if you need any help, explaining information that others would pick up visually. Like we've just plonked a pot of tea and a cup and saucer in front of you be careful it's hot and do you need any help?

I only have ever had one ear that works. Over the last 6 months I have lost almost all hearing in that ear. I have had checks etc. and a stronger hearing aid has been prescribed. My issue is that from that date early December my next appointment to collect my new aid is February [...] the Meanwhile I can hardly make out any speech with the aid I have. I think this is an unacceptable length of time to wait. Sorry for

being negative, the people who are dealing with me are very nice but don't have the time to fully sort out problems.

It would be better if I or we able to CHOOSE our BSL interpreter and able to book ASAP not two weeks' time becomes delay in my health or appointment. Most places say we don't have the budget for BSL interpreter. Become our right is very weak and have no power to book BSL interpreter therefore we missed out information and missed out opportunity to improve health and social care support

[...]

If all information was in e mail then would mean I could correspond quicker and be able to organise support to help me

I have tried to ensure my local practitioners give me information in alternative formats, even though my needs are flagged-up, I still get print letters which is not accessible for Deaf people and poor quality in Health and Social Care for all ages.

Large majority are not Deaf Aware at all. No Specialist Deaf Social workers e.g. for Children and Young People or for Adults.

Senior Management don't accept terminology 'Deaf' - and giving us names like 'Complex Needs' or 'Hearing Impaired'. Should respect Deaf Identity.

It is tremendously difficult to access a GP - it's impossible to book an appointment in advance e.g. for advice about a non-urgent issue. There is no privacy or dignity in the surgery reception; everyone hears everything everyone says to receptionists - and the receptionists make people tell their whole story before they allow them to book an appointment [...] Upsetting

My audiology departments in [...] only shout out people's names when it is their appointment time. Why don't these departments have, as standard, LED displays which show your name? You wouldn't hold up a written notice and expect a blind person to read it, so why do they shout out names for people who are deaf/hard of hearing? Seems like simple common sense to me yet NHS audiology departments are the worst offenders!!

I wear 2 hearing aids and can't hear on the phone any more yet the hospital insists I ring up to make an appointment. I can't do it so need my husband to ring on my behalf. Why there isn't an email address or online chat facility to help us? It shows a complete disregard for the DDA and making reasonable adjustments to help people with disabilities.

Often your name is called out at hospital and GP appointments, this is impossible and uncomfortable for Deaf/deaf and people to hear or see. I have often missed my slot due to not hearing my name being called. It is also stressful waiting for your name to be called which hearing patients do not have to go through. Therefore you can make you feel anxious at the start of your appointment simply due to the stress of trying to hear your name.

I feel that there should be more of an effort to get information to the general public about how to communicate with people with communication difficulties, but I don't know if that falls under the purview of the NHS.

That all waiting rooms had visual "calls" to appointments. My GP has board where my name appears when it's my appt.

That all reception areas were trained in deaf awareness.

Local social care services ought to have a web site where people can find local address of providers of care, wheelchairs, equipment, and help for specified problems, relevant support groups &c. This would then be available even to those who have saved to pay for needs in old age.

The only time I have any problems with my hearing, I have a hearing aid in my left ear, my right ear is almost dead, is when I am in hospital. Nurses and doctors always approach me on my right side which makes it difficult to hear clearly so I ask for them to go the other side. It would be a great help if there was a note about my hearing clearly obvious on the cover/first page of my notes and a hearing symbol on the bed.

NHS hearing aids supplied are of such poor standard that one does not use them. My employers have purchased new private [...] units that work correctly. Local NHS has stopped providing batteries at local health centre.

I have support from a fabulous Brain Injuries team which without this in the early days my life would have been unbearable.

Too many times, one tells the person you are speaking to that you are deaf, and they say 'sorry' or 'oh, dear' and then carry on as if you are a hearing person. I am quite elderly and I feel isolated by my deafness

PEOPLE OFTEN SEE THE GLASSES ON SOMEONES FACE. I HAVE TRIED USING BADGES THAT SAY I AM DEAF / HARD OF HEARING THERE NEEDS TO BE MORE DONE TO MAKE ABLE PEOPLE TO UNDERSTAND THE NEED FOR PATIENCE AND CO-OPERATION TOWARDS US FOLK WHO NEED EXTRA COORDINATION. IT WOULDNT HURT THEM. I HAVE BEEN CALLED [...]. IF ANYTHING [...] HEARING AIDS ARE NOT MY EARS THEY ARE MECHANICAL AND HELP ME TO HEAR NOT REPLACEMENTS. I WOULD LOVE TO HAVE MY EARS BACK BUT ITS NOT GOING TO HAPPEN.

Just having text boards with my name when it is my turn would be an improvement.

Also nurses, care workers, receptionists etc. need Deaf awareness training

I don't understand why the only apparent way to communicate with hearing services is on the phone. Why not online?

Right to choose communication provider. Interpreter...to be able to book and coordinate my own provider...need to have finance support that is free from mean testing. Direct payment



I know the NHS is understaffed and underfunded, but the staff are generally excellent and cannot do enough to help, if there were more time available for consultations so I could ask about my tinnitus problems that would be good, but I realise that time needs funding and [...].

My main complaint about GP or Hospital services is the impossibility of getting in touch with them in the first place. My GP only books appointments by phone and as I cannot use the phone I have to go the surgery in person to make an appt. They will not allow me to make an appt by e-mail. This also applies to hospital appointments.

I am finding the questions ambiguous. I am profoundly deaf. I can read normal text. I cannot understand speech. I need someone to write things down. I use text relay as an excellent source of communication as well as email and text messages and of course letters where it is possible to send a letter. I believe everyone should be trained to offer a service or deal with a specific need without having to make special arrangements, and especially those who deal with health and social care.

Qualified interpreters needed at all times

This is such a general question. "organisations" covers a multitude. Generally, in the area I live in, I can't complain most times about the services. I get good support.

Have u ever tried using mini com/[...] phone system to make complaint, request assistance from utilities, or [...]!! Training for my GP practice, testing of equipment for deaf people by deaf people.

It would be helpful when in GP or hospital waiting rooms that a screen with name on could be highlighted when called for appointments, as in busy areas it is very difficult to hear when name is called

Really bad GP... Not willing to refer....more interested in saving money.

Nobody is interested

It would help if the NHS personnel were competent and helpful,

In almost every situation if I say I have to lip-read then they make sure they face me. I feel more people are having deaf awareness training. Also I'm not frightened to articulate my needs.

There are too many administrators too busy administrating, so that patients do not receive a fair share of the resources available.

Poor, or non-existent understanding of tinnitus.

I cannot hear my name being called out and although I always make this clear at reception a lot of health professionals still use this system. This also includes my local audiology department which should know better.

It is all too confusing. My doctor takes three weeks to give me an appointment. The NHS is a disgrace - not the staff, they remain wonderful, but the management and administration are a disaster.

Hard of hearing people don't always need more complicated support other than the person they are seeing to speak slowly and clearly and preferably in clear English (obviously when appropriate) i.e. [...]

Generally I find that [...] people are reluctant to "press their case". I am sorry to say that I am of the other persuasion and will keep on until I do get the information I need. I have a standing rule [...]

I have managed my tinnitus [...] for the about 20 years now it is getting very bad if I use my arms and shoulders an osteopath has helped but now from my left arm pain and noise are instant but nobody cares

PLEASE MAKE ALL BSL VIDEO ON INFORMATION.

I feel that you do not get an answer to what you are asking and they are avoiding the question, like that is what the NHS provide so take it or leave it, this is what I felt at my last appointment [.....].

I go to the hearing clinic in [.....] and I watch what happens with staff and patients. Patients are asked to hand in their hearing aids and when it's their turn they are shouted in and none of the patients can hear them. I think a little bit of understanding is needed.

I don't use BSL at all as I am oral lip reader but I always bring my relative to come with me for hospital appointments to reassure me what is all about outcome from specialist but don't feel private at all. The worst is visiting GPs that I may not always to have relative to come with me at short notice and I never felt 100% sure what the GP says cos it was very little time between appointments. It would be helpful if someone like nurse or from receptionist to note taking between doctor and myself and give me advice about what's next action I should take like make a blood appointment?

When my name is shouted out with regards to my turn at an appt I can't always tell it's me they are calling, even when I explain to the reception staff I am hard of hearing. When NHS staff wear masks and attempt to speak to me, I am obviously not able to lip read. When staff talking to me turn their face again I can't lip read.

Heath especially ...GP s and front line staff should know when a person is struggling to cope or to understand. Not all deaf people need BSL. Just a small majority of deaf people are BSL users ....it's not rocket science .clear speech and knowledge of communication skills is all that's needed.

Audiology at my local hospital tells deaf people to take a number and wait for their name to be called. This doesn't work very well, especially when you are there because your hearing aid is broken.

I find it very hard to phone my GP for an appointment.

My Audiologist behaved quite appallingly when I visited to say I thought my hearing aids weren't working. Surely it's BASIC to talk to hard of hearing people with their aids in? Certainly it is inappropriate to shout at people (shouting doesn't help deaf/hard of hearing people hear any better, in fact we are mostly swamped with so much noise it only makes things worse), and it is unprofessional to talk to them in [...] - I'm sure you are familiar with this tone – [...]. Refusing to believe that I was having extra difficulty hearing, snatching the aids off me, refusing to test them and trying to send me back to my GP - were these all ploys to save money? She did not apologise when she finally tested them and found them not working. I can't complain as I have to go back there.

GPs in general don't seem to be deaf aware.

Please give BSL video, I am BSL user and need information in BSL like on video on website, I watch and understand everything.

Always see different language in leaflet for [...]. Never for Deaf people why?

Generally the service is awful.

NHS and other organisations are hit and miss. Sometimes interpreters are booked and others not

Must always have interpreter at every appointment. I find hard to write things down to explain what I am going through. I find at ease if I am signing in my first language. - more expressive. I once tried to explain to the nurse by writing things down but the nurse who doesn't have patience, and took the pen out of my hand which I find very rude. This results me becoming very angry.

Without support, it's more difficult for me to access my needs.

I went to Hospital many time and there is nothing Interpreter and also doctor as well

I think that if all staff (doctors included) undertook deaf awareness training, plus refresher courses, it would make deaf people's lives more manageable.

Deafness being an invisible disability is often discounted. People can mistake hearing loss for confusion or stupidity which is humiliating.

Staff need to trained in the cultural awareness and disability awareness, GP staff need re training in how to communicate with public, keep confidentiality and treat people with respect and dignity.

There is definitely a shortage of information for social care and welfare rights [...]

We need to book BSL interpreters and have information relayed from BSL to English and vice versa

Bad experience - most time never book BSL interpreters for me for appointments - they say bring mother or father - my mother and father don't sign and its personal appt - nothing to do with them - I should have equal access to appointments like hearing person.

I have no need to access social care and when there has been a need to access health care, generally my experiences have been favourable.

As a disabled person, using mobility aids, who also has visual and hearing difficulties I sometimes get frustrated because some officials talk whilst pushing and of course as they are behind me I can't hear, I also feel sometimes officials, if they are seeing you about something not connected with your disabilities (whatever they may be) don't take them in to consideration

All support seems cost based and government ruled and does not benefit the service user in their needs or improving living standards

In this world technology is improving so are services. For example, people with hearing problems can be texted via mobile like text messaging/e-mail which could improve the communication level rather than telephone. Similarly, if they're deaf a sign language could be texted to the mobile so they do not have any difficulty in understanding. Blind people could be guided in a way that they could understand. The barrier between communication is very important to patients like different languages etc.

Aphasia, especially if there is a receptive element is largely ignored as it is so hard to manage, communication wise.

As it is hard to quantify the understanding a person with receptive Aphasia has it is important to talk with close family or friend of the service user and also have an in-depth repetitive conversation with the service user themselves to ensure the answers given are the same each time.

Ask the deaf person what works for them. Ask them if they need to provide a SLI. Look after the deaf person if they are on their own in busy waiting rooms, as its stressful waiting to see and to try and understand if your name is being called out.

All health and social appointments should be accessible in BSL. All appointment letters should be translated into BSL. All requests for communication support should be accepted without contest, because it concerns my health, not theirs.

Twice I have gone to a medical appointment and no interpreter was booked. The problem is with the receptionist who forget or make an assumption that no provision exists, or the 'appointment is not that serious, you can manage'. Health professionals tend to forget that hospitals are intimidating places with documents and decisions that have consequences. I would like to access these services equally to my non-deaf people and be equally informed as them.

I have just found out from the local authority that they have produced BSL videos about some of their services. Although, I found them excellent, there are still much more work need to be done.

Appointments etc. would be are easier if they were sent by e-mail.

Providing letters arrive written in text I can listen to them on a scanner reader but if they have hand writing then it is not possible

Now I am 16, I don't always want my mum there, we have explored support for me but because I am very articulate and studying a levels I don't tick any boxes for support so for now it's going to have to be my mum. If I am asked questions they need to be in context and be really clear as to what they are wanting to know, my mum preps with me so I can articulate what I want to say. The lighting and crowded waiting areas, that are unclearly marked are tricky for me, I just want to get out of there and use headphones and shades to help me cope. Long waiting times really stress me out and also stress staff, I really hate that - rude

Support is rarely consistent.

Staff lack basic knowledge on sight loss and require Vision Awareness Training.

The [.....] has assisted me in accessing health organisations and they provide training.

It would also help if I could access healthcare reliably by non-telephone methods especially as currently I'm trying to access treatment for an arm problem which stops me typing on my minicom and I can't take incoming calls at all

I wear hearing aids & have for about 7 years now....What really upsets me today, is that no one will remind you that you are due an appointment,...or check-up that you are being seen 6 monthly....I'm fairly young, so usually remember, but there must be lots of elderly people who forget...& thus are forgotten about by the NHS,....obviously if one doesn't attend for a while, to have tubing changed, etc.,.....inevitably there will be a negative impact on one's hearing....It's worrying....I've also realised that for a while now, when I go to the audiology clinic, I am being seen by technicians & not audiologists,...so if there is a problem, they're less likely to have the knowledge to be able to pick up on it...

I am very lucky and do not require any communication assistance or need information in a special format. However I work with Deaf, Deafened and Hard of Hearing people who struggle greatly in receiving the specialist assistance they require when accessing these services.

Can the NHS wean itself off its obsession with telephones and use a variety of communication aids such as text messaging, [.....], email and VRS?

Respect us as deaf person's right to request for registered BSL interpreter and access to information through BSL because it is our human right

Don't force us to use phone to contact NHS and use video relay services such as [.....] or emails or text

There is a very important need for Healthcare Trusts to put more emphasis on all levels of communication & assistance from GP's to Hospitals. [...] Healthcare Trusts could ask each GP practice for numbers from their patient records which then could be applied nationally and to see the worsening effect on Healthcare services

The social workers for the deaf in rural areas need to improve their BSL.

When I went to GP, I realised I didn't get all the information I needed from the GP once after I had my GP and I searched on [...] to find out more about it and I didn't know what it for or why does it helps me...

Time to be treated as an individual and assumptions not made that my condition is exactly the same as others. [...]

Better and fuller information would help. Not only about the condition now but what will happen into the future, what the prescribed medication may do to my body and any side effects like weight gain etc. The effect on other conditions should be taken into account as things like weight gain can affect them

It would also be helpful if doctors in the NHS took a few minutes to check if the environment is accessible to patients to maximise the information that they could understand. For example, my consultant neurologist knows that I have visual difficulties and have difficulty looking into light i.e. facing a window but every time I see him he always has his back to the window so I have to sit facing it and I have to ask to have blinds closed to help me see better. It would be helpful and courteous if he took a few moments to ask if the set-up was ok for me rather than me always having to stop and ask.

Letters sent by the NHS should be in a readable font and size - please stop using that awful old-fashioned print that is so small and difficult to read!

Have in house interpreter on call to cover emergencies rather than waiting 2 weeks (treated like second class).

Fed up of having to ask and argue about booking fully qualified Level 6 interpreters. We have enough problems before asking for interpreter and found it no interpreter booked or staff who "can sign" not professional!

People forget you are deaf as soon as you have told hospital staff - I feel like I'm wasting my breath most of the time.

My family feel getting the right support is very difficult at times. My needs are not really unique- I don't understand risk or dangers of many sorts, I need 24/7 support due to this, I am quite independent- I can wash and dress myself, I just need prompts sometimes. But my family need respite and getting appropriate respite has been extremely difficult since I turned 18 (I am now 28).

When shout name on hospital how you know

Staff need DEAF AWARENESS training! Sometime stupid question

Would be good if NHS offered a buddy or support service

Never see information available in BSL, always large print/audio or Braille. This survey should be in BSL!!

Poor service in the ward bed where deaf people are often left out due lack of communication

This may not be relevant to the survey and is more relevant to my daughter whose hearing deteriorated and is now profoundly deaf. She has only recently had a cochlear implant and although can hear much better we don't know how well she will manage with NHS or Communication services. However, despite several requests during the years of deteriorating hearing, we were never managed to get any BSL training for the family. My daughter had to move school so she could learn some Sign supported English and we, as parents have struggled to get to classes due to childcare and timings of the classes clashing with work commitments. My son has never managed to pick up more than a few basic signs. It was very difficult to support my daughter through this period and it would have been difficult for her to follow BSL interpreters provided by the NHS as she didn't have the knowledge.

We need all information produced done in easy read too.

I have asked for all my correspondence to be in large print. Out of about twenty letters since the request was made only two have been in large print and one of those did not show the time of my appointment so I had to telephone the appointments office to find out the time. Also when I was in hospital for a few days recently I got an eye infection and had more difficulty in seeing but was given no extra help as it was noted that I was partially sighted.

I find it very frustrating when [.....] hospital don't write appointment letters in large print. They don't always book interpreters (I have made a formal complaint about this and they blamed [...], I complained to them and they haven't replied!).

I would like to access online information about health but it's all in written English and if can't read it - I would like it translating into BSL.

I have never, to date, been given any information in an accessible format by any department within the NHS with whom I have dealt. This includes GPs, Eye Specialists, in hospitals, etc. However, as any typed information I do receive is produced in at least 12 Point Font Size, I can struggle to read it, but it would be better if things were made more accessible, particularly when having to read signs and visual displays and when there is nobody around to provide any verbal cues, and such like. So when it comes to accessibility-related matters within the NHS, I have been failed so far.

I love email, text alerts and online systems.

Communicating with parents/carers/support not ME

In 23 years I have never been asked my preferred communication method.

Receptionists filling out forms because they are inaccessible, with the whole waiting room able to hear my private information.

[...]

I want to be sure that my information is kept 100% confidential and would not want any presumption of consent for use of my personal information even if in an anonymised form.

My GP surgery is woefully in the dark ages when it comes to communicating with me. I am treated as 'stupid' because they are not deaf aware. Very belittling.

Even when I inform contacts of ways to produce information in the right format, there has frequently been a tendency to resist anything that wasn't cheap or immediate.

IT IS IMPORTANT I FEEL PARTICULARLY FOR LEARNING DIFFICULTY CLIENTS THAT ONCE SOMEONE IS ASSIGNED A SOCIAL WORKER THAT THIS REMAINS CONSISTENT AND THAT THE SAME SOCIAL WORKER IS SEEN, IF THEY ARE STILL IN EMPLOYMENT, BY THE CLIENT

Please can the easy read with photo's which do not match the words stop. [...] If you really want to teach about health or social care put the information on YouTube with a symbol and written word commentary.

Information is always too text based. It should be given with less jargon, more visual, and with translation into British Sign Language.

One problem in crossing from one NHS to another. My usual interpreter from one NHS Trust couldn't be booked for another NHS Trust due to contract reasons. This was not acceptable excuse for me.

It would be good to have all the information in Easy Read, BSL etc.

I am a person with aphasia, a communication disability. Because I look alright, there is no reason for anyone to treat me differently - but I have problems with my speech, memory and moving around. There is no training that I have seen which involves the staff at GPs and hospitals and social care agencies to deal with aphasia. I get sick and tired of explaining to people what I have - for 22 years I have fought to get the services I have owing to me. Now I feel that it is "just one of those things" - and I have withdrawn from the NHS and social services because no-one seems to care.

You may have to work hard to get the info that you need. Many people would not bother

I am on the autism spectrum, but because I do not have a learning disability, I do not get any additional communication support, even though autism affects my communication. I would benefit from everything being written, there being an option to email appointment confirmations rather than ring up, and to have information presented simply and unambiguously. Sometimes I have followed the instructions exactly, but they have been incorrect, e.g., the letter said "When you ring up, ask for Women's Health Physiotherapy", it should have said "When you ring up, ask to make an appointment with Women's Health Physiotherapy" because when I asked for WHP I was put through to their extension and then had to be transferred back, which was stressful. Their deaf awareness is non-existence

I had an emergency eye operation [...] - no interpreter was available so I had to rely on my hearing husband to communicate for me - but at the next appointment at my request for an excellent and most professional interpreter from [...] - they agreed to provide it via [...]. I had another appointment last year - they provided me a wrong and inappropriate interpreter from [.....] without checking my preferences - I had to



ask the interpreter politely I am using my husband. It looks like [.....] brings in ANY interpreter! This is not right.

I don't understand what a social care organisation is?

Not good enough to explain to me as I am deaf, my first language is BSL

This English is too hard for me to understand

All I want is the same access to information that everyone else gets. It's not a big ask is it?

I personally am fluent in written English, but require a BSL interpreter to communicate face-to-face without resorting to pen and paper (and in the process, creating a record of confidential information which really should be shredded).

My experience is that reception staff are usually the worst for accessibility (perhaps due to their higher turnover) and are where communication breaks down (e.g., when calling a patient to go and see doctor/nurse) unless one happens to find the interpreter before arriving.

To continue from my comments above: [...]

I have always requested that NHS book Interpreters for me at all appointments, however, if the appointment is cancelled by the consultant or health professional, they don't always book the Interpreter for the renewed appointment, just because the appointment has had to be moved, does not mean my communication requirements have changed! Also they do not ask me whether I would prefer a male or female interpreter, depending on the nature of the illness. There are some agencies of Interpreters who do not ask this and send incompetent Interpreters who do not adhere to codes of conduct, such as contacting the patient before the appointment to offer them lifts and so on which is a breach of confidentiality. They also don't interpret in the context it is supposed to be hence more misunderstandings if you are using an Interpreter who is qualified but hasn't been assessed for their experience and or skills

I find it very difficult to get an urgent appointment with GP

When GP/ dentist cannot see me I should be able to get a prescription written and dispensed by the pharmacist.

I find Pharmacist to be the most knowledgeable and helpful in the NHS.

Having a number of agencies involved does not lead to clarity in communications. There is a need for high standards here and there are frequent communication failures, across the pathways electronic media aids could assist here.

Services are still not geared up to the fact that family carers are pivotal in relaying information to the person being cared for.

Only that when make complaints it slows service right down so they sort complaint first (which takes long time as wait for interpreters etc.).

[...]

Hearing mental health organisations are shocking. Had high intensity therapy through IAPT and woman (apart from having poor deaf awareness and no cultural awareness), booked a female interpreter because it would be 'too long' in her opinion to wait for my usual male interpreter. She okay backed down when my wife gave information that forced her to admit that she did not think it was important to ask me what I wanted and needed.

[...]

Some people who have Aphasia after a stroke would have difficulty filling this form in

Support is often refused, or other people have to fight to secure funding for me to access services. At times support is booked for me but it's wholly inappropriate, I don't use sign language!

If support is given, then there are often time limits that do not apply to those who can hear, I can't use a telephone interpreter that you access at the right moment only. Instead if the doctor on a ward does not visit at the right time, then I have no access to my medical information.

I can be told that people are going 'to do things to me, or for me', I don't want to be ordered about - why should another person decide it is my bath time, or what I should eat for dinner, I have the capacity to make decisions for myself.

- a) Most Health and Social Care (H&SC) workers are not deaf aware and have little understanding of how to interface with deaf/deafened people or how to overcome the barriers to communication. Hands-on deaf awareness training should be included in training of all staff and personnel (receptionists, secretaries, catering, cleaners, etc. as well as Doctors nurses and other specialists).
- b) Most H&SC Establishments do not have an effective (or timely) process of providing communication support for deaf / deafened service users.
- c) Most H&SC workers don't know how to provide the relevant communication support for the various types of hearing impairments - deafness is very diverse and individual preferences vary enormously from one deaf/deafened person to another.
- d) Deaf BSL Users [...] This group requires a BSL / English interpreter to facilitate verbal 'two way' communication. Note that BSL is NOT 'English in sign', it's a unique language in its own right, with grammar more akin to French than English thus it needs to be 'interpreted' by a professional. Sometimes, but not always, H&SC provide this service, but often not in a timely fashion (booking processes for BSL Interpreters are often lengthy, thus appointments are delayed / postponed until an interpreter can be secured, resulting in poor service provision for the deaf BSL User).
- e) Deafened and hard of hearing people form the largest group within the deaf / deafened community and very few of this group are familiar with or use BSL (British Sign Language). They are English oriented and rely on English for communication (both spoken and written English). They may be able to benefit from the use of a hearing aid via amplification of sound, including a loop system (which transmits sounds via a microphone directly to the hearing aid). When

hearing aids are of little or no benefit (i.e. serious to profound hearing loss) the deafened person may be able to use lip-reading to supplement residual hearing to help understand the spoken word, but this depends largely on the quality of the lip-patterns of the speaker, the clarity of the speaker's voice and the ability of the deafened person. Where lip-reading is not possible, then written English may be required (i.e. in the form of an electronic note-taker or Speech-to-text reporter). Health & Social Care need to start thinking more about how to support this Deafened and hard of hearing group re providing appropriate support for them, as well as providing BSL Interpreters for the BSL Users,

- f) Deaf/deafened service users are not made aware that support can be provided for them by the authorities (? an example of lack of information / communication / service provision).
- g) Even when services are available, many deaf / deafened people are afraid to ask for it.
- h) When providing communication support, the User should be asked if they have a particular supporter that they would prefer (i.e. give them a choice). .. They may feel more comfortable with someone they can use easily and can trust (especially for personal health related situations).
- i) Don't assume that friends or family in attendance can relay your information / messages. They may not be able to do so properly - use a professional.

Again would like organisations to understand about aphasia in people and be aware that a nod to say no could mean yes

One hospital has been particularly good, listening when they got it wrong and putting it right immediately. That's the [.....] hospital.

### Appendix 3 – Patients, carers and service users survey, Q10.

**“We think that your doctor, care worker or a receptionist at a hospital should ask everyone if they need any support. We want to write a question for them to ask, so that everyone is asked the same. What do you think about this question: Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said? Please explain your answer.”**

The question is too long.

it is a good question simply because in my experience the staff concerned have never addressed these issues before and the levels of deaf awareness are really shocking in GP surgeries and hospitals

Receptionist at the hospital goes out of their way to help

I think it should be "Do you have problems with be able to see, hear, speak, read or understand what is being said?"

If the word difficult is used, it puts people off as they do not want to be seen as being difficult. Also the Shorter the question, the easier it is to understand. Don't complicate it.

Do you find it difficult....that could be embarrassing for some people as they may not find it difficult but need a little extra help. It can be offensive and embarrassing.

It would not mean ANYTHING to a person with learning disabilities

It would be much better if their computer system indicated this - I don't want to be asked this in front of other patients

Also hard of hearing people may not hear the question being asked...!

Do you need support to communicate or understand what is being said?

As I can read English well it's no problem not sure about BSL users though

The question is too wordy !!!

Q Do you need any help?"

It is confusing, too long, medical model and inadequately thought-through.

I would like a bit added on do you need a Carer with you

Sometimes I find it helpful to read the question/ notice as well has hear/ lip read it.

I would like help being shown the way to the Dr's room rather than being told it's down there and help filling in any prescription I may get

Don't like the question the way it is written why not break it down to ask: What help can we offer to you to improve your appointment? And offer a leaflet with a range of prompts that you tick and these are added to patients notes as requirements under the SOCIAL MODEL OF DISABILITY not once has this been mentioned in the accessible information it is all about medical model.

ALL people be asked regardless

"When you are attending your appt do you have any communication preference you want to make us aware of so we can provide?" if the answer is yes then ask "What is that preference?" You could then have a list of all e.g. BSL, lip speakers, STTR, easy read, braille, face to face and have a box for 'other'. Second question same for communication outside of appointments, then add list of email, SMS, face to face etc. etc.

You choose to focus on their inability to see or hear, rather than using words more appropriately. We should focus on what type of supports they need rather than what wrong with you? Better question would be like this? Will you need BSL interpreter, or other type communication supports?

It covers all possibilities without being offensive

it seems rather long winded. it would be better, if they asked "do you have any support requirements when using our service, such as information in a different format?"

It is a good question, however when the disability is obvious the member of staff should be able to tailor the question. For example "how can we help you understand to hear/see etc. what is being said"

It is too long and could cause confusion. I think it should be split into 2 questions. Do you have difficulty... and do you need support...

This is too long in one question is would be better to ask in short questions with an example of support that can be provided

I would find out by asking the patient if he/she had any vision, and/or could hear me clearly or ask the signer or interpreter if one was present to ask the patient what support and communication methods assistance/help to see, to hear, to speak, to read or to understand what is being said?

Seems to cover it all. I can't see anything.

I think the question should be Do you have an impairment which makes it difficult to hear/see/understand. We can offer support to you.

If you find it difficult to see, to hear, to speak, to read or to understand what is being said would you like some support or information in a preferred format.

Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said and how can we do that for you?

To long winded...can i assist you in any way?

In the case of Deaf people, being asked if does one "need support to speak" is insulting and naive question to ask. Asking them if they would need support to communicate would be more appropriate, because it is not only the patient who would need support, the doctor/care worker/receptionist would need a support in order to communicate with Deaf people too! Communicate is a two way things, so both would need a support, e.g. by using interpreter(s), so that both of the parties would understand each other.

It sounds patronising and I lost the will to live half way through the sentence. Plain English, please!!

It's a very complicated question for someone with a disability to answer if they have a severe impairment.

Have you got a disability which we could help you with or just a simple saying do you need help due to your disability or care needs.

It is too long.

Perhaps you could ask: "is there any way in which we could make this visit easier for you....interpreter, guide, etc. or any information we could give you, if so, how would you prefer it?"

It should be simple and short. i.e. simply ask what assistance the patient would find helpful and explain how this will be provided.

A section on communication should be on the front of the notes!

That sounds like you'd have to admit to being unable to understand and thus could be taken with offence or lack of self-esteem. It needs to be more positive like: 'would you like any support to understand what is being communicated', or 'would you like someone to go through this with you'. It needs to be kind and understanding.

[...]

It would be easier to have a question for each item which may take more time but are more specific.

Patients always complain about not understanding some doctors but are afraid to say so.

It seems, because of the way it is written, only to apply to understanding what is being said. There is lots more in a health interaction that I need to be able to see, such as letters, posters, leaflets, health records, notes, prescriptions, etc. - much more than just speech.

For anyone like my son, this would be very complex, and you would need to add in visual support, before he could grasp any meaning.

Should always be asked and not put in small print as it sometimes is on letters

No good for dyslexia as if the paper is the wrong colour most people will not even read it.

Question can be too lengthy and hard to understand especially if their English is not good enough

Better to make it more focused i.e. do you need a BSL interpreter for your appointment

It's patronising and demeaning. It should be a statement followed by a question. We provide information in a variety of formats to suit individual needs. These include...Would you prefer to receive information by any of these methods?

It puts me on a level playing field

It is just a little black and white, maybe it just needs "can we offer any additional support?" adding

"Would you like support to understand what is being said?" sounds better BUT there is the problem of privacy here. My daughter has high-functioning autism & despite needing support, would feel humiliated and refuse the support if the question was asked within earshot of other people.

Question is too long. Would suggest that the question should be "Do you have any special requirements for support during this visit and follow up care?"

It doesn't sound like a viable question at a reception or customer service point. Surely people could be asked if they will need any help or assistance in accessing their appointment.

It is a negative question and patronises the deaf patient.

It is not just for the deaf patient but also for the doctor who cannot communicate with the deaf patient.

Do you have any access requirements needed for the appointment?

Do you find it difficult' and 'do you need support' mean the same thing. You could say it just once, i.e. 'do you find it difficult' or 'do you need support'

It reads better as: 'Do you need any support to see, to speak to read or to understand today (or at or for this appointment)?'

It's straight to the point.

It needs to be made easier to understand.

It is a good question but should be followed up by a second question to check extent and clarity in understanding after the information has been given.

The question should be: "Have you got any questions regarding your online records - do you need anything to be explained"

The question as above will provide evidence to the patient that it is a partnership of trust and that the patient is not regarded as an inferior partner.

It is very lengthy for people with Learning Disabilities and they might respond yes or no before hearing it all. The idea of asking everyone the same question is ok in theory, but it might need to be slightly rephrased depending on who is being asked. The focus could be on just asking the question without getting the most relevant response.

Don't use the first phrase 'Do you find it difficult' as it seems very patronising

The first part is unnecessary. Begin the question after the word 'or'. I also think the question would flow better with the word 'any' inserted between 'need' and 'support' as in 'Do you need any support ....'

Long and clumsy sentence. How about Do you need any help today - and then see what the person says.

Too many options. Do I find it difficult to see, do I need support seeing; do I find it difficult to hear, do I need support hearing; etc. etc.

Also, what about asking what sort of help I need, or how I'd like to be helped

The question is too long

I think the question should be varied depending on the person's disability which should be already known or should be obvious to the doctor i.e. a deaf person could be asked if they needed a signer or a blind person could be asked how they would like any written information sent to them.

I feel the following question should cover most situations and give patients the opportunity to express their individual needs. Do you need any form of communication support? If you do, please specify your preferred method of communication support.

This question covers everything it needs to but it needs to be adapted for each individual. It needs to be more colloquial and friendly but I think the person asking the question will be able to do this. For example, no one would ask "Do you find it difficult or do you need support to see?" to someone with a cane or guide dog! Common sense will dictate how this is phrased but it is a good basis to start with.

A better question would be, "do you require any communication support?"

Asking if people can read, when they have to read a question is ironic.

I'm not sure what you mean? some places offer loop systems, but don't always train their staff to implement it.

too complex English language, need more visual aid and plain English language

keep simple like black and white,



give an example of picture of medication, what it is for? give a good picture of food dietician. give a good picture of how many take tablet per day like morning, afternoon, evening, before or after food etc. !!

Think it shouldn't have 'difficult', support is fine, sometimes it's all the different accents that can make it difficult for deaf people

For deaf people that might be difficult. You could say - would you like me to book a BSL interpreter? You have to remember that for a lot of deaf people, [...]

Asking questions in public is inappropriate and illegal as well as the fact that how do you ask a deaf person the question?

What you need is some method of alerting the healthcare professional that this patient needs help and what sort of help!

Oh look [.....] Trust have an electronic alert which is triggered by bringing up the patient record

It seems a bit too long but if you don't find a shorter way to say it just leave it because a question is better than no question at all! Thanks a million for this!

it could be a bit degrading for the patient

Often it is not the question that needs to be standardised, but the response. Asking the question above to someone could be seen as calling them [...] in the first place - and if they answer 'Yes, I need an interpreter/BSL support/this information in Braille' and don't get it, then is their experience improved at all?

Would you like any assistance or support at your appointment to ensure you can see, hear or understand what is happening.

As written, this is an insult to the majority of the population who have no problems in this respect and would be a waste of time for the professionals asking the question.

If a person needs support, how do you know they understand the question? At the very least it should be written and in braille as well as spoken.

"Can we help you in any way to make sure that you always get all of the information which you need whilst you are with us today? We can help people who can't see or hear well or have problems understanding. Please let us know if this is true for you and we will try to help you."

"Do you find it difficult..." forces the patient to admit that they have a problem which is often not nice, rather than putting the onus on the staff to make sure they offer info appropriately.

"Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said, or to access online any of the information on your health or Social Service data and/or record?"

Question is clear and does cover all the impediments patients may face.

Given my respiratory problems, I often arrive at a reception desk unable to speak due to drop of oxygen saturation (caused by change in ambient temperatures, for instance). Using My Medication Passport where all the information required by a receptionist [name, DoB, address, NHS No etc...] is contained is a real saviour, a fantastic help but receptionists need to be educated to understand patients may have all kinds of "access" problems which are not visible. Some react very well and will use the information listed in My Medication Passport; others will insist on my answering questions even though I am wheezing and gasping...

If I had those problems would I understand the question?

For autistic people it's not really the right question. [...] We should be asked something like: "What format would you like to communicate in, and what environment would make it easiest for you?"

Add - What can we do to help you?

Assuming the person can hear it and really does understand it, it is a good question, but what about the person, perhaps with learning disabilities, who says yes and does not really understand?

Confirmation of understanding should be sought.

It's too long-winded. It needs to be more concise.

It seems too long?

My concern is that asking about it all in one question will fail to capture the detail of what support is needed.

Combining a question about accessing spoken and written information needs doesn't easily work. I would have two.

It is too wordy. Keeping in mind it's a question for those that may have difficulty hearing or understanding etc. You could ask if they find it difficult to see, hear etc. If they answer yes you can then ask them if they require support. Those that have difficulties don't always need or want assistance.

Need to make it simpler if you have someone with limited understanding

not helpful for people with ASD

I do not like the part about finding things difficult being first, personally I would prefer to be asked if I would need any support to hear, speak read or understand!

No one should find it difficult

you should ask if they find it difficult first, then ask if they want support (in a second question). Some might find it difficult, but do not want support...

This question is far too long for many people with learning difficulties or communication impairments to process.

It would be better to divide the one sentence into two or more, for example, Do you need help understanding what people say? Is that because of your hearing, ...your sight,..... communication,..... etc.

Some people will need this information presented in a symbolic format.

I would word it like this "Do you find it difficult to see, to hear, to speak, to read or to understand what is being said and would you like support?"

You need to put the bit about understanding at the front of the question [...]

Communication is a complex area and what suits one group will not suit everyone. I am articulate and appear confident and able but I have deeply hidden communication difficulties. What I want is a focus on my health conditions, how they affect me and for people to make adjustments as to how they communicate with me. You should ask me if I would like my carer to participate, or my regular support worker? You should stop looking at the computer and make good eye contact with me, as appropriate. Smile, please! That will engage my attention and speak to me like an adult, not like a child. Think about what you want to ask me and make sure the question is clear and specific. If at all possible give an indicator before the appointment as to what specific information you are seeking so that I can think about what I need to report to you.

The sentence is too long for some people to be asked.

I am a wheelchair user with MS and the [.....] hospital does not have a stand aide to use on the wards, neither have they realised that a person like me cannot "hop up onto the table"

Please put a question about access and physical ability

If people are hard of hearing they may well not hear the question. Asking someone if they will be able to understand what is being said may be a bit patronising.

Common sense

It needs to be short and clear - 'Do you need any support to.....' (The shorter and more straightforward the better).

"Do you need support?" We are not dealing with silly people, folks are relatively pretty intelligent.

[...]

Lots of people with hearing loss are very proud people and would just say no, but if said as may I be of help with your communication needs etc. better

It is too specific and some people may be offended by the tone. It needs to be a little less direct whilst still putting the relevant point across!

Because I was born hearing and started to lose my hearing in my teen and significantly after the birth of my first child I lost a huge amount of confidence and

self-esteem. I am still the same now to a certain degree. I had extreme problem explaining my hearing loss not just to doctors and health practitioners but family and friends. This question is very good.

I think it is a good question, but it would be better to ask, Do you need support to understand what is being said?

If you have difficulty hearing - you'll also have difficulty hearing the question! It would need to be on posters to reinforce the message when asked out loud.

I'd prefer something like, "Please can you let me know if you need anything, repeating, explaining or writing down as we go along?"

Needs to be shorter, and in a form that would be easily lip readable.

It is a bit long and complicated for people who have communication needs.

Could it be "how can I make it easier for you to use our service?"

It's too long... and the first 5 words seem disconnected to the rest - I think it will confuse people. I think it would be better to just ask if people need help to see, hear etc...

I don't like asking for help as I think I can manage then find out that I have no idea what people are talking about it would help to be offered this as a normal service

The question also needs to ask if I will need additional time to think about what has been said to me.

Why not ask if the person has difficulty hearing seeing or reading or has any other problem they wish to raise first. You can then ask what support they require.

All you list must ask the question on past experience as a [...] they have not.

It's ok but I think the focus should be on the information requirement that someone might need rather than the impairment. So for example, off the top of my head, "Is there anything we can do to help you access information we send you. Big print or Sign Language interpretation for example?"

Saying "Do YOU find it difficult..." seems to blame the patient/client for having any difficulty, and will incline people to respond NO, even if that's not their true answer. The question should not imply any problem with the individual rather than the service. Also, the two clauses either side of the first 'or' make the sentence difficult to understand as that first part of the question is too long / difficult. And the long list of things with which people may have difficulty will be extremely hard to take in aurally, so people will again be inclined to respond in the negative.

How about something really simple and much more open like: "Do you always understand everything about your health/social care appointments, or are there some areas where we could make things clearer?" or "We have a few ways of helping people to understand their health/social care appointment more clearly, could I show you what they are?" If they answer that it is not always completely

clear, or they show any sort of interest in tools to help make the process more understandable, then you follow up with questions or examples of support to establish what sort of support they may benefit from, if any. With these sorts of more open questions, then even if people don't need specific support, they might give you feedback on your general communications, e.g. in signing in for appointments, which could well prove useful.

'to see, to hear, to speak' is a bit long winded.

I would prefer 'Do you find it difficult to understand what is being said' that should cover all areas

A more direct question may be helpful

It would be better saying do you or your relative/friend need support to communicate during your visit? This covers those who attend the appointment with the patient as they can ask staff for support on the patient behalf.

slightly long-winded and confusing.

it's too long and complicated for a person with a hearing loss or with difficulty understanding what people say to actually hear or understand, receptionists are usually dealing with several people at once and maybe there are phones ringing in the background and they don't always face the person and speak clearly, a loop would be much easier for the deaf and hard of hearing I also think that all of the above people that would be asking the question should go on a deaf awareness course and possibly a sight awareness course

For my son's needs the question is too long. 'Do you need help to listen/see?' would be all my son needed and would understand this question better.

Make sure this is asked in a loud and clear voice, or available as a written question.

Break the question down as it could confuse people e.g. do you need support to communicate.

All they need is training. If receptionists had any common sense all they need say is "can I help you"

Aware that Deaf people have own communication methods and should check what kind of communication support we require.

The sentence is too long. Will people remember all the options at the end of the sentence? It needs to be broken down into chunks.

Covers everyone

Not sure how it could be worded better, but it does sound a little condescending.

They should know when registering at a doctor's surgery that you have additional requirements - database systems should highlight this.

If seeing a new doctor for example at A&E then yes the question is relevant.

If there is no hearing loop, how do you hear the question in the first place - a lot of the NHS does not have the necessary equipment to allow access to information in different formats. Braille letters, Large Print Letters and booklets are still some of the problems.

the receptionist has a hard enough time without adding to the burden. If I need help I will ask or tell them, they do not need to ask everyone.

The question should be: Do you need help finding information or accessing services in the hospital/GP practice? If so please tell us what help you want.

It can be put in a much more straightforward and less invasive way, such as, do you require any special assistance during your appointment?

I have seen the difficulty some patients have in understanding even the simplest questions at my local GP surgery. The idea of a "one size fits all" question is fundamentally flawed, and seems pointless. If you expect receptionists to keep asking this kind of question I foresee bottle-necks, misunderstandings, lost tempers. What answers would you expect from such a question? This idea seems highly impractical - has the person who thought of it ever worked in a real, busy, NHS reception? The whole idea is the wrong way around. Patients should be offered the services available, e.g. BSL interpreter, not asked to describe their communication problems.

Try making the sentence simpler (for those with learning difficulties) and then give a series of bullet points or tick boxes that the receptionist can then fill in. e.g. "Do you need information in a different format or support such as a signer?" and then the options could be: None, Audio information (CD), Braille (various formats and grades), Electronic files via email (list of file formats), Signer BSL, Carer, Interpreter (language)

As a visually impaired person I find the above question very condescending.

Any decent professional should be able to pick up very quickly a person's disability and just ask "Would you like any help"

The question is quite long and might be complicated for people who cannot understand the words used

It's important to understand what is being said and the implications of any treatment being recommended

It is a perfect question and more people will be more likely to own up to their problem.

Better to ask about each of these (seeing, hearing, speaking, reading, understanding) individually. One long question can be confusing for people who struggle with spoken language.

For Deaf People whose first language is BSL, that question will not be understood.

They need a direct question - Do you need a BSL interpreter?

it should cover different situations and offer solutions e.g. do you need support to make appointments? Text Relay, email, phone, BSL etc. for all the different things

Perhaps the statement, not question, might be: "Please don't hesitate to tell us if you need any extra help when using our services"

I think that it addresses all the possible needs of a patient.

I think it's very good because it covers a range of some of the supports they can access rather than just saying "support" as a lot of people don't realize that this word is an umbrella of terms.

It is too long: ask people what support they need, don't list all the options.

I feel that the question should simply ask if any assistance is needed and if the answer is yes then asked what help you require.

You really wouldn't want to ask that to a person with a white stick would you, isn't it obvious I can't see? You need to ask the following questions. Do you need information in an accessible format? Please specify. Do you need information in another language? Please specify. Do you need any other support? Either please specify or a list of possible support to be ticked. The existing question is vague and patronising

need to clarify what are they mean.

I think that this question covers everything that needs to be asked if support is needed.

I think the question covers everything but in case it hasn't, there should be an option for "any other support not included in the above question". A catch-all clause.

[...] people find difficulties to respond the long question as it will be putting them off or they are unsure what to say as they confuse which answer should be said as too long question. Need to break it down into short questions. Also their memory won't stay longer to remember to say the answer after long questions.

A simpler question such as "Do you have communication difficulties?" would cover the above and not sound as rude or intrusive

my son has ASD and this means he could understand and answer correctly

It could be "Would you like some help and support to see, hear, to speak, to read or to understand what is being said?" Also it needs to be in all formats. Braille, large print etc.

The way it is worded sounds a bit clumsy and elongated. If it could be condensed without losing the sense it would be better.

If you were 100% Deaf - these verbal questions won't help. Having prominent signs might.

Receptionists are almost always phone based - in order to make the first appointment / confirm appointment - these should have Deaf options at that point.

I think the question should be a bit more general.

Personally I try to downplay my 'disabilities'.

Answering 'Yes' to above question almost seems like you have all the problems!

"Do you need any assistance?" "What assistance do you need?"

Often the answer will be obvious, E.G. if a person is blind, so it should be possible to adapt the question.

As regards d/Deaf people [...], so this wouldn't resolve the situation in what assistance they require. I feel putting it on their Medical Notes Re Profoundly Deaf, requires Interpreter Either BSL or Sign Supported English etc.

It is an ambiguous question- need yes no questions

how are they going to ask it? It will be too late when a person arrives. They need to know beforehand in order to make arrangements.

I think it would be better broken down into 2 or more questions

too much being said at one time - would have to repeat several times to some patients

It is simple and to the point

It's a good question because it covers all aspects of support that may be required for those with sensory and/or learning disabilities however it does not cover those with mobility issues. It should be clearer that 'support' does not only mean providing BSL interpreter. The health professionals must also do their part. Some deaf people do not need a BSL interpreter, however health professionals must be deaf aware (speaking clearly but NOT in a condescending manner, be prepared to write down any medical terminologies etc.).

This question shouldn't be asked but a client should state if needs support and explain what kind of support

The question is too long, not clear. I would suggest Do you need communication support? If yes, what support? Shall we book BSL interpreter?

Simple, clear question

This is the best way, by default. In fact, should be made into law to have this question every time.



Whilst I think It would be a good idea to ask patients a question such as this; I feel that this question could be taken as patronising to someone who does NOT need any support.

Could have improvements, it is a little vague...

It is too wordy and difficult to understand in itself!

I would suggest something like: "If you find difficulty in understanding what I am explaining, please tell me, and I will see what we can do to improve this."

This is prescriptive and bureaucratic, wholly unnecessary and assumes staff cannot use their common sense.

Classic case of NHS wasting money.

It seems to make sense.

I don't think it is good to have one generic question because one size does not fit all. That question makes it difficult for a person to determine if they fall in that category or not. There are either physical accessibility needs (wheelchair access etc.), or communication needs (BSL, lip speakers, foreign languages etc.). English is often a second or foreign language for deaf BSL users, and if you give them a question saying "Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?" my bet is that they will not understand this question due to its length and complex grammar. It would be better to ask them: "Do you need communication support?"

It is quite long and wouldn't the patient's notes be flagged up as a person needing support?

It's too long, if that were said to me I would still be working out the first part of it by the time the second part has finished being said. It needs to be more like "How can we help you to express what you need to say and understand what is said to you?"

I do need support to access services equally but it should not be perceived as a difficulty, requiring communication support is the same as people who speak a different language.

Could add "Do you need help?" for example "Have you got paper and a pen to make a note of what us being said, or would you like someone to take notes for you to take away with you?"

It's too long, windy and a bit patronising

Do you need support for reading or for communication

The question needs to be shorter....Do you have any communication needs? Y/N If Yes please say What do you need? - have a list of options: Lip speaker, Note taker, Sign language interpreter, Deaf blind interpreter, Communicator guide, Loop system

I totally understand why a generic question would be preferable but the question is nonsense. I don't need support to see, no one or thing can help me to see! What I need is information in an accessible way. Also this question focuses on the person's impairment it's like saying do you have a problem? The social model approach would be questions like: Can we do anything to make information more accessible?

That is too long a question need to be broken down to smaller questions

The same question needs to be broken down into component parts.

Deal with one item at a time. Do you have difficulty hearing? Can you usually understand what is being said? Do you have any problems with your sight? Are you able to read ok? Can you speak ok, are do you have problems?

Do you need access to communication? Have a list - BSL Interpreter, Other languages, Do you need support with your appointment to have someone - advisor or relay interpreter?

I feel when I read that make me feel I have failed to SPEAK to HEAR - I don't feel it's the correct wording to be used. Access to communication BSL interpreter Are the correct words to use

The person asking should be trained to recognise, say for an older person, or someone who has a Learning Difficulty that they give that person time to understand the question and that they may have to explain the question giving time for it to be assimilated by the person, or that the question may require further break down of its component parts.....

Question is rather ponderous, personally, I would prefer to tell an organisation/person/doctor's surgery that I need information in alternative formats such as email or text message, and then they ought to be able to click on an appropriate flag to ensure this happens

No good asking a deaf person if they need support - you would need to have a written copy on a card to hand them.

Not clear and should be much clearer.

Would you like any support to help you see, hear, speak, read or understand what is being said?

This needs to be available in written, spoken and braille formats too so that it can be said/shown/given to patients.

I would remove 'Do you find it difficult' as you either need support or you don't

It's too long - don't need "Do you find it difficult". Suggest "Do you need assistance etc." (Assistance being easier to lip read than "support"

"Do you have any problems" instead of "Do you find it difficult"?

Do you have any problems in seeing, hearing, speaking, reading or understanding what I am saying? Then, if the answer is affirmative: "would you like some help?"

Do you need help to read, hear and understand what is being said? Have you speaking problems?

The beginning is a bit complicated. Why not "Do you need any help with....."

People with hearing difficulties may struggle

No explanation necessary

Long winded and formal. 'Do you need any help with communication problems'?

OKAY TO A POINT. IT COULD SAY SOMETHING LIKE: DO YOU HEAR ALL OF WHAT WAS SAID IF NOT WOULD YOU LIKE ME TO REPEAT IT. SAYING DO WE UNDERSTAND MAKES US SOUND [...]. AT LEAST I THINK SO.

It is a good question as we are never asked anything at the moment

It is too complex for people with hearing loss, learning disabilities etc. Break it down into small chunks.

Allow users control on choices of provider and interpreter

The questioner should know the persons problem(s) and therefore be more specific, i.e. to hear, read OR understand, to reduce the complexity of the question. A person like me with hearing difficulties is able to decode a short sentence easier. Remember we only hear some of the words and have to make sense from those words.

Whilst trying to be all encompassing it gets a little convoluted, perhaps a simpler "Do you need any help making sense of what is being said to you?"

I am not sure from what you say if the receptionist is going to speak the question or give the question in writing? This makes a great difference to people like me.

I think you should break the question down according to need, such as: If you are deaf or hard of hearing would you like someone to help you? ... We can write things down for you so that you are fully informed and confident that you have not missed anything. Would you like us to do that? If you have limited vision would you like someone to help you? ... and so on ...

most times the question is not asked. The assumption is everyone can hear even in the ENT dept.

often there is a leaflet in foreign languages [...] but help or immediate needs for the deaf are not always apparent everywhere-that is it can be patchy

Too much English and not clear

It covers the subject well

Many people with disabilities - verbal, written etc. are embarrassed to highlight it. This is not a one size fits all.

Omit the 'do you find it difficult'

rather long question, split into 2 e.g. Do you find it difficult or do you need support to see or hear? Or to speak, read or understand what is being said?

It is very wordy and the patient, even without any real disabilities, would find it difficult to take it in. It needs to be broken up into much shorter phrases so that it is more like real speech.

It is far too long. As a deaf person I would find it hard to understand. You need to break it into: Do you find it difficult to hear what is what is being said? Do you understand what is being said or do you need support? Do you need help to see or read or speak?

Put hearing first, as a person with hearing problems will not hear the other two questions.

the question is fine but you would need the question in several different formats i.e. audio, BSL, braille, email, on a secure website etc. as well as in several different foreign languages

This sentence seems to cover everything and is put in a very clear and straight forward way

I think the question needs to be simpler and more direct. Maybe just ask if the person would like any support sensory support or help with reading and understanding what is being said.

It is including every aspect of a possible communication problem, although it is a little long-winded.

Do you need help - 'ask'? What if I can't hear through the glass, with a woman talking to me, not looking at me, often hidden behind a computer screen.

Perhaps I would word the question; Do you need or would you like help with any of the following- Understanding what is being said, Reading, Hearing, Speaking, Seeing.

A lot of elderly people [...] are often too embarrassed to say they don't understand what is being said to them, particularly if the doctor/specialist/receptionist etc. [...]. Also, having asked for something to be repeated more than once they will not ask again

people with any disability should let you know if they need help

The question should be posed in a way that indicates that the "questioned person" has understood the question. The "you understand that don't you" type of question should be BANNED. [...]

nobody has asked me anything like this

Don't understand

never been ask this type of question and yes they could ask if you need help, for example a GP ask "me why I had ear plugs in" so what was I to think of his ability as a doctor.

It will be a source of great amusement for those not in need and could even turn out to be derisory.

Too complex and convoluted. Need to find a way to say this with fewer clauses/options so that it is easy to ask and follow.

I wouldn't like to see the word of "difficult" made me feel uneasy and [...] -why not to just say "would you like us to help you to....." Then my answer would be "Yes, please!" with my smiling face!

I think the question covers what most people with sensory loss would need

You will have to ask this question in different ways for different people. Verbally, written down, or perhaps explained for those who cannot understand. You will also have to be prepared to respond in different ways. Don't send letters to blind people - like my GP. Do be prepared to respond to deaf people in some way other than speech.

[...] for deaf people. Do you want BSL interpreter? [...]

Sometimes, if the disability is not severe, no additional support is needed. Rather it is about the health professional having an awareness, so that they can be mindful of the impairment when communicating with an individual.

Not clear. Need to say "Do you need an interpreter" Because those who do need one won't understand this question

Since our names are on their Database, and it should automatically come up on what our needs are rather than them keep asking me the same questions every time. And also if this question is asked directly to me, how can I explain back to them in sign language??

It's fine. Give people choice to explain what their needs are.

Receptionists need a BSL signer

I am Deaf and don't understand what my GP is saying [...]. It is so frustrating and most of the time I couldn't be bothered to go....

Need to have BSL communication support with an interpreter

I think it is a long question.

I think that although the question is long, it covers everything and deafness is not something which is always obvious so a question needs to be asked.

Do you need help with seeing or hearing or speaking? How can we help you?

MAKE THE QUESTION CLEAR AND SIMPLE

how can you expect a sensible answer if the person cannot hear or understand what is being said....?

just change around the question i.e. have you understood what I have said, do you need any more explanation of what to do next, can I write it down etc.

Much too long winded for practical purposes

Difficult - depend on deaf person English

BSL is not a written format - it is a visual language so doctor, care worker or receptionist should learn to sign BSL

I think the beginning could be shortened to "Do you need help or support....."

The choice of words must cater for all. That means using those in everyday usage by the majority of people, especially those who have only a basic command of English. For example I would use the word "help" in preference to the word "support" and "hard" in preference to the word "difficult".

May be saying "Do you have difficulties or would you like support....." This just feels less harsh

Feels a little wordy. Is there a more succinct way to say this?

It varies from person to another person if they really need any support depends on the person who needs it. I think it is a good way of asking because a person will not feel neglected/ ignored in a way that they feel uncomfortable to speak what they really need. I guess some people are introverts who will not say much but they hesitate to take a help. I think older people might need more support rather than younger ones. But support applies to people who really need it.

It is too complex for people with receptive Aphasia.

It should say something like; "Would you like help to understand?"

This question is for too many audiences. Break it up.

Do you need any support for your appointment? What do you need? SLI/Speech to Text/writing down. Something to that effect, Needs to be 3 questions to cover each situation.

Cut out the see, hear, speak, and read. Just keep the word, 'understand'. If the answer is yes, then ask for more detail.

Would you like someone to be present, and help you understand the information given to you?

It would be better if it was in BSL but realised it's not possible.

You need to keep it brief. For example: Do you have a disability? if yes, do you need special support e.g. BSL interpreter or lip speakers?

It covers all aspects of disability.

I don't like the question because it concentrates too much on the negative aspects. The person asking the question should be in a position to tailor the question more specifically to the person in front of them. The use of the word 'difficult' suggests the individual being questioned has a deficiency or is lacking in some way.

Could be shorter

Put - You may need help. We can offer help with: (Use [...] symbols here), talking, listening, reading, understanding what to do next. Also staff to be [...] total communication trained, and wear a badge with their symbol name so people who find it hard will know that person will understand and help

it seems too long and the more words there are means there is more of a chance of me mishearing or not hearing.

It's got too many conditionals in it. Maybe split it into two questions. Do you have difficulty with your sight, hearing, speech, reading or understanding of what is being said. Do you need support to see, hear, speak, read or understand what is being said.

That also allows multiple versions of a word to be used which might help people find one they recognise. The key thing is to offer alternative formats by default. Tell people what they can have. e.g. someone to come and get them cos they can't hear a name being called or needs guidance or mobility support etc.

personally I would find it useful if I could request any information in written form so I could refer to it later or discuss it with my carer.

I THINK IT'S CONCISE & CLEARLY PUT...

Many Deaf people [...] will struggle with this sentence. It is too long, with too many choices.

A blind person may not be able to see this if written down.

My difficulties are with staff attitudes and poor communication - why label me difficult? The question should be: "What support do you need to be able to understand everything you need to know?"

Rubbish question I have seen

So the question could be like this: Do you need BSL interpreter for your appointment? Do you understand? Is there anything you are not sure about? Do you need help and support to understand what is being said?

Each area with personal files should be flagged with a deaf sign, then all communications could be read only so clear distinctive knowledge is gained between patient & practitioner.

Start the question; Do you have difficulties .....

Some front-line staff sometimes feel nervous when they approach any Deaf patient. Sometimes they are very confident and approachable. Depends on the individual. Sometimes they do not know on how to get BSL interpreter when I request.

Such a question is long overdue and would to me be acceptable.

It is far too long especially for some elderly people with signs of dementia.

It appears to be a good question, it may just need asking in different ways according to individual's methods of understanding what is being said to them. From people always ask what sort of support is available as they don't necessarily understand the word "support". Maybe replace "support" with "help"?

It is a very long sentence to understand at a time when patient probably stressed.

"We can help if you have difficulty hearing, speaking, reading or understanding. Can we help you? What with?"

It is a closed question so there will be people who will just say, yes or no and then what does the doctor, care worker or receptionist ask next? It is also too long a question. Something like, 'We want to make sure you are satisfied with your NHS service today - how can we support you to see, hear, read or speak so you can get the most from our services?' Something like this is an open question and will give people the opportunity to say how they can best be supported or to say that they do not require help.

This should be in BSL, not English

For deaf people it would be nice if they could see the information needed or have it in writing before giving an answer. [...]

Because there are many patients with various levels of hearing loss information needs to be interpreted for them to understand.

Question is still written in not accessible way (English is not my first language)

Pointing out that someone finds something difficult is poor and not best practice.

Simply ask 'do you require support to understand what is being said'? Then have sub questions - to hear? to speak? to read? to understand?"



It is a good idea but will be lost in translation when passed to the next nurse or doctor.

My GP surgery know I'm deaf but refuse to speak to my husband and want to speak to a deaf person on telephone it is very frustrating

It is too 'wordy' for some people, broken down into 2 shorter sentences would be better.

For an example, I'm Deaf myself and it should say on the file that I'm Deaf so automatically should be requested BSL interpreter if I already asked beforehand.

No need to mention see, hear, speak, and read you would know if the patient got sensory issues or learning difficulties.

Some of them can read so the question on a card or written note should say 'Do you need. And the list underneath for each will be BSL interpreter, note-taker, etc.'

The question is too long, You may lose the interest of your audience before you have finished the question.

Because need help I deaf BSL

I personally don't ALWAYS struggle to hear (very much dependent on environment)

The question is too fixed and gives the impression that this only applies to those who have communication difficulties constantly.

I would feel more comfortable with being asked if I felt I might have any difficulty at a given time, giving me then the opportunity to explain this in more detail.

It does not need the first 6 words. It should start with 'Do you need support etc'.

Why should you be asking question? Why don't you use initiative and offer support anyway? You can tell if person is deaf from records. Just say we can book an interpreter if u want one or inform how get information in BSL. This 'one fits all' attitude is not always suitable for individuals, usually for convenience of staff.

If you want to ask someone something, make it simple. Don't overboard with words. Something like, Do you need any help or assistance with hearing, speaking or understanding what is said to you? The question takes too much to understand. The one I've suggested means people will understand the question as soon as they hear do you need help

Perhaps the message should be broken up into a few easily-understood and answered short sentences. The sentence quoted is much too long.

The hospital should provide relay video via BSL on the laptop screen if the BSL Interpreter is not present.

Don't like the word "difficult"

Needs to include a written format for deaf people but will need a different format for others such as visually impaired.

Would you like us to give you support to either to see, to hear, to speak, to read or to understand what is being said?

I think you should ask 'Do you need support?' then if they answer yes ask what support e.g. to hear, to speak etc.

I believe the people identified above should use some common sense when deciding to ask this type of question and the person being supported should have some responsibility in asking for assistance.

It covers most areas but people may also need support with mobility.

Would you like support (help)?

I would be really upset if someone asked me a question like that. I think it is totally inappropriate and unnecessary to ask it of everyone. How on earth are people going to give support to anyone to see or to speak? Silly question! Understanding is also dependent on the clinician most of the time - you need to teach them to communicate.

People, when faced by such authoritative questions will say 'no' not to appear silly and will feel unable to access support. I think it is very much better for people to be trained to identify these sorts of issues. If GPs ask for disabilities/communication needs and then alert hospitals so that support is sensitively and sympathetically provided it is better. The leaflets sent out from the hospital could make it clear what is offered.

If the reception staff and clinicians were trained to be aware of potential difficulties most can be dealt with in a sensitive manner without the humiliation your question will engender.

If people need support to communicate how are they going to understand the question which is complicated

It is a bit long winded.

This question is a bit long-winded and could be seen as being rather patronising. A better question might be: "Excuse me, Sir or Madam. Do you need any assistance with hearing, seeing or understanding what is being said to you today?"

Too long and convoluted. Also not very human. Would prefer something like, "Would you like any help today with xyz?" Should also be in a printed form (easy read) at the reception desk, for the receptionist to point to as she says the words.

So negative, How can we help you understand what is being said? is more positive and welcoming, a good way to lead into examples of how they can help, particularly if you are new and you may not know what communication barriers exist

no need to say more

As a registered blind person I would like to be asked if I need any help to find where I am going

It is surely a basic question?

A robotic scripted question implies lack of a personal touch - the spirit of the question is appropriate but staff should be made to think of communication difficulties rather than ask a question by rote.

It sounds patronising!!!

You should ask whether there is any support they need during the appointment? And give examples like BSL interpreter? Information in Braille? So they know what you are trying to ask.

Self-explanatory

It would be better like this: "Do you find it difficult or do you need support to see, hear, speak, read or understand what is being said?"

OFTEN RECEPTIONISTS DO NOT ASK THE PATIENT IF THEY REQUIRE SUPPORT, I HAVE NEVER BEEN ASKED IT IS JUST ASSUMED THAT I AM OK

What is your preferred communication style?

The question you have assumes that I have a problem. The problem is that YOU can't communicate with me. A more "Social Model" question would be..."What is the best way for us to communicate?"

As written this is confusing for anyone who is struggling to read or understand English. It's too long.

This is two questions really. 1. Do you find it difficult to see, to hear or to read? if the answer is yes, do you need support to understand what is being said?

I think they should understand how we communicate.

How are the staff going to ask Deaf people ???

Take out the "Do you find it difficult" part of the question, as my first thought is about opening hours, which make it difficult. The questions needs to be clearly about support needs.

doctors have your notes you should not feel as if you have to do even more to help them you tell them what you need them to do a thousand times and they just do what they want.

It is demeaning and embarrassing to be asked "do you find it difficult...".

How about you just ask very simply "...would you like any help or explanations..."

The word DIFFICULT is negative - should we tell the health professionals - is it difficult for them to sign to us? Would you use DIFFICULT to [...] ??

communication barrier - what support do we need? (works both ways not one!)

How would you like us to communicate with you (and then offer options)

The question asks too many things. It asks the person to consider if they 1) find it difficult and 2) whether they need support for: a) seeing, b) hearing, c) speaking, d) reading, e) understanding. Effectively ten questions! Even in written form, I had to read it two or three times to understand fully.

The support that patients want and need is not always going to relate to visual or hearing disabilities. In many cases it will be wanting support in the form of: Information, Where to get the best treatment, Information on Clinical Trials, Access to other patients and learn from their experience, So the question would be better phrased if it said: We offer many forms of support to help you, are there any areas where you would like us to help? And provide a list of the services to include hearing, seeing, contact with support groups, access to information about illness, counselling, financial etc. etc.

Because the statement is quite broad it is a little difficult to understand if it relates to me personally in my preference for large print- which I don't consider as needing "support to see". or "find it difficult to see". I wonder if you could add some examples? For example, "do you require information in large print or need a BSL interpreter"? I also think you need a comma after "to read" because some of the sense is lost to me as is.

As long as this question is competently translated into BSL this should be fine.

sentence is too long.

I would add "do you have any language difficulties that will require assistance from an interpreter"

I am answering this survey on behalf on my mother as I am her carer. I could not find anywhere in part 1 to say this. On that point I think this survey - which is billed as for patients and carers - is badly designed. Back to this answer - My mum is 93, registered blind (although she does not look it) and has mild dementia. This question is too long. It needs to be broken down so she can hear it, think about her answer and give it. Lots of alternatives confuse her. And what does 'do you need support' mean? I suggest it reads: Do you find it difficult to see or hear? Do you find it difficult to speak? Do you find it difficult to read? Do you find it difficult to understand what is being said? Then if they answer yes to any of these questions ask, "Do you need help with... what sort of help do you need?"

Many people are over-awed by the experience of a hospital consultation. There is a tendency for the mind to go blank especially if they have come to discuss a serious illness. Many would not ask for help themselves or assume that it is not available.

The word "help" might be better understood than the word "support". I would also suggest that this question is asked discreetly and out of earshot of other patients. People who have dyslexia and many other difficulties may be sensitive to others knowing they may need help.

For most people with learning disabilities it contains too much information. [...] I often would have to re-phrase questions or ask the same question 2 or 3 times in a different way to get a confirmed response. There is the danger that without some awareness of the person in front of them the question could be read out in a parrot fashion. It is sometimes not what is said but how it is said. There is also the danger that for certain individuals that they would be too proud to admit they needed any form of support. Surely it needs to be looked more from the point of "What do you need from me to help you get the best from this appointment/visit etc."

Do you find 'it' difficult- what is 'it'? Change that so the first bit makes it clearer you are talking about communication

What is it? It's a tongue twister for any people with Aphasia. Make it sentence shorter if possible.

The question is too long and complex, I would give communication issues in the first place not be able to understand the question quickly enough - then assumptions could be made again that it means I lack either capacity or mental cognition.

Do you need information in a different format? What format? Do you need communication support? What support? Empower me to tell you my needs - and then meet them!

Mean they are aware of it than no one know themselves if need support or not

But...A hard of hearing / deafened person may not be able to 'hear' that question, if it was spoken. They would probably be able to understand, if it were written down, say on a flash card.

A BSL User may not be able to understand it at all (either spoken or written) without someone to interpret it from English to BSL and vice versa for any responses

It's very awkward sounding. Not easy for a busy receptionist to fit into their normal dialogue with a patient or their carer.

can be good for some but too long for stroke survivor

I understand why you want just one question, but as a BSL user if someone asked me this, I wouldn't really understand. I'd prefer something like this: Would it be useful for you to have some support with your appointment, (and then give examples as appropriate) for example [.....], or [.....], a BSL interpreter, or anything else that would help you communicate and understand? I understand that you can't list everything, so examples could be matched to the person's apparent needs. I repeat though that the phrase used above wouldn't make sense to me.

It needs to be followed up with another question such as 'What support do you need?'

You should ask about what people need to remove information and communication barriers they face when using health and social care services and give examples of the barriers and solutions

If you want to ask a question it should be more specific e.g. How would you like us to communicate with you? The original question is far too confusing. As I am totally blind I would reply either email or phone for correspondence. If I did not understand the word communicate then I would need an advocate to support and explain everything to me

it covers all

just keep it simple question. i.e. need help or support with your appt?

If people have difficulty speaking they will not be able to answer the question. It is also obvious that some people will have difficulties, for example, I am totally blind, and that is obvious to anyone who meets me, so it will be clear to them that I may need help getting around, reading information and knowing when my name is being called.

A hearing person to communicate with? I need BSL. I am a deaf person. It's life, that's it.

That question needs to change, I need support through lip reading

How can we improve our information and communication access for you OR How would you like to communicate with us so you can understand us?

It's too wordy, I'd suggest them asking "Do you need any support to understand what is said to you?"

The question is very good and it is very helpful and should not be changed at all and it's a very good question and should be kept as a question.

It needs to be done using other types of communication, not just speech e.g. pictures.

It is too wordy

I go to the reception and I assume there would be an easy way to inform them that I have arrived, like a piece of paper with easy words so I can point. I have to write everything down. They get confused about my name and don't use the computer files to find out who my doctor is when I can't remember. I inform them that I need an interpreter. They say it is better to phone you for contact details but I am deaf, I cannot use a phone.

Offer the support, i.e. would you need any help or assistance

The word "difficult" is not appropriate term. [...] would question the term "difficult" as it is offensive to them. It would be better if you modify that term into "language support". [...] would tend to request an interpreter as English isn't their first language. There should be other options such as writing things down, or lip-reading. With

interpreting, it would remove the communication difficulties between them and me. I wouldn't know the right answers if I didn't understand what was being said. Staff seem to be unaware of Deaf issues or sign language. Such as receptionist, are they fluent in signing?

Interpreters should fully understand in medical. This is a very good question, do not change it

That question shouldn't be used. All those people with disabilities are human and have feelings; they all would be offended by it! It is too patronising.

I feel that the term "difficulties" doesn't suit me or who I am. Perhaps it should read "Are you Deaf?". A simple but direct question, along with "Do you need a BSL interpreter?" plus other supports, such as "SSE Interpreter", or "Braille", and so on. It's a need of a language, visual, sight, and speech. Most hearing people do not understand that we are Deaf, and they feel they should shout or speak louder, that doesn't work and is unrealistic. I am completely Deaf, and I need sign language, all in hands, not speech to speech. That question with the word "difficulties" should be changed.

Question must be in BSL so there are no barriers, because BSL is ingrained in Deaf lifestyle

That question should be taken off! It is labelling us as difficult. Why not ask us what support we need, such as interpreters and so on, and not implying it is going to be too difficult for us. We would be given the impression that they (the staff) are the clever lot and will take control of our needs. It's too patronising. Just ask us what we want, and then provide. [...]. Be ready. Use sign language, visual aids and so on. Get them ready, don't plan it out, and get on with it

They should ask questions like, Are you deaf? Do you need help?

a good question but too many words to listen to

pictures would help me understand and retain what is being said

question is too long and confusing

it is a good question but may not meet the needs of all individuals, particularly those who find complex sentences more challenging

too many questions in one sentence

shorter

make it shorter or bullet points. For people with aphasia it is too long

it is too long. I got confused

too many bits in one question. Break it down

I always have someone with me in these situations

question is too long for people with difficulties understanding

my sister is always with me and understands questions better

may be add "can we help anybody with their speech / understanding or any other help that is needed"

does anybody need any help with their speech, reading, writing or any help at all

Should be shorter - too long, doesn't need to be

very wordy, question could be broken down into 2 questions

questions are not well worded, too long a question, jargon

question should be shorter, too much information being asked. Be more specific

it's a bit long winded - would it be better to tell the doctor/care worker/receptionist to ask about a person's communications needs and leave it to them as to how they phrase the question? E.g. they should be able to tell what sort of disability (if any) a person has (or should be able to find out by questioning)

it's too long winded

it's about 5 questions put into 1

it needs to be broken down

the different parts of the question need to be asked slowly

let people answer the different bits in-between

it's not a yes / no answer

question is too long

"do you need any help?" would be a better question

simplify the question

make the question easier

the communications can sometimes be hard to understand so braille would be better for me as a visually impaired and sometimes the GP is very hard to understand

question is too long - it should be: "do you need support with (your appt today / whatever your visit is for)." Then they could ask what support you need

question should be small - like "what help do you need?"

this question is fine if the person can hear and understand it

do you really need support is a better question



make it easier to understand

there is a display, you're next I can't read it

they might need to repeat the question it needs to be easier.

it's a good question but you must not be too personal

it would have been better to just ask if a person need assistance. Initially to flag up an individual's impairment is a very negative approach

would be better to complete a simple form to explain any disability and best method of communicating and requirements before I meet up with a new GP perhaps this could be part of the registration form in the new GP surgery

would be easier to understand in 2 short questions. Do you need help to see, hear, or speech, read? Do you need help to understand me clearly

make it easy

when you registered at GPs and have a learning disability, deaf etc. this information about you should flag up in every dept. at a hospital

it is too wordy. Be more specific. Also the tone of voice could ruin any good intentions

question should be "do you require a registered BSL interpreter for deaf people, and a separate question for blind people."

the question is too detailed so make it a list. Do you find it difficult or do you need support to: see, hear, read, speak, understand....what is being said?

the question needs breaking down

too much in the question. I require a short verbal question - more specific

people need time to think about the question then answer it

it covers a lot of aspects of health almost too much info for some people

too wordy

it's too wordy, I'd suggest them asking "do you need any support to understand what is said to you"?)

I would like that question to be asked at the GPs or hospital

it needs to be done using other types of communications not just speech e.g. [...]

I think it sounds slightly patronising, I would change the question to, for example: Please let us know if you have a disability or any specific access requirements for attending an appointment e.g. communication support, visual support or support with medical condition or specific learning difficulty? .....

People are sensitive to what questions they are asked and what they are willing to admit to so it might be better not to ask them what they find difficult but to ask do they need additional support in a different format to gain a better understanding of what is being discussed

It is a good question if the information is then logged on a database accessibility to the whole NHS and Social Care Service. It would remove the stress of asking every time.

Prefer information to come to me at all time when I need it but most preferably face to face.

## Appendix 4 – Patients, carers and service users survey, Q11.

**“How do you think we should ask people about their information and communication support needs? In another way – please tell us.”**

NHS to follow same signals as hotel [...] with paging system and airport arrivals with names displayed prominently. Disembodied name calling far too stressful where one in two people over age 60 have a hearing loss. No costing whatsoever with large white sheet and marker pen for patients to write name for nurse to display when ready meet consultants and other staffing.

Use braille, large print, moon, audio

I need webcam access with BSL communication, this is really important. A response in written format such as an email or pen/paper means I don't understand what is going on. I don't know what it says. Webcam access is better.

I would like support staff to help.

[.....]

With support from my support workers.

Pictures

They don't have any old style phones, only newer versions I wish they carried on the old version.

Email or texting seems to be the popular options, but it's English! Video calls may be better. However, with written information, it could be taken out in wrong context, and misinterpreted. This is where sign language should come in. Video calls, such as [...], [...], and so on, provide sign language access, video mail would be a good idea if used in BSL.

[...]

I prefer face to face, but there is no evidence to back up that I have told them my information. That is one area that needs to be addressed

Email and text are linked with English language, and I may get the wrong idea of the true context or meaning of the message. I prefer emails with a sign language video, same for text messages, in sign language, websites with BSL user, [...] with interpreters. All this needs to be made and run by Deaf people so I can feel connected. [...]. I would like to have that

I need help to read, I don't have a computer. Staff help me to read letters

help from [...]

hospital / communication passport

hospital passport

fax

if the letter is in easy read

pictures on letters

let my carer / support worker know

letters to be more easy read

deaf / blind interpreter

BSL

fax for elderly deaf people

give lots of time

need 18 font

I would like support staff to help

with support from my support workers

pictures

It should be asked every time as people who are fine one day, may suffer the next time. This is especially true in people who face age related hearing loss.

these are from visually impaired perspectives - needs to be a range for different patients

I think it is vital that once the information and communication needs are established they should be recorded and kept for future reference. I do not want to have to repeat myself over and over as at present

You should offer ALL forms of communication and preferences and also provide terminals in the hospital settings as not everyone has email, text and where is VIDEO deaf people want choice of face to face visual contact not just using a minicom and using text relay.

[.....]???? [.....]??? [.....]??????

it would be good to have all of the above available, as different people would have different needs. This question has radio buttons rather than check boxes, so only one answer can be selected.

In a straight forward manner, i.e. 1st. question should find out the person's needs and then could be a list of solutions, e.g. alternative formats for information, email, braille, large print what font size, easy to read etc.

email face to face letter telephone and text and have somewhere to store this in their notes/file so that after the first time you can just ask have your support needs changed or have your communication needs changed

using a computer to printout braille, having a sign language video i.e. BSL or using [...] i.e. someone types what is being said and this is communicated in braille or otherwise on the patient's specially adapted computer (the software isn't expensive and [...]could teach NHS to use it)

"How would you like us to communicate with you?" give a list including braille, telephone, email, etc.

In what format would you like information to be given to you? braille, email, etc.

This will vary from person to person depending on their needs.

Cost would be an issue face to face but talking to someone would really help me

Different ways suit different people. It is best to ask in a clear way.

A simple form that the patient can complete themselves ... maybe a choice of answers requiring just a tick / cross in a circle!

Too many questions are asked in very public areas e.g. a hospital ward at night when sound really carries!

The person speaking to the patient has to be at eye level with them."

Using Makaton pictures, would enable an increase in what is understood. The language may need to be simple and basic. Explaining this face to face with the aid of pictures may help, or by Email, or website, so long as the site was visually based.

You should ask them individually how they want to be asked of course.

A significant minority of people [...] are not able to use all media mentioned. Hence the need for the three options chosen.

Full online access to their own record/data, so that they can "pull" the data whenever it is required.

You need to be aware that people have different information and communication support needs, so using 1 method is self-defeating. e.g. someone with reading difficulties would find difficulty with receiving email, letter, online form, text unless it contained accessible information (pictures/symbols that they understood). We need to avoid situations such as sending a letter to someone with a Learning Disability and unable to read or write and asking them to respond in writing.

In a way that is suitable for the person's specific needs

I can't read. This form is being filled in by my supporter

You need to bear in mind not everyone has access to a computer and the internet so 'old fashioned' ways like telephone and letter should still be used

I feel this question should be part of any communication with patients, especially alongside questions regarding mobility and transport. Otherwise there is an assumption, that the patient has no sensory needs.

Information should also be provided in all communications on how to make contact with the individual organisation, if the patient is unable to use the telephone.

Whichever is appropriate at the time!!!

there are so many deaf people angry with NHS for refused contact with text message or email, all contact only telephone !!

they text message to us but can't reply !!

what about older people with hearing problem, they don't have email or mobile ! how ?????

It should be whatever the patient preferred method of communication, but hospitals are NOT very good at updating contact details when informed by patients.

In an alternate format usable by the patient, People are individuals and cannot be catalogued the needs of each patient are unique to that patient so the NHS needs to be as flexible as its doctors in how they treat the individual

partially sighted partially deaf mobility issues and a life threatening and terminal medical condition. so cannot tick a single box

F2F is always best if done sympathetically and actions arising followed through. However, for routine care surely this should be in the patient's notes and so passed through with them in the new seamless NHS? This should only arise in acute/emergency care where the patient is out of context, possibly unconscious/reduced awareness etc....

Reception desks need to ensure confidentiality though it is inappropriate to ask in front of other patients.

People have different preferences depending upon their disability therefore there should be a choice of formats.

This should be included in all referral/documents and so on and ascertained at primary interview - for example with the GP in much the same way as ethnicity is recorded.

Ask person and those who support them how they usually communicate and what can help.

Patients with a learning disability will generally only understand face to face

Other methods may apply, if the abilities of the user are already known. e.g. can they cope with written communications, if so email or letter may be appropriate.

I think people should be asked via the way they prefer to communicate. You could also ask people when they first register with a GP or during a health check. People's circumstances do change so it should be an ongoing question, rather than once only.

if face-to-face the results should be recorded

you need to do ALL of these [...] - plus communicate with their carer and family

All ways possible

Most elderly people prefer face-to-face; phone might be acceptable to some, letter or e-mail to others. Web-sites can be confusing and there are still many older people who do not use the internet.

What about Braille?

I think you should ask them to contact the hospital/clinic direct prior to the appointment in a manner in which they feel comfortable.

Personally there is no way I use a telephone I have to see the speakers face and mouth. But this obviously depends on the individuals hearing loss.

Form to fill in at the doctor's or hospital

But we should only be asked once - and this noted in our medical records. Being asked constantly and having to say the same thing time after time is really annoying and makes me feel like I'm the cause of the problem...

It should be part of all communication with patients for all appointments and access to health and social services. There is no one answer which fits all situations therefore all should be used.

You should record information needs on patient's records and use this every time you contact someone. On paper systems use a sticker as with people who are allergic to particular things like penicillin for e.g.

Asking at the reception when booking in also in case the patient realises they need support despite other forms of communication

Notice at service counters i.e. bank counters or reception desks

It may be sensible to have a large poster prominently displayed asking people to make the staff aware that they have difficulty with communication, most of us hard of hearing find it difficult to just come out and say that we have difficulty but if we're invited to say we probably would

deaf sign language, lip reading

Only as the need arises

I think that once someone has said "I need Braille" this should be marked on their notes so that print letters are sent all the time.

As said above, the principle should be to list the support available and ask which service, if any, the patient would like to use, NOT to ask them what communication difficulty they have.

Ask in whatever format works! Be creative and use common sense! For example, a simple face-to-face question upon enrolling at a surgery should be sufficient. However, if a person is telephoning to enrol, then ask them over the phone. It's not rocket science and most people I've ever met in the VI world or deafblind have no trouble explaining their needs.

Also, there should be a well-known way for NHS staff to make changes to patient preferences if they are needed.

May I refer you to do a case study at any high street bank to see how they do it.

It all depends on the situation but having form without assuming all you need is to ask if BSL is needed is a very good way forward.

the letter should set out the options for people to explain their needs

I ticked the boxes relevant to my case. I don't call up by telephone as I need to lip-read therefore I find it too stressful. Luckily I live close to my GP practice so I call down and speak to reception face-to-face. I would love to be able to email or text for an appointment but I'm unaware if these services are available. I can text my audiologist via a work phone and I find this brilliant as I can arrange appointments this way without stress.

I think the telephone option should only be used when the service is called (i.e., not a cold call).

It depends on people's needs everyone is different it is no good sending a blind person a letter. On the other hand it is no good telephoning someone who is deaf. The person's disability should be a red alert on their notes and the appropriate format used accordingly

The more options given, the better. In Basic English Written and visual pictures. Letter - not too long written, best is simple written. For Website would be better for use BSL video on it that they can watch in repeat. Text - it depends how long information is, best to email. In appointment - face to face fully explains with interpreter. All of the above depending on the person.

if face to face then as privately as possible

Also prominent signs at reception etc.

In my GP's surgery the walls are covered 100% with posters and signs and information.

Send them a letter in their preferred format for example braille



Webcam

Minicom/text relay

Send information in an accessible format which should be checked before sending out.

## NEED TO BE AWARE THAT SOME ADULTS CANNOT READ

This needs to be a personal preference. It depends on how the person needs to communicate. Younger people may be happy to do it by email/text, elderly people might prefer to do it by letter, telephone or face to face - and sometimes it may be the other way round. It may be that an older person has a younger family member they can trust with also receiving information via email.

Most appointments are confirmed by letter so the question could be on the back of the letter advising the person to send it back if they have additional needs

easy read use [...] for people with learning disabilities

Face to face is the best way. However having just been to a drop in hearing clinic at [...] that opens for one hour on Wednesdays. Being confronted with at least forty five people in the queue in front of me I understand that this is not practical. So e-mail would be my next choice. (I didn't wait I just want advice on equipment to help me with using the phone again). I'm new to being deaf so forgive this comment. But perhaps the queues may not be so large if the initial set up of people's hearing aids was given more attention at the time of issue!!

As a poster in the surgery etc.

In a letter but you need to provide option to email someone in the relevant department so that it can be accessible for all to respond.

Disability is often missed by the GP at the point of GP referral to a hospital i.e. even if you have a known minicom number at your GP surgery they often fail to provide the full 18002 number so that you can be contacted. There is a lack of general deaf awareness at most health providers including GPs and Consultants, with the exception of nursing staff & administration staff

I believe text should be an option, because speaking on the phone is very difficult for me.

"support" is rather a jargon type word. What is wrong with 'help'?

Only written questions as telephoning would be a complete waste of time. We are dDeaf.

It will depend on their problem. I hate to use the telephone because of my hearing and would always choose email.

Use any method available. Don't be afraid of asking about support needs. I need help and if getting it was the norm I would be exceedingly grateful. People will get

used to seeing the question and not be offended and if they don't have a need they will be glad and move swiftly on.

basic training in clear speech for all in contact with the public. Some loudspeaker systems are useless when patients are being called

leaflets relevant to the services

None of these will suit everybody but questions need to be asked in advance of an appointment. This is why I have excluded face to face.

Braille and sign language including finger spelling and you would have to find out what's best first by having a trained communicator guide who specialises in all types of communication to find out what is best as each disabled person's requirements are very different

I think it would help service users if they were asked about their needs at least once a year to ensure service users' needs are up-to-date. For example this could be done at an initial appointment to avoid asking the service user the same question all the time.

Via a carer if necessary

All of the above - whichever is appropriate to the needs of the individual

Not everyone responds to a question in the same way. The questioner must probe the subject until it is certain that a valid response is given.

these three will be better to hear and understand

I like text all [...]

A call from a social worker would be best with information about the person from medical notes from GP so you can get first-hand information as to their needs if this is possible to do.

Have to use all available options to cover as many people as possible. And you may have to do it more than once as many will ignore the first request.

I would be a lot happier to have some summary after been seeing doctor in text format like explaining about what we have been discuss (hopefully with name of my illness) and what action I need to take next?

All forms of communication should be used.

Everyone will have their own preference. Leave as many options open as possible

I use e-mail all the time. Still waiting for a response from my local hospital audiology department though - it's over a year now. Face to face sometimes works for me - if the person is patient and prepared to write things down. Telephone for me is limited to me asking questions and demanding a yes or no answer, I'm afraid.

Make sure reception know deaf awareness and some BSL.

VRS

Face to face is fine so long as not in a public place e.g. not by a receptionist in a busy waiting room. Not everyone feels comfortable admitting to a disability particularly if it is has been acquired recently or at a young age.

All of them as different people communicate in different ways

Braille and Signing.

This is the only true way of ensuring that the person understands the question fully

I think it is important to gather this information in multiple ways to ensure you reach as many people as possible.

Hospital applications on mobiles which contains private information that could easy access to patients that is kept on system for records regarding medical needs as well as communication support by selection of various disabilities that applies to the patient as all as doctor/nurses....etc....when treating patients so doctors are aware of what kind of communication the patient finds easier. Also appointments could be added like reminders and instructions to follow. Proper use of the system could be advanced with many facilities available.

This information is open for other people to know - it doesn't matter how the information is picked up. What is more important is what the requester does with that information.

Reception - face to face

When booking an appointment, either text, email or online form

When GP or hospital confirmed the appointment in writing, please ask in writing, email or text if we need communication support.

When interpreter is booked, it would be very helpful to confirm this by text, email or letter

Face to face is hard for me, I talk to my support tutor side by side and sometimes via chat room safely even though we are in the same room

How about asking people to use the computer that you sign in, like at the GP, and have the question there, then this alerts the staff and they can come and offer support, staff need training or they do not get it right and end up annoying me or treating me like [...]

Lots of different ways, it should be a ubiquitous question asked as a matter of course and remembered if possible (and consented to).

All of the above, depending on need (also included a Telephone to Sign language service). The problem is trying to find one method to cover all needs and it just isn't possible or practical

[.....], [.....] and [.....] are other possibilities.

please include Video relay services to follow other providers as [.....], [.....] and banks

I understand some GPs or hospital do not use the emails at all.

Individual Medical records should be highlighted to indicate e.g. Profoundly Deaf - Support Required.

In any way the individual likes to communicate

For some people this might change on a frequent basis so it would be better every time they saw a health professional at the start of an appointment and a note made or perhaps a health professional could check a certain section in a file and then ask if the same support applied or if there was a change and go from there.

Letter in BSL not English

You will need to know the patients communication needs

Website with BSL so can book appointment with my preferred time myself.

In order to get accurate information you should keep it to the 4 ticked, if people who are deaf for example receive a text asking the above but have no communication support at the time they are likely to answer sending the wrong information.

Some of the people I know do not have a computer but have fax machine. Telephone will be for someone who is hard of hearing. I won't be able to hear on the phone.

Need Deaf can access use text to GP

All above options rely on having English language. None suitable in BSL! On screen in surgeries waiting areas in BSL

You should always be sure you are talking to the patient or the patient's proxy. An email can easily go to the wrong address. People change mobile numbers and emails can often go into spam. With a phone call you speak to someone to find out if it is the right person and face to face is obvious.

Most hospital/NHS service does not provide Text (SMS) on the letter, website, posters, etc. Your service should be improve and better access for deaf people. This is vital of everyday life communication

Not text or telephone

This information should be stored on the GP record and updated as needs change.

The essence about contact is to be discrete and sensitive. If anyone were to telephone me to ask if I need support with understanding I would be beside myself with anger. The chances are that you would phone when I was in work and would have disturbed me. Then your suggestion [...] would have really upset me. If I then arrived at hospital/surgery [...] and being less than cooperative you would only have yourselves to blame.

[...]

I am happy with all of the options given above, but would suggest that, if people prefer to be contacted by letter, the font size of the text needs to be at least 14 Point and the Font Style needs to be "Arial", as that is a Font Style that most people find easy to read.

All of the above are fine, but this will skip out on cohorts of people, e.g. homeless. Suggest also using voluntary sector to support this piece of work. Should also be asked in advance, e.g. outpatient letters and during booking of GP appointments

Use all opportunities to ask this question - that way you will find out when or if someone's needs change.

You should ask the individual person how they would like to be asked about their needs, because this will vary widely. I would prefer face-to-face in a one-to-one appointment, but not at a reception desk. A sign on the desk with a pile of forms and a link to an online version of the form would personally suit me the best.

Letter - but need simple English

Information in BSL DVD - 1st choice

I'm sure there must be a way to insert communication needs into a patient's file which is subsequently noted upon registration and can be updated throughout life.

If the information has not been collected, then simply ask for it whenever a patient turns up.

All of the above are of use and different people receive information in different ways.

Of all of them, face to face is the most powerful and can set the scene for how things progress from then on and which of the other communication methods are used..

In British Sign Language Translation on a Website would be the best.

It would be best if the hospital knew in advance if someone needed help so that it could be provided quickly and easily and be available as soon as the person arrives.

Therefore if appointment letters or other means of contact asked patients whether they needed this help and, if so, to contact the Receptionist X number of days before their appointment that would help. Some may not but at least the system would be prepared for some patients' needs ahead of time to help organisation and avoid patient embarrassment.

There is no 1 single way that meets everyone's needs and really needs to start at the 1st point of contact. A variety of the above may be needed before you get the information you need.

face to face is the better option. .

At an appropriate time, i.e. when anyone realises the information has not been recorded, so all of the above could apply.

Any of the methods ticked above would be suitable for me, BUT not everyone has access to / can use email / website; BSL Users may not be able to communicate face-to-face without a BSL Interpreter; BSL Users may not be able to understand written English in a letter; not everyone has a mobile phone; a lot of elderly deafened people can't use SMS texting on a mobile (though young deafened people tend to use SMS texting a lot)

depends on situation people with aphasia vary with my partner most of above are no good

The main thing is to give options.

I find it really frustrating when the only option is to phone (I'm profoundly Deaf) or use a computer (I'm 81, and can barely use one).

## Appendix 5 – Patients, carers and service users survey, Q12.

**“It can take time for organisations to get information in different formats or to find communication support workers. Sometimes things can be planned in advance, for example if you have an appointment in a few days’ time or if you live in a care home and always use the same support. Sometimes, you need treatment or support in an emergency and there is no warning, or it might be late at night. What should organisations do to make sure that you can get communication support and information in the right format quickly?”**

Have a conversation with me. Listen to me. Help me. Provide emotional support.

To include on the brand new NHS coding the required communication support in letters to deaf patients and GP medical notes – this will signal relevant information at the early stages. This will eliminate all the 'sorry we didn't know' syndrome given by NHS staffing. Perhaps the A&E as well as the paramedics should be briefed to expect possible hearing loss at their initial assessments?

Staff should be aware that not everybody can communicate in a straightforward manner and should have the relevant skills to assess the situation

email it ASAP

Always have back up plan and have clinicians or reception staffs who are bilingual language and someone who can be advocate in event of interpreter may not turn up.

Staff should learn to explain things in words before they do them, especially when treatment is being given. Verbal communication has not been mentioned much, but it is one of the most important ways of informing people what is happening to them. There should also be a way of letting staff know in an emergency that someone has difficulties. This could be in the form of a necklace or bracelet which the person wears all the time and which has a strip giving details such as blind, deaf, etc.

Have a bank of communication workers available e.g. BSL via video, use [.....]. For access to information be able to produce in accessible formats via email and text dynamically, for audio, use tape recorders or answerphone if short, have contract with transcription service which involves next day delivery of information, have standard information in accessible forms at health delivery points or be able to order these for next day delivery if necessary. Teach staff a range of communication and information skills. Employ Deaf and disabled people as workers on the front line who have these skills.

Doctors should be able to sign so that they can communicate with us. Also GPs should sign so they can communicate with us also. I want the same as everyone else, but there is nothing. I feel frustrated, as when you bring an interpreter, time just seems to waffle on. I don't want an interpreter. I prefer signing with the doctor as they know what they are talking about.

Most interpreters have to be booked in advance, but if there is an emergency then I can text them to arrange one before going to hospital.

Please note that I would prefer to use registered and qualified BSL/SSE interpreters in any medical appointments, not communication support workers as stated in your question above. It would be helpful if qualified interpreter is booked to be present at most of my health appointments. In the past, I have had to ask or phone to ask the receptionist to book interpreter for each appointment. It would be useful to have a flag system set up in your computer database for when you open up our file and this will notify the receptionist or other professionals of our disability and prompt them to book interpreters or write us a letter/text / email us to ask if we need an interpreter for the appointment or not. You can encourage us Deaf patients to give GP and hospital's receptionists a list of preferred interpreters with their contact details for future bookings. If you are unable to find an interpreter, you can use [...]. This can also be used for emergency and accident appointment. For emergency use, you can use [...] or [...] with interpreters at the initial meeting with the receptionist and nurse. While we are at it, try to find a qualified interpreter to be present at the appointment with the doctor or consultants

Same as 11, having a 24 hour interpreter on-line which makes my experience smoother is what I would like. I would like services to talk to the deaf users to find out what they want. If you ask the deaf user what they want if it is last minute then you can prepare better. The organization needs to listen to them. If it is last minute it is better to ask the deaf people what they would prefer. The professionals need to be involved in awareness training.

I think each hospital should either have an in house or on call interpreter who can be available all the time.

Make sure I am given all appropriate information as soon as possible for my support to discuss with me fully.

I live in supported living and if anything should happen I would be informed by support staff, I have emergency numbers to call.

I do live in supported living.

To communicate with my support staff.

My mum supports me.

Good communication between family and support staff.

To communicate well between my family.

If I am able, I will give phone numbers to any professionals.

Medical and personal information e.g. family contacts in a file, picture form.

I don't need a communication support person.

Make sure you get communication support and information quickly and it must be stored in a place where anybody can find it.



Ask me for my mum's phone number as I know it off by heart, speak slowly and easy speaking so I understand.

Not relevant as I always have a support worker with me.

They should contact me by letter or contact me by phone.

Speak to her support worker to see which way is best to meet her particular needs.

I do not need any help.

Speak to me.

My support workers have access to all my personal data in case of an emergency

I worry about my father being ill, but how can I call emergency services? There is no email or any way to contact them. I need it for an emergency, there is no direct line to contact them and it is an emergency.

Ask week before the appointment

Whenever I go to any medical services, I usually ask if there any staff members who can sign, even a very little bit of signing is much better than writing notes to each other. I would love that! Seems none of the medical staff have any knowledge in sign language. I would love to see someone who can sign in hospitals, also 24/7 access in sign language, it may be a live video call, or more staff signing. Nowadays, I use [...] with my mobile phone to call my wife to interpret for me in hospitals or doctors. I just put the phone on and watch my wife signing to me as she listens.

Interpreter should come anytime unless it is an emergency or if there visual graphic DVD that provides information so I don't need to worry

I had received some support if it were booked in advance, but what if it was an emergency? It would be very difficult, and a lot of treatments are delayed due to booking an interpreter. However, it would be a good idea if the staff were Deaf aware, or at least have passed level 3 or 4 in BSL classes. So they can assure the patients before the interpreters come along. Video calls are also a good idea

I regularly go to the dentists and opticians. I want the staff to know how to sign, so that an emergency interpreter is not needed.

If I book appointment tomorrow, I expect they will book a communication support worker.

The main thing is that the emergency service needs to have technology that can provide access to BSL interpreter on 24/7. For example, in emergencies, they can bring a trolley with a video call machine, that can call interpreter, and do live interpreting, so I can watch interpreter from the bed, so I can get information I needed, such as treatments, or questions etc. Maybe they need to set up an agency to have interpreters on standby. It would make my life easier.

It should be on our records that we have a learning disability. There should also be a nurse or a doctor present who understands people with a learning disability

I prefer communication support by face-to-face, but I don't mind texting as long as it is BSL based not formal English. NHS should be responsible for access, to have an interpreter there 24/7. If there is an emergency, there would be less hassle to get an interpreter. If there are no interpreters, then there is a communication breakdown.

I get the feeling that medical staff haven't heard of "scouts" before. You don't need to plan ahead. Be prepared for a Deaf person to turn up rather than "work things out" upon their arrival.

Getting an interpreter in an emergency never happens, but there should be some alternative like a live web translator.

keep records

staff to speak clearly

have hospital book and easy read book in hospital or other place

staff to liaise

information book, staff training

use phone to communicate and email

hospital passport is a great tool but I don't carry it with me all the time. We need some way of ensuring that my communication needs and requirements are on record so in an emergency the nurses and doctors know I have a learning disability

find our communication, dietary? needs i.e. care passport

give me the right info

contact my care manager / support workers

use emergency sign and information in box in fridge to assist communication

speak plain English

make people overcome

I have receptive aphasia but I am not stupid. I just need information delivered in a more straightforward way. I can't cope with lots of background noise or interruptions. I lose my train of thought if I get asked too many things in 1 go or when I am trying to answer one question and get asked another

be more aware of needs

refer people to [...] communication groups

inform about the [...] groups

refer to services quicker

have staff trained to help with people with communications problem, speech, and language reading and general advice

make people aware of services in their area where they can get help with their needs

find BSL from internet, or [...] on computer

[...] on computer

flagging system

understand your needs from beginning, telephone, who

ask for hospital passport, phone next of kin

if you are having a blood test you should get the communications support and accessible info quickly. They should get info from my GP. You should make sure the ambulance people talk first

find out what communications is used and what is acceptable to you as an individual

people have info. Staff should ask things more clearly

I think the meeting was really good

more training to ensure good communications skills, better English language

take time when they talk to you

when I am not well in the night to telephone the hospital then send a specialist

if it is necessary telephone is the quickest method to communicate, which should be closely followed by support workers visiting to confirm.

Try to ensure that if we have a hearing loss [...] we shouldn't have to struggle to hear what professionals [...] are saying. Admittedly arranging this could be tricky [...]

they should have a copy of your medical / hospital records

have a database of info in easy read (pictures and words) or just plain English

staff should be trained in communicating clearly at all times

work with other agencies including voluntary sector to offer support

I think they should work with other agencies

find out info of other services to act as quickly as possible

make sure all info is available, braille or audio

staff or receptionists should be trained in basic BSL

talk to my key worker, parents, staff at my care home. Use my emergency grab sheet

talk to your parents. Make sure you read my paperwork (emergency grab sheet)

there is no pressing need because any full time carer takes care of all of the above

I will always have support from my family so the services should contact my mum or sister

staff should answer the phone. There should be 2 staff on duty at night

more staff at night on call. I used to have 10 nurses but not anymore

for people who can't speak and ill people should have a list of things in case of emergency including how I want to be spoken to

the nurses are good to me and look after me

ambulance paramedic to ask if you have a learning disability or a black book. More training for paramedic and ambulance people

good links with community nurses. Paramedics to ask about black books

they are doing the best they can

better training

just ask people what they need

communication support and give GP, hospitals and receptionist a list of my preferred qualified interpreters and their contact details for future info - print in large print and bold on white or yellow paper

have a sign on your paperwork such as an asterisk and have details of who can provide support immediately

they should have the information before I come into hospital, and have easy read info already

have easy read available

to have easy read info ready and community nurses now

some things can be planned in advance. I need A&E 999. I need treatment, I ask for interpreter support

produce info on all medical conditions and some specific ones for me

part of your record which can be accessed 24/7. templates of e.g. written info ready on the computer system

my GP and local hospital know me and my family - it is on our records that we are deaf and require communications support- this should always be provided, but it rarely is, it should be booked automatically

always be prepared for someone who cannot read or has difficulty with understanding

Speak to me

ask

to have staff that are trained to deal with communications problems

staff had more training

individuals asked if a carer will be supporting or is one required

talk to me in simple sentences

emergency phone number

easy read, small book or audio book

to keep yellow health books updated and contact sheets, to have regular reviews

Speak to me

my support workers have access to all my personal data in case of an emergency

ensure I am given all appropriate information asap for my support worker to discuss with me

I live in sheltered accommodation and if anything should happen I would be informed and my support workers have the emergency numbers to call

I live in supported housing

to communicate with my support staff

mum supports me

good communications between family and support staff

to communicate well between my family

if I am able I will give phone numbers to any professionals

medical and personal info e.g. family contacts, in a file, picture form

I don't need a communications support person

make sure all staff have basic training of communications needs of others

make sure you get communications support and accessible info quickly. It should be stored where it is easily accessible

ask me for my mum's phone number as I know it, speak slowly and easily so I understand

not relevant as I always have a support worker with me

they should write me a letter or contact me by phone

speak to support worker to see which way is best to suit her needs

When it isn't possible to provide BSL interpreters for deaf patients at short notice or in case of an emergency, the medical professionals and deaf patients can communicate with each other through the use of [...]. It works using a computer and webcam, or a smartphone or tablet. A deaf person can connect instantly to the interpreter and sign to them what they want to say. The interpreter relays the information to a hearing person and sign back the reply.

Ensure that there is an on call rota for interpreters and language to [.....] telephones are available on all wards and that alternative formats on the main topics are available

Ensure each hospital has a few copies, maximum 10, of leaflets in accessible formats. Have an On-Call BSL Interpreter(s).

pay attention the first time a patient raises the issues and make notes on medical records

advance planning from the records of the person.

Put it on the Internet

Liaise with professional communication agencies. For example, the one used in the North East England is called [...]. They are the single biggest provider for people with BSL requirements and the service that offers the most professional Interpreters with regular assessments of the Interpreters to ensure they are providing the best possible service. My GP knows to contact this service to arrange appointments then they send out a letter to me to confirm this. This is an excellent interpersonal way of working, and this should be encouraged. More liaison between the NHS staff and the Language agencies.

For deaf people, at least make sure that the NHS staff who will be treating deaf people are deaf aware and have more patience/flexibility to adjust their communication methods. For example, write down everything on paper and give to deaf person so that they are aware of what is going on if they are conscious.

Have a repository of EasyRead information

Use IT

Otherwise have to rely on carer, which is pretty much what happens now as routine

Ask me. But if it is when there is no emergency, then patience is the essence communicating with the patient according to their needs. Organisations should read up so they are knowledgeable to help the best they can when there is no support, like having deaf awareness training for example.

They should have an agreement in place for short notice support or maybe have trained staff in the organisation if its large especially hospitals

Sight loss --- as part of Computer System keep the information in Audio and the patient can listen to it

Keep a shared clear record of communication needs and use it. It is not an extra or a luxury. It is essential to ensuring what someone needs and how they feel is properly understood by health and social care staff.

It is essential that any previous times that the needs are established are easily accessible. Many people attend numerous appointments at the same place and should not have to tell the same things over and over and if this is recorded then in an emergency this will be known.

Email or Text

It has been in the care plan

[.....] is so obvious have it listed in the correct manner in notes and systems in place to make sure it happens.

Ensure that we are asked in right way that it is what we need and make it easy to complain!

There are now so many accessible supports via technology so for example remote BSL [.....] remote STTR (many organisations providing this now) so can be access 24/7

There are applications on smart phones and tablets/[.....] which assist communication if a CSW cannot be in attendance.

I think all interpreters should be registered with NRDCP, health services should use interpreters that are registered. Support workers or family members are welcome to come along to support their clients/family but they should not perform the role of interpreters as they are not trained or accredited. More importantly children should be banned from any interpreting or translation assignment (children act) but it is common occurrence in health services.

Ensure that there is a way to obtain the assistance as quickly as possible

Have in-house staff who are trained in disability awareness, and have people who can produce information in different formats like braille or audio quickly, such as in house staff. Also, teach doctors/nurses sign language if possible so if necessary they can use it, or have in house support workers available quickly. People's health is of supreme importance, and the wait for a support worker to become available, could mean life or death.

surely they can have info in other formats prepared in advance. But support workers will depend on availability

make sure a plan is in place for such situations, no support and a panic to get some can make a distressing situation worse. try to have as much information as possible in accessible formats on hand

Understandably support may not be available with immediate effect so long as every effort is made to provide this as soon as possible I don't think any complaint can be made. As each individual has very different needs, it is not practical or fair to expect every eventuality to be catered for on the spot.

I am blind so the quickest format for myself and the easiest in an emergency situation would be email or text and of course good verbal communication.

there should be a red flag system on med info on line at the hospital

Provide information in accessible electronic information that blind people can access using their text to speech software by email web or text.

As soon as possible i.e. at a first visit to a doctor's surgery (as most of these have computers nowadays to keep records), it should be found out what communication and support a disabled patient needs, this should be electronically recorded and the type of communication and/or support be on a secure computer which could be secured by pin and second type of secure id similar to online banking so that authorised doctor/hospital/clinic could have access to a patients records online and anywhere in the world and these records would have all communication and support requirements detailed therein.

1. Consult medical records if available. 2. If medical records not available, ask patient. 3. Have access to a panel of staff or volunteers trained to ask patients what they need and go some way to providing it at short notice.

A person could speak it. It could be emailed if I have my mobile with me. Ask me.

In an emergency I would understand that I would just have to accept the normal standard of information but would hope there would be a follow-up procedure to produce and send out the correct format at a later date.

[.....] available with access online to all various formats

Always note communication needs on records and in emergency situations, if appropriate, ask.

Have a 'communications needs' form or field immediately after contact details

How about an emergency number 24/7 holding a database of all Registered Disabled people in the area e.g. Birmingham so maybe hospitals/police could contact them to gain information.

For the NHS settings, and in serious situations, communication support workers should NOT be used with Deaf people. To get support for the communication



between two parties, one should book a fully qualified interpreter who is registered with NRCDP.

One of the suggestions for getting support, e.g. BSL interpreters, at the last minutes was to get a list of the contact details for the freelance BSL interpreters. Or have a rota of the interpreters on call in case of emergency.

The most important thing is to make sure that the mainstream communication methods are as good as they can be - so that means plain English, clear print, good illustrations and photos to explain the text. Secondly, it's important not to make assumptions e.g. queuing systems which assume that everyone can read a screen. Train your staff in disability awareness.

Out of hours support! Is a must

listen would be a start and actually prove they are

They should ensure staff are aware that not everyone can understand usual speech, especially if it is a stressful situation. Why don't they just double check if things are clear and if not, then ask how to communicate best and keep a note for next time.

Make a note of it on your hospital file. Preferably at the front. Maybe have a colour coded sticker or box indicating that this patient has a particular need.

Ensure that all general information is kept in stock rather than being produced specially on an individual basis.

Always have a range of resources in different formats available to hand so that if there is an emergency and a service user needs that information quickly it will be available to them.

In my case if the health care professional is aware that they may not quite be on the same 'wave length', that would greatly help.

Each organisation needs to have a communications support professional employed and a written policy outlining what appropriate support could be offered to individuals, this policy can be referred to in the employee's absence. The support worker must be aware of conditions such as autism and how they affect an individual's understanding of communication.

NHS is a 24/7 service so the support systems available should be too.

Have [.....] that can show larger print in different formats!

Have on line forms available in wards / departments etc. available in different formats that can be printed on request, rather than have heaps of forms cluttering up the place.

In my case (I am blind), make sure that print information that I would be given is properly sent on to me in an accessible, email form.

This can be highlighted on a calendar, showing the time and date within the context of a week or month. If someone needs help in an emergency, then the medical staff, could show them picture from books or tell [...]. I think all hospital staff should be offered autism awareness training, so that the patients' needs are recognized and met.

Ask me

have people on 24/7 as delays can make things worse!

Be proactive not reactive. Use new technologies to full advantage, treat people as individuals, with compassion and respect. Be honest when meeting individual needs cannot be achieved.

My electronic health records should show what special needs I have and then they would be available at the point of use

Read the patients notes beforehand so they are forearmed!!!!

My daughter has an autism alert card which warns emergency staff of her communication difficulties. Perhaps this scheme should be rolled out to everyone who has a communication difficulty?

Need to ensure that disabilities are recognised and the person is kept up to date with what is going on and everything is explained clearly.

They should have an alternative route for communication and information support for short notice events - basically a contingency action that can be planned for.

By the service user holding a passport type document that gives details of their needs that can be shared with anyone.

By Letter.

Check with patient re: their preferred format at the BEGINNING and have it noted in RED on the front of their file/electronic notes. Staff need training in how to book interpreter & have access to local/emergency interpreting services at all times.

Have timely access to alternative or adjunctive communication support.

A follow up communication letter or note, even if only in bullet format after any urgent care episodes or input from support workers, would mean that any discussions are reinforced. This ensures that everything has been fully understood and give the opportunity for challenges. Older people cannot always remember what has been said in stressful circumstances and need time to consider what has been said or agreed.

Hold a permanent record of my preferred methods of communication.

In an emergency situation it would be useful if I always carried a card detailing my communication needs

There should be a note on your file saying that you need support.

Support needs should be recorded on your file.

Note made on my file that I need support.

They should ensure that all public facing staff are fully trained to ask the right questions and are aware of support options available 24/7. A support requirement card or a secure RFID tag card with memory carried by them, would assist people who require assistance which would immediately inform receptionists/emergency staff of their needs. It would only need a very low cost reader and microprocessor to convey the information required.

I suggest Process should provide functionality to "pull" data when required, and should include: 1. Record for individual maintained online, unique ID = NHS#. 2. Whenever person seen, record updated online within 24 hrs. at max. (even in an emergency), including changes in support needs. 3. The updated record will then always be available to the patient and/or NHS/Social whenever required. 4. Information also available, via patient, to anyone who may need to treat the patient in an emergency - anywhere in the UK or abroad.

Organisations need to ensure that all staff are aware that people have different communication needs and rather than develop separate cumbersome communication systems look at producing information in a simple format that meets the needs of most people. The first thing is to check how someone prefers to be communicated with. Hospital passports need to be more widespread.

There should be a list of communication support workers who are 'on call'.

They should have contingency plans in place for the provision of each type of support and information format so that this can be provided as soon as possible. Until this can be provided, any emergency action that has to be carried out should be done with due regard to the unfulfilled needs of the person receiving the care which might mean modifying the way things are done. Again, there should be contingency protocol in place for this.

Give staff basic training

Don't understand the question

Have some members of staff on duty within the organisation who are trained to offer support until professionals can be tracked down or written / alternative formats of information sourced. Have generic information available via the intranet which can be printed in a number of different languages and shared with the patient. Could support this with generic videos in different languages, including sign language and a written questionnaire, which could be shown to patients using a tablet computer and the patient points to/selects the most appropriate answer from a selection - for the healthcare professional to read - the ability to translate those responses back to spoken English could be built into the software. Telephone interpretation services can be used for patients for whom English is a second language.

Discuss with the patient or their support person the quickest and best way to communicate. This information should also be included clearly and to stand out on patients NHS records which are accessible by doctors hospitals dentists etc. it maybe a nominated person is contacted as well as the patient

There is a team of communication support workers working within the organisation

A data base of all organisations which provide approved and qualified communication support workers, as may be done for foreign language interpreters. It may be appropriate in some instances, to employ qualified staff or train existing staff in these specialities.

Encourage staff to "train their [.....]" as in [.....] dictation app/voice recognition programmes, these can work well BUT it does take work to get them to recognise individual voices/dialects etc.

Email and text would be the cheapest, quickest and easiest way to get information to an individual as the two can have the same short message.

Failing these, a phone call would suffice but takes up more staff time

asking individual best ways of getting the support.

I think patients do understand if there is some treatment which is unplanned that support can be difficult to put in place.

Have a backup of support which you can call upon quickly; or the health professionals should be willing to make adjustments themselves e.g. reading to a visually impaired person, writing for someone who is hearing impaired.

Find out any specific needs and database them for future use i.e. add to SCR!!

Don't assume that you don't have a communication problem. Don't play loud background music. Speak loudly and clearly when calling names in a waiting area.

simple all deaf people have own mobile phone, for any emergency calling, use text message with 999

I think all any emergency services should have access wide range like text message, fax, email, [...],

[...] is not very good, they don't provided us to use any [...] or mobile phone for communicate, they used only mainland telephone with minicom equipment!! can't use computer !!!

Should be allowed to take in someone they know and trust in the room with them, some form of writing pad should be made available for those patients that may need to ask questions if they feel doctors/nurses don't understand what is being said, shouting at a deaf person is a big no no.

Have in house support staff

If it is a last minute appt- ring the local interpreting service on their emergency number.

This is simply a statement of management failure to plan correctly for the needs of patients. Electronic communication methods provide a cost effective substitute in emergency situations.

Adapt, Improvise, or die

Have a record of the type of support you need and organize appointments accordingly

take advice from people who know

Have on hand either a few people who can sign/interpret etc. or a contract with such an organisation who can provide 24-7 support. IMCA's in acute trusts currently only work 9 to 5 on week days for example - so a quick fix for anyone needing such support would be to recruit more people and have one on call outside of normal working hours.

train existing staff at hospitals and walk in centres to sign/Makaton, or have people who can be called upon, a pool of people

Have link roles or advocates in departments, everyone should have disability training as part of their mandatory training when they start work.

It should be on the social services database that someone needs this kind of support.

Organisations should not do too much. The individual has to take a certain amount of responsibility so that they are able to understand what is being said to them.

For a start, the information should be included on the patient database which I believe is being developed (sorry, I cannot remember what it is called, but I know I was asked by my GP surgery if I wanted to opt out of it). Also maybe a national register of volunteers? And in emergency departments then there should be necessary information clearly available in written and braille.

It would be fantastic if organisations could share this information with each other. In the old days a big red sticker or yellow sticker could easily be put on the notes to show that someone had a specific problem. Now with computers maybe it's a bit more difficult. As a patient I seem to get constantly asked the same questions again and again and hospital staff don't seem to bother reading the notes.

Engagement in the use of online services - particularly with the increasing availability of electronic translation of information.

Online access by the patient to their own GP records, other NHS data, and Social Care records will increase Patient safety - particularly if an emergency arises when the Patient is outside his/her geographical location, when information will not be otherwise available.

Big question!!

First of all, make sure every patient has a Medication Passport in which s/he will have entered personal data, NHS numbers, hospital numbers, medication, allergies, key medical information. This will save lives in emergency situations. Patients can also use their My Medication Passport to indicate what disability/impairment they suffer from. 30 per cent of registered disabled people have disabilities which are not visible. Deaf people often complain that doctors/nurses fail to look at them when speaking to them. A label with statement on being deaf stuck on cover of My Medication passport is a great help.

have a range of resources readily available at all times. For example a list of signers, Makaton, pictures and so on. There should always be someone on duty with these skills.

For autistic people, to have priority access to someone who understands autism and can advocate.

Make sure you ask those who support the person about communication needs as well as clinical details

Consult with an advocate, appointee, power of attorney, carer, parent or friend

Anyone with profound communication difficulties, perhaps have a standard card that they can carry to show a contact person or communication method - like carrying a donor card?

Similarly, if people have learning difficulties but have a mobile phone, you could publicise a national standard name for use in the contacts list like [...]. If urgent help for communications is required, you can get straight to a person who can help?

Perhaps have a pool of appropriate workers available to cover such circumstances.

Centralised source of information that all the parts of the NHS care/social/etc. all have access to.

There needs to be more flexibility and better links with interpreters. For example, I have had situations where I know an interpreter is available but the hospital use an agency but the available interpreter doesn't work through the agency, so I've gone without support.

In terms of written information, for people like me who are confident with technology, it would be quicker to ensure that printed documents are scannable, or include a [...] or [...] code that can be scanned.

Also for communication more willingness to use technology (e.g. typing on my computer or [...] phone, and me reading it on the braille display)

For VI patients, they just need to communicate through speech.

Manage people's expectations. Don't assume that people will understand or know that these things take time. If staff are sensitive to individual needs then common sense should hopefully prevail.

Have a copy of communication passport

keep a personalised & regularly updated profile page

Patient notes (hard and electronic) should display at the front any needs that the patient has

have all staff trained in basic methods of communication support

A letter

Some basic/standard information should be available routinely. In other cases, a flagging system alerting staff to individuals 'communication needs.

In many cases, training staff well will enable them to make information more accessible to service users.

have a pre-set package (template) that caters for most information types on a computer network that is accessible by all who need it and then you can just add small pieces to the template in unusual circumstances

speak with family and carers

don't assume a level of cognition

In an emergency, I would always want someone with me who knows me, knows about me and who can answer questions on my behalf. This is my Mum, but when she isn't around in the future, I need social care providers to step in and be my mouthpiece. Strangers will just raise my stress and anxiety levels.

Ensure they have a budget for it, authorise people to engage the APPROPRIATE support and confirm payment, and ensure staff members are OBLIGED to fulfil that part of their role in order to make sure that people are appropriately facilitated at the emergency or other appointments.

Be assured, this does not happen now even for appointments in advance, and even where finance is not an implication.

Deliver the info in the simplest form by telephone or if there is time letter without all this data protection rubbish. People who use the services need speed and accuracy regardless of who else knows.

Doctors and at the hospital for appointments

Difficult because needs vary so much. Maybe an [...] is easiest, if people can cope with written English; would need audio for sight impaired and others who cannot read/write.

Draw up a procedure to accommodate.

Get the right people to do this properly. People to know sign language, People who know braille, People who know various languages, People who have an understanding of various medical conditions and diseases.

Have a support worker who didn't just work two days per week

Use telephone or, in the event of personal illness, contact a pre-named person, who lives locally to the individual.

It should be officially recorded on all medical records (red flagged) a bit like allergies are listed. Obviously there are going to be some situations when you just cannot give advance warning.

Always make sure the patient knows that the option of bringing a friend or family member with them to their appointments is always there. If the surgery has a high level of Deaf/HOH patients it would be worth having a member or members of staff who can sign to BSL level 1 and are Deaf Aware.

I have never been offered communication support at hospital or doctor's (and wouldn't know how to go about asking for it). Even when I went suddenly profoundly deaf and was seen at ENT there was no offer of communication support or even the offer to write things down.

For me, I find it helpful when there are leaflets about the topic under discussion especially those with 'frequently asked questions'.

The best support is awareness of potential issues, and the basics needed by staff to help address immediate issues.

As far as possible they should have large print etc. already. Keep a list of BSL interpreters (not less qualified CSWs: they are not suitable) and authorize staff to book someone at short notice (without a complicated procedure to follow). Make sure staff know they are allowed, and expected to do this.

They should have a note of how many patients they have that need that sort of support. Set up a contract with local providers so they can call it in as needed, and monitor it so they can increase / decrease it as required. We all know that it's not always possible to get support every time, but at least having plans in place and monitoring of them should help.

Make sure that all people with a diagnosis of an Autistic Spectrum Disorder (ASD) have a communications passport that they can give to a care / health worker. Ensure that all care / health workers read the passport when it is shown to them

Medical records should have a prominent notice showing record of deafness, blindness, dyslexia etc. which appears on notes or electronic records.

Ensure they receive answer and log it



People will understand delay and differing needs. But the length of time a patient has to make a decision or whatever needs to be adjusted to take account of your delay in contacting them accessibly.

Most importantly information needs to be considered in a range of formats at the outset and one original copy in a particular format produced from which copies can be made. This will cut down the response time.

I have lived abroad, and even though English is the main international language, I didn't expect everyone to be able to speak English to me, and certainly not in an emergency, though I did hope that they would slow down and use simple language when speaking the local language to me.

There must be a limit to what different organisations can do in an emergency, but all emergency workers should be trained to deal with some of the main different communications issues that they may come across, such as people with mental health issues, people with learning disabilities, people with sensory impairments, and people with limited English.

Nowadays, staff can use [...] translate on their phones, or type words into their phone for people who can't hear, etc., which might help a bit in an emergency.

I don't see that we can expect all organisations to provide a perfect service for all different types of communication problem at the drop of a hat. That simply isn't practicable.

It should be highlighted in hospital notes or with NHS number

Have an [...] ready and type it on there (or use a computer). One can always resort to pen and paper. Much depends on the patient's awareness

Deaf awareness training for all A&E staff, including fingerspelling

Have designated staff employed at the hospital to communicate in various forms. They need to work on site at the organisation in order to attend to the patient quickly. It would save money employing third party staff.

Have enough people available to implement the tasks

Advertise it on posters

email

phone (from emergency specialist worker)

For me making staff all having to do a deaf awareness course would help enormously as most staff do not have any idea how difficult it is to be deaf and hard of hearing, also having forms and leaflets in bigger print and information posters in large print.

Also keeping background noise to a minimum e.g. no televisions with the sound on and no music playing however quietly also having the reception desk in a quiet an area as possible and good lighting available

Ensure that staff have basic skills in communication i.e. some basic Makaton signs.

Simply ask the question in section 10 every time.

they should have information about that person on their files to be accessed in an emergency.

There is no out of hours support

ask for confirmation from the patient that they have in fact prepared for the consultation

Have trained staff or specialist voluntary service assistance.

To ensure they provide fully qualified interpreters with extensive experience and knowledge of cultural mediation in BSL.

Staff in A/E should be aware of patient's history and provide basic information in accessible formats, or provide pen and papers etc.

maybe patients should carry a card saying if they have a speech or reading problem.

People should carry a card with them explaining their situation and communication needs.

They need to have a way of recording a person's access needs so they are aware of this when and before they contact with an appointment.

If they do this then a lot of time will be saved as the right people will be there.

They should employ their own support workers directly, have an agency like bank workers who do nursing shifts. Also should encourage NHS staff to do additional training while training for their career themselves - for example BSL medical and basic should be taught. Sight loss awareness courses should be given during inductions (run by [...]), along with general disability awareness training.

Ensure adequate staff training so that the uncovered times are kept to a minimum, or at least one member of staff on duty at all times in A and E, and one between two hospital wards who can be moved to another one if necessary.

Employ people who have better skills (e.g. at least 2 members of staff should be able to sign for the deaf) and make sure all printed material is in a larger print than sighted people need so that those with sight impairments don't struggle. Make larger print the 'norm' rather than something that has to be sought out.

ensure the number to call is on the GPs website or information leaflet, encourage use of 111 number as a universal first point of contact

They should ask if you need help at the point when your appointment is made, or in the appointment letter they send out to patients. They should give a telephone number you can ring for further assistance.

Have people on standby who are able to attend at short notice if required. Under equal opportunities everyone is entitled to the same service.

maybe have an emergency pack, it could have basic information about the hospital, who runs it, who can be called on i.e. a priest, social worker etc. and this leaflet or pack could be made in a few different formats ready for when someone with a disability uses the service. lots of people now use smart phones etc. so it could be something that you could email or text them.

The appointment booking system should include facilities for recording the type of support needed, and prompt the receptionist/ on-line patient, to ask for the support at time of booking. for some services, it may even be suitable for a large surgery/department to have set days when support staff are always available, and steer patients towards those time slots when booking appointments, e.g. BSL interpreter present every Thursday p.m. Communication needs should be highlighted to receptionist, doctor, nurse etc. on appointment screens/patient records.

Have trained staff available, or train staff to at least a basic level of awareness.

I recall one occasion where I was in hospital and the man in the next bed [...]. The next morning I learnt he was [...]. I know a bit of the deafblind manual (signing for deaf and blind) and he was so pleased that I could communicate ... I'm not sure the ward staff could.

Recently I had an eye operation in an eye hospital. I thought it was shocking that the lady who gave me the medication to take home when I was discharged didn't know there was braille on the boxes. That's an EU regulation now and applies to all pharmaceutical products, so all medical staff should know about it, including in chemists.

Talk in plain understandable English.

[...]

Human communication staff could be asked to join a list of available people to be called-in in the event of an emergency while information can be transcribed in advance or on a call-off system as long as a master is produced in advance. I am the manager of the [.....] and we are asked for information frequently in Braille, and large print information can be produced quickly whereas audio information takes a little longer and master recordings are important in this way

Communication training in hospitals and GP surgeries

The organisations need to have deaf awareness. The training provides information of how to book communication support. Another good point is to ask deaf or hard of hearing person themselves. They will be willing to help especially if they use support often and might put organisation with right person in touch.

They should ensure they have two agencies on contract with a condition that the interpreters can be available 24 /7

Once this is done - ensure that EVERY SINGLE NHS STAFF is aware and has access to the number to ring straightaway.

TELL staff NOT to say 'they will not book one' if asked. It is not their place to decide for the patients if they need communication support.

medical records should hold the information about my needs

Organisations should have trained workers

Put in place arrangements to provide info in a form which will suffice for an emergency, and accept that a preferred format may take a day or two longer.

I don't mind if there is a delay to my appointment if my needs need to be met. For example, if I need somebody to read a document for me before my appointment, then I don't mind waiting while it is organised.

Suggestions for deaf/hard of hearing:

- Someone e.g. a nurse/other health profession should write out what's being said by doctor/other health professional as it's unfair that treatment has to be consented due to communication barriers with the patient.
- All health professionals could learn basic BSL finger spelling to help communication with those that use BSL.
- Make short video clips to show the patient e.g. a GP, BSL interpreter and subtitles (easy to read) explaining a procedure that needs to be done/condition that needs to be treated. This could be on an [.....]/tablet with an index of mini video clips of each condition and treatments that go with each acted out by a GP and pretend patient. These videos could also be written information. The doctor/GP could click on the condition and play it to the patient.

By using the formats above you cover all deaf people who use BSL (BSL interpreter)/those who lip-read and those with mild hearing losses (subtitles).

Those with hearing aids that have a t-switch can be helped by having a portable induction loop system (small laptop shape device) near them. These should be kept in emergency rooms at all times and all staff should know how to work them.

there should be a registration form set out in all forms and answerable in all formats and then someone who has sworn something like The Official Secrets Act translate a braille or audio or other format that hasn't been filled in on a secure website to a secure database which could be used by organisations nationwide but they wouldn't be able to access confidential information, only the communication info and what other info a patient has asked for

A person should be on hand who can give a summary of important information verbally.

A new HHS scheme is being introduced where all health services have access to your details when using HHS as long as people do not opt out of this scheme then a note can be put on the top of patients records. This can be a coloured sticker for example which is a universal code so staff know if a person is blind, deaf, have other disabilities. Thus it would be easier at a glance to work out at a glance the sort of support to be offered.

All business should be done by email where possible, it's more secure than a stranger reading it all to you. More blind people use email than braille, for instance. Large hospitals should have condition leaflets available in all formats, they probably only need one copy of each and this should be done nationally. Staff should all be trained in talking to disabled people like ordinary people, not treating us like we are incapable of everything just because, say, we can't see, they should simply ask what help we need and use our words for things, like guiding not taking or escorting, they are too vague. Information systems should never be visual only, us blind people can't see what name or number has gone up on the screen, I often get taken to an unstaffed, upstairs, waiting room at my GP surgery, fortunately the doctors are usually good at finding me.

#### In-house support

There should be a record of what a particular person needs. It is understandable that those who need personal support IE. sign language interpreter to have issues with such information, but for the most situation as for example of myself being blind, if I need urgent treatment I would most likely need to contact the organisation myself therefore there will be no option for written material to be sent to me so I would not be presented with any difficulties.

A pre-arranged set of contingency plans to cover all options considered likely and this should be an open list to which any emerging needs can be added.

[...]

[...]

[...]

Having visual supports either pictures written info or braille available for the common problems available to all health professionals

organisations should have as much information in different formats available to hand at all times

If time is of the essence I think that initially a phone would be best, since it is the most direct means of communication.

If the person has access to a computer, I would suggest an e mail follow up with further information if needed.

I would have thought online support - that is that each depart should have one PC set up to be able to support BSL and the like. This might be a cheaper option all round - eliminating travel times / delays if interpreters were needed.

As much as possible or find an alternative way of communicating till the assistance can be put in situ.

SMS/email should be available even for emergencies. They could also produce information in Braille in-house rather than having to contract for it which may incur minimum timescales.

They should call you and keep in contact with you

Exchange relevant information about the client within the agencies concerned

I feel you should always have an out of hours access number to an Interpreter.

Advertise information online, or with appointment letters

have access to a 24 hour interpreting agency.

At the very outset when you are referred for treatment by your GP, you should be asked how you would like information provided, and the outcome should be made available to, and acted upon, by all parties likely to be involved in delivering treatment/services

emergency support is not good especially in rural areas - you have to ask and answer several questions only to be signposted further

Keep it simple. Organogram or signs accompanied by written actions/further signs. Yes/no criteria. (good on line or visually but not good for telephone for instance). Telephone calls for help need to be to a human with very plain questions mimicking the organogram idea. Do not consider automated response systems! They are too inflexible.

British Sign Language interpreter

They should use text, as it is just as quick as telephone or write things down and use gestures or finger spelling.

Deaf people need to know where to stand

Clear information or fact sheet for deaf people how to request the NHS to book BSL interpreter. I think it would stop regional or local NHS providers to argue who pay, etc. Why not NHS England take responsibility to manage central booking system for deaf people to request. One place, one number, one email address - SIMPLE

That there should be signers on standby if there is emergency, otherwise I would be lost in communication.

Organisations can't do anything until they are faced with the problem. It is impractical (not to mention against the DP Act) to have every organisation know about every potential patient's needs. A patient who has specific needs should carry a card to show (or be found by) emergency services if the person got into difficulty or had an accident.

Have common formats always on hand e.g. always keep large print and braille documents to hand, and have an 'on-call' interpreter, or member of staff trained in BSL or similar.

Have somebody available at the end of a telephone 24 hours a day.

[...]

My son has Severe Learning Difficulties and is non-verbal. His GP and his dentist both know him and understand how to communicate with him. For a hospital appointment, he would take his Hospital Passport with him. [...] has Disability Liaison Nurses, one of whom might be available to help.

To be able to provide good access to BSL users, these organisations should have a contract with a Video Relay Service (VRS). This means that when there is a situation where a deaf patient needs urgent access to communication, staff can bring a tablet such as an [...] and connect to a BSL interpreter instantly on the spot via Wi-Fi. This service is provided by [...] for example: [...].

Within 24 hours however it should provide automatically like there need to have 24 hours/7 days full access

Ask if there are any special requirements.

Have a bank of staff they can call on and make sure they are qualified to an appropriate level.

Speak clearly!

Don't speak whilst looking away from the person or covering any part of your face.

Don't rush the person, they may need time to get the words into the right order, being rushed just makes that harder.

If the person has a "communication passport" or similar, don't just glance at it and dismiss it. It's been put together for a reason, not just because someone had nothing better to do for the afternoon.

Making standard information like "what to do after XYZ injury" leaflets available as accessible electronic formats (e.g. for e-readers/e-reader software on phones and tablets) so that the user can adapt the font size, spacing etc. to make it easier for them to read.

Have good face to face contact with an identified person having the responsibility you have read to you anything that is relevant and for them to check that you are satisfied

Have staff who actually understand what support is available and how to book it. I have tried lots of times to book a support worker only for the department at the hospital who deal with it not to know anything about it so have never managed to have anyone with me.

Use the same computer and communication systems

Do their best - have alternatives recorded in a plan that can be used when needed. The plan could be administered/updated by the patient or a nominated member of the patient's family - similar to loyalty card /membership information.

Staff awareness is often a bit of a barrier, many people have some skills that would assist in an emergency even if they aren't fully qualified. Keep a "skills" register so those talents can be used as a stop gap until proper arrangements can be made.

More use of IT and better information about where interpreters and communication support can be obtained.

Less emphasis on the obvious like BSL - there are many more ways of communicating, including cued speech, also general deaf awareness and communication skills are poor in the NHS in my experience.

Before hospitals used [...] who gave excellent support. Since funding changed they used cheaper agencies with substandard communication including non-qualified interpreters and high cancellation rate

Know where they can get 24 hour on call communication / interpreter services

Have staff members at the health services who can do some basic clear speech / sign language to communicate with the hearing impaired / deaf person until the notetaker / interpreter arrives

If it's an emergency then good verbal communication followed up with an email for example if I need to take that information away is perfect and quick and cheap to do,

This is a difficult question to answer for a novice like myself. But one thing that I think needs addressing is that people who access health services i.e. hearing aids should be on a database where health care professionals can quickly access via a secure terminal so that many problems with equipment can be readily addressed. I.e. if my hearing aid goes defective in another part of the country, by entering my details in the secure system the settings required for my deafness can be easily set up in a replacement or restored in a repaired item.

24/7 service to contact to book an interpreter ASAP not two weeks have an appointment. Need to change the booking system rule.

Video relay available for emergency at A&E or Doctors or NHS receptions

Have available formats in hand instead of waiting to order - means more time and less delay in things.

The practitioner should be aware these situations will occur and it should be part of their job to work with these situations.

an e mail format similar to the hospital passport stored on a central computer so when it come up with my name it will automatically alert the service.



if the information is made available as a data set which organisations can easily access, it should be easier for that to happen than to explain every time you need anything to a number of organisations separately

Have pool of Deaf Advocates, Registered Interpreter or Deaf Relay Interpreter on standby.

Have access to telephone support

Keep up-to-date with modern technology e.g. [...] provides lip-speakers and type-talkers for deaf/hard of hearing people. Using a mobile phone, tablet, or laptop/computer, you can book them at short notice to provide assistance. They listen to the conversation then type what is being said in real time so that patients/doctors can both see it on the screen. As these people work via the internet, they are based worldwide and can do this at any time of the day/night. You can pay for it yourself or it could be a service from the NHS.

Information should be written down if in an emergency someone with hearing loss may need to know exactly information on where to go for blood tests etc. or what medication they require.

Contact to the GP should be made within 24 hours if no communication support is available with a report on what has been advised and what the concern was so that the GP can follow up in the community with appropriate communication support in place.

card (like donor card) with any communications disabilities listed

Perhaps there should be some sort of video system, such as [...], so that an interpreter can be on hand immediately.

No idea! I normally have support from, my husband/daughter.

Maybe (for hearing impaired) have a computer in front to type questions/answers.

not sure

The first question should be Can you hear and understand what I am saying?

Have email / online support forms for appointments in order to be aware of the individual's needs.

Survey to see preferences

Send a letter when your appointment is first set up. Before the appointment date arrives.

I think it would be very helpful if all records for a deaf person were recorded in large letters, clearly on their patient notes. I don't always see the same GP or other health worker and I have to explain each time that I am deaf. I an emergency access to the patient notes would be clear.

Not an easy thing to cover every deaf person!

To have this information contained within the notes. I asked for my notes to have the red hearing impaired sign on my notes so that the consultants understood that I am hearing impaired but was told this was against hospital policy! I also carry a card with me from [...] which I show to people in A & E. However when transferred to the ward I come across ignorant doctors, who being told that I am hearing impaired reside to either shout (which not only distorts the words but also invades my privacy), stand at the end of the bed and ask me questions (meaning I miss hear or don't hear the question and then they walk away as if I am [...]) or they cover their mouths, drop their heads, turn away etc. (meaning I can't pick up what they are saying through lip reading or snatches of the sentences). If I attend A & E late at night or at a weekend I find that the staff on the wards are unable to photocopy the card so I have to worry whether the staff know and understand my needs or whether my card will go astray.

Have a 'signal' system on notes/letters/communications about patient so that all coming into contact are made aware of a need and can PLAN ahead for this.

MAKE SURE BY NOTICE AND OR PHONE NUMBERS WITHIN WEBSITES OR BUILDINGS AND HAVE IT MADE KNOWN THAT THE HELP IS AVAILABLE LIKE I.E A CHAPERONE IN DOCTORS SURGERIES AND WE CAN ASK FOR IT. A LOT OF ASSOCIATIONS DONOT MAKE THESE OFFERS CLEAR.

Make sure that there are enough people trained or being trained to cope with these emergencies

Ask and I would have list of named interpreter's. .need to be logged in files computers

As any answer will cost money to implement and the govt. will not increase funding to actually help people I feel these questions are moot sadly.

This is a very tricky one in an emergency...obviously if you can bring someone with you that is the ideal otherwise help should be available on a one to one basis to help you understand and answer questions you might be asked.

Individuals should be trained to provide whatever support might be needed. It's no surprise that many people will need help with communication methods and especially as they get older.

Why do you need a support worker? Is a support worker always necessary? Does the doctor need a third party to explain what is going on?

Information in the right format is a different question. Printed documents can easily be reformatted in larger text. They could always be provided in larger text. Nobody minds big print.

In the present climate I don't think this is possible especially late at night. However the process should be expedited as soon as possible.

staff and patient understanding-e.g. when reporting at the reception desk a notice to tell the receptionist if you are hard of hearing so they know when you are called. My

last GP made a note of this and came from his office to call me in/also wrote down notes to remind me of anything important in case I misheard his advice. Not many are like that!!

Know how to book interpreters for deaf

NOT by telephone calls. It is not suitable for hard-of-hearing or deaf people.

Emergency services e.g. ambulance plus on call GPs

Staff training

Should be kept on national database so when attending any NHS appointment the problem would be highlighted

Ensure family member or friend accompanies patient. Have some basic equipment available and staff trained e.g. mini whiteboard and marker pens and magnifying glass for poor sight, personal listener for hearing loss, ensure patients are able to wear their hearing aids if appropriate.

All one can say is 'do their best'. Can't ask for more in difficult circumstances.

Be more sympathetic to people's needs

Talk to me

If you have a speech or understanding problem, your GP should make it clear to you that you need to carry a card explaining your problem and giving a contact number that staff can phone (like your family or named friend). If you have a seeing or hearing problem, the hospital staff must just do their best to communicate slowly and clearly. Speaking slowly helps deaf /hard of hearing people and it also helps those with imperfect English.

I don't know

In my case make sure everyone has had deaf awareness training.

More front line audiologist required and less bureaucrats

There should be a co-ordinated approach to a person's care so that this sort of information can be easily accessed by all relevant healthcare/social care professionals. Agencies need to co-operate more with regards to information sharing on these matters. However, data security is important too.

At first contact with an organisation, details of any support required should be elicited and recorded so that prior to future contact these requirements are flagged up and met.

train staff to a basic level e.g. in deaf awareness so that the patient experience is not so traumatic before more skilled communication support workers can be put in place.

Too many organisations. My friend; bed-ridden at home has 56 care workers (often all different) every week - that is a stupid waste of money. Yet they have just sold a convalescent home to a developer to turn into luxury flats.

I think giving the person being treated a small mp3 type device that records what is said to them and by them in the treatment session that they can themselves listen to via headphones later or ask a relative/carer/friend to listen to at a later time so they can refer to what was said.

do not treat ear problems as a nuisance

Keeping accurate records to hand with correct phone/email/Postal address or a close contact Relative/Friend as a backup.

You could use the same as a 999 call or a direct line from a call out phone the I know can be install and a pendant worn around your neck to press in an emergency for help

Make sure you have a list of people who can do all those things at any time.....in or out of hours

Ask what format the patient would prefer.

Ensure to get up to date patient phone numbers and email addresses.

Know who the patient's carer is and how to contact them.

Improve awareness about 999 by using SMS ( not every deaf people know about this). GPs need deaf awareness training badly especially for all kind of deafness like old people. Does A&E know the unknown confused patient is deaf (i.e. the person may have lost his cochlear implant aid from car crash) and need MRI scan? Does the dept. have routine quick check like airport style hand scanner before put the person into MRI??

Staff even in an emergency situation should always ask a patient at the point of care if they need support. it is less stressful for the patient when you know that those treating you are therefore aware of your situation and treat you with courtesy, kindness and respect. it is frightening situation for anyone but especially if you are also frustrated by a lack of due diligence.

For me and many other none BSL users having staff trained in communication skills and clear speech would benefit the majority of deaf people

Always have a spare support worker to give one to one help. A note pad and pen to write everything down.

As a deaf person, in an emergency its likely I would not be able to hear. A pen and paper would help people to ask questions. Then I would probably be able to reply verbally. There is an assumption that when an instant response is not given to a question, the person is stupid, and that repeating the question, loudly and impatiently, will work. Please consider

ask about your needs when you book the appointment

Your question is waffling what you talking about?

[.....] are by far the best and quickest at getting me an interpreter

Be prepared to be flexible and patient. Don't just assume that an individual understands. Ask them and be prepared to adapt style of communication to make things easier. Making an effort and showing willing (not impatience or frustration) is more important than getting it 100% right every time.

Put it on our data base on our communication needs.

confirmation email/letter of support with date and times. (proof as well)

to make sure to connect 24 hours support working

You should read my one page plan/ patient passport.

Text

Email

Teach staff Deaf Awareness and fingerspelling

have a communication passport for each person so that everyone will know even in emergency what the person needs are.

the right information at hand i.e. telephone numbers etc. in the format the patient can understand for emergency's

Work with good organisations who work 24/7

I know good BSL interpreting who work 24/7 [...] - can provide good time and like organise things last minute as deaf people live real world like hearing people do.

Look at [.....] or call [.....]

Encourage people to use / carry [...] or similar or to carry a personal card of their individual needs & wishes on how to be asked, keeping it brief.

This is virtually impossible to answer. The only way I can think of is to have someone who would visit the person needing help almost immediately.

[...]

I'm not really sure how this could be done other than health professionals being more aware or as in next of kin there could be a name of someone known to the person who understands their needs and is willing to step in until the right format can be obtained, just a thought really.

hospital doctors, social services, police, courts, dentist

Have some standardised letters / consent forms etc. in alternative formats.

I think it would be great if the hospital can hire interpreters in sign language/lipreader/ braille or other languages that are needed emergencies otherwise it is wiser to have an application on [.....] that helps easier to communicate by text message, writing pad, notes, or an application that helps all kinds of disabilities in communication in case of emergencies at hospitals like emergency notes/questions asked and the answer could be written on the other [.....]. Blind people could have [.....] application. If blind and deaf you could have a special Braille language notes in form of a card/plastic with English translation for doctors. Answer could be sought by an interpreter.

Read the service users notes BEFORE the appointment. There should be an icon on the initial screen and/or contact details indicating the need for support.

Organise themselves better.

Know how to source communication professionals locally at short notice.

Ask the deaf patient if they have any preference, they may come up with a name.

I do not use communication support workers, I use sign language interpreters.

Most deaf people know exactly who they want to work with and will most probably contact the interpreter themselves to check if they are available. This is mostly GP appointments. But hospital appointments are nearly never immediate, which is ample time to find an interpreter.

Need a support worker, who understands communication difficulties, and can sign and lip read, and have a loop hearing facility.

Make a note of my disability via GP records and Summary Care Record

Ask me for a list of interpreters' names and contacts that I prefer to use for any health appointment.

Check with the interpreters if they are happy to be on your list for emergency cases and note in the Summary Care record.

GP

Hospitals in all departments

Dentist

all should check my profile and see that I am deaf would require a BSL interpreter.

Make sure all information requirements are on the patients notes.

In such cases then email, telephone or text message where the circumstances are appropriate. In the event of an emergency then verbal communication in a timely, sensitive and professional manner.

Use the question like I have said, give people options. Mum says I don't know what support I need and that is a really hard question for me, especially if stressed and strip lighting is doing me in. Give options of help on offer

train all employees to enable them to be aware of the needs of others.

Have a 24/7 telephone line that can be rung for support.

Provide information where possible in advance e.g. written notes or print off from NHS websites. My GP already prints off NHS [...] pages for me about anything we discuss.

Services such as [...], [...] could be used currently or in a wider NHS invested in partnership to provide emergency access to BSL.

Remote STTR providers such as [...] and [...] could be worked with to provide 24/7 emergency access for NHS like this as well. These would need some investment but could be more utilised.

Staff also need awareness of disabilities and maybe if the regular staff can't do this, there could be staff at the hospital available to provide "support" e.g. take notes and re-explain and help arrange communication support as soon as practicable and then explain using the notes what has happened again once the support has arrived.

Keep your preferred communication needs on your file

I am having difficulty answering this. Perhaps there is an electronic solution in the form of a tag or wristband holding basic information or a computer link to information held at GP surgery?

THIS COULD BE VERY DIFFICULT & PERHAPS IN EXTREME EMERGENCIES IMPOSSIBLE,...BUT IF IT WAS ON A PERSONS' MEDICAL NOTES,...KNOWN BEFOREHAND, THEN THINGS COULD PERHAPS BE IMPLEMENTED FASTER..??

- Have emergency contact numbers for communication agencies on file.
- Have 'emergency communication method' details in a patients file.

Organisations should have a 24 hour list of interpreters they can call upon either to work live, or remotely using VRS.

[...] is a possible option that should be explored for remote interpreting.

Great use of video relay technology to consider

Access to 24 hours BSL interpreting provision by itself not with the other language agencies

Regular consultation/engagement with local deaf communities face to face

Could a family member help?

[...]

Make it the first question asked.

24 hours Out of Hours and also any interpreting agencies and they need to provide online bookings.

In an emergency, if conscious, handwritten questions, otherwise partner or medical staff should be responsible for actions.

Have a 24 hour call line covering all social service disciplines so that any on call emergency can be dealt with

We should have 24/7 for communication support like everyone has.

IT systems where information is shared and relevant details are seen by necessary health and social care staff. The NHS are far too strict about sharing information with other professionals and could share more whilst still remaining within the law and bounds of confidentiality.

the patient to have information on their records that says they need help. A prepared letter or form saying they need help to show in an emergency

Have 'on call' services.

Emergencies could be difficult to manage in terms of support being available quickly. I think it is about services having a system in place that enables them to access the various means of support as soon as possible and knowing where to go and how.

Should always have communication support.

Staff with deaf awareness, staff with signing skills.

In my case I think texting would be the best way.

Communication needs should be on the patients record.

In house interpreters or on call 24 hours 7 days a week

There should be an out of hour's system for interpreters or support required.

Understand you are deaf - most people tend to not look at you.

You can write things down but patience isn't normally a choice in hospital

All their staff should be TRAINED from the start of their employment, they should be made aware of different communication needs, communication tools, and how to access these. They should have simple fact sheets in their work place so they know quickly and effectively who to go to for the support that's needed.

Have someone available to do flexible hours because once you received a letter saying the appointment is made in the month time with BSL interpreter booked.



Within a month time, you turned up for an appointment and been told that BSL interpreter has not been booked.

If you had suitably qualified staff who work on a rotational basis for a trial period to try and calculate the actual overall need of the service and then try to provide it at peak/busiest times.

Have standby can easy access to

Text

Liaise with family & carers in the first instance, with consent, to give them the opportunity to respond during these 'emergency' scenarios.

They need to have informed, aware and trained staff who can deal with anyone's communication difficulties.

Have somewhere you can call

[...] online interpreting service

Make sure information is accessible for Deaf people. For example providing sms number for booking treatments or support in an emergency. Or an email address.

Leave a card with the patient with the important information about the patient with the patient in English. Similar to the medic alert system.

When you make an appointment you should be asked if you need any help or support and it should be noted in your notes

Ensure that details of tel. no's., email addresses, etc. are recorded with patient notes together with details of a nominated friend/relation who is also contactable

Provide 24 hours emergency service from the Interpreter Agency

Staff on duty that can communicate in different ways. E.g. sign. All staff to have basic training in good communication.

It's impossible to support everyone's needs in an emergency and so basic training and tools for everyone should be provided. E.g. pen and paper for working with deaf people and a few basic signs, (thanks, hello etc.). Cue cards for popular languages used in Britain besides English Access to an interpreter services as soon as possible

Have marked on front of hospital and GP records that support is needed so it is seen as soon as possible.

Don't ignore my request - don't assume that they know what I need, I am an adult and I know that I need an interpreter to best help me access my appointments (the things they have said to me over the years - use pen or paper, or there's a nurse who learnt how to fingerspell, told me to bring a family member (even asking my 11 year old daughter to tell me what is being said!!) or telling me there's no interpreters

available when they haven't even lifted the phone or typed an email - they are saving money but not looking after my wellbeing which is what they are there for!

Train the staff! Train them to accept and expect disability rather than considering it as a nuisance.

The other thing you could do is to have a communicator in every unit. Someone who is adept at communicating with the disabled and can support them during a consultation. That person, or team, could be 'on call'. This will not solve a specific language problem but [...] can offer a lot in an emergency and BSL interpretation is available on-line.

Have a list of communication support professionals who might be available at short notice.

They should have information available 24 hours a day 7 days a week.

They must be sympathetic to my needs and be patient in their attempts to assist me.

If they TRY and help, I will be happy

There should be systems in place within the premises of all organisations to produce information in whatever format is required at the drop of a hat. There should also be a number of copies of all printed material made readily-available in a wide range of formats in all NHS organisations, so that they can be accessed at short notice. As all printed documents are produced on computers these days, it should not be too difficult to make information available to people who require it in alternative formats at exactly the same time as it would be made available to the rest of the general public.

Not always possible to do this in an emergency, some helpful ways for patients

- A teleconference on speakerphone with linguist
- In worst case scenario, [...] can usually translate key bits of information. It's usually archaic, but gets the message across
- [...] with sign language
- Standard NHS picture flashcards available online, that can be accessed on screen or printed and mixed and matched to be used according to the situation.

Awareness of the potential barriers and flexibility to overcome them

Have a support worker on the staff or ask a week in advance

This is only realistic with lots of funding and a linked IT system so that all healthcare professionals have the correct information and contacts to hand.

Work in partnership with agencies and source a list of local interpreters locally so in this way you have a better chance

Have an emergency flexi bank register of people willing and able to attend at short notice

Information should be kept in electronic format even at local sites, so that it can easily be converted to accessible formats on demand. e.g. audio using speech synthesizers, Braille, large print and so on. It should also be ensured that there are staff trained to produce this information quickly and easily, either using local software for personal and sensitive information, or Internet services for public information.

**HOSPITALS/SOCIAL SERVICES SHOULD KEEP A BASE, WITH PATIENTS PERMISSION, WITH CONTACT DETAILS AND SUPPORT NEEDS CLEARLY IDENTIFIED**

The family carer is usually the main point of contact communication support workers should only be used if there is no family involved and as any decision made is challengeable the CSW should be independent from both health and social care.

Arrange system for emergency / out of hours Qualified English/BSL interpreter.

Have information readily to hand - on line and then make sure patients can get to on-line facilities at say a surgery or hospital appointment.

Book BSL interpreters make sure contract provide 24 hour emergency BSL interpreters

Every member of staff should be TRAINED. Communication support is vital.

Contact fire, police or Ambulance

Train staff in communication skills so that each member of staff knows what to do, rather than relying on an expert to arrive and ignoring the person's needs. [...] scheme is very good. Have printed easy-read information available. Ask the person what they need.

With people who r deaf just write it down if there is no impairment of sight

How about having some computed audio request/response or diagrammatic books/texts available with simple things like areas of pain, medications, procedures, surgery, doctor, nurse, clock to show wait times etc. It doesn't have to be rocket science and you certainly CANNOT ever make it work for everyone and shouldn't even try.

Someone at the hospitals should explain to you in emergencies. If a planned appointment, information should be sent with the appointment letter. There should also be a telephone number you can ring to have things explained.

I feel the words CSW are dangerous - this can lead to some abuse by low level signers. There is an excellent agency like [.....] or [.....] who would provide most professional interpreters.

BSL interpreter emergency list (24/7)

Video BSL interpreter

[...] - need BSL interpreter

All of this should be adopted as standard practice.

When any information is provided it should, as standard and at the same time be produced in BSL, Audio and Easyread

If it's an emergency - what are the set questions you would ask a patient? Put them in the above formats

This is really basic stuff I am telling you

Get an interpreter on an emergency call-out. They do them and it is absolutely critical. There have been instances of deaf people undergoing surgery without giving sufficiently informed consent. [...]

Tell them about the main support services at the outset.

Arm them with written information

Make sure that this information and contact numbers are easily accessible on the internet.

SMS them the most important telephone numbers

Make sure that the hospital staff also have this information so that when someone rings in an emergency they can advise what to do.

Make sure everyone in the NHS has a code of communications form with the details of agencies that are used to provide communication support. Also there should be awareness training given to all members of staff bi-annually outlining which organisations are responsible for what. A lot of staff think that BSL falls under a foreign Language agencies remit, which it actually doesn't, because A) BSL is not a foreign Language! B) It is a specialised skill and requires specialist agencies to provide this. The specialised agencies also have emergency numbers for contact so there should be no reason why they cannot be contacted in emergency. It is the procedures at the hospitals and the awareness the staff have or lack of that impedes support!

Understand what Easy Read is and have the tools to do so.

Have a multilingual help line.

Integrating services will clearly help and clearly the ambulance services and paramedic services will have a major part to play in an emergency. Where the outcomes from treatment are understood then forward planning of the persons care/ treatment pathway should be planned before discharge with multi agency involvement when required. Close relatives need to be fully informed and involved to assist in decision making where necessary, they have a role to play in communication support. Multi agencies involved should have an agreed tailored checklist to ensure that the communications necessary for ongoing treatment and care assistance are complete across all agencies and the immediate family of the person concerned.

Keep records - so if someone has told an organisation they are blind etc., this is flagged up on the system!

This is difficult in the global world in which we live. Contacting next of kin is a start because they will have means of communicating with their relative (language, be familiar with their needs etc.). They can then interpret. Failing this, standby interpreters (volunteers if possible) and others who do sign language etc. could be in reserve ready to be called in depending on the patient population of nationalities. If these could form part of a volunteer corps this would mean no costs to the NHS. However the standards of competence of these volunteer interpreters needs verifying.

Have better forward planning. Use hospital passports to clearly identify communication needs. Follow up appointments with confirmed actions. Check with every new point of contact that information is being received in the right format or needs to be adjusted. There also needs to be consideration to have a simple flagging system to identify people with communication needs.

Have technology e.g. tablets and phone network so you can use something like [.....] interpreting service

Use technology like video phones or [.....] to connect to interpreting online services.

Have better trained health and social care professionals, who understand how to communicate with a wider range of people's needs. Then communication support workers would not be needed as often.

Question is too long winded

Firstly make sure you have a record of my needs, then have a record of how those needs can be met.

In an emergency, I want to be helped and quickly, so deal with me first, then organise the support or accessible information as quickly as practical. You may not have a braille printer, but you should have a supplier who can provide a quick service. Then ask me if anything else could mean I can get quicker access, I might be able to use email, or be able to for a short time read large print. An alternative could be provided in the short term while my actual needs are met.

a) Ensure that any 'Agencies' contracted to provide communication support have an 'emergency' procedure in place to allow them to be contacted 'out of normal hours' and to subsequently provide at short notice, the relevant professional ... change the way the Agencies work, put this into 'contracts'.

b) And/or ... ensure that individual organisations have procedures in place to allow them to contact professional communication support workers directly, when the need arises (e.g. in emergencies) or have some on stand-by / call-out rotas / on site.... or use Video telephony for 'live' BSL Interpretation.

c) Ensure that any 'contracted' Agencies are themselves 'deaf aware'.... many agencies are Foreign Language Interpreter providers and have little or no professional experience of dealing with the deaf community or understanding their needs.

d) Be more pro-active re: the provision of communication support rather than being re-active - synchronise appointments (book the communication support at the time of booking the appointment, or book the communication support first).

Keep an 'on-call' list of communication supports available for all practitioners.

pictures and words

- 1) Either have a contract with an agency that really can contact and get interpreters at short notice (spoken language agencies always say they can, but usually can't). Or have an arrangement with local interpreters to contact them directly.
- 2) Have flexible systems that allow an appointment to be booked according to the communication support worker's availability, then booked with the Deaf person.
- 3) Use Video Interpreting in an emergency, whilst waiting for a face to face interpreter

## Appendix 6 – Patients, carers and service users survey, Q13.

**“Is there anything else that we should think about when finding out about people’s information or communication support needs?”**

Ask them

I strongly believe you must immediately provide alternative methods of accessing out of hours GP services and contacting hospitals/surgeries. Far Far too many are phone only

Whether they would prefer a Male or Female Interpreter, whether they have a specific interpreter they require due to many interpreters being the preferred choice of a patient.

I have 2 lady BSL Interpreters that I rely on and who know my full medical history, and when arranging appointments, I always ask for either one, as I do not want to have to explain to the doctor if different from my normal doctor what my issues are and having the Interpreter aware of what has happened can make this a more seamless transition and quicker also.

Just ask in a way that people would understand - it’s about relationships and reaching out

I would prefer to say what my needs are only once and then everyone else should be aware of this

Some people have personal assistants who may provide communication support but may need to be paid by the NHS if it’s an emergency out of hours support

Front line staff should be trained in sighted guiding and be aware of communication needs.

Question of patient needs must be made at GP level and flagged on their computer system to initiate

There is no mention here of peer support or funded advocacy for people with Learning difficulties and others. These again are essential and should be demonstrably independent of health and social care services.

You need to ask if there is a Carer who is the person who knows the patient best and should be consulted

Keep asking us

mental health

Why is this questionnaire so blinking long? I've already answered this :(

don't be afraid to ask and make a mistake in how asked - yes you might get it 'wrong' that's ok as you learn when 'corrected' and not make a patronising response - be open and acknowledge error and thank them for what you have learned from them

and assure them how helpful that has been so you know for future (whatever it is they have corrected you on)

Sometime, people needs more support than just communication supports especially if they have some additional needs such as mental health or learning disability. You should consider allowing a scheme that can support Deaf Health advocacy workers or Deaf relay to ensure the information is fully understood.

Further to my answer above, ensure that any on-line forms are accessible for screen readers

if an appointment is booked over the phone the patient should be asked if they have any additional information needs

Make sure the information is accessed at the earliest point of contact and that the information is then circulated to those who need to know Maybe people could be issued with some type of card so they would just hand that in and a member of staff would be able to access the information they required from the code on the card. In that way there would be no embarrassing explanations in front of other people.

that some people like myself do not just have one disability but a combination of and that forms like this should enable you to choose multiple answers unlike the question on the next page question 17 in which I would have stated 3 or 4 of them

Learn about how people can use existing technology to access electronic information easily and efficiently. It is nonsense to keep on sending letters to blind patients which they cannot read.

Their understanding might be made worse by their worsening health condition

Always ask. Make the range of options clear. If there is a difficulty, ask for expert support which should always be available.

Just how much support the person needs - no assumptions.

Train staff in the issues, just telling them there are issues but not explain what they are is not got diversity and equality training

Stop thinking about it, do it!

Awareness is paramount for the understanding of any disability

If people are deaf, find out which sign language they use. If they need help to learn BSL, arrange classes through local adult education services.

See my comment in no. 12.

And please do be sure to provide the client with information including the name of the BSL interpreter in advance before the appointment. Deaf community is small and they do tend to know interpreters and would have their own preferences for which interpreters. When the BSL interpreters have been booked for me for medical related appointment, I tend to ask them who will be interpreting and I get the same response



which is that they cannot tell me till my arrival for the appointment. I often use interpreters for my work, and I do not want to use the same interpreter for health related information. It can create awkward and embarrassment for both of us.

Ask them!

Visual cues are the best forms of communication.

Just talk to people and respect that we are different. Also remember that needs can change. Sometimes I can cope better than others. For me, a summary letter or email is good. And copy in my parents too so they are aware as they help me a lot.

Yes, every time my father is admitted to hospital I always have to say he is totally blind, quite deaf, has a heart condition, cannot swallow, has kidney failure etc. If this info was marked on his notes in a special box, screen, I would know his needs would be known immediately.

The individual's level of comprehension and understanding.

Good autism awareness among healthcare professionals would greatly help.

An individual with communication support needs should have a passport to hand to a professional who outlines their needs on paper, so that they can just hand it over if they can't communicate or explain their needs at the time. The [...] has a very good example of this for Autistic individuals to use, but the NHS could easily provide GPs and individuals with a standardised communication needs passport.

Some people, particularly older persons, don't want to be a nuisance and may not declare any support needs for this reason.

Patient privacy e.g. taking patient history at night on a ward where everyone can hear! A regular experience for me!

Getting the person to talk at eye level.

Talk / type program that allows the patient to answer the questions and the 'tablet' types in the answers. Modern technology!

Ask the same questions a few days later when the patient is more settled, you would be surprised how answers will change!

Having a single record so that every health organisation doesn't need to ask me again.

Ask the parents and look in the medical notes. Some things are sensory or social, and because of this anxiety alleviating strategies need to be thought of in advance. e.g. in hospital it is noisy, with lots of people, bright lights, having to wait, and scary procedures that are not easy to understand.

Just ask that question to me not third parties or letters

why not record it on the system so you don't have to ask every time as it is tiring

Always ask what suits the individual best in each circumstance. A sign language interpreter may be required for an important consultation but writing manually or electronically may be sufficient in a routine appointment. A blind person may require an electronic transcript of drug information, but they shouldn't need this for each repeat prescription.

Find what situation fits what

Asking the patient what they want!! We are human, talk to us not about us.

GP's should inform the service they are referring you to, i.e. when requesting x-rays, outpatients, physio etc. Your appointment letter could ask the question re additional comm. needs. The patient could then inform the service prior to the appointment.

Support needs are clearly marked in patient records and acted upon.

Getting health information and appointment letters in accessible formats has been a struggle despite the DDA and the equality act. The NHS must get to grips with this through this initiative to stop stakeholders from sensing an exercise that really won't produce the results so badly needed.

Always ask the patient first, do not assume!

Ensure all professionals involved are aware of their preferred format at all times and inform patient that an interpreter has been booked (qualified and use the NCRPD yellow card) and provide the name of the interpreter with a photo to identify them on arrival.

Consider the needs of the person you're treating (not rocket science, but rarely taken account of).

Whether or not patient feel comfortable having family members present, or whether they want a family member present for support when discussions are taking place. Privacy of the individual should always be a consideration too.

Surveys like this should be in EasyRead.

Language that health professionals use is quite confusing and is not explained properly for people with learning difficulties.

RFID tags can have sufficient memory to carry information such as recent medical history, medication and support needs, social care plans etc. This information can be encrypted and used across the medical, social care spectrum and be downloaded to hospital mainframe systems, GP systems and social care systems. The cost is relatively low and communication issues would be largely overcome especially in emergency situations.

People have the full functionality to engage in their Financial health through online information, and many do so. There is, however, no functionality for people to engage in their physical health as all of the information is kept secret, and no personal data/information is available online. Why?

Ensure that Carers & families are included in providing this information. A person with very complex needs may only respond to 1 person at a time using a certain tone of voice or they might get anxious if the person is dressed in a certain way. The key thing is to try and get this information prior to appointments/admission to hospital/seeing specialists etc.

Just don't treat those who need such support as being [...], or shout at them! It happens all the time and despite being a professional I am often spoken to as if I am [...]!

Privacy. A person should not have to explain their needs in a crowded waiting room or in an area where they are interrupted by other staff or patients/clients.

Use sensible language - don't access things - use them!!

Make sure that everyone who is going to deal with you know about your condition and what the best way to help is

Make sure they have access 24/7 to their chosen line of communication i.e. a person may give an email address or mobile number but these may be work numbers only available during working hours. In addition make sure messages are left on answerphones where possible most people do pick up their messages.

medical record

I am not aware of all needs, and realise there must be many areas I have not covered!

help the person to be learning easy ways of understanding to develop communications.

Bear in mind that some people may have multiple disabilities.

Don't leave it to the last minute

Check whether any information given has been heard - consider offering to write down any information as well as giving it verbally as a backup.

There are BSL interpreter online like [...], so we can use any mobile, [...], computer webcam so we can sign through BSL interpreter online 24 hours and seven days so we can access easy.

at the moment [...] only used Monday to Friday 9am to 5pm ! Also we can't afford online sign language so expensive £3 per minute !!!

Often I see there isn't anything on the front of the person's medical notes about their disabilities. Doctors/nurses need to be trained, for example looking at patients ears to see if they wear hearing aids not always necessary in both ears, some only wear one.

How individual these needs would be, don't assume it will be a one cuts all.

I feel once a patient has their first appt, ask them if they need support and to automatically book them for every appt.

NHS systems and structure are designed around a single type of patient. White male in good health, basic education and speaks English with a single illness or condition. This model has been invalid for a number of decades so it's about time the NHS changed some of its models were used by my great grandfather when he came back from the Boer war

listen to what they say

Often the information provided for service users who don't need additional support is badly written, highly clinical and/or patronising and rarely better than a F2F conversation. Trying to isolate people's information needs away from their communication support needs is actually a different project entirely.

Their health condition for example mental illness

The information, once communicated to the GP surgery, social services, NHS out-patient / in-patient services should be readily and instantly available near the very beginning of patient information. For example, immediately after a patient's name, because this information is far more important and relevant than address or telephone number or NHS number.

You should look at how you communicate with carers and relatives. I expect you to tell my daughters everything so they can remind me, but this does not always happen.

Information and online access for patients to their own GP records and other social care records should be a basic element within the communication strategy. Essential for patient safety!

Keep an open mind and stop making assumptions about age, gender, education levels etc... Simply ask the patient what difficulties they have encountered in medical situations.

Specifically ask autistic people as our needs are specific.

Data protection and patient confidentiality are in place to protect the most vulnerable, however these can be detrimental to establishing patient problems.

Patient health records should have named advocates on file with the approval of the patient.

People's lives and circumstances can change - so e.g. they may require large print text at first, but then need Audio as sight deteriorates (just an example).

All receptionists and front line staff should have compulsory deaf awareness.

Records should have communication preferences on the front!!

Needs can change over time, so people should be asked about it regularly.

It's very important that needs are recorded accurately and that information used appropriately. For example, I need a deafblind manual interpreter, it is a total waste of time and money if a BSL interpreter is booked instead.

Sighted guiding requirements are often ignored and staff don't have the confidence or skills to offer practical assistance.

Keep checking with the service user that they really understand things. People often cover up their lack of understanding so they can bring the situation to an end. I appreciate that not all staff can be specialists in this area but any recruitment process should reflect the skills required.

ask

How they want to be supported and will longer appointments be available to accommodate needs

If they will be able to/feel comfortable in telling this information

Talk to them

Do individuals typically use resources like symbols or [...] to help them with communication?

What a person issues were say a year ago may change later so maybe just ask every so often has something changed

stop sending incomprehensible letters from social services out to people with recognised and known learning difficulties - it's crazy - even people with no problems can't understand their letters - they make NO sense

If someone is known to social services it is because they meet Fair Access to Care criteria and as such will have had a needs assessment. Right at the start of this process is where the discussion should be had about how I want people in NHS and social care to communicate with me and it should be documented in the assessment documents (Universal Assessment, for example). I might say I want my Mum included in everything or if she isn't around, my Dad, or someone close to me who knows me very well, but at least it is recorded as my wishes.

Everything

Some care companies open people's mail without the client knowing so a big TO BE OPENED BY THE ADDRESSE ONLY should be on the front

Preferred language? People who are unwell can be rather confused and so need something easily understood. Yes, their families and carers are usually present at appointments. In situations where these support mechanisms cannot be present, then arrangements can be made by the hospital to accommodate.

Text message sent to hospital before arrival so support can be waiting, lots of hearing loss people myself included can't find work so the hospital could do a paid buddy service

People who can be contacted in an emergency.

Ensuring that regular checks are made to ensure long term support is in place and also ensure that people are made aware in advance of the support network available to them should they need it - appropriate literature kept up to date in hospitals clinics GP surgeries etc.

The first step is actually asking - which I wasn't. Why aren't standard leaflets given out at appointments when your deafness is confirmed. This would have helped me greatly. I have found all my info on the [...] website - which I found myself - again I wasn't even told it existed. The NHS staff work with these issues everyday- do they not realise how this affects young, middle aged people.

I think there needs to be a media campaign about what communication support IS (e.g. STTR, electronic note-taking). Most people wouldn't have a clue what it is, that it exists, that it's available for medical appointments - or how they would benefit from it. A short video explaining it or a feature on something like [...] would do wonders for raising people's awareness.

It should be made 'front of mind' not just for the person concerned, but for any dependants they may have - my children help me greatly but they should not be depended on in times of need.

No. But always use fully qualified interpreters.

As above - make sure those who need access to it can get it, so I don't have to keep answering the same question. I have had to tell 4 different receptionists at my GP's that I am deaf. I often have to tell the same person the same thing as they don't remember. It shouldn't be down to me to tell people in my GP practice all the time, they should be able to record that.

Liaise with [...] on communications guidance for people with ASD.

Ask the patient. Do not assume anything.

Ask all appropriate searching questions

Probably but not enough space here.

Key allies to recruit will be Leaders and info designers who do not have this mind-set at present.

Yes, you should always find out what people want to be called when people speak to them. E.g., does Mrs Neeta Patel want to be called Mrs Patel, Neeta, Neet, or some nickname? This is basic to respecting people as individuals and should always be one of the early questions asked.

yes make sure the staff are deaf aware!!

NEVER assume anything always ask

People are unsure if they need help or plans can change in regards to someone attending with the patient. People may be unaware what help can be provided.

Do their facial expressions match their emotions? If not, great care needs to be taken when interpreting 'wishes'

do they have more difficulty talking/seeing when they are stressed ? (i.e. do they need extra time?)

People want to know every aspect of their treatment and illnesses so as much information should be available as possible, specialist units should have leaflets on their particular specialities in larger print available and plenty of leaflets on support groups and help available maybe every appointment letter should have a specialist phone number to call to help people organise support

Patience and awareness that a patient may not necessarily be uncooperative but may not understand the procedure as they may not have heard/seen or understand the process.

when falling ill difficult to express symptoms when struggling to hear

Only if NHS use an in-house pool of highly qualified interpreters, it may address the lack of communication access for BSL users at short notice.

More interaction between NHS data bases e.g. consultants and GPs.

Voice activated computers would help people who can't write.

Yes I think telephone translation services are good and can be used in the majority of occasions for routine style appointments but a friend told me that in [...] if the GP has to tell someone bad news it is done over the phone!! I don't think this is acceptable. Please rethink this!!

As far as deaf people as concerned, it really is a case of individual needs and preferences - each of us are different.

Not everybody is the same - so don't generalise people. For example I am profoundly deaf, I cannot use sign language I rely on lip reading. Shouting and raising your voice does not work for me, it is clarity and making sure you face me that works. So in general training is needed to make people aware that not everybody is the same.

GP surgeries need to be more accessible by allowing deaf patients to have the option of using email, text or online booking forms to make appointments. Same with A&E I cannot call for an ambulance or the emergency services, so a system is needed for this i.e. [...] (that allows you to contact emergency services in real time messaging like [...] for those with disabilities but only give it to those who are registered with a PIN number so it is not abused.

Be sensitive, many people struggle to come to terms with the things they need help with and being made to feel so different from other people doesn't help and may even stop them for asking for help.

Keep an identifier on peoples files so that all staff are aware of what each person's needs are. This should be done in a way that does not affect people's privacy.

Don't make assumptions. I have friends with little or no vision who still prefer to use a magnifier device, but I also have friends who have slightly more vision who read Braille, it's down to the individual and what helps them best.

Often the actual appointment system in a waiting room is badly flawed, e.g. a patient having to be able to see instructions on a wall, take a ticket and wait for their name/number to be flashed on a wall screen. A visually impaired patient is not able to use such a system, but it is very common in health care. Also, information is provided as posters/leaflets which many patients may not be able to read.

Make sure it is appropriate. Make you there is a good range. Make sure you have a good relationship either with your own accessibility department or third-party provider. Make sure that staff know the terminology.

The latest fad seems to be that after an appointment letter hospitals / dentists send out text reminders ..... but why so many duplications? I have received two or three text reminders or phone calls on numerous occasions for the same appointment. I would like to add that I am fully compos mentis and never miss appointments so there is no medical need for this. The cost when multiplied tens of thousands of times must be enormous without even thinking about admin workers

No, just be proactive and allow the people to guide you on their needs. However some late deafened people who never used any support before since they were hearing need your guidance in what is available. Information in text, electronically will make them realise that this support is available.

Once NHS is aware of a patient that has communication needs, it should be reported and by practice communication support is booked as standard instead of waiting for the patient to ask. Some deaf people have another additional disabilities or lack the confidence to ask for one will not asked. Staff should and must recognise that if the person is using BSL an interpreter is booked asap.

The information should be on a person's records

Just ask!

anything a person is allergic to

Language

People's dignity, it is lovely to be asked if you need another format or assistance but not treated as if you are a child

Extend it to mobility needs, getting into and around the hospital is often the biggest barrier and hospital transport not always suitable or available

confidential and trust. to own support they prefer



At the time of any admission, all these needs should be established and shown on the records displayed with the patient, not just on computer records.

On form to say Deaf, Deaf/Blind, that we can apply to tick which one and also tick for need interpreter (BSL). It is very rare to see on the form about who I am. It is useful for professional and a person who responsible booking to know who I am and what I need when got an appointment to be prepare for. on the appointment letter need to be said that completed to booked an interpreter that we will know as often on appointment letter never said as I had to phoned to check whether they have booked an interpreter or not.

keeping language simple

privacy and dignity

What kind of communication back up they have in their home environment - could be useful

What is best for the individual to help communication. I.e. for me it would be that people should be on my right side and that I can see their lips (I lip read a bit)

Whether they would like someone to hold their hand if they are being told bad news or if having a procedure done.

Not Formal. People don't like admitting they are deaf

Assessing their needs.

Asking them directly

many people have carers and they sometimes know better than the patient

Ask them to rank understanding of pictorial/verbal/multi choice tick box type questionnaires. Could be as part of initial consultation as a new patient at surgery/hospital. Part of Patient Passport???

When you find out about people information for example in this case you find out about the patient's information, under the law the patient have the right to access their information file such as medical history with the doctor and British Sign Language interpreter if the patient's deaf over 16 years.

You should also think about religious and cultural beliefs.

What's wrong with using VRS - for NHS England to commission - GPs appointments. All GPs have computers accessing internet, VRS. Much cheaper than booking an interpreter who normally charges 3 hours fee plus travel costs. If in-depth consultation, treatment etc., yes we need BSL interpreter to be there, VRS cannot do that. Please accept this is 21st century technology!

Deaf as well deafblind people.

The person may be unconscious or otherwise unable to speak or communicate when in an emergency situation.

We need to be aware of Data Protection Issues at all times.

Being respectful of privacy

Their mobility problems may also have a bearing on their requirements.

see Q10 [...]

It is important for Health and Care professionals to understand Disability and whether they should communicate with the Patient/Client or with the Carer/Support Worker or both.

All GPs and hospitals should allow booking appointments via emails, text messages or an online booking system. Making a phone call is not accessible for deaf people.

Must provide the qualification with NRCDP card with qualification of British sign language interpreter not use communication support

Take more time and wait for a reply then confirm that is what they meant.

Don't assume that a person only has one difficulty. It is just as likely that a person will have (for example) a receptive language problem and a fatigue syndrome that makes concentrating difficult, especially in a stressful situation.

Some needs aren't obvious or particularly well understood. Some organisations and people are really very good at dealing with hidden difficulties, others don't understand them at all or dismiss them as new-fangled nonsense.

Identifying a single point of contact for each person

A health/medical alert should automatically come up when you contact any NHS service detailing your needs it should be on the front of notes as a reminder so it is the first thing the Dr etc. sees. It is very frustrating having to go through the whole thing each time.

People's sensibilities and fears

The people around them that they need to share information with.

Many websites and publications are poor for people with visual impairments - too cluttered, bad contrast and fonts etc. You can't find out information if people are unable to read the information, and not everyone with a visual impairment uses braille.

not from my perspective

Always ask 'open' questions -what is your name? where? who? what/ etc. to get definite replies as we will nod our head and say yes to anything as we don't understand

Please say you will get an interpreter if we ask for one -

Yes you only need to know what communication support or format they need. You don't need their impairment etc.

My own experience is that had I not had a caring family to support me I would have or would be in a sorry mess using the phone is my biggest issue following losing my hearing. I think it is essential that people with sudden hearing demise are supported. I am supported, however someone living alone manages I dread to think.

When book an appointment should ALERT system of our communication needs' and our preferred interpreter names to match our communication method on all systems for NHS doctors hospital dentist all so have that front page before enter to save time and make sure we get the right access and format in the first place.

Be aware that a person's situation may change due to age or illness and/or presenting condition.

clinical support and other social care/health professionals should find out if there are any campaigning groups for adults falling into vulnerable groups including people with disabilities, mental health problems and learning difficulties

-It should be left to the receptionist to decide who can have communication needs.

Ask the people who use services and who have problems

Yes, awareness training for staff. I just spent an hour with an audiologist getting new hearing aids because I can't hear on the phone any more. She then asked me to ring up to make another appointment. Err hello, didn't she hear a word I said??? She didn't even realise or comprehend that she'd totally missed the point of the whole conversation! If audiologists don't get it right, what chance do we have with other NHS staff??

Preferred method of contact would be good with opportunity to be contacted via email or sms text, if this is possible. Online access to information regarding results or advice given for all health information in an easy to follow format.

[...] facial expression does vary/ the way we put words together, etc.

keep it simple.

Lip reading I rarely thought about but can be important for people who rely on it so it is important that they can see the shaping of the mouth clearly.

Yes, have them stop assuming that because one is over fifty years of age and has a hearing impairment that one has retired and does not work.

Again pre appointment form would rectify this problem.

If the client is on email and provides their address when the appointment is being organised then the service would be able to send messages.

I think I have covered this in Q.12

Contacting [...] to obtain copies of the card that can then be slotted inside the notes so that everyone who looks after you are able to meet your needs

Ask the NHS to ask patients if they wish a sticker to be on patients notes

Have a flag against patients electronic notes which then displays the information for the user

Privacy when asking, and when giving this support.

HAVE MORE ORGANISATIONS AND PEOPLE NETWORKS RUNNING AND DEAF CLUBS FOR NOT JUST ELDERLY BUT FOR YOUNGER PEOPLE SAY 20 YEAR OLDS TO 40S A LOT THAT IVE SEEN AROUND DONOT HAVE YOUNG ADULTS IT SEEMS TO ME THEY ARE FORGETTING THAT DEAFNESS / BLINDNESS IS NOT JUST ABOUT THE OLD IT CAN HAPPEN ANY AGE. IM 42 AND IVE BEEN HARD OF HEARING FOR 10 YEARS.

All agencies should have a list of people who may need support

Yes more needs to be done for the people with dementia and more training needs to be done with staff

It should always be in large letters on one's notes that help will be required either in written form or by careful lip speaking.

Anyone trained in providing customer service will ask the question: "Is there anything else I can help you with today?"

Ask me will I need help and what kind of help I will need.

Treat everybody as though they might need extra help.

constant reminders perhaps in staff training

If deaf need interpreter should write on file

This is a difficult questionnaire. it is too general in context.

All information should be clear and everybody concerned such as family should be aware of the situation.

Free flow between service users

patients who require e.g. lip speaker or BSL interpreter should be able to request that NHS pays for one of their choice, since it is important that patient is familiar and comfortable with the support worker in these circumstances

Not everyone has a computer...

put it on patient records, so that an alert flashes up

Make sure people are empathetic when finding out people's needs.

Contact for regular assessments

That the person's dignity is respected and that confidentiality procedures apply to prevent any embarrassment to the person.

We need more local information. I have no idea what is available locally.

Yes - you are not going to get it right every time. [...]

just listen properly and try to understand

I SAID before BSL video, fed up always braille or foreign language, never BSL

That the information is up to date as possible

yes elderly people re independent and will not always ask for help so you could use other services to help, people are house bound and would trust there care worker or meals on wheels who could do you survey face to face to find out what they need and so use dial a ride to be taken out to a club run by [...].

Just checking with the person if the info can be shared. It would be annoying if you were asked every time. I can sometimes go to the hospital every few weeks.

maybe the folders with patients note could be different colours for people with hearing difficulties or sight problems. That would make it easy for the staff to identify straight away.

Why not try giving out leaflets that people can respond to when they attend Hospital, GP, etc. They can be given the information at the end of their appointments and fill the leaflets in if relevant, either at home, or, whilst still in the premises.

Some people will not want to give you contact details. We have to ensure they understand why we want them and, if necessary, how they are stored confidentially.

I really think that deaf people are not understood. It may be tedious having to say the same thing 3 times, but believe me it's even more tedious having to hear it 3 times and not be able to make out the words. I am fortunate I can still talk, so I don't use BSL, or a textphone - whatever that is - but surely written questions and/or e-mail are not out of the question?

ask carers about the needs of the person they care for. Unpaid Carers are the forgotten two thirds of the health service - yes, that's right, two thirds. Isn't it shameful how they are treated? I am an unpaid carer - and some (Male) doctors actually have deliberately excluded me from the consulting room when my husband's treatment has been discussed. And I had to do all the complicated aftercare!

[...]

Not everyone feels comfortable admitting to a disability particularly if it has been acquired recently or at a young age. Don't put people on the spot by asking them questions in front of friends or other members of the public.

BSL interpreter from a trusted agency led by deaf people themselves

On first timers, find out what their communication needs and put it on the database. questionnaires.

Speak to my mum, keyworker or support staff.

Be patient and considerate. Do not look cross when we ask for help. We are not deaf deliberately just to annoy you! Do not condescend

all information should be gathered at the registration with GP, Hospital and community support. Regular updates should be carried out annually.

if not from peoples records friends or family to ascertain the information as sometimes the patient is not always willing to admit they have a problem or need

Make sure you book support for the deaf person and let them know about it!

Make sure all staff have deaf awareness and stop treating deaf people like second class citizens with no access or support.

NHS social workers need training on how to care for deaf OAP in their own homes when released from hospital. NHS Social Worker attitude appalling from certain hospitals/boroughs

Make sure front line staff know how to approach & welcome people, with a smile & a give the person time & attention, not rushed or indifference.

Perhaps it would be possible to have details of friends/relatives who could pick up information and take it to those in need.

I see Applications are the best way otherwise you could have hospital website especially for communication support for patients.

Do not assume the next worker will know about the problems. Share information.

Offer this support, don't hide it. Be transparent.

The initiator of the request for an interpreter should come from the health professional and not the deaf person. It is the professionals' responsibility to make sure their service is accessible and not my responsibility to remind you. I don't need to remind you to provide toilets for women, a pair of stairs or directions to premises, why do I have to remind you to book a sign language interpreter.

It's important to make sure whether we would prefer to have a female or male interpreter for any health appointments. Note this in the records for future info.

It would be very helpful to stick to the same interpreters throughout my specific serious or life threatening health issue. This way, the interpreter will understand the background of my health and it would enable a clear communication, also will help me to focus on my health rather than having to try to understand the interpreter that I have never or rarely met.

Ask directly if they need BSL support. in letters (appointments etc.)

Apart from asking the patient or their supporter I am not aware of any other ways to find out information.

If Braille is requested, then does the individual require grade 1 or grade 2 Braille.

Don't miss out people like me, look ok but find it really hard to communicate

Computer systems should be FLAGGED so if a person is vision impaired it comes up for ALL staff.

Don't make assumptions. Not all deaf people sign. Not all blind people use braille. Ask more open questions. Have a broad range of support offered. Think about what can be done as well as communications support e.g. private consulting rooms for deaf/HH people who can't hear over other conversations. Double appointments so staff can speak slower and take more time and be patient with anyone who may have more needs. Encourage staff to not be impatient.

Think about how this information is stored, ideally it would be a once for all NHS services thing with occasional review to check it is accurate and allow people to change the info.

People need to know who can access this and indeed that if it is intended to be widely used that it is widely used. I know many blind/deaf people who in hospital had "X is blind" "Y is deaf" on a sign by their bed which was not read properly by staff or accounted for. Staff need to know what to do with this kind of information. Consistency of staff where possible is vital and helps disabled people.

[...]

YES,....HOW FRIGHTENING IT CAN BE, IF FOR SOME REASON YOU CAN'T UNDERSTAND WHAT'S HAPPENING, BECAUSE A DISABILITY HAS IMPAIRED YOUR ABILITY TO COMMUNICATE WITH OTHERS....

Bear in mind that many people will need communication assistance right at the beginning (i.e. when you are asking them what communication assistance they need).

Staff attitudes. It is unhelpful when staff are visibly panicked at the thought of communicating with Deaf people.

Provide annual deaf equality training for NHS staff to improve their attitudes or face lawsuits from deaf people cos they breach the deaf people's human rights!

What support network do they have in place? Do they have a close friend or family member that can help.

All patients recorded by GP's of patients with Hearing problems should be automatically sent to Audiology/ Consultants and not given steroid tablets

Information to be writing down on the patient's file for the future use.

Any draft proposals should be widely circulated and Medical Staff aware of the patients' needs without constant repetition of ones sensory problems.

Just ensuring that the person has understood what has been said to them by checking with them or asking them to feed back to you what they think they have been told

they might be embarrassed. They might not realise that they have a hearing difficulty or poor eye sight.

Allowing time for it where possible. I am always taken by a nurse to the appointment room to see my consultant neurologist - this would be an ideal time for the support needs question to be asked and then the doctor could be aware/change the room set-up so it was helpful/best supported my needs and enabled me to understand by maximising what I could see.

Communication is always difficult

it is important that patience is used or we tend to clam up! we don't want to be a nuisance or appear stupid.

Every region has different sign language like accent - should use two fully qualified Level 6 NRCPD interpreters, male or female who lives in area.

Cultural and religious belief will have an impact on the responses.

A note on front of the file would be useful as Drs don't always read patients notes

Use Interpreters from the beginning, if you hold feedback or consultation sessions, make sure you invite people in appropriate ways - get charities and support workers on-board.

Makes sure that you are aware that that person need a communication support. The information given should not mention hearing impaired. Should say Deaf or Hard of Hearing. Deaf with BSL.

Can problems read

Text

How every individual wishes to be supported by obtaining clear information and instructions from patients.

Not to assume that people understand



Offer presentations of this facility through local deaf organisations and provide SUITABLE FORMATS i.e. BSL DVDs

Ask them what they prefer and don't assume you know

The NHS need to improve and more accessible for deaf people to watch the video with BSL Interpreter and subtitles on the website

Giving people time to communicate. People might be stressed or could be autistic and need to have time to process information.

Most big organisations have a single phone number to telephone to get information in accessible formats but in the NHS you have to inform every different department which can mean informing many different people so lots of phone calls.

When you ask questions, then LISTEN and act upon the request, don't make assumptions.

Things change. Be aware of changing needs – [...], the woman whose hearing loss gets worse.

Remember that people are very proud. Being asked directly whether they want an interpreter usually meets with a 'no' because they can cope in English. They can tell the time, pass the time of day and ask for goods in a shop - this is a world away from being told you have cancer, that you need an operation or that your child is disabled. The skill is in knowing that a patient needs help when they have not yet realised it.

This involves training staff to be aware of needs. It involves a more personal approach.

Make sure that you ask them what support they would like am severely deaf but a sign language interpreter would be no good for me. I need a speech to text typist. I have heard of deaf people being provided with a sign language interpreter although they do not use sign language.

Elderly / vulnerable people, people who have difficulty communicating in general and individuals with mental health issues. In a busy environment they are not always the priority.

Privacy! Don't ask me if I can read or write when others can hear my reply!

It is a matter of finding out from each individual person what their needs are and to find out if they require information in an alternative format and what format in which they require any such information. It is also a matter of treating each person as an individual and as an equal with all members of society, and not treating people who need extra assistance and support as second-class citizens. We are all human beings at the end of the day and need to be treated as such.

Needs may change and should be regularly updated.

Letting them talk about the many times they have been made to feel inadequate due to the bad deaf awareness issue in the NHS

Care must be taken to ensure separation of private and public information. When sensitive, personal information is converted to accessible forms, it must be done securely.

#### WHETHER OR NOT THE PATIENT IS HAPPY TO GIVE THIS INFORMATION

Yes one should check if there are outstanding support issues such as provision of communication aids

Respect that individuals have individual preferences.

Never assume.

Improve patient booking system so that communication preferences are flagged up on the 1st screen accessed.

Suggest that they bring someone with them (a friend or family member) who can help them. Make sure that this is clearly stated in communications and said in a friendly manner so that the NHS welcomes people who can support you.

it should be filed on the system of their preferred communication methods

Everyone is different. Staff should be TRAINED.

May sure that you are not in a hurry

Ask, but do this in private.

I like to be enabled to be as normal as possible and you just ask a doctor to come get you instead of tannoy systems and they can't do that.

Use the current patient support groups/volunteers to go around asking patients while they are delivering or visiting (how easy is that?)

Do they need a carer with them?

Bring in a Deaf consultant! Do a road show to explain to Deaf communities - bring in a Deaf person to do this.

all deaf have different communication needs

need to ask what communication they want

Just ask them what works for them and what makes them feel comfortable

I am happy to meet with you to discuss this in more detail if it would help.

Yes, this questionnaire should also be offered in a BSL format also! There are people out there who have been prevented from doing this questionnaire because it is not in the appropriate format. Ironically!

Check what medications they have had with GP, Pharmacy, clinics, carers.

Some people are very timid when communicating with public agencies and may require support from a family member or from their regular carer when meetings take place face to face. This support approach should be encouraged where important treatment/care options are being discussed providing the patient is happy with such arrangements.

You will need to be patient and resourceful - the whole point is that these people are finding it difficult to communicate.

Ensure that carers have an input as they often, can help with this. Don't turn it into a process driven exercise - people are individuals. Be aware that communication is more than what is being said, it includes how it is said and by whom. Some people with LD who have had a bad experience of hospitals get extremely anxious around anyone in a white coat, so they would not be receptive to receiving any information from someone so attired. There needs to be more focus on preparing for giving information.

How you find out- if people get asked e.g. by letter they might usually distrust an NHS letter or be worried

Ask Deaf people and trial. Don't let hearing people read these results and decide for us.

Listen to the friend/supporter/family member with the patient if the patient wants them there.

We are all different, make no presumptions. I would rather be asked to clarify what I need and have to take longer to explain, than quickly receive the wrong interpreter or a document I can't access.

- a) Let the general public know that communication support is available – many deaf / deafened people are afraid to ask for support because they are not aware that it will be provided free and it's their right to have it provided.
- b) Advertise that communication support is available ('deaf friendly' posters near reception areas, within clinics, etc.)
- c) Remember that 'one size doesn't fit all' - everyone's needs are different, especially regarding deafness and support.

time a ten minute appointment is no good

Ask, make it clear that Registered interpreters will be used, always confirm that they have been booked (otherwise Deaf people believe they haven't been due to previous experience), provide the interpreters name if possible, to avoid embarrassment (as it is a small community).

What about safety and making sure people are safe? Speak to friends and people that care about me. Speak to my support workers.

There are in house employees for bereavement, welfare and other pastoral care – so there should be a system for communication support too. There are, officially, TEN MILLION people with hearing loss in UK a big figure impossible to ignore?

Please remember that information and communication is power. If you don't provide info and communication in accessible formats and systems, you are demanding that people who can't read or communicate have to ask someone else to help who may not be a professional. This will violate privacy. Every time a hospital or doctor writes to me, I have to ask someone to read it to me, thus exposing private information that I may not want anyone else other than the health professional concerned and myself to know. This infringes my human rights as a blind person.

Staff should treat people as individuals with dignity and respect and allow them time to consider the implications of the situation

Set up workshop in deaf club and or set up meeting on NHS hospital to invite deaf and others kinds of disabilities people to feedback to meeting.

Health and social care organisations should already have records of their patients and clients, so they should already know whether someone is blind, deaf, has learning difficulties, etc. This should mean that these organisations will be able to provide information in formats which are accessible.

I want all doctors, hospitals to know how to use BSL. I need that. Their level of BSL skills need to be high not low, otherwise it becomes frustrating for me. If they all can sign well and fluently in BSL, then it is pure BSL. They need to match that.

It would be useful to have a flag system set up in your computer database for when you open up our file and this will notify the receptionist or other professionals of our disability, health condition and prompt them of our disability, preferred method of communication, list of our preferred interpreters with their contact details, also useful tool to prompt the receptionist to book interpreters. This could be useful for sharing the summary care record.

Same as 12, but if I have some resources like a DVD with visual information rather than a book with formal English this would be more accessible.

More appropriate consultation with me and support that know me well.

The staff are proud of me. They can support me with problems.

Give me time to process information.

Ask me and I will tell you.

To contact my mum, carer or my outreach staff.

To communicate with my parents and support workers.

I feel have I no more suggestions at this point as I have already mentioned them above.

Interpreter should know what I need in terms of my communication level e.g. slow, fast or simple or breakdown.

I regularly go to the dentists and opticians. I want the staff to know how to sign, so that an emergency interpreter is not needed.

If they provide information, I don't want it in English format. I want it in BSL. I want the English to be translated to BSL.

In addition to question 12, while I am having physiotherapy for my knees and being massaged, I would love to ask questions, such as why this part of the knee is massaged that way etc. It would be nice have an interpreter there, or via a video link, it would make my visit more comfy. I would feel good when receiving answers to my questions for my health and wellbeing. It would be brilliant to see it everywhere.

contact our providers, carers or support workers

NHS should make a note that I am Deaf, that I need an interpreter and make sure that the interpreter is present.

Most resources should mention that BSL is available. Also please avoid using the term "Hearing Impaired". It's very offensive. We should use Deaf and Hard of Hearing. [...] I am always a Deaf person, I was born Deaf so that's who I am. It may appear too politically correct, well, it isn't! [...]

Hearing people have phone calls, but deaf people need live web chat instead

think about the words you are using - don't use very long words or jargon or v long sentences

communication needs and health needs

it's not a problem the communication because I have support workers who help me by communicating with the GPs

feedback forms from the doctors if I have a health appt which I attend without support so I can take it back and give to my support networks to let them know what has happened and any actions required

take time, speak slowly, use pictures, be able to read some information about my communication needs on my records

I respond well to habitual forms of communication. Use a proven / successful channel as often as possible

ensure health professionals ask

use [...] support services

the NHS should have more information available and speech therapy services

make use of communications support services

services to be all able to access this info

make use of support information

the [...] run communications support groups across the north west. Referrals need to be made to the [...] to help with support needs

the [...] needs to be more advertised in the NHS about the services which they run

contact sign language agency by internet – [...], [...], freelance interpreter locally

I think about to find out a GP doctor

look at communications passports / yellow health books

talk to us and our support - talk to me first not my support - it's like I am invisible

talk to [...], favours key worker, hospital passport

this question was difficult to answer

the need of the doctor to communicate with you

doctor takes their time

you should make sure the ambulance people look first, then I go to the hospital to find out more

less jargon and more plain English, more patience required by staff on surgery reception when explaining lots of info

to explain more when they send a letter, rather than a lot of jargon, which I can't understand

make absolutely sure that the carers or support workers have the telephone number to communicate

Note takers or verbal interpreters would be valuable in those situations where I cannot hear key points of what the professional is saying. I am not a BSL user incidentally.

do not use jargon

hospitals should check peoples records in advance

everyone is an individual - do not treat everybody the same

try to see the patient as another person not just another body

the communications support should be a high standard

check if person has a communication passport

make life easy for my full time carer please

use trained staff

waiting times are too long. Trained staff

the support worker should learn not to speak on behalf of the patient unless asked to do so. Get communications support to say slow down

work with community nurses

checking out if you need it to be explained again, or if you want more detail or help with the problem

waiting times are too long

staff ready. Trained staff

I need BSL interpreter to support me at wellbeing centres

to find communications support workers in a few days' time receptionist at hospital should ask everyone that need an interpreter because can't speak or hear

having people available to help me understand info

the environment where you ask it e.g. my GP's reception has a radio so other people can't hear your business- but it means I can't hear my own business !

info should be provided when people register with a service and should not be necessary to keep repeating the info - it should be on their NHS card

when info is given how do you assess that the patient has understood? They will always say yes if you just ask "have you understood that?"

so long as I have someone to be with me I am fine

all people involved in my care have access to same info

using groups to discuss things

To communicate with my partners and support workers

more appropriate consultation with me and support that know me well

the staff support me with my problems

ask me

contact my mum, carer, or outreach staff

It might be useful if the person's needs is highlighted in their records or if the receptionist is aware of their needs. In a deaf person's case, it would be excellent if the person is instantly provided with an interpreter for their appointment without having to ask repetitively or reminding the hospital/GP surgery every time. It would work if the person's needs automatically come up next to their name

It is important to remember that privacy is also essential when discussing what alternative formats the patients require to support their health needs

The communication/information needs of a spouse, partner, next of kin, person responsible for the patient's care at home

Whenever I meet people providing social care I need them to speak up - because I prefer face to face.



## Appendix 7 – Patients, carers and service users survey, Q14.

**“Is there anything else that we should think about when recording or sharing information about people’s information or communication support needs?”**

make sure everyone knows before I go to hospital

Ask the Person first whether you can share this with a specific organisation, I certainly don't want my details shared with the "[...] BSL Translations Agencies" I've come across.

Can we not have a sticker on notes so health pros know someone needs alternative formats?

don't hide behind data protection - it is annoying to keep on having to explain

With the NHS system in place. Communication needs should be up there next to where allergies are. So you see the information quickly.

Always have a note on NHS systems that alerts everyone looking at a patients record that they are deaf or have learning disability

Far greater emphasis should be placed upon promoting the proactive use of electronic communication with patients and members of the public.

It is essential that people are made fully aware of when and what are being recorded and should be able to check this to check it is correct. Also ANY sharing should only be done IF the patient and /or Carer agrees.

Keep us informed

"Ask" as this is important information you have given to me about your communication support are you happy for me to make highlighted note of this on your record to share with any staff and services who you will be seeing you?" explain to them it will help them not having to keep repeat themselves. Assure them it remains only for their benefit and the main problem here is that how those notes/records are shared - the next member of staff often doesn't read this information and that's the frustration - consent is given to share but staff don't read!!!

We should have an IT system where all NHS system can recognise deaf people's access needs on database and can recorded details such as preferred interpreters, communication methods and others etc. Attached should be some web-link to further deaf awareness online package for staffs who would like to know more about working with deaf patients.

Ensure confidentiality is maintained as much as possible

ensure that it is on a central database and require all organisations to adhere to the database

it would be useful if support needs are shared when a referral is made. For instance if a GP refers a patient with a known support need to another organisation, or indeed

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within the NHS, any needs should be passed on to make the process as easy and stress-free as possible for the patient in question.

Always make sure it is accurate and kept up to date

Do some case studies into how blind people can access electronic information by text or email relatively easily.

Always ask if another person is going to be given the information. Is it ok to share your private information with this person?

Making sure the person is aware that their information may need to be shared with other professional in order to gain support.

Train staff appropriately

Maybe a card for the Disabled person to hand to someone when help is needed.

Info like: lives alone, no family, 2nd floor flat, neighbour has a key.

Common sense and sensitivity go a long way.

Autistics are not good at answering questions especially open ended questions.

It would be a better option of giving some kind of visual cue with a choice of answers preferably between two answers at a time.

in my experience the sharing of information tend to happen only when it is against you. Again something else which is very common in [...].

Ask how I want to be communicated with, record it and do it. Also record who it is not OK to share the information with.

Yes, check with the patient if they don't mind that info being shared ,e.g. eye clinic, hearing clinic etc.

Ensuring that all the relevant information with regards to the information/communication support need of an individual is recorded and shared appropriately.

The sensitivity of this information in a public area such as a reception area

Confidentiality

Keep the information up to date as our needs change over time.

Don't allow too many staff / doctors to ask the same questions repeatedly e.g. when admitted to A&E it is distressing to have so many [...] doctors ask the same questions so many time!

Having a single, shared record so that every organisation doesn't have to ask me again.

[...] people like to be informed and included. Not speaking does not make them not human. We need to give them a voice. It is attitude that is wrong.

Make sure I know you'll be sharing and to who involve me

It's not enough to ask and record - you have to keep asking - people needs evolve over time. Don't be too precious about absolute confidentiality. You may think email is unsecure but I may accept the risk - is it really any less secure than conventional mail which can equally be intercepted and for me, as I'm blind, is less private since I may have to ask someone to read it to me?

Be sensitive to people and their privacy, sharing is good, but not to everyone. A receptionist does not need to know all the intimate details.....

Discretion & respect all the time please.

Plain English in letters.

Provide alternative options of contact instead of a telephone number such as email or text.

People with additional needs will often gesture that they understand everything that is being said. Please consider a belt and braces approach if additional needs are identified, so that at least one alternative method of recording is given, i.e. spoken and written, spoken and signing, spoken and symbols.

Ensure that the patient understands who the information will be shared with and that they are happy for that.

Only the relevant people need to be aware and the person concerned should be aware that their support needs information is be shared across a number of agencies.

Yes - use technology effectively and engage patients. Technology used extensively to engage in Finance health, tax health, etc.

Look at better use of hospital passports to be used in other scenarios. Information needs to be clearly visible.

I am happy to have a statement of fact recorded but this statement should be checked with me. Staff are so often woefully ignorant.

These should be accurately recorded and follow the patient/client around so that the next person/clinic to see them is aware of their needs before they arrive. There should be no need for the question to be asked again, other than to ascertain if there has been any change and if there has been no change the recipient of care should not have to go through their needs again. Everyone dealing with the person should know about their support needs as it is very wearing to continually have to say 'You'll have to .... because,' or 'I can't access that; I need ....' and one is not always in a place to be doing it if one is in need of such care.

Keep it simple

Allow communication needs to be flagged on the patient administration systems and to come up whenever patient records are accessed. Automatically share those requirements when electronic referral etc. are sent, and for a recognised symbol to automatically print in the header or footer of any correspondence / medical notes etc. to alert the recipient.

Do not assume one size fits all and that all patients can use the telephone for instance - try more than one method of contacting them.

Be patient with us and caring

Make sure the message is clear and easy to understand clearly stating time date location of appointment also easier access to confirm or change appointments. For a deaf person make sure the speaker speaks slower and clearly [...] but not in a way to make the patient feel inadequate [...] or incapable of managing.

medical record should be share between GP, consultants and health care professionals

Always ask for the individual's permission to share their information, as I would assume the Data Protection Act requires.

use simple and plain everyday language to ease understanding.

cultural differences

Be sensitive, and remember that if even if you are not sure how the person wants to communicate, ask in an empathic, respectful way and they shouldn't be offended.

Remember they are just people after all, just with difficulties in certain areas.

Have a unified database across NHS and social care

Ensure that there is some way to mark the notes so ALL professionals know there is a communication issue - and give advice to those professionals on how to overcome any difficulties - contact no's for support, speak clearly face to face, write down info etc.

come on more new technology like webcam, face to face with sign language, more training deaf awareness training, more communication awareness training for all clinical, front line, volunteer, mandatory training !!

how does they communicate with patients every day with variety people like [...], learning disability, deaf, dementia, speech impaired, deafened like older people, so on

If recording, then I think it only fair written format is provided.

Checking the person is aware of what this means.

Information is provided to patients throughout the NHS model not just the specific places you have asked about it needs to be accessible in all of them which means looking at all patient journeys and identifying the pathways

Ask them how they would like to proceed! Are they happy to have their need for an interpreter/signer etc. to be recorded on their notes for example?

I think it should be a very basic part of training for any health care, social care or emergency professional that many people have different communication support needs - and that they are not always immediately apparent.

Yes. Share it more !

Ensure transparency for the patient, by having online access to their own data, so that the patient can become engaged in their own care.

Make it easy for the patient to decide and effect who they want to share the information with (e.g. family and care facilitators).

There should be no decisions about the patient without the patient (and without the patient having full online access to their own data)

Transparency is important. As an elderly person with LTCs and comorbidities I want anyone involved in my health and social care to have full access to my medical records and to fully understand my health situation.

A colour/figure or another symbol could be used to depict that a client has an additional need.

Publicise what autistic people need.

Make sure you have proper informed consent as far as possible, within context of Mental Capacity Act

Seek approval from the patient/individual

Ensure follow up with carers of persons with learning difficulties to ensure they are fully aware of anything that is going on.

Please remember they are PEOPLE, not numbers! And these issues can be particularly sensitive to a person who has newly acquired the condition.

Make all records standardised across the entire NHS. I have difficulty having to verbally repeat my entire medical history with every new consultant or NHS department

See above comment about accurate recording.

If a service user refuses support when asked, it shouldn't mean they aren't asked again in the future. The door should be left open, as they say.

Consent to keep and share information and how it's reviewed and updated

public organisations are notoriously bad at protecting confidentiality. what more can be done to protect data privacy? Under no circumstances should these data be shared with other organisations that might have a commercial interest e.g. in selling communications aids

Ask the patient's wishes

Staff training on the communication needs of people with a range of difficulties.

that this should be crossed shared, for instance if a person is under drug/alcohol and is handled by that agency, they do blood tests that information should automatically be available to the service users GP as well or they should be handshaking the system so that information is accessible by all related to the patients case

Recording peoples wishes is very important and making sure that those wishes are respected by everyone who comes into contact with me. For me it is about trust and if I don't know someone, I do not trust them, so it is important that even in an emergency if I am in the hands of strangers, there is a person who can reassure me that people know what they are doing and that they will contact my regular doctors or one of my parents or someone else who I know well. Perhaps a card to say who should be contacted in the event of an emergency? Or it could be included in the [...] information, or on a patient specific protocol held by ambulance?

What they want you to do; what is absolutely necessary; not what less than scrupulous and downright nosey agencies ask you to divulge.

TRANSPORT it is no use the patient getting the info if they then cannot arrive at their destination so liaising with the ambulance service is essential

Confidentiality is first and foremost.

Knowledge, better still, experience of the medical conditions of others.

Empathy and offer the support

Deafened people need to know they can be given the support and help when they need it not fear not being able to hear the doctor or nurse

Text phones available for helping with communication if lip signer or signers not available

Ensure that the person concerned is comfortable about their information being passed around. It is usual for healthcare professionals to share information within their circle, however not everyone is happy for this to happen.

make the staff more deaf aware, I have a lot of problems understanding the consultants/doctors mainly

To try and keep a person's health records up to date.

[...] put it at the top of people's notes that they 'have hearing loss' or 'Is a lipreader' or 'uses hearing aids', etc. It is a real pain to have to keep telling every single person

you come across at a hospital visit. Please just put an ear symbol sticker on our files so everyone knows and make sure there's the training to ensure that staff know WHAT it is they need to do differently when they see the sticker!

If the individual is happy to share the information, then this should be highlighted across their records, and any of their dependant's records, i.e. CODA.

I think it is fine to share people's communication preferences within a single practice, but we should be asked if we are happy for that information to be shared anywhere else as a courtesy.

Ask the person with a disability if it is OK that the care / health worker dealing with you can let other people that you may need to deal with, know that you have a communications passport.

If patient is happy to share....then share! It can get frustrating explain to everyone you meet on one hospital visit the same information.

Give person a copy of report

Data protection but not as a blanket difficulty preventing action

[...] share the info properly across all different sources of health and social care so that people aren't constantly giving the same info to different people and different organisations over and over and over and over.

Health and social care should develop better links with Voluntary and Community Sector organisations, so that they can feed in info to a central database about individual's communications preferences, to help to reduce the number of times that people have to tell anyone.

as I am deaf I would like deaf written on my notes to make staff aware

If [.....] or computer is used a printout should be available and the patient can take that and read it as a reminder of what had been said

Ascertain what support is needed and create a plan of action that can be changed depending on the patient needs

Be sensitive

always deal in FACTS, never conjecture or assumption (unless you are 100% sure)

take all the aforementioned points into account.

however severe the PHYSICAL disability, NEVER underestimate the intellectual capacity

have a pop up window or something that highlights that this person has communication or support needs whenever anyone accesses their information on computer or a highlighted area on the front of the hospital notes showing that they have support needs

Ensure that everybody who needs to know, knows about any communication problems so that it does not have to be repeated several times over.

Let them know what is happening

To have interpreters regularly monitored by [...] and [...].

Be sensitive to people's feelings.

There is only so much you can do around legislation, staff need to be trained to do recognise where someone may have access issues and be able to access it in a timely manner.

Yes! Don't write 'DEAF' on health files in big red letters for all to see - including the public - it's embarrassing!! I don't go around with a sign on my brow so please not on file covers either!!

An onsite braille machine, [...] or large print photocopier would be a start.

Make sure the notes that are kept on file for people are actually read by staff members and adhered to. After I was registered blind I sent a formal request to my GP surgery and the hospitals in which I have treatment telling them that I need information in large print, they all acknowledged receipt of my letter, in large-print, but not one piece of correspondence that I have been sent since (and there has been a lot) has come to me in large print. When I phone and point this out I am told that they didn't actually bother to check and sent it as standard. This is not good enough.

ask the individual they know their needs better than you do, most people don't mind being asked do you need Braille? do you need X, Y or Z.

If you are planning to capture this data in a one-off exercise it will be a massive workload for NHS administrative staff. Is this really a top priority exercise? Given the massive cut backs going on in all kinds of public services, the cost-effectiveness of this exercise needs to be examined very carefully.

Again, make sure it is reasonable terminology and don't be embarrassed. "oh, Mr Smith he's a bit deaf" shouted across the room, is just as bad.

Take into account a person's mental health/ learning disabilities and support needs

Ask people if they don't mind that information about deafness and their communication needs are shared. I am sure they will be happy with sharing this information as it is in their favour.

Just remember that people's needs change - and sometimes they change suddenly.

Staff need basic awareness including doctors (who are often the worse) to recognise and under the range of communication support.

NHS Staff must be aware that failing to get a communication support to sign a consent form without understanding the context of the agreement is illegal.



Many Deaf people using BSL to communicate do not understand English.

common sense!

Just a simple question to check with the patient that it is ok for this to happen is fine with me.

All patients who are deaf/HOH should have their disability at the top of their file for the GP/doctor/other health professional to see firstly when they open it up not down at the end as it is at the start of the consultation that this information is vital. By missing out on this, the patient misses out and advice is not taken on board fully therefore wasting both the patient's time and the health professionals. The more this happens the less the patient will seek healthcare therefore disproving their health and quality of life.

confidentiality

Store it centrally so that if I move from Plymouth to Carlisle I will not need to repeat my requirements after I have moved.

If I know that all my needs are known I feel comfy and safe, my needs are complex as I am sure others are too. It is comforting if you have an appointment that someone at the healthcare facility you are using will be able to help you without having to ask for help. Also I have been for appointments not so long ago where I was not told that help was going to be offered when I went to see the doctor struggled on my own gone into the wrong [...] mistaken for another patient and given wrong medication. This was only picked up I reached the chemist and wrong name was called out for prescription. I had to go back to the doctors and was embarrassed and made to feel it was my fault. All this due to lack of communication.

You should ask if people are happy for this information to be shared within the NHS and/or other people, just as companies do, so that we can give immediate consent and the data protection act is never thrown in our face as a reason for other parts of the NHS not knowing we are blind

Communication Support worker should be able to keep confidential or signed a contract

Ask patient consent to share this information and explain why in an emergency it would be an advantage to have this information

on a need to know basis and feedback it is successful or not

Communication between health and Social Care workers so everyone who needs to is aware of the person's needs.

Privacy and possible impact on employment / insurance / crime.

Many employers ask to see medical records before employment Crime - if it were 'well' known that a person is fairly deaf or blind I would have thought that would make them an 'easier' crime target. For instance I am a lot less likely to hear a break in than someone with normal hearing..

Ensure that as they move through the system that their needs are met at each stage. Use either specific codes on files or specific colours or files for different needs.

Ask their consent if they want their data shared. A lot are very private people.

Double checking details with patients

a lot of the time you can tell one doctor you're deaf but when you go to nurse 10 minutes later they don't know, or other way round. and it's not noted on your notes at next appointment. same at GP! if you have anaphylaxis it comes up straight away on your GP notes in the corner. why not for deafness?

Previously provided details about information needs should be recorded, shared, and used as a starting point when future treatment/services are delivered.

that they actually get to the right person first time all the time

It is important to understand what is important to the individual patient. What may appear a minor matter to one could be of major importance to someone who is not able to express their feelings accurately.

When you recording or sharing out about people information for example in this case NHS recording or sharing out about the patient's information, under the law the patient have the right to access their information file such as medical history with the doctor and British Sign Language interpreter if the patient's deaf over 16 years. This patient's information shouldn't show anyone outside NHS as long the patient give the permission then you can do anything to show off the patient's information.

Strong emphasis must be placed on confidentiality and privacy.

NHS England should publish the [...] that gives contact details how to request communication support. Also put information in BSL via their website - Deaf Page? There is good local support for deaf people. e.g. health workshops, counselling, etc., Why not to publicize them that will reduce deaf health problems

That some deaf people prefer SSE (Sign Supported English) rather BSL

We need to be aware of Data Protection Issues at all times.

Keep the data private as far as possible.

Local disability registers accessible to 24hour monitors

Minimise bureaucracy and red tape

You should keep the information on your computer so that deaf people don't need to repeat their communication needs every time they book an appointment or visit hospital.

Please delete the communication support please use qualified British sign language interpreter

Give more staff training.

If someone is a regular user of services help them compile a communication "passport" with a summary of their needs.

It would be really useful if, when referring a person from one service to another, all their communication needs are clearly transmitted as this saves an awful lot of time and confusion.

Degree of blindness

Ensure information is secure and shared with the relevant people only

Information could perhaps in the future be self-administered/updated by the patient or a nominated member of the patient's family - similar to loyalty card /membership information.

While some people have concerns about data security as parent of a deafblind child it is more irritating that hospitals don't share important information like her communication needs.

SMS, if person unconscious how to wake them up, file to have colour code for deaf BSL users

I like to have the details on my file and on my bed if I am in hospital

It is always better people know that I cannot hear so I do not miss my name being called out and to be aware I may have someone with me

Yes it's important that I don't have to keep giving this information over and over again. My preferences should move with me through the NHS travelling with me from service to service.

Again I'm not experienced enough to provide a useful answer to this.

Make sure you explain to us what you are doing and entering the details and have a consent what allow to share or not.

Make sure it is kept up to date and current and do not assume that matters will stay the same for ever

Consult with Deaf people not with 'Expert' panels that is tokenism.

It would be good if people didn't have to tell their story every time they meet a new worker - on the other hand things can change and it would be important to check whether what was in someone's records about their information support needs had changed

Yes, put a red flag (or similar) on patients' records to show they have a disability e.g. hearing loss. That means they'll stop ringing me up to ask me questions when the reason I use the NHS is because I can't hear on the phone! Just as they'd highlight the fact that a patient has a nut allergy if they're staying in hospital, could there be a

badge/sticker/notice which flags up other special needs, e.g. deafness/needs hearing support?

Just to remember that we have a sensory impairment, not [...].

listen to them and take note of what they say.

Just accuracy in the data.

Difficulties with communicating the needs to the relevant staff when staff change over

Our rights to privacy - maybe better to take to a separate room to discuss condition etc. rather than shouting it out for the whole ward

Disability Awareness training every 3-6 months for ALL members of staff

IT NEEDS TO BE IN CONFIDENCE AND THEY NEED TO BE ASSURED THAT UNLESS ITS DANGEROUS WHAT THEY DISCUSS IE SELF HARM THEY CAN TALK OPENLY WITHOUT THEIR BUSINESS GOING TO OUTSIDERS WITHOUT THEIR KNOWLEDGE FAIRNESS DOES NEED TO BE ADDRESSED.

Yes, all agencies should have an up to date list

You are being too cautious. I remember when somebody said to me that when you go into hospital to have a baby there is no embarrassment.

In today's world, I might want to know with whom you are going to share my information. If my doctor makes an appointment for me to see a consultant and he makes the consultant aware that I am deaf then fair enough. It is something that I don't have to deal with. The problem will be can the consultant deal with me! The doctor only has to tell me that he will be telling the consultant that I am deaf. I'll be happy with that.

confidentiality should be applied at all times.

Obtaining consent to share information

It should be clearly marked on patient records so that all medical staff are aware of the needs. This is particularly important for inpatients who see many staff on a ward.

give the person details of who you're sharing the information with and for confidentiality give a disabled person the option to say no to having their info shared unless it's absolutely necessary

I don't mind who the information is shared with so long as it is beneficial to me. Shared information needs to be acted on or it is a waste of time and effort.

Why when millions of pounds are spent by [...] does the Audiology department have to rely on volunteers?

Data security. Consent of service user.

That a clear "need to know" protocol is followed so that consistency and confidentiality are applied.

We have technology - use it.

To ensure the person whose information it is has immediate access to the information held on them.

Needless to say the obvious "What was the result?"

When possible the person should be informed and choice given as to how much information is passed on or shared with non-medical persons.

don't make it sound like charity say what they can have and to make life better for them, tell them to try it out for a week or two to see if they are better off with the service that they can have.

Even if they give you the info always make sure they are happy for it to go further

use appropriate language and be sensitive when describing someone's needs. I do not refer to myself as deaf as I consider myself hard of hearing or hearing impaired. That's my preference so maybe patients should have a choice about how staff refer to their disability or needs out of respect. Ask the patient how they would prefer their disability to be referred to and provide multi choice if necessary.

Yes put on computer they are deaf and use BSL, so in future everyone know what they want.

Just to respect the usual confidentiality rules so information doesn't get into the wrong hands and is not misused in any way e.g. for the purpose of advertising goods or services.

just make sure it includes deaf people needs as well

Privacy - I don't want my business shouted out in the waiting room.

all medical records would be centrally accessible.

only data protection and a standard consent form to be produced so information can be given or got at a short notice

Don't use technical terms or industry common phrases that ordinary people will not understand.

Deaf people have been treated appallingly and need to be offered communication support or support worker support with people who can sign. No point put deaf BSL OAP with support worker who is hearing and can't sign. How they communicate with each other?

Always remember to see the person not the disability. Everyone Matters! Record information sensitively.

I do think having this information on secure records is essential and health officials checking them first so they are better prepared could save a lot of frustrations, misunderstandings and difficulties for all concerned

Recorded information can be kept on application that strongly privacy of the patient but applies to medical staff and patient only for record needs.

Shared information could on a hospital website or social site for NHS hospitals that could improve their services/barriers of communication needs and support.

It is worth recording individuals preferences so that they do not have to keep asking again and again.

I am perfectly fine with having a record in your notes that state, this gentleman requires a sign language interpreter.

Mark computer records, so that it is flagged up to the personnel what is needed, e.g. deaf, deaf and partially sighted

Note my disability as individual have different type of deafness, just hard of hearing, profoundly deaf, deafened or deafblind.

Understand patient's own communication methods and stick to it.

Always make sure the patient or their supporter understands how information will be sent and who it will go to. People with dementia who live on their own may not always be able to understand their information so it might be sensible for it to be sent to someone on their behalf.

How about a personal sheet patients can complete: I need help with... [...] and support services in colleges use good ones - can be kept in file and on record

staff need training

Your questions are hard to understand, my mum is helping me

what if the situation changes? e.g. my hearing deteriorates in the future

It should be shared.

for me it is all about understanding and remembering what is said to me. I find it embarrassing to have to ask for things to be repeated or put in writing so very often don't, to my cost.

**ALWAYS GETTING THE PERSONS' PERMISSION, OF COURSE, IS CRUCIAL....**

There should be a pathway from reception to an internal booking system for interpreters and all staff should be made aware of this. There should be signage alerting Deaf people that interpreters can be booked.

Audit of BSL provision within NHS and share good practices that other NHS Trusts have to support other inaccessible NHS Trusts

Think about special need persons. They use BSL and Makaton Sign Language as well as Makaton Symbols. Or pictures.

It depends initially on every individual case but has to be the starting point

Ensure that everyone knows about my visual problems.

Yes this would be helpful to avoid any difficult access.

From experience most people want their basic information to be shared between agencies. Obtain individuals sharing preferences and act on them instead of organisation procedures disallowing that sharing.

need their permission

Should be in BSL

I'm against 'sharing information' for lots of reasons

Fed up of having to contact by telephone only for appointment. I cannot use the telephone! Have other contact methods - online website or SMS

Would you be happy for your personal information to be shared as you are doing? if yes then you doing the right things, if no you need to improve.

People with communication are generally intelligent - don't treat them as a problem because of issues

Put it on the front page of records/files so other professionals involved with that person, will know their needs straight away. Too often information which is vital is hidden in a file, or wrote in such small print that no-one ever sees it.

The information given should not mention hearing impaired. Should say Deaf or Hard of Hearing. Deaf with BSL and interpreter will be needed.

Text

Make a policy not to use family members to help communicate because can't get interpreter. Why should we have to rely on families? Confidentiality issues. People left in hospital beds for days because no one thought to book an interpreter, administered medication without communicating what it was and why.

When recording information, check with deaf people it is correct

Improve publicity and what they have offer service and accessible for deaf patient, this is vital in everyday life

Communication support or needs should be at the top of a patients notes so staff know in advance of communicating with the person and they should have been trained how to provide that support. On the ward, Doctors walk in assuming we can hear or have got our hearing aids in. Also care workers assume you are asleep if you

lie there with your eyes closed. Both my daughter and I have missed meals because we've been resting and not heard the food arrived.

Encourage patients to carry communication passports or to wear jewellery/watches that tell you about their communication problems.

Always speak to the person not their support even if they cannot communicate themselves.

When you're sharing information please, ask me first - I've had receptionists share information with PALS offices that I've complained to, nurses ring my home and leave me a spoken answer machine message (including details of my illness and talking when I'm Deaf - consequently my children had to listen to it for me and found out information that I didn't want them to hear).

Sensitivity and specificity. The support needs to be the right support offered in the right way. [...]. Get it right by asking those with the problem how they view it.

electronic case notes accessible to all acute treatment areas to enable quicker more appropriate treatments if the patient take ill away from their local area.

Where someone accesses NHS Services from two or more NHS organisations, such as their GP, hospital, specialists within different fields, social care services and such like, every effort should be made to make sure that all of the staff with whom any person needing extra support deals, are made fully-aware of the needs of the individual concerned. This will lessen the need for the individual concerned to recite their needs to people every time they visit an organisation within the NHS.

My consent to do so, awareness it is personal and confidential information, disclosure of disability

With current Information Governance rules it is very difficult to ensure that everyone will have access to the information they need whilst ensuring patient confidentiality

confidentiality - it should only go to people who are directly involved in my care.

Do not share information without express consent of patient

Check with the recipient from time to time that the information quality is good and that it makes sense. for some formats, such as Braille, the person producing it may not be able to proof read it, and so may not be aware of errors.

**ASK PERMISSION ALWAYS, SOME PATIENTS DO NOT TRUST ORGANISATIONS TO KEEP THEIR DETAILS PRIVATE.**

Information should only be shared if the patient has given permission.

Use a flag system that highlights a person's support needs and prompts clinicians to ensure that these are covered/taken into account.

it should be filed on the system of their preferred communication methods



The staff should be trained to write down briefly the transaction they're having and give the transaction, in whatever form, at the end of the session to the person they're interviewing.

Some written instructions

Information should be kept confidentially.

it should be on your records with your permission and what form of communication you use e.g. sign, lipreading, spoken English or combination of all of them

How do you keep that information safe? How do you use it appropriately? How do you stop it becoming a bureaucratic nightmare and getting way out of hand? How do you stop it being used to "prove" negativity?

If a passport is available for the patient, staff should have a process to review the passport, so that it does not just sit in a draw in the ward or surgery.

Create a new central Database for whole of UK's specialised language and communication support so that when we make appointments, or attend emergencies - our names could come up for the health professionals to ask us or our families to double-check, etc.

put down DEAF on record/file

must book BSL interpreter on the file

Yes - their communication requirements may change overtime due to age or additional disabilities - keep reviewing

Put it in the patient's file that every medical personnel working with them has access to.

Consider age, gender, cultural and [...] issues.

Sharing any personal information across agencies needs agreement from the person involved and any transfer of information should be in a secure restricted format when electronic information transfer takes place.

No but the recorder needs to be exact in describing the particular needs of a patient clearly so that others understand the notes.

As above any information on how it should be presented & by whom.

Make it clear what level of BSL is acceptable e.g. level 3 for social services especially when they are meant to help protect vulnerable adults is not acceptable. If a person level 3 BSL or less has a concern of harm to children or adults, there must be a policy of making sure with a fully qualified interpreter they have understood what has been said. [...]

Need to think what about those where BSL is not first language but another signed language e.g. ISL (Irish)

Don't rely on social services for the answers- some social services provide really poor support for deaf and deafblind

Include a date stamp, needs can change over time so it is important to know how recently the information has been checked. A simple question is braille still your preferred written information? Do you need a deafblind manual interpreter?

a) Use special colour coded labels alongside names on patient records, notes, appointment sheets etc. to indicate that communication support is required and the specific type of support. b) Ask the patient / client if they have a preference (not just the type of support, but a preferred supporter). c) Remember that British Sign Language (BSL) Users may not have good 'English' skills (written as well as spoken English) and because of this may need all information in BSL format. E.g. Written English in leaflets may not be understood, DVD's with both BSL and subtitling would cater for deaf / deafened and hard of hearing people.

General Comments on survey... 1. I only found out about this survey a week ago (2nd February 2014) but it has been 'open' since 4th November 2013. It's obviously not reaching the majority of the people who 'need' to complete it (those people who actually need communication support and need improved access to information). 2. This survey was targeted to English oriented readers – there was no offer of other formats such as BSL support / translation of the questions (which could have been incorporated into the survey and switched on if required?) As a result, many BSL Users have probably been 'excluded' from this survey unless they've had communication support at hand to help them understand and reply to the questions... Which implies that your results will not reflect a good 'sample' from those who actually require communication support.

Hospitals & GPs need to have the systems so that everyone knows how to book them, and can be flexible in booking them. E.g. it's no good if the GP will book an interpreter, but has no way of a Deaf person contacting them to book an emergency appointment, or of providing an emergency appointment with an interpreter since they have all gone by the time an interpreter is found

Speak to me and ask me face-to-face or by telephone or text.

Take on volunteers with all range of hearing loss to work in various departments – fracture clinic, x ray, bloods, so it becomes commonplace for medical staff to become familiar with adapted adjusted communication. This way the volunteers can raise alert for the appropriate support in readiness. Deaf patients are all too aware of the concept of "Duty of care" and this is sadly amiss with communication. Too many nurses short tempered and unfocussed in some cases

You should ask people what their preferred method of communication is and record it and share it (with their permission) across the same institution (docs surgery, hospital) and even better, across the whole NHS so it goes with the NHS number wherever the patient is going

This may be difficult due to data protection Perhaps an individual's communication needs could be mentioned in the referral process. E.g. The patient I am referring to you is blind and perhaps this could be taken into consideration

when...communicating with him, I understand he would be happy to receive information either by email or phone (We don't all read braille)

Patient centre and EPR need to be flag up straight away display the need of communication but these are not happening and people working in NHS are not aware of people's requirement

Confidentiality may need to be considered, but information about communication needs should not have to come under this because professionals need to know in advance how to communicate with patients and clients.

I told the doctor that you need to learn BSL, it is important. Come on! The doctor never makes a move towards access.

I want all the NHS professionals to know my record and be aware that I need communication support and to have it prepared for when I attend my appointments.

I want feedback now, otherwise I don't know what is going on. If you don't then it is the same as 'all talk no action.'

I think we should share links with disabled people, they need to be aware of deafness and know that I need BSL at appointments and meetings. They can then give me the right and clear information.

Please consult me first.

Talk to support workers and line managers.

Always have a support worker present.

I would like my mum, my carer and my outreach staff to now.

That my parents and my support workers are my first point of contact.

They won't give me any information. I can ask friends and they tell me about waiting lists and getting letters when it is necessary. I ask what happens in the tests as I am a bit worried. I go to the doctors but they say no need to, go to hospital as it is quicker. If the injury is severe then you go to hospital otherwise you go to the GP.

confidentiality risks

I feel that for any forms, there should be a note stating that there is a BSL format available, also on waiting list, or medical records, there should be note in bold or highlighting, stating the need of language- BSL. This is because it is very easy for the staff to assume I am a hearing person. If there are a list of language preferences, and if BSL is mentioned, it would take a lot of weight off my shoulders knowing I can be stress-free in communication. Being comfortable is what counts.

Face to face communication support service, or register on a website that includes a log or list of what I need, etc.

I would be happy if the information states I am Deaf and share it, it would save me a lot of effort explaining to everyone I meet that I am Deaf

I accept information being shared, it means less hassle for me.

Yes I agree, I don't want to repeat myself that I am Deaf all the time. They say they aren't aware, but I have told them so many times. I am sick of it.

I would support the information shared, if there is a note stating that I am Deaf, in bold so it can't be missed. So when that information is being passed, staff can be aware. Usually at the initial meetings, there would be a shaky start, and then after a few frequent visits, we become aware of each other and more acquainted. At one experience at physiotherapy, there is a blind therapist, and I am Deaf, he cannot see my signing, so the receptionist had a main role in our communications. I write things down, so the receptionist can read it out, and the therapist listened, then responses, and receptionist writes down what he had said for me to read. She was overwhelmed with this situation, as she never had a Deaf person with a blind person together in one room. This therapist became aware of my needs and knew I needed an interpreter for future visits. I was impressed with him. I feel that the receptionists need to be trained in Deaf Awareness and "Deaf English". Also they can be prepared if a Deaf person happens to bring a friend or family. It is receptionist's role is to be prepared for any kind of visitors and know how to handle.

Flag it up

NHS should make sure the information about my Deafness is passed on to the relevant staff, but will it still be confidential? I don't know!

I don't mind being filmed for the information, if the interpreters didn't like that, well tough. I have a right for my information to be stored and to be shared with appropriate bodies.

All NHS professionals should have a record of and be aware of my deafness

need to check with me about information sharing and keep me up-to-date

make staff listen carefully to me and check if anything is troubling me

picture cards with information on

no, because my information needs and communication needs are catered for by support workers

dietary needs, things we like to do i.e. watching TV, favourite music, what is 1st language, keep language plain and simple

a full evaluation of my active and latent communication potential / ability might reveal how best to support my needs

[...]

I have aphasia

I have expressive aphasia. It takes me longer to form my answers and it would be useful to record that I need time to respond so will need proper time in appts to do so. And can they not rush me or jump in to finish my sentences

care planning for all that access social care services

better access to info

make the NHS more aware of the services run by the [...]. To help more people with communications difficulties

I go along to the [...] communications support group. This service needs to be recommended more to people with speech problems

on the computer system deaf person need interpreter

There is info out there in easy read but lots of people I know have never seen it. It is not easy to understand

the wording is difficult on the questionnaire. Better with more pictures and symbols

this question was difficult to answer

I tell the GP or nurse what the blood test is for

the need to keep information private

give me a chance to write things down

I will let people talk to me, then I want to know more about it. I think people are polite

a communications passport I can give to someone so I don't have to keep telling the same thing to each person I see

always explain clearly

a booklet of different paper colours of what is wrong with me. A passport of my health problems

give respondents the choice of anonymity or otherwise

communications and support needs should be on your hospital / GP records just as much as medicines you are allergic to are.

be aware of other support services available in the community and make sure these are offered

privacy and dignity of the person

you should be asked this question every time. This shouldn't be shared with different places (services) without getting permission first

when receptionist asks me a question they should ask me the name of who they can give the info to

easy read and pictures. If jargon is used, explain to me

easy read with pictures and large numbers

staff should be trained. Slow down - don't speak too quickly. Keep things confidential

making sure providers have been properly trained to meet these communications needs

this document was hard - it's not easy read

more easy read info with very clear words. Your easy read info is very clear, but need some words to be changed to make more clear

I know it's difficult about info or sharing. Need to help between 2 or 3 people. There is not what about interpreter or communications

info about access should be shared with all NHS depts. and the emergency services. Interpreters should be available at A&E depts., preferably in person but at least in the form of a "remote" interpreter over a video link such as [.....]

medical records should have a marker indicating that there is a particular communications need / issue

please contact my wife, reading is difficult for me. Verbal communications is best for me

to have details of your communications problems in your medical records

recorded info needs to be checked but too much info may be too time consuming to read

That my parents and support workers are my first point of contact

please consult me first

to give me time to process info

talk to support workers and line managers

always have the support worker present

a section to indicate any other communication needs I have

I would like my mum to know my carer and outreach staff

Information should be kept confidential but should there be case of an emergency for deaf people, their communication support needs may be shared.

People may have several different ways they like to be communicated with so it will be important to highlight their preferred method of communication.

## Appendix 8 – Health and social care professionals and organisations survey, Q2.

**“Where do you / your organisation currently record patients’, service users’ or customers’ information or communication support needs?”**

[.....]

Members belong to regional networks so information on their needs is stored in each local office

There is also an electronic copy on a secure server

[.....]

[.....]

Electronic health record – [.....]

This might be recorded in several places. The key one is probably a 'Patient Passport' for adults with learning disabilities which lists things that professionals need to know about an individual

Our own database

I work for a Learning Disability & Mental Health NHS Trust we use a system called [...]. Records are not 'flagged' for Learning Disability, so information is only provided following assessment

[.....] - mental health secondary care electronic patient notes system

[.....]

[.....]

Always in the notes and also on Patient Admin Systems. I cannot answer two in this question!

The wider organisation will record people's communication needs on their electronic social care record, furthermore providers are encouraged and expected to support people to develop personal communication profiles in the form of personal passports or communication dictionaries either as standalone documents or as part of a Person Centred Plan. As an involvement worker I record people's communication needs as appropriate in the plans for specific projects.

Performance monitoring database [...]

We record on our own database

Police IT systems

and paper record



Restricted internal information system

Electronic NHS system , [.....]

[.....]

[...] Records

We use a patient health passport to record needs including communication needs.

patient and carer information leaflet schedule - central storage due to size of the NHS Trust

medical form on a custody record

We use 2 systems in the trust - PAS in hospital and paper in community services - as integrated

We have a Learning Disability alert, and a separate Autism/Asperger's alert on our PAS system.

We have an external register on [...] (A&E) which gives a text box to record e.g. that the person has a Learning Disability, what reasonable adjustments may be required.

We use a Learning Disability/Autism sticker in patients' medical records.

We try to complete a Hospital Passport for each patient with LD / Autism to give information to professionals supporting them about any additional needs they may have

On progress notes, accessible to other AHPs

Communications requirements are gathered upon registration or referral.

These are stored On the Trusts [...] system and in the Pharmacy system with flags placed on PAS

and some information in the organisation computer system.

all information is available and or help by each Service User

we also create communication passports in easy read formats and use [.....] (mini websites) to create person centred multimedia profiles - you can check out this innovative easy read format at [.....]

[.....]

We add information onto the Social care electronic system but have only recently been given permission to do this due to information governance issues, this is a positive development. We are a S&LT service and hold vital information about the information needs of individuals, particularly how much someone is able to understand. Communication impairment is hidden and unlike other disabilities it is

not always immediately obvious. Many of the people we support are vulnerable due to people over estimating their abilities to comprehend

I handle commissioning complaints and record specific requirements in our complaints handling system.

We are a charity - commissioned to provide local services to older people. We record certain information about our users on our own bespoke database

At [...] we support people with Learning Disabilities and/or people with Autistic Spectrum Disorder. We support over 3000 people and their families across England and Wales, offering a range of personalised support services.

We currently record information on support and communication needs in individual support plans [...]. This document has 3 main sections: My Information (personal information, contact details etc., Getting to know you (a person-centred assessment of what is important to the person), and My Support (an outline of what support is needed). We have paper copies for quick and convenient reference in people's homes or services but also keep an electronic copy on our secure IT system

Our own designed system

Usually recorded on the front page of their social care record. However this is not consistent and there is often insufficient detail. I would like to think it is consistently recorded but not sure what happens at our call centre who take the initial referral.

IT WOULD BE DOCUMENTED IN THEIR CARE PLAN.

I use both [.....] and [.....]

We have also now gone on to the PAS – [.....] system as well since December 2013, this gives us extra information

Recorded in patient notes.

Stickers highlight specific needs - used on the cover of patient notes if patient agreeable

[.....] system

[.....]

Two electronic systems and paperwork files.

Care Notes

Electronic and paper records

Also on [.....]

[.....] system for our [...] Service and [.....] for our Psychological Therapy Service.

[.....]

A combination of systems (primary and secondary)

we also use paper records

Recorded from when a client first makes contact so that any info is sent out in chosen/preferred format

[...]

Recorded on computer

Paper records are kept and some text on an internal data base and through use of an internal outcomes tool.

We mainly use [...] to store client's data, which will include notes on their communication support needs where we have it. There was no appropriate option to select for this, as it's not a GP, PAS, PDS nor Electronic Social Care system.

As a dentist I record it on our electronic patient records system

On the [...] Internal Information system.

[.....]

[...] - a data management system that is used for all contacts of the organisation. This is not a tool which is shared with health or social care.

Communication support needs are logged wherever the person has additional needs. Where someone does not have additional communication support needs, these are not consistently recorded.

And electronically on [...]

On our organisation's [...] system

The IT systems do not allow you to record sufficient information on patient/service users' information or communication support needs. This causes problems for the organisation as we cannot be proactive in supporting the needs of our patients/service users.

Also on our organisation's database

And paper record in addition, or just on paper.

Paper record at home visit. Details transferred to the [.....] system.

Word document summarising people's comments and suggestions for each event or document (commissioner at CCG)

[...] data base.

[.....] and [.....] (records on both social care and NHS systems due to integrated team)

We have a web based database called [.....] and we also use a paper based system which we will be phasing out over the next few years

I use [.....] and [.....]

[.....]

[.....]

[.....] and paper records in patients' homes.

We have a combined patient admin system and electronic social care record.

currently this is ad hoc, but i have just drafted new documentation to record patient's communication support needs and also highlight what reasonable adjustments need to be made. this documentation will go live in April 2014.

also on paper records.

We have a different IT system to the ones named but electronically

it may be possible to record this info in a standard way on this system

Not sure if linked to NHS spine

Initial Assessment - can be electronic and paper record

We are moving over to a computer system called [...]. Current systems include paper records for some services and [...] databases for others.

We are moving over to [...] to monitor outcomes

in their files

paper records plus [...] database

Department specific patient management system

In a communication assessment, which informs a communication profile in their support plan

for my home eye check service, I will receive specific information in the referral letter requesting a home eye check

On a more general note people with learning disabilities are flagged on paper notes and on the PAS system

Health Trust IT system – [.....]

The individual may also have a 'Communication Passport' which they keep with them

On the pharmacy patient medication record system, against the patient record in community pharmacy [NB the response options above are not appropriate to pharmacy/other NHS contractors]

by data entry on [.....] from [.....] from [...] (primary care)

This is a required element of our Trust's electronic patient record – [.....]

We also have our own local electronic record within our department, which is where most of the useful information is stored - communication needs seem to be poorly distributed within the hospital - it is mentioned briefly in health passports for LD patients but i feel this is not highlighted enough.

As a small/medium voluntary charity supporting people with a learning disability, and with only a minimal level of (current) funding from the LA, and with being parents/carers and family members who may only have a limited amount of IT experience, we are therefore committed to produce/issue our documentation in hard copy format. If however, money was re-focused into grass-roots organisation like ourselves, much more meaningful information and support could be readily made available to those most at need in our local community. After 64 years of 'paddling away' in the local community, isn't now time for local LA officials who seem to generate mountains of useless paperwork that just has little or no bearing/support for those 'doing' the work at the 'coalface' so to speak.

The recording system we use is [...]

Our electronic data base – [.....]

We are a third sector organisation

WE ARE A PHARMACY. We do a free delivery service to need patients. On our Delivery rounds we notice patients other needs for: social care

## Appendix 9 – Health and social care professionals and organisations survey, Q5.

### “Where do you / your organisation currently record carers’ information or communication support needs?”

Carers' assessments are routinely completed and should account for communication needs.

in [.....] as above

If the parents need interpretation then this will be recorded on the Patient Admin System. Other details that are told to us are recorded in the notes and are known to the team.

We keep details on our stakeholder database - and have local knowledge and experience of working with specific groups, and use this knowledge as part of our engagement preparations

On our database for specific carers grant work

Restricted internal information system

Carer- use [...], information about carers

In some services – e.g. special schools this would also feature in the schools records

Not aware how this is recorded in the hospital

Depending upon who we are assessing, info will be held on clients record, or carers own record.

Sometimes, as part of the LD risk assessment or Hospital Passport, or even in the patient records if deemed appropriate.

Electronic system

Carer’s assessments are also undertaken and saved in electronic form.

The information is stored on [...] as part of the patient record

Again, if a complainant is acting on behalf of a patient and is therefore a carer/relative we record any specific communication needs on the complaint record if required.

Support for staff would be assessed on an individual basis.

We regularly communicate as a team the needs of both service users and their families, we use email and communication books as well as hold information in the service users file with regards key contacts and preferred methods of communication

When an Adult comes through Social Services in [...], for a Community Care Assessment the carer is always offered a separate carers assessment in their own right, this can be done on the same visit as the communicate care assessment, or separately and away from the home if the cared for person does not want any services or if the carer would prefer their assessment to be private.

within our own organisational database after checking with the individual, that they give their permission for records to be kept

In general, we do not record carers' support or communication needs. It is possible though, that during the business of supporting a person we it will be useful or even necessary to know how best to support a person when they are with family members or additional carers. This may well lead to an indirect recording of what others require when communicating or having a conversation about something with someone we want to support to engage in a social activity or conversation.

Also a [...] file

Our specific software also stores information

Carer information is gathered but not in relation to their communication needs

Carer's details tend to be deleted from records once the client has trained with us. However some key workers info may still be stored with client's knowledge

We record as appropriate the carer's information when members register in case of an emergency or where carers hire scooters or wheelchairs on behalf of those they car for.

If appropriate cares communication needs may be recorded on SU's records.

we use person centred thinking tools a communication passport or communication chart would be completed.

If the carer wishes, they are entitled to an individual assessment of their needs as a carer, in this instance, they would have their own record.

Sometimes, carers would rather their details be recorded jointly with the cared for person.

Communication support needs are logged wherever the person has additional needs. Where someone does not have additional communication support needs, these are not consistently recorded.

Or electronically and on paper record if carer has separate case

The info is separately recorded but we have a recording system of associated contacts and so can access the carer's record and the cared for person's record

We seek carer views through: Six monthly open carers forum - all carers welcome; Quarterly Carers Advisory Partnership (CAP) meetings including 6-8 carers and local Carers Support Centre; Quarterly Carers Strategy Implementation Group involving

4-6 carers and local Carers Support Centre. Back in 2011 we consulted widely on our Joint Carers Strategy 2011-2014. (commissioner at CCG)

[.....] under consultation or care history dependent on information.

INFORMATION! LOTS OF IT! AS MUCH AS YOU CAN!

on the child's electronic record usually, or sometimes on the adult carer's record

Sadly very rarely done

On the referral form initially

On the initial assessment form

If this is applicable, it would be recorded on the pharmacy PMR system against the patient record in community pharmacy (as 2)

With limited space, limited staff, limited facilities, 'persons supported'/parents/carers needs are directly addressed as they occur (night and day). We do have a small office facility, but only one/two responsible part time staff to manage. We have around 65/70 people having a learning disability on our records, plus approx. 110/120 elderly parents/carers as 'colleagues' to whom we offer our support. Similarly we are on hand to pick up/correct the failings of the various local [...], most of whom are managing with insufficient, underpaid, and 'often' incompetent staff for whom we have to fill in and support the person who is at risk when things go wrong.

Information about the carers needs and understanding regarding information is always reflected in the nursing assessment stage. If the service user relies on the integral support of their carer to communicate/relay information to them, then it is priority the carers needs are also addressed.

Carers Assessments

very ad hoc, only if it is mentioned as a very specific factor in the patient's care.

Usually this is a note in the [.....] file.

Patient medical records on the computer

As part of the patient's / cared-for-person's record



## Appendix 10 – Health and social care professionals and organisations survey, Q6.

### “What is the main reason for not recording patients’, service users’ or customers’ information or communication support needs?”

We record needs in SLT notes but not sure other parts of the service would routinely record this information

We need to improve our ability to record information on our electronic patient records. We are currently going through a change in system.

Staff doesn't seem to understand the need

There is no excuse for a failure to record

As there is no specific question in the record system about this, it might sometimes get missed.

You cannot 'flag' records on [...] system to alert secretaries and admin staff as to who has particular communication needs. If a full assessment has been carried out the information is there...but you have to look for it. Learning disability Service uses easy read appointment letters etc. but not in Adult or Older People's Mental Health Services as far as I know.

Should they not give consent

We would record ( both in the notes and on PAS ) if we were made aware of the service users support needs but not sure if we have a sufficiently robust process to ensure support needs are always made known to us

If we do not know the needs then we cannot record them.

not seen as important by the organisation

carers communication support needs may not routinely be captured at the initial stage of referral if about the person they care for, for example. We may omit to return to this question until an issue arises, a carer volunteers the information or until the opportunity arises when a carer accepts the offer of having their needs assessed

Not routine and regular contact in most cases

We do not as a routine record carers' communication needs, but we will make notes if on initial assessment it becomes apparent that there are needs which need to be met.

Information given to patients/carers is recorded electronically, although this is ad-hoc based on difference services and their knowledge of the system - not sure if this is covered as part of the system training

I always record this information as I work in children's and learning disability services - so this information is vital to delivering good care. - however records often arrive without the information prominent or sometimes recorded

I work for an emergency service. We do not case hold and a different emergency crew would attend each time possibly. Whilst we would record it on the single patient record form for the hospital hand over our own staff would not see it.

all patients with registered disabilities details are recorded in [...]

They are also referred by Social services and local charities like [...]

to enable staff to deliver service provision it is essential that information is shared and recorded consistently. time is a factor that have to be managed and should not compromise peoples wellbeing, without information sharing process the service user will be unnecessarily stressed and at risk as per safeguarding practices.

We are a charity that serves people with hearing loss so we assume all our service users need extra support with hearing. Many of the deaf awareness techniques would apply to others with communication needs. As most of our service users are elderly and may also have sight problems we try and make sure our literature is clear and in big print.

Can put on [.....] system as an alert

Most commissioning complaints come in the form of a letter or email and we judge from that the communication requirement. I do have concern that the nature of commissioning means that we are unlikely to receive a complaint from a person with a severe learning difficulty as commissioning complaints cover quite a specific area and this is not easily understood or explained and is therefore inaccessible. That said, in my short time acting on complaints, we have responded to at least 3 individual complainants with communication needs and whilst this has in one case proven difficult, it at least shows that our complaints process is being accessed.

This is part of the Initial Contact Record and any subsequent community care assessment undertaken.

Don't think we have thought about this before. We don't seem to have any issues around Carer communication.

Or if carer did not want this information to be recorded / refused consent.

Sometimes it is unclear to staff whether someone may have a communication difficulty and the question may not have been asked. Sometimes a member of staff may know the person has, for example, a hearing problem and will therefore be aware when telephoning etc. but not have thought to record it.

Also I think there is not a prominent enough space for recording these details which are recorded as generic (i.e. English/visual loss needs information in large print or on tape). To have a free text box to say what the person's first language was (might be BSL) and then what the preferred and individualised method of communication is would be more useful.

I would always record this information.

Not systematically though.

We can identify if a carer is registered as disabled however we cannot use our system to identify any other needs in relation to specific communication. This is something I will raise with our [...] team as this information would be useful to us as professional supporting clients and working alongside families.

If the question is not asked at referral, it can get missed until the file is audited as staff will be concentrating on delivering a service rather than updating electronic records.

Very often the information is not shared with us prior to a first admission/consultation. Another issue is that we are currently unable to produce letters in e.g. easy read or braille easily as our OP letters are outsourced. We are better at providing interpreters as the need is logged at the time of booking follow up appts.

Question on assessment form but is not routinely asked or completed. Information often held in summary or elsewhere on the form.

There seems to be a number of issues but even when it is recorded the practicality of where that information is recorded so everyone that is involved with the person knows about it from the very beginning is an issue. Plus a discussion with person must take place to ascertain the right way to support the particular need not just staff assuming or generalising about what is required.

we might record this information, I do not know as it's not my department

We undertake an annual survey of members through a questionnaire about their experiences of the service.

We do record this where we can, but not in all cases, for example if someone contacts us with a simple query or signposting need, we may not take their full information, rather we take what is required to fulfil their query.

Unless they only want signposting, information or advice.

Where someone does not have additional communication support needs, these are not consistently recorded as this should not have an impact on how they interact with staff of the organisation

[...] is not entirely friendly for recording this information e.g. it seems to want the carer to be a registered patient at the practice, which is often not the case.

Needs are so variable it would be best to have a free text box for them.

Team members lacking of knowledge in identifying their communication needs/lacking confidence in their ability to correctly identify needs.

in cases where it has been missed

Once armed with the information RECORD IT.

No excuse.

Currently, in general terms the practice of recording patients support needs is ad-hoc and depends upon the competency / awareness of the practitioner completing the paperwork.

I work as an interpreter and interpreter trainer, interpreting researcher. My interest in this matter is in improving the interpreting, translation and language support needs and since interpreters in visual or spoken languages are required by their code of conduct to be impartial and confidential, recording such data is outside their remit.

There is no credible reason for not doing this.

As a Learning disability service it's a vital every day thing for us and our S/Users

Our requirements to record more information are becoming more important when looking for more funding streams. I am changing our customer service model to more accurately evidence the work that we do.

This will be eased by a new computer based system but also a change in charity ethos.

It depends what part of the organisation the person is accessing - we do not provide patient care

As part of a patients support plan

Occasionally due to admin errors or if referrer does not inform us but then will be rectified

A number of factors may apply in pharmacy (more than one response above). It is likely to be not enough time, but it may also be that the PMR system is not designed to easily enter and access this information.

The main difficult we have is being aware of the communication needs for the patient before they come into the department. ~Often we are given little if any information about the patient's communication needs in our referrals from the GP. We record well once we have seen them within the department

We are a local voluntary/part time paid charity, and therefore for which we do not have the resources to provide a professionally managed admin system. However, where we consider it necessary to do so we will place any relevant and/or appropriate information on file, and will immediately register our concerns with the Duty Officer of Social Services. Whilst thereafter we will maintain a 'brief overview' of matters as they occur, it is extremely rare for Social Services to keep us advised of their progressions/ actions in such matters. Where then is the 'Working Together' scenario fit in here???

staff not knowing why some information is asked for and therefore not seeing the importance of collecting it.

We do not have authority to get a social worker or carer or GP to do more for the patient.

we record when it is applicable

the main reason for not extending the recording of needs is the ability to respond consistently to a need, this is due to the complexity and size of the organisation – these areas can be addressed in individual services but putting in place a consistent system across the organisation is the main challenge

## Appendix 11 – Health and social care professionals and organisations survey, Q7.

**“If your patients, service users or customers need information in an alternative format or communication support, what do you currently do about this?”**

Sometimes this is not possible due to time constraints and IT issues within my organisation.

the system only lets you tick 1 option! i would tick number 1 and number 3 for this.

Unable to 'tick' more than one response to this question but we have a Total Communication Now project that was developed by our speech and language therapist to help people with communication difficulties produce information to help them in their daily lives - e.g. pictorial daily activity planner; pictures to support what the person was trying to say - i.e. on the bus, having a card with destination written on it. Funding may not continue beyond this year!

This is an anticipatory duty under the Equality Act 2010. Any answer other than 1, 2 or 3 is NOT acceptable. We use a combination of 1, 2 and 3, but the survey doesn't allow more than one choice.

This varies by way of communication support reqd. I was only able to select one and not able to select all as requested therefore copied below each that is relevant below.

We have a small number of staff who produce accessible information, and have been trained to do this. However, they all have other full-time jobs, so their capacity to do this is limited. However some documents are routinely produced in an accessible easy-read format - e.g. minutes and agendas for all Learning Disability Partnership Board meetings.

There is no overall process for deciding which documents need making more accessible and ensuring that this happens

Other languages is via a contract

Through our PALS dept.

It depends. If the patient requires a leaflet in large print then we can provide that. If they require language interpretation then we routinely provide that for the appointment and use that occasion to have the interpreter read information leaflets to the patient/parents. A lot of the leaflets are available through the [...] in other languages and we can download and print those off for parents if needed. Appointment letters we do expect the parents to make alternative arrangements themselves to have a friend translate.

Will use resources we have as well, pictograms etc.

Varies.

Social work documents (e.g. assessments) - don't know.

General information - via communications dept.

Involvement

- Audio disc - agreement with supplier
- Font size / paper colour etc.- alter internally.
- Easy Read - use readily available (e.g. DOH) or make our own

If not possible in-house, use external services e.g. advocacy/interpreter

Easy Read documents are produced in house. Other methods of delivery can be sought as and when required by external suppliers

it states tick all that apply, but the computer won't let you tick more than one. As well as in house Trust accessible information, we also access other services, such as BSL, and interpreters service. Also we can personalise information to the person, using individual plans.

We are not able to tick more than one choice. We have prepared some commonly used easy read information. We also use manikins, pictures or CD information where it is available. We also have access to staff that have learnt Makaton. We usually use the passport to support patients with a learning disability, though we have used it successfully with a patient that had profound deafness with success.

This would dependant on personal need - it could be any of the above dependent on service user need - but will only let me highlight one answer

Unable to tick more than one above although it states to tick all that apply. We have a language line for translation or we use family. We have easy read communication books for use on ambulances and easy read information available for patients on various aspects of the service

Interpreting services including sign language interpreters are very difficult to obtain,

Would not allow ticking more than one option - also want to select arrange through a contact with one or more supplier.

All of the above except Ask the patient, service user or customer to arrange it themselves

also this is done with involvement from other bodies such as [...], Speech & Language Therapist. Staff will use own expertise and training is also provided to facilitate staff gaining skills

Company provide all information in easy read format, but this is not always accessible for people with profound learning disabilities

If interpreter required this is done via contract with an external supplier.

We do this through our speech and language therapy team and through our dedicated accessible information post

It would depend on what the support needs are e.g. dyslexia in house, translation into another language is according to need - if legal responsibility translation service can do, if no legal responsibility then payment can preclude us meeting the need.

I am conscious that I have not yet been asked for communication in a format other than written letter, written email or verbal contact in person or by phone but that it should be expected that I be contacted by complainants for whom English may not be the preferred language, or they would prefer easy read or some other method of communication. I know that I am resourceful and that when someone comes to me with a complaint requiring specialised communication support, I will find what is required, but that seems flawed to me, as the process should work regardless of the resourcefulness of the facilitator.

We have facilities to produce audio, coloured backgrounds, easy-read, large print etc. in-house. In other cases, we would outsource via approved providers (e.g. foreign language, braille).

If a spoken/signed translation is required e.g. signing or verbal translation we source this requirement locally - for example, the manager of the local service will find an interpreter locally.

In [...] we have a translation service and we also have a member of staff on the adult access team that speaks several languages/dialects. We also have in-house sign-language practitioners. We also have a text phone for clients without speech.

it would be defined by the individuals personal needs and we would find a way of making information available to them

We have very few service users who need alternative forms of communication. For those who do we have staff who are trained in the use of Makaton. We also use symbols, pictures, flash cards etc.

Each individual circumstance is different and is treated accordingly. This may mean that it is best that we produce what is needed internally, or it may be that some equipment or technology is best sourced from elsewhere.

We would use the L.A for support if required.

Dependant on situation and format that was identified to meet the need. We have some facilities in-house but may be required to go to external agencies on occasion.

I would say that no-one in the organisation is very clear about this aside from the few people who deal specifically with sensory issues.

I would attempt to provide it in the most appropriate format for the individual but if required would seek through a contract or agreement with the departmental identified supplier.

also have used the following site [...]



We also occasionally produce information in alternative formats internally.

Sensory support teams, interpreting services.

Request via communications lead

We have speech and language therapy in our service so if this needed we refer to SALT

We also provide information/support internally

Won't let me tick all that apply - easy read, I can produce in-house. Braille or moon through personal contacts. Interpreters - we have a contracted service and also employ our own in-house interpreters for the most commonly requested languages. We have excellent relationships with [...] and [...] for DBM communicators.

Also have a contract with a company who are able to translate information into a BSL format.

We provide some formats internally (large print, easy read) and other formats are arranged (certain languages, braille)

If the person is registered blind and usually read braille - we are unable to provide certain information in this format. In these instances we ask the patient to seek Support of friends/family/carer to read information sheets/advice regarding exercises etc.

Sorry would not let me tick more than one so answer is depends on the situation, may use outside professional for communication or in house material if available or our own equipment and sometimes patients will make the arrangements given the option

in house can produce large print, braille or CD/tape. Many clients now prefer things sent by e-mail

We do more than one of the above but this is set as radio buttons not check boxes so can't record

Arrange through contracts as well as in-house

Would probably refer to the local authority for potential support

Some things we can do internally.

We provide easy read information using [...], plain English and some British Sign Language interpreters or DVD's.

We also provide Braille information to people who maybe be deafblind.

Interpreting is provided by a contract with one supplier. Putting information into easy read format is done in-house usually with support from Speech and Language Therapy.

We can provide in house in limited instances, e.g. large print info can be ordered. We may also signpost the person, e.g. to the local [...] who can provide a more appropriate service.

Sometimes I provide the material (adapted) myself.

We make extensive uses of [.....]. Formal and informal carers can help with interpretation or BSL sometimes.

If the communication difficulty is not stroke related we would source what support the stroke survivor could have from statutory, private or voluntary organisations.

Also through personal contacts on occasions.

Although at present this does not happen consistently and there is nothing in place to control the quality.

We have our own easy read leaflets which were developed within the team

Speech & Language therapy is an essential component for providing accessible information. People with communication impairment are not included in your definitions of those who will benefit. For example, 1/3 of people with stroke have acquired aphasia (language impairment) but this is not taken into account when providing generic organisation-level information. It is possible to devise 'aphasia friendly' materials and there is a growing literature about this.

It depends on the need. If the client requires an interpreter then this has a standard arrangement with a company. However for people whom have poor literacy then a practitioner tries to find a resolution/tries to alter their practice if possible, although this often is not resolved.

Limitations of clinical research are that all documents must have been reviewed by ethics committee. Have in past enlarged photocopies to allow larger print to be read

It depends on needs, if they require a British Sign Language (BSL) interpreter and information translating into BSL we do this in house with our staff interpreters. If they require other communication support i.e. deaf interpreter, lip-speaker we buy this in directly as we have a pool of communication professionals that we have honorary contracts with and they have undergone DBS with our trust. For other spoken language interpreters we go through the Trust as they have a contract with an agency. This is also the same when we require letters translating into another language (except BSL where this is done in house).

We use [.....] and the local council interpreting service. have not used any visual impairment aids though

Custom support

I would like that in large print. No problem.

In addition the information can be supplied in alternative formats via in-house publications.

translation services

interpreters

depends on need and available resources

Some information through in house Occupational Therapists, other through access to external services such as Interpreters, other times through local third sector services.

I have a sign language qualification so I give patients translation however I am not specifically trained to interpret dental/medical issues

We currently use a provider of services who are very approachable and efficient.

Interpreting and language support workers will be commissioned soon, and will be supplied via agency contracts. The vital link is to train staff to notice when support is needed and to challenge interpreters who turn up without ID.

Part of my role is the sourcing or development of easy read information.

Large print, Braille, CD and data stick.

Some in house others in partnership.

We would ask the supplier to provide appropriate communication support

We use [...] to help us with information for people with a learning disability

We develop easy read documentation in-house, use objects of reference, assistive technology, etc.

plus contract with suppliers for telephone interpreter maybe others but these are the ones I have used

Adapt to meet the person's needs e.g. [...] or ensure someone who knows the person is present. Depends on the individual.

We also have interpreters if this is appropriate.

Would seek local support for this, if appropriate agencies are available locally to do this.

may require support from Sensory team,

translator etc. IMCA may also be involved if Mental capacity is a concern

Whereas it is acknowledged that we do, and will, continue to work with our members, parents, carers and family members in a very professional manner, there is obviously a limit to what we can achieve with the very minimal resources we have on hand. We are a multi varied organisation of many skills, our Executive Committee comprises a representative view of parents, carers and family members, and

therefore, subject to levels of privacy, we seek to manage and support our colleagues to the best of our ability - and theirs - wherever we can before taking any other avenue or support.

Please note that the system is not allowing me to tick all that apply, as option 1 (formal contract) and option 3 (in-house) both apply

sadly, nothing.

Good communication access is a hallmark of our organisation. We ensure that all text follows good access guidelines and we provide people with the possibility of different formats (auditory, visual, etc.). We train volunteers and all staff on good communication access and to be able to have conversation with people with a range of communication impairments.

We explain in person, by phone how to better manage their medication.

Depends on the need and the resources available and whether interpretation services are needed, in which case they would be brought in. [...] helpline is also able to support provision of information to people who need it in different languages. We use a telephone interpretation service where required, to make arrangements for an interpreter to attend where the contact does not speak any English. Family members are not used. We can also call upon [...] to translate any of their resources.

## Appendix 12 – Health and social care professionals and organisations survey, Q10.

**“Please add any comments or explanation about the difficulties you / your organisation experience in recording and / or responding to patients’, service users’ or customers’ information or communication support needs.”**

Personally I have difficulty with my health partners where they are not forth coming with offering joint funded support services, for S/User who wishes to remain in the community via direct payment.

we refer to our superintendent dept. for help

Recording and responding to needs on an individual basis on request is not a problem. The Trust has clear guidance and systems for producing easy read and access to BSL interpreters. The challenge for the Trust is a systematic way of identifying patients with a need and responding to this when systems are automated or where systems do not easily adapt.

I feel very strongly that people with Learning Disability should have access to some materials that contain text that is supported with symbols. Most of the resources focus on easy read text versions and these are not accessible for the majority of the people I work with.

I work as part of an LD service so assessing communication and supporting people's needs in this area is a big part of what we do. Often in generic services this is not found to be the case however, possibly due to time constraints, lack of experience/anxiety with working with people with learning disabilities.

Time / capacity and resources to do this.

Service Users in my service are visual impaired and not able to use braille, we normally read it out for them and then explain things to them ourselves.

accessible information is not readily available and littered with logos and corporate information and branding which detracts from the original point of the document.

lack of accessible or easy read information from partner organisations

We don't have any issues, but then we are an organisation led by disabled people, so that's unsurprising.

As far as I am aware we do not have a system of finding out whether patients and others find our communication systems accessible.

We have staff who can and do produce easy-read information. However, there is no system in place for prioritising which of all the Council's documents need producing in easy-read formats.

Our database has been designed to include all forms of alternative communication requests and staff are required to record the persons preferred choice before closing a case.

This year, as every year, my NHS Trust (A Learning Disability and Mental Health Trust) didn't produce any of its annual reports or business plans in Easy Read. They do not routinely supply Easy Read information on its services. Its website is not designed for someone with communication or comprehension difficulties.

The only difficulty is that as we become more aware of the Clients situations and needs we need to record more and more information. This provides an excellent level of care and understanding but the admin needed to achieve this can be hard when services are being so stretched.

Often a referral states someone can lip read and communicates orally, when they are given the opportunity to communicate in British Sign language they prefer to use this.

Everyone is given this option irrespective of the referral information

The only difficulties we have is when we are not informed about a patient or parent's need for different support. If their spoken English is not adequate for discussion then we may have to rebook with an appropriate interpreter. That said most of us sign so can manage BSL.

Addressing additional communication needs is an embedded part of good practice engagement and therefore addressed at the planning stage of engagement activities

Occasional IT difficulties

Funding for translation, easy read, braille etc. Very expensive to do. Also focus on online information only, limiting paper materials.

Staff generally have a very limited awareness of the communication needs of PWLD. This awareness is growing but is not yet embedded in practice or systems.

Recently completed [...] training adapting these principles to our literature we produce.

Every person with a learning disability is different no one generic accessible format fits all need. Pictorial information is different and there has been no standardisation of what depict what so different organisations use different pictures even from the [...]. If one picture was agreed then this would help if used in accessible info such as consultation easy read documentation and procedures. Obviously for personal needs photos may help and different symbols would be needed to be used. This however, is time consuming.

Lack of easy read / pictorial information available

we have a range of accessible, easy read leaflets about a range of topic, but can also access resources externally. There is lots of information in accessible formats on the intranet.

time constraints

inconsistency of practice

difficulties arise due to time constraints in recording all information in detail.

Having the right amount of information available for patients and in a format which meets all of their needs is challenging. Living in an area of diverse population information in a range of languages is important but storage and amount of usage is hard to predict. A central library for downloading as necessary would be ideal, both written and auditory information.

We do not have problems in this area, we work with those who have learning disabilities, complex needs, autism, we use a number of methods to aid our communication with the service user

We have a standalone Sensory and Telecare Services Team, supporting people with hearing loss, sight loss and telecare solutions. Staff are experienced and well qualified to support people with the full range of hearing loss / sight loss / dual sensory loss.

There simply not enough information that is accessible to all. Patients with additional needs are not always identified as needing support on current systems, this means it is difficult to establish their requirements.

Most accessible information that is used is developed externally or found via internet

In an instance where an interpreter is required, service users may experience a delay in service provision.

Getting IT systems to produce easy read versions of forms and information

Everyone needs information in a different form, so standardised leaflets are seldom appropriate.

I tend to make bespoke information for a small numbers of patients, with the highest level of need, but am aware that there are many who miss out because I am too busy.

I also feel that other staff are not confident/skilled enough to pull together non-standardised information accurately and appropriately.

Primarily technical and statistical output so generally consumed by capable users

Our electronic system is very slow

our process of contacting clients to triage is usually by phone as this is difficult. if communication difficulties are not known, this can lead to a difficult and confusing conversation. if unable to communicate by phone we will write to clients, but this can delay intervention with them.

Care needs are not always accurate as Health colleagues do not fully appreciate the roles and responsibilities of Adult care teams.

Electronic systems do not support recording this information.

There isn't enough Speech & Language Therapy provision to support communication partners in the production and implementation of personalised accessible information.

Delay in having information transferred into alternative formats.

recording is taken over the direct provision the demands to keep records are greater than the time invested in it and this mean time that could be spent with service users are compromised if we need to do both well, staff priorities lay with communicating and working directly with service users, the organisation have to demands and emphasise in staff to make more records to meet regulations and concentrate in demonstrating to inspecting bodies the delivery of provisions with tight budgets.

Deaf customers frequently text the office but do not give their name.

Feedback indicates that we meet the communication needs of our service users.

Organisational communication to the people we support is not in 'easy read', we expect the support staff to give them the information in a way that they find meaningful.

People with profound learning disabilities are sometimes difficult to reach and communicate information to, we try and use all methods of communicating with people including objects of reference, pictures, photographs, but this doesn't always work

I work in a specialist Learning disability service and so Communication needs are consistently considered, however other services do not always respond to the information that is passed on. GP practices are ideal for transferring information and adding this to summary care record, they do see this often as part of their role or know how to do this.

limited sharing about information communication issues

Loss of skilled staff, lack of awareness that one size does not fit all. Service providers need training to understand the range of options required to truly meet the communication needs of people with LD. Staff need training in symbolic development as there is a tendency to assume everyone will be able to understand process symbols. although we have come a long way since the introduction of total communication approaches in the early 1990's we still have far to go to ensure services and staff adapt their practice.

work needs to be undertaken at a strategic level-in under graduate training- social workers, LD Nurses, support staff all need training in Total communication. Knowledge of a range of approaches ought to be a pre-requisite for any staff supporting people with LD, the issue is wider than accessible information.



Financial cost.

Making all staff aware of issue.

providing information leaflets appointment letters in accessible format as can be very time consuming -

One of the biggest recent hurdles has been the restructure. The commissioning structure has altered dramatically with significant implications in respect of confidentiality and information access and sharing. The fact that the NHS is not a single organisation is a complicated thing for the public to understand and so our inability to share information without consent seems ridiculous to many of our complainants. Similarly, it seems ridiculous that our new structure should so dramatically affect who can handle what in terms of complaints.

Sometimes there can be a delay in information being sent out from our main office

We don't have any difficulties with information or communication with our service user needs. Our difficulty is in getting other professionals to listen to us as the people who know our service users and their needs best. We can take information with us to appointments but we are not listened to. Prior to appointments with a complex person we would let GP's, dentists know that this person cannot be kept waiting but we still end up waiting.

Sometimes it can be difficult to get hold of other relevant professionals with regards gaining detailed information, more joined up working is required here to ensure needs are met. Out of hours needs can sometimes prove difficult, especially when requiring a GP as they do not always have the information they need about ongoing care and support so far.

Difficulty in booking signers at short notice

We find that easy read, and audio versions PLUS 1:1 support to understand info solves most problems without the need to outsource too much.

Mostly because of the language barrier.

None - we will always manage to respond or we will ask a partner organisation to assist us, particularly around items that may be needed in Braille or audio,

generally speaking, we look for appropriate ways of communicating with the individual.

For older people with sight - hearing impairment then they will often need additional funds if they are to receive appropriate support - this is not always the case in terms of financial support e.g. an interpreter for sign language at perhaps a tribunal mtg. The interpreter is needed so the individual can take a full part in the proceedings which are about them and their situation. This will often cost a significant amount of money

Symbols (Easyread) can be useful dependent upon the individual's level of understanding but do not work for everyone. For example, if you read the minutes

from a meeting that has symbols alongside it to explain the text, try taking the text away and see if you can make sense of what the symbols tell you. It is virtually impossible yet we expect people with learning disabilities to understand this!! For me, the best form of communication is the spoken word using simple language. A CD containing the spoken word is a much better way of communicating with service users. It allows the service user the time to digest what has been said, and any areas that they are uncertain with can be rewound and played again. Most service users are familiar with CD's or even voice recording on their mobile phones which is another mode of communication we have used. If the CD is re-writable then it is also cost effective, it also allows other agencies/parents/carers involved with the service user to listen to how the service is communicating with the individual, (if the individual wants them to).

None we are a Deaf Charity so can accommodate a range of communication methods for those people who are Deaf or Hard of Hearing. Where Service Users have English as a second language we endeavour to meet their needs of providing information in an alternative format.

We use external sign language help as appropriate and some of our team are trained as well. Short staffing leads to a reduction in recording. Better resourcing would help.

Availability of accessible materials - standard packages can be costly ([...], etc.)

Staff have variety of skills including BSL, so allocate according on worker who is most appropriate to meet the needs.

making sure people's needs are met with accurate recording from all people involved in their support.

Sometimes circumstances changed and as a social care team we are not informed

We endeavour to provide timely and appropriate support,

Sometime patients goes home before staff gets a chance to record information, due to shortage of staff and not having enough time, but that no excuse we all should make the time because it reflects badly on the service we provide if we do not get back communication on patient needs

No difficulties in responding to needs / requests.

Not all staff may be aware that this information is provided although it is advertised within the organisation

Within my current service it is more external agencies who have difficulty in giving accessible information to our clients often we are asked to convert their work into accessible format for the client.

When translations are needed they can be very expensive. Also few people understand that only 10% of blind adults read braille

- Not all council services use compatible systems.

- Changes to delivery arrangements of council services e.g. transferring to community interest companies, staff mutual, shared service arrangements, third sector providing council services etc. makes it

we have difficulty supplying BSL interpreters because of cost

is time consuming to make all info accessible but is vital to do this and to advocate for people who have reduced communication skills either clients who have difficulty understanding verbal or written information.

we have not been asked for information in any of the formats described below

Staff do not always complete the relevant sections of the form. But, if they did, it would not be immediately apparent where to look for this information.

People can have complex difficulties which require an individualised approach which social care have had very little training to be able to implement. There is no way of recording if people need reasonable adjustments e.g. letters in easy read as part of the assessment process.

Requested information needed cannot be disclosed due to Data Protection.

We have little if any difficulties as we are an organisation with a Deaf, BSL user focus.

This has not been a problem in the past.

translation services - only generally are available for 'booked appointments' and sometimes it is difficult to ensure the patients attend their appointment due to their lack of understanding of why they have been referred and translation services don't tend to contact the patient to book the appointment.

Multi computer systems and the way the information is put on the PC does not make it easy to share or see the obvious.

No cohesive approach, issues about confidentiality, patients choice and rights, even we see an obvious need patients may not want to accept or face it so it has to be sensitively handled and it is their choice but it may have consequences which affect treatment so it can be a complicated situation and again how that is documented so everyone is aware is difficult.

can't find responsible people, everyone works in silos and when asked simply say "don't know"

Previously had dedicated teams to work with people with specific needs, for example sensory teams and learning disability teams. Now more generic working and skill base is reduced - a need for learning across teams.

Sign Posting to other support services as well as our own.

Few of our members suffer with a learning disability and we tend to discuss any potential issues with the carer/relative in terms of safety issues. This may include

ensuring the member has the carer with them at all times and to keep the speed at a minimum.

If members have deteriorating vision or cognitive impairment a judgement is made as to how safely a member should continue using a scooter. Should a disagreement arise we suggest the member seek confirmation from a GP or consultant regarding suitability to use.

Communication support in terms of interpreters can be costly as can providing all information in a signed DVD format so sometime resources are limited.

D/deaf staff use their access to work agreements but people we support aren't entitled to this unless they work which could then interfere with their benefits.

Providing information in an easy read format is still not seen as everyone's job so a very small number of people are trying to provide this service for the whole organisation. Often information is provided with inadequate time to produce it in easy read.

It is difficult to get consistency of information across the organisation.

Often nationally produced information is being made into easy read by loads of different people across the country which seems like an enormous waste of NHS resources as one good version could be produced and then disseminated for individual additions from organisations e.g. Mental Health Act information

Questions arise as to who's budget is responsible.

Lack of understanding for the need to look after the mouth and information required for dental team to provide care

We have a co-ordinator who works specifically with people with a communication problem after stroke.

In primary care, significant support is needed relatively rarely, and the time and expense of outside support is difficult to justify. [...] works for us as they are quickly accessible, there is little waiting time, and I think the contract is shared throughout the area.

Some services that were once met through Social Services have now ceased locally e.g. support for people with hearing difficulties. Telephones and equipment was once loaned by Social Services but now has to be purchased privately. People used to be assessed in their own home and provided with or advised about the most appropriate equipment to purchase.

Challenges which present in the job are service users who have profound communication difficulties including extreme emotional responses to visits. These are usually overcome by repeat visits and use of total communication

Difficulties arise not because of lack of willingness but due to lack of skills. There is also a desire not to do things in a tokenistic way and that one size does not fit all when it comes to accessible information. There is also currently a lack of access to

the correct resources and staff lack knowledge/skills and confidence in adapting information to individual needs. There has also been nobody to drive forward the development and use of accessible information.

Service users often are given accessible information by other services that is not accessible to them need to provide very individual responses to people's needs

Lack of technology , equipment and understanding of how to use it

I from the local CCG work with Council colleagues to support and learn from service user/ patient experience as shared at: Quarterly meetings with representatives of the deaf, hard or hearing and visually impaired communities; Bi-monthly meetings with (i) older people and service providers and (ii) people with mental health issues and providers. Agendas driven by all attenders. Other more ad hoc get-togethers and consultation

Lack of external resources.

It is extremely time consuming completing clinic/interaction if a patient or service user who has communication difficulties does not have the appropriate/working coping device e.g. hearing aids/pen and paper/pictures/ interpreters etc.

sometimes we are not aware that patients require extra communication needs until they walk through the door and then we might need to re arrange a consultation so that it benefits them

In a specialist clinic, there are no nationally agreed resources for patients with communication difficulties. We have to create them with each patient.

I believe as we are a learning disability team we aim to provide easy read information and appropriate communication for all. There have been some difficulties in the past with regards to use of interpreters as messages have been misinterpreted.

I work with a caseload of communication impaired adults in my SLT role. I am paid for patient contacts not for educating/training staff or improving systems, although SLT input could make a radical difference to design and delivery of accessible information, as well as advising on useful information for recording about patients and carers which will inform strategies for those individuals

People with poor literacy skills are very poorly provided for. People whom have some form of learning difficulty can only be seen by a specialist service if it is profound. Persons with mild to moderate learning difficulties fall into mainstream service and are very poorly provided for as there is no skill set within the staff, no training available for staff and no specialist resources available. As a service we non-intentionally heavily discriminate against persons of this type due to the aforementioned factors.

The only exception would be if the service user's parent / carer did not inform us that they have a language need or for signing where a parent / young person is deaf.

More often than not we can check on [...] whether there are any previous bookings for such clinics and act upon the findings.

Difficulties organising interpreters for clients who are deaf

In taking referrals, there tends to be at least a degree of information in the patients' records. There is also a contact through the referrer, who will be asked for anything that the referral teams might need to know. However, in the patient-facing part of our role (Walk In Centre) there is simply not enough time to take this kind of information, short of asking non-English speaking patients or their carers if they require an interpreter. Any in-depth enquiry into patients' communication needs would simply be impossible due the time and volume constraints already on the service.

We find that it is extremely important to make sure we always find out and understand a child, adolescent and families communication and language needs, so much so that we have been innovative and created a communication profile for this very purpose. We now use this throughout [...] and it has become part of the care pathway.

There are some languages which [.....] do not cover.

out front door is not automatic so difficult for self-propelling non/motorised wheelchair users to open the front door without assistance.

no grab rails in toilets, no disabled toilet

Each patient is holistically assessed. We deal with the patients' needs/requirement and act upon any problems/referrals on that day

Service users have to repeat their story a number of times. Risks may not be reported accordingly and information can be lost.

Patients do not necessarily volunteer this information themselves, or identify themselves as a carer when looking after their spouses.

NHS system and social care records not compatible, individuals end up with several ID numbers and we cannot share information easily across services. Human error in recording ID numbers can cause delay and several entries for the same person.

I feel British sign language users are not treated as well as hearing patients in many areas of the NHS and am very hopeful your survey may improve things.

Staff really all need Deaf Awareness training. To deal with both deaf and hard of hearing people. We have nothing for Braille users at all. I will raise this at my practice.

Would like to be able to take electronic database on the move. Making it available on tablets and other similar devices.

do not experience any problems.

we encourage the patient and family to be open and honest as much as possible, we give them time to talk about problems or fears, and try to find a joint solution

Lack of information/unable to contact certain individuals.

This has been a problem area and has resulted in patient complaints and sadly poor patient experiences. we are introducing a wealth of changes and support but are challenged due to lack of funding and / or other areas seen as a priority for funding. We are changing our core assessment document and offering staff training to reflect patients communicating needs. we have scoped all equipment we currently have available in ward and depts. to support patients , i.e. portable hearing systems, hearing aid batteries, magnifying glasses to ensure consistency and equality of availability. we have conducted a hearing loop audit throughout the Trust and are working on our maintenance contract to support our findings. we hold awareness raising sessions for staff and celebrate deaf / blind week inviting local and national agencies to hold events / have stalls in our Trust to raise awareness. this is just a sample example of what we are trying to do to improve patient experience and raise better awareness with staff.

Poor internal communications lead to interpreters not turning up, possibly due to low pay and a better last-minute job offer. Interpreters often arrive to interpret in the wrong language. Many interpreters have neither training nor appropriate qualifications. They are not affiliated to any professional body or regulator meaning that they exercise power without accountability because they are not bound by any code of conduct, which trained professionals are. Mental health patients can often spend months being interpreted for and still not know what their diagnosis is, because it has not been possible for the doctor to follow any hypothesis or treatment plan. This leads to patient DNA rates going up and the costs of wasted clinic time.

[...] does have a list of approved BSL interpreters and communication support workers they use. There can at times be delays in responding to service users or customers support needs mainly due to timescales. For example, when arranging an interpreter or for information to be put into different formats such as audio tape, braille or easy read, we use external third party organisations and there can be a slight delay in arranging these services. We are always able to arrange these services, but cannot always fulfil requests immediately. [...] also provides [...] telephone and written translation services. When telephone translation is required, this can be accessed immediately by the person accepting the call. Written translation can also be accessed, although these types of translations can take longer to organise, from 24 hours up to 10 days dependent on the nature of the request. Service users, carers and customers are always kept informed of any potential delays and given and anticipated timescale for the request to be completed.

The absence of an NHS IT system which would standardise recording across the whole NHS structure

Lack of standard set of visual images

A lack of standardised accessible information, every different trust produces (and probably pays for) its own version or branded pieces

The NHS photo library is for producing corporate info it needs revamping to allow for real life images that would be relevant to explaining things to patients/carers with communication needs

Waiting list for SALT can be a problem.

We try to make our own resources especially when explaining something for consent.

Although for us specialist LD nurses/community teams it would be wonderful and speed things up to have a nurse assistant who is clever and whose job it would be, was to support us with making tailored pictorial resources on the computer that we need for every day work. for example ,teaching new skills, health promotion, behavioural etc.

We don't have problems. We are lucky enough to be able to respond to most requests.

The variety of information provided and the ability to put this into the various formats required - easy read, languages other than English.

Easy read information available from third parties is often not of an appropriate quality

Each person has a communication assessment so we are able to interact in their preferred method before we begin to provide them with support.

we are aware of information currently not available in an easy read format and as an organisation are currently looking to address this issue

only difficulty is inflexible appointment times-hence clinics may run late

The biggest issue we have is access to suitable graphics software and license limitations placed upon us.

We work in a community learning disability team. Our clients have difficulty with other organisations that are not adapting their communication styles to meet their needs.

Various NHS Trust websites provide different formats for general medical information (e.g. information about procedures, hospital appointments etc.), but there are few resources for specific medicines, although commercial translation services can provide this at a cost. For this reason, many pharmacists will not seek alternative information formats, unless they know they are readily available

There are no difficulties, as this can be included on the communication assessment part on the holistic assessment. However, the assessment requires time to be completed, time that is allocated to paper work, however needed, time also needs to be spent with patients.

We have generated our own easy read information but this was time consuming and we had little support. Other languages are poorly catered for in our department for



written information, although we use interpreters for appointments. We have [...] (online translation) set up for when we see the patient without future notice, this also takes extra time and means that we run late for our other patients.

Firstly a recognition of the work that we DO carry out in the local authority by providing us with the financial/admin support that is sadly missing in our work locally. 'Care in the Community' (Health & Social welfare) can only be established and provided by individuals who have been appropriately trained and skilled to understand a person's needs, and what is being meant by what is being said.

[.....] is perhaps no different to any other authority in having a team of young Social Workers who have been taught their skills in an educational establishment, but who in turn continue to fail in clearly understanding the needs and pathway through life of what the client needs. Whilst then 'ideals' are often the goal, the 'reality of living in the real world' is the medicine of cure for those we support in our local community.

historically this has not been done and staff continue to work in ways they have in the past. external standards are a must if there is to be systemic change.

occasionally, we may find the needs of people with profound multiple disability more demanding. For instance aphasia + visual impairment. Here we would seek to collaborate with other organisations to best meet the client needs

## Appendix 13 – Health and social care professionals and organisations survey, Q12.

### “What is the main reason for the amount of time taken to provide information in alternative formats?”

Due to having to source services externally and normally low demand we do not have resources on hand to deliver such a service more quickly

we refer to head office / superintendents with these issues, however we have not been requested at branch level

there are delays in contacting or receiving information from an external provider

we provide info in alternative formats as required, bespoke for each patient

Easy Read – produced ‘in house’ and usually information not generally available in easy read. Staff producing Easy Read are not experts. Large Print – automated systems cannot produce large print – this has to be produced on an individual basis. Do not always know about a need in advance. Providers of information, when this has been produced, do not send the alternative

very small team - can be difficult to locate appropriate resource or get access to office to print off copy of materials

Not enough resources.

We do not currently have an internal system for braille, audio or easy read. Large print can be turned around fairly quickly but otherwise it can be a slow process using external providers which we have contracts with.

I don't work directly with service users which is why I'm not aware of specific time frames on providing various types of info. We have a lot of easy-read information in-house and Nurses and Therapists can produce pieces of information specific to individual's specific needs.

consulting with service users, re-drafting versions, etc.

It not being available already - some things have to be created.

Knowing how to request items - i.e. braille documents is not always clear.

whether funding is an issue due to the cost of printing alternative information - e.g. colour photo copying for easy read documents.

It would depend very much on whether it was general information (e.g. on personal budgets) that we already have an easy read leaflet on - this may take only 1 day as it would be sent out in the post/handed to person following the request. However, if there is no leaflet or the information needed to be tailored more to the individual this would take much longer. We make easy read leaflets in house (i.e. in our social services learning disability team).

Finding time to develop easy-read ourselves. Also, info relating to criminal justice system are usually more complicated. There seems to be no resource to use or to help us develop easy to understand info.

information is processed via the Trusts Documentation Group, who check for it being user-friendly,

Audio equipment required to assist in carrying out assessments are available on request in the Trust.

translating into easy read or developing accessible information can take time

This is an anticipatory duty. All of these materials should be available on demand and their production should be built into publisher's planning schedules. Failure to do so exposes an organisation to a risk of litigation.

I have never had a request for Braille or Audio so cannot comment on how long this would take. I would approach our E&D team if required

Delays in receiving help/advice from external agencies.

We have some standard information already in easy read e.g. leaflets, appointment letters but if we need to provide an easy read copy of a report this will take some time to produce and depends upon the priority. We would not wait to be asked to provide this, as speech and language therapists in learning disabilities we would provide this as part of our input. We use [...]

Most requests for easy-read information can be processed quite quickly. However it does depend on the length of the document and other demands on staff time. Most short documents can be done within 3 days. Longer documents take more time. However we've not had any requests for information for specific individuals. All our work has been on documents that are to be widely circulated.

Large print can be done by staff internally via their computers. Braille, audio etc. are transcribed by contractors and sent to the service user once transcribed. If a document is urgent and requires transcription it could be done internally by qualified members of staff.

Arranging for the requests to be made available in other formats unless this is a piece of information that we have identified that is readily available in particular formats

Lack of appreciation of the requirements at Executive Level and lack of willingness to see it as a priority and make improvements

use [...] website. can go through PALS

Delays in delivery, we don't have a big stock of alternative formats. For that reason, I think all leaflets should be easy to read as standard, so we don't have to stock extra, and also so we don't make a big deal about people not being able to read very well. Easy read seems to be aimed at people with learning disabilities, but actually a high proportion of people can't read well, and it's nothing to do with IQ.

Most requests are met internally

Internal system but busy

I would need to refer this to a different part of the organisation.

We don't routinely send information in braille (as our specialist service works with Deaf people) so would need to arrange this through using local contacts.

I do not provide this - it is done by a different department.

These are specialist industries that require notice to prepare literature.

Braille required external provider

Easy read is not something we use very regularly so it takes longer to think it through

Large print is easy as we can edit documents

Access to appropriate IT programmes and working part time.

not seen as a priority within the organisation

Easy read - I routinely provide all information in easy read, it's simply the format I use. This is not the case for other departments.

Admin time required to do this

Availability of internal staff required to support with this

we need to arrange through an external provider

We don't have a dedicated staff member/ team to develop easy read info.

It depends on the information. Braille and extra-large print are usually available but the content may not be updated regularly. Easy read and plain English documents are not widely used

Keep some copies internal if not external so need to be produced and sent over.

No set format or procedure for info. Cost of [...] for small organisations. Most important no actual specific staff or money to do this. So ad-hoc and dependant on staff skill/commitment and more importantly time

Level of urgency and the availability of trained staff internal will determine the waiting time.

I'm sure we have audio, or web links etc., but I have not been required to use them

Time required to make resources as they are done internally.

we are able to provide easy to understand information internally however information in other languages, audio or braille would need to be requested from other services

We use accessible information routinely and so will provide this when appropriate.

in response to the above question, it depends on what information is required. We have menus available in a variety of languages, Easy read, braille and large print but this is exceptional, rather than routine.

Our service users need communication aids that are relevant to their needs, therefore we may need to enhance what we use.

Resources within the Trust to provide this, if there isn't already the information available in Easyread format etc.

Generally our leaflets are in easyread form.

Able to meet requests internally

Time for agreement with relevant staff about ensuring the best quality in supplying the correct information for each request and admin associated with this.

not routinely available or directions on where to obtain this from

We liaise with an external provider to ensure that the individual needs of the service user are met, [...] communications team work in partnership with the service user to ensure that the correct amount of information is offered.

I am able to access information in my services - but not aware how the wider organisation affects this

They have to be created and developed - there is no one person who is allocated to do this. - external providers are used

There are no undue delays in providing information in other formats.

I tend to pull together information myself so at times there is a long delay (if I'm on holiday) though I try to respond quickly, usually within a day

Would generally be a novel request

Availability of supplier

takes time to simplify and find appropriate pictures etc.

It would be the time between making the request internally to the order being fulfilled. This can take a while dependent upon demand at the time.

Lack of assistant support in the production of resources.

Delay in receiving information in alternative formats.

In relation to Q11 time taken can depend upon what information is being requested in alternative format and what that format is.

all formats are internal except Braille which is contracted to [...] Documents are Emailed Printed and sent by Post hence the delay

we do this internally usually Keyworkers and manager is responsible for this, the information is individualised therefore each person relate information differently. staff and manager have to do this at the same time they dealing with other day to day task and activities. no time aside is available to attend just to this task which is a main factor for the delays.

the administration department provide accessible information that is general to everyone and could type stuff pending of the main cares/staff forwarding information and request clearly what is needed.

Audio due to lack of equipment on premises and needing to borrow.

External for Braille and never able to get a quick turnaround.

External provider response.

We do not provide a lot of literature to service users. The service is provided one to one and we seek to explain through speech what needs to be understood. Online information is available which can be read in large print. This is mostly about timetables.

Because of the nature of the charity we can always provide loops and personal listeners for people with hearing loss. But most of what we do is try and get people to use hearing aids which will be the main aid to communication.

The people we support cover a wide geographical area, therefore one of the better ways of communicating to them is by letter. Should anyone need braille or audio communicating tools, we would liaise with the appropriate professionals to ensure this is done.

This is all provided by head office, where there is a dedicated department making information accessible to the majority of people we support.

The nature of our work i.e. community information re activities and services, means that the range of information is large. Some of the information is already available in alternative formats others have to be made available as 'one offs' or to be accessed externally e.g. via external websites and organisations.

for individual patients this means clinicians taking time out of other planned work to produce information. For standard info this can take longer as it is often not required in a hurry.

we can meet most of these requests internally but usually rely on our accessible information worker to do the work - speed of response will be determined by the worker's current capacity/workload

delays in knowing what is needed and outcomes

The production of accessible information is skilled and extremely time consuming. We find the easiest method is to involve the owner of a document to training then offer a couple of support sessions to complete this work. We have a care pathway which outlines this approach as otherwise the clinical team would be inundated with requests.

Specialist software is needed and decent IT support which can cope with video images etc. far more efficiently. the key is to ensure the service provider or person wishing to adapt the information retains ownership of the piece of work and understands it is their responsibility to make the adaptations.

Information needs sourcing and it depends on what the information is how available it is.

time consuming as we do not have admin support

We do it in-house. In a learning disability team so most people are able to convert things into easy-read themselves.

Contacting our main office to arrange for alternate format can result in a delay as we are not based in the same building.

As a mental health provider, the majority of our service users manage with the standard format. Therefore, alternative formats take time to organise.

We are reliant on other professionals to provide information for any treatment that may be needed. If available we would request immediately.

I feel we respond well to these needs and that as a local authority we have systems in place that are readily available on request.

I'm sure we can print info in large print but this is up to the Admin staff so I don't know the details

We have easy read and audio versions of most key docs but these would need to be posted out.

We currently have no service users who read braille so do not routinely offer this - therefore we are dependent on suppliers turn-around times.

Because the service user is not provided in house so assistance has to be sought elsewhere.

The main reason for taking the time would be that we would have to contact a partner agency with regarding to issues relating to Braille or audio, Large Print and Easy Read are not a problem, but translation of forms would be purely due to the cost of translating a large document. However, we would be able to provide an interpreter to read the form.

We have to use external agencies/other charities who provide this help....the time is needed to make these referrals for support

There is different software with differing symbols on the market today which can lead to confusion for some service users and make a bad situation worse. It is not always possible to sit down and make time to prepare an easy read document whereas speaking into a microphone or a mobile phone voice recorder can be done in minutes.

We have internal facilities to create audio, easy read and large print information, however these are normally reserved for organisation-wide matters and rely on an exhaustive resource.

We would have to contact an external provider to produce Braille, and therefore would rely on timeframes that are beyond our control.

When supporting people day-to-day we would expect their support teams to respond in a way that meets the individual's personal needs.

delay from provider mainly but also staff capacity where done internally

Made sure the information is correct and nothing to miss out. Lots of people to see, therefore more paperwork to be doing.

We work with a charity for those with a visual impairment to provide audio descriptions or braille translations.

We meet requests internally.

Having to produce documents internally alongside other responsibilities.

Audio requires support from other internal departments and Braille is currently facilitated through external agency. However, we are looking at internal resources and this may change.

Certain things, such as braille, are able to be done by our library service. Easy read is done centrally by our publications unit. Large print can be requested from our business services. Not sure if everyone knows this.

may have to go outside of service

time scales are hard to put a time on, as this would depend on access to the correct equipment and admin support

This would depend entirely on the situation and the need. Where information was needed urgently then this would be made to happen

We have had no Service Users requiring braille and would have to have this produced professionally. All other media are either available immediately or could be produced quickly.

We have not yet been asked to provide audio or braille material, but would source this externally if it were requested.

look for an alternative source



Delays in the receiving of the alternative format from an external provider

We are able to meet the request internally.

usually the delivery from outside contracts

external requests are usually longer pieces of work and may take some time to produce accurately.

We are able to provide Braille in-house. The other formats have to be ordered through an external provider working to a service level agreement.

We are unable to supply Braille, to my knowledge we have not had a request for it, but I expect we would have to commission it from an outside agency if asked.

If requested I am sure this could be dealt with in the minimum of time

Our organisation already has a wide range of easy read materials which are available to use with service users. However where a service user requires individualised information for them this would take longer, as starting from scratch, and we often have to get the pictures etc. specific for the service user. We cannot use symbol banks for this individualised information as it would not be appropriate.

We rarely have to provide information as audio or braille. We would have to send the information away to have it put into braille.

Able to meet requests internally via symbolic language advisor

complexity of communication needs

Cannot meet these all internally.

Need time to get the information to patient. based in a clinic so information needs to be sent and then taken to the patient

work load as it will be me as a professional who does this

we have never been asked for information in these formats, so I am unable to give a time estimate.

Braille - need to source externally. Audio - time available to record material

Reliant on an external provider for formats such as Braille, audio. Easy read information can be produced by our user consultation officer, training packages have been delivered in the past about producing easy read information.

Should imagine it's workload

Question 11 did not meet fully our response. Most of our information is in BSL format (video) and this is already prepared. However if we are asked for something that has not already be translated and therefore on our website this can take some time

to arrange and also find the funding for. Translation costs are expensive and take time to prepare.

The forms within the electronic data system are difficult to be transcribed. They are not in a deaf friendly format /or easy read.

We will provide information in-house in audio, easy read or large print - information in Braille would need to be out sourced to a different department within the council so this could take a number of days due to the posting system.

Not sure what happens as it has not been an issue re audiology information but getting information in the right format from external organisations can be quick or not possible

done as and when required but then we have the means to do so

can't find responsible people, everyone works in silos and when asked simply say "don't know"

Not sure who to contact for Braille, audio etc.

Restricted time, busy schedules

This does not apply given people who use the service will have an appropriate level of vision and understanding.

Most of the above can be done internally however not everyone is able to do them all so may need to wait for a trained member of staff.

We do not have the resources.

we have a small team who try their best to deliver efficiently.

We need to use an external contractor to provide information in Braille

Providing good, clear easy read information does take a long time and if for an individual requires knowledge of the individual's communication skills.

Most information is provided by clinicians who therefore are doing it alongside busy clinical workloads

For large print, if we have a [...] document we can alter to large print, or write a letter with the information in large print, we can often send the same day. If we need to obtain from elsewhere, it can take over a week.

Lack of knowledge of procedure.

Lack of funding and resources

Never been asked for audio or braille

Many requests for supported information will be created in-house by staff engaging with clients in a one-to-one or group environment. This will often be produced in anticipation of the person's needs or due to specific client-lead goals and requests, having assessed their communication requirements.

Other demands on time (visits to service users or running groups, e.g.) Or receiving info from external provider.

Large print could be done quite easily. Other formats would require external supply.

We cannot provide braille or easy read formats in-house

We do not as far as I am aware routinely offer the above with our publications. Some of our publications are available in an audio format as is our magazine.

I have said don't know as I believe it to be a long time as we are reliant on another part of our organisation to supply these different formats. There have been questions asked about why we need different formats and costs of. We could provide ourselves with certain PC packages but again cost implications in buying. Personally I often feel barriers so often put up you dread asking as you know you will have a fight on your hands.

Lack of skills and resources

No access to external providers

Developing bespoke information for an individual's needs

Very few requests received - it's on an ad-hoc request basis only

Internally

Most of the commissioning and service user involvement described above is joint with the local Council. I forward the limited number of requests for information received by the CCG to the Council and they meet them. (locally the Council is very much the senior partner, providing most of the resources to support these forums)

Time scale is dependent on information required. Some information is 'in stock', others needs creating or trying to source elsewhere.

usually takes time as have to contact external providers.

Lack of staffing

There is no external provider established for the service. The admin team can go through our own documents and enlarge the font, but this is the only capability we have.

Time to contact members of staff for information internally.

Meet needs normally internally.

## CONTACTING SWITCH BOARD AND WAITING FOR REPLY AND SUGGESTIONS ON WHERE TO GET INFORMATION

Very rarely receive requests,

Referrals/finding text

I have not been involved in requesting any of the above therefore cannot comment

Direct contact between ourselves and patients is rare in our referral-taking role, but usually takes place over the phone after the patient has already been through multiple points of contact in the service. In our Walk-In-Centre role, we currently only have the facilities to provide a verbal reading of the forms filled in by patients, for patients who are short-sighted or are not appropriately literate.

it's all done internally on an ADHOC basis, with no resources to do it properly

Limitations of clinical research are that all documents must have been reviewed by ethics committee.

We would need to send a request to the trust for other communication needs other than that of BSL and it depends upon their turnaround time.

IT searches to locate appropriate documentation

we cannot meet requests internally - we rely on standardised leaflets example [...] on contraception. since change in NHS structure do not know where the health resources library where we used to order leaflets is located or how to access

Printed "easy read" and "large print" information is available on line/ in hard copy format. "Audio" and "braille" can be provided but can take more time to arrange - unsure of timescales involved.

book interpreters for face to face visits. can use telephone interpreters otherwise (if urgent). assessments etc., can be printed out in easy read or large print if necessary.

All requests are internally dealt with

Difficult to find links on who provide these alternative formats

no available resource

Some services are not well "advertised" within trust.

Someone has to be available to enlarge it and format it

have never been asked to provide braille, but have good links with local [...] so would ask them

electronic request is made

We would have to approach an outside provider.

Availability of individuals to interpret, provide large text etc. outside "normal" working hours. This is usually the time when it is critical to ensure individual is fully informed of the situation.

Do not think it has ever even been considered at my place of work!

Most print options are internal to the best of my knowledge, however audio and braille I'm not sure of.

delays from external provider or post/fax

leaflets usually available in large print

Cost of production of other formats

Audio, Braille and easy read are provided by an external provider hence the time difference.

Large print we are able to do in-house.

For the most part we use external providers

These delays are normally due to receiving information from an external provider or the time necessary to organise an interpreter/signer. However, please note that all requests are met even if they do take a little time to organise as highlighted in question 10.

Some information needs to be bespoke whilst information available from the internet is not all available in one place or widely publicised.

Availability of supplier

Internally, we usually do our own large print or picture format so it has to be done around work load

It's the time for ourselves to design and make the intervention or for the team clerk to squeeze in as a favour or the waiting list for more specialist SALT input. This is now a job by itself

Some material is always available i.e. Newsletter is produced in a number of formats. Information sheets are currently in large format print and on accessible website. Hoping to have audio on website shortly.

A specific piece of bespoke Braille or audio has to be undertaken as a commission. Very few people use Braille these days.

We are able to meet all the requests listed above internally. Many of our policies and guidelines are in easy-read format.

It's a mixture of information, some is provided internally, some externally.

usually it is difficult to ask the suppliers to provide the communication support to those who need them.

Pressure on staff time and occasionally needing to contract the work out

resources externally (e.g. Braille)

Can meet some requests internally but mostly provided through external provider

We are able to produce easy read and large print documents immediately. We do not have capacity to produce Braille and we do not support anyone who is blind. We have software to convert text to audio, but the speed in doing this depends on the workload of our small support team. We also produce video.

Don't know how long it takes but it would be arranged through the PAS office and generally would be done at the time of the request

We are able to provide some information immediately using pre-prepared easy read leaflets etc.

If the person has specific communication needs, or if the information is not common, we may need to tailor make a leaflet/report/letter etc. for the person, which may take several days due to clinical caseload pressures.

It depends on the information that we provide. If we are working with the person to develop a pictorial timetable for their week this may take several sessions working with the person.

Sourcing an appropriate information provider, if there is not one locally known to the pharmacist

It would depend on the assessment, the needs of the client / patient and access to the communication support team. Also the availability of the support to be provided.

Within our learning disability service, we have 2 designated posts for the development of personalised accessible information. These post holders also develop generic accessible information for the Trust.

Audio formats are not as applicable as I work in the Audiology department, we tend to use more visual formats for information provision. Braille we have one booklet, that's provided by the publisher. All our other leaflets are produced in house and we do not have the means of generating this format.

Our restriction is solely based on the element of staffing we have on hand. In reality this is little more than one/two people at any time. Whereas we do have an office facility (in a Solicitors Practice), access in/out of the facility is strictly controlled by their own hours of business and security needs. Online access can of course be reached from our own personal addresses, but again this is subject to us being contacted at a time which is appropriate to self needs.

These can be provided internally. 10-15 working days is typical for reproduction.

We believe that we respond in a reasonable timescale, it is simply about the size/scale of the support required and the time it may take to complete.

no established relationships with providers of such services. seeming inability to absorb that some people will need alternative formats.

Not currently available internally and budget of the charity is small but we are investigating audio access to our web resources as we think this will benefit more groups and hope to raise funds to achieve this.

While we can often do it immediately or within the hours, sometimes we end up waiting for copies to come back to us.

We need a prescription before we can provide medication for acute episodes.

where there are delays they are around bespoke production of resources on a named patient basis as it would be impossible to have resources for all eventualities

## Appendix 14 – Health and social care professionals and organisations survey, Q14.

### “What is the main reason for the amount of time taken to arrange or provide communication support?”

We have staff members who are specialised in these field but can be pre-booked but can accommodate if there is an emergency assessment requested.

We can usually meet demand but due to low need we have to externally source support

we refer to head office for support on these issues

we can arrange all the above in a short time frame, however we are dependent on the turnaround time of independent organisations being able to meet face to face

Providing BSL can vary dependant on the amount of notice provided and the availability of BSL interpreters. Providing BSL via a computer has been trialled but was not usable in the service they were trialled in due to available space and internet access. Where indicated that the Trust cannot or do not provide a request would be considered if it was made.

arranging funding for additional support, waiting lists for services

Delays in external provider but also lack of process and clear responsibility for internal.

Delays in receiving external support.

Availability of people with the right skills I would imagine.

We can offer support on the spot, also the organisation has a communication officer who can help directly. In addition we have good contact with the visual impairment team and social services whom we can ask for advice.

We need to get advocates from an external agency so this may take time (the time scale above is very approx.)

The 'communication support worker' would be an S&LT from our team. The time scale and prioritisation for this would very much depend on the urgency of the issue. It could be arranged in a few days if very urgent or maybe able to wait a week.

I cannot comment on BSL or Lipspeaker as very few of my clients use BSL (they use Makaton).

Time used to request for external support.

A central resource / register of support is maintained within the Trust

we have staff members who can provide such support.



Sometimes the resources are scarce and in heavy demand. The market of BSL interpreters, etc., needs enlarging.

Again have never had a request for CSW / DB manual or lip speaker.

Don't know.

Delays from external agencies.

As a specialist learning disability service staff should have the necessary skills to communicate with the clients or be able to ask someone in the team for support

I don't know how long this takes as I am not involved in this. However, I do know that we use an external agency to provide these services for us.

We have staff who could provide some immediate support but in the main we prefer to bring in qualified people / interpreters such as BSL or Deaf/Blind communicator guides because they are trained to a higher standard than our current staff.

The trust books communication support in advance when we know patients have communication support needs they will have an interpreter available on arrival at the hospital. If a patient presents at A & E that needs communication support we arrange this and can have an interpreter within the hour through the contract with our service providers.

Lack of appreciation of the requirements at Executive Level and lack of willingness to see it as a priority and make improvements

We'd need to engage an external support worker.

Contract arrangements mean not always available

unaware of how to access those services.

Delays in order to find the appropriate support.

All our staff are able to communicate in BSL at some level with Deaf staff and some hearing staff using BSL as their first language. It is best practice to use a fully qualified interpreter and this is the way we work for any assessment or therapeutic work. We have an in house interpreter working part time and have built good relationships with a network of qualified freelance interpreters.

We never use communication support workers - it's not appropriate they haven't got the skills.

Lip speakers and [...] are the hardest to get hold of.

We have members of staff who can use BSL but as a principle we expect to get a BSL interpreter and that takes some time. All of us are trained to communicate with deaf people and lip speaking is what we do.

I think that as part of the planning stage the current times of up to 7 days is reasonable.

Delays in receiving support externally

Not all staff have the skills, confidence or time.

I would be unsure who to contact

Reliant on external provider

need to liaise with an external provider

We use a local advocacy service who can provide support within a specified time. I'm not aware that we have any communication support workers. As a speech and language therapist in the organisation, I'm sometimes called upon for specific issues such as safe guarding investigations or Mental Capacity Assessments, but that's all.

Internal teams insist on having details up to a week before meetings. There isn't a huge amount of services currently available

To arrange the most appropriate person and availability of the resident.

Very few people with learning difficulties known to us use any of the supports listed above so we have never been asked to arrange these.

No money/funding or expertise within the organisation

Staff are not aware of the support providers.

Internally completed mostly. Caseloads at capacity

Regularly used services can be accessed directly as there are clear pathways in place. The less frequently used services may need a little time to sort out

Dependant on the need, if this cannot be provided in house the length of time is variable dependant on what is required.

Lack of provision generally

THE MAJORITY ARE EXTERNAL PROVIDERS EITHER THROUGH [.....] OR SOCIAL SERVICES

We have agreements with external providers as well as links to an agreed list of BSL Interpreters, the Sensory and Telecare team can provide immediate support if appropriate and urgently required.

I have not had to access above - I access [.....]

Lack of resources and reliance on external providers

Availability of appropriate support from external provider.

I have approximately 40 LD champions working in the hospital, so even at weekends there would hopefully be some support available face to face. Resource files on each ward/dept. have a list of these champions and their contact numbers.

I carry a pager and try to see patients on the same day if they need support with communication. I try to ensure they have a Hospital Passport and LD risk assessment in place, and if necessary a familiar carer to support them.

Would generally be a novel request

We currently have two social workers for the deaf but they do not provide an interpreter service.

People's availability is not easy to find

Delay in obtaining external support

All of the above would be provided by an external provider.

unaware of process or services available to support service.

Some support is provided internally so little time delay but when outsourcing can be booked.

delays in receiving support from an external provider

we have staff who can provide the support but there may be 1 staff shared between 4 people with high needs. Service users have learning difficulties and mental health as well as complex needs hence information have to be consistent for a period of time as well as clear

BSL interpreter on team is part time. have been advertising for BSL SW unsuccessful recruitment

This is either due to internal capacity issues or the time taken to engage an external provider.

There are not enough people available so you have to book a long way on advance. For BSL we could provide someone who could informally translate within 48 hours but this is not the same as a trained interpreter.

Historically, we have not had need for external communication support other than SaLT.

It takes time to find more specialist communicators, advocates are very busy and are sometimes needed at very short notice.

More specialist communicators would need to be sourced from an external provider

some staff are able to effectively use Makaton, but others know only a few signs

where the patient is known and assessed the support will be planned for the next appointment. if the patient is new and communication needs not determined this takes longer as the service is often provided by an external agency and budget for this has to be approved.

sometimes we can provide support internally - time taken will depend on staff availability

If we use an external contractor it will take a bit longer to organise

Within teams there are support workers and therapists who will provide communication support for people with a learning disability

As a S&LT team we are sometimes asked to support people with their communication in difficult circumstances, for example if someone uses [...] and they are being interviewed by the police. we can only provide this if they are known to us and on the case load. Support staff can provide communication support if they have received the appropriate training and if they are consistent. One of the barriers to this is the lack of sustainability in communication support- staff move or are moved regularly so a S&LT may train up everyone in the communication environment only to find several months later the entire team has left and the person no longer has adequate communication support in place.

My concern with this list is that the needs of people with Learning disabilities need to be considered in detail, there are specific issues with comprehension which are well documented in the research but in practice are often missed. this can lead to people's impairment being under estimated and to them being placed in risky situations. As a team we see this over and over again. If someone is able to speak it does not follow they are understanding everything which is being said to them. social Workers are under phenomenal pressure and people's needs, especially communication needs are being over looked.

In order to address this well for people with LD, the S&LT teams need resourcing to train up workers to carry this role out. I'm glad you are asking about the amount of time required but unfortunately the way the question is worded it is impossible to answer properly. It would depend on the piece of work, generally it takes hours if not days to do well.

External

delays caused by booking interpreters

As previously explained we are a commissioning organisation and as such have limited public contact. I (in my complaints role) do have significant public contact and yet have not (to date) required any of the above other than advocacy.

not seen as a priority

I have not had an occasion to attempt to access any of the above services

All staff provided to attend with the service user would be able to communicate with the person attending.

Only really had experience of advocacy in our service. A request is made and someone will visit.

Delays in provision from external provider

We work with a regular client base in a planned way and can service the needs of this group quickly. Local staff and volunteers will receive training on meeting the needs of the individuals with whom we work so that we should not be surprised or unable to meet these needs. The times given are the usual times between a request for additional support and an appointment.

I am able to use and understand British Sign Language.

Some in house staff members are able to provide communication support i.e. BSL, communication support worker, but for in-depth BSL interpretation we would have to contact BSL and for an Advocate (IMCA) we would need to contact an outside provider who is contracted to [...]. However, if an advocate was needed for a welfare rights, or something along those lines, these could be provided in-house much quicker.

The time is needed to make the contacts happen

Delays in receiving support from external providers.

Supply and demand

It is not usual for our organisation to book appointments in the same way that a medical service does. If needed, we would arrange support.

If someone we support requires any of the support above we would ensure it is considered when employing the person's support worker or team.

lack of BSL Interpreters and their availability in the area can cause delays in accessing the service. can request one and can come within the hour and others can take days if can provide at all

Not enough qualified BSL interpreters. Or lack of availability of BSL interpreters. Usually I got the confirmation of their availability in 2 or 3 weeks' time. Within a week, it is high likely to not able to secure any interpreter in around region.

Most of the support is provided in house and can be available at short notice, more specialist support such as Speech to Text Report are freelance and therefore we need time to contact them.

We have staff to provide support directly but for reviews we use an external person to remove possible bias.

Lack of in-house staff with specialist skills required.

We have staff members who use BSL and therefore availability will depend on other client commitments.

Advocacy services are provided through external agency but can be provided quickly in emergency situation.

Other services are provided through external agencies and response depends on availability of workers.

Lack of clear information about where to obtain communication support including interpreters for people without English as their first language.

Ensuring availability of communication support

Question 13 is tailored to specialist support and not needed as 'standard'

We would commission this from outside of the service.

We have not been asked to provide specific additional communication support as support staff are always present when we visit people.

support would be required from an external provider

Getting the correct and most experience person in for the patient needs and wants from the service we provide

there are no internal delays in providing communication support however it is more timely and not always possible for us to access external support for certain areas of communication, we make reasonable adjustments where possible.

In the event of an urgent enquiry it is often possible to arrange for communication support to be provided more quickly. The response time will also depend on the availability of the appropriate support provider.

We have staff able to provide support directly.

A large number of communication needs we are able to meet internally however we need to go external for signing apart from [...]

Sensory support teams follow up requests when referred.

We have a dedicated communication officer, a number of speech and language assistants and speech and language professionals. For the others mentioned above e.g. BSL and lip speakers we have a database we can go to but we would then be dependent on their availability.

delays external provider

Appointment system pressure of time

arranging a convenient time

direct communication support can be provided within our team so not need communication support worker

We have access to interpreters including sign language, but have never been asked for other methods above

Only one advocate for Sensory impairment from an external provider which leads to delays in organising support.

The BSL Interpreting Service has freelance linguists who need 48 hours' notice.

Advocacy service for people with learning disabilities which also includes people who lack capacity. There may be delays due to the number of people who require support on visits, in reviews, meetings etc.

Arranged through another department

We do not use interpreters as all our psychological therapists are either Deaf and BSL users or hearing BSL fluent.

Basic interpreters, BSL/deaf-blind manual can be booked easily, the more specific individual needs can take longer to address

Most of the above would need to be out sourced from the council.

It depends whether it is an appointment in advance or emergency. It does not take long to arrange a booking, but it depends on the availability of the interpreter to attend at short notice. In such cases, we have developed an in-house emergency translation team (at the hospital) - these people have been trained by our provider to ensure that patient safety is paramount.

Has to come from external provider so we have to give as much notice as possible and there is a limited number of qualified people. Not sure in emergency situation how the NHS gets interpreters for signing

other people's availability

We go out to individuals to do an assessment for our Tenancy Support, if we have vacancies we take them on if not they go onto our waiting list or we sign post but we keep them informed.

No workers in the local team able to provide this support - would have to refer to another team internally or an external provider.

Unclear where to go to get assistance and advice.

Is it related to the contract agreement?

Some internal staff can provide this support directly (i.e. specialist support workers) but role is mostly liaising with external agencies that provide support.

Delays in receiving support from external provider.

This does not apply given people who use the service will have an appropriate level of vision and understanding. However as indicated we will discuss with the carer of

those members experiencing a deterioration in cognitive ability in any risk assessment

If the appointment is made in advance the BSL interpreter will be booked in advance, normally 2 weeks or so, I do not know how long if it was an emergency.

there are limited a number of BSL interpreters across the country so bookings need to be made with as much notice as possible.

There is a very limited number of deafblind manual interpreters which has caused us problems in the past

Working within Learning Disability services so most staff able to support with communication with mainstream services.

Long waiting list for Speech and Language Therapy if more specialist support needed.

Although we don't have specific communication support workers, staff will offer support where we can. We also have someone who can interpret for BAME communities.

In general we signpost to more appropriate charities or organisations when people have a specific communication need.

Delays and let down by external providers.

No provision in our health board for dentistry

Necessary to go to an external provider in the client's home area.

no staff available and no budget to provide this

Communication Support co coordinator

Communication Support Co-ordinators are employed by the organisation, but they are a commissioned service. Where funds are not provided, these services cannot be provided. Staffing levels depend on what the commissioners have contracted.

I am able to provide communication support directly.

This is not something an individual practice would have the time or expertise to investigate and set up. We would need contracts to be set up by the CCG or the area team, which we could then buy into as needed.

We have learning disability link nurses who may not always be available due to work commitments.

It takes time in receiving support from an external provider



If the communication support required is due to a stroke then we can deal with this quickly in house if it is due to another cause I do not know how long it would take to provide support.

Reliant on outside support.

time to organise appointment and locate numbers for support

Support that is not available within the staff team has to be brought in not had to do this recently so unsure of response times

Ambulance service so not appropriate in an emergency face to face situation or when transporting patients to hospital.

Need to arrange on an individual basis.

Staff provide support directly, but work load creates a delay.

have not used this service yet so unknown

Delays due to external providers

You have totally omitted speech and language therapy in question 13 above! We are often called on to interpret/facilitate/advocate for patients in hospital settings (and elsewhere) as part of our role and we have considerable expertise in this area

We need to book interpreters a minimum of 24hrs in advance and then it depends on capacity within that service. The [...] can be accessed anytime that I am aware of but the staff member would need to know in advance so that they can prepare.

Contact of relevant member of staff within Trust to provide support.

The availability of the specialist interpreters

AS WE WORK IN A MULTI LINGUAL ENVIRONMENT WE HAVE SEVERAL PEOPLE WHO CAN TRANSLATE IF REQUIRED. HOPEFULLY, MOST INTERPRETERS ETC ARE SET UP BEFORE PATIENTS ARE ADMITTED FOR SURGERY

Staff members able to provide some support, would need to purchase specialist input.

referral time

Standard booking procedures take time

Thus far, I'm not aware of us ever having needed the services listed above, but if the situation were to arise, I do not believe that we could get one of the above services within a reasonable amount of time for a Walk In Centre situation.

under resourced, and no corporate information is in easy read

We are not an emergency service and therefore there is no need to book this support as matter of urgency.

We rely upon the diaries of the communication professionals and their availability.

Contractual arrangements with the providers

our external providers usually require 24 hours' notice.

we have to book these from other organisation example the local council

In many instances these types of support would need to be arranged via an external provider.

prefer to book appointments in advance with service user and will book face to face interpreter at the same time. Can use telephone interpreters any time - no delay.

Staff are allocated patients ensuring continuity and satisfaction for patient/carer

Do not know where to find the support as not given this information by our service  
no available resource

My and others ignorance of services available

Have to book in advance so we can ensure we are free as well as an interpreter  
delays finding and then accessing external support

we request this from another service team

This is asked so rarely of us.

We have staff who have a variety of communication skills that can be called upon.

I am a part time worker. As far as I am aware if the patients are not in pain they are given an appointment on the days I work. I do not know how other staff establish that the deaf patient is in pain. Written word I assume. What I am saying is that treatment of deaf patients is delayed because of communication issues.

I know the first options are provided through a contract / partner but of the others I'm not sure.

delays are from external suppliers. if they have the facilitators for what is required.

I would go to those interpreters already in organisation to see if they could help - not aware of any formal way of doing this otherwise.

Delays and cost

support currently comes from our external provider. However depending upon funding we are hoping to provide training for sensory loss champions.

delays receiving support from an external provider.

In relation to advocacy we can organise this in 1 hour if this is an urgent request e.g. safeguarding or Mental Health. In relation to BSL interpreter on line and speech to text reporter - we have not answered this questions as we have never had this type of request.

The length of time to arrange the service is dependent on the nature of the referral or the request, or the date which the support might be required for e.g. BSL interpreter/communication support worker for an event or to assist social work staff with an assessment. This will be mutually agreed with the person requiring support.

With more specialist communication areas there is a limited availability of specially trained personnel

I have never had to arrange this but it will be external provider

delays external provider and costs

Most of our clients are elderly and have sight loss and sometimes hearing issues.

Have not had a requirement for any of the above so would have to arrange as requested.

Staff are trained in communication skills. We are able to access other services such as advocacy via local links and partnership.

there are shortage of qualified British Sign Language interpreters in UK so it is not easy to find and book one at short notice.

externally resourced

Some staff members provide support directly (e.g. BSL, typing) but most often book interpreters ahead of appointment

Support staff work with people we support and are trained in the communication techniques they use. If more specialist support is required this must be outsourced and accessed.

I don't know - the only time I have needed communication support e.g. support worker or interpreter via [...] this had already been arranged in advance of the appt

I always request people with severe learning disabilities being referred into the hospital after a home eye check are accompanied by a carer who knows the person well

takes time to book in a sign language interpreter, can use [...] instantly, not used online options yet

Internal staff with the necessary skills would need to balance this piece of work with the priorities of other clinical work. External providers often need some time to identify a worker and arrange their visit.

Many of the above are not appropriate for people with learning disabilities. It can take some time for interpreter to be booked. However, we tend to plan appointments and not provide urgent service so this does not delay intervention.

In practice, pharmacists very rarely need to seek communication support for a face-to-face consultation. Usually, this would be provided by a carer or relative. If this needed to be obtained from a third party agency, this might take a while to arrange, if the agency was not already known to the pharmacist

The support would need to be planned and booked in advance.

Availability of staff from Advocacy or an interpreter with the right skills.

We rely on external providers for our interpreters, we prefer to have an interpreter in the room rather than online but some patients request the online translation (mainly for BSL)

All of our clients have a learning disability/difficulty, as are some parents/carers having a limited [...]. Whereas the LA does have an 'Out of Hours' contact facility, this is very often far too slow to respond to a person's needs. Past experiences have proven that the LA response has been a matter of a few hours, whereas being a voluntary local organisation we are able to respond immediately (24 hours on call) to a person's needs.

There are variations in access to services, generally the service user if needs any of the above may already have access.

[.....] from the [.....] in [.....]. They provide fully qualified sign language interpreters, communication support workers, deafblind interpreters, lipspeakers and speech to text reporters for a variety of settings. They are all freelance interpreters and are based all over the North West. There is a short supply of deafblind interpreters and also lipspeakers, there are around 6 of each in the North West.

To ensure that they can meet requirements, as much notice as possible is required when booking interpreters. However in some circumstances, especially in an urgent situation appointments have been made for within 24 hours, or even a few hours' notice and we have been able to provide an interpreter.

Lack of diversity means that very few staff are able to provide communication and accessibility support to service users with diverse needs.

No immediate access to these services unless we know to set them up beforehand.

We primarily focus on working with people with language disability - aphasia. The other formats are specific to broader / different conditions and we would need to source this provision externally.

We can help with medicine management directly.

This service is not funded by NHS

It is not trust policy to use staff members and only recognised interpretation services are used.

## **Appendix 15 – Health and social care professionals and organisations survey, Q15.**

**“If you have any other comments about the difficulties or challenges you or your organisation experience in recording or responding to people’s information or communication support needs please tell us?”**

Our organisation does not use a centralised system for appointments

It would be helpful if more agencies were willing to share their good work around easy read policies etc.

Partner organisations not understanding the importance of accessible information and the need to provide support for people to understand easy read.

Mainly linked to GPs not providing the info in the initial referral. We are looking to amend our appt letters to address this by asking ourselves.

GP surgeries apparent unwilling to keep a list of clients with learning disabilities as there is 'no money in it for them'.

I think that we have some of the skills and experience to do this well. However, these skills are held by a small number of people with other jobs. What is needed is a process for deciding which documents need to be made more accessible and sufficient resources to do this.

One of the main problems for supporting service users' communication needs is the availability of qualified people and/or interpreters. They cannot be booked / hired at short notice due to the limited number of qualified people available within your area.

Referrals do not always include information on communication support needs.

Drug information - the NHS should make it a requirement on medicine manufacturers that they must provide a patient information leaflet in easy read.

A standard all Trusts must follow would be a help.

A method of sharing information so people don't have to keep re-inventing the wheel would be good.

Staff don't realise how many people can't read well at all.

One has to make a judgment call at the planning of each activity which invariably includes an assessment of cost and the likely use of such services.

These specialist industries are not cost neutral and the money has to come from somewhere

For more complex work then we have to use Speech and Language Therapy services which belong to a different agency and we cannot always get these when we need them

Not all staff have the skills, confidence or time.

Too often staff say 'XXX can't communicate' rather than 'We have not worked out how to communicate with xxx yet?'

We have encouraged our organisation to better support the needs of people with communication needs but this has not been particularly successful and therefore response to customers communications needs is poor.

IT systems do not meet our needs generally, recording communication needs is one of the many things not possible

Changing legal documents and policies to an easy read format. Very time consuming, started to do this with our benefits and housing options service.

We want to do this and be professional and timely but we are resource driven and do not have funding. we do try and use different ways of getting this work done but it is not easy or consistent.

We provide easy to understand information to service users and their carers using pictures (not symbols) and short, simple, easy to understand information, provided in house. This information is translated in to other languages when required. We have used BSL signers in the past when required.

I have not used any of the other services mainly as they have not been required but more so that I was not aware of their availability or how to access them.

Different services use different easy read information, usually [...]. As a specialist learning disability service we use [...].

Responses to question 13 do not include any Alternative and Augmentative Communication that has a symbol option.

People are not always easily identifiable as having communication needs so support may not be offered quickly

Availability of interpreters

Cultural changes are needed to change the concept of accessible information. It needs to be viewed as a multifaceted process rather than just a resource. The implementation phase is of key importance in tailoring the information to meet the needs of the individual.

more resources needs to be allocated through funding people with special needs take longer to process information and to make decisions, it is not just about being blind/deaf/mobility it is about exercising own rights for which information have to be processed in their own time, under the right environment and communication tools for adults not children.

Lack of awareness across the organisation.

Charging for communication guides if they have been identified in assessment stops customers having this needed provision.

We make a range of efforts to ensure that we provide information in a way that people can understand. In particular we translate key information into Easy Read formats. This often takes some time and gets a mixed response from people who use and rely on services. We have established routes to engage interpreters but this can sometimes take some time to put in place.

There is a lot of confusion about who pays for the communication support. Is it the person with the communication need or the organisation? BSL interpreters are expensive because they can only cover a fixed time and if for example an appointment extends beyond their time limit you lose the interpreter. This doesn't fit with the NHS where appointments can be delayed or cancelled at short notice.

To support people with moderate to profound learning disabilities to understand information is very difficult

Lack of knowledge within team structure causes delays in responding to queries

S&LT teams need resources to lead this, they have the skills and the expertise to address this but not the resources. This is a very welcome initiative.

Strategically the communication needs of people with Ld. could be addressed in under graduate training of professionals.

There needs to be an emphasis on the quality of support staff training and an expectation about the preservation of the communication environment and a reduction in staff being reassigned to other workplaces without consideration of the communication needs.

The recommendations of S&LT ideally ought to be reviewed by CQQ or a quality team/procurement- support staff would never dream of stopping medication, so why is it acceptable to stop signing or using pictures?

A further issue is access to bilingual communication development workers- there is a need over and above the use of interpreters for specialist staff with skills in communication assessment and adaptations who also speak languages other than English. Assessment of people with LD using interpreters is not best practice from a clinical perspective. A number of the communities do not have a written form of their language or do not read English, which provides an additional challenge.

Emphasis is more on cultural communication needs rather than additional needs/disability

Cost has some implications.

We would like somewhere to access information leaflets for treatment and new medication available to us as and when we require it instead of having to keep requesting the information from sources that don't always get back to us.



Sometimes information recording can involve a lot of duplication and I feel it is about identifying systems that are easy to read and understand, informing staff of preferred approaches and ways of working with individuals.

Regular reviews of recordings need to be made by the appropriate senior staff to ensure needs are identified and more importantly any changes in needs.

We know the people whom we support well through good application and referral processes, support planning and regular contact. There is also a lead in time between people becoming known to us and joining so we have time to plan for communication needs.

Delays are usually caused by delayed paper work and having to rely on management for approval.

The issue we have is the cost of these services - not the actual providing of services. For example to translate a Self-Assessment Questionnaire in paper form would be prohibitive, however, we would in those instances provide an interpreter to read the form to the individual and document their answers.

Preferred communication style should be part of every service users support/person centred plan. I had one service user with autism who it was virtually impossible to communicate with. However, after some time we established that he had two TV programmes that he really liked. By replicating some of the actions/sayings of characters from the TV show we were able to begin communicating with him and his trust in us grew. This mode of communication would not work with anyone else I have worked with but it was perfect for him.

At [...] we are committed to being guided and monitored by the people we support. As part of our governance structure we created the '[...]', a representative body of people we support that brings to our attention the important issues as our customers see them. It is a constant challenge to improve communication not only with this body but with any group or individual that wishes to engage with and/to contribute to the organisation.

We are also very keen to develop and increase the number of forums that include people with learning disabilities and complex communication needs. The use of graphic facilitation, clear jargon-free language and pictorial representation are things we have tried and will continue to improve on to ensure people have equal access to information and debate.

it is a matter of timing and take up quite a lot of my time to do one person's information.

When people require a BSL Interpreter for a GP appointment or hospital appointment at short notice we can in most cases meet the demand but not in all instances.

We no longer have a specific sensory team who used to have a very good understanding of the problems facing people with sight loss and/or hearing loss. Although we have a team for people with profound hearing loss, this is not widely

understood by other workers. It is not always clear that people who use BSL must have a qualified interpreter when carrying out an assessment and that someone with level 2 is NOT sufficiently qualified to act as an interpreter.

If the Service User has been referred via Social Services, we are beholden to their time scale in commissioning specialist services. This can delay the service being provided.

The team in which I work is not an acute team and the urgency an acute team would experience is not the same for the involvement of this team.

sometimes the most experience is not available when we need them and therefore, we are having to wait and delays then happen

We are in a very lucky situation that we have a symbolic Language advisor within our team. However working across a large rural area there may sometimes be a small wait for specific pieces of work however urgent communication needs can usually be delivered that day where viable.

I suspect that not many staff actually know their range of options for communication!!!

To get it right often takes time. For example developing appropriate easy read information takes time to develop. Also you need to get to know a service user to really understand their communication needs, especially if they are new to the service with no previous assessments.

A deaf person cannot text [.....] Council. Can email

Recording and responding to the need for Easy Read information. People with a learning disability can access the Easy Read website provided by the council but may find it difficult to email or use the [...] forms used by the council. Staff are not currently trained to respond to complex communication difficulties.

The cost of translation of materials are expensive. Also, there is still a lot of information relating to health issues that are not signed in BSL so the health of Deaf people generally is very poor due to the lack of access to information.

Necessary information is recorded but staff do not act upon it as would be expected probably due to lack of awareness.

The challenge to us is the financial burden of providing everything in alternative formats, particularly written. It would be helpful for NHS England to develop a set of easy read symbols that can be used consistently across the NHS so that patients / carers and staff are in no doubt what they mean.

People do not always inform us of their needs

Cultural issues or pride may mean they prefer to use a family member but this may not always be appropriate and difficult to be sure translation is professional and not subjective

Local cuts will have a negative regarding support whom have long term mental health issues as we are having more and more people coming to us for support.

[...] will not exclude people with limited vision or cognitive impairment or those with learning disabilities if appropriate measures are taken to ameliorate risk as conveyed.

We rely on the information received by carers and of the support carers provide to members who use the service.

Lack of training for all staff across the organisation in communicating with people with LD

Financial constraints are affecting the level and quality recording or responding to requests for information or communication support needs. We are told that where possible to get for free or as cheap as possible.

I think some of the difficulties are due to cost implications.

Foreign languages a big issue.

When service users speak little English and interpreters are not available for example Somali or South Asian community languages. I am working on recruiting volunteers from these communities.

I worry that people sometimes feel they have ticked the box by providing easy read there is a difference between accessible and understandable and if we are to aspire to understandable we have to use more individual approaches

we use [.....] who are very efficient and helpful

I will ask colleague who is more involved to complete this survey as well, He is more aware of what is available locally and how long it would take to arrange.

should have tools like text to speak and online records as common practice.

Lack of awareness is still a huge barrier

People with poor literacy skills are very poorly provided for. People whom have some form of learning difficulty can only be seen by a specialist service if it is profound. Persons with mild to moderate learning difficulties fall into mainstream service and are very poorly provided for as there is no skill set within the staff, no training available for staff and no specialist resources available. As a service we non-intentionally heavily discriminate against persons of this type due to the aforementioned factors. These factors are driven by a severe lack of finance availability for training, possibly because of the small size of population that present to service.

Some of the booking requests I have made to the organisation our organisation uses for interpreters have failed to provide an interpreter on the day of the booked assessment/therapy session - causing wasted clinic time and money.

We find that we are often leading the way in terms of providing good accessibility to our service and that the biggest difficulty is persuading other statutory organisations (i.e. GP's, Dentists, social care etc.) of their duty to provide appropriate communication support.

We have recently printed a leaflet about "working with interpreters" for other professionals to remind them about their duty and responsibilities. Alongside recommendations and good practice.

since the NHS change, it's difficult to know which services are still available and how to access them. there's a gap - the CCG website doesn't have all the answers and responses take a long while to come back as they don't know either and there's confusion as to if it's the council or CCG that commissions these services

Main difficulty is with elderly people who refuse/cannot wear hearing aids and do not have alternative ways of communication.

No we build a relationship, improving current/future needs through familiarity

NHS England does not commission the services PCT did

central information about all of these would be good if provided on an area basis, rather than each little organisation having to find out for themselves

After reading this survey I think I am being used as the easy/cheap option. Will be discussing the issues with the management. I would point out that I would interpret for a deaf person in any situation as I have a skill. But on reflection I am not trained for this purpose.

lack of funding has been a huge barrier to enable resources / training to be given to improve communication support.

We need a nationally consistent ITALS (interpreting, translating and language support) service with at least broadly consistent contracts that are transparent to interpreters themselves, especially in terms of degree level qualifications and working conditions. Ongoing joint training for staff and ITALS workers would help develop mutual understanding of roles, role boundaries, needs and constraints. Lack of this understanding leads to suboptimal outcomes as each full interlocutor presses inappropriate demands on the interpreter. Interpreters booked by telephone either from their agency or direct from the clinic need to know what they are taking on. There are about 273,000 headwords in the [.....] English Dictionary. There are at least as many in the other language and nobody can remember them all. A university educated person knows around 17,000 base words. It is unlikely at present that an interpreter will make a living in one single clinical specialty. So we need information in advance whether we sign or speak. We need to be told the patient or service user's name, spelled out, their nationality and the type of interview. There are many variables of dialect within nations. The specialty may be unfamiliar. Interpreters keep their own glossaries but cannot carry them all about, they need a short briefing to do the job well. On the other hand we don't need details that are not relevant to the conversation with the patient or service user. Those of us who are bound by a code of conduct and good practice are confidential and impartial.

Online is not 'the answer' in all cases

The only real issue is the move away from cassette tapes to CD and data sticks. Some clients need to update their equipment.

In the hospitals they book the BSL interpreters themselves through their contracts and they do not inform their patients if the BSL interpreter is booked for their appointment until they arrive for their appointments. That can cause great anxieties for the patients as they arrive not knowing if the BSL interpreter is booked or not? and that results in our organisation calling to find out if the BSL interpreter is booked or not which can be quite time consuming.

We work with people who have very complex needs right through to minimal support needs, so we ensure that staff are able to communicate effectively with each person they support. Staff receive training (such as Makaton, BSL, etc.) and are able to access pictures/videos/easy read.

hospital has appointed a sub group of our disability action and awareness group to look at improving quality of easy read info for our trust

All of the service users with learning disabilities who we work with have some degree of communication impairment. We often have to decide between providing information to lots of people in an easy read format that may only suit some of them or providing information to a few in a tailor made way.

Sometimes there is a conflict between organisational image/presentation (e.g. use of approved NHS fonts) and individual need.

We can be asked to help explain documents for other services. We do not have the capacity to do this.

Ideally, it would be helpful for the pharmaceutical industry to provide medicine patient information leaflets (PILs) routinely in a range of different formats. Also, it would be useful for pharmacists to be told proactively what information sources are available for medicines at a national level.

public health publication availability with relevant information related to patient specific social or health needs.

Some are generic, still takes time to receive such publications.

A registry updated with support from interpreters, sensory needs etc. should be made easy to access.

use of health passports for LD patients only have little about hearing and vision - these are vital to communication and are often thought of as lower priority. This seems to be lack of understanding - of the high prevalence of hearing loss and visual problems within this patient group and diagnostic overshadowing. We have lots of carers/ other professionals not notice hearing loss or feel that the patient is untestable, which is not the case.

In common with many other voluntary organisation locally we are currently facing up to a future without a meaningful level of funding support. As a service provider our focus should be on providing a service, and not having to think or to seek out/generate a level of financial support that assists in the hugely demanding - but necessary - work we undertake daily in our local area. If then our funding is stopped the hugely increased amount of voluntary work we currently undertake will incur much greater increased in the statutory sectors.

getting staff to buy on. training staff about the needs of a diverse customer base.  
getting this information on clinical engagement in the community. reliance on others  
Community nurses to collect and provide this information.

Funding is the main difficulty we aim to support people with epilepsy some also have learning disabilities and we aim to produce resources and helpline services to meet their needs and carers needs.

Care workers are not trained in the administration and management of medicines  
Poor medicine management can lead to falls, adverse drug reactions resulting in  
Hospital admissions.

## Appendix 16 – Health and social care professionals and organisations survey, Q17.

**“Please explain your answer to question 16. Why do you think this is or is not a good question?”**

it is comprehensive and covers all aspects of disability

question is fine - if used verbally

The question is too general i.e. significant numbers of patients would answer yes to this question but may not have a disability where there would be a requirement to provide reasonable adjustments in the context of this standard. For example it does not take into account someone who has difficulty seeing but which can be corrected with glasses. It also does not take account of the differences between patients who are Deaf and those who have hearing difficulties. The wording ‘do you need support to ...’ is ambiguous i.e. open to a range of interpretations and therefore assumptions about why the question is being asked. The emphasis on ‘support’ does not sit well with the social model of disability i.e. a patient may not need ‘support’, they may be very independent, but may still need a ‘reasonable adjustment’ making to access information. This is the statement/ question we intend to pilot: We want to make sure the information you receive from us meets your needs. For some of our patients we recognise that this may need to be in a different format due to a specific communication need. You may have a specific communication need if you have: Significant problems with your sight, (i.e. registered blind or partially sighted), Significant problems with your hearing (i.e. you are Deaf rather than hard of hearing), you have a learning disability, you have difficulties reading or understanding English.

it is too long. needs to be broken down into several shorter questions.

The question is too long. Needs to be broken down into smaller parts.

It is simple, clear to understand but also not patronising- could be effective.

It might not be easy for someone with a learning disability to understand, as it contains too much information. It would need to be broken down and simplified for this particular group.

this is far too complicated wording. don't be afraid to break it into 2 sentences/questions also.

It is too long. If the person had communication difficulties they may well have lost track by the end. I would suggest breaking this down into smaller chunks.

I think the question is asking too much information in one sentence.

It may be more helpful to ask: Do you find it difficult to see, hear, speak, read or understand what is being said? Do you need support to see, hear, speak, read or understand what is being said? What support would help you?

Too long, break it down.

The question is too long. Most people with a learning disability would find this too long to be able to take in all the options listed.

Perhaps the question could be split up into difficulties understanding and difficulties expressing.

It is a good question, though perhaps break it down. There's a lot to think about for one question. The answer may need to be more than just 'yes' or 'no' as different support is needed for the different needs covered.

It is too long for people with memory changes to understand, how can a person with hearing deficits hear the question?

An idea may be that there is a part on the front page of all patient information to record if communication issues are present, then this broken down into a series of short questions.

Too many parts. Far better to ask 5 separate questions e.g. do you need any help with reading?; do you need any help with seeing;

It focusses on the client's impairment, not on the barriers the provider is failing to remove. It is a very good example of the medical model of disability. The question should be rephrased to reflect the Social Model. "How would you like information given to you? We can provide large print, Easy Read or any other type of material you might require. Just let us know"

It is useful to id if there are diffs but then need to ensure there is a further step in place to obtain details on what is needed from that point on

It needs breaking up into different parts. I think it is better to ask a few short easy-to-understand questions than to try to fit everything into one long complicated question such as this one.

It's concise, and easy to understand.

A good question but it needs to be put across more clearly

If someone has difficulties in understanding, this question is too long. It needs to be simplified.

I work with people with learning disabilities who will find this question too long and with too many phrases. It might be possible to improve this by splitting it up though. E.g. "Do you have difficulties with reading, hearing, seeing, or speaking? Do you find it hard to understand what people say? Do you need help with any of these?"

If your staff understand the nature of their patient's disability / illness then they should be able to identify what the barriers to communications are going to be. If they don't then the question is valid.

It is good to ask this question but it needs to be reworded as the first part seems a bit abstract "do you find it difficult" (find what difficult?) or do you need support to see, to hear, to speak, to read or understand what is being said. I think you are asking two



questions here i.e. a. "Do you find it difficult to understand what is being said? b. do you need support for: -understanding, -seeing, -hearing, -speaking, -reading

Why not just say "Please tell us what communication support you need?"

Simple, no jargon

thorough but too long

I think it's a very long question. I think it would be better if you did bullet points for each thing e.g. one for see, one for hear etc.

Question is both comprehensive but at the same time is simple and easy to understand

Asks about all potential difficulties.

The only difficulty I've encountered is using written forms to enquire whether people have difficulty reading!

It's too complicated. Deaf people often struggle to understand written English.

It would be better to ask each question separately and have a tick box e.g. Do you need a BSL interpreter? Do you need a lipspeaker? Do you need letters in BSL?

I think it is a good question, but it may be difficult for everyone to follow. I would suggest that it is supported by a visual message - diagrams - which make it clear.

It positions the service user as being deficient. It is simpler to ask - do you have any additional communication needs.

You would have to break it down to actually use this question

It is a good prompt, but I would not use it verbatim

I think it is a good question but must also be asked in an easy read format.

some people may be embarrassed if they are illiterate

The sentence is too long. Many people have a 2 or 3 key word level of understanding.

Simple, covers all angles, but have unsuccessfully tried to find a way to replace the word difficult with a less negative connotation...sorry! this is the only thing I would like to see changed if possible.

Using the word 'difficult' has a negative connotation and some may not answer correctly as they do not identify with it being difficult.

simple and straightforward will it be delivered in alternative formats?

I think it's far too long and wordy. Needs to be broken down so that people can understand it. Maybe 'Do you need help to understand? then 'why do you find it difficult to understand? and list the alternatives as bullet points for people to tick

There are too many questions in the one question and it isn't following plain English guidelines. It should be broken down into parts or bullet points should be used for each part e.g. Do you find it difficult to see, hear, speak, read, Do you need support to understand what is being said?, Yes, No

I think this needs to be simplified even further with pictures e.g. easy write format

the question is too long and complicated for many people with learning difficulties to understand. For someone with learning difficulties there are at least 5 questions in one sentence.

plain and simple with no 'big' words.

Many service users of learning disability services would have difficulty answering this question. Assessing communication needs should be a fundamental aspect of all initial appointments/visits. More formal assessments of communication are undertaken, if required, by speech and language therapists.

Too many options in one sentence for someone with challenges in understanding verbal or written communication i.e. learning disability.

it is too long

break it down to 5 questions

It would be better as a multiple answer question so that it is broken down more. So that each one requires a response. Such as Do you find it difficult or require with support with vision? (this could include type of spectacles).....hearing....this could include hearing aids etc.

Grammatically complex and long sentence/question. Asking someone to say if they have difficulties in understanding in one of the most complex way.

Perhaps consider reducing the load by breaking it up. e.g. Is it difficult to - see information, - hear information, - speak, - read, - understand words, Do you need support with, seeing information, hearing information, speaking reading, understanding words

the language is plain

The question is too long and complex. It should be broken down into short sentences using easy to understand words.

It is very "medical model". An alternative question is: "How can we make sure that you are able to hear, speak, read or understand what is being said?"

the question could be broken down into five separate questions to make it easier to process, e.g. do you find it difficult/ need support to see?

The question is good as it covers most needs. A patient may find such a long question difficult and keeping it short and simple may be preferable. Do you need any support with communication?

Not suitable for those with autistic conditions, that may need concise language, too lengthy for those with complex needs.

We are a mental health trust, this question is too long and should be broken up.

There is perhaps lack of consideration for mental health service users. The question seems to be more for acute organisations.

Too many variables that cannot be answered within this one question.

Finding it difficult and requiring support are two separate questions.

ITS STRAIGHT TO THE POINT

Too much information in the one question

we don't ask this question in any other way - it covers all aspects, we just need to be able to record their responses

I feel it is clear, easy to understand and without jargon

This covers too many issues - need to be separate questions for each need

It may not cover every aspect of support required/

It is several questions in one - maybe bullet points would make it appear less daunting.

It is a bit long and needs breaking up a little, it is a lot to take in if person struggles to process information

It's too long

A bit long, but covers all relevant points.

It is quite wordy

its ok a bit long and complicated but not sure how it could be shorted whilst being politically correct at the same time..

Short statement and covers the main areas without having to go into specifics.

Anybody who has difficulties in communicating would probably find the question too long and with too many bits to answer. It would be better broken up or rephrased. There is an 'or' element but then 5 different parameters to respond to that 'or'. That's a lot for someone with good communication skills. For some parameters it might be difficult, other ones they may need support. You can't answer that question easily.

need to keep it simple and clear,

think it could be quite misleading as people may have multiple of these problems.

Closed question client can respond yes or no, would be preferable to ask "Describe any difficulties, should you have them etc. etc."

I would ask; Do you need help to read or understand what is being said? Is it difficult to see or to hear? Do you need support to communicate?

Good question as long as it can be asked in different formats according to the needs of the individual.

asking questions in public is inappropriate and illegal as well as the fact that how do you ask a deaf person the question?

What you need is some method of alerting the healthcare professional that this patient needs help and what sort of help!

Oh look [.....] trust have an electronic alert which is triggered by bring up the patient record on PAS

but the format may have not mean to someone who do not speak the language, does not read.

it can be a very complex concept in the way it is presented,

Think if this is being asked to you in Arabic what would your answer be?

There are too many words. Both blind and Deaf people have difficulty reading.

Content of question is excellent and is something we ask all customers.

This is a long sentence with a number of questions in it. It should either be simplified or written as a number of questions.

I don't think a standard question is a good idea as everyone is an individual. There won't be a standard response to a standard question so how does it help with consistency? This question tries to cover everything and therefore becomes difficult to understand. I think a more open question would be better, with staff trained to ask follow up questions.

The question is quite long. It needs to be split up into the separate categories.

I'm not sure the word "support" will always be understood.

A lot of older people are reluctant to admit to their disability, particularly hearing loss so asking the question may not help.

The beginning of the sentence is too difficult, it should ask only one thing; at the moment it's two questions in one.

I think the question is too long.

One question to identify that the person has a difficulty when information is given would be better e.g. a sensory or learning difficulty followed by prompts to identify what would facilitate communication.

Often people with learning disabilities want to please and will answer whatever they think is required. It would be better to have an open question (the answer to your question is either yes or no and does not determine what the need is).

It's long, complicated and poorly constructed

It is confusing, to see, to hear, to..... etc. Breaking the question up into each area on separate lines would assist the individual to recognise the issue they have problems with

I would break down the question into smaller questions as there is a lot to digest and would use pictures to facilitate the question

I needed to read it more than once and slowly to be sure of what it was asking. I don't have any support needs.

It's an OK question however people sometimes do not want to admit they have difficulty or they may be unaware they have some impairment. The wording is complex and requires a high level of comprehension, so it needs simplifying grammatically. Need to separate out issues of expression and comprehension.

Ask what adaptations are helpful? What about competency in languages other than English?

Too Complex

I think this is 2 questions may find difficult but do not need support.

It's quite a long question and therefore needs careful reading in order to be understood.

What do service users think? I am not sure whether I would want to answer in the negative. Is there a more sensitive approach to use - again what would service users want?

It is too long, with too many variables which people may find difficult to follow. A simpler way would be to ask how they like to receive information.

I think the question needs to be more basic and less wordy

I think that this question covers everything and support staff would be able to answer this if service user is unable and be able to explain why.

It is a simple question, my only concern would be 'to understand' as this could make someone feel quite inferior and vulnerable. I would leave this out.

1. Needs to be broken down into component parts: too long a sentence, complex clauses, would never pass the Crystal clarity criteria 2. Surely it needs to be available in large print? I think it then needs to ask 'how can we help you?'

I do believe the question covers all areas of difficulty which may apply to everyone's daily living needs.

It's a bit longwinded. I can understand that you are trying to cover all bases, but someone with dementia is likely to answer "No" to that question, but they will not remember that it has been asked, will be unrealistic about their abilities or give incorrect information.

A blanket statement for so many different situations

Many people with learning disabilities would just pick up on the last example within that question, 'or to understand what is being said'. [...] Unfortunately I cannot think of another way of seeking the information you require from that question without breaking question down into sub questions. Why is there a need to ask just one question? It is not exactly person centred.

The question is jargon-free and quite clear in what is asking for.

To mitigate any confusion I recommend the following amendments: 1. Adding 'and' to the 'or' i.e. 'and/or do you need support...' 2. It may read to some that they can only choose one of the options listed, so it may help to separate them out and explain that they should select all options that are relevant. For example: Do you find it difficult and/or do you need support to (Select all that are relevant to you), a. see, b. hear, c. speak, d. read, e. understand what is being said. Finally, it is worth considering adding a component to the question that addresses those people that find it difficult to interact socially due to their own experience of Autism or Asperger's, for example. This information would enhance the person's (and professional's) experience greatly, if acknowledged and understood.

I think this is an ok question. Only thing is that, individuals needs are different. Level of support and communication.

It is easy to understand but seems patronising

Question would be too long for some people with a learning disability or cognitive impairment as it is multi part. Some of our users need questions of one or two parts maximum. Might be better to split it up: Do you find it difficult to: See, Hear, Speak etc.

There is irony in asking people if they have difficulty reading if the question is in text form of course.

Is clear and covers all bases in a single sentence.

It is a very long question and may be difficult for those with sensory impairments to understand, especially BSL users. It may be more beneficial to break down into parts.

the word 'support' is professional' jargon. Do you need someone to help you.....? do you need to use equipment to....?

Whilst the principle is good, it is hard to know how the person being asked the question would understand it if they had a communication problem. Would this query be asked of a carer or relative (if one was available). Should this be something that is also recorded in GP records so that is accessible to other parts of the NHS? Indeed, should this query be raised by GP surgeries in the first place with the clear understanding that this would form part of shared information with other necessary agencies?

Please ensure that use of hearing aids is included in this recording scenario especially if someone is admitted to hospital: do they have the hearing aid with them/where is it now/do you take it out at night and where do you keep it when not using it etc.

It is asking a number of different questions in the same question so people might not understand what is being asked.

Asks for the information required without making the client feel embarrassed

I feel it is important to ask people their understanding.

I think the question should be broken down, e.g. do you find it difficult or need support with reading.... then for writing...etc. Communication is not an umbrella set of requirements.

It is a long question, which will make it hard to understand for some people, such as those with a learning disability or those who do not have English as their first language. It would help to split it up, e.g. "Do you need any support to access information? Do you have any problems with communication? This could include seeing, hearing, speaking, reading or understanding what people say or what people show you.

it's to the point and direct and also asks if any support as opposed to full support

Why not just drop the difficult making it Do you need support

I think it is good as it covers all of the possible difficulties that affect effective communication.

It gets to the point and not causing any distress to the patient who will want answer and support right there and then at the point of need.

It covers everything but for people with a learning disability it needs to be broken down rather than covering it all in one sentence.

It would obviously need to be in appropriate format when asked.

"Does your <insert disability> affect how you like to receive information from our services?" "What would be your preferred format of information?"

The question seems 'wordy' but we're unable to suggest a suitable alternative.

Confusing to some? Seems like several questions in one sentence.

How about using less words - perhaps just 'Do you need any help to understand information?'

the question is too long for people with learning disabilities each difficulty has to be asked separately

Is OK when the client / carer has simple rather than complex needs. There are many clients who have complex combined sensory problems, language problems, cognitive problems and one question will not enable full outcome.

Plain English language, would elicit a yes or no response however a tick box next to each May be of benefit otherwise you would then need to ask another question to highlight the specific response.

It covers a range of needs in a very simple way.

Often the NHS and other large organisations can make even the most simple things complicated.

Carers, service users, advocates etc. can then respond from their own perspective with the support they feel they need.

It is a complex question with a lot of information. It would be easier to understand if it was a series of simple questions e.g. Do you find it difficult to hear what is being said? Do you find it difficult to read? Do you find it difficult to understand?

I would remove the first part "Do you find it difficult"

the question is far too long and too complex. It should start with a question about the persons understanding. of verbal language, and then depending on the persons level of understanding grade the other parts of the question to take account of this.

It is too long for people who have comprehension difficulties and should be broken down into a number of questions.

asking to many information questions within a question

It is a good question but needs to be followed up with, 'What support do you need?'

question too long.

Do you find it hard to hear, speak, read or understand what is being said

This is not a question that should be asked on a daily basis, it would take up too much time, both to say it to all users and then to explain what we mean by it. I think some would take objection to being asked the question and think we were inferring something negative about the patient. Aggression and violence is a daily occurrence in GP surgeries. If communication needs require assessment it should be done when



they join the surgery or by the clinician during consultation as the patient raises the query.

May be too wordy for patients with learning disabilities

Too wordy and confusing. It would need to be broken down and asked in stages and as appropriate.

Some people would not grasp it. Think first half might be difficult, not sure.

The question is 'ok' but again it will need to be in BSL for deaf, BSL users to understand it.

It is in plain language and not demeaning.

This questions has many parts - I work with people who have a learning disability and feel that this question would be difficult to understand as you are asking 5 things in 1 question. May I suggest you ask: Do you find it difficult to hear? Do you find it difficult to speak? Do you find it difficult to read? Do you need help to understand what people are saying to you?

Read it out aloud, it sounds patronising. If one or more of the difficulties is there already, how will this question be communicated?

I think it's a bit long as one sentence. There are quite a few things being asked in that question and should be broken up.

it is a long question for someone, who may struggle to read to understand.

Would people understand the words difficult or support but so long as the prompts were clear then hopefully you will get the right answer

It's a bit long winded and surely with some patient knowledge/records and face to face meeting that some issues should be obvious? EG if they come in with a guide dog it is safe to assume that they will have problems with written communication.

too much info needs a tick list for wants needed.

too long and contains or in the question structure

Quite lengthy and complex. People who have difficulty understanding would need this broken down into shorter chunks.

Succinct

It's straight forward and easy to understand.

I think the question is clear and straight forward

To the point, concise, incorporates all potential difficulties with communication in one (relatively) short question.

It is clear and concise, does not appear to be patronising or derogatory.

I would ask the questions as two questions i.e. Do you find it difficult to see, to hear, to speak, to read or to understand what is being said? Do you need support to see, to hear, to speak, to read or to understand what is being said?

The idea is good but the sentence needs to be changed.

It's quite a long question for someone who might have severe learning difficulties for example.

I think if the key is to know how the person prefers to communicate or whether they need support the question needs to be less wordy, more plain English and to the point. Maybe; How do you communicate? What support do you need? List options here and have tick boxes and photos to symbolise different methods

The question is very complex and asks lots of different questions within the one question. For example if you have hearing difficulties but can read are you supposed to answer yes or no to the question. Do you find it difficult or do you need support are basically asking the same thing so you only need one part of the question. The question should be broken up much more, for example: Do you need support with your communication? Do you need help with: - Hearing, -Speaking, - Reading, - Understanding

Obviously if a person does have difficulties then they will find it hard to respond. You could also ask if person has a communication passport which would then help to answer the above.

Straight to the point

It's ok but it focusses on the person having a difficulty, rather than how can we best help you to ..... It gives a sense of the person having an issue rather than being an individual who happens to require assistance.

It's a little wordy and confusing.

Far too complex needs to be broken down into short chunked sentences

It is quite lengthy and may be difficult to understand in the first place although it covers all communication needs.

it is a long question with several topics within it .

some of our clients would not understand this, they need picture prompts to help

The sentence is too long.? Ask about difficulty and need for support separately.

Could be shortened to Do you need support to.....or Do you find it difficult to.....

Some people will be able to express themselves through other methods than speaking. "to speak" could be changed to "to express myself"

It's too long. Simplify it.

Your example is too wordy and does not 'flow'

The fewer words the better

I think a better version might be....'Do you have difficulties with speaking, hearing, seeing, reading or understanding?' 'How can we help?'

If someone can see then the use of a clear image adjacent to key words may be helpful sight-eye hearing-ear etc.

When a patient comes to register at a GP practice, communication difficulties become quickly apparent. A formal question could appear silly. However, once difficulties are identified, the follow-up is important e.g. what support would be helpful to you? But then we in primary care need support ourselves to access support services.

Sentence is too long and needs to be broken down in to smaller questions or made easier to understand

Could the question have pictures or symbols included to help with understanding the question?

Too wordy. How do you find it difficult should maybe be emphasised and what solutions do you need?

I think it is a very long question with many parts which I think would be better if it was broken down into short sentences with key words.

I think it's ok but I would substitute 'to speak' with 'get your message across or express yourself'. I would also want to add in 'to write'

I think it covers all aspects of communication, but could say would you require support in any of these areas in order to improve/help you understand your treatment/stay

The question is very complex for many people and would not be suitable for many individuals with a learning disability needs to be broken down into the individual items

It's not the person that necessarily finds it difficult it is the receiver. Just because there requirement is different to ours, it is not their problem. This is a very medical model of disability approach. Do you require additional support or adjustments for us to talk, hear each other, read or understand what is being said?

Need to ask separate questions for see/hear/speak etc. If a person answers yes to the question as it stands, which are they answering yes to?

Maybe it could be a bit shorter?

It is better than not being asked, but depends entirely on the clients difficulties. Comprehension is sometimes a problem.

I think there are too many elements all in one sentence, this will be rather difficult to ask without getting confused about all the different elements or the person being asked forgetting what was said. Need to split it up.

covers what is needed, may be slightly intrusive if you are to ask this on first meeting for different health professionals.

not very clear wording. the end of the question i.e. what is being said... what is being said by whom?? a healthcare professional?

Too complicated. Could it be bullet points? i.e. Do you need support to: -see? Hear? -speak? -read? -understand what is being said? possibly pictures to explain?"

It is well worded but the question used in my organisation is equally good

it is not simple enough for a person with learning disabilities to understand, as you ask do you find it difficult (one question) or do you need support (second question) and then list five different areas understanding being the last one. A simpler question is needed for people with learning disabilities such as "do you understand everything people say to you?" this is more likely to get a truer response than above and if they do not understand the question and answer incorrectly then you will have failed to achieve your goal of making things accessible.

The question is linguistically complex and difficult to read and process.

What about a question with tick boxes: Do you want extra help or support to: See (insert picture of eye), Read (insert picture of book with type), Hear (insert picture of ear), Speak (insert picture of mouth), Write (insert picture of hand with pen), Understand (insert think bubble or similar)

As part of the question the staff member should first normalise any potential difficulty the patient has, which they may well feel embarrassed about and therefore feel uncomfortable about admitting to, especially if there is a perceived social stigma to it such as poor literacy ability. An example of doing this may be; All people in life have greater or less difficulty with some aspects of functioning, so we often alter the way we work with them to help ensure they get the treatment they need. Bearing this in mind.....

It is a good statement as it covers all aspects of problems people can face within an organisation.

Along with many other questions this would be our priority, to meet the needs of the individual to fully understand and be able to participate fully they would need this to be actioned first.

IT IS CLEAR AND CONCISE AND ASKS WHAT YOU NEED TO KNOW

As long as it can be used in different languages it's a good question

Too many questions in one question, needs to be broken down into several small questions.

Too much information for a person with Learning disabilities to take in.

I think it would be better to leave out all the 'tos' i.e.: "Do you find it difficult or do you need support to: see, hear, speak, read or understand, what is being said?"

I would remove the "to" before hear, speak and read. it may be grammatically correct but it makes it clumsy to use

It is a very sensible question, but the length and syntax of it might be difficult for some patients that we regularly see. Breaking the question down into simpler, or multiple questions might be more appropriate. For example; "Do you understand what you are being told? Please tick if you have difficulty with: Seeing; Reading; Speaking; Hearing."

Something like this might be more appropriate for the kinds of patient we regularly see who need help filling in our Walk In Centre forms.

It asks the right things but is too long a sentence for people with limited understanding to understand (complex)

It is poorly constructed, the desire for a single sentence has resulted in what is almost a paragraph.

I don't see things in terms of being difficult!

I would re-frame the question so that it is positive and not see the person as a problem, something like: What can we do to make sure we can do our best to help you?

It is a bit wordy, but gathers the information. Perhaps break it down in to sensory need so that the appropriate response/action needed is clear. They could just answer yes, and then you would have to delve deeper..... for the actual need

I think the "do you find it difficult" should be removed, leaving "do you need support"

the word difficult is too negative, consider "do you need help for you to properly: see, hear, speak, read or understand what is being said to you?"

All support question criteria is met.

I think it would be sufficient to ask "do you need support to....."The "do you find it difficult" introduction could be omitted. I do not think people should be asked to say they "find it difficult" as it is a negative way to introduce an offer of support. If people are offered support they can then describe/ disclose their "difficulties" themselves.

It asks the basic question, offering a wide range of requirements, short and to the point, if they don't understand the question. How can you offer to improve/assess/refer help available?

Because it is clear and concise

too complex

Straight to the point.

I work mostly with people living with a dementia during a period of crisis. This question would need to be much simpler and may need activities to make communication less challenging. Having said that, this question would work for around 20% of my service users. So if it is used as an entry to further assessment it might be quite helpful.

It covers the main issue concisely

it may be worth considering not stating that the person finds it difficult, but simply Do you need support to see, to hear, to speak, to read or to understand what is being said?

Too long

Needs to be more succinct EG Do you need support with a b c ....

This question would have been asked prior to interview in order to meet service user need

It should be asked in two simple questions and remove all the commas. e.g. Do you find it difficult to see or hear or read or understand what people are saying? Do you need support to see or hear or read or understand what people are saying?

I would prefer to ask, "would it be useful to have assistance with any of the following"

At least it will establish the need. At the moment I don't recall anyone ever asking these questions. Will consider adding the question to our medical history form

It is a mouthful, but at the same time it does ask all the things it needs to.

as the average read and language age is 9yrs across the UK, keeping the question simple and direct will cover all persons reading it.

If people do have difficulty in understanding (e.g. people with learning difficulties) this question is too long and complex- it needs to be broken down into several shorter parts

It is long to give to someone who has difficulties in communicating. It does not ask them how we should do it.

It is a concise question, although there is a lot of information in it.

open question - assessing and then will support next steps about communication needs etc.

The question is alright but how is it administered? Orally, in writing or in sign? If interpreters are involved they should be given a moment to consider how they will relay this question before they meet the patient or service user. Interpreting is not a simple question of dual literacy and cultures differ in their responses.

The question was slightly unclear. Are you asking people if they have difficulties with hearing, seeing, speaking, reading or understanding what is being said, if they need support in these areas or both?

A person may have difficulties in these areas, but may not need support. Perhaps the question needs to be broken into two parts, asking whether people have difficulties in any of the designated areas, and if they need any support in these areas.

It is a good question, but perhaps a bit wordy? Perhaps difficult to understand for someone with LD

Far too long needs breaking down into separate questions!

scrap support use help instead it's a broader more understandable term

Better would be - "We can provide additional help for people who may have difficulties with seeing, hearing, speaking, reading or understanding what is being said. Would you like us to provide this help for you?"

The language is simpler, it makes a positive offer, it's less patronisingly framed. It's a very long winded question and when dealing with Learning Disabilities it needs to be simplified

It covers the senses and is reasonably sensitive to the persons feelings

It is trying to ask too much in one line! It is also very patronising!!

With an ageing population you need to ask specific questions with yes and no answers or a list of alternatives. Do you suffer from sight loss? Do you have a hearing problem? What format would you prefer? Then list formats available.

It's good to encompass all of the support needs - see, hear, speak, read - but the first part of the sentence could be better worded.

it could be more Deaf friendly - could do with bit more of a visual than wording e.g. "you Deaf or Hard of Hearing - need communication support e.g. BSL interpreter or lip speaker etc".

This needs to be broken down into several questions for people with low levels of English comprehension

perhaps a little bit complex to understand

Will need to be provided in different languages to capture those who need language interpreters. Patients who cannot see or read might find it difficult to respond but hopefully should have support at home for this. The majority of our patients in

Audiology will say they cannot hear but this does not mean they need additional support as we can usually manage this in house. Perhaps remove the 'do you find it difficult' and just ask if they need additional support?

Is there anything that would help you understand this information more easily, such as video, pictures, easy-read, a different language or an interpreter?

I feel the question too general if the person has a vision impairment they will require info to be large print and high contrast, whereas if someone has a learning disability they will require easy read information and possibly enlarged print if they also have a visual impairment. the information needs to be adapted to the individual and the question does not distinguish the different communication diffs that may arise

it sounds appropriate

This question would need to be broken down into a series of yes/no questions for many people with learning disabilities.

It needs to be broken down to one question at a time and a yes no and sometimes answer for each. Too complicated. e.g. Do you find it difficult to hear yes no. Would you like support yes no. If yes loop system, quiet room, ask me to repeat, write down etc. with a photo of each option...

The question is simply put, but it might be helpful for it to refer specifically to "information in braille, large print, a language other than English etc.", so that it is obvious what it is asking

it's a start, but make each question separate.

First you will need to establish if they have sensory deficit, and what is the main spoken language? Do you understand English language? Interpreter need? Using British sign language? as possible questions examples

It covers all the concepts, but is complex. It should be made simpler: Do you need support with: - seeing, - hearing, - speaking, - reading, - understanding"

It's a bit wordy

It is NOT a leading question, and will only generate a 'Yes' or 'No' answer. The object of your question is to gain an answer that has a meaningful answer, and therefore should begin with a .....What, Where, When, How, etc. etc. Your question could therefore read as follows, "How do you find it difficult..... etc."

On consideration for use with people with learning disabilities the following points could be considered; 1. To have pictorial representation of each sense, e.g. an ear for hearing. 2. To break the sentence up into bullet points. 3. To ensure that the person who has asked the question gets the service user to relay back their understanding of the question to ensure retention of the information and not that the service user has simply acquiesced. This will confirm the last part of the question regarding understanding.



It is an open question which allows the person to then explain their own communication needs.

It is simple and will be able to be answered by all.

It groups too many categories together, what is the person responding yes or no to?

places onus on service user. sometimes it is the provider who has difficulty communicating with the person.

Asks two questions in one better just to ask if support is needed with list.

Sounds a bit awkward.

It is clear and covers multiple disability - great well done this is SO needed!

This is a good question only for people who can understand the question.

A judgement has to be taken by a professional person to assess the need of the patient.

It is too general and should be broken down so it is possible to identify which category or categories support is needed in.

## Appendix 17 – Health and social care professionals and organisations survey, Q18.

**“We are keen to learn about good practice in recording and responding to people’s information and communication support needs. If something you do is working well, please tell us about it.”**

Due to having a small specialist team, we are currently looking at up skilling frontline staff with basic knowledge and awareness, equipping staff with skills / training to deal with basic sensory and telecare equipment’s

we are partaking in the info standard national accreditation as an organisation

The Trust has guidance and templates for producing easy read information and has produced locally relevant photographs in partnership with [...]. The Trust is planning to pilot more extensive opportunities for patients to receive email (for patients who are blind or partially sighted and use a computer reader). The Trust has local lead champions/advocates for Learning Disability.

We are considering using an in-house service to provide easy-read information for patients on specific treatments/ operations or care within 48 hours of request (e.g. referral from LD Liaison Nurse).

I have shared my work with [...] - I am collating and promoting Easy Read in the criminal justice system. Have held an event at the House of Lords with [...] to this end, host material online and am developing a strategy to encourage the CJS to take it up. Have also met with the MP for prisons and recommended the use of Easy Read recently. [.....]

Making sure that people know about others' needs.

The use of communication profiles within [...] that Speech & Language Therapists are instrumental in setting up.

Communication passports work well.

Use of flags in IT systems to alert Professionals who are involved in that persons care of additional needs.

Use of a different colour on the wrist band (discreetly) to alert staff that different and additional care needs are required.

Every document, form, file, newsletter and policy document to be in easy read.

See my blog – [...]. Sometimes good practice is destroyed through a failure to transfer information from, for example, primary to secondary care.

We have close links with BSL interpreters in our region and will have inform meetings with them if we receive a referral to ensure we are both briefed when BSL communication support looks to be non-routine e.g. for those with Learning disabilities / cognitive impairment

We have a specialist post of an accessible information worker [...] who trains up staff in the team and can provide support for other council and health services.

We have many good examples, please contact us

We do produce good quality easy-read information for people with learning disabilities and others. However, the scope of this is limited by staff time.

Our workforce are encouraged to establish any difficulties with communications on the first face to face visit with our service users and record their preferred choice on our database. Staff are also encouraged to check communication difficulties before making appointments and contact service users in their preferred format, whether it be by phone, email, text, braille, audio or large print.

We have introduced an accessible publications policy this policy helps to define categories of information including those that should be readily available in a range of accessible formats, what should be available on request and what we won't do.

We have a patient survey in easy read which is on trial.

We have employed an expert by experience quality checker (someone with a learning disability) to develop a quality checking tool in easy read and carry out quality checks of our learning disability inpatient services.

[...] website

Arrangements for booking foreign language interpretation and BSL both work well and are frequently used.

We have a good multi-disciplinary team. Before every out-patient appointment we briefly remind ourselves of the needs of the patient so that everyone is aware of difficulties for the family be it with regard to communication, mobility or social problems. This enables all of us to give the best to that family. We are lucky to have low volume throughput of clinical work which allows us the opportunity to respond appropriately to patients and their needs.

We have included the above question in our GP referral forms - as they are refreshed to ensure patients are supported if they need it.

It is in standard forms

I produce all of my information in various degrees of easy read format tailored to a particular patient

Just treating people with respect and as individuals.

Plain English is paramount. People spend too much time repeating information, using jargon and acronyms when the message can usually be put across simply.

I work with service users on a regular basis who tend to engage more when included in decision making and when language isn't a barrier

We produce all our information in easy read with pictures or photos

Good communication including recording and responding to people's needs, is about having good skills, listening skills, and awareness of people's abilities and modes of communication. Also you need to consider the person's ability to understand the information, have they the capacity to use the information and make choices. Often information needs breaking down, discussed in several appointments and revisited to ensure the person is fully involved. Time doing this cannot be underestimated.

Support all written information with photos, and uploads this information to the person's file to give others an idea of what is helpful

There is a question on our assessment form which covers all aspects of communication needs. This is recorded and uploaded electronically into the service users file, the main aspects of their communication need is recorded on the front page of the service notes. More detailed information is provided by the Speech and language Therapist. Also recorded on the service users notes

Sending out accessible letters.

Use of the passport to identify early people's support needs is working well.

As stated we use a lot of easy read documents, all documentation is personalised, we use tablets, recorders, but most importantly our staff understand the people that we work with.

We feel that a standalone sensory and telecare team - working across all ages and client groups works well. It helps to raise awareness and offer the appropriate support needed

We work with [...] Hospital and [...] health services making improvements for patients with learning disabilities.

We have a number of tools that we have developed for use with people as communication tools you can see them on our website. [...]

Hospital Passports are very popular

Repeat questions in different ways and ask person to repeat the question to ensure they have understood it

Direct contact made with NHS England re: local developments.

use face to face personalised communication with individuals

read and implement information provided by main carers

Train all staff in any kind of industry/services to understand and communicate with people with learning difficulties and disabled

respect and provide informative choices directly to service users

We have developed a form so Audiology departments can refer directly to us. This has resulted in a major increase in numbers of Deaf/hard of hearing referrals.

Using [...] to support us with the use of plain English/ Easy Read information.

We assume everyone needs to have advice simply and clearly articulated and we write down any advice where names or numbers are concerned. We ask people to repeat back what they have understood so we can be sure they have processed the information.

'How I want to be supported' document contains the following questions: I like to be called. My family and close friends call me. I like people who don't know me to call me. I communicate by (Please also see my communication profile). Positive interaction with me looks like this (Please pay particular attention to the supporter's tone of voice, eye contact, body language and content of the conversation.) Before sharing personal information about me, this is how I want to be asked. (Please include how you respect my privacy and dignity at all times) If I want to keep some information to myself, this is how I'll tell you. This is how you can help me to feel safe (i.e. What does this look like). Sometimes I need more support (Include how supporters are sensitive to this.) These activities and interests are important to me. (Include how I like supporters to engage with me during these times.) I like to do these things on my own (Include how supporters encourage this). This is how I respond/feel about physical contact (Include how supporters encourage me to be as independent as possible). If you need to tell other people what I want or need I would like you to do it like this. (Please include how you respect my privacy and dignity at all times). People from [...] Trust will sometimes visit to see if the support workers are supporting me properly. This is how I will tell them if I don't want them to come.

Communication passports are used with good results for some people e.g. people with learning disabilities/ difficulties, people with neurological conditions.

we use [...] and find these work really well for most of the people we work with

our easy read documents are of a very high standard and do not cut corners or gloss over the difficult stuff; we consult regularly with service users to make sure we are doing things in the right way

we also use multimedia formats where appropriate, either as standalone videos/DVD's or in presentation formats - these might include video, audio, photos and [...] - or as online multimedia profiles using the [...] software developed by [...]

there are times when line drawings work better than [...] and people with more profound learning disabilities generally need a different, more tailored approach using tools like the [...] software or objects of reference

[...] NHS Foundation Trust has a Learning Disability service user editorial group called the [...] group who review information produced by the trust. They will make recommendations to ensure information produced is in an easy to read format and has supporting visuals that are relevant to the text

Happy to discuss any of the projects we run or any of the comments I've made

[...] community services are now ensuring an alert is placed on [...] system. Along with learning disability status.eg statements

Person's communication needs: limited to few words simple sentences; able to communicate basic needs; nonverbal-uses facial expression sounds and body language; uses sign language; uses pictorial aids/easy read info; appointments to be made with care

Having the right attitude towards individuals and understanding that not everyone can understand or interpret spoken language and that assumptions should not be made. Alternative formats are useful for everyone - less jargon and lengthy written discussion and more pictorial representations.

Continuous recording and reporting and reviewing of recording works really well for us. Communication needs are paramount within care plans and risk assessments in ensuring all elements of care planning are met and ensures that we are doing the best that we can for that individual. Monitoring is crucial.

We are supporting easy read in the CJS system and would be happy to discuss the issues we have encountered.

We have lots of experience in communicating with people with LD and low literacy

We work with many individuals over a year so difficult to quantify

Simply to work in a person centred way and to communicate in a way that the individual is happy with and is able to fully participate. (two way)

Our use of one-page-profiles and communication charts works well. 1. One-page-profiles typically have three sections: an appreciation about the person; what is important to that person from their perspective; and how to support them well. These are a short and practical introduction to a person and can provide the foundation of a fuller personalised description of someone's support and/or communication needs. We aim for everyone we support to have a one-page-profile as part of their support plan. 2. Communication charts are a simple way to record the most important information about how someone communicates and - importantly - how best to respond. These also take an important place in each person's support plan.

Broadly speaking, it is worth noting that our experience is that each person has their own unique way to communicate. This will range from using sign language, pointing at photos or pictures, cutting out background noise, speaking clearly and avoiding technical or complicated language, etc. It is one thing to know how someone communicates or what support they need, it is quite another to be successful in responding to it (helping someone understand and be understood).

It is good way to recording all information from clients.

I think information need to be more accurate, for example, what types of communication, how much does professional and clients understand each other. Professional views and Carer View, this is good way to reflect on each other. Will receives a better support.

At same time, d/Deaf clients often receives the support quite late, compare to hearing clients. This is because of communication needs. This will or can affect their mental health, emotional, depression. I am sure and with the information from other organisation recognise individuals disability experiencing the same problem as d/Deaf clients.

The [...] system in Sensory Impairment Team is managed by workers with extensive knowledge and experience of sensory impairments with two workers using BSL.

The initial contact is completed in a way to meet the client's needs.

We do have the facility to put warning notes on a person's front page record which can be used to record communication issues. These warning notes are very easy to see (they are in red) and are at the top of the electronic page so it would be hard to miss them.

We check communication needs, not only upon referral, but during reviews also. This enables us to maintain up to date information.

We produce all our information in Easy Read by default. These means that people do not have to request an alternative format and it is easier for everyone to read, as it is clear, simple and accessible.

Easy Read can benefit people with: - a learning disability, - poor literacy / numeracy, - visual impairments, - English as a second language, - no time to read, - a condition or illness that is causing them distress, anxiety, or making it difficult for them to concentrate or think clearly, - limited knowledge of health/social care or 'jargon' words, - limited mental capacity which means they need extra support to understand information.

I always try and talk to my patients and ask what are their needs and wants, then try and approach others within my discipline area to give the best at the end of the, after all we need to give best patient care at all times.

This Trust has a Patient Information Manager who co-ordinates the services from external providers and produces easy read generic and patient specific information.

Our symbolic Language advisor has worked to develop numerous easy read documents and resources and we would be willing to share and discuss these further a couple of examples are as follows:- Easy read CPA documents, easy read police booklet, easy read section 136, Birth plans, and some more specific to clients, health info documents and lots more.

Having worked with a number of blind clients, I am familiar now with the talking technologies such as scales, but have found that use of scoops to make accurate portions can help enhance independence. Also have used the [...] from [...] for labelling prompts for things such as portion size or carbohydrate amounts on packets of food.

We keep files and samples of accessible forms and resources that can be photocopied or adapted by members of the LD Team.

We use a booklet when during initial assessment which supports the service user (and carer) to make decisions about how they want to receive information, be contacted etc.

Our in house easy read information is received well by both patients and carers

In my service people are assessed and have an individual communication plan developed. Then support workers adapt complex information for them.

We put a statement on our leaflets saying that a person who knows the person well and understands their communication needs should support them according to their individual needs.

When assessing patients we link needs within an activity e.g. Hearing do you have problems hearing?

Please look at [.....] website. This is a good example of how a website can be in sign language and therefore available to all BSL users.

Within our service we provide sensory awareness training to all Social service staff

[...] information leaflets are available in many formats e.g. braille, large font, different languages, online etc. which is very useful for us.

Our team does not have the staff resources or time to construct info leaflets or revamp them so it is reliant on resources freely available outside the Trust.

We are looking at such issues currently but I feel that it is critical that you encourage GP's at the point of referral to discuss with the patient their needs, something the GP should be very aware of and addressing him/herself anyway but then transferring that information with the hospital referral.

As a team we have developed some easy to understand flow charts / info sheets for complex issues such as financial assessments and the assessment process.

Communication passports - traffic light system which summarises very important info re: what the person likes/needs (green), unsure of/may dislike or struggle with (amber), does not like/will not work/may upset (red)

Prompt accurate recording is something we strive for and feel we achieve well. Manager monitors recording at intervals and provides feedback.

We have some people who are unable to write and have written down what people have been saying to ensure their points are raised.

In a previous role I wrote a letter on behalf of a service user which he could produce should the service user act in a strange way and draw attention to themselves due to a disability. Having the letter available defused any potential conflict and anxiety.

We use a range of approaches including Makaton, Symbols and Objects to convey information and assist people in communication.



communication passports and charts work well

[...] work well to aid easy read text with associated photos

- Communication passports work well
- communication section on Hospital Grab sheet for quick, instant information
- Symbol/photo packages available to all staff on intranet
- Training for staff in how to make information easy to understand

One of the standard first questions asked and then attention paid to on every subsequent contact.

Ask what their difficulties, what makes it easier for them and respond accordingly

We have training and experience in responding to individuals with receptive and expressive aphasia. experienced in the use of [...] .. establishment that 'yes' means 'yes' and 'no' means 'no'- thumbs up -thumbs down; use of images; symbols; alphabets; pen and paper; elimination of broad subject matter to hone in on particular issue; mime/gesture/facial expression; pointing; reframing/checking out what is understood so far is correct; Use of [...] Setting: aim for few distractions; as much quiet as possible; give the person plenty of time; try not to make assumptions about what the person is planning to say - don't jump in with the solution; persevere to establish meaning but also recognise when a break is needed or to drop the attempt. Choose time when person may be less tired. Query - break issue into manageable chunks to be dealt with over time to avoid 'information overload'; summarise; use advice from [...] and [...]; good lighting; larger text/magnifier; highlighted key words; bullet points

Sensible and empowered reception staff. They are too often mocked and belittled in popular media, but they do a demanding job in difficult circumstances, and some public support from politicians and DH would be nice!!

Our Trust paid to have our PAS system altered to record if a patient or service user has a sight impairment. The flag used for these patients is used automatically when generating an appointment letter so the printer uses yellow paper from a different tray and larger font.

We provide good support to people with aphasia - a common communication difficulty as a result of a stroke.

An easily accessible database that you can flag up issues on.

I think that suitable images to accompany text would help service users. Key words could be highlighted in bold.

Options could be listed in a table so that someone without speech could clearly point to the option they wish to select.

Using [...] to support people with a learning disability/cognitive impairments/acquired language difficulties to support them to express their opinions.

This is a link to an article myself and a colleague wrote about the work that is being done to adapt information for people with acquired communication disorders. [.....]

Happy to discuss our experiences at [.....] Trust LD services. It is very much a journey - we have made a good start but are committed to making information understandable to each individual and it's not easy

Pre-op assessment identifying specific needs prior to admission

If we know we are going to need any kind of interpreter once a young person has been referred to our service. We endeavour to make an initial booking for a clinic appointment and send out a reminder sms or use [...] services to remind the parent / carer of the appointment so it is not missed.

From the [...] would block book appointments suitable for the family to come along to on a weekly basis where their needs would be met.

We have successfully used language interpreters and deaf sign interpreters with good affect in the service.

BEFORE WE SEND FOR PATIENTS FROM THE ADMISSIONS LOUNGE WE CHECK IF THE PATIENT IS THERE AND PREPARED FOR THEATRE AND SO ANY PROBLEMS ARE SORTED BETWEEN US - THEATRES AND ADMISSIONS

Accurate reporting & recording.

Referrals as and when needed.

Good communication between staff and parents and carers.

I respond to individual requests for additional communication support and do what I can to provide this for my clients.

The most important thing I think our team and related teams do for communication support is to display patience when working with service users. While we cannot always make extra time to work with patients, being calm and reasonable usually allows us to communicate most effectively with the public.

As a Deaf service, we are aware that we need good qualified interpreters registered to work with our service, therefore we run in-house interpreter training sessions (run by our in-house lead clinical BSL/English Interpreter) and have honorary contracts in place before they take any bookings with us.

If we are working with a spoken language interpreter, again one of our team interpreters will share suitable reading materials (to help them learn about this specialised setting) and have a pre-meeting to discuss working together.

We translate any written materials in to BSL DVD letters i.e. a clinical letter sent to a patients GP is translated into BSL on DVD and sent to the patient. This is so they can watch it as many times as they like in their first or preferred language.

We are transparent about how we gather information about a child, adolescent and families communication and language. We see it as them helping us to understand how we can best serve them.

We have Deaf staff as part of our multi-disciplinary team, which means we have a deeper understanding of the clients that we serve.

We have written various policies: Working with interpreters; Translation; Communication (policy for a service with hearing and deaf staff working together)

We ensure that planning, preparation and de-briefing time is added to all appointments, to ensure we all know what we are discussing and think about what we might need to do differently next time.

Preferred method of communication works well as it allows the service user to express their needs to us without asking questions that may not be relevant to them e.g. if they need BSL interpreter it may not be necessary to ask about sight/reading....

instead of asking which is the first language, we ask which language do you feel more comfortable communication in. we felt people felt their immigration was threatened by asking which was their first language

RECORD EVERYTHING, EVERYTHING, EVERYTHING YOU LEARN ABOUT THE PATIENT. Detail: People often leave out important detail such as patient initiated encounters (I think I might be pregnant but my husband doesn't know, what shall I do?), what patients expressed over the phone, what mood a patient was in when they came to the practice (crying, afraid, etc.) noticing a patient has brought an interpreter; RECORD IT. Record all communication encounters. This prevents stress and frustration on the patients' side having to call and express the same thing over and over. RECORD IT. So when another member of staff enters patient record they can see what the patient has communicated in previous encounters. When calling a patient RECORD IT so when they call back colleagues are aware of why the patient has been called.

COMMUNICATION IS EVERYTHING

ASK QUESTIONS and record answers.

Courtesy calls to known patients who need extra support/monitoring

Face to face with patient/carer asking basic daily living requirements, any problems will show in their answers, you can offer to improve any difficulties, keep them informed about what you can offer

typing questions on [...] useful for hearing impaired patients

Communication support needs are recorded on the electronic system

We are initiating a project with our Patient Group to identify carers, and their needs, to help them with daily living and tasks such as form filling. This is a work in progress.

Many deaf people have said to me it is the first time they have had any direct communication support at any surgery. They usually rely on relatives for interpreting. So on reflection the fact that deaf patients are booked in on the days I work is good practice. I would welcome more training.

Have an integrated PAS system and electronic social care record is a must.

we code as much as possible. we meet weekly to discuss issues and include coding in these meetings. we have designated coders- i.e.; a receptionist responsible for coding calls/recalls for cervical screening- another for immunisations. we code all invites and log attendees

There is so much to discuss and share in terms of current action and future plans. please feel free to contact me

There should be a method for recording the presence of every interpreter or ITALS worker in the clinic notes. These should include: Date and venue of interpreted communicative event (ICE); Name of clinician; Name of interpreter; Name of agency supplying the interpreter; Gender; Languages used; National Regulator's (NRPSI) registration number; If not registered, highest qualification e.g. DPSI (Health)

[.....] provides day opportunities for a number of different client groups including older people, people with learning disabilities and people with physical disabilities. Within one of our day centres the staff all receive Total Communication training on a regular basis. Total Communication is about the use of a variety of methods, including different signing techniques and pictorial aids, that assist people with communication difficulties. It enables people to have an equal say in how the service is delivered, and the future direction it will take, as well as indicating preferences and making choices. These choices can be as basic as deciding what to eat, or as complex as a Person Centred Plan, which is a document which outlines an individual's wishes and dreams. This plan is then used to deliver a service based on an individual basis. Communication passports can also be made on request for clients which ensures that staff can fully communicate with clients in a way which best suits client needs. The day centre uses a variety of methods to communicate with people which include key word signing, access switches to promote independence and to support choice making, large visual timetables with photos, symbols and objects of reference to assist with communication. Other methods include access to an onsite speech and language therapist, large print keyboards and the facility to adapt written information into easy read formats.

We have an internal interpreting and translation service in the Trust.

In our initial assessment we have a section for communication which is completed for all new open cases and sometimes at screenings.

The majority of our clients are ok with just larger print 16 point.

Don't write what can be said in one line in three paragraphs!

Don't use drop down menus on websites get advice from [...] and [...] on spec for leaflets and websites.

We are trialling tablets in services to support visual communication. [...] and [...] are also used to aid communication with nonverbal people.

The Referral Management Service does good work around the needs of people with learning disabilities, in terms of information, access and support. We are looking to expand this to include other areas of communication needs.

it would be great if all the hospitals /GP surgeries and health clinics could have a red flag on their screen to show this patient needs communication support then the admin can book the chosen communication support without us calling up to request one as it does create delays or sometimes means they have to re schedule their appointments.

Easy read documents using pictures from [...]are well received. We involve people in developing our standard written information to check out that it's going to meet their needs.

person getting involved is the key to providing the right information.

We use communication passports to record all information about a person's communication needs in one place. This covers: - a dictionary (words that a person uses/understands and what they mean) - how a person communicates - at 'W' situation or time, if the person does 'X' it means 'Y' and you should support them like 'Z' - How they make choices - How they express feelings (likes, dislikes, pain, tiredness, boredom, hunger, thirst, attention, happiness and sadness) - Objects of reference - Understanding of verbal words and gestures - How to support them to understand things

I am co-ordinating a service to improve access to eye care for people with severe learning disabilities. I use a combination of a report using clear English with an easy read version. we are introducing the [...] forms designed by [...] to encourage sharing of information around a person's communication needs when attending the outside optometrist and as a hospital trust are evaluating our patient information and flagging patients to highlight the people who require information in specific formats.

We have been successful in securing funding for a project worker to review and improve the information we provide to service users with learning disabilities.

We have a well-established 'editorial group' ([...]) of people with learning disabilities who review and advise on easy read information.

Using [...] for all local services and having consistent photos for common words and services.

I am a Community Matron and on my initial contact with all my patients there are mandatory questions as part of the assessment process currently used. They are as per above in [...]. is English the main spoken language? Speak English well, poor or does not speak Do you understand English language? Interpreter need? Using British sign language

Accessible signage has been developed for all hospital environments across the Trust. This is being rolled out into all new developments and upgraded environments. Although this was originally developed to support people with learning disabilities, it is of benefit to anyone who needs support with communication. Patients have been involved in developing some of the signage.

In addition, there has been accessible information on Mental Health Act - this is being further developed to include accessible leaflets on specific issues and an accessible first contact pack.

Our service provision is significantly affected by the way we communicate with our individual service users. We ensure that any direct work or work by others follows basic accessible principles. Also that personalised communication strategies are developed so as to support understanding and consent within certain aspects of health care decision making processes.

We have a corporate translation and interpreting service of up to 80 languages available for interpreting requirements.

We commission [...] to provide Easy Read and other pictorial forms of communication, as well as to facilitate discussion groups, and feedback forums for people who need support with communication, and to help us communicate more appropriately

genuinely asking the person sincerely.

[...] runs training courses on good communication access - we have a toolkit and cascade training manual. We have great expertise in working with people with aphasia and are very keen to raise awareness and enable others across the spectrum of society to have better conversations and to understand what the issues are and how they can better engage with people with communication disability.

CAREFULL EXPLANATION OF ISSUES NEED TO BE DONE ON A REGULAR REPEAT BASES, AND AN ASSESMENT MADE BY AP PROFFESIONAL.

## Appendix 18 – Support and supplier organisations and patient groups survey, Q6.

### “Do you have any other comments about accessible information and communication support?”

We think the proposed question is fine from a hearing service point of view. However, the wording is based on the assumption that it is the Deaf person that needs the support, rather than the member of staff. If it could be framed in a more positive fashion then that would be great. It may also make the member of staff stop and think that, without an interpreter, they are going to struggle. [...] fully supports the proposed Standard and looks forward to seeing it introduced

as an idea I think it would be good for all healthcare organisations. to have a trained sign language people on site that is accessible for patients

most of points set out have been made many times before by deafness charities, but the NHS obsession with forcing its patients to use the phone gets stronger and stronger. Most NHS depts. Are ignorant of the existence of speech to text reporters and how they can help a deaf person communicate accurately. Communicating accurately with patients who have sight and hearing problems is a huge challenge and is under appreciated and under resourced

speech to text reporters could be useful for complex explanations to patients. Training and deaf awareness are vital.

policies must be implemented, good communications between different organisations. and depts. is essential

[...] happy to work with NHS England to ensure that info on bowel health, symptom awareness and bowel screening is accessible to everyone

A central NHS library of Easy Read images would be useful - at the moment you have to buy them. NHS organisations should also share their best resources - for example, good generic leaflets in Easy Read.

Our Easy Read section includes both home-produced leaflets and some from other NHS bodies.

[.....] In a nut shell: Offers the opportunity to take the lid off current systems by using secure technology and multimedia to support children and young people with disabilities create online person centred plans, virtual circles of support (that could include key health care practitioners) and operate alongside current safeguarding strategies. The opportunities are limitless and apply to all vulnerable people, across all services and supports (Health, education and social care for example) with a potential world wide application. Testimonials below give a bit of insight into what's possible – the films are especially powerful. [...]

We would like to see EasyRead come out at the same time as the generic information and not to have to be requested

The need to have access to suitable software is important and consistency in producing easy read information that is reviewed by service users

Patients and service users with communication and support needs also suffer if a service is withdrawn and they are not advised this has happened or what happens next. For example, a particular service user who is deaf and partially blind had access to the BSL service funded by Community Services. This was suddenly withdrawn and the service user was left without much needed support to access her GP and Dentist and was also sent unpaid invoices from the BSL service requesting payment. After the intervention of NHS England the invoices were paid however, the service user is still struggling to understand why the service was withdrawn or how this will be managed in the future.

Timescales are also an important key element here, without the appropriate time to involve people with access needs we see an inequality creeping in to consultations which invariably means they are seen as tokenistic.

Information and communication support needs to be universally available and that costs.

We should all try to use the opportunities of modern I.T. in order to present information in a number of formats.

We need to capitalise on available technology to help those who have access to it (audio-guides, web info, podcasts) for those who are able/willing to access information this way whilst not forgetting to cater for those who cannot at present access info in those ways.

This is confusing. You are talking about a new Information Standard for those with communication difficulties. But there is already an Information Standard with connections to NHS England which is for general patient information for the wider public <http://www.theinformationstandard.org/>. Is this development an extension of the scheme already in place, or are you trying to start a new scheme with the same name?

Asking people who have the specific needs directly, trials of the initiatives and the use of experienced professionals who can support and help build skills within the workforce and support patients and professionals.

More consultation should be done with Deaf people, communities and local organisations working with the local communities to identify needs as they are not all the same across the country.

Create peer support groups to help those patients who cannot use computers to access online records

Patient leaflets are sometimes available in other written languages, but never in British Sign Language - which is [...] and is the primary language of approximately 180,000 people. Clinics invariably rely on staff shouting out a name, a scrolling sign would be better.



Need national guidelines and consistency

Patients' needs to know what they have a right to expect and request

There is no communication if both the receiver and the sender do not understand each other and it is much more likely that an embarrassed patient or representative will not admit their ignorance in front of a public meeting.

People with a sensory impairment should be able to read their medical information in private for themselves, instead of having to ask someone to read things to them.

BSL videos on health issues are very valuable. However not all deaf people have access to computers, therefore a series of DVDs in BSL on various health issues would be helpful. These could be made available through the GP, hospitals, voluntary organisations etc. Local hospitals use different agencies to book BSL interpreters. Again it depends on the awareness of the staff booking the appointment. It should be noted at the outset that the patient always requires a BSL interpreter and this should be automatically flagged up on the system in such a way that it must be done in order for the appointment booking to continue - e.g. constant flashing across the screen which can only be removed when the BSL interpreter is confirmed.

Key priorities: Ensure all BSL interpreters booked for appointments are NRCPD registered. Ensure that all information has a BSL translation embedded in the website. BSL videos on websites.

Staff need to be aware that interpreters are a necessity and that written English may be poor and not fully understood by the patient so this is rarely a good replacement for an actual interpreter

There is often a conflict between providing good-quality communication support and the need to do so economically. The case must be argued that by getting communication right the first time saves money in the long term. Systems may pay lip service to this, but all systems depend on individuals. And all too often nobody within an organisation takes responsibility for ensuring that deaf people's needs are met appropriately.

Stop using [.....]

Deaf BSL users should be provided with interpreters by right. They shouldn't have to argue their case or feel grateful for this.

Produce this survey in a format accessible to BSL users - i.e. with BSL video clips and allow them to respond in BSL. Otherwise it's likely you will have very few responses from deaf patients themselves

There are many internet resources with medical information in BSL which medical professionals should be aware of.

I would suggest having a contract with [...] is the smoothest way to ensure that LSPs are always arranged.

one size does not fit all- we have worked hard to establish consistent and service user led recommendations around easy read (e.g. no symbols but use of photos and [...]) for our borough

Staff, managers, decision makers in healthcare must change their ideas and break the barriers of we are staff and they are patients and see ourselves as all patients/users of the NHS. Changing perspective may and should get more engagement of staff.

I have worked in the third sector almost all of my life and am nearing retirement. More resources are spent on speaking about information and communication than on practical action - could this trend be reversed please?

Providing key patient information in video form in BSL on websites or DVD's is necessary for Deaf patients, as is correspondence in plain English

Large contracts have been awarded to interpreting agencies that specialise in spoken language translation such as [.....] and [.....]. These agencies are not experts in the field of deafness and sign language interpreting. They do not have the depth of knowledge, awareness of Deafness, Deaf culture and the community and the interpreter contacts that BSL specialist agencies have. Contracts should be awarded with expert organisations such as: [.....]

There is already an effective national network of libraries (both public and NHS) that could be better utilised to deliver this kind of service.

It is important for NHS staff to understand the legal ramifications of giving health treatment without the appropriate communication and information support

As I have stated above, this survey itself is not accessible to the very community it discusses.

Communication support is currently based on the cheapest option and sometimes seen as 'too expensive'. This turns out more expensive in the long run, as [...] demonstrates.

Access to information and services is not just about provision of an interpreter or a clip in BSL. It is about awareness of the cultural issues, information provided by Deaf BSL-using professionals themselves, awareness of the gaps in general knowledge and impoverished education that many Deaf people have due to inaccessible schools where they have been forced to try and lipread.

Ideally, the profession of British Sign Language / English Interpreter would be a protected profession [...]

I am sure that there is always space for ensuring that information is given in BSL. Really, just don't contribute to the demise of the interpreting profession by using the wrong agencies to supply interpreters. One stop shops do not understand the requirements relating to the provision of interpreting services for deaf people so this is never value for money. They drive down fees and eventually interpreters wonder

what the point of training and being good is if anyone with a bit of BSL is sourced and paid the same as them.

Access to communication support for deaf and hard-of-hearing people at doctors/hospital appointments etc. needs to be provided, in English text (verbatim Speech-to-text), Lipspeaker and BSL, depending on the needs of the patient etc.

Having a standard for all NHS staff/services to adhere to will help enormously with achieving consistency with what is produced and will raise awareness amongst different staff and services that people with communication needs access all types of services!

Accessible information is only helpful if it totally meets the need of the individual person. I.E if a deaf client requires BSL signed document he/she may not understand it if they are SSE.

Efforts should be made, as much as humanly possible, to provide information either in BSL, a deaf persons first language (if a sign language user). If this is not possible then plain English would be preferable, or invite the Deaf person to an appointment to discuss information face to face with the use of an appropriately registered interpreter.

There is currently a campaign group looking at improving access for deaf patients to NHS services, please visit [...] for more information and to contact for advice.

[.....] are providers of accessible information and communication support. They already work with several NHS healthcare trusts to create accessible documentation.

Pictures alone do not make information accessible and some documents have been turned ridiculously long because of the photos added.

BSL DVDs/videos are a good way to explain health matters/conditions, these should be made available widely in the community, GP surgeries, local hospitals. Seek help from Voluntary groups with close links to this Community, maybe arrange to give information/advice sessions on health matters on a regular basis.

All front-line staff should be aware of how to book Qualified BSL interpreters. It should not be the responsibility of the Deaf person.

It should be done as easily as booking a translator.

All front-line staff should have full information and training on Deaf Awareness which should then be refreshed on an annual basis. This hopefully should not only ensure that the skills are updated but that training is provided for any new staff in the interim.

Family member or friends should NOT be booked or assumed to act as facilitators of the communication, given that issues raised may not only be sensitive but confidential too.

Electronic communication and sending letters would be the best and most efficient way forward.

## SHOULD BE WRITTEN IN SIMPLE LANGUAGE

It needs to become part of the everyday way of doing things. All information and communication should incorporate access. Services need to plan for it - with someone taking responsibility, a realistic budget and making sure that users are engaged in designing the system so that it is easy for them to interact with. Services need to understand this as a rights issue - disabled people have a right to equal communication; as a quality issue - better communication leads to better outcomes; and as an efficiency issue - poor communication leads to waste of resources.

It needs to be remembered that in the thrust to use the new technologies many people are still not IT literate

Communication support at the point of entry is often poor.

Size and font of print needs to be considered

Experience has shown that there is a culture within the NHS and Local Authority of wanting to simply tick a box to say that they are compliant with equality standards etc. This is often justified by organisations commissioning/producing easy read leaflets/posters which are often unused or ineffective in meeting the communication support needs of individuals.

A joint up approach is needed, organisations need to be pro-active in working with experts within the field, information needs to be produced which is relevant to the client group.

My only other comment is that I understand what accessible information is but I have to say that I have not come across communication support. This really is a very good example of what I am trying to put across to you. Which is that you consistently fail to use simple and straightforward language. In fact, without wishing to appear rude it seems to me that you go out of your way to use phrases which do not mean a great deal.

I would suggest you contact [...] I do not, though, necessarily support the [...]. Instead I would suggest working with [...] to improve the training of interpreters, which can be maddeningly inconsistent.

Communication support can be expensive but this should not compromise on the quality of access afforded to deaf people. The NHS should strive to only use registered personnel; this point cannot be emphasised enough.

it is vital to include the communities to have their say and ask them to help with the decisions on purchases, designing of services / leaflets etc.

Vital information for example on specific surgical procedures or health conditions needs to be translated into BSL. or failing that, made more accessible by bullet points and summaries with plenty of illustrations and diagrams - visual clues as to what the text means.

Obligatory provision of BSL interpreters.

Obligatory subtitles on all information screens.

Move to onscreen interpretation of all information displayed as leaflets are not accessible

Using modern communication support is good for younger people but isn't what older people like Face to face support is most important

Easy read or other accessible information is often seen as an afterthought. It is also seen as one of the first things that can be cut when savings have to be made. Anything that can be done to push it up people's agendas will be very worthwhile.

There needs to be a broad approach of accessibility & inclusion but also ability to really personalise it when needed

It should be a common place thing and easy to access not a special consideration that takes ages to organise.

All information should be accessible in various formats if needed. Advocacy could be used too if needed.

Deaf people are dying across the country for no reason other than they are not being provided with interpreters for medical appointments. There are many newspaper articles highlighting the issues around denial of access. Without an appropriate interpreter, Deaf people cannot give informed consent.

If nothing else, funding should be available to book NRCPD registered interpreters.

Too much to include in this little box - but happy to discuss

Internet good... perhaps people could be given tablets and training to facilitate their own communication

Teach people BSL EARLY in their deafness process for Hard of Hearing people.... Training needs to be CHEAP enough to access.

Personal preferences of the service user are vital to follow, especially in view of the often stressful nature of appointments or interviews. Also being aware that this can change.

Difficulties communicating with medical staff is a common complaint amongst both disabled and non-disabled patients. Improving accessibility for disabled people usually leads to overall inclusivity.

Internet is helpful.

Not everyone will wish or need to access the same level of information to have understanding of their condition and treatment. Keep care individualised and respond to individual's needs.

Very often health care professionals seem to think that without a BSL interpreter written English is an acceptable substitute however, many deaf people do not

understand written English. Consideration and training should be given to ensure that if staff members have to resort to this, that they write in PLAIN BASIC English which is more likely to be understood. Alternatively, the use of remote interpreting for these and other emergency situations where a physical interpreter cannot be booked should become more common.

It is personal - and has to be appropriate to the individual patient.

It's very mixed - some excellent work has been done but relies on individual professionals being open to the use of easy read documentation. For example the use of Health Action Plans for people with learning disabilities can be excellent but is very dependent on GPs and other health professionals completing the appropriate sections and keeping them updated and current - time can be an issue here.

There are many specialist agencies that can book qualified register interpreters but there are many agencies that do not understand the needs of BSL users. always check that interpreters are qualified and registered before booking

Don't assume that if a member of staff has a little bit of sign language that is enough - it is great for welcoming in at reception but not appropriate for the health appointment itself - always use appropriately registered interpreters (see NRCPD website about registration and [...] campaign) interpreters should always carry their ID with them and it can be asked for.

It's been very good to have the video clips in BSL on this website. More can be made of video clips of general info shown in BSL that can be shown in waiting rooms in hospitals or doctors surgeries. (there are often general health videos shown where there is no access). Deaf people's literacy level can be quite low, so they can miss out on picking up health tips from these informal video clips.

As above, interpreters should be registered with NRCPD and be fully qualified, in order to ensure accurate information is given to patients. Medical situations can often be dense in specific jargon, emotionally charged, and challenging linguistically, therefore, 'people who can sign a bit' are totally inappropriate - and dangerous for legal and litigious reasons.

Don't have your head turned by what appears cheap – [...]. Interpreters care about the access that their users have but not at the cost of their livelihood - if we accept ridiculous fees then it has a massive impact on our ability to continue to provide a high quality and appropriate service. I would say to really listen to what people feedback in this survey and resist the temptation of agencies that are not being honest, they don't know what they are doing and they are not giving you the service and value for money that you hope for. Work with smaller, local providers.

How do you deliver or give access to information to diverse groups of people? As a user of information, in my role as a carer for my sister, I had interaction mainly with Social services, supplied by [...] Council, I had a good level of support, but this is/was my third period of being a carer, having cared for my mother, then my Step father, so I knew where to get help by experience. At present there are so many changes of title, for Health organisations, it does seem a more complex task to find information.

Groups should be willing to provide 1-1 support if people need extra help to complete forms/questionnaires etc.

It's the 21st century and we need to all wake up - people have died in the past and will do again unless we can achieve equality and access for Deaf people.

It is crucial that people have assistance in being able to identify a reliable carer, friend or professional they can call on who will help them communicate and take notes during medical appointments. Many stroke survivors feel they have forgotten or don't understand what was said after an appointment if they don't have this support. It is also key that professionals are able to identify and print off information which is suitable for them to take home and think through the whole pathway to accessing services, not just the contact time with the relevant service.

Transport is a continuing issue for those with sight loss along with trying to access signs, touch screens and displays.

Time and effort must be spent on an individual basis. This will cost money and needs to be included in the cost of needs assessments.

In one actual case a hospital administrator booked a sign language interpreter for a Deaf patient's appointment, but on the day the patient failed to show-up. The administrator turned to the sign language interpreter and said 'Well I don't know why they are not here. I called their mobile and left a message on their answerphone!

All information must be not only available in a variety of formats to enable communication regardless of impairment but must also be actively sent to any organisation supporting and empowering those who, due to their impairments, are unable to actively access or directly respond in the usual channels despite having valid contributions to make to the debate.

Great design and embedding accessibility at the beginning is not expensive and does not put a major overhead on the project

Awareness training for front-line staff about how to greet a patient would be useful. A means for addressing complaints for Deaf people would be useful.

I hope that this consultation is a meaningful exercise. We are regularly approached by individuals who cannot access the internet - through lack of skills and access to equipment and due to poor health. Therefore, any information and communication needs to be available in different forms: not just online. Also, we are aware of the need to support clients who do not have English as a first language. This should not be overlooked. There are cultural implications which should not be ignored.

One format does not fit all.

Train receptionists better

We would recommend that the needs of blind and partially sighted individuals are considered from the initial stages of the design of any communications to patients and the design premises. We would recommend that this piece of work not only thinks about the needs of patient who are blind or partially sighted but also blind and

partially sighted members of staff who work for the NHS. We are pleased that NHS England is carrying out this piece of work and hope that we will see improvements in communication with people who are blind or partially sighted.

We would be happy to input further into this project and can be contacted via [.....], or go to our website for further contact details: [.....]

[...] is currently developing guidelines for developing good information resources, which will cover various aspects of production. The guidance will cover important areas such as content, navigation and layout, authorship, graphics and design and accessibility. This work is different from the Information Standard which looks at the process of development, rather than at the resources themselves. It does however aim to complement it. [.....] This work obviously has relevance for the work you are undertaking and there is a huge amount of expertise within our membership that you could tap into.

Options and choice need to be available wherever possible for the whole range of service users. Education and awareness amongst staff on being able to adapt their face to face communication to suit the patients as individuals.

Better that such services be rationed - but that a high quality be maintained - than that they be placed in the care of [...]. The latter is increasingly the case, while those who commission the services look the other way.

Involve people personally. Involve voluntary agencies to help individuals with specific needs and provide ongoing support

[.....] have recently published a highly critical report about Deaf people's access to healthcare in [.....]. I am aware of several horror stories and I would urge NHS England to deal with this before there is a fatality. I truly believe it is only a matter of time if things don't change.

NHS would save a fortune by NOT drawing contracts with BSL Interpreting agencies but instead contact the register direct. The NHS will save MILLIONS by doing this and it is not a difficult change to make.

Are there a few examples of organisations who provide all information and support in an accessible manner, or a few orgs that do each area particularly well that can be held up as examples as how to follow their best practice?

I have been fortunate to have the use of a text phone supplied by [.....]. On the recommendation of the Therapist I have bought a [.....] listening device to supplement my hearing aids (not available on NHS).

Anyone making or using accessible information with a person with a learning disability should be underpinning their work/ support with a sound knowledge of that person's linguistic and literacy comprehension skills.

Translation service offers language, BSL, Deafblind/guiding support and different information formats e.g. to cater for partially sighted. For hard of hearing lipspeakers, note takers are few and far between. More should be done to embrace



technology, to help accessible information like speech to text done via [...] available 24/7 e.g. [...], [...]. More needs to be done to cater for information formats in easier language/pictures for learning disabled, people with mental health problems and people with cognitive problems (dementia), such as the Communication book we use at [...] Trust on the wards. The real challenge is to make accessible information available 24/7 for Deaf, hard of hearing, partially sighted, at all stages of their healthcare journey. At the moment this is not happening and as a result people are not properly informed which in turn may impact on compliance for treatment, taking medication and impact negatively on their health and making health choices. There is a lot of education and raising awareness to sensory needs needed and this should start across the board at training level for healthcare staff but also earlier in education at schools etc., so children, grow into disability aware adults and more positively in media and social, cultural context. I have developed in my Trust e-learning [...] other Trusts are interested but I can't find the forum to promote this nationally, can NHS England Help? e-learning is a good media for training because staff have flexibility and it does not take as long as face to face training, I feel a universal Sensory Awareness programme is needed, to help bring continuity and endorsement of best practice.

Communication support like my role as a Hearing Therapist and also lip-reading teachers, notetakers have all seen reduction in funding to train, de-skilling with rehabilitation not being on the agenda for commissioners as seen with the 'Any Qualified Provider' (complex patients not covered and not clearly defined for support/funding at commissioner level). The rehab 'grey area' has resulted in service cuts and professionals/their skills are lost, this is despite the modernising of scientific careers strategy. I did this and now have a MSC but no job opportunities/career progression has followed because Hearing Therapists are no longer trained.

Communication support/accessible information needs to be endorsed by government as important and mandatory. To date various public petitions, have been blocked by government (lipreading funding and BSL more recognition), despite having a cross government Hearing Alliance working party - why!

Finally, subtitling and/or transcripts should be available without the need to ask, hard of hearing people rely on this and this should be included on the agenda for communication support and be nationally improved upon.

I am heartened that NHS England are conducting this consultation, please could I be kept on the mailing list for the report? Good luck!

Provision of translated information is a very expensive process, fraught with potential legal implications of translation errors. I believe that the NHS should not have that responsibility. [...]

Information needs to be unambiguous i.e. if you/someone can only have a clear liquid (before bowel prep) it needs to be made explicit that it means without milk etc.

Some body parts need explanation in simple words and jargon needs to be removed without oversimplifying the content - an art in itself.

The availability of communication support for defendants should be equal in law for both witnesses and defendants with communication support needs. This is not the case.

More DVD's with [...] signing.

Subtitles on all TV's within the NHS.

Blind and partially sighted people have fought for their right to accessible information for the past 15 years (since the DDA 1995 came into force) it has been a hard battle but currently energy companies, other utilities and banks have policies and processes in place to provide accessible information to their customers. It is not always a perfect system but on the whole it works. As private companies they have less of an imperative to meet the needs of blind and partially sighted people and yet they are ahead of the game when contrasted with NHS and local authorities. I think the main difference is that private companies view their customers as just that "customers" and they are used to putting processes in place to meet their customer's demands or needs. It may be worth looking into the challenges these companies faced when changing their policies and processes in order to provide accessible information.

It should be available to everyone who needs it at any time and in any place. It should also be shared (if it is written material) by all NHS organisations.

I feel the biggest issue regarding easier to read information is the lack of a national standard across all sectors and services. In [...] we have taken steps toward such a standard through a Communication Strategy promoting a consistent approach and advocating the use of the same [...] symbols across adult services. The intention being that symbols will gradually become familiar through association. I and my colleagues have been disappointed by the increasing commercialisation of some of the main symbol packages, requiring hefty royalties to be paid on publicly distributed documents. In effect giving people a language and then charging them to use it.

The work of specialist SaLT services takes a very person centred approach - whereas generally distributed easier read information has to be a compromise; to be accessible to the highest number of people, but not always a perfect fit. It's the difference between a bespoke, tailored suit and an off-the-peg supermarket jacket. The latter will never be the best for an individual, but it's the most economical way to reach a lot of people. In my opinion, too much energy is wasted on discussions around symbols vs. photos vs. cartoons. None of the packages are a "perfect fit" for everyone, but at least if everyone is using the same one, we can begin to develop the element of meaning by association.

There is no one solution for every family and patient. Therefore the NHS, CCGs and other organisations should look towards delivering information and support through multiple channels.

We believe that the outcome of this work, must include a clear and enforceable right to appropriate accessible information and communication support. With a duty for services to meet the information and communication needs. Enforcement must be realistic and open to the individual to pursue, without a basis on being able to secure

funding or self-fund to reach a resolution. In theory these are already enshrined via the Equality Act 2010, however the able to seek enforcement under the disability discrimination criteria is costly and beyond the reach of most individuals. National monitoring should also be a requirement via the Equality Act 2010, specific duty.

The use of family to interpret is still encouraged by some and this should not be allowed unless by patient choice.

#### 10. Other issues:

- Our members were concerned that we stress the point that there is no point in having very good policies for the use of accessible information if these policies are not implemented effectively.
- Members also told us that information seems to be provided in alternative formats inconsistently, and that information in appropriate formats is not always available when required by patients.
- Communication between different organisations and departments
  - o On a broader theme, our members made a variety of comments related to a lack of communication between different NHS and social care departments and organisations about the access and support needs of disabled patients and service users. These comments included:
    - o There is a lack of co-ordination between different organisations and departments about the access requirements of patients. This means that it can be very 'hit and miss' whether a patient's needs are met or not, particularly if their treatment means needing to receive services from more than one department organisation. One example of this is where a patient moving to an x-ray department in one hospital was told he could get out of a temporary wheelchair himself and was dragged out by a member of staff, although he was in great pain.
    - o Members have experienced notes not being scanned onto computer systems effectively. This can result in other departments having out of date records.
    - o Also, members had a variety of concerns about how information about how their access needs is shared between different departments or organisations. These included:
      - A plea for better explanations of how information being received from a patient will be shared between different departments.
      - Accompanying information with this and other NHS surveys and information, including recent information which currently contains vague information about data protection and other regulations on sharing information, should be made more open and transparent and described in clear and simple language.

11. Conclusion [...] would be happy to be consulted further on any of these issues or to provide additional information for the proposed guidelines [...]

The provision of registered interpreters provides access to patient to all areas of health care. More awareness of service provide health care in BSL for example [...] and [...] should be available to clinicians/ nurses and GPs that have deaf patients.

The needs of Deaf/deaf people vary - someone who has been deaf from birth, uses sign language and has low levels of written English, has very different communication needs from someone who has age-related hearing loss.

\*DON'T make assumptions. \*ASK the patient how they prefer to communicate.  
\*RECORD their preference. \*ACT on their preference.