



**Analytical report on the
consultation “making health and
social care information accessible”
- summer / autumn 2014**

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Document Status

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3 Summary

From 13 August until 9 November 2014 there was a consultation on the draft 'accessible information standard'.

The experiences and opinions people shared as part of the 'engagement phase' during winter 2013 / 2014 were used to write the draft standard.

As part of the consultation, NHS England asked people what they thought about the draft accessible information standard. This is a report detailing the responses which were received to a survey as part of the consultation. This report will be used to write the final accessible information standard.

In total there were 393 surveys completed. 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 survey which could be emailed or posted.

All of the responses to questions which required a "free text" answer have been included in the appendices.

In the interest of transparency, the 'free text' responses are published verbatim, and key themes have been drawn out from these – these do not therefore represent the view of NHS England.

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	Survey
Online	283
Posted	8
Posted (Easy Read)	64
Emailed	30
Emailed (Easy Read)	8
Grand Total	393

Source: Accessible Information Standard 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.

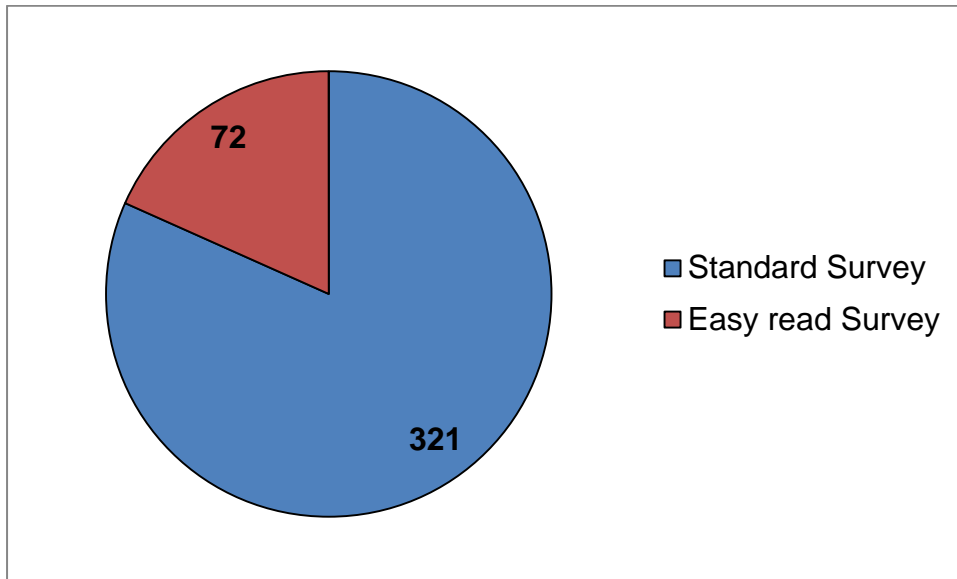
Note that some questions from the "Easy Read" version of the survey were numbered differently from the equivalent questions in the standard survey. Also

some questions from the standard survey were omitted from the “Easy Read” version.

Appendix 13 contains a list of assumptions that have been made when producing this report.

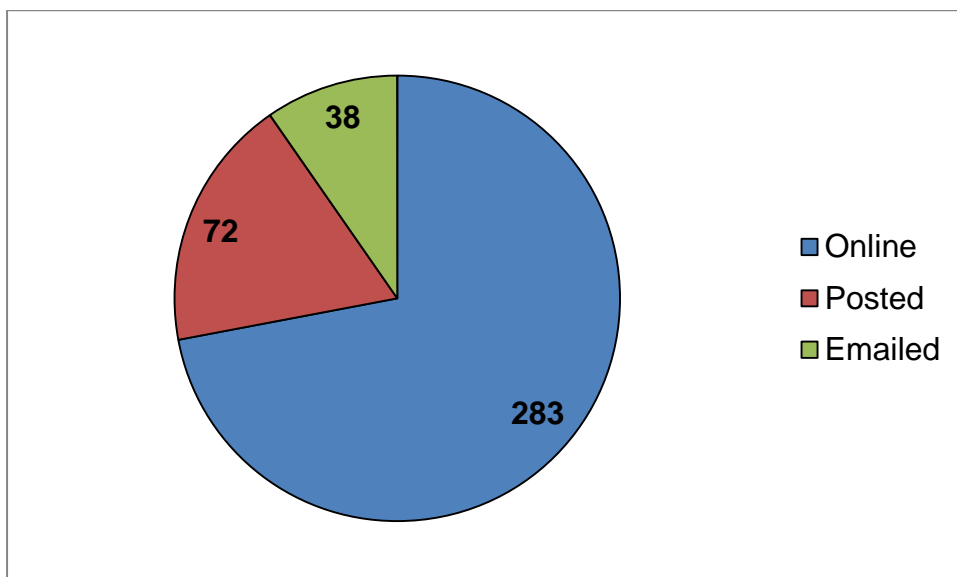
A breakdown of the type of survey responses received is shown in Figure 1.

Figure 1: Survey response by type:



A breakdown of the method of collection of survey responses is shown in Figure 2.

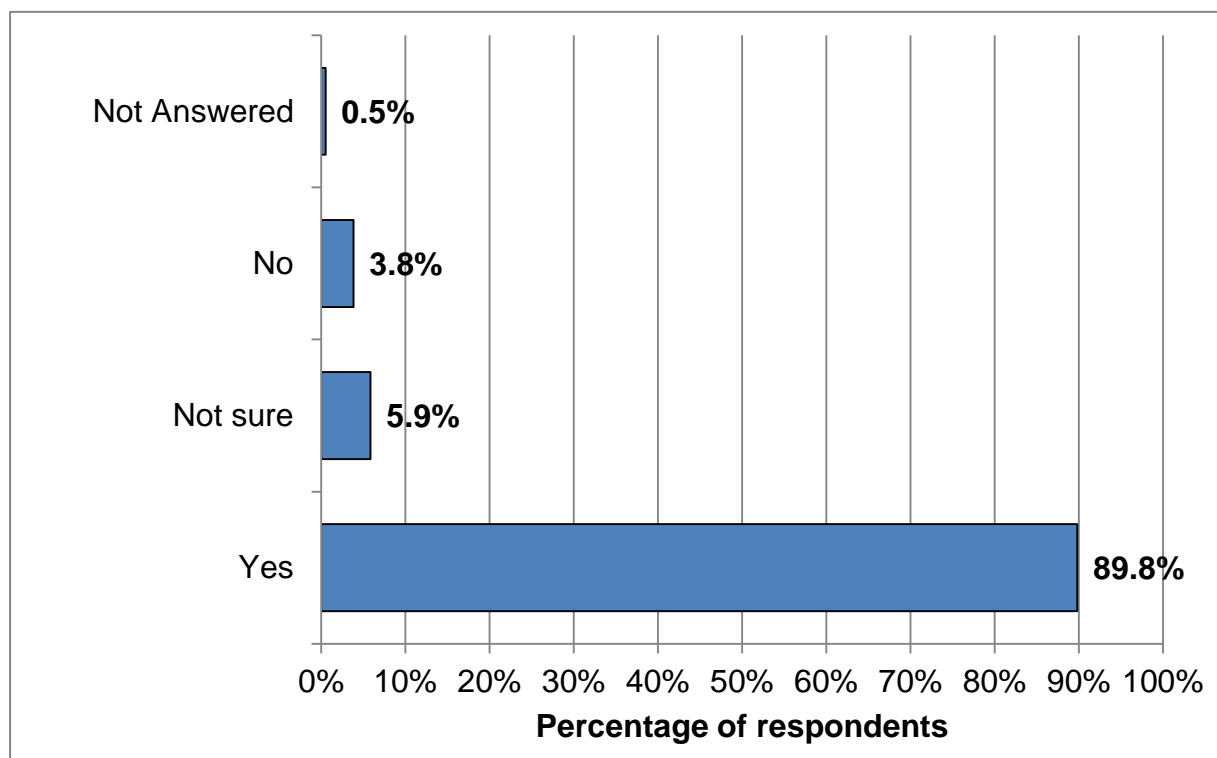
Figure 2: Method of collection of survey responses:



4 Consultation survey

4.1 Question 1

Figure 3: Do you agree with the vision for the standard?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 2: Do you agree with the vision for the standard?

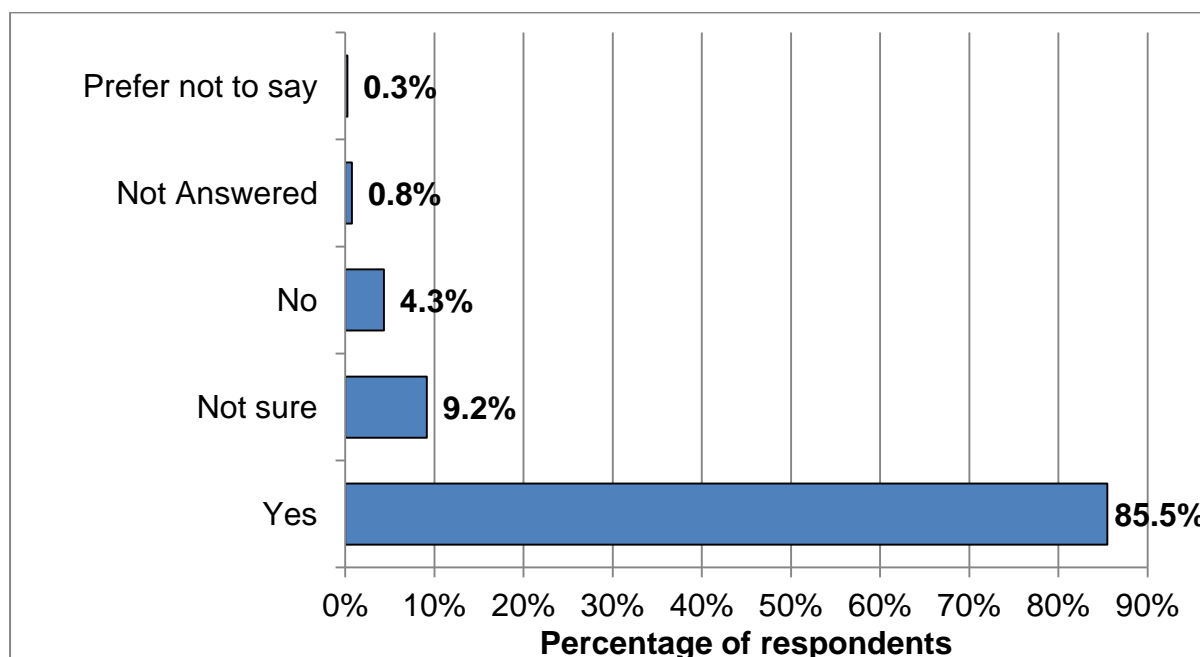
Response	Total	Percentage of Respondents
Yes	353	89.8%
Not sure	23	5.9%
No	15	3.8%
Not answered	2	0.5%
Total Respondents	393	100.0%

Source: Accessible Information Survey Consultation, NHS England, 2014

The highest proportion of respondents (89.9%) stated they agree with the vision for the standard, whereas 3.8% of respondents stated they did not agree with the vision for the standard.

4.2 Question 2

Figure 4: Do you agree with what the standard will do?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 3: Do you agree with what the standard will do?

Response	Total	Percentage of Respondents
Yes	336	85.5%
Not sure	36	9.2%
No	17	4.3%
Not answered	3	0.8%
Prefer not to say	1	0.3%
Total Respondents	393	100.0%

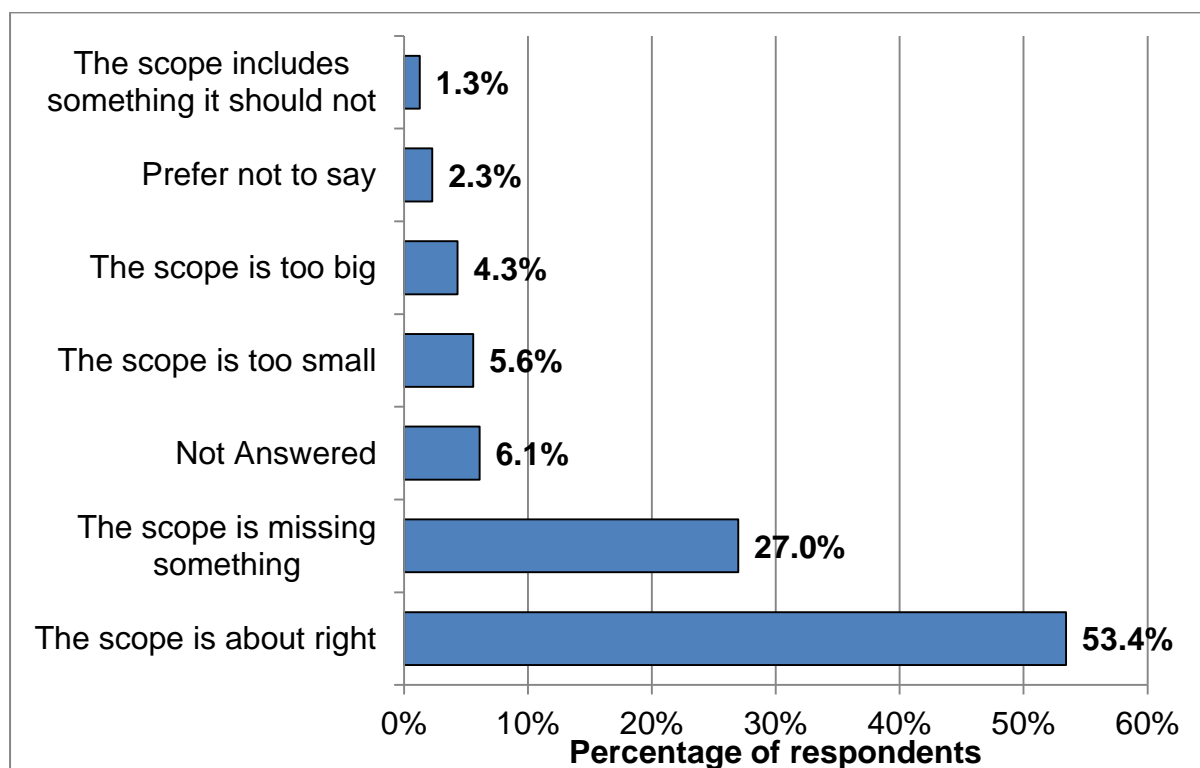
Source: Accessible Information Survey Consultation, NHS England, 2014

The figures in this table add up to more than 100% and this due to rounding.

The highest proportion of respondents (85.5%) stated they agree with what the standard will do, whereas 4.3% of respondents stated they disagree with what the standard will do.

4.3 Question 3

Figure 5: Do you agree with what the standard includes?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 4: Do you agree with what the standard includes?

Response	Total	Percentage of Respondents
The scope is about right	210	53.4%
The scope is missing something	106	27.0%
Not answered	24	6.1%
The scope is too small	22	5.6%
The scope is too big	17	4.3%
Prefer not to say	9	2.3%
The scope includes something it should not	5	1.3%
Total Respondents	393	100.0%

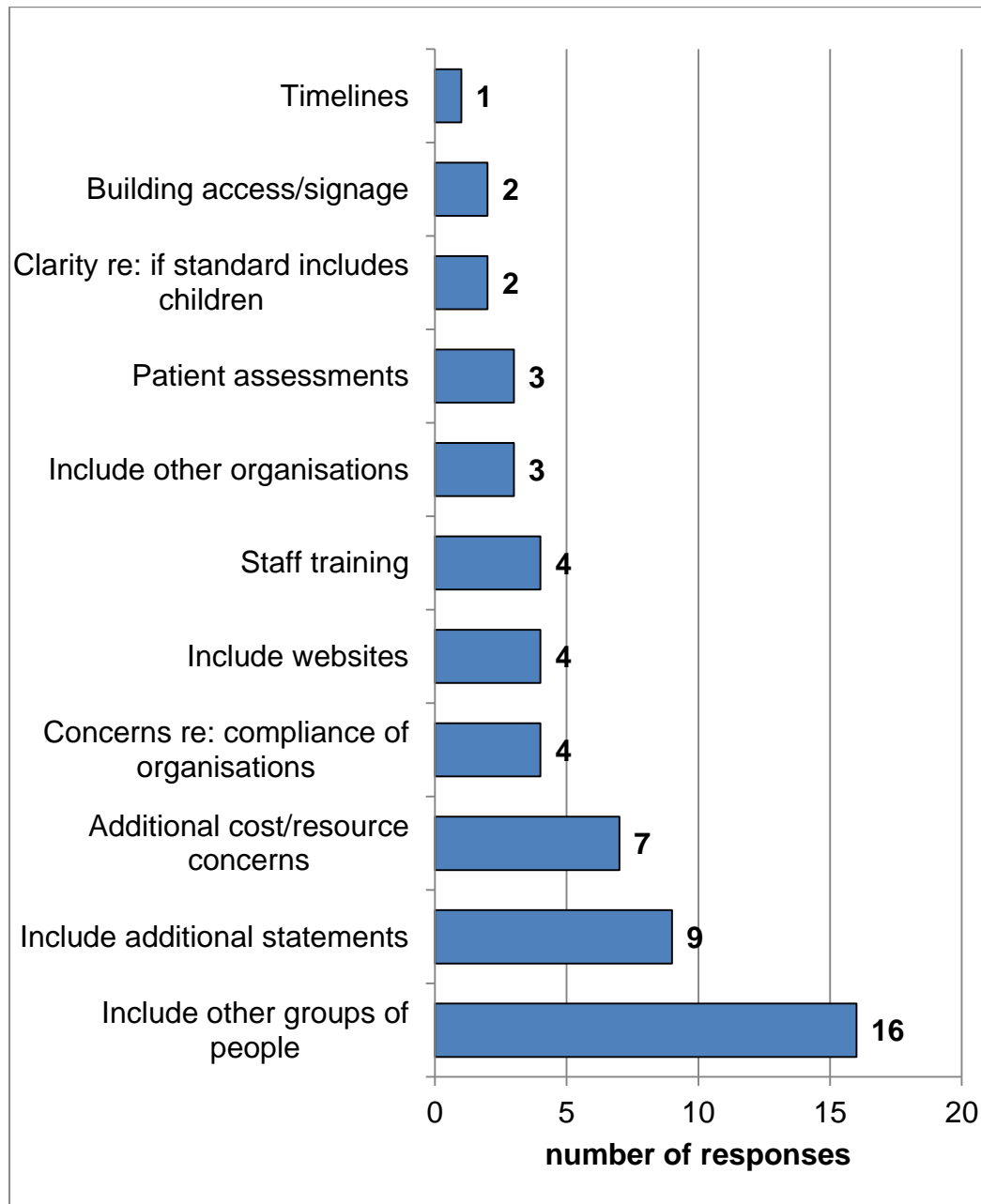
Source: Accessible Information Survey Consultation, NHS England, 2014

The highest proportion of respondents (53.4%) stated they believe the scope is about right, whereas 27.0% of respondents stated they believe the scope is missing something.

4.4 Question 4 / 5

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

Figure 6: If you believe that the scope is too small, please explain here?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 5: If you believe that the scope is too small, please explain here?

Response theme	Total
Include other groups of people	16
Include additional statements	9
Additional cost / resource concerns	7
Concerns about compliance of organisations	4
Include websites	4
Staff training	4
Include other organisations	3
Patient assessments	3
Clarity about if standard includes children	2
Building access / signage	2
Timelines	1
Total Responses	55

Source: Accessible Information Survey Consultation, NHS England, 2014

The corresponding question on the “Easy Read” survey was “If you think that the standard is not looking at enough, or is looking at too much please tell us why?” These responses have been aligned to questions 4 and 5 of the standard survey based on the comments provided.

Table 6: If you believe that the scope is too small please explain?

Number of responses	Themes raised
16	<p>Include other groups of people:</p> <p>People with memory difficulties, low literacy skills, cognitive communications impairments such as acquired brain injury, people who may lack mental capacity.</p> <p>Deaf and hard of hearing people who do not use British Sign Language (BSL).</p> <p>People with development disabilities, Asperger's, Autism / Autistic Spectrum Syndrome, dementia and dyslexia.</p> <p>People who have speech and language / communication needs with no underlying disability.</p> <p>Prisoners.</p> <p>People with speech and language difficulties due to neurological injury or illness.</p> <p>People who have progressive communication disorders, for example</p>

	<p>due to Motor Neurone Disease or Parkinson's disease.</p> <p>People who have communication needs but are not registered as disabled.</p> <p>People who require the use of simple familiar vocabulary, short sentences, chunking of information, support with abstract concepts.</p> <p>People with cross-cutting communication support needs, for example a person who is disabled / has a learning disability and does not speak English.</p>
9	<p>Include additional statements:</p> <p>Information about NHS screening services.</p> <p>Patient narratives / examples of when "accessible information" has supported a patient.</p> <p>Standards for: cross-cultural communication; interpreter services; multilingual leaflets / audio-visual material.</p> <p>Diversity monitoring.</p> <p>Proactive and flexible use of a range of communication tools.</p> <p>Reference to specific procedural requirements such as gaining consent, complaining, reporting abuse, patient evaluation of services.</p> <p>Checking for patients' understanding and empowering people to make meaningful decisions / choices.</p> <p>Information about making appointments at GP surgeries / hospitals.</p> <p>Information about facilitating the provision of communication support by family members and carers.</p> <p>Information about tools which can help people to understand, act upon and share information, for example hospital passports and health action plans.</p> <p>Reference to legal regulation.</p>

7	<p>Additional costs / resource concerns:</p> <p>Concern about the cost of implementing the standard.</p> <p>Concern about the cost of staff training.</p> <p>Concern that it is not financially viable to have all pieces of information available in all formats.</p> <p>Concern over access to alternative formats such as braille / CD, storage of alternative formats and sending larger quantities of paper.</p> <p>Concern that information systems will not be able to cope</p>
4	<p>Concerns about the compliance of NHS providers and non NHS providers providing NHS services:</p> <p>How will non-compliance be reported and addressed?</p> <p>Suggestion to include a statement confirming which organisations the standard applies to.</p> <p>Suggestion to include compliance with the standard in NHS contracts.</p>
4	<p>Include websites:</p> <p>NHS websites should be accessible in line with recognised accessibility standards.</p> <p>Websites for GP surgeries, pharmacies and hospitals should meet specific accessibility criteria.</p> <p>Downloadable documents / information which can be downloaded from websites / external material uploaded onto websites should be accessible.</p>
4	<p>Staff training:</p> <p>Staff should understand the importance of giving verbal information about the care environment to people who are blind or have some visual loss.</p> <p>Consider braille training for staff producing letters / medical information, to enable them to ensure accuracy.</p> <p>Encourage staff to be tactful in supporting patients to explain any communications needs they may have.</p>

3	<p>Include other organisations:</p> <p>Manufacturers of NHS equipment.</p> <p>Drug companies / producers of prescriptions and medicine bottles.</p> <p>Health advertising on TV / internet / social media.</p>
3	<p>Patient assessments:</p> <p>Suggestion to include a statement that some people will need a full assessment of their communication abilities by a speech and language therapist.</p> <p>Suggestion that the standard allows for the fact that people's information and communication needs may change over time.</p>
2	<p>Clarity around if the standard includes children:</p> <p>Suggestion that the standard should include children, and therefore should refer to 'people of all ages' including children and young people.</p> <p>Children and young people have different information needs.</p> <p>Need to meet the needs of d/Deaf young people.</p>
2	<p>Building access / signage:</p> <p>Suggestion that the standard should include physical building access.</p> <p>Clear signage around hospitals.</p>
1	<p>Timelines:</p> <p>Suggestion that the standard should include a timeline to support organisations in planning for implementation.</p>

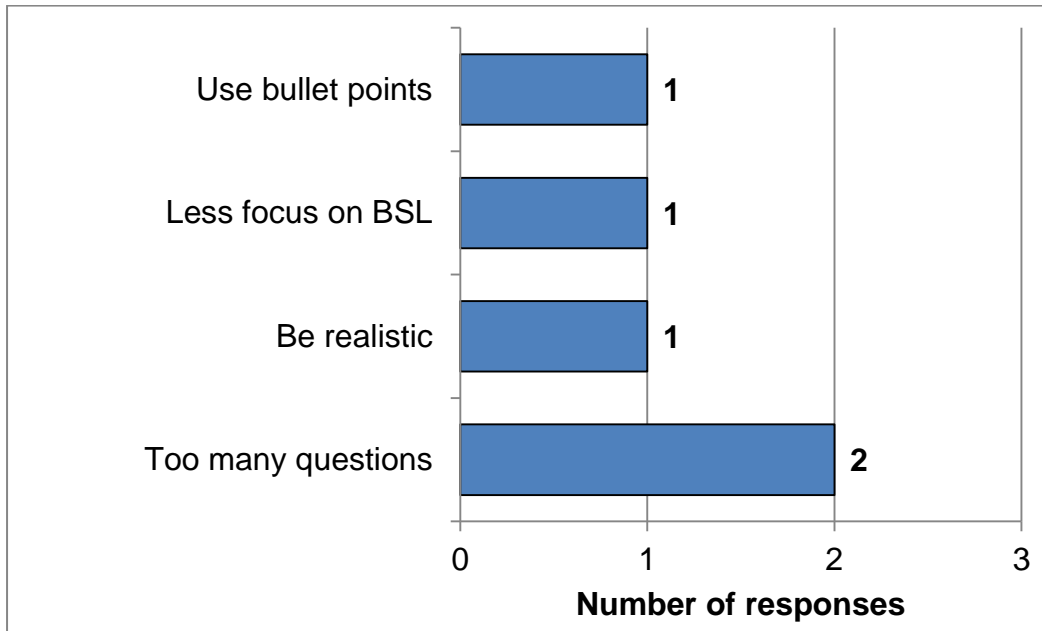
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed "themes raised" do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.5 Question 4 / 5

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

Figure 7: If you believe that the scope is too big, please explain here?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 7: If you believe that the scope is too big, please explain here?

Response theme	Total
Too many questions	2
Be realistic	1
Less focus on BSL	1
Use bullet points	1
Total Responses	5

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 8: If you believe that the scope is too big please explain?

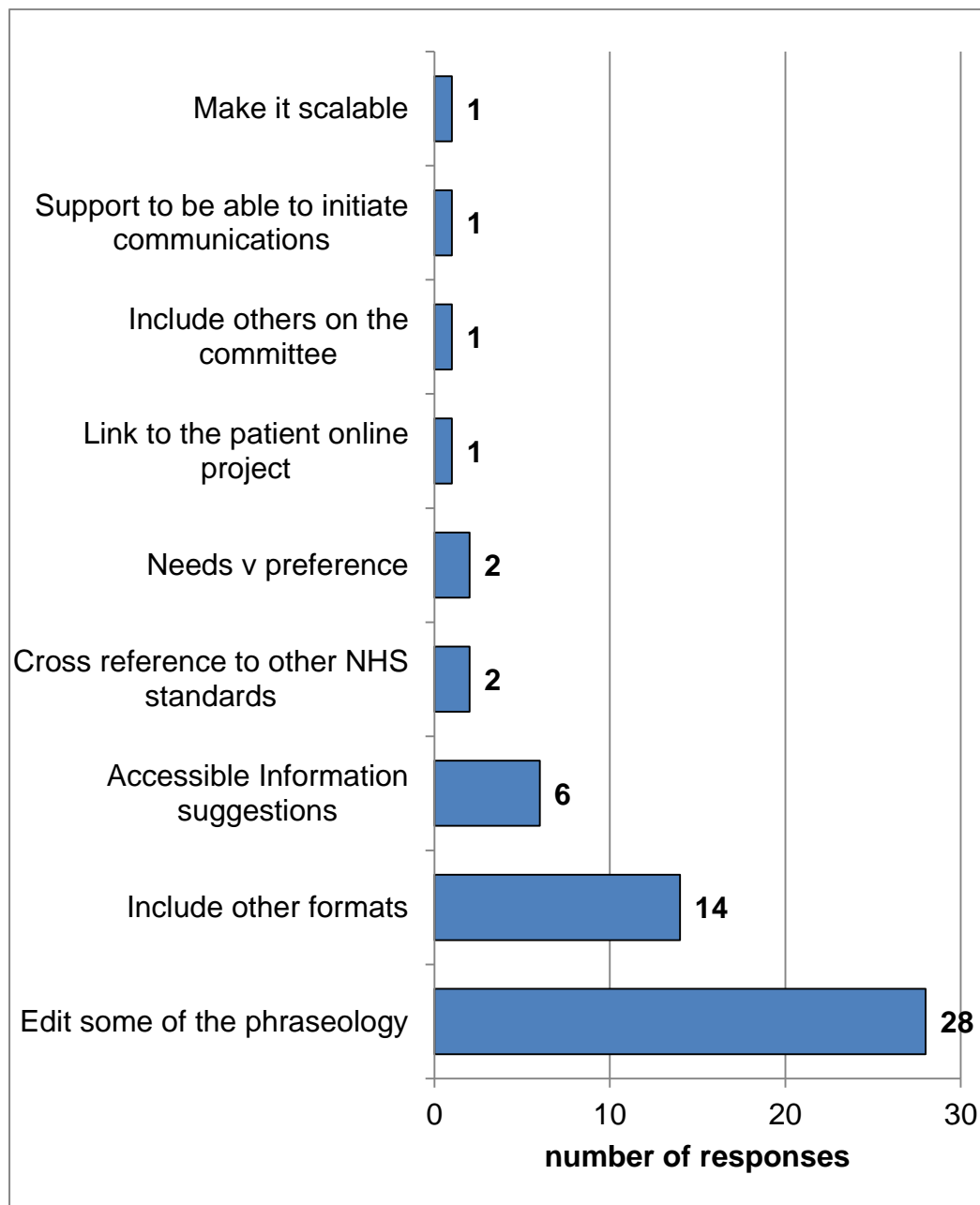
Number of responses	Themes raised
2	Too many questions: ask the question about communication needs once.
1	Be realistic: do not ask organisations to do too much as they may then not do anything.
1	Less focus on BSL: more recognition of the support needed by deaf people who use English.
1	Use bullet points: the standard should be shorter and snappier.

Source: Accessible Information Survey Consultation, NHS England, 2014

4.6 Question 4 / 5

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

Figure 8: If you believe that the scope is about right, please explain? (Please note this section contains some suggested minor amendments to the scope)



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 9: If you believe that the scope is about right, please explain? (Please note this section contains some suggested minor amendments to the scope)

Response theme	Total
Edit some of the phraseology	28
Include other formats	14
Accessible information suggestions	6
Cross reference to other NHS standards	2
Needs versus preferences	2
Link to the patient online project	1
Include others on the committee	1
Support to be able to initiate communications	1
Make it scalable	1
Total Responses	56

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 10: If you believe that the scope is about right please explain? (Please note this section contains some suggested minor amendments to the scope)

Number of responses	Themes raised
28	<p>Edit some of the phraseology:</p> <p>Acknowledge that people can have a number of co-occurring needs, for example a learning disability and a sensory loss.</p> <p>Be careful not to exclude people who do not think of themselves as having "needs" or wanting "support".</p> <p>Do not be too specific about font size; it should be based on individual need.</p> <p>Refer to "information and communications needs" and not to "disability", "impairment" or "loss".</p> <p>Define what accessible means.</p> <p>Should apply to all care / nursing homes, not just some – clarify</p> <p>Should apply to next of kin, volunteers and friends - not just parents and carers.</p> <p>Ensure that provision is made for family members to provide communication support / act as interpreters, where this is appropriate.</p> <p>Specify that material should be well-written and grammatically</p>

	<p>accurate.</p> <p>Replace the word "should" with "will" in the scope – and be explicit about which organisations the standard applies to.</p> <p>More emphasis on the needs of people with learning disabilities.</p> <p>Patient choice and support for patient choice should be mentioned.</p> <p>Ensure the term "Registered" is included when referring to British Sign Language interpreters and deafblind manual interpreters.</p> <p>Need to record a person's disability as well as their information or communication need.</p> <p>The standard should include accessible information provided by health and social care organisations and should guide them to signpost people to good information provided by others.</p> <p>Need clarification on services' obligations around provision of communication support when there are limited numbers of particular types of professional.</p> <p>Be explicit that providers should always gain consent from an individual before their information is shared / flagged or explain in what circumstances they would not do this.</p> <p>Be explicit that any costs incurred will be met by the provider and not the patient, and that the booking and administration should be done by the provider and not the patient</p>
14	<p>Other formats to include:</p> <p>DVDs with information in BSL.</p> <p>“Contracted” braille (as well as standard braille).</p> <p>Audio file on a CD should be on an “Audio CD”.</p> <p>Electronic Notetaker.</p> <p>Cued Speech.</p> <p>Relay Interpreters.</p> <p>BSL Relay Service.</p> <p>[...]</p> <p>[...] as a replacement for text.</p>

	<p>Respect individual decisions about communication and ensure that less-used formats are not excluded.</p> <p>Include low cost ways of accessing images, for example for “Easy Read” documents.</p> <p>Emphasise ensuring all contact methods are available, for example text, fax, email.</p> <p>Ideally all new information should be available in accessible formats simultaneously.</p>
6	<p>Accessible information suggestions:</p> <p>Share templates among organisations to help reduce the time taken to produce accessible information for service users.</p> <p>The organisation / staff should take responsibility for checking that communication has been received and understood, and not assume it has.</p> <p>Include an option for written information to be sent / given to the individual which they can read / discuss after a visit.</p>
2	<p>Cross reference other NHS standards:</p> <p>Standards around guide dogs.</p> <p>For care and nursing homes make reference to the Deaf Care Aware Quality Standard.</p>
2	<p>Needs versus preferences:</p> <p>Need for clarity on the definition of a "need" versus a "preference" and who makes this assessment.</p> <p>Do not differentiate between "wants" and "needs".</p>
1	<p>Link to the patient online project: so patients are better able to self-manage.</p>
1	<p>Include others on the committee:</p>
1	<p>Support to be able to initiate communication:</p> <p>More reference in the standard to ensuring that a person with a communication need is supported to be able to initiate communication / contact the service, for example people who are unable to use</p>

	automated telephone systems.
1	<p>Make it scalable:</p> <p>The scope of the standard should be scalable for large and small organisations.</p>

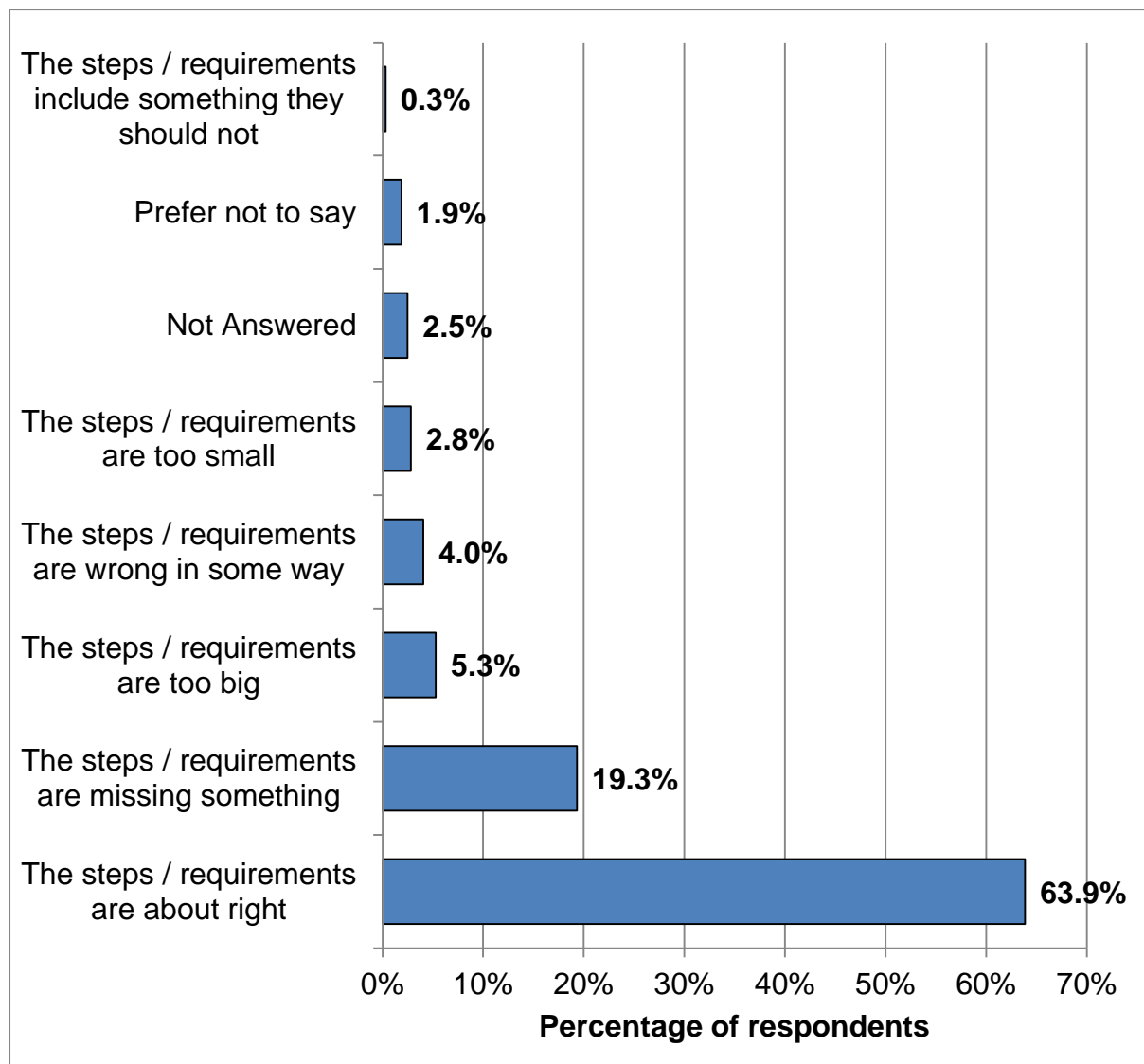
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.7 Question 6

This question was omitted from the “Easy Read” survey and therefore there are only 321 responses and not 393.

Figure 9: What do you think about the steps of the standard / the requirements set out for health and social care organisations and IT suppliers?



Source: Accessible Information Standard Consultation, NHS England, 2014

Table 11: What do you think about the steps of the standard / the requirements set out for health and social care organisations and IT suppliers?

Response	Total	Percentage of Respondents
The steps / requirements are about right	205	63.9%
The steps / requirements are missing something	62	19.3%
The steps / requirements are too big	17	5.3%
The steps / requirements are wrong in some way	13	4.0%
The steps / requirements are too small	9	2.8%
Not answered	8	2.5%
Prefer not to say	6	1.9%
The steps / requirements include something they should not	1	0.3%
Total Respondents	321	100.0%

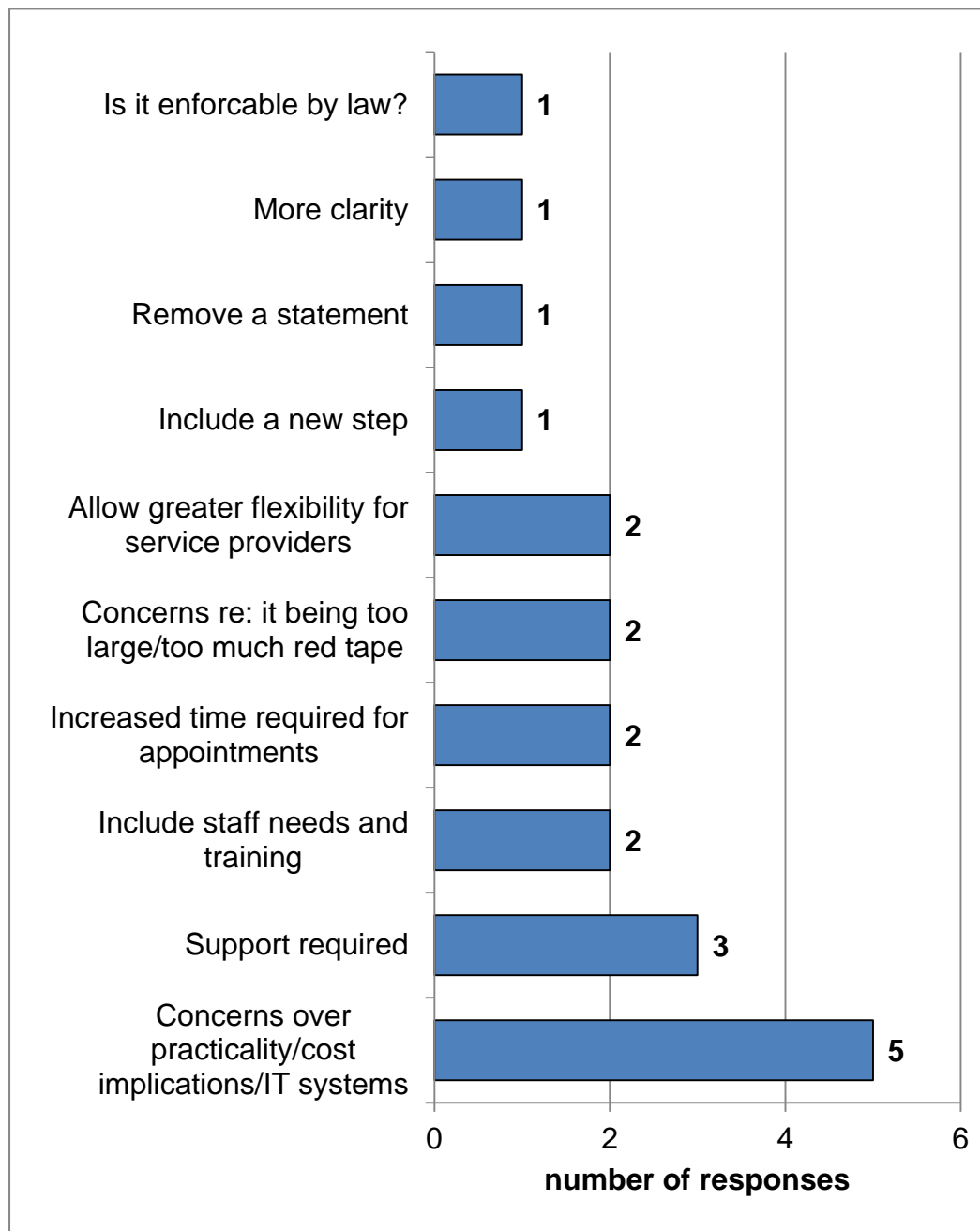
Source: Accessible Information Standard Consultation, NHS England, 2014

The highest proportion of respondents (63.9%) stated they believe the steps of the standard / the requirements set out for health and social care organisations and IT suppliers are about right, whereas 4.0% of respondents stated the steps / requirements are wrong in some way.

4.8 Question 7

This question was omitted from the “Easy Read” survey and therefore there are only 321 responses and not 393.

Figure 10: If you think the steps / requirements are too big or include something which they should not please explain?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 12: If you think that the steps / requirements are too big or include something which they should not please explain?

Response theme	Total
Concerns over practicality / cost implications / IT systems	5
Support required	3
Include staff needs and training	2
Increased time required for appointments	2
Concerns about it being too large / too much red tape	2
Allow greater flexibility for service providers	2
Include a new step	1
Remove a statement	1
More clarity	1
Is it enforceable by law?	1
Total Responses	20

Source: Accessible Information Survey Consultation, NHS England, 2014

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

Table 13: If you think the steps / requirements are too big or include something which they should not please explain?

Number of responses	Themes raised
5	<p>Concerns around practicality / cost implications / IT systems:</p> <p>Organisations will not be able to implement the full standard due to cost implications, for example around providing alternative formats.</p> <p>Changes needed to IT systems to enable implementation of the standard are not practical / feasible.</p> <p>A disability flag on systems would improve patient experience - system suppliers will need to be engaged for the necessary systems development.</p> <p>More detail is needed about capturing and sharing details, particularly around confidentiality, consent and data sharing.</p>
3	<p>Support required:</p> <p>The first question asked should be “do you want support,” with no further action being needed if the answer is ‘no’.</p> <p>Include language support.</p>

	As well as the format of accessible information, the “level” of support and information needs to be suitable for the patient.
2	<p>Include staff needs and staff training:</p> <p>Staff will need to acquire new skills to support accessible communication.</p> <p>Include d/Deaf awareness training for all staff.</p> <p>Speech and language therapists may need to provide advice on accessible information.</p>
2	Increased time required for appointments and follow up appointments:
2	Concerns about it being too large / too much red tape:
2	<p>Allow greater flexibility for service providers:</p> <p>Accommodate differences in service provision, for example primary care provided in the community.</p>
1	<p>Include a new step:</p> <p>Assess how useful recipients found any accessible information they have been sent / provided with.</p>
1	<p>Remove a statement:</p> <p>The statement that organisations should “record or write down people’s needs in the same way and then share” should be removed as it oversimplifies the complex set of questions and processes behind it.</p>
1	More clarity on: “staff should support people to lip read”.
1	Is it enforceable by law?

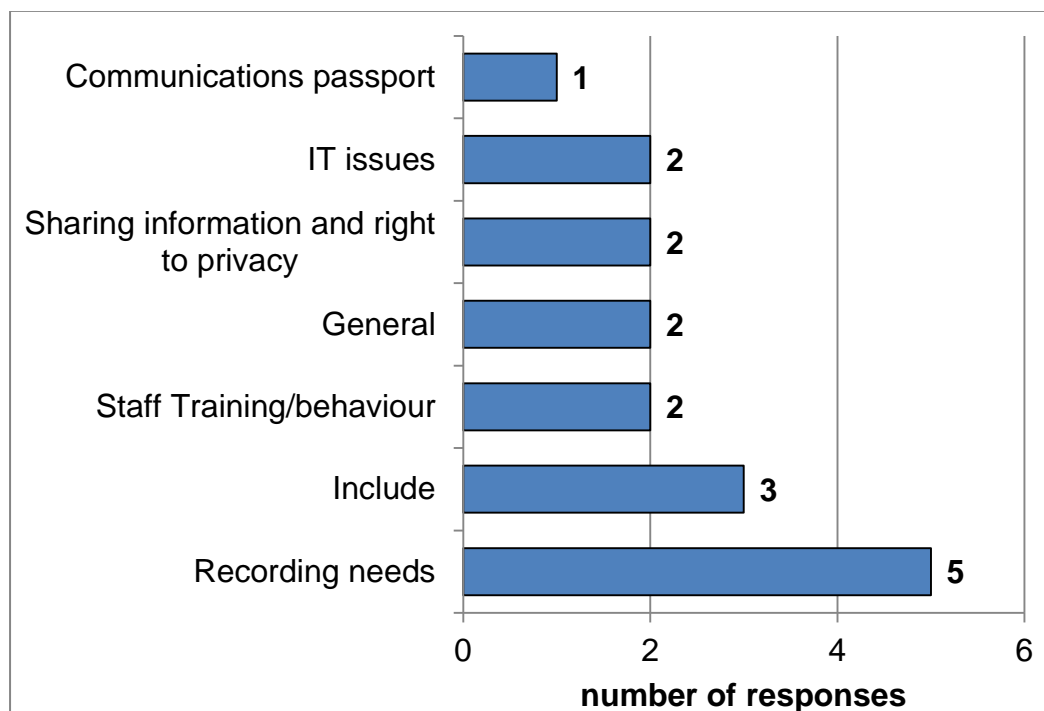
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.9 Question 8

This question was omitted from the “Easy Read” survey and therefore there are only 321 responses and not 393.

Figure 11: If you believe the steps / requirements are too small, or do not include something which they should, please explain?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 14: If you believe that the steps / requirements are too small or do not include something which they should please explain?

Response theme	Total
Recording needs	5
Include	3
Staff training / behaviour	2
General	2
Sharing information and right to privacy	2
IT issues	2
Communications passport	1
Total Responses	17

Source: Accessible Information Survey Consultation, NHS England, 2014

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

Table 15: If you believe that the steps / requirements are too small or do not include something which they should, please explain?

Number of responses	Themes raised
20	<p>Recording needs:</p> <p>The emphasis must be on the organisation to record needs, but service users should be encouraged to participate and assumptions should not be made about individual needs.</p> <p>State that an information or communications need is recorded on paper and on electronic systems to ensure it is “flagged up”.</p> <p>Be more specific about what the “front page” of a document is.</p> <p>Refer to “personalised preferred communications support”.</p> <p>Include support for people to identify their needs, for example prompts / follow-up questions.</p> <p>Clarify legal duties to make reasonable adjustments. Make clear that organisations must provide accessible information and communication support at no cost to the individual, promptly and without unreasonable delay.</p> <p>Patients’ needs change over time – ensure that there are regular reviews.</p> <p>Have a recommended timeframe for providing support, for example 24 or 48 hours, “as soon as possible” is too vague.</p> <p>The service provider should have to identify who will ask about and record needs, and who will verify that this has been completed.</p> <p>Use prompts to help staff identify needs.</p>
16	<p>Include:</p> <p>Daisy [Digital Accessible Information System] format.</p> <p>Children.</p> <p>Information in “plain English”.</p>

	<p>Lipspeakers.</p> <p>Speech-to-text-reporters (STTR).</p> <p>Remote captions.</p> <p>Dysarthria.</p> <p>People in hospices.</p> <p>People with developmental disabilities.</p> <p>More contact options as a minimum requirement, for example text messaging, email, telephone, text relay.</p> <p>Standards for: cross-cultural communication; interpreter services; multilingual leaflets / audio visual material.</p> <p>Organisations having the most common formats readily available and 'anticipating' needs.</p> <p>Change the following phrase "the standard does not include: people who would like to get information in a different way but who can still read the information...." to ".....understand and act upon the document".</p> <p>Include information around medicines, including patient information leaflets and medication labels in accessible formats.</p> <p>Consider methods of information and communication as well as formats, for example a letter may not be an appropriate method of communication, even if the letter itself has been adapted.</p> <p>Services must be able to receive communication in different formats / using different methods to ensure communication is two-way and effective.</p> <p>Use communication professionals registered with the NRCPD [National Registers of Communications Professionals working with Deaf and Deafblind People].</p> <p>Access to support from a Speech and Language Therapist.</p>
10	<p>Staff training / behaviour:</p> <p>Staff must be sensitive and comfortable talking to patients and service users about their information and communication support needs.</p> <p>Include a requirement for organisations to record the percentage of</p>

	<p>staff that have completed training on recognising and responding to communication support needs.</p> <p>Staff will need to check that the information has been understood.</p> <p>Staff will need to understand terminology associated with communication needs, for example aphasia.</p> <p>Consider that service providers may overestimate their performance in meeting people's communication needs.</p> <p>Staff will need to know how to produce pictorial information and to have access to appropriate software and printers.</p> <p>Pharmacy staff will need training on different communications systems and to be able to check that dispensed medicines are labelled correctly, for example if braille or moon are used.</p> <p>Suggest some resources which could be used for training NHS staff.</p>
7	<p>General:</p> <p>Be explicit that the standard will apply to all NHS organisations.</p> <p>Be clear that the standard applies to the whole of a patient's inpatient stay.</p> <p>Clarify how a "preference" will be assessed.</p> <p>Clarify what the repercussions are for services which fail to comply with the standard.</p> <p>Clarify how a patient can raise concerns that their needs are not being met.</p> <p>Acknowledge that more time will be needed at appointments.</p> <p>Include a reference to the electronic patient care record.</p> <p>Signpost service providers to sources of support, for example producers of alternative formats.</p> <p>Suggest examples of best practice.</p>
6	<p>Sharing information and individuals' right to privacy:</p> <p>Include more detail about consent, right to privacy and sharing data.</p> <p>State that sharing information always requires consent; but also explain the benefits of information sharing.</p>

	<p>Include reference to a “best interests” decision about sharing information if the person does not have the capacity to consent.</p> <p>Quote the Caldecott principle about the dangers of failing to share information appropriately.</p> <p>Strengthen the wording around sharing of information between organisations to try and prevent patients repeatedly being asked for the same information.</p> <p>Change the wording around consent to share data.</p>
3	<p>IT issues:</p> <p>Make the standard mandatory as and when new IT systems are implemented.</p> <p>Consider putting a banner / ribbon across the top of each page on an IT system showing what their preferred method of communications support is (once it has been identified).</p>
3	<p>Communications passport:</p> <p>Highlight the communications passport.</p> <p>Refer to advice from the [...] about communicating with people with learning disabilities.</p>

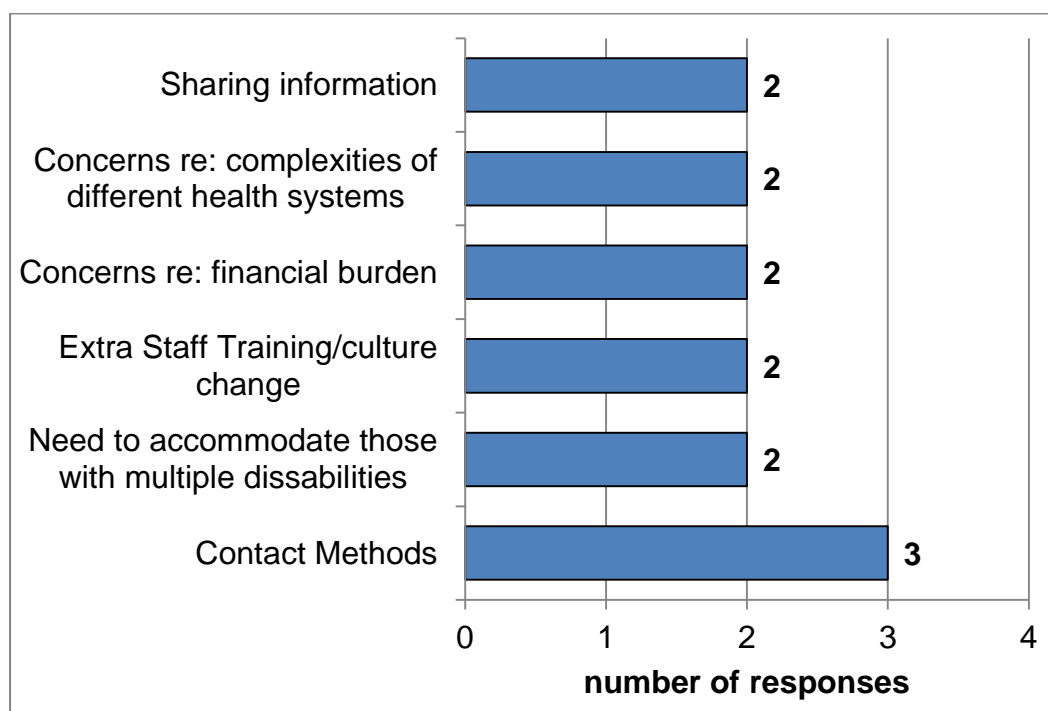
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.10 Question 9

This question was omitted from the “Easy Read” survey and therefore there are only 321 responses and not 393.

Figure 12: If you believe one or more aspects of the requirements is / are wrong, please explain?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 16: If you believe one or more aspects of the requirements is / are wrong, please explain?

Response theme	Total
Contact methods	3
Need to accommodate those with multiple disabilities	2
Extra staff training / culture change	2
Concerns about financial burden	2
Concerns about complexities of different health systems	2
Sharing information	2
Total Responses	13

Source: Accessible Information Survey Consultation, NHS England, 2014

The answers to this question were “free text”, and have been analysed and disseminated into broad categories. Due to the diversity of responses, it has not been possible to group many of these responses into broad themes.

Table 17: If you believe one or more of the requirements is / are wrong, please explain?

Number of responses	Themes raised
3	<p>Contact methods:</p> <p>Include video messaging or ‘live chat’ as contact methods, and include lipspeaker and Makaton.</p> <p>The specification should specifically include visual information.</p>
2	<p>Need to accommodate those with multiple disabilities: and autism.</p>
2	<p>Extra training for staff and culture change:</p> <p>Supporting people to use hearing aids and communication tools, to lip read and to use different ways of communicating.</p> <p>Allowing people with communication needs more time at appointments.</p> <p>Include lip speakers / speech-to-text-reporters / remote captions.</p> <p>Query: should the BSL qualification be at level 3 (instead of 6)?</p>
2	<p>Concerns about the burden of financial costs:</p>
2	<p>Concerns about the complexities of the different health systems:</p> <p>Concerns about sharing of information across organisations.</p> <p>Need to ensure the correct recording of information needs, in sufficient detail so it can be shared and acted upon correctly.</p>
2	<p>Sharing information:</p> <p>Need for consent before sharing information with other organisations.</p> <p>Consent to share information should be implied not sought.</p>

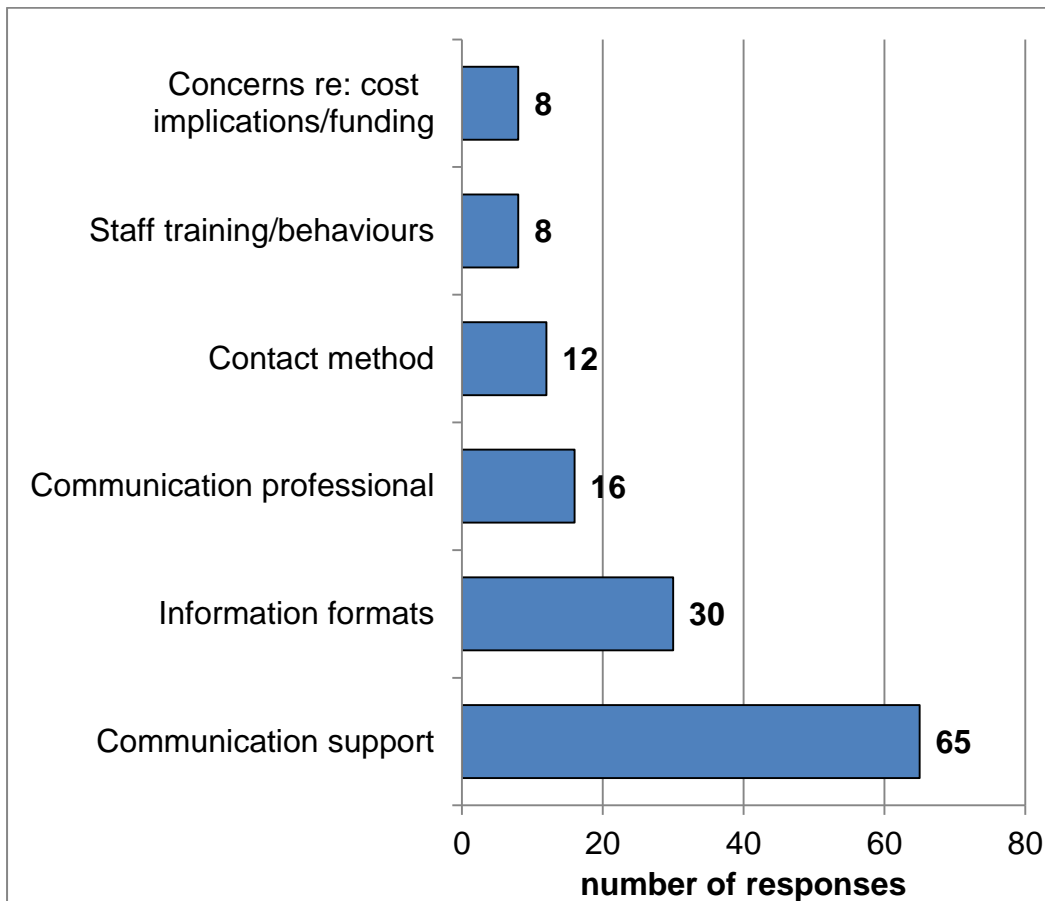
1	Concerns about the prescriptive list of formats, for example cassette tapes are no longer current. Perhaps include a 'reasonable expectation' clause in terms of cost and effectiveness.
1	Need to be clearer about circumstances when the standard will apply.
1	There should be some onus on service users to notify the NHS of their needs.
1	Consider the format of information and the way in which is delivered.
1	Need to explain how staff should find out if someone needs information in a different format or communication support because they have a disability, impairment or sensory loss. Also patients' needs will change over time and so will need to be reviewed.
1	The requirement to "record people's information or communication needs, and not their disability" is problematic. If no record is made of why someone has a requirement for a certain facility, it will not be possible to judge whether it is a need or a preference.
1	Include a follow up step to assess whether information provided in an accessible format was useful and how it was used.
1	The amount of options may confuse some people – perhaps a simple question to ask what they require is easier for the patient.
1	Automated responses, such as letters, should be categorised in two ways: 'must' should apply to standard letters such as those for appointments; and 'should' should apply to more specific documents, for example information about specific aspects of care.
1	Need to clarify what pictures will be used to make information accessible for people with learning disabilities.
1	Concerns about who would be responsible for determining communication needs – this should be jointly agreed between the patient and professional.
1	The identification and recording of needs should be person centred and led by the patient / carer.
1	Need for clarity about the use of hearing aids and about the definition of a "communication tool."
1	Include emergency situations.

Source: Accessible Information Survey Consultation, NHS England, 2014

4.11 Question 10

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

Figure 13: What do you think about the types of communication support and information formats we have included?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 18: What do you think about the types of communication support and information formats we have included?

Response theme	Total
Communication support	65
Information formats	30
Communication professional	16
Contact method	12
Staff training / behaviours	8
Concerns about cost implications / funding	8
Total Responses	139

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 19: What do you think about the types of communication support and information formats we have included?

Number of responses	Themes raised
65	<p>Communication support:</p> <p>Include “requires clear, audible verbal communication”.</p> <p>Include need for the healthcare professional to adjust the way they talk or communicate, for example when speaking to a person who has aphasia.</p> <p>Include screen-readers.</p> <p>Include face-to-face communication / information.</p> <p>Include tactile signing.</p> <p>Include “uses a loop system”.</p> <p>Include “uses a cochlear implant”.</p> <p>Include “use an inclusive / total communication approach”.</p> <p>Include need for a vibrating or physical alert.</p> <p>Be clear this list is not exhaustive and can evolve over time.</p> <p>Include communication apps.</p> <p>Include head and body language.</p> <p>Include “Minimal Speech Approach”.</p> <p>Include “objects of reference”.</p> <p>Include [...]</p> <p>Include “simple gestures”.</p> <p>Include “simplified language”.</p> <p>Include “symbols” and specify which type.</p> <p>Include “uses a signing support system such as Makaton” – note that Makaton is one form of “keyword signing”.</p> <p>Include “Signalong”.</p>

	<p>Include all types of symbol support.</p> <p>Include “uses other aids or visual supports such as symbols, photos, pictures, drawings or cartoons”.</p> <p>After “uses Makaton”, add the wording “or any other augmentative or alternative communication system using signs or symbols”.</p> <p>Include “video conversation”.</p> <p>Include speech-to-text-reporters (which should be registered).</p> <p>Include BSL video relay.</p> <p>Put "uses a hearing aid" and "uses non-verbal communication" together.</p> <p>Change “uses a learning disability passport” to “has a LD passport”.</p> <p>Include “needs the support of a parent or familiar carer.”</p> <p>Add “any other specific support need, or a combination of the above”.</p> <p>Include “cross-cultural communication”.</p> <p>Include “device for playing MP3 files to be made available”.</p> <p>Include "patience and time".</p> <p>Include use of a “patient logbook” or other record of written information.</p> <p>Include having pictures on doors to support what is behind the door, for example a photograph of the relevant professional or a book to indicate the library.</p> <p>Refer to “communication passports” instead of “learning disability passports”, also include “hospital passports”.</p> <p>Include “pen and paper.”</p> <p>Include implantable hearing devices or radio aids / FM systems.</p> <p>Include “simplified language” (in line with key word comprehension).</p>
30	<p>Information formats:</p> <p>Make “Easy Read” available in all information formats.</p> <p>Include contracted and un-contracted for braille and moon.</p> <p>Use “other” rather than listing less commonly used formats or state</p>

	<p>that the list is not exhaustive</p> <p>Remove the option for “cassette tape”.</p> <p>Include the option to specify different information formats for different levels of information.</p> <p>Remove “deafblind haptic communication interpreter”.</p> <p>Clarify that audio files should be provided on an audio CD.</p> <p>The reference to “easy read” should be more specific and include reference to the type of visual information required as well as the level of information within the document.</p> <p>Be clear that this list is not exhaustive, can evolve over time, and that the different options are not mutually exclusive.</p> <p>Include “easy read with photos”.</p> <p>Include “easy read with symbols” and detail the type of symbol to be used.</p> <p>“Easy Read” and “Accessible Information” need to be more clearly defined and differentiated.</p> <p>Include colour and contrast.</p> <p>Large print should include Arial bold font 28.</p> <p>Include a need for coloured paper.</p> <p>Include more detailed guidance about the accessibility of Word documents and PDFs.</p> <p>Designating typeface sizes for large print may be inflexible.</p> <p>Include / develop standards for easy read to improve consistency.</p> <p>Do not include items which lack a clear definition.</p> <p>Change the grouping of categories, to include “audio/visual formats” and “specialist formats”.</p> <p>Include [...]</p>
16	<p>Communication professional:</p> <p>Include “guide for blind people” when attending appointments.</p> <p>Include “Speech and Language Therapist”.</p>

	<p>Clarify whether “note taker” is manual and or electronic.</p> <p>Include support for people with aphasia.</p> <p>Include lipspeakers.</p> <p>Include a requirement for hospitals to provide advocacy if a communication professional cannot be found.</p> <p>The term “learning disability communication support worker” requires definition.</p> <p>"Deafblind manual alphabet interpreter" and "deafblind manual interpreter" are the same.</p> <p>Include “communication support for people with developmental disabilities”.</p> <p>Include “independent advocates”.</p> <p>Include “independent advisers”.</p> <p>Include “relay interpreter”.</p>
12	<p>Contact method:</p> <p>Include fax.</p> <p>Include “video relay for sign language users”.</p> <p>Include a “chat now” option.</p> <p>Be clear that this incorporates alternative communication / information formats.</p> <p>Include the option to send a copy of relevant information to a person’s supporter / advocate, with their consent.</p> <p>Include “web based tools”.</p> <p>Include “face-to-face”</p> <p>Differentiate between plain text and HTML emails.</p>
8	<p>Staff training / behaviours:</p> <p>Training is needed on general communication requirements for all people with hearing loss.</p> <p>Training about how to support someone who is lip-reading.</p>

	Training in how to communicate with people with Asperger's and autism.
8	Concerns about cost implications / funding: Concern that the standard will be difficult to implement in practice. Concern about lack of resources to implement the standard. Some organisations will need to establish new mechanisms and contract arrangements in order to access some alternative formats.
1	Manage expectations: about communication needs as opposed to preferences, and be clear about how information and communication services will be funded.
1	Don't sacrifice grammar: and avoid patronising language. The initial question asked of everyone should be, "do you understand what I have explained?"
1	Helpful for organisations to know the disability / reason behind an individual's communication / information need: to support staff in meeting needs. This should link to relevant sources of advice.
1	No "one-stop" solution for each type of communication impairment: individuals' needs vary.
1	Extra clarity: around inclusion of support for individuals with a mental health need, Motor Neurone Disease, or other neurological conditions.

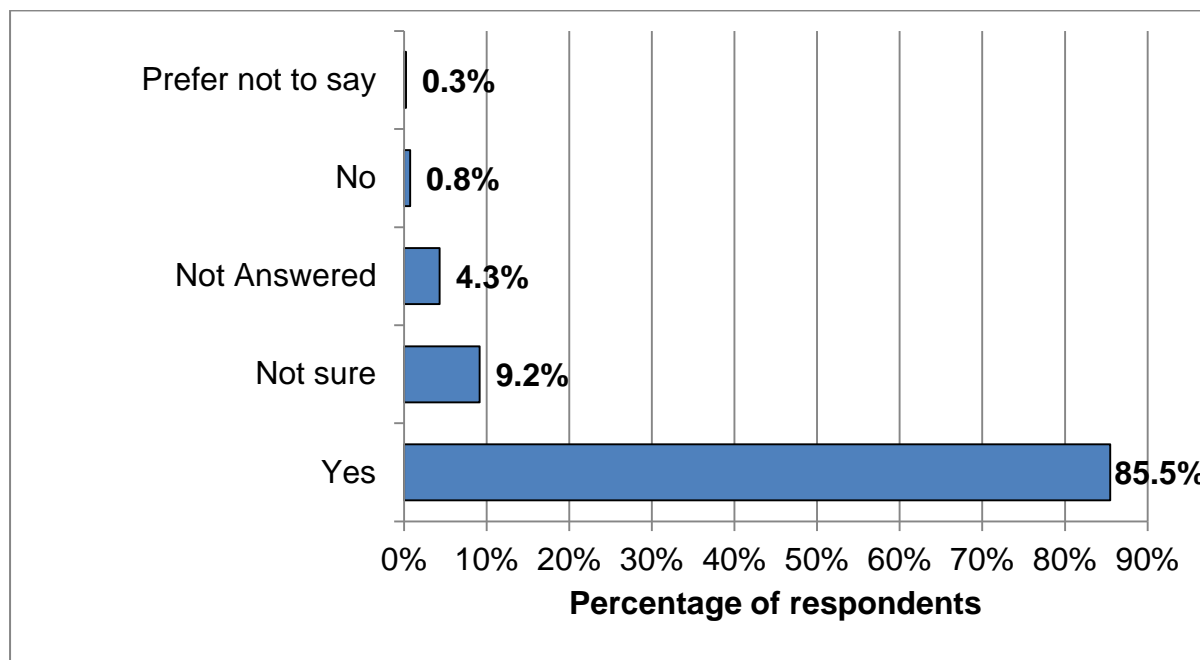
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed "themes raised" do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.12 Question 11

The equivalent “Easy Read” question was “what do you think about our plans for making information and communication support good?” Responses were allocated to the “Yes” / “No” / “Not sure” / “Prefer not to say” categories based on the free text responses given.

Figure 14: Do you agree with the quality considerations we have included?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 20: Do you agree with the quality considerations we have included?

Response	Total	Percentage of Respondents
Yes	252	85.5%
Not sure	71	9.2%
Not answered	35	4.3%
No	31	0.8%
Prefer not to say	4	0.3%
Grand Total	393	100.0%

Source: Accessible Information Survey Consultation, NHS England, 2014

The figures in this table add up to more than 100% and this due to rounding.

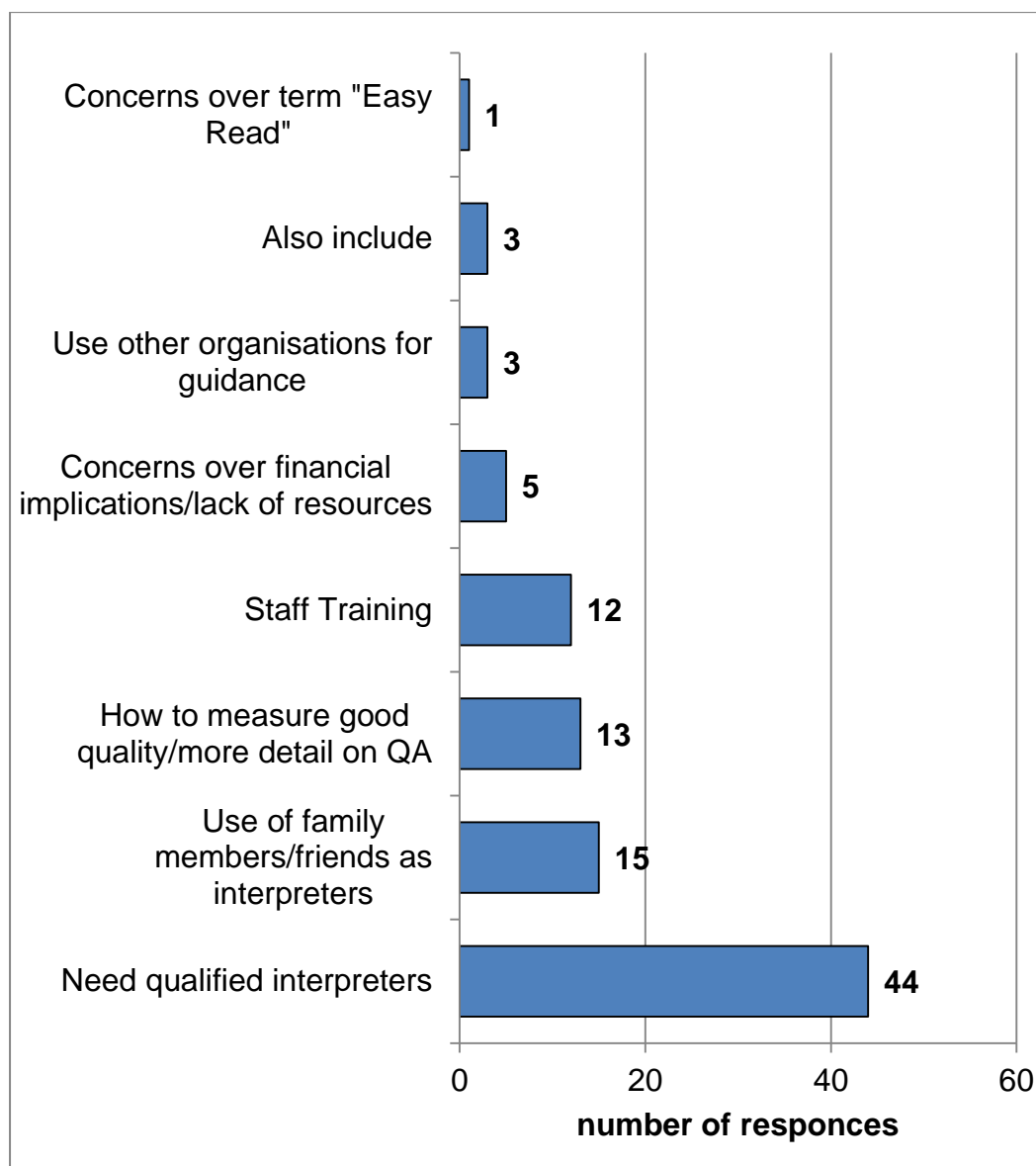
The highest proportion of respondents (85.5%) stated they agree with the quality considerations that have been included whereas 0.8% of respondents stated they did not agree with these.

4.13 Question 12

The corresponding question on the “Easy Read” survey was “what do you think about our plans for making information and communication support good?” Responses were aligned to question 12 of the standard survey based on the comments provided.

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

Figure 15: If you have any comments on the quality considerations we have included please explain?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 21: If you have any comments on the quality considerations we have included, please explain?

Response theme	Total
Need qualified interpreters	44
Use of family members / friends as interpreters	15
How to measure good quality / more detail on quality assurance (QA)	13
Staff training	12
Concerns over financial implications / lack of resources	5
Use other organisations for guidance	3
Also include	3
Concerns over term "Easy Read"	1
Total Responses	96

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 22: If you have any comments on the quality considerations we have included, please explain here?

Number of responses	Themes raised
44	<p>Need qualified interpreters:</p> <p>Need more qualified interpreters nationally.</p> <p>Consider collaborative approaches to involving family members / friends in communication support, as well as interpreters.</p> <p>Communication professionals for d/Deaf people should be NRCPD registered. The standard should define appropriate qualifications and include a requirement for experience of interpreting in a health care setting.</p> <p>For braille users, individuals should be able to request contracted or non-contracted braille.</p> <p>Patients using an interpreter should be given the name and identification number of the interpreter in case they need to complain.</p> <p>Include use of online video interpreting technology to enable access to BSL interpreters to support</p>

	<p>communication with d/Deaf people.</p> <p>The requirement should be for BSL interpreters to be registered with the NRCPD and / or SASLI (and not “...qualified to Level 6”).</p> <p>The independence of interpreting is vital for reasons of safeguarding.</p> <p>Need for clarification about qualification requirements of deafblind manual interpreters as there is currently no qualification route.</p> <p>Will people be able to request a known and trusted interpreter or advocate (assuming they meet the standards)?</p> <p>Concern that there may be instances when people are too ill to consent or object to a healthcare professional acting as an interpreter / supporter.</p> <p>The standard should state a minimum standard for registered interpreters to include having the right skills, NHS experience and qualifications.</p> <p>Agree that BSL / English interpreters in medical settings must have qualifications equivalent to NVQ level 6 interpreting.</p> <p>Need to ensure that lip speakers and speech-to-text-reporters (STTRs) also have appropriate qualifications, enhanced CRB checks and are registered with the NRCPD.</p> <p>The quality requirements should state that BSL interpreters should be ‘registered sign language interpreters’, and that only fully trained, qualified interpreters, registered with a recognised national registration body should be used.</p> <p>The standard should make clear that partially qualified or trainee interpreters should not be used in medical settings.</p> <p>If health and social care staff are to act as interpreters the standard should state what qualifications they need and should make explicit that this requires the patient's agreement.</p>
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<p>15</p>	<p>Use of family members / friends as interpreters:</p> <p>The standard needs to recognise that there are scenarios in which a family member or friend will need to act as an interpreter, for example where individuals have their own adapted form of communication and / or have particular learning disabilities. The standard should clarify that this is appropriate in certain instances / for particular individuals.</p> <p>Acknowledge that some people may prefer a family member to interpret instead of a professional interpreter.</p> <p>Acknowledge that some people with communication needs will need the support of a trusted family member / friend / supporter in order to engage in conversation.</p> <p>Concern that family members may 'edit' the information passed onto a patient.</p> <p>Concern about lack of insurance if family members or friends are used to interpret and something goes wrong.</p>
<p>13</p>	<p>How to measure good quality / more detail on quality assurance:</p> <p>More detail is needed about how to check that information is correct and that communication professionals are competent.</p> <p>Link to guidance published by [...] on assessing the quality of health information.</p> <p>Need to ensure that the original information is of a high standard, prior to adaptation or translation.</p> <p>Information should meet the requirements of The Information Standard.</p> <p>Need for a requirement that contracts / agreements with interpreting providers include quality check mechanisms and standards.</p> <p>Need to include standards for Makaton signers.</p> <p>Concern over how the quality of 'easy read' will information be checked.</p>

12	<p>Staff training:</p> <p>Staff training is needed on use of equipment, for example hearing loops.</p> <p>Staff need training on how to speak more clearly, louder and slower, and to support verbal information by writing down key words.</p> <p>Staff need training / advice about what to do when appropriately qualified interpreters are not available for appointments, for example when to delay appointments and when this is not acceptable.</p> <p>Examples of good / poor practice should be included in staff training.</p> <p>Extra funding should be made available for staff training.</p>
8	<p>Patient groups:</p> <p>The standard should put more emphasis on working with patient groups to ensure communication support and alternative formats are good quality.</p>
5	<p>Concerns over financial implications / lack of resources:</p> <p>Noting the range of communication types listed and potential for delays.</p>
3	<p>Use other organisations for guidance:</p>
3	<p>Also include: quality of acoustics and lighting and clear speech of staff.</p>
1	<p>Concern over term “Easy Read”: need for explanation and advice.</p>
1	<p>Include quality of images:</p>

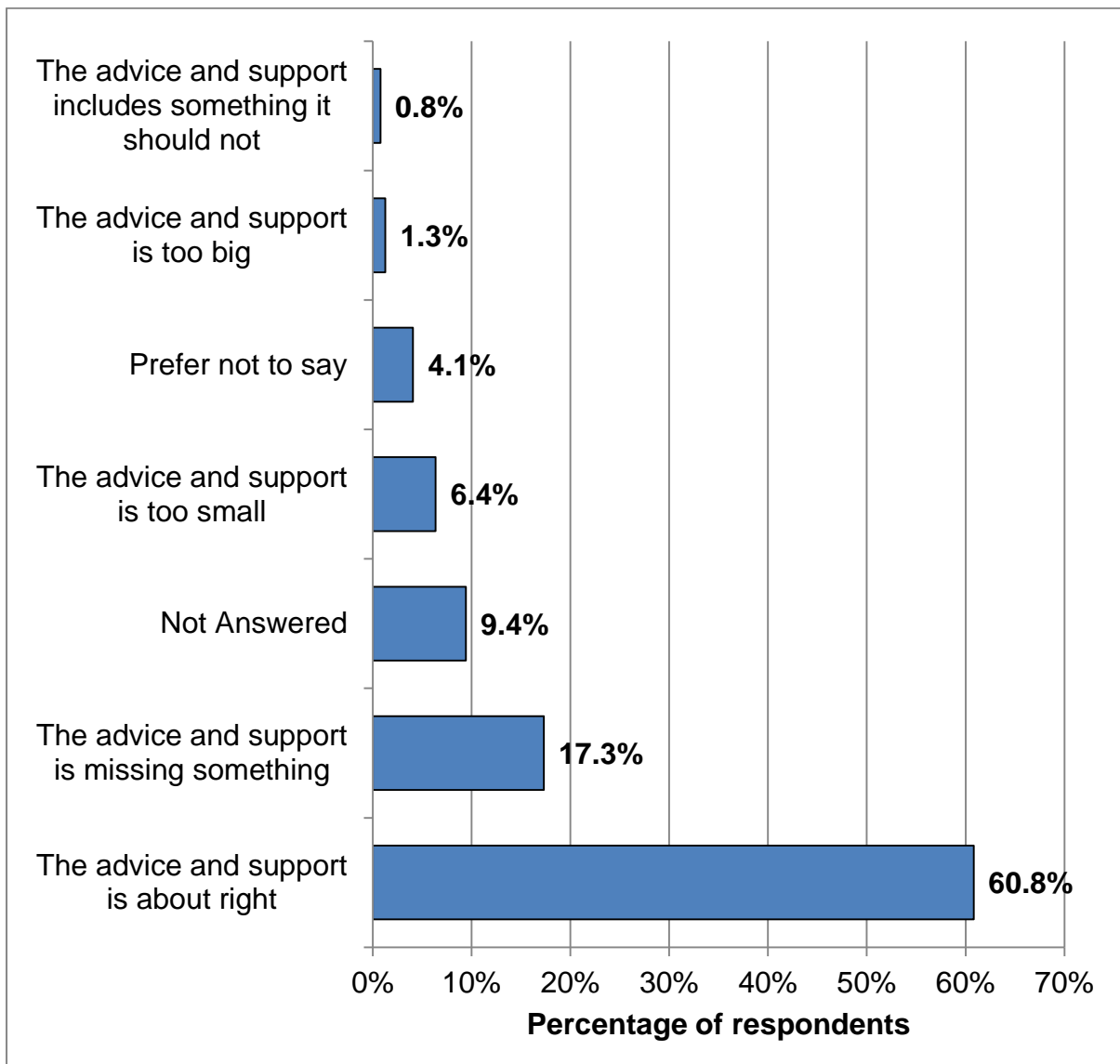
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.14 Question 13

The corresponding question on the “Easy Read” survey was “what do you think about the advice we are going to give organisations?” We have aligned these responses to question 13 of the standard survey based on the comments provided.

Figure 16: What do you think about the advice and support which we are planning to give to organisations?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 23: What do you think about the advice and support which we are planning to give to organisations?

Response	Total	Percentage of Respondents
The advice and support is about right	239	60.8%
The advice and support is missing something	68	17.3%
Not answered	37	9.4%
The advice and support is too small	25	6.4%
Prefer not to say	16	4.1%
The advice and support is too big	5	1.3%
The advice and support includes something it should not	3	0.8%
Total Respondents	393	100.0%

Source: Accessible Information Survey Consultation, NHS England, 2014

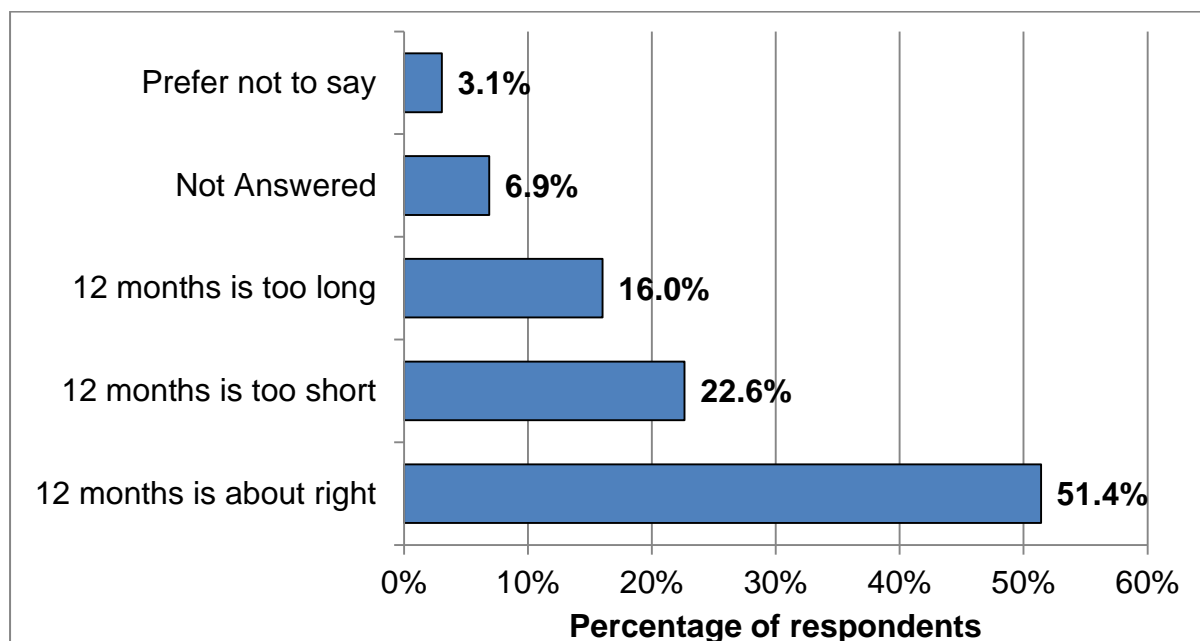
The figures in this table add up to more than 100% and this due to rounding.

The highest proportion of respondents (60.8%) believe that the advice and support that NHS England is planning to give to organisations is about right, whereas 6.4% of respondents stated they believe the advice and support is too small.

4.15 Question 14

The corresponding question on the “Easy Read” survey was “do you think that a year is the right amount of time to give organisations to follow the standard?” We have aligned these responses to question 14 of the standard survey based on the comments provided.

Figure 17: We are planning to give organisations 12 months to implement the standard. What do you think about this?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 24: We are planning to give organisations 12 months to implement the standard. What do you think about this?

Response	Total	Percentage of Respondents
12 months is about right	202	51.4%
12 months is too short	89	22.6%
12 months is too long	63	16.0%
Not answered	27	6.9%
Prefer not to say	12	3.1%
Total Respondents	393	100.0%

Source: Accessible Information Survey Consultation, NHS England, 2014

The highest proportion of respondents (51.4%) believe that giving organisations 12 months to implement the standard is about right, whereas 16.0% of respondents stated they believe 12 months is too long.

4.16 Question 15

The corresponding question on the “Easy Read” survey was “what do you think about our plans for making sure that organisations follow the standard?” We have aligned these responses to question 15 of the standard survey based on the comments provided.

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

Figure 18: What do you think about our plans for making sure that organisations follow the standard?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 25: What do you think about our plans for making sure that organisations follow the standard?

Response theme	Total
Will need to be mandatory / strong monitoring and sanctions required	93
Plans / timetable are good and achievable	78
Plans are not achievable in the timeframe with current resources	28
Concerns the standard will not be met	24
Require a feedback / complaints system	20
Ongoing organisation and staff training required	19
Other	6
Include other organisations	3
Total Responses	271

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 26: What do you think about our plans for making sure that organisations follow the standard?

Number of responses	Themes raised
93	<p>Will need to be mandatory / strong monitoring and sanctions required to help enforce the standard:</p> <p>Fines for organisations that do not comply.</p> <p>Use local Healthwatch / groups of people with learning disabilities to assist with monitoring of the standard's introduction and to encourage organisations to follow it.</p> <p>Implementation of the standard could be monitored by the Equality and Human Rights Commission.</p> <p>Include the standard in the NHS Equality Delivery System.</p> <p>Regular, formal assessment is needed to see whether providers are adhering to the 'must' requirements of the standard.</p> <p>Relying on local Healthwatch, patient groups and patients themselves to monitor performance is insufficient and requires resources.</p> <p>A nationwide audit by NHS England or specific inspections by the Care Quality Commission (CQC) are required to ensure that providers meet the standard.</p>

	<p>Compliance with this standard should be a mandatory aspect of all contracts, and should be regularly reviewed by commissioners when they review compliance with other contractual requirements.</p> <p>Annual performance should be recorded with evidence that demonstrates improvement to meet the standard.</p> <p>Need for clear consequences for organisations that do not meet the standard and clearer guidelines for how to report non-compliance.</p> <p>Clinical commissioning groups (CCGs) should make their public meetings and consultations accessible to d/Deaf people.</p> <p>The standard should be included in all contracts.</p> <p>Organisations will need to know what good practice looks like and be able to share good practice.</p> <p>Use patient champions.</p> <p>Have a “lead” for the standard in each organisation.</p> <p>Organisation should provide evidence of their compliance with the standard in annual reports / for the Equality Delivery System.</p> <p>Develop a kite mark which organisations can use on their websites to demonstrate their commitment to the standard.</p> <p>Need for processes to be put in place to measure the overall effectiveness of the standard.</p> <p>Need to involve the CQC.</p> <p>Without legal obligations the standard is not enforceable.</p> <p>Make the standard a CQUIN (Commissioning for Quality and Innovation) target.</p>
78	<p>Plans / timeframe are good and achievable:</p> <p>Achievable as long as all parties cooperate.</p> <p>The provision of tools and templates will support implementation.</p> <p>Sensible and appropriate.</p> <p>Hope that the standard will become legally binding.</p>

28	<p>Plans are not achievable / in the timeframe / with current resources:</p> <p>More investment is needed if the standard is to be implemented properly.</p> <p>Unreasonably short timeframe given the scale of the task of identifying and recording needs, and then providing the range of different communication support types.</p> <p>Changes needed to IT systems are not achievable within the timeframe / without additional resources.</p> <p>Plans are not specific enough – there are too many “should” elements.</p> <p>Given the scope of the standard, break the goals down and have a staggered timetable for meeting different aspects.</p> <p>Remove ‘should’ phrasing as this will lead to variation / inconsistency.</p> <p>Need for leadership, dedicated processes and identified staff.</p> <p>Concern about lack of levers to ensure implementation by independent contractors.</p> <p>Concern the standard does not acknowledge that the timescale is not achievable for some groups; therefore plans to ensure compliance are flawed.</p> <p>Concern that frontline staff will lack the time to implement the standard.</p> <p>Need for a high profile campaign with a high profile figurehead.</p>
24	<p>Concerns the standard will not be met:</p> <p>Concern that health and social care organisations will not follow the standard.</p> <p>Concern that the standard will not be met by GP surgeries / for pharmacy leaflets on medication.</p> <p>Concern about objections on cost and practicality grounds.</p> <p>Concern about lack of compulsion for GP practices and other organisations to follow the standard.</p> <p>Concern that the standard will become a “tick box exercise”.</p> <p>Concern about how the standard will apply where services are</p>

	<p>outsourced.</p> <p>Concern that more flexibility is required, and that more understanding is needed about compliance by specialist small organisations.</p> <p>Concern that organisations will say they do not have the money to implement the standard, even though most of the changes do not require additional costs.</p> <p>Concern about cost and complexity.</p> <p>Concern that the standard will be hard to implement in pharmacies.</p> <p>Concern that the standard is too vague for example as to how publication of an accessible communications policy / service user feedback will be used by NHS England, or others, to ensure compliance.</p> <p>Concern about lack of clarity as to expectations of the role of local Healthwatch organisations, patient groups and charities in encouraging organisations to follow the standard. Need for NHS England to provide more detail on the mechanisms that exist to ensure or encourage compliance with the standard.</p>
20	<p>Require a feedback / complaints system:</p> <p>Need for an accessible central contact point for individuals to be able to raise concerns if their needs are not being met or for organisations to contact if they would like support.</p> <p>Need to publish and disseminate information about the standard and how to raise concerns, including in alternative formats.</p> <p>Need for a mechanism by which health and social care organisations can pass on patient comments / concerns.</p> <p>Concern about proposed measures of compliance. For example publishing an accessible communication policy / accessible complaints policy, does not mean that the policies are being followed. Focus on patient feedback is problematic as it may not reflect an organisation's efforts. Services should be assessed on how well they have responded to feedback and adapted their services accordingly.</p> <p>Promote the collection of data and holding of regular forums with service users.</p> <p>The feedback needs monitoring, perhaps include a question on the Friends and Family Test.</p>

19	<p>Ongoing organisation and staff training / education required:</p> <p>To improve awareness and skills.</p> <p>Link to promotion.</p> <p>Health and social care staff need training in how to book / work effectively with interpreters.</p> <p>Need for staff to become more d/Deaf-aware and for greater availability of aids such as portable loop systems.</p> <p>Receptionists will require extra training, for example d/Deaf awareness training.</p> <p>Need for staff to be aware that some people minimise their communication difficulties / to be alert for signs of communication difficulties.</p>
6	<p>Other:</p> <p>Need to specify whether the “communications policy” relates to a whole organisation or smaller departments.</p> <p>Need to clarify that GPs are included in the standard as well as hospitals.</p> <p>Need to ensure information is clearly documented on service users' records and users are always kept up to date with regards to accessing alternative formats.</p> <p>Consider how to extend the standard to include social care.</p>
3	<p>Include other organisations: local authorities, not for profit and for-profit organisations supplying health and / or social care.</p>

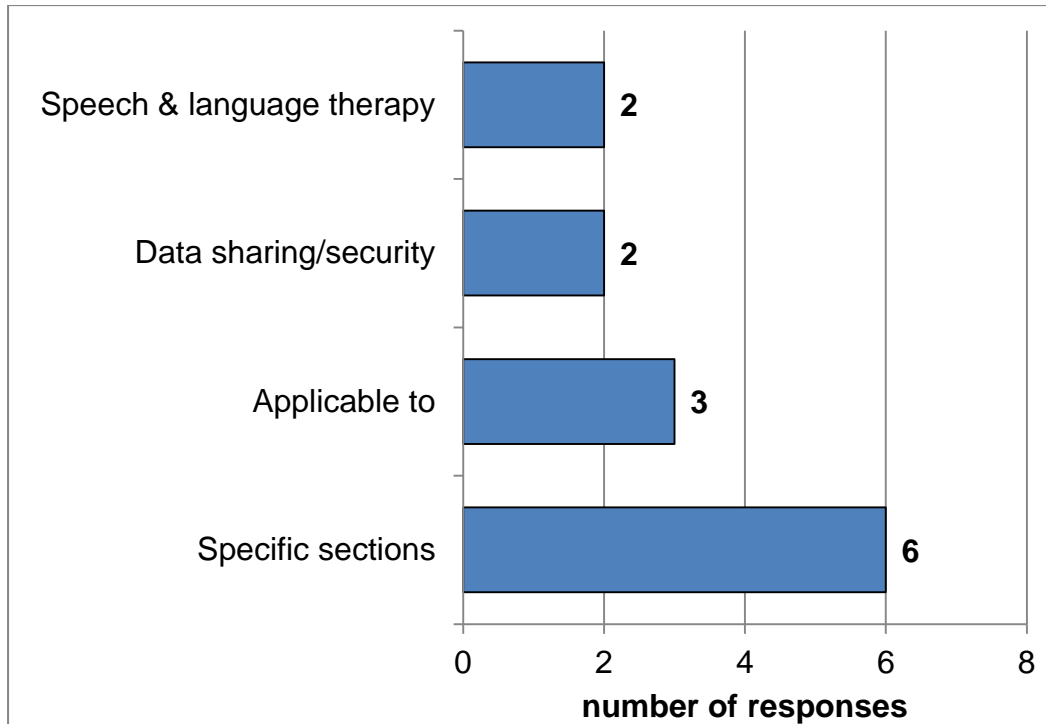
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.17 Question 16

The answers to this question were “free text”, and have been analysed and disseminated into broad categories. Due to the diversity of responses, it has not been possible to group many of these responses into broad themes.

Figure 19: Do you have any comments on the specification for the standard which are not included as part of other questions?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 27: Do you have any comments on the specification for the standard which are not included as part of other questions?

Response theme	Total
Specific sections	6
Applicable to	3
Data sharing / security	2
Speech and language therapy	1
Total Responses	12

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 28: Do you have any comments on the specification for the standard which are not included as part of other questions?

Number of responses	Themes raised
6	<p>Specific sections:</p> <p>Need to be clearer about the range of support needed by people who are “hard of hearing” (section 2).</p> <p>Signalong should be included alongside Makaton (section 8.4). ;</p> <p>Should include signposting to specialist organisations, for example [...] (question 13).</p> <p>Inclusion of support for 'communicating with patients by email and text message' is restrictive as support may be required via many media (section 12).</p> <p>Staff need to check that information has been understood by people with learning disabilities, as even information in an easy read format may not be understood (point 24).</p>
3	<p>Applicable to:</p> <p>Need to clarify if this standard is applicable to children as well as adults and older people.</p> <p>Include people with Asperger's.</p>
2	<p>Data sharing / security:</p> <p>More specific comment is needed on ensuring individuals are able to give <i>informed consent</i> or that they have an appropriate advocate who is formally able to consent for them.</p> <p>Need to include reference to data security.</p>
2	<p>Speech and Language Therapy:</p> <p>Need for the standard to recognise the role of speech and language therapists.</p>
1	<p>Include ability for re-assessment if needs change.</p>
1	<p>To reflect the importance of communication support, the title should be changed to ‘making health and social care communication and</p>

	information accessible' and the 'accessible communication and information standard'. Include reference to guidance produce by specialist bodies. Include reference to other services which could benefit from the standard.
1	Need for greater focus on the needs of the patient and staff training, rather than "efficiency".
1	Evidence of need available on social media.
1	Needs more information on: what communication needs people may have; how to identify communication needs; what conditions can cause communication needs; supporting people to communicate.
1	Acknowledge the expertise of family members and friends, especially when communicating with people with limited verbal communication.
1	Include development of standards for "cross cultural communication" and for interpreters / multilingual leaflets and audio-visual material.
1	Acknowledge that there will be delays in providing some types of alternative format / communication support.
1	Categories are too limiting / prescriptive and should be "and / or" not "or" for different disabilities. Enable application of a 'best interests' decision.
1	The standard reads as being obligatory with CQC monitoring. Concern about impact on primary care.
1	Concern that standard is proposing micromanagement of activity which GP practices currently do informally.
1	Need for details about what makes information easy read / accessible.
1	Acknowledge the role and responsibilities of patients in enabling effective communication.
1	Include video interpreting technology and services for remote BSL.
1	Need to include reference to font colour and background to improve accessibility. Need to acknowledge that some formats are not appropriate for lengthy or complex information.
1	Need to make clear that it is the responsibility of all professionals to ensure that they are using information and communicating with people and families in ways that maximise understanding – communication is not a "specialist's job". Acknowledge that not everyone has access to

	the internet.
1	The name 'Accessible Information Standard' is confusing, because it is so similar to The Information Standard: consider changing the name.
1	Consider contacting [...] to discuss the Communication Charter which has been implemented in [...] Learning Disability Community.

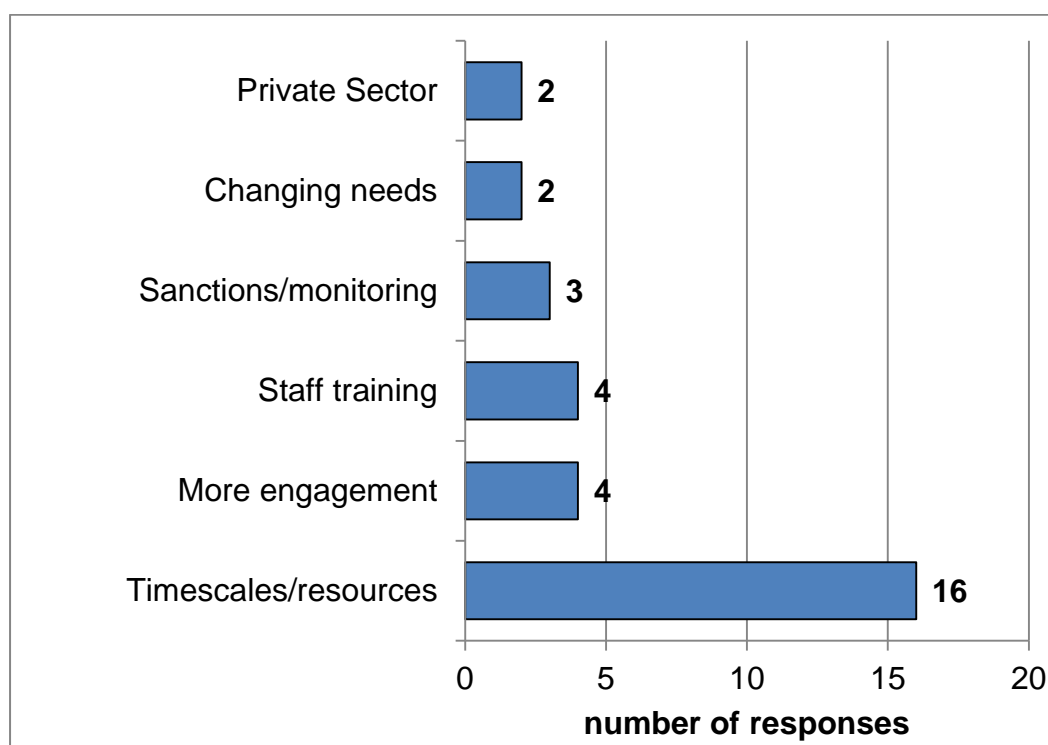
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.18 Question 17

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

Figure 20: Do you have any comments on the implementation plan for the standard?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 29: Do you have any comments on the implementation plan for the standard?

Response theme	Total
Timescales / resources	16
More engagement	4
Staff training	4
Sanctions / monitoring	3
Changing needs	2
Private sector	2
Total Responses	31

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 30: Do you have any comments on the implementation plan for the standard?

Number of responses	Themes raised
16	<p>Timescales / resources:</p> <p>Implementation in 12 months will be difficult to achieve due to size and complexity of organisation.</p> <p>Issues regarding changes to national systems which are used by local organisations.</p> <p>Timescales for implementation may vary dependent on software suppliers being able to upgrade the systems which are used for patient management or electronic patient records. Some of the information is likely to be already captured but not all of it.</p> <p>Implementation will be easier once the new GP referral form is introduced next year to include the question about preferred communication mechanisms.</p> <p>NHS England must work closely with providers of both care services and IT systems to understand the feasibility of its requirements and any system, process and resource changes that may be necessary prerequisites to compliance.</p> <p>The ability of organisations to accurately record and keep up to date preferred information and communication formats should not be underestimated.</p> <p>There will be additional financial implications for organisations which should be acknowledged. Very few organisations currently have a dedicated accessible information budget.</p> <p>As a CCG the timeframe for implementation is about right. Provider organisations especially those with multiple electronic record systems may struggle to implement by Spring 2016.</p> <p>Could there be different time lines for different aspects? Some will be easier to implement than others.</p> <p>The standard is right - it is not so high that it cannot be achieved but put where it can be achieved and should be able to be maintained at</p>

	<p>that level.</p> <p>Timescales are ambitious, and unrealistic - further pilot work would be needed before whole implementation.</p> <p>Unlikely that organisations will be able to implement a full reporting standard in a single year and so they should have 12 months to put everything in place to begin operating against the standard but 24 months before a national published assessment.</p>
4	<p>More engagement:</p> <p>[...] is in favour of the plan including recognition that working with local charities and voluntary organisations can be of benefit to local health and care providers in achieving acceptable standards of accessible information. However we are concerned that the standard and the implementation plan and guidance have been developed without proper engagement with community optical practices. Many of the assumptions made – about patient registers and the role and use of IT in patient records and referrals – do not currently apply.</p> <p>Useful to engage with patient and user groups during the implementation phase to gauge levels of experiences and get user input into future plans.</p> <p>Ensure you consult with disabled people.</p>
4	<p>Staff training:</p> <p>Frontline staff need to be adequately equipped to meet the needs of their patients.</p> <p>It is important that staff have an awareness of the different needs for communication and know where to find the information they need to implement the standard.</p> <p>This needs to come from top down within organisations and requires central encouragement, support and training.</p> <p>Training, for example working with interpreters, working with specific communication tools. This should be included in the implementation guidance.</p> <p>Training by the private sector in how to convert some parts of the formatting.</p>

3	<p>Sanctions / monitoring:</p> <p>What sanctions will be applied if organisations fail to comply with the standard?</p> <p>One of the most challenging things will be to ensure organisations are using the standard effectively.</p>
2	<p>Changing needs:</p> <p>Older people have changing needs and sometimes complex problems so it cannot be a 'once and for all' assessment. Therefore when recording an individual's needs, a review date should also be set to assess and record any change.</p>
2	<p>Private sector: private care providers should be included.</p>
1	<p>Widen the scope: to include foreign language interpreting.</p>
1	<p>Need to consider how to include implementation of the standard in contracts alongside CQC requirements.</p>
1	<p>Need more detail about the implementation stages.</p>
1	<p>Needs to be set out in greater detail with a timeline broken down by month and sources of support and advice linked at each stage of implementation.</p>
1	<p>Whilst everyone would agree on the need and importance of making information accessible, there are major challenges for organisations working in an acute setting to meet required needs in terms of BSL interpreters who are very short supply, are expensive and not easily accessible out-of-hours.</p>
1	<p>The plan should include recognition that working with local charities and voluntary organisations can be beneficial to local health and care providers in achieving acceptable standards of accessible information. These organisations are often the local experts in accessibility and can provide good advice and guidance.</p>

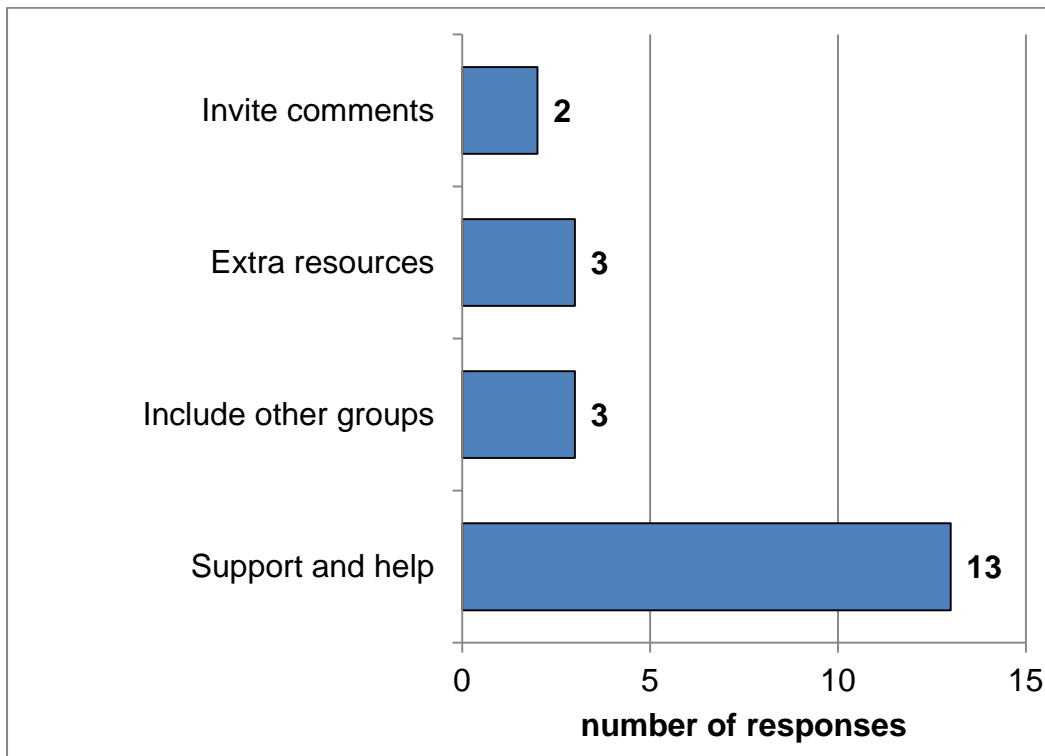
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.19 Question 18

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

Figure 21: Do you have any comments on the implementation guidance for the standard or support for organisations?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 31: Do you have any comments on the implementation guidance for the standard or support for organisations?

Response theme	Total
Support and help	13
Include other groups	3
Extra resources	3
Invite comments	2
Total Responses	21

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 32: Do you have any comments on the implementation guidance for the standard or support for organisations?

Number of responses	Themes raised
13	<p>Support and help:</p> <p>Refer / signpost to the 'preferred format request card'.</p> <p>Refer / signpost to research and best practice guidance on producing and providing high quality health information.</p> <p>Part of the guidance should be about adhering to the Nolan principles.</p> <p>Work with [...] and members to support dissemination of information and development of guidance.</p> <p>Signpost organisations to their local speech and language therapy service for advice around supporting people with communication difficulties.</p> <p>Work with [...].</p> <p>For support for people with learning disabilities, refer / signpost to the [...] website and the [...] learning disability website.</p> <p>Develop a register of accredited / approved communication professionals.</p> <p>Develop a 'how to' guide for organisations include recommending organisations / charities.</p>
3	<p>Also include other groups:</p> <p>Include people with a need for foreign language interpretation / translation.</p> <p>Include specific guidance around supporting people with learning disabilities.</p> <p>Include specific guidance around supporting people with Autistic Spectrum Conditions including Asperger's Syndrome.</p>
3	<p>Extra resources:</p> <p>Consider the funding implications for organisations required to implement the standard.</p>

	<p>Consider the additional demand that may be created for Speech and Language Therapy services.</p> <p>Consider alternative approaches to accessibility / provision of support which are more cost effective.</p>
3	<p>Invite comments:</p> <p>Invite local champions and local Healthwatch to comment on draft documents.</p> <p>Pilot 'easy read' resources about the standard with people with learning disabilities to ensure that they are accessible. Develop a two page summary highlighting the key points of the standard.</p>
1	<p>Link the standard to the rights outlined in the NHS Constitution and clarify how someone can raise a complaint if they feel that they are not being given the support outlined in the standard.</p>
1	<p>The list of additional guidance is welcomed; however, NHS England should ensure that duplication and overlap between guides is avoided. Guidance should be concise and comprehensive.</p> <p>NHS England should produce additional guidance highlighting the role of accessible information, communication support and patient engagement in person-centred care.</p>
1	<p>More emphasis is needed on verifying information and communication support needs to ensure accurate recording.</p>
1	<p>Guidance should include advice for communicating with people with hearing loss.</p> <p>Concern about the standard's use of separate categories for 'requires communication professional' and 'requires communication support,' and potential for confusion. Need for a definition as part of the glossary.</p> <p>Offer to support development of materials and training associated with implementation of the standard.</p>
1	<p>Checking of implementation needs to be agreed and publicised, including who will 'police' the standard and how non-compliance will be handled.</p> <p>Concern about implementation of the standard into existing NHS IT systems.</p>

1	<p>Professional bodies should disseminate information about the standard to their members and support preparation to enable compliance.</p> <p>References should advice / guidance / standards from the [...]. Examples are needed of people with complex communication support needs.</p>
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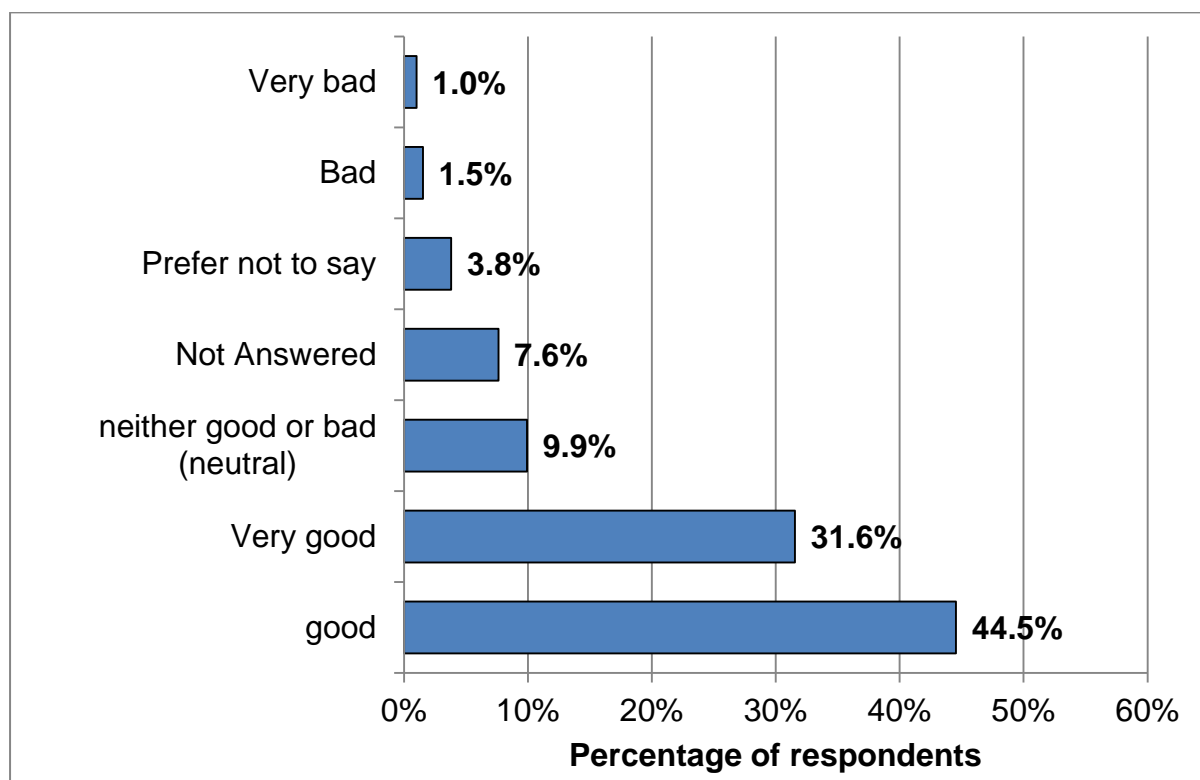
Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed “themes raised” do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

4.20 Question 19

The corresponding question on the “Easy Read” survey was “what do you think the impact of the standard will be?” We have aligned these responses to question 19 of the standard survey based on the comments provided.

Figure 22: What do you think the impact of the standard will be?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 33: What do you think the impact of the standard will be?

Response	Total	Percentage of Respondents
Good	175	44.5%
Very good	124	31.6%
Neither good or bad (neutral)	39	9.9%
Not answered	30	7.6%
Prefer not to say	15	3.8%
Bad	6	1.5%
Very bad	4	1.0%
Total Respondents	393	100.0%

Source: Accessible Information Survey Consultation, NHS England, 2014

The figures in this table add up to less than 100% and this due to rounding.

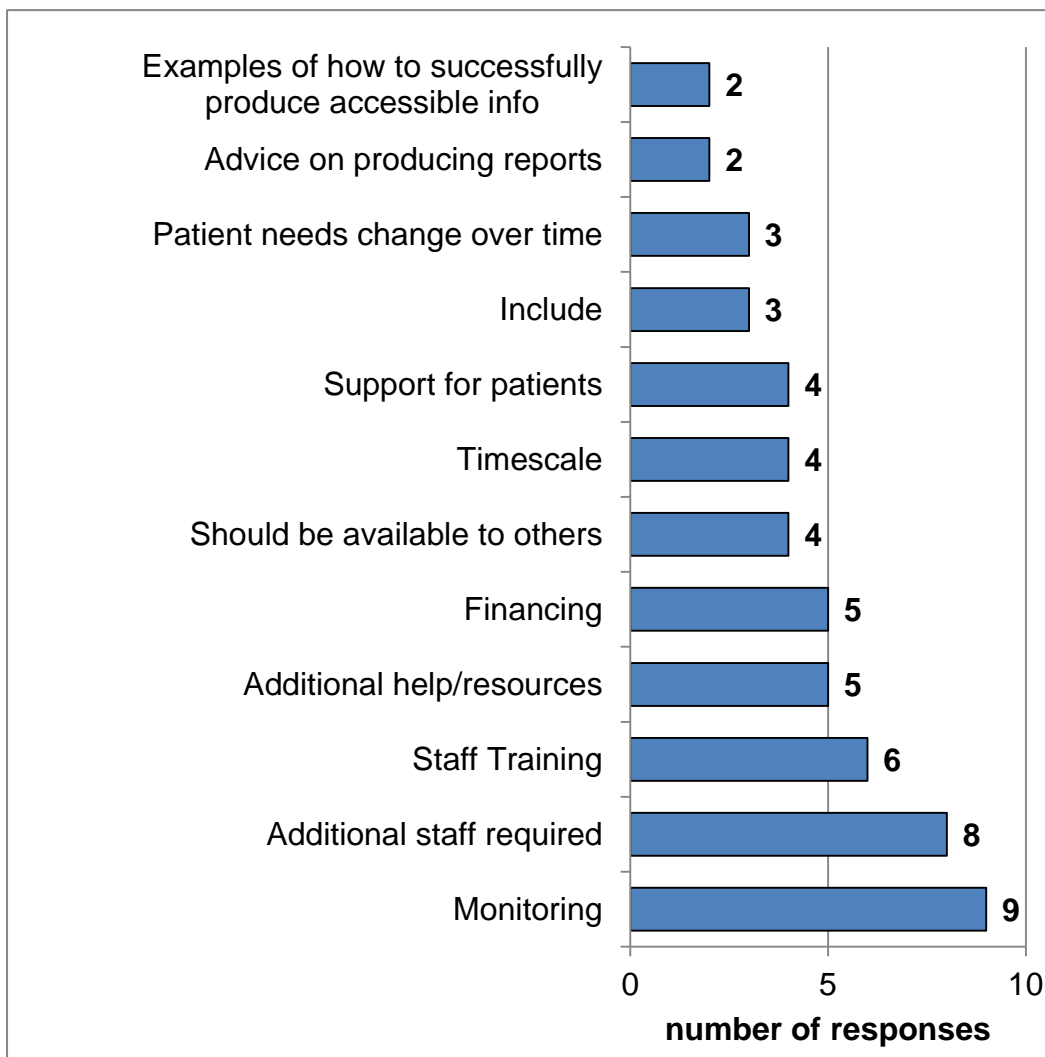
76.1% of respondents believe that the impact of the standard will be either good, or very good, whereas 2.5% of respondents stated they believe the impact of the standard will be either bad or very bad.

4.21 Question 20

The corresponding question on the “Easy Read” survey was “do you have any comments on the standard which are not included as part of the other questions?” We have aligned these responses to question 20 of the standard survey based on the comments provided.

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

Figure 23: Due to the short timescales we have to read everyone's responses and make changes to the final standard, we have limited the space for free text. If you have already given your views as part of the engagement phase, these have been considered in drafting the standard. If you do not feel that you have been able to share your views as part of this survey, please tell us?



Source: Accessible Information Survey Consultation, NHS England, 2014

Table 34: Due to the short timescales we have to read everyone's responses and make changes to the final standard, we have limited the space for free text. If you have already given your views as part of the engagement phase, these have been considered in drafting the standard. If you do not feel that you have been able to share your views as part of this survey, please tell us?

Response theme	Total
Monitoring	9
Additional staff required	8
Staff training	6
Additional help / resources	5
Financing	5
Should be available to others	4
Timescale	4
Support for patients	4
Include	3
Patient needs change over time	3
Advice on producing reports	2
Examples of how to successfully produce accessible information	2
Total Responses	55

Source: Accessible Information Survey Consultation, NHS England, 2014

Table 35: Due to the short timescales we have to read everyone's responses and make changes to the final standard, we have limited the space for free text. If you have already given your views as part of the engagement phase, these have been considered in drafting the standard. If you do not feel that you have been able to share your views as part of this survey, please tell us?

Number of responses	Themes raised
9	<p>Monitoring:</p> <p>Implementation should be independently monitored and enforced.</p> <p>For the standard to be effective, all providers need to follow it. Appropriate measures should be put in place to encourage compliance.</p> <p>The standard needs to be mandatory.</p> <p>Providers should be reminded of their existing legal duties and prompted to implement any necessary changes as soon as possible.</p>

8	<p>Additional staff required:</p> <p>It is likely that organisations will need project management support to implement the standard, which they will struggle to find funds for.</p> <p>Concern about increased demand for communication professionals, especially as there can be long lead-in times for arranging support. This needs to be considered – suggest involving Health Education England.</p> <p>Concern about capacity of organisations to meet additional demand for information in alternative formats such as ‘easy read’ and braille.</p> <p>Concern that insufficient consideration has been given to the practicalities of arranging professional communication support / alternative formats, and that this will limit the value of the standard.</p> <p>Concern about time taken to produce information in alternative formats and need for resources to be made available.</p> <p>Concern about ability of organisations to effectively implement the standard – specialist support will be required and it will be challenging to meet the proposed 48 hour deadline to produce alternative formats / arrange communication support.</p>
6	<p>Staff training:</p> <p>All staff working in health and social care services should have training to make sure they understand learning disabilities and how to communicate with people.</p> <p>Additional training requirements will be very challenging.</p> <p>How will training be supported / resourced?</p> <p>Staff awareness and training will have cost implications, as will the provision of interpreters and alternative format communications. Budgets will need to be ring-fenced for these requirements.</p> <p>d/Deaf awareness training.</p>
5	<p>Additional help / resources:</p> <p>Advice could include details of specific organisations that can provide specialist communication support, for example for deafblind people.</p> <p>Offer of support and signposting to resources.</p> <p>Look at [...] this website helps people to support people with learning</p>

	<p>disabilities to communicate.</p> <p>Produce templates that all organisations can use, instead of each organisation producing their own.</p> <p>Support for the standard as it will benefit people with Parkinson's - consider the specific communication needs of people with Parkinson's.</p>
5	<p>Financing:</p> <p>Concern about how implementation will be funded.</p> <p>Concern that implementation may have an adverse effect on current services if resources are diverted.</p> <p>Need for involvement and funding from NHS England area teams to enable implementation of the standard in primary care settings.</p> <p>Concern that the standard and consultation are pointless without funding and staff to provide an equitable service nationally.</p>
4	<p>Should be available to others:</p> <p>Accessible information should be available to everyone, including for example older people. Older people's organisations should be invited to monitor the effectiveness of the standard.</p> <p>Include patients on the autistic spectrum.</p> <p>Concern that the phrasing of the consultation document reflects the medical model of disability as opposed to the social model and comes across as reactionary not anticipatory. Organisations should anticipate people's needs and make reasonable adjustments. There is not enough emphasis on health and social care professionals making their communications as inclusive as possible to begin with.</p> <p>Individuals may not be aware of their rights around information and communication support, and the standard should include requirements about informing people.</p>
4	<p>Timescale:</p> <p>Concern that the 12 month timescale for implementation is unrealistic.</p> <p>A quality approach is preferred over rushed implementation.</p>
4	<p>Support for patients:</p> <p>It may not always be possible for someone to have a supporter with them, however, if they do, doctors should always speak to the person</p>

	<p>and not just their supporter.</p> <p>Concerns about provision of support for people with learning disabilities and the need for funding.</p> <p>The standard should include people's needs for guiding from the waiting room to a treatment or consultation room.</p> <p>Concern that some people have very severe communication needs, and that 'easy read' information is not accessible for everyone. Services need to recognise when this is the case, but also avoid assuming someone cannot access any information when they could if that information was presented in a different way.</p> <p>Concern that arrangement of professional communication support should be led by the individual, and they should have the choice of being supported by friends or family if they prefer.</p>
3	<p>Include:</p> <p>In section 5 of document, add "opticians and pharmacists".</p> <p>Where relevant add "effective" to communication.</p> <p>All forms of care should be included, including care which people fund themselves.</p>
3	<p>Patient needs change over time:</p> <p>Consider the need to take into account the changing nature of people's needs, for example sight or hearing loss may deteriorate. Needs should be regularly reviewed and records amended. Best practice guidance should be included about reviewing needs annually / three yearly and to record the 'last review date'.</p> <p>Consider that people's needs may be different depending on the health or social care environment, and that a range of staff may need to be aware of people's needs, for example mobile library staff during an inpatient stay.</p>
2	<p>Advice on producing reports:</p> <p>Pages of documents should be numbered (as well as paragraphs). When seeking online returns ensure the survey is in returnable format.</p>
2	<p>Examples of how to successfully produce accessible information:</p>

	<p>Good practice example: specialist service manager reviews all Choose and Book referrals for all patients with a learning disability or autism to ensure that 'reasonable adjustments' are put in place.</p> <p>Good practice example: [...] support for patients with hearing loss including immediate access to BSL interpreter via video.</p>
1	Suggestion that the 'help card' be called a 'need card'.
1	Ensure that services can receive information and communication from patients (as well as providing it to them), for example patients must be able to send / reply to texts and send / reply to emails.
1	Include examples of visual information and communication, for example live video chat and visual information (online or DVD). Also consider providing information about the standard in this format.

Source: Accessible Information Survey Consultation, NHS England, 2014

The number of responses and the number of paragraphs in the column headed "themes raised" do not always match - this is because either a single response has contained more than one comment or multiple responses have contained the same comment.

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 appear in "speech or quotation marks" to indicate that they are a quote from a survey participant and not a statement from NHS England.

Responses are unedited except:

- where information identifies, or may identify, an individual or organisation;
- references to brand, company, trade or product names (with the exception of those names which were included in the consultation document);
- 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 and grammatical errors have also been corrected for ease of reading. Where words have been inserted to aid understanding this is indicated by way of square brackets [around the inserted word].

Effort has been made to indicate quotes which relate to a single response, however, it should be noted that individual responses may be split where their attribution is unclear.

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 – (Question 4): If you think that the scope is too small or includes something that it should not, please explain here?

“Does not include people with lack of mental capacity.”

“I can understand that Access To Work funding would meet staff communication need but what about those who require information in an accessible format, e.g. Braille, easy read, large print, etc.? Similarly, what about the needs of prospective employees?”

“If possible, the scope should include landlords.”

“Schools and universities as they are included in people's health. The scope does not include manufacturers at the NHS level that produce equipment for sensory impaired people. The scope is not big enough to include manufacturing material to be in different formats.”

“For people to understand information about their health, communication /language support should be available to all who need it. Therefore when considering the NHS organisations’ obligations to reduce health inequalities and ‘reduce inequalities between patients with respect to their ability to access health service and reduce inequalities between patients with respect of outcomes achieved for them’ as stated in the Health and Social Care Act (2012), the accessible information standards should also cover issues and usage for those with different spoken language and poor literature skills.

Poor communication is contributing factor in health inequalities and can impact on patients being able to make decisions about their care, conversing with medics about their health which will impact on diagnosis and can affect them abiding to medicine regimes. There is research evidence of the impact of lack of interpreters on patient’s health and the potential for miscommunication, misunderstanding and misdiagnosis if an interpreter is not present or the procedures and processes for working collaboratively with an interpreter are not attended to. To ensure patients not only understand the information that is given to them about their health, as well as get information in a way they can understand, foreign language as well as BSL interpreters should be covered within the standard.

Use of Easy Read documents are also useful for those with none or limited English language and not just those who are deaf or disabled. Thus the different formats covered within the standard should extend reach to those where English is an additional language.

The implementation guide mentions under 6.1.2 that diversity monitoring will not be covered in the guidance, but noting a patient’s ethnicity as well as disability may also trigger organisations to consider whether information or communication support is needed.”

“Whilst we welcome the range of service providers who need to comply with the Information Standard, we have concerns as to how this will work where non-NHS providers are contracted to provide NHS services. We would welcome the inclusion of a clause requiring organisations who contract their work out to include adherence to the standard in their procurement and tendering processes. It may also be beneficial to clarify where the responsibility for adhering to the standard lies in these situations.”

“[...] strongly welcomes the acknowledgement and inclusion of deafblindness in addition to single sensory loss. Whilst many people who are deafblind don’t have an associated learning disability, some do and we feel that it would be appropriate to edit the phrase ‘people who are blind, d/Deaf, deafblind, have had a stroke, or have a learning disability’ and say ‘and/or a learning disability’ to strengthen the point and serve as a reminder to providers that there may be more than one need to address as part of the standard.”

“Section 8 - size and font should be based on individual need. Section 6 - last point - need to expand on this and can be seen as unfair as this may lead to direct discrimination. Information should be available to all in diverse and different formats and especially websites & this should be part of the standard.”

“Throughout the standard there is no mention of people with low literacy skills or cognitive communication impairments such as acquired brain injury or progressive disorders. Accessible information is of significance for these groups of individuals and therefore should be included in the scope. It is also important to acknowledge that difficulties with memory can impact on an individual's ability to access information and therefore should also be included.”

“Terms such as 'disability', 'impairment', and 'loss' are in themselves quite disempowering. Could the standards focus more on individual information and communication 'needs'? This issue was highlighted by the service users we spoke to who did not like the use of the term 'disability' commenting that; I'm not disabled; I'm the same as everyone else in the community (Service user with Learning Disability and Dementia). I'm not disabled, I just need some help (Service user with Learning Disability). People need to be careful using the word disabled. I prefer special needs. People should be treated normally (Service user with Learning Disability and Mental Health Needs).”

“The standard should be explicit that providers should always inform an individual if their information is being shared/flagged or explain in what circumstances they would not do this. The standard needs to be explicit that any costs incurred for meeting access requirements are to be borne by the provider and not the patient. We also feel that booking and administration of this should be managed by providers and not fall to patients.”

“Website exclusion: [...] agrees there is no need to duplicate existing guidance but there needs to be clearer directions on the standard providers are required to achieve and where that is specified (i.e. what standards or guidelines they should be following).”

“Why only adult social services?”

“[...]’s experience shows that providing patient leaflets in different formats does not ensure that health information is ‘understandable’. We are concerned that this scope will perpetuate misunderstandings about what it means to deliver health information that is accessible and understood by patients, which will have wider negative implications. This point is explained further in the free text section of this survey.”

“Overall there needs to be reference to bodies providing services to people of all ages – [...] would have a concern that because of some explicit references to adult social care services etc. that there may be a tendency for this not to be seen as applying to services in their work with children and young people as patients and service users. Children and young people often have different ways in which they will access and make sense of information. Attention needs to be given to the appropriateness of content of information, as well as format, so that it can be accessed by users of various ages.”

“Whilst speech, language and communication needs (SLCN) are a feature of many disabilities, we would be concerned that there is no mention of the 5 - 7 % of children and young people who have persistent SLCN as their primary presenting need with no other underlying disability or impairment. These children and young people will require information to be made accessible, and extra time at appointments, to facilitate their communication and this should be addressed in this document.”

“We welcome...

- The inclusion of a communicator guide as a form of communication support;
- The acknowledgement of deafblindness as a separate condition in addition to hearing or vision loss;
- The acknowledgement for the need for suitable communication support provision for overnight stays, long term care and in care homes;
- The recognition of carers/family members;
- The option to select more than one communication need type/format i.e. someone may use SSE and also need visual frame signing;
- The support guide for organisations;
- The statement that the need for accessible information/communication support shouldn't delay access to treatment.

We would like...

- Clearer outlines for how to report non-compliance;

- Clearer outlines for how non-compliance will be addressed;
- Acknowledgement that people can have a number of co-occurring needs – for example learning disability and a sensory loss;
- Acknowledgement that in some cases an interpreter may not know the form of communication that the individual uses and that, where appropriate, a family member may also need to support - some of our members have raised concerns that they have family members where they use an adapted form of BSL and that interpreting word-for-word will have no meaning to the service user. They are concerned that the section regarding using family members as interpreters may be read in such a way that means they are not allowed/able to support.”

“Not too small, but sometimes the language used e.g. Sections 2 & 8 may exclude people who don't think of themselves as having 'needs' and/ or don't have, or maybe don't think they want, support. There are many people who will have difficulty understanding un-adapted information who don't easily fit into these categories, so these may be the people more difficult to identify.”

“What has not been addressed is to encourage staff to use their observational skills to prompt patients in a tactful way to disclose any communications difficulties. Many people may not realise that future information will be compromised by their difficulties; older people are often too proud and independent to declare voluntarily any problems. Staff need to be encouraging by their good communications skills the identification of any problems. A culture which can be both tactful and encouraging is key to making this theoretical programme work.”

“I think it should include the Care Supporter or unpaid Carer of the patient concerned unless there is a specific problem put forward by the patient. They usually know the accessibility problem best and want the best for their cared for. Contact [...]”

“People with speech or communication difficulties due to neurological injury or illness need very specific, individual communication plans. These need to be diagnosed and developed by communication specialists such as Speech & Language Therapists - positions which are at risk of being cut due to the NHS budget constraints.”

“It is too small, many deaf and HOH people will need communication in English and therefore your scope for BSL interpreters in the document, throughout does not cover the needs. Lipspeakers and remote captions using registered Speech to Text reporter are needed as much as interpreters - and all should be registered with NRCPD.”

“22,500 BSL users in UK - compared to 800,000 profoundly deaf people who will not benefit from a hearing aid or loop - and likely to need English support. (Lip-reading is only 30% accurate and many consultants have accents, which make them impossible to lip-read anyway).”

“You need to focus on deaf people who use lip speakers, speech to text reporters as they need access to English. Do not [...] cos we are all diverse with different needs. The majority of deaf people are English users, whereas BSL is only the minority. Please be aware of that!”

“I don't understand why it doesn't include something like a ramp to enter a building or with a guide dog. Many wheelchair users are unable to get good or safe medical care cos they cannot access the building or get onto a medical couch in the first place. Information about physical access should be included!”

“It seems as if it would be reasonable to include people who do not have English as a first language as the solutions are similar.”

“I appreciate where the designers are coming from, but, in a sense it makes no sense, to me, to exclude some other forms of accessibility e. g a ramp or guide dog. If people cannot access the building where the service is provided, they cannot access the information. I do not think it is possible to be quite so categorical as to avoid all overlap with e.g. the 1970 Act.”

“As a carer getting access to information in electronic format would be a massive benefit. Whilst I recognise that information needs to be made available in different formats, such [as] sign language and easy read - it is important not to miss the opportunity to specify to organisations the need to allow access to electronic information on the care records. With such limited integration in electronic systems the carers are often the source of information and key to driving the best care. Currently letters take too long to arrive in paper format and are difficult to keep and transport to every setting. This work should link better into the current electronic access to GP records project and should define a set of standards to allow access from apps and patient led records that can enable far better self-management.”

“It's the patient's onus to [...] and not health professionals' responsibility to [...].”

“The scope could be bigger for example:

- There should be stronger emphasis on making sure that all contact procedures are open to choice of contact options such as SMS, email, fax, telephone, text relay. No service should be allowed to restrict to telephone contact option only.
- Letters could be phased out in favour of more cheaper solutions such as email or SMS (they can bring huge savings to NHS and increase accessibility for customers).
- All NHS services should record data of all accessibility requests so they can make sure any new information will have suitable numbers of accessible formats ready same time as general information.”

“The title overall is 'Making health and social care information accessible', is there a separate one for children as this is only for adults? Many of our young people go

through transition and in the health system, at 16 have the right to go into appointments without their parents. So is this the document organisations would refer to whilst they are in this process?”

“I am the Clinical Commissioning Lead for Learning Disability for [...] CCG. One of our current work streams is trying to change the experience of the Learning Disabled (LD) when they interact with NHS screening services (Breast, Cervix, and Bowel cancers, Aortic aneurysms and Diabetic retinopathy). There is also a group, including NHS England personnel, examining this arena shortly.

Personally, given that patients with a LD do not engage well with screening services, and that can lead to poor outcomes, I would value, given their size and impact, explicit statements including screening services in your remit.”

“There appears to be no [...] representation on the committee and I believe that (with other colleges) such representation would be helpful at an early stage as the issue here is not just about setting the standard (and this document is clear, concise and appropriate about that) but, from the very early stages, thinking about realistic implementation of this agenda. Passionate about a 'whole system' approach, it is exciting to see the horizontal integration of the accessible information agenda in this consultation document, including all health and social care services. However, vertical (i.e. timeline) integration needs also to be addressed so that organisations can begin to consider their educational, financial and delivery arrangements of this enormous agenda.”

“What is always helpful when informing people and trying to change behaviour is to have some patient narratives of when 'accessible information' might have advantaged a patient and some examples of good practice already educating services (such as the [...] project), and, locally, proactively recognising and developing, the need to improve the accessibility of information provided by the [...] to their patients, with whom myself and the CCG [...] [...] are working closely.”

“How are they to arrive if their mobility is not allowed for?”

“I am concerned about 'people lacking mental capacity' not being included in the scope. What happens to trying to communicate with them?”

“I am concerned that once again, the people who are paying for their own care are ignored and left out. I want to see all providers of care covered by the same standards. All humans should have the same human rights without regard to income.”

“My concern is if a patient/client is asked for their preferred medium and it is something like braille - the standard does not make mention of providing braille training to people producing letters/medical information. This could be fatal if wrong information is sent because people producing the braille cannot read the braille! Or will there be funding put aside to produce the braille information? Whatever option

this will add a much longer lead time to the production of braille - has this been considered?"

"There is no reference to requiring a professional in the field of speech and language therapy or being active to an SLT caseload."

"The questions 1,2 and 3 are leading."

"I believe strongly that better communication is required to assist everyone in accessing timely healthcare, however the communication in the vision is unclear and there is no clear path set out in the document. So although I agree with the vision, I do not agree in some aspects in the way it has been documented."

"From reading the document, I had a few questions unanswered:

- What exactly do you want to do?
- How exactly are you going to achieve what you want to do?
- Are you basing organisations following this new plan on good will or incentives?
- Why is this only focusing on those that communicate that they have a communication difficulty, how do you plan to reach those that cannot communicate that they have a communication difficulty?
- Why have a title of 'making health and social care information accessible' if the plan is not to focus on some groups (staff, those where communication is required in another language)."

"One particular group excluded that concerned me [were] 'People who would like to get information in a different way but who can still read information in a standard letter. This could be called a 'preference' not a 'need'. How does this apply to individuals with dyslexia or dyspraxia, who are capable of 'reading' a letter, but are unable to comprehend the content of that letter? Many people with dyslexia and dyspraxia are aware of this and request different formats of information, such as having a letter read to them. Under the draft standard these individuals would be excluded.

Also 'Help that people might need because of a disability which is not to do with information or communication. For example the standard does not include having a ramp or allowing a guide dog into a building'. In this example you may be excluding people who because of a physical disability have their communication limited, for example an individual in a wheelchair unable to reach a counter, is unable to read an information form on the counter.

'Help that people might need because they cannot make decisions for themselves. This might be called lacking mental capacity', does this exclusion infer that there is no need to attempt to communicate with those individuals lacking mental capacity?"

"Why on the list of 'requires specific information format' is Makaton sign video not included?"

“Why on the 'requires communication professional' is a Makaton interpreter not included?”

“It is very disappointing that no consideration has been given to develop standards for Cross Cultural Communication considering Britain has such diversity in population with many cultures and languages. Why has standards for interpreter services and multilingual leaflets/ audio-visual material been completely excluded? Very disappointing and worrying.”

“I did notice was, often, when alternative formats were listed, info in audio i.e. tape or CD were not included.”

“Foreign language translation and interpretation.”

“The last excluded item, 'help that people might need because they cannot make decisions for themselves. This might be called lacking mental capacity' should be included, with the proviso that the person's representative (e.g. Power of Attorney) should be included in the method of communication. Everyone has the right to communication, however simply it has to be expressed. Lacking mental capacity is no excuse for not trying to communicate!”

“I wasn't able to comment on the scope because it is not obvious for me as a visually impaired person how to access the consultation document. There should be a clear link labelled consultation document available in a word document.”

“The standard appears to concentrate on persons with a known disability, however, I believe that this standard will apply across the board to all patients, but think that this should be made clearer.”

“It is, I believe, quite common for elderly patients not to fully understand what they are being told and having a written confirmation that they are able to read and discuss after a visit would be invaluable.”

“I would suggest that rather than different agencies passing information about a client between agencies then consent must be obtained first.”

“I think that general information on websites should be accessible. A provider's website is equivalent to another entrance. Not including website accessibility requirements here is an opportunity lost.”

“I think that the standard includes the right amount of information with regards to what aspects of communication need to change. However, I think that the standard needs to include how accessible information should be implemented to suit an individual's needs. Sending an easy read letter to an adult with a learning disability may be helpful, but how will the person sending the letter know what type of images to include and whether photographs or symbols should be used? A generic letter

may suit many adults with Learning Disabilities needs but will not suit all and in this instance it leaves some people still not receiving accessible information.”

“I also think that there is no standard way of organisations showing how they are going to communicate differently to suit a person's needs. Will NHS organisations have a core set of recourses to use when a person has a communication need e.g. a set of pictures that will support the consultation, braille or other communication aids? I think that the standard outlines the right things that need to be done however I think without having detailed information about how this can be done, organisations will struggle to really produce accessible information.”

“I had misunderstood the term accessible. I would prefer it if we used a term that was more clear, and less euphemistic and coy. If we mean making information more easily used by the disabled, we should say so.”

“I took accessible to mean open and easily usable. I think that is actually the foundation of what this standard is trying to achieve, and it doesn't seem to get much mention.”

“A vast amount of public information is still published as documents, in complex multi-stranded narratives and proprietary file formats that are difficult to adapt and re-use. I suggest the standard should emphasise that making data available in open, re-usable file formats benefits all users, and is a valuable enabler for disabled users as they can adapt the data into a form and a tool that suits their needs.”

“This consultation seems to regard to just those individuals who are classed and registered as disabled. There are other individuals whose needs are disabling but are not classed or registered for whatever reason.”

“This should be about how all people access health information not just those with disabilities. The key is not the information that is provided by how it is used.”

“Providing the practice follows the policies.”

“I think you will be making a huge improvement, I think it's a lot to take on getting braille or CDs can take time to make brochures or leaflets accessible, will staff know where the stock is because having them out on display they will run out. Being in a store area Braille info will get squashed. You [need] somewhere that can make and send out same day.”

“Why oh why do NHS England continue to invest millions of pounds in admin, management and strategy costs on projects like this that are going nowhere. Cost up how much this exercise has cost then consider how the money can be diverted to something that will make a difference. The NHS has managed for over 60 patients and is excellent. Stop meddling.”

“I strongly feel online access should be included within the scope. If the true equality of access is to be achieved, then all should be able to access the home page of NHS/LA websites, then be able to navigate directly to more accessible areas. This would then allow online content such as video/spoken word to be accessible in this format.”

“It seems language support is missing. I do not mean to ask for a lifelong support towards interpreter/translator, but at times of emergency and crises, some carers and patients who have not lived in the UK long enough will not be able to understand the medical terminology should be still getting some support.”

“This includes making sure that people get information in different formats if they need it, for example in large print, braille, easy read or via email.’ You have a unique opportunity to make information more accessible yet you seem to see it only as something extra that needs to be provided to disabled and older people.”

“You should include in your standard generally available information as well. How often do we see signs and posters in healthcare establishments that are in all capital letters or in a font so small that it is nigh on impossible to read? Many older people do not perceive themselves to be disabled yet they would qualify under the Act, they also do not see themselves as older or requiring additional support yet a few simple changes to the way in which information [is] presented would cease this discrimination. Why should someone who has learning difficulties have to request information in a different way – mostly it’s not necessary if there is some consideration to the way it is displayed (non-capitalised text free from jargon and punctuation clutter) and the size of the font?”

“Or leaflets in the surgery or hospital that have too much information in such small print that even with the use of reading glasses is difficult to read.”

“Letters from hospital departments in size 6 – you need a magnifying glass.”

“Providing information that is accessible should be the norm rather than by special request!”

“I think that health and social care organisations should aspire to making their websites accessible to all users. There could be separate more accessible sections of websites, which users could navigate to. I agree that there is a lot of guidance about making websites accessible, however this is not widely available in relation to specific user groups, e.g. people with aphasia, language impairment after stroke or brain injury.”

“How can organisations provide a service that they have no access to?”

“It is fine in principle but totally impractical.”

“Good.”

“All patients/carers should be able to say they don't understand the information and want it presented in an easier way. This shouldn't just apply to people with disabilities which affect communication.”

“Given we live in an ever increasing digital age, a paperless society, how would some of the requirements be met?”

“The standard presumes that all information issued is for that location, it does not take into account information issued nationally by a service provider.”

“The scope [is] fine in so much as it meets its own objectives for improving information and communications access specifically for disabled people. However, were a public body to adopt this model, it could only fulfil one facet of an overall Accessible Communications Strategy, as there is no provision here for people for whom English isn't their first language. This infers that disabled people and people for whom spoken English is a second or third language are mutually distinct groups, which is contrary to many demographic trends.”

“I believe this should apply to private providers as well. What part of the plan covers communication problems due to developmental disabilities? I see hearing and vision problems. I see learning disabilities and mental health problems. I see nothing to suggest that people with developmental disabilities (e.g. ASD) get any accommodation at all. Do their problems not count cos [...]? Just because they may be able to read the information doesn't imply that they will understand it.”

“The scope should include consideration of health literacy needs of the population and how to provide information that people can understand and use. Recent research shows that 43% of working age people do not have the literacy skills to understand and use health information in common circulation rising to 61% if numeracy information is involved.”

“It should include reference to an assessment of the health literacy needs of people and how to provide appropriate information for people with lower levels of health literacy - many people with a disability will have HL needs.”

“I think it is about right to start the ball rolling and is something that should be built upon once it is successfully up and running.”

“We fully support your communication standard however I wish to put on record [that the] standard has a big gap. For example if you are looking at cost saving and mitigating risks I suggest seriously you don't omit language support when NHS and public sector professionals are providing services to the non-English speaking users. This is a huge mistake not to make same provision for the language support in your standard as this can be as a result newly arrived refugee with a contagious illness.”

“As a person's ability to understand information in order to make decisions about treatment/care I feel that communication support for people who lack capacity is a

really key element that needs to be included. Communication is key to a person being involved as much as possible in their care even if they lack full capacity to make decisions.”

“Some people in my health field think they are telling these organisations the problems they are having. But because of the way they describe their problems, they are not getting across the real problem they want addressed.”

“Many organisations don't understand they have communication problems in getting things across, which can be very frustrating for them.”

“It does not recognise the fact that some people (such as those with mental health or those with Asperger's or autism) may not recognise their needs or have access to specific advocates. Defining the needs of people with Autistic Spectrum Condition or their communication needs is far more complex and does not appear to be mentioned in this guidance. Communication needs are not just caused by sensory issues or learning disabilities.”

“Standard does not include people who need a different language to English unless it relates to disability. We think this is wrong and needs to be included to ensure equality across the system.”

“The scope should impress on health professionals that as they are prescribing for and treating patients they have a responsibility to make sure they understand their patients - it is as much about them getting the information right as the disabled/Deaf person.”

“Although it does not include communication needs where people do not have mental capacity it should include the information/communication needs which will support people to have the mental capacity to make a decision.”

“I think it needs to state that it will include guidance for providers of health and social care on where to source support for additional needs for 'How' do we implement the guidance would be really helpful.”

“It needs reference to health/NHS in the criminal justice system. This harder to reach group of NHS staff work in police stations and prisons and the offender population definitely need Easy Read (for health care, social care and just in general in the CJS).”

“This seems to start from assumption of an individual consultation, and that only some people have information and communication needs. Isn't there also a systemic level of information provision that needs to be addressed, such that information is routinely 'accessible' to as large a number of people as possible?”

“The standard does not include 'help that people might need because they cannot make decisions for themselves. This might be called lacking mental capacity' If

anything this should be the most important group of people to try and communicate with. Unless someone is given information in a form that is accessible to them then they might not have capacity to take the decision.”

“I feel it should include the provision of online material provided by healthcare providers, as this is an important source of information for Deaf people. For instance, the NHS Choices website has several hundred video clips, but only ten are in BSL.”

“The standard also talks about sending letters out in large print, etc. This should include DVDs with BSL clips.”

“Re Q1 i.e. the vision we prefer the straightforward version but remove the word disabled as the Care Act is for all people.”

“We believe the scope is too small and does not include something which it should.”

“There should be an inclusion in contracts with all providers of NHS services that they will provide information in accessible formats which meets the NHS England Accessible Information Standards.”

“The standard should say that websites should meet a specific standard. We would recommend those leading this consultation obtain initial guidance via [...] web accessibility standards which details how they use Website Accessibility Initiative (WAI) and World Wide Web Consortium (W3C) standards as a basis. This information is available here: [...].”

“The standard should also make it clear that not all people, especially older patients, make use of websites so alternative means of communication need to be considered for these individuals.”

“There needs to be clarity with regards how ‘need’ is measured compared to ‘preference’ and who is qualified to provide this distinction. People may have coping mechanisms to read text in a standard letter but find it easier to be provided a large print or other version.”

“Please see [...] response to question 10.”

“It deals very well with people who have specific info or communication needs, but does not go far enough to say how they will help people access info - it says about advocacy, braille etc., but does not acknowledge that everyone, even if they do not have a disability, will at times need access to an info service or advice service.”

“We need to take into account that health and social care services can be overwhelming whether or not you have a particular vulnerability, so there needs to be an individual assessment, not just asking standard questions.”

“Also, the standards should require practitioners to work hand in hand with children’s services. There are different information duties (e.g. Children and Families Act 2014)

but in practice, we will be using the same info websites across children and adults so the standards need to be the same.”

“Policing reviewing and improving the standard needs careful consideration and to be realistic and resourced.”

“[...] believes that the scope is comprehensive and reasonable; information relating to patients and carers' health needs should be accessible to all. However, on p.7, it is specified that the standard does not include 'people who need a different language to English but not because of a disability'.

Firstly, we appreciate that it would be disproportionate to state that the standard would ensure all information to be available in a multitude of languages. However, we believe strongly that the standard should make explicit reference to the Equality Duty, outlining that while it would be disproportionate to translate in all circumstances, it would be best practice to ensure that regularly used information be available in a range of languages commonly used by the local population.

Secondly, there needs to be an explicit allowance made for non-English information to be provided to non-English-speakers at the very least in emergency circumstances. For instance, if an English speaking patient is brought into hospital in a coma, but their only family or carers are not English speaking, it should be incumbent upon the NHS services to be able to engage with the family member/carers in their language. This would be in order to clarify the patient's perceived wishes while it remains impossible to communicate with them directly.”

“Page 6 of the standard talks about it only applying to some care homes - surely the intention should for it to apply to all.”

“I think the standard is looking for enough.”

“People with dementia are not included. GP surgery websites.”

“Not looking at people with dementia or people where English isn't their first language.”

“It should include GP surgery websites and pharmacists.”

“Dementia and not explaining it and using big words that we don't understand.”

“Dementia and not explaining it. Better to people with health issues. Put it in easy read.”

“It should include dementia and where English is not a first language.”

“It should include dementia and GP surgery websites and pharmacists.”

“Tenants found it was too long.”

“Not sure.”

“I think standard is looking enough.”

“Missing help to fill out forms.”

“From what I have read standard is enough.”

“Just right - but some of the images are not clear.”

“The normal standard should focus on catering for the majority and there should be separate standard communication methods for people who need them.”

“Consideration of others: people with severe disability, visual / hearing impairment. [...].”

“I think standard is looking enough.”

“Looking at enough.”

“Looks about right - if you ask people to do too much they might not do any of it.”

“Just right.”

“The standard needs to cross-reference other relevant NHS standards, for example on assistance dogs and information in other languages, and include what should happen if people have cross-cutting communication needs, for example a person with a learning difficulty whose first language isn't English. It also needs to be made clear whether this standard applies to private services contracted to provide services to the NHS. In addition, the standard should also include next of kin where appropriate as well as parents and carers, and it should be noted that these people may also be disabled and have communication needs of their own.”

“The standard should look at prescriptions, medicine bottles, and health advertising on TV/internet / social media (choice of [care] v important and so advertising needs to be accessible too).”

“Because some people are hypochondriacs and waste doctors' time.”

Appendix 2 – (Question 5): If you believe that the scope is too big or includes something it should not, please explain here?

“In not considering wheelchair users normally trust with instructors? Use wheelchairs signs should be very visible and audible?”

“It is predicted that there will be an increasing number of older people with dementia who will have communication needs so they should not be excluded.”

“You often include national & social bodies and or organisations. What about the carer, volunteer or friend who can have the fullest picture of the situation?”

“I think the standard must request websites to be accessible as some people may wish to refer to them for information prior to seeking medical/social care advice. I agree the standard does not need to explain how but simply refer organisations to appropriate guidelines.”

“Too general?”

“It is a missed opportunity not to include the communication needs of patients whose first language is not English and the needs of children and young people who should receive age appropriate information.”

“We were slightly surprised that the standard applies only to those in need, rather than general preference, which could raise the question of who decides.”

“Not all patients have communication tools that allow for all health and social care situations. Moreover, one size does not fit all. The scope of the standard should include the proactive and flexible use of communication tools held by services and appropriate to that service. If patients benefit from the use of new communication tools used in this way then that can be recorded in their notes. The scope of the standard does not include any reference to specific procedural requirements such as gaining consent, complaining, reporting abuse, patient evaluation of services. Finally, communication is two way and not just about providing information - it's also about checking for understanding and empowering people to make meaningful decisions/choices.”

“Please refer to question 3.”

“The scope does not include people who need information or interpretation in foreign languages. If we include them we can meet everyone's needs as one piece of work.”

“See point 4.”

“Private providers of NHS services.”

“The scope should make clearer that private providers of NHS services are required to follow the standard. This is stated in the specification summary (‘the standard

applies to... non-NHS providers of NHS and social care services including organisations from the voluntary and independent sectors’) and in section 2 of the implementation guidance (‘providers of publicly-funded health and social care including but not limited to independent contractors and providers from the private and voluntary sectors’). However it should also be clarified in the scope itself, perhaps by adding the statement ‘publicly-funded health or adult social care includes NHS or social care services that are being delivered by independent contractors or private or voluntary organisations’, after ‘the standard relates to ... patients or service users of publicly-funded health or adult social care, or their parents or carers’.”

“Websites.”

“In the specification, it is stated that the scope will not include the accessibility of health and social care websites as health and social care website accessibility is supposed to be covered by other standards.

At present, very few health and social care websites are accessible to people who use British Sign Language (BSL). In particular, it is very worrying that only 10 of the 900 video clips on the NHS Choices website have been translated into BSL. With an ever-increasing number of people turning to the internet as their first source of information about their health and care, substantial efforts are needed to improve the accessibility of health and social care websites for people with hearing loss. This standard should form parts of these efforts by including requirements to make information on health and social care websites accessible to people with hearing loss, including BSL users.”

“We are surprised to see no mention of the needs of people who do not read or speak English fluently and wondered why there was no specific reference to people who lack capacity and how their communication needs would be met. We feel the scope needs to clarify what is meant by ‘some care and nursing homes’.”

“There are approximately 5,400 community optical practices in England and over 10,000 optometrists. These deliver around 13 million NHS sight tests and a further 5.6 million private sight tests each year. In addition approximately 400,000 domiciliary sight tests are provided for those who are unable to visit a practice.

Just like all other parts of primary care, optical practices are private business which deliver the same range of services to both NHS funded patients and privately funded patients. In addition, there are a variety of private sector companies which provide IT systems for optical practices; these systems are used to manage both NHS and private patients’ data and records.

The scope indicates that all of these providers will be required to follow the standard. However it does not address the practical implications of this requirement: how the distinction between NHS and other services should be managed, or how these

additional costs (both time and financial) to businesses will be covered. The scope also sets out in some detail what the standard includes, but again does not address how these services will be provided or funded.

A potential solution would be for NHS England and CCGs to provide a list of registered professionals in local areas who can assist patients with additional needs and provide guidelines of how the NHS will fund this. Unfortunately the consultation document and implementation plan do not address these important issues. The practical and funding aspects leave a large hole in any implementation plans. There should be a funded inclusion in contracts with all providers to NHS services that they will provide information in accessible formats.”

“On web accessibility the standard should say that all websites should meet a specific standard. We would recommend those leading this consultation obtain initial guidance via [...] or [...] web accessibility standards which detail how they use Website Accessibility Initiative (WAI) and World Wide Web Consortium (W3C) standards as a basis. This information is available here: [...] and here [...].”

“Asking people with a communication support need if they have a communication support need is too simplistic. It is a yes/no question that requires comprehension and understanding of a communication difficulty.”

“The standard fails to mention speech and language therapy. Speech and language therapists are crucial in supporting people. They should be added.”

“The scope does not include individuals who have specific speech, language and communication support needs in the absence of any other difficulty. Although the document refers to ‘learning disability’ and ‘impairment’, there is no specific mention of specific speech and language difficulties, which may be acquired in adulthood, or developmental but have persisting effects into adulthood. Equally there is no mention of the autistic spectrum continuum or social communication difficulties. The needs of individuals with these types of problem are not sufficiently identified within the document – and therefore the needs of such individuals are unlikely to be recognised by health and social care workers.”

“Services and organisations need to match the way they communicate to the needs of people who use services; a one size does not fit all.”

“The standard does not include help that people might need because they cannot make decisions for themselves, due to a lack of mental capacity. It needs to be recognised that people with severe communication problems will need support to consent to treatment and care and a lack of capacity will be an issue.”

“Comments/queries:

- Does adherence to the standard apply to services that are outsourced e.g. agencies providing care in peoples home?

- How far does NHS or adult social care extend? For example would the standard cover leisure facilities if the patient was referred to exercise classes as part of a GP referral scheme?
- How is need measured versus a preference? Do people have to be on an official register to be covered by the standard requirements?"

"A list of definitions is needed (if not already available) to ensure clarity on what is meant by the terms blind and deaf, for example are degrees of impairment covered? (This also relates to comment above around need vs preference)."

"The standard identifies not covering those who have English as a second language, however does not clarify where people may use sign language other than BSL e.g. international sign language or French sign language."

"Does the standard include being able to make an appointment (not just being supported when at an appointment)?"

"The statement about websites is not entirely clear as they are not included here, but included again later under section 11."

"Easy read yes but could pictures be included? BSL interpreters yes but also relay interpreters?"

"Important to suggest low cost ways of accessing images for easy read documents."

"As above. Leaving the onus on patients to disclose their problems may mean that many communication problems will go without being identified. In particular memory problems for example in the elderly where written information they can take away and read several times is useful. Whilst the relevant formats need to be available the key is using two way communication between staff and patient to identify the problem. A staff commitment to this is needed in a practical way rather than issuing a directive only."

"As a severely hard of hearing person, I believe that yet again my communication needs have been overlooked. I can still speak and do not use BSL - nobody I know uses it and I doubt very much that it will become the norm. When dealing with NHS professionals, I would prefer to be able to contact them by e-mail, as I cannot use a phone. I would prefer to have a response by e-mail or letter. In face to face situations, I would prefer not to have my name 'called' as I cannot hear, not to be spoken to without functioning hearing aids in place, as I cannot hear, not to be shouted at, as this does not enable me to hear any better, and for complex information to be written down. You seem to have entirely overlooked the basic needs of the service user at the point of contact."

"Your Q4: includes something that it should not, is the same as does not include something which it should! Certainly your questionnaire isn't in plain English - sorry!"

“The scope should include Lipspeakers, STTR and remote captions as highly as interpreters.”

“The scope needs to be explicit. The more general the scope is the more opportunity people have to opt out of not providing the reasonable adjustments.”

“Furthermore, a list of organisations responsible for implementing the scope should be made available and I do not see how the information will be adjusted for young people, disabled people or [those] who may have basic skills issues.”

“I think the scope should include learning difficulty as well as disability. As a person with a learning difficulty I use BSL as a means of communication and in hospital have required a friend or relative to break down information and [I] don't understand the letters I am sent as they are not in the right format for communication.”

“It seems as if it would be reasonable to include people who do not have English as a first language as the solutions are similar.”

“I am wondering about dyslexia. You may class this as a learning difficulty but I think it needs spelling out or people will not recognise the requirement to help them, which may be as easy as putting the information on yellow paper.”

“The standard should link into other work that is underway to allow easier access to electronic information. E.g. the electronic access to GP records is a wonderful idea for us carers. To be able to take the care record with us wherever we are meeting would be fabulous. My family currently use [...] to record our care record for our daughter but this requires us to scan letters and enter manual information, still often without the details that we need and get asked for. Please use this opportunity to create, not just better access to languages, but just better open access to the information held in health and social care systems so that carers and patients can manage their care better.”

“It is missing some things such as:

- BSL video relay service, which will be useful in places like A&E, Maternity, and any other emergency incidents where it is difficult to find interpreters at short notice.
- It did not detail how each NHS service will be judged on how they are complying with the standard, whether there is rewards or sanctions involved.”

“As above, transition in the health process - for our organisation this refers to people with inherited metabolic diseases which are very rare so wherever the young people present themselves, they will have to explain a lot about their unusual disease but they need to know clearly about which information is for them and how they can access it and if it is for them or their parent/carers.”

“If mobility is not allowed for, how do folk arrive?”

“There is mention of text message/relay but what about video relay and the use of video for communication? Technology allows this now so should be included as part of a solution.”

“It would help to specify that material should be written well. Grammatical accuracy, accurate spelling and punctuation are all important. This document appears to take for granted that NHS standards are high in this respect, and this is certainly not the case. For those patients who are well educated and highly literate, many NHS communications are unclear.”

“Does every organisation have the resources and expertise to comply? I think not!”

“My concern in that section is there is the use of the word 'should' this is a word that has to be removed and taken out wherever it is used within this guide. The reason I say this is because personal experiences of guides becoming passive and not acted on because the word that gets pointed out as an excuse is it says 'should' not 'will' or any other word to be bold in its meaning.”

“What is great in the draft is already in that part it starts by saying 'will have to do' and then next sentence it loses its weight by saying should ask people. Let's look how to make use of language that stands out and says it has to happen full stop.”

“Specifically in respect of care homes and nursing homes readers should be made aware of the Deaf Care Aware quality standard - designed to make care and support services more accessible to Deaf people. This was launched [...].”

“Could be more compact.”

“[...] hospital, on arrival I had to take an elderly gentleman up to the first floor for an outpatient appointment. Knowing the layout of the hospital I had the choice at the bottom of the stairs to walk 50yds right or 50yds left to the other lift. I chose the right side lift, (bad choice). It took this old person 10mins to walk this distance with a [walking] frame. On arrival at lift a notice was stuck on lift door saying 'lift o/o/o/ please use other lift' i.e. 100yds other way. Asked him if he wanted a chair, replied no. Independent [...] walked back to other lift then 300yds & 20mins late for app. Why not put notice at entrance telling people a lift is o/o/o? This person could have collapsed due to NHS not showing any consideration with regard to any infirm person – no thought, no care.”

“I would be keen to know why the scope does not include information for those who require the information in an alternative language. I think this should be included in the standard as across the country we have many of the population where English is not their first language, however only BSL seems to be recognised as an alternative language. This could be perceived as discriminatory against the BME community, should it not be standard for all organisations to make reasonable adjustments for these members of the population. Especially if this is going to be monitored by the

CQC, how will information be monitored on requests for information in alternative language?”

“Being blind, it is almost impossible to cross reference. Also, my speech software is not completely compatible with this survey. I notice that my previous comments have appeared in the wrong place.”

“It should include internet and web accessibility especially as there is increasing use of the web within the NHS and local authorities e.g. to book appointments, to bid for housing. Need to look at non-literacy based options and the web is good for that.”

“I don't think it includes methods of making an appointment. Many doctors' surgeries have multi choice menus on their phone systems which confuse people with learning disabilities and make it difficult for them to make an appointment.”

“To be asked the question about communication needs at every appointment would be impossible for staff and often annoying for the patient.”

“It would not be financially viable to have all pieces of information available in all formats.”

“Although I wholeheartedly agree with the concept this is a very aspirational document and in the current climate I do not see how it can be implemented without massive financial impacts on already overstretched systems.”

“Should it not be incumbent upon, not 'if possible', to share this information with other organisations who are involved in the person's care? They may need to ask for the person's consent to do this.”

“The scope does not include people who need different language to English, which will disadvantage those groups who cannot communicate in English due to various reasons [...]. These groups of people [...] cannot explain their conditions to the health professionals, which make them as disadvantaged as the people who need a sign language interpreter.”

“I believe the standard should also include people who are lacking mental capacity as this is a form of disability.”

“Surely there should be reference to the use of [...] for sign language interpretation. This is now, I believe, being employed in a number of areas, especially in urgent situations. I do not use sign language, but I am aware that, for instance, the [...] sign language service in [...] is using this system.”

“The Scope fails to mention the legal duty under the Equality Act.”

“It also does not deal with 'reasonable' adjustment, i.e. could have a patient placing unreasonable demands on a service where there is a cheaper alternative format.”

“It uses ‘must’ and ‘should’ without real consideration for what these words mean in places. It’s just guidance isn’t it? It’s not legally enforceable. If it’s going to use ‘must’ then it would need to be a policy that is formally adopted by organisations – if that’s the case how does it expect the local authority to formally adopt it and what if we don’t want to because we feel the guidance/policy we have written ourselves is sufficient? With so many services outsourced/commissioned – how does it expect the standards to be adopted across all providers?”

“Services should be able to determine how they record/ask for needs.”

“The obligation is on the individual to tell someone they have a disability for a reasonable adjustment to be made.”

“The Standard does not include information on foreign language interpreters; this may be perceived as indirect discrimination and a failure of the duty to advance equality.”

“I think it would be better to record in a sentence what communication/information needs the person has and what support they need e.g. I have a learning disability and cannot read well, I need information in easy read and I need support from my staff to read and explain if needed the information for me. This is the kind of information in social care that would be recorded in an assessment of need document.”

“I am concerned about people whose first language is not English. I understand why they have been omitted to some extent, but given that this group is growing in number and is relatively young in demographic profile, it inevitably includes a large number of young parents who need to be communicated with on behalf of their very young children.”

“The scope should include all local government and NHS contracted services and Education. Children and families departments should have to follow the standard - consistency across whole life in the spirit of the Children and Families Act.”

“Should not focus on sensory need or disability – [...] gets numerous comments from people with regards to difficulties accessing information - you need to look at what is happening across the board.”

“I am concerned that Information Systems currently in use may not consistently be able to record the desired changes. Processes too may not have the flexibility to accommodate changes when only just getting used to sending large quantities of letters electronically.”

“As a visually impaired person I find it very difficult to find my way around hospitals due to the size, placing, colour of signage etc. and feel that these problems could and should also be covered by this, or maybe a separate standard.”

“Missing a need to cope with change. A person newly Visually Impaired has no working medium, so cannot immediately read Braille, so may initially need things read to them and could progress to magnification or speech reading on PC, and so on. Braille also comes in two grades and so some may request the contracted form which takes less space to produce but fewer users can access that. It may come up later, but if the notification is on the front page there needs to be ability to review that and be sure that all other similar entries are updated as time goes by.”

“I think the scope needs to include a reference to the fact that for some people, a full assessment of their communication abilities would be necessary: some people have very specific needs which would need to be known about in order to provide them with information that they understand. These specific needs (for example, about the kinds of words someone understands, or their needs in terms of understanding non-literal language - people often use analogies to help explain complex ideas to people, but these can actually be more confusing than helpful -) might only be identified during a full assessment carried out by a speech and language therapist.”

“If the intention is to engage directly with someone with very specific communication needs, the list of specific information format is missing out on [...] not as a means of supporting simple text, but as a total replacement for text. Producing this for an individual can only be done accurately and safely in this context by someone who knows the program well, and knows the individual.”

“I strongly feel online access should be included within the scope. If the true equality of access is to be achieved, then all should be able to access the home page of NHS/LA websites, then be able to navigate directly to more accessible areas. This would then allow online content such as video/spoken word to be accessible in this format.”

“When producing accessible information for service users then some of the tools have to be tailored individually to that client.”

“A lot of people underestimate the amount of time it takes to produce easy read information.”

“Templates are a really good idea to share amongst organisations.”

“I was confused about whether the standard will include guidance on making websites accessible. It said that it would not early on (as lots of guidance already exists) but then later said implementation guidance would contain information on making websites accessible.”

“I think it should contain information about making websites accessible or at least a link to the best piece of guidance.”

“I wasn't sure if the guidance was for adults and children or just adults.”

"I think basic information in the major foreign languages spoken by ethnic minorities in England should be provided. Many people living in this country, especially the older generation (who make up the majority of sick people in any country) do not speak English well enough to receive the care they need."

"The scope should not exclude the needs of staff as they are going to be the ones who will need to follow the requirements of this standard. This is a much needed and valuable exercise of course but resources should be put in place to allow staff to meet its vision - is there a plan to recruit more staff to cope with the increased workload? Like many NHS/DH initiatives and documents, it's all very well laid out as a proposal and sounds great in theory but how will you ensure it's realistic and can work in practice? Have you asked the staff what they need in order for it to work? Have you thought about the right infrastructure that will need to be implemented? How do you ensure that the right information, in the right format is available to those patients if the patient information posts in the NHS trusts are highly under-resourced, in terms of staff (usually one person in post managing the information needs for the whole of the trust) and tools to do their jobs efficiently?"

"[It] is unattainable."

"NA - great place to start something so huge."

"Good."

"All patients/carers should be able to say they don't understand the information and want it presented in an easier way. This shouldn't just apply to people with disabilities which affect communication."

"Same reply as 4."

"You often include national & social care bodies and/or organisations -- what about the carer, volunteer and or friends who can often have the fullest client picture."

"There needs to be more emphasis on the needs of people with learning disabilities. This population is only mentioned once in the document but they often need the most support. Given adequate support this population would be able to understand information when it is provided in the correct format for them."

"It's too prescriptive."

"If the patient has an NHS referral to a contracted out service will that private provider have to follow the same protocols?"

"Our vision is that: 'Patients and service users, and where appropriate carers and parents, with information or communication support needs relating to a disability, impairment or sensory loss have those needs met by health and social care services and organisations'. I think patient choice should be mentioned here; something along the lines of 'in a way which respects the individual's preference as regards to how

their support needs may best be met'. I.e. this would allow the patient to make a choice to have a family member or friend or other advocate - not necessarily someone assigned by the organisation. For example, someone may wish to have as an advocate someone who is also culturally sensitive to their religious beliefs."

"With regards to the exclusion of the needs of people who need another language than English - this makes general sense but the needs should be considered of people who ordinarily have a satisfactory command of English but may revert to an earlier language because of the stress of illness or a disability such as dementia."

"The standard does not have any reference to legal regulation/regulation and only has inferred commitment."

"People with acquired brain injuries - but don't feel bad, there's only 3million+ of them in the UK, so very easy to overlook! And you're in good company - most health and social care policy makers and commissioners make the same error."

"It is important for me that it specifies that the audio file on a CD should be on an Audio CD as a computer CD doesn't work in my player and in the past I've received things that I haven't been able to listen to."

"We think it should include websites too."

"It would have been helpful if the draft standard was available to look at as this is not the same as the consultation. Currently I think it is too long - organisations are too busy to read it. It should be short and snappy - making people want to read it. There are too many unnecessary words in the consultation such as 'we think'. You need to get to the point straight away. It is a turn off for many people. Bullet points may help."

"It does not say whether it is enforceable."

"As a person's ability to understand information in order to make decisions about treatment/care I feel that communication support for people who lack capacity is a really key element that needs to be included. Communication is key to a person being involved as much as possible in their care even if they lack full capacity to make decisions."

"Section 6 states: Arranging a professional to provide communication support or to be an interpreter. For example a British Sign Language interpreter, deafblind manual interpreter or an advocate. As anyone out there could call themselves a British Sign Language Interpreter without any credentials we need to protect both the health professional and the deaf patient by adding registered in front of both British Sign Language Interpreter and deafblind manual interpreter. This is important as registration means that the person has achieved a level of competence that ensures that he/she is safe to work as a professional interpreter and could be struck off if found guilty of poor interpreting and/or malpractice, a further safeguard. This has to be cited throughout the document - the term registered."

“It would be helpful if adults with acquired communication disorders such as aphasia due to stroke or brain injury, along with people who have progressive communication disorders due to Motor Neurone Disease, Parkinson's disease etc. were given as much consideration in the document as people with learning and sensory disabilities. Speech and Language Therapists, as the main trained communication specialists in the UK, are not mentioned, despite being funded, trained and employed by the NHS. The use of the umbrella term 'organisations' means that there is little accountability for who should be 'finding out' what someone's communication needs are or who should be communicating that information to others (health professionals, community and voluntary sector). It would be good to see some kind of evidence base for the creation of the standard.”

“I think that there should be a consideration of people with fluctuating conditions or being aware that a person's needs may change. For example, a deteriorating condition or mental health needs. It should be made clear that a person's needs may change, and professionals who communicate with people might be asked (or judge it appropriate) to change the communication mode. I am trying to say that once a communication need is identified, it should not be set in stone, and this needs to be made clear in the standard. My worry is that once a communication format has been specified there is no room to change and people will not take responsibility for checking that communication has been received, assuming that it has. Also, with so many different organisations relying on the information, there needs to be an effective way of responding to the changing communication needs across all services that a person uses.”

“There is not enough reference in the standard to making sure that a person with a communication need is supported to be able to initiate the communication. The standard particularly focuses on communication coming from a service to be received by a patient. But I think that services should make sure that patients can contact them. For example, getting put through to a machine that filters calls can be difficult to a person with a learning disability ('press 1 for...').”

“The needs of people with Asperger's or Autism are not defined within the current guidance. Their needs appear to be overlooked.”

“I am aware from already implementing The Information Standard in our small social enterprise that the scope of the standard has to be scalable for large and small organisations with small teams to put this in place. I would suggest a phased approach[...], and to have toolkits and information sheets, templates available.”

“Need to record person's disability as well as their information or communication need.”

“I am concerned that it only talks about information being provided by health and social care and does not include good information provided by others. It should say that health and social care will provide good information themselves but will also

signpost people to good information provided by others - not assume that the only good information is from health and social care.”

“Section 6 standard should include people who need a different language regardless of whether they have a disability.”

“Standards should also include people who fund their own care.”

“The inclusion of IT systems seems very broad.”

“There are four key areas I think the standard should include however I think it should include these topics in slightly different ways.

I think the standard should make mention of the importance of clear signage as this is a type of information which if not deployed properly can cause problems for everyone but especially for people with learning disabilities and those with visual impairments. I am not aware that the existing guidance / standard on signage actually includes anything on making signage clear and easy to understand and it should include this. So although I don't think this standard should include lots of technical information about signage I do think that it should mention the importance of clear and easy to understand signage.

The second area is in regards to websites - I do not think that this standard is the place for technical information about how to make websites accessible however I do think that it should include a rule which says something like: NHS services should make their websites accessible by following industry agreed accessibility standards such as WC3 or the government digital service standards.

The section around where a non NHS website is referred to by a health or social care practitioner should remain as it is e.g. if the non NHS website is not accessible that information needs to be provided in a way which is accessible.

Thirdly there is a particular area missing around staff behaviour and how the verbal information they provide to blind and partially sighted people is of vital importance. The best way I can describe this is there needs to be a rule which says something like: NHS and adult social care staff must consider what supplementary information they need to provide about the care environment to visual impaired people to enable the patient to be comfortable and confident receiving care in that environment. This will cover situations which arise like this: a clinic displays an estimated waiting time on a white board which a blind person cannot see; a nurse calls out a patient's name but doesn't identify where she or he is and where the visual impaired patient needs to go; a visual impaired patient is admitted on to a ward and just left without being told the orientation of the ward and important things like where the toilets are, the nurses' station is or where the exit is.

Lastly I would like to see the standard specially say that disabled people should be involved in the implementation of the standard on a local level within health and

social care settings. At the moment it says this may happen but the wording needs to be stronger. It should not be an optional extra. By involving disabled people in the planning and implementation, health and social care settings will have a greater chance of succeeding with the standard and will be less likely to make mistakes.”

“We agree with everything included in the scope, but believe that one further point should be added to the ‘what the standard includes’ part of section 6. While we understand that all NHS services should already be doing this, we believe that it would be helpful to include and explicitly state this in the standard - facilitate family members and carers to provide communication support, to be an interpreter or act as an advocate.”

“Additionally, we believe that mention should be made of providing people with other tools which can help people to understand, act upon and share information. This could include hospital passports or health action plans; vital tools for people with a learning disability, both when managing their health and sharing information with others.”

“It should include children.”

“Information should be provided in DVD signing.”

“Professional support should include lip speaking.”

“Should include websites - many people use these.”

“There needs to be clarity on the overlapping issues of accessibility, communication formats and understanding. An organisation may make information accessible and in an appropriate format but still not help the person understand the information given.”

“Only brief detail on general communication difficulties; look to include people who require the use of simple familiar vocabulary, short sentences, chunking of information, support with abstract concepts etc.”

“It presents quite a demanding challenge for the organisations involved, they will need to be supported and may need additional resource to achieve and maintain compliance.”

“The scope does not seem to include late deafened and hard of hearing people [with] support needs to communicate in English rather than BSL. BSL is not a language used by all deaf people [...]”

“NHS letters routinely contain a section on need of BSL interpreter; there is absolutely no option to request different form of communication support: Lipspeaker; Electronic Notetaker; Speech to Text Reporter.”

“The scope is about right, but we would welcome clear guidance that it is the person’s communication decision, so that less used formats such as [...] are not excluded from provision due to a small number of users.”

“The scope does not include provision or clarification on availability of support, i.e. can a service be held up as not complying when the reason is too few qualified language service professionals / interpreters etc.?”

“[...] thinks that the provision of information in a different language is equally about communication support and so it should be included in this standard rather than being covered by a separate piece of work. A person should be considered holistically, meaning that their different needs should not be put into boxes. It may not be obvious at the time of gathering information that someone needing a different language also has a particular impairment, and if they have an impairment requiring communication support, they will also need that support to reflect their language needs.”

“We think that it is problematic to differentiate between whether someone wants or needs information provided in a different way. Firstly, why would someone be requesting information in a different format if it does not relate to their impairment needs? Secondly, although they may be able to read small pieces of information in a standard letter, they may not be able to read much longer documents (such as patient leaflets) in that same format. There is also a problem here in terms of who makes the decision about whether the request is a need or a preference. It should always be remembered that disabled people are the experts in the solutions to removing barriers that they experience, so if they identify a need for information in a more accessible format, then this should be considered as a need without justification.”

“We accept that there are lots of guides about how to make websites easy for people (including those with different impairment needs) to use, and these should always be taken into account when designing health and social care websites.”

“In times of austerity when resources are stretched, it is tempting for organisations to cut costs by simply providing information online. Whilst more and more of the population are making good use of the internet, it should always be remembered that there is a significant proportion of the population who does not access the internet, either because they do not have their own computer, because they do not want to access particular information in a public place or because their impairment needs mean that this is not a suitable format for them to access and retain the information they need.”

“If the expectation is that the service provider must make sure that someone can find and read information they want them to look at on their website, there is a real danger that this will not be followed through. In many situations the person will not have access to the internet at the time of the appointment, and they will likely leave

the appointment and try and find the information several hours or days later. If they have difficulties with this, unless they feel particularly confident to contact the service provider to discuss this further, they will likely simply not access the information that they need. Also, if they do find that they need the information provided in a different format, this could cause further delays if the information has to be specifically transcribed into a different format by an external organisation.

Another factor to consider when asking people to look up information on a website is that of downloadable documents. Whilst information on the website may be presented in an accessible way, it's also important that the information in downloadable leaflets is accessible. PDF (Portable Document Format) is often used as it is presumed to be a universally accessible format. It is possible to produce PDF documents which are accessible to screen reader users, yet many documents are not accessible simply because accessibility guidelines have not been followed. This can also be true of documents in Microsoft Word, particularly if they contain fancy layouts, text boxes and pictures. Bearing this in mind, it is not just websites which organisations need to ensure are accessible; it is also external material uploaded on to those websites.”

“We believe there needs to be a specific recognition that the information needs of disabled children and young people will be different from those of disabled adults. In relation to deaf children and young people, although deafness is not a learning disability, some deaf children and young people may have low levels of literacy and/or low levels of confidence in engaging with health and social care professionals. We support the drive to making information accessible through, for example, the provision of communication support. However, for deaf children and young people, we strongly believe that for information to be accessible, special and separate consideration needs to be given to how it is given and presented.

Many deaf young people have raised concerns with us about information not being engaging or matched to their needs, as found in [...]. We believe that a new field should be added so that it is possible to record that a disabled person has information needs relating to being a young person. The definition of young-person friendly could include:

- Information presented visually with use of images, animation and/or colour;
- Broken down into chunks, using boxed out text, sub-headings, bullet points and bold text;
- Uses simple language and avoids complex words, jargon or idioms;
- Using short sentences.

Further advice on making information accessible to deaf young people can be found online at [...]. Other potentially helpful resources include [...].”

“Easy read’ version of resources may go some way to addressing the above needs. However, most deaf children do not identify as having learning difficulties and would not normally look to use ‘easy-read’ versions as an alternative.”

“I think the standard is looking for enough.”

“People with dementia are not included. GP surgery websites.”

“Not looking at people with dementia or people where English isn’t their first language.”

“It should include GP surgery websites and pharmacists.”

“Dementia and not explaining it and using big words that we don’t understand.”

“Dementia and not explaining it. Better to people with health issues. Put it in easy read.”

“It should include dementia and where English is not a first language.”

“It should include dementia and GP surgery websites and pharmacists.”

“Tenants found it was too long.”

“Tenants found it was too long.”

“Tenants found it was too long.”

“Tenants found it was too long.”

“Easy read letters.”

“I think standard is looking enough.”

“Missing help to fill out forms.”

“From what I have read standard is enough.”

“Just right - but some of the images are not clear.”

“The normal standard should focus on catering for the majority and there should be separate standard communication methods for people who need them.”

“Consideration of others: people with severe disability, visual / hearing impairment. [...]”

“I think standard is looking enough.”

“Looking at enough.”

“Looks about right - if you ask people to do too much they might not do any of it.”

“Just right.”

“The standard needs to cross-reference other relevant NHS standards, for example on assistance dogs and information in other languages, and include what should happen if people have cross-cutting communication needs, for example a person with a learning difficulty whose first language isn't English. It also needs to be made clear whether this standard applies to private services contracted to provide services to the NHS. In addition, the standard should also include next of kin where appropriate as well as parents and carers, and it should be noted that these people may also be disabled and have communication needs of their own.”

“The standard should look at prescriptions, medicine bottles, and health advertising on TV/internet / social media (choice of care v important and so advertising needs to be accessible too).”

“Because some people are hypochondriacs and waste doctors' time.”

Appendix 3 – (Question 7): If you think the steps / requirements are too big or include something which they should not, please explain here?

“It needs word documents as PDF cannot be sized up to print and documents are normally saved [as] PDF.”

“I feel that the stages could be squashed into one, common sense really, too much red tape.”

“The steps seem adequate and it is ultimately dependent on the leadership within the health organisations that will see how fast or effective the standards will be implemented and not seen as additional administrative work.”

“While no-one could object to what the standard sets out to achieve, there is an issue of practicality for us; like so many other NHS organisations, we face many other pressures and priorities at present and I suspect we might struggle to achieve everything within the standard as envisaged.”

“Stage 1 – it is not just about the format of the information, but also the ‘level’ of information. Speech and Language Therapy (SLT) assessments will often advise on an individual’s understanding in terms of how many chunks of information they can understand at one time, whether or not they can understand negatives, various other aspects of grammatical understanding, memory auditory processing etc. All of these details are important to consider when designing accessible information.

Stage 2 – the need to share information with consent and how this information is shared should be described in more detail. One service user commented ‘I’d rather tell people myself’. She strongly felt that she should be supported to independently share information about her communication and information needs. The use of an alert card was discussed. An empowering model of information sharing was preferred, rather than a process that occurs between professionals. Less verbally able service users commented that they would be happy for professionals to share information about their needs. They struggled to describe their individual communication and information needs in detail and frequently were only able to comment that they needed help.

Stage 3 – there will be significant resource and cost implications for this which may impact on the successful implementation of the standards in the current economic climate.”

“Again, there is no mention of respecting confidentiality.”

“We fully support the standard but there seems to be little scope for flexibility or proportionality of approach, or recognition of how in particular primary care is provided in the community.”

“Healthcare professionals based in community optical practices see patients less frequently than for example GPs, pharmacists and dentists do. People also exercise real choice, are not tied to any one practice and do shop around.”

“A big issue is that of IT systems and connectivity. [...] supports the use of technology to improve services and assist every individual in accessing relevant information. IT has an important role to play in ensuring a more efficient primary care service. This includes making information more available for people with disabilities. It is also part and parcel of the Government’s aim to create a ‘paperless NHS’ by 2018. Unfortunately community optical practices have not been included in NHS and primary care IT investment programmes.”

“Second to last point on stage 2 - what is meant by staff should also support people to lip read?”

“IT suppliers need to [be] on board with the requirement so that it can be incorporated into their development roadmaps.”

“LAs will then need time to implement these new software versions, time scales are unrealistic.”

“These changes to software will be on top of the multiple changes already being demanded by NHS integration with social care.”

“There is a cost implication to this new standard and you do not offer any supportive information to realistically deliver the standard requirements. As a charity we use every source we can to support our clients accessing our services however, this is time related and uses the good will of others at times! Will there be any support to organisations as you do not yet know the demand that will be made for this support? I agree to equality of access principles but also recognise that services cost money and I am not sure how you will do this.”

“Keep it simple otherwise it will not work - you have it about right.”

“I am reading the easy read version of the document and can find no reference to 'steps' so am not able to answer this question.”

“Again all very aspirational but in reality will become another expensive tick box exercise and will not improve quality of care.”

“Can't obviously access the consultation document.”

“After a particularly stressful hospital stay if my disability and needs had been flagged up at the appropriate time for my operation, the whole in-patient experience would have been a better one.”

“Excellent proposal that at subsequent follow-up appointments could have increased time available for the client/patient to discuss their communication needs.”

“Communication support essential for visually impaired, so letters, booklets, test results etc. offered in a format chosen by the patient, sign language interpreters as well as advocates.”

“I totally agree that all information should be accessible to everyone however there will be cost implications in the requirements particularly around advocates, interpreters and producing accessible information e.g. producing easy read information properly is time consuming if you are properly involving people who use services.”

“At a time when funding barely covers the most essential costs of services I'm not quite sure how these additional resources for substantial numbers of people are going to be funded.”

“As mentioned previously I think that the idea of sharing information about the communication needs of an individual is good but further identification of how needs can be met should be included or how NHS organisations can get this information.”

“The apparently simple statement that organisations should record or write down people's needs in the same way and then share that information hides a complex set of questions around having a universal unique identifier for everyone, and around personal data sharing. Given the risks involved it would be better to have this item removed lest this issue derail the whole initiative.”

“The step that is missing is the follow up - in terms of when information was accessed how useful/relevant/helpful was it?”

“Concerns of the capacity and capability of electronic systems.”

“Providing the practices [abide] by the wording.”

“I believe the steps are about right but would strengthen the requirement for social and health care to be using the same documents. Some CCG's and LA's are already making significant strides working together, e.g. Better Care Fund, and I feel there's an opportunity to pilot high standards now for new documentation.”

“Scrap it. Waste of money.”

“The main concerns relate to GP IT systems and hospital IT systems being able to communicate with each other.”

“Extra time would be needed to carry out recommendations.”

“[A] specialist from Speech Therapy would need to help advise on accessible information produced.”

“Once again, language support seems missing. Is politics influencing the lack of language support? Hopefully this communication improvement policy idea is not to

demolish the existing needs for language support. At times of emergency / crises for some Carers/patients/family should be able to access right information. Perhaps, optional service could be attached with this project. Otherwise there will be some 'losers' created."

"The standard does not include: the needs of staff. Service providers have a duty under the Equality Act to the needs of employees. You are assuming that the NHS does not employ any disabled people - I hope they do?"

"This document makes promises that are laudable but impractical and very costly to implement in full - who will fund given the current economic climate?"

"I think the steps are great if the government provide the tax earned money to help everyone's right to the same information in a format they can understand. This should be law!"

"Good."

"You cannot be so prescriptive for all information issued by service providers. There requires greater flexibility to allow for individual and specialist service provision."

"Not enough details in the easy read version for us to comment."

"They are not very clear again it would be much improved if the draft standard was available for the discussion. There's not much point in consulting without being able to see the standard as what is said in the standard may be very complex and unnecessarily convoluted - not thinking of the simple ways of supporting people. It needs to be short and snappy. Is it going to be adopted by everyone?"

"The first question in any standard is 'do you require support'. If the client says no then just leave it as they may want family members or someone else to support them."

"Is it enforceable if so how? I know it's enforceable under the law but how are you going to spread the word as the NHS structure is extremely complex."

"I am in full agreement that these steps need to be taken but I fear that practically there is a massive amount of adjustment that needs to be made. I am a Speech and Language Therapist working with adults with learning disabilities and have been working for many years to try and enable services to meet the communication needs of people with LD. For staff teams who do not have experience of learning disabilities there are many skills that need to be acquired in order to meet these needs including how to make spoken language simple, using signing or pictures etc. and I feel it is unrealistic to assume that these can be acquired easily or immediately and I am concerned as to where these skills would be acquired from as Speech and Language services are extremely small and under pressure at this time. I do feel that

it is greatly needed and really appreciate this move forward but I am concerned as to how it would work in practice.”

“As before: the understanding and specific support of those within the autistic spectrum particularly those who do not have a learning disability.”

“As before, just to make sure that if we want to keep everything uniform, that toolkits and templates are put in place to follow to make this easy to implement and to keep information consistent and clear across different organisations.”

“The steps are OK but organisations need to be supported to move onto step 3 - meeting the needs.”

“I think too much information is given in this section. It may cause confusion because it is very long. Also there is a lot of repetition in the BSL clip which makes it longer. It might be better to condense it slightly and keep the information explained in the 3 steps to the point.”

“As before - it should ensure that people are sent or given information about what is available to help, inform, support them - not just information provided by commissioners and providers.”

“Providers will need to include Deaf Awareness training to enable their staff to comply with the Standard. This should be explicitly stated.”

“The steps may need to change as the population changes e.g. Dementia.”

“The requirements such as the capturing and sharing of data are complex. These issues need to be addressed in more detail.”

“A large number of different information formats are listed, and it might be difficult to implement some of these in pharmacies. The scope of the standard could be met with a more straightforward requirement.”

“It is hard to say from the information provided in the consultation but I do have some concerns regarding the expectations surrounding the provision of patient information in different formats in terms of timescale. This is mentioned under section 9 briefly but more detailed information about this would be useful. For example, routine care does not necessarily mean routine information.”

“Sharing information with other organisations may be a challenge. Elements of NHS and social care do not always communicate effectively. This will require much closer cooperation between organisations and sectors.”

Appendix 4 – (Question 8): If you think the steps / requirements are too small or do not include something which they should, please explain here?

“Daisy CD.”

“Should start from basic standard of information for everyone in plain English and noting advice (e.g. from [...]) about legibility such as size of print and colour.”

“To ensure a person's information or communication need is flagged up wherever someone looks I would like to see the standard specifically state the necessity to record on both electronic and paper notes. In the case of people with sensory impairments it is possible that a person's needs change over a period of time through improvement/deterioration of their condition. An annual check on need would be helpful. I believe there should be a recommended timeframe for providing support in an emergency. As soon as possible is far too vague. Perhaps there needs to be different timeframes for different needs, i.e. someone with communication needs will require assistance fairly quickly (say in a maximum of 12 hours), whilst provided staff read information as a temporary measure 48 hours may be acceptable for information provision. I am not a health professional to give proper guidance.”

“It does not include a checkbox. What is the front page of a document? Is it a person's name? They should ask people what information they want on the front page. People need help with the form.”

“We feel they are very comprehensive.”

“Need to consider the cost and complexity of adopting this standard within a large organisation with existing systems/processes in use that cannot readily meet the standard without significant investment of resources. Should consider that the standard be mandatory as new systems are implemented. Need to consider information sharing of communication needs across and between organisations - other NHS and social care organisation and also the private or voluntary sector.”

“The steps/Requirements included are thorough and we welcome the three stage approach that is outlined. However, the inclusion of the need to check that the requirements recorded are correct would be beneficial. Some of our service users have reported that they have had their needs recorded incorrectly and have struggled to have these adjusted, for example, having the wrong type of interpreter booked despite repeated explanations leading to wasted appointments and delays in care. It may also be that people's communication needs change over time and their details will need to be checked and verified – just as with address and contact details.”

“Stage 1/2 should allow for changing as well as fixed needs. If a patient/service finds a new or better way of supporting communication, this should be recorded.”

“The steps for organisations do not include encouraging individual patients and carers to self-advocate. For example by carrying help cards or personal profile that outlines their information and/or communication support needs (e.g. [...]).”

“‘Asking people if they have any information or communication needs’ is too simplistic. Many people with accessible information needs would have difficulty describing their needs, as described above.”

“The guidance needs to clarify that individuals with complex information and/or communication needs may require a specialist assessment to fully identify their needs.”

“As previously mentioned, accessible information is not just about ‘formats’ but also the ‘level’ of information and the frequent need for additional support in the delivery of the accessible resources. Therefore, sending letters may not be the best method of communication for everyone, even if the letters have been adapted.”

“Individuals that could support communication should reference communication specialists e.g. Speech and Language Therapists.”

“It is also important to recognise that accessible information is a sensitive topic for some. Research has shown that there is often a stigma attached to the use of accessible information and frontline staff may be reluctant to talk to patients and service users about their information and communication needs. A cultural change is needed.”

“It is important that information and communication needs are categorised and recorded appropriately. It’s not about asking if they need an advocate or sign interpreter, but rather who is the best person to support sharing the information – this of course may vary depending on the nature of the health or social care information and therefore should be reconsidered with each new piece of information. Research highlights that ‘who’ delivers the accessible resource is often not considered e.g. for a complex health issue, such as cancer screening, it would be more appropriate to have a skilled professional delivering the information rather than a support worker who may not have the knowledge to expand the topic and add additional information as required to support understanding.”

“The issue of who should support the use of accessible information was raised by one service user who commented ‘some information is private, isn’t it. I wouldn’t want just anyone to help me; I’d want someone I trust. There are lots of nosy people out there and I don’t want everyone knowing my business’.”

“Identification and Recording of Needs – prompts to identify needs.

It is positive to see the requirement that ‘professionals and relevant staff should proactively prompt individuals to identify that they have information and / or communication needs and support them to describe the type of alternative format

and / or support that they need'. However, we feel that improvements could be made to the guidance to ensure that staff know how to prompt and support individuals to identify their needs.

Firstly, the guidance recommends suggested questions that may be initially used to identify needs, including 'Do you have any communication needs?' and 'What communication support should we provide for you?' The terms 'communication needs' and 'communication support' are quite technical and are not widely understood. We therefore recommend that services avoid using these as initial questions and instead start with more familiar language such as 'Do you have any difficulties communicating with us and is there anything we can do to help?'

Secondly, many people who have a communication or information need may not be aware what support is available so once a need has been identified, we strongly recommend that staff list the alternative format/ communication support options that might apply to that need. For example, if the person has difficulties communicating because of a hearing loss, the staff member should ask if they would benefit from any of the following options, and then list the options available. That way, the individual will be aware of what is available and will not feel uncomfortable asking for the support that they require."

"Meeting of individuals' needs - costs of providing alternative formats or communication support: health and social care services are legally required under the Equality Act 2010 to make reasonable adjustments so that people with a disability such as hearing loss or deafness are able to access their service. This could include providing access to a loop system or a communication support professional. Currently, many health and social care services neglect this legal duty and fail to make reasonable adjustments, for example by refusing to pay for a qualified BSL interpreter. We therefore recommend that requirement 25 makes clear that organisations must 'take steps to ensure that communication support, professional communication support and information in alternative formats can be provided without charge/ at no cost to the individual, promptly and without unreasonable delay'.

Meeting of individuals' needs - registered interpreters: it is stated in the Quality and Governance section of the specification that 'professionals providing communication support, interpretation and translation MUST be suitably qualified to perform the role effectively, including having the necessary knowledge and skills to handle clinical, sensitive and personal information appropriately'. The specification should make it clear that services should book communication professionals who are registered with the National Registers of Communication Professionals working with Deaf and Deafblind people (NRCPD). NRCPD is the accepted regulator of communication professionals who work with deaf and deafblind people, and they keep the only register of interpreters for deafblind people, lip speakers, note takers, sign language interpreters, sign language translators and speech to text reporters. NRCPD

registration guarantees the registrant has met the minimum requirement to practise. Ensuring a communication professional is registered with NRCPD is the only way that a service and service user can be confident that the person: has the necessary qualifications; is bound by the Code of Conduct; has completed a Fit and Proper Persons Declaration; and is required to continue their professional development. We know of many instances where services believe they are booking suitable communication professionals but those professionals are in fact not properly qualified nor signed up to an appropriate code of conduct.

Using a NRCPD-registered professional also means that if there is a problem with the communication professional, a service user can make a complaint to NRCPD and this can be objectively reviewed and action taken as necessary. If the communication professional is not registered, then these regulatory procedures may not be consistently applied, which puts people with hearing loss at risk.

The Ministry of Justice has made it a requirement to use NRCPD-registered communication professionals, and we believe it should also be a requirement in health and care settings, where the lives of people with hearing loss are similarly at risk.

Meeting of individuals' needs - responses from or communication initiated by people with communication needs: it is very positive to see the emphasis throughout the standard on providing information or communicating with people in a way that they can understand. However, we are concerned that systems may only be put in place to ensure that services provide people with information in accessible formats, but not necessarily that services must be able to receive information back (and therefore to truly communicate) through these alternative formats. For example, systems to send people SMS messages should also be prepared to receive responses through this method. The specification should make this requirement clear.”

“The text should be more explicit that these requirements apply to all organisations providing NHS services including private contractors and it needs to be clear who pays for this. It is not made clear about how 'preference' will be assessed. What is not clear in these steps is what the repercussions are for services which fail to comply with these requirements, and how a patient can raise concerns that their needs are not being met.”

“There is no reference to the timescale for the provision of accessible information.”

“Stage 1: identification and recording of needs: the steps need to include a training element in order for those who have contact with patients / users are able to identify when someone has a communication need. Training will be essential. An organisation should be required to record the percentage of all staff who have undergone specific training on recognising and responding to a wide range of communication support needs. Some health and social care colleagues often underestimate their patient/client's communication support needs and overestimate

how well they are meeting these needs (this is very clear in the literature). This is why staff training is so crucial. Such training could include the presentation of strategies for staff to use when communicating with someone who either has identified communication support needs or may have communication support needs. The [...] is developing an inclusive communication project, which includes good practice examples and tips and techniques for communicating with people. We would be happy to work with you use this as part of staff training.”

“For stage 1 to be properly implemented increased access to Speech and Language Therapy will be essential.”

“There is an inherent difficulty in asking people with communication support needs to use their communication to describe their difficulties. There needs to [be] some acknowledgement that some individuals (for example people with learning disabilities, people on the autistic spectrum, people with dementia, people with specific language impairments, people with Dysphasia) may need a more in-depth assessment of their communication difficulties so that appropriate information/support methods can be identified. It should also be acknowledged that there are some individuals who will be unable to access information in any format due to the severity of their cognitive impairment.”

“Stage 2: sharing and referring to recorded needs: there needs to be more information about how consent to share the collected information will be gained/recorded. There may be some individuals who are not willing to have this information shared. IT systems need to be compatible to ensure that data on communication support needs can be shared between health and social care departments.”

“Stage 3: provision of support – meeting needs: to ensure you can provide communication accessible services, it is good practice for services to allow time to arrange different formats or communication support depending on the needs of your audience.”

“Although reference is made to 'communication professional' there is no mention of access to Speech and Language Therapy. This should be made explicit.”

“When somebody has communication support needs, it may take more effort and time to ensure that service provider and person who is using the service understand each other. It is absolutely crucial that staff give individuals with communication support needs more time at appointments. This will need to be added into the diary planning process, so receptionists need to know to allow more time when booking these appointments.”

“Information also needs to be available in plain English and free of technical jargon.”

“There is reliance here on the service user being able to articulate their own needs and on the service to acknowledge and understand how to meet those needs. [...]

would be concerned that this may not work in practice. We know from the evidence base and activities linked to the Government's Better Communication Action Plan, that identification and understanding of SLCN remains poor. Children and young people with SLCN can be difficult to identify and parents and the children's workforce often see what they understand; for example poor attainment, but they may not notice the SLCN difficulty underneath.

We would advise clear guidance and training for those developing accessible information and overseeing implementation of the standard in their services which provides for increased knowledge of SLCN and to develop their skills in identifying and supporting those with SLCN. We have a range of resources and information to support workforce development in relation to understanding and supporting children's communication needs and would be delighted to work with NHS England on this. This training and support would be particularly useful in guiding organisations in the 3 stages."

"The communication needs of children are not mentioned. This is particularly relevant for older children who may have different communication needs from their parents and be able and interested to read information for themselves, even if parental consent is required."

"The standard needs to ensure an individual's right to privacy. This may be compromised by asking people about their need at the reception desk and by having a note about their need on the front cover of patient notes."

"Sharing patient information should always require patient consent; the consultation document only identifies that it 'may need to ask for the persons consent' to share'."

"I think the lack of reference to speech and language therapists is a gap - they are the experts in accessible communication and I think direct reference to their skills and support abilities within the professionals section is an omission. Further, many people have a poor understanding of the work of SLTs and this serves to reinforce the lack of opportunity for individuals to receive the right support for their communication needs to be met."

"They do not include anything for people with aphasia."

"If someone needs support from a communication professional such as British Sign Language interpreter, deafblind manual interpreter or advocate, then organisations must arrange for this professional to support the person. This includes making sure that they have this support at appointments, so that they can use services, and to support them to make decisions about their health, care or treatment'. You have missed out lip speakers and STTR / remote captions - again only 22,500 BSL users compared to 800,000 profoundly deaf who are more likely to need communication support in English."

“You need to focus on deaf people who use lip speakers, speech to text reporters as they need access to English. Do not [...] cos we are all diverse with different needs. The majority of deaf people are English users, whereas BSL is only the minority. Please be aware of that!”

“The 3 stages set out look fine. For most people with a learning disability services have been working to ensure that they have a communication passport or profile which helps people know the best ways of communicating with them. It would be helpful if any guidelines remind services to ask people if they have one of these. This may not be in the format you are recommending as it is the person's own document but it would give a lot of helpful information.”

“The [...] have produced the [...] for people with learning disabilities as part of the response to Winterbourne - these are now being adopted for other groups of people with speech, language and communication needs. They can be accessed from the college website [...].”

“It is great that there are options for email and word but this does not go far enough. There need to be standards to support personal electronic care records - further definition of this would drive the market to improve/develop more apps for carers and patients.”

“The requirement should have more contact options as minimum requirement such as SMS, email, telephone, text relay available to public. It would end indirect discrimination where deaf people can't make appointments without using telephone contact only. They can't make initial appointment with GP if GP is only contactable by telephone.”

“I believe the steps should include a duty to refer on to speech and language therapy for additional support with communication if the person's communication needs are unclear.”

“You use the phrase ‘if possible’ to share information. If someone explicitly states they don't want their information shared then of course you must respect that, but organisations working in health and social care should share this information for the benefit of the client. There is nothing worse than being repeatedly asked for the same information when the system/service already has it somewhere.”

“Much of the material in the document is familiar to those of us who work in education. Why is there not more collaboration between the education sector and the NHS?”

“As already stated there are a few more times the word 'should' has been used and needs to be removed from all statements. The use of [the] word 'must' is in there which is good to see as that is a move in the right direction. Another word to replace the word 'should' is 'consider', for example: when looking at sharing information, consider each of the options available to securely share information [and] clearly

explain to the person the benefits e.g. not having to be repeat their request / preferred communication need, this then links to a list of all the options and they action that. If it's left as a 'should' the risk is it will get overlooked. Let's use language that is positive throughout to ensure this happens which is why the odd 'should' has to be removed throughout."

"Let's start using terms such as 'personalised preferred communication support' and [ensure] IT systems are set up to have a 'banner' type ribbon that flicks up on the opening page or new pages to remind anyone accessing the records etc. (once a preferred communication has been identified) so they see it directly in their eye line - then it comes across/ flicks back right to left or left to right."

"It is very disappointing that no consideration has been given to develop standards for Cross Cultural Communication considering Britain has such a diversity in population with many cultures and languages. Why has standards for interpreter services and multilingual leaflets/ audio-visual material been completely excluded? Very disappointing and worrying."

"The section on the provision of accessible information is too vague. For instance, were I to leave A and E with a letter for my GP, I would expect this to be made accessible to me also. So, perhaps there needs to be a clearer definition e.g.: any info which is needed in an A and E, as part of the treatment, must be made available in the correct format within 2 hours. If info only needed on discharge from A and E, then that would form the deadline. Similarly, if I was an inpatient, I would expect info to be made accessible to me straight away. This should not be limited to medical information, but should also include things like menu choices and help to locate toilets etc., if the signage isn't (and it usually isn't) accessible enough to read."

"There needs to be greater clarity about the need to provide communication support for all communication during inpatient stays. Too often, it is only provided for a tiny part, leaving people unable to communicate the rest of the time."

"The steps have not included the following: health and social care organisations must find [out] if a patient or service user needs information in different format because they need different language to English."

"The Standard would not include help needed by someone with a disability which did not involve information or communication - their example not providing a ramp or allowing a guide dog into a building. As the Standard is only to do with information and communication, I agree with this. In any event buildings should be wholly accessible anyway."

"I think that the responsibility for finding out if a patient requires information/communication support should lie with the agencies. That requirement should then be recorded and easily flagged up the next time a patient/client visits or is visited."

“It does not mention the need to ‘anticipate’ reasonable adjustments for service users and have most common formats readily available. For example large print. Different services in adult social care will have different priority needs for adjustments. For example, learning disability services may need to produce ‘readily available’ material in Easy Read but this may not be needed in a Care Home setting. And it depends upon the information, its purpose, the service user profile etc. We say that everything is done on a case by case basis.”

“Stage 2 refers to may need to ask for [a] person’s consent to share information. Under information sharing laws it is highly likely that permission will be needed. Each organisation will need to consider who they will share the information [with], why and in what format. As a way showing respect and dignity the standard should indicate that the organisation should ask for the person’s permission - say what they will share, with who and why.”

“Having been previously involved in an advisory capacity in Summary Care Record work, my query here is really to do with how information will be shared adequately, and in an emergency. For example, in an emergency situation, if someone uses non-verbal communication and has a gesture to show they are in pain, how will this be quickly brought to the attention of practitioners? And if someone is recorded as using a learning disability passport (health passport), how will the passport be integrated into the person's care pathway so practitioners have more detailed information about the person's communication needs - again, especially in an emergency. I appreciate this standard may be more about supplying information in a required format and highlighting needs, but the two seem closely intertwined, hence me raising it.”

“The step that is missing is the follow up - in terms of when information was accessed how useful/relevant/helpful was it?”

“There is no mention of where organisations are to find this support. Oh yes, I remember, NHS Direct used to provide information in various formats e.g. braille, large print and audio but were disbanded earlier this year.”

“There should be a central/national resource provided to all Trusts, at least as a referral point to guide organisations so they know where to start as I realise it varies regionally. Signposting could include local NHS interpreting services, BSL, charities etc. Do you have a librarian/knowledge service??”

“The steps suggest asking people about whether they have a communication difficulty. I think there are potential issues with that:

- Many people with mild / moderate learning or communication difficulties don't realise they have a difficulty and would say that they did not.
- Examples given for how to ask someone if they have a communication difficulty, all include the word 'communication'. Some people with communication difficulties won't understand fully what the word 'communication' means.

- Many people have very specific difficulties which they might not be able to identify themselves.
- People's communication needs might not be apparent during everyday conversations and well 'rehearsed' scenarios (e.g. at a doctor's reception desk), but might only cause difficulties for them when the topic under discussion is something new to them (i.e. the kinds of issues that might be discussed when someone is very unwell and needs a particular treatment, or are due to be going through a new life-changing experience, such as moving home)."

"Sharing information which it is good but the steps/requirements did not include the security of accessing information - unless it has been mentioned elsewhere."

"Stage one: Recording communication/info needs: good aim, but I do not think we yet have the shared language for this, and this needs to be developed and shared widely. E.g. when a doctor writes aphasia, what does the receptionist understand by the term? We need to specify that communication needs may change over time, e.g. after stroke or brain injury. Info needs to be recorded about the role of the family member in supporting the person - this is a very variable phenomenon, as you've recognised elsewhere in the consultation doc.

Stage 2: Sharing: This can be done assuming a shared electronic patient record - this is a fundamental potential barrier as these are not currently in place, even within healthcare trusts, and certainly not across health and social care organisations. I agree about seeking consent where possible, but if people have very severe communication impairment, I think the record of their needs should be shared in their best interest.

Stage 3: The aim is correct, however it is important that organisations avoid making assumptions about what individuals need - this also needs to be balanced with overwhelming people with choice! There is not always a clear solution to an individual's communication/information need, due to the range of reasons for the impairment."

"The standard needs to specify the inclusion of people with aphasia, a language impairment after stroke/brain injury. Also to include people with dysarthria, an impairment of motor speech due to various neurological reasons. Within these two groups, people will have varying needs due to different degrees of impairment."

"Stage 3 should include that organisations will have a duty to provide comprehensive training for staff in awareness of communication impairment. This needs to include input from specialist staff e.g. Speech and language therapists."

"Good starting point :-)."

"Good."

“There needs to be opportunity for spontaneous requests when patients/carers are given information in a way they don't understand. As a carer I don't have communication difficulties but I would sometimes like to be able to ask staff to present information differently, e.g. as a chart. Communication needs can arise at any time.”

“I see no requirement to accommodate people who need help to communicate due to developmental disabilities. They may not need a carer or parent for everyday activities but need an advocate for extraordinary circumstances.”

“Please consider health literacy as above.”

“Again - descriptions or examples of who may need support with communication to clearly include people with a learning disability.”

“In an allied doc it is stated that the standard does not include: ‘People who would like to get information in a different way but who can still read information in a standard letter. This could be called a ‘preference’ and not a ‘need’’. Suggest this should be changed to ‘read, understand and act upon the document’. People might be able to read word by word but not understand and then act upon the doc appropriately e.g. if can't write/not able to deal with phone. (In other words, they may have communication needs related to the actions required by the doc.) E.g. many people turn up at the wrong place for appointments because they do not process the information correctly. Dyslexia is classified as a hidden disability but nowhere is there mention of this and for some individuals with dyslexia communication is an issue. I hope they will be given the opportunity to make their needs known and health professionals will be trained in this need. And to be honest if all written communication were made easily accessible to those with literacy/ or dyslexic type difficulties as a matter of course it would benefit everyone.”

“In Stage 1 (identification and recording of needs), the health or care organisation needs to specify who should identify and record needs, and who should check that this has been done. Needs should be reviewed periodically, so a review date should be specified - interval may vary depending how quickly the person's needs may change.”

“Stage 1: There is an inherent difficulty in asking people with communication difficulties to use their communication to describe their difficulties. There needs to some acknowledgement that some individuals (for example people with learning disabilities, people on the autistic spectrum, people with dementia, people with specific language impairments, people with dysphasia) may need a more in-depth assessment of their communication difficulties so that appropriate information/support methods can be identified. Speech and Language Therapists are often the clinical specialists best placed to assess communication impairments and this needs to be more strongly reflected in the final paper. My concern is that health and social care colleagues often underestimate their patient/client's communication

difficulties and overestimate how well they are meeting these needs (this is very clear in the literature). Although reference is made to these standards not requiring additional resources, I think there will be a need for rigorous training and increased access to Speech and Language Therapists if Stage 1 is going to be properly implemented. We should also acknowledge that there are some individuals who will be unable to access information in whatever format it is provided because of the severity of their cognitive impairment.

Stage 2: There needs to be more information about how consent to share the collected information will be gained/recorded. There may be some individuals who are not willing to have this information shared.

Stage 3: Although reference is made to 'communication professional' there is no mention of access Speech and Language Therapists. This should be made explicit and thought will need to be given to how this can practically happen."

"My 'not sure' to Q2 is related to this point. The standard and the steps do not seem to take account of the need to anticipate potential problems with communication of understanding information. For example, section 4 and stage 1 refer to finding out about someone's needs when they register. This may be too late. Someone who cannot read may not get to the stage of registering. For example, a person with learning disabilities who is sent non-easy read information about screening may not take up the offer. Reasonable adjustments must be anticipatory as well as responsive."

"Stage 2 should make reference to making a best interests decision about sharing information if the person does not have capacity to consent. The Caldecott principle that failure to share information appropriately can be dangerous is worth citing here."

"Will the standard cover those who are in hospices? I haven't heard it mentioned."

"Registered' to be added for BSL Interpreter and deafblind manual interpreter as already explained above."

"It is important to be able to consider specifically how someone communicates, their level of ability to understand language and to match this with information in a usable format along with support that can be tailor-made to suit the person's language and cognitive abilities. This process is a lot more complex than simply picking the type of format and the type of support. We should be aware that if the standard becomes a 'tick-box' exercise, it will continue to fail to meet the actual needs of people who are communication impaired in receiving necessary information."

"They should provide for an evaluation stage or an integrated requirement to periodically ensure that the patient and their carers feel they are being communicated with effectively."

“Organisations must also have the opportunity to provide 'Best Available Technology Economically Achievable' (BATEA) rather than simply 'Best Available Technology' (BAT). However the BAT solution should be recorded and it should be acknowledged that a BATEA solution is being used at the moment. The BATEA can then be assessed when the review (above) takes place i.e. does the patient think it's good enough?”

“Understanding that the assessment of communication must include understanding of the needs of people within the autistic spectrum and the specific way the understanding of the affect it may have on the individual understanding of the world and the consequences.”

“There needs to be a step about implementation of all these needs - where do I go to get something in Braille for example?”

“Our concern is that unless people receive information in a format that is accessible to them then they may not have contact with the organisation and so will not ever get to step one. For example, many people with learning disabilities do not take part in screening programmes, in part because they do not understand the invitation letter. Therefore there is a need to send accessible information in the first place. In order for this to be possible there is a need for clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems, as recommended by the Confidential Inquiry into Premature Deaths of People with Learning Disabilities.”

“Stage 2 – sharing and referring to recorded needs: This stage is a more difficult and, with the move to electronic and paperless systems, will need to be incorporated into all the different IT systems that are used and this information will also need to be transferable between systems. This is likely to be a major issue as our experience of the various systems is that they do not readily communicate with one another. This would need to be taken into account when compliance with the standards is being looked at.

Stage 3 – provision of support / meeting of needs: This is the most challenging. Whilst information leaflets that are used en masse may be relatively easy to produce, in braille for example, we wish to raise the issue of information around medicines. This would include: Patient Information Leaflets (PILs) in an accessible format, or medication labels. We understand that the pharma industry may be obligated to produce [...] (a large print version of all of their PILs) on request. If this is not the case could pharma be obligated to produce PILs in an accessible format, however that is defined – braille / audio or an app or audio version of the PIL on [...], which would be a significant step forward.”

“How feasible is it for all pharmacies to have these facilities and what arrangements will be in place to ensure they are communicated through to the patient's community pharmacy? Transfer of information from hospitals to the community pharmacist is not

made easy by the fact that patients are not registered with a single pharmacy. There are also issues with electronic communications due to the myriad of different systems used by community pharmacies. As well as Braille, there are audio devices that can 'read' labels and give verbal instructions. Again continuity of care will need to be raised and addressed. Whether or not these are practical solutions with regards to labels on medicines will need serious consideration. In order to deliver on the patient needs there will likely to be significant resource invested for pharmacy departments. There are also likely to be significant training needs as staff will require training on the different communication systems to be able to check dispensed medicines are labelled correctly if, for example, Braille or Moon are used."

"The steps should include provision that takes account of other languages for all and self-funders."

"Training for staff to ensure they understand how to make pictorial information in the right way for the person."

"Staff must understand person-centred working."

"Staff [must] have access to software, a range of pictures and colour printers."

"It should be made much clearer that it is unacceptable to not provide any kind of assistance. At the moment the steps make it appear that it is ok to not provide support as long as they learn from the experience."

"People do not always know the support choices that are available to them. A range of options need to be given, particularly for the majority of people with hearing loss that use the spoken word as their means of communication."

"Also, it needs to be borne in mind that people's needs change so what is recorded needs to be reviewed at each meeting."

"The first step should be to anticipate the possible needs of patients rather than having to react to different circumstances. This should then be followed by steps one to three as provided in the consultation document."

"In step three there should be detail provided about evaluating and monitoring quality, feedback, individuals' satisfaction with the format provided and so forth."

"We very much welcome the emphasis placed on identifying the communication needs of patients but would like to ask that confidentiality is highlighted; for example, the ability for a patient to disclose their communication requirements in a private area rather than at the reception desk."

"While we support all of the steps and requirements suggested, we believe that mention should be made of providing people with other tools which can help people to understand, act upon and share information. This could include hospital passports

or health action plans; vital tools for people with a learning disability, both when managing their health and sharing information with others.”

“People’s communication needs should be recorded as part of regular reviews as well as on front page etc.”

“When asking for consent to share information service users and carers should be made aware of the benefits.”

“Asking an individual if they have a communication needs or not is not sufficient. As someone with communication needs may not, by definition, understand what they have been asked or the implications for this.”

“Consideration of how individuals with no verbal communication or written language skills could contact or find out about organisations.”

“Consider how people who cannot read can access information about services.”

“Support at appointments for individuals who use other sign or symbol systems or other high tech communication aids.”

“In stage 3, there should be a requirement to check that the person has understood the information. Also a requirement to have user participation in designing and reviewing the information and communication services.”

“The requirements should be set out in more detail - in a staged fashion, so that it is easily understood how the Standard will be implemented and how organisations seeking compliance will go about doing so, and the support available.”

“A consistent approach is essential.”

“The steps are missing basic right to choose different communication support.”

“Staff are not aware of them for deafened and hard of hearing people.”

“Again, we believe it would be helpful if the standard encouraged health professionals to have specific regard for the needs of deaf children and young people. For example, when information is delivered, as well as providing extra time, we also believe that health professionals should also be asked to check and confirm the young person’s understanding of what they have been told. It would also be helpful to highlight as well that young people should be spoken to directly, unless there are good reasons why not.

It would be helpful if resources accompanying the standard provide examples of best practice and also resources which could help professionals in training and their continuing professional development. For example, the [...] is currently developing a module on working with deaf young people. This could be highlighted as a possible way of complying with the accessible information standard in relation to deaf young

people. Other possible resources include: Making information accessible to deaf young people: [...]. The resources developed with deaf young people for the [...], available online at [...]. Glossary for British Sign Language interpreters: [...].”

Appendix 5 – (Question 9): If you believe one or more aspects of the requirements is / are wrong, please explain here?

“You are not accommodating these with multiple disabilities such as [...] with co-morbidities?”

“We have some concerns about the prescriptive nature of the formats suggested - is it really reasonable, for example, to expect us to produce cassette tapes in the 21st century? Could some kind of 'reasonable expectation' clause be included? For example, would it be reasonable to undertake to produce patient literature as an audio file on an existing website, with a reasonable expectation that this would be most appropriate for most users, with other formats available on request and as reasonable in terms of cost effectiveness?”

“The document is not precise enough about the circumstances in which the standards will apply. Lack of precision about the level of disability or impairment or sensory loss could lead to misunderstanding, unrealistic expectations and potentially disputes as to whether the ‘rules’ do apply. If the document intends to set out requirements that organisations must follow, the terminology must be precise.

Another concern about the requirements are that the document applies the same standard across the NHS without taking into account the difference between the facilities and resources available to providers in different sectors – for example the differences between secondary and primary care. It is reasonable to require GP practices to make appropriate arrangements for the communication needs of patients who need support because of a disability, impairment or sensory loss. This is also already enshrined in legislation and the professional duties of general practitioners. However the information standard proposes to set standards that expect primary care providers to make arrangements and/or provide support in the same way as secondary care providers when in some circumstances it may not be reasonable or practicable for primary care providers to achieve the same standards.

To take the example of an elderly patient who is blind with a painful knee whose GP finds the patient’s ligaments are intact and the cause of pain is osteoarthritis. The patient is prescribed quad strengthening exercises as part of the treatment plan and, where most practices would have a leaflet illustrating such exercises, the standard would appear to require the practice to provide such a leaflet in Braille or one or more of the other formats specified. GPs must ensure patients understand the information and any treatment plans they provide, and that they communicate clearly, in a way that is appropriate for each particular patient’s communication needs. However, [it] would be unreasonable and disproportionately onerous, as the information standard requires, to hold a GP practice to the same standard as, say, a hospital orthopaedic department in terms of the provision of information to different groups of patients.

Producing an information standard that requires all providers to maintain the same standard in circumstances where it may not be possible, practicable or affordable may create unrealistic expectations on those receiving these services. This may lead to complaints in circumstances where a primary care practice has done all it can be reasonably and fairly expected to do, but because it is being held to a standard that was always impossible for it to meet, it could be found wanting.

To draw an analogy, CQC as the regulator of all healthcare providers does not make the same specific requirements of all providers because it recognises there are differences between the different sectors that affect their ability to provide services for patients. The same principles are applied to all healthcare providers but CQC allows that the detail of the delivery must differ from sector to sector. We suggest the information standard adopts the same approach.”

“Visual information must be explicit in the draft specification, if not an explanation should be provided as to why not, otherwise this guidance is not offering anything new to Deaf people.”

“Needs [...] should not only be addressed individually. How will any change in service provision of information be affected if individual needs, not group or community needs in the area are required to be addressed by the guidance? Individuals do not seem to be commissioned for.”

“Stage 3 should list an accommodation of contact by video messaging or live chat. Any cited examples do not list visual means of learning or communication.”

“This is all written from the viewpoint of the NHS - not the service user. How about the option for the service user to notify you?”

“Organisations must support patients, service users, carers and parents to communicate. This includes making sure that staff support people to use hearing aids and communication tools. Staff should also support people to lip-read and to use different ways of communicating. Organisations should give people with communication needs more time at their appointments if they need it.”

“You forget lip-reading is only 30% accurate, so to protect staff from misunderstandings, you need to make sure lip speakers / STTR / remote captions are as high on your agenda as BSL interpreters.”

“I think where the steps say ‘except in an emergency situation’ could cause problems. Ideally patients with communication needs would have this identified with their GP and it would be on their shared medical records to hospitals so that they know the patient has communication needs e.g. BSL interpreter, deaf blind [interpreter] or lip speaker and the emergency department does not have to figure out they have communication needs, instead they can save time and organise getting the appropriate communicator.”

“To implement these steps the NHS will be unnecessarily burdened with financial costs [...].”

“It is important, not only to consider the format of information, but also the way in which is delivered. A lot of the standards focus on information material/letters etc. (which is great). You also need to look at the simple thing of how people actually talk to one another. Often, professionals use complicated medical terms and complex language when talking to people. People with learning difficulties not only benefit from easy read but also from easy speak. It would be good if staff could have some training in how to get information across in an easy to understand manner.”

“Listening to the document via YouTube, I think the BSL qualification was to be level 6. A professional interpreter should have level 3.”

“I am aware that the phrase: ‘must find out if a patient or service user (or their carer or parent) needs information in a different format or communication support because they have a disability, impairment or sensory loss...’ does not allow for the details of how they will find out. Also I think that a patient's circumstances will often change even over a short period of time (in dementia cases, sight loss etc. etc.). So the step may have to be repeated regularly.”

“Consent must be sought before sharing information with other organisations.”

“The requirement in section 8 to record people’s information or communication needs, and not their disability, is at odds with the earlier statement that you want to support needs vs. preferences. If you don't record why someone has a requirement for a certain facility, you don't know whether it is a need or a preference.”

“Not wrong exactly, but I would like to highlight a concern that relates to the above (in case it hasn't already been addressed). Having played an advisory role in the Connecting for Health project, I appreciate the complexities of the different health systems used and how to standardise processes across them. Therefore, I am presuming there is no 'tighter', more standardised way to ensure information is recorded and shared? It's just that it sounds a little arbitrary to have information recorded on paper somewhere, on a computer somewhere else, or somewhere else altogether, even if it is recorded using a standardised approach. Obviously it is a case of whatever works best for each organisation and where the information can best be viewed, but it seems that there could be increased margin for error, especially with sharing information across organisations. Will this be done manually in some cases? I'm not sure where we're up to with progress on sharing information such as this electronically across health and care systems?”

“I imagine that since monitoring arrangements have been built into the standard, any failings could be picked up there, but I think the crucial things to ensure are: the correct recording of information needs, the making sure it is shared and acted upon

correctly and that it is detailed enough to provide practitioners with sufficient information on the patient's communications needs, especially in an emergency.”

“There should not be an assumption that all [...] are good readers. There is a hidden part of the population who should be understood.”

“The step that is missing is the follow up - in terms of when information was accessed how useful/relevant/helpful was it? How the info was used.”

“It may confuse some people if they are offered so many options; surely a simple question to ask what they require is easier for the patient. If they are not aware of what is available then offer the list of what there is.”

“I believe that automated responses e.g. letters etc. would be better served in 2 categories; 1. 'Must' - this applies to all standard letters, e.g. appointments, instructions for use/medication etc. 2. 'Should' - this would apply to more specific documents, for example information about specific physiotherapy regime, changes to a direct payment/personal budget etc.”

“I feel you have left the words Lip Speaker out of step 3 paragraph 4.”

“Providing accessible information should also be the norm rather than by special request.”

“I'd like to see how you propose for the information needs to be always met with next to nothing resources in the patient information services.”

“Letters are a problem for most organisations due to a variety of systems used. IT systems are not streamlined at the best of times so I'd be curious to see what you propose to eliminate this problem.”

“Good.”

“Makaton is a system of signing and also symbols. It is used in Education and follows the National Curriculum, so every child has access to it whilst learning. There is no mention of Makaton symbols in the document. A lot of people with LD use this system, it needs to be included.”

“There is no mention of what pictures will be used to make information accessible. I know from experience that this has practical implications for IT systems which are mentioned but also there are financial implications of licences for symbol packages and issues about agreeing which pictures to use across services to provide consistency for people with LD.”

“I have some misgivings as to who would be responsible for determining the communication needs. This documentation seems to suggest that this lies with the health/care professional. [...] research findings state that this is an area of concern as most health/care professionals believe that deaf people understand them without

an interpreter or when using a family or friend with them when in fact they do not (usually the family or friend themselves do not have fluency in sign or takes over the medication/care needs leaving the deaf patient still in the dark as to what is happening to them). This identification of communication need would be best resolved if it is a joint agreement between the professional and the deaf patient before their medical record is augmented with the type of communication support the deaf person requires.”

“It does not include the specific needs of those with high functioning autism who may not have understanding of their difficulties and are unable to articulate them.”

“Consent to share information should be implied - not sought as an individual exercise which can be time consuming and directs resources away from important patient care.”

“The needs and recording should be person centred and led by the patient / carer, working with them and their own circle of support whenever possible rather than assuming that everyone will fit in with the health and social care agenda.”

“It will need a massive culture change.”

“As above set out in stages or chunked up in achievable blocks for those in scope.”

“‘Supporting people to communicate through using a hearing aid, lip-reading, or using a communication tool’. I find this statement absolutely ignorant of how people communicate who have a hearing loss. Those people need communication support professionals quite often. Is your standard proposing to provide a hearing aid for consultation?! What is a communication tool?”

Appendix 6 – (Question 10): What do you think about the types of communication support and information formats we have included?

“Daisy CD is missing.”

“Fully comprehensive - good - a lot of thought given.”

“These should be accessible when the service user communicates for the first time. They should be made available in the required format requested.”

“Seems comprehensive - would only suggest that 'easy read' should apply to all communications.”

“Fine.”

“Seems adequate except under paragraph 2, ought we not include 'clear, audible verbal communication'.”

“There are 2 possible ways to receive Braille and Moon - contracted and uncontracted. Uncontracted is written letter by letter with punctuation and can be read by any reader of the format including those for whom English is a second language. Contracted: This is like a shorthand and is read by the more proficient reader. Symbols stand for words or groups of letters, but their meaning differs across foreign languages, e.g. English sign for ed is German ein. Although we are not meeting the needs for people speaking a foreign language I am aware of somebody who was handed a hymn book but could not understand it, much to the confusion of the church that provided it. Please add both Contracted and Uncontracted as an option. It is easy for the format provider to comply. (This responder is an accredited Braille teacher, transcriber, and founder member of the [...]).”

“It's a comprehensive list.”

“I think the whole spectrum of communications has been covered, but wonder if resources are going to be able to deal with the skills needed to deliver.”

“Seems to have thought of everything!”

“You have listed all the necessary communication.”

“Inclusions are good provided they actually happen. Add blind people need a guide when attending appointments.”

“Good but (i) there should be guidance which will ensure that word documents are accessible (e.g. are not protected forms and do not include text boxes); and (ii) for communication support, there should be a means of noting that a person might need the healthcare professional to adjust the way they talk or communicate e.g. with a person who has aphasia.”

“In an ideal world we can fill out this form and people help you. This ideal world does not fill but creates problems for individuals, people and the government. People are ashamed to admit they need help. People cannot fill out forms. There should be audio available that will help you to understand all this information. Making sure information is available in different formats and when it is not available in different formats it should be available in different formats. This includes a screen reader etc.”

“We feel that the range of types of support and information formats is comprehensive.”

“Perhaps simpler to use an 'Other - as specified by user' rather than a list of formats not widely used or recognised e.g. Moon. Should also include 'large print - size specified by individual'. Need to consider the information needs of carers or parents.”

“Audio cassette is now a format that has been superseded and [it] may not be possible for service providers to obtain and provide information in this format.”

“It is good to have a clear list that differentiates between different forms of information. It would be useful to note that the list is not exhaustive so that if a format is not listed, it is not deemed to be unusable as innovative ways of providing information should also be encouraged.”

“[...] welcomes the thorough list of communication support types and information formats. Due to the combination of hearing and vision impairment, deafblind people often have multiple requirements and struggle to 'select one option' so the facility to be able to select more than one communication or information need is a positive step in supporting and meeting their needs appropriately. The inclusion of a communicator guide as a recognised form of communication support is also of significant importance to deafblind people and we strongly welcome the reflection of this in the standard.”

“Whilst the list of information formats is detailed and comprehensive we have some minor concerns that the breadth of options combined with the 'duty' may make it challenging for organisations to comply with the standard and may become a barrier to their engagement with it. With so many detailed and sometimes specialist formats listed there is the risk that it may hinder communication rather than promote it. Perhaps an option to specify information formats for different levels of information may assist with this. For example, a BSL user may wish to have information leaflets about their condition in a BSL video format but would be happy to receive appointment letters via email. Specifying 'BSL video' as their preferred communication format may make it costly and cause an unnecessary time delay when communicating about appointments which could be expedited in a more appropriate manner.”

“Regarding the listed formats and support we have a few minor corrections to suggest:

- Deafblind haptic communication interpreter: some deafblind people have developed a personal protocol for haptic communication which they may use with their friends, family or known interpreters but it is unlikely that they would have a specialist interpreter purely for this purpose.
- Audio files: in the past deafblind people have been sent audio files on CDs not correctly formatted for CD players so have not been able to access them. It is therefore important to clarify that these should be provided on an Audio CD. “

“The list is very comprehensive - perhaps too comprehensive/prescriptive. See comment above about cassette tapes.”

“All sections need to have a flexible ‘other’ option to allow for development of new technology and tools, and other highly personal methods of communication that can be facilitated by services.”

“Looks very comprehensive.”

“Information recorded should also include the level of information and any specific SLT recommendations.”

“1. Contact method should also include face-to-face contact. 2. Only BSL is mentioned yet there are other types of signing e.g. Makaton, tactile signing etc. Easy Read should be more specific i.e. referencing the type of visual information required (i.e. photographs, line drawings, or symbols & which symbol system) as well as the level of information within the document. Inclusive/total communication approach (i.e. using more than one method simultaneously to maximise understanding e.g. face-to-face communication, Easy Read resources and signing) should also be included. 3. Speech and Language Therapists and professionals trained in specific communication approaches should be referenced.”

“Loop systems: We can see no mention of loop systems, which can be very helpful for people with hearing loss and are an important way that health and social care providers can make their service more accessible to people with hearing loss. Loop systems help people who wear hearing aids to pick up sounds more clearly, by reducing background noise. They work in a particular area when a person’s hearing aid is switched to the ‘T’ setting (or loop programme). This allows them to focus on a sound – or a person’s voice – from the loop system microphone, rather than the internal hearing aid microphone, which will normally amplify all noises in the area. The system helps hearing aid users to communicate effectively and confidentially, even in noisy environments where deaf and hard of hearing people often struggle.

Cochlear implants: We can see no mention of cochlear implants anywhere in the consultation document, technical document, specification or implementation guidance. Using a cochlear implant should be included as it indicates that a person has a hearing impairment, and therefore that they have communication needs.

General communication requirements for all people with hearing loss: There are several general requirements that professionals and staff should adhere to when communicating with anyone with hearing loss- whether they use BSL, hearing aids, a cochlear implant and/or lip-reading, as well as the provision of communication support, equipment or accessible information. These include: reducing background noise; facing the person and not covering the mouth when speaking; conversing in good lighting; speaking clearly and not too quickly; rephrasing something if the person has not understood; not shouting and avoiding using jargon or unfamiliar abbreviations. These general communication requirements are not currently referred to in the guidance or list of requirements, but they make a big difference in ensuring that staff communicate effectively with people with hearing loss. It is therefore important that all of the identified information or communication needs related to hearing loss prompt the staff member to adhere to these general communication requirements.

Lip-reading: In reality, almost everyone with hearing loss relies on lip-reading to a certain extent. The behaviours that a staff member would adopt to enable a person to lip-read (e.g. facing the person, speaking clearly, avoiding jargon) would be helpful communication practices to use with all people with hearing loss, regardless of whether they have actually been identified as a person who 'uses lip-reading'. In practice, it would therefore be helpful if all people who have identified a communication need related to a hearing loss be asked about and identified as using lip-reading, to ensure that they are communicated with in the most effective manner.

Needs a longer appointment to support communication needs: As with lip-reading, most people with hearing loss will need at least a little bit more time in appointments to make sure that they have understood information correctly and to allow for information to be repeated or rephrased if it is not initially clear. Therefore we strongly recommend that all people who identify as having a communication need related to hearing loss are asked if they will need longer appointments. Where a person requires a communication professional, they will definitely require a longer appointment (usually approximately double the length) so this need should automatically be prompted and identified when a need for a communication professional is selected.

Needs a vibrating or physical alert: Under 'requires communication support', one of the identified needs is 'needs a visual alert (for example to be able to read their name on a screen instead of having it called out)'. Having to watch a screen continuously for a long period of time until your name appears is much more tiring than it would be (for a hearing person) to wait to hear your name. An additional or alternative option is to offer a person with hearing loss a vibrating pager or to physically walk over to collect them, to ensure they do not miss their appointment. This is also most likely the most appropriate option for the increasing number of people who have hearing loss and sight loss, and who would therefore struggle to see their name on a screen or hear it called."

“The list needs to be clear that this is not exhaustive. It should also be made explicit that staff must check with users about which solution meets their communication needs, and not assume the solution, for example, many blind people cannot read Braille and not all Deaf people can sign. This information should be included in the patient’s records so that it is shared as appropriate by all staff within the organisation. A detailed list of places to go for support would be helpful. Reference should be made to Plain English for patients with low literacy levels.”

“[...] fully supports the standard’s proposal that organisations should record people’s information or communication needs rather than their disability. We also believe it will be important to manage expectations. The consultation document makes reference to communication needs as opposed to preferences. It will be important that NHS England makes available clear guidance to practices, patients and commissioners to enable them to understand this distinction and make decisions accordingly and understand what the NHS will and will not fund. NHS England should also provide information for patients and their families, and for practitioners, as to how information and communication services will be funded.”

“These are comprehensive and cover a significant range of needs.”

“It will be important for NHS England to have a mechanism by which they can evolve the list of options for types of communication support and information formats as time moves on, without needing to revise whole standard, so the standard can keep up to date with developing technologies.”

“Contact method: Some people may have difficulty using a phone and may prefer a face to face meeting with communication support. There should be a greater emphasis on face to face support, where people can use context and environmental clues, objects and read facial expression, body language etc. all of which [are] unavailable in letters/phone calls.

Information format: To provide communication accessible services, it is good practice to allow time to arrange different formats or communication support depending on the needs of your audience. The list should include: Easy Read with photos; Easy Read with symbols - the type of symbol must be detailed (this will have implications for staff having access to symbol software, which is often problematic). Easy Read and Accessible Information need to be more clearly defined and differentiated as these terms are often used interchangeably in learning disability and other services.

Communication professional: The list should include: Speech and Language Therapist.

Communication support: Many people with communication support needs will require longer at an appointment, or a double appointment, and this needs to be inherent in the booking process. The list should include: Communication Apps (e.g. [...] etc.);

Head and body language; Minimal Speech Approach; Objects of reference; [...]; Simple gestures; Simplified language (in line with key word comprehension) and 1 or 2 key ideas at a time; Symbols - specify which type; [...]; Touch Cues; Uses a signing support system such as Makaton, Signalong, (people do not only use Makaton); Uses other aids or visual supports such as symbols, photos, pictures, drawings or cartoons.”

“Under 4, requires communication support - Uses Makaton, we would recommend the addition of the wording or any other augmentative or alternative communication system.”

“In reference to section 8 of the consultation document: Requires specific contact method – should include fax and video relay. Requires specific information format – should include colour contrast. Requires communication professional – should include advocate for visual impairment to encompass people needing to fill out a form or read something in a health or social care setting. Should also be more specific about note takers as this could be both manual and or electronic. Requires communication support – should ensure that people will not just be told about an appointment (through an audible alert), but shown through to the appointment room for instance.”

“I have mentioned pictures and BSL relay interpreters.”

“Not just Easy Read but pictorial images on their own.”

“Good, all inclusive.”

“I do believe you have well covered the different types of communication patients (service users, carers, parents) with impairments need. But my main concern is the recording of data by, for instance, GP surgeries. Because I have been registered with my surgery for many decades, my records have not been amended to take my Disability Registration in 2001 [into account], nor my needs for written (email preferable, but also post) communication. I am sure there are many other such examples in the community. My lung impairment is well documented to the GP surgery by my hospital...but surgery ignores it and treats me as if I were an able 20 year old without oxygen therapy needs.”

“If patients are to be given access to their medical records in April 2015 (online access that is, with functionality for feedback to point out errors), let's have a joint campaign to focus on accessibility and the plight of all those suffering from impairments (physical or mental, which most of the time are not really distinguishable) who are not offered appropriate communications channels in primary care.”

“Section 8 must also list specific visual means of communication through live video conversation (1), and that if DVD is listed what will be on that DVD- more specificity is required here as [is] given for other formats (2).”

"I am nearing the end of my MSc research on Easy Read, which has identified some potentially problematic issues in theoretical basis and effectiveness, and hope to be able to share this with you."

"I think they are very comprehensive and have all the things I can think of in them."

"Comprehensive list but will need good guidance for staff to understand what they mean and how to get them. Advocates are only listed for people with mental health needs and learning disabilities, many others need an advocate - even [...] though there is a lack of funding they should be included in the list."

"Very good."

"Brilliantly comprehensive."

"There seem to be a large number of types of interpreters, we work with [...] and haven't been made aware of a need for many of these versions of support before."

"Ok on the whole."

"Ditto above, support from SLT departments appears to be an omission."

"Personally, allowing service users to contact the NHS via e-mail would be a huge help."

"I think it sounds like a fantastic idea but wonder what the cost implications for Trusts will be. There is the fear that Trusts will have to make financial investments in order to adhere to the guidelines that might impact on staffing levels and ultimately patient care."

"Focuses on deaf/blind and learning disabilities. Nothing about aphasia which is a major cause of disability after stroke or head injury."

"Section 2 - 'easy read' is mentioned which I presume means in an accessible format which would take into account presentation, however more information would be useful, i.e. use of keywords, bold text, simple sentences (grammar), reading age, use of informative and relevant pictures. Section 3 - no mention of requirement for Speech and Language Therapy input/consultation/assessment. Section 4 - written support is mentioned but no mention of supplementing verbal communication with other supportive conversation / total communication techniques e.g. pictures gestures, mime, demonstration, drawing."

"Also use of voice output and communication devices mentioned. [It] would be useful to highlight the difference between comprehension and expression i.e. the need for supporting someone to express themselves vs supporting them to understand."

"I think they accurately reflect possible standards of accessible information and adjustments that people may need although I would not include memory stick."

“You have included them correctly, but you have not placed them into the document in such a way to protect those deaf people [...] from harm by not providing them with communication support in English. Asking Staff to do it will not help.”

“Well thought out and comprehensive.”

“I'm pleased to see the mention of 'audible alerts' at GP's surgeries. A visual display for patients to read their name will be a great help. This should be extended to hospital clinics too.”

“All organisations have a system that can hold and retain information. These systems should be the source of having up to date information about the service user. It is important that staff take the responsibility to update the information - at least once a year.”

“Consideration should also be given to having systems that link in - following the patients journey when accessing any provision.”

“Include lip speakers and speech to text reporters.”

“1. Video relay should be included for sign language users. Very few people use text relay now. 4. Needs something about whether the medics themselves write things down for later recall or provide a follow-up letter to the patient.”

“I wonder if in the event that a communication professional cannot be obtained that hospitals have specialist people always on-site who can accompany the disabled person to advocate for them and ensure that the medical professionals do their best. This would be a hospital employee for example which means medics would realise their presence indicated they need to make extra efforts. This advocate would also be responsible for ensuring all best efforts were being made e.g. to access video relay sign services or remote speech to text services or similar. Commissioning groups should have emergency contracts with providers of communication support to provide emergency and out of hours support e.g. [...] or [...] services.”

“STTR relay operators should be NRCPD or equivalent registered. If remote is used then we need to make sure USA, Australia and New Zealand standards are included as worldwide professionals may be used by remote providers. Electronic note takers should be registered with association of note taking professionals. It shouldn't just be BSL which is held to high standards.”

“I would be very unhappy with health and social care staff providing interpretation / communication support services unless contracted emergency communication support services were not available. People will often agree to take whatever they can get; hence the prevalence of family interpreting as it is for deaf people.”

“2. Requires specific format - should also include coloured paper (off white) but overall I think this is inclusive and as someone with learning difficulties if I did not

have BSL video I could use an email attachment and assistive software I have at home to understand things. Also large print should include Arial bold having worked with deafblind I know of numerous people who use Arial bold 28. 3. Communication professional – good. 4. Communication support - good and agree should be able to use more than one type of support.”

“I think that you have covered all.”

“Comprehensive list.”

“OK.”

“Reasonable and fit for purpose.”

“This is a great start but a word document may come in lots of different layouts as do letters from all health and social care providers. Some definition of a standard information exchange using XML for example would really help drive the personal health record apps on. Then I as a carer or patient could have easier access to my information and make better informed decisions on my daughters or my care. Plus, I would not have to remember everything in my head when asked the same questions over and over by different providers.”

“Providing information through electronic means is possible, but braille and other languages is [...]”

“All does seems fine, would like to have BSL video relay services included though.”

“I think a lot of thought has gone into this. Well done. My only other thought, as a communication process both ways, is that for some people who have needs, if they have periods where they are well then ill suddenly, [...] may be the best way if possible to access the patient/patient access the doctor/doctor access the hospital as many of our metabolic diseases are volatile very quickly.”

“An excellent list. You might want to put ‘uses a hearing aid’ and ‘uses nonverbal communication’ together.”

“From my point of view (as a learning disability commissioner) they are complete.”

“The list is good but in practice some will be difficult to supply such as MP3 and DVD formats. If these are not commercially available there will be a need for someone to produce them, not sure clinicians will have the expertise or equipment to do this.”

“It is excellent.”

“I think this is a good list which includes steps that any organisation can reasonably make.”

“Ok.”

“Speech and Language Therapist and Assistant Speech and Language Therapist/Technical Instructor should be included in the list of communication professionals.”

“Advocate doesn't need to be limited in my mind as there are advocates who work with communication needs that aren't due to learning disabilities or mental health needs.”

“I think 'learning disability communication support worker' requires further definition.”

“‘Uses a learning disability passport’ needs changing to 'has a...’ The term ‘learning disability passport’ is not universal, sometimes known as hospital passports, health action plans, communication passports.”

“‘Uses Makaton’ should be changed to 'Uses Makaton or Signalong or another key word signing system’.”

“Also should be included is ‘requires the support of a parent or familiar carer’.”

“It is useful to have a list of the expected support and information formats for each of the 'need' categories. Useful also to note the same day access services and the challenges they may have in providing the right support at that specific time.”

“I think they are about right.”

“Have already mentioned method of contact should include video as this is very viable and will become more so.”

“In information format, you speak of different font sizes but there is no mention of colour and colour contrast for material.”

“A good summary of available formats.”

“I wonder if hearing loops or [...] might be easier to provide than STTR - and this would be less intrusive when discussing personal matters.”

“You have met those but have you considered all combinations that may not be appropriate.”

“Most of these are already familiar in other professions. The NHS has some catching up to do.”

“They are good, however I have a family member who has both mental health [needs] and is deaf and cannot speak, the standard listings do not cover her need, so I think you should put in a clause that says any other specific support need, or a combination of the above.”

“I am concerned that there will be delays in providing support for an appointment e.g. sign reader or Makaton translator.”

“I feel that when patients are asked at a reception desk [about] their needs then this should be done a[s] privately as possible.”

“I think these are really good.”

“Need to include symbol users. [...], and SLT.”

“Agree the types are correct.”

“Very good. Although I read braille, I could also use email or text message.”

“I am not sure where this comes in but another form of communication on list is 'video chat' VIOPs such as [...] etc. [or] a recorded video message even then replayed, real time captioning on the 'web chat' links. What is interesting to see now are more technical services have a 'chat now' button such as [...] if I have a problem with phone. Plus my [...], or my printer plus my [...] I can do real time 'chat' texting to and fro. This might [not] suit everyone of course however there will be those like myself who prefer something like that. Even when I link onto my weekly [...] after I click on one of the films I want to see a trailer for a 'banner' flicks up from bottom of screen to ask: Query? Talk to us now! That's the type of thing I am suggesting as another form of real time communication.”

“In principal, I like the model which you are planning to adopt. However, it must be made clear that not all four types may be needed. For instance, I do not require a specific contact method (point 1) per se, in that I can read emails, text messages and letters; I would therefore wish to express no preference here. However, if it is the organisation's preference to send out letters, I do require that those letters are sent out in Braille; I would therefore wish to express that I require a specific information format (point 2). To reiterate, it must be clear to the organisation that my preference in point 2 does not apply if the organisation would prefer, say, to email me, as I will be able to access these emails without third party intervention.”

“I am particularly pleased that point 4 (requires communication support) recognises the need for audible alerts for appointments.”

“Under specific contact method - some people with learning disabilities might need face to face contact.”

“A comprehensive list of communication support types.”

“See previous open text box.”

“The types of communication support and information formats are very comprehensive.”

“Excellent; I think you have covered all types.”

“Formatting should be of choice.”

“Seem to cover all eventualities.”

“Seems to be a comprehensive list.”

“Not bad, trying to go too deep into things instead of looking at the simple things which does upset people i.e. when a lift is o/o/o please inform patients and also staff as well before arriving at the broken down lift. What would happen if a nurse was carrying a defibrillator or whatever to an emergency unaware the lift was o/o/o, who would be held responsible for that??”

“I think the range and categorisation is helpful. My only concern is that the categories are not mutually exclusive and this would need to be made clear to organisations when recording the information. For example, a Deaf person who uses BSL is likely to have needs relating to each of the four categories.”

“I think they are thorough. Just a personal thought of the font used for written accessible information - I work with people with learning disabilities and in a pilot project run by speech and language therapy, it was concluded that 'century gothic' font was more appropriate to use (mainly due to the a's being clearer).”

“Seem very thorough.”

“It is very disappointing that no consideration has been given to develop standards for Cross Cultural Communication considering Britain has such a diversity in population with many cultures and languages. Why has standards for interpreter services and multilingual leaflets/ audio-visual material been completely excluded? Very disappointing and worrying.”

“Fewer rather than too many.”

“I think that the formats that you have included are good.”

“Information formats have been included to hopefully provide something for everyone. That said, the means by which someone might access that in a clinical setting may need some consideration e.g. Will a device for playing MP3 files be made available? Also, simply telling someone what is written on an electronic sign e.g. to go through for their appointment with a GP, is not enough. A person who is visually impaired would need to be told where the room is, as the number on the door is unlikely to be of adequate size and contrast to be readable (e.g. you are seeing Dr X, in room 3 - this is the 3rd door on the left).”

“See above re, audio not being included in many places in the document.”

“They seem to cover everything.”

“Would include web sites and internet as said before.”

“Good but perhaps the ‘requires communication support’ could list some examples, say, ‘patience and time’ or ‘appropriate surroundings’ (no background noise, no distractions) etc. etc. Sometimes a person may need someone of the same sex? Or an older person - just to give them confidence in the communications. It may be that the barrier to communication needs to be tested? How would I know that the patient has grasped the message??”

“Not sure about the wording ‘learning disability passport’ - people with learning disability in [...] have Health Action Plans which health professionals need to be aware of and complete at appointments.”

“Whilst I understand the need for consistency and, therefore, why a list of options is provided, I am concerned that this will further disadvantage people whose needs are complex or unique. If a person needs a format or communication support that is not listed, they will have even greater problems than now. There should be an option to explain in the person's own words. The consultation document lists deafblind manual alphabet interpreter and deafblind manual interpreter. Deafblind manual is the deafblind manual alphabet, so only one of these options is needed. In the consultation document, under 'needs communication support', it includes visual alert and needs an audible alert but neglects any means to alert a deafblind person who may, for example, need someone to walk up to them and tap them.”

“All are appropriate and I felt that there were a far greater amount of services available which I feel is vital to ensure that all Service Users' needs can be met and all information provided is in a relevant format to ensure that all information provided is transparent and clear. I believe that it is only right and fair that all individuals who have assessed communication needs receive information in the correct format else I feel that this could lead to frustration on their part which would not be fair or right.”

“In the easy read version section 8 is 'How will the standard be put into practice'.”

“Great in theory but expensive and difficult to implement. Outside of large cities access to some of these services may be extremely difficult again making them costly to more rural communities who already face financial difficulties providing healthcare. The alternative will be that patients have to travel to hospitals further afield which will place the burden of time and costs to travel on the patient. The other possible outcome will be that the standard of these services may be of a poorer quality in less densely populated areas.”

“While this is an ideal, in reality will organisations be able to access enough of these professionals at appropriate times to meet these needs across the country?”

“Easy read needs to be defined - there are a lot of poor examples around where the information is poorly organised, the language too complex and picture use poor. SLTs can help add quality to this.”

“Would be good to identify a font which uses an easy read 'a' as in comic sans - however appreciate this may be considered too informal for some things.”

“1. Initial contact - needs to be clear that this incorporates communication formats as for information e.g. easy read letter, font size. 4. Communication support needs to include supporting verbal explanations with visual support such as pictures, demonstration/modelling, anatomical models, video etc.”

“Good to include support with written notes - specify that people may need to leave all consultations with something in writing to enable them to remember/revisit the information, discuss with others, and to ask questions.”

“There is emphasis on written and telephone communication but nothing much about face to face; this is especially important with the more vulnerable in society. (Those with mental health impairment, young people, aged people, those with dementia etc.) They need the reassurance of proximity to trusted people in frightening situations.”

“Good. I would like to see 'needs communication supported by written notes' a little clearer. This would lead some people to write down long sentences or give a comprehensive hand-out, or bullet points, when the individual may need them to write single words.”

“Consultation document not obviously accessible.”

“Perhaps consider the issue of a 'Patient Logbook' which is used to record the necessary information. Fact sheets or written documents could be pasted in as a permanent record.”

“Fully accept that this would have cost implications which would need to be considered.”

“Very thorough.”

“Section 4: Makaton is not used in a high number of services supporting people with learning disabilities, so suggest that more generic term is used. Suggest 'person with learning disabilities who uses signing e.g. total/inclusive communication, Makaton, Signalong'.”

“I fully agree that agencies should record the information/communication support needed, not the disability.”

“I'm happy with the types of communication covered here.”

“It is a comprehensive list of support. I think that all staff including doctors and consultants should be given deaf awareness training and other types of disability training and be able to show empathy to the person.”

“Again, I can find no reference to the use of [...]”

“Well-structured and relevant.”

“They are comprehensive but I think a sentence describing in the persons own words where possible their need and the support they want/need would be better.”

“They are comprehensive except for my earlier comment about language.”

“About right could include using pictures to support appointment, having pictures on doors to support what is behind the door e.g. professional’s photo, library, kitchen, toilet.”

“Seems about right.”

“It covers a good range of options.”

“What is a learning disability passport? [I] assume this is attempting to refer to a Communication Passport or a Person Centred Plan. There are elements of a Health Action Plan that may also outline the support for someone with a learning disability. This could include an emergency grab sheet.”

“1. It's great that longer appointment times have been included (crucial for people with a learning disability).

2. Just to check how someone's needs, which don't fall into a specific information format, will be recorded and acted upon? For example, if someone with a learning disability uses pictures only rather than easy read. And is the idea that this will be provided via an advocate or communication support? And if so, how will health/care staff be made aware of the specific methods of communication the person requires, even if they won't be supporting the person directly? Also, it may be that someone needs pictorial-based communication, but would not necessarily need a communications professional to work with them - so how will this be accounted for?

3. Also, a point around inclusion and the vision of the strategy. It's great that general communication tips/guidelines seem to be built into the standard. It's a question of how this will tie in. For example, if someone has a mild learning disability, to enable them to participate successfully in their own healthcare, it may be that all they really require is for staff to follow some basic communication guidelines: using everyday language, no jargon, taking at a reasonable pace, talking directly to them. In my consultation work with people with learning disabilities, these are the communication stumbling blocks that people mentioned time and again. If these simple guidelines were followed, it could be that someone is able to maintain total independence in their healthcare without relying on (expensive?) additional communications support such as advocates - unless of course this was in their best interests anyway.”

“What about the people that find it difficult to access information but do not require specific support??”

“Seems quite comprehensive but no mention of printed info on coloured background or reverse printing (white on colours) for people with dyslexia.”

“Information should also be provided in visual formats for those with poor English or levels of literacy. Even the Easy read version of the consultation has long words in it e.g. including having an accessible complaints policy. The word accessible is not explained anywhere, only assumed the reader will understand.”

“OK.”

“This seems to be a fair list of what is available.”

“Pleased to see a wide range of things - maybe a little more about different font types as it is not just the size of the font but the type of font, the colour and the style (e.g. bold).”

“I would also like to see some further guidance about the use of symbols in easy read information as I believe a single symbol set would be beneficial (although I understand this is difficult as they are commercial properties). I was surprised to see line drawings not [...] used in the easy read standards as [...] seem to be using [...] as standard.”

“So pleased to see BSL included in here, I am a BSL user, and have found this document difficult to understand. However, I have grasped the basic, but I would need a BSL interpreter to translate this document in a context I understand better.”

“It is also about time, that all organisations work together to improve accessibility for people with communication difficulties due to disabilities. The scope includes nearly everything for a person who is Deaf, which I am happy to see.”

“Only thing that is missing is a Deaf Relay Interpreter. This is different from a BSL Interpreter. A BSL Interpreter can only relay exactly what is being said to a patient, and does not have the flexibility to explain. A Deaf Relay Interpreter does. They are also qualified and trained to spot whether a Deaf Person fully understands what is asked of them, or what is being asked of them.”

“See my earlier response.”

“About right - I can't see that adding more would be of any help.”

“The list seems pretty comprehensive, but I'm not an expert in all communication types.”

“You seem to have thought of more than most people would think of.”

“It is not necessary to sacrifice grammar. The document is peppered with possessive pronoun errors, making it seem very patronising. Also, the notion of 'vision' is inappropriate. It is too airy-fairy. You have a plan or an intention.”

“Finally, the question addressed to everyone, not just people with disabilities or communication 'needs' should be 'Do you understand what I have explained?' It is all much simpler than the document implies.”

“They appear to be adequate in the exchange of information between service provider and client/patient.”

“They are very general. This will be adequate for many people, but for those with more specific or complex communication needs, the support needed for them will need to be given with an understanding about what those specific needs are; it is likely that guidance would need to be sought on how information should be presented to the person (i.e. from a speech and language therapist who has carried out a detailed assessment). I think the document should state this.”

“We do not have enough professional knowledge to judge.”

“Information overload. Far too much.”

Missing: Information format - use of [...], as a total replacement for text.
Communication professional - for a congenitally Deafblind individual, with a severe learning disability, none of the suggested professionals would know where to start. Only someone who knows that individual well would be able to communicate accurately, and for the best clarity would need access to the appropriate program during an appointment etc.”

“Picking more than one type of support is not the answer if none of them are right! 1 patient, 3 communication support people - but none have the exact skills needed by the individual. Crazy.”

“These are comprehensive without being overburdening.”

“Lots of ideas shared again concern regarding the IT systems currently used by hospitals and GP practices and some concerns regarding funding in General Practice to deliver the standard.”

“Good.”

“Add symbol support (not just Makaton symbols).”

“Some tools could be accessible via [...].”

“Different ways to contact: Could also include asking the person whether you need to send a copy to their supporter/advocate. In our experience in our learning disability team some people throw away letters and then miss important hospital appointments.”

“I wasn't clear on what 'someone who helps people with learning disabilities to communicate' was. This isn't a job role (unlike some of the others e.g. BSL

interpreter). Could it be clearer and suggest people: 'such as an advocate, family member or someone from a community learning disability team'."

"'Learning disability passport' is mentioned. Generally these are most often called 'Communication Passports'. Hospital passports could also be mentioned."

"Appear to be comprehensive, but will need to be updated as and when needs change."

"They seem to cover most. It is good you are including Easy Read advice/layout as people may not know how to do this sufficiently well."

"Format raises some issues:

(a) Word documents: Cabinet Office has advised Government departments that they should use ODF rather than Word or other proprietary software. For screen-reader software users, Word/ODF document format works for the delivery of information (assuming that there are no images); Word forms can be hard to navigate if they're not set up with form field and status bar help text.

(b) PDF format can work well for screen-reader software users, but only if it has been set up to be fully accessible (tagged, reading order set, etc.).

(c) Designating typeface sizes for large print may be inflexible - I've had requests for 32pt body text large print.

(d) Do you plan to set standards for easy read format? There are several different ways of presenting information as easy read, and consistency would help easy read users."

"Comprehensive."

"Excellent and you have included Lip Speakers here thanks."

"Again, there is nothing included if language needs are identified at time of assessment."

"You have omitted a very simple method of communication - paper and a pen - equally a reasonable adjustment."

"Looks great on paper! Again, how do you propose this to be implemented and actually work on the ground?"

"I think it can be helpful to organisations to know the disability/reason behind an individual's communication/info need to support staff to seek resources. E.g. if a person has aphasia, we would want them to make use of the Accessible Information Guidelines for people with aphasia, published by [...]. This could be an adjunct to the four headings proposed in section 8."

“1. Contact method: is ok, except that needs or preferences may change, adding complexity to recording need.

2. Info format: I think this list is wrong as is a mixture of things like DVDs, formats, like font sizes, and items which lack clear definition, e.g. easy read. I haven't heard of Moon. I think this section would be better if items were grouped into, say, audio/visual formats; specialist formats (e.g. for people with aphasia). Again, I think some reference back to the person's disability might actually be helpful here, to guide the provider to even talk to the person about what sort of formats might be helpful for them.

3. Communication professionals: please include speech and language therapists!

Given that the list provided in this section is examples, there are some very specific e.g. and many others missing.

4. I'm not sure how comprehensive this list is meant to be: again, there could be different levels e.g. many people will need extra time; many people will need additional support (as per 3, above); some people will need specific means to communicate, e.g. Makaton, AAC; some people will need modified communication, e.g. extra nonverbal, supported conversation techniques developed for people with aphasia/brain injury.”

“Overall comment: The language of the steps suggests that there is a one-stop solution for each type of communication impairment, e.g. deafblind interpreter for people who are deafblind. This is not the case for many people with acquired communication impairments where people have different (and changing) needs and preferences. Further research is needed and ongoing for this large population.”

“They are reasonable ideas for a gold standard service but is government going to fund this? Is some of this actually available nationwide?”

“They seem very comprehensive, and lots I don't know about but I love the emphasis being taken away from a person's disability and focus more on their communication needs. I was a bit perturbed by the exclusion of staff...but I'm hoping that is because access to work step in with an employer. I think the bits that are excluded need to have guidelines on why and where to get the support...in case they don't know already.”

“Good.”

“I think it covers most things but people with extreme learning difficulties [...]”

“These are very thorough but patients/carers' communication may change or be spontaneous requests. The NHS should be able to respond without patient/carer needs being 'set in stone'.”

“Generally ok, but it may be difficult for some small organisations or departments to accommodate e.g. putting a name up on a screen. This does not mean people might not have a need for this, but organisations might need to be advised on acceptable alternatives and guidance on how far they are expected to go to meet some needs with regards to proportionality.”

“Impractical and limiting.”

“The types of info/comms formats are appropriate for this type of strategy. It's important to note though, that in some instances, this is likely to cause public bodies to have to establish new mechanisms and contract arrangements (i.e. if they don't have in-house Brailers or Easy Read functions), which in the sector's current state of budget reductions could cause conflict. The proposed formats are perfectly valid, but the inclusion of some of the more expensive items may put some bodies off the strategy.”

“Where is the communication professional for developmental disabilities?”

“Seem adequate except under Para2 ought not - clear, audible verbal communication - be included.”

“8.1 Some people may require face to face contact. 8.2 Not everyone uses BSL, a lot of people with a LD use Makaton. Shouldn't you be advocating the best method for them? 8.2 Large print - a lot of people with a LD find Arial a difficult font due to the a. Could you consider suggesting / including alternatives: [...]?”

“The easy read format is written at far too complex a level for most people to understand. The [...] reading level is above age 19 years so will be understood by less than 50% of the population. The [...] tool, funded by [...], is accessible online and can be used to simplify text. If text can be simplified to a reading age of 11 or less it could be understood by 92% of working age adults. See [...]. The easy read is written at a level that is above that of the majority of the population and in many ways what organisations need are tools to enable them to assess the level of information they are providing e.g. [...] test.”

“Re Point 4 - Requires Communication Support: currently states ‘needs communication supported by written notes’. In this description it should also mention and highlight the importance of using symbols - they are used in easy read but I feel they also need to be explicitly mentioned to remind people to use this medium as written notes can imply words - visual information is a more appropriate way of including writing and symbols.”

“I think that the communication support and the various formats mentioned are very good.”

“These seem to be about right. Certainly as a vision impaired person, my needs would be met.”

“Very comprehensive.”

“Good, but also I want it clear that no trainee interpreters are used, and that there is a list of interpreters used so that they are familiar so that there is no need to repeat information for each appointment - important for continuity.”

“All formats appear to have been covered.”

“They seem sufficient to me but I can't remember them all now.”

“As long as they include Braille, CD, email and large print then all the people I work with should be covered.”

“Very comprehensive list.”

“8.3 Include Makaton interpreter. 8.4 point 4 'needs communication supported by written notes'..... (add) 'or pictures'.”

“They are fine but I do think that individuals should have the right to decide what support they need as at present e.g. my mother has significant memory and processing difficulties and she always wants me present as support in medical situations. Would she be deemed as needing communication support? If so, could she refuse? Could someone decide to go ahead with a communication professional present instead of me despite her wishes? With my mother's permission, could I be present in such situations? I think if such situations arise where there is concern about the influence of family/friends medical professionals should go to the courts if they feel it is a major problem.”

“Ok.”

“About right.”

“They are good.”

“They are fine insofar as the vision they are seeking to support. Clearly, they will only be successful if implemented on the front line consistently and sympathetically across all care organisations sharing information with the NHS and vice versa. There will need to be a significant training and development support package for all staff involved in the standard to make it work in practice.”

“Technical details need updating periodically (I suggest at least every 10 years) because of changes in data formats and the kind of computer tools that are widely used. Had this standard been drafted 10 years ago it might have made reference to floppy discs, which few people use nowadays.”

“OK but a little to stereotypical - we need to personalise above all else.”

“Generally looks appropriate. I note that in the 3rd point there is no mention of Makaton. While many speech and language therapists / Makaton signers would not

consider themselves to be interpreters, use of Makaton will facilitate a discussion. I work with a number of people with LD who use Makaton to communicate and think this level of need should be considered here as well as in point 4.”

“Under section 3 talking about a communication professional there is mention of mental health and learning disability advocates. It should be recognised that a parent or carer can act as the person's advocate.”

“Section recognising longer appointments is good but recognising that additional appointments may be necessary should also be included (for example talking therapies).”

“It's a need that needs to be met and is fantastic that it has been mentioned about the text messages because deaf people all over the country / world can't speak like hearing people on the telephone and it does get tiring sitting there saying 'sorry what was that' & 'pardon' or 'say that again please'. Even though it can boost our confidence it's still a main and major factor in deaf people's lives and especially as it's something important like a hospital/doctor's appointment. It should have already been noticed but now it's being seen to and our needs are being met to that's all that matters, deaf rights are starting now.”

“Contact method.”

“This should include face to face, which is especially important for patients in inpatient services.”

“Information format should include/specify: Easy Read with photos; Easy Read with symbols - the type of symbol must be detailed (this will have implications for staff having access to symbol software, which is often problematic). Easy Read and Accessible Information need to be more clearly defined and differentiated as these terms are often used interchangeably in learning disability and other services.

Communication professional should include: Speech and Language Therapist; Key word signer - Signalong or Makaton.

Communication supports: It is essential that there is a clear differentiation between support for receptive communication difficulties and support for expressive communication difficulties. Often the former is underestimated and requires the professional [to] make more effort to adapt their own communication. Supports must include: Minimal Speech Approach; Touch Cues; Objects of reference; [...]; [...]; Photos; Symbols - specify which type; Key word signing - Signalong or Makaton; Simplified language (in line with key word comprehension); Communication Apps (e.g. [...], [...] etc.).”

“I think they are good.”

“I think they are extensive and hopefully represent the bulk of the alternative support and formats that would meet client’s needs. I think the fact that they are broken down into four different types of possible need with examples under each is both clear and takes the 'guess work' out of establishing what needs to be put into place to make information accessible.”

“The types seem fine. However, it must be recognised that some people will require continuing support to understand and retain information, however it is presented. For example, someone with learning disabilities might need a supporter to go through the information a little at a time, repeating it frequently. This means that the supporter needs to understand the information themselves. Therefore the service that is giving the information may need to communicate with the supporter (as well as the person) to ensure they can provide the right information. For example, many people in the general population dislike the idea of the process for bowel cancer screening. Yet a family member or paid supporter may be expected to convince a person with learning disabilities to take part, and support them to do so.”

“About right, see my response to question 5.”

“Sounds good, covers a lot but it would be good to include websites.”

“They are fine but our experience is braille is little used these days with the advent of email mobile phones, screen readers etc.”

“The question of support: some people may want family members/ support workers to support them. I could not find any reference to this in the consultation. I agree family/ support workers may not be available but this should be included too.”

“It is disappointing that as Speech and Language Therapists are health professionals with specialist knowledge of communication they are not mentioned in the document at all.”

“Although easy read is mentioned for people with LD there is no mention of adapting spoken language or the use of pictures for communication (not just in documents).”

“Only Makaton signs are mentioned where a lot of services for adults with LD use Signalong.”

“All good apart from the omission of ‘registered’ as a safeguard.”

“As above, identifying type of communication support and format is person specific, complex, context specific, and environmentally influenced.”

“No.1 doesn't include video messaging or web based tools or face-to-face.”

“The type of communication that is definitely needed in my health field is the longer appointment. Many feel pressured when organisations get the wrong idea, but then

give up because they know others are waiting. Some need a bit more support and more patience to get the organisation to understand the real problem.”

“It is essential that the care worker/assessor has a thorough training and experience in autism and Asperger’s to be able to support, understand and assess the needs of individuals with the spectrum particularly those who do not have [...] Learning Disabilities, mental health issues etc. especially as some individuals who come into the system may not have a diagnosis.”

“Comprehensive list of communication and information formats. Our main concern relates to how achievable this will be to deliver. There will be an impact on organisations to deliver the required developments and process changes required to ensure a successful implementation. This should not be underestimated given the amount of change already happening.”

“Some lip readers may sometimes require additional support as some people are impossible to lip-read.”

“It’s about right. It seemed to include most formats.”

“Comprehensive.”

“This list seems fine, although it is perhaps unrealistic to expect all organisations to be able to produce all of their information in all of the different formats.”

“Need to ensure that face to face communication is available for people with a learning disability.”

“Specific contact needs may vary with the complexity of the information.”

“Information needs for some might vary considerably.”

“Colour of paper can make a difference to some people.”

“Comprehensive.”

“Very good.”

“Really helpful.”

“All types of communication support and information formats appear to be covered.”

“I assume the advocate for PWLD will be expected to have Makaton sign language as part of their communication repertoire? Otherwise Makaton is missing.”

“These appear to be comprehensive.”

“The types of communication support and information formats included seem fine. However many people with learning disabilities may still need support to understand an easy read document. Therefore it may be necessary to engage with a family

member or paid supporter to ensure they will get the support they need to understand the information provided.”

“Just about right.”

“Communication professional should include independent advocates and independent advisers for anyone who needs help or support - not just MH, LD and ethnic minorities.”

“Please see comments above in Q 8.”

“Some of these methods would be difficult to provide in an acute hospital setting.”

“3. Should include Relay Interpreter. 4. Needs vibrating alert (as used in some ENT depts.) for deaf clients.”

“Generally seem comprehensive but suggest the use of translation services too.”

“Don’t know what 'moon' is.”

“Makaton is a brand of signing. The correct term should be Keyword Signing.”

“Easy read covers lots of formats. This must be person-centred; staff must have the skills to do this and support to deliver it.”

“Have you considered rolling out the Communication Charter (as [...] Learning Disability staff have implemented).”

“Please dispel the belief that if somewhere makes their information available in braille then they have ticked the box.”

“The word Makaton should be replaced as this is a brand name; it should be replaced with ‘key word signing.’”

“Note taker.”

“Just make sure in the documentation you have a regular update and relook as things change over time.

“Ok.”

“It might be worth considering the following additions:

- Use of an electronic note taker by visually impaired people - this is often used for important info like dosage and times for medication;
- Someone to read information to a visual impaired person (in an emergency situation).”

“We would echo many of the comments made in the [...] submission particularly the use of relay interpreters. It is really encouraging to see that the standard will focus on a person’s information and communications needs rather than their disability.”

“There is a need to differentiate between plain text and HTML emails.”

“Colour contrast should be included within information formats.”

“When using a communication professional, a suitable space should be provided which offers confidentiality for a patient disclosing confidential information on a medical form.”

“I wonder whether [...] should be included in the specific information format.”

“In communication professionals, the use of the term ‘learning disability communication support worker’ could confuse. I believe that you are trying to capture the support provided by a front line worker who knows the individual and how their communication needs can be met - probably best as ‘learning disability support worker/key worker’.”

“Piloting the information standard might expand the options under each heading.”

“Possibly too wide a range.”

“Would be good to expand into in-vision Video Relay systems for sign language users - interesting work being done in this area to harness technology.”

“Services are very inaccessible to those with hearing loss at present as more services/access become telephone based.”

“Under communication support add: for fluctuating conditions, people need appointments at a particular time of day when medication is most effective so the person is best able to communicate. Evidence: [...]”

“There needs to be a better definition of what easy read entails or involves. Considering all aspects of vocabulary, sentence structure and concepts, order and quantity of information, adding appropriate visual supports as necessary in relation to that individual’s needs. Consider including referral to specialists in communication such as Speech and Language Therapy.”

“The use of the term communication tools is very broad and unclear.”

“Audio information will also have to be adapted to ensure it is easy to understand for those individuals who have difficulties with receptive language skills.”

“It may be worth considering the basics. The list is very heavy on specific categories like Makaton, braille etc. but not on general good communication strategies i.e. not using jargon, short sentences, allowing for extra time to process information,

breaking it down etc. The vision should include simplification and use of visual supports.”

“[...] believe that the four different types of information and communication need highlighted in the scope are broadly sensible and we welcome NHS England’s commitment to ensure the sector addresses these needs.”

“We noted with particular interest that need 3 (‘requires communication professional’) includes the category of ‘advocate for people with a mental health need’ and we fully endorse the inclusion of this category. However, we highlight that the vision for the standard appears to focus solely on ‘disabled individuals’ and does not explicitly include individuals with a mental health need. We believe there is a risk that this inconsistency will create confusion about the aims and purpose of this standard and we urge NHS England to provide additional clarification on this point.

Moreover, section 6 of the consultation document suggests that the standard includes information or communication support needs because of a disability, impairment, or sensory loss...(including) people who are blind, deaf, deafblind, have had a stroke or have a learning disability. We do not believe this is a fully representative list of groups who have specific information and communication needs. For example, it is not clear to us that the needs of individuals with motor neurone disease, or other neurological conditions, would be adequately captured by this definition or the associated requirements in section 8 of the consultation. We therefore urge NHS England to consider this categorisation in more detail before finalising its standard.”

“We welcome NHS England’s work on the standard and very much appreciate the efforts it is making to ensure that disabled people have access to appropriate and meaningful information, communicated in a way that individuals can fully understand and engage with. However, we would also like to highlight that these principles should not only apply to a standard for disabled people’s information. Rather, every health and care service user has the same right to accessible information. We believe that NHS England could do more to articulate and commit to this by setting out more clearly the broader context within which this particular information standard sits. We believe that without this context, NHS England may inadvertently create a perception that appropriate and meaningful information is only necessary for particular types of service user.”

“Type 1: include ‘via intermediary’. Type 2: include ‘verbal plain English’ and ‘face to face’. Type 3: include ‘advisor’- see my previous comment.”

“These are comprehensive.”

“This seems comprehensive. Regular updates and newsletters to share how to best achieve and maintain compliance could be useful and best practice examples as they are identified and collated.”

"[...] agrees with the range of formats outlined."

"Whilst I support these I feel that all letters, information leaflets and reports that are either sent directly or copied to patients/carers should avoid clinical and social care jargon and be written in plain English."

"They seem to be fairly comprehensive but probably too exacting for smaller organisations."

"Satisfactory."

"Speech to text, Lipspeakers and note takers are constantly missing when we need it. Your standard does not improve anything for us."

"Emails and SMS formats should be included."

"They seem reasonable however two needs have been excluded; Cued Speech Transliteration (LSP); Uses written notes to communicate (this can be a preference)."

"These are reasonable but there are concerns about the availability of some of the professionals listed."

"The listing of different formats and types of support under category headings is clear and will make sure people's needs are recorded in the same way. Some particular comments are that: It may be acceptable to use more than one communication method - e.g. e-mail, phone and text, so we would welcome the ability to cater for this. An example could be that someone may be receive appointment letters and associated information regarding their health and social care situation by e-mail, whilst a phone call or text message may be acceptable for appointment reminders."

"The different options for receiving electronic information are very useful, particularly in view of people's differing ability to access e-mail attachments and different electronic file formats."

"CD, DVD and memory / data stick are listed as stand-alone options, but these should be linked to the different formats - e.g. audio / sign language (as already listed), large print, easy read. It is also possible that someone may need large print easy read material."

"The list of different communication support professionals is very comprehensive. However, there is provision for people with mental health needs, learning disabilities and deaf / deafblind people but not physical or visual impairments. Specifically, someone with a physical or visual impairment may need someone to be able to take notes for them at an appointment but this does not appear to be catered for."

"We suggest that the following be considered:

a) It would be helpful if under possible requirements for a communication professional, there is a recognition that there may be a need for an advocate with experience of working with disabled children and young people. This should be added to the list.

b) Under the possible requirements for communication support, it is recognised that some people may use a hearing aid, but not implantable hearing devices or radio aids / FM systems. These should be added to the list.

c) There doesn't seem to be a recognition that some services can be delivered online – for example, online British Sign Language interpreters or remote [STTR].”

“Communication support - people might want / need a particular family member / member of staff with them - someone close to you who you are happy to know your personal information.”

“Good.”

“Enough to cover most disabilities.”

“We think had good understanding.”

“Good.”

“I think it is Ok.”

“Develop ideas for using [...] and tablets.”

“Ensure hospital know if you have a hospital passport. If people need home visits this should be facilitated. Write down if people also need letters sent to a carer (any form of contact Re: phone).”

“Easy to understand. Liked the use of pictures.”

“Ok.”

“Good.”

“All good helpful ideas.”

“It covers just about every format.”

“Ok it is very good.”

“They are great.”

“It is ok.”

“Good.”

“Contact me for appointment one to one. Give me information one to one.”

"I'd like to have more face to face contact."

"Very good."

"Need clear big letters, small words, pictures."

"Books."

"Adequate and cover a good wide/broad range of facilities of information and communication."

"Yes perfect (what we need)."

"The use of the latest technologies is a great idea. Reasonable but consider non instructed advocacy. Reasonable."

"Very good."

"Good."

"Yes I think it's a good idea."

"We think you have chosen the most important ones."

"They are good, sound practical as long as patients have been asked as it is easy to miss a few things."

"Ok."

"Overall the types of communication support and information formats included seem to have covered everything. It is very important to set up focus groups around each type of communication to make sure that what is offered by the NHS and social care meets everyone's needs. Attached to this response are the [...] Easy Read standards [...]. We believe that these should be the Easy Read standards used. A very important point in these standards is that Easy Read is not a summary, but the same information translated into Easy Read."

"We think they're fine."

"We agree it is very important that services have easy read leaflets. This is something we check for when we do review visits. We think that some people would need information with just pictures on. Even Easy Read is too difficult for some people with a learning disability. We also agree that it can be important for people with a learning disability to have someone to support them to communicate. It is good to include different types of support. We are glad this includes support to help people communicate who cannot use speech."

"Good ideas."

"Carers' needs on individual, very good."

Appendix 7 – (Question 12): If you have comments on the quality considerations we have included, please explain here?

“There aren't enough interpreters or qualified trainers to fulfil this, it's only what should happen under [...] / copyright law / duty of care.”

“Good especially for privacy.”

“Quality is important and should include quality of acoustics and lighting in all places, also audibility and clear speech of staff and staff training in use of equipment e.g. hearing loops.”

“Para 7 of section 10...Whilst I agree health or social care staff, maybe, should not be used as interpreters – initially they and family and friends have to get involved in reinforcing interpretation especially in dealing with Dementia cases.”

“The whole aim is very ambitious, and it would be brilliant if you could bring it off - well done for trying.”

“There are so many types of communication listed that perfection may be hard to achieve without causing longer delays for the information to be available. There have been so many cutbacks to such things as local health organisations it all sounds very good but is it going to happen??!

“As a Deafblind person who can use clear speech - clear speech applies to live appointments as well as on audio media - so speaker needs to speak a little clearer louder and slower - presentation standard.”

“Send letters out in different formats easy read etc. individual has sensory disabilities. How do you get the information out to the patients - CD audios and compact disc? Not everyone uses CD players. The issue of including cassette players nobody uses cassette players. There should be instructions on how to use the information with CD audio.”

“The term ‘easy read’ should be used with caution. To someone unfamiliar with the accepted convention/principles of easy read, they might respond that ‘what’s easy to read for one person might not be easy to read by another’. When communicating with someone with special needs it is often good practice to communicate with their support person first for the best advice when delivering information to the client.”

“Need to have assurance that the information being communicated is quality assured therefore contracts/agreements with interpreting providers needs clear quality check mechanisms and standards.”

“It is very good to have the specified level for BSL interpreting to ensure the service provided is effective, and usage of interpreters at a lower level is alleviated.”

“On the whole we agree with the quality considerations included in section 10 and welcome the statement that family members shouldn’t be used as interpreters. There are, however, some scenarios where individuals have their own adapted form of communication or where they may not understand a verbatim interpreter, for example due to an additional learning disability. In these scenarios it may be essential for a family member to intervene or support the individual and staff to have a meaningful dialogue. We therefore have a concern that this statement may lead providers to not allow family members to support in this manner due to privacy concerns and qualification levels as written in the standard. A clarifying sentence such as ‘some people may have a learning disability in addition to a sensory loss, meaning that merely providing an interpreter is not sufficient. In these situations it may be necessary for a family member or carer to participate in the conversation to ensure that the person has understood and been able to communicate their views effectively’ may alleviate this.”

“The principle is sound, but again, it might not be workable in practice; some cultures have a strong sense of the need to help out older members of their communities/families and might prefer a family member to a formal interpreter-again, some notion of 'reasonable expectation' might assist.”

“Ok.”

“Again they seem comprehensive.”

“Given the multifaceted nature of accessible information and the huge variety of individual needs, quality is a complex issue. The information and communication competencies require more detail to support the implementation and operationalisation of the standards.”

“Family and friends should not automatically be excluded. For people with complex needs accessing a new service for the first time, family and friends can provide invaluable support and a collaborative approach should be considered.”

“To ensure that people with hearing loss are not put at risk, communication professionals should be NRCPD-registered. Please see our response to Q8 for a further discussion of this issue.”

“‘Appropriate qualifications’ is too vague. For example, for BSL interpreters, the specification should define appropriate qualifications as qualified to the highest level of qualification in BSL, and qualified in interpreting, and with experience of interpreting in a health care setting. For Braille users we have spoken to [...] and they recommend that whether contracted or non-contracted Braille is used is discussed with the recipient of the information. The standards need to include a reference to not making assumptions or judgements about what a person's needs are or how to meet a person's need, but to communicate with the patient about how best to meet their needs.”

“[...] standards for the production of accessible formats must be used to set the quality standards for the NHS standard. [...] is the industry association which is setting standards and promoting best practice for quality accessible information based on user needs and enabling businesses and organisations to deliver a quality service to meet the needs of people with print impairments. [...] is recognised by the accessible format industry and major advocacy and charitable organisations as the organisation responsible for creating quality standards for accessible formats in the UK. [...] welcome the opportunity to work with the NHS to draft the quality standards for this NHS standard. [...] has already published a number of standards for accessible formats in the UK and these must form the basis of any standards that the NHS sets for itself.”

“If the original health information is not of a high standard to begin with, as is the case too often, how can the translation or adapted format be of a high standard? We would question how realistic this aim is.”

“Quality assurance and the use of appropriate materials is likely to be a challenge, since very little guidance exists in some areas. [...] produces guidance on assessing the quality of health information which the standard could usefully link to.”

“We welcome the reference to working with patient groups to ensure communication support and alternative formats are good quality. However, we believe this is a fundamental principle to improving the accessibility of health information and would argue for having this integrated more widely and prominently within the standard.”

“Staff training should be added, to ensure relevant staff are trained to effectively simplify speech and to speak clearly, and to support verbal information by writing down key words.”

“Our members report that some people with communication support needs will only speak in certain situations and to trusted people. These individuals would need to have a trusted conversational partner with them and be unlikely to speak to an unknown mentor or communication support worker.”

“We particularly welcome the quality consideration that relates to professionals who provide support having the right skills, knowledge and qualifications. Whilst this is really welcome, we would also recommend that those who arrange for support for a patient with communication support needs are sufficiently aware of the evidence and the good practice in communication support.

However, we are concerned that the statement says that organisations should not use family and friends as interpreters as this may not work well for all users. This is particularly worrying for us with younger children. Whereas this may be a very good principle for adult service users and it is absolutely right that the user of the service be the focus of information and support - for some children and young people with SLCN there is a lot of value in involving their families in their care and support.

Services should absolutely not rely upon family as informal support but neither should there be a quality statement which might negate against any involvement of family and friends as interpreters in all circumstances. For example - in some cases an interpreter may not know the form of communication that the individual uses and that, where appropriate, a family member may also need to support - some of our members have raised concerns that they have family members where they use an adapted form of BSL and that interpreting word-for-word will have no meaning to the service user. They are concerned that the section regarding using family members as interpreters may be read in such a way that means they are not allowed / able to support. Some individuals who use alternative and augmentative communication (AAC) methods require support from individuals who are extremely familiar with their own highly personalised methods of understanding and expressing communication. In some instances family members would be crucial in providing this level of familiarity and understanding.

Additionally we believe that the [statement] 'it would be good if they worked with patient groups to do this' in relation to the quality of formats and support should be strengthened to 'organisations should work with patient groups to do this', ensuring that they link with groups of patients representative of the user groups e.g. users of all ages and those who use specific formats or aids."

"Are interpreters going to be needed to be registered interpreters?"

"It is essential to work with patient and public groups not just 'it would be good'."

"Quality of images [is] important to include."

"Quality considerations and definitions are fine but how will you be able to check??"

"Any information provided should meet the standard of The Information Standard, and be an accredited member (where information comes from an outside source)."

"Ensuring quality standards is a very complex issue due to diverse communication needs. Variation can be a good thing if it reflects the needs of a specific group, but there is a need for improved training in how to simplify language, so that methods are systematic and as effective as possible. In the past the provision of adapted information has focused on people with learning and sensory disability, but it is important to increase awareness of the needs of all people with a communication disability."

"Advice needed for staff when they cannot get interpreters in time for appointments or treatment who meet all the quality requirements - when to delay appointments and wait for suitably qualified person and when this is not acceptable."

"I wholeheartedly agree that BSL/English interpreters in medical settings must have qualifications equivalent to NVQ level 6 interpreting (so are full members of [...] rather than registered trainees). NHS staff do not generally understand the difference

between an interpreter with blue or yellow badge and do not specify 'qualified only' in Service Level Agreements with agency providers such as [...]. At my hospital we are regularly sent people with level 4 only (which doesn't exist anymore and which patients are not happy with).”

“In some exceptional circumstances patients relatives may be allowed to interpret. This, although not recommended, should be allowed as a matter of patient choice. If a patient wishes not to use the professional interpreting service an interpreter should be used to explain the associated risks to the patient and the patient sign and accept the risk before allowing a relative to interpret.”

“In interpreting situations, if you think that a friend or family may get the information wrong, or misunderstand - then you are not communicating effectively are you?”

“In principal I agree as it is important to ensure that interpreters are sufficiently qualified to pass on important information to patients accurately. There is a worry that if Trusts have specific qualification requirements that are too rigid, there could be situations where patients are unable to receive timely information because the interpreter that is available has not got the right level of qualification...thus having to wait until one becomes available.”

“I do agree that if a professional is employed to provide communication support they should have appropriate qualifications and DBS clearance. However, I do not think it is necessary to exclude the option of using friends/family as interpreters as long as service user is given a choice of either using a professional or family/friend. It should be up to them what they prefer and what works for them.”

“I also think that if a particular healthcare or social care professional has the skills to communicate with service user directly, without the need of interpreter, this skill should be utilised even if they are providing care. I actually think this could improve the relationship and the quality of care provided.”

“You need to make sure that lip speakers and STTRs also have appropriate qualifications, have enhanced CRB checks and be registered just as much as BSL interpreters on the NRCPD register. You are putting patients at risk if they use English and are deaf and asking them to rely on parents / children / or even asking staff to be a lip speaker... you are not giving them the same level of protection you give those who use BSL.”

“I agree with this: ‘We do not think that organisations should use family or friends as interpreters. This is because everyone has a right to privacy. It is also because they might not have the right knowledge, skills or qualifications so they might get the information wrong’. And it must also apply to deafened and HOH people as well. (I am an English user, totally deaf - I need access to English by a lip speaker or STTR).”

“Get in touch with [...] there are the people you need to speak to, most of them are not BSL users.”

“STTR and electronic note taking professionals need to be registered to a standard too. I am wary of the idea of health and social care staff interpreting at all cos they won't be experienced enough to do it reliably.”

“I agree to BSL interpreters being level 6. They should be NRCPD registered and ideally be registered sign language interpreters (RSLI) or at minimum TSLI trainee sign language interpreters as they would still have level 6.”

“Patients using an interpreter should be given the name and id of the interpreter in case they need to complain.”

“For people with learning disabilities and other communication needs speech and language therapists often provide training for other staff on how to meet their needs.”

“Staff should have basic competencies in communication - in learning disability services the needs are often complex and the communication support required needs to be very skilled.”

“We have written guidelines on how to involve people with profound and multiple learning disabilities which could compliment other guidelines to ensure that this group of people are not excluded.”

“A flag of some kind should be available for metabolic disease patient info, because everyone knows roughly what a diagnosis and caring of a cancer patient means but presented with a metabolic disease patient, there is no national awareness and they are very rare. A flag could signify something like ‘think outside of the box with this patient’ or ‘contact the specialist network for this disease’ and the website or phone details. For us this is essential in saving people's lives when they go to A and E for a life-saving drip and then have to wait 4 hours to be assessed. Also the information should show clear reporting procedure such as if rare, who do the A and E staff seek, who do they report to, who contacts the rare specialist for advice quickly.”

“An ongoing issue with introducing change is that it works best when evidence is provided of both poor practice (usually identified through feedback/complaints) and, done less often, good practice. Real understanding is achieved with a 'Hearts and Minds' approach - health and social care professionals are, on the whole, highly committed people, but will change more effectively when their hearts understand as well as their minds.”

“It is important to know that people being used to provide support or information/interpreting services have the right qualifications to enable them to their job. This increases the confidence of both clinicians and patients. For specialist services, there may be some bespoke training that could be done with interpreters/signers etc. that would increase the level of engagement of the support

being provided and also a shared understanding of some of the language, words etc. used in typical consultations.”

“Whilst in some circumstances it would be inappropriate to use family to communicate for their protection, this blanket statement of not doing so I believe will disadvantage a great number of people whose family would be the best rather than some professional. This will be especially true for those with profound disabilities and sensory loss and could actually damage the quality of communication rather than improve it.”

“They are excellent but again are they achievable across organisations who are over budget for example, where would equality sit then?”

“I should like to see how these qualifications compare with those required in other professions.”

“The only issue is that there is a national shortage of fully trained BSL interpreters (hence the 48hr and no delay compared to any other patient may be difficult to organise, especially in an in-patient setting, where the patient may only be in for a day or two), and many providers try and avoid this where they can as it is a very expensive service.”

“Only reason I say ‘not sure’ is I wanted to make a comment here to add that in quality it has to be stated whoever is used for interpreting skills etc. they are reminded they are not there to ‘make an opinion’ on what the persons is saying etc. I am aware there have been examples of interpreters who think it is ok in their ‘code’ to offer beyond the advice on what language would be helpful to use (that is correct they are good advising on how to simplify language), some then have subtly crossed professional boundaries and believe it is ok when ‘patient’ is out of room they then offer an opinion in the persons behaviour e.g. I noticed they were not having eye contact with you and were afraid of you etc. etc. Those are statements which are for a professional to observe not for the interpreter to tell the clinician or practitioner - that is not the interpreter’s role and runs the risk of assumptions being made on behaviour and emotion. Only convey what is being said and why people insist level 6 which you have in there.”

“On the subject of not using family members as interpreters, I think this is a fair consideration. However, a situation may arise where a patient would be more comfortable using a family member, or even a friend or private professional with whom he/she already has a good working relationship, as their interpreter, despite the lack of privacy which will be afforded as a consequence. I therefore would like to suggest that the standard specify that, although all patients are entitled to an NHS interpreter, the patient may alternatively elect to provide his/her own on the understanding that he/she will assume responsibility for any inaccuracies etc.”

“I do feel that on occasion family and friends or health professionals should be able to act as interpreters if the person is happy with this approach - as they may be the best people to do this.”

“The development of easy read information should also follow clear standards so this is at an appropriate standard in all organisations.”

“Again, missing the bigger picture. It is not just all about specific communication requirement (braille, hearing aids, sign language) but also some people (I dare say most people) just need more patience and less jargon. There does not seem to be any 'tick box' in the system to record this (because there is not a 'diagnosis' or 'specialist term' for this?). I think a great many people with disabilities could be helped just by acknowledging the need for simpler language. Professionals should be helped to and trained to be able to talk to people in a way they can understand.”

“BSL interpreters should have all the requirements set out in the document but they should ideally have some subject specific knowledge, as translating medical concepts can be very difficult. Also it must not be assumed that if a person has something in easy read they actually understand it, they may still need support to understand what the information says, so it is very important that there is a way of doing this.”

“Whilst it is appropriate to ensure that the BSL interpreter has a minimum of Level 6, organisations are unlikely to know that this level is broken down into separate language units and interpreting units. Therefore, the quality specification should be more clear and precise, specifying that only fully trained, qualified and registered interpreters, registered with a recognised national registration body, should be employed, and that this person should possess the title of Registered Sign Language Interpreter. It should also make clear that partially qualified or Trainee Interpreters should not be used for medical settings.”

“It should not advocate the use of health and social care staff to act as interpreters. It currently says that this may be acceptable if they have the right qualifications - however, it does not state what qualifications this refers to and does not make it explicit that this requires the patient's agreement. This statement gives organisations an option to save money by not employing qualified interpreters and instead using internal staff with substandard skills.”

“Section 10 has a paragraph in which it is stated that health care workers should not act as interpreters while caring for a patient. This section is a little bit ambiguous. In one sentence it seems that it is alright for a carer to also act as an interpreter if the carer has the right skills - this seems like a sensible option.”

“It is very disappointing that no consideration has been given to develop standards for Cross Cultural Communication considering Britain has such a diversity in population with many cultures and languages. Why has standards for interpreter

services and multilingual leaflets/ audio-visual material been completely excluded? Very disappointing and worrying.”

“Is all this affordable, doable, enough staff in the present climate when the NHS is being privatised daily? The most important thing to do is save the NHS.”

“Are there going to be enough qualified interpreters? Sometimes a patient cannot wait for one to be available. And I do have worries that some family/friend members will put pressure on some patients for them to take over. It happens now.”

“Might be worth considering clinicians with specialist skills re communication e.g. speech and language therapists.”

“As in my last comment, it may not be the qualifications which matter. Sensitivity may be more important. Or awareness of the problem may mean a health professional has to be willing to step back and let another person take over (say a woman may need to be replaced by a man?)”

“I fully support the intention behind saying that BSL and deafblind manual interpreters should be appropriately qualified. However, with such a desperate shortage of qualified deafblind manual interpreters, I am extremely concerned that deafblind people who communicate using deafblind manual will be unable to access health or social care because no qualified interpreter is available, even though the deafblind person might know of an unqualified person who is capable of doing the assignment. In addition, with many of the forms of communication used by deafblind people (including deafblind manual, hands-on signing, visual frame signing) it is vital that the interpreter has appropriate experience, not just a qualification. Therefore, I would like to see the addition of requiring appropriate experience in the method(s) of communication used, and a statement to say that qualified interpreters should be used when available and appropriate but that unqualified interpreters may be used with the informed consent of the deafblind person.”

“I can't find 'quality considerations' in the easy read version of the consultation document.”

“I think the considerations should include the qualification and skill requirements for foreign language interpretation and translation (e.g. MA Translation & Interpretation).”

“Again on the whole I agree but getting level 6 BSL interpreters would be problematic in rural areas and therefore costly. Not sure how organisations can realistically ensure the quality of alternative formats particularly if they aren't required on a regular basis. This is less problematic if you are using nationally produced resources but if there is a need to produce local information in alternative formats I can see that they may be rarely used and will either be outdated or produced on an ad hoc basis in a hurry and be of poor quality.”

“It is often very desirable /important for these professional to be at a level with medical knowledge.”

“Spoken language interpreters’ quality considerations have not been included, which should be up to level 6 or DPSI or equivalent qualifications.”

“Some communications need consideration of the further needs of the client. For instance, it is no use ringing to cancel or alter an appointment at the last minute if the client also needs to change transport, carers or other help.”

“I can't obviously access the consultation document.”

“We think that organisations should check to make sure that communication support and alternative formats provided to patients, service users, carers and parents is good quality. It would be good if they worked with patient groups to do this.' This would be good practice.”

“When dealing with deaf patients all communication support professionals should be registered with the National Register of Communication Professionals working with Deaf and Deaf Blind.”

“I also think that for many people particularly with learning disability/mental health issues having a person they know and who understands them supporting their information/communication needs is important to them and there are lots of staff who have developed good skills to support people they work with well around their information/communication needs. These staff should not be overlooked.”

“Why have BSL interpreters and deafblind manual interpreters been identified as needing DBS clearance? There was a long list of people who could provide support yet the DBS suggested list is quite small.”

“I think it's great that the standard covers ensuring alternative formats are of a good quality and are tested with user groups. However, the issue of quality is still of concern to me, when talking about easy read. As former accessible communications lead at [...], I know there is no simple answer. Easy read is produced in different ways and there is no one agreed approach! The testing with user groups may be the only way to ensure the actual quality is tested - but it needs to be done in the right way, and the testers need to be mindful of who they are consulting with (for example, people with very mild learning disabilities may not be representative of other people who will be using the information).”

“I also have some concerns with the existing easy read information produced for this standard. Easy read information of 30 pages long is likely to be prohibitive to many. Also, words like 'providers', 'health and adult social care 'bodies' and expressions like 'moving forward' are things I would stay well clear of in my easy read work. For example, what is a 'body' and what is 'moving forward' most likely to mean to someone? A lot of people with learning disabilities can take things literally, and these

words and concepts are likely to be confusing, complex or open to misinterpretation. I'm not sure there is an easy solution here as the issue of what makes good easy read is rather 'political'. However, if the information can be tested with the target audience that is a good start.”

“Methods such as getting people to fill in very simple, individual score sheets, with support if necessary, may overcome some concerns about not capturing people's true views. Also, giving people an easy way to feedback on the quality of the work, or getting health staff to ask people directly what they think of it might be useful.”

“The [...] policy on easy read could be incorporated, or basic guidelines on easy read (most organisations follow similar guidelines but the outcome is the thing that is variable). Perhaps this could be thought about for the pilots? I would be happy to offer my thoughts on this. What could be useful is national research into easy read, but that of course, is a separate discussion!”

“Need to take into account person's preference in working with a regular BSL interpreter.”

“Also would like to see something about using BSL via [...] rather than booking and waiting for physical person to attend.”

“We think that organisations must still try their best to meet people’s needs’ (consultation section 9). This is a serious quality issue, see above comments re national/central resource or guide. This also applies to 13 below (NB no comment box to qualify response). ‘We think that organisations should use computers and the internet to help meet people’s needs more quickly’ (consultation section 9). How are they going to do this? Clinical staff have no time and no-one else has responsibility/remit: librarians? PALS? Governance? Knowledge manager? Will funding be provided for a new department with enough staff to meet patients' requirements??? This could be extensive in deprived areas (lower literacy levels, educational achievement etc.) where healthcare provision is already stretched.”

“Yes the quality considerations are ok but will require monitoring through PLACE assessment etc. to ensure they are being worked to and maintained.”

“Would require constant monitoring to ensure no drop off.”

“Individuals in receipt of support may be passive and not willing or able to say that the support is not quite what they need or that the quality is poor. I would like to see something more included about follow-up with patients and the importance of feedback - positive and negative. I wonder if there might be scope for user-led organisations to do some spot-checking.”

“Providing they are adhered too.”

“In line with my comments above, I think in some cases the involvement of a speech and language therapist will be needed in order to assess what is needed for the client and then to be involved in looking at the quality of what is produced, with the specific needs of the individual in mind.”

“Specifically outline what 'appropriate qualifications' are.”

[...]

“Professional interpreters etc. would have no knowledge of how best to communicate with a congenitally Deafblind individual who also has a severe learning disability. They would have no knowledge of the individual. For this adult individual, if the accompanying parent who delivers the necessary care cannot interpret, are you suggesting the consultation should involve the doctor, the interpreter (whose input will help no-one), the patient and the parent? Too many people in a room is distressing and impractical. Or is the parent supposed to get information 3rd hand from the interpreter, afterwards? If the parent is not included, the appointment cannot take place as the individual cannot respond to questioning etc. which is a vital part of any appointment. Therefore patient receives no care.”

“User testing within governance is essential. I would be more specific about the target groups, i.e. adults or children.”

“Great idea to include patients in what they need.”

“The quality of easy read documentation should be considered, with care: in my experience organisations promote their own style of easy read documentation and are critical of the style of other organisations.”

“The document makes reference to it 'sometimes acceptable for health & social care staff to act as interpreters'. This is misleading - it is highly unlikely that staff will be qualified to interpreter level so the reference should be 'to act as communicators'. Staff should never replace interpreters. The next paragraph refers to using family and friends as interpreters. We feel that this should be a strong statement against the use of family members and to point out that organisations are liable for any misinformation.”

“Very vague. The below is unrealistic: ‘We think that organisations should check to make sure that communication support and alternative formats provided to patients, service users, carers and parents is good quality. It would be good if they worked with patient groups to do this.’”

“1. The qualifications, DBS and code of conduct mentioned in relation to interpreters is applicable to all communication supporters, if coming in from outside health and social care organisations.

2. Specifying qualification level of BSL interpreters suggests that there should be competency levels for all.

3. Organisations need to work with patient groups to check quality - if it's at 'it would be good level', it may well not happen."

"I agree about family members/friends not being routinely used as interpreters. However, is there a need for flexibility in this, especially say in emergency situations?"

"See previous comments. Available? Affordable?"

"Don't just make it a money-making scam to get the qualifications!!! Considerations to support those who have been doing this beforehand to obtain the qualification should they need it to continue the work they are doing."

"Good."

"Quality of communication should be part of basic doctor/nurse training as well."

"But how would this affect an external supplier of specialist information."

"Paragraph 7 of section 10. Whilst I agree health or social care staff should not be used as initial interpreters they and family and friends have to get involved in reinforcing interpretation especially in Dementia cases."

"Consider people are making easy read information all the time but it does not meet to the standards of [...] or [...] guidelines so professionals will need training and support. Providing people with symbol packages can make information harder to understand."

"Since the NHS & social care should be patient / client centred, all information should be written at a literacy level most people can understand (see above). Quality considerations for support staff should include their skills in improving accessibility of information for people with low literacy & numeracy skills. Support staff assessment should support this."

"It is not clear how the quality of the support staff who will help people e.g. BSL signers will be assessed."

"Makaton signing is not discussed here, it should be. Makaton is not the same as BSL (which has its own grammatical structure and [...]). Makaton like BSL has many levels and the support provided would need to be of a satisfactory level."

"2% of population have a learning disability. 2.5% of population will have a stroke. 1% of population use Braille. But the LD population are not always represented equally; your document can help address this."

"I work in an NHS facility where we strive to resolve the patient's problem within the day from initial contact to diagnosis. Although I am not a professional I am able to communicate with the deaf at BSL level 2 and have a Deafblind communicator guide level 2 qualification also. I have a lifetime's experience of deaf culture and Deafblindness. If someone presented with a problem which could be immediately resolved with a clinician and my input would this be acceptable, with the patient's agreement, rather than waiting 48hrs for a level 6 interpreter? Perhaps the decision should rest with the patient as to what is best for each situation, as long as they are given all the options and a free choice - appointments can range from blood tests to complex mental health issues."

"I think it is essential they work with patient groups to do this!"

"In documents the assumption is [that] organisations must provide support e.g. communication support professional like an advocate and that family/friends should not be used, but where is individual choice in this? Ok if someone prefers this for privacy or other reasons. But what if someone does not want to have a communication professional because their preference/need is to have someone who knows them well and can interpret non-verbal signs and support/respond appropriately? E.g. our son does not experience pain in the same way as others but we recognise non-verbal indicators. True communication happens when there is trust and some individuals would not trust health & social care workers and/or those employed by the organisation. Indeed at [...] in [...] there is a policy which requires the use of external foreign language interpreters and staff who speak the language cannot interpret. Yet in these documents the assumption is that trained admin / health staff in-house can be used. Fine if the role is to impart information in a neutral fashion, but could there not be a potential conflict of interest if advocacy is required which is a more complex role and includes enabling someone to process options? (And some of those options may not be in line with the organisation's policies/values/preferences). E.g. as a hospital visitor I have been told by more than one patient that they have been persuaded that they should go back home rather than into a care home as they wished. (I suspect this is cheaper for the council)."

"In the associated documents, there appears to be no detail on what training/qualifications an advocate would need or the expected pay rate. My fear is that this will end up as a low paid admin or voluntary role as realisation dawns that the cost of providing all these services (in time and money) will be very heavy."

"Families as interpreters should be allowed, but it should be up to the patient based on privacy and whether they think their family member will offer a good interpretation. For example, deaf children may benefit from their parents signing the information to them."

"I think that staff have to work with patient groups to ensure the information they create is understood by patients. As professionals we have a tendency to think we

have made something easy to understand when it isn't! I create a lot of accessible information in my role and have learned this the hard way!"

"I have a learning disabilities focus due to my profession. But feel there should be standard easy read health information developed by the NHS for use across the NHS rather than the varying quality of accessible information currently available (much of it from one or two original sources then copied, pasted and rebranded with different trust or company logo's)."

"Whilst mention is made of linking to patient/service user groups - I think that the application of the standards will need some external scrutiny. It is likely that this area of practice would be one of the first to suffer within an organisation undergoing change or financial restrictions."

"I am concerned that whilst some organisations may appear to be complying, their use of generic information/supports may mean in reality that individual needs are not being met - how will this be assured?"

"What is the consequence of not applying/meeting the standards?"

"I think the guidance around quality could be strengthened. I like the statement 'We do not think that organisations should use family or friends as interpreters. This is because everyone has a right to privacy. It is also because they might not have the right knowledge, skills or qualifications so they might get the information wrong' as I believe this ties in with what [...] recommend specifically around clients with English as an additional language and non-English speakers. I think that the quality guidance could do with further input from organisations that specifically work with people who need accessible information as they have already produced some very comprehensive guidance e.g. [...]."

"Perhaps, at a local level, speech and language therapists could take the lead in ensuring that services in the area that they work within are supported and guided in how to do this effectively for clients with different difficulties and needs."

"Section 9 refers to three categories of care. This does not mention screening; it might be intended that this is covered under 'routine care', but should be made explicit."

"Section 10 says family/friends should not be used as interpreters. This may be right in most cases, but there will be occasions when this is the only option and this should be recognised. If this is the case, great care should be taken to ensure the family member/friend does understand the information that is to be given."

"In addition to communication professionals being qualified, all staff should have deafblind awareness training."

“When working with people with LD, it is important they are included in the development of this.”

“Family members/support workers could help and they may not have the required qualifications!!”

“There needs to be a recognition of a national shortage of STTRs and sign language interpreters. Perhaps one way round the issue of STTRs is for the client and professional to communicate on a word document or writing it down which would serve as the record of the visit too!!”

“Although I feel that it is extremely important to ensure quality of communication support I fail to see how this will work in practice. All the examples given are regarding BSL interpreters but how, for example, will the quality of easy read information be checked? The national standard is that health information should be checked by the target audience but this is already extremely difficult to implement.”

“As online video interpreting technology is proven - see [...] who is the market leaders and has provided this technology for the past ten years to a wide range of corporates, businesses and public services (some of which are in a heavily regulated industry sector, i.e. banks and financial institutions) there is no reason why the health/care professionals have access to on-site video communication technology that will enable deaf people to have access to professional and registered sign language interpreters within seconds fulfilling their obligations under section 9.2. From research into current provision to healthcare trusts like [...], it has proven to be a much more cost effective way saving up to 60% over that for a face to face interpreter.”

“Section 10 states: ‘In a medical setting, we think that British Sign Language (BSL) interpreters used to provide interpretation should be qualified to Level 6’. This is incorrect as Level 6 does not qualify anyone to be a BSL interpreter. Only registration with the NRCPD and/or [...] makes a person a professional BSL interpreter. This must be changed as holding Level 6 does not compel anyone to follow a code of ethics and conduct and there is no recourse should malpractices happen. I am surprised that deaf organisations who you have consulted with have not stated the above unless they have been ignored? I hope that the latter is not the case.”

“This section seems to focus on BSL interpreters. It is not clear how quality considerations will be included for other formats of information or types of support. The design and use of quality written information requires understanding of /by the target audience, language, communication, document/ product design and an analysis of the purpose and goal of the document and the information it aims to convey.”

“I think family should be a valid option in certain circumstances but not be the default option.”

“Health and social care staff should not be used unless they are qualified (and practising) interpreters also. This is because whilst they may be able to accurately interpret medical information their receptive skills might not be good enough. Information is a two way process and in a medical setting it is vital that the medical professional accurately understands the patient for them to treat correctly.”

“Family members tend to edit information according to what they think the patient should know and should not be used.”

“In mental health situations BSL interpreters experienced in working in mental health should be used.”

“A national database of qualified and checked people to use would be helpful.”

“Maybe needs a bit more on this, service user input on easy read design?”

“I believe it's essential to engage with PWLD and other patient groups when developing information as our view of what is easy read / accessible may not be the same as those requiring the information.”

“We think that independence of interpreting is vital for reasons of safeguarding - a local SUI related to interpreting [...]”

“We also think that language interpreters should be subject to quality standards and that use of [...] should not be advocated.”

“Whilst it may be a good idea for organisations to avoid using family or friends as interpreters, there may be times when they are the most appropriate person. Therefore it is important to think about how to engage with them and ensure they do have a good understanding of the information.”

“It is very important to be aware and make others aware of the fact that family, friends, or unqualified interpreters are not covered by insurance to interpret in this area. If a mistake happens or something goes wrong it could cause massive problems for the individual and the health service. (All interpreters used need to be RSLI with NRCPD).”

“I am not an expert in the qualifications people should have for this purpose - but it should include funding to pay for the right standard and expertise.”

“BSL interpreters should be registered with NRCPD.”

“Concern regarding the statement in Section 10 regarding translation - feel there is a paradox with social care/health staff acting as interpreters to the people they support. Needs clarification.”

“It needs to be more robust and if using people who use the services they should be employed and paid for the work.”

“The easy read version is not easy read, the first page comes out with a [...] reading of 19! That exceeds the [...] level of [...] newspaper!!!”

“Keep updating and reviewing them over time and collect experiences and outcomes.”

“I think there needs to [be] quality considerations and guidelines around formatting of emails and texts so that they work with screen readers on computers and mobile devices.”

“The issue about health and social care staff acting as interpreters is a difficult one. I am assuming that you mean in relation to languages. For people with learning disability and/or sensory disabilities, it could be that social care staff are the people who provide the communication support.”

“As well as translators & advocates needing right skills, knowledge & qualifications, there may be times when they need membership of appropriate professional bodies, i.e. BSL interpreters.”

“This section should make reference to choosing written health and social care information from organisations that hold The Information Standard as this is a highly relevant quality standard. NHS England holds responsibility for both standards, and promoting both standards, so it seems logical that the standards cross-reference.”

“How will quality be measured? How will you know what quality of easy read information looks like and the standards it should meet and whether the people producing easy read information have the appropriate qualifications/knowledge and skill.”

“How will you know which qualifications are the right qualifications/accredited etc.”

“[...] warmly welcome NHS England’s commitment to ensure that information and communication support provided to service users are of good quality. And we wholeheartedly endorse its proposals that interpreters should be appropriately qualified and that organisations should seek feedback from service users, patients, carers and parents on the quality of information and support. However, we believe that the requirements for quality information and communication support extend beyond these two important prerequisites. In particular, we believe that first and foremost that the information provided needs to be representative, reliable and based on high quality data or qualitative evidence as appropriate. Equally importantly, we believe that for information to be truly good quality at an individual level, it must be appropriately tailored to the specific needs of the individual recipient. In this respect, good quality information is a fundamental part of, and is therefore intrinsically linked with, a broader culture of person-centred care.

In addition, good quality communication support cannot be delivered through a one-way process of dissemination to an individual. Rather, it must be an integral part of a two-way (or three-way) engagement between the service-user and care giver (and interpreter). We believe the information standard needs to also clearly articulate these requirements.”

“All people giving information or communication support should follow a strict impartiality policy and receive training. Impartiality of the service should be monitored, and user groups involved in scrutiny.”

“Worked examples could be useful to organisations seeking compliance so that they can understand what is expected of them.”

“Should also include quality of information given. E.g. not skipping information or deciding whether the patient needs to know something or not without consulting them.”

“We agree that BSL and deafblind manual interpreters should have appropriate qualifications, however there is no qualification route at this time for deafblind manual interpreters. So whilst we support that only qualified individuals should be used, the provision of this will be difficult for deafblind manual - we would like to see clarification on this aspect. If a service / treatment etc. should not be delayed to find appropriate communication support, then there must be an adequate supply of such interpreters. In reality supply of interpreters is short.”

“We feel that the aspiration to only [use] qualified [interpreters] is absolutely appropriate and paramount - however the supply, patient / client preferences, and availability of qualified deafblind manual interpreters is an issue.”

“In a medical setting, we think that British Sign Language (BSL) interpreters used to provide interpretation should be qualified to Level 6. The current interpreter qualification is a Level 6 however there are fully qualified and highly experienced interpreters who qualified when the qualification was a Level 4. It may be more appropriate to say that only qualified, registered interpreters can be used, this would then not allow a trainee interpreter for example.”

“[...] fully supports the principle that it is important for information provided to people by health and social care organisations to be correct and of a good quality. Although this section includes information in formats such as audio, braille and easy read, the only reference to how this quality will be checked is via patient user groups. Unlike the provision of sign language interpretation and deafblind manual, there is little known work around quality of formats such as audio, Braille, large print and easy read. [...] is currently working on production of guidelines to ensure good quality accessible formats used by visually impaired people, and we would recommend discussion with [...] on this matter.”

“We fully support the requirement for sign language and deafblind manual professionals to have specific levels of qualification, but we would like to see specific quality controls included in contracts for provision of information in formats such as audio, large print, Braille and easy read. We would recommend further discussion with Disabled People's Organisations on this matter.”

“We support the belief that family and friends should not be used as interpreters, to ensure that the patient or service user has the privacy they deserve and that the interpreter has the appropriate knowledge and skill level to interpret the information correctly.”

“It is important that the communication support is good.”

“I think is good.”

“How are you going to make sure easy read is of a good enough standard?”

“Quality control on easy read. Let people who use easy read check it first.”

“It needs to be quality checked as it's no use if the person still can't understand the information.”

“It needs checking with quality control it needs explaining better so people with learning disabilities can understand it better.”

“Explain it better. It needs checking with quality control by people with learning disabilities.”

“It needs to be checked by people who make the easy read leaflets.”

“Not all easy to read is well done. This document is not good. You need to check documents with users to make sure they are properly accessible.”

“This was well understood once 'interpreter' was explained. Why can't staff be interpreters was one question.”

“Good and makes it safe.”

“That's good.”

“It's good.”

“It's ok.”

“Good.”

“Make sure the interpreters are there at the scene. Maybe already there in the practice. It's a good idea to have a help card.”

"It's ok. I agree I think a help card is a good idea. Organisations should know the law."

"Very important and good."

"I think it is good that things are checked."

"I think the idea is very good and should improve the life of those living with disabilities."

"Yes agree this is good."

"The plans make a lot of sense. Interesting."

"Very important and good."

"Good plans."

"Not much has been said about helping people with extreme mental health problems i.e. personality disorders. These people often get disregarded."

"We think that your plans should help to make information and help with communication good quality."

"They're good but the draft standard didn't make much sense as it was very vague and therefore difficult to pay attention to topics such as this."

"There are a few issues that don't seem to have been considered, such as; will people be able to request a known and trusted interpreter or advocate (assuming they meet the standards)? There are often not many people with learning difficulties on patient groups and many Disabled People's User Led Organisations are under-resourced, so health and social care organisations will have to make a special effort to work with these groups. It should also be considered that sometimes people will be too ill to ask or care if a healthcare professional is qualified to interpret/support, or to object to them acting as an interpreter/supporter."

"You should put something in about asking supporters parents and carers and advocates about someone's support needs because they may know the person best."

"We agree it is a good idea to work with patient groups. It is important to make sure these groups include people who the information is for. Including people with a learning disability. We agree that people should be able to choose have support from someone who is not in their family if they want."

"To ensure that people and staff have the support they need."

"Good as it gives a platform to work on, which is good for individuals."

Appendix 8 – (Question 15): What do you think about our plans for making sure that organisations follow the standard?

“It appears too many sections of the health sector are trying to do the same thing. All it needs is a user group of various disabilities to offer their expert advice independently.”

“Display feedback in viewable format.”

“I feel that providers should engage to make the standard work and [make] access to services more accessible.”

“Proposed arrangements are too weak, there should be a wider range of organisations involved in monitoring what happens in practice as the standard is implemented.”

“Fine.”

“Health and social care organisations should also have a mechanism to pass on patient comments/concerns.”

“I am worried that organisations and the NHS will not follow the standard, whatever you do.”

“It all looks great on paper, but we know that corners are cut very easily, (you can take a horse to water but you can't make it drink!!)”

“Seems ok and good to involve CQC and local Healthwatch.”

“The time limit is about right fines should be imposed if limit is lengthened by a considerable time.”

“The standard sets out clearly what organisations are expected to do. I feel, however, that in a great many cases the standard may not be met, and I am particularly thinking of GP surgeries and pharmacy leaflets on medication. A common response might be ‘we have no staff to deal with this’.”

“Good - training very important.”

“Two clicks away-try to keep all links clicks away and make sure information is easily reachable in that manner.”

“There could possibly be a role for local Healthwatch organisations to assist with monitoring of the standard's introduction, as well as its role in encouraging organisations to follow it.”

“This is appropriate and achievable in the timescale specified.”

“The support appears adequate and we also welcome the support to voluntary organisations and third [sector] to help them assess, monitor and challenge compliance with the standard outlined in the Implementation Guidance. We would hope the support is offered to a wide range of organisations working on health care issues including smaller and organisations working with marginalised groups such as black and minority ethnic communities.”

“To ensure that this standard is adhered to it is essential that organisations are monitored on their progress and success. We welcome the engagement that you have had with CQC and PLACE and appreciate that this is still a ‘work in progress’ but feel that a definitive measure is essential. Whilst Healthwatch, patient groups and charities will be interested in encouraging organisations to follow the standard they may lack the capacity or authority to enforce or support when services need improvement.”

“We would also welcome a central contact point for individuals to be able to raise concerns if their needs are not being met or for organisations to contact if they would like support. This would also need to be accessible in itself, for example a text enabled phone line and email address, as well as information about the standard, the rights of the individual and how to raise concerns produced in other formats such as Easy Read to be disseminated to relevant organisations.”

“These seem reasonable and achievable and link to existing mechanisms.”

“Agree. Patients and carers should be included at all stages including decision making.”

“The implementation of the standard could also be monitored by the Equality and Human Rights Commission. Including the standard in the NHS Equality Delivery System would also help implementation.”

“More detail and information is required. Services would benefit from resource packs to promote the standards e.g. posters and leaflets about the NHS England standards and resources to monitor the quality e.g. audit templates, accessible patient feedback resources etc.”

“We are very concerned that the excellent content of the standard will not translate into the necessary changes in practice without a more concrete commitment to formally, regularly, assess all providers’ adherence to the standard, by an established regulator. Under the Equality Act, providers are already required to ensure that their service is accessible to people with hearing loss but lack of enforcement of the Act has meant that providers fail to make the necessary adjustments. We are keen to ensure that a similar situation does not occur when this standard is published.”

“Regular, formal assessment is needed to see whether providers are adhering to the ‘must’ requirements that have been proposed in the standard. For example,

although the standard states that providers must have a published and publicly available accessible communication policy, it is not clear by whom and how frequently compliance with this criteria will be assessed.”

“Relying on local Healthwatch, patient groups and patients themselves to monitor performance is insufficient and requires resources. Even if there is the capacity to do this in some areas, it is likely to be only a piecemeal approach across the country, and in any case providers may not consider it necessary to engage with or act upon the feedback that they are given since it has not come from a formal regulator. We believe that a nationwide audit by NHS England or specific inspections by the Care Quality Commission are required to ensure that providers meet the detailed and well-considered requirements of the standard. We also believe that the suggestion for commissioners (to assure themselves that organisations that they commission are complying with the standard) should be strengthened. Compliance with this standard should be a mandatory aspect of all contracts, and should be regularly reviewed by commissioners when they review compliance with other contractual requirements.”

“Where measures have been proposed to assess and assure compliance we are concerned that these may not always be a good indication of success. Publishing and displaying an accessible communication policy, or an accessible complaints policy, does not mean that the policies are being consistently adhered to. Focussing heavily on receipt of feedback to assess a service’s accessibility is problematic because even if an organisation is performing well in accessibility and encourages service user comments and complaints, this does not guarantee that they will receive feedback that reflects their efforts. Several of the ‘assessment and assurance of compliance’ criteria relate only to the receipt of feedback; there should also be an outcome that assesses how services have responded to feedback and adapted their services accordingly. Otherwise there is a danger that organisations will encourage a high volume of feedback but will not act upon it, which will ultimately be even more frustrating for the service user.”

“The impression given is that we can only encourage providers to meet these requirements, which is unlikely to have much impact given the current strain that services are under. It is a good idea to require organisations to show their accessible communications policy and to work with CQC, PLACE assessments, patient groups, Disabled People’s Organisations and Healthwatch to encourage and monitor implementation of the standards.”

“Our membership have brought up various issues including the point that access to information is a current legal requirement which health and social care providers should be adhering to currently. Providers should be reminded of this and prompted to implement any necessary changes as soon as possible. However it is clear that the focus should be on the principles of the standard rather than focussing on a prescriptive approach.”

“The document states that organisations will ‘have to’ follow the standard but how mandatory is it and how could it be enforced?”

“How will this standard be incorporated (if at all) into CQC regulations? If not seen as a mandatory requirement it risks marginalisation.”

“There are likely to be objections on cost and practicality grounds despite the Standard’s worthiness in principle.”

“It is essential organisations follow the standard. However, ensuring compliance can be difficult without regular audits. Annual improvement should be recorded with results that demonstrate improvement to meet the standard.”

“The [...] has worked with the government to develop the [...], with SLTS and service users heavily involved. This contains ten performance indicators which could be used to record how services and organisations are meeting the vision and aspirations of the standard. This also contains a self-assessment tool for services to review their own practices. Such tools will be crucial to record what services and organisations are doing to meet the standard.”

“There will need to be clear consequences for organisations that do not meet the standards. We are concerned that whilst some organisations may appear to be complying, their use of generic information or support may mean in reality that individual needs are not being met.”

“User feedback should be recorded. The percentage of people with communication support needs who use services who agree their needs and preferences were responded to sensitively when interacting with the service would be a good measure.”

“We agree that these should provide useful routes which are sustainable and part of overall health service accountability. However, we would appreciate clearer outlines for how to report non-compliance and clearer outlines for how non-compliance will be addressed.”

“There do not seem to be any clear plans for effectively monitoring implementation.”

“What role will the local CCG and NHS England play? What will happen if organisations fail to comply?”

“The suggestion of using PLACE inspections doesn’t seem appropriate.”

“This is overly ambitious - it has taken so long to get the consultation available. We have only one chance to get this right for everybody.”

“As explained previously to change the ICT systems and to implement, within an LA with no resources, in such a short time frame on top of all the other requirements in the NHS change programme is not feasible.”

“Good.”

“Mandatory clear explanation on website (GP surgeries, for instance).”

“Mandatory clear explanation posted at all reception points. By clear I do mean simple bullet points to let patients know they can request special accessible communication modes.”

“Good plans have explained in this section, however, there should be encouragement for service providers and Healthwatch to use patient champions who will benefit from this standard.”

“I think the proposed provision time line is about right as it gives a framework for implementation. However communicating with people with communication disability to ascertain needs could become a box-ticking exercise without skills in place to know how to adapt language to ensure dialogue is meaningful. There needs to be ongoing training to improve awareness and skills.”

“I think including these in CQC inspections and involving local Healthwatch is a very good idea.”

“I think they are good and need to be enforced.”

“I strongly agree organisations should produce a communications policy. Too many have nothing or only an interpreting policy, but of course access is about more than providing an interpreter.”

“Communications is essential and can make all the difference to patient outcome by enabling patients to have sufficient information to self-manage, return to hospital only if there is a real need to do so etc. It assists cost efficiency and enhances patient experience and can have a good psychological boost which can aid recovery and speedy return to normal life. Good communications needs to be linked to incentivisation i.e. QUIPs etc. and importantly patient experience of communications should form part of PROMS and patient surveys and given prominence in outcomes evidence.”

“It needs to have proper promotion by health and social care organisations and be included in education sessions so that it is probably embedded.”

“Organisations should already be doing this under the Disability Discrimination Act 2010. That they are not is unfortunate. Clearly current guidance and the policing of that in action, is failing. Please include a reference in your guidance for nurses not to make comments to deaf patients such as [...]”

“I am not sure if PLACE visits/inspectors are the appropriate vehicle to monitor this although the visits might be a good opportunity to see if the appropriate information aids are available for specific services.”

“I think they are adequate.”

“I think local healthwatches and CCGs need to make their public meetings and consultations accessible to deaf and HOH people before they can implement their roles in making sure organisations follow the standard.”

“I think everyone should be aware of the needs of all deaf and HOH people, whatever communication method they chose, and I think that whoever wrote this report needs to understand the roles of all communication professionals - BSL interpreters are only one type - there are others.”

“Good.”

“I just hope checks will be carried out regularly.”

“I agree that this should be part of the audit process for CQC, Healthwatch, Monitor, TDA, etc.”

“It is important to audit to ensure implementation and opportunities to share best practice across the areas.”

“Patients need to be able to access support to complain as it may not feel possible to complain through official processes.”

“I think that once implemented spot checks should be made by users to see that the plan and standards are working. Perhaps there can be an accessible NHS website where users of services can report their experiences on a set day, location and what communication support etc. they received so that it can be actioned if not satisfactory and if it is the NHS can praise areas.”

“I am still not sure about the quality of inspections especially the CQC. I would also think that the Quality report of Trusts should provide an assessment of compliance audited by service users and carers.”

“Not sure this will make a real difference, we have been working to achieve a more inclusive approach to communication for many years and progress is slow. To do this properly does require more resources and more time.”

“Not qualified to comment.”

“I worry that if there is no national audit to check against compliance that some organisations won't deliver the standard during this time of cuts and austerity. I think people need to be held more accountable and audited against delivery.”

“Let the money follow the standards and the organisations just might help you. If not, go and pitch this to the [...] and CCGs and see what they tell you.”

“A great start, would like a regular reviews of how it is working, all data should be collected and regular forums with service users should be promoted at every level.”

"I think as a guide it is excellent. I think knowing many of the small organisations or large departments, it may prove difficult unless there is monitoring, it may become just another thing they should do and do not know how to implement or have the time. That's where we come in and our role can be to make everyone aware of the standard and be open to questions that we could forward to you."

"If you review my long answer above, your timeline is too short to activate nationally across a host of organisations. As a GP myself, I know the current agenda is huge, and the task of identifying and recording disabilities is a large job, and the introduction of the various communication modalities will take a long time. I suggest you do not dishearten staff with an unreasonably short timeline."

"For services who have not done this before this will be quite a challenge, I also wonder how good the quality of this accessible information will be. Just ticking boxes? There will be a cost implication for services that have not provided this information. Will there be any training? Poor accessible information is not helpful."

"Fine."

"Quite weak as there is no compulsion for GP practices and other organisations to do this- though it should happen via Equality Duty already it does not happen."

"Without a concrete way of checking organisations follow the standard I think that the implementation will be patchy and lack quality."

"So many patient level IT systems are in use across NHS services to manage patient information. Work will need to be done with software developers to ensure that any future upgrade of software includes the communication of need question/assessment so that this can be recorded at the point the patient registers or is seen in a service. I am unsure how such development takes."

"Here I am somewhat cynical since the CQC has failed dismally to check the quality of care it was set up to do. I am not confident that they will do any better with this new initiative."

"This must form part of the CQC inspection and be specifically reported if it is to be embedded and become part of the culture."

"I think having a feedback form and suggestion box in each department would be good."

"Given the chaos apparent at present you will probably need more time."

"These sound good on paper, but run the risk of adding yet another layer of paperwork. They are likely to become yet another series of boxes to be ticked."

“I think the Chief Executive should be held personally responsible for ensuring that the resources to adopt the standard are followed and that CQC should always check its application in all inspections post April 2016.”

“I think this is good. But I think there should be a lead person to see this through within organisations especially the acute sector. This could be the acute liaison nurses or the equality lead?”

“Time frame may not be realistic considering the resource issues mentioned previously.”

“This is the area that concerns me most as we already have guidelines not being followed and to make this real it has to have an absolute measure of monitoring to ensure all services are following. This could include local organisations with local knowledge to be the trained sources for monitoring - in same way as mystery shoppers. However they have to be selected and trained to ensure they are going in with correct remit and not own agenda - it can get so personal. Yes add it to the CQC however they are not necessarily the experts on communication either?! I don't know enough about PLACE however it is encouraging to see in this review 'thinking out side of the box' from the usual suspects - if you get my drift :-).”

“You could also utilise the expertise of local groups such as [...] or [...]. They consist of people with learning disabilities and more than any outside experts would be able to tell if the implementation actually works.”

“It would be helpful if the CQC did random checks to ensure that the standards were being followed.”

“See previous open text box.”

“The Accessible Communications Policy should also be monitored and results of the monitoring should be readily accessible/available.”

“Could include a question on the friends and family test.”

“Appropriate.”

“A bit weak, they must train their staff on the standard and have checks that they are doing so but also regular checks with people who need information in other formats should also be done and in a variety of ways. It is not clear what will happen if the standard is not followed, presumably it would be pursued through the complaints system but often they are not accessible so the organisation needs to test their complaints system with real people who might need to use it.”

“Should be ok if everyone plays ball!”

“This seems reasonable - it needs to ensure that it is robust and that organisations are required to report explicitly on their performance against the standard.”

“The whole document is carefully thought out. There are some areas of repetition which may be necessary to ensure that people who only read one or two sections are fully informed. The Implementation Plan is as comprehensive as the rest of the document.”

“Fine.”

“I agree that this needs to be monitored in some way to ensure equal access for all across England. If not monitored by the CQC, could this be included in such a way that allows commissioners to follow up providers and gain assurance that organisations are following the standard?”

“A process would also be needed to ensure the CCG are also following the standard.”

“Could it be good practice to provide evidence in annual reports, or used as evidence for the Equality Delivery System?”

“This is key to ensuring the standard is met. Encouraging local Healthwatch & voluntary agencies to be aware of this is a good idea as they are well placed to receive feedback from the people they support.”

“Think the responsibility for passing on the information about their patients hearing problems should be with their GP when they write requesting a consultant consultation. Also the medical schools should give proper training about all disabilities which they do not at present. Why should it always be the voluntary organisations who have to do the checking?”

“I think that it needs to be made clear that GPs need to provide their information in braille not just hospitals.”

“Unclear what will happen to an organisation which fails to follow the standard. If there is no incentive, then it won't happen.”

“It will be difficult.”

“Seems appropriate - need some consumer feedback of what is actually happening and this would need to be done in a variety of ways e.g. questionnaires won't necessarily work for people with poor literacy but focus group type work might. Many of the people who will need these standards will be sensitive about needing the assistance so feedback needs to be sought in creative ways.”

“I'd like to beseech you that you apply what you suggest! Especially in the case of care homes who seem to be self-governing with standards too often.”

“Health and social care staff need training in how to work effectively with interpreters. It is pointless booking an interpreter if the member of staff then speaks directly to the interpreter, rather than letting them interpret, or the member of staff avoids asking

questions or saying something because they feel the interpreting process is too slow. They have to know how to use an interpreter effectively.”

“I agree with the proposals however would just like to take this opportunity to vocalise that to my knowledge the Directorate whom I am employed by [...] ensure that such information is clearly documented on service users' records and we are always kept up to date with regards accessing a variety of formats to ensure that all information provided to service users meets their assessed communication needs. Personally, I have highlighted the requirement for information to be provided to one of my service users who was blind and requested that all information is provided in an audio format. I approached [...] who provided this type of communication method which the Directorate funded.”

“I think it is a shame you use words such as 'make sure' I would prefer enable and support.”

“It would be good to develop a kite mark which organisations can use on their websites to demonstrate their commitment to the standard.”

“I think it is woolly. There are a lot of should. That makes it optional and in the current climate it will end up on the back burner. Having an accessible complaints policy is just a tick box exercise that will achieve nothing.”

“The provision of tools and templates would provide a national standard and appear to make the transition easier for organisations.”

“I think that the monitoring of organisations should be more clear cut. And sanctions for not meeting standards better described.”

“I think that proper implementation of the standard has huge implications for organisations/services and it may be helpful/more realistic to break the goals down and have a staggered timetable for meeting different parts of the standard. Telling people what they need to do doesn't enable them to do it; developing accessible information and support services takes time, expertise and resources. It will be better to have high quality development in some areas than to have lip service paid to many. Proper auditing of the standard is important so that it is clear that this should be a priority for services what the overall standard being aimed for is. Whoever is auditing needs to have necessary expertise. Defining the standards/information formats is key.”

“In general, 'other body' checks e.g. CQC take far too long to be implemented. The second paragraph in this section is the most essential, as long as the response can be made swiftly and meaningfully. It should also include details of how to follow a complaint through to the next level (whatever that might be!)”

“I think there will need to be a lot of training, as most people probably don't know what accessible information means, don't know how to support people and would not know how to access interpreters.”

“I can't obviously access the consultation document.”

“This standard has been a long time in coming and I can fully agree with all other matters set out in the consultation.”

“Organisations should be given a 'kite mark' to show that they are following the standard.”

“The NHS is not, in my experience, good at communicating with hearing impaired people (that being my own problem). There is a real need for staff to become more deaf-aware and for greater availability of simple aids such as portable loop systems. Many of us can't hear consonants properly without a loop and there are few occasions when it is more important to hear clearly than in a medical consultation. Staff need training in this area, and it is sadly lacking at present.”

“Acceptable.”

“I think rather than using punitive measures around compliance giving organisations an opportunity to work towards the standard, be assessed in some straight forward way and then when achieved display a logo at a minimal cost would be a far better incentive to organisations.”

“Ok.”

“As well as having accessible complaints services organisations should have accessible comments boxes or comments boards so that positive feedback can be left as I am sure it would be if the standards are embraced. It will also allow for organisations to learn from each other about what works well and what could be done better.”

“About right.”

“It is vital that they do and this should be assessed.”

“They are, in the round, sensible and appropriate. The sooner they are implemented the better.”

“This is fine. Again, I would say that encouragement on the part of health and care professionals would be good - to proactively check with people if they have understood the information or are happy with it, and if there is anything they would change. Doing an audit of the quality with patient groups (in this case, specifically of people with learning disabilities) may help. Also, organisations monitoring their recording and sharing methods to make sure they are fit for purpose.”

"I'm not sure if there will be processes in place to measure the overall effectiveness of the standard? In other words, is the standard demonstrably achieving its aims?"

"I think the bit that is missing is the responsibility of the information provider not just to produce accessible information to ensure (as far as possible) that once the information is accessed it is relevant."

"Poor- Section 17 says it all: The Specification for the standard defines a number of conformance criteria which should be used to assess and ensure implementation of the standard. Leaves the process open to huge local variation (due to costs, higher local priorities) and inconsistent patient care, so why bother at all? Some places already provide this and others don't - nothing will change without dedicated processes and staff identified above, led from the top."

"There may not be the appropriate levers to apply for the many independent contractors in the health service."

"Ok, but needs to be specifically included in every contract service specification."

"These are fine but an audit trail must be kept through PLACE etc. to ensure continuity of the standard is kept."

"Great. I hope this will become a legal and binding plan in the future."

"It has been needed for a long time and once implemented should be closely monitored to ensure organisation stick to it."

"I am concerned that bad practice may go unchallenged but recognise the value of involving the CQC. Awareness-raising by user-led organisations will be key in ensuring that individuals request and receive the information they should be receiving. Thought should be given to when and how the standard should be extended to social care as health and social care providers work more closely together. Also, how will the standard apply where services are outsourced?"

"Adequate."

"PALS is also another source where people might ask for help. But dentists and opticians need these formats to."

"Perhaps needs to be more explicit but you will need to do a pilot first to test out anyway."

"They are well-intentioned. Whether they work remains to be seen."

"Monitoring is always difficult: proof will hopefully be provided by patient/customer response."

"I think the plans sound good. I think it would be helpful to involve the Care Quality Commission in checking that organisations are following the standard."

“Adhering to the accessible information standard should be regulated by the CQC. Such a standard is essential to ensure that all individuals are able to access and engage with healthcare services.”

“Garbage.”

“The standard makes no mention of the group of people for whom the suggested framework would not work. Therefore any plans to ensure compliance are seriously flawed!”

“I am keen to see if this has any real 'teeth' for organisations who do not comply.”

“Good.”

“Training might help organisations to carry out implementations.”

“It mentions a 'Communication Policy'. I wasn't sure if this related to a whole organisation - e.g. a whole council or whole NHS trust or whether it related to smaller departments - e.g. housing / one clinic. I think this could be clearer.”

“Required to have a standard procedure by all organisations.”

“Good that Healthwatch can be involved.”

“I think it is fine as long as the organisations have the resources to make the implementations and the message is passed on through the organisations - that will be the main challenge. Hopefully you will advise/give tips on how to make this happen.”

“It seems inadequate - for the standard to have an effect, there needs to be a process for evaluating whether the standard is met and consequences for not meeting the standard.”

“I think the PLACE assessments and Healthwatch involvement will prove useful, but the other methods are probably not that worthwhile.”

“Seems reasonable but more support for the groups would be valuable.”

“This is always a challenge when there is no requirement to implement standards. Every effort should be made to embed the standard in strategic policies and plans. Consideration could be given to recognising 'champions' and the sharing of good practice.”

“This is good but I think you should include mandatory training on Deaf Awareness and Communication Training.”

“There is no section 17 on the document.”

“Given that it's almost 20 years since the DDA 12 months is a relatively short time. You will need to positively reinforce anything you do until it becomes accepted practice.”

“It's important to ensure that these standards are met and I'm glad that the first step towards improved care for patient with learning disabilities is made. However, with no or very little practical support available, and without taking into consideration the practicalities around implementation, we are setting ourselves up for failure.”

“It's good.”

“Advice is not the same as supply of resource/funding.”

“This idea needs to be prioritised against the many other demands being made upon a broken overstretched primary care system. This is exactly what is destroying primary care - a dictat that will then be measured with no obvious funding attached to resource the implementation.”

“As an organisation we have public documents that are sent out monthly and change each month....which are only currently done by band 3 admin. Their needs to be more staff employed to get these formats produced online and through paper consistently. Jobs need to be created and focused on till this standardisation becomes familiar and routine.”

“Just about right.”

“Good.”

“We need everyone to be singing off the same [hymn] sheet.”

“Just ask patients/carers if they understand the information being given - ask them if communication is working.”

“It is very prescriptive, and limiting. Small organisations that provide excellent patient support information may not have the financial support or facilities to provide the long list of 12 - impractical to say the least!”

“More flexibility and an understanding of specialist small organisations compliance to what is obviously designed to create another quango within the NHS.”

“There is scope for third sector groups to support the implementation of the standard, which is intimated in the Implementation Plan but which should be more explicitly detailed.”

“Your final sentence is presumptuous - it needs the suffix - standard if it is seen to be valid in practice.”

“A policy is a good idea as long as it is specific to that service as not all services have the same needs. Also the correct departments/ [...] are included in writing the policies to make sure everything is included.”

“Needs to include local authorities, not for profit and for-profit organisations supplying health and / or social care.”

“It also needs to include all the organisations who now provide health services who are not part of the NHS e.g. private sector bodies and charities.”

“It would also be useful if a 'how to' element was included as hard pressed staff on the ground often do not have time to think about how to implement important initiatives such as this.”

“Without teeth it may be difficult to ensure this is employed and utilised consistently.”

“The plans are good, but I feel it is going to take time for it to be up and running properly.”

“They seem to cover the requirements. Once this has been implemented, adjustments may need to be made when you can see how it is working in actuality.”

“Not convinced the capacity exists.”

“Good but the organisations will say no money. I do not want this to be an excuse - most of the changes do not require additional costs.”

“Ok.”

“Again these will need to be reviewed depending on the uptake of implementing the standard.”

“The first contact for any patient is the receptionist either face to face or on the phone. It is vital that they have appropriate training to be able and confident enough to implement the new standard and recognise patient’s needs.”

“I think a contents template for the accessible communications policy will be important. Our Trust has its own guidance for creating policies but a contents template will help us ensure we've covered everything, particularly if different departments are involved in developing different sections of the policy.”

“I think the training needs will be significant if organisations are to be able to assess how effectively these plans are being implemented e.g. if part of the assessment process may involve Healthwatch or similar, how will this be funded?”

“Adequate.”

“About right.”

“I think that it is good.”

“Again, this is fine, but the accompanying communications, training and development package needs to be robust.”

“These look adequate, in particular the use of the PLACE inspection programme, and the involvement of local Healthwatch.”

“I don't see how one can make sure this standards are followed since these plans are only inferred and don't have any legal obligations.”

“Needs more teeth – [...]”

“Not sure whether this is going to mandatory or not. The consultation document uses the word 'should'”

“It is my honest belief that this needs leaders and spoon-feeding to organisations. Why doesn't the group commissioning this survey write a standard policy for example rather than expecting each organization to produce their own?”

“If we measure compliance by organisations like the CQC checking this will become a tick box exercise for organisations with wonderful sounding policies and boxes of unused easy read info and audio tapes etc.”

“It's good that they have used the law as a factor because the law is there to follow and should be respected not brushed off.”

“As described above, I would support external scrutiny. There will need to be clear consequences for organisations that do not meet the standards.”

“I think it is a good thing.”

“I think that the consultation suggests some ways in which organisations will be 'checked', however at this stage it does not seem that any of the ideas are particularly developed. I think that ensuring there are rigorous auditing measures in place is essential. If they are not in place there is a risk that the whole proposal about making information accessible will become simply a 'tokenistic' pie-in-the-sky idea that is never actually put into practice in a 'real' way for clients.”

“My answer to Q13 above is because I think section 12 should include family carers in the first bullet point (about sharing information with others). The Confidential Inquiry into Premature Mortality in People with Learning Disabilities noted the importance of family carers understanding a person's health needs and being involved in supporting treatment plans.”

“I also think there is an opportunity for the 'help' card proposed at the end of section 12 to be made common across the public sector (for example, to include police).”

“Someone should have overall responsibility for checking compliance - someone independent but with local knowledge.”

“We think that NHS England should do more to check this will happen. They could give funding to other organisations to help check this is happening e.g. self-advocacy organisations etc.”

“It needs to be concise simple, short and straight to the point.”

“NHS England is a very large and complex organisation and it may be difficult to monitor the standard. I know the equality act and the equality duty may be driving this but it may be difficult to follow up unless it is short and simple for organisations.”

“As per my reply to question 12 although I think that it is extremely important to check that organisations follow the standard, those checking also need to possess sufficient skills to check and I am unclear how this will happen in practice. For example checking that organisations have easy read information is not the same as checking that this information is of good quality and can be understood by people with LD.”

“Section 12 stated: Sharing people’s information with interpreters, translators, communication support workers and advocates. This is a breach of patient confidentiality and must not be done without the patient present and/or agreement. Medical/care professionals have often done this to me and I felt extremely disempowered as I have no idea what has been said about my condition - for some it adds extra stresses and/or generates some level of paranoia as to what has been shared. This is unacceptable without the consent of the patient.”

“The items for advice and support are relevant as a checklist. However it is not clear how these will be implemented or what the processes are or content is for ensuring that 'quality' is maintained.”

“A BAT required versus BATEA used ratio (see above) could be a useful metric in combination with satisfaction levels.”

“I just hope that organisations do follow the standard, and we do get the communication problems addressed.”

“My hope for the future is that people have more patience to understand others’ frustrations. And they do get the support they need and not what the organisations think they need.”

“Recognition and specific understanding of the communication needs of those within the autistic [spectrum] are missed.”

“We are content that the right organisations are involved to assess compliance with the standard.”

“Value for money does not always equal good professional service in my experience.”

“BSL interpreter provision should be provided through specialist BSL agencies and not generic translation/interpretation services - they are very different.”

“Medical professionals have the right to insist on using an interpreter if they feel they are not correctly understanding a patient as they have responsibility for prescribing and treating. Some Deaf people will say they can manage without an interpreter but it is equally important, possibly more important that the medical professional is able to obtain accurate information. Traditionally the BSL interpreter is seen as being there to support the Deaf person but this is not the case, the interpreter is there to ensure that accurate information flows both ways.”

“Re: second paragraph about feedback - a lot of organisations already have their own feedback method with technical partners for NHS England’s FFT - please make sure everything you do joins up.”

“Linking into existing frameworks/ inspections (e.g. CQC and Local Healthwatch) seems appropriate and far better than creating a completely different system.”

“Need to make sure that advocates are available to people with learning disability.”

“More regular checks may be needed on communication needs.”

“Organisations need to be able to identify people with learning disability.”

“Who will enforce the standard and will there be consequences if organisations don’t?”

“We think they are good but we are aware from personal experience how difficult it can be to actually get organisations to do this sort of work. We would suggest educating service users and carers about what they should expect combined with educating organisations.”

“q13 - healthcare in the CJS [Criminal Justice System] will need more support. They work as a silo often and will not have the momentum of the rest of the NHS doing it. Could there be specific advice for implementation in unusual settings? I could possibly help with the CJS info.

q14 - I say too long (for the criminal justice system) as everything takes longer and they need the support of [...] and the prison governor to often make big changes or spend extra time on things. You need the healthcare managers on board.

q15 - you definitely need the inspectorates to include this in their criteria for it to be implemented in the CJS. The other good practice examples would need a lot of push to make happen.”

“It is not clear on who is going to make sure that organisations follow the standard. It appears that the standard is seen as good practice rather than mandatory therefore it will be difficult to enforce.”

“Will obviously need to be monitored closely. Will the standard be mandatory? What will the consequences be of not adhering to the standard? I've been trying to champion the need for accessible info across the 2 organisations (1 health, 1 social care) in which I work for the last 2 or 3 years. No-one has been prepared to commit any resources or time. I think there's a faint awareness that organisations have to do something (I believe the Equality Act says this) but it always seems too costly(?) Needs a high profile campaign with a high profile figurehead.”

“These are helpful in terms of promoting accessibility for patients. We think it should also form part of the NHS contract so that commissioners can monitor compliance and seek assurance from providers.”

“It may be appropriate for organisations to share information with family carers as well and so the advice and support for organisations should address this issue as well.”

“Yes it is about right.”

“Sadly I think organisations can manipulate any information and stats to prove a point - so careful monitoring - probably independent of the organisation - may be essential.”

“This appears to be satisfactory.”

“(Re 13 above) Deaf Awareness training should be provided.”

“Consideration should be given to making this a CQUIN standard.”

“Re: q13 would recommend that the authors include examples of good practice.”

“Q15 It's ok.”

“How will organisations know about the standard to respond via an Accessible Communications Policy?”

“I am glad it is now being implemented. It should have been standard policy a long time ago.”

“Impose fines if high quality information and support is not given.”

“This is going to be tough but give local Healthwatch and Health and Well Being Boards a role to monitor and comment on what is happening in their patch.”

“There needs to be extensive support and advice provided to NHS and adult social care services. One way of ensuring that they get expert advice is to direct them to involve disabled people wherever possible.”

“I really welcome the plan for training and support materials online for services to use but there also needs to be a programme to promote these resources and the standard itself as well.”

“This is probably the biggest area of concern. Providers will need an incentive for consistently meeting the standard. Involvement of Healthwatch and CQC are possible options to be considered to make this more robust.”

“We think this needs more work with organisations asked to self-audit against a given set of criteria backed up by CQC inspections. CQC inspections will not cover everyone due to the sheer volume of this work.”

“We think scrutiny could be provided by local Healthwatch groups via the use of patient feedback and satisfaction surveys.”

“My concern is that the complexity of implementation by various organisations will be underestimated e.g. developing skills in producing easy read.”

“Organisations such as CQC, PLACE programme and Healthwatch will require extensive awareness-raising to enable them to monitor the delivery of the standard effectively and to know what good practice looks like.”

“Cost and complexity issues may confound the ambition behind the standard. Smaller social care bodies may find it difficult to implement.”

“We agree with the principle of accessible information but this will be hard to implement in pharmacy due to the number of stakeholders involved in pharmacy practice.”

“Under the advice and support given to organisations, they will need advice around how to choose good quality accessible information. This should include advising them to use information from organisations that hold The Information Standard. NHS England holds responsibility for both standards, and promoting both standards, so it seems logical that the standards cross-reference.”

“Patient stories and patient experience should form the core of feedback to ensure that it does not become an administrative process or based on the reports of others. That if the standards are in place there is evidence from users that they are actually being implemented.”

“[...] believe that section 13 of the consultation document setting out NHS England’s plans to ensure compliance with the standard is too vague. For example, whilst it states that organisations should publish an accessible communications policy and seek service user feedback on their experience of receiving information, it does not state how this publication or feedback will be used by NHS England, or others, to ensure compliance.”

“NHS England’s expectations of the role of local Healthwatch organisations, patient groups and charities in encouraging organisations to follow the standard are also unclear. We urge NHS England to provide more detail on the mechanisms that exist (statutory, regulatory and otherwise) to ensure or encourage compliance with the standard.”

“This is relating to section 12- but no box available. -The support needs to include a proforma policy on giving impartial advice, and impartiality training.”

“Organisations should be required to do an annual report- much like local authorities are required to do in relation to the SEND Local Offer.”

“These are appropriate so should be effective.”

“This is rather top level and needs to be explained, such as whether there will be regular audits, spot checks or requested submission of compliant materials.”

“The plans are fine in principle, and charities such as [...] will be able to support the monitoring of the standard's use. However, we must emphasise that it is vital for there to be a consistent and regular review of organisational compliance, which should be undertaken (as suggested in the document) by the Care Quality Commission. If the CQC are unable to undertake this duty due to lack of resources, an alternative body or organisation must be engaged to ensure monitoring coordination and overall quality of accessible information in the NHS.”

“With regard to section 12 and 13 a) within the guidance it needs to be recognised that some people minimise their communication difficulties perhaps because they are embarrassed about it or 'not wanting to make a fuss', staff need to be aware of this and may need training into how to be alert for signs of communication difficulties. b) to do this properly and train staff and change practice will take time perhaps in terms of timescales they could be phased.”

“It is reasonable to expect every organisation to have its own policy.”

“The organisations need to be aware that many people especially recently deafened will not have any knowledge of communication support available to them.”

“The organisations may need to take into consideration to be proactive themselves towards newly disabled person.”

“Ideally we would welcome more 'teeth' to the plans, i.e. there are organisations that can rate the services, and challenge but no reference to how that rating or challenge could be pursued further when non-compliance continues.”

“These are reasonable but would expect that these organisations would offer support as a 'critical friend' and share good practice.”

“We support the provision of guidelines around implementation of the standard. We would also include information about where providers of support. We know that it is common for social care and health providers to commission block contracts with providers of services, such as sign language interpreting agencies and transcribers of information in different formats. This is often done in the belief that money can be saved by regular use of the service; however, people may have relationships with local providers of services that they would feel comfortable to have support from in their health or social care situation, so [...] would encourage use of local service provision.”

“We would recommend guidance to health and social care providers and how they can make their standard documents as accessible as possible, firstly so that they can be read by as many people in the community as possible, and secondly so that where conversion into different formats is necessary, that conversion can be done as cheaply as possible.”

“We fully support the introduction of systems to enable people to highlight their communication needs and to feedback on their experiences of the support they receive.”

“[...] and its members will fully support and encourage health and social care organisations to follow the standard, and would wish to engage with local providers to provide service user feedback on their experiences of its implementation.”

“We believe that it will be important to ensure an external check on whether the standard is being met. We would support measures to involve the Care Quality Commission. We would ideally like to see involvement and feedback from disabled young people, as distinct from adults, as part of this process to ensure that their needs are being met. We would suggest that if any organisation’s accessible information policy be proactively provided to any person after it has become apparent that they have a communication need. We would also suggest also that they receive a reminder about it every, for example, two years. We would be concerned that information about the policy may be ‘published’ but not be easy to find or that a deaf young person would not think to look for it unless their attention was drawn to it. We also recommend that NHS England proactively promote the accessible information standard directly to deaf young people. We would be pleased to support efforts in this area.”

“Good plan.”

“It seems a bit voluntary. What happens if it isn't followed?”

“Some surgeries might not take any notice of the new standard and there's nothing in the standard saying what would happen if they didn't follow it.”

“There isn't enough about what will happen if organisations don't do it.”

“Not enough reinforcement.”

“Not enough enforcement. Too voluntary.”

“I think there is not enough enforcement to follow the standard.”

“Not enough enforcement.

“Happy with this.”

“Not sure.”

“Good.”

“It's needed.”

“Not sure.”

“It is good.”

“Too weak.”

“That is good.”

“Very good.”

“Very good plans.”

“It will make things better when you are sick.”

“There should be rules in the council.”

“I think that this is very important. I do have concerns as to exactly how you are going to do this.”

“Not sure if all organisations will do this.”

“They are probably ok. Very good. Professional. Ok. Reasonable.”

“Very good plans.”

“Good plans.”

“The implementation policies seem thorough.”

“The plans are good - we will be able to challenge organisations that do not follow the standard.”

“Standard was difficult to understand but it did seem practical.”

“These plans seem good, and particular emphasis should be placed on including Disabled People's User Led Organisations in making sure that the standard is implemented and followed.”

“You need to keep an eye on this to make sure people stick to it.”

“We are worried that organisations only have to do the best they can to meet the standards. We are worried that because of money cuts they will say they are not able to do all the things in the standard. We want to know if there is going to be special money for services to make sure they do the things in the standard. We want to know what will happen if organisations do not follow the standard. We will use the standard when we carry out review visits. We will use it to tell services that they need to have this kind of information and support. But because of lots of cuts to health and social care money we do not know if projects like [...] will get funding in the future. We think that if you want projects and charities like us to tell people about the standard and checking if services are using it, there needs to be more funding available.”

“Financially it's compulsory.”

“Good, [...] will then be able to help each individual.”

Appendix 9 – (Question 16): Do you have any comments on the specification for the standard which are not included as part of other questions?

“Individuals rather than organisations.”

“Agree that needs should be noted and prominently recorded in notes but there is a need for re-assessment if needs change.”

“It seems mostly thorough.”

“Landlords may attempt to evict tenants because of their disability. It is essential that the tenant can access all relevant medical correspondence.”

“If your document is fully accepted the outcome will make a tremendous difference.”

“The specification for the standard should include a penalty. It should not include any stress.”

“More specific comment is needed on ensuring individuals are able to give informed consent or that they have an appropriate advocate who is formally able to consent for them.”

“We found this quite repetitive and confusing - but it has not yet been reviewed by anyone with a technical/IT background.”

“On computer systems there should be clearer information and good quality systems which are accessible and people friendly.”

“Reference to communication support is a very important and a much needed inclusion to the standards. To emphasise the importance of the communication support we would recommend a change to the title e.g. ‘Making health and social care communication and information accessible’ and ‘Accessible Communication and Information Standards’.”

“The definition of accessible information provided focuses on accessible information as a resource rather than the ‘process’ of making information easier to understand, which includes communication support in the delivery of accessible information.”

“Supporting policies should reference [...] Communication Standards and other key documents produced by [...]”

“It would be good to reference other services that would benefit from these standards e.g. the Criminal Justice Service – given the legal ramifications of non-compliance with the standards under the Equality Act, Mental Capacity Act and Deprivation of Liberty; it would be beneficial for these standards to go across the board. A whole systems approach is needed.”

“Within the implementation guidance, it is important to highlight that accessible communication and information should be embedded within all levels of the organisation.”

“It is not clear if this standard is applicable to children as well as adults and older people, please clarify.”

“Not able to consider the specification.”

“How will this work for commissioned services from NHS? I am commissioned to do Easy Read by my CCG.”

“In section 9, the final paragraph, an example of video conferencing, like [...] or [...] should be included.”

“I could not find the Specification on the website.”

“More incentivisation to identify communications problems where patients do not declare them or only partially declare them - relies on good communications skills - otherwise all this will just become a box ticking exercise and perhaps not reach patients in genuine need of help.”

“It is a valiant try. My responses are influenced by my personal circumstances, but I do know I am not alone. I regularly open a blind friend's mails - and there are always threatening letters from his GP about nonattendance at appointments of which he was notified by letter. It's ridiculous.”

“Having worked as a medical receptionist, I know how easy it is to flag up a patient's needs on the computer system. What is not so easy is to respond adequately. Perhaps I was extremely fortunate to work in a group practice where we were allowed to leave the counter and actually help people: to write things down, to take time, to assist them in any way goodwill and common sense dictated - albeit untrained. Would be nice if the focus was more on the needs of the patient and staff training, rather than 'efficiency'.”

“Needs to include people with acute communication impairments, i.e. due to stroke, head injury, etc.”

“Suggest you look on the [...], we need access for all to get your evidence of need. Many people here are struggling - especially with NHS - and they are not all BSL users. [...].”

“Happy to advise / support in any way.”

“I feel that communication of the specification needs to be thought through to ensure all organisations responsible for implementation are aware and start to make the changes to support good patient care.”

"I think this is long overdue and all professionals should make BSL interpreters available for everyone who is Deaf. At the moment it's like a postcode lottery if we get an interpreter. I think more Deaf awareness training should be given to NHS staff as I find they are worse for not booking interpreters as they say they aren't allowed to book face to face interpreters but can use [...] by phone, which is a joke for Deaf people."

"Section 2: People who need support to communicate, for example through a British Sign Language (BSL) interpreter, deafblind manual interpreter, or from an advocate. I think it needs to be clearer that more people are hard of hearing than Deaf and mention them specifically here as they are a group most likely to miss out."

"Don't just use BSL as the example, it perpetuates the idea that all deaf people can hear fine with hearing aids or need BSL when it's much less binary than that."

"Hospitals for example are hideously difficult to hear because of a lot of poor deaf awareness by design practices. Curtains do not a soundproof space make. Confidentiality and privacy is being eroded as more and more multiple consultation rooms are used. I have great difficulty insisting on a private room for consulting, even one other person talking or making noise in the room means I can't hear the speaker I need to hear. Medics have atrocious deaf awareness on average, they are not good at things like explain first before examining as I can't follow examination instructions and give feedback - it's too hard."

"Clarity of Finance information [...]."

"I would also like to see care and nursing homes have to provide clear information to clients."

"Only to consider metabolic rare diseases that do not fit the usual bill, do not fit into boxes on anyone's list and that if standards and speed are not implemented for care, this can mean death very quickly."

"Also, where do the transition young people (16-18) fit in?"

"Looks good."

"The standard needs more information on what communication needs people may have and how to identify communication needs (without relying on just asking the person). It also needs more information on what conditions can cause communication needs to help organisations to consider groups that aren't immediately associated with communication needs (brain injury, dementia, stroke etc.). I know the focus is on giving people information but communication is 2 way so some guidance on supporting people to communicate is also needed."

"I would like to see all people being cared for whether by state funded care or by their own means, covered by the same standards. I would like all care providers to have to comply with the same national standards."

"It seems odd that you need to explain the Vision, this would imply it's not clear enough in the first place."

"Asking a person once when they first come into contact of their needs is not sufficient. People's needs change over time so there needs to be a proactive approach to ensuring the most appropriate communication is provided over time."

"Dissemination and training of the implementation and usage of alternative communication for staff will be critical to make this work. Training and understanding of need by staff will therefore be crucial and must be addressed."

"What plans are there to actually ask someone if they need alternative formats, writing to everyone won't work!"

"This has been a long time coming and I welcome the improvements."

"I would like to see something included about how people are made aware of their turn to see the consultant. Most hospitals still just have staff calling out names: this is no good for people with hearing loss. We need visual displays - or a text messaging service."

"I rather like the fact that you have removed race and focused on people, I hope you understand my comment is not racist but based on equality for all!"

"The standard does not make mention of Speech and Language Therapy. As part of an NHS Communication Therapy team made up of Speech and Language Therapists and council employed Communication Development Workers we provide a service to adults with a learning disability. SLT's play a key role producing detailed reports regarding the communication needs of individuals and they provide invaluable information and support to professionals and others who support people with a learning disability. SLT's should be mentioned prominently in the Standards Document."

"Also, Makaton is listed in section 8.4; Signalong should receive an equal mention as it is adopted as the preferred signing method by many services."

"Research should be taken before Braille is implemented. It is a common misconception that blind people read Braille, unless you are taught when young, it is most difficult to learn and therefore the percentage of people actually using it is very small."

"I probably do just cannot think of them! Apart from what I have already commented and fed back on already within this survey."

“To keep in mind the knowledge that family members and friends may have, especially for people with limited verbal communication. Family members and friends will know the person best and what their specific needs are.”

“For a document that is a draft standard on ensuring accessibility, the document in some points is unclear and repeats itself.”

“Ref Q13 - there should also be some signposting to specialist organisations e.g. [...] etc.”

“It is very disappointing that no consideration has been given to develop standards for Cross Cultural Communication considering Britain has such a diversity in population with many cultures and languages. Why has standards for interpreter services and multilingual leaflets/ audio-visual material been completely excluded? Very disappointing and worrying.”

“Can we be sure that all people with communication/interpretation problems will be properly briefed about the new standard?”

“In response to the section on how quickly will information and support have to be provided, I agree that it should not lead to delays, however, I am concerned that in reality it has to. There is, for example, a desperate shortage of deafblind manual interpreters and it is highly unlikely that one will be able to be booked at short notice and that appointments will have to be moved to find an available interpreter. In addition, transcribing information into Braille, audio and Moon typically takes several days and sometimes much longer. I am concerned that appointment letters for short notice appointments will not arrive in reasonable time or may even not arrive until after the appointment was scheduled. Therefore, I think that it is absolutely vital that organisations find out how long it will take to transcribe information and move appointments to take account of this if necessary. If somebody does miss an appointment because the accessible information arrived too late, it is essential that the person is not penalised for that.”

“I think that the section of population that come under your labels of 'people with a mental health need' and 'people with learning disabilities' are the ones who will be least well served by this. The two categories cover such a varied range of needs that they should not be lumped together, but thought about more carefully as specific needs.”

“The consultation document should be more obviously accessible so I can have a say as a visually impaired person.”

“See above - too many different documents to seriously consider in the time available.”

“I think it has been researched well and put into an easily maintained system but must be continuously monitored for updating as required and as things change.”

“Hopefully enough people will be employed to undertake the vision.”

“As a person with a moderate level of visual impairment, I do wish organisations would stop using sans-serif fonts for body type. They are fine for headings and short sentences, but are exhausting in paragraphs. Please encourage [...] to think harder about this one.”

“Categories are too limiting.”

“Deafblind - a huge difference between congenital/acquired, and within those two categories a wide range of different needs.”

“Not or a learning disability. Needs to be and / or. Or are these complex patients not included in these recommendations?”

“Suggest an ‘other’ category, that a GP in discussion with a carer, (with probably best knowledge of a complex individual) could dis-apply the restrictions of the standard and specify what is in that particular patient’s best interest. This may be a person/people specifically discouraged by the standard.”

“No mention of the security of the data.”

“Overall the ideas look good. But the matter is when and after it is implemented. I hope there are some contingency planes available.”

“Only what I have already stated.”

“There is evidently a massive training need for organisations. I think it would be useful to work with organisations, e.g. [...] more about this.”

“It will be important to make sure that people with specific communication/info needs do not have delays to their treatment.”

“This reads as being obligatory with CQC monitoring and will be seen as another nail in the coffin of primary care.”

“No issues about the content as an idealistic system but it seems to make what GP practices currently do informally and targeted to individuals become a micromanaged administrative monster.”

“Good.”

“The vision statement is too wordy. It doesn't allow for communication issues arising for patients/carers without 'information or communication support needs relating to a disability, impairment or sensory loss'. There are many general communication issues between patients and staff.”

“Who monitors the monitor?”

“How much is all this extra inclusion going to cost?”

“No details of the information you will give out in terms of what makes information easy read/ accessible.

The [...] have recently released [...], have you considered these in you plan?”

“Nothing else to add.”

“As a consultation is a 2 way process the patient him or herself has a very important role to play and has responsibilities. If someone needs their hearing aid to hear they must wear it and install a working battery. If they wear glasses to see and read they should have them with them. If dark glasses or a peaked cap help don't forget them. If the glare from a window is causing a problem ask to move or draw the blind. If background noise is interfering ask for it to be turned off or to be moved to a different location. All of this will help and inform both parties and smooth the interaction to come.”

“Make sure that all documents meet plain English standards.”

“Unless language support is recognised as a serious needs and considered in every Public Sector and CCG JSNA it will be very difficult to avoid risk mitigation and cost saving.”

“It is not clear if this standard is applicable to children?”

“There is increasing reliance across the public sector on providing information online. However, many disabled people and family carers do not have access to the internet and/or cannot afford to print out lengthy documents. It is important to retain the option of paper copies and face to face explanations.”

“All views expressed above.”

“I feel that video interpreting technology and services should be considered as a viable service especially when one cannot find a face to face BSL interpreter within short notice. Furthermore because BSL interpreters on video come from a different region from the one I live in (last interpreter I used on video was based in the Orkneys!) I feel more able to be open and free with my medical condition as I do not know who the interpreter is personally. With an interpreter locally I see them in other work or social contexts and it has proven difficult for me to be open with the doctor if they are there as my interpreter - for me I prefer video interpreting over face to face interpreter and this hopefully should be added to the standards now.”

“I cannot seem to find information on the Specification for the standard.”

“Section 12 highlights support for 'Communicating with patients by email and text message'. I think support will be required via many media and so this seems restrictive.”

“Needs of people with Asperger's.”

“See response to no 15. The standards would need to be enforced and not left to the discretion of the individual. At present Deaf people are often told we will manage writing things down, it’s ok when the guidelines say an interpreter should be used.”

“There does not appear to be any reference to font colour and background which can be important for some people to improve accessibility.”

“In some cases (e.g. very long documents/ user surveys) it is perhaps unrealistic to expect all of this information to be provided in some formats (e.g. text message) so there needs to be a recognition of this somewhere in the standard.”

“Yes, point 24 - Organisations must ensure that patients, service users, carers and parents with information needs (a need for information in a non-standard print format) are sent or otherwise provided with information, including correspondence, in formats which are appropriate, accessible and that they are able to understand (in line with their identified needs). PWLD won't necessarily understand info even in an easy read/ accessible format and this must be considered by those sharing the information with them. Staff will need to check info has been understood.”

“We feel it is the responsibility of all professionals to ensure that they are using the information with people and families in ways that maximise understanding. For example, talking through written information with people (which may take more time), checking out people’s understanding, and doing this on more than one occasion. We are concerned that there is a danger that this standard will encourage health professionals to see ‘communication’ as a specialist’s job.”

“It is important not to assume that everybody has access to the internet. Evidence shows that many people with learning disabilities do not have easy access to computers.”

“About right.”

“A good start - but not sufficiently innovative to change culture for the benefit of patients/carers.”

“I fully support this Standard. I think it will encourage organisations to be more Deaf Aware, and to comply with the Equality Act, and UN Convention on the Rights of Persons with a Disability, (section 25). As a Consultant Psychiatrist working in Mental Health and Deafness, I often come across examples of providers failing to meet the needs of deaf people, putting themselves in breach of the Equality Act and the UNCRPD. Hopefully, this standard, if properly implemented, will help challenge this.”

“Whatever is published please keep it.”

“Short.”

“Simple.”

“Well linked to other initiatives (i.e. not stand alone).”

“Maybe a quick guide with links to other sections for those who want more.”

“Less is more!”

“The Vision is an example - keep it brief and meaningful.”

“Please consider contacting [...] from [...] to discuss the Communication Charter which has been implemented in [...] Learning Disability Community.”

“The whole process when up and running must be owned and shaped by service users and carers.”

“The draft standard has real potential to change the extremely frustrating experience of those living with hearing loss, at whatever level. With most people affected by hearing loss using the spoken word as the method of communication, sign language is of absolutely no help. That's around 6m people. We agree with many of the comments made by [...] in this regard.”

“Once the standard has been approved, there needs to be a real drive to support its implementation. Organisations will need to be persuaded and will need lots of tools and practical examples of good practice to adapt. My worry is that people will get stuck between wanting to get it right but not knowing the next step.”

“The name 'Accessible Information Standard' is confusing, because it is so similar to the name of the pre-existing Information Standard. This issue has been raised on numerous occasions by The Executive Council of the Information Standard, on which NHS England sit as they hold responsibility for this Standard. Health information professionals have commented that they find the similar names unclear. So the similar names will be even more confusing for those not within the industry but who the standards affect – health and social care professionals and patients. We would urge you to consider changing the name, before the Accessible Information Standard is formally rolled out to a wide audience.”

“As highlighted in our response to question 10, [...] would like to reiterate that the principles upon which the standard is built should not only apply to a standard for disabled people's information. Rather, every health and care service user has the same right to accessible information. We believe that NHS England could do more to articulate and commit to this.”

“We also believe that the standard should set out more clearly who will need to follow its requirements. We note with interest that the requirements apply to all NHS and adult social care 'bodies', however it is not clear from the consultation document whether this includes for example statutory and non-statutory bodies operating within the NHS in a non-care provision capacity (for example regulators and NHS England itself).”

“It does not feel at all joined up with the other information duties i.e. the Children and Families Act relates to adults up to 25 who are receiving the same services, but have separate info duties under Local Offer regulations. Locally, this is making it very hard for us to plan for the 16 to 25s.”

Appendix 10 – (Question 17): Do you have any comments on the implementation plan for the standard?

“Staff will need training by 3rd sector in how to convert some parts of the formatting.”

“Given 12 months will think about it until month 11 if at all. 6 month maximum with certification that it has implemented it.”

“Older people have changing needs and sometimes complex problems so can't be a 'Once and for all' assessment.”

“Meeting timescales.”

“It seems mostly thorough.”

“I can't help thinking that in the 21st century, we are in a sad state if we are not already taking care of every type of communication. I don't understand about the discrimination made to parents not being able to pass information on sometimes, especially for adults, may be not children because of accuracy. Privacy is important, but in matters of urgency that can't always be considered.”

“There are a lot of voluntary organisations and the third sector should be included and a penalty should be imposed.”

“Implementation in 12 months will be difficult to achieve due to size and complexity of organisation. Issue regarding systems that are not owned by the Trust - for example some are large national ones such as [...], therefore changes would need to be initiated nationally. As such there would be the need to engage with system providers and include them in the adoption of the standard and the consultation.”

“With regards to the strategic assumptions and the mention of ‘reasonable adjustment’ duties under the Equality Act, this is also an opportunity to widen the scope of the scope to include foreign language interpreting due to the health inequality and access to healthcare that organisations should be enabling as part of their duties around health inequalities under the Health and Social Care Act.”

“We anticipate that implementation will be easier once the new GP referral form is introduced next year to include the question about preferred communication mechanisms, but we are concerned that the plan is too tight and over-ambitious given other pressures and priorities.”

“Some training may be required for key health and social care staff, e.g. working with interpreters, working with specific communication tools. This should be included in the implementation guidance.”

“Regular monitoring and accountability.”

“From our perspective as a Clinical Commissioning Group the timeframe for implementation is about right. Provider organisations especially those with multiple electronic record systems following trust mergers may struggle to implement by Spring 2016.”

“Need to recognise that for some, information and communication needs will change over time. Therefore when recording an individual's needs, a review date should also be set to assess and record any change.”

“[...] is in favour of the plan including recognition that working with local charities and voluntary organisations can be of benefit to local health and care providers in achieving acceptable standards of accessible information. However we are concerned that the standard and the implementation plan and guidance have been developed without proper engagement with community optical practices. Many of the assumptions made – about patient registers and the role and use of IT in patient records and referrals – do not currently apply.”

“We feel it would be useful to engage with patient and user groups during the implementation phase to gauge levels of experiences and get user input into future plans.”

“Not able to consider the implementation plan.”

“You need to consult wider. Providers should not be running consultations e.g. [...]”

“As mentioned above, I would like the April 2015 date for online patient records access to coincide with campaign for accessible communication channels.”

“GP surgeries need to understand this is a Must do not a simple would be nice to have.”

“How will the third sector be required to be involved in the pilot?”

“I could not find the Implementation Plan on the website.”

“See earlier re implementation.”

“Just that it needs to be consistent and done simultaneously.”

“The implementation of the plan should be across the board and someone needs to check that it's being put in place as Deaf people won't complain or make a fuss.”

“I would be interested to know what sanctions will be applied if organisations fail to comply with the standard.”

“This is a mammoth task. Could there be different time lines for different aspects? Some will be easier to implement than others.”

“Timescales for implementation may vary dependent on software suppliers being able to upgrade the systems which are used for patient management or electronic patient records. Some of the information is likely to be already captured but not all of it.”

“I would like to see private care providers included in the implementation.”

“I really think someone should lead on this even if only for 12 months? This should be equality leads or equivalent within acute care (hospitals).”

“I'd like to see it done in 12 months, but think giving 13-24 would be safer in that people might think 12 months too short and give up before starting! I really need such information and would wait a bit longer, rather than being told it was unachievable, which I have been told in the past.”

“Financial implications, especially if there is an increase in requirements for interpreters etc. and how this will be met - what will be the impact? We need to ensure all avenues of support have been considered to meet people's needs.”

“No because the consultation document is not obviously accessible.”

“Detailed. Have significant concerns about the ability of services to implement this within relatively tight timescales and service pressures.”

“Need to consider how to include in contract implementation alongside CQC requirements.”

“Pilots are a very good idea and should highlight any major areas that need further work.”

“Would like to see health and social care working closely on this.”

“See above- too many different documents to seriously consider in the time available.”

“No, have not accessed it.”

“The standard is right - it is not so high that it cannot be achieved but put where it can be achieved and should be able to be maintained at that level.”

“Just talking to some of the health charities.”

“Being shorter would focus the priority needed to implement any improvements required.”

“I think that 12 months is much too long a time for clients to have to wait to have this implemented it is way overdue and we have suffered unacceptable standards for years!”

“Quality service costs more.”

“Timescales are ambitious, and I fear, unrealistic. I think that further pilot work would be needed before whole implementation.”

“This needs to come from top down within organisations, us minions have to wait for the hierarchy to be bothered and I don’t have a lot of faith that they care at middle management level!!”

“Good.”

“The only comment I can give is the sooner the better.”

“Please please involve patients/carers in the implementation. Let us show you what we want/need.”

“Just to say I hope CQC are able to offer ways of monitoring the standard as I think one of the most challenging things will be to ensure organisations are using the Standard effectively.”

“The implementation of this standard is left to be used as a tick box no more no less.”

“All views expressed above.”

“An excellent standard and I hope that the above comments with regard to registered status of the interpreter and the introduction of video interpreting technology would bring the standards and implementation plan up to the 21st Century and prevent wasting more resources in adding this on.”

“I cannot find 'process' information about the Implementation Plan for the standard.”

“I think it is unlikely that organisations will be able to implement a full reporting standard in a single year and so they should have 12 months put everything in place to begin operating against the standard but 24 months before a national published assessment.”

“Communication needs of people with Asperger’s.”

“You should ensure you consult with disabled people - deaf, blind and people with a learning disability.”

“The ability of organisations to accurately record and keep up to date preferred information and communication formats should not be underestimated.”

“There will be additional financial implications for organisations which should be acknowledged. Very few organisations currently have a dedicated accessible information budget.”

“[...] would be happy to help you.”

“Good standards are needed, implementation is essential - but am concerned that people are holistic individuals and health and care should be only part of their aims - and needs to be treated as part and not the whole of their life or care.”

“Whilst everyone would agree the need and importance of making information accessible - there are major challenges for organisations working in an acute setting to meet required needs in terms of BSL interpreters who are very short supply, are expensive and not easily accessible out-of-hours.”

“It will require central encouragement, support and training.”

“Sounds ok with the above caveats.”

“It is important that staff have an awareness of the different needs for communication and know where to find the information they need to implement the standard. As a Deaf person I am forever raising Deaf awareness issues linked to my communication needs with staff and forever getting frustrated at the failure to follow through because others have not understood the issues. Without this awareness of needs I fear as a Deaf person I will still be banging my head against a brick wall when it comes to my needs as a Deaf person. I am not sure it is realistic to expect all staff to have had this training in 12 months in order to understand the communication needs.”

“Use local Healthwatch to ensure delivery by NHS organisations.”

“Couldn't find the implementation plan so no comments!”

“Ensuring that commissioned services are also working to the same standard will be crucial with so many services outsourced.”

“We think that the plan should include recognition that working with local charities and voluntary organisations can be beneficial to local health and care providers in achieving acceptable standards of accessible information. These organisations are often the local experts in accessibility and can provide good advice and guidance.”

“The implementation plan should go beyond providing advice and guidance by providing accredited training for staff. The front line staff are where this standard will either succeed or fail and they need to be adequately equipped to meet the needs of their patients.”

“[...] believe the implementation stages set out in section 7 of the consultation document are broadly sensible however we note that they are vague in many important areas.”

“We also have concerns about the practicalities of implementing some of the stages, in particular the requirements in relation to recording and responding to information and communication needs using existing computer systems and resources which may not be set up, or adequate, to do this. We urge NHS England to work closely with providers of both care services and IT systems to understand the feasibility of its

requirements and any system, process and resource changes that may be necessary prerequisites to compliance.”

“I could not find the info on the pilots. Please could you email me? [...]”

“This should be set out in greater detail with a timeline broken down by month and sources of support and advice linked at each stage of implementation.”

“Needs some advice or indication of what measures should be taken if an organisation fails to meet the standards.”

“[...] welcomes the requirement for health and social care organisations to actively record the communication needs of patients and service users. It is important that people receive information relating to their health and social care needs in a timely manner and in a format that they can access easily. There have been past examples of patients having to wait until they see family, friends, work colleagues, or even someone they do not know (e.g. taking a letter to a local Post Office) to have vital information about their health condition read to them, and it is often inappropriate for someone who is not close to them to have to relay such sensitive information.”

“It is also important that information can be shared from one department to another so that people only have to explain their need once to a particular organisation. There are moves to integrate health and social care records so that both organisations can access related data, but whilst this is not the case we acknowledge that both organisations will need to record this information separately.”

“We support the introduction of a pilot to test out the implementation of the standard. However, beginning this in Autumn 2014 may be a little tight given that this consultation ends on 9 November 2014.”

Appendix 11 – (Question 18): Do you have any comments on the implementation guidance for the standard or support for organisations?

“Not all parts of healthcare give feedback some even try and change it alone formatting?”

“Should allow for revised assessments as stated above.”

“It seems mostly thorough.”

“Perhaps a telephone helpline for organisations could be set up as well as looking for evidence i.e. policies.”

“Beneficial that standard does not record disability - just needs. People focus far too much on the disability and not the person.”

“Part of the guidance should be about adhering to the Nolan principles. Some sort of honesty or charter that says we are doing everything we can to implement the standard.”

“Again, there could be role for local Healthwatch in being invited to comment on draft standard documents for organisations wishing to comply with the standard.”

“We do feel that the patients with foreign language need should also be included in the standard as mentioned above. As importantly because of the inconsistency in addressing and providing interpreters which will enable such patients to be better informed and have a better experience of health services. Notwithstanding the evidence (e.g. [...] [...]) of the effect of poor language interpreting provision for communities who by and large have poorer health outcomes.”

“We welcome the information given to providers and recommend that you include signposting to relevant organisations in this. This would also serve to be an awareness raising element to the standard.”

“Support such as the toolkit will be crucial and will need to be delivered on time if you want to meet the deadlines suggested.”

“Funding implications for implementation for some or most organisations and support mechanisms required...”

“Easy Read resources produced in relation to the standards should be piloted with a range of individuals with communication and information needs.”

“Service users with cognitive communication needs found the Easy Read Standards too long and quite complicated. During the delivery of the resource, the facilitators found the document a little repetitive and the key facts became a little lost in the detail. A two page summary highlighting the key points of the accessible communication and information standards would be beneficial.”

“At present, the implementation guidance does not include the general communication requirements that a staff member should adhere to when communicating with anyone with hearing loss. The most basic but often overlooked communication requirements are outlined in the ‘General communication requirements’ in our response to Question 10. We strongly recommend that these are included in the Guidance so that they can be referred to in writing, as well as being covered in any training sessions.”

“Communication support vs communication professionals.

The Implementation guidance and consultation document refer to four categories of communication/information needs: (1) requires specific contact method; (2) requires specific information format; (3) requires communication professional; (4) requires communication support. Whilst we understand the distinction between (3) and (4), these are not the terms that are normally used – communication support is usually a generic term which would include ‘communication professionals’ (as well as the devices, equipment or tools that might support an individual). If communication support is chosen as a term to refer to any communication support that is not a communication professional, then it would be helpful to provide a definition in the glossary, and also to ensure that the term is consistently applied throughout the Guidance and accompanying documents.”

“Support materials and training

The Specification and Implementation Guidance refer to a range of support materials that will be produced to help organisations implement the standard and to raise staff awareness and confidence in identifying and meeting needs. We would be very happy to contribute in any way we can to the process of developing these resources and supporting the implementation of the standard. We would also be happy to be part of the training offer to help organisations understand the information and communication needs of people with hearing loss.”

“Checking of implementation needs to be agreed and publicised. Who will police the standard and what will their powers be to deal with non-compliance? Will they have budget to assist and advise?”

“We do note that although some of the issues surrounding IT systems and data collection have been noted in the Implementation guidance (p18-19), there is no practical suggestion of how this can be achieved and how NHS England will support NHS service providers in potentially redesigning IT systems.”

“[...] has published research and best practice guidance on producing and providing high quality health information which could be usefully linked to for organisations who are implementing the standard.”

“Professional bodies must play a crucial role disseminating information on the Standard to its members and ensuring that they are geared up to respond.”

“References should include [...] standards of conduct and/or [...] – not just doctors’ and nurses’ standards. In particular the [...] should be referenced. This highlights reasonable adjustments to communication that individuals should expect. Standard 5 is discusses good practice for involving people in appointments and standard 1 is based on knowing how people communicate. We would be happy to share this with you.”

“The [...] is disappointed that all the examples of finding out if someone has a communication support needs are far too simplistic and focus on people with verbal abilities, who are deaf or blind. There is not one example of someone with complex communication support needs.”

“[...] and our consortium of [...] would be delighted to support with dissemination of information and production and development of guidance.”

“Not able to consider the implementation guidance.”

“I could not find the Implementation Guidance on the website.”

“Will need local champions to make this work.”

“Need to link with speech and language therapists and [...] who are experts in this field and have already done a lot of excellent work. This project will provide a stronger motivation for services to take this work forward.”

“As already given - has to include somewhere the benefits of ROI - e.g. less errors when information is communicated first time effectively and evidence of that by true examples and evidence. Already there are examples of having captions on videos the ROI for even businesses so make use of those stats as real evidence.”

[...] has already prepared a 'preferred Format Request Card'. I would suggest that this is used rather than devising an entirely new system for the health and social care industry. This is not only an expense consideration, but it also revolves around the idea that some users will already be familiar with the [...] card and will hence find it easier to complete than an NHS alternative. Please see [...] for further information and contact details for the organisation.”

“Looks good.”

“A possible source of support for service providers = their local SLT service who have expertise in communication difficulties and support with a range of client groups.”

“Consultation with [...] is highly recommended.”

“Apart from what I've already mentioned, perhaps highlighting particular resources that staff may find helpful? For example, in the case of learning disabilities, [...] website (a website with lots of accessible health information) [...] And the [...]

website [...]. Along with some basic top tips on learning disability and communication that may alone greatly enhance the communication experience of some people.”

“Probably but too many different documents to seriously consider in the time available.”

“I think it's comprehensive but should not include too much information or too many documents. Make it as easy to implement as possible.”

“Fab!!”

“Good.”

“Practical advice on steps to take to make information accessible to people with low literacy and numeracy skills.”

“Section 7

I think specific guidance would be useful on how to support those with Autistic Spectrum Conditions including Asperger's Syndrome would be useful. I think you need to look at the illustrative examples and think through the cost implications e.g. an interpreter for a GP routine repeat prescription appt. Is there another way of dealing with this? Perhaps give ideas.

I think the resource/financial impact of implementing these standards appropriately has been underestimated. In particular consideration should be given to the demands that may be created for Speech and Language Therapy services.

I think that there needs to be more emphasis on the need to check information and communication support needs and to recheck them to ensure that they have noted it down correctly.”

“I cannot find information on the implementation guidance for the standard.”

“Need to include guidance specific to Learning Disability.”

“A 'How to' guide for organisations would be really helpful, for example which organisations/charities are recommended to use? Is there a database for interpreters? This is really important if people are to implement effectively, especially in a times of sparse resources. It needs to be made easy for providers to put in place.”

“It is a good start but must make reference to the holistic needs of people and not just health and care - people can do a lot before needing care if they have non-medical non-social care information, advice and support.”

“Quite dense in places - keep it short etc. as above.”

“It is not easy read!”

“When considering contact by email. It needs to be two-way. This will make a massive difference to people who are not able to use the telephone as their main channel of communication.”

“It should be linked to the rights outlined in the NHS Constitution, to afford it traction within the existing framework. Similarly with the developing work on feedback and complaints i.e. what happens if someone feels they are not being given the support outlined in the standard.”

“[...] welcome the list of additional guidance headings set out in section 12 of the consultation document and believe that clear guidance in these areas should help organisations comply with the standard. However we highlight that some of the areas appear to overlap or be closely related. For example there is potential for overlap between ‘what makes good ‘easy read’ information’ and ‘making standard documents easier for people to read’ and also between ‘making sure that translated or transcribed information is good quality’ and ‘making sure that interpreters, communication support workers, translators and advocates have the right skills, knowledge and qualifications’. We would urge NHS England to ensure, when it develops its guidance, that unnecessary duplication is avoided and that similar and related topics are combined in concise but comprehensive guidance.”

“In addition, as suggested in our response to question 12, we believe there would be merit in NHS England producing additional guidance highlighting the important and fundamental role played by accessible information, communication support and patient engagement in person-centred care. We believe this will help not only to provide the broader context of the standard (as referred to in our response to question 16) but also to reinforce NHS England’s ongoing commitment to encouraging a culture of person-centred care.”

“Could not find this, but I guess it will be important to ensure that agencies link up with children and young people's services, as comment above.”

“It would be helpful to plan in an evaluation of the implementation process.”

“It would be helpful to have a central or regional register of professionals who meet the required standard for interpreters and communication support (including DBS checks).”

Appendix 12 – (Question 20): Due to the short timescales we have to read everyone's responses and make changes to the final standard, we have limited the space for free text. If you have already given your views as part of the engagement phase, these have been considered in drafting the standard. If you do not feel that you have been able to share your views as part of this survey, please use the space below. We will try to consider any views you record in this section, but will not be able to respond or report on them in detail.

“Answer to previous question depends on how fully it is implemented and roll out times. It will take engagement to roll this out fully as the understanding in sector of formatting is very minimal. Training by users is what is required.”

“We wish to emphasise the point that a key principle of providing accessible information is that it should be available to everyone not to restricted categories of disabled people. Old age is not in itself a disability. There are large numbers of older people who are not strictly speaking disabled but still need information in plain English, easy to read, and in a preferred format i.e. as defined by themselves. Older peoples organisations should be invited to monitor the effectiveness of the standard on behalf of their members.”

“When producing reports please number the pages even if the paras are numbered. Most private individuals have basic printers at home which can give problems on multi page runs. Also when seeking on-line returns ensure that survey is in returnable format.”

“It has been difficult to find the sections referred to in this questionnaire because some IT devices used by blind and partially sighted people do not recognise auto paragraph numbering to the extent that the number is often not displayed. The limitations of these devices should be taken into consideration as it can often save you money! For example, without the device I am using I would have required a hard copy in Contracted Braille but, because this has an electronic Braille line display an emailed text document was sufficient. Note: Braille should continue to be included as these devices are very expensive and often only possessed by those in employment (approximately 1 in 5) or with access to considerable sums of money.”

“Does the patient need to be guided from the waiting-room to the surgery, and Vice Versa for instance? I would need this, as well as guiding at all other times on the NHS site, and staff would need to be aware of this. I know that it is not strictly a communication/accessible information need, but it might be EN Route to that, and without guiding, theoretically, your appointment/need for accessible information might not happen.”

“Q13 continued – Advice could include details of specific organisation that can provide specialist communication support where to access it i.e. [...] and [...] for

Deafblindness. I think I have answered your questions via this email and via the events I have attended but if you feel you want further input please do contact me.”

“The proposed standard should be rated very good but nothing like this has ever been attempted before. It could prove neutral with some improvement but your work is appreciated. Two key points to remember about blind people: When looking at them, speak to them; when in a hospital or surgery environment, remember that they may not know where they are, so extra help is required.”

“Q2 continued no - because it does not include the requirement to record information. The standard should include a separate box for patients to declare what they require. On any information authorities provide hearing induction loop not always available at receptionist desks. Hearing induction loops. The use of text and emails is not always appropriate. Q13 contd. Communication should be by a letter with CD audio. No everyone has emails and mobile phones. All document should be in plain English (no jargon). q20 continued • Ask the individual if they are happy with the information that they have received. It is not enough to go the patient group for feedback as this might not adequately capture the patient’s feedback. • Organisations should be required to pay a penalty fine for not complying with the standard. It should be policed. Regulations came out in 1994 and now it is 2014. There has been a slow uptake of regulations. • Penalty considerations. Organisations should be penalised for not abiding by it. • NHS England should have a role in monitoring whether people are abiding by the standard. • Requirements to record meetings on different formats. • Induction loops need to be checked regularly. The organisation has paid a lot for it and it should work effectively. • Be aware that some users wear tinted glass and information should be provided in a different colour other than white so it can be accessed. Additional comments. • The list did not cover someone who is making appointment etc. for any reason. Text system in place, voice reminders in place. Someone who is disabled is unable to access these reminders. This reminder needs to be accessible. There is a clear distinction between verbal reminders and written reminders. • Disappointed that his feedback has not been available in the format he required. He could have made a written copy of his survey response if he filled it out. However he requires his feedback to be made available to him in the appropriate format - audio. • Audio e-mail- not only should you receive in audio e-mail but you should be able to respond in audio e-mail. • Not only should the standard state what you expect people to do but you should also be able to receive in accessible formats. Heavy reliance on verbal formats.”

“a) Should guidance be given to organisations to cover the fact that an individual’s needs might well change over time? Best practice might be to check (say annually, or three-yearly) whether information and communication needs have changed – and to record the ‘last review date’. Guidance should be set surrounding the expectation that every patient needs clear information. Patients who are ‘borderline’ and choose not to report their needs, or perceive that they have no specific needs, should nonetheless be treated appropriately and all care and administrative staff continue to

be sensitive to a patient's needs, whether or no these are declared and recorded. A specific example of the need for accessible information ... when required to sign a 'consent form' (for example prior to surgery) a blind patient is simply asked to 'sign here', without having been able to read the detail of the form. A suggested improvement would be for the family member/support worker to read out the form and then also sign the form confirming that they have read it out to the patient; the patient then signs to confirm that this has happened and that they consent. A similar specific example would be if a blind person attends a medical consultation unsupported. They should be allowed/encouraged to take a recording device with them in order to capture the conversation. Obviously some caveat would be needed along the lines of 'recorded information would be for personal use only'. The consultation form itself was NOT user-friendly/accessible to one of our registered-blind board members!"

"In general [...] have considered the scope and purpose of the draft standard and agree that the standard will improve patient experience. However, the standard will impact of a number of existing systems and processes in use in the Trust and the implementation of the standard will need to take into account the timescales and the resources required to adopt the standard across the board. Added to this is the complexity of the current systems provided by third parties. A scoping exercise is underway to assess the impact and requirements."

"[...] welcomes the development of the Accessible Information Standard. A lack of communication support and information formats is a common barrier to deafblind people accessing the care that they need and are entitled to, so to see NHS England addressing this is a very welcome step."

"Please note that this response has been drafted by a small group with responsibility for producing patient-facing materials; we have not had the chance yet to share any of the documentation more widely across our organisation, but plan to do so as a next step."

"In general, we think this is a good plan and suspect that many organisations – ourselves included – may be going some way to achieving some of the objectives already. However, we have concerns in relation to the timescales and the additional resources required, especially in terms of suitable IT programmes, project management and training as follows:

- Training staff is essential, but we already struggle to keep everyone up to date on the bare minimum in terms of mandatory training, so adding to the burden will pose practical problems for us;
- It seems likely that additional project management support will be required to implement the standard fully and we might struggle to make the case for that in light of the many other financial and resource pressures we face at present."

“NHS England should always consider involvement and engagement of patient and carers and co-production process. This consultation was hard for blind and partially sighted people to complete as the questions kept referring back to sections in another document.”

“It's not clear what the impact will be as it is not clear what levers there are to ensure that organisations meet these requirements. The impression is that we can only encourage them to meet these requirements, which is unlikely given the current strain that services are under.”

“We support the principles and the introduction of the standard but have to express concerns about the practicalities of how it might be implemented. These issues will impact on both providers and patients/service users and solutions need to be well thought out and practical.”

“We are keen to see this standard work and would be happy to discuss our concerns, and how they can be addressed and also put you in contact with our member organisations who have differing opinions while uniformly supporting the principals of the standard.”

“Q1: The Vision does not give a timescale for the supply of accessible information. Q2: Section 4 of the specification does not refer to the [...] standards for accessible formats. Q13: Guidance provided on implementing the standard should include reference to [...] standards for producing accessible formats.”

“Further to the comments above we would like to raise a number of issues below, which we have aimed to do succinctly in line with your request. We would be very happy to discuss these in more detail if you would find that useful.

- [...] is a strong advocate for the need to ensure information about health, care and treatment is accessible to all patients and members of the public.
- However, our work highlights that ensuring health information is accessible and understandable (both terms that are used within the draft standard) cannot be achieved solely through the ‘format’ of the health information.
- In the Vision section of the Standard it includes ‘information they can understand’. We would like to highlight accessibility as narrowly defined by this Standard will not guarantee the provision of information that people with a disability can understand. The understanding of information is a more complex issue. For example: being able to interpret and use the information that has been provided; health literacy is entirely missing from the draft and arguably low health literacy and low literacy and numeracy present a major information and communication need and affect millions of people in the UK.
- Irrespective of their condition, every user of health information has their own needs, which might be physical, but may also be social or literacy related. To make information accessible to the audience, we need to look not only at the format (whether Braille, video etc.) but also what content is included, what

language is used, what elements are used to make the information appealing and meaningful.

- Similarly in the Scope section of the Standard it states “We want organisations to make sure people get information they understand’. We would argue that improving the suitability of the format the information is provided in, will not ensure patients will be able to understand the health information.
- We are concerned that focusing a standard for ensuring information is ‘accessible and understandable’ solely on format will have a negative impact on the understanding by healthcare and other professionals around the wider requirements for creating health information that works.
- [...], and soon to be published [...], identify the key components of creating health information that is of a high quality. We would recommend that the support resources (section 12) for this Standard recognise the wider determinants of creating accessible and understandable information and signpost to publications such as ours which will support organisations to improve the overall quality of the information support they provide.
- We would like to see the focus of the Standard (i.e. audience and limitations) expressed at the start of the document to highlight that the steps included within this Standard will not guarantee information is accessible and understandable to all patients.
- On top of the above, we have a further concern about the name of the Accessible Information Standard which is already being informally called ‘the information standard’ in some places, confusing it with the existing Information Standard scheme.
- Organisations will be asked to find out if their patients need ‘Easy Read’ information – we are not sure that most people will know what this means or that everyone will have the same understanding of what this type of information is.
- The spectrum of learning disabilities is huge and it is likely to be a challenge for many organisations to meet information needs in this area. Many organisations will have limited expertise in providing this type of information, and where expertise exists it is likely to be under pressure when the standard becomes mandatory. Implementation needs to be carefully thought out.”

“[...] would like to offer our support to further development the standards. There should be mandatory training for all workers who interface with patients/the public on communication impairment and needs. [...] has already developed training for a number of audiences, and would be happy to work with you to develop the content for training for staff interfacing with individuals with communication support needs. References should include [...] standards of conduct and/or [...] – not just doctors’ and nurses’ standards. In particular the [...] Good Communication standards should be referenced. This highlights reasonable adjustments to communication that individuals should expect. Standard 5 is discusses good practice for involving people in appointments and standard 1 is based on knowing how people communicate. We would be happy to share this with you.”

“[...] is a coalition of 50 voluntary and community organisations with expertise in speech, language and communication. We harness our collective expertise to support the children's workforce and commissioners to meet the speech, language and communication needs (SLCN) of all children and young people, particularly those with SLCN.

We do this by raising awareness, providing information and workforce development opportunities, influencing policy, promoting best practice among the children's workforce and commissioning work from our members. [...] is advised by specialist advisors and works with a broader network of partners. [...], which is partner of the [...].

We very much welcome the opportunity to feed into this consultation. We would recommend specific reference within the scope of the standard to those with communication support needs as their primary need, where there is no underlying disability causing the need in addition to those with communication support needs relating to a disability, impairment or sensory loss.”

The vision within the standard is also currently generic across age groups and we feel that specific assertion of how the vision applies equally to patients and service users of all ages would be wholly positive. Disabled children and young people with communication support needs will be disproportionately high users of health services in relation to their non-disabled peers. They will use services throughout their lives. Getting services right from the start and providing for an involved and engaged relationship between service and service user can be effective in terms of outcomes.

Overall the standard has positive intent which we warmly welcome. However there needs to be clear guidance on the range of communication support needs a patient can have. It is certainly welcome that there's an explicit reference to specific support such as advocates or BSL interpreters, but they may benefit from a little more use of examples of more subtle reasonable adjustments – there's nothing about how people are spoken to for example. It talks about format of information but not about the use of language and vocabulary.

[...] firmly believes that a skilled and knowledgeable workforce can provide a positive impact on the outcomes of children and young people with SLCN. We would be very keen to be further involved in the work to support refinement and implementation of the standard where it can be used to have better outcomes for the 1 million children with speech, language and communication needs and their families.”

“Qu 2: Peoples needs may change over time e.g. deteriorating sight or hearing loss. The standard (and guidance) must ensure this is taken into account and peoples' communication needs are regularly reviewed and open to amendment? Qu 2: Peoples needs may be different depending on the health or social care environment, for example as an inpatient in a hospital setting all staff on the ward, including the

tea trolley or mobile library staff, will need to know an individual's communications needs. How does the standard address this differentiation across environments?"

"The help card mention in section 12 might be better called a need card."

"Overall adherence to the standard is likely to require a significant increase in the number of communication professionals (current local experience – it takes 3 weeks to book STTR support). How is this being managed/supported/planned for? Are Health Education England (HEE) involved?"

"Adherence to the standard is likely to require an increase in the production of easy read, braille and other materials. Do local and national organisations have the capacity?"

"Is the timescale of 12 months realistic? A quality approach is preferred over rushed implementation."

"Where is the money coming from to support implementation?"

"How will it be implemented without an adverse effect on current services (if existing resources have to be diverted)?"

"Further assurance is needed around an effective monitoring system for the standard."

"Individuals may not be aware of their rights around information and communication needs. The standard must have some role/obligation around informing people."

"The standard will likely require ongoing and regular training opportunities for staff at all levels of health and social care provision. With a high turnover in some cases, how will this training be supported/resourced nationally?"

"The consultation document seems to be focussed on the provision of information and communications. Services must also be able to receive information and communications from patients. For example patients must be able to send/reply to texts and send/reply to emails (and be assured that these are checked by service staff)."

"We applaud the intentions of the standard, but are concerned about how realistic they are in terms of both timescales, resources to implement and deliver, but also in the specialist nature of the support that may be required, and the ability of services to put this in place effectively, for example within the 48hrs mentioned for routine appointments under section 9."

"Could the issue of assessment paperwork being BSL friendly be discussed? Also the need for deaf awareness training for all staff - this would enable a better understanding of the need for accessible information."

“Disappointed how long this has taken to get the consultation to happen.”

“Do not think provider of services should be running consultations e.g. [...].”

“Pleased to see computer generated letters will be made accessible but can’t see this happening in reality.”

“The step change potential of this guidance will only be effective if there is involvement and funding from NHS England area teams in commissioning primary care information where it does not currently exist, but is required by the standard.”

“Visual information and communication, such as live video chat and visual information (online or DVD) must be included as examples. This format addresses a broad scope of needs and has long-standing value. This format should also be considered in publicising this guidance so that patients are empowered to know that this standard is forthcoming, and when implementation rolls out this is crucial, otherwise people will know and will not have the correct expectations of service providers.”

“The Standard is excellent in raising awareness of communication needs and improving provision. However I am uncertain of the impact of Easy Read. My research provides quantitative and qualitative evidence that 'Easy Read' is very varied, and the method can actually make text more difficult to understand.”

“I have not been consulted as part of the engagement phase, and it is really important you read my views as I have been responsible for the development of qualifications in the non-BSL field and have a lifetime's experience of being a totally deaf person who uses English - there are a lot like me out there, you haven't found us yet!!!”

“I have almost missed hospital appts. because I couldn't understand the nurse's accent when she called me. Hospitals should have dispensers for numbers and visual displays showing the next patients number.”

“This is a positive piece of work in the right direction.”

“In section 5 of document, add opticians and pharmacists.”

“Where relevant add effective to communication.”

“I appreciate the size of your remit, but would be happy to get involved or contribute further if that would be helpful [email address removed].”

“The standard will have a good impact if implementation is monitored and enforced by someone external to the organisation implementing it.”

“If the standards are applied to all forms of care then the impact on people receiving care will clearly be good. Informed choices can be made, people can be more

involved with what is happening to them, professionals can make better decisions. If the standards are only applied to state funded care then many people who are having to fund care because of savings/home ownership will continue to be mistreated, misled, and uninformed by some providers. A basic unfairness in the system will ensue.”

“In general, this is a top-down initiative. Grass roots measures stand a better chance of success.”

“I feel pleased that even at this late stage I have been able to view and comment on this standard (registered blind).”

“I am the manager of the liaison nurse team supporting children and adults who have learning disabilities and or autism. We have in place a system where I receive all the choose and book referrals for this patient group that come in from the GP. I then make contact with the patient or their parent/carer and ascertain if there are any 'reasonable adjustments' that are required for their appointment - this often includes accessible information and or access. I feel this is a very proactive way of ensuring patients have all their needs met this way they are specific to them. For example some patients like photos of the department but other patients prefer symbols etc. - no person with a learning disability and or autism are the same and may need things delivered in a different way.”

“Unless we make this a rock solid mandatory has to happen guide then the impact will be not so great as people will always find a way not implementing if they see it as cost and not as ROI.”

“The people who the standard is actually aimed to help are mostly excluded from this consultation, as many will not be able to use a computer/the internet or read or indeed understand the questions as they are not in easy read. If you want to include the opinions of people that this standard is actually meant to help, you need to think about the format of how you give and ask for information at the consultation stage already. Otherwise you will not get the feedback that would actually matter in making this work.”

“NHS England appear to be justifying their own existence. This document looks and sounds good but in all honesty how much of an impact is it likely to have? Surely their time would be better spent in other ways, e.g. primary care, which needs fixing?”

“Everything appears to be in place.”

“What concerns me is that making information 'accessible' is do-able (e.g. using Braille, text messaging and so on), but it is the language used by the NHS that deters service users. Words such as 'implementation', 'KPI', 'outcomes' 'strategic' - I could go on! These are management terms beloved of NHS personnel and how they communicate among themselves, not to service users. Not understanding the very

words used in information documents can make people feel small, humiliated, inferior. They don't ask what it means - they just keep quiet - so you never know what their views are, which is vital if you are really going to ask for service user or patient involvement. How can they be consulted when they don't even understand the words used? Why use a more complicated word when a simple one will suffice (!) ? This is about power and how it is used to keep existing hierarchies in place. Nuff said!"

"It is very disappointing that no consideration has been given to develop standards for Cross Cultural Communication considering Britain has such a diversity in population with many cultures and languages. Why has standards for interpreter services and multilingual leaflets/ audio-visual material been completely excluded? Very disappointing and worrying."

"I think that the standard is good. Whether the hospitals or doctors listen is another matter. I will give you an example, I have submitted a letter to my GP informing them that I want my letters to be in braille but so far I haven't heard anything. It is like they are not interested."

"There will be some people with poor use of English - foreign nationals - who also have sensory problems. How will this be dealt with?"

"I hope the standards will make a difference but it will be very much down to the individual professionals as to how well they will be implemented. Too often doctors stare at their computer screen, talk only to the disabled person's carer and don't explain things simply and clearly. I don't think these standards will alter this but it's a start!!"

"I am concerned that there has not been adequate thought to the practicalities of arranging transcription of information and of booking communication professionals and that this will limit the value of the standards."

"I think this standard is bureaucracy gone mad and a big waste of NHS money."

"As previously stated in principle the concept of this standard is good but I am concerned about how this will work in practice without ring fenced central resourcing for dedicated staff with the right skills to ensure it is implemented correctly. If not resources could be wasted, resources could be of poor quality and the whole thing will be reduced to an expensive tick box exercise. Individual Hospital Trusts will not be able to implement this by drawing on existing resources without compromising on other areas of patient care. Smaller organisations such as GP's, dentists and care homes are going to struggle with many aspects of implementation."

"I suspect most organisations will want to know the extra financial burden being put upon them, and how they will meet this."

“What concerns me is that this will be yet another set of tick box pages for already overworked people to read, absorb and act upon. Could I suggest that specific time is set aside for each group of recipients to read and implement together?”

“Please can you send me an accessible copy of the consultation document and make it more obvious on your website for visually impaired people in the future.”

“These responses have been on behalf of our local authority colleagues who have a stakeholder interest in this topic.”

“Unfortunately, we think they have overcomplicated things and the really useful tips are lost.”

“I found this very hard to access on the website itself.”

“The Standard does not include information on foreign language interpreters; this may be perceived as indirect discrimination and a failure of the Duty to advance Equality.”

“I think the aim of the standard is great but I think requiring full implementation with the costs associated with that and in a short time frame will be difficult.”

“I feel it should be a requirement of local Healthwatch organisations to ensure this plan is being used and adhered to. This information should feed in to Health Watch England and if it is proven health services are not making information accessible then CQC should hold them accountable for it.”

“The name is not wise. There is already The Information Standard in use, including in health care, which means something quite different [...] It seems ridiculous to call this proposal the same thing. Will cause lots of confusion.”

“I am happy to offer further guidance/thoughts: [...] [...]”

“A good idea as long as tight control is on its use and that organisations are not allowed to ignore it.”

“Without information can patients have real choice?”

“An excellent idea in principle but without funding and staff to provide a UK/England-wide service equitably across all services to all patients this is not really worth the consultation.”

“Reserving my judgement for the actual implementation. Unfortunately, I have heard this all before, and never happened. So I have my reservations.”

“Formerly hearing, I am now Deafened and have joined the Deaf Community. I have thus realised how pre-lingual Deaf people struggle with English, especially jargon or specialised terms, knowledge the rest of us acquire by osmosis. Part of the guidance

for health professionals in communicating with the Deaf might include awareness of this problem.”

“Something like this is long overdue! My husband has become severely sight impaired over the last year and yet the gp surgery still expect him to be able to see when his name is put up on the screen at the surgery. This should be on his notes so that the doctor know to go & look for him when it is his turn.....!!”

“Remember that if you are hard of hearing you may need someone to help you at the point of contact but this needs to be augmented with written back info too.”

“Would you like me to help sort out the grammar?”

“I just wanted to note that creating written information for people that is in a format that they are able to understand can take a long time. I think this needs to be identified and resources will need to be put in place (i.e. adequate staff resources) so that organisations to meet the standard properly (and not in a tokenistic way).”

“I also think that it's worth noting that some people have communication needs that are too severe for any different means of communication to be effective for them: i.e. that there is no point in creating 'easy read' documents for the sake of it, when some people can't access them at all. It's important that people recognise when this is the case, and a place for sharing this information would need to be identified, although people must also be careful to ensure they are not assuming someone can't access any information when in fact they could if that information was presented in a different way.”

“[...] welcome the development and implementation of the accessible information standard. However, for this standard to be effective, it is important for all providers to adhere to the guidelines. We would welcome measures to be put in place to encourage providers to follow the standard.”

“Won't make a blind bit of difference what I say. the handful of people agree will be heard ,rather than the sceptical majority.”

“Would have been easier to follow the survey if it didn't keep jumping back and forth in the consultation document! Why not deal with each section in the order it appears in the consultation document.”

“Impact in its current state - for some, good. For others faced with jobsworth's and there are many in the NHS, terrible.”

“Look at [...], this website helps people across [...] to support people with LD to communicate.”

“Also consider signage and environments to support communication.”

“Please make sure it works.”

"I struggled to answer Q19, hence left it unanswered. It is a great initiative indeed but it may have an adverse impact on healthcare services if not implemented carefully. Staff should feel supported to follow the guidelines and not as if it was just another tick-box exercise - which it may as well turn out to be."

"I think this is a good consultation. I am a SLT who has a particular interest in this area. It has taken me several hours to read, digest and comment. I am concerned that service users with language impairments may not be able to take part in this consultation in the timescale available."

"I am concerned that there has been no engagement with people with aphasia and their families to date, therefore their concerns are clearly not represented in the documents."

"This suggests that the 'consultation' has been predetermined."

"There are detail issues e.g. SNOMED-CT is not used in primary care."

"How can interpreters be checked as having DBS checks?"

"Consent issues and data sharing."

"Thank you for beginning this essential document."

"Good."

"I think this will be great for the user, carer and family but it will make it harder for those that have to carry it out."

"I don't have 'information or communication support needs relating to a disability, impairment or sensory loss', but I get fed up with having to take in and remember verbal information all the time. I want to be able to tell my son's consultant that I want information in a different way - e.g. email me the results."

"When producing reports please number the pages even if the paragraphs are numbered. Most private individuals have basic printers at home which can give problems on multi page runs."

"When seeking online returns ensure that survey is in a returnable format."

"This show great potential but must be implemented across all relevant sectors (health, social services, public health), with evidence provided of compliance. The initiative must be adequately resourced. Service users (i.e. patients and the public) must be involved."

"It is unclear how organisations will be monitoring their compliance with this standard - both self-assessment and external assessment. There needs to be a clear portfolio of evidence, drawn up in consultation with users, which organisations must show they have met."

“Asking questions about communication needs may make some acknowledge for the first time that they have a problem particularly the elderly with acquired deafness and/or blindness. Information for where to go for help for these patients would be very useful to have to hand.”

“My main query is who is driving this? I feel it should be person-centred i.e. driven by the individual. Therefore, it would seem to me that all these professional communication support personnel should only come into play if the patient wants this. This would have the added benefit that many may then prefer friends/family which would not have cost implications. In my area, our A and E dept. ranked worst across England because of lack of beds due to bed blocking i.e.. problems with discharging patients who require care. If everyone with memory/processing info. issues has to have support (irrespective of whether they want friends/family to act as advocates if available) to make decisions about discharge the situation will worsen. The aims are laudable but I fear that the reality of implementing all of this will prove unsustainable if the default view is that friends/family should not be allowed to fulfil the role even if this is the patient's wish. At the moment there is flexibility in the system for common sense. My adult son's experience of the health system has been excellent to date e.g. my husband has been in the recovery room after operations so he can interpret and be a reassuring presence when our son comes round from operations; our son prefers us to phone for medical results and to be available for medical appts. and then he chooses as to whether we accompany him inside (but he knows we are outside if needed). I do hope these arrangements will be able to be continued under this guidance. If not, I fear our son will start to avoid all medical settings.”

“Just to let you know that I am submitting this response on behalf of [...]”

“I like the idea of making organizations communicate effectively with everyone and providing some standards. However why not provide some standard adapted documents or audio files for organisations to use rather than every organization wasting time and increasingly limited resources to produce a local version of the same information being used in the County/Trust/GP surgery/Care Home 2 miles away.”

“I would like to offer my support/time to further development of the standards, in particular ensuring that any standard headings/lists accurately and fully reflect possible clinical needs.”

“In case it is not obvious from my comments, I am responding as chair of the [...], a charity that connects organisations supporting families that include an adult with learning disabilities.”

“I would like to have answered 'very good' for question 19 but I think that's too optimistic - there are lots of people and organisations involved.”

“We welcome this standard for people with LD who have been calling for this for a very long time. Too often we hear people with LD have been given information in formats they do not understand.”

“Some guidance produced by NHS is voluntary I would hope this is compulsory.”

“This standard is extremely welcome and much needed however I feel it is unrealistic to just implement overnight and fear that this may result in staff feeling negative about making these positive changes. Staff will need adequate training and the correct resources before they can implement these changes and the document lacks detail as to how this will happen.”

“Please check with [...] as I am really grateful for their forward thinking that enables me to have immediate advice and access on an equal basis with my hearing peers as now I can call up or walk in and have an interpreter on video without any fuss immediately. This model should be highlighted and incorporated in the final standard.”

“It is very difficult to provide a 'standard' for a diverse group of people who will each have very different communication abilities and therefore varying requirements, conditions, and preferences for how information is communicated to them.”

“This has been fine for me.”

“Again the communication needs for people within the spectrum is omitted. Either an assumption is made that charities or family will step in support the individual but this is not practical as there are many within the High functioning end of the spectrum who are isolated from families and may not be in the position to request help from Autism charities or understand that there is access to help or that they need it.”

“In response to question 19 we are of the opinion that this will be very positive for service users/public accessing services as the communication will be tailored to their needs. As stated already, there will be an impact on organisations to implement the technical changes required and how to deal with the challenge of providing information or communication support in a timely manner. Are there sufficient resources available to support immediate communication needs.”

“19. Impact will be good if the standards are enforced.”

“Need to ensure that this is not just about recording but that people are enthusiastic about its real purpose of improving communication and recording.”

“Maybe some sharing of good practice examples may help with this.”

“Need to avoid it becoming just another question on referral papers.”

“[...] are really enthusiastic about these standards but having worked for years to try and influence local services to think about communication we are aware of some of

the barriers you will face implementing them and also of how they may be done as a box ticking exercise.

If however this comes off it would make services massively more accessible for our patients and massively improve the care they receive and potentially reduce the costs of our services (which would make NHS England very happy)."

"Local Authorities were not listed in the target audience; given the current focus on health and social care integration this may be a consideration for future consultation/publication."

"I still have concerns that organisations won't adhere to the standard. What will be done to try to ensure compliance?"

"We would like to emphasise the benefits of easy information for everybody. For example in the consultation document the first version of the vision is not very clear. The version in straight forward words is much clearer – so why use the first version at all? People rarely complain that information is too easy to understand."

"The above responses have been submitted on behalf of the [...] Team."

"I have made some comments that could be conceived as negative - but are intended to be constructive."

"[...] very much looks forward to this standard being implemented as soon as possible for both health and social care services delivered by NHS, local authorities, third sector or private sector. It will truly make a massive difference particularly to people trying to make the most of their hearing."

"With regards question 14, this is a legal requirement which health and social care providers should be adhering to currently. Providers should be reminded of this and prompted to implement any necessary changes as soon as possible."

"Overall the phrasing of the consultation document reflects the medical model of disability as opposed to the social model and comes across as reactionary not anticipatory. Organisations should anticipate people's needs or reasonable adjustments. There is not enough emphasis on health and social care professionals making their communications as inclusive as possible to begin with. For example in the scope – 'People who would like to get information in a different way but who can still read information in a standard letter. This could be called a 'preference' and not a 'need.' This significantly undersells the advantage to all patients not just those with a disability and misses other benefits such as the potential reduction in 'did not attends' and so forth. There also needs to be consideration as to how this fits with the personalisation agenda."

"Staff awareness and training will play a major factor in the implementation of this standard. This will have cost implications, as will the provision of interpreters and

alternative format communications, so budgets need to be ring-fenced for these requirements.”

“The impact of the standard is dependent on many factors. It will require a proper evaluation to identify what are the barriers and what are the enablers. Because healthcare professionals tend to overestimate the amount of information they supply it is essential that users/advocate groups are asked about how it is being implemented.”

“The draft Accessible Information Standard is very well written - it's an excellent example of Plain, accessible English and is a great demonstration of NHS England leading by example.”

“The draft Accessible Information Standard is very well written - it's an excellent example of Plain, accessible English and is a great demonstration of NHS England leading by example.”

“Overall we feel the Standard will be of benefit to people affected by Parkinson’s who have significant communication issues caused by the condition. To find out more about how Parkinson’s affects communication, please see our information sheet on this topic: [...]”

“The [...] would be happy to work with the NHS on any of the above issues raised. We have already developed a range of resources for our [...]campaign which we would be happy to share. These resources are online at [...]. We would also be keen to support measures to promote the standard to deaf children and young people and their parents. We can be contacted at [...].”

“Thank you for the opportunity to respond to this consultation.”

“It would be good for organisations to know how people like to communicate and what help they might need - then you don’t have to tell everyone each time you go for an appointment.”

“I don't think this feedback form is easy read.”

“The questionnaire and standard, although it said it was easy read, were not very easy to understand.”

“What a patients information access needs are.”

“Difficulty to understand.”

“Prefer not to say.”

“This will make things better when you are sick and better everything else. It's good we will get the time (to talk to people about illnesses/what we want).”

“For those suffering from mental health an easy to read booklet about diagnosis relevant to patient would be most useful.”

“This should have happened years ago.”

“More racial respect.”

“We have waited a long time for organisations to listen to our need to have info in a way we can understand. It is a huge relief that this is happening now.”

“No, I have highlighted the main issue that the booklet was vague and not clear, apologies for the sharp criticism. I think people who can't speak English despite not being so because of disability, should automatically have that used as a communication need.”

“It should be considered that many people with learning difficulties don't have internet access, some cannot read and others have no support available to access it, so directing people to resources on the web shouldn't be relied upon as a fall back. A year is not a long time for organisations to implement this standard and with spending cuts and restructuring, roles such as Information Officer roles which aren't front line could be seen as an easy target. However, if staff at all levels are committed to implementing these standards then they are likely to have a good impact.”

“We know through the national forum that in some areas they get good care and in others they don't. Have a regular check to make sure they are doing the right things. Advocacy groups are a good way of doing this. You could try using people with learning disabilities (experts by experience) to do inspections or communications to make sure things are good.”

“We think that all staff working in health and social care services should have training to make sure they understand learning disabilities and how to communicate with people. Staff should always use easy words and make sure they speak in a way that is easy to understand. It may not always be possible for someone to have a supporter with them. Even if they do, doctors should always speak to the person and not just their supporter. We are not sure it will be possible for everyone who needs it to have the right support. We know that lots of people with a learning disability do not have support from community nurses to go to appointments. Some of the health checkers have been told they will not be able to have support at health appointments in the future as this support has to be reduced. We do not know how this extra support will be funded when services have to follow the standard.”

“Patients hygiene and theft - that needs to be communicated well.”

Appendix 13 – Assumptions

A small number of the Easy Read surveys were completed by a group (e.g. of 7 people) – we have reported on these as 7 individuals in the analysis. Some of their responses differ, and there is no way of being able to match these between the 7 individuals.

Questions 4 and 5 of the standard survey have been analysed together, and have been broken down by Question 3

The standard survey and Easy read survey had answers to some questions that were worded differently, but in essence meant the same thing e.g. Standard Survey, Q3 “the scope is missing something” and Easy Read Q4 “it is missing something”. Because analysis needs a combined response of the two surveys, these have been combined these into 1 answer – in this case to “the scope is missing something”.

Any blank cells in the template sheet have been filled with “Not answered” to show the respondent didn’t answer the question

Answers from question 11 on the standard survey, and question 7 on the Easy Read survey have been combined as part of the analysis. By way of enabling this, the “free text” responses for Easy Read survey question 7 have been interpreted as accurately as possible as either “Yes”, “No”, “Not sure” or “Prefer Not to Say” in response to the question.

Question 5 on the “Easy Read” survey was “If you think that the standard is not looking at enough, or is looking at too much please tell us why?” We have aligned these responses to questions 4 and 5 of the Standard survey based on the comments provided.

Question 6 was omitted from the Easy Read survey and therefore there are only 321 responses and not 393.

Question 7 was omitted from the Easy Read survey and therefore there are only 321 responses and not 393.

Question 8 was omitted from the Easy Read survey and therefore there are only 321 responses and not 393.

Question 9 was omitted from the Easy Read survey and therefore there are only 321 responses and not 393.

Question 7 on the Easy Read survey (“what do you think about our plans for making information and communication support good?”) was equivalent to question 11 on the standard survey (“Do you agree with the quality considerations we have included”). We allocated responses to the “Yes”/”No”/”Not sure” categories based on the free text responses given.

Answers from Question 3 on the standard survey were analysed along with answers from the corresponding question (number 4) on the “Easy Read” survey.

Answers from Question 10 on the standard survey were analysed along with answers from the corresponding question (number 6) on the “Easy Read” survey.

Answers from Question 12 on the standard survey were analysed along with answers from the corresponding question (number 7) on the “Easy Read” survey.

Answers from Question 13 on the standard survey were analysed along with answers from the corresponding question (number 10) on the “Easy Read” survey.

Answers from Question 14 on the standard survey were analysed along with answers from the corresponding question (number 9) on the “Easy Read” survey.

Answers from Question 15 on the standard survey were analysed along with answers from the corresponding question (number 8) on the “Easy Read” survey.

Answers from Question 19 on the standard survey were analysed along with answers from the corresponding question (number 13) on the “Easy Read” survey.

Answers from Question 20 on the standard survey were analysed along with answers from the corresponding question (number 12) on the “Easy Read” survey.