



# **Making health and social care information accessible**

**Report of engagement activity  
November 2013 – February 2014**

**NHS England INFORMATION READER BOX****Directorate**

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# **Making health and social care information accessible**

## **Report of engagement activity**

### **November 2013 – February 2014**

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# 1 Executive summary

From mid-November 2013 until 21 February 2014 NHS England invited views to inform the development of a new accessible information standard.

Under the banner of 'making health and social care information accessible' a range of individuals, groups and organisations were able to share their experiences and put forward suggestions for improvements with regards to accessible information and communication support.

A dedicated section of the [NHS England website](#) was established to act as an online hub for the activity.

Information about the project and details of ways to get involved were promoted through a wide range of communication mechanisms, contacts and networks including bulletins, newsletters, direct email, websites and social media.

Three surveys were developed to seek views from different target groups:

- patients, carers and service users;
- health and care professionals and organisations;
- patient groups, local Healthwatch, voluntary organisations and communication professionals.

The survey for patients, carers and service users was available in a range of formats including online, on paper or on disc, as well as in British Sign Language (BSL) and easy read.

A series of workshops were also held, in partnership with key national voluntary organisations, to seek views from particular patient groups.

During the three month period, 1,147 completed surveys were received, and over 150 people participated in a face-to-face workshop.

Responses from patients, service users, and carers showed that they often did not receive information in an accessible format or communication support, and that this had a significant negative impact on their independence and privacy, ability to access services, care outcomes and experience. Suggested solutions included improving staff awareness and training, planning and preparation, and the recording and sharing of information.

Responses from health and care professionals and organisations showed that existing practice with regards to recording and meeting people's needs varied, but that there were common challenges around capacity and staff awareness, and lack of clarity around systems and processes, including how to arrange external communication support and access information in alternative formats.

Responses from patient groups, local Healthwatch, voluntary organisations and communication professionals made clear that improvements were needed with

regard to staff awareness and training, the use of appropriately registered (and therefore qualified) interpreters, and the availability of information in alternative, accessible formats including easy read.

The feedback received as part of the engagement activity has specifically informed the development of the accessible information standard, plans for its implementation and assessment of the impact that the standard could or should have.

Further detail about responses and feedback received, and the impact that this has had, is outlined in the report below.

## 2 Acknowledgements

NHS England would like to thank all of the individuals, groups and organisations that supported the engagement in some way.

We are particularly grateful to those who supported people to complete the surveys either as individuals or in groups, and to those voluntary organisations and self-advocacy groups who supported people to have their say as part of workshops or meetings.

Thanks are also due to all those who promoted the online surveys or workshops on their websites, blogs or social media accounts.

The number and richness of the responses received, especially from groups who the NHS has traditionally found 'hard to reach,' is testament to your support.

### 3 Communications – promoting engagement opportunities

A dedicated section of the [NHS England website](#) was created to act as a hub point for information about the project and opportunities for people to get involved. Going forwards, this page will continue to be used to provide updates on progress.

A communications plan was developed and implemented from November 2013 onwards. This was targeted at reaching individuals and groups identified as having an interest in the accessible information standard and / or who were anticipated to be affected by or expected to implement it. The target audience therefore consisted of:

- NHS bodies including clinical commissioning groups and foundation trusts;
- Adult social care bodies (local authorities);
- Organisations providing NHS or adult social care services;
- Relevant royal colleges such as the Royal College of Nursing (RCN) and Royal College of Speech and Language Therapists;
- Relevant professional bodies such as the Association of Speech and Language Therapists;
- Voluntary and community sector organisations working with and / or led by people with disabilities which affect their communication and information needs;
- Professionals and individual service users who had previously expressed interest in this work;
- Local Healthwatch and other patient groups such as the National Association of Patient Participation.

Information introducing the project and encouraging completion of an appropriate survey was included in a range of bulletins including:

- *NHS News* (published by NHS England and distributed to NHS and social care organisations);
- The Department of Health, Public Health England and NHS England Voluntary and Community Sector Strategic Partner Bulletin;
- NHS England's clinical commissioning group bulletin;
- The newsletter of the Foundation Trust network;
- Newsletters produced and distributed by voluntary sector organisations including Action on Hearing Loss and the Royal National Institute of Blind people (RNIB).

The activity was also promoted online by a number of organisations who published information on their websites, including:

- [Action on Hearing Loss](#)
- [CHANGE](#)
- [Dementia Action Alliance](#)
- [Dignity in Care network](#)



- [NHS England](#)
- [Royal Association for Deaf people](#)
- [Royal National Institute of Blind people \(RNIB\)](#)
- [Sense](#)
- [SignHealth](#)
- [UK Council on Deafness](#)

An invitation to participate in the engagement activity was sent directly to a wide range of individuals and organisations including:

- Healthwatch England and local Healthwatch organisations;
- NHS England's national partner organisations including the Association of Directors of Adult Social Services, Care Quality Commission (CQC) and Monitor;
- National stakeholders such as the British Medical Association (BMA) and the Royal College of Nursing (RCN);
- Commissioning Support Unit (CSU) Communications Leads;
- Charities and voluntary sector organisations including The Richmond Group of charities, the Department of Health, Public Health England and NHS England Voluntary Sector Strategic Partners, and other organisations felt to have an interest in accessible information;
- Members of Specialised Commissioning Clinical Reference Groups (CRGs) with a particular interest in key affected groups;
- All individuals who had previously expressed an interest in this work.

The engagement activity was also promoted on Twitter by a number of individuals and groups including clinical commissioning groups (CCGs), voluntary organisations, charities and service users. This included @NDCS\_UK @Limping-Chicken @oldhamccg @ValeofYorkCCG @HwatchDorset and @Healthwatchcam

Enquiries and requests for information, including information in alternative formats, could be made directly to NHS England by email or telephone. A significant number of enquiries were received and handled during the engagement period.

## 4 Summary of survey activity

From mid-November 2013 until 21 February 2014 views were sought to inform the development of a new accessible information standard.

Three surveys were developed to seek views from different groups, as follows:

- A survey aimed at patients, service users and carers;
- A survey aimed at health and care professionals and organisations;
- A survey aimed at voluntary organisations, patient groups, local Healthwatch and communication professionals.

The three surveys were hosted online at [www.engage.england.nhs.uk](http://www.engage.england.nhs.uk) with links from the dedicated accessible information standard project webpage [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo).

All three surveys were also available in Word document format to facilitate completion by people using assistive 'screen reading' technology, and to enable printing or production of hard copies.

The patient, service user and carer survey was also available from the website in easy read format (to view, download and / or print), as a British Sign Language (BSL) video with subtitles, and in audio format. It was also available on request – for immediate dispatch – in braille. Paper copies of the survey in standard print, large print, and easy read were also available on request, as well as DVD and CD copies of the BSL video and audio file respectively.

In addition, where people had difficulty reading or responding to the survey in any of the above formats, arrangements were made to send the survey by email, for response in the same format, and for telephone completion of surveys or workshop questions as appropriate.

The total number of completed surveys received by the 21 February 2014 deadline (with postal surveys accepted throughout the following fortnight) was as follows:

- Survey aimed at patients, service users and carers – 675;
- Survey aimed at health and care professionals and organisations – 299;
- Survey aimed at voluntary organisations, patient groups, local Healthwatch and communication professionals – 173.

A summary of the key findings from the three surveys is available below.

A more detailed breakdown of the survey responses, including detailed and peer-reviewed analysis of quantitative ('tick box') and qualitative ('free text') responses is available as a separate document, entitled 'Analytical Report on Questions from the NHS England Accessible Information Surveys: May 2014.' This also includes the results of diversity monitoring questions and a complete list of free text responses.

## 5 Key findings from patient, carer and service user surveys

This survey was targeted at individual patients, service users and carers.

A total of 675 completed surveys were received, including 478 online responses and 162 in an easy read format.

- 208 respondents stated that they always found it difficult or needed support to see, to hear, to speak, to read or to understand what is being said. 167 respondents said that they sometimes did, while 135 respondents stated that they did most of the time.
- 139 respondents stated that they never received the communication support they needed when using NHS services. 118 respondents stated that they did not need any communication support. 69 respondents stated that they always received the communication support they needed.
- 211 respondents stated that they never received information in a format they can understand when using NHS services. 87 respondents stated that they did not need information in a specific format. 62 respondents stated that they always received information in a format they can understand.
- 434 respondents stated that they missed out on almost all, most or some information when using NHS services. 88 respondents stated that they got all of the information they needed.
- 98 respondents stated that they never received the communication support they needed when using social care services; whilst the same number stated that they did not need any communication support.
- 117 respondents stated that they never received information in a format they can understand when using social care services. 44 respondents stated that they always received information in a format they can understand.
- 253 respondents stated that they missed out on almost all, most or some information when using social care services. 60 respondents stated that they got all the information they needed.
- Common points made by respondents in response to a free text question about the difference it would make if health and social care organisations always gave them information in a format they could understand and if they always got the support they needed to communicate, were that they would have greater independence, autonomy and control over their lives, more privacy and a right to

confidentiality, they would be more confident and less stressed / anxious, and there would be improvements in patient safety, choice and access.

- Views on the proposed 'standard' question, "Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?" were mixed. 197 respondents stated that it was a very good question, 131 stated that it was an ok question but could be better, and 126 stated that it was a good question but could be better. 51 respondents stated that it was really not a good question and should not be used.
- Respondents were able to record multiple responses to the question about how people should be asked about their information and communication support needs. The most popular choice (501 respondents) was face-to-face, followed by email (352), letter (336), text (238), online form (230), and telephone (219). 46 respondents preferred an alternative format to those listed, with easy read, BSL and social media being the more commonly suggested options.
- Respondents put forward a range of suggestions as to actions health and social care organisations should take in order that people can get communication support and information in the right format quickly. Analysis of free text responses has identified 'better planning / communications / more staff' as the most frequent suggestion (164 respondents), followed by having communications specialists / interpreters 'on call' (90 respondents), having better trained staff (86 respondents), including information as part of patient notes / coding / records (76 respondents) and having more information in an accessible format available (71 respondents).

A detailed analytical report of responses is available separately, as the 'Analytical Report on Questions from the NHS England Accessible Information Surveys: May 2014.' This also includes the results of diversity monitoring questions.

## 6 Key findings from health and care professionals and organisations survey

This survey was targeted at individual health and care professionals, and teams or organisations providing or commissioning NHS or adult social care.

A total of 299 completed surveys were received.

- 207 respondents stated that they recorded information about patients', service users' or customers' information or communication support needs consistently / as a routine. 70 respondents stated that they recorded them occasionally or on an ad hoc basis.
- 95 respondents stated that they currently recorded patients,' service users' or customers' information or communication support needs on an electronic social care record, 71 on a paper record, 37 on a GP IT system and 36 on a Patient Administration System (PAS). 99 respondents stated that they recorded such information 'somewhere else,' with common alternatives being a local / internal database or records system, patient or care notes, care plans, and health passports.
- 138 respondents stated that they currently found out about patients', service users' or customers' information or communication support needs via relevant assessment forms or documents, 60 stated that they would ask the patient directly, 49 referred to referral letters or referral documentation, 36 are informed by a GP, clinician or carer. Note that this question allowed for multiple responses.
- 143 respondents stated that they currently recorded information about carers' information or communication support needs consistently / as a routine, 91 did so occasionally / ad hoc. 47 respondents did not currently record carers' needs.
- 170 respondents currently recorded carers' information or communication support needs as part of the patient's / cared for person's record and 98 recorded this information as part of the carer's record.
- If their patients, service users or customers needed information in an alternative format or communication support, 233 respondents stated that they would provide the information or support internally or in-house. 110 respondents stated that they would arrange this through a contract or agreement with one or more suppliers. Note that due to an error in the online survey respondents were unable to give multiple responses to this question, and therefore figures include analysis of free text comments in this regard.
- 157 respondents stated that they had not experienced any difficulties in recording or responding to patients', service users' or customers' information or

communication support needs. 131 respondents stated that they had experienced difficulties.

- With regards to difficulties experienced in recording and / or responding to patients', service users' or customers' information or communication support needs, 69 respondents stated that it is difficult to make colleagues or other services aware of needs. 66 respondents stated that there are delays in delivery or difficulties in meeting requests. 64 respondents stated that it is unclear where or who to get information or support from. 48 respondents stated that it is not clear where to record this information. Note that this question allowed for multiple responses.
- Respondents were asked how long it would usually take them / their organisation to provide information to patients, service users or carers in a range of alternative formats – audio, braille, easy read and large print. In all cases, the most common response was 'do not know.'
- Common answers given in free text responses as to reasons for the amount of time taken to provide information in alternative formats included capacity / time constraints, waiting for production by an external agency, lack of internal facilities or skills, and infrequency of requests (especially for particular formats).
- Respondents were asked how long it would usually take them / their organisation to arrange or provide communication support for a face-to-face appointment. The most common responses as to how long it would take to provide specific types of communication support were as follows:
  - Advocate: 25 - 48 hours (34.4%)
  - BS interpreter: under 1 hour (37.1%);
  - Communication support worker: 4 to 7 days (40.8%);
  - Deafblind manual interpreter: 49 to 72 hours (50.5%);
  - Lip speaker: under 1 hour (52.8%);
  - Speech-to-text-reporter: 25 to 48 hours (58.9%).
- Common answers given in free text responses as to reasons for the amount of time taken to arrange or provide communication support included reliance on external agencies for support (which could result in delays), issues with staff not being aware of how to arrange support, and availability of staff members with the necessary skills.
- Views on the proposed 'standard' question, "Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?" were mixed. 91 respondents stated that it was an ok question, 72 that it was a

good question, 68 that it was not a good question and should be changed. 27 respondents stated that it was really not a good question and should not be used.

- Most respondents (197) had completed the survey as an individual, 59 on behalf of an organisation and 41 on behalf of a team, ward or site.
- 63 respondents would describe the organisation they work for or are responding on behalf of as a local authority adult / social services department, 48 as a learning disability service provider, 47 as an acute hospital or acute foundation trust, 41 as a community service organisation or foundation trust and 34 as a voluntary or community sector provider.

A detailed analytical report of responses is available separately, as the 'Analytical Report on Questions from the NHS England Accessible Information Surveys: May 2014.'

## 7 Key findings from support and supplier organisation survey

This survey was aimed at voluntary organisations, patient groups, local Healthwatch and communication professionals.

A total of 173 completed surveys were received.

- 59 respondents stated that they were a provider of communication support, 37 respondents stated that they were a voluntary or community sector organisation working with people who are blind, d/Deaf, have some hearing or visual loss or a learning disability, 57 stated that they were a different type of organisation.
- Most respondents (88) stated that they were responding as an individual, 69 on behalf of an organisation and 14 on behalf of a team.
- Respondents stated that, based on their experience, the key challenges faced by patients, carers and service users who have information or communication support needs when accessing NHS or social care services were:
  - Lack of any information or good information in different formats (62 respondents);
  - Poor communication, use of jargon and acronyms (61 respondents);
  - Lack of BSL interpreters or using poor / unqualified interpreters (46 respondents);
  - Need for better staff training (30 respondents);
  - Insufficient time and suitable support not being available (29 respondents);
  - Inconsiderate, rude or impatient staff (23 respondents).

Note that this question allowed for multiple responses.

- Respondents stated that, based on their experience, the key challenges faced by NHS and social care organisations in meeting, or trying to meet, the needs of patients, service users or carers with information or communication support needs were:
  - Lack of suitable support and understanding (54 respondents);
  - Insufficient physical and financial resources (51 respondents);
  - Lack of staff training and education (39 respondents);
  - Inadequate communications (34 respondents);
  - Lack of procedures / insufficient planning / no joint working (33 respondents);
  - Providing access to information in a suitable format, for example easy read (27 respondents).

Note that this question allowed for multiple responses.



- Respondents had a range of suggestions as to how the experience of patients, carers and service users who have information or communication support needs could be improved, with common themes being:
  - Deaf awareness and customer service training, perhaps including some level of BSL training for all staff (53 responses);
  - Easy read material available nationally in different formats (31 responses);
  - Using local, National Registers of Communication Professionals working with Deaf and Deafblind people (NRCPD) interpreters (29 respondents);
  - Efficient sharing of information (27 responses);
  - All hospital and GP surgery staff to know how to book a BSL interpreter (20 responses);
  - Using different methods – recognising that ‘one size does not fit all’ (17 responses).

A detailed analytical report of responses is available separately, as the ‘Analytical Report on Questions from the NHS England Accessible Information Surveys: May 2014.’

## 8 Summary of workshops hosted on behalf of NHS England

### 8.1 Workshops hosted by national voluntary sector organisations

In order to better understand the views of particular patient, carer and service user groups a series of workshops were held in partnership with key national voluntary organisations:

- [Action on Hearing Loss](#) formerly the Royal National Institute for Deaf people (RNID)
- [CHANGE](#) a leading national human rights organisation led by disabled people
- [SignHealth](#) the healthcare charity for Deaf people
- [Sense](#) the charity which supports and campaigns on behalf of deafblind people
- [The Royal National Institute for Blind people \(RNIB\)](#) the charity supporting blind and partially sighted people

Summary details of these events are as follows:

SignHealth hosted three workshops in British Sign Language (BSL) to enable d/Deaf people to have their say:

- 14.01.14 in Manchester with 2 participants;
- 11.02.14 in Bristol (afternoon session) with 9 participants;
- 11.02.14 in Bristol (evening session) with 15 participants.

The RNIB hosted three workshops to enable people who are blind or affected by visual loss to have their say:

- 19.11.13 in Wallsend (near Newcastle) with 8 participants;
- 27.11.13 in London with 9 participants;
- 03.12.13 in Birmingham with 12 participants.

Action on Hearing Loss hosted a workshop in London on 04 February to enable people who are d/Deaf or affected by hearing loss to have their say. A total of 16 participants took part.

CHANGE worked with partner organisations across England to host five workshops to enable people with learning disabilities to have their say:

- 21.11.13 in Leeds (hosted by CHANGE) with 13 participants;
- 03.12.13 in Coventry (hosted by Grapevine) with 10 participants;
- 09.12.13 in London (hosted by the Elfrida Society) with 11 participants;
- 10.12.13 in Weston Super Mare (hosted by North Somerset People First) with 9 participants;
- 16.12.13 in Newcastle (hosted by Skills for People) with 8 participants.

Sense hosted a workshop in London on 22 January 2014 to enable deafblind people to have their say. This event was attended by 6 participants.

The workshops either enabled participants to respond to the full set of patient, carer and service user survey questions, or focused on a reduced but related set of questions more specifically designed for group discussion, these questions were:

1. Thinking about when you use NHS or social care services:
  - Do you usually get information in a format you can understand?
  - Do you usually get the communication support you need?
  - Do you think there is any information you are missing out on?
2. What difference would it make to you if organisations always gave you information in a format you could understand and if you always got the support you needed to communicate?
3. How should organisations find out about your information or communication support needs?
4. What questions should they ask?
5. What should organisations do to make sure that you can get communication support and information in the right format quickly?
6. Is there anything else that we should think about when recording or sharing information about people's information or communication support needs?

## **8.2 Other workshops held as part of the engagement phase**

In addition to the workshops hosted by national voluntary sector organisations on behalf of NHS England, a number of other workshops are known to have taken place to support people to have their say. This included the following:

- Wandsworth Council Adult Social Services Department held a workshop with 12 d/Deaf service users as part of a regular Deaf Drop-In on 29 January 2014, and a workshop with 15 d/Deaf residents and carers at a care home in Wandsworth on 30 January 2014.
- Bradford Talking Media hosted a workshop with the Access to Information Action Group and the Health and Well Being Action Group of the Bradford Strategic Disability Partnership on 29 January 2014, attended by 52 participants.

## 9 Key messages from workshops

At all of the workshops, participants were clear that patients, service users and carers who need communication support or information in alternative formats rarely received the communication support or accessible information they needed from health or social care services.

There were some common themes for specific improvements which could be made, as follows:

- Organisations and services should offer a range of different ways for people to contact them and to receive information including telephone, text message and email;
- Staff in both clinical and administrative roles should be more aware of how to support people with information and communication needs;
- Details of people's information and communication support needs should be consistently recorded and shared – with consent – with other services involved in an individuals' care;
- Information about an individual's information and communication needs, and of steps which should be taken to meet those needs, should be automatically included as part of GP practice registration forms and be shared between services through, for example the NHS e-referral system ('Choose and Book');
- Staff should ask patients, service users and carers whether they have any communication needs and of steps which can be taken to support them in accessing services;
- Services should provide correspondence and information in a range of accessible formats, including easy read, large print, email, braille, audio and BSL video;
- BSL users should have support from an appropriately skilled, qualified and experienced BSL interpreter – either remotely or in person – when accessing health and social care services;
- Accessible information and communication support are essential tools to enable people with sensory loss and / or a learning disability to access services independently and to participate in decisions about their health and care;
- Increased availability of information in a large print, easy read format would significantly improve access for a number of different service user groups.

## 10 Themes arising from the workshop discussions

### 10.1 Personal experiences

- Participants needing information in an alternative format (i.e. a format other than standard print English) rarely received information in an appropriate format from health or social care services. A significant majority of participants had experience of receiving correspondence which they were unable to read.
- Participants needing communication support, for example a British Sign Language (BSL) interpreter, to access health and care services, often found that such support was not arranged or otherwise not available.
- Where participants had received information in alternative format they had often experienced a significant delay. Likewise, when participants had had professional communication support arranged, they had often had to wait several days – sometimes up to a fortnight – for an appointment with an interpreter present.
- Some d/Deaf and deafblind participants raised concerns about under-qualified or unregistered British Sign Language (BSL) interpreters being used by organisations. Many BSL users also wished to be able to request a male or female interpreter, particularly for appointments of a personal or gender-specific nature, and / or to request a regular interpreter for longer courses of treatment; very few had been able to do so. A number also requested that they received confirmation that an interpreter had been booked for an appointment, with suggestions made that this be included as part of existing systems such as the NHS e-referral system ('Choose and Book').
- A number of participants felt that they had to 'fight' to get information in an accessible format, support from staff to access services and / or access to professional interpretation or communication support.
- Participants shared examples of good practice from organisations and individual staff members who had taken steps to support them. A number of participants highlighted the difference that a positive relationship with an individual staff member can have, for example a GP Practice Manager, social worker or regular GP.
- Good and bad experiences had occurred across all types of health and care organisations, with no one type of provider seeming to be consistently better or worse than others. For example, some GPs and social workers were felt to be exemplary in providing support whereas others were felt to have refused to make even basic changes. Experiences were also felt to vary significantly between different wards and departments of the same hospital trust or local authority. Services which participants felt should be particularly well-prepared to support

people with communication needs, because of the service user group they served, were particularly heavily criticised when they did not provide this support, with audiology departments being a notable example of this.

- Recording systems do not seem to work effectively – participants shared experiences of services being apparently unaware of communication needs on follow-up visits and information not flowing with referrals or following the patient on their journey.
- Waiting areas can be very frustrating places. Many participants struggled with ‘scrolling screen’ or other visual alerts or displays, and with touch-screen ‘check in’ systems, because they were unable to see or read them. Many participants also struggled with verbal or audible alerts because they were unable to hear them and / or unsure where to go or what action to take based on the alert. Some participants had waited for several hours in a waiting area unaware that their turn had been and gone, and / or waiting for an interpreter to arrive.
- Some participants shared positive experiences of simple steps taken by individual members of staff to overcome the difficulties presented by visual or audible alerting systems, for example guiding the person to a seat outside the relevant consultation or treatment room or coming to ‘collect’ them when it is their turn. Positive experiences were also shared of members of staff who had made a significant impact on individuals by taking the time to ensure that they had understood information.
- Participants who used hearing aids expressed frustration that many health and social care premises either did not have induction loops, and of those that did, they often did not work or staff were unaware of how to use them.
- Many participants who were blind or had some visual loss had experienced significant barriers to receipt of correspondence and / or information via email, often despite frequent requests. Email enables a person to use assistive software to ‘read’ the information, for example a ‘screen reader’ which converts text to speech. Concerns over information governance and / or breaching confidentiality were common reasons given by services or staff for not using email. However, participants were quick to point out that sending a printed letter to someone unable to see or read it was a significant risk to their privacy.
- Many participants recognised the need for organisations to be aware of their information or communication support needs in advance of their appointment and in an emergency. Some had taken steps to carry details of their disability and / or support needs about their person, and / or to ensure that this was recorded by their local hospital or ambulance trust. However, this had rarely resulted in improved experiences in an urgent care situation.

- A number of participants had experience of staff suggesting that a family member or carer should read information to them instead of producing it in an accessible format, or that they could interpret in place of a professional interpreter. Participants felt that this breached their rights to privacy, undermined their independence and risked inaccurate interpretation of important information.
- Many participants with a learning disability had experience of staff speaking to their carer, support worker or family member instead of to them, undermining their independence and right to be involved in decisions about their health and care.

## **10.2 Recording and sharing information about communication needs**

- A significant majority of participants felt that details of patients, service users or carers information or communication support needs should be included as part of standard registration, referral and information-sharing processes. The registration form when joining a new GP practice was the most commonly suggested place for this information to be recorded. Another popular suggestion was the NHS e-referral ('Choose and Book') system, with some participants also suggesting Summary Care Records.
- Some participants felt that their GP practice should record and 'hold' information about their communication needs, and this should then 'flow out' to other services involved in their care. Some suggested that communication needs should be linked to their NHS number.
- Many participants felt that their communication needs should be recorded once, or at least only once by each service, and that they should not have to repeatedly explain their needs to services (which was a common current experience).
- Some participants suggested that registration with their local authority as d/Deaf or blind should 'trigger' sharing of this information with relevant professionals, such as their GP practice or dentist.
- The need to be able to access, review and update or amend information held about individuals' communication or information needs was highlighted as important, especially as conditions may deteriorate or circumstances change.
- Some participants felt strongly that their consent should be gained before details of their communication support needs were shared; however, others were happy for this to be automatically shared with other professionals involved in their care – especially if this was within the NHS.
- The need for 'flagging' systems to be built into patient record and administration processes was raised by a number of participants as a way of ensuring that staff

were aware of their communication needs. A range of alternative suggestions were also made for ensuring that this information was prominent, for example that it should be 'top of the page' or on the front page of a patient's notes or (electronic or paper) record.

- Opinions differed as to whether there should be a standard question for recording people's communication needs or not – although all agreed that they should be recorded. Those in favour felt that it would reduce stigma and therefore encourage people who may not consider themselves to be disabled to explain their communication needs. Those against felt that a 'one size fits all' approach would not work, and that services would need to tailor the question to meet the needs of different patients or patient groups.
- Although recognising, and supporting, the rationale for recording communication needs and not disability, some participants queried whether this would limit organisations' ability to meet their wider – non-communication-related – needs. For example, recording that someone needs information via email does not alert the service that the patient is blind and may have an assistance dog. Some queried whether this would be a 'missed opportunity' and others whether the question should be linked to recording of disability (as part of diversity monitoring). As with the use of a 'standard question' (or not), there was not a consensus on this.
- Most participants who were invited to comment on the proposed question, 'do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?' felt that it was too long and too complicated.
- Common suggestions for questions which could or should be asked to identify people's information and communication needs were:
  - Do you have any communication needs?
  - Do you have any special requirements?
  - How do you prefer to be contacted?
  - What is your preferred method of communication?
  - How would you like us to communicate with you?
  - Do you need a format other than standard print?
- Some participants felt that examples of types of communication support and / or alternative formats should be given to support people in answering effectively. The importance of clarity as to individuals' specific needs was highlighted, for example a range of font sizes may come under the term 'large print.'



- Many participants highlighted the importance of accurately recording their communication needs and not making assumptions based on their disability or use of aids.
- Participants felt that there should be a range of different formats available and / or methods used by services to record their communication needs, noting the need to be flexible to ensure inclusivity. This included paper forms in large print and easy read, online forms, email, telephone, text message, and face-to-face.

### 10.3 Impact

- Many participants felt that they missed out on information regarding their health or wellbeing, for example that contained within patient information leaflets about long-term conditions, self-care and keeping well. Suggestions were made for more information to be available in an easy read, large print, audio or BSL video format, including online.
- Some participants had been left unclear about how to take medication or manage their condition due to not receiving relevant information in an appropriate format. A number of participants had missed appointments due to not receiving letters or reminders in appropriate formats.
- The most common feedback with regards to the difference it would make if participants always received information in a format they could understand and the communication support they needed were increased independence, autonomy, inclusion, confidence, control, privacy and dignity, and reduced stress and anxiety. Equality, fairness, respect and empowerment were also key themes, as was an enhanced ability to play an active part in society and / or be an equal partner in care.
- Lack of accessible information and communication support was felt to be a risk to patient safety and health, as well as compromising independence and wellbeing. It can also make both routine and urgent interaction with services a frightening experience. Some of the experiences shared by participants who had not received information in a format they could understand or had not had the communication support they needed were very distressing.
- A number of participants explained that they had been, or were, reluctant to access services due to concerns that appropriate communication support would not be available and therefore they would be unable to communicate effectively and / or to understand what was going on.

### 10.4 Staff

- Many participants highlighted the need for improved awareness amongst health and care staff – both administrative and clinical – about supporting people with

communication needs, for example 'd/Deaf awareness.' It was felt that many difficulties could be overcome by health and care staff being more flexible and understanding. Reception staff, doctors (GPs) and paramedics were most frequently highlighted as roles being of particular importance.

- A number of specific suggestions were made around compulsory 'awareness' training for both clinical and administrative staff. This included suggestions that it should be included as part of training of clinical and / or medical staff, and more regular training for qualified / practicing staff. Some participants felt that key staff should be able to communicate using basic BSL. Others felt that such training should include or be led by people with sensory loss and / or a learning disability.
- Some participants shared experiences of staff being unaware of how to book an interpreter or otherwise meet communication needs, even once known.
- Many participants felt that staff were too afraid of 'saying the wrong thing' or causing offence, and therefore did not offer or provide help or support even when it was obviously needed.
- Simple steps taken by individual members of staff can make a significant impact to people's experience, for example allowing time for the patient to ask questions, writing information down or guiding them to a seat in the appropriate waiting area.
- Some participants highlighted the difference that additional time could make to their experience of accessing health or care services. This included some specific requests for longer appointment times to accommodate patients with communication needs, and for clinicians and reception staff to be prepared to 'take their time' to ensure that information had been correctly understood.

## **10.5 Solutions – meeting people's needs**

- Innovation, flexibility and personalisation were felt to be key (although these were rarely the terms used). Organisations should not be afraid of trying new things, using technology and adapting to individuals' needs. One clear message was that staff should ask people how they can help or support them to access services.
- Most participants felt that most services needed to improve:
  - systems for recording people's information and communication needs;
  - awareness amongst their staff as to how to support people with communication needs;
  - processes for arranging internal and external support to meet people's needs;
  - the availability of information in alternative formats;
  - their ability to provide correspondence in different formats.

- Some participants felt that greater engagement with people with sensory loss and / or a learning disability would support increased staff awareness, and therefore improve their experience of accessing services.
- Many participants acknowledged the challenges faced by organisations and individual staff in being aware of their communication needs in advance, and of meeting those needs in a climate of increasing workloads and reduced budgets. Some felt there was a need to improve understanding of the impact of providing information in accessible formats and communication support, and that many adjustments – such as sending correspondence via email – were inexpensive or at no cost.
- Having 24 hour a day, seven day a week, access to interpreters, communication support and information in alternative formats was felt to be critical. The use of modern technology, including video calls to enable immediate access to an interpreter or advocate, and bespoke applications or software for mobile devices such as smartphones and tablet computers, were actively encouraged and seen as ‘the way forward’ by many – but not all – participants. Most participants agreed that there was a time and a place for remote access to support, particularly in emergency or out-of-hours situations, even if they would not wish this to be used for routine or sensitive appointments.
- Many participants needed an alternative to a telephone number as a way of contacting services with queries or concerns, or to book an appointment. A number of participants found text messaging (SMS) and / or email to be the most convenient and inclusive communications methods. However, some were keen to highlight the needs of people who were digitally excluded, particularly older d/Deaf, blind or deafblind people, who may need support to communicate in more traditional ways, such as receipt of information in braille.
- Some participants suggested the use of wristbands, ‘help cards’ and / or communication ‘passports’ (such as those provided by some hospital trusts to patients with a learning disability) to support people in indicating that they had a communication need. There was greater support for a discreet card or passport than for wristbands or other visual alert. However, there was not a consensus about the use of any standardised ‘tool’ or document in this regard.
- A number of participants highlighted the need for sufficient time with a clinician to ensure that they understood any information given, and could ask any questions.

## 10.6 Other

- A number of participants raised concerns about ‘enforcement’ of the standard, including ensuring that all organisations were required to comply and querying how compliance would be ‘assessed’.

- Some participants highlighted the difficulty that organisations may experience in meeting the needs of individuals with complex, multiple needs. This was in the context of both the difficulty of recording these needs using a standard approach and the difficulty in providing or arranging for support or information in lesser used formats or communication systems.
- Some participants raised concerns about the availability of suitably qualified interpreters.
- Some participants highlighted the importance of learning from and building upon existing good practice, from both within the health and care system and beyond. The proactive steps taken by some private companies, for example some supermarkets, were noted.
- Some issues may be particular to some staff, which can cause particular embarrassment for the service user. Examples included staff with 'illegible' handwriting, staff with a beard which restricted lip reading, and struggling to understand dialects and accents of some health and care staff and interpreters.
- The importance of using appropriate terminology to describe and refer to people's communication needs and / or disability was highlighted. Although participants used, and were comfortable with, a range of different terms, there was a consensus that people should be able to 'self-define' and the words that they use should be used by professionals wherever possible.
- Some participants suggested that production of information / correspondence in alternative formats and / or arrangement of communication support should be centralised either in total or in part.
- Many participants suggested that more information should be readily available in a range of accessible formats online. This included information about common conditions, symptoms, services and healthy lifestyle advice.
- Some participants felt that complaints policies and information were inaccessible, meaning that poor experiences and lack of support were difficult to report.
- Some participants were keen to point out that changes made to support one group of patients would also have a positive impact on others and / or on all patients. Examples included increasing availability of easy read and use of email.
- Many participants found it difficult to find their way around health and care buildings, especially larger hospitals, with suggestions made for guides (perhaps volunteers) to be offered and / or for improved clarity of signage, or maps and guides in alternative formats. Some participants suggested that photographs of staff would support them in knowing who they were to see.

- Many participants commented that changes to staff and / or being seen by new staff could be particularly challenging and cause concern as they were unaware of their communication and / or support needs.
- Some of the most traumatic experiences had occurred in emergency situations, especially where services or staff were not previously known to the service users. Many participants worried about what would happen to them if they needed to access health care in an emergency, often because of previous poor experiences of being unable to understand what was happening to them.

The notes from all of these workshops are available as a series of separate documents which have been published on the [NHS England website](#)

## 11 Feedback received outwith of a survey or workshop format

### 11.1 Letters / statements from voluntary organisations

Instead of or in addition to completing a survey, some voluntary sector organisations submitted a letter or narrative statement in response. Some also signposted to existing reports about the challenges faced by people needing communication support and / or advice or guidance around support / improvements.

The points raised supported many of those raised by participants in workshops, including in particular highlighting:

- The challenges faced by people who need information in alternative formats or communication support in accessing health and care services, and the impact that not receiving accessible information or communication support can have;
- The need for greater awareness amongst health and care staff – both administrative and clinical – of how to support someone with sensory loss, a need for communication support and / or a learning disability;
- The need for information to be available in alternative and accessible formats, including easy read, large print, braille, British Sign Language and via email;
- The positive impact that receipt of accessible information and communication support can have, including increased confidence and independence.

Some illustrative quotes and key messages from submissions are as follows:

“The standard needs to set out a clear process for capturing patients’ communication needs and preferred formats and how that information is turned into provision of such assistance and formats. A standard is only ever as effective as the people who implement it, which is why we believe any standard must be backed up with supporting guidance and training, including disability and visual awareness training.” [The Royal National Institute of Blind people \(RNIB\)](#)

“The [Bracknell Be Heard group](#)...consists of people with Learning Disabilities...the main concern captured from the group was imparted information being lost or forgotten if not written down or recorded in some other way unless support staff are present...‘Health passports’ which detail individual needs and could be kept on your person at all times, were raised as a way for health and social care professionals to easily know health and support needs.”

“We’re extremely pleased to see that NHS England is currently working to ensure that information is accessible to disabled people. We hope that...it will be possible to take into account the specific needs of deaf young people. This includes, for example, the need for information to be broken down into manageable chunks and presented in visually compelling ways, where possible,

so that younger deaf people find it easier to access.” [The National Deaf Children's Society](#)

The [BHA](#) highlighted the particular difficulties faced by the d/Deaf Black and Minority Ethnic (BME) community, including, “a need for appropriately trained and experienced interpreters who have worked with the deaf BME community.”

[Health Deafinitions](#) raised concerns that the standard focused on the provision of British Sign Language interpreters and accessible information to Deaf patients, without addressing what they feel are more fundamental issues of knowledge and understanding about human biology and health. They call for greater health education for Deaf people, and point to issues with interpreters’ knowledge and use of medical terms, and also with Deaf patients’ abilities to understand these terms, if used.

[Learning Disability Partnership Boards in the North East, supported by Inclusion North](#), shared their experiences of being involved in producing and receiving ‘easy read’ information, and provided advice in this regard. They highlighted the importance of engaging with a wide range of people with learning disabilities, pointing to significant diversity in opinion of effective ‘easy read’ information. The importance of providing accessible information to people with learning disabilities and their carers was also felt to be essential, including correspondence and information about screening, keeping healthy and common conditions.

## **11.2 Feedback from individual service users via email or telephone**

Some individuals provided specific comments or suggestions via email or telephone, reinforcing some of the points made through surveys and workshops, including:

- The need for accessible correspondence and information about health information, services and early intervention / prevention opportunities such as screening and ‘flu jabs’;
- The importance of recognising and including email as an accessible format for people who are blind or have some visual loss;
- The importance of staff attitudes and awareness, and the need to be flexible to adapt to people’s individual needs;
- Concerns over the registration and qualification of BSL interpreters, and that some health and social care staff expect family members to act as interpreters;
- The potential for people with communication needs to carry a ‘help card’ or similar alerting staff to their need for support.

One individual respondent summarised many of the key points from the feedback from patients, service users and carers particularly eloquently:

“In my surgery all new patients are asked to complete a 'new patient form'. There is no specific question on that form about communication difficulties, the patient's

preferred method of communication and what help may be needed at appointments etc. When a patient indicates a difficulty it should be recorded on the notes what needs to be done to help and it should flash up at every contact so all staff are aware.... When a patient is referred to a hospital or other provider the patient's communication needs etc. should be passed on. Maybe there should be a specific box on every referral letter where these can be put so the information is not lost in the body of the text. Instantly the recipient would know to book an interpreter or know that the patient will need help..."

### **11.3 Feedback from service users collated by Durham County**

#### **Council**

Durham County Council collated responses from 18 people who were part of County Durham Pathways or the Learning Disability Parliament. Their report was received too late to enable inclusion as part of the in-depth survey analysis however, key themes are summarised below:

- Experiences of receiving communication support and information in an accessible format were mixed;
- Most respondents felt that they missed out on some information when accessing services;
- Common responses about receiving appropriate communication support were that it made respondents feel confident, happy, and less anxious;
- Respondents' preferred ways for finding out about people's information or communication support needs were face-to-face, or via telephone or letter;
- Some respondents wanted to ensure that their family or carer received relevant information from services, and some stated that help from their support worker enabled them to understand information;
- Respondents also commented that they found the survey too long, and that they found some questions difficult to understand.



## 12 Feedback received on the engagement process

Some voluntary sector organisations and individuals provided specific feedback on the engagement process itself. This included concerns about:

- The British Sign Language (BSL) video of the patient, service user and carer survey, specifically that:
  - it was inaccessible for d/Deaf people with a learning disability, as “the original language was at a high level”;
  - division of each question into a separate video clip including the list of answer options would improve d/Deaf people’s ability to respond.
- The (written) patient, service user and carer survey being overly-complicated and / or difficult to follow;
- The survey questions, particularly that multiple issues or questions were raised by a single question, and that there were too many answer options;
- The inability to select more than one disability or impairment as part of the diversity monitoring questions;
- The phrasing of the survey questions, specifically the view that they implied that “...interpreters provide a sufficient platform to help Deaf patients communicate.”
- The easy read survey questions were too long, that there were too many answer options for some questions and about inconsistent use of images.

This feedback has been taken on board, and we will endeavour to address these concerns where possible and as appropriate in future engagement exercises.

## 13 Impact of engagement

The feedback received as part of the engagement activity has specifically informed the development of the accessible information standard, plans for its implementation and assessment of the impact that the standard could or should have.

Some examples of where views expressed have had a direct impact on the drafting of the standard are as follows:

- The proposed question for use by organisations in finding out about people's information or communication support needs will not be used as part of the standard. Based on responses received, there is a lack of consensus about how any such question should be phrased, and recognition that this may need to be varied to meet the needs of particular services or patient groups. Therefore it is proposed instead that the standard will require organisations to find out whether patients, service users and carers have any communication and information support, without stipulating a specific question which must be asked. However, a range of potential suitable questions which may be used will be provided to organisations as part of supporting implementation guidance for the standard. These questions will be based on those suggested by workshop participants and survey respondents.
- Patients, service users and carers were frustrated by having to repeat details of their communication and information needs to different professionals and organisations involved in their care. They were also concerned that details of their needs did not follow them as they were referred to different services. Health and social care professionals told us that one of the challenges they faced was that 'it is difficult to make colleagues or other services aware of needs.' In response, we will continue to explore how we can ensure that this information is transferred between organisations, perhaps using the Choose and Book or Summary Care Record systems.
- Participants agreed that details of communication and information needs should be recorded as part of registration or first interaction with services, and then kept on file for future appointments or visits. In response, we will ensure that the standard defines a clear and consistent way for communication and information needs to be recorded, as part of existing patient record and administration systems.
- Many d/Deaf and deafblind participants and organisations supporting or working with these communities raised concerns about the skill, experience or knowledge of British Sign Language (BSL) interpreters used by health and social care services. It is proposed to include guidance to organisations about ensuring that interpreters are appropriately skilled and experienced as part of implementation guidance for the standard.

- Respondents and participants highlighted the importance of ensuring that communication and information needs were accurately and unambiguously recorded. In response, we are proposing to include a multiple-choice 'tick box' list of different communication support or alternative formats which may be needed, including different font sizes and different types of interpreter, as part of the standard.
- Many participants highlighted their need for additional time when seeing health and care professionals, to enable them to ensure that they had fully understood any information, allow for any communication support required, and enable them to ask questions. In response we are proposing to include 'longer appointment time to support communication needs' as one of the 'support categories' of the standard.
- Some respondents were keen to point out that many of the changes needed could be delivered by in-house staff and / or were inexpensive, cost-neutral or would result in longer-term savings. In response, we will be highlighting the support which clinical and administrative staff can themselves provide to patients, service users or carers with communication or information needs, as part of implementation guidance to support the standard. We will also take feedback into account when assessing the impact of the standard in terms of supporting people to access services and to look after their own health better.
- Many of the free text responses from health and social care organisations and voluntary organisations pointed to the challenges faced by organisations and potential solutions. These issues and ideas will be addressed, and where appropriate included, as part of implementation guidance which will be published alongside the standard.

## 14 Contacts and alternative formats

Copies of this report are available in easy read, British Sign Language (BSL) video (with subtitles), and audio formats from the NHS England website [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)

The report can also be posted out as a hard copy, in large print, easy read, on CD, on DVD or in braille on request.

If you wish to request a copy of the report, or if you have a query or concern about its contents, please email [england.nhs.participation@nhs.net](mailto:england.nhs.participation@nhs.net)

Alternatively, you can telephone us on 0113 8251324 or write to Sarah Marsay, Public Voice Team (Accessible Information), NHS England, 5E01, Quarry House, Quarry Hill, Leeds, LS2 7UE.

For updates about the development of the accessible information standard please visit the NHS England website [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)