



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

**Report of consultation**

**13 August – 09 November 2014**

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**NHS England INFORMATION READER BOX**

**Directorate**

Medical	Commissioning Operations	<b>Patients and Information</b>
Nursing	Trans. & Corp. Ops.	Commissioning Strategy
Finance		

**Publications Gateway Reference: 03009**

<b>Document Purpose</b>	Report
<b>Document Name</b>	Making health and social care information accessible - of consultation 13 August - 09 November 2014 <span style="float: right;">Report</span>
<b>Author</b>	Sarah Marsay
<b>Publication Date</b>	March 2015
<b>Target Audience</b>	CCG Accountable Officers, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, Directors of Adult SSs, Allied Health Professionals, GPs, Communications Leads, CCG PPI Lay Members, patients, carers, the public, voluntary and community sector organisations
<b>Additional Circulation List</b>	Consultation partners
<b>Description</b>	NHS England invited views as part of a consultation on the draft accessible information standard from 13 August to 09 November 2014. This report summarises the consultation activity and the responses received from a range of individuals, groups and organisations.
<b>Cross Reference</b>	N/A
<b>Superseded Docs (if applicable)</b>	N/A
<b>Action Required</b>	N/A
<b>Timing / Deadlines (if applicable)</b>	N/A
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## **Report of consultation – 13 August – 09 November 2014**

Version number: 1

First published: March 2015

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Classification: OFFICIAL

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## 1 Executive summary

NHS England is developing a new ‘accessible information standard.’ The standard aims to ensure 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.”

From 13 August until 09 November 2014 NHS England invited views as part of a consultation on the draft accessible information standard. Under the banner of ‘making health and social care information accessible’ a range of individuals, groups and organisations were able to comment on and put forward suggestions for improvements with regards to the draft accessible information standard.

The draft standard itself was informed by engagement activity during November 2013 – February 2014, with over 1200 people sharing views and experiences which directly influenced the standard which was consulted upon. A [report of the engagement activity](#) is available in a range of formats.

During the consultation period, 393 completed surveys were received, and approximately 140 people participated in a face-to-face workshop. Additional feedback was also received via email, letter and telephone.

The key themes which emerged as part of consultation were:

- **Support for the aims and vision of the standard.** Most participants agreed that the standard was needed and that the aims and vision were correct.
- **Support for the standard’s approach and the steps of the standard.** Most participants agreed that the ‘whole systems’ approach and the inclusion of a specific process outlining the need to identify, record, highlight, share and meet people’s needs was appropriate.
- Belief that the **impact of the standard would be good or very good.** Most participants believed that implementation of the standard would have a positive impact.
- Many participants suggested **additional quality considerations** and / or approaches to assure the quality of accessible information including alternative formats.
- A number of participants stated that they believed there was a need for **greater clarity and enhanced requirements around British Sign Language (BSL) interpreters** (in particular) and other communication professionals.
- There were mixed views about the **use of family members or friends as interpreters**, with some participants believing that the standard should make clear that they should not be used, and other participants believing that the standard should make allowance for or encourage their involvement in supporting communication where appropriate.

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- There were mixed views about the 'sharing' aspect of the standard, with some participants expressing concerns about the need to gain explicit **consent to share details** of people's information or communication needs, and others believing that consent should be implied.
- Most participants supported the overall scope of the standard. A significant number of participants thought that the standard should include the accessibility of health and social care **websites** – or signpost to relevant guidance. Many participants thought that the standard should include the accessibility of **signage**.
- A number of participants made suggestions for additions to the **list of communication support and accessible information formats**. Most participants supported the proposed categories. Some participants expressed concern about the ability of smaller service providers to offer all of the different options listed.
- A number of participants highlighted the important role played by **Speech and Language Therapists** in assessing and supporting people with communication needs.
- Many participants expressed **concerns that the standard will not be implemented** – or not implemented in full – and therefore that it will not have the intended impact, although it should be noted that many participants were clearly unaware of the mandatory nature of information standards.
- A number of participants made suggestions about **supporting or monitoring compliance with the standard**, including a role for the Care Quality Commission, local Healthwatch and the use of an audit or reporting requirement. Some also suggested the use of incentives and / or penalties.
- Many participants suggested that **patients and service users and / or voluntary organisations should be involved in supporting the effective implementation** of the standard and / or in assessing compliance.
- Some participants expressed concerns about the **cost** of implementing the standard.

The feedback received as part of the consultation will directly inform the final version of the accessible information standard which is submitted to the Standardisation Committee for Care Information for approval – this is currently scheduled for June 2015. It will also inform the implementation approach and guidance, as well as other supporting documents.

Further detail about responses and feedback received is outlined in the report below.

## 2 Acknowledgements

NHS England would like to thank all of the individuals, groups and organisations that supported the consultation 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 the consultation

The dedicated section of the [NHS England website](#), established in 2013 to support communication and engagement around the accessible information standard, was used as the hub point for information about the consultation and opportunities for people to get involved. Going forwards, this page will continue to be used to provide updates on progress.

The webpage included copies of the consultation document and survey, and the full suite of fourteen documents which made up the draft accessible information standard.

The consultation document and survey were available from the website in both PDF and Word document format to facilitate completion by people using assistive 'screen reading' technology, and to enable printing or production of hard copies. In addition, the consultation document and survey were 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. They were also available on request – for immediate dispatch – in braille. Paper copies of the consultation document and 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 files respectively.

A communication plan to promote participation in the consultation was developed and implemented from August 2014 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 British Medical Association and British Academy of Audiology;
- Voluntary and community sector organisations working with and / or led by people with disabilities which affect their communication and / or information needs;
- Professionals and individual service users who had previously expressed interest in this work;
- Local Healthwatch and national patient groups.

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

- The Department of Health, Public Health England and NHS England Voluntary and Community Sector Strategic Partner Bulletin;

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- NHS England's *Informed* bulletin (previously 'NHS News'), bulletin for clinical commissioning groups (CCGs), Chief Nursing Officer's bulletin, GP and Practice Team bulletin, and bulletin for local Healthwatch organisations;
- The Foundation Trust Network newsletter;
- The Health and Social Care Information Centre's GP Systems of Choice (GPSoC) bulletin;
- Newsletters produced and distributed by voluntary sector organisations.

NHS England, Department of Health and Health and Social Care Information Centre (HSCIC) staff were made aware of the consultation via the publication of information on their respective intranet sites and / or in staff bulletins.

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

- [Action on Hearing Loss](#)
- [CHANGE](#)
- [Sense](#)
- [Signature](#)
- [SignHealth](#)
- [The Limping Chicken](#)
- [The National Deaf Children's Society](#)
- [The National Registers of Communication Professionals working with Deaf and Deafblind People \(NRCPD\)](#)
- [The Royal College of Nursing \(RCN\)](#)
- [The Royal National Institute of Blind people \(RNIB\)](#)

An invitation to participate in the consultation was sent directly to a wide range of individuals and organisations, with requests for response and / or for onwards distribution as appropriate. This included:

- NHS England's national partner organisations including the Association of Directors of Adult Social Services (ADASS), Local Government Association (LGA), Healthwatch England, Care Quality Commission (CQC) and Monitor;
- National stakeholders, relevant royal colleges and professional representative bodies including the British Medical Association (BMA), the Royal College of Nursing (RCN), Royal College of Physicians (RCP), the Professional Records Standard Body, the Royal College of Speech and Language Therapists (RCSLT), Association of Sign Language Interpreters (ASLI), and British Academy of Audiology (BAA);
- Members of the HSCIC's GP Systems of Choice (GPSoC) Advisory Group and GP IT New Requirements Group (NRG), and suppliers of GP IT systems;
- Commissioning Support Unit (CSU) Communications Leads;
- Members of Specialised Commissioning Clinical Reference Groups (CRGs);
- Clinical Commissioning Group (CCG) Patient and Public Involvement (PPI) Lay Members;

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- Members of [The Information Standard](#);
- NHS and adult social care organisations via the HSCIC's Independent Appraisal and Assurance Service (IAAS);
- Charities and voluntary sector organisations;
- All individuals who had previously expressed an interest in this work.

The consultation was also promoted on Twitter by NHS England [@NHSEngland] and a number of other individuals and groups including local Healthwatch organisations [such as @HWWilts @HWatchMedway and @HealthwatchGlos], voluntary organisations [such as @Sensetweets @SignHealth @NVTweeting and @changepeople\_], clinical commissioning groups [such as @NEWDevonCCG and @ManchesterCCGs] as well as high profile individuals in the NHS accessibility field.

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 consultation period.

A press release was prepared and issued by the NHS England Media Team to coincide with the launch of the consultation. The press release also appeared as 'latest news' on the [NHS England homepage](#) on 13 August 2014.

Olivia Butterworth, Head of Public Voice at NHS England, was interviewed about the accessible information standard as part of the BBC Radio 4 'In Touch' programme which aired on 30 September 2014 <http://www.bbc.co.uk/programmes/b04jk3rv>

## 4 Summary of survey activity

From 13 August until 09 November 2014 views were sought on the draft accessible information standard.

Alongside the consultation document, a survey was developed to seek views on specific elements of the draft accessible information standard and its implementation.

The survey was 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).

The consultation document and survey were also available from the website in a range of accessible formats (see section 3 above). In addition, where people had difficulty reading or responding to the consultation, arrangements were made to send the consultation document and 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 09 November deadline (with postal surveys accepted throughout the following week) was 393.

A summary of the key findings from the survey is available in section 5 below.

## 5 Key findings from surveys

A total of 393 completed surveys were received, including 283 online responses and 72 in an easy read format.

- The majority of survey respondents (353 respondents / 89.8%) stated that they agreed with the vision for the standard.
- The majority of survey respondents (336 / 85.5%) stated that they agreed with what the standard will do.
- The majority of survey respondents (210 respondents / 53.4%) stated that they believed the scope was about right. However, 128 respondents (32.6%) stated that they believed the scope was too small or missing something.
- The majority of respondents (205 respondents / 63.9%) stated that they thought that the steps / requirements of the standard were 'about right.' Whereas 62 respondents (19.3%) stated that they thought that the steps / requirements were missing something. [Note that this question was not included in the 'easy read' version of the survey, so that the total number of respondents to this question was 321].
- There were 139 responses to the 'free text' question with regards to the types of communication support and information formats listed in the draft standard. The majority of respondents (65) commented on communication support, 30 commented on information formats, and 16 commented on communication professionals. Most of the comments received related to suggestions for additional types or categories of support which people may need.
- The majority of respondents (252 respondents / 85.5%) agreed with the quality considerations included in the draft standard. The main theme of 'free text' comments on the quality considerations related to the need for qualified British Sign Language (BSL) interpreters.
- The majority of respondents (239 respondents / 60.8%) believed that the proposed advice and support for organisations to implement the standard was 'about right.' 68 respondents (17.3%) believed that the advice and support was 'missing something.'
- The majority of respondents (202 respondents / 51.4%) thought that 12 months to implement the standard was 'about right'. 89 respondents (22.6%) thought that 12 months was 'too short' and 63 respondents (16%) thought that it was 'too long.'
- With regards to plans for making sure that organisations follow the standard – a 'free text' question – 93 respondents commented that the standard would need to be mandatory and / or that strong monitoring and sanctions would be needed. 78 respondents commented that the plans / timetable were good and achievable. 28 respondents stated that the plans were not achievable in the current timetable with current resources.

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- Additional 'free text' comments on the Implementation Plan and Implementation Guidance most commonly referred to the timescales and resources needed to ensure effective implementation, and / or support which should be provided to organisations.
- The majority of respondents (299 respondents / 76.1%) thought that the impact of the standard would be good or very good.
- 55 respondents provided additional 'free text' comments, with key themes including monitoring (9 respondents), the need for additional staff (8 respondents) and staff training (6 respondents).

A detailed analytical report of responses is available separately, as the 'Analytical report on the consultation "making health and social care information accessible" – summer / autumn 2014', which includes graphical representation of the results. This report also includes all of the 'free text' responses received as part of completed surveys.

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

### 6.1 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 sector organisations:

- 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 two workshops on 22 September in Bristol (one afternoon session and one evening session) in British Sign Language (BSL) to enable d/Deaf people to have their say. In total 15 participants attended.

The RNIB hosted three workshops to enable people who are blind or affected by visual loss to have their say, on 15 September in Newcastle, on 19 September in London and on 23 September in Birmingham. In total 30 participants attended.

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

- 08 October in Coventry (hosted by Grapevine) with 10 participants;
- 09 October in Leeds (hosted by CHANGE) with 7 participants;
- 14 October in Manchester (hosted by Manchester People First) with 12 participants;
- 15 October in London (hosted by The Elfrida Society) with 13 participants;
- 20 October in Darlington (hosted by Darlington People's Parliament / Darlington Association on Disability) with 11 participants.

Sense hosted a workshop in London on 28 August 2014 to enable deafblind people to have their say. This event was attended by 3 participants plus relevant communication and other support staff.

The workshops enabled participants to respond to questions which, whilst similar to those included in the consultation survey, were more specifically designed for group discussion. These questions were:

1. Overall, do you agree with what the standard is aiming to do?
2. Do you agree with what the standard includes?
3. What types of information format and communication support should be included on the standard's list?

4. Do you agree with what the standard says about how quickly people should get accessible information and communication support?
5. Do you agree with the quality considerations?
6. It is proposed to give organisations 12 months to implement the standard. What do you think about this?
7. What do you think about plans for making sure that organisations follow the standard?

The notes or reports from these events are published [on the NHS England website](#).

## 6.2 Other workshops held as part of the consultation

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:

- Bradford Talking Media and Bradford Strategic Disability Partnership hosted a workshop on 3 October 2014, attended by approximately 30 participants.
- Sight Service Gateshead and South Tyneside hosted a workshop with 13 participants from South Tyneside on 30 October 2014.

## 6.3 Other events

During the consultation period, presentations / information about the accessible information standard were given in a number of different forums as part of awareness raising and encouraging people to participate in the consultation. This included:

- [Health and Care Voluntary Sector Strategic Partner Programme](#) Working Day on 10 September 2014;
- 'Mind the Gap: Putting research into practice' [RCSLT \[Royal College of Speech and Language Therapists\]](#) Conference on 18 September 2014;
- ['Empowering Patients: A discussion event about high quality, accessible information, decision making and supporting patients to develop knowledge, skills and confidence to be active in their health and care'](#) on 14 October 2014;
- NHS England and Public Health England workshop on 'Increasing access to cancer screening for people with learning disabilities' on 14 October 2014;
- [Fulfilling Potential Forum](#) meeting of disabled people's user led organisations on 23 October 2014.

## 7 Key messages and themes from workshops

### 7.1 Overview of key messages and themes from the workshops

Overall, participants were very supportive of the aims of the standard, the scope and the proposed approach to implementation. The most commonly made further suggestions were:

- To broaden the scope to include websites and signage;
- To include additional categories of support; and
- About how to support effective implementation, in particular training for staff and assessment of compliance.

### 7.2 Comments on what the standard is aiming to do

All participants agreed with what the standard is aiming to do.

Some participants noted that the standard was reinforcing existing duties included in the Equality Act 2010, and that this should be explicitly stated and guide expectations around provision of support.

### 7.3 Comments on what the standard includes

All participants agreed with what was currently included in the standard, with some participants suggesting additions to the scope.

The most common additions suggested, which were raised by many – if not most – participants were for the inclusion of websites and signage.

With regards to websites, some participants felt that the standard should direct health and social care organisations to follow existing good practice guidance. Others felt that the standard should include specific advice about website accessibility for particular groups.

Many participants highlighted the importance of people's needs being regularly reviewed, and records amended as necessary, as needs – and ways of meeting those needs – may change over time.

Many participants felt that disability awareness training for health and social care staff should be included within the scope of the standard. Suggestions included including this as part of induction for new staff and e-learning, as well as provision of training by people with disabilities. Some participants felt that staff should learn basic sign language.

Some participants felt that the standard should include a requirement for organisations to appoint and train staff as 'accessible information experts' and / or for organisations to identify a senior figure with responsibility for ensuring effective implementation of the standard.

Some participants thought that clarity was needed about the support which would be provided as part of an inpatient stay, for example from a BSL or deafblind manual interpreter.

Some participants thought that people who needed foreign language interpretation should be included in the standard, especially if they also had a disability.

#### **7.4 Comments on information formats and communication support which should be included**

Participants agreed with the proposed list of information formats and communication support types, and also made suggestions for additions. Commonly suggested additions were:

- dictaphones (enabling a service user or a professional to record information to play back at a later point);
- 'readers' (a person to read through written information);
- alternatives to / support for using 'touch screen' check-in systems;
- sighted guides / guiding to appointments;
- remote / video interpreting services for BSL.

Some participants felt that there should be a 'hierarchy of choices' such that their records should indicate a 'preferred choice' which may be braille, but alternative options for example for shorter or more urgent communication, which may be email.

Some participants highlighted the importance of being able to select multiple categories of support needed and / or ways of receiving information. The importance of considering people with multiple and complex needs was highlighted.

#### **7.5 Comments about how quickly people should get accessible information and communication support**

Participants agreed that, in an ideal world, accessible information and communication support should be received without any delay.

Many participants acknowledged that requirements needed to take into account the difference between routine or planned care, and emergency or unplanned care.

Some participants pointed out that an acceptable timescale for receiving information in an accessible format would depend on the intended use or impact of that information.

Some participants felt that the standard needed to be clearer about acceptable timescales for receiving particular types of information and particular formats, so that organisations and service users knew what was expected. It was felt that 'as soon as possible' was too vague.

Some participants felt that some types of accessible information, for example large print or easy read, should be provided straightaway. Most participants acknowledged

that there was likely to be a delay where an interpreter or advocate was needed, however, some participants felt that, with the use of a BSL video relay service (VRS), there should be no delay in accessing BSL interpretation.

Some participants felt that the standard needed to be clearer that not meeting an individuals' needs by any means was never acceptable, as some support should always be provided.

## **7.6 Comments on the quality considerations**

Overall, participants agreed with the proposed quality considerations, and suggested additions.

Many participants commented that patients / service users with information and communication needs should be involved in the implementation and evaluation of the standard / accessible information, as this would ensure quality.

Additional suggestions made for ensuring or assuring quality included:

- 'Mystery shoppers';
- Patient surveys and feedback;
- Sharing of good practice and lessons learned between organisations;
- 'Standards' to ensure the quality and consistency of 'easy read' information;
- Training for health and social care staff in producing accessible information and supporting people with communication needs;
- Quality checking of information by patients / service users.

Some participants suggested that BSL interpreters should be required to have particular experience or expertise in the relevant setting – for example knowledge of medical terminology – as well as an appropriate qualification. Some participants suggested that BSL interpreters should be NRCPD (National Registers of Communications Professionals working with Deaf and Deafblind People) registered.

Some participants felt that the standard should include the involvement of family members / parents to support communication between individuals and professionals, especially where individuals had multiple or complex needs.

Some participants felt that that health and social care staff should not be used as BSL interpreters, even if they were qualified to do so.

## **7.7 Comments on the proposed 12 month implementation period**

Most participants felt that 12 months was about the right amount of time to give organisations to implement the standard.

However, many commented that organisations should be required to start working towards compliance immediately after the standard was approved, and suggested that some elements – such as longer appointments – could (and should) be put in place straightaway.

Many participants suggested a 'staged' approach to implementation, with some elements prioritised and the provision of milestones by which particular aspects should be completed.

## **7.8 Comments on making sure that organisations follow the standard**

Many participants highlighted the importance of having clear, robust plans in place to support implementation, which included milestone dates for completing particular actions. Some participants were concerned that organisations would not follow the standard.

Most participants felt that there should be a role for patients or service users, and / or for voluntary sector organisations, in supporting and monitoring compliance with the standard.

A number of participants commented on the importance of 'promoting' the standard to patients and service users, including proactive, accessible communications.

Some participants expressed concerns about the effective implementation of the standard, given resource constraints within the health and social care system.

Suggestions for encouraging or enforcing compliance included:

- Assessment of compliance by the Care Quality Commission (CQC) and / or local Healthwatch;
- Inclusion of the standard in Patient Led Assessments of the Care Environment (PLACE);
- Requirements for organisations to report on their implementation of the standard as part of 'Quality Accounts', to Local Health and Wellbeing Boards or to NHS England;
- Requiring health and social care organisations to work with patient groups / voluntary organisations as part of implementation;
- 'Mystery shoppers';
- Publicly reporting poorly performing organisations;
- Provision of advice and support.

The notes from all of these workshops are available on the [NHS England website](#)

## 8 Feedback received via email, letter or telephone

### 8.1 Letters / statements from organisations

Instead of or in addition to completing a survey, some 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 survey respondents and participants in workshops, including in particular highlighting:

- Support for the aims and objectives of the standard, and of the inclusion of the need to identify, record and highlight people's needs.
- Concerns about the practicality and / or impact of implementing the standard in particular care settings, most notably in primary care. Such comments were often linked to concerns about IT functionality and / or services' ability to provide all of the formats / types of support listed. There were also some concerns about the 'turnaround times' for information in alternative formats and communication support.
- The need for greater clarity about: which organisations are required to follow the standard; the extent to which the scope includes people with disabilities other than those highlighted in the consultation document and people who may lack mental capacity; expectations around the provision of support.
- The need for staff training in supporting people with disabilities, in assisting people to identify their needs, in production of accessible information, and in types of communication support.
- Suggestions for widening the scope to include (most commonly) websites and signage, with some respondents also suggesting that people with foreign language needs should be included.
- Respondents agreed with the suggested list of information format and communication support types and put forward additions, including communication passports, access to sighted guides, verbal information, 'follow up' information in an alternative format, BSL VRS, alternatives to easy read for people with a learning disability, and support from a speech and language therapist.
- With regards to quality considerations, respondents highlighted the need to ensure accuracy and quality of information prior to putting it into an alternative format, and some respondents indicated that BSL interpreters should be NRCPD registered.
- With regards to implementation of the standard, some respondents expressed concerns about how realistic the 12 month timetable was.

- In terms of supporting effective implementation, key suggestions included identification and sharing of best practice, rollout of a 'help card' or 'communication card,' training for health and social care staff in supporting and communicating with people with disabilities, and the need to clarify the mandatory nature of the standard. A number of respondents suggested that voluntary organisations and patient groups should support local implementation of the standard.
- A number of organisations also put forward specific offers to work with NHS England to support the finalisation and effective implementation of the standard.

## **8.2 Feedback from individual service users**

Some individuals provided specific comments or suggestions via email or telephone, and one response was also received in braille. These reinforced key comments made by survey respondents and workshop participants, and in particular demonstrated support for the standard, whilst also in some cases raising concerns about the practicality of implementation or suggestions for ensuring that the needs of particular groups were included.

## 9 Feedback received on the consultation process

Some organisations and individuals provided specific feedback on the consultation process itself. Comments received related to:

- Difficulty finding the consultation document or survey in a particular format on the website.
- The accessibility of the 'easy read' consultation document and survey.
- The potential for confusion of this 'accessible information standard' with [The Information Standard](#) quality scheme.
- The accessibility of the consultation process for people with visual loss.
- Finding the consultation document easy to follow and understand.
- Suggested improvements to the grammar and / or language used in the consultation document.
- Being unable to receive submitted comments by return in an accessible format.

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

## 10 Impact of consultation

The feedback received as part of the consultation will specifically inform the revision and finalisation of the accessible information standard, and plans for ensuring and assuring its implementation.

Some examples of where views expressed will directly inform the review of the draft standard prior to finalisation are with regards to:

- Alternative key word signing systems (in addition to Makaton).
- Clarity about the inclusion of people with autism, aphasia, and those who are covered by the Mental Capacity Act.
- Clarity about the legal status of the standard.
- The 12 month compliance deadline.
- The need for clear and detailed plans to support implementation, including priorities and milestones.
- The registration and qualification requirements of BSL interpreters and deafblind manual interpreters.
- The role of 'communication passports'.
- The role of Speech and Language Therapists.
- Use of family members / parents / carers as interpreters for people with additional or complex needs.

Some examples of where views expressed will directly inform plans to support effective implementation of the standard include:

- The advice, tools and guidance to be made available by NHS England to support organisations in effectively implementing the standard.
- The need for training / guidance for health and social care staff.
- The need to provide structured implementation plans / guidance relevant to particular care settings.
- The provision of support for the identification and sharing of best practice.
- The role of voluntary organisations and patient groups in assisting organisations with effective implementation at a local level.

## 11 List of responding organisations

NHS England would like to acknowledge contributions received from the following organisations who are known to have responded to the consultation (note that this list is likely to be incomplete as some organisations did not identify themselves when submitting an online survey):

Action on Hearing Loss  
Bart's Health NHS Trust  
Be Heard (Bracknell)  
Books Beyond Words  
Brent Mencap  
Comet Group  
Cyrenians  
Doncaster Speak Up  
East Sussex Community Voice / Speakup Countywide Forum  
Health Matters  
Healthwatch County Durham  
Healthwatch East Sussex  
Healthwatch Islington  
Healthwatch Redcar and Cleveland  
Healthwatch Waltham Forest, Waltham Forest Vision and Waltham Forest Deaf Forum  
Inclusion London  
Involvement Now  
Just Advocacy  
Leeds Teaching Hospitals Trust Blind and Partially Sighted Advisory Group  
Macmillan Cancer Support  
Medical Defence Union  
Moorfields Eye Hospital NHS Foundation Trust  
National Deaf Children's Society  
National Federation for the Blind (Leeds Branch)  
Newcastle Society for Blind People  
Newcastle upon Tyne Hospitals NHS Foundation Trust  
National Community Hearing Association and British Society of Hearing Aid Audiologists  
NHS Enfield Clinical Commissioning Group  
NHS West Hampshire Clinical Commissioning Group  
People First (Self Advocacy)  
Pharmacy Voice  
PiF (Patient Information Forum)  
Race Equality Foundation  
Reach  
Royal College of Speech and Language Therapists  
Sense  
SignHealth  
Solent NHS Trust  
South London and Maudsley NHS Foundation Trust  
SpeakEasy N.O.W. Health Checkers  
The British Academy of Audiology (BAA)

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The British Medical Association (BMA)  
The Communication Trust  
The Joint Health Strategy Group (of library organisations who have health interests)  
The Optical Confederation  
The National Registers for Communication Professionals working with Deaf and  
Deafblind People (NRCPD)  
Thomas Pocklington Trust  
UK Council on Deafness  
UKAAF (UK Association for Accessible Formats)  
VISION 2020 UK

## 12 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, 7E56, 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)