



Accessible Information Standard: Post-Implementation Review – Report

NHS England INFORMATION READER BOX**Directorate**

Medical	Operations and Information	Specialised Commissioning
Nursing	Trans. & Corp. Ops.	Commissioning Strategy
Finance		

Publications Gateway Reference:**06691**

Document Purpose	Report
Document Name	Accessible Information Standard: Post-Implementation Review - Report
Author	NHS England, Patient and Public Participation and Insight Group
Publication Date	July 2017
Target Audience	CCG Accountable Officers, Care Trust CEs, Foundation Trust CEs , Directors of Nursing, Directors of Adult SSs, Communications Leads, NHS Trust CEs, Stakeholders with an interest in the Accessible Information Standard
Additional Circulation List	NHS England's partners and stakeholders, including voluntary and community sector organisations, with an interest in accessibility and inclusion
Description	This report summarises the findings from NHS England's post-implementation review of the Accessible Information Standard (DCB1605 Accessible Information) and outlines next steps.
Cross Reference	N/A
Superseded Docs (if applicable)	N/A
Action Required	For information
Timing / Deadlines (if applicable)	N/A
Contact Details for further information	Accessible Information Standard Patient and Public Participation and Insight Group NHS England 7E56, Quarry House, Quarry Hill, Leeds LS2 7UE Email: england.patientsincontrol@nhs.net www.england.nhs.uk/accessibleinfo

Document Status

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet.

Accessible Information Standard: Post-Implementation Review Report

Version number: 0.1

First published: July 2017

Prepared by: Patient and Public Participation and Insight Group, NHS England

Classification: OFFICIAL

Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- had due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- had regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email england.contactus@nhs.net stating that this document is owned by the Patient Centred Care team in the Directorate of Nursing.

Contents

Contents	4
1 Executive summary	5
2 Background	6
3 Communications – promoting participation in the review	7
4 Summary of engagement activity	7
5 Summary of feedback from health and social care professionals and organisations	9
6 Summary of feedback from patients, service users, carers and parents	11
7 Summary of feedback from support, supplier and representative organisations	13
8 Summary of feedback from local Healthwatch organisations	14
9 Summary of feedback received on the review process	15
10 Impact of the Standard	16
11 Next steps – the impact of the review	17
12 Acknowledgements.....	20
13 Contacts and alternative formats	22

1 Executive summary

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care must follow the [Accessible Information Standard](#) ('the Standard') in full.

During January-March 2017 NHS England led a post-implementation review of the Standard, with the aim of assessing its impact and ensuring that it is, and continues to be, 'fit for purpose'. This report summarises the actions and findings of the review.

Input into the review was sought from individuals and organisations affected, or expected to be affected, by the Standard. This included organisations that provide and / or commission NHS care and / or publicly-funded adult social care, voluntary and community sector organisations, professional representative bodies, patient groups, and patients, service users, carers and parents with information and / or communication needs relating to a disability, impairment or sensory loss.

Participation in the review was promoted in a wide variety of ways, including via newsletters and bulletins, and distribution to networks and partners. The primary feedback mechanism was via one of three surveys, targeted at different groups. A small number of meetings and events also took place.

During the review period:

- 231 surveys for health and social care professionals and organisations were completed;
- 1,312 surveys for patients, service users, carers and parents were completed, including 133 in an easy read format;
- 66 surveys for support, supplier and representative organisations were completed.

Additional feedback was also received at meetings and events, and via email and letter.

The key themes which emerged as part of review were:

- There is widespread support for the overarching aims of the Standard, and for the Standard itself, although some organisations have concerns about costs.
- Patients, service users, carers and parents are clear that receiving accessible information and communication support is essential if they are to receive safe, high quality care, to maintain their privacy and dignity, and to be involved in decisions about their care and treatment.
- Implementation of / compliance with the Standard is variable both across and within organisations, with particular (but differing) challenges identified by both large and small organisations of all types.

- Similarly, the impact of the Standard on individual patients / service users and on organisations differs. Where organisations have implemented the Standard, they, and their patients / service users, have noticed benefits.
- Many participants felt that the Standard could have a significantly greater impact than it had done to date, suggesting that monitoring or enforcement of compliance needed to be put in place at a national level.
- There is no indication of a need for significant changes to be made to the Standard, although some specific suggestions for additional clarity have been made.
- The most commonly raised implementation challenges relate to difficulty in adjusting electronic patient record systems (specifically as regards to recording and flagging of needs, and producing alternative formats), lack of awareness / the need for improved communications about the Standard and competing demands on staff time.

The feedback received as part of the review will directly inform revisions to the Specification and Implementation Guidance for the Standard which will be reissued in Summer 2017, following approval by the Data Coordination Board.

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

2 Background

2.1 Introduction to the Standard and the review

The [Accessible Information Standard](#) was published by NHS England, following approval as a new 'information standard' for the NHS and adult social care system, in July 2015.

Officially called DCB1605 Accessible Information (and formerly SCCI1605 Accessible Information), the Accessible Information Standard ('the Standard') directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting individuals' information and communication support needs, where those needs relate to a disability, impairment or sensory loss.

By law ([section 250 of the Health and Social Care Act 2012](#)), from 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care must follow the Standard in full.

Organisations that commission NHS care and / or publicly-funded adult social care, for example Clinical Commissioning Groups (CCGs) and local authorities, must also support implementation of the Standard by provider organisations.

During January-March 2017 NHS England led a post-implementation review of the Standard, with the aim of recording and analysing views and experiences in order to assess its impact and ensure that it is, and continues to be, 'fit for purpose'.

2.2 Overview of engagement activity prior to the review

The engagement activity as part of the review built on extensive communication and engagement activity from summer 2013 onwards to raise awareness of the Standard and enable stakeholders to influence its development. This included [engagement activity](#) from mid-November 2013 until late-February 2014, and a [consultation](#) during August – November 2014.

Feedback and learning from the engagement and consultation phases, and from previous communication activity, influenced activity as part of the review. Throughout the development, implementation and review phases, the Standard Setting for Accessible Information Advisory Group continued to have oversight of the Standard.

3 Communications – promoting participation in the review

In September 2016, NHS England began communication with providers and commissioners of NHS care and publicly-funded adult social care, representative bodies and other stakeholders, to inform them that there would be a review of the Standard during January – March 2017.

In January 2017, NHS England rolled out a wide-ranging communications campaign to promote participation in the review by individuals and groups identified as having an interest in the Standard and / or who were affected by or required to implement it. The target audience therefore included NHS and adult social care professionals and organisations, voluntary and community sector organisations, relevant professional representative bodies, and NHS England's partners. It also included the patient, carer and service user community, especially 'experts by experience' with information and / or communication needs relating to a disability, impairment or sensory loss.

Participation in the review was promoted via the NHS England, NHS Digital and other websites, through articles in a range of bulletins, and through direct communication to a wide range of individuals and organisations.

The review was also promoted on Twitter by NHS England (@NHSEngland) and a number of other individuals and organisations including the Department of Health (@DHgovuk), NHS Employers (@NHSE_Diversity), the Professional Records Standards Body (@ProfRecordsSB), local Healthwatch organisations and voluntary sector organisations.

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 review period.

4 Summary of engagement activity

4.1 Surveys

From 10 January until 10 March 2017 views were sought as part of the review, primarily via one of three surveys, available from the NHS England ['consultation hub'](#)

(with links from the Accessible Information Standard webpages). The surveys were aimed at three different ‘target audiences’:

- Health and social care professionals and organisations (231 completed surveys);
- Patients, service users, carers and parents with information and / or communication needs relating to a disability, impairment or sensory loss (1,312 completed surveys);
- Support, supplier and representative organisations with an interest in the Standard, including voluntary and community sector organisations, local Healthwatch and professional representative bodies (66 completed surveys).

As well as being available online, all of the surveys were available electronically as Word documents, and in hard copy. The patient, service user, carer and parent survey was also available from the NHS England website in audio, British Sign Language (BSL) video and easy read formats. For those who are not online, this survey was also available as a paper copy (including in large print and easy read), on audio CD, in braille and on BSL DVD. In addition, where people had difficulty reading or responding to the review survey, arrangements were made to send the survey by email, for response in the same format, and for telephone completion of surveys.

Some of the survey questions were repeated from the engagement and consultation phases to allow assessment of any changes over time.

The surveys were anonymous, with no questions which allowed identification of respondents. In addition, completion of all questions, in all surveys, was optional and / or there was a ‘prefer not to say’ option.

The key findings from the surveys are summarised in later sections. A detailed analytical report of responses is also available on request, as the ‘Analytical Report on the Accessible Information Standard Review – Spring 2017’, which includes graphical representation of the results. This report also includes the ‘free text’ responses received as part of completed surveys.

4.2 Meetings and events for patients, service users, carers and parents

As part of the review, a small number of face-to-face workshops were supported by NHS England and members of the Standard Setting for Accessible Information Advisory Group to ensure that the views of some of the key groups intended to benefit from the Standard were heard:

- Action on Hearing Loss hosted a workshop on 16th February in London to enable people who are d/Deaf or have hearing loss to have their say. This event was attended by five participants.
- CHANGE hosted two workshops to enable people with learning disabilities to have their say – on 2nd March in Leeds (attended by eight participants) and on 7th March in Coventry, in partnership with Grapevine (attended by 13 participants).

- Sense hosted a workshop in London on 8th February 2017 to enable people who are deafblind to have their say. This event was attended by four participants.
- At these workshops, a limited number of questions, similar to those asked in the patient, service user, carer and parent survey but specifically designed for group discussion were asked. The notes or reports from these events are available on request (see contact details in section 13).
- The Royal National Institute of Blind people (RNIB) also supported people who are blind or have visual loss, including those who are digitally excluded, to have their say as part of scheduled meetings and events during the review period.

Some other organisations and groups also held meetings or events to support people to participate in the review.

4.3 Other meetings and events

The review was also discussed at a number of meetings and events aimed at health and social care professionals, including the [NHS Employers Diversity and Inclusion Partners Network meeting on 15th February](#). In addition, views were recorded as part of roundtable discussions at a meeting of the Association of Directors of Adult Social Services (ADASS) Physical and Sensory Impairment and HIV/AIDS Network on 17th February. Feedback was also received as part of workshop discussions at an AbilityNet event on 28th February.

4.4 Working with local Healthwatch

As part of, and prior to, the review, a number of local Healthwatch organisations undertook local activity, including events and surveys, to gather feedback from individuals and organisations about the impact of the Standard and experiences of implementation.

5 Summary of feedback from health and social care professionals and organisations

5.1 Summary of survey responses

A total of 231 completed surveys were received during the review period. Headline findings were that:

- Respondents responded on behalf of and / or worked for a wide range of organisations, including GP practices (36 respondents), acute hospitals / acute foundation trusts (34 respondents), community service organisations / foundation trusts (29 respondents), learning disability service providers (24 respondents), voluntary or community sector providers (18 respondents) and local authorities (16 respondents).
- 95 respondents (41.5%) stated that the impact of the Standard was 'good' or 'very good', 121 respondents (52.8%) stated that the impact was 'neither good or bad'

(neutral)' and 13 respondents (5.7%) stated that it had been either 'bad' or 'very bad'.

- The majority of survey respondents (146 respondents / 65.5%) stated that their organisation had implemented the Standard either 'to some extent' or 'mostly', 57 respondents (25.6%) stated their organisation had implemented the Standard 'completely' or 'completely and demonstrating good practice'. 16 respondents (7.2%) stated 'not at all'.
- 61 respondents (27.0%) stated that they had noticed 'significant benefits' or 'some benefits' associated with implementing and following the Standard. 90 respondents (39.8%) stated that 'it is too early to say'.
- Free text comments suggested that most respondents were generally supportive of the Standard / thought it was 'a good thing' but that the extent of implementation was variable (even within organisations). The need for greater awareness-raising about the actions which must be taken under the Standard was highlighted. Some concerns about the cost of implementing the Standard and of producing alternative formats were also raised.
- Challenges with implementation commonly focused on cost and IT issues (including regarding recording and flagging patients' / service users' needs and being able to send correspondence in large print or via email). When asked to identify costs in implementing and following the Standard, most respondents referred to 'staff time', specifically to coordinate and oversee implementation and to make changes to systems or documentation.
- Some respondents suggested that there should have been more national coordination with regards to information in alternative formats and changes which needed to be made to IT systems.
- Some respondents included examples of how the Standard had been implemented in practice, for example the use of agreed questions to routinely identify individuals' needs, and the use of flags and alerts. The positive impact that the Standard had had included increased confidence (amongst staff and service users), creating the impetus to make specific changes to improve patient / service user experiences and that the clarity around expectations was helpful.
- Specific suggestions for additional guidance / tools included sharing good practice, use of email, and access to a central library of information in alternative formats.

5.2 Summary of feedback from workshops and events

Comments received at events and meetings with health and social care professionals during the review period suggested that the impact of the Standard was variable, with some organisations reporting significant impact on them and / or their service users, and others reporting limited impact.

Participants felt that the key challenges were around lack of awareness, difficulty in sharing information about individuals' information and communication needs (both within and across organisations), and access to alternative formats / communication support. Suggested support focused on resolving these issues. Some organisations had experience of compliance monitoring, including self-assessment, involvement in local steering groups and monitoring of service user experiences.

5.3 Summary of collated feedback from Clinical Commissioning Groups

As part of the review, a report was submitted by Action on Hearing Loss, CHANGE, Sense and the Royal National Institute for Blind people (RNIB) summarising responses they had received from a total of 90 Clinical Commissioning Groups (CCGs) (in response requests from the charities) regarding implementation and impact of the Standard, providing a high level snapshot of approaches, progress and issues.

The report highlighted the importance of CCGs' role in monitoring implementation of the Standard by providers as well as the positive impact of partnership approaches, looking at implementation across a local area. Recommendations included promoting good practice and raising awareness of available tools and resources to support implementation.

5.4 Other comments

Instead of or in addition to completing a survey, some organisations and individuals submitted comments via letter or email.

Responses highlighted progress that had been made in implementing the Standard, including how it had been embedded into some 'business as usual' processes and about staff training / awareness, however, concerns were also expressed about barriers to effective implementation, especially with regards to electronic patient / service user record systems. Responses also highlighted the actual and potential benefits associated with implementation of the Standard, particularly around quality improvement.

6 Summary of feedback from patients, service users, carers and parents

6.1 Summary of survey responses

A total of 1,312 completed surveys were received, including 133 in an easy read format. Headline findings were that:

- A significant majority of survey respondents (1,010 (79%)) stated that they found it difficult or they needed support to see, to hear, to speak, to read or to understand what is being said 'always', 'most of the time' or 'sometimes'.

- With regards to the impact of the Standard, the majority of respondents (555 / 43.8%) stated that they ‘had not heard of the Standard before now’. 402 respondents (31.8%) felt that the impact had been neutral, 192 respondents (15.2%) felt that it had been ‘good’ or ‘very good’. 97 respondents (7.7%) felt that it had been ‘bad’ or ‘very bad’.
- Many patients, service users, carers and parents had not received accessible information and / or communication support from NHS and / or adult social care providers. ‘Free text’ responses to the surveys often explained the difficulties this had caused, including with specific examples of distress, poor experiences and being unable to communicate effectively with staff / understand what was going on and / or be involved in decision-making. Others outlined positive steps which services and staff had taken to meet their needs, and the positive impact this had had.
- The potential impact of the Standard was also clearly articulated, with comments including that receiving accessible information / communication support would be “life changing”, improving confidence, reducing anxiety, protecting privacy and autonomy, and empowering people to manage their own health and wellbeing.
- Common specific themes included the need for greater staff awareness, understanding and / or training about how to communicate with people with a disability, impairment or sensory loss (especially with people who lipread), for requests for communication in large print (especially) to be met, and for British Sign Language (BSL) interpreters to be consistently and reliably arranged for appointments. Many respondents found the use of text message to be a positive development.
- Comments from many patients, service users, carers and parents suggested that there should be greater monitoring or ‘enforcement’ of compliance with the Standard, as this would increase the positive impact / ensure that potential benefits were seen.

6.2 Summary of feedback from workshops and events

Participants at the events reported mixed views regarding the impact of the Standard, about their experiences of receiving information in an accessible format and / or communication support, and of being asked about needs.

Access to easy read information and correspondence continued to be a major issue for people with a learning disability, as did the ability of professionals to communicate in an accessible way. For people with hearing loss, use of ‘scrolling screen’ systems in waiting areas and text messaging for appointment reminders were positive developments, but a lack of awareness amongst health and social care staff about supporting someone to lipread continued to be a barrier.

Participants who are deafblind usually received accessible information, but mostly because they had been proactive in asking for it, and many had had issues with access to support from a Communicator Guide, including because of disputes about funding.

With regards to the impact of receiving accessible information and communication support, participants' responses focused on increased autonomy, improved privacy and being able to be directly involved in decision-making.

Participants agreed that the Standard had the potential to have a significant impact / a greater impact that it had to date. Some participants felt that it would take longer to see the full impact of the Standard.

6.3 Other comments

Some individuals provided feedback via email and / or letter, either instead of or in addition to completing a survey. These comments focused on the need to raise awareness of the Standard and accessible information / communication support amongst health and social care staff, including especially amongst primary care providers. There were also specific suggestions for greater training and education of staff in how to communicate effectively with people with a disability, impairment or sensory loss.

7 Summary of feedback from support, supplier and representative organisations

7.1 Summary of survey responses

A total of 66 completed surveys were received. Headline findings were that:

- Respondents responded on behalf of and / or worked for a wide range of organisations, including a provider of communication support (15 respondents), a voluntary or community organisation working with people who are blind, d/Deaf, have hearing or visual loss, or a learning disability (12 respondents), a professional representative body (7 respondents) or a local Healthwatch organisation (6 respondents).
- 25 respondents (37.9%) stated that the impact of the Standard was 'good' or 'very good', 36 respondents (54.5%) stated that the impact was 'neither good or bad (neutral)' and 4 respondents (6.1%) stated that it had been either 'bad' or 'very bad'.
- Perhaps representative of the diversity of respondents, mixed views were expressed on the Standard and both its impact / potential impact, although there were a number of very committed supporters of it. Common concerns were with regards to costs of accessible information / communication support, including the need for clarity on responsibilities for meeting these costs, and about the need for greater awareness of the Standard / publicity.
- Many respondents highlighted the need for greater monitoring / enforcement of compliance with the Standard, with specific suggestions including that this should be via a dataset and / or through the Care Quality Commission (CQC). It was felt that this would increase the positive impact / ensure that potential benefits of the Standard were seen. The challenges that the d/Deaf community continued to

experience were also highlighted. Some representative bodies requested additional guidance about implementing the Standard in particular settings, notably community pharmacy, and / or for a 'relaxing' of the Standard's position with regards to the use of family members / friends as interpreters. In contrast, some voluntary and community sector respondents felt very strongly that the need to always use professional, qualified, registered interpreters needed to be reiterated.

7.2 Summary of feedback from workshops and events

Feedback from the AbilityNet ['Implementing the Accessible Information Standard in a digital NHS' event](#) showed that, whilst there was agreement that there were 'pockets of good practice' – which it was felt should be better promoted – many participants called for a greater focus on supporting effective implementation of the Standard. Suggestions were made for incentives, penalties, enhanced monitoring of compliance and greater use of technology.

7.3 Other comments

Instead of or in addition to completing a survey, some organisations and individuals submitted comments via letter or email.

The points raised supported many of those raised by survey respondents including in particular highlighting the variable impact of the Standard to date, the need for greater awareness about the Standard and for training for health and social care staff, the potential for greater impact and highlighting some of the challenges organisations had faced with implementation, including with regards to IT systems and the cost of professional communication support / alternative formats.

The positive impact of partnership working between NHS organisations, local authorities, local Healthwatch, patient groups and voluntary sector organisations to support effective implementation of the Standard was highlighted.

Respondents from the voluntary and community sector expressed their strong support for the Standard, and a wish to see it implemented more universally across health and social care providers.

Some respondents suggested that there should be increased monitoring and 'enforcement' of compliance.

8 Summary of feedback from local Healthwatch organisations

Healthwatch England submitted a [response](#) drawing on the work of 41 local Healthwatch organisations, incorporating the views of more than 700 people and including information from visits to 50 healthcare providers.

In summary, "...While local Healthwatch have clearly supported the AIS, including working with local partners to emphasise its importance and, in some cases, providing training on how to implement it, the majority of experiences shared by local

people suggest the new standards are yet to have a significant impact on experience. However, more comprehensive research is required to assess the impact of the AIS across the country...”

The briefing included a number of recommendations to increase the impact / support greater compliance with the Standard, notably greater training and awareness for health and social care staff about how to support people with a disability, impairment or sensory loss, improved recording and flagging of patients’ / service users’ information and communication needs in electronic record systems, improved availability of information in alternative formats and more consistent arrangement of interpreters for British Sign Language (BSL) users.

Healthwatch Essex shared a [detailed report](#) of their work to capture the views of people with sensory loss, which also made recommendations around how services could better meet their needs (through following the Standard). “It is without doubt that full adherence to the Accessible Information Standard by service providers will make a positive difference to patients with sensory impairment.”

Healthwatch Bristol also shared a [‘you said, we did’ report](#) outlining actions taken by local providers to meet the Standard, following their engagement event with people who are d/Deaf or have hearing loss in April 2016.

In addition, a number of local Healthwatch organisations separately completed an online ‘support, supplier, and representative organisation’ survey – these responses are included as part of the analysis summarised in section 7.1 and covered in detail in the ‘Analytical Report on the Accessible Information Standard Review – Spring 2017’ (available on request).

9 Summary of feedback received on the review process

Some organisations and individuals provided specific feedback on the review process itself, the surveys and supporting communication / information.

The majority of comments received related to the accessibility of the review, and of the ‘easy read’ version of the survey for patients, service users, carers and parents, for people with a learning disability. A number of individuals and self-advocacy groups for people with a learning disability expressed concerns that they had found the ‘easy read’ version of the survey difficult to complete, including because of the length and complexity of words, questions and answer options. Suggestions included simplifying some of the questions, adding examples as ‘prompts’ and for an easy read version of the survey to be made available to complete online.

Concerns were also raised about the accessibility of the British Sign Language (BSL) video version of the survey for patients, service users, carers and parents, including that the language should have been simplified, and the availability of a mechanism for d/Deaf people to submit responses in BSL.

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

In addition, an issue was identified and corrected early in the review process with one of the diversity monitoring questions, to enable respondents to select multiple answers regarding the type of disability or impairment they had. An additional sentence was also added into question 12 of the online survey for patients, service users, carers and parents, to support accessibility for screen-reader users.

10 Impact of the Standard

The survey for health and social care professionals and organisations included a number of questions to provide information to the [Burden Advice and Assessment Service \(BAAS\)](#) at NHS Digital, to inform consideration of the burden imposed by the Standard on organisations required to implement it.

All of the surveys asked respondents for their view on the impact of the Standard. To note that percentages do not total 100% as 'not answered' and 'not applicable' responses are not summarised here. The majority of respondents to the survey for health and social care professionals and organisations felt that the impact had been neutral (121 respondents (52.8%)), with a significant number / percentage stating that it had been 'good' or 'very good' (95 respondents (41.5%)). Just 13 respondents (5.7%) stated that it had been either 'bad' or 'very bad'.

The majority of respondents to the survey for support, supplier and representative organisations also felt that the impact had been neutral (36 respondents (54.5%)), with again a significant number / percentage stating that it had been 'good' or 'very good' (25 respondents (37.9%)). Just 4 respondents (6.1%) stated that it had been either 'bad' or 'very bad'.

The majority of respondents to the survey for patients, service users, carers and parents (555 respondents (43.9%)) stated that they 'had not heard of the Standard before now'. 402 respondents (31.8%) felt that the impact had been neutral, 192 respondents (15.2%) felt that it had been 'good' or 'very good'. 97 respondents (7.7%) felt that it had been 'bad' or 'very bad'.

Patients, service users, carers and parents responding to the review were asked some specific questions aimed at measuring improvements in experiences / access:

- Over the last 6 months, have you noticed any improvement in getting accessible information or communication support from NHS services? 269 respondents (20.8%) had noticed either a 'big improvement' or 'some improvement'. 680 respondents (52.7%) had not noticed any improvement.
- Over the last 6 months, have you noticed any improvement in getting accessible information or communication support from adult social care services? 117 respondents (9.4%) had noticed either a 'big improvement' or 'some improvement'. 256 respondents (20.4%) had not noticed any improvement.

Patients, service users, carers and parents were also asked what difference it would make if organisations always provided accessible information and communication support (a 'free text' question). 249 respondents (37.5%) made comments highlighting that this would make a big difference / make life easier, 120 respondents

(18.1%) that it would increase their independence / self-worth / confidence, 64 respondents (9.6%) that it would reduce their anxiety, and 63 (9.5%) that it would reduce confusion and increase clarity / understanding.

Health and social care professionals and organisations were asked how well they thought their organisation had implemented the Standard and if they had noticed any benefits associated with implementing and following the Standard. The majority of survey respondents (146 respondents / 65.5%) stated that their organisation had implemented the Standard either 'to some extent' or 'mostly', 57 respondents (25.6%) stated their organisation had implemented the Standard 'completely' or 'completely and demonstrating good practice', and 16 respondents (7.2%) stated 'not at all'. 61 respondents (27%) stated that they had noticed 'significant benefits' or 'some benefits' associated with implementing and following the Standard, and 90 respondents (39.8%) stated that 'it is too early to say'.

11 Next steps – the impact of the review

11.1 Overview

One of the main reasons for conducting the review was to enable identification of aspects of the Standard which needed updating, clarifying, elaborating on and / or adjusting to support effective, consistent implementation.

The feedback received as part of the review will specifically inform revisions to the Specification and Implementation Guidance for the Standard, which will be reissued in Summer 2017.

The surveys for health and social care professionals and organisations, and for support, supplier and representative organisations included some specific questions seeking views on potential amendments which had previously been identified for consideration. Free text responses from all surveys, and other comments received, also suggested additions or amendments.

As part of the review, specific requests which had previously been received for changes to the Standard were also considered (or in some cases reconsidered) by the Standard Setting for Accessible Information Advisory Group – as outlined in the [Maintenance Plan](#). Where these requests have been taken forward, they are included as part of this section. Where these requests have not been taken forward, direct communication with individuals and organisations who requested the change(s) will take place.

11.2 Impact of feedback

Feedback received as part of the review will inform the following amendments, clarifications and / or the inclusion of additional guidance as part of the reissued Specification and / or Implementation Guidance:

- Supporting mental health service users with communication needs.
- The use of email to communicate with patients / service users.

- Website accessibility.
- Flagging requirements / the definition of 'highly visible'.
- Recording of needs in non-coded systems.
- Support for people with learning difficulties, such as dyslexia (as distinct to learning disabilities).

Responses to the review will also inform consideration of whether organisations should identify an 'Accountable Officer', or similar designated role indicating an individual with responsibility for implementation and compliance with the Standard at a senior level, and whether a dataset should be established. Any changes in this regard will be reflected in the reissued Specification and / or Implementation Guidance.

Feedback from health and social care professionals and organisations will inform a review of the [Clinical Safety Case](#) for the Standard, which will be reissued if necessary.

Additional terminology which has been suggested to support effective implementation of the Standard will be reviewed and, where appropriate, will be progressed through relevant processes to potentially be released as new SNOMED CT terms in October 2017.

In addition, as suggested by a number of respondents, actions will be taken to promote good practice and case studies describing effective implementation of the Standard.

11.3 Supporting effective implementation and compliance

Respondents to the health and social care professionals and organisations survey were asked whether they / their organisation would find any additional support, guidance or tools useful in supporting compliance with the Standard, and, if so, to explain. Specific suggestions for additional guidance / tools included sharing good practice, use of email, and access to a central library of information in alternative formats. Some responses suggested that respondents were unaware of some of the resources which have been made available to support implementation of the Standard, in particular the [e-learning modules](#) and [toolkit for GP practices](#).

Respondents to the support, supplier and representative organisation survey were asked about any support they had provided to their members to assist them in implementing / following the Standard and whether they had monitored their members' or others' compliance with the Standard.

With regards to supporting their members' and / or others' compliance with the Standard, a significant majority of respondents (46 out of 57) said that they had. With regards to monitoring compliance, of 53 respondents, 23 respondents had monitored compliance in some way and 27 respondents had not.

Respondents to the health and social care professionals and organisations survey were asked if they had monitored their own / their organisation's and / or other organisations' compliance with the Standard, and / or if their compliance been monitored by another organisation. 58 respondents (37.4%) said that compliance is not monitored, 53 respondents (34.2%) said that this took place through performance reports / reviews / checklists, 18 respondents (11.6%) said that compliance is monitored by audit and 3 respondents (1.9%) said that they had outsourced compliance monitoring. Some organisations had monitored their own compliance, with this commonly coming under 'quality assurance', with external interest also referenced from local Healthwatch organisations and Clinical Commissioning Groups (CCGs). Some respondents specifically suggested a role for the Care Quality Commission (CQC) in monitoring implementation of the Standard, and asked for clarity on what this would mean in practice.

In March 2017, the Care Quality Commission (CQC) published their Equality Objectives for 2017-2019, including an objective on 'accessible information and communication'. In order to meet this objective, one of their commitments is that, "From October 2017, all inspection reports include how providers are applying the standard." Further information about the CQC's Equality Objectives is available [from their website](#).

11.4 Future review and retirement of the Standard

As outlined in the Maintenance Plan, the review enabled consideration of whether it is appropriate to plan for retirement of the Standard. Feedback received as part of the review has made clear that this would not be appropriate in the mid to long term. To consider retiring the Standard, there would need to be clear evidence of 'universal compliance' with the Standard as 'business as usual' throughout the NHS and adult social care system, which is not yet apparent.

Future reviews of the Standard to ensure that it remains fit for purpose will be undertaken in line with guidance from the Data Coordination Board. Established practice is that reviews take place within three years of a standard being published.

Any further change requests received or potential changes identified will be considered on a 'case by case' basis.

11.5 Related workstreams

Some of the feedback received as part of the review was not directly relevant to the Standard, but was relevant to one or more related workstreams, including around improving accessibility and the inclusion of people with a disability, impairment or sensory loss more widely. As appropriate, feedback captured as part of the review, and relevant learning or conclusions, will be shared with relevant workstream leads.

It should be noted that the Standard is referenced in the recently-published '[involving people in their own health and care: statutory guidance for clinical commissioning groups and NHS England](#)'.

12 Acknowledgements

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

Input from the following organisations that are known to have responded / contributed to the review and / or supported others to respond is acknowledged (note that this list will be incomplete as some organisations did not identify themselves when submitting an online survey):

- AbilityNet
- ACE Anglia
- Action on Hearing Loss
- Association of Directors of Adult Social Services (ADASS) Sensory Impairment and HIV/AIDS Network
- Bedfordshire and Luton Fair Play
- Blind and Partially Sighted Advisory Group (Leeds Teaching Hospitals NHS Trust)
- Bournemouth Borough Council
- Bradford Talking Media (BTM)
- CHANGE
- DeafDirect
- Deaflink
- Health Deafinitions
- Healthwatch England
- Healthwatch Barking and Dagenham
- Healthwatch Barnet
- Healthwatch Bath and North East Somerset
- Healthwatch Bristol
- Healthwatch Bromley
- Healthwatch Camden
- Healthwatch City of London
- Healthwatch Cornwall
- Healthwatch Cumbria
- Healthwatch Darlington
- Healthwatch Derbyshire
- Healthwatch Devon
- Healthwatch Enfield
- Healthwatch Essex
- Healthwatch Hackney
- Healthwatch Halton
- Healthwatch Hampshire

- Healthwatch Haringey
- Healthwatch Havering
- Healthwatch Hillingdon
- Healthwatch Islington
- Healthwatch Kent
- Healthwatch Leeds
- Healthwatch Leicester
- Healthwatch Lewisham
- Healthwatch Lincolnshire
- Healthwatch Milton Keynes
- Healthwatch Newham
- Healthwatch North Somerset
- Healthwatch Northamptonshire
- Healthwatch Northumberland
- Healthwatch Redbridge
- Healthwatch Rochdale
- Healthwatch Shropshire
- Healthwatch Somerset
- Healthwatch Southampton
- Healthwatch South Gloucestershire
- Healthwatch Stoke-on-Trent
- Healthwatch Suffolk
- Healthwatch Thurrock
- Healthwatch Tower Hamlets
- Healthwatch Trafford
- Healthwatch Wakefield
- Healthwatch Waltham Forest
- Healthwatch Wiltshire
- Healthwatch Wokingham Borough
- Healthwatch Worcestershire
- Healthwatch York
- Grapevine
- Manchester Disabled People's Access Group
- Mears Care
- Newcastle City Council
- Newcastle Society for Blind People
- Nottinghamshire County Council
- Our Voice Learning Disability Representatives (Westminster)
- Poole Forum for People with Learning Disabilities
- SeeAbility
- Sense
- SignHealth
- Solent NHS Trust
- Staffordshire and Stoke on Trent Partnership NHS Trust
- Synertec
- The Advocacy Project
- The Optical Confederation

- The Pharmaceutical Services Negotiating Committee (PSNC)
- The Royal College of Ophthalmologists (RCOphth)
- The Royal College of Radiologists (RCR)
- The Royal National Institute of Blind people (RNIB)
- VISION 2020 UK

13 Contacts and alternative formats

Copies of this report are available in Word document, PDF and audio formats, in easy read and British Sign Language (BSL) video (with subtitles) from the [NHS England website](#).

The report can also be posted out as a hard copy, in large print, easy read, on audio CD, on DVD (BSL and subtitled version) or in braille on request.

If you wish to request a copy of the report, or if you have a query about the Accessible Information Standard, please email england.patientsincontrol@nhs.net or write to Accessible Information Standard, Person Centred Care team, NHS England, 7E56, Quarry House, Quarry Hill, Leeds, LS2 7UE.

Patients, carers and members of the public can also contact the NHS England Customer Contact Centre by telephone on 0300 311 22 33.

For updates about the development of the Accessible Information Standard please visit the [NHS England website](#). To receive regular updates about engagement activities and opportunities to get involved in the work of NHS England, [sign up to receive our newsletter 'InTouch'](#).