



Accessible Information: Test Report

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SCCI1605 Accessible Information: Test Report

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1 Glossary of terms

Term / abbreviation	What it stands for
Advocate	A person who supports someone who may otherwise find it difficult to communicate or to express their point of view. Advocates can support people to make choices, ask questions and to say what they think.
Accessible information	Information which is able to be read or received and understood by the individual or group for which it is intended.
Alternative format	Information provided in an alternative to standard printed or handwritten English, for example large print, braille or email.
Braille	A tactile reading format used by people who are blind, deafblind or who have some visual loss. Readers use their fingers to 'read' or identify raised dots representing letters and numbers. Although originally intended (and still used) for the purpose of information being documented on paper, braille can now be used as a digital aid to conversation, with some smartphones offering braille displays. Refreshable braille displays for computers also enable braille users to read emails and documents.
British Sign Language (BSL)	BSL is a visual-gestural language that is the first or preferred language of many d/Deaf people and some deafblind people; it has its own grammar and principles, which differ from English.
BSL interpreter	A person skilled in interpreting between BSL and English. A type of communication support which may be needed by a person who is d/Deaf or deafblind.
Communication support	Support which is needed to enable effective, accurate dialogue between a professional and a service user to take place.
Communication tool / communication aid	A tool, device or document used to support effective communication with a disabled person. They may be generic or specific / bespoke to an individual. They often use symbols and / or pictures. They range from a simple paper chart to complex computer-aided or electronic devices.
d/Deaf	A person who identifies as being deaf with a lowercase d is indicating that they have a significant hearing impairment. Many deaf people have lost their hearing later in life and as such may be able to speak and / or read English to the same extent as a hearing person. A person who identifies as being Deaf with an uppercase D is indicating that they are culturally Deaf and belong to the Deaf community. Most Deaf people are sign language users who have been deaf all of their lives. For most Deaf people, English is a second language and as such they may have a limited ability to read, write or speak English.
Deafblind	The Policy guidance Care and Support for Deafblind Children and Adults (Department of Health, 2014) states that, "The generally accepted definition of Deafblindness is that persons are regarded as Deafblind "if their combined sight and

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	hearing impairment causes difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss” (Think Dual Sensory, Department of Health, 1995)."
Disability	The Equality Act 2010 defines disability as follows, “A person (P) has a disability if — (a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.” This term also has an existing Data Dictionary definition .
Disabled people	Article 1 of the United Nations Convention on the Rights of Persons with Disabilities has the following definition, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”
Easy read	Written information in an ‘easy read’ format in which straightforward words and phrases are used supported by pictures, diagrams, symbols and / or photographs to aid understanding and to illustrate the text.
Impairment	The Equality and Human Rights Commission defines impairment as, “A functional limitation which may lead to a person being defined as disabled...”
Interpreter	A person able to transfer meaning from one spoken or signed language into another signed or spoken language.
Large print	Printed information enlarged or otherwise reformatted to be provided in a larger font size. A form of accessible information or alternative format which may be needed by a person who is blind or has some visual loss. Different font sizes are needed by different people. Note it is the font or word size which needs to be larger and not the paper size.
Learning disability	This term has an existing Data Dictionary definition and is also defined by the Department of Health in Valuing People (2001) . People with learning disabilities have life-long development needs and have difficulty with certain cognitive skills, although this varies greatly among different individuals. Societal barriers continue to hinder the full and effective participation of people with learning disabilities on an equal basis with others.
Lipreading	A way of understanding or supporting understanding of speech by visually interpreting the lip and facial movements of the speaker. Lipreading is used by some people who are d/Deaf or have some hearing loss and by some deafblind people.
Notetaker	In the context of accessible information, a notetaker produces a set of notes for people who are able to read English but need communication support, for example because they are d/Deaf. Manual notetakers take handwritten notes and electronic notetakers type a summary of what is being said

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	onto a laptop computer, which can then be read on screen.
Patient Administration System (PAS)	Mainly used in hospital settings, and especially by NHS Trusts and Foundation Trusts, Patient Administration Systems are IT systems used to record patients' contact / personal details and manage their interactions with the hospital, for example referrals and appointments.
Read Codes	A coded thesaurus of clinical terms representing the clinical terminology system used in general practice. Read Codes have two versions: version 2 (v2) and version 3 (CTV3 or v3), which are the basic means by which clinicians record patient findings and procedures.
Speech-to-text-reporter (STTR)	A STTR types a verbatim (word for word) account of what is being said and the information appears on screen in real time for users to read. A transcript may be available and typed text can also be presented in alternative formats. This is a type of communication support which may be needed by a person who is d/Deaf and able to read English.
SNOMED CT (Systematised Nomenclature of Medicine Clinical Terms)	Classification of medical terms and phrases, providing codes, terms, synonyms and definitions. SNOMED CT is managed and maintained internationally by the International Health Terminology Standards Development Organisation (IHTSDO) and in the UK by the UK Terminology Centre (UKTC) . SNOMED CT has been adopted as the standard clinical terminology for the NHS in England .
Text Relay	Text Relay enables people with hearing loss or speech impairment to access the telephone network. A relay assistant acts as an intermediary to convert speech to text and vice versa. British Telecom (BT)'s 'Next Generation Text' (NGT) service extends access to the Text Relay service from a wider range of devices including via smartphone, laptop, tablet or computer, as well as through the traditional textphone.
Translator	A person able to translate the written word into a different signed, spoken or written language. For example a sign language translator is able to translate written documents into sign language.

Note: a more extensive 'glossary of terms' to assist organisations in effectively implementing the Standard is included as part of the Implementation Guidance.

2 Introduction

2.1 Background to the Standard

SCCI1605 Accessible Information – the ‘Accessible Information Standard’ – will require health and social care organisations to identify and record the information and communication support needs of patients and service users (and where appropriate their carers or parents), and take action to ensure that those needs are met.

The Standard applies specifically to patients, service users, carers and parents with an information or communication support need related to or caused by a disability, impairment or sensory loss.

It will be implemented through changes to IT and administrative systems, and to the processes followed by health and social care organisations for recording and responding to individuals’ needs.

Further detail and context is provided in the Specification.

2.2 Background to testing

The test period followed engagement activity to inform the development of the Standard, which took place from November 2013 to February 2014. A Report of Engagement has been produced.

To support the testing process, a preliminary outline draft of the Standard was developed (see Appendix D). This defined the nine step process of the Standard (as at April 2014), breaking it down into specific actions, and detailed all of the proposed data items, including with reference to [SNOMED CT®](#) codes as appropriate.

In addition, twelve hypothetical patient scenarios were developed, alongside supporting guidance around different communication support needs and a glossary. Together these documents formed a ‘test pack’ for partner organisations.

2.3 High level summary

During April and May 2014, the preliminary outline draft of the Standard was tested by five providers of health and social care to assess the feasibility and impact of implementation in ‘real life’ health and social care settings.

The testing process included consideration of the ‘as is’ and ‘to be’ states, and assessment of potential IT solutions, data collection methodologies and processes for delivery of information in alternative formats and of communication support. Assessment was undertaken using a paper exercise to support structured consideration of the impact and implications of the Standard, with a record being made of outcomes and learning.

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During the test phase, expert advice and technical input was also received from suppliers of patient administration and record software to health and care organisations, and from subject matter experts in the field of health and care IT. This included the GP IT New Requirements Group, known suppliers of hospital Patient Administration Systems (PAS), and the Worshipful Company of Information Technologists (WCIT) health and accessibility panels. This feedback is also summarised below.

3 Approach to testing

3.1 Overview

As well as the preliminary outline draft of the Standard, test organisations were provided with advice and guidance, record forms to support structured consideration and feedback on the Standard, and a series of hypothetical patient scenarios.

Organisations were asked to consider the preliminary outline draft of the Standard and identify whether their current systems or processes could comply with the requirements, and if not, of the changes or adjustments needed. Views on impact, feasibility, benefits and costs were also sought.

The hypothetical patient scenarios were aimed to support consideration by test organisations of how the Standard could work in practice. Input from actual patients, service users or carers was also invited as part of the process (via testing organisations).

The complete test exercise asked for organisations to use three different record forms, included at Appendix A, to consider and record:

- How the information and communication support needs of individuals would be identified, recorded, flagged, shared and met, using current systems and upon implementation of the Standard; and
- Barriers to implementation, benefits, risks and the anticipated impact of implementing the Standard on patients and staff, including time and resources.

The timescale for testing was four weeks, which was judged to be suitable for a desk-based review.

3.2 Rationale

The preliminary outline draft of the Standard was tested with the expectation that the results would inform the full draft Specification. The approach to testing aimed to build on engagement activity and test the conclusions which were drawn from feedback as part of this phase.

3.3 Purpose of testing and criteria for success

Testing aimed to:

- Identify inconsistencies or issues with the preliminary outline draft standard, so as to learn from them in refining the draft Specification;
- Gain insight from test partners' reflections on current processes and practice (the 'as is' state) and how current practice differs from that proposed by the Standard (the 'to be' state), and what actions would be necessary to move from one to the other (i.e. to fully implement the Standard);

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- Provide evidence that the requirements of the Standard would not be too difficult or costly to implement, and that the benefits of the Standard outweigh the costs.

Testing also sought to enhance understanding of:

- How the Specification for the Standard could be implemented operationally in health and social care settings;
- Potential issues arising from implementation of the Standard;
- How organisational process, practice, and policy will need to change in order to implement the Standard;
- The anticipated impact of the Standard upon service users, services and the wider health and social care system.

4 Structure of testing

4.1 Timescales

Testing took place between 16 April and 16 May 2014.

4.2 Participants

During early April 2014, an identified list of interested NHS bodies, adult social care bodies and organisations providing publicly-funded health or adult social care services were invited to act as 'test partners' for the Standard.

Interested organisations were asked to complete an application form outlining their expression of interest which included details of their organisation and care setting(s) and current systems for supporting patients, carers or service users with information and / or communication support needs.

In addition, and in recognition of the importance of engaging with designers, suppliers and commissioners of health and social care IT systems, feedback on the preliminary outline draft Specification for the Standard – including proposed data items – was also sought from a number of suppliers of patient administration and record software to health and care organisations, and from subject matter experts in the field of health and care IT.

Following assessment of application forms, and any necessary clarification, organisations were then invited to be formal 'test partners' and to work alongside NHS England and the Health and Social Care Information Centre (HSCIC) to test the preliminary outline draft of the Standard.

The following 'test partner' organisations submitted structured responses on the preliminary outline draft of the Standard:

- Cambridge University Hospitals NHS Foundation Trust
- Devon Doctors
- Leeds and York Partnership NHS Foundation Trust
- Manchester City Council – Sensory Team
- South Tees Hospitals NHS Foundation Trust

A further six organisations provided general feedback on the Standard:

- County Durham and Darlington NHS Foundation Trust
- GP IT New Requirements Group
- Orchard Care Homes
- Sheffield Teaching Hospitals NHS Foundation Trust
- System C
- Worshipful Company of Information Technologists

Feedback from specific teams, wards, and departments was welcomed, and received, as well as that from whole organisations. The focus was on gaining 'real life' and 'real time' insight from frontline professionals.

Relevant excerpts from the Minutes of the GP IT New Requirements Group meeting held on 1 May 2014 can be found in Appendix B.

4.3 Scope of testing

Test partners were asked to consider and assess the preliminary outline draft of the Standard in the context of their own health or social care setting, and provide feedback on the impact and implication of requirements to:

- Identify and input data about the information and communication support needs of patients, service users and carers with a disability, impairment or sensory loss;
- Refer to, act upon and share the recorded information and communication support needs of patients, service users and carers with a disability, impairment or sensory loss;
- Meet patients, 'carers' and service users' information and communication support needs – including turnaround times, reasons for any delays and quality assurance.

Specifically, organisations were also asked to provide an operational or 'front line' perspective as to the practicality of elements of the proposed Specification for the Standard.

They were also asked to identify any particular benefits and challenges or barriers associated with the approach / proposal and contribute data / views to enable an impact assessment of 'current' and proposed 'future' states to be completed, including financial costs and (potential or actual) savings.

4.4 Amount and type of data

The data from testing was submitted in narrative feedback form both formally and informally. Formal feedback was submitted by completing Forms 1 – 3 in the test pack. Informal feedback was submitted in the form of written statements and emails.

4.5 Task list / test schedule

Test partners were asked to complete a maximum of 14 forms; Form 1 was to be completed once to consider practice in regard to each of the 9 stages of the Standard, Form 2 to be completed 12 times (one for each patient scenario), and Form 3 to be completed once to reflect on the testing process and assess the changes necessary to implement the Standard.

Test partners were given four weeks, between 16 April and 16 May 2014, to complete the forms.

4.6 Test scripts

The test pack contained the following information:

- Guidance
- Preliminary outline draft standard
- Glossary of terms
- Patient scenarios
- Record forms for responses

The preliminary outline draft of the Standard can be found at Appendix C, the patient scenarios at Appendix D and the record forms at Appendix A.

4.7 Assumptions

Due to the 'self-selection' process, it was assumed that test partners already had some knowledge of the information and communication support needs of their patients, service users and carers, and had some existing processes in place in order to meet (at least some of) those needs. It was assumed that testing would help to identify where these processes were insufficient to meet the requirements of the Standard and indicate where further work would be necessary to support implementation.

4.8 Control process / governance

The test pack documents were designed by the Developer, based on feedback and observations during the engagement phase, and approved by correspondence by the Standard Setting for Accessible Information Advisory Group in early April 2014. This Test Report has also been approved by the Advisory Group.

5 Test results

5.1 Overview

Test partner organisations were requested to submit the outcome of their assessment using pre-defined forms and standard questions. The returns indicated that:

- The steps in the preliminary outline standard are appropriate and acceptable;
- Current practice around meeting the information and communication support needs of patients, service users and carers is varied;
- Organisations will need to make some changes in order to implement the Standard;
- Costs and impact of the Standard on services and staff remain unclear;
- The Standard is welcomed and benefits from implementation are expected.

It is important to note that some feedback was not specific to the Standard and has not been included in the test results. Some feedback included a wider scope than the Standard, such as accessibility of services by disabled people more widely, and this has also not been included in this Test Report.

5.2 Summary of test results

5.2.1 Organisations providing feedback

Five organisations returned forms from the test pack, as listed in the table below.

Type of Response	Organisation
Form 1	Cambridge University Hospitals NHS Foundation Trust ('Cambridge NHS FT') South Tees Hospitals NHS Foundation Trust ('South Tees') Leeds and York Partnership NHS Foundation Trust ('LYPFT') Manchester City Council – Sensory Team
Form 2: Scenario 1	South Tees Manchester City Council – Sensory Team
Form 2: Scenario 2	South Tees Manchester City Council – Sensory Team
Form 2: Scenario 3	South Tees Manchester City Council – Sensory Team
Form 2: Scenario 4	South Tees Manchester City Council – Sensory Team
Form 2 – Scenario 5	South Tees Manchester City Council – Sensory Team
Form 2: Scenario 6	South Tees
Form 2: Scenario 7	South Tees
Form 2: Scenario 8	South Tees
Form 2: Scenario 9	South Tees
Form 2: Scenario 10	South Tees
Form 2: Scenario 11	South Tees

Form 2: Scenario 12	South Tees
Form 3	Cambridge NHS FT Devon Doctors LYPFT Manchester City Council – Sensory Team South Tees

General feedback was also received from:

- County Durham and Darlington NHS Foundation Trust
- Leeds and York Partnership NHS Foundation Trust
- Orchard Care Homes
- Sheffield Teaching Hospitals NHS Foundation Trust
- System C
- The Worshipful Company of Information Technologists

5.2.2 Current issues with collecting data about information or communication support needs

Many test partners are not currently able to ascertain an individual's information or communication support needs until the point of assessment and, as appointment letters or confirmation of referral may be posted automatically, this may not be the first communication.

Many services receive initial information as part of the referral process but this often does not include information about an individual's information or communication support needs. Most test partners report that they do not use any standard or required questions to identify such needs.

There are also no specific fields to record information or communication support needs in either paper or electronic records, which is recognised as increasing the risk that a need would not be met even if it was recorded.

5.2.3 Current issues with electronic systems and recording of needs

Test partners report a number of issues with collecting and storing patients', service users' and carers' information and communication support needs in electronic systems. If fields for recording information or communication needs exist, the list of options as to how to address those needs do not include all the categories stated in the Standard.

None of the test partners reported the ability for systems to record complex communication needs.

Many partners record communication needs in a free-text area in the notes, which is unlikely to be checked by staff before sending out communication. Multiple IT systems exist, even within the same organisation, and these do not interact with other systems; this results in a lack of data sharing about individuals' information or communication needs with other teams and difficulties in providing alternative formats if software is incompatible.

A list of patient administration and record systems and documentation types utilised by test partners can be found in Appendix E.

5.2.4 Current issues with flagging of needs

Test partners report an overwhelming lack of flags or alerts in electronic systems which would indicate that an alternative communication format is needed. Similarly, none of our test partners reported processes which would require staff to check for these needs manually on the system or in paper notes. While there are some alerts for patients with learning disabilities, the alert does not include preferences for how that patient wants to receive information.

5.2.5 Current issues with meeting of needs

Test partners seem confident in their ability to provide large-print material quickly and efficiently. There is some knowledge and some processes are in place to enable the provision of a BSL (British Sign Language) interpreter, and easy read versions of documents can be made available with up to 5 days' delay. The majority of test partners did not mention processes for providing information by email, audio or braille.

5.2.6 Actions to address gaps in collection and recording of needs

Test partners identified that mandatory recording of this information will be necessary and the categories currently used to record type of information or communication need will need to be expanded. There is an issue with the quality of information, which may be initially provided by other organisations, especially in the case of referrals; information sharing protocols and agreements may need to be adjusted. Staff training in collecting and recording needs is felt to be necessary. It will be difficult to standardise collection and recording procedures across services in large organisations, like hospital trusts.

5.2.7 Moving to the future state: issues with implementing the Standard in electronic systems

The main hindrance with electronic systems is in sharing information between organisations and teams, which makes consistent communication within an episode of care or social services support difficult. Another consideration is how electronic systems will flag a communication need, and how this will interact with other software to produce alternative formats or instigate administrative procedures to meet the need.

5.2.8 Moving to the future state: issues with flagging

Most test partners reported a need to develop a flagging or alert system and mandatory fields in electronic systems. This is likely to have cost and time implications which were felt likely to delay implementation.

5.2.9 Moving to the future state: issues with meeting of needs

Test partners report the ability to produce large text easily and quickly, and procedures are in place to book BSL interpreters. Other forms of information have either not been mentioned or are not in place. There will be a need for processes to

be established to source information in alternative formats where these are not produced in-house.

Test partners were asked to estimate how long patients would have to wait for information to be provided in a range of alternative formats. With the exception of large-print, most alternative formats create a delay of 2-5 days.

5.2.10 Positive impact of implementing the Standard

Test partners expect positive impacts on patient experience, staff awareness and confidence and service efficiencies. There will be better outcomes for patients with improved communication around history and symptoms leading to faster diagnosis and improved management. There will be fewer complaints and better outcomes for patients as a result of improved communication. Patients will have greater independence and increase the choice and control they have over their lives.

Staff will benefit by increasing awareness and confidence to communicate with patients, service users and carers with a disability, impairment or sensory loss.

The Standard may lead to an improvement in the effectiveness of services, as there will be more accurate appointment times, allowing extra time for communication where needed, which will lead to fewer overrunning clinics. There will be a reduction in 'Did Not Attend' (DNAs) – appointments wasted as the patient does not arrive – as patients will be able to get information in a timely and understandable format.

Specialist services that directly support people with a disability, impairment or sensory loss should experience a reduction in demand, as some needs could be met without the intervention of these services. There will be fewer complaints.

5.2.11 Impact on time

Test partners identified an impact on the time it will take to initially implement the Standard in setting up processes and training staff, but acknowledged that the time to meet individuals' needs once processes are in place should have minimal impact. Some concern was expressed as to the ability of out-of-hours and urgent care providers to effectively meet the Standard, in the context of time-specific targets. There will be a challenge for providers to ensure that patients who (currently) need to wait longer for alternative formats of information are not disadvantaged.

5.2.12 Implementation costs

Interestingly, test partners did not identify a large financial cost to alter IT systems to implement the Standard, and such changes may fall within existing contracting agreements. More IT hardware may be required, especially in community settings. There are anticipated costs associated with providing alternative formats of communication, especially braille and BSL interpreters, and in training staff and conducting audits. There was no information provided on overall costs to implement the Standard.

Although test partners did not specifically refer to operational, process or resource costs (with the exception of those referred to above), it is implied that operational and administrative processes will need to be reviewed and amended, and resource will

be required to review / amend processes and IT systems, then train staff on the changes.

5.3 Effectiveness of change management

Feedback from test partners indicated that the testing process had stimulated some discussions on how the Standard will need to be implemented in organisations, and that senior management leadership will be necessary in order to enact the changes. Feedback has been useful in informing the draft Specification for the Standard and in assessing costs, benefits and barriers associated with implementation.

5.4 Lessons learned through testing

A number of useful lessons and observations were drawn from the testing process. Test partner returns confirmed previous observations from the engagement phase that there is variance in how organisations are currently adhering to legislation (including the [Equality Act 2010](#)). Some organisations will have to undertake minor adjustments to systems and processes in order to fully implement the Standard while other organisations will need to enact more significant changes in order to complete implementation.

Test partners reported that the steps included in the preliminary outline draft of the Standard are acceptable, however, there was some confusion around the purpose of the Standard and precisely what organisations are expected to do. Clear Implementation Guidance to accompany the Specification for the Standard will be essential, including detail of minimum requirements for compliance.

It was evident by the lack of data provided on the overall cost of implementation that organisations were not able to easily assess how much this would cost. Similarly, how the Standard would impact organisations in terms of, for example, any increased workload or ongoing cost, was difficult for organisations to quantify. Resources to support implementation will include templates and advice for local implementation plans and assessment of risk and impact.

5.5 Data quality report

Test partners were asked to provide feedback on use of the preliminary outline draft standard in practice. As such, the data is qualitative in nature, and the quality and consistency in the test returns was varied. Some test partners completed all of the questions on all of the forms while other test partners completed only some of the questions or provided a summary of general feedback based on the questions. While all of the responses provided useful feedback, the disparity in returns made direct comparisons across organisations difficult.

Some assumptions were made in the interpretation of the response data. It was assumed that if certain aspects of the response were not provided then the service either did not have a process in place or did not know the information. This approach was taken when reviewing how a patient's needs would be met, as no information was submitted for certain types of alternative formats, such as braille. This approach was also taken in regard to estimating the cost or impact of implementing the

Standard, assuming that organisations did not know, or had not yet considered, the costs or impact the Standard would have on services, patients, processes or organisations.

5.6 Risks and issues raised

Risks identified by test partners include:

- A risk relating to the quality of information provided in alternative formats, due to errors in information produced by conversion software or misinterpretation by interpreters;
- A risk that implementation will not take place within the given timescale for implementation due to a lack of commitment at a senior / executive level;
- A risk that funding will not be available to enact changes required;
- A risk that staff will not record information or provide alternative formats leading to non-compliance with the Standard;
- A risk that data sharing across organisations involved in a care pathways will not be considered;
- A risk that a paper-based implementation of the Standard will not be sufficient to meet needs.

6 Impact of testing

6.1 Adjustments needed as a result of testing

It was clear from test results that compliance with the Standard would be greatly supported by a comprehensive Implementation Plan and Guidance. Test partners made clear that Implementation Guidance and supporting resources should include:

- How to assess current practice;
- How to identify areas of improvement necessary for compliance with the Standard;
- How to assess the cost of implementing the Standard;
- How to assess the impact that implementing the Standard will have on processes and systems;
- How to audit compliance with the Standard.

Most importantly, there need to be clearer definitions of what organisations are expected to do in order to be compliant with the Standard, including specifically what is required as a minimum.

6.2 Timescales

Testing has not impacted on the schedule for developing and assuring the Standard, as no issues have been identified which require changes significant enough to require wholesale changes to the scope, content or approach being followed. Some test partners expressed concern as to the length of time implementation would take, however, it should be noted that the deadline for full implementation of the Standard is 12 months after publication of the Information Standards Notice (ISN).

6.3 Lessons learned

The testing process would have been enhanced by allowing more time for the application process, more time for the testing process and forms which were easier to complete.

More organisations would have been able to undertake testing if the time to apply had been extended. Some of our test partners were not contacted directly; they were recommended by other organisations and stakeholders. With additional time organisations would have been able to consider participation and gain any necessary approval to participate. It is considered likely that a number of organisations that were invited to take part did not respond because there was not enough time to undertake these actions.

More test returns and / or more detailed feedback may have been submitted by test partners if the timeframe to test had been extended. It was unfortunate that two Bank Holidays fell within the testing period. The short timescale is most likely the reason why no testing was undertaken with patient groups or by software and systems developers; there was not enough time to arrange meetings or undertake the work.

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Finally, while the quality of the feedback was good, the returns were not standardised in nature; some were summary based and some answered the questions in the structured way in which they were asked. Although test partners had free-text responses to every question, there may have been some aspect of the form design which prohibited a standard return.

We are grateful to all of the organisations and individuals who contributed as part of the test phase.

Appendix A – Record forms

Record form 1 – Assessment questions for completion as part of trial or desk-based test of draft standard steps

1. Identification of communication and / or information needs
 - a. How would your service ask patients, service users or carers if they had any communication or information needs (for example face-to-face or registration form)?
 - b. Who would ask patients, service users or carers this question (job title / role)?
 - c. What question(s) would you ask?
 - d. When would they be asked?
 - e. Do you currently ask this question of your patients, service users and / or carers?

2. Recording of communication and / or information need
 - a. Where would you record that a patient or service user had communication and / or information needs?
 - b. Where would you record that a patient or service user's carer had communication and / or information needs?
 - c. Do you record foreign / community language needs differently to the needs of someone with sensory loss and / or a learning disability?
 - d. Is this information currently recorded?
 - e. Who would record the information initially?
 - f. Would any further handling of the data or processes be required (for example inputting of a paper form into an electronic record system)?
 - g. At what point would these needs be recorded?

3. Identification of type of communication and / or information need
 - a. How would your service identify the specific support needs which the patient, service user or carer has?
 - b. Who would ask?
 - c. What question(s) would you ask?
 - d. When would they be asked?
 - e. Do you currently ask this question of your patients, service users and / or carers?

4. Recording of type of communication and / or information needs

Noting the categories proposed by the Standard:

- a. Is this, or similar, information currently recorded?
- b. What categories do you currently use to record these or similar needs?
- c. Where would this information be recorded?
- d. Would any further handling of the data or processes be required (for example inputting of a paper form into an electronic record system)?
- e. Who would be involved in / responsible for recording and / or inputting this data?

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- f. Are you currently able to record communication and / or information needs using some or all of the stated categories?
- g. What changes which would be needed in order to record data using stated categories?
- h. In your view, what would be the impact, cost and feasibility of these changes?
- i. Are there any additional needs which you would wish to capture but which are not included on the list of stated categories?

5. Sharing of communication and / or information needs

- a. How would the data you have recorded about the individual's needs be shared with other individuals or organisations involved in their care, including for example via an electronic social care record, referral letter or e-referral system, Summary Care Record, discharge note?
- b. Is this information currently shared in this way?
- c. What changes would be needed in order to share this information?
- d. In your view, what would be the impact, cost and feasibility of these changes?

6. Recognition of communication / or information needs at subsequent visits

- a. Given where you have recorded the information, and what information you have recorded, do existing systems alert staff appropriately to enable appropriate actions to be taken to arrange correspondence in alternative formats and / or communication support at appointments / as part of subsequent interaction with your service?
- b. Is this information currently highlighted?
- c. What changes would be needed in order to highlight or flag this information?
- d. In your view, what would be the impact, cost and feasibility of these changes?

7. Provision of information in alternative formats

- a. How would you create, arrange for or provide correspondence and patient information (including that known to be immediately relevant to the individual) in one or more of the information formats recorded as appropriate for them?
- b. How long would it take to provide information in one or more of the specified formats?
- c. How much would it cost?
- d. Would you consider any assessment or assurance as to the accuracy or quality of the information provided?
- e. Have you previously provided information in the alternative formats specified?
- f. Do you have existing arrangements in place to provide information in the alternative formats specified?
- g. What changes would be needed in order to provide information in the alternative formats specified?

8. Provision of communication support by a communication professional

- a. How would you arrange for or provide the communication support needed by the patient (as recorded)?
- b. How long it would take to arrange for this support, and therefore how long would the individual be required to wait to access your service supported by a relevant communication professional?
- c. How much this would cost?
- d. How you would identify or select an appropriate professional?
- e. Would you consider any assessment or assurance as to the expertise of the professional selected?
- f. Have you previously provided a communication professional of the type specified?
- g. Do you have existing arrangements in place to provide the specified type of communication professional?
- h. What changes would be needed in order to provide support from the communication professional specified?

9. Provision of communication support by in-house staff and using aids

- a. How you would provide the communication support needed by the patient?
- b. How long would it take to arrange for this support, and therefore how long would the individual would be required to wait to access your service with relevant communication support in place?
- c. How much would providing this support cost?
- d. Have you previously provided communication support of the type specified?
- e. Do you have existing arrangements in place to provide the communication support specified?
- f. What changes would be needed in order to provide the communication support specified?

Record form 2 – Recording of hypothetical patients' needs using proposed standard categories

Using the categories below, please indicate which needs you would record for each hypothetical patient.

Patient name:

Recording of need for information in an alternative format

- Requires contact by email
- Requires contact by letter
- Requires contact by telephone [795661000000104]
- Requires contact by text message (SMS)
- Requires contact by text relay [796081000000106]
- Requires information by email – HTML
- Requires information by email – PDF
- Requires information by email – plain text
- Requires information by email – Word document

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- Requires information in braille – grade 1
- Requires information in braille – grade 2
- Requires information in Easyread [796161000000101]
- Requires information in electronic audio file (MP3 file) by email
- Requires information in electronic audio file (MP3 file) on compact disc
- Requires information in large print – point 16
- Requires information in large print – point 18
- Requires information in large print – point 20
- Requires information in large print – point 22
- Requires information in large print – point 24
- Requires information in large print – point 28
- Requires information in Makaton
- Requires information in Moon
- Requires information on audio cassette tape [795801000000104]
- Requires information on compact disc [795731000000104]
- No requirement

Recording of need for support from a communication professional

- Requires advocate
- Requires BSL interpreter
- Requires BSL interpreter - hands-on signing
- Requires BSL interpreter - Sign-Supported English (SSE)
- Requires BSL interpreter - visual frame signing
- Requires learning disability communication support worker
- Requires lipspeaker
- Requires notetaker
- Requires speech-to-text reporter (STTR)
- Requires sign language interpreter – not BSL
- Requires deafblind communicator-guide [796201000000109]
- Requires deafblind intervener
- Requires deafblind manual interpreter
- Requires deafblind manual interpreter - block
- Requires deafblind manual interpreter - deafblind manual alphabet
- Requires deafblind manual interpreter - haptic communication
- No requirement

Recording of need for support to communicate and / or use of aids

- Does lipread [441092009]
- Does need a longer appointment needed to support communication needs
- Does need audible alert
- Does need communication supported by written notes
- Does need visual alert
- Does use communication tool or aid
- Does use non-verbal communication [288581006]
- Uses a hearing aid
- Uses a learning disability passport
- Uses Tadoma
- Uses Voice Output Communication Aid [762361000000101]
- No requirement

Record form 3 – Testing overview

Having completed your trial, test, desk-based exercise or review, please consider and respond to the following questions.

1. How have you trialled, tested or assessed the Accessible Information Standard? Who was involved in this process (roles / job titles)?
2. What do you think about the Accessible Information Standard?
3. Have you identified any barriers or difficulties in implementing the Standard? If so, please explain.
4. If you have identified barriers or difficulties in implementing the Standard, how could these be overcome?
5. Have you identified any particular benefits of implementing the Standard? For example on the patient experience or potential financial savings.
6. What impact would implementation of the Standard have on administrative processes or time?
7. What impact would implementation of the Standard have on clinical processes or time?
8. What would be the financial impact of implementation of the Standard? Consider expenditure and potential efficiencies / savings.
9. Would implementation of the Standard impact on the patient, service user or carer experience, health or wellbeing?
10. Would implementation of the Standard have any impact on service delivery, including the quality of the service provided?
11. Has participating in this testing process led you to make changes or to explore the potential of making changes to your service or processes?
12. What advice, guidance or support should NHS England provide to assist organisations in implementing the Standard? How useful have you found the supporting information provided as part of the test pack?

Appendix B – Excerpts from Minutes of the GP IT New Requirements Group

Meeting Agenda – published 30/04/2014

Time	Paper No.	Agenda Item	Owner
13:00		Welcome and Introductions	Richard Jefferson
13:05	1	Minutes & Actions from previous meeting	Richard Jefferson
13:20	4	Local Authority Prescribing	Barbara Kyei
13:50	2	Update on change requests and IC2	Mike Curtis
14:05	3	ISB Standard - Making health and social care information accessible	Sarah Marsay
14:30		NHS 111	Tony Yates / Steven Rawstorne
15:00		Undefined Subsidiary Services	Li Jenkins
15:15		GPSoC Stakeholder Groups and NRG Terms of Reference	Richard Jefferson / Kemi Adenubi
15:40		AOB	Richard Jefferson
15:55		Action steps and close	Richard Jefferson

This meeting: 1st May 2014
13:00 - 16:05
DLA Piper, London

1. Welcome and Introductions

Attendee Name	Organisation
Richard Jefferson (RJ)	NHS England, Head of Business Systems SRO – Chair
Kemi Adenubi (KA)	HSCIC, GP IT Programme Director
Martin Warden (MW)	HSCIC, GPSoC Programme Head
Dr Manpreet Pujara (MP)	HSCIC, GP National Clinical Lead
Mike Curtis (MC)	HSCIC, Lead Technical Architect
Christina Grant (CG)	HSCIC, GPSoC Project Officer and NRG Secretariat
Toto Gronlund (TG)	HSCIC, GPSoC Benefits & Patient Facing Services
Dr Peter Short (PS)	HSCIC, GP National Clinical Lead
Li Jenkins (LJ)	HSCIC, GPSoC Lead Business Analyst
Tony Megaw (TM)	HSCIC, North of England Lead

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Dr Mike Robinson (MR)	Medical Director INPS
Dr Paul Maddy (PM)	End User Representative, EMIS NUG
Kathy Applebee (KAp)	Chair of National Vision User Group
Sarah Marsay (SM)	NHS England
Tony Yates (TY)	NHS England, NHS 111
Steven Rawstone (SR)	NHS England, NHS 111
Mohammed Pandor (MP)	Department of Health – by phone
Helen Kendall (HK)	NHS Business Services Authority – by phone
Ralph Sullivan (RS)	RCGP – by phone

Apologies	
Shaun O'Hanlon	EMIS – Chief Medical Officer
Philip Green	Patient Representative

5. ISB Standard for Accessibility

Presentation (Sarah Marsay)

SM introduced herself as the developer of a new information standard for accessibility, to provide for patients who are disabled or require specific assistance. The draft information standard document, circulated in advance, is under review and hoping to be approved in August by the Standardisation Committee for Care Information (SCCI). Extensive stakeholder engagement has taken place (Nov 2013 – Feb 2014) to outline current issues faced by patients with disabilities. The extensive list of patient requirements at the end of the paper is based on the principle of recording the patient's specific data need, rather than recording their disability as a clinical piece of data. The main benefit of this standard is that patients' needs are better provided for, but it will also help clinicians by providing a consistent way to record this information.

Discussion

KAp asked are we able to do absolutely everything in this list? Is it worth changing systems to introduce large print paper prescriptions when we're moving to electronic prescriptions? SM said the critical first step is recording needs, and then will look at other changes in the pipeline (e.g. EPS) to ensure effort isn't wasted. PM also said some items in the list of additional requirements, are rather out-dated e.g. recording GP letters onto cassette tapes. SM said obviously the higher priority is to help patients go digital, but the idea with this list is to start with a long-list and edit down. MC reminded the group that some requirements are already defined by legislation (e.g. that alternative print sizes should be available) – these should be considered during development.

PM said most practices already record info about additional needs of patients, although this is often as free-text and needs to be more specific. Read-codes will need to be developed and should record "do not" rather than "do". More thought needed around the possibility of multiple issues. SM said there are some problems

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with no. of read-codes allowed by Read V2 and the need for a hierarchy of read codes.

PM asked if the system could be developed so that the 'fix' is automatic. Also need to think of issues down the line (e.g. if large print letter, must ensure envelope window is wide-enough).

PS praised the spirit behind the move but requested legal clarification – if GPs record this info, will they then be legally required to provide the correct assistance? This might lead to negative attitude among GPs. SM reminded PS that there is already a legal requirement to provide for disabled patients.

KAP said some patients have lots of alert screens already (e.g. child protection notice) - could we add info about additional data requirements to these alerts? MaPu said any alert would need to also be present throughout the consultation, not just at the start. MR suggested that it could be placed in the patient banner and asked if the info could also be transferred to the pharmacy? MaPu suggested he could arrange a separate meeting with MR to pass on info about transfer of data to pharmacies. TG confirmed that this standard will apply to other care settings too.

Next Steps

The draft Information Standard is going to SCCI for approval in August 2014. If accepted will be introduced in Jan 2015 with a 12-month implementation period. KA asked if the NRG could be part of the on-going consultation. PM suggested SM consults the JGPIT board too.

LJ said we would need to understand what the remit of the ISN is as it seems that it is just capturing the relevant information. Specifying exactly what a system must do in response to this information would be a change to the Principal Clinical System and would need a CCN as outside of the remit of the ISN. MC suggested he could talk to Rob Gooch at EPS (**Action 01.05.08**). PS noted that there'll be implications for PFS suppliers as they develop their solutions.

SM thanked the group for comments and left the meeting.

Appendix C – The steps of the preliminary draft standard

Identification of communication and / or information needs

- Purpose: To identify if a patient, service user or carer has any communication or information needs associated with a disability.
- Requirement: Communication and / or information needs should be identified at registration / upon first contact with the service or as soon as is practicable thereafter. This initial question may be asked over the telephone, at a reception desk, as part of a registration or admission form or through an alternative process.
- Note: For the purposes of testing each hypothetical patient has responded to the question, 'do you have any communication needs?'

Recording of communication and / or information needs

- Purpose: To record that an individual has communication and / or information needs, that they do not have any such need or that they have chosen not to respond.
- Requirement: Following identification, a record should be made as to whether the patient, service user or carer has any communication needs or not, or whether the question is unanswered.
- Note: If identification of need is included as part of a registration form which is completed by the patient, service user or carer themselves, then steps 1, 2 and 3 may be combined. Note that some patients with a communication need will be unable to complete a registration form unaided. Consider where you could record that a patient's carer has an information or communication support need.

Identification of type of communication and / or information needs

- Purpose: To identify the type or nature of the individual's communication or information need(s).
- Requirement: Following identification of the existence of a communication or information need, the specific nature of the support and / or format required should be identified.
- Note: Some individuals may offer this information proactively following a positive response to the question about communication needs, others may need support or prompting to enable accurate identification of needs. Suggested questions include: Can you explain what support would be helpful? What communication support should we provide for you? What is the best way to send you information? If identification of need is included as part of a registration form which is completed by the patient, service user or carer themselves, then steps 1, 2 and 3 may be combined. Note that some patients with a communication need will be unable to complete a registration form unaided.

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- The draft standard is *at this stage* proposing the recording of this data using the following categories. Categories with an existing SNOMED CT code have this indicated [in brackets] and selection of any one category would result in a 'Patient information status (finding) (310386007).'

Recording of need for information and / or contact in an alternative or specific format

- Requires contact by email
- Requires contact by letter
- Requires contact by telephone [795661000000104]
- Requires contact by text message (SMS)
- Requires contact by text relay [796081000000106]
- Requires information by email – HTML
- Requires information by email – PDF
- Requires information by email – plain text
- Requires information by email – Word document
- Requires information in braille – grade 1
- Requires information in braille – grade 2
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- Requires information in Makaton
- Requires information in Moon
- Requires information on audio cassette tape [795801000000104]
- Requires information on compact disc [795731000000104]
- No requirement

Recording of need for support from a communication professional

- Requires advocate
- Requires BSL interpreter
- Requires BSL interpreter - hands-on signing
- Requires BSL interpreter - Sign-Supported English (SSE)
- Requires BSL interpreter - visual frame signing
- Requires learning disability communication support worker

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- Requires lipspeaker
- Requires notetaker
- Requires speech-to-text reporter (STTR)
- Requires sign language interpreter – not BSL
- Requires deafblind communicator-guide [796201000000109]
- Requires deafblind intervener
- Requires deafblind manual interpreter
- Requires deafblind manual interpreter - block
- Requires deafblind manual interpreter - deafblind manual alphabet
- Requires deafblind manual interpreter - haptic communication
- No requirement

Recording of need for support to communicate and / or use of aids

- Does lipread [441092009]
- Does need a longer appointment needed to support communication needs
- Does need audible alert
- Does need communication supported by written notes
- Does need visual alert
- Does use communication tool or aid
- Does use non-verbal communication [288581006]
- Uses a hearing aid
- Uses a learning disability passport
- Uses Tadoma
- Uses Voice Output Communication Aid [762361000000101]
- No requirement

Recording of type of communication and / or information needs

- Purpose: To record the specific type(s) of communication support needed and / or the appropriate format for information.
- Requirement: The specific nature and type of communication support needed and / or information formats accessible to the individual should be recorded.
- Note: It is anticipated that multiple categories will be selected for most individuals. Consider that the requirement is to record the needs of patients / service users *and carers*, where applicable / appropriate.

Sharing of communication and / or information needs

- Purpose: Testing of the requirement to share recorded information about individual's communication and / or information needs as part of existing data sharing processes.

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- Requirement: To include information about a patient, service user or carer's information or communication support needs as part of existing transmission and data sharing processes and / or to identify / test new approaches to sharing such data.

Recognition of communication / or information needs at subsequent visits

- Purpose: Testing of the requirement to ensure that information recorded about an individual's communication or information support needs is highly visible to staff upon subsequent interaction with the service.
- Requirement: To flag or otherwise highlight a record of communication and / or information needs to relevant staff when the individual has subsequent interaction or contact with the service (to enable appropriate actions to be taken to meet those needs).

Provision of information in alternative formats

- Purpose: Testing of the requirement to provide information to the patient, service user or carer in an alternative format.
- Requirement: To provide information including correspondence in one or more alternative formats appropriate for the individual – in line with records made in this regard.

Provision of communication support by a communication professional

- Purpose: Testing of the requirement to provide communication support to patients, service users and carers with such needs.
- Requirement: To provide appropriate, professional communication support to enable the individual to effectively access / receive care from your service.

Provision of communication support by in-house staff and using aids

- Purpose: Testing of the requirement for services to support patients, service users and carers to communicate in alternative ways.
- Requirement: To provide appropriate support to enable patients, service users and carers to communicate with staff by modifying behaviour and using aids or tools.

Note: It is anticipated that the support required to 'communicate by an alternative means' is such that it could be provide via in-house staff, perhaps following awareness training, without the need to arrange for external support.

Appendix D – Patient scenarios

Scenario 1

Patient full name: Mr Brian David Anderson DOB: 03.07.52

Do you have any communication needs?

“I am deaf, have been all my life. Don’t use BSL, wasn’t an option when I was a kid. I have hearing aids which help a bit, but I still don’t catch all of the conversation. If there’s a loop system that helps. But I lip read and look at people’s facial expressions, gestures and so on to see if I have understood correctly. I can read English fine – I know lots of deaf people can’t, but I can. So it can help if people write things down, especially if there’s a lot of background noise or if I can’t understand a particular word or phrase.”

Scenario 2

Patient full name: Ms Rosemary Anne Philpot DOB: 12.11.38

Do you have any communication needs?

“I’ve just been told I am deafblind. I knew my eye sight was getting worse, it’s never been good, and then a couple of years ago I started finding it harder to hear, I had to turn the telly up really loud, then my daughter showed me how to put subtitles on. I can still read a bit, if things are in really large print and I have plenty of light, but not small writing. I can’t really hear anything now, unless I’m in a quiet room with one other person and they speak really loudly and clearly. I don’t know if a hearing aid would help at my age. I am really frightened of losing all my sight now – will I have to go into a home? I don’t want to do that but I find it hard to see my friends now as I can’t really have a conversation.”

Scenario 3

Patient full name: Mr Joseph William Turner DOB: 11.06.82

Do you have any communication needs?

“I wear glasses, does that count?”

Scenario 4

Patient full name: Miss Hannah Chatterjee DOB: 23.08.89

Do you have any communication needs?

“I am Deaf. I use British Sign Language. I can understand simple words and phrases which are written in English but anything about my health is a mystery unless it’s in BSL. I’m on tablets for my heart, something to do with my heart; I don’t know what to be honest. I wish I understood more about what was wrong with me. If there’s no interpreter I have to take the prescription to the chemist and ask a friend to tell me how many tablets to take. It’s the same with letters; I don’t understand them so I have to get someone else to sign them to me. This is embarrassing and takes away my privacy. I never really know what is wrong or what tablets I’m taking. I worry if I should do more exercise, or if that would put too much strain on my heart. And I’d like to lose weight, but I don’t know how to do that – are there classes in BSL? Or low fat recipes? I worry about getting diabetes, or if I might have diabetes but not know. Do they do screening for that? I also worry because I care for my mum and I don’t really

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understand what to do for the best. She has dementia so can't make decisions or look after herself properly – I have to make sure she goes for appointments and takes her medication, but I never get a BSL interpreter when I go to appointments with her, so neither of us ever knows what's really going on."

Scenario 5

Patient full name: Mr Paul Frederick Johnson DOB: 04.01.76

Do you have any communication needs?

"I can see and hear ok, is that what you mean? Sometimes I find it hard to say what I think, but I like to do things on my own, I hate it when I go to appointments with my dad and everyone speaks to him and not to me. He is there to help me but it is my health, my choice. I can't read the letters I get from the doctors or the hospital or the council, it is all gobbledegook to me. I have to get my mum or dad to read it to me, but this takes away my independence. I would like to get letters in easy words and pictures so that I could read and understand myself. And I would like to go to appointments on my own. When I see one doctor she is really good, she speaks slowly and uses easy words and she asks me if I want to ask any questions. But the other doctors speak too fast and use jargon and I don't know what they're saying. When I went to the hospital I got a passport and a nurse came and showed me where to go and what to do. That really helped."

Scenario 6

Patient full name: Mrs Indira Srivastava DOB: 30.05.57

Do you have any communication needs?

[Question answered by Indira's husband, Samir]

"I speak English but my wife does not. Either I come with her or if it is for a female matter she will need a female Urdu interpreter so that she can understand. We need letters and information in Urdu too."

Scenario 7

Patient full name: Mrs Louise Josephine Chinn DOB: 13.10.47

Do you have any communication needs?

"I am blind. I was born blind. I used to live on my own but then I went into a home a few years ago after I had a fall. It's ok. There's not much information in braille which I find frustrating, I love reading. I listen to the radio and I watch telly and I go to lunch club on Tuesdays. But I miss out on bingo and dances and walks because I am blind. That makes me sad. And I know I need to get a bit slimmer but I don't really know how. I'd like to exercise a bit more. One of the carers will read my post to me if I ask her nicely, but I know they're busy, so I only ask her if I think I've had something important or if I'm expecting a letter from the hospital or something. I wish I could get post in braille or on tape so I could read or listen to it myself. I am going for a breast check-up next week and I wish I could keep the results private, but if they're sent in a letter I have no choice. I can't get out on my own any more but there's a volunteer comes out and takes me to the hospital or to the doctors or to the dentist. I'd be lost without them."

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Scenario 8

Patient full name: Miss Jane Victoria Palmer DOB: 22.09.79

Do you have any communication needs?

“Yes, I am deaf. I have two children who are hearing but I am deaf. I am fed up of the council and the doctors not booking an interpreter for me and instead suggesting that one of my children acts as an interpreter. The oldest is only 10. This is inappropriate and unsafe – she doesn’t know about medical terms and symptoms and medicines. I need a BSL interpreter at my appointments – otherwise you can’t understand me and I can’t understand you. I know they can be expensive but the hospital use an online system so you get an interpreter using a webcam. This takes a bit of getting used to but it is a massive help – it means I can understand and it means I don’t have to wait and wait for an interpreter. I can read English ok but not medical terms, not jargon. So I can understand most of the letters I get from the NHS – even if just the basics, I can pick out key words. But lengthy documents or more complex information I don’t understand. My son has asthma and I still don’t really understand how best to look after him – the leaflet with his inhaler was impossible to read and I’ve had no information from the doctors since his diagnosis. There should be videos about important conditions online in BSL.”

Scenario 9

Patient full name: Ms Georgina Amanda Cold DOB: 30.12.77

Do you have any communication needs?

[Answered by Georgina through her deafblind communicator guide]

“I am deafblind. I have congenital deafblindness. That means I can’t really see anything and I can’t really hear anything. It’s been the same all my life. I read braille, that’s the only way I can read. I’m hoping to get a braille reader, an electronic thing so I can read emails in braille. That would be wonderful; it would mean I could be independent. But they are not cheap so I am still waiting...I use the deafblind manual alphabet to communicate. So I need an interpreter when I have any appointments. Or if a deafblind communicator guide can accompany me, that’s better, otherwise I have to rely on my sister to guide me and then hope that there is an interpreter booked and that they’ve turned up. Oh, and that it’s not a BSL interpreter – that’s happened before and it’s of no use to me!”

Scenario 10

Patient full name: Mr George Andrew Clark DOB: 04.08.79

Do you have any communication needs?

[Question answered by George’s personal assistant, Mohammed]

“George can’t talk very well and finds it hard to express himself. I help him with that, and so does his communication support worker, Mel. We came up with a communication chart to help George know what was happening during the day, and to help him get involved in decisions as much as possible. Also, we are able to understand the meaning of his non-verbal communication, for example if he is in pain or scared. George can’t read so myself and Mel try to explain important bits of information to him and involve him in making choices where this is possible. In reality a lot of the decisions are made by George’s mum, Sue, though, as he cannot understand anything complex or with a variety of different outcomes.”

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Scenario 11

Patient full name: Miss Ella Mary Williams DOB: 27.02.91

Do you have any communication needs?

“I am registered blind. I am not totally blind of course, but I have a dog and a white stick so I suppose to most people I’m what they’d think of as blind. But things have changed, I don’t read braille and I live on my own. I rely on my computer and my phone. I have a screen reader which speaks all of my emails and documents to me, and I have a few different apps on my phone which mean I can hear text messages and so on. I just wish people would stop sending me letters! I can’t read them – it doesn’t matter how big you make the print. Send me an email I say, it is 2014, how hard can it be! It’s not like it’s expensive either, it should save you the cost of a stamp – just attach the document to an email instead of printing it out.”

Scenario 12

Patient full name: Ms Annabel Natasha Smith DOB: 22.01.90

Do you have any communication needs?

“I need information in easy, simple words. I find it hard when people speak too fast or use hard words or long words. I can read easy words and it helps if there are pictures. Also, I need to be able to ask questions and check things with people to make sure I’ve got it right. Then I can make my own decisions. Sometimes my mum comes with me to appointments, but she is Deaf so she can only help me if there’s a sign language interpreter there and often there isn’t. She can’t really understand the letters and things I get either. Either I need letters and information in easy read or my mum needs them in BSL. I prefer to read things myself if I can but sometimes if it is a serious thing I need my mum’s help.”

Appendix E – List of record systems used by test partners

- Admission assessment forms
- Case management software (for example from Corelogic)
- Electronic patient / service user records
- NHS Pathways
- Paper notes
- Patient Administration System (PAS) / clinical record management system / electronic patient or service user record system (for example eCaMIS, eHospital or SystemOne)
- Personalised patient information document held as a hard copy such as a hospital or learning disability passport or 'About Me' book
- Referral letters
- Social care electronic record system / personal electronic system
- Special patient notes
- Summary Care Record