



# **Accessible Information: Pilot Report**

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## **SCCI1605 Accessible Information: Pilot 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 <a href="#">Care and Support for Deafblind Children and Adults (Department of Health, 2014)</a> states that, "The generally accepted definition of Deafblindness is that persons  |

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|                     | are regarded as Deafblind “if their combined sight and hearing impairment causes difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss” ( <a href="#">Think Dual Sensory, Department of Health, 1995</a> )."  |
| Disability          | The <a href="#">Equality Act 2010</a> 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 <a href="#">Data Dictionary definition</a> .  |
| Disabled people     | <a href="#">Article 1 of the United Nations Convention on the Rights of Persons with Disabilities</a> 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 <a href="#">Equality and Human Rights Commission</a> 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 <a href="#">Data Dictionary definition</a> and is also defined by the Department of Health in <a href="#">Valuing People (2001)</a> . 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  |

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|  | d/Deaf. Manual notetakers take handwritten notes and electronic notetakers type a summary of what is being said 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 <a href="#">International Health Terminology Standards Development Organisation (IHTSDO)</a> and in the UK by the <a href="#">UK Terminology Centre (UKTC)</a> . SNOMED CT has been adopted as the <a href="#">standard clinical terminology for the NHS in England</a> .          |
| 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 <a href="#">'Next Generation Text' (NGT) service</a> 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 Background

SCCI1605 Accessible Information – the ‘Accessible Information Standard’ – directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss.

Piloting of the Standard followed a consultation (August – November 2014) and a desk-based review / expert input exercise (‘testing’ (April – May 2014)). Prior to this, engagement activity had informed the development of the draft accessible information standard (November 2013 – February 2014). Reports from the test, engagement and consultation phases are all available.

### 3 Purpose

Piloting of the draft accessible information standard aimed to ensure that it was fit for purpose – including to evidence successful ‘first of type’ implementation – and to enable evaluation of the impact of its future application in health and social care settings.

Piloting was also intended to contribute to assessment of the effectiveness and clarity of the Specification, Implementation Plan, Implementation Guidance and Clinical Safety Case.

In addition, the reports from pilot organisations have been used to inform assessment of the burden of implementing the Standard by the Health and Social Care Information Centre’s Burden Advice and Assessment Service (BAAS).

## 4 Scope

The scope of the pilot encompassed the full scope of the Accessible Information Standard, and in particular sought to record evidence of effective implementation of the whole standard ('end-to-end') and each of the five stages: identification, recording, flagging, sharing and meeting of needs. Participating organisations represented a good range of applicable organisations including GP practices, NHS Trusts and adult social services.

## 5 Overview

Piloting of the draft accessible information standard took place during January – March 2015, with a range of NHS and adult social care organisations taking part. Participating organisations were required to effect changes in patient / service user record and administration systems (whether IT and / or paper based), as well as processes and procedures.

This report summarises feedback from pilot sites, with a focus on identified challenges, benefits, costs and recommendations – i.e. feedback to be considered and if appropriate actioned by NHS England in finalising and supporting the implementation of the Standard. Where text appears in “speech marks” it represents a verbatim quote from the report received from the pilot site, any editing – mainly in the interests of length, is indicated by [square brackets] or with three dots ‘...’.

Detail as to how each organisation implemented the Standard, as well as additional comments and learning, is contained within the full reports received from each of the pilot sites. These reports are available separately along with a range of tools, example documents and templates which were shared. Organisations preparing to implement the Standard are encouraged to review these reports and the associated materials, which include practical advice and insight.

## 6 Overview of outcomes

Key learning from the reports received from the pilot sites included the reflections that:

- The Standard was clearly part of delivering high quality care and a positive experience for patients / service users.
- Implementation of the Standard could (and should) be part of a 'culture change' and moves towards a more compassionate, person-centred, personalised service.
- Involvement in implementing the Standard can bring staff together and forge new connections across sites / disciplines, and between staff in clinical and non-clinical roles.
- Implementing the Standard should have a positive impact not only on patients / service users, but also on staff – although concerns about the potential / initial impact on staff time should be acknowledged.
- Experiences of working with patients, patient groups and voluntary organisations were very positive.

Key recommendations included:

- Providing templates, case studies and guidance about how to implement the Standard in different settings – focusing on practicalities;
- Simplifying documentation describing the Standard, and making it clearer what must be done, when and how;
- Making the Specification simpler and more concise;
- Offering advice about clinical terminology and use of the English definitions or categories.

## 7 Approach to piloting

### 7.1 Recruitment

The opportunity to pilot the draft accessible information standard was promoted directly to professionals and organisations who had previously been involved or had expressed an interest in this project and also made available via the NHS England website.

Following an initial call for applications in late September 2014, a second round of applications were invited in January 2015, including from organisations proposing to test or trial particular aspects of the Standard / provide data about implementation focusing on particular user groups.

In all cases, interested organisations were required to complete an application form providing details of their organisation and outlining how they planned to pilot the Standard, and any particular aspects of the Standard or service user groups which they would focus on.

### 7.2 Documentation

Alongside the application form, briefing information outlining the Accessible Information Standard and the piloting opportunity was made available to those interested in taking part. Organisations that went on to pilot the Standard were then provided with 'Information for Pilot Leads', 'Information for Staff' and 'Reporting' information. The content of these documents has informed the Implementation Guidance.

### 7.3 Support

As part of their applications, organisations were invited to outline the financial support needed from NHS England in order to complete their pilot activity as proposed – and to enable completion of reporting requirements. Amounts provided to pilot sites ranged from £200 to £17,000.

## 8 Participating organisations

Organisations participating in the pilot of the Accessible Information Standard were as follows:

- Berkshire Healthcare NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- City of Bradford Metropolitan District Council
- Dorset HealthCare University NHS Foundation Trust
- East Lancashire Hospitals NHS Trust
- Ellison View Surgery, Hebburn
- NHS Bradford City and Bradford Districts Clinical Commissioning Groups (CCGs)
- GTD Healthcare
- The Clatterbridge Cancer Centre NHS Foundation Trust
- The Phoenix Medical Centre in partnership with Dynamic Health Systems

NHS England would like to thank all of the organisations who participated in the pilot phase of the Accessible Information Standard, and in particular those individuals who took a lead role in the project within their organisations. Your support has been invaluable.

## 9 Summary of feedback from pilot sites

### 9.1 Berkshire Healthcare NHS Foundation Trust

#### 9.1.1 Scope of pilot

This pilot focused on making information accessible to people with learning disabilities. It included the development, implementation and evaluation of an information pathway, information passport, information targets and information guardians.

The pilot was based within the community team for people with learning disabilities (CTPLD). The pilot looked at referrals regarding accessible information to Occupational Therapy and Speech and Language Therapy between February to March 2015 within CTPLD. During the piloting period, there were two individual referrals and seven within a group setting. The pilot used an 'accessible information pathway' as a pro forma to look at the process of developing and providing accessible information.

The second aspect of this pilot involved liaison with the team managing the Trust's electronic health record (RiO) to negotiate for the information passport to be made an alert on the main screen for each patient to raise awareness and promote consistency of implementation and support. This aspect of implementing the Standard is ongoing.

#### 9.1.2 Feedback on costs, implementation challenges and benefits

In reporting on their participation in the pilot, the leads identified that the main cost / impact was with regards to staff time.

In addition to pre-pilot work to develop the information pathway and case studies, reported time 'costs' were, "Development time for accessible information pathway and information passport within pilot study – 5 hours" plus 'intervention' within an individual or group setting (including assessment and completion of information passports) – 35 hours in total, although this is a reflection of the complex needs of some of the individuals and the in-depth nature of the information pathway established. "The main cost implication has been around staff time to prepare information and for paperwork."

The key challenges identified by this pilot site were:

- Competing demands on staff time and organisational priorities;
- The capacity of staff to complete the information pathway / information passports with patients;
- Availability of hardware such as laptops;
- Delays in the incorporation of the information passport and associated flags into the Trust's electronic patient record / notes system.

The benefits of implementing the Accessible Information Standard which were identified by this pilot site were:

- Raising awareness of the importance and impact of accessible information;
- Delivery of accessible information to individuals, resulting in improvements in their health and wellbeing, and enabling people to fully participate in their healthcare, including empowering them to be part of decision-making.
- Meeting people's human rights as outlined in the UN Convention on the Rights of Persons with Disabilities 2009.

### 9.1.3 Recommendations from this pilot

Key recommendations included in the pilot report were to:

- Establish a virtual community, hub or other mechanism to enable NHS organisations to share knowledge and resources;
- Educate Clinical Commissioning Groups (CCGs) about the resource implications and benefits of accessible information;
- Promote consistency and improve data-sharing processes between different services, to reduce duplication of information and effort;
- Allow for flexibility within services to ensure that each individual's needs can be addressed, and ensure that all professionals have access to a range of different resources that can be tailored to individual patient needs;
- Address the need for staff training and awareness building sessions;
- Recognise the benefit of involving clinical staff in the assessment and development of accessible information resources, whilst also acknowledging the impact on capacity.

## 9.2 Cambridge University Hospitals NHS Foundation Trust

### 9.2.1 Scope of pilot

Cambridge University Hospitals NHS Foundation Trust is an acute hospital with approximately 1200 beds and 8000 staff. This pilot focused on:

- Review and assessment of current processes, changes and support required to effect changes in the electronic patient record system (Epic) such that patients' needs can be recorded and flagged in line with the Accessible Information Standard;
- Introduction of new ward picture menus across the Trust.

"Epic currently flags patients on the front page with a drop down box of options regarding disability including blind, deaf, learning disability, speech and communication. Underneath this drop down option list, there is a box where free text can be added. This can be used to expand on the communication support(s) that a patient may require. Those who regularly work with patients with communication difficulties are aware of this, for example our learning disabilities specialist nurse and staff working with patients with aphasia who we have spoken to. However, given that there is no prompt for what to write in this section, we hazard a guess that most staff may not use it to the best of its ability. Issues identified: potentially refine the options available for the drop down list of disabilities / add a prompt for staff to advise of information to add to text box for further support / increase staff awareness."

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Additional actions identified in order to fully implement the Standard included changes to existing policies and procedures, and changes to staff 'tip sheets' for using Epic to support consistent recording of necessary data. The auto-generation of letters in alternative formats, and variable formatting of test results provided to patients using the inbuilt 'my chart' portal on Epic to improve accessibility was also noted as something to be explored.

The Trust also implemented a new picture menu in January 2015. "The focus of these is to enable patients to make their own menu choice at the start of each day with the aid of helpful images and fewer words." As well as images and simpler language, the menus also include strong colour contrast and a large font size to increase accessibility. "Staff taking orders have reported that patients with communication difficulties are more empowered to make their own decisions, which are now understood by staff. This has reduced stress among staff and patients."

### 9.2.2 Feedback on costs, implementation challenges and benefits

The only cost implication identified as part of this pilot was with regards to staff time, however, "Staff time may be reduced if the Standard is mandatory and guidance is clear." Concerns were also expressed about the cost of providing different alternative formats and communication support in the future.

With regards to implementation, "We are lucky that we are a step ahead with Epic, therefore implementing the Standard and recording patient disability and communication support is achievable. However, we are not clear who is adding the flag / alert on the front page within Epic. In carrying out a small spot-check of patients' records with known disabilities, the level of support information differs greatly. Standardisation would therefore be beneficial. How do we communicate with GP surgeries and social services to share information instead of duplicating?"

Additional barriers to effective (and timely) implementation included the need for changes associated with the Standard to be prioritised for building into electronic systems, with solutions suggested as being senior level support (locally), clarity about the requirements of the Standard and mandatory direction, "If the Standard was brought in as mandatory the people who find the principles difficult to understand would have clear guidance on what the NHS should provide." It was also noted that some staff struggled to appreciate that accessible information may be needed by patients on any and all wards, rather than just on particular specialist wards, for example elderly medicine or stroke.

In terms of benefits, "Although we do not have any data to support these points, we believe that the Standard will:

- increase efficiency of appointments – correct support available
- reduce missed appointments – improve patient experience
- reduce patient frustrations with not being understood
- reduce patient frustration in receiving information in the correct format

the two above points may have a positive impact on reducing concerns alerted to either clinic and ward staff and PALS [Patient Advice and Liaison Service] and will also reduce staff frustrations.”

### 9.2.3 Recommendations from this pilot

- Recognition of the need for staff engagement and increased awareness of the prevalence of communication disability / the impact of accessible information.
- Provision of staff training, ideally mandatory and regularly refreshed.
- “If the Standard is made mandatory and fed into CQC [Care Quality Commission] standards, this will greatly reduce the local difficulties of making changes to existing systems and ensuring that staff are ‘on board’.”

## 9.3 City of Bradford Metropolitan District Council

### 9.3.1 Scope of pilot

This pilot focused on the ‘Adult Services Access Point,’ Bradford District Care Trust (BDCT) Single Point of Access (SPA) and the Sensory Needs Service. “Adult Services Access Point is the council’s first point of contact for adult social care enquiries. It is responsible for recording all new and existing contacts, for older people, people with a physical disability and people with a learning disability. People with a sensory need contact the Sensory Needs Service and people with a mental illness are served by Bradford District Care Trust within the NHS.”

“Adult Services Access Point handles 4000 telephone calls per month. A further 10% are online contacts. The initial pilot will collect 50 service users’ preferred information needs. This is specifically within the Access Point and does not include the SPA or Sensory Needs Service. When these services completed their mini pilots the total number of services users/patients is expected to be 100. The sensory needs service will use an app called Glide to enable Deaf people to book interpreters in real time. This will involve 30 people using the interpreting service. The BDCT mini pilot will collect the information needs of 20 patients”.

“In the Adult Services pilot all Access Information Advisors [AIAs] were given specific training on the need for accessible information. This training was provided by Bradford Talking Media a social enterprise,” in addition the two most popular publications were made available in audio format.

“Originally it was thought that when the pilot took place it would have been at the same time as the implementation of SystemOne [to replace the current database]. Due to unforeseen circumstances there is a delay in the implementation. The AIS database (existing database) has a warning symbol on the first screen and every subsequent screen. It was agreed that the easiest solution would be to maintain the information needs within this system...”

### 9.3.2 Feedback on costs, implementation challenges and benefits

In terms of challenges, unfortunately, the pilot site were unable to connect / integrate records / processes with the parallel pilot completed by two local CCGs due to delays in implementing a new database. However, this pilot demonstrated how the Accessible Information Standard can be effectively implemented into existing

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systems, including accurate / routine recording and flagging of individuals' information and communication needs. This pilot also demonstrated the benefits of working with a social enterprise to deliver staff training, and the importance of having clear arrangements in place for the production of information in alternative formats and access to British Sign Language (BSL) interpretation.

“There is a concern going forward that when the existing data is migrated to SystemOne that the warning indicator will not be replicated. The other Bradford Pilot “Flagging Patient Access Needs on SystemOne” Bradford and District CCGs, and Airedale Wharfedale and Craven CCG, working with a number of GP practices has set up a protocol on SystemOne within the booking appointments process of the database. When this pilot starts to go live the services of AIAs have been offered to the practices as some extra support. This may not work for social care, however it is envisaged that through the ongoing development and deployment of the social care module of SystemOne the IT provider TPP will assist with a solution that works for health and social care.”

“It is expected that there will be an increase of telephone time to sufficiently explain why the information is being collected and recording the outcomes. This is likely to be between 1 and 3 minutes.”

“As Adult Services Access Point is the single point of contact for all of Adult Services is has been quite straight forward to manage the training and the consistency of how the implementation has been delivered. Delivering the training to the rest of the service would present more of a challenge as there are over 1000 FTE staff. All staff are mandated to complete a number of online training courses including health and safety and data security. It would be possible to work with a social enterprise Bradford Talking [Media] to develop an online training resource which staff are required to complete annually which also forms part of their appraisal.”

“Adult Services Access Point has clearly developed policies, procedures and a telephone script. When the pilot is reviewed, procedures and script will be updated to reflect the changes.”

This pilot identified a number of specific benefits:

- Reduction in missed appointments – due to improved understanding and clarity about BSL interpretation / direct access to BSL interpretation through the ‘Glide’ app;
- “Improved information and communication will always lead to better outcomes.”
- Support to ensure that the [Care Act 2014](#) commitments around responsibility to provide expert information and advice, and recording of individuals' information needs, are met.

### 9.3.3 Recommendations from this pilot

- “Develop a self-audit tool that services can use to test their own abilities to meet the Standard.
- Working with user led organisations of disabled people has really helped in developing the pilot and to act as an expert by experience.

- One of the big challenges post pilot will be the ongoing production of accessible information.
- There are a number of levers currently that could be used to make the implementation run more smoothly. Many areas have Integrated Care Boards assisting with the implementation of integrated working. This is a joint health and social care board and will provide all the necessary governance. It would be able to unblock any data sharing problems.”

## 9.4 Dorset HealthCare University NHS Foundation Trust

### 9.4.1 Scope of pilot

“Dorset HealthCare University NHS Foundation Trust (DHC) provides integrated community health and mental health, specialist learning disability services, community brain injury, community dental services including community hospitals and prison healthcare.” A project group was established for the pilot, involving staff engaged in accessible information from a range of sites and disciplines – the group met fortnightly from December 2014 – April 2015.

Key actions as part of the pilot were to:

- Review the Electronic Patient Record (EPR) systems used within the Trust to identify “...how they could support the recording, alerting and sharing of information collated from service users on their communication support needs.”
- Develop and rollout a Communication Support Form (in paper, electronic and online formats) to record service users’ information and communication needs;
- Implement staff training and awareness sessions;
- Develop easy read documents and identify a quality assurance process for easy read information produced by the Trust;
- Review and revise the Trust’s ‘Policy for Interpreting and Translation (including Sign Language)’;
- Produce an accessible information standard poster to raise awareness.

The ‘project team’, including a dedicated ‘accessible information standard pilot facilitator’, completed most of the preparatory work, with the following services then trialling the Communication Support Form with their patients: Audiology (Adults with Learning Disabilities / Elderly); Bournemouth Community Team for People with Learning Disability; Acute Admissions Unit (Mental Health); Intensive Support Team (Learning Disability); Eating Disorders; Speech and Language Therapy (four local teams). The forms were completed with approximately 68 patients in total.

The Trust uses two electronic patient record (EPR) systems – SystmOne and RiO. “Due to the technical specifications and the in-house support of SystmOne, changes could be made to SystmOne via the in-house EPR support team. The project team were able to request specific tailoring to meet the needs of the pilot. It was agreed that a template could be created on SystmOne, which would be accessible via the navigation tree. Alternatively, a paper form could be completed and scanned onto an individual’s EPR.” Unfortunately, it was not possible to effect changes within RiO during the pilot phase, and so a paper-based approach was taken by services who

used this system, however the Trust understands that in future it may be possible to make changes within RiO.

The Communication Support Form was created initially using the draft technical document as a framework, however the form was continually evaluated throughout the course of the pilot and adjustments were made based on feedback from staff and patients. In addition, "Once the Communication Support Form was completed, an alert needed to be made to bring attention to the form and its contents to other staff. This alert mechanism varied between the electronic systems.

- The SystemOne template was set up to automatically create an alert when the form was added, which presents an alert on the 'home' page of the service user's EPR.
- If a paper form is scanned in to either of the systems (SystemOne or RiO) a manual alert must be created by the practitioner to alert future EPR users to review this form."

"The sharing of data across the Trust is one major area that, despite lengthy discussions with IT providers and in-house system support, is not currently possible. The system a professional uses determines which other teams can access this information."

As part of the pilot, the Trust's 'Policy for Interpreting and Translation (including sign language)' was reviewed and a revised version is currently awaiting approval from the Trust's Equality and Diversity Steering Group. "One of the actions in amending and updating the policy was to update the list of Trust staff who have non-verbal communication skills. This has, in itself, created interest and heightened awareness of communication support needs of service users."

#### **9.4.2 Feedback on costs, implementation challenges and benefits**

"Collaboration between specific DHC teams within the AI project and a local 'People First' advocacy group, for people with learning difficulties, has resulted in a number of outcomes. Easy Read leaflets and packs of Flash cards have been created within the duration of the pilot, for use within the DHC teams.

Whilst there is no quantifiable data on the number or costs of AI communication support translators or interpreters, awareness has certainly been raised on the access, processes and staff responsibilities with regard to using translators or interpreters, as a direct consequence of the AI pilot."

"Pilot site users' feedback indicate[s] that a few (5-10) extra minutes were needed to complete the form, however staff anticipated that this would reduce as they became more familiar with the paperwork and standard. It was felt important to allow additional time, as this emphasised the importance of the process and standard."

"The use of personalised appointment letters or bespoke contact (text or email), where a need is indicated, is not currently available. It has been advised that if a service user has a need (for example a braille appointment letter) yet the Trust cannot currently provide it, then an incident report / Ulysses form ought to be

completed. This would ensure that the frequency and type of such occurrences could be established and steps can be taken to make changes or acquire new services or equipment as required. The refreshed Trust policy will include details of all services who can provide alternative formats of documentation for patients...” Note that during the pilot phase no such incidents were recorded.

“There have been discussions on ascertaining service users’ needs versus their preferences. Whilst it was acknowledged that the AI Standard places an obligation on the Trust to meet service users’ needs, in some cases, meeting their preferences also ensures that we are engaging with them and their perceived ‘needs’.”  
The main costs identified by this pilot were the pilot facilitator’s time, followed by conversion of documents into alternative formats.

“It has been very difficult to judge the impact of piloting the AI standard at Dorset HealthCare in terms of benefits and / or efficiency savings... There was no measurable increase or decrease in Did Not Attends (DNAs) during the pilot period which could be associated with relevant changes in practice. There were no complaints but the patient / service user experience seemed more positive as patients appreciated being asked what their communication needs / preferences were.”

“The Standard, if implemented in an effective and meaningful way, presents a tremendous opportunity to shift the culture within services and make a real difference to the experience of people with communication support needs.”

#### **9.4.3 Recommendations from this pilot**

“Having a tool / form that services can tailor to meet their service users’ individual needs would enable practitioners / teams to exercise autonomy in delivering personalised communication support.”

“The AI Pilot team found that there was a plethora of documents and information available to support the pilot project. Several comments were received on the need for the AI Standard itself to be in a simpler, easier accessible format, rather than a 36 page technical format, to reflect the message it is delivering...”

“We feel less, but simpler implementation guidance would be more effective, and encourage full participation. Healthcare professionals, administrators, service users and carers will all need to be made aware of the AI standard and how organisations will meet their needs. A simple guide (leaflet, poster, newsletter) would be a helpful tool to inform all relevant people of their expectations.”

Other suggestions included:

- Promoting the increased accessibility of ‘standard’ documents.
- Providing clarity about recording a carer’s information / communication needs in addition to a service user’s – when both may need information and have differing access needs.
- “Review the coding system to ensure that when used it is capable of providing a description that truly reflects and can meet people’s support needs.”

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- Including a tool for gathering information about people's communication needs as part of implementation guidance.
- Having a service user held 'information alert card'.
- Recognition that people with cognitive impairments are likely to need support to provide an accurate description of their communication needs.
- A directory of useful services and organisations.
- "National standards for easy read information and quality assurance".
- A national network for sharing good practice and experiences (and avoiding duplication of work).
- Staff training, including awareness-raising, local policies and knowledge / skills.

"The greatest obstacle in implementation of the Standard has proven to be the sharing of data between EPR systems. Trusts within CCGs using more than one EPR will require their EPRs to link to allow data sharing. Central support (from NHS England or IT contractors for NHS systems) will be invaluable in ensuring parity of services. This would be a more cost effective alternative to individual teams, Trusts or CCGs negotiating with EPR companies to engage in changes to their systems... Having a template already accessible on the EPR systems would be a large step forwards in making the data collection easier to implement."

Note that, "Dorset HealthCare is a partner in the development of a new system called Dorset Care Record which has recently won a bid...from the NHS England Integrated Digital Care Fund to create a seamless electronic record system for patients...The DCR system would allow health and social care practitioners to record, alert and share communication support needs, to meet the AI Standard."

This pilot also put forward a number of recommendations / advice which could be used by other organisations in implementing the Standard, including outlining how they are taking forward full implementation.

## 9.5 East Lancashire Hospitals NHS Trust

### 9.5.1 Scope of pilot

"East Lancashire Hospitals NHS Trust (ELHT) was established in 2003 and is a large integrated health care organisation providing acute secondary healthcare for the people of East Lancashire and Blackburn with Darwen and community healthcare services for the population of East Lancashire." The pilot was conducted within: Urgent Care (Minor Injuries Unit), Speech and Language Outpatients and Ophthalmology. A project group including staff, service users and voluntary sector organisations was established to take forward the pilot.

"A review of current systems and mechanisms, policy and procedure with regards to supporting patients / service users with information and or communication needs was undertaken."

"During the testing phase, patients were interviewed by members of the project group within waiting areas of all pilot sites. Members of the project group used [a] questionnaire as [a] prompt, however it was up to the individual patient to self-define." The communication needs of 22 patients were recorded in this way during the pilot.

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In addition, “Focus groups, Information and Signposting events (Healthwatch) and Coffee Mornings (Blind Society) were held in March 2015 during which service-users shared their opinions and feelings about how accessible information and communication is for them personally and also make...recommendations on how / if there could be improvement.”

“Sign Communication has been working in partnership with ELHT to raise awareness of communication support available for people with hearing loss. Information leaflets are displayed in waiting areas and advertised across the Trust and this has led to an increase in uptake of alternative formats being requested including BSL interpreters.”

### 9.5.2 Feedback on costs, implementation challenges and benefits

“The role of ‘first point of contact’ staff, for example receptionists, is crucial in asking [about] patients’ information / communication needs. The project team proposed a few questions which staff felt comfortable asking to patients. The staff agreed on a standard question; “Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?” Staff at all the pilot sites mentioned that they did not stick to asking the same question about needs and tailored the question to each individual patient. It is interesting to note that for all pilot sites with the exception of urgent care the provision for communication support is organised well in advance so in many cases there is no requirement to ask questions.

Nonetheless there are occasions where the provision is not in place. A common example is of BSL interpretation. If a patient attends the clinic without an interpreter booked, as [a] contingency staff have to organise an interpreter and this will delay the appointment as it takes one hour to source a BSL interpreter, although there was a lack of awareness from staff that there was a facility available to utilise the SignPhone (video) service which [enables] immediate access to a BSL interpreter, thus [the] patient can be seen immediately.

In general, there were difficulties collecting data as staff at all the pilot sites were incredibly busy with complex schedules, increased patient activity, holidays, and year end pressures. Despite the aforementioned difficulties it was decided members of the project group would go through the questionnaires, therefore members of the project group conducted 1:1 interviews with patients in clinical waiting rooms.”

“A major challenge is knowing which of the formats is required by a specific individual. Some participants felt that examples of types of communication support and / or alternative formats should be given to support people in answering effectively. The importance of clarity as to individual’s specific needs was highlighted, for example a range of font sizes may come under the term ‘large print’. Participants felt that there should be a range of different formats (catalogue) available and methods used by services to record their communication needs, noting the need to be flexible to ensure inclusivity.”

With regards to benefits, “Within the pilot areas the project has been received as extremely positive as [the Standard] impact[s] on patient safety and quality and it resonates with our mission statement of providing “Safe, Personal and Effective”

Care. Everyone involved in this project supported the overall aims and objectives of the Standard.”

### **9.5.3 Recommendations from this pilot**

“Accessible information and communication support should be built into the service level agreements with providers / suppliers taking into account routine or planned care, and emergency or unplanned care, and include a caveat of penalty if the supplier fails to deliver the service on time. For secondary care it is vital to have a dialogue with the commissioners as the majority of patients are referred via the GP or NHS e-referral Choose and Book system and staff in the pilot sites suggested that in [the] majority of cases there is no sharing of information on the patient’s information and communication needs.”

“Many participants suggested that the Standard should include reference to Equality Delivery System particularly Goals 2.1 and 2.2 as implementing the Standard will provide organisation[s] with evidence of meeting these indicators. Also as part of the EDS patients and third sector organisations can be involved in supporting the effective implementation of the Standard or in assessing compliance. There is also recognition that action must be taken to equip health care staff with the skills needed to meet the communication needs of the people with sensory impairments they come into contact with. We cannot stress the importance of staff training and the production of an accessible information policy or guide.

A marketing campaign to raise awareness of the initiative and tools such as the Communication Card will, in future, act as a good measure of performance against the Standard. We also recommend that organisations need a coordinated cross industry effort from a range of stakeholder organisations – GP’s, local authorities, community and voluntary groups, healthcare providers etc.

Patients and members of the public in the focus group advocated that the Standard should not be implemented in isolation and that Trusts take a holistic approach, this means looking at things like accessibility of signage which in most cases is the first barrier in accessing health care.

This study has highlighted that the Trust is well positioned to improve equality of access to information / communication needs of patients through implementation of the Accessible Standard.

The precautionary note would be to ensure that the accessible information project cannot unintentionally decline, over time, into ticking off the documents. The key is to be clear that it is not the documents per se that we are looking for but what they contain and can demonstrate about either genuine equality of outcomes or a move towards that state.”

## **9.6 Ellison View Surgery, Hebburn**

### **9.6.1 Scope of pilot**

Key actions taken in order to pilot the draft accessible information standard were as follows:

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“GP and members of staff (Practice Manager and Deputy Manager) met to discuss potential read codes for the computer to be used to search and identify patients coded with a visual / hearing problem. We were already aware of the patients we had with learning disabilities. Deputy Manager then set up a search on computer to identify possible patients.

GP and member of staff (Practice Manager) looked through the list to agree who should be classed as having a visual / hearing problem and the correct diagnosis. Practice Manager then went through each patient record, ensuring the problem was coded in the correct section of our EMIS system.

Practice altered new patient registration form to include a question about whether that new patient had any specific communication needs, and to get patient consent to share this information in communications from the Practice to other healthcare professionals. This consent is recorded on patient record...

Member of staff went through each of these patient records and put an alert on asking staff to ask the patient if they had any particular communication needs as and when they attended surgery. This would then be noted on their record and consent to share this information sought from patient.

Staff meeting held with Manager to explain [the] project to staff and what staff need to do if they identify a patient with a possible communication need. Staff also advised to be aware of these patients and assist them where they may not be able to use the self-check in system or the patient call board, which is visual...

Discussion with medical secretaries and GPs about including special communication needs information in referrals to other healthcare professionals and recording the patient consent to share information.”

“We have 67 patients identified so far who have either hearing or visual problems who may need different accessible information. All 67 patients’ notes have been marked, either with the way they wish to be communicated with, or a note on to ask them opportunistically when they next come to surgery.”

### 9.6.2 **Feedback on costs, implementation challenges and benefits**

The impact of piloting the Standard included time taken to:

- Set up searches, review, code and add alerts to electronic patient records;
- Redesign the patient registration form to include a question about communication needs;
- Create a poster for the waiting room to encourage patients to alert the practice to their communication needs;
- Gain and record patients’ consent to share information about their communication needs with other services (an ongoing action);
- Engage with voluntary sector organisations to seek expert advice about communication support needs.

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“...the main time / cost implication to the practice was setting up the guidance, e.g. identifying read codes, computer search, agreeing the list, ensuring diagnosis code is correct and in the right place, adding alert to patient record, staff meeting time to discuss [the] project, changing Registration Form and meeting with Healthcare Assistant to explain; PM discussions with LD team and Sight Service and investigation of Type Talk, Speak and Read, etc. Apart from extra staff time costs and GP time costs, practical cost of having leaflet put into large print.

There will also be additional staff time involved as patients are identified and attend surgery, in explaining to them the Project, getting their agreement as to what communication needs they may have and obtaining consent. This cannot be done ‘over the reception desk’ and a member of staff will have to be identified to take charge of this aspect of the project.”

This pilot identified some specific challenges around the cost and practicality of arranging BSL interpreters for d/Deaf patients and the provision of alternative formats such as audio.

With regards to benefits, “The Pilot has not been running long enough to see any changes in DNAs. We only have 67 patients and only two have been contacted for advice. None of the other patients have yet attended. It is unlikely that extra appointment time for such a small cohort of patients will impact on the practice.”

### 9.6.3 Recommendations from this pilot

“This project, we feel, can only be done opportunistically. Our patient numbers are 5800 and we have identified 67 potential patients with communication difficulties. The numbers are obviously going to be greater for bigger practices, which would make it impractical to do ‘everyone at once’.

“It will be essential under Information Governance that the practice gains the consent of the patient to share their disability and communication need with other healthcare providers. It could prove difficult to record the communication needs of a person’s carer, if that carer is not registered with the Practice. Consent would then be difficult to be got.”

“General reception staff feel a bit daunted about having to have such a communication conversation with patients, which is why we thought we would appoint a ‘patient champion’ to discuss with patients rather than ask each member of staff to have the conversation at a busy reception desk, or telephone switchboard. Further support should be given to Practices through guidance as to where to obtain other forms of communication such as audio, CDs etc. and the availability of computer applications, rather than leaving each Practice to investigate themselves. We feel that the Standard, whilst very laudable, could be pared down a little to make it more practical to implement, particularly in smaller General Practices, who are not part of large organisations with the resources to investigate and implement some of the suggestions put forward in the guidance.”

## 9.7 GTD Healthcare

### 9.7.1 Scope of pilot

“gtd healthcare is a not for profit organisation. Our main business is the provision of primary healthcare services including both urgent and scheduled services to patients across Greater Manchester and Merseyside...It was agreed that the pilot would be carried out across a sample of GP Practices, GP-Led Health Centres and Out of Hours Primary Care Service across gtd healthcare’s Greater Manchester sites with a view to extending any learning to all gtd's sites.”

This pilot focused on identifying, recording and flagging of needs, including exploring how best to capture information from patients, use of Read Codes for recording this information and the use of patient alerts within clinical systems.

#### 9.7.1.1 GP Practices / GP-Led Health Centres

“Arrangements were made to visit the first GP-led health centre and work with one of the administrators responsible for note summarising and running reports on the clinical information system, EMIS Web. Together, the administrator and QAM [Quality Assurance Manager] identified any READ codes that might indicate that a patient had some sensory loss that might affect communication...Searches were then run for each area and a sample of patient records scrutinised to ensure that the report results were relevant.” Following input and advice from a GP at another pilot practice, “The search criteria was refined slightly and used to generate reports at each of the pilot sites.”

“Once the search criteria had been agreed, the searches were easy to transfer and run at the other pilot sites as they all use the same clinical system. Patients coded as having a learning disability were already identified through the register required to be maintained by each practice as part of the Quality Outcomes Framework...”

“...One of the simplest methods of identifying patient needs at practices is to try to capture that information at registration. Each of the gtd healthcare practices uses a paper registration form for general information usually accompanied by a health questionnaire...The clinical information supplied is reviewed with the patient at a new patient health check once they have registered at the practice. Although a standard form was developed when the organisation commenced management of the practices, the majority have since made their own amendments. It was therefore agreed...to review the existing forms with a view to producing a standard form which includes the identification of communication needs, which is currently limited to language requirements.

At the start of the project, the QAM had made an assumption that gathering communication needs information would simply be a matter of adding a prompt, possibly a small table detailing the different requirements, into the registration / health check form. However, through the project, it has become apparent that this is not the case due to the wide variety of communication methods available. Following discussion with the GP Advisor, a general question regarding communication needs has been added to the registration form: Do you / the patient require any assistance with communication due to hearing, sight or speech difficulties? Yes / No.

It is envisaged that this will prompt the completion of a more detailed form either at this stage or as part of a discussion at the new patient check. The proposed documents are to be presented for discussion and agreement at the next practice managers' meeting at the end of April 2015.”

#### **9.7.1.2 Out of Hours**

“The identification, recording and flagging of patients encountered in the out of hours setting was explored by members of gtd healthcare's Information Management and Technology group. The computer system used is Aداstra. Patients will typically access the service by telephone...Communication needs are usually identified upon contact with the service by the call handler taking the initial patient demographics and presenting condition and would be recorded within the main body of text. Whilst there are codes available on the clinical system, there do not appear to be any related to communication needs. This means that it is currently not possible to run any searches to identify such patients. The out of hours service is therefore reliant upon any information that may have been recorded in a previous encounter or information provided from other sources such as the patient's GP practice.

The out of hour's service currently receives information from practices in the form of 'Special Patient Notes' (SPN's). These may be initiated by the practice themselves or additional information may be requested from the practice where any cause for concern has been raised with regards to supporting clinical care during the out of hour's period. Practices supply this information through faxed documents or they can record this information electronically via a web portal directly into the clinical system. Aداstra Web Access has three standard templates for palliative care, high risk adults or safeguarding children, but again there is the opportunity to add free form text which could be utilised to inform the out of hours service of any communication needs. Unfortunately, the use of Web Aداstra by GP practices has been limited across the areas we serve.

gtd healthcare is currently exploring the use of the Medical Interoperability Gateway (MIG) to enable the secure sharing of data from practices via EMIS Web. It is envisaged that where communication needs are READ coded within a practice, that the out of hour's service will be able to view this information via Aداstra. However, the project is in the early stages and it is therefore difficult to assess the practicalities and impact of this option.”

### **9.7.2 Feedback on costs, implementation challenges and benefits**

#### **9.7.2.1 GP Practices / GP-Led Health Centres**

“The highest numbers of conditions [identified through searches to identify patients who may have information / communication support needs] were those affecting hearing, sight and speech. On closer inspection of a random sample of these records, it would appear that in many cases these related to a temporary sensory loss, especially for those patients attending on a walk-in / unscheduled care basis. This potentially means that a suitable / appropriate member of staff would need to review the records of all the patients from the reports to identify those that may have ongoing communication needs. These patients could either then be contacted to go

through those needs or an alert could be added to the clinical system to review those needs when the patient next attends the practice.”

“There are READ codes available on the EMIS Web clinical system relating to communication needs. From the results of the searches run, these are not currently being used...Until the use of READ codes is phased out in favour of the [SNOMED CT®](#) codes, the ability for the practices to record any patient communication needs within the clinical system is limited to the far smaller list of READ codes available, with the addition of free text as appropriate...”

“Within the EMIS Web system, there is a facility to add alerts which flash up on the screen once a patient record is accessed. This is a relatively simple process to set up manually once any communication needs are identified. Whilst attending the pilot sites, the QAM was made aware of the potential for automating this process upon application of specific READ codes through the use of a computerised protocol. Unfortunately, the expertise was not available within the practices at the time to test this.

In terms of sharing information, it was noted that there was a prompt within the alert set up to allow information to be viewed by other organisations...However, it was not clear how this could be utilised, who the information could be shared with and whether this could be done with other systems; further advice will be sought from EMIS.”

#### **9.7.2.2 General**

“For the practices, in terms of identifying patients with communication needs, there would appear to be little impact or cost implications if done on a prospective basis as part of the initial registration process. However, this would be dependent upon the patient and / or their representative being able to provide this information easily on the documents provided. Should additional involvement be required from either the administrative staff or clinical staff at the time of the new patient health check or other consultations as needs arise, this may have some impact on the time required to gather this information. Although the same is true of any other assessment carried out and should therefore not be considered out of the ordinary or therefore a barrier. The same is true of recording and setting up alerts for this information. As the Standard becomes more embedded in practice, with GP2GP transfers it should become easier to identify new patients with communication needs as if the information has been accurately recorded in one practice it will be transferred each time the patient registers elsewhere. However, it is important to remember that the information will need to be reviewed on a regular basis to keep up to date with any changes in a patient’s requirements or communication methods available.

There is likely to be a bigger impact for practices trying to review the needs of their current registered patients, and this may need to be managed on an ongoing basis as and when patients present.

Within primary care there is a heavy reliance upon IT systems. From the pilot, there are already a number of IT solutions available to support the identification, recording and flagging of communication needs. However, the expertise may not always be

available to use these to their full effect and additional training and / or system supplier input may be required.

It is assumed that once SNOMED codes are introduced, any communication need READ codes recorded within a patient's clinical records will be mapped across to the corresponding SNOMED code. However, these will need to be reviewed with patients to take into account any further information detailed within the free text, any additional needs that can be coded using the longer SNOMED list and / or any advances in communication methods / technologies.

...consideration will need to be given to the costs of producing materials in different formats and whether current systems could be adapted to facilitate this process. There may be resource needs to even review what is already in place that could be used and also in maintaining a database list of available resources.”

### **9.7.2.3 Benefits**

“It is recognised that communicating with patients using methods appropriate to meet their individual needs will improve the experience for the patient, support the delivery of high quality care by staff, ease the pressure on both staff and patients and ensure a much more meaningful and productive relationship. This will hopefully avoid complaints due to an improved patient experience and minimise the risk of untoward incidents caused through any misunderstanding and miscommunication.

Through accurate recording of this information, it is envisaged that communication needs can be met more promptly and appropriately which may help to avoid missed, cancelled or repeat appointments (where the necessary support has not been available) for scheduled care. However, for unscheduled care such as in the out of hours service or walk-in centres it is far more difficult to anticipate when and how to meet communication needs on an individual basis and the choices of what can be accessed within a short space of time appear to be quite limited.”

### **9.7.3 Recommendations from this pilot**

This pilot report included a series of ‘internal recommendations’ which will be taken forward by gtd healthcare, and a range of comments on effective implementation and the infrastructure to support implementation – with key points included above.

## **9.8 NHS Bradford City and Bradford Districts CCGs**

### **9.8.1 Scope of pilot**

“A project steering group consisting of a GP from Bingley Medical Practice, with CCG and CS [Commissioning Support] staff working in engagement, equality and diversity and data quality and with some local disabled people from Bradford's Strategic Disability Partnership board (SDP) began meeting approximately one year ago. The group were reviewing poor patient experience feedback received from patients and carers whose accessibility information needs were not being met...The group has identified a way of flagging patients with communication and access needs in SystemOne...The Local Authority in Bradford is also moving to SystemOne in Aug 2015

and the results of this pilot will be shared with colleagues together with recommendations for rolling out to a wider cohort of member practices.”

This pilot site completed engagement with local people to identify their specific access needs in contacting / attending local GP practices. As a result, a simple process was identified which could be followed by any GP practice (using SystmOne) to implement the Accessible Information Standard. This included identifying patients likely to have information and / or communication needs, placing alerts or flags on the system, and ensuring ‘protocol triggers’ and prompts for staff were enabled and followed.

In addition, “Working with the VCS [Voluntary and Community Sector], Bradford City and Districts and AWC [Airedale, Wharfedale and Craven] CCGs have developed a questionnaire that will act as a guide for practice staff when talking to patients about their access needs, it will support the patient and practice to agree an adjustment that is reasonable to both parties and will be used before and after flagging to evaluate its success in improving patient access and experience”.

### **9.8.2 Feedback on costs, implementation challenges and benefits**

This pilot did not progress as far as anticipated in the given timescales, and so feedback on costs, challenges and benefits is limited.

Benefits identified focused on enabling people with a disability, impairment or sensory loss to access services independently, and to have private / personal access to information about their health and care.

Challenges included the need to ensure that patients are aware (and confident) that any communication support they need has been arranged, and ensuring clarity about the specific adjustment / support needed by an individual.

### **9.8.3 Recommendations from this pilot**

This pilot site highlighted the importance of clear local protocols and procedures associated with the Standard, supported by training for relevant staff, and the benefits of taking an approach beyond an individual practice. This site also provided very practical guidance about how the Standard could be implemented by a GP practice, which will be made available.

## **9.9 The Clatterbridge Cancer Centre NHS Foundation Trust**

### **9.9.1 Scope of pilot**

“The Clatterbridge Cancer Centre is one of the largest networked cancer centres in the UK...The Pilot site for the draft accessible information standard was the whole organisation excluding The Clatterbridge Clinic (our private patient unit).”

“During the pilot phase...our Clinical Specialist for Additional Needs made contact with 31 patients known to have information and / or communication needs, this contact was on the initial visit where the patients were reviewed, along with their carers where appropriate...All records were adjusted to include details of the

individuals' information and / or communication needs in line with the Trust Policy. For each patient a Reasonable Adjustment Plan was completed, a 'blue dot' sticker was applied to the Patient's case notes / patient folder and an annotation regarding the communication needs documented."

"A paper-based system to identify, flag and record if a patient / service user has communication or information needs relating to a disability, impairment or sensory loss was implemented immediately prior to the pilot phase and is documented in the Trust policy 'Use of Additional Needs Alert Sticker' policy...During the pilot we investigated the possibility of introducing electronic flags and this work is still ongoing. The Trust plans to introduce a new Electronic Patient Record system early next year (February 2016) and this will allow us to flag patients with communication or information needs relating to a disability, impairment or sensory loss...A draft Accessible Communication Policy has been compiled based on the ISB 1605 Accessible Information Standard Specification draft. Once the Specification draft has been finalised the Trust policy will be updated accordingly, document controlled in line with Trust policy and made available to all Trust staff. A programme of training will also accompany the introduction of this policy...During the pilot it was decided that an annotation should be included in Aria, the electronic system that holds the radiotherapy treatment plan, for patients with an alert sticker. The memo...was circulated to all relevant staff and guidance will be included in the 'Accessible Communication Policy'.

As a Trust we are confident that once a patient / service user is identified as having communication or information needs relating to a disability, impairment or sensory loss we are thorough in our approach and are able to provide appropriate information and communication support. We are now working on ways to ensure that all patients with communication or information needs are identified and flagged in advance of their treatment commencing. As a result we have updated our policy 'The management of patients attending with additional needs' which now includes an Audit section...We are looking to convert the 'Use of Additional Needs Alert Stickers' policy to a procedure document and change its title to 'Alert Stickers' as this document is not limited to patients with additional needs.

Our Trust Wide Guideline 'Communication Support Guidance: accessing and using interpreters, translation services, assistance and facilities' is also currently under review..."

#### **9.9.2 Feedback on costs, implementation challenges and benefits**

With regards to costs, "The Trust utilised the funding provided as part of the pilot study to fund the Clinical Governance Manager for Patient Safety to dedicate 60 hours of her time to reviewing the pilot documentation, updating and creating Trust policies in order to fulfil the requirements of the Standard and to investigate IT options to convert the paper-based system into an electronic system...The impact on staff has been minimal due to the small numbers of patients identified during the pilot phase as having communication or information needs relating to a disability, impairment or sensory loss...Staff training for supporting and caring for patients with additional needs is already embedded within the Trust and is part of our 'business as usual'. We currently offer mandatory communication skills, safeguarding and equality

and diversity training, dementia awareness training, caring for patients and service users with learning disabilities training and Deaf awareness training. We are looking to expand the scope of our training over the coming months...”

An additional outcome from the pilot has been the agreement to include a new sentence as part of letters sent to patients informing them of how to request alternative formats.

The following comments were provided on benefits:

- “‘Did Not Attend’ (DNAs) – We were unable to measure any increase or decrease in DNAs during the pilot period.
- Clinical scheduling: implementation of the Standard did not have an impact on clinics / sessions running on time.
- Complaints and the patient / service user experience: the patients for whom accessible information was provided reported that they were happy with the information provided. No complaints were received regarding information and communication support during the pilot period.”

### 9.9.3 Recommendations from this pilot

“The comprehensive array of documents that accompany the Standard, whilst helpful, did provide a barrier to the implementation of the Standard due to the time required to read the documents and translate them into practice...The Standard states that ‘Paper-based systems and documentation MUST enable recording of needs in line with the human readable definitions of the data items associated with the subsets defined by the Standard’. This was not possible for the Trust to implement during the pilot phase as the staff involved in the project did not have experience of using these codes and found it difficult to identify expertise in the Trust in such a short timeframe. More guidance on what is required with regards to the recording of needs in line with the human readable definitions of the data items for Trusts implementing a paper only based system would be valuable.”

“...The scenario examples in the Implementation Guidance are very helpful and staff would value more examples if available.”

“The Standard Specification draft is a comprehensive document. It would, however, benefit from being more concise, if possible. The Specification draft refers to SNOMED CT and Read Codes however it expects the reader to have knowledge of these. It would be helpful to provide a lay description for those readers who have no prior knowledge.”

“It would be helpful to have a leaflet, produced by NHS England, in a variety of formats (easy read, braille, audio etc.), that describes the Accessible Information Standard for patients / service users, which encourages them to request information in alternative formats if required, asks for their feedback (questionnaire?) if alternative formats are provided and also tells them how they can raise comments, concerns or complaints within the providing organisation. In addition, it would also be helpful if NHS England could provide poster templates for Trusts to advertise their commitment to the Standard and the services available.”

An additional suggestion was for the development / provision of a 'tick sheet' of information / communication support options which could be linked to SNOMED CT codes and used by staff and patients to support identification and recording of needs.

Feedback was also received on the Clinical Safety Case, which has informed the final version of this document.

## **9.10 The Phoenix Medical Centre in partnership with Dynamic Health Systems**

### **9.10.1 Scope of pilot**

The scope of the pilot included:

- “Completion of review of systems, policy and procedure with regards to supporting patients / service users with information/communication needs and identification of changes / improvements needed.”
- “Implementation of changes necessary to enable proactive and routine identification and recording of patients' / service users' information and / or communication needs in line with the draft standard...to improve or establish systems for referring to or flagging a communication need...to introduce or improve flags or alerts.”
- “Implementation of changes necessary to improve or establish systems for meeting the information and communication needs of patients / service users with information / communication needs.”
- “Provision of training to any / all staff in order that they can effectively implement the Standard and participate in the pilot.”

As part of the pilot, initial actions included:

- “Run searches and identify the number of patients affected by disabilities
- Assess policies and procedures to see how comprehensive they are
- Alert the 'patient participation group' and seek their involvement to inform and be part of the process.”

“317 people had been coded as registered disabled, blind, deaf or with physical or sensory disability. Of these some may have been coded as e.g. 'temporary deafness or partial deafness'.”

“The identified patients (with a READ code identifying the disability) were invited to feedback on their needs relating to their disability.

- Icons were created in the medical system (TPP SystemOne). These are clearly visible on opening a patient record.
- Admin staff would then know about the disability when dealing with these patients immediately on opening the record and know how to help e.g. the need to provide information in braille or using the hearing loop etc.”

Additional actions taken as part of the pilot included:

- “Raised awareness with all staff to create the interest in delivering a better service, enable staff to take proactive actions such as arranging for an interpreter.
- Used READ coding for communication needs to ensure that these needs can be accurately transmitted to the systems used by other organisations so that they too can respond appropriately to the identified needs of the patients.
- We are also in the process of integrating the patient records with VitruCare which is a patient facing platform which enables patients to record their needs and requirements and share these with carers, clinicians and significant others. This will enable front line staff to see important information concerning the person’s needs and respond in a proactive way. All patients in the practice could have an account and this could be kept updated and shared as necessary as the patient receives care.”

#### **9.10.2 Feedback on costs, implementation challenges and benefits**

With regards to the impact and cost of implementing the Standard, and following it as part of ‘business as usual,’ “Use the capabilities of the digital systems to support rapid, consistent and operationally convenient implementation. We were fortunate to understand our clinical system very well, support and templates may be needed for other practices.”

With regards to benefits, “The practice scores high in Patient Experience (PE) as it stands. But patient feedback on this pilot points clearly to a further improvement opportunity in the PE for this cohort of patients.” This pilot noted that feedback from patients was positive.

“Implementing the Standard has been helpful in ensuring that an appropriate amount of consultation time is allocated where it is needed and improved patient experience and reduced complaints relating to not having systems and processes in place to address patients’ needs.”

#### **9.10.3 Recommendations from this pilot**

“Best to be clear about the steps needed to implement the Standard and time span so that organisations are clear that this is an evolving process. To help with implementation focus on simple tasks which can be done readily by the organisation to build confidence and provide support with tools or experience from the pilot sites to help guide.”

“...case studies showing ‘how to do’ in a practice, hospital, community facilities etc. would be most valuable and help with implementation. The guidance could also be presented in a form which makes it more attractive and appealing rather than a lengthy document.”

“A complex area that requires raising of awareness and a cultural shift in mind set of practices to implement. Successful implementation may well need to be mandated by NHS England and linked to core activity to be implemented at scale. Clinical leadership in the organisation helps to drive the change. Engaging patient participation groups helps (‘patient power’) by raising profile of this need and that it is taken seriously.”

## 10 Conclusion and next steps

Feedback – including specifically key learning and recommendations (as outlined in section 6) – from the pilot sites has informed the final versions of the Specification, Implementation Plan, Implementation Guidance and Clinical Safety Case, as well as other documentation associated with the Accessible Information Standard. For example, in response to feedback from some of the pilot sites about ‘searching’ for patients who may have information / communication needs, additional detail has been included in the Specification and Implementation Guidance about requirements to identify needs (which must be identified opportunistically and proactively, but not retrospectively).

Feedback will also be used to guide resources which are developed to support organisations in implementing the Standard (as outlined in the Implementation Plan), particularly noting requests for short, straightforward, practical guides to implementation.

The reports and resources received from the pilot sites will be made available to support implementation by other organisations, including to reduce the burden of implementation.

Piloting also provided evidence of successful ‘first of type’ implementation of the Standard, including demonstrating that it can be implemented effectively and safely in a range of different health and social care settings.

Moving forwards, it is hoped that organisations involved in piloting the draft standard will act as ‘front runners’ for implementation of the final standard, as they will have already undertaken much of the preparatory work needed.