



Accessible Information: Implementation Guidance v1.1

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Description	DCB1605 Accessible Information 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 with a disability, impairment or sensory loss. This document is the reissued (version 1.1) Implementation Guidance for DCB1605 Accessible Information.
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Document Status

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DCB1605 Accessible Information: Implementation Guidance

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Equality and Health Inequalities Statement

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

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

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Data Coordination Board

This information standard (DCB1605) has been approved for publication by the Department of Health under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Specification
- Specification – Change Paper
- Implementation Guidance
- Implementation Guidance – Change Paper.

An Information Standards Notice (DCB1605 Amd 27/2017) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the [NHS Digital website](#). Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

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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 describes 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 description, “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 disability charity Scope defines impairment as, “long-term limitation of a person’s physical, mental or sensory function.”
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 SNOMED International 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 in appendix c.

2 Contacts

All enquiries regarding implementation of the Accessible Information Standard should be directed to NHS England by emailing england.patientsincontrol@nhs.net with the subject 'Accessible Information Standard'.

Information and documentation about the Accessible Information Standard, including resources to support implementation are available on the [NHS England website](https://www.england.nhs.uk/accessibleinfo) at www.england.nhs.uk/accessibleinfo.

3 Overview

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.

It is of particular relevance to individuals who are blind, d/Deaf, deafblind and / or who have a learning disability, although it will support anyone with information or communication needs relating to a disability, impairment or sensory loss, for example people who have aphasia or a mental health condition which affects their ability to communicate.

The Standard applies to service providers across the NHS and adult social care system, and it specifically aims to improve the quality and safety of care received by individuals with information and communication needs, and their ability to be involved in autonomous decision-making about their health, care and wellbeing.

Commissioners of NHS care and publicly-funded adult social care must also have regard to this Standard, in as much as they must ensure that contracts, frameworks and performance-management arrangements with provider bodies enable and promote the Standard's requirements.

4 Purpose

This document provides detailed advice for staff with regards to implementing and using DCB1605 Accessible Information – the ‘Accessible Information Standard’. It specifies roles, processes and actions needed to implement the Standard from a user perspective, and clarifies elements of the scope. It outlines how routine practices will be affected and signposts to resources and materials to support effective implementation.

It aims to provide clarity on particular aspects of the Standard and to support the embedding of new or amended processes and changes to human behaviour and systems. Ultimately its aim is to facilitate successful implementation and use of the Standard in all settings and by all organisations to which it applies.

The document is broken down into specific sections including elaborating on the five steps of the Standard, and providing guidance and examples of use, to provide context and to support implementation. It includes:

- A detailed breakdown of the elements which make up the Accessible Information Standard including explanation and clarity as to specific sections or aspects;
- Explanation and examples of how the Standard should be used in practice, including notes, advice and guidance;
- Clarity as to the scope of the Standard, including in and out of scope elements, and MUST, MAY and SHOULD actions.

5 Audience

The target audience for the document are senior officers (such as Directors of Nursing, Directors of Adult Social Care and Clinical Leads) and key members of staff (such as Practice Managers, Patient Record Managers and Information Governance Managers) from organisations who are required to implement the Standard. This includes, but is not limited to:

- NHS and adult social care bodies, including (but not limited to) NHS Trusts, NHS Foundation Trusts and local authorities;
- Providers of publicly-funded health and adult social care including (but not limited to) independent contractors and providers from the private and voluntary sectors;
- Suppliers of IT systems, software and hardware to health and adult social care organisations and providers.

It may also be of interest to those who will be affected by the Standard and / or who may wish to encourage or support its implementation, including:

- Local Healthwatch;
- Patient groups;
- Patients, service users, carers and parents with information and / or communication needs relating to or caused by a disability, impairment or sensory loss;
- Regulators and professional bodies;
- Voluntary and community sector organisations.

Public facing materials, and communications targeted at particular audiences, have also been produced – as outlined in the Implementation Plan and the Communication Plan – and are available on the [NHS England website](http://www.england.nhs.uk/accessibleinfo) at www.england.nhs.uk/accessibleinfo.

6 Implementation guidance

6.1 Overview

Successful implementation of the Accessible Information Standard is based on the following elements:

1. **Identification of needs:** a consistent approach to the identification of patients', service users', carers' and parents' information and communication needs, where they relate to a disability, impairment or sensory loss.
2. **Recording of needs:**
 - a. Consistent and routine recording of patients', service users', carers' and parents' information and communication needs, where they relate to a disability, impairment or sensory loss, as part of patient / service user records and clinical management / patient administration systems;
 - b. Use of defined clinical terminology, set out in four subsets, to record such needs, where Read v2, CTV3 or [SNOMED CT®](#) codes are used in electronic systems;
 - c. Use of agreed English definitions indicating needs, where systems are not compatible with either of the three clinical terminologies or where paper based systems / records are used;
 - d. Recording of needs in such a way that they are 'highly visible'.
3. **Flagging of needs:** establishment and use of electronic flags or alerts, or paper-based equivalents, to indicate that an individual has a recorded information and / or communication need, and prompt staff to take appropriate action and / or trigger auto-generation of information in an accessible format / other actions such that those needs can be met.
4. **Sharing of needs:** inclusion of recorded data about individuals' information and / or communication support needs as part of existing data-sharing processes, and as a routine part of referral, discharge and handover processes.
5. **Meeting of needs:** taking steps to ensure that the individual receives information in an accessible format and any communication support which they need.

A practical 'one page guide' to the Accessible Information Standard is included at appendix a. In addition, a 'maturity index' outlining different 'levels' of implementation, ranging from 'basic' meeting of Requirements up to 'exemplar' or best practice, is included at appendix b. Organisations implementing the Standard may find these appendices useful to support internal communications and improvement plans respectively.

6.2 The Accessible Information Standard – quick prompt

There are five basic steps which make up the Accessible Information Standard:

1. **Ask:** identify / find out if an individual has any communication / information needs relating to a disability or sensory loss and if so what they are.

2. **Record:** record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record / administrative systems / documents.
3. **Alert / flag / highlight:** ensure that recorded needs are 'highly visible' whenever the individual's record is accessed, and prompt for action.
4. **Share:** include information about individuals' information / communication needs as part of existing data sharing processes (and in line with existing information governance frameworks).
5. **Act:** take steps to ensure that individuals receive information which they can access and understand, and receive communication support if they need it.

6.3 Education and awareness-raising

Lack of knowledge about the communication and information needs of people with a disability, impairment or sensory loss, and lack of skills and confidence in how to support individuals with such needs, is a known issue amongst both clinical and administrative staff working in health and adult social care settings.

Whilst this Implementation Guidance is intended to support effective implementation, it should be considered alongside and with reference to the Implementation Plan and the resources and learning opportunities outlined in the Plan, which are intended to complement and build upon guidance included here.

6.4 Improving the accessibility of all information and communication

6.4.1 Introduction

One of the most practical ways of reducing the burden of implementing the Accessible Information Standard is to improve the accessibility of 'standard' information / documents – which will in turn reduce (but of course never remove) the need to produce / provide alternative formats – and to improve staff members' communication skills generally. The following 'top tips' are intended to support organisations and staff to make their information and communication more accessible and inclusive – they may be used as part of internal communications / awareness-raising.

6.4.2 Tips for clear face-to-face communication

- Make sure you have the person's attention before trying to communicate with them. If they do not hear you, try waving or tapping them lightly on the shoulder.
- Identify yourself clearly. Say who you are and what you do – it may be more relevant to explain your reason for seeing the person rather than your job title.
- Check that you are in the best position to communicate, usually this will be facing the person, but consider whether seated or standing is more appropriate. Communication at eye level is usually easiest so if you are speaking to a wheelchair user consider sitting down if possible.

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- Find a suitable place to talk, with good lighting and away from noise and distractions.
- Speak clearly and a little slower than you would do usually, but do not shout.
- Keep your face and lips visible – do not cover your mouth with a hand, your hair or clothing. If a member of staff is concerned about religious expression they should discuss this with their manager.
- Use gestures and facial expressions to support what you are saying.
- If necessary, repeat phrases, re-phrase the sentence or use simpler words or phrases.
- Use plain, direct language and avoid using figures of speech such as 'it's raining cats and dogs' or euphemisms such as 'expecting the patter of tiny feet'.
- Check if the person has understood what you are saying. Look for visual clues as well as asking if they have understood.
- Encourage people to ask questions or request further information. Ask if they would like anything in writing as a reminder or reference.
- Try different ways of getting your point across. For example writing things down, drawing or using symbols or objects to support your point.

6.4.3 Tips for printed communication

- Use a minimum font size of 12 point, preferably 14 (which is readable by a significantly greater number of people).
- Use a clear, uncluttered and sans serif font such as Arial.
- Align text to the left margin and avoid 'justifying' text.
- Ensure plenty of 'white space' on documents, especially between sections. Avoid 'squashing' text onto a page and, if possible, include a double-space between paragraphs
- Print on matt and not gloss paper.
- Use page numbers.
- If printing double-sided ensure that the paper is of sufficient thickness to avoid text showing through from the other side.
- Correctly format Word documents and PDFs using styles and accessibility functions / checks. Ensure a correct and consistent heading structure, and that the cursor can move throughout all text.
- Use descriptions ('alt. text') to explain diagrams or photographs.
- Consider making all 'standard' printed letters / documents 'easier to read' – using plain English, highlighting important information, and supporting text with diagrams, images or photographs.
- Keep track of the electronic originals of documents you print out so you can re-print in larger font or convert to an alternative format when required.

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- Further advice about creating accessible documents, including for users of assistive technology, has been made available as part of the suite of tools to support implementation of the Standard.

7 Guidance for stage 1 – identifying needs

7.1 Overview of requirements – identification of needs

Communication and / or information needs MUST 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, face-to-face at a reception desk, as part of a registration or admission form or through an alternative process.

In addition, communication and / or information needs MUST be identified proactively and opportunistically – the next time an existing patient / service user makes contact with / is seen by the service – but not retrospectively. There is no requirement for a retrospective search or ‘trawl’ of records to identify patients with needs, although this would be considered good practice, particularly for some groups of patients (see section 7.3).

Following identification of the existence of a communication or information need, the specific nature of the support and / or format required MUST be identified.

7.2 Note about consent to share information

As outlined in the Specification, all professionals and organisations must take care to ensure that they comply with relevant existing legal duties, including those set out in the [Data Protection Act 1998](#) and [Mental Capacity Act 2005](#) around the handling and processing of data.

Wherever it is possible to do so, consent to the sharing of personal data should be obtained from the patient / service user and clearly recorded, as should any limitations on that consent. Those seeking consent to share should be clear about what information will be shared, with whom, in what circumstances and for what purpose.

If consent to share cannot be obtained, because the individual involved lacks the capacity to make the decision, and because nobody has been formally appointed to make it for them, a decision to share information can be made in the patient / service user’s best interests in accordance with the [Mental Capacity Act 2005](#).

On each occasion where information is shared, the professional involved should be satisfied that there is consent to share for that purpose, or that such sharing of information is lawful.

Bear in mind that whilst the protection of confidentiality is very important, there are some circumstances where the sharing of information is just as important as maintaining confidentiality.

7.3 Methods for identifying needs

One of the fundamental principles of the Accessible Information Standard is that patients, service users, carers and parents should be asked to self-define their information and / or communication support needs, and it is these needs (and not

their disability) which should be recorded. There is a clear rationale for this, in that the aim of the Standard is to ensure that an individual receives information in a format that they can understand and any support which they need to communicate.

Recording that a person is 'deaf', for example, does not explain whether they are able to read written English, if they use British Sign Language (BSL) or are a lipreader and / or hearing aid user. Assumptions about communication support or alternative formats required, or any recording of needs, must not be made without consultation with the individual themselves and / or, where appropriate, their carer or parent.

Individuals **MUST** be asked about any information or communication support needs by a member of staff upon their first or next interaction with the service. This could, for example, be over the telephone when calling for an appointment, results or repeat prescription, or face-to-face. Where the conversation is held face-to-face a private room or area should be offered and made available as appropriate.

As a minimum, individuals should have two options or ways in which they can identify or explain their needs: a face-to-face conversation in a private room; and an online / paper form or similar document. One of these methods is likely to be suitable for many people, particularly if relevant members of staff have had appropriate awareness training in supporting people with communication needs.

If questions are included as part of an online or paper form, for example a new patient registration form, many individuals will be able to read and complete such a form unaided or without professional assistance (particularly if relevant documentation is in line with 'tips for printed communication' (section 6.4.3) and websites are accessible (see appendix e). Data may then need to be manually entered onto patient record or administration systems by administrative staff, or, in the case of online entry, it may automatically be uploaded into the patient's record.

In addition, individuals **MAY** be asked to advise the service of their communication or information needs via inclusion of a request in a 'generic' letter such as an invitation to attend a 'flu jab' clinic, newsletter or via posters or onscreen information in a waiting area, or via contact by email or text message. Patients with such needs may then be prompted to speak to a member of staff, and may feel more confident or comfortable in doing so. For example:

Anytown Surgery

"We want to get better at communicating with our patients. We want to make sure you can read and understand the information we send you. If you find it hard to read our letters or if you need someone to support you at appointments, please let us know.

We want to know if you need information in braille, large print or easy read. We want to know if you need a British Sign Language interpreter or advocate. We want to know if we can support you to lipread or use a hearing aid or communication tool.

Please tell the receptionist when you arrive for your next appointment, or call us on xxxxxxxxxx between xx and xx. Thank you.”

“**Text from Anytown Surgery:** We’re improving how we communicate with patients. Please tell us if you need information in a different format or communication support.”

It would be considered good practice to include a ‘standard line’ as part of all correspondence to encourage people to contact the service if they have any information or communication needs, for example: “If you would like this letter or information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call us on xxxxxxxxxx or email xxxxxxxxxx.”

Note that print-ready templates for letters and posters have been made available as part of resources to support implementation (as outlined in the Implementation Plan).

Consideration should also be given as to how to identify the information and communication needs of people who are unable to read a letter or information on a poster, for example people who are blind or deafblind. Staff knowledge of individuals known or considered likely to have needs should be utilised as a way of targeting those individuals who are most likely to benefit from the Standard, but may also experience barriers to alerting the service to those needs. For example, they could be contacted via telephone to discuss their needs. A range of approaches should be used.

It would be appropriate – and considered good practice – to use existing data held about individuals which indicates that they are more likely to have information or communication needs to proactively target such individuals to identify and record their needs in line with the Accessible Information Standard. For example, lists or records of patients who are d/Deaf or databases of patients with a learning disability. In a general practice setting, it would be appropriate to refer to the register of patients with learning disabilities (17/18 QOF ID LD003), where available (see [‘Summary of Changes to QOF 2017/18 – England’](#), [‘2016/17 General Medical Services \(GMS\) Contract Quality and Outcomes Framework \(QOF\) - Guidance for GMS contract 2016/17 April 2016’](#) and [‘Technical Requirements for 2017/18 GMS Contract Changes May 2017 – version 2’](#) for further information).

Individuals identified as likely to have information / communication needs (from existing records, including clinical diagnoses) MAY be flagged to prompt / prioritise a conversation or contact to ascertain and record their needs in line with this Standard. However, organisations are not required to undertake any retrospective search (or ‘trawl’) of registered patients / service users to identify their needs as part of the Standard – although this would be considered good practice. It may also assist organisations in understanding current levels of ‘unmet need’ for accessible information and communication support, as part of preparing to implement the Standard.

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Local authorities should make use of their record of deafblind people in their catchment area (as held under a requirement of the [Care and Support for Deafblind Children and Adults \(Department of Health, 2014\)](#)) and, as part of their duty to maintain up to date records, ensure that communication and information needs have been included in existing records. In addition, on first addition to the record, individuals should be asked about their communication and information needs. These needs should then be included as part of the record, on other appropriate databases, and included in relevant local information sharing protocols (with the service user's consent).

Local authorities should also consider liaising with their Sensory Team to identify, contact and update the records of people known to have experience of sensory loss, including registers of people who are severely sight impaired (blind) or sight impaired (partially sighted).

It is important to recognise that many people with information and / or communication needs may find it difficult to articulate or explain what those needs are. There is the obvious challenge of being able to communicate your needs effectively when you have a sensory loss, learning disability or other condition, impairment or disability which can make it harder for you to communicate. Some individuals, particularly those with more significant needs, will be unable to read or complete a written form or to converse with staff unaided, and will need support.

In addition, many people with sensory loss, especially people who have been affected by sensory loss later in life, do not consider themselves 'disabled' and may not have a good understanding of the types of alternative format / communication support available. Prompts can be very helpful in these instances and good practice would be for services / key staff to familiarise themselves with the more common types of format and support which may be needed by individuals with particular disabilities, impairments or sensory loss – including as outlined in appendix d.

An individual may need support from an interpreter or other communication support professional in order to accurately identify their needs and, therefore, for them to be accurately recorded. In such instances, it would be prudent to use the next occasion when the individual accesses the service with the support of such a communication professional to support a conversation to identify and record the individual's needs.

Where difficulties are anticipated or experienced, services are advised to identify available local expertise and make contact with relevant specialists who may be able to support or assist with identification and assessment of needs, and increasing understanding / putting plans in place to meet those needs effectively and efficiently in future. For example speech and language therapists and specialist learning disability nurses. The individual and / or where appropriate their carer or parent may be asked whether they have had a comprehension assessment or other assessment of their communication support needs, and whether the outcome is documented in a 'communication passport' or elsewhere.

Many people with a learning disability (and some people with other communication needs), have a 'communication passport' 'communication book' or 'hospital passport' or similar document which includes a detailed record of their communication needs

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and preferences – this can be a very useful source of information and advice where available (and staff would be advised to proactively ask individuals if they have such a document where communication difficulties are experienced).

If an individual needs information in an alternative format or communication support because of a learning disability the conversation may take longer as greater explanation and examples or prompts may be needed. For example, the individual may not provide any details of communication support needs when asked an initial question, but, if prompted, may explain that they need written information in easy read. If an individual is known to the service and known to have a learning disability, it would be appropriate to offer support and prompts to support the individual in accurately identifying their needs. An illustrative example follows:

Receptionist: *Hello John. We've started to ask people if they need any support from us. For example if they need a different type of letter or help to say what they think. We want to put this information on their records.*

Patient: *Ok.*

Receptionist: *Would you like any help when you see the nurse or doctor?*

Patient: *Sometimes I find it hard to say what I think. When I see the doctor I find it hard to say what I think.*

Receptionist: *Ok. And sometimes you have someone else come to your appointments to help you, don't you?*

Patient: *Yes. It is much better when I have Tony there. I can ask the questions I want and he makes sure I understand and can say what I think.*

Receptionist: *I think Tony is a type of support person called an advocate. An advocate helps people to say what they think. Is Tony your advocate?*

Patient: *Yes, I think so.*

Receptionist: *I am going to write on your notes that you have an advocate at your appointments, is that ok?*

Patient: *Yes.*

Receptionist: *And what about letters. Can you read the letters we send you ok?*

Patient: *I find letters hard to read, I can't read long words. I prefer it when there are pictures to help me understand the words.*

Receptionist: *Should we send you letters with pictures and using easy words, would that help?*

Patient: *Yes.*

Receptionist: *Ok. We call that easy read information. I am going to write on your notes that we need to send you letters and other information in easy read.*

Patient: *Ok, thank you.*

7.4 Questions and prompts to identify needs

Some individuals may offer information about the detail or type of their needs proactively following a positive response to a question about whether they have any communication needs (or not); others may need support or prompting, including follow-up questions, to enable accurate identification of needs.

This question MAY be asked alongside recording of contact details and / or demographic data.

The initial question or questions will need to be sufficiently generic and easy to understand that it can be asked of any / all patients or service users, and their carers or parents where appropriate.

The organisation, service, team, department or ward SHOULD agree one or more questions which they will use as standard, this will support consistency.

Feedback from patients and patient groups indicates that use of the term 'disabled' or 'disability' should be avoided wherever possible, in order to maximise response rates and reduce stigma. It should also encourage staff to ask the question of all patients – including those who they do not perceive to be 'disabled'. However, organisations may wish to be mindful that people without any disability, impairment or sensory loss, but who do not speak or read English – because they use a different language – are not included in the scope of the Standard.

It should be noted that this Standard does not impact upon the recording of patients' diversity monitoring / protected characteristic strand affiliation, the collection of which is covered by separate guidance. This is because recording that a person is 'disabled' as part of diversity monitoring does not indicate their information or communication support needs – if any. That said, questions to identify information or communication support needs MAY be asked alongside recording of protected characteristic strand affiliation, for example, following a positive answer to the question, "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? This includes any issues or problems related to old age" (or similar) and indication of a disability relating to vision, hearing, learning or concentrating or remembering, mental health, or social or behavioural issues.

Suggested questions which MAY be used to identify if an individual has any information and / or communication support needs, and the nature of these needs include:

- Do you have any communication needs?
- Do you need a format other than standard print?
- Do you have any special communication requirements?
- How do you prefer to be contacted?
- What is your preferred method of communication?
- How would you like us to communicate with you?

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- 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?

Specific additional or follow-up questions which it MAY be relevant to use as prompt or follow-up questions when communicating with particular individuals and / or in particular care settings are as follows:

- Do you have difficulty hearing, or need hearing aids, or need to lip-read what people say?
- Do you have difficulty with memory or ability to concentrate, learn or understand?
- Do you have difficulty speaking or using language to communicate or make your needs known?

Staff may find the document [‘Have you got a learning disability? Asking the question and recording the answer for NHS healthcare providers’](#) by Improving Health and Lives: The Learning Disabilities Observatory a useful source of onwards reading with regard to identifying the communication needs of people with a learning disability.

With regards to recording of the specific types of information format and communication support required, it is anticipated that multiple categories will be selected for many individuals.

Whatever the format used, communication and information needs MUST be recorded using the data items associated with the subsets defined by the Accessible Information Standard or their human readable definitions / categories. Detail is included in the Specification.

The length of time taken to identify and record an individual’s information or communication support needs will vary depending on:

- the number and complexity of those needs;
- the method used to identify and record those needs;
- the support needed by and / or provided to the individual to explain their needs.

Two illustrative examples follow:

Scenario 1

Receptionist: *Do you have any information or communication support needs?*

Patient: *Yes, I need written information via email because I am blind. If you email information to me I can access it via my screen-reader software.*

Receptionist: *Ok, I’ll put that in your notes. Do you need any other support?*

Patient: *No.*

Scenario 2 (conversation supported by a British Sign Language interpreter)

Receptionist: *Do you have any information or communication support needs?*

Patient: *Yes, I am Deaf. I need a British Sign Language interpreter at my appointments.*

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Receptionist: *Ok, I will record that in your notes. Do you need any other support from us? Do you need us to send you information in a particular format or contact you in a particular way?*

Patient: *I cannot use a telephone. I need you to contact me via email or text message instead.*

Receptionist: *Ok, I will record that in your notes too. Do you need any other support, or is there anything else you think we should know?*

Patient: *I will need a longer appointment because the conversation will be three way because of needing an interpreter.*

Receptionist: *Ok.*

8 Guidance for stage 2 – recording of needs

8.1 Overview of requirements – recording of needs

Where individuals have information and / or communication needs relating to or caused by a disability, impairment or sensory loss:

- Such information **MUST** be recorded as part of the individual's first or next interaction with the service.
- In electronic systems which use SNOMED CT, Read v2 or CTV3 codes, such information **MUST** be recorded using the coded data items associated with the subsets defined by this Standard.
- In electronic systems which use other coding systems or terminologies, or where paper records are used, such information **MUST** be recorded in line with the human readable definitions / categories associated with the data items.

Further information about terminology and the four subsets associated with the Standard are included in the Specification.

Additional codes / data items may be requested and, if appropriate released, in future, as outlined in the Maintenance Plan. It is the responsibility of the IT systems supplier or lead organisation to ensure that the coding used in patient record and administration systems is current and up-to-date.

Systems and documentation **MUST** be formatted so as to make any record of information or communication needs 'highly visible' (see section 9).

Organisations **MUST** ensure that information recorded about individuals' information and communication support needs is accurate. Systems for edit checking and quality assurance of data **SHOULD** be put in place, including establishment of alerts or mechanisms to prevent or discourage the recording of mutually incompatible data in related fields (see section 8.2).

In addition, the Specification makes clear that, "Where online systems enable patients or service users to access their own records, and subject to [Data Protection Act 1998](#) safeguards, such systems:

- **MUST** enable an individual to review the data recorded about their communication and information needs and request changes if necessary; and, where necessary functionality exists,
- **SHOULD** enable an individual to record their own communication and information needs using this system where appropriate." Organisations may wish to review information and guidance associated with the [Patient Online](#) programme in this regard.

8.2 Guidance for recording of needs

Some of the types or categories of information and communication support included in the Standard's subsets are mutually incompatible, i.e. it would not be possible for one individual to need some types of support in combination with one or more others. For example, someone who needs information in braille will not require support to

lipread (because the former implies significant visual loss and the latter relies on sight). Conversely, some combinations of recorded needs are highly likely to occur, for example, 'does use hearing aid' and / or 'does lipread' plus 'requires contact by short message service text message' or 'requires contact by email'. Staff should consider both of these aspects when recording individuals' needs and when prompting patients, service users, parents and carers to identify their needs.

Data items may be deliberately used in combination and / or with appropriate additional free text to support clarity, where appropriate and where supported by relevant local policies. For example the combination of 'uses British Sign Language' and 'requires information on digital versatile disc' to indicate that the individual requires information presenting as a British Sign Language (BSL) video saved (and sent to them) on a DVD.

Further advice is available as part of resources to support implementation (as outlined in the [Implementation Plan](#)).

Information recorded about patients', service users', carers' and parents' information and communication support needs must be based on information from the individual themselves or, where they are unable to provide this information, on information from their main informal carer or parent. The individual patient, service user, carer or parent should be aware of the information recorded about their information and communication support needs, including to verify accuracy.

8.3 Guidance on recording of data in non-coded systems

The clear, unambiguous, consistent and objective recording of patients', service users', carers' and parents' information / communication needs is a fundamental aspect of the Standard. The importance of accurate and routine recording of needs cannot be overestimated as, if needs are not properly recorded, they cannot be effectively met. Individuals' needs must be recorded as a matter of course or 'business as usual'.

Patients', service users', carers' and parents' needs must be recorded in such a way that the data as recorded enables actions to be taken to meet those needs, by any member of staff – including someone who has had no previous contact with the individual.

Note that it is individuals' information / communication needs which must be recorded, and how to meet them, and not their disability. Organisations may wish to also record details of the person's disability, but they are not required to do so as part of this Standard. In considering recording details of an individual's disability, organisations should be mindful that this information is classified as sensitive personal data (under the [Data Protection Act 1998](#)), and that information should only be recorded where 'relevant and necessary'.

Where organisations and systems use READ v2, CTV3 or SNOMED CT codes, individuals' information / communication needs must be recorded using the coded data items associated with the subsets defined by the Standard.

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Where organisations use systems which do not use READ v2, CTV3 or SNOMED CT codes or any other defined coding system or terminology, including where paper records are used, individuals’ needs must be recorded “...in line with the human readable definitions / categories associated with the data items.”

In the interests of consistency and clarity, and to support (current or future) data sharing, integration and / or interoperability, the preference is for organisations to record patients’ needs using the precise ‘Fully Specified Name’ associated with the relevant data item (also called a ‘human readable definition’ or ‘category’) or one of the synonyms listed in the [Accessible Information Standard terminology document](#) (note that a revised version of this document is expected to be issued in October 2017 and will be available from the [NHS England website](#)). For example:

SNOMED CT	FSN (Fully Specified Name) (also known as ‘human readable definitions’ or ‘categories’)	READV2	CTV3	Synonyms
285055002	Does use hearing aid (finding)	2DH1	Xa2yX	Does use hearing aids. Uses hearing aid. Uses hearing aids.

Where it is not possible, or not practical, to use such terms or phrases, organisations must record patients’ / service users’ needs in line with the requirements of the Standard, Information Governance duties, accepted good record keeping practice, and in such a way that a third party can understand and act to meet them, including as evidenced by their actions.

It is recognised that the differing format and structure of organisational patient / service user record management and administrative systems will affect what constitutes ‘effective’ recording of individuals’ needs in different contexts / by different organisations. In all cases, organisations must ensure that the amount and type of data recorded about individuals’ needs, how it is recorded (including words used) and where it is recorded (including in specific documentation, sections or systems) enable (and indeed result in) meeting of the person’s needs.

Where ‘free text’ boxes or other ‘unstructured’ sections are used to record individuals’ needs, organisations must ensure that sufficient detail is recorded to ensure all of the person’s needs – and how to meet them – are captured. This includes being mindful of the Standard’s inclusion of four different ‘categories’ of needs or adjustments which may be needed: contact method, information format, communication support and communication professional.

When recording patients’, service users’, carers’ and parents’ needs, organisations must ensure that such recording is both accurate and that the data as recorded will provide sufficient, and sufficiently clear, direction such that those needs can be met. For example, ‘Mr Smith is deaf’ does not enable appropriate adjustments to be made or arrangements to be put in place so that the service can communicate effectively with Mr Smith. Whereas, ‘Mr Smith uses a hearing aid and lip reads’ or ‘Mr Smith

needs a British Sign Language Interpreter' or 'Mr Smith needs information sent in Arial size 16' would meet the requirements of the Standard and should ensure successful outcomes for Mr Smith.

In recording additional information about patients, service users, carers and parents, organisations should be mindful of their duties under the [Data Protection Act 1998](#), including ensuring that information is 'relevant' and 'not excessive' (to the purpose of recording it).

Ultimately, the effectiveness of any recording practice will be judged by whether the record leads to the individual's needs being effectively met on a regular and routine basis.

9 Guidance for stage 3 – flagging of needs

9.1 Overview of requirements – flagging of needs

A record of communication and / or information needs **MUST** be flagged or otherwise highlighted / made 'highly visible' 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).

'Highly visible' is defined in the Specification as follows:

"A recording of an individual's information or communication support needs must be 'highly visible' to relevant staff and professionals. In the context of this Standard 'highly visible' means:

- Obvious and overtly apparent; and
- Visible on the cover, title and / or 'front page' of a document, file or electronic record; and / or
- Visible on every page of an electronic record (for example as an alert, flag or banner); and / or
- Highlighted in some way on a paper record so as to draw attention to the information as being of particular importance, for example in a larger or bold font, and / or a different colour."

9.2 Guidance for flagging of needs

Once recorded, the Standard requires that records that an individual has information and / or communication support needs are 'highly visible' and prompt for action to be taken to meet those needs when the individual next interacts with the service / when the record is accessed.

Where paper records are used, a clear process **MUST** be established such that all staff are aware of the correct actions to be taken in order to highlight such a record to their colleagues, and of the meaning of relevant notifications or alerts. This may include drawing attention to the fact that an individual has an information or communication support need by using a larger print, highlighter, sticker or other mechanism. Such information **SHOULD** appear on the front cover and / or front page of a patient or service user's notes, file or record (as appropriate). If a patient or service user's notes, file or record has multiple volumes, information or communication support needs **SHOULD** be visible on the front cover and / or front page of each volume.

Where electronic record or administration systems are used, a record of information or communication support needs **MUST** be flagged (or linked to an alert) to ensure that, once recorded, staff are prompted to respond to individuals' information and / or communication support needs and / or automatic processes are triggered in order that needs can be met, for example auto-generation of correspondence in an alternative format.

Although not a requirement of the Standard, automatic triggering of actions to respond to needs is preferred over manual processes which rely on staff awareness.

Further information about the 'maturity index' of Standard implementation is detailed in appendix b.

9.3 Guidance on reviewing and updating needs

As made clear in the Specification, once data is recorded about individuals' information or communication support needs, systems MUST prompt for, and staff MUST ensure that, such data is regularly reviewed and if necessary updated. Services should set up appropriate prompts and include review of this information alongside reviewing and updating data held in other fields, for example demographics, and as part of longer appointments, such as for a health check.

The purpose of review is essentially two-fold, first to identify if the individual's needs have changed (for example due to a change in their level of sensory loss) and second to identify if the most appropriate methods of meeting those needs have changed (for example due to advances in technology / a change in an individual's access to particular tools or technology). As an example, a person with some visual loss may initially request information in large print, but in future request information via email or in an audio format as their condition deteriorates / they gain access to relevant technologies.

10 Guidance for stage 4 – sharing of needs

10.1 Overview of requirements – sharing of needs

Having first obtained the relevant consent or other authority to share, organisations MUST ensure that information about individuals' information and / or communication support needs is included as part of existing data-sharing processes, and as a routine part of referral, discharge and handover. Note that this data-sharing is to support direct patient / service user care, and is not for reporting or analysis (so called 'secondary use').

10.2 Guidance for sharing of needs

Where consent or other authority to share has been secured, all applicable organisations should include information about individuals' information and communication support needs as a routine part of referral and handover communication, and as part of other data-sharing processes with other professionals and services involved (or soon to be involved) in an individual's care. Information as shared should be formatted in line with relevant Read v2, CTV3 or SNOMED CT codes or using the associated 'human readable' definitions / categories.

All information-sharing as part of this Standard should utilise existing data-sharing processes, including following existing information governance protocols and processes for the obtaining and recording of patient / service user consent. Remember that consent cannot be assumed.

The Standard should not significantly impact upon – or fundamentally alter – existing processes for the obtaining and recording of consent from patients, service users, carers and parents to record, use, hold, store or share their data. Organisations should follow (and be mindful of) their existing legal duties including under the [Data Protection Act 1998](#). Any data obtained / recorded by organisations about individuals' information / communication needs (as part of implementing and following the Standard) should be added / included into existing processes, including being integrated into existing approaches for obtaining / recording consent (including 'consent to share' (where applicable)).

Where consent or other authority to share has been obtained, information about individuals' information and / or communication needs should be included as part of referrals both within and between organisations, including (but not limited to) referrals from primary into secondary care, transfers and handovers between wards or units, and discharge from an inpatient setting into the community.

Data recorded as part of this Standard should be included, with consent, as part of shared and integrated records, and using existing systems for the sharing of patient information with other services such as the [Summary Care Record](#) and [NHS e-Referral Service](#).

All of the data items associated with the four subsets of the Standard have been included in the 'inclusion dataset' for [Summary Care Records with additional information](#). This means that, if the patient's information and / or communication

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needs are recorded in their GP patient record using the identified codes, and the patient has consented for 'additional information' in their Summary Care Record (SCR), then details of their information and / or communication needs will automatically be available to anyone viewing their SCR.

When recording individuals' information and / or communication needs as part of the Standard, GPs and other relevant practice staff should also discuss the benefits of the individual consenting for 'additional information' to be included in their SCR. Patients must give their explicit consent for this information to be added. The consent is enduring, so the SCR is kept up to date in real time as the GP record is updated. The SCR is updated with additional information once the SCR consent setting in the GP system has been changed to 'express consent for medication, allergies, adverse reactions AND additional information'.

For further information about SCR visit the [NHS Digital website](#) where specific advice about SCR with [additional information](#) can be found. Leaflets and other resources are available to help ensure that patients are fully informed about additional information. There is no requirement to gain written consent, however, resources include a combined information leaflet and consent form for GP practices that wish to use it.

Information on how the Standard is implemented in the NHS e-Referral Service can be found in the [NHS e-Referral help files](#) and can be opened by clicking 'Accessible Information Standard' in the index.

For more information about implementation of the Standard into and using electronic systems, see the Implementation Plan.

11 Guidance for stage 5 – meeting needs

11.1 Overview of requirements – meeting of needs

Services MUST provide one or more communication or contact methods which are accessible to and useable by the patient, service user, carer or parent. The method(s) MUST enable the individual to contact the service, and staff MUST use this method to contact the individual. Examples of accessible communication / contact methods include email, text message, telephone and text relay.

Information, including correspondence and advice, MUST be provided in one or more accessible formats appropriate for the individual – in line with records made in this regard. Where systems are used to auto-generate correspondence, systems MUST identify a recorded need for an alternative format and either automatically generate correspondence in an appropriate format (preferred) or prompt staff to make alternative arrangements. Systems MUST prevent correspondence from being sent to a patient in a standard format where this is not suitable / not in line with their recorded needs.

Where needed, appropriate, professional communication support MUST be arranged or provided to enable individuals to effectively access / receive health or adult social care, to facilitate effective / accurate dialogue, and to enable participation in decisions about their health, care or treatment.

Appropriate action MUST be taken to enable patients, service users, carers and parents to communicate, including through staff modifying their behaviour and / or supporting the use of aids or tools. This includes provision of communication support for individuals accessing both outpatient and inpatient services, including long-term care, and those in receipt of publicly-funded social and / or NHS care whilst resident in a nursing or care home.

11.2 Response times

As stated in the Specification, “Organisations MUST take steps to ensure that communication support, professional communication support and information in alternative formats can be provided promptly and without unreasonable delay. This includes making use of remote, virtual, digital and telecommunications solutions.”

11.3 Costs of accessible information / communication support

In order to ensure equity and promote equitable access to services by people with a disability, impairment or sensory loss, organisations should be aware that it is their responsibility, and not that of the disabled person, to cover the costs of meeting an individual’s information and / or communication support needs. [Guidance from the Equality and Human Rights Commission \(EHRC\)](#) states that, “If an adjustment is reasonable, the person or organisation providing it must pay for it. As a disabled person, even if you have asked for the adjustment, you must not be asked to pay for it.”

11.4 Stocking alternative formats

The Standard requires that patients, service users, carers and parents with a disability, impairment or sensory loss receive information which they can read (or otherwise access) and understand. It does not stipulate that all organisations must offer every type of alternative or accessible format, rather that organisations must provide information in a format which is accessible to the patient, service user, carer or parent as an individual. It is likely that different organisations will provide information to the same individual in different formats, depending on the person's needs, the nature of their service and their facilities. For example, accessible information for a person who is blind may include that sent via email or text message, as well as that produced in braille or audio format.

The Standard does not require organisations to have 'stocks' of information in various alternative formats in anticipation of requests. However, organisations should have an identified process for obtaining information in alternative formats (including those which are not able to be produced in-house) if needed by a patient, service user, carer or parent. Such processes should ensure minimum delay in receipt of accessible information by the individual. Good practice would be for organisations to have a limited number of the most commonly used patient- / service user- facing documents / information readily available (i.e. 'in stock') in the most commonly required alternative formats (as determined locally / from the organisation's receipt of requests), but this is not a requirement.

In order to minimise (although never remove) the need for information to be produced in alternative formats, organisations should consider improving the accessibility of their 'general' information and documents, including templates, so that they are accessible to as many people as possible. 'Top tips' in this regard are included in section 6.4.

It is expected that most providers will be able to provide information in larger print 'in-house', and many will also be able to communicate with patients, service users, carers and parents via email or text message. All providers should also be able to make use of individuals' own devices which can support communication – for example dictating information into a smartphone.

With regards to the most commonly needed externally-produced alternative formats, including audio (electronic audio files and CDs), braille, easy read and British Sign Language (video file / DVD), organisations should consider both value for money and 'added value'. For example, many local charities – and local branches of national charities – who work with people with particular disabilities and sensory loss are able to produce information in alternative formats (for a fee) and, having established a relationship, may also be able to offer wider support to the organisation in how to improve accessibility for their client group (and therefore encourage them to use relevant services).

Consideration should also be given to understanding the alternative format production and procurement arrangements which other local NHS and adult social care providers and commissioners have in place, as they may have a framework arrangement, be able to recommend a trusted supplier and / or have other advice.

Organisations may also wish to explore a collaborative approach to the production of information in alternative formats, including considering local sharing of alternative formats of documents which are most commonly used by multiple providers.

The [UK Association for Accessible Formats \(UKAAF\)](#), an industry association aiming to improve quality and practice in accessible format provision, also offers a list of services provided by their members.

Organisations are reminded that, for many patients, email is a highly effective, quick and economical communication format (see section 12.7).

11.5 Needs versus preferences

The Standard does not necessarily require the provision of information in a patient, service user, carer or parent's '*preferred*' format; rather it requires the provision of information in *a* format that the individual can read or otherwise access and understand. It is the patient, service user, carer or parent's information and communication '*needs*' which must be met, which may differ from their preferences. The 'judgement' or 'assessment' about whether this requirement has been fulfilled lies with the individual patient, service user, carer or parent themselves, i.e. can they read, access and understand the information? Can they 'use' the information as it was intended? If they can, then the organisation has met this aspect of its obligations under the Standard.

In the context of person-centred care, organisations may wish to be mindful of patients', service users', carers' and parents' preferences, and best practice would of course be to accommodate them, however it is not a requirement of the Standard. Organisations are advised to discuss accessible formats for information with individuals, including suggesting alternatives which are most economical for the service, to determine whether they are accessible (i.e. will meet their needs).

11.6 Meeting of needs under the four categories / subsets

11.6.1 Overview

As outlined in the Specification, the Accessible Information Standard defined four subsets to which SNOMED CT, Read v2 and CTV3 codes have been associated and which are available for use (noting that their use is mandated in line with the conformance criteria and timescales set by the Standard):

- Accessible Information - requires specific contact method
- Accessible Information - requires specific information format
- Accessible Information - requires communication professional
- Accessible information - communication support

Advice about different types of information and communication needs, including formats and types of support which may be needed by different groups, is included at appendix d.

11.6.2 Specific contact method

This category relates to the need for services to provide accessible methods or mechanisms which individuals with information and / or communication needs are able to use to contact the service, and which the service uses to contact them. This may require adjustment to current systems or processes. For example, many service users, including those who are d/Deaf or have some hearing loss, will not be able to use a telephone to, for example, book an appointment or receive test results. Alternative communication / contact methods which may be accessible to individuals with information and / or communication needs include email, text message, telephone and text relay.

Organisations **MUST** ensure that an individual's need to use or be contacted by an alternative communication method is flagged and / or highly visible to staff to enable appropriate action to be taken.

11.6.3 Specific information format

11.6.3.1 Overview

This category relates to a need to send correspondence or provide information to an individual in an alternative (non-standard print or non-print) format, and will be of particular relevance where auto-generation systems are used and / or 'standard' or 'generic' letter formats.

Organisations **MUST** ensure that an individual's recorded need for information in an alternative format is flagged and either triggers the automatic generation of correspondence / communication in an alternative format (preferred) or prompts staff to make alternative arrangements. A standard print letter **MUST NOT** be sent to an individual who is unable to read or understand it.

Organisations **MUST** also ensure that they have effective processes in place to ensure and assure the accuracy and quality of translated or transcribed information.

As well as correspondence in alternative formats, the Standard includes the provision of patient information – such as that often contained with leaflets or booklets – in alternative, accessible formats where this is in support of direct patient / service user care (including self-care). Organisations should consider their most frequently used patient information leaflets / booklets and take steps to ensure that these are readily available in commonly used accessible formats.

It should be noted that, although expected standards of general health and adult social care communication / information (i.e. that provided to individuals without additional information or communication support needs) are excluded from the scope of the Standard, actions taken to maximise the accessibility of 'standard' documents, including those published electronically, will reduce the number of alternative formats which are required by individuals with particular needs (see section 6.4.3 and appendix d).

Organisations should take steps to ensure and assure the quality and accuracy of 'standard' documents / information prior to any translation or transcription into

alternative formats. One framework for this is [The Information Standard](#), a quality assurance kitemark scheme for organisations producing health and care information for the public. Note that, despite the similar terminology, 'The Information Standard' is a voluntary scheme and is not an 'information standard' in the sense of the [Health and Social Care Act 2012](#) (and is therefore entirely separate to DCB1605 Accessible Information).

Organisations are advised (although not required) to consider the accessibility and usability of their website, where this offers information or advice for patients, service users, carers and parents. Individuals MAY be signposted to online information by way of meeting their needs, however, the service provider MUST ensure that this is accessible to the individual, including where they have a disability, impairment or sensory loss.

Appendix e provides further advice about website accessibility. Organisations should note that increasing web and digital accessibility will reduce (although never remove) the need to produce information in alternative formats.

11.6.3.2 Note about 'large print'

Data items associated with one or more of the four subsets of the Standard include those to record individuals' requirements for information in 'large print'. Such codes specify font size and type of font needed, and the recording of a need for 'large print' has been deliberately avoided due to ambiguity.

Many individuals will ask for / require printed information in 'large print' – i.e. a larger point size than 'standard' (i.e. above 10 or 12 point). It should be noted that individuals requiring a particular font size, such as point 16, can read a larger font size (such as point 20) – and provision of a larger font size should not cause difficulty, and may often make reading easier for the individual.

'Sans serif' fonts are easier to read for most people with visual loss and for most people with a learning disability. A 'sans serif' font is one that does not have the small projecting features called 'serifs' at the end of strokes. A well-known example is Arial.

Printing in a point size above 28 is generally considered to be impractical and unwieldy, and in most instances individuals' needs would be better met through the provision of information in an alternative format, for example audio.

11.6.4 Communication professional

11.6.4.1 Qualification, registration and other assurances

Where a need for support from a communication professional is identified, services MUST ensure that such support is arranged / provided and that interpreters and other communication professionals are suitably skilled, experienced and qualified. This SHOULD include verification of accreditation, qualification and registration with a relevant professional body.

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Organisations **MUST** ensure that communication professionals (including British Sign Language interpreters and deafblind manual interpreters) used in health and adult social care settings have:

- appropriate qualifications;
- Disclosure and Barring Service (DBS) clearance;
- signed up to a relevant professional code of conduct.

Assurance of the above **SHOULD** be obtained by applicable organisations including through reviewing relevant professional identification / registration.

Organisations **SHOULD** ensure that communication professionals working with d/Deaf and deafblind people (including British Sign Language interpreters and deafblind manual interpreters) are registered with the [National Registers of Communication Professionals working with Deaf and Deafblind People \(NRCPD\)](#). Registration confirms they hold suitable qualification(s), are subject to a Code of Conduct and complaints process, have appropriate insurance, hold an enhanced disclosure from the Disclosure and Barring Service, and engage in continuing professional development. The NRCPD includes the following professional categories:

- Interpreter for Deafblind People
- Lipspeaker
- Notetaker
- Sign Language Interpreter
- Sign Language Translator
- Speech to Text Reporter

If it is impossible to engage an NRCPD Registrant, organisations **MUST** ensure that the communication and language professional holds relevant interpreting qualifications and, in the case of British Sign Language (BSL), has achieved BSL level 6 or an honours degree in their second language, in line with NRCPD registration requirements. They must also have appropriate insurance and an enhanced disclosure from the Disclosure and Barring Service.

A professional who is registered with the NRCPD can be found using the 'find a communication professional' function [on the NRCPD website](#) - (www.nrcpd.org.uk/) - which enables a search to be completed for all communication professionals of a particular type (for example sign language interpreters) in a particular area or town.

The site also allows for registrants to be searched by name, facilitating assurance and verification of individuals' status. NRCPD registrants can be easily identified 'in person' through their identification card, which should be carried at all times – see example below.



Where professional communication support for a d/Deaf or deafblind person is arranged through an agency, organisations should seek confirmation and assurance from the agency (including as part of any contract, service specification or agreement) that only NRCPD registrants will be provided. Similarly, where communication support – most usually British Sign Language interpretation – is provided ‘remotely’ or ‘virtually’ over the internet, organisations should ensure that communication professionals providing such services also meet the requirements as summarised above.

Separate and more detailed guidance about the use of professionals who are a Registered Interpreter for Deafblind People is provided in section 12.3.

11.6.4.2 Use of health and social care staff as communicators / interpreters

Where health and social care staff are themselves appropriately qualified, experienced and registered as communication professionals (including with reference to the NRCPD registration requirements listed above) they **MAY** take on the role of communicator or interpreter. This **MUST** only occur with the patient, service user, carer or parent’s explicit consent – which **MUST** be clearly recorded – and the provision of an independent communication professional **SHOULD** always be offered.

Where staff members within a team, organisation or service are able to communicate using British Sign Language (BSL) or deafblind manual (or using Makaton or another key word signing system), and with the agreement of the patient, service user, carer or parent, it **MAY** be appropriate for them to communicate with the individual directly (for example in BSL). Where the individual consents to this approach, steps **SHOULD** be taken in order that the individual can be seen by the individual with the relevant skills. For example, if a particular Practice Nurse is able to communicate in BSL, if the patient, service user, carer or parent agrees, it would usually be appropriate to arrange for the individual to be seen by this Practice Nurse whenever they require access to this service. The level of skill and knowledge held by the health or social care professional in BSL or deafblind manual **MUST** be assessed and assured to be sufficient so as to enable effective, accurate dialogue and care of the individual.

Members of health or social care staff **MUST** only be used in an interpretative role (i.e. to enable dialogue between a service user and other professionals) where they

are appropriately qualified and registered (including complying with guidance above). In addition, where it is proposed that a member of health or social care staff acts as an interpreter or communicator, consideration **MUST** always be given – including with the involvement of the patient, service user, carer or parent – as to the appropriateness of the health or social care professional acting in this role.

Further advice about specialist Deaf services – where communication between staff and individuals directly in BSL is likely – is included in section 12.4.

11.6.4.3 Use of family members, friends or carers as interpreters

As the Accessible Information Standard aims to support individuals' rights to autonomy and, specifically, their ability to access health and social care services independently, in general, British Sign Language (BSL) interpretation and other communication support **SHOULD** be provided by an appropriately qualified and registered professional (see section 11.6.4.1) and not by an individual's family members, friends or carers.

In all instances, the individual patient, service user, carer or parent **MUST** be offered professional communication support where they have an identified need for communication using British Sign Language, deafblind manual or other alternative communication system.

Where an individual has sensory loss (hearing loss and / or visual loss) and no other impairment, a professional interpreter / communication professional **MUST** be used (see section 11.6.4.1) unless there is documented, supported evidence of the individual's explicit preference for the use of a family member / friend / carer. The parameters in which the individual's family member / friend / carer is to be used **MUST** be agreed with the individual and recorded as part of their record or notes. This preference **MUST** also be regularly reviewed and **MUST** be reviewed whenever a new course of treatment / episode of care is started or proposed or significant decision or choice is to be made.

Where an individual has sensory loss (hearing loss and / or visual loss) **AND** one or more other impairments which impact upon their ability to communicate, for example a learning disability, and especially where individuals have multiple or complex needs, it **MAY** be appropriate for one or more family members, friends or carers to support communication and / or act as an interpreter or communicator instead of or alongside one or more communication professionals. Discussion about how an individual communicates and the support needed to enable effective communication with a health or social care professional **MUST** take place with the individual and / or with their parent or carer as appropriate. Whatever decision is taken **MUST** be clearly documented and, where the individual may lack capacity, **MUST** be demonstrably in their 'best interests'. Use of family members, friends or carers to support communication / act as interpreters is most likely to be appropriate where an individual has multiple / complex needs (for example a moderate to severe learning disability and sensory loss) and / or a personal method of communication (i.e. not 'standard' BSL or deafblind manual).

Access to appropriate, and suitably skilled / qualified / knowledgeable support, from a communication professional provides assurances that important information is

interpreted accurately, which is essential for safe, effective care. However, there is a need for flexibility to respond to individuals' needs and preferences, as outlined above. Such flexibility is most likely to be appropriate where 'bespoke' / highly personalised communication approaches are used by individuals and their families / friends / carers, especially where they have complex needs.

In all instances, consideration **MUST** be given to the most effective way of enabling effective, accurate dialogue between a health or care professional and the service user to take place. Communication support **MUST** enable individuals (as much as possible) to provide or withhold consent, and to make informed choices about care or treatment. Services **MUST** also recognise that communication support and interpretation supports both the health or care professional as well as the service user – and clinicians reliant upon family members, friends or carers do so 'at risk' with regards to associated lack of assurance about not only their skill and ability to communicate / interpret effectively, but also how their lack of objectivity may affect accuracy and completeness of the messages conveyed.

Services should be mindful of their responsibilities to ensure that individuals' rights are met, including rights to privacy and confidentiality, to accept or refuse treatment, to information to support choice, and to make choices about care and treatment, including as outlined in the [NHS Constitution](#). However, this also states that, "NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers...Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment."

11.6.4.4 Requests for / use of particular professionals

Wherever possible, requests from individuals for a male or female communication professional, for a particular professional and / or for the same professional to provide support to an individual during a course of treatment, **SHOULD** be met. This will support continuity of care and is likely to improve the experience of the patient, service user, carer or parent.

Good practice would suggest that particular efforts should be made to accommodate requests for individual, consistent and / or male / female communication professionals where an individual is undergoing particularly invasive, intensive or sensitive procedures / courses of treatment, including care relating to pregnancy, maternity or sexual health, radio- and chemo-therapy, end of life care and when accessing mental health services. Such preferences should be clearly and objectively recorded in a free text area of an individual's notes or record, linked to the basic (and mandatory) recording of needs, for example: Special Requirements: 204331000000107 British Sign Language interpreter needed (finding). "Pref. interpreter Jane Smith (NRCPD ID 1234567) or if unav. other female interpreter."

Organisations should also consider the use of interpreters with additional skills, knowledge or experience in relevant terminologies and / or care settings. This is recommended but not required and may be linked to an individual's preferences. For example, a Mental Health Trust may wish to stipulate in relevant contracts / include in their policy that only interpreters with experience in mental health settings should or must be used, either generally or in particular circumstances. All services may wish

to consider the stipulation of knowledge / proficiency in medical / care / social care terminology as part of contracts / policies.

11.6.4.5 Remote access to communication support

In addition to the ‘traditional’ approach of arranging for a particular communication professional to attend an appointment to support dialogue between an individual and a service provider, it is now possible for services to access such support remotely (or ‘virtually’) over the internet.

Working in a similar way to a video call, and using telecommunications application software to support a video conversation over the internet, video relay services / video remote interpreting services enable a three way conversation to take place between a d/Deaf BSL user and an English speaker via a BSL interpreter.

The technology can be accessed via a smartphone, tablet or computer, enabling quick and easy access to communication support for d/Deaf people. The technology has been available to users of the [NHS24](#) service (in Scotland) and the [NHS111](#) service (in England) for some time

Video interpreting services are particularly useful in urgent or emergency care settings, when it may not be possible to arrange for face-to-face support from a communication professional in time. They should not be seen as a total replacement for face-to-face interpretation / communication support, and may not be appropriate in some circumstances, especially for longer appointments. Best practice would be that, where possible, and for routine care, individuals should be given the option of remote or face-to-face interpretation.

Note that in using remote interpretation services, organisations MUST ensure that interpreters used meet the qualification and registration requirements as set out in section 11.6.4.1.

11.6.4.6 Key word signing including Makaton

‘Key word signing systems’ use signs (given as gestures or described in pictorial format) to enable and support communication. They are most commonly used to support people with a learning disability. Two of the most commonly used, and well known, key word signing systems are Makaton and Signalong:

“[Makaton](#) uses signs, symbols and speech to help people communicate. Signs are used, with speech, in spoken word order. This helps provide extra clues about what someone is saying. Using signs can help people who have no speech or whose speech is unclear. Using symbols can help people who have limited speech and those who cannot, or prefer not to sign.”

“[Signalong](#) is a key word sign-supported communication system based on British sign language and is used in spoken word order. It uses speech, sign, body language, facial expression and voice tone to reference the link between sign and word.”

Communication using a key word signing system, such as Makaton, is included within the scope of the Accessible Information Standard. This includes ‘translation’ of

information using Makaton or another key word signing system (as part of the 'specific information format' category), use of Makaton or another key word signing system as a type of 'communication support', and requiring a Makaton or other key word signer as a 'communication professional'.

11.6.5 Communication support

This category relates to the provision of support to enable effective communication / conversation, for example by the provision or use of aids or equipment, or by health or social care staff making adjustments to their behaviour. It is recognised that staff may need training or other awareness-raising in order to effectively provide some of the types of support / adjustments indicated. Further advice is included as part of section 6.4.2 and in appendix d, and as part of resources to support implementation (as outlined in the Implementation Plan).

Perhaps the most commonly used additional aids to communication are lipreading and hearing aids – often used by individuals in combination – and easily supported by provision of a (working) hearing loop and ensuring that the lipreader has a clear line of sight to the speaker's lips and face.

Requests from individuals with communication needs / requiring support to communicate to be seen by one or more particular members of staff should be accommodated wherever possible. Familiarity with the nuances of a staff member, clinician or professional's dialect, accent and manner of speaking can assist an individual with a disability, impairment or sensory loss to communicate effectively.

11.6.6 Longer appointments

The scope of the Standard includes accommodation of an individual's need or requirement for a longer appointment to enable effective communication / the accessible provision of information. Applicable organisations should ensure that systems and processes for scheduling and managing appointments enable this flexibility. In particular, any appointment requiring support from a communication professional will almost invariably take longer – because of the 'three way' nature of the conversation – and allowance for this should be made. Commissioners should ensure that they support this requirement including through tariffs, contracts and performance-management frameworks with provider organisations.

12 Guidance on specific aspects of the scope

12.1 Carers' and parents' needs

Note that the scope of the Standard includes patients and service users *and carers or parents* where applicable / appropriate.

Relevant definitions are included in the Specification, as follows:

- Carer: a patient or service user's carer (defined by [SCC11580: Palliative Care Co-ordination: Core Content](#)) as follows, "A carer is a person who is either providing or intending to provide a substantial amount of unpaid care on a regular basis for someone who is disabled, ill or frail. A carer is usually a family member, friend or neighbour and does not include care workers. (Carers (Recognition and Services) Act 1995.)" SCC11580 also includes a note that, "the main carer will be identified by the individual or the person's GP or key worker if the person lacks capacity to identify one themselves." The Accessible Information Standard includes within its scope the needs of a patient or service user's main carer, as well as other important or regular informal (unpaid) carers.
- Parent: the legally recognised parent or guardian of an individual under 18 years of age or an individual with parental responsibility or delegated authority for a child.

Where what is being considered is the obtaining of consent, considerable care should be exercised when considering who, apart from the patient / service user, can consent on their behalf, and particular care should be taken when considering what may be very sensitive personal and health-related information:

- Where the child is young, anyone with parent responsibility or delegated authority for the child may consent on their behalf.
- Where the child is old enough to understand the risks and benefits of what is being proposed (in other words, is Gillick competent), the child can consent themselves. Individuals with parental responsibility or delegated authority may be consulted, and may be able to consent on behalf of the child, but cannot override the child's consent if it has already been given (there are some exceptions to this, for example in the case of refusal – for further information see [Guidance from the General Medical Council \(GMC\)](#)).
- Where the patient / service user is a young person (aged between 16 and 18) and has capacity to understand what is being proposed, the young person should consent themselves. Consideration should be given to involving other members of the Multi-Disciplinary Team, an independent advocate or named or designated doctor for child protection if their involvement would help young people in making decisions.
- Where the patient is over the age of 18, only they can consent to what is being proposed if they have capacity to do so. If they lack capacity, if someone else has been formally appointed to make that decision on their behalf, by way of a court

order or formal power of attorney in relation to the issue in question, they can make that decision on the incapacitated person's behalf. If there is no such power, those involved in the person's care should be consulted before a decision is made under the [Mental Capacity Act 2005](#).

Where a patient or service user has an identified carer, a discussion should take place to identify whether their carer has any information or communication needs. If they do, and with the consent of the patient or service user – and their carer – the information and / or communication support needs of the person's carer should be included as part of the patient / service user's record or notes, and flagged appropriately for action. This is the case whether the patient / service user has needs of their own or not. If both the patient / service user and their carer have information and / or communication needs, both should be identified, recorded, flagged, and – with explicit consent – shared. Organisations must also take steps to meet the needs of both the patient / service user and their carer.

The same principles and requirements apply where one or more parents of a patient / service user have information or communication support needs – they should be identified and recorded as part of the child's records / notes. The requirement to automatically flag such needs should be reviewed at the point at which the child appears to be Gillick competent and / or begins to attend the service independently and / or reaches the age of 16.

Where existing systems enable the linking of records, then it may be appropriate not to duplicate information about a carer or parent's needs on the patient / service user's record but instead to include a flag or prompt to review information held on the carer's / parent's record about their needs when accessing the patient / service user's record and before making contact with them / sending correspondence.

12.2 Mental Capacity Act 2005

The [Mental Capacity Act 2005 Code of Practice](#) (Chapter 3) provides clarity on the requirement to provide information in alternative formats and communication support, "To help someone make a decision for themselves, all possible and appropriate means of communication should be tried." This includes consideration of when might be the best time to communicate, whether pictures of objects may help to explain what needs to be considered, breaking down complex information into simple points, speaking at the right volume or speed and using the right language.

Of note, "Certain categories of people are legally required to 'have regard to' relevant guidance in the Code of Practice," this includes, "...anyone who is...acting in a professional capacity for, or in relation to, a person who lacks capacity..."

There is a duty under the [Mental Capacity Act 2005](#) to take all practical and appropriate steps to help people to make a decision for themselves. This includes providing the patient with information tailored to their needs and abilities and in the easiest and most appropriate form of communication for the individual concerned.

The Standard includes the provision of information in alternative formats and communication support to mental health service users to support their access to,

understanding of, involvement in decisions about and receipt of NHS and adult social care. This may include support needed by individuals to enable them to effectively understand their rights and communicate their needs and preferences.

However, communication support which is needed by or provided to a patient or service user as part of an agreed care plan or other pathway of care – and which may be termed ‘therapeutic’ in nature – is outside of the scope of this Standard.

Individuals’ requirements for and the provision of ‘bespoke’ or highly personalised communication support packages as part of their care or treatment are also therefore excluded from scope. Where such needs are identified, individuals should, in the first instance, be referred onwards for specialist input, for example from Speech and Language Therapy.

Where an individual lacks the capacity to make a decision about the sharing of their information and / or communication support needs (as identified and recorded in line with this Standard) – or other aspects relating to their information or communication support needs – relevant professionals should refer to the [Mental Capacity Act 2005 Code of Practice](#) and make decisions in the patient / service user’s best interests.

The potential for the information and communication support needs of individuals to vary or fluctuate, and to be greater at times of crisis or when experiencing an acute episode of illness, and lesser (or non-existent) when well, should be acknowledged. This may require more frequent review of recorded needs to reflect such changes, as appropriate to the individual, and records should be flagged accordingly to prompt for review at appropriate intervals.

12.3 Support for deafblind people

12.3.1 Note on this section

This section specifically considers the provision of deafblind manual interpretation and other support which may be needed by deafblind people, and includes a case study. It should be noted that the needs of deafblind people vary and the guidance in this section should be considered illustrative and not exhaustive – there will be different actions needed to meet the needs of different deafblind people in line with the Accessible Information Standard.

12.3.2 Deafblind manual interpretation

Deafblind manual is a form of tactile fingerspelling. Each letter of the alphabet has a sign that is made against the deafblind person’s hand. Words are spelt out letter by letter.

A register of deafblind manual interpreters is held by the [National Registers of Communications Professionals working with Deaf and Deafblind People \(NRCPD\)](#) however there are currently no training or qualification options available for those wishing to become deafblind manual interpreters. This therefore means that there is a diminishing number of registered deafblind manual interpreters; there are currently

fewer than 15 in the whole of the UK compared to around 1000 British Sign Language (BSL) interpreters.

This shortage means that finding an available and suitable communication support provider may be challenging. It may be necessary to have flexibility to book an interpreter from further away or to make the booking directly with the interpreter rather than through an agency.

In situations where it is impossible for a registered deafblind manual interpreter to be booked, communication support for deafblind people may need to be provided by someone who is unregistered but has the appropriate skills and experience.

If there are problems booking the requested type of interpreter, the deafblind person should be asked whether there are any alternative arrangements that could be used as a one off occurrence – with lessons learned and arrangements put in place to make sure that the necessary interpretative support is available in future.

12.3.3 Case study – providing support for a deafblind person in primary care

The case study which follows was first published in [‘What does good care look like for a deafblind person?’](#) a report prepared by Sense for the Care Quality Commission (CQC).

“Lloyd, aged 25, is deafblind. He communicates using deafblind manual but also has a laptop with assistive technology and an attached refreshable braille display. Lloyd receives 5 hours a week of support from a communicator guide but otherwise lives alone.

Lloyd has diabetes so often requires blood tests and check-ups with his GP. In the past, Lloyd has had difficulties with booking GP appointments and having access to a qualified and NRCPD registered deafblind manual interpreter. It is important that Lloyd has a registered interpreter at his appointments so that he can fully participate in the appointment and access all of the information that he needs without miscommunication and with the assurances of confidentiality and impartiality.

When Lloyd registered with his new GP surgery he asked if he could have an introductory appointment with his GP to discuss his communication needs. The GP obliged and between them they came up with an action plan on how to support Lloyd and best meet his needs:

- The surgery now has the appropriate contact details to be able to arrange for a registered interpreter to attend appointments for Lloyd and whenever he books an appointment they arrange this accordingly.
- Lloyd is allowed to book a double appointment slot as it allows more time for him to communicate via his interpreter.
- If Lloyd has a blood test the surgery will email him the results to save him having to attend the surgery or wait for his communicator guide to be able to read the printed results posted to him.

- Whilst the GP surgery has a telephone based appointment booking system, Lloyd is able to request and arrange his appointments via email.
- If Lloyd's GP needs to refer him to another clinician he always ensures to include Lloyd's communication needs in the referral letter so that they can put appropriate arrangements in place

Sometimes Lloyd needs appointments at short notice which means it isn't always possible for a communicator guide and/or interpreter to be arranged. In these situations, Lloyd's GP will visit him at home and communicate with him by typing on his laptop and using the braille display. He has also taken the time to learn the deafblind manual alphabet so can introduce himself when Lloyd opens the door to him; something which is not only useful but also reassuring for Lloyd.

The person-centred approach to Lloyd's care has meant that he is able to access primary care services in an effective and appropriate way; he is much more able to manage his diabetes and feels that he has control of his own health, as well as needing fewer GP appointments. In addition to Lloyd having the support that he requires, the surgery now has a much greater understanding of the needs of people with sensory loss and make sure that they record all communication needs where appropriate. Staff have also recently undertaken sensory loss awareness training which is now included in their induction package and a number of patients have commented that they have noticed a significant improvement in the care they receive as a result."

12.3.4 Visual frame and hands-on BSL variations

- Visual frame signing is an adaptation of British Sign language where the signs are kept within the deafblind person's field of vision.
- Hands-on signing is another adaptation of British Sign Language, where the deafblind person feels the hand-shapes and movements.

Some, but not all, BSL interpreters are also able to work with deafblind people who use visual frame signing or hands-on signing. It is very important that a BSL interpreter working with a deafblind patient who uses visual frame or hands-on signing has experience of using the appropriate method. There is a register of BSL interpreters but there is no separate registration for interpreters with visual frame or hands-on signing experience and so it is vital that they are asked about their experience before a booking is made.

12.3.5 Interpreter registration

It is recognised that using registered interpreters helps to safeguard professional standards. However, registered interpreters are not necessarily the best people to meet the unique communication needs of deafblind people and it may be necessary to use communication support providers who are unregistered.

The type of support a deafblind person needs will depend on many factors including which methods of communication they use, their proficiency in using them and their

level of understanding. It is important to arrange the right type of support. The only way to know what a deafblind person needs is to ask them. Often deafblind people will have preferred providers.

12.4 Specialist Deaf services

Some services, such as specialist Deaf Mental Health Services, are commissioned and provided specifically for Deaf people, many of whom will use British Sign Language (BSL) as their first, preferred or only means of communication. Staff working in these services are likely to be proficient and competent in using BSL, and indeed facilitation of this 'direct communication' is one of the reasons behind the provision of such specialist services – as it avoids the intrusion of a third person acting as a BSL interpreter, enabling direct interaction between service user and professional in their preferred language.

It is recognised that implementation of the Standard will be different in these settings, however, the five stages of the Standard still apply – and organisations providing services in specialist settings are still required to identify, record, flag, share and meet patients', service users', carers' and parents' information and communication support needs. Specific decisions about the BSL qualifications held by staff working in specialist Deaf services, and circumstances in which professional interpreters should be used, will need to be taken by commissioners at a local level.

It is likely that specialist services will make a far more thorough assessment of communication needs than that undertaken as routine by other services, and it is hoped that specialised services will be able to lead the way for non-specialised providers in this regard.

12.5 Support for children and young people

The Accessible Information Standard includes within its scope all NHS organisations / services and service users of all ages, including children, young people, adults and older people. With regards to social care, the Standard covers adult social care (but does not include children's social services). This is in line with the [Health and Social Care Act 2012](#).

Consideration should be given to ensuring that children and young people with information and / or communication support needs are provided with appropriate – including age-appropriate – information and communication support.

12.6 People with multiple / complex needs

The Accessible Information Standard is concerned with ensuring that people with information and / or communication needs relating to or caused by a disability, impairment or sensory loss have those needs met by organisations providing health and / or adult social care. In the vast majority of cases, such needs can be met using 'standard' or 'standardised' alternative formats (such as braille), 'mainstream' contact methods (such as email), 'standardised' communication methods (such as British Sign Language) and / or other 'generic' adjustments (for example facing someone to enable them to lipread).

However, a minority of people with information and / or communication needs relating to a disability, impairment or sensory loss have multiple and / or complex needs, meaning that they require bespoke tools and / or communication support to enable communication. Individuals with multiple and / or complex needs are more likely to use alternative and / or non-verbal communication methods, and may use a highly personal communication system, for example particular gestures or eye-pointing, which may require interpretation from someone close to them who understands them well.

In these instances, services should make use of the communication devices or tools usually used by the individual, and work with their carer(s), family members, support workers and others who know them well to identify and use communication approaches which maximise the involvement and inclusion of the individual. Services may find documentation of the needs of individuals with bespoke or highly personalised information and / or communication needs challenging, and use of a 'communication passport' or similar document to support standardised / coded recording would be advisable.

12.7 Use of email and text message

12.7.1 Introduction

For many people with a disability, impairment or sensory loss, email is a highly effective, quick and economical information format or contact method.

Email (or text message) may serve as an alternative to telephone communication for d/Deaf people and for blind people / people with visual loss use of email enables the recipient to use (their own) assistive technology or software, for example a 'screen reader' which converts text to speech or to a refreshable braille display. Depending on the software or assistive technology used, a person who is blind or has visual loss may require information sent to them electronically (emailed) in one or more specific formats such as plain text (with or without attachments), HTML, and with attachments in Word or PDF format.

12.7.2 General principles

It is essential that use of information is in line with fair processing guidance and best practice. Fair processing is an element of the [Data Protection Act 1998 \(DPA\)](#) which makes clear that the use of personal data and information by an organisation must be understood by that individual. An NHS organisation or service provider should explain to the person: what information they need about them; for what purpose; who the information may be shared with; what they will do with that information, in terms of compliance with the DPA.

Services should be clear about the rationale for using email and / or text messaging to communicate with their patients / service users, and should clearly define the purpose and scope of communication by these means.

The service's approach to, and use of, email and / or text messaging as ways of communicating with patients / service users should be clearly set out in policy, supported by an internal procedure for staff to follow.

When implementing the use of email or text messaging for the first time, consider that an 'opt out' approach is unlikely to work in practice, as it assumes that all patients / service users have an email address and / or mobile telephone number. An 'opt in' process is likely to be the best way to achieve results. This must be implemented with the explicit consent of the patient / service user, ensuring that they are aware of the facts and the risks associated with the communication method(s).

In all instances, a patient / service user should be able to change their preferences at any time and without having to give a reason. Requests to change contact or communication preferences must be actioned accurately and in a timely manner (where possible, immediately). There is a risk that if a request to change a number / address or communication preference is not acted upon promptly, a breach of confidentiality could occur.

12.7.3 Guidance

- Services that have implemented, or are intending to increase, the use of email and / or text messaging for communication with their patients / service users may wish to encourage them to ask about use of these methods of communication. The display of posters or notices, and other ways of explaining to patients / service users about the use of electronic communications by the service, would be considered good practice – this helps inform patients / service users about their choice.
- In the first instance, proactively and explicitly check with the patient / service user that they are comfortable with being contacted via email and / or text message (as appropriate).
- In either case, if the patient / service user agrees to the use of email or text message as a communication method, ask them to provide and confirm their email address and / or mobile telephone number. Please note that the record of a number or and / or email address **does not** indicate consent (which must be explicitly sought).
- With regards to text messaging, having obtained the correct mobile number from the patient / service user, the service should send a 'test' text message to that number to verify accuracy. This should either be done whilst the patient / service user waits with a member of staff (so that receipt of the text message can be verified) or alternatively, the patient / service user should be asked to reply to confirm their identity and the accuracy of the number. In all cases, organisations should ensure that best endeavours have been made to confirm the accuracy of the information provided.
- The patient / service user and the service should mutually agree the parameters or limits of what information is to be communicated via email and / or text message. Each organisation may have differing service offerings and these

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should be discussed with the patient / service user prior to using the service. It may not be practical or technically possible to agree different parameters with different patients / service users. Organisations should offer the service to patients / service users where possible, fully informing them of what service is available, so the patient / service user can make an informed choice based on all the available information.

- Explain to the patient / service user about who will have access to their emails / text messages and why, with reference to the agreed parameters for the types of information to be communicated in this way.
- It is essential to explain to the patient / service user that it is their responsibility to keep and provide an up to date email address and / or mobile number, and to be clear that the service is not responsible for onwards use or transmission of an email or text message once it has been received by the patient / service user.
- The patient / service user should also be advised that internet email accounts, such as those commonly used by individuals for private purposes, are not secure. The patient / service user must, therefore, be made aware (and accept) that there is a risk (however small) of the email being intercepted or 'hacked'. Likewise, there will always be risks that text messages may be intercepted or otherwise accessed by a third-party and patients / service users should be made aware of these risks.
- The service should strongly recommend to the patient / service user that they use a private email account / private mobile telephone, not a family or shared account or mobile telephone, for the purposes of communication with the service. However, this is their decision and the service cannot insist on use of a private account or mobile telephone. The risks associated with use of a shared account / shared mobile telephone should be explained.
- The parameters of how much contact is conducted by email and / or text message should be agreed, with the service setting clear limits and ensuring that the patient / service user is aware of them. It is likely that the service will wish to limit two-way dialogue via email or text message which risks becoming a 'virtual consultation' and instead direct the patient / service user to make an appointment, for example to discuss test results.
- Services, and their staff, should only send emails from generic team accounts (for example diabetes@example.nhs.net / oncology@example.nhs.uk) and established corporate text messaging accounts. This ensures that patients / service users can be confident that the sender is legitimate. Individual staff email addresses should not be used. Use of generic accounts also ensures that emails and text messages can be accessed and actioned by multiple members of staff, providing cover in the event of absence.
- It is best practice to acknowledge receipt of an email within 24 hours.
- Emails are classed as records and should be retained for the appropriate period of time. Where possible, a copy of the email should be stored in the patient /

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service user's record. If this is not possible, then an entry should be written into the patient or service user's notes detailing the important content of the email and subsequent actions (for example, 'blood test dated 24.6.14; results emailed to patient 25.6.14; patient replied asking for outpatient appointment; booked for 1.7.14 at 14:30'). This covers the interaction with the patient, and the original emails can be found in the email archive / system if required."

An example consent form for the use of email or text message communication is included as appendix f.

13 Assessment and assurance of compliance

13.1 Local assessment and assurance of compliance

The Specification for the Standard includes conformance criteria which should be used in order to assess compliance.

Commissioning organisations are required to seek assurance from provider organisations of their compliance with this Standard, including evidence of identifying, recording, flagging, sharing and meeting of needs (see section 13.2).

At a local level, applicable organisations will wish to assure themselves that they are complying with the Standard. It is recommended (but not required) that organisations identify an Accountable Officer or similar designated role indicating an individual with responsibility for implementation and compliance with the Standard at a senior level.

Consideration should be given to recording a formal incident each time an individual's information or communication support needs are not met. This will inform assessment of unmet needs, support the making of relevant adjustments / arrangements to meet needs, and highlight the importance of the Standard internally within organisations and to commissioners.

As part of the Standard, organisations are required to publish an accessible communications policy, to implement an accessible complaints policy and to support individuals with information and communications needs to provide feedback on their experience of services and of receiving information in appropriate formats and / or communication support.

Organisations should consider how they can capture feedback from individuals with information and communication needs as part of their existing patient experience and patient engagement approaches. This may necessitate development of relevant materials, such as feedback forms and comment cards, in alternative formats and the establishment of mechanisms for the receipt of feedback in formats such as audio or British Sign Language. Face-to-face opportunities for feedback, supported by relevant communication professionals, should also be considered.

Organisations may wish to work in partnership with their local Healthwatch organisation(s), with patient groups and / or with organisations from the voluntary and community sector to facilitate the development of accessible materials and approaches for individuals with information and communication needs to feedback on their experiences. Such groups may also be able to directly support engagement with individuals and communities with information and communication needs.

As part of resources to support implementation, guidance has been produced to support local assessment and monitoring of compliance and to support effective implementation and best practice.

13.2 The role of commissioners

Beyond adhering to published requirements, commissioners are not required to take any specific or particular approach to assurance, and should use their judgement to implement an approach most appropriate to their own, and their providers', circumstances. It is recommended, however, that commissioners explicitly include the requirement to comply with the Standard as part of procurement / tender documents, service specifications and contracts with providers, and clearly indicate expectations around the receipt of evidence in this regard, which should be documented.

Commissioners may also wish to include explicit statements with regards to the Standard as part of their Annual Operating Plans, Business Plans, Commissioning Intentions, Equality and Diversity Objectives / Strategy (including linking to EDS2) and / or as part of Annual Reports.

Commissioners may also wish to consider their role in supporting locality or region-wide initiatives which support cost-effective, efficient and added value approaches to implementation of the Standard across the local health and care system.

13.3 Other interested organisations

There is significant interest in, and support for, the Standard from a range of voluntary and community sector organisations, patient groups, and local Healthwatch organisations. It is anticipated that many such organisations will request evidence of conformance with the Standard from organisations that provide and / or commission NHS care and / or publicly-funded adult social care, for example through [Freedom of Information \(FOI\)](#) requests. There may also be interest from local stakeholder and partner organisations, and in some areas, there is the potential for local media interest.

In addition, the Care Quality Commission (CQC) have included 'accessible information and communication' as one of their [equality objectives for 2017-19](#). Specific commitments include "we will look at how all services are applying the standard in our regulatory work. Healthwatch England will also look at this it through their work" and "our assessment frameworks will include key lines of enquiry, prompts and ratings characteristics on the standard." As a result, "from October 2017, all inspection reports include how providers are applying the standard."

13.4 Practical assessment of conformance

Judgement about conformance may be made in a variety of ways including by assessing evidence of performance against the conformance criteria, by looking at evidence that key aspects of the Standard are being followed, and through assurance of key outputs. Potential aspects which may be used as evidence of conformance include:

- Confirmation that the organisation has published an accessible communications policy, which explains how they will follow the Standard, and an accessible complaints policy.

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- Reviewing whether there is evidence of an organisation routinely and consistently following the 'five steps' of the Standard as part of 'business as usual'. The 'five steps' require organisations that provide NHS care and / or publicly-funded adult social care to identify, record, flag, share and meet the information and communication needs of people with a disability, impairment or sensory loss.
- Confirmation of completion of the 'checklist for preparatory actions' (section 15.4), produced to support organisations with implementation, which may also be used by other organisations, after the full implementation date, to assess conformance.

Organisations interested in improving their performance / assessing organisational improvement over time may wish to assess progress against the 'maturity index' included at appendix b.

14 Resources to support implementation

A range of resources have been made available to support organisations in effectively implementing and following the Standard, as outlined in the Implementation Plan. These were promoted as outlined in the Communication Plan and are available from the [NHS England website](#). They include two [e-learning modules](#) developed in association with Health Education England, a [toolkit for GP practices](#), an [interactive guide](#), a [microsite](#) and [poster templates](#).

15 Approaches to implementation

15.1 Introduction

Outlined below are some recommendations as to the actions which may be taken in order to implement the Accessible Information Standard locally. These are not mandatory, but may be useful to organisations preparing to implement the Standard.

15.2 Implementing the Standard – high level approach

The process followed to implement the Standard will vary according to the starting position of each organisation, however, a high level generic approach is:

1. Assessment of existing data collection, recording, flagging and sharing processes against the published Standard documentation;
2. Assessment of existing arrangements for meeting the information and communication support needs of patients, service users, carers and parents with such needs, including systems for the manual and automatic generation of correspondence;
3. Assessment of staff ability to effectively and sensitively identify and record information and communication needs, and provide relevant support to individuals with such needs;
4. Development of an implementation plan with reference to resources, tools and guidance published by NHS England and assessment of technical changes needed to implement the Standard locally;
5. Rollout of the implementation plan.

Typically an implementation plan would include taking the five steps of the Accessible Information Standard in turn and developing, agreeing and implementing an approach to each, with additional overarching actions linked to internal communications. Organisations may find the 'high level process' diagrams, included as part of the Specification, useful when formulating implementation plans as well as advice included elsewhere in this Implementation Guidance.

15.3 Implementing the Standard – policy and process

All organisations will need to establish a clear, local policy and processes for following the Accessible Information Standard, this should include:

1. How to identify individuals with information / communication needs, including who will ask, what question(s) will be asked, how, where and when.
2. How to record individuals' information and communication needs as part of existing patient / service user record systems and administrative processes, including using specific categories / codes.

3. How to ensure that there is an alert, flag or other prompt to notify staff of an individual's information / communication needs such that they are 'highly visible' whenever the record is accessed and prompt for relevant action(s) to be taken.
4. Alternative ways to contact individuals with information / communication needs and for them to contact the service, for example via email, text message or telephone.
5. How to send correspondence in alternative formats (for example in large print, via email, in easy read, in braille).
6. How to obtain patient information in alternative formats (for example patient information leaflets in easy read).
7. How to arrange for a communication professional to provide support to a patient / service user either as soon as possible (in an urgent situation) or for an advance appointment. Note whether there are facilities for remote British Sign Language (BSL) and / or speech-to-text-reporting (STTR).
8. Guidelines for arranging a longer appointment for a patient / service user with communication needs.
9. How staff can support individuals with communication needs, for example to lipread / use a hearing aid.

15.4 Checklist for preparatory actions

- Developed / modified accessible communication policy which is in line with the Accessible Information Standard.
- Agreed approach to identifying individuals with information / communication needs relating to a disability, impairment or sensory loss.
- Clear process for recording individuals' information / communication needs in line with the Standard.
- Flags, alerts or prompts established to highlight / make individuals' information / communication needs 'highly visible' to staff, supported by relevant prompts to action.
- Identified range of ways for individuals with communication needs to contact the service, and for the service to contact them, supported by agreed process for using any 'alternative' approaches.
- Agreed process for sending out correspondence in alternative formats.
- Agreed process for producing / obtaining information in alternative formats.
- Agreed process for arranging / booking professional communication support.
- Agreed process for booking / arranging longer appointments for patients / service users with communication needs.
- Training / briefing given to staff to explain the Accessible Information Standard, detail processes to be followed and raise awareness of support which staff can provide themselves.

- Consideration given to accessibility of relevant website(s) and availability of relevant information online.

15.5 Considerations for implementation leads

The following advice is provided with a view to supporting organisational leads to effectively implement the Standard, and to minimise / mitigate identified challenges. Note that this section is advisory and not mandatory – applicable organisations are not required to follow these steps, and some of the actions represent good practice over and above the minimum Requirements.

1. Think carefully about how to identify individuals with information and communication needs when they contact the service (for example at the reception desk, over the telephone), and when they register. Who will ask, when, and how? This is most likely to be the role of 'first point of contact' staff, for example receptionists. It can be helpful to agree on a 'standard question' which staff can feel comfortable asking patients / service users – the most appropriate question is likely to vary locally and depending on the nature of the service / patient group – services are advised to consult with relevant patient groups if possible. A question about communication / information needs should be included on 'new patient' or patient registration forms (where used).
2. Brief staff about the Standard preferably via a face-to-face session (particularly for those most directly involved in its implementation), and follow-up with email information about what it will entail. Include information about or signposting to local policies / procedures for arranging the production of information in alternative formats and communication support.
3. Inform patients / service users about the Accessible Information Standard – via posters or onscreen information in waiting / reception areas. Encourage patients / service users to inform staff of their communication needs.
4. Noting that the Accessible Information Standard does not include environmental / facilities matters, certain aspects are very relevant to people with a disability, impairment or sensory loss, and can facilitate clear communication. Consider whether some rooms are 'better' than others for people with communication needs (for example less cluttered, better light, more soundproof). When assessing lighting, be aware that this can help or hinder a person trying to lipread – the aim is for good light but not blinding, and consider whether curtains / blinds can be drawn.
5. Consider your workforce. What training have individuals and teams had previously around disability-awareness and / or communication? Consider if any individual staff are best placed to support people with particular / complex communication needs, for example a Learning Disability Liaison Nurse or staff who have had any specific training. In addition, be aware that (some) patients / service users with communication needs may have particular difficulty communicating with some members of staff. For example, it can be a delicate subject but people who lipread often struggle (or can even be unable) to lipread a member of staff with a beard (or large moustache). Individuals with communication needs may request to see a particular member of staff who they know they can understand more easily.

6. Can you easily access information in the common 'externally produced' alternative formats of easy read and braille? Clarify the policy for arranging conversion of documents and consider having the one or two most commonly used documents converted in advance of any request.
7. Can you access communication professionals, specifically a British Sign Language (BSL) interpreter, speech-to-text-reporter (STTR), deafblind manual interpreter or advocate? Clarify the policy and process for arranging / booking such a professional. Is remote / virtual BSL interpretation and / or STTR possible?
8. Identify which communication formats can be used or produced 'in house'. For example, email and text message (for people who are d/Deaf as an alternative to telephone and for people who are blind as an alternative to printed information), and large print. Consider any practical steps that staff will need to take to use / access these methods if they are not currently part of 'business as usual,' for example which printer(s) can be used to produce large print / what email address should be used for emailing patients.

15.6 Considerations for commissioners

Although exempt from implementing the Standard themselves, commissioners are required to ensure that their actions, especially through contracting and performance-management arrangements (including incentivisation and penalisation), enable and support provider organisations from which they commission services to implement and comply with the requirements of the Standard. This includes ensuring that contracts / frameworks enable and support provider organisations to be responsive to the needs of individuals with information and communication support needs, for example by facilitating the provision of longer appointments and allowing for flexibility within patient pathways.

Commissioning organisations should review their existing contracts / frameworks and make any adjustments necessary to allow for, and indeed support, providers to comply with the Accessible Information Standard.

16 Timescales

Since 01 August 2016, all applicable organisations have been required to follow the Standard in full, and to meet all relevant requirements – compliance with the Standard should now be embedded into ‘business as usual’.

The original timetable for implementing the Standard is set out below, for reference.

By 01 September 2015 organisations MUST have begun to prepare for implementation of the Standard, including through assessing their current systems and processes, and developing and commencing roll out of a local implementation plan in order to achieve implementation of and compliance with the Accessible Information Standard in line with published deadlines.

By 01 April 2016 organisations MUST have made necessary changes such that they routinely identify and record the information and communication needs of their patients or service users (and where appropriate their carers or parents) at first registration or interaction with their service.

From 01 April 2016 services MUST identify the communication or information support needs of their existing registered or known patients or service users (and where appropriate their carers or parents) during routine appointments or interactions with the service.

By 31 July 2016 organisations MUST be fully compliant with all aspects of the Accessible Information Standard.

Task	Date
Implementation date: organisations MAY begin to implement the Standard.	Immediately upon publication of the [previous] ISN.
Organisations MUST have begun to prepare for implementation of the Standard, including developing and commencing rollout of a local implementation plan.	By 01 September 2015.
Organisations MUST identify and record information and communication needs when service users first interact or register with their service.	By 01 April 2016.
Organisations MUST identify and record information and communication needs as part of ongoing / routine interaction with the service by existing service users.	From 01 April 2016.
Date of full conformance: full implementation of the Standard is required.	By 31 July 2016.

17 Illustrative patient scenarios

Some illustrative examples of how the Standard could work in practice are as follows. The 'high level' diagrams included in the Specification should also be reviewed.

Gladys is 87 years old and lives in a nursing home. She has some hearing loss, and has dementia. Recognising that both conditions are likely to increasingly impact upon Gladys' ability to communicate in the future, staff at the nursing home design a communication chart to support Gladys in understanding important parts of her routine, for example, daily activities and meal times. Members of staff at the nursing home have received training in developing and using communication charts to support service users to communicate, so no intermediary is needed. When the GP visits the care home to give Gladys a check-up, one of the care home staff supports Gladys to understand what is being said, using the chart. Gladys' records indicate that she 'uses communication device'.

Esther is deafblind. She collapses at home late at night and her neighbour dials 999 for an ambulance. She is admitted to hospital as an emergency whilst further tests are carried out and her condition is stabilised. Esther's neighbour informs hospital staff that she requires a deafblind manual interpreter. It is not possible to arrange for a deafblind manual interpreter to be present at the hospital upon admission; however, a booking is made for the following morning. The consultant in charge of Esther's care explains the procedures which are being carried out and a likely prognosis whilst the interpreter is present to enable Esther to ask any questions and raise concerns. The interpreter is booked to attend again later that day when more news will be known.

Brian is Deaf. He needs a repeat prescription of Warfarin and books a routine appointment at his GP Practice in 3 days' time. Reception staff note that he has a requirement for a British Sign Language (BSL) interpreter recorded on his patient record, and book a BSL interpreter to attend Brian's appointment. If an interpreter is not available – or if Brian needed a more urgent appointment – a internet video-link could be used so that he can be provided with BSL interpretation remotely.

Hardeep is blind. She has recently been diagnosed with Diabetes. She begins to feel unwell and makes an urgent appointment at a walk-in facility. Reception staff note that she has a requirement for information to be presented verbally or in an audio format, and for any written information to be available in braille. During her appointment, the GP explains to Hardeep about managing her Diabetes better, including improving her diet and taking more exercise. Usually, patients would be given an information booklet about lifestyle changes and Diabetes to read at home. The GP arranges for the booklet to be transcribed into braille and sent to Hardeep's home address. This will take 3 or 4 days.

18 References

18.1 Related standards

- [SCCI1596: Secure Email](#)
- [SCCI0011: Mental Health Services Data Set](#)
- [SCCI0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems](#)
- [SCCI0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems](#)
- [Information Governance Standards Framework \(ISB 1512\)](#)
- [SCCI0034: SNOMED CT](#)

18.2 Related documents

- [Access all Areas? \(Action on Hearing Loss, 2013\)](#)
- [Action Plan on Hearing Loss \(NHS England, 2015\)](#)
- [Equality Delivery System 2 \(NHS England, 2013\)](#)
- [Final report of the Confidential Inquiry into premature deaths of people with learning disabilities \(CIPOLD\) \(University of Bristol CIPOLD Team, 2013\)](#)
- [NHS Five Year Forward View \(NHS England, 2014\)](#)
- [Patients First and Foremost: The Initial Government Response to the Report of Mid Staffordshire NHS Foundation Trust Public Inquiry \(Department of Health, 2013\)](#)
- [‘Sick of It’ \(SignHealth, 2014\)](#)
- [The Care Act 2014](#)
- [The Equality Act 2010](#)
- [The NHS Constitution \(Department of Health, 2015\)](#)
- [The Power of Information \(Department of Health, 2012\)](#)
- [Transforming care: A national response to Winterbourne View Hospital, Department of Health Review: Final Report \(Department of Health, 2012\)](#)
- [Valuing People: A New Strategy for Learning Disability for the 21st Century \(Department of Health, 2001\)](#)
- [Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities \(Department of Health, 2009\)](#)
- [Your rights to equality from healthcare and social care services \(Equality Act 2010 Guidance for service users, Volume 4 of 7\) \(Equality and Human Rights Commission, 2014\)](#)

Appendix a – Practical one page guide

Overview of the Standard – scope (who, what and where)

DCB1605 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.

It is of particular relevance to individuals who are blind, d/Deaf, deafblind and / or who have a learning disability, although it should support anyone with information or communication needs relating to a disability, impairment or sensory loss, for example people who have aphasia, autism or a mental health condition which affects their ability to communicate.

The Standard applies to all providers across the NHS and adult social care system.

The Accessible Information Standard – quick guide (how)

There are five basic steps which make up the Accessible Information Standard:

1. **Ask:** identify / find out if an individual has any communication / information needs relating to a disability or sensory loss and if so what they are.
2. **Record:** record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record / administrative systems / documents.
3. **Alert / flag / highlight:** ensure that recorded needs are 'highly visible' whenever the individual's record is accessed, and prompt for action.
4. **Share:** include information about individuals' information / communication needs as part of existing data sharing processes (and following existing information governance frameworks).
5. **Act:** take steps to ensure that individuals receive information which they can access and understand, and receive communication support if they need it.

Aim of the Standard (why)

The aim of the Standard is to establish a framework and set a clear direction such that patients and service users (and where appropriate carers and parents) who have information or communication needs relating to a disability, impairment or sensory loss receive:

- 'Accessible information' ('information which is able to be read or received and understood by the individual or group for which it is intended'); and
- 'Communication support' ('support which is needed to enable effective, accurate dialogue between a professional and a service user to take place');

So that they can access services appropriately and independently, and make decisions about their health, wellbeing, care and treatment.

Timescales (when)

Organisations must comply with the Standard in full from 1st August 2016 onwards.

More information

Visit www.england.nhs.uk/accessibleinfo or email england.patientsincontrol@nhs.net.

Appendix b – A ‘maturity index’

Overview

The Accessible Information Standard allows for flexibility in implementation approaches, subject to the successful achievement of requirements and outcomes. There is, however, a ‘maturity index’ or improvement trajectory, ranging from ‘basic’ implementation (in which the organisation is compliant but as part of which the Standard has limited integration with other systems / processes and there is limited or no automation) working up to an ‘exemplar’ level in which the essential requirements of the Standard are embedded into systems / processes, highly supported by automation and activities go beyond this baseline to achieve good / best practice.

It is hoped that all organisations seek to strive towards good and best practice with regards to meeting the information and communication support needs of people with a disability, impairment or sensory loss.

Basic level

The requirements of the Standard – typified by the five step process – are achieved using separate processes – either paper-based or using electronic ‘work-arounds’.

A paper-based approach would involve recording of an individual’s information / communication support needs (most probably by hand), and ensuring that these were ‘highly visible’ / flagged using a highlighter or sticker system. The ‘prompt for action’ would rely on staff awareness and following of policy, and sharing likewise would be reliant on staff including information as part of handover / referral conversations and correspondence (for example copying relevant data from paper records into a letter). Meeting of needs would be achieved again through staff awareness of the need to make adjustments / send out information in alternative formats / arrange support from communication professionals, as prompted by a sticker or other flag on paper records.

An electronic approach would involve recording of an individual’s information / communication support needs using ‘free text’ (in line with the ‘fully specified names’ (FSNs) or categories of the data items associated with the four subsets of the Standard). Staff must manually select – and elect – to add a flag or alert to a patient’s record when they record that they have information / communication support needs. Once a flag is (manually) applied to an individual’s record, a ‘special requirements’, ‘access needs’ or ‘communication needs’ alert appears whenever the record is accessed. Having noticed the alert, staff must then search for relevant information about the type of information / communication needs which the patient has, and follow relevant policies in order to meet those needs.

Staff must arrange for the printing / production of any and all information needed by patients using manual processes. The service’s website is not screen-reader compatible and there is no availability of information in alternative formats online.

Intermediate level

The Standard is implemented using clear approaches and supported by relevant policy, but remains somewhat separate to 'business as usual' processes. There is use of electronic systems, but no automation of processes.

Individuals' information / communication needs are recorded using Read v2, CTV3 or SNOMED CT codes. Electronic flags are available, and electronic systems prompt for their use, but must be applied by staff when recording individuals' needs (they are not automatically applied by electronic systems). The flags do not trigger any auto-generation of correspondence or other automatic processes in order to meet individuals' needs, but are highly visible and prompt staff to take action, however, they do not send specific alerts.

Staff are able to manually select and print / produce some alternative formats using standard templates, but are reliant on external or bespoke processes for others. Longer appointments can be arranged, as well as support from communication professionals, however, whilst there are clear policies, successful implementation relies on staff awareness and ability to make adjustments in systems.

The service's website is accessible to some screen-reader users, but there is no availability of information in alternative formats online.

Advanced level

The Standard is partly embedded into 'business as usual' processes, with some automation in electronic systems.

Individuals' information / communication needs are recorded using Read v2, CTV3 or SNOMED CT codes. Electronic flags are automatically applied upon selection of any of the data items associated with one of the four subsets of the Standard. The flags do not trigger any auto-generation of correspondence or other automatic processes in order to meet individuals' needs, but are highly visible and prompt staff to take action – including sending alerts at relevant points. Staff are able to manually select and use a range of standard templates to enable correspondence and other information to be printed 'in-house' and provided in alternative formats. Effective processes are in place to enable provision of longer appointments, and the arrangement of support from communication professionals, and these are supported by clear policies and protocols which can be followed by any and all staff.

The service's website is accessible to most or all screen-reader users, with some information available online in alternative formats.

Exemplar

The Standard is highly embedded into 'business as usual' processes and highly automated in electronic systems.

Individuals' information / communication support needs are recorded using SNOMED CT codes, with flags automatically applied upon selection of any of the data items which are associated with one of the four subsets of the Standard. The electronic

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flags automatically trigger actions to enable needs to be met, without relying on staff, for example, leading to automatic generation of correspondence and printed information in alternative formats, selection of a longer appointment time and sending an appropriate email to agencies to book a communication professional as appropriate. Staff input into processes is minimal, and prompted by automatic processes, for example drop-down lists requiring selection of information / communication needs prompt (and require) staff to record / review individuals' needs whenever they contact the service.

Online registration forms include a section about information / communication support needs which is in-line with the SNOMED CT codes (and their FSNs) and which is then directly included onto the patient's record. Patients with online access can view, verify the accuracy of and if necessary update their records as and when their needs (or ways of meeting those needs) change. Full use is made of remote, virtual and digital solutions to meet individuals' needs, including access to remote BSL interpretation and speech-to-text-reporting.

The service's website is highly accessible, enabling individuals to access information online using a screen-reader or other assistive technology, and includes key information in easy read and BSL formats too.

Staff have received training in Total Communication approaches and basic BSL / deafblind manual to support communication with patients in reception areas and the building of rapport (with communication professionals used to support appointments / clinical conversations).

Appendix c – Expanded glossary of terms

The following glossary defines and explains some of the key words and terms used in the Implementation Guidance and elsewhere in documentation associated with the Accessible Information Standard. It should be read in conjunction with the FSNs (Fully Specified Names) linked to the SNOMED CT codes associated with the four subsets of the Standard.

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.

Aphasia: a condition that affects the brain and leads to problems using language correctly. People with aphasia find it difficult to choose the correct words and can make mistakes in the words they use. Aphasia affects speaking, writing and reading.

Audio: information recorded from speech or synthetic (computer-generated) speech onto cassette tape, CD (compact disc) or as an electronic file such as an MP3.

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.

BSL interpreter - hands-on signing: a BSL interpreter who is able to sign with the hands of the person they are interpreting for placed over their hands, so that they can feel the signs being used. A type of communication support which may be needed by a person who is deafblind.

BSL interpreter - visual frame signing: a BSL interpreter who is able to use BSL within the visual field of the person with restricted vision. A type of communication support which may be needed by a person who is deafblind.

BSL interpreter - Sign-Supported English (SSE): a BSL interpreter who is able to communicate using BSL signs but in the order that they would be used in spoken English. A type of communication support which may be needed by a person who is d/Deaf or deafblind.

BSL translator: a person able to translate written or printed English into British Sign Language (BSL), to support face-to-face consideration of a document, or for recording for use in a BSL video for example for publication on a website.

BSL video: a recording of a BSL interpreter signing information which may otherwise only be available in written or spoken English. A BSL video may be made available on DVD or via a website.

BSL video remote interpreting (VRI) - also known as video interpreting, remote interpreting or virtual interpreting: an online service in which a BSL interpreter interprets via video software. It works using a computer and webcam, a smartphone or tablet. Provided through contract or on demand by a range of organisations, it enables a direct connection to an interpreter so that the d/Deaf person can sign to them what they want to say. The interpreter then speaks this to the hearing person (via video link) and signs back their (spoken) reply.

Communication passport: sometimes called a communication book or 'hospital passport'. A document containing important information (usually) about a person with learning disabilities, to support staff in meeting those needs. It will include a person's likes and dislikes, and outlines ways in which they communicate. Many hospital trusts provide communication passports to people with learning disabilities.

Communication support: support which is needed to enable effective, accurate dialogue between a professional and a service user to take place.

Communication tool or aid: a tool, device or document used to support effective communication. 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 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](#))."

Deafblind communicator-guide: a professional who acts as the eyes and ears of the deafblind person including ensuring that communication is clear. A deafblind person may have a communicator-guide provided by a charity, through a personal budget or by their local authority.

Deafblind intervenor: a professional who provides one-to-one support to a child or adult who has been born with sight and hearing impairments (congenital deafblindness). The intervenor helps the individual to experience and join in the world around them. A deafblind person may have an intervenor provided by a charity, through a personal budget or by their local authority.

Deafblind manual interpreter - deafblind manual alphabet: a person skilled in interpreting between the deafblind manual alphabet / block alphabet and English. The deafblind manual alphabet is a tactile form of communication in which words are spelled out onto a deafblind person's hand. Each letter is denoted by a particular sign or place on the hand.

Deafblind manual interpreter - block: a person skilled in interpreting between the deafblind block alphabet and English. The block alphabet is a tactile form of communication in which words are spelled out on to the palm of the deafblind person's hand.

Disability: the [Equality Act 2010](#) describes 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 description, “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.

Hearing loop system: a hearing loop or ‘audio frequency induction loop system’, allows a hearing aid wearer to hear more clearly. It transmits sound in the form of a magnetic field that can be picked up directly by hearing aids switched to the loop (or T) setting. The magnetic field is provided by a cable that encloses, or is located close to, the intended listening position such as a reception desk. The loop system allows the sound of interest, for example a conversation with a receptionist, to be transmitted directly to the person using the hearing aid clearly and free of other background noise.

Impairment: The disability charity [Scope](#) defines impairment as, “long-term limitation of a person's physical, mental or sensory function.”

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 [NHS Data Model and 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. A person can be supported to lipread by the speaker clearly addressing the person and facing them whilst speaking, avoiding touching or covering their mouth, and ensuring conversations are held in well-lit areas.

Lipspeaker: a person who repeats the words said without using their voice, so others can read their lips easily. A professional lipspeaker may be used to support someone who is d/Deaf to communicate.

Makaton: a communication system using signs, symbols and speech. There are three levels of Makaton, used according to the individual's circumstances and abilities – functional, keyword and symbol reading. Makaton may be used by people with deafblindness or a learning disability.

Moon: a tactile reading format made up of raised characters, based on the printed alphabet. Moon is similar to braille in that it is based on touch. Instead of raised dots, letters are represented by 14 raised characters at various angles.

Non-verbal communication: communicating without using speech and instead using gestures, pointing or eye-pointing.

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 onto a laptop computer, which can then be read on screen. Notetakers are commonly used in combination with other communication support, for example people who are watching a sign language interpreter are unable to take notes at the same time.

Sign language: a visual-gestural language and way of communicating.

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. A STTR may also be known as a Stenographer® or Palantypist®.

Tadoma: Tadoma involves a person placing their thumb on a speaker's lips and spreading their remaining fingers along the speaker's face and neck. Communication is transmitted through jaw movement, vibration and facial expressions of the speaker. A type of communication which may be used by a deafblind person.

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.

Voice Output Communication Aid (VOCA): also known as a speech-generating device (SGD). An electronic device used to supplement or replace speech or writing for individuals with severe speech impairments, enabling them to verbally communicate.

Appendix d – Advice about communication support needs

Introduction

This section briefly outlines groups who are anticipated to be most affected by the Accessible Information Standard, and provides generic advice as to likely and foreseen support which may be required. The advice and groups included are indicative but not exhaustive. Words or phrases **highlighted in bold** are included in the extended glossary (appendix c). Further advice is available as part of resources to support implementation (as outlined in the Implementation Plan).

Patient groups

The following groups of patients / service users are anticipated to be affected most directly by the Accessible Information Standard:

- People who are blind or have some visual loss;
- People who are **deaf** or **Deaf** or have some hearing loss;
- People who are **deafblind**;
- People who have a **learning disability**.

The following groups are likely to also be affected by the Accessible Information Standard:

- People with **aphasia**;
- People with a mental health condition which affects their ability to communicate;
- People with autism.

It should be noted that these categories do not represent all of the groups who may be affected – the scope of the Standard includes all patients, service users, carers or parents with information or communication support needs relating to any kind of disability, impairment or sensory loss.

Types of communication support and alternative formats

i. Support for people who are blind or have some visual loss

A person who is blind or has some visual loss may need information which is usually written down or provided in standard print in an alternative format such as: **audio** (on CD or as an MP3 file), **braille**, email or **large print**.

Note that people who are blind, deafblind or have some visual loss may require information to be sent or shared with them electronically (via email) instead of in a written or printed format. This is because use of email enables the recipient to use (their own) assistive technology or software, for example a 'screen reader' which converts text to speech. Depending on the software or assistive technology used, a person who is blind or has some visual loss may require information sent to them electronically (emailed) in one or more specific formats such as plain text (with or without attachments), HTML, and with attachments in Word or PDF format.

A person who is blind or has some visual loss may need visual information in the form of an audible alert. For example many blind people cannot read their name on a screen or notice and so will need to be told or guided to the appropriate room and / or seat.

ii. Support for people who are d/Deaf or have some hearing loss

A person who is **d/Deaf** or has some hearing loss may require support from a communication professional, including a **British Sign Language (BSL) interpreter, BSL interpreter who uses Sign-Supported English, Lipspeaker, Notetaker, or speech-to-text reporter (STTR).**

A person who is d/Deaf may also need information which is usually provided in standard print in **BSL video** format.

A person who is d/Deaf or has some hearing loss may also need support to communicate because they:

- **Lipread** – in which case the speaker should clearly address the person and face them whilst speaking, avoid touching or covering their mouth, and ensure conversations are held in well-lit areas; and / or
- Use a hearing aid – in which case care should be taken to speak clearly and a **loop system** may support conversation in reception or waiting areas.

It should be noted that the ability of d/Deaf people to read and understand written English varies considerably and it should not be assumed that having a conversation via written notes is an appropriate way of holding a dialogue. Similarly, it should not be assumed that because someone is wearing one or more hearing aids they no longer need any support to communicate, they may, for instance, be supporting their hearing via lipreading. The person's communication needs must be established with them in the first instance.

A person who is d/Deaf may need verbal or audio information in the form of visual alert. For example many d/Deaf people cannot hear their name called in a waiting area.

iii. Support for people who are deafblind

Types of communication support which may be needed by a person who is deafblind are as follows. It should be noted that many deafblind people will use a combination of different mechanisms to support communication.

A deafblind person may require support from a communication professional:

- **British Sign Language (BSL) interpreter**, who may need to be particularly skilled to work with deafblind people who need BSL adapting in the following ways:
 - **BSL interpreter - hands-on signing**

- **BSL interpreter - visual frame signing**
- **Deafblind manual interpreter**
- **Speech-to-text-reporter (STTR)**

A deafblind person may receive individual support from an identified professional to support them in communicating, such as a **Deafblind communicator-guide** or **Deafblind intervenor**. If so, it would be expected that this person would accompany the deafblind person.

A deafblind person may need written information in an alternative format, such as **braille** or via email.

A deafblind person may also need support to communicate using a **communication tool or aid**. They may also rely on the use of **Tadoma** to communicate or use a **Voice Output Communication Aid (VOCA)**.

A deafblind person may also use **non-verbal communication** including gestures, pointing or eye-pointing.

iv. Support for people with a learning disability

A person who has a learning disability may need information which is usually provided in standard English provided in an alternative format such as **easy read** or explained using **Makaton**.

A person with a learning disability may require support from a communication professional at their appointment, for example an **advocate**.

A person with a learning disability may also need support to communicate using a **communication tool or aid**. They may also have a '**communication passport**'. A person with a learning disability may also use **non-verbal communication** including gestures, pointing or eye-pointing.

It should be noted that the level of a person's learning disability will have a significant impact on their ability to communicate and therefore level of support needed. People with a mild or moderate learning disability may be living independently and need information in easy read format and verbal information explained more slowly and simply. A person with a more severe or profound learning disability is likely to be supported by one or more carers and will need additional support to communicate, including using a communication tool or aid. People with a more severe learning disability are more likely to communicate in non-verbal and non-traditional ways.

Appendix e – Advice on web accessibility

Noting that the accessibility of health and social care websites is excluded from the scope of this Standard, organisations are advised to consider maximising the accessibility of their website(s) as increasing web and digital accessibility will reduce (although never remove) the need to produce information in alternative formats as well as empowering individuals to access information directly and without delay.

Organisations should ensure that websites comply with the [World Wide Web Consortium's \(W3C's\) Level AA guidelines](#) for accessibility and may find the [British Web Accessibility Code of Practice: BS8878](#) a useful source of guidance. A helpful summary of the latter document has been [published online by the digital inclusion charity AbilityNet](#).

Organisations should also refer to [accessibility guidance](#) set out in the [Government Service Manual](#) and be aware that the minimum standard for NHS Digital digital application or services is Level AA of the [Web Content Accessibility Guidelines](#) (WCAG) 2.0.

The specific accessibility needs of the users within a local organisation using the system should also be taken into account.

It should be noted that web pages which follow accessibility principles (including being properly structured and tagged) are easier to convert into other formats, often by automated means. When considering web accessibility, organisations are advised to ensure that they involve end-users (including patients / service users with different types of disability, impairment or sensory loss) at every stage, follow approaches to design and testing widely known to work in the accessibility field, and communicate with users via an accessibility policy and / or statement.

Organisations should consider the needs of all patients / service users when designing, (re-)developing and evaluating the accessibility of their website(s), including those with a disability, impairment or sensory loss. For example, as well as being accessible for users of assistive technology, such as screen readers, consideration should be given to ensuring that websites are easy to navigate, written in plain English and include information in alternative formats such as easy read and British Sign Language video. All videos should include subtitles or 'closed captions'

Appendix f – Example consent form for communication via email or text message

The example consent form below may be customised for use by individual organisations, and 'email communication' replaced with 'text message communication' and 'email address' replaced with 'mobile telephone number' if appropriate.

[.....Insert name of organisation.....]

Patient / service user consent for email communication

I understand that I choose to make use of the email communication service with the [name of department / unit] at [insert name of organisation].

I confirm that I have had explained to me by [insert name and job title / role of staff member], how this email communication works and the type of communication that can take place via email. I also confirm that I have read and will comply with the requirements outlined in the patient information leaflet / fact sheet [delete / amend as appropriate].

I would like to communicate with [insert name of department / unit] by email. I understand that internet email is not a secure medium. I understand that there is a possibility that my emails and the responses could be intercepted and read by someone else. I will bear this in mind in deciding how much information to seek and how much information to disclose by email. I understand that if I require urgent clinical advice or attention I should contact my GP.

My email address for communication is:

Patient / service user's name: Date: __ / __ / ____

Patient / service user's signature:

On behalf of [insert name of department / unit and organisation]

Name: _____ Date: _____

Position: _____ Signature: _____

Appendix g – Considering patient / service user communication: additional advice for information governance leads

Information governance leads will be aware of the key role patient / service user communication plays in the lawful use and flows of patient / service user data. As the Standard will identify individuals with specific communication needs, this requires detailed consideration of what should be put in place.

For example:

- Where fair processing, privacy notices and other material is provided about how patient / service user data will be used and shared (to meet Principle 1 of the [Data Protection Act 1998](#) to be 'fair') – consider what additional material or options need to be available for staff and for patients, service users, carers and parents.
- Where an explicit consent process to use or share data is used, support should be in place to make sure those with identified information and / or communication needs are adequately informed when they give consent.
- In circumstances where implicit consent is used, consider whether patients / service users with information and / or communication needs require additional information to demonstrate that the proposed use of data meets reasonable expectations i.e. that on average they would find the proposed use a sensible and desirable action to support their direct care.

Developing a communication plan and material to support patients, service users, carers and parents with information and communication needs relating to a disability, impairment or sensory loss will require the expertise and input of staff across the organisation not just the information governance function.

Note on the GDPR

The [General Data Protection Regulation \(GDPR\)](#) will replace the [Data Protection Act 1998](#) as the key legal framework from 25.05.18. It is likely that this will have an impact on many, if not all, information standards, including the Accessible Information Standard. Further advice and guidance will be provided as appropriate and in due course.