



Accessible Information: Specification

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Document Status

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Prepared by: Sarah Marsay, Public Engagement Account Manager, NHS England.

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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

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

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

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

2 Contacts

All enquiries regarding implementation of the Accessible Information Standard should be directed to NHS England by emailing england.nhs.participation@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

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

The Standard applies to service providers across the NHS and adult social care system, and effective implementation will require such organisations to make changes to policy, procedure, human behaviour and, where applicable, electronic systems. Commissioners of NHS and publicly-funded adult social care must also have regard to this standard, in so much as they must ensure that contracts, frameworks and performance-management arrangements with provider bodies enable and promote the Standard’s requirements.

Successful implementation will lead to improved outcomes and experiences, and the provision of safer and more personalised care and services to those individuals who come within the Standard’s scope.

The scope of the Standard is significant and so is its intended impact. It is unashamedly ambitious in seeking to set the framework and provide clear direction for a dramatic improvement in the ability of the NHS and adult social care system to meet the information and communication support needs of disabled people. Applicable organisations have a legal duty to follow this standard; however, the moral and ethical imperative in this case is also compelling.

Significant support to enable effective, efficient implementation is to be made available to organisations, as outlined in the Implementation Plan, along with detailed Implementation Guidance. The Standard allows for flexibility in implementation approaches, subject to successful achievement of the stated requirements and outcomes.

4 Background and context

4.1 Legal, strategic and policy context

The [Equality Act](#) became law in October 2010. It replaced, and aimed to improve and strengthen, previous equalities legislation, including the Disability Discrimination Act 1995. The Equality Act (the Act) covers all of the groups that were protected by previous equality legislation, known as Protected Characteristics, one of which is [disability](#).

The Act places a legal duty on all service providers to take steps or make “reasonable adjustments” in order to avoid putting a disabled person at a substantial disadvantage when compared to a person who is not disabled. [Guidance](#) produced by the Equality and Human Rights Commission (EHRC) states that, “Anything which is more than minor or trivial is a substantial disadvantage.” The Act is explicit in including the provision of information in “an accessible format” as a ‘reasonable step’ to be taken.

In addition, the [Care Act 2014](#) details specific duties for local authorities with regards to the provision of advice and information, this includes the requirement that, “Information and advice provided under this section must be accessible to, and proportionate to the needs of, those for whom it is being provided.” The [NHS Constitution](#) also states that, “You have the right to be involved in discussions and decisions about your health and care...and to be given information to enable you to do this.”

Many professional bodies and regulators include support for communication and / or understanding as part of their codes of conduct for members or similar statements of expected behaviour. For example, [The Code: Professional standards of practice and behaviour for nurses and midwives](#) (Nursing and Midwifery Council, 2015) states that, “you must:...take reasonable steps to meet people’s language and communication needs, providing, wherever possible, assistance to those who need help to communicate their own or other people’s needs” and “use a range of verbal and non-verbal communication methods...”

In addition, the Standard should be considered by NHS organisations as part of applying and implementing [EDS2](#) (‘Equality Delivery System 2’), including as a tool and guide for improving performance.

4.2 Evidence of need

Despite the existence of legislation and guidance – as outlined above – in reality many service users continue to receive information from health and social care organisations in formats which they are unable to understand and do not receive the support they need to communicate. This includes, but is not limited to, people who are blind or have some visual loss, people who are d/Deaf or have some hearing loss, people who are deafblind, and people with a learning disability.

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The impact of the current lack of consistency and clarity around the identification, recording, flagging and sharing of individuals' information and communication support needs cannot be over-estimated, for example:

The [final report of the Confidential Inquiry](#) into premature deaths of people with learning disabilities (CIPOLD) published in March 2013 found that, "The lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly attendance at clinic appointments and investigations, was a contributory factor in a number of deaths. GP referrals commonly did not mention learning disabilities, and hospital flagging systems to identify people with learning disabilities who needed reasonable adjustments were limited."

In 2013 Action on Hearing Loss (formerly the Royal National Institute for Deaf People (RNID)) published [Access all Areas?](#) The report showed that 28% of people with hearing loss had left their GP unclear about a diagnosis, and 19% had been unclear about their medication. 14% of people with hearing loss had missed an appointment due to not hearing their name being called in the waiting room. Separate research from SignHealth entitled [Sick of it](#), published in 2014, found that British Sign Language (BSL) users had worse health outcomes than the general population. They estimated that missed diagnosis and poor treatment for BSL users was costing the NHS £30 million per year.

The Accessible Information Standard is very clearly in line with current health and social care strategy and policy that supports the reduction of inequalities, enhanced personalisation and choice, greater empowerment of service users as equal partners in their own care, improved transparency and access to information. These are key themes in the [NHS Five Year Forward View](#) and the importance of access to advice and information is one of the fundamental components of the [Care Act 2014](#). It is also in line with the Care Quality Commission's commitment to ensuring safe, effective, compassionate, high quality care for people who use health and social care services.

The Standard also specifically supports the response to the tragedies at [Mid Staffordshire NHS Foundation Trust](#) and [Winterbourne View Hospital](#), where patient and carer voices were not heard – to devastating effect. "A key theme running through the Francis Report was the observation that patients, their carers and families were not listened to during and after care... This is a particular concern for older people and other groups whose voice can sometimes be harder to hear and where we need to listen more carefully." "The patients at Winterbourne View were not listened to or believed when they told people about abuse. Their families were often not involved in decisions about where they were sent, parents and siblings found it increasingly difficult to visit and families' concerns and complaints were not acted on..."

A key reference publication is '[The power of information](#): Putting all of us in control of the health and care information we need (Department of Health, May 2012),' which made clear that, "For those of us who need support in accessing information, health and care professionals as 'information givers' have a vital role... This includes thinking about language and interpretation support and ensuring that all

communications are in formats that each of us – as the individual recipient of the care – can understand.”

Further information about the anticipated impact of the Standard is included in section 13, and additional exploration of current practice with regards to accessible information and communication support is included in the Implementation Plan.

4.3 Clinical record keeping

The Standard provides indicative content for the ‘special requirements’ sub-heading set out in [‘Standards for the clinical structure and content of patient records’](#), published in July 2013 by the Health and Social Care Information Centre (HSCIC) and the Academy of Medical Royal Colleges (AoMRC), and developed by the Health Informatics Unit, Clinical Standards Department, Royal College of Physicians (RCP). “This document describes standards for the structure and content of patient records, covering hospital referral letters, inpatient clerking, handover communications, discharge summaries and outpatient letters. They have been developed using published evidence and consultation with doctors, patients, nurses and allied healthcare professionals. The standards were signed off as fit for purpose for the whole medical profession by the Academy of Medical Royal Colleges (www.aomrc.org.uk) in April 2013.”

Engagement with the RCP and AoMRC will continue post-approval with a view to including specific reference and direction as to the inclusion of the data items associated with the four subsets of this standard as part of the ‘special requirements’ heading.

4.4 Supporting 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 \(Department of Health, 2013\)](#)
- [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 \(Department of Health, 2001\)](#)

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- [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 \(Equality Act 2010 Guidance of your rights, Volume 5 of 9\) \(Equality and Human Rights Commission, 2011\)](#)

5 Scope

5.1 Purpose and definition of the Standard

The Accessible Information Standard directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting individuals' information and communication support needs by NHS and adult social care service providers.

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');

Such that they are not put "[at a substantial disadvantage...in comparison with persons who are not disabled](#)" when accessing NHS or adult social services. This includes accessible information and communication support to enable individuals to:

- Make decisions about their health and wellbeing, and about their care and treatment;
- Self-manage conditions;
- Access services appropriately and independently; and
- Make choices about treatments and procedures including the provision or withholding of consent.

Note that [guidance](#) produced by the Equality and Human Rights Commission (EHRC) states that, "Anything which is more than minor or trivial is a substantial disadvantage."

It is these ultimate aims which govern the scope of the Standard (and should be referred to by organisations in any doubt about applicability having exhausted the advice below and that contained within the Implementation Guidance).

5.2 Scope – required activities

In implementing the Standard, applicable organisations are required to complete five distinct stages or steps leading to the achievement of five clear outcomes:

- 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 specified English definitions indicating needs, where systems are not compatible with any 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.

5.3 Applicable organisations

The list of organisations which must have regard to information standards is defined within the [Health and Social Care Act 2012](#).

The Accessible Information Standard applies to – and therefore must be implemented and adhered to by – all providers of NHS and publicly-funded adult social care. This includes (but is not limited to) the following organisations:

- All providers of NHS care or treatment;
- All providers of publicly-funded adult social care;
- Adult social care or services bodies (in their role as service providers);
- Independent contractors providing NHS services including primary medical services (GP practices), dental services, optometric services and pharmacy services;
- NHS Foundation Trusts and NHS Trusts;
- Providers of NHS and / or adult social care from the voluntary and community or private sectors;
- Providers of public health services, including advice and information.

The Standard must also be implemented and adhered to by suppliers of IT systems, software and hardware to health and adult social care organisations and providers.

Note that because the Standard is concerned with enabling individuals to make decisions about their own health and care, organisations who make contact with individual service users (for example to invite them to attend screening or vaccination) are included within the scope of the Standard as the outcome of their correspondence / the information they provide (and an individual's ability to read and understand this information) may have a direct impact on their health or wellbeing.

Although commissioners are exempt from implementing the Standard themselves, they must 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.

5.4 In scope

The scope of the Accessible Information Standard encompasses activities which relate to:

- Patients or service users of publicly-funded health or adult social care, or their parents or carers.
- Patients or service users of all publicly-funded health or adult social care, or their parents or carers, including (but not limited to) that received as an inpatient or outpatient, as part of urgent or emergency care, routine or elective care, acute care, day-care, and long-term and residential care.
- Information or communication support needs or requirements which are caused by or related to a disability, impairment or sensory loss.
- An individual's need or requirement for information or correspondence in an alternative (non-standard print) format including print alternatives such as braille, and electronic and audio formats.
- An individual's need or requirement for communication support.
- An individual's need or requirement for a longer appointment to enable effective communication / the accessible provision of information.
- An individual's use of communication tools or aids.
- An individual's need or requirement for support from an advocate to support them in communicating effectively.
- An individual's use of alternative or augmentative communication tools or techniques.
- The detail or specific type of alternative format or communication support which is needed or required by the patient, service user, carer or parent.
- All information provided to individuals with particular information or communication support needs including 'personal' or 'direct' communication (for example appointment letters or prescriptions) and 'generic' / 'indirect' communication (for example leaflets or manuals).

5.5 In scope – service user groups

The scope of the Standard extends to individuals (patients and service users, and where appropriate the parents and carers of patients and service users) who have information and / or communication support needs which are related to or caused by a disability, impairment or sensory loss. This includes needs for: information in 'non-standard', alternative or specific formats; use of specific or alternative contact methods; arrangement of support from a communication professional (for example a deafblind manual interpreter or British Sign Language interpreter); and support to communicate in a different or particular way / to use communication aids (for example to lipread or use a hearing aid).

The Standard is, therefore, of particular relevance to individuals who have sensory loss (including people who are blind, d/Deaf or deafblind) and people who have a learning disability. However, it will also support people who have other 'communication disabilities' such as aphasia, autism or a mental health condition which affects their ability to communicate.

Individuals with any form or type of disability (or impairment) which affects their ability to read or receive information, to understand information, and / or to communicate, are within the scope of this standard.

5.5.1 Explanatory note about mental health service users

The Standard includes the provision of information in alternative formats and communication support to mental health service users to support their access to, involvement in decisions about and receipt of NHS and adult social care. However, communication support which is needed by or provided to a patient or service user as part of an agreed mental health care plan or other mental health pathway of care – and which may be termed 'therapeutic' in nature – is outside of the scope of this standard.

Decision-making support under the [Mental Capacity Act 2005](#) is also out of scope (see '5.6 Exclusions'). The distinction between 'support to communicate' (in scope) and 'support to make decisions' (out of scope) should be noted.

Further advice with regards to mental health service users is included in the Implementation Guidance.

5.6 Exclusions

5.6.1 Key aspects determined to be out of the scope of this standard

The following aspects, which may be considered relevant to improving the accessibility of health and social care, are explicitly out of scope of this standard:

- The needs or preferences of staff, employees or contractors of the organisation (except where they are also patients or service users (or the carer or parent of a patient or service user)).

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- Recording of demographic data / protected characteristic strand affiliation.
- Recording of information or communication requirements for statistical analysis or central reporting.
- Expected standards of general health and social care communication / information (i.e. that provided to individuals without additional information or communication support needs).
- Individuals' preferences for being communicated with in a particular way, which do not relate to disability, impairment or sensory loss, and as such would not be considered a 'need' or 'requirement' (for example a preference for communication via email, but an ability to read and understand a standard print letter).
- Individuals who may have difficulty in reading or understanding information for reasons other than a disability, impairment or sensory loss, for example due to low literacy or a learning difficulty (such as dyslexia) (as distinct from a learning disability).
- Expected standards, including the level of accessibility, of health and social care websites.
- 'Corporate' communications produced / published by organisations which do not relate to direct patient / service user care or services, and do not directly affect individuals' health or wellbeing.
- Implementation of the [Equality Act 2010](#) more widely, i.e. those sections that do not relate to the provision of information or communication support. This exclusion includes other forms of support which may be needed by an individual due to a disability, impairment or sensory loss (for example ramps or accommodation of an assistance dog).
- Foreign language needs / provision of information in foreign languages – i.e. people who require information in a non-English language for reasons other than disability.
- Matters of consent and capacity, including support for decision-making, which are not related to information or communication support.
- Standards for, and design of, signage.

5.6.2 Explanatory note about foreign languages

The provision of foreign or non-English language interpretation or translation is out of the scope of this standard. Organisations MAY record details of individuals' need for

foreign language interpretation or translation alongside recording of information and communication support needs in line with the Standard, but this is optional.

The rationale for the exclusion of foreign language interpretation and translation from the scope of this standard is primarily two-fold:

- i. The legal position differs: the Equality Act 2010 duty to make reasonable adjustments relates specifically to people with a disability – and this is the primary legal framework for the Accessible Information Standard.
- ii. The level of burden placed upon organisations would be highly variable (and in some cases far more significant): due to huge national, regional and local variations in the numbers of people needing foreign language interpretation / translation, the level of burden placed by any national framework would vary substantially between different organisations depending on their geographical location. With regards to foreign language needs, there is no such thing as a ‘typical’ GP practice or local authority, for example, suggesting that a single national standard to meet such needs may be inappropriate.

5.6.3 Explanatory note about individuals with low literacy / a learning difficulty

Individuals who may have difficulty in reading or understanding information for reasons other than a disability, impairment or sensory loss, for example due to low literacy or a [learning difficulty](#) (such as dyslexia) (as distinct from a learning disability), are excluded from the scope of the Standard. This is in line with the Standard’s focus on individuals with information and communication needs related to or caused by a disability, impairment or sensory loss – who are therefore protected by the [Equality Act 2010](#).

A definition of learning disability is included in the Standard’s glossary, and is also defined by the Department of Health in [Valuing People \(2001\)](#) as follows:

“Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development.”

The same document also clarifies that, “‘Learning disability’ does not include all those who have a ‘learning difficulty’ which is more broadly defined in education legislation.” For further guidance with regards to learning difficulties see for example, [Section 139A Learning Difficulty Assessments Statutory Guidance \(Department for Education 2013\)](#) and / or [Special educational needs and disability code of practice: 0 to 25 years](#) (Department for Education and Department of Health January 2015).

NHS England recognises the importance of enabling everyone to have access to information about their health and care which is accessible and appropriate for them,

and this is being taken forward as part of a wider 'high quality accessible information' work programme which encompasses health literacy and related matters.

It is also hoped that the impact of this standard provides further evidence by way of demonstrating the benefit of accessible information, and thus supports wider behaviour and culture change with regards to accessibility, inclusion and personalisation, which ultimately has benefits far wider than those individuals within the Standard's scope, including those with learning difficulty and / or low literacy.

5.6.4 Explanatory note about health and social care websites

The accessibility of health and social care websites is out of scope of the Accessible Information Standard. However, the Standard remains relevant in circumstances where a health or social care professional would usually refer a patient or service user (or their carer or parent) to a website for information. In these instances, it will be the duty of the professional – or their employing organisation – to verify that the website is accessible to the individual and, if it is not, to provide or make the information available in another way. For example, if a GP would usually direct a patient newly-diagnosed with Diabetes to information on the Practice's website about Diabetes, he or she would need to check with the patient that they are able to use the website for this purpose. If, because the website is inaccessible to them, they are not, the GP will need to provide the information in an alternative format, for example as a paper copy, via email or on audio CD.

Organisations are therefore advised (although not required) to review and if necessary take steps to improve the accessibility of their website(s) as part of preparation to implement the Standard – as increasing web and digital accessibility will reduce (although never remove) the need to produce information in alternative formats.

Information about web accessibility standards is included as part of Implementation Guidance, and will be included as part of resources to support implementation (as outlined in the Implementation Plan).

A future information standard covering web and digital accessibility may be developed in the future (see section 6). Note that, whereas the Accessible Information Standard (this Standard) is directed at information-givers and information producers, any information standard covering web and digital accessibility would be directed at web and digital developers and commissioners (a distinctly separate professional group).

5.6.5 Explanatory note about commissioning organisations

As outlined above, this standard is concerned with the provision to individuals of information and communication support to enable them to access services appropriately and to make decisions about their own health, care and wellbeing. Therefore, the Standard applies to – and must be implemented and followed by – providers of NHS and / or adult social care (and IT system suppliers) and not commissioners (except where commissioning organisations also provide services / have direct contact with patients / service users).

However, commissioners of NHS and publicly-funded adult social care MUST have regard to this standard, in so much as they must ensure that they enable and support compliance through their relationships with provider bodies (see section 8).

In addition, it is intended that the Standard sends out a strong signal to all organisations – including commissioning bodies – as to the importance of accessible information and communication support and the integral role played by effectively identifying, recording, flagging, sharing and meeting individuals' needs as part of safe, effective, high quality, personalised care.

5.6.6 Explanatory note about 'corporate communications' including consultation

As outlined above, 'corporate communications' which are aimed at informing people about the activities or intentions of an organisation – and have no impact on individuals' health, wellbeing or access to services – are excluded from the scope of this standard. Examples of typically excluded publications would include annual reports and accounts, strategy and policy documents, meeting papers, consultation documents and reports.

In noting this exclusion from the Standard's scope, organisations are reminded of their existing legal obligations under the [Equality Act 2010](#) and [Health and Social Care Act 2012](#) to respond to requests for information, to reduce inequalities and to avoid discriminating against 'protected characteristic' groups when making decisions about the publication and availability of corporate documents in alternative languages and formats. In the case of consultation and engagement activities, organisations are recommended to consult the NHS England publication '[Transforming participation in health and care](#)' for guidance about accessibility and inclusivity.

5.6.7 Explanatory note about signage

Signage is outside of the scope of '[information standards](#)' and therefore not included in the scope of this standard.

The importance of accessible signage in enabling independent access to health and social care services is recognised however, and it is hoped that the increase in awareness about accessibility associated with implementation of this standard will lead, indirectly, to improvements.

Advice about accessible signage for NHS organisations and service providers is available on the [NHS Identity website](#) and as part of '[Wayfinding](#)' (Department of Health, 2005).

6 Related and future standards

6.1 Related standards

The Accessible Information Standard is a new information standard and will not lead to any superseding or retirement of existing information standards. However, a number of existing information standards are recognised to be of particular relevance to the Accessible Information Standard, as follows:

- [Secure Email](#) (ISB 1596)
- [Mental Health and Learning Disabilities Data Set \(MHLDDS\) \(SCCI0011\)](#)

The following information standards should also be referred to by organisations to ensure safe and effective implementation of the Standard:

- [Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems \(ISB 0160 Amd 38/2012 Version 2\)](#)
- [Clinical Risk Management: its Application in the Manufacture of Health IT Systems \(ISB 0129 Amd 39/2012 Version 2\)](#)
- [Information Governance Standards Framework \(ISB 1512\)](#)
- [ISB Information Governance baselines](#)
- [Read Codes \(ISB 1552 and 1553\)](#)
- [SNOMED CT \(ISB 0034\)](#)

Post-approval, this standard is expected to require reflection in other information standards as part of their scheduled review processes.

Whilst not an 'information standard', further engagement with relevant bodies as to inclusion / direction as part of the '[Standards for the clinical structure and content of patient records](#)' will also be explored (see section 4.3).

6.2 Future standards

Once the Standard has been implemented, NHS England will continue to have strategic oversight and provide governance for future developments including periodic review of the Standard, changes and future development of the Standard and (if appropriate) eventual withdrawal of the Standard. Future developments might include:

- A data set or central data collection;
- Changes to the data items;
- Development of related information standards with regards to:
 - Web and digital accessibility;
 - Accessible information and communication support for service user groups excluded from the scope of this standard;
- Standardisation of flow mechanisms and data formats.

Further detail is included in the Implementation and Maintenance Plans.

7 Requirements – health and social care providers

7.1 Definitions

The definitions of the key words MUST, SHOULD and MAY are taken from the [Internet Engineering Task Force Best Current Practice Document](#). Other terms used below and elsewhere in this Specification are defined as follows:

Term	What it stands for
Organisations	Organisations required to implement and comply with the Accessible Information Standard, that is: <ul style="list-style-type: none"> • Adult social care bodies; • NHS bodies including (but not limited to) NHS Trusts and NHS Foundation Trusts; • Providers of publicly-funded (NHS) health care including (but not limited to) independent contractors and private sector providers; • Providers of publicly-funded adult social care or services including (but not limited to) care homes, nursing homes and day care.
Professionals	Employees or contractors of organisations to which the Accessible Information Standard applies, i.e. people providing services in a professional capacity for or on behalf of organisations.
Relevant staff	Employees of organisations to which the Accessible Information Standard applies who have a patient or service user contact role and / or responsibility for accessing or utilising patient / service user records, whether this is in a clinical or non-clinical capacity.
Individual	A patient or service user, or the parent or carer of a patient or service user, with information or communication support needs relating to a disability, impairment or sensory loss.
Carer	A patient or service user's main informal carer (defined by ISB 1580: End of Life Care Co-ordination: Core Content as "The individual, excluding paid carers or carers from voluntary agencies, identified by the person to hold major responsibility for providing their informal care and support." ISB 1580 also includes a note that, "The main informal carer will be identified by 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 informal carer, as well as other important or regular informal (unpaid) carers.
Parent	A person with parental responsibility for an individual under 18 years of age or, where the individual lacks capacity, of any age.
Highly visible	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: <ul style="list-style-type: none"> • Obvious and overtly apparent; and • Visible on the cover, title and / or 'front page' of a document, file or electronic record; and • Visible on every page of an electronic record (for example as an

	<p>alert, flag or banner); and / or</p> <ul style="list-style-type: none"> 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.
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Note that, in implementing the Standard, all professionals and organisations should take care to ensure that they follow 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.

7.2 Requirements

#	Requirement
Implementing the Standard: Procedures, Systems and Governance	
1.	Organisations MUST effectively prepare for implementation of the Standard, including assessing their current systems and processes, and developing and rolling out a local implementation plan.
2.	Organisations SHOULD refer to and utilise the Implementation Guidance accompanying this standard to steer decisions.
3.	Organisations MUST review their current patient or service user administration and record systems, platforms, processes and documentation and, if necessary, update, change or replace those systems so that they conform to the Standard by 31.07.16.
4.	From 01.04.16, organisations developing, implementing and / or contracting for new electronic patient or service user record or administration systems MUST specify compliance with this information standard in IT systems and software supplier contracts.
5.	Information governance leads MUST review the information governance implications of implementation of the Standard within their organisation(s), and if necessary plan for and implement mitigating actions to address any identified risks such that they are as low as reasonably possible.
6.	Clinical governance, social care governance and IT safety leads MUST consider and take mitigating action to address the identified hazards as outlined in the Clinical Safety Case and any other locally identified risks or hazards associated with implementation of the Standard such that they are as low as reasonably possible.
7.	Clinical leads and adult social services team leaders / service managers SHOULD review the Implementation Guidance accompanying this standard and consider whether changes are required to current professional practice, business practices, training and local policies / pathways.
8.	Organisations MUST establish a clear, stepwise approach (or procedure) which all professionals and relevant staff are supported to follow to enable consistent, effective compliance with the Standard as part of 'business as usual'. This MUST include a clear procedure for the accurate and consistent identification, recording, flagging and sharing of the data items or categories defined by the Standard. It MUST also include a clear and locally well-known procedure for ensuring that such needs are met.
Implementing the Standard: Workforce, Human Resources and Training	
9.	Organisations MUST review the ability of their workforce to implement the

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	Standard and, if necessary, plan for and implement a training and / or awareness programme so that conformance with the Standard is achieved by 31.07.16.
10.	Organisations MUST provide, arrange for and / or support relevant staff to receive any training which is identified as locally necessary to enable effective implementation of the Standard.
11.	Organisations SHOULD support their staff to access training and resources offered by NHS England to support implementation of the Standard.
Ongoing Compliance with the Standard: Identification and Recording of Needs	
12.	<p>Professionals MUST identify and record the information and / or communication needs of their patients and service users – and where appropriate their carers or parents – where such needs relate to or are caused by a disability, impairment or sensory loss, and:</p> <ul style="list-style-type: none"> • 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.
13.	Professionals and relevant staff SHOULD proactively prompt individuals to identify that they have information and / or communication needs, and support them to describe the type of alternative format and / or support that they need, at their first or next interaction with the service.
14.	<p>Organisations MUST ensure that the information and / or communication needs of patients and service users – and where appropriate their carers or parents – where such needs relate to or are caused by a disability, impairment or sensory loss, are identified and recorded:</p> <ul style="list-style-type: none"> • Upon registration with the service; • As part of the initial contact or interaction with the service; • In an emergency or urgent care scenario, as soon as is practical after initial interaction with the service; • At first appointment; • Upon receipt of a 'certificate of vision impairment' from an ophthalmologist; • Upon receipt of notification that a person has a sensory loss or learning disability; • When a diagnosis or symptoms indicate a new or revised communication or information support need; • As part of a health check; • As part of care or support planning. <p>This MAY require changes to existing electronic and paper recording systems and / or documentation. Electronic recording and administration systems MUST enable recording of information and communication needs in line with the data items or categories associated with the subsets defined by the Standard. Paper-based systems and documentation MUST enable recording of needs in line with the human readable definitions of the data items</p>

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	associated with the subsets defined by the Standard. Systems and documentation MUST be formatted so as to make any record of information or communication needs highly visible.
Ongoing Compliance with the Standard: Verification of Accuracy of Data	
15.	Organisations MUST ensure that information recorded about individuals' information and communication support needs is accurate. Systems for edit checking / 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.
16.	Organisations MUST ensure that data recorded about individuals' information and communication support needs is current. Systems MUST enable records made about individuals' information and communication support needs to be revised and SHOULD include prompts for review at appropriate points.
17.	The individual patient, service user, carer or parent SHOULD be aware of the exact information recorded about their information and communication support needs, including to verify accuracy.
18.	Where online systems enable patients or service users to access their own records, and subject to Data Protection Act 1998 safeguards, such systems: <ul style="list-style-type: none"> • 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.
19.	Professionals SHOULD review, and if necessary update, data recorded about individuals' communication and information needs alongside verification and revision of data held in other demographic fields.
Ongoing Compliance with the Standard: Supporting Documents	
20.	Where an individual has a care plan, the organisation responsible for developing or holding the plan MUST ensure that it includes information about the individual's information and / or communication support needs, recorded in line with the Standard.
21.	Where used, local documents used to support professionals in understanding the information and communication support needs of individuals, such as health passports, communication passports, 'my health need' cards and 'NHS help cards' MUST include information about the individual's information and / or communication support needs (where they exist).
Ongoing Compliance with the Standard: Flagging and Prompts to Action	
22.	Organisations MUST ensure that electronic patient or service user administration and record systems include electronic flags or alerts to indicate that an individual has a recorded information and / or communication need. Such flags MUST be highly visible and MUST 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.
23.	Organisations MUST ensure that paper-based patient or service user administration and record systems include flags or alerts to indicate that an individual has a recorded information and / or communication need. Such flags MUST be highly visible and MUST prompt staff to take appropriate action.
24.	Organisations MUST ensure that electronic patient or service user administration and record systems automatically identify a recorded need for

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	<p>information or correspondence in an alternative format and in response:</p> <ul style="list-style-type: none"> • Automatically generate correspondence or information in an alternative format (preferred); OR • Enable staff to manually generate correspondence in an alternative format upon receipt of an alert. <p>Organisations MUST ensure that a standard print letter is not sent to an individual for whom this is not an appropriate or accessible format (due to automatic generation or any other reason).</p>
Ongoing Compliance with the Standard: Sharing of Needs	
25.	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. All information sharing SHOULD follow existing processes and information governance protocols.
Ongoing Compliance with the Standard: Meeting of Individuals' Needs	
26.	Organisations MUST ensure that patients, service users, carers and parents with information and / or communication needs related to or caused by a disability, impairment or sensory loss have these needs met.
27.	Organisations MUST ensure that patients, service users, carers and parents with information needs (a need for information in a non-standard print format) are sent or otherwise provided with information, including correspondence, in formats which are appropriate, accessible and that they are able to understand.
28.	Organisations MUST ensure that patients, service users, carers and parents with information and / or communication support needs have access to accessible contact methods and are contacted using accessible means.
29.	Organisations MUST ensure that patients, service users, carers and parents are provided with appropriate communication support, including using aids or equipment and / or by staff making adjustments to their behaviour to enable effective communication.
30.	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.
31.	Organisations MUST ensure that communication professionals (including British Sign Language interpreters and deafblind manual interpreters) used in health and social care settings have: <ul style="list-style-type: none"> • Appropriate qualifications; AND • Disclosure and Barring Service (DBS) clearance; AND • Signed up to a relevant professional code of conduct.
32.	Organisations SHOULD ensure that patients, service users, carers and parents with information and / or communication support needs are given a longer appointment where this is needed to support effective communication / the accessible provision of information.
Assessment and Assurance of Compliance with the Standard	
33.	Organisations MUST prepare and publish or display an accessible communications policy or similar which outlines how they will identify, record, flag, share and meet the information and communication needs of patients,

	service users, carers and parents, in line with this standard.
34.	Quality assurance MUST be undertaken by organisations to ensure that the type of communication support or alternative format provided to patients, service users, carers and parents is effective in meeting those needs. Such assurance SHOULD be undertaken in partnership with one or more patient groups.
35.	Individuals MUST be encouraged and enabled to provide feedback about their experience of receiving information in an appropriate format or communication support, including having access to an accessible complaints policy.

7.3 Conformance criteria

- All MUST requirements must be met.
- All SHOULD requirements must be met or there must be a credible, legitimate reason documented for why they have not been.
- MAY requirements are optional.

The following specific conformance criteria should be used to demonstrate conformance.

Conformance criteria
Implementing the Standard: Procedures, Systems and Governance
By 01.09.15 organisations have begun to prepare for implementation of the Standard, including assessing their current systems and processes, and developing and commencing roll out of a local implementation plan.
By 01.09.15 Implementation Guidance accompanying the Standard has been read and used to inform local decision-making.
By 31.07.16 patient / service user administration and record systems, platforms, processes and documentation adhere to the Accessible Information Standard.
By 31.07.16 contracts for patient / service user record and administration systems include the requirement for the system to adhere to the Accessible Information Standard.
By 31.07.16 information governance risks associated with implementation of the Standard have been identified and mitigating actions completed such that residual risks are as low as reasonably possible.
By 31.07.16 clinical and other safety risks associated with implementation of the Standard have been identified and mitigating actions completed such that residual risks are as low as reasonably possible.
By 31.07.16 and following assessment, any and all actions required to change current professional practice, business practices, training and / or local policies / pathways to enable implementation of and compliance with the Standard have been completed.
By 31.07.16 a clear, stepwise approach (or procedure) to ensure compliance with the Standard as part of 'business as usual' is in place and being followed by professionals and relevant staff. There is a high level of awareness of the approach / procedure amongst the workforce.
Implementing the Standard: Workforce, Human Resources and Training
Where identified as necessary following local assessment of the workforce, a

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programme of staff training and / or awareness-raising has been completed (by 31.07.16).
By 31.07.16, staff competency / training records indicate that relevant staff and professionals have received any training identified as locally necessary to enable effective implementation of the Standard, including accessing training and resources offered by NHS England to support implementation of the Standard where appropriate.
Ongoing Compliance with the Standard: Identification and Recording of Needs
By 01.04.16 organisations identify and record information and communication needs when service users first interact or register with their service.
From 01.04.16 organisations identify and record information and communication needs as part of ongoing / routine interaction with the service by existing service users.
By 31.07.16, patient / service user records include consistent population of fields relating to information and communication support needs.
By 31.07.16, staff competency / training records indicate that relevant staff and professionals have received any training identified as locally necessary to enable effective implementation of the Standard.
By 31.07.16 record systems and relevant documentation enable recording of information and communication needs in line with the Standard, and are formatted so as to make any record of information or communication needs highly visible.
Ongoing Compliance with the Standard: Verification of Accuracy of Data
By 31.07.16 quality assurance / edit checking processes are in place to enable verification of the accuracy of data recorded about individuals' information and communication needs.
By 31.07.16 mechanisms are in place to alert, prevent or discourage the population of mutually incompatible data fields associated with individuals' information and communication needs (in line with best practice).
By 31.07.16 systems enable revision / amendment of records made about individuals' information and communication support needs and, where possible, include prompts for review at appropriate points.
By 30.09.16 feedback from patient surveys, PALS (Patient Advice and Liaison Service), local Healthwatch or other sources demonstrates that individuals are aware of the exact nature of the information which has been recorded about their information and / or communication needs.
By 30.09.16, where online systems enable patients or service users to access their own records, there is evidence that individuals have viewed and / or contributed to their records with regards to information and communication needs.
By 31.07.16 data recorded about individuals' information and communication needs is reviewed and refreshed alongside other data held in demographic fields.
Ongoing Compliance with the Standard: Supporting Documents
By 31.07.16 care plans include information about individuals' information and communication needs, where applicable.
By 31.07.16 local documents used to support professionals in understanding the information and communication support needs of individuals (where used) include information about individuals' information and communication needs, where applicable.
Ongoing Compliance with the Standard: Flagging and Prompts to Action
By 31.07.16 electronic patient or service user administration and record systems

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<p>automatically identify a recorded need for information or correspondence in an alternative format and / or communication support, and flag, prompt or otherwise make this highly visible to staff whenever the record is accessed.</p>
<p>By 31.07.16 electronic patient or service user administration and record systems automatically identify relevant recorded needs and either automatically generate correspondence or information in an alternative format or enable staff to manually generate correspondence in an alternative format upon receipt of an alert.</p>
<p>By 31.07.16 systems are in place to ensure that a standard print letter is not sent to an individual for whom this is not an appropriate or accessible format.</p>
<p>Ongoing Compliance with the Standard: Sharing of Needs</p>
<p>By 31.07.16, arrangements and protocols are in place such 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.</p>
<p>Ongoing Compliance with the Standard: Meeting of Individuals' Needs</p>
<p>From 30.09.16 feedback from patient surveys, PALS, local Healthwatch and / or other sources demonstrates that individuals with information and / or communication needs have had those needs routinely and regularly met.</p>
<p>By 31.07.16 records show that individuals with information needs have been sent or provided with information, including correspondence, in formats which are appropriate, accessible and that they are able to understand.</p>
<p>By 31.07.16 there are policies and procedures in place to enable communication support, professional communication support and information in alternative formats to be provided promptly and without unreasonable delay.</p>
<p>By 31.07.16 staff awareness of policies and procedures with regards to provision of communication support and information in alternative formats is high and they are embedded as part of 'business as usual'.</p>
<p>Assessment and Assurance of Compliance with the Standard</p>
<p>By 31.07.16 an accessible communication policy has been published and is publicly available. This policy outlines how the information and communication needs of patients, service users, carers and parents, will be identified, recorded, flagged, shared and met.</p>
<p>By 30.09.16 feedback from patient surveys, PALS, local Healthwatch or other sources demonstrates that individuals with relevant needs have received communication support and / or information in alternative formats which is of a suitable quality and is effective in meeting those needs.</p>
<p>By 30.09.16 feedback has been received from individuals with communication and information needs.</p>
<p>By 31.07.16 there are mechanisms in place for individuals to make a complaint, raise a concern or pass on feedback in alternative formats and with communication support.</p>

8 Requirements – health and social care commissioners

8.1 Definitions

In the table below, ‘commissioners’ refers to “organisations with responsibility for commissioning NHS and / or adult social care”. This includes, but is not limited to, clinical commissioning groups (CCGs), local authorities and NHS England.

8.2 Requirements

#	Requirement
1.	Commissioners MUST ensure that their commissioning and procurement processes, including contracts, tariffs, frameworks and performance-management arrangements (including incentivisation and penalisation), with providers of health and / or adult social care reflect, enable and support implementation and compliance with this standard.
2.	Commissioners MUST seek assurance from provider organisations of their compliance with this standard, including evidence of identifying, recording, flagging, sharing and meeting of needs.

8.3 Conformance criteria

This section describes the tests that can be applied to indicate that a commissioning organisation is complying with the Standard.

Conformance criteria
By 31.07.16 contracts, tariffs, frameworks and performance-management arrangements reflect, enable and support implementation and compliance with the Standard by providers of health and adult social care.
By 01.09.16 commissioners have sought and received assurance from provider organisations of their compliance with this standard, including receipt of evidence of identifying, recording, flagging, sharing and meeting of needs.

9 Requirements – IT system suppliers

9.1 Definitions

In the table below ‘systems’ refers to “patient or service user record and / or administration systems supplied to or used by providers of NHS or publicly-funded adult social care”.

9.2 Requirements

#	Requirement
Overview	
1.	Suppliers of patient or service user record and / or administration systems to providers of NHS and / or adult social care MUST update, change or replace those systems so that they conform to the Standard by 31.07.16.
Design: Safety and Accessibility	
2.	Systems used for the recording of individuals’ information and communication needs SHOULD be designed and built with consideration for the clinical safety risks identified in the Clinical Safety Case published alongside this Specification.
3.	Systems used for the recording of individuals’ information and communication needs MAY allow the patient or service user (or their carer or parent) to access their own record electronically, and to have editing rights for specific fields relating to information and communication.
Functionality: Data Items	
4.	Systems MUST enable recording of all of the data items or categories associated with the subsets defined by the Accessible Information Standard, in their specified format. Local systems MAY hold more information than is required by the Accessible Information Standard.
5.	Systems SHOULD alert users – in line with other review reminders – when none of the data items / categories in any one of the subsets associated with the Standard has been selected.
6.	Systems SHOULD support edit checking / quality assurance of data recorded about individuals’ information and communication needs. This MAY include generating an alert or preventing users from populating mutually incompatible data fields (in line with best practice).
7.	The system MUST allow for changes to the data items associated with the Standard over time, including following release of new or amended SNOMED CT, Readv2 or CTV3 codes (where used by relevant systems), and enabling any locally defined additional information to be captured.
Functionality: Notification or Flagging	
8.	Systems MUST include functionality to notify staff involved – or to be involved in the near future – in the administration or care of patients or service users of their communication and information needs (and where appropriate the needs of patients’ or service users’ parents or carers).
9.	The system MUST automatically identify a recorded need for information or correspondence in an alternative format and / or communication support, and flag, prompt or otherwise make this highly visible to staff whenever the record is accessed.

Functionality: Auto-Generation	
10	Where systems automatically generate correspondence, the system MUST automatically identify a recorded need for information or correspondence in an alternative format and in response: <ul style="list-style-type: none"> Automatically generate correspondence or information in an alternative format (preferred); OR Enable staff to manually generate correspondence in an alternative format (upon receipt of an alert); AND Not produce the standard printed output for sending to the individual.
Functionality: Review	
11	The system MUST enable records made about individuals' information and communication support needs to be revised / amended.
12	The system SHOULD prompt for a review of data recorded about individuals' information and communication needs alongside and concurrent with review of data held in other demographic fields.

9.3 Conformance criteria

This section describes the tests that can be applied to indicate that the Standard is being used correctly by an IT system supplier.

Conformance criteria	
Design: Safety and Accessibility	
By 31.07.16 systems used for the recording of individuals' information and communication needs have been designed and built with consideration for the clinical safety risks identified in the Clinical Safety Case published alongside this Specification.	
By 31.07.16, where online systems and local procedures enable patients or service users to access their own records, the system allows the patient or service user (or their carer or parent) to access the data recorded about their information and / or communication needs.	
By 31.07.16, where online systems and local procedures enable patients or service users to edit their own records, the system allows the patient or service user (or their carer or parent) to edit fields relating to information and communication.	
Functionality: Data Items	
By 31.07.16, systems enable recording of all of the data items or categories associated with the subsets defined by the Accessible Information Standard in their specified format.	
By 31.07.16, systems alert users – in line with other review reminders – when none of the data items or categories in any one of the subsets associated with the Standard has been selected.	
By 31.07.16 systems support edit checking / quality assurance of data recorded about individuals' information and communication needs.	
By 31.07.16 systems generate an alert or prevent or discourage users from populating mutually incompatible data fields when recording individuals' information and communication needs (in line with best practice).	
By 31.07.16 systems allow for changes to the data items associated with the Standard over time, including following release of new or amended SNOMED CT,	

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Readv2 or CTV3 codes (where used by relevant systems), and enable any locally defined additional information to be captured.
Functionality: Notification or Flagging
By 31.07.16 systems include functionality to notify staff involved – or to be involved in the near future – in the administration or care of patients or service users of their communication and information needs (and where appropriate the needs of patients' or service users' parents or carers).
By 31.07.16 systems automatically identify a recorded need for information or correspondence in an alternative format and / or communication support, and flag, prompt or otherwise make this highly visible to staff whenever the record is accessed.
Functionality: Auto-Generation
By 31.07.16, where systems automatically generate correspondence, the system automatically identifies a recorded need for information or correspondence in an alternative format and in response either automatically generates correspondence or information in an alternative format or enables staff to manually generate correspondence in an alternative format (upon receipt of an alert).
By 31.07.16, where systems automatically generate correspondence, the system automatically identifies a recorded need for information or correspondence in an alternative format and in response does not produce the standard printed output for sending to the individual, and alerts staff accordingly.
Functionality: Review
By 31.07.16 the system allows for records made about individuals' information and communication support needs to be revised or amended.
By 31.07.16 the system prompts for a review of data held about individuals' information and communication needs alongside and concurrent with review of data held in other demographic fields.

10 Data management and quality

10.1 Data requirements of the Standard

The Accessible Information Standard is not establishing any new data set or national collection. However, it is specifying recording practices and standards with regards to individuals' information and communication support needs (for use to support direct patient / service user care and access to services / support).

10.2 Terminology and coding

10.2.1 Overview

Whilst not establishing any new data set or national collection, the Accessible Information Standard is concerned with increasing the consistency and clarity of recording practices with regards to individuals' information and communication support needs. Therefore, the Standard has defined four new subsets, listed within the [Data Dictionary for Care \(dd4c\)](#), with associated data items available in SNOMED CT, Read v2 and CTV3.

The four subsets are:

[Accessible information - communication support](#)
[Accessible Information - requires communication professional](#)
[Accessible Information - requires specific contact method](#)
[Accessible Information - requires specific information format](#)

Current SNOMED CT, Read v2 and CTV3 codes / data items associated with the four subsets defined by the Standard MUST be used to record individuals' information and / or communication support needs in line with this standard, where electronic systems use / refer to any one of the three clinical terminologies.

Additional codes / data items have been requested across the three terminologies, and will be made available and associated with the existing subsets in line with the next scheduled biannual release (01.10.15). Further 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.

Where systems do not use / refer to any of the clinical terminologies, and where paper-based systems are used, information about individuals' information and / or communication support needs MUST be recorded using the 'fully specified name' as listed alongside SNOMED CT codes / the 'human readable definitions' of the data items or 'categories'.

Further advice about the data requirements of the Standard is included as part of the Implementation Guidance, under ‘recording of needs.’

10.2.2 Requirements

#	Requirement
Terminology and Coding	
1.	The specified codes MUST be used where electronic systems use / refer to any one of the three clinical terminologies, and these codes MUST be up-to-date in line with scheduled code releases.
2.	In electronic systems which do not use SNOMED CT, Read v2 or CTV codes, and where paper-based systems are used, information MUST be recorded in line with the human readable definitions of the data items (also known as categories) or the ‘fully specified name’ as listed alongside SNOMED CT codes.
3.	NHS organisations and suppliers implementing SCCI1605 Accessible Information MUST refer to ISB 0034 (the SNOMED CT fundamental standard). NHS organisations contracting for new patient record and administration systems must specify that suppliers use SNOMED CT for all coded information within systems that are developed, but there may also be a need to support other coding systems where required for interoperability.

10.2.3 Conformance criteria

Conformance criteria	
Terminology and Coding	
By 31.07.16 systems implementing the Accessible Information Standard use the specified accessible information codes in the native code system with codes up-to-date in line with scheduled code releases. Where there is no native code system, information is classified and recorded using the human readable definitions (fully specified name) of the relevant code / the applicable category.	
By 31.07.16 health and social care organisations and suppliers implementing the Accessible Information Standard use ISB 0034 (the SNOMED CT fundamental standard), and include this in the specification in any new procurement, irrespective of any other coding systems that are also required.	

10.3 Mandatory fields

10.3.1 Requirements

It is mandatory for IT systems to support recording of the data items associated with the subsets defined by the Accessible Information Standard or their human readable definitions / categories.

#	Requirement
Mandatory Fields	
1.	Organisations and systems MUST comply with the Accessible Information Standard in recording individuals’ information and communication support needs, including using defined data items and codes (where relevant terminologies are used in systems or human readable definitions where not).
2.	Recording of this data is REQUIRED, that is, where data is available – i.e. where

	the individual has a need – the data item or its human readable definition / category MUST be supported and populated.
3.	Organisations implementing the Accessible Information Standard MAY decide on any additional content to be included as part of local data collection and recording practice.

10.3.2 Conformance criteria

Conformance criteria
Mandatory Fields
By 31.07.16 systems comply with the Accessible Information Standard through recording individuals' information and communication support needs using defined data items and codes (where relevant terminologies are used in systems) or human readable definitions (where relevant terminologies are not used in systems).
By 31.07.16 where an individual is identified as having a need, the data item or its human readable definition cannot be left blank.

10.4 Data flows

The Standard requires that recorded data 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 processes. All information sharing SHOULD follow existing processes and information governance protocols.

Following publication of the Information Standards Notice (ISN) for the Standard a request will be made to include the data items associated with the subsets defined by the Standard as core or standard content for sharing via the [NHS e-Referral Service](#) and [GP2GP](#). Note that the codes associated with the four subsets of the Accessible Information Standard have been included as part of the '[inclusion dataset](#)' (SCR v2.1) for Summary Care Records (as of April 2015). Consideration will also be given to the future flow of data using the [Electronic Prescription Service \(EPS\)](#).

Further information in this regard is included as part of the Implementation Plan and Implementation Guidance.

10.5 Information governance

#	Requirement
Information Governance	
1.	All IT systems MUST comply with legal information governance requirements, including ISB 0086 Information Governance Toolkit , for data security and confidentiality to ensure security and protection of the data when viewed, transferred and stored. Organisations should also refer to, and ensure that they comply with, any and all relevant professional or sector-specific protocols with regards to information governance in implementing this standard.
2.	Implementation of the Accessible Information Standard MUST follow existing information governance standards and frameworks including complying with ISB 1512 Information Governance Standards Framework

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Guidance around sharing of patients' data with external organisations for the purposes of interpretation, translation or communication support and the use of email to communicate with patients will be provided as part of resources to support implementation (as outlined in the Implementation Plan).

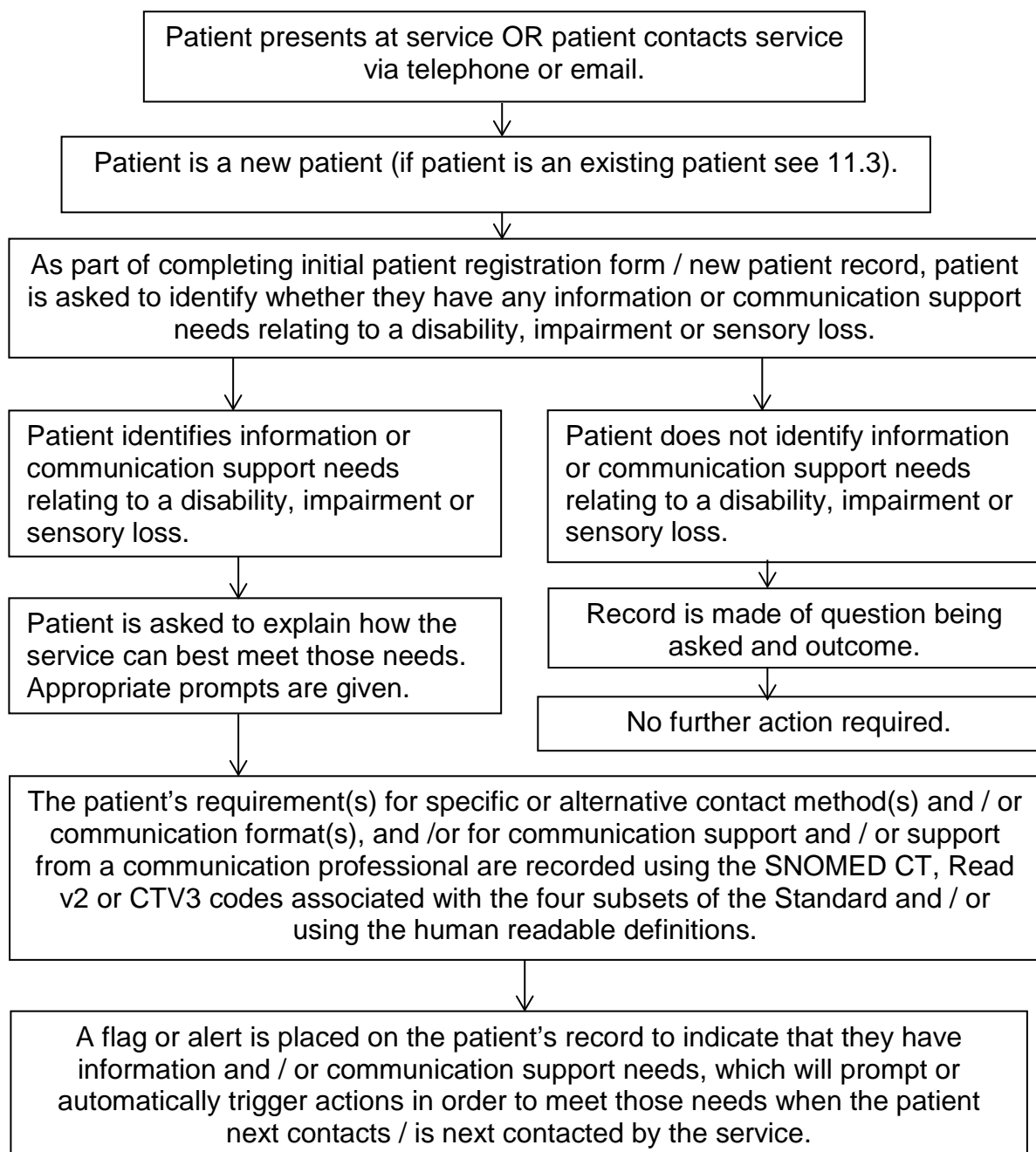
Conformance criteria
Information Governance
By 31.07.16 systems used for the recording of individuals' information and communication needs comply with legal information governance requirements for data security and confidentiality ensuring security and protection of the data when viewed, transferred and stored.
By 31.07.16 systems implementing the Accessible Information Standard follow existing information governance standards and frameworks complying with ISB 1512 Information Governance Standards Framework .

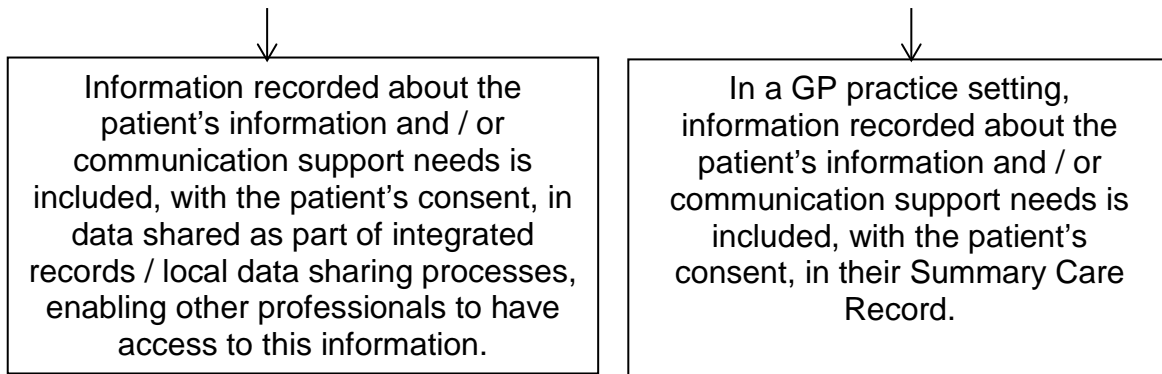
11 High level process

11.1 Overview

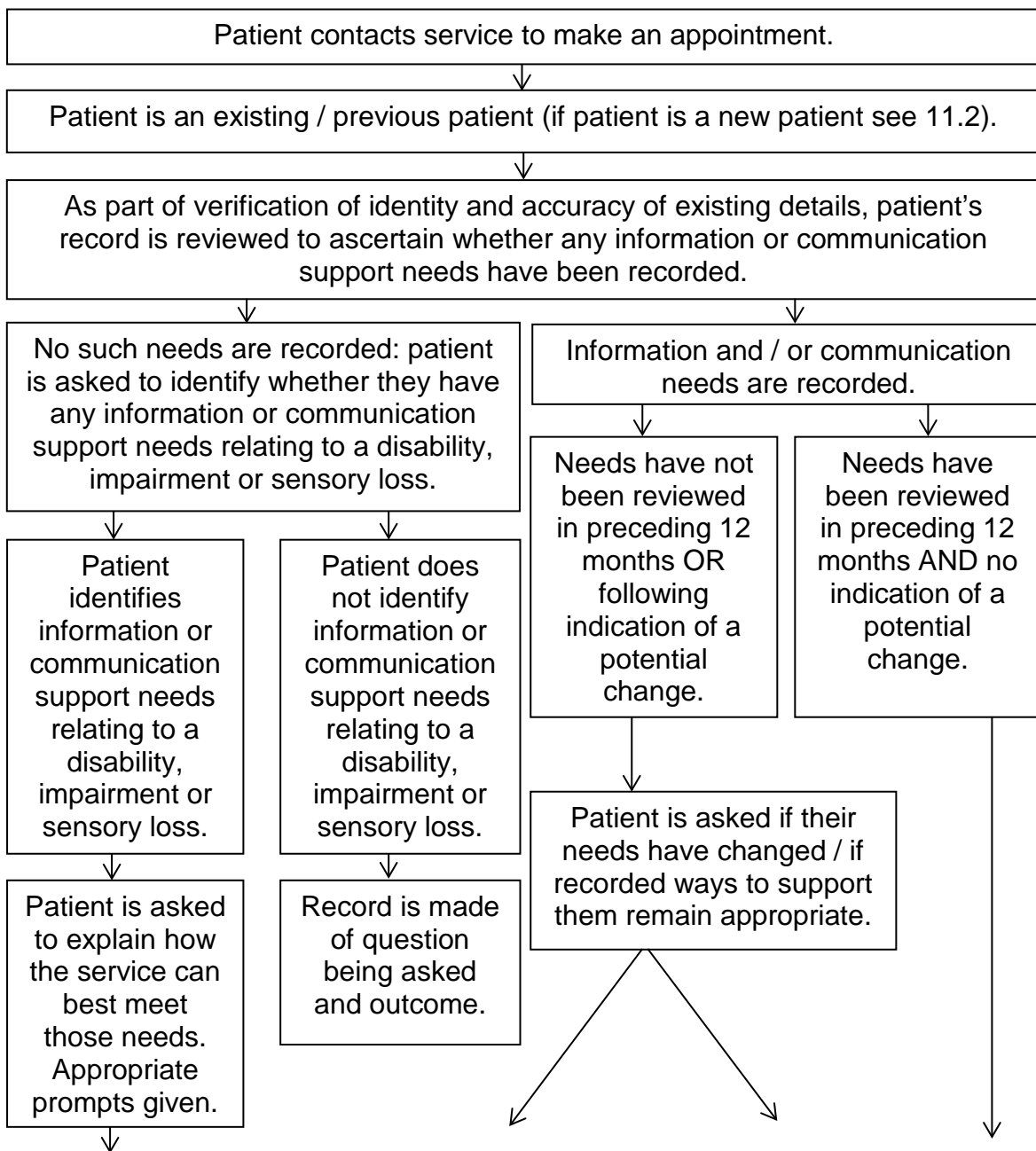
The following diagrams provide a high level overview of how the Standard should work in practice, using two common scenarios. Advice about implementation of the Standard is included as part of Implementation Guidance, and will be expanded upon as part of resources to support implementation (as outlined in the Implementation Plan), which will include additional examples / use cases / scenarios. The diagrams will also be made available separately as part of resources to support implementation.

11.2 New patient registration

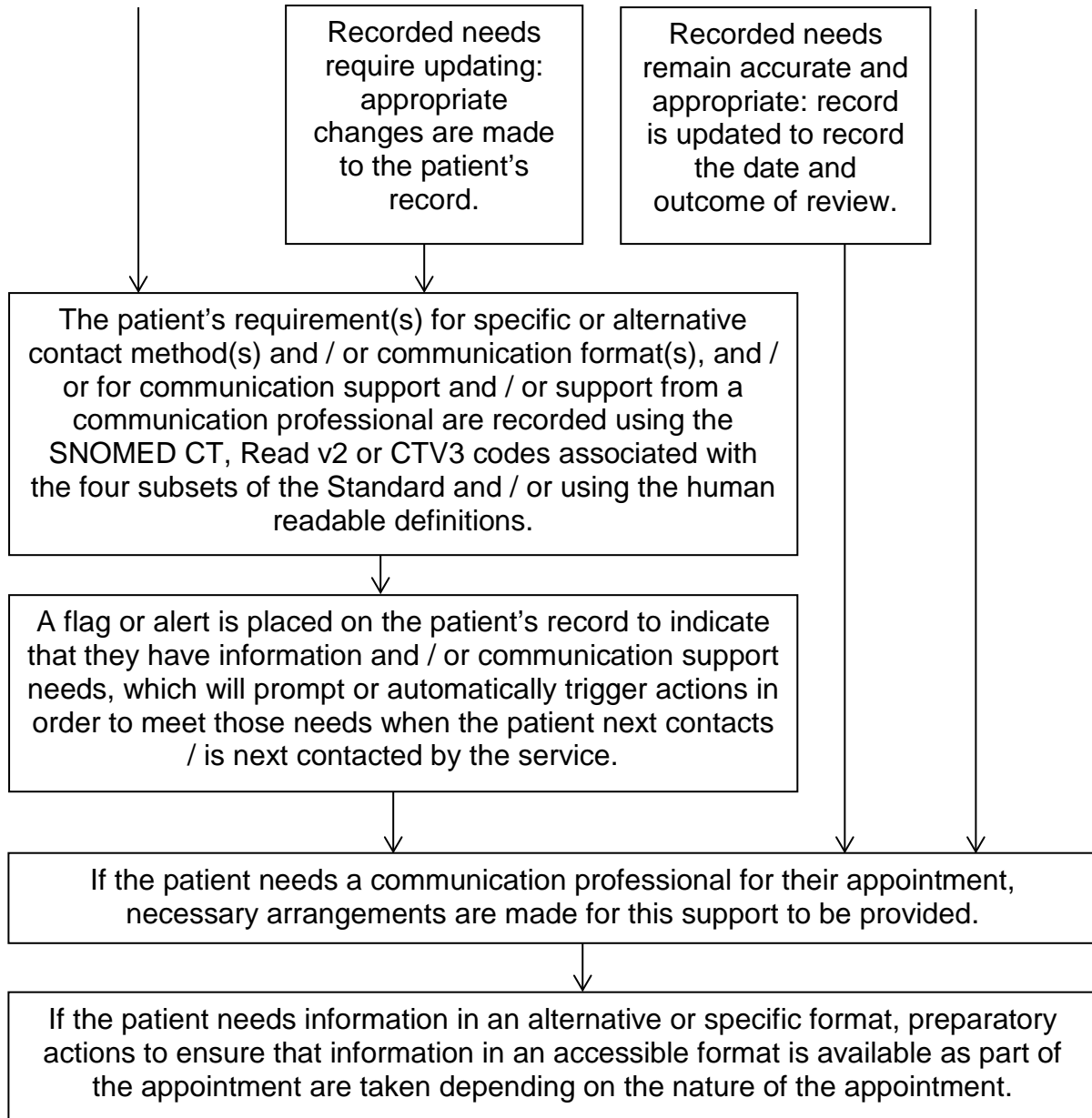




11.3 Existing patient repeat contact to make an appointment



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12 Communication and engagement

12.1 Communication, engagement and consultation activity to date

A coproduction approach has been taken throughout the development of this Standard, ensuring that it has been shaped by health and social care professionals and organisations, other professionals with relevant expertise (such as academics and providers of accessible communications / assistive technology), relevant organisations from the voluntary and community sector, and experts by experience (patients, service users, carers and parents with experience of disability, impairment and / or sensory loss).

An Advisory Group was established to oversee the development of the Standard. This group first met in May 2013 and has now met 10 times. Membership includes: Action on Hearing Loss, CHANGE, Sense and the Royal National Institute of Blind people (RNIB), two patient and public involvement members and representation from NHS England, the Health and Social Care Information Centre (HSCIC), the Care Quality Commission (CQC), Department of Health Directorate of Social Care and the Professional Records Standards Body (PRSB).

There was extensive engagement activity to inform the drafting of the Standard, with over 1200 people giving their views between November 2013 and February 2014. A formal, 12 week consultation on the Standard took place August – November 2014. This enabled individuals and organisations to review and comment on the draft Specification for the Standard and supporting documents. Over 500 people participated in the consultation.

Updates, engagement and consultation documents and reports have been published in a range of formats, including audio, braille, British Sign Language and easy read, to reflect the nature of this standard.

Further engagement with health and social care professionals and providers, and with IT system suppliers, has been achieved as part of the testing and piloting phases, and through additional more targeted communication and engagement activity, including:

- Attendance at the GP IT New Requirements Group (NRG) meeting on 01.05.14;
- Hosting of two 'effective implementation' workshops on 27.03.15 and 14.04.15;
- A presentation at the GP Supplier Terminology Specialist Interest Group on 16.04.15.

Further information is included in the Report of Engagement, Report of Consultation, Test Report, Pilot Report and Report of Effective Implementation Workshops.

In recognition of the extent of the coproduction approach, and demonstrating the level of external interest and support for this standard, particular thanks are due to those who have contributed significant time and energy to share their enthusiasm and expertise to inform the Standard, including Advisory Group members, test partners (Cambridge University Hospitals NHS Foundation Trust, Devon Doctors, Leeds and York Partnership NHS Foundation Trust, Manchester City Council –

Sensory Team, South Tees Hospitals NHS Foundation Trust), pilot sites (Berkshire Healthcare NHS Foundation Trust, Cambridge University Hospitals NHS Foundation Trust, City of Bradford Metropolitan District Council, Dorset HealthCare University NHS Foundation Trust, East Lancashire Hospitals NHS Trust, Ellison View Surgery (Hebburn), NHS Bradford City and Bradford Districts Clinical Commissioning Groups, GTD Healthcare, The Clatterbridge Cancer Centre NHS Foundation Trust and The Phoenix Medical Centre in partnership with Dynamic Health Systems) and professionals from Sheffield Teaching Hospitals NHS Foundation Trust, Tees, Esk and Wear Valleys NHS Foundation Trust, Mid Yorkshire Hospitals NHS Trust, SignHealth, and the Worshipful Company of Information Technologists.

A full list of stakeholders who have been involved in the development of the Standard is available at appendix c.

12.2 Communication Plan

A Communication Plan is available. This aims to support effective implementation of the Accessible Information Standard alongside the Implementation Plan. The Communication Plan outlines key stakeholders for the Accessible Information Standard, core messages and communication methods.

12.3 Support from key stakeholders

There is widespread support for this Standard from a range of external stakeholders, and formal letters or statements of support have been received from: Action on Hearing Loss, Age UK, Care Quality Commission (CQC), Parkinson's UK, the British Computer Society Digital Accessibility Specialist Group, CHANGE, the Royal National Institute of Blind people (RNIB), Sense, SignHealth, the Technology and Information team at the Health Innovation Network (the Academic Health Science Network for South London), and a personal statement of support from Dr Howard Leicester.

A roundtable meeting with representatives from the British Medical Association (BMA), Royal College of General Practitioners (RCGP) and Royal College of Nursing (RCN) took place on 06 May 2015. Outcomes included agreements to raise awareness of the Standard with members, and to support implementation as appropriate. This engagement will be ongoing throughout the implementation phase.

13 Impact

13.1 Overview of identified benefits

Significant financial benefits have been identified, including some which are potentially cash-releasing, as well as qualitative and societal benefits. The top five identified benefits are as follows:

1. Improved health and wellbeing amongst patients in the key affected groups due to increased take-up of early intervention and prevention opportunities as part of national programmes (for example NHS Health Checks and 'flu vaccination), ability to participate in decision-making and improved compliance with treatment / medical advice.
2. Improved patient safety due to ability to understand and follow information regarding care and treatment, including medicines management and pre- and post-operative advice.
3. More appropriate use of services by patients in affected groups including increased use of primary / routine care and services and reduction in urgent and emergency care usage.
4. Improvement in the effectiveness of clinical care due to addressing barriers to communication.
5. Improvement in patient experience and satisfaction, and reduction in complaints and litigation associated with failure to provide accessible information and communication support.

A more detailed 'table of benefits' is included at appendix a.

It is proposed to evaluate the impact of the Standard, including whether anticipated benefits have been realised and assessing its impact for key groups (outlined below), as part of the scheduled review of the Standard in September 2016 and April 2017. Benefits assessment will also be included as part of the wider 'high quality accessible information' work programme being taken forward by NHS England, which includes this Standard alongside other related projects.

13.2 Anticipated impact of the Standard on key groups

13.2.1 Overview

As outlined above, a number of specific benefits have been identified as expected to result from implementation of the Accessible Information Standard. However, given the potential costs associated with implementing the Standard, the significant impact that it is anticipated to have on the lives of individuals with information and communication needs warrants particular attention.

In addition, although it seems improper to quantify the financial savings associated with an earlier diagnosis, better support and more appropriate care, when what matters is an individual's experience of health services, life and wellbeing, nonetheless there are significant savings for the system in 'getting it right' for the

groups of people likely to be most affected by the Standard. A few short examples may help to illustrate this.

13.2.2 Lack of reasonable adjustments for people with hearing loss

The 2013 Action on Hearing Loss report, [Access all Areas?](#) included the statistic that 14% of people with hearing loss had missed an appointment due to not hearing their name being called in the waiting room. For those individuals, this is a frustrating and often upsetting experience, and may also lead to a delay in diagnosis and / or treatment – potentially a personal tragedy in its own right. Financially, however, the facts are also somewhat shocking. There are an estimated 10 million people with hearing loss across the UK, if 14% of them have missed an appointment due to not hearing their name being called, that is 1.4 million missed appointments. Estimates for the cost of a missed appointment in a primary or secondary care setting vary significantly, from £10 to £100. Even at the lowest estimate, if 1.4 million people with hearing loss miss one appointment a year, that is costing the NHS £14m annually as a minimum.

13.2.3 Lack of reasonable adjustments for people with a learning disability

The [Final Report of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities \(CIPOLD\)](#), included the distressing findings that, "...men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died." These stark figures represent the continuing reality of years of life lost by people with a learning disability, to which a lack of 'reasonable adjustments' in the form of support to communicate or receive accessible information plays a significant contributory part. There are [estimated to be nearly 1 million people in England with a learning disability](#), representing a huge potential for positive impact on length and quality of life.

13.2.4 How reasonable adjustments translate into social value

Beyond medicine and immediate clinical outcomes, consideration must also be given to the wider social impact and social value of reducing and removing barriers to the active participation of people with a disability, impairment or sensory loss in their own health, as part of their communities and in the world of work. Improving people's health, wellbeing and confidence – all outcomes associated with a greater ability to make decisions about and manage your own health – increases individuals' ability to be colleagues, volunteers, employees, neighbours and friends, as well as 'patients and service users'. This added '[social value](#)' leads to widespread benefits felt not just by individuals and their families but by whole communities and local economies.

13.2.5 The impact in (human) numbers

According to [Action on Hearing Loss](#) "There are more than 10 million people in the UK with some form of hearing loss ...From the total number of 10 million, more than 800,000 people are severely or profoundly deaf..."

The [RNIB reports](#) that there are around 360,000 people registered as either severely vision impaired or vision impaired in the UK (i.e. 1 in 180 adults). However, they

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estimate that around 1 in 30 adults have "uncorrectable sight loss" which means their reading vision cannot be improved to average acuities with glasses. It is estimated that 1 in 5 people aged 75 and over, and 1 in 2 people aged 90 and over are living with sight loss.

According to [Sense](#), there are approximately 259,000 deafblind people in the UK. Of these, 222,000 are aged 70 or over. An estimated 1 in 20 people aged over 75 are deafblind. It is estimated that there will be almost half a million deafblind people in the UK by 2030 – 418,000 of which will be older people.

[Research](#) undertaken by Eric Emerson and Chris Hatton of the Institute for Health Research at Lancaster University estimated that there are a total of 985,000 people in England with a learning disability, a prevalence rate of 2% of the general population.

The Accessible Information Standard aims to make a significant impact to the health, wellbeing and life expectancy of thousands, if not millions, of people. It aims to enable people who are unable to read a standard print letter to independently read correspondence about matters which are the most private and personal to us all, a level of confidentiality and autonomy that those of us without communication needs take for granted. It will also mean that they can, perhaps for the first time, have the confidence and ability to make real decisions about their own health and care, about the support they do or do not need, and the life they wish to lead.

14 Operation

14.1 Testing

A Test Report – detailing the outcomes of desk-based review of the Standard – and a Pilot Report – detailing the findings of piloting or trialling of the draft Standard by a range of health and social care organisations, are available. Piloting of the draft Accessible Information Standard aimed to ensure that it was fit for purpose – including to evidence successful ‘first of type’ implementation – and to enable evaluation of the impact of its future application in health and social care settings.

14.2 Implementation

An Implementation Plan is available. This outlines in detail the planned approach to ensure effective and efficient implementation of the Standard by applicable organisations. Implementation Guidance is also available separately. Both documents SHOULD be reviewed by applicable organisations.

14.3 Maintenance

From the date of publication, NHS England will retain oversight and strategic responsibility for the Accessible Information Standard. A Maintenance Plan has been prepared. This includes scheduled review of the Standard and the change control process.

As outlined in the Maintenance Plan, users and stakeholders should direct any feedback about the Standard to the Maintenance Manager. Such feedback, and data received as part of monitoring or assessment of compliance, will be impact assessed and prioritised, and where appropriate proposed changes will be taken forward for development, testing and consultation prior to submission to the Standardisation Committee for Care Information (SCCI) for formal approval.

The Standard Setting for Accessible Information Advisory Group will continue to meet as necessary during 2015 to facilitate consideration of feedback and assessment of impact. The Group will consider any relevant feedback and proposed changes to the Standard prior to any testing, development or submission to SCCI.

To raise a query or log a change request please contact NHS England by emailing: england.nhs.participation@nhs.net Please state ‘Accessible Information Standard’ in the subject.

14.4 Risks and issues

The Standard Setting for Accessible Information Advisory Group will act as the governance body and retain oversight of the risks and issues associated with the Standard, whilst the Senior Responsible Officer will remain ultimately accountable for their mitigation and resolution.

Appendices

Appendix a – Table of benefits

The table below outlines the anticipated benefits of the Standard. Where the term ‘patients’ is used in this table, it should be taken to mean, “patients or service users, and their carers or parents, with information and / or communication support needs relating to a disability, impairment or sensory loss”.

Enabling functionality	Result	Description of benefit	How valued
Patients receive information from health and social care organisations in formats that they can understand.	Patients are able to make informed decisions about their health and care, and to better manage their own health, due to increased knowledge, skills and confidence.	More appropriate use of services including increased use of primary / routine care and services.	<ul style="list-style-type: none"> • Reduction in missed appointments (‘Did Not Attends’ (DNAs)). • Reduction in inappropriate attendance at A&E / urgent care use / emergency admissions. • More appropriate use of primary care. • Improved patient outcomes: <i>Right Care, Right Place, Right Time</i>. • Improved patient satisfaction and experience – reduced complaints and litigation. • Reduction in premature death and increased life expectancy (especially for people with a learning disability).
		More patients take up screening and prevention opportunities (e.g. NHS Health Checks / immunisation).	Improved outcomes for patients due to increase in take-up of immunisations, earlier diagnosis and treatment. Resulting in reduction in time off work, increase in time individuals able to be active in their communities and reduction of health and social care costs.
		Increased ability of patients to recognise signs and symptoms of disease / injury / illness at an earlier stage.	Improved outcomes for patients due to seeking appropriate intervention / treatment at an earlier stage (e.g. increased cancer survival rates / improved outcomes following a stroke). Resulting in reduction in time off work, increase in time individuals able to be active in their communities and reduction of health and social care costs.

		Better support to make healthy lifestyle choices.	Improved health and wellbeing amongst patients due to not smoking, drinking alcohol in moderation and maintaining a healthy weight. Resulting in reduction in time off work, increase in time individuals able to be active in their communities and reduction of health and social care costs.
		Better support to self-care and self-manage long-term conditions.	<ul style="list-style-type: none"> • Reduction in inappropriate attendance at A&E / urgent care use / emergency admissions. • Reduction in unplanned admissions and readmissions. • More appropriate use of primary care. • Shorter hospital inpatient stays. • Improved patient satisfaction and experience – reduced complaints and litigation.
		Improved compliance with treatment programmes / medical advice / medicines.	<ul style="list-style-type: none"> • Reduction in operations / procedures cancelled due to patient being incorrectly prepared (resulting in improved usage of facilities / surgical time). • Improved patient safety and reduction in adverse incidents / harm caused due to patient's non-compliance with advice / incorrect taking of medicines. • Improved outcomes due to increased adherence by patients to long-term medication and other clinical advice. • Improved patient satisfaction and experience – reduced complaints and litigation.
	Improved privacy and confidentiality for patients.	Improved patient satisfaction and experience, improved knowledge and confidence.	<ul style="list-style-type: none"> • Reduction in complaints and litigation. • Increase in patients' ability to play an active role in their community due to improved confidence and autonomy.
Patients receive support to communicate with health and	Patients are able to participate in decision-making about care	Patients exercise their rights to choice.	<ul style="list-style-type: none"> • Increase in patients' ability to play an active role in their community due to improved confidence and autonomy. • Improved patient satisfaction and experience – reduced complaints and litigation.

social care organisations / clinicians / professionals.	pathways and treatments.	Patients participate in decisions about, and take an active role in, their health, health care and treatment options.	<ul style="list-style-type: none"> • Increase in patients' ability to play an active role in their community due to improved confidence, autonomy and outcomes. • Cost savings due to reduction in A&E attendance, planned and unplanned admissions, and outpatient admissions due to greater involvement of patients in the management of their long term conditions. • Improved health and wellbeing of patients due to better understanding of their condition and increased ability to self-care.
Clear and consistent systems and processes for recording and referring to patients' information and communication support needs, and for the provision of information in alternative formats / communication	Health and social care staff and clinicians are able to improve the quality and efficiency of care they provide to patients.	Improved ability of clinicians and other health and social care professionals to communicate effectively with patients.	<ul style="list-style-type: none"> • Improved outcomes for patients and patient experience due to: <ul style="list-style-type: none"> ○ high quality care in line with the '6 Cs.' ○ increased efficiency and accuracy of diagnosis and adherence to advice / treatment regimes; ○ reduction in misdiagnosis and delayed diagnosis. • Increased ability for patients to provide informed consent to treatment, and to receive treatment (or not) in line with their wishes. • Improved patient satisfaction and experience – reduced complaints and litigation.
		Reduction in overrunning / late clinics due to ability to allow additional appointment time for patients with communication needs	<ul style="list-style-type: none"> • Costs savings for health and social care organisations due to reduction in wasted staff time and more efficient use of equipment / facilities

support.		Reduction in duplication of effort and time wasted due to lack of knowledge of patients' information and communication support needs and / or actions to be taken to meet those needs.	<ul style="list-style-type: none"> • Cost savings for health and social care organisations due to avoidance of duplication of effort and double-booking / incorrect booking of communication support. • Reduction in staff time spent identifying, understanding and acting upon patients' / service users' needs (due to there being a clear and consistent process in place as part of business as usual).
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Appendix b – Assessing the information governance and privacy impact

Introduction

Having completed the ‘Standardisation Committee for Care Information (SCCI) Initial IG Checklist’ (see appendix i of this appendix), and following discussion the Senior Information Governance Advisor at the Health and Social Care Information Centre, it was agreed that there was a possibility that a Privacy Impact Assessment may be needed to support SCCI1605 Accessible Information. Therefore, in order to more thoroughly explore any impact on privacy, the ‘privacy impact assessment screening questions’ from [the Information Commissioner’s Office](#) publication ‘[Conducting privacy impact assessments code of practice](#)’ have been completed to provide further evidence.

Privacy impact assessment screening questions

These questions are intended to help organisations decide whether a PIA is necessary. Answering ‘yes’ to any of these questions is an indication that a PIA would be a useful exercise. You can expand on your answers as the project develops if you need to. You can adapt these questions to develop a screening method which fits more closely with the types of project you are likely to assess.

1. Will the project involve the collection of new information about individuals?

The Accessible Information Standard is not proposing to establish any new national data set or collection.

The Standard will direct the more consistent and frequent recording of information about individuals’ information and communication support needs, in order to support direct patient / service user care. This data has been recorded by some – but not all – health and social care organisations to date. The Standard aims to remove ambiguity, improve the regularity of collection and introduce clarity and consistency into recording practices.

2. Will the project compel individuals to provide information about themselves?

No. Individuals will be *asked* to provide information about whether they have any information or communication support needs and, if so, the detail of how those needs may be met, but they will not be compelled to provide this information.

3. Will information about individuals be disclosed to organisations or people who have not previously had routine access to the information?

All information ‘disclosed’ as part of the Standard will be part of existing data sharing processes, which are in themselves subject to information governance and data protection safeguards.

As such, information collected as part of the Standard will only be made available to organisations or people who already have a ‘legitimate relationship’ with that

individual and as such already have access to their patient or service user records. Note that the Standard is only concerned with the use of information as part of direct patient / service user care.

In some instances the Standard will mean that information about individuals' information / communication support needs is disclosed or made available to organisations or people at an earlier stage in the patient / service user journey than currently, but in all cases they will already have an existing right of access to the patient's / service user's records and an ability to access this information once they come into contact with the patient / service user.

For example, at present many secondary care professionals will only discover that their patient has information or communication support needs upon their arrival at hospital, although they will have access to other information about their medical history and treatment. The Standard aims to ensure that relevant professionals have access to information about the patient's information / communication support needs in advance (at the same time as they receive other data via a referral letter or similar).

It should be pointed out that the information will be recorded with the explicit consent of individuals, or if they lack capacity, in line with the [Mental Capacity Act 2005 Code of Practice](#).

4. Are you using information about individuals for a purpose it is not currently used for, or in a way it is not currently used?

No. However, information should be used with greater consistency.

5. Does the project involve you using new technology which might be perceived as being privacy intrusive? For example, the use of biometrics or facial recognition.

No.

6. Will the project result in you making decisions or taking action against individuals in ways which can have a significant impact on them?

No. The Standard will not result in action being taken 'against individuals' and its impact on decision-making as regards to individuals is to support direct patient care, including individuals' ability to be involved in decisions about their own care.

The Standard will support health and care service providers, and individual professionals, to provide improved, higher quality and safer care to individuals with information and / or communication support needs. It will support individuals with information or communication support needs to take a more active role in decision making about their health and care.

By improving disabled people's access to accessible information, it will improve their privacy through reducing their reliance on a family member or carer to read information on their behalf.

7. Is the information about individuals of a kind particularly likely to raise privacy concerns or expectations? For example, health records, criminal records or other information that people would consider to be particularly private.

The Standard will direct the recording and use of data about individuals' information and communication support needs but not any data which is clinical in nature. The Standard will direct the recording and use of information about how to meet an individual's information and / or communication needs, for example that they require a British Sign Language interpreter or information in braille, but it will not direct any recording or use of data as regards to the clinical reason or diagnosis behind such needs. It is acknowledged, however, that some data may be considered sensitive by some individuals, and may imply a clinical diagnosis.

8. Will the project require you to contact individuals in ways which they may find intrusive?

No.

Appendix i – SCCI Initial IG Checklist

This checklist should be used to determine whether your SCCI proposal uses identifiable information about patients and if it does, how this is done. Depending on the answers provided you may be asked to complete a Privacy Impact Assessment of your SCCI proposal.

New Information Standard: SCCI1605 Accessible Information.

1. Does your proposal involve using information about patients?

Yes, but only as part of direct patient care (there is no data set, collection or secondary use of data). The information is to be used by service providers for the purposes of supporting direct patient care.

2. Will the information about patients be in an identifiable form?

Yes, but see explanation in response to question 1.

3. If the answer to (2) is yes, is there an existing legal basis for this use of patient information?

Yes, patient information is being used by service providers to support direct patient care.

4. If the answer to (3) is yes, what is the legal basis?

Patient information is being used by service providers to support direct patient care.

5. If the information about patients is not in a directly identifiable form, can you please describe the form it will be used in.

Not applicable.

6. Whether the patient information is directly identifiable or not, can you please set out which organisations or types of organisation will be using this information.

The information will be used by service providing organisations (NHS and adult social care bodies, and providers of NHS and adult social care) directly to support patient care / the service user experience.

7. How will the information be transferred between organisations?

Using existing information transfer routes, for example Summary Care Records, discharge and referral letters. The Standard is not proposing any new system for transferring data.

8. Where will the information be stored?

As part of existing patient / service user records and service providers' own data storage systems.

9. How will the information stored?

Electronically and in paper form - as part of existing patient / service user records and service providers' own data storage systems.

10. Could you please set out how it is planned to keep the information secure?

This will remain the responsibility of service providing organisations, in line with their existing duties to keep patient / service user information secure. There is no new information storage system or approach being proposed.

11. What do you see as the HSCIC's role in this proposal?

To support the development, appraisal, approval and release of this new information standard. To provide specialist advice as required. To support integration of the Standard into existing data sharing processes and records.

Appendix c – List of stakeholders involved in developing the Standard

1. Advisory group member organisations

- Action on Hearing Loss
- CHANGE
- NHS England
- Sense
- The Care Quality Commission
- The Department of Health (Directorate of Social Care)
- The Health and Social Care Information Centre (HSCIC)
- The Professional Records Standards Body (PRSB)
- The Royal National Institute of Blind people (RNIB)

Note that the group also includes two Patient and Public Involvement (PPI) members.

For further information about the Advisory Group visit the [NHS England website](#).

2. Pilot sites

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

For further information see the Pilot Report.

3. Test partners

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

For further information see the Test Report.

4. Organisations participating in the consultation

The following organisations are known to have responded to the consultation (note that this list is likely to be incomplete as some organisations did not identify themselves when submitting an online survey).

- Action on Hearing Loss
- Bart's Health NHS Trust

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

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- Thomas Pocklington Trust
- UK Council on Deafness
- UKAAF (UK Association for Accessible Formats)
- VISION 2020 UK

For further information see the Report of Consultation.

Note: a list of organisations participating in the engagement phase is not currently available. However, further information about the engagement phase can be found in the Report of Engagement.

5. Organisations attending an 'effective implementation' workshop

- Action on Hearing Loss
- Addenbrooke's Hospital NHS Foundation Trust
- Hertfordshire Partnership University NHS Foundation Trust
- Berkshire Healthcare NHS Foundation Trust
- BMJ (the British Medical Journal)
- Bradford Talking Media (BTM)
- Bradford Teaching Hospitals NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Camden Social Services
- CHANGE
- City of Bradford Metropolitan District Council
- County Durham and Darlington NHS Foundation Trust
- Docman
- Dorset HealthCare University NHS Foundation Trust
- East London NHS Foundation Trust
- Enabled City
- Generate
- GTD Healthcare
- Harrogate and District NHS Foundation Trust
- Healthwatch England
- HSCIC (the Health and Social Care Information Centre)
- InterpreterNow
- Lancashire County Council
- Leeds Community Healthcare NHS Trust
- Microtest Ltd.
- Mid Yorkshire Hospitals NHS Trust
- Moorfields Eye Hospital NHS Foundation Trust
- MSD Ltd.
- NHS England
- NHS Yorkshire and Humber Commissioning Support
- PAERS Ltd.
- Phoenix Medical Practice
- PRSB (the Professional Records Standards Body)
- Regify
- RNIB (the Royal National Institute of Blind people)
- Robobraille

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- Sense
- Sheffield Health and Social Care
- Sheffield Teaching Hospitals NHS Foundation Trust
- SignHealth
- Social Care Institute for Excellence
- Software of Excellence UK Ltd.
- Solent NHS Trust
- South West Yorkshire Partnership NHS Foundation Trust
- System C Healthcare
- Tees, Esk and Wear Valleys NHS Foundation Trust
- The Clatterbridge Cancer Centre NHS Foundation Trust
- The Worshipful Company of Information Technologists
- TPP
- University of Central Lancashire

For further information see the Effective Implementation Workshop Report.

6. Organisations represented at a professional bodies roundtable on 06 May 2015

- Advisory group members (as above)
- British Medical Association (BMA)
- Royal College of General Practitioners
- Royal College of Nursing

7. Others

In addition to involvement as recorded above, significant input has also been received from professionals from:

- Mid Yorkshire Hospitals NHS Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Signature
- SignHealth
- Tees, Esk and Wear Valleys NHS Foundation Trust
- The Worshipful Company of Information Technologists
- Yorkshire and Humber Commissioning Support