



Accessible Information: Implementation Guidance – Change Paper

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Description	DCB1605 Accessible Information directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. This document is the 'change paper' to support the reissued (version 1.1) Implementation Guidance for DCB1605 Accessible Information.
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DCB1605 Accessible Information: Implementation Guidance – Change Paper

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Equality and Health Inequalities Statement

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

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

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1 Introduction

DCB1605 Accessible Information (formerly 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.

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care must follow the Standard in full. Commissioners of NHS care and / or 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.

During January-March 2017 NHS England led a post-implementation review of the Standard, providing an opportunity to assess impact and ensure that it remains ‘fit for purpose’. As a result of this review, including as a result of feedback from applicable organisations and other stakeholders, a revised version of the Implementation Guidance has been issued. This ‘change paper’ outlines amendments which have been made to version 1.1 of the Implementation Guidance (as reissued in August 2017).

Organisations that have already implemented the Standard (also known as ‘existing users’) MUST consider this ‘change paper’ and take any necessary steps to ensure that they remain compliant.

Organisations that have not previously implemented the Standard (also known as ‘new users’) MUST consider this ‘change paper’ alongside the reissued Implementation Guidance, to ensure that they implement the Standard correctly and completely.

2 Changes to the glossary, definitions and contacts

2.1 Section 1 ‘glossary of terms’ and appendix c ‘expanded glossary of terms’

There has been an amendment to the definition for ‘disability’, with ‘describes’ replacing ‘defines’. The new definition is:

“Disability – The [Equality Act 2010](#) describes disability as follows, “A person (P) has a disability if — (a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.” This term also has an existing [Data Dictionary definition](#).”

There has been an amendment to the definition for ‘disabled people’, with ‘description’ replacing ‘definition’ and a revised link added. The new definition is:

“Disabled people – [Article 1 of the United Nations Convention on the Rights of Persons with Disabilities](#) has the following description, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.””

There has been an amendment to the definition for ‘impairment’, as the previous link and reference are no longer accessible. The new definition is:

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

There has been an amendment to the definition for SNOMED CT (Systematised Nomenclature of Medicine Clinical Terms) – links and references have been updated. The new definition is:

“Classification of medical terms and phrases, providing codes, terms, synonyms and definitions. SNOMED CT is managed and maintained internationally by [SNOMED International](#) and in the UK by the UK Terminology Centre (UKTC). SNOMED CT has been adopted as the [standard clinical terminology for the NHS in England](#).”

2.2 Contacts

Section 2 ‘contacts’ and appendix a ‘practical one page guide’ have been amended, to include a revised email address for enquiries – england.patientsincontrol@nhs.net.

2.3 Section 9.1 ‘overview of requirements – flagging of needs’

This section has been amended in line with the amendment to the Specification, as follows:

“‘Highly visible’ is defined in the Specification as follows: “A recording of an individual’s information or communication support needs must be ‘highly visible’ to relevant staff and professionals. In the context of this Standard ‘highly visible’ means:

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

3 Changes regarding sharing of information and consent

3.1 Section 7.2 ‘note about consent to share information’

This section has been retitled 'note about consent to share information' (replacing the previous title of 'note about consent'). It has also been amended, in line with legal advice, as follows:

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

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

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

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

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

3.2 Section 10.1 'overview of requirements – sharing of needs'

This section has been amended as follows:

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

3.3 Section 10.2 'guidance for sharing of needs'

This section has been amended as follows:

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

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

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

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

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

All of the data items associated with the four subsets of the Standard have been included in the 'inclusion dataset' for [Summary Care Records with additional information](#). This means that, if the patient's information and / or communication needs are recorded in their GP patient record using the identified codes, and the patient has consented for 'additional information' in their Summary Care Record (SCR), then details of their information and / or communication needs will automatically be available to anyone viewing their SCR.

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

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

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

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

4 Changes regarding the role and status of, and support for, parents

4.1 Section 12.1 'carers' and parents' needs'

Further to legal advice, this section has been amended as follows:

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

Relevant definitions are included in the Specification, as follows:

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

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

- Where the child is young, anyone with parent responsibility or delegated authority for the child may consent on their behalf.
- Where the child is old enough to understand the risks and benefits of what is being proposed (in other words, is Gillick competent), the child can consent themselves. Individuals with parental responsibility or delegated authority may be consulted, and may be able to consent on behalf of the child, but cannot override the child's consent if it has already been given (there are some exceptions to this, for example in the case of refusal – for further information see [Guidance from the General Medical Council \(GMC\)](#)).

- Where the patient / service user is a young person (aged between 16 and 18) and has capacity to understand what is being proposed, the young person should consent themselves. Consideration should be given to involving other members of the Multi-Disciplinary Team, an independent advocate or named or designated doctor for child protection if their involvement would help young people in making decisions.
- Where the patient is over the age of 18, only they can consent to what is being proposed if they have capacity to do so. If they lack capacity, if someone else has been formally appointed to make that decision on their behalf, by way of a court order or formal power of attorney in relation to the issue in question, they can make that decision on the incapacitated person's behalf. If there is no such power, those involved in the person's care should be consulted before a decision is made under the [Mental Capacity Act 2005](#).

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

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

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

5 Changes regarding mental health service users and the Mental Capacity Act 2005

5.1 Overview

Further to legal advice, the section relating to mental health service users and the Mental Capacity Act 2005 has been amended to improve clarity, especially regarding support for people who may lack capacity.

5.2 Section 12.2 ‘Mental Capacity Act 2005’

This section has been retitled ‘Mental Capacity Act 2005’ (replacing the previous title of ‘mental health service users’). It has also been amended, in line with legal advice, as follows:

“The [Mental Capacity Act 2005 Code of Practice](#) (Chapter 3) provides clarity on the requirement to provide information in alternative formats and communication support, “To help someone make a decision for themselves, all possible and appropriate means of communication should be tried.” This includes consideration of when might be the best time to communicate, whether pictures of objects may help to explain what needs to be considered, breaking down complex information into simple points, speaking at the right volume or speed and using the right language. Of note, “Certain categories of people are legally required to ‘have regard to’ relevant guidance in the Code of Practice,” this includes, “...anyone who is...acting in a professional capacity for, or in relation to, a person who lacks capacity...”

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

The Standard includes the provision of information in alternative formats and communication support to mental health service users to support their access to, understanding of, involvement in decisions about and receipt of NHS and adult social care. This may include support needed by individuals to enable them to effectively understand their rights and communicate their needs and preferences.

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

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

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

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

6 Changes regarding the use of email and text message

Section 12.7 'use of email and text message' has been amended as follows:

“12.7.1 Introduction

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

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

12.7.2 General principles

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

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

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

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

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

12.7.3 Guidance

- Services that have implemented, or are intending to increase, the use of email and / or text messaging for communication with their patients / service users may wish to encourage them to ask about use of these methods of communication. The display of posters or notices, and other ways of explaining to patients / service users about the use of electronic communications by the service, would be considered good practice – this helps inform patients / service users about their choice.
- In the first instance, proactively and explicitly check with the patient / service user that they are comfortable with being contacted via email and / or text message (as appropriate).
- In either case, if the patient / service user agrees to the use of email or text message as a communication method, ask them to provide and confirm their email address and / or mobile telephone number. Please note that the record of a number or and / or email address **does not** indicate consent (which must be explicitly sought).
- With regards to text messaging, having obtained the correct mobile number from the patient / service user, the service should send a ‘test’ text message to that number to verify accuracy. This should either be done whilst the patient / service user waits with a member of staff (so that receipt of the text message can be verified) or alternatively, the patient / service user should be asked to reply to confirm their identity and the accuracy of the number. In all cases, organisations should ensure that best endeavours have been made to confirm the accuracy of the information provided.
- The patient / service user and the service should mutually agree the parameters or limits of what information is to be communicated via email and / or text message. Each organisation may have differing service offerings and these should be discussed with the patient / service user prior to using the service. It may not be practical or technically possible to agree different parameters with different patients / service users. Organisations should offer the service to patients / service users where possible, fully informing them of what service is available, so the patient / service user can make an informed choice based on all the available information.
- Explain to the patient / service user about who will have access to their emails / text messages and why, with reference to the agreed parameters for the types of information to be communicated in this way.
- It is essential to explain to the patient / service user that it is their responsibility to keep and provide an up to date email address and / or mobile number, and to be clear that the service are not responsible for onwards use or transmission of an email or text message once it has been received by the patient / service user.
- The patient / service user should also be advised that internet email accounts, such as those commonly used by individuals for private purposes, are not secure.

The patient / service user must, therefore, be made aware (and accept) that there is a risk (however small) of the email being intercepted or 'hacked'. Likewise, there will always be risks that text messages may be intercepted or otherwise accessed by a third-party and patients / service users should be made aware of these risks.

- The service should strongly recommend to the patient / service user that they use a private email account / private mobile telephone, not a family or shared account or mobile telephone, for the purposes of communication with the service. However, this is their decision and the service cannot insist on use of a private account or mobile telephone. The risks associated with use of a shared account / shared mobile telephone should be explained.
- The parameters of how much contact is conducted by email and / or text message should be agreed, with the service setting clear limits and ensuring that the patient / service user is aware of them. It is likely that the service will wish to limit two-way dialogue via email or text message which risks becoming a 'virtual consultation' and instead direct the patient / service user to make an appointment, for example to discuss test results.
- Services, and their staff, should only send emails from generic team accounts (for example diabetes@example.nhs.net / oncology@example.nhs.uk) and established corporate text messaging accounts. This ensures that patients / service users can be confident that the sender is legitimate. Individual staff email addresses should not be used. Use of generic accounts also ensures that emails and text messages can be accessed and actioned by multiple members of staff, providing cover in the event of absence.
- It is best practice to acknowledge receipt of an email within 24 hours.
- Emails are classed as records and should be retained for the appropriate period of time. Where possible, a copy of the email should be stored in the patient / service user's record. If this is not possible, then an entry should be written into the patient or service user's notes detailing the important content of the email and subsequent actions (for example, 'blood test dated 24.6.14; results emailed to patient 25.6.14; patient replied asking for outpatient appointment; booked for 1.7.14 at 14:30'). This covers the interaction with the patient, and the original emails can be found in the email archive / system if required.

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

7 Changes regarding communication professionals

Section 11.4.4.1 / 11.6.4.1 'communication professional – qualification, registration and other assurances' has been amended.

In the fourth paragraph, the list of NRCPD registered professionals has been amended, with 'Registered' removed from each of the professional categories and the links removed due to no longer being accessible.

In addition, the following text has been included immediately prior to the final sentence in this section:

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

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



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

The final sentence in this section has also been amended; ‘of’ has been added, as in “...the use of professionals...” and the link has been removed from ‘Registered Interpreter for Deafblind People’ as it is no longer accessible.

8 Changes regarding website accessibility

Appendix e ‘advice on web accessibility’ has been amended as follows:

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

Organisations should ensure that websites comply with the [World Wide Web Consortium’s \(W3C’s\) Level AA guidelines](#) for accessibility and may find the [British](#)

[Web Accessibility Code of Practice: BS8878](#) a useful source of guidance. A helpful summary of the latter document has been [published online by the digital inclusion charity AbilityNet](#).

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

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

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

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

9 Changes regarding, and additional guidance on, assessment and assurance of compliance

This section (section 13) has been retitled ‘assessment and assurance of compliance’ (replacing ‘local assessment and assurance of compliance’) and has been amended as follows:

“13.1 Local assessment and assurance of compliance

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

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

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

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

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

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

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

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

13.2 The role of commissioners

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

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

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

13.3 Other interested organisations

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

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

13.4 Practical assessment of conformance

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

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

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

10 Additional guidance – recording of data in non-coded systems

A new section, 8.3 'guidance on recording of data in non-coded systems' has been added into section 8 'guidance for stage 2 – recording of needs', as follows:

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

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

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

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

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

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

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

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

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

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

When recording patients', service users', carers' and parents' needs, organisations must ensure that such recording is both accurate and that the data as recorded will provide sufficient, and sufficiently clear, direction such that those needs can be met. For example, 'Mr Smith is deaf' does not enable appropriate adjustments to be made or arrangements to be put in place so that the service can communicate effectively with Mr Smith. Whereas, 'Mr Smith uses a hearing aid and lip reads' or 'Mr Smith needs a British Sign Language Interpreter' or 'Mr Smith needs information sent in Arial size 16' would meet the requirements of the Standard and should ensure successful outcomes for Mr Smith.

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

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

11 Additional guidance – stocking alternative formats

An additional section has been added into section 11 'guidance for stage 5 – meeting needs', as section 11.4 'stocking alternative formats', as follows:

"The Standard requires that patients, service users, carers and parents with a disability, impairment or sensory loss receive information which they can read (or otherwise access) and understand. It does not stipulate that all organisations must offer every type of alternative or accessible format, rather that organisations must provide information in a format which is accessible to the patient, service user, carer

or parent as an individual. It is likely that different organisations will provide information to the same individual in different formats, depending on the person's needs, the nature of their service and their facilities. For example, accessible information for a person who is blind may include that sent via email or text message, as well as that produced in braille or audio format.

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

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

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

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

Consideration should also be given to understanding the alternative format production and procurement arrangements which other local NHS and adult social care providers and commissioners have in place, as they may have a framework arrangement, be able to recommend a trusted supplier and / or have other advice. Organisations may also wish to explore a collaborative approach to the production of information in alternative formats, including considering local sharing of alternative formats of documents which are most commonly used by multiple providers.

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

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

12 Additional guidance – needs versus preferences

A new section, 11.5 ‘needs versus preferences’ has been added into section 11 ‘guidance for stage 5 – meeting needs’, as follows:

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

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

13 Additional guidance for information governance leads

A new appendix, appendix g, has been added, ‘considering patient / service user communication: additional advice for information governance leads’, as follows:

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

For example:

- Where fair processing, privacy notices and other material is provided about how patient / service user data will be used and shared (to meet Principle 1 of the [Data Protection Act 1998](#) to be ‘fair’) – consider what additional material or options need to be available for staff and for patients, service users, carers and parents.
- Where an explicit consent process to use or share data is used, support should be in place to make sure those with identified information and / or communication needs are adequately informed when they give consent.

- In circumstances where implicit consent is used, consider whether patients / service users with information and / or communication needs require additional information to demonstrate that the proposed use of data meets reasonable expectations i.e. that on average they would find the proposed use a sensible and desirable action to support their direct care.

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

Note on the GDPR

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

14 Changes to references to other information standards

Section 18.1 ‘related standards’ has been amended, as follows:

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

15 Minor corrections, amendments and updates

The following minor wording changes have been made to sections of the reissued Implementation Guidance to correct grammatical or typographical errors, amend the tense / wording to reflect the passage of time, and / or to add clarity:

- All references to ‘the standard’ and ‘this standard’ have been corrected to ‘the Standard’ and ‘this Standard’.
- Speech marks have been removed from all references to ‘easy read’, so this is now written as easy read.
- Minor grammatical and typographical errors have been corrected, where identified, for example misuse of apostrophes.
- Section 3 – ‘overview’, an amendment to the final paragraph, “Commissioners of NHS care and publicly-funded adult social care must also have regard to this Standard, in as much as they must ensure that contracts...”

- Section 4 ‘purpose’, an amendment to the first sentence, “This document provides detailed advice for staff with regards to implementing and using DCB1605 Accessible Information – the ‘Accessible Information Standard’.”
- Section 5 – ‘audience’, an amendment to the final sentence, “Public facing materials, and communications targeted at particular audiences, have also been produced – as outlined in the Implementation Plan and the Communication Plan.”
- Section 6.1 – ‘implementation guidance – overview’, an amendment to step 2 ‘recording of needs’, option c, “Use of agreed English definitions...”
- Section 6.3 – ‘education and awareness-raising’, an amendment to the final sentence, “Whilst this Implementation Guidance is intended to support effective implementation, it should be considered alongside and with reference to the Implementation Plan and the resources and learning opportunities outlined in the Plan, which are intended to complement and build upon guidance included here.”
- Section 6.4.1 – ‘improving the accessibility of all information and communication – introduction’, the last phrase in the last sentence has been removed, so this section now ends with, “...they may be used as part of internal communications / awareness-raising.”
- Section 6.4.3 – ‘tips for printed communication’, an amendment to the final bullet point, “Further advice about creating accessible documents, including for users of assistive technology, has been made available as part of the suite of tools to support implementation of the Standard.”
- Section 7.3 – ‘methods for identifying needs’, the text boxes have been removed, however, the associated text is unchanged. Speech or quotation marks have also been added around the example text message. Amendment to text on page 19, “Note that print-ready templates for letters and posters have been made available as part of resources to support implementation (as outlined in the Implementation Plan).” And, “In a general practice setting, it would be appropriate to refer to the register of patients with learning disabilities (17/18 QOF ID LD003), where available (see [‘Summary of Changes to QOF 2017/18 – England’](#), [‘2016/17 General Medical Services \(GMS\) Contract Quality and Outcomes Framework \(QOF\) - Guidance for GMS contract 2016/17 April 2016’](#) and [‘Technical Requirements for 2017/18 GMS Contract Changes May 2017 – version 2’](#) for further information).” The last sentence on page 19, which began ‘Suggested READ v2...’ has been removed. Amendment to text on page 21, “...Where difficulties are anticipated or experienced, services are advised to identify available local expertise...”
- Section 7.4 – ‘questions and prompts to identify needs’, has been amended in light of changes to the previously referenced dataset and associated guidance. The text immediately following the bulleted question ‘what is the best way to send you information?’, is now, “Specific additional or follow-up questions which it MAY be relevant to use as prompt or follow-up questions when communicating with particular individuals and / or in particular care settings are as follows:

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

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

- Section 8.1 – ‘overview of requirements – recording of needs’, an amendment to the third paragraph, “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.”
- Section 8.2 – ‘guidance for recording of needs’, the penultimate paragraph has also been amended, “Further advice is available as part of resources to support implementation (as outlined in the [Implementation Plan](#)).”
- Section 9.3 – ‘guidance on reviewing and updating needs’, an amendment to the first sentence of the second paragraph, “The purpose of review is essentially two-fold, first to identify if the individual’s needs have changed (for example due to a change in their level of sensory loss) and second to identify if the most appropriate methods of meeting those needs have changed...”
- Section 11.3 – ‘costs of accessible information / communication support’, the reference / link has been amended to, “[Guidance from the Equality and Human Rights Commission \(EHRC\)](#) states that, “If an adjustment is reasonable, the person or organisation providing it must pay for it. As a disabled person, even if you have asked for the adjustment, you must not be asked to pay for it.””
- Section 11.4.1 / 11.6.1– ‘meeting of needs under the four categories / subsets – overview’, the first sentence has been amended, “As outlined in the Specification, the Accessible Information Standard defined four subsets to which SNOMED CT, Read v2 and CTV3 codes have been associated and which are available for use (noting that their use is mandated in line with the conformance criteria and timescales set by the Standard)...”
- Section 11.4.3.1 / 11.6.3.1 – ‘specific information format – overview’, the reference to ‘SCCI1605 Accessible Information’ has been amended to ‘DCB 1605 Accessible Information’. The penultimate sentence in this section has also been amended, “Appendix e provides further advice about website accessibility.”
- Section 11.4.3.2 / 11.6.3.2 – ‘note about ‘large print’’, the first sentence has been amended, “Data items associated with one or more of the four subsets of the Standard...”

- Section 11.4.4.3 / 11.6.4.3 – ‘use of family members, friends or carers as interpreters’, the references to ‘section 11.4.4.1’ have been amended to ‘section 11.6.4.1’. The link to the NHS Constitution has been updated (to <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>) and the quote has been amended, ““NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers...Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.””
- Section 11.4.4.5 / 11.6.4.5 – ‘remote access to communication support’, the second sentence of the third paragraph has been amended, “...The technology has been available to users of the [NHS24](#) service (in Scotland) and users of the [NHS111](#) service (in England) for some time.” In the last sentence, the reference to ‘section 11.4.4.1’ has been amended to ‘section 11.6.4.1’.
- Section 11.4.4.6 / 11.6.4.6 – ‘key word signing including Makaton’, the link and reference for ‘Signalong’ have been amended, “[Signalong](#) is a key word sign-supported communication system based on British sign language and is used in spoken word order. It uses speech, sign, body language, facial expression and voice tone to reference the link between sign and word.”
- Section 11.4.5 / 11.6.5 – ‘communication support’, the last sentence of the first paragraph has been amended, “Further advice is included as part of section 6.4.2 and in appendix d, and as part of resources to support implementation (as outlined in the Implementation Plan).”
- Section 12.5 – ‘support for children and young people’, the second sentence of the first paragraph has been amended, “With regards to social care, the Standard covers adult social care (but does not include children’s social services).”
- Section 12.6 – ‘people with multiple / complex needs’, in the first sentence of the second paragraph, the word ‘or’ has been removed, so this is now, “...they require bespoke tools and / or communication support to enable communication.”
- Section 14 – ‘resources to support implementation’, has been amended and replaced with, “A range of resources have been made available to support organisations in effectively implementing and following the Standard, as outlined in the Implementation Plan. These were promoted as outlined in the Communication Plan and are available from the [NHS England website](#). They include two [e-learning modules](#) developed in association with Health Education England, a [toolkit for GP practices](#), an [interactive guide](#), a [microsite](#) and [poster templates](#).”
- Section 15.1 – ‘approaches to implementation – introduction’, the previous second paragraph, which began “Organisations should note...” has been removed.

- Section 15.5 – ‘considerations for implementation leads’, point one, the fourth sentence has been amended, “It can be helpful to agree on a ‘standard question’ which staff can feel comfortable asking patients / service users...”
- Section 15.6 – ‘considerations for commissioners’, the last phrase in the last sentence has been removed, so this section now ends with, “...comply with the Accessible Information Standard.”
- Section 16 – ‘timescales’, the first and second paragraphs have been amended, “Since 01 August 2016, all applicable organisations have been required to follow the Standard in full, and to meet all relevant requirements – compliance with the Standard should now be embedded into ‘business as usual’. The original timetable for implementing the Standard is set out below, for reference.” In the first line of the timetable, the text in the first ‘date’ column has been amended, “Immediately upon publication of the [previous] ISN.”
- Section 17 – ‘illustrative patient scenarios’, the introductory text has been amended and is now, “Some illustrative examples of how the Standard could work in practice are as follows. The ‘high level’ diagrams included in the Specification should also be reviewed.”
- Section 18.2 – ‘related documents’, the link to ‘Sick of It’ (SignHealth 2014) has been amended and is now <http://signhealth.org.uk/wp-content/uploads/2016/09/Sick-Of-It-Report.pdf>, the link / reference to the NHS Constitution has been amended and is now, “[The NHS Constitution \(Department of Health, 2015\)](#)”, and the final link / reference has also been updated, “[Your rights to equality from healthcare and social care services \(Equality Act 2010 Guidance for service users, Volume 4 of 7\) \(Equality and Human Rights Commission, 2014\)](#).”
- Appendix a – ‘practical one page guide’, ‘overview of the Standard – scope (who, what and where)’, in the first sentence ‘SCCI1605’ is now ‘DCB 1605’ and the third paragraph has been amended, “The Standard applies to all providers across the NHS and adult social care system.” ‘Timescales (when)’, this section has been amended, “Organisations must comply with the Standard in full from 1st August 2016 onwards.”
- Appendix d – ‘advice about communication support needs – introduction’, the final sentence has been amended, “Further advice is available as part of resources to support implementation (as outlined in the Implementation Plan).”