



Accessible Information: Maintenance Plan

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Description	SCC1605 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, where those needs relate to a disability, impairment or sensory loss. This document is the Maintenance Plan for SCC1605 Accessible Information.
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Document Status

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SCCI1605 Accessible Information: Maintenance Plan

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1 Glossary of terms

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

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

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

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

2 Contacts

For information on the Accessible Information Standard please visit the [official notification page](#) or [NHS England's dedicated site for the Standard](#).

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.

3 Overview

3.1 Introduction

The Accessible Information Standard directs and defines a specific, consistent approach to identifying, recording 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.

This Maintenance Plan describes the procedures, approval and control requirements for maintaining the Accessible Information Standard.

NHS England will continue to have strategic oversight and operational ownership of the Standard, and will also provide governance for future developments including periodic review of the Standard, changes and future development. This will include directing and overseeing any potential future development of the Standard, which may include:

- Changes to guidance or direction around meeting of individuals' needs, including to reflect policy or technology changes;
- Changes to relevant data sharing processes, including increased standardisation;
- Changes to terminology, including addition or removal of specific terms from any or all of the subsets associated with the Standard, and requesting additional terminology in response to identified need;
- The establishment of a data set or national collection.

No changes to the Standard will be made without the explicit approval of NHS England.

3.2 Summary

Standard	
Standard Title	Accessible Information
Standard Number	SCCI1605 (ISB1605 - Amd 8/2013 Initial Standard)
Description	<p>Accessible Information aims to ensure that people with a disability, impairment or sensory loss get information about their health and care which they can read and understand (for example in easy read, braille or via email) and communication support if they need it (for example British Sign Language (BSL) interpretation).</p> <p>The Standard will establish a clear and consistent framework and provide direction as to the identification, recording, flagging, sharing and meeting of disabled people's information and communication needs. Implementation will require changes to recording practices (including electronic systems) and to processes for identifying and meeting people's communication needs.</p>

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	<p>Accessible Information will require providers of NHS and adult social care to:</p> <ul style="list-style-type: none"> • Identify the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss; • Record or input data using identified definitions / codes (including using relevant SNOMED CT®, Read v2 or CTV3 codes where used in systems); • Refer to, act upon and share the recorded information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss (within existing information governance and data-sharing protocols); • Meet patients, 'service users,' carers' and parents' information and communication support needs, wherever reasonably possible.
Applies to	<p>All providers of NHS and publicly-funded adult social care services, including, but not limited to:</p> <ul style="list-style-type: none"> • NHS Trusts including Foundation Trusts, Acute Trusts, Community Trusts, Care Trusts, Ambulance Trusts; • Independent contractors providing NHS services – GP practices, optometrists, pharmacists, dentists; • Non-NHS providers of NHS and social care services including organisations from the voluntary and independent sectors. <p>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.</p>
Release	
Release Number	SCCI1605
Release Title	Accessible Information
Description	The consistent identification, recording, flagging, sharing and meeting of the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.
Voluntary Implementation Date	Organisations MAY begin to implement the Standard immediately upon publication of the Information Standards Notice (ISN).
Mandatory Implementation Date	By 31 July 2016, all applicable organisations MUST comply with the Accessible Information Standard in full (date of full conformance).

4 Purpose

The purpose of the Maintenance Plan is to describe the procedures, approval and control requirements for maintaining the Accessible Information Standard. It seeks to identify instances where amendments may need to be made to the Standard in response to requests or as a result of review, and to outline the change process.

It contains the mechanisms to ensure that the Standard remains 'fit for purpose', including reflecting any changes in clinical practice or coding, changes to the NHS Data Model and Dictionary and changes to policy requirements relating to accessible information and communication support.

5 Related documents

This Maintenance Plan should be read in conjunction with the following documents:

- SCCI1605 Accessible Information Specification.
- SCCI1605 Accessible Information Implementation Plan.
- SCCI1605 Accessible Information Implementation Guidance.

6 Maintenance plan

6.1 Overview and scope

On successful implementation of the Standard, NHS England will retain responsibility for ensuring that it continues to remain fit for purpose, including directing any changes needed to reflect changes to policy, practice or terminology.

The scope of the maintenance process covers:

- management of change requests from users and stakeholders, including assessment and prioritisation;
- specification of changes to data recording and / or delivery in response to changes in policy, practice, coding and classifications;
- managing the process for authorisation and approval of changes (including obtaining any approvals required);
- assessment and prioritisation of actions to be taken in response to feedback received as a result of monitoring and assessment of compliance;
- dissemination of approved changes to standard users and stakeholders.

Any change requests received, or necessary / added value changes identified, will be prioritised, impact assessed and where appropriate taken forward for development, testing and consultation prior to submission to the Standardisation Committee for Care Information (SCCI). All requests received or potential changes identified will be considered by the Standard Setting for Accessible Information Advisory Group prior to any submission to SCCI.

Each change request should be supported by a valid business requirement (i.e. what change is needed, justification (i.e. why is it needed) and also any associated timescales).

Approved changes will be communicated to NHS bodies and local authorities, and to providers of NHS and adult social care services, as well as to system suppliers, through the publication of an Information Standards Notice (ISN) by SCCI.

Approved changes and updates will also be communicated to users and stakeholders through the [NHS England website](#) and other appropriate forums.

6.2 Change process

A change control process has been established to control changes to the Standard. All change requests will be logged along with the outcome of the assessment process, i.e. whether the change request was approved or rejected, and the rationale. The results or impact of all approved change requests will also be documented.

A documented audit trail, containing relevant information, will be maintained at all times. This will include change request documentation, change authorisation and the

outcome of the change. No single person will be able to effect changes to the Standard without the approval of other authorised personnel.

A flowchart outlining the process to be followed upon receipt of a change request or other indication that a change may be needed or desirable is included at section 7. The potential changes could be applicable to the following:

- Changes in clinical practice or guidance;
- Changes to policy;
- Changes to terminology.

Please note the list above is not exhaustive.

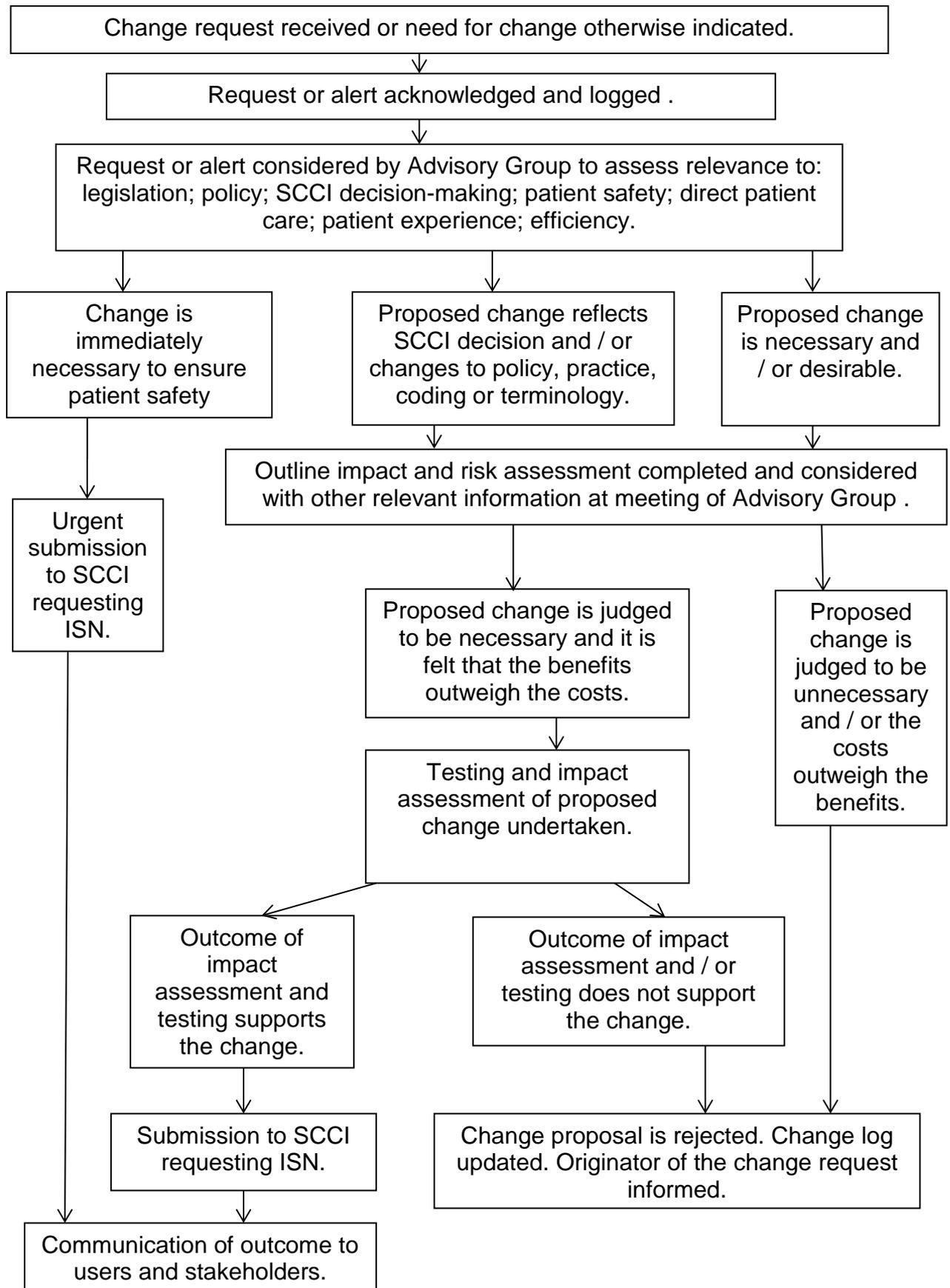
Any changes to the Accessible Information Standard will require formal request to NHS England via england.nhs.participation@nhs.net in the first instance.

Any subsequent work required in response to accepted / necessary changes will be managed by NHS England, in consultation with the Health and Social Care Information Centre (HSCIC) and involving SCCI if and as appropriate with regards to necessary formal approval of changes.

6.3 Risk management

A risk assessment will be performed for all changes and, dependent on the outcome, an impact assessment will be performed. The impact assessment will include the potential effect on other information resources and potential cost implications. The impact assessment will, where applicable, consider compliance with legislative requirements and other standards.

7 Flowchart of process for consideration of change requests



8 Policies, directives and procedures

The following policies, directives and procedures apply to both the use and maintenance of SCCI1605 Accessible Information:

- Standardisation Committee for Care Information (SCCI) approvals;
- NHS Data Model and Dictionary definitions and subsets;
- SNOMED CT and Read v2 / CTV3 codes.

9 Review and retirement

9.1 Scheduled review of the Standard

There are two reviews of the Standard planned. One in September 2016, and another in April 2017. At both of these dates, the review will include a review of policy and procedure. This proactive review will identify if there have been any changes to the above documents which have not been identified under the maintenance procedures. Evaluation of benefits (as outlined in the Specification) will also be conducted at this point.

Review of the coded data items associated with the subsets defined by the Standard will take place as part of the biannual SNOMED CT release process, with new or amended data items being associated with one or more of the Standard's subsets as appropriate.

9.2 Retirement criteria and plan

Retirement of SCCI1605 Accessible Information is considered unlikely in the short to medium term due to its continuing relevance to ensuring that the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss are met. However, it is hoped that fulfilling the requirements of the Standard will, in future, become a routine part of 'business as usual' for all providers of NHS and adult social care.

The appropriateness of scheduling / planning for the retirement of the Standard will be considered as part of each of the two planned reviews (i.e. in September 2016 and April 2017).

For retirement of the Standard to be considered, strong evidence in support of all of the elements of the Standard being met as a consistent, routine part of the provision of NHS and adult social care, and universal inclusion in patient record, clinical management and administration systems, would need to be put forward.

Should retirement of the Standard be identified as considered appropriate in the proceeding 12 to 24 months, a formal retirement plan for the Standard will be developed. Given the nature of this standard, any such plan would need to be the subject of consultation with users and stakeholders, prior to any finalisation and rollout. In addition, the plan would be supported by a comprehensive communication plan to ensure key messages reached users and stakeholders.

Any retirement plan would include schedules, resource estimates, management controls and reporting procedures, as well as documenting the risks and how they will be minimised and managed. An impact statement would be produced outlining the potential impact of the transition of retirement on infrastructure, operations and support staff and to the user community.

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At present, responsibility for overseeing the retirement of the Standard would be the responsibility of NHS England, with support from the Health and Social Care Information Centre, and involving SCCI as appropriate.