



Accessible Information: Implementation Plan

NHS England INFORMATION READER BOX

Directorate

Medical Nursing Finance Commissioning Operations Trans. & Corp. Ops. Patients and Information Commissioning Strategy

Publications Gateway R	eference: 03572	
Document Purpose	Other (see Description)	
Document Name	SCCI1605 Accessible Information Implementation Plan	
Author	NHS England, Patients and Information	
Publication Date	03 July 2015	
Target Audience	CCG Clinical Leaders, CCG Accountable Officers, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of Nursing, Directors of Adult SSs, NHS Trust Board Chairs, Allied Health Professionals, GPs, Communications Leads, NHS Trust CEs	
Additional Circulation List	Voluntary and Community Sector Organisations, Professional Representative and Membership Bodies, Public Sector Partners	
Description	SCCI1605 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 Implementation Plan for SCCI1605 Accessible Information.	
Cross Reference	N/A	
Superseded Docs (if applicable)	ISB 1605 Accessible Information Implementation Plan Draft	
Action Required	N/A	
Timing / Deadlines (if applicable)	N/A	
Contact Details for	Accessible Information Standard	
further information	Patient and Public Participation and Insight NHS England 7E56, Quarry House, Quarry Hill, Leeds, LS2 7UE 01138 253002	
	http://www.england.nhs.uk/accessibleinfo	

Document Status

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet. **NB:** The National Health Service Commissioning Board was established on 1 October 2012 as an executive non-departmental public body. Since 1 April 2013, the National Health Service Commissioning Board has used the name NHS England for operational purposes.

SCCI1605 Accessible Information: Implementation Plan

Version number: 1.0.

First published: 03.07.15.

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

Classification: OFFICIAL

Contents

Contents	4
1 Glossary of terms	6
2 Contacts	9
3 Background	10
4 Overview	11
4.1 Overview of the Standard4.2 Key milestones	12
 5.1 Purpose and scope of the Standard – overview 5.2 Purpose and scope of the Implementation Plan 5.3 Related standards 6 Accessible information standard summary 	13 14
7 Strategic assumptions	18
8 Change required	19
 8.1 Current situation – the 'as is' state 8.1.1 Process 8.1.2 Overview of current practice 	19
8.1.3 Overview of current record and data management systems	
8.2 Migration – moving from the 'as is' to 'to be' states	21
8.2.1 Overview 8.2.2 Electronic systems	
8.2.2 Electronic systems8.2.3 Paper-based systems	
8.2.4 Human behaviour	
8.2.5 Primary care interpreting services	
9 Success criteria	
10 Implementation plan	28
 10.1 Implementation approach 10.2 User acceptance testing 10.3 Full implementation 	28
10.4 Timetable for implementation	
11 Accessible information standard adoption	
12 Project work streams	31
 12.1 Governance 12.2 Communication, engagement and support 12.3 Clinical architecture and terminology	31 32 32 32
12.4.2 External stakeholders	33

12.4 12.4 13 Ro		34
13.1 13.2 13.3 14 Leg	NHS England Department of Health HSCIC gal, strategic and funding position	35 35
14.1 14.2 14.3 15 Su	Legal position Funding position Strategic position oport for health and social care organisations	36 37
15.1 15.2 15.3 15.4	Overview Resources, tools, advice and guidance E-learning module Learning events	38 39 40
15.5 15.6 15.7 15.8 15.9	Peer champions An online community Promoting good and best practice Peer-to-peer events Support from external organisations	41 41 41
15.9 15.9 15.9 Grou 15.9	 The voluntary sector strategic partner programme Other specific support from organisations who are part of the Advisc 44 	41 ory
	st-implementation maintenance and review	

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 which is able to be read or received and	
information Alternative format	 understood by the individual or group for which it is intended. 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 <u>Care and Support for Deafblind Children</u> and Adults (Department of Health, 2014) states that, "The generally accepted definition of Deafblindness is that persons	

	are regarded as Deafblind "if their combined sight and hearing impairment causes difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss" (<u>Think Dual Sensory</u> , <u>Department of Health, 1995</u>)."	
Disability	The <u>Equality Act 2010</u> 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 <u>Data</u> <u>Dictionary definition</u> .	
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 <u>Data Dictionary definition</u> and is also defined by the Department of Health in <u>Valuing People</u> (2001). People with learning disabilities have life-long development peeds and have difficulty with certain cognitive	
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 onto a laptop computer, which can then be read on screen.	
	Mainly used in hospital settings, and especially by NHS	
Patient	Trusts and Foundation Trusts, Patient Administration	
Administration	Systems are IT systems used to record patients' contact /	
System (PAS)	personal details and manage their interactions with the	
	hospital, for example referrals and appointments.	
	A coded thesaurus of clinical terms representing the clinical	
	terminology system used in general practice. Read Codes	
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.	
	A STTR types a verbatim (word for word) account of what is	
	being said and the information appears on screen in real time	
Speech-to-text-	for users to read. A transcript may be available and typed text	
reporter (STTR)	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.Classification of medical terms and phrases, providing codes,	
SNOMED CT	terms, synonyms and definitions. SNOMED CT is managed	
(Systematised	and maintained internationally by the <u>International Health</u>	
Nomenclature of	Terminology Standards Development Organisation (IHTSDO)	
Medicine Clinical	and in the UK by the UK Terminology Centre (UKTC).	
Terms)	SNOMED CT has been adopted as the standard clinical	
	terminology for the NHS in England.	
	Text Relay enables people with hearing loss or speech	
Text Relay	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 <u>'Next Generation Text'</u>	
	(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.A person able to translate the written word into a different	
	signed, spoken or written language. For example a sign	
Translator	language translator is able to translate written documents into	
	sign language.	
L		

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 <u>england.nhs.participation@nhs.net</u> with the subject 'Accessible Information Standard'.

Information and documentation about the Accessible Information Standard, including resources to support implementation are available <u>on the NHS England website</u> at <u>www.england.nhs.uk/accessibleinfo</u>.

3 Background

The <u>Equality Act</u> 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 the groups that were protected by previous equality legislation, known as Protected Characteristics, one of which is <u>disability</u>.

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. <u>Guidance</u> 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.

However, despite the existence of legislation and guidance, 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. This lack of access to accessible information and communication support has significant implications for patient choice, patient safety and patient experience, as well as directly impacting upon individuals' ability to manage their own health and wellbeing.

4 **Overview**

4.1 **Overview of the Standard**

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

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

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

Successful implementation of the Accessible Information Standard is based on the completion of 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 <u>SNOMED CT®</u> 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 paperbased 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.

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.

4.2 Key milestones

Task	Date
Implementation date: organisations MAY begin to	Immediately upon publication
implement the Standard.	of the ISN.
Organisations MUST have begun to prepare for	
implementation of the Standard, including assessing	
their current systems and processes, and	By 01 September 2015.
developing and commencing roll out of a local	
implementation plan.	
Organisations MUST identify and record information	
and communication needs when service users first	By 01 April 2016.
interact or register with their service.	
Organisations MUST identify and record information	
and communication needs as part of ongoing /	From 01 April 2016
routine interaction with the service by existing	From 01 April 2016.
service users.	
Date of full conformance: full implementation of the	By 31 July 2016.
Standard is required.	By 51 50ly 2010.

Further detail about the timetable for implementation is included in section 10.4.

5 **Purpose and scope**

5.1 Purpose and scope of the Standard – overview

The Accessible Information Standard directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting individuals' information and communication support needs.

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 "<u>at a substantial disadvantage…in comparison with</u> <u>persons who are not disabled</u>" 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 <u>guidance</u> produced by the Equality and Human Rights Commission (EHRC) states that, "Anything which is more than minor or trivial is a substantial disadvantage."

Further explanation about the scope of the Standard, including detail of in and out of scope aspects, and applicable organisations, is provided as part of the Specification.

5.2 **Purpose and scope of the Implementation Plan**

The purpose of this Implementation Plan is to support, enable and ensure the effective implementation of the Accessible Information Standard by all of the organisations to which it applies. As such, it details:

- How the Accessible Information Standard should be implemented by applicable organisations;
- The support to be provided or made available by NHS England;
- Key implementation milestones; and
- How compliance will be assured.

This document sets out how the Accessible Information Standard will be implemented by NHS and adult social care bodies, by providers of NHS and publiclyfunded adult social care and by their IT system suppliers. The Standard applies to all providers of NHS and publicly-funded adult social care services, including, but not limited to:

- 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 adult social care services including organisations from the voluntary and independent sectors.

Note that organisations responsible for commissioning NHS or publicly-funded adult social care services must also have regard to this Standard (as outlined in the Specification).

This Plan aims to demonstrate how organisations will need to migrate from the current or 'as is' state to the new or 'to be' state – in order to implement and comply with the Accessible Information Standard.

It includes all the actions required to support all applicable organisations to implement the Accessible Information Standard, and the governance structures that will be required to ensure that the appropriate steps are clearly defined in order to support the implementation of the Standard locally and nationally.

This Plan should be read alongside the Specification for the Accessible Information Standard, the Implementation Guidance and the Communication Plan.

NHS England is proposing to make available a range of resources and mechanisms to support organisations in effectively implementing the Standard, and to support patients / service users and stakeholder organisations in both understanding individuals' rights to accessible information and communication support, and how they can support implementation locally. This support is detailed in section 15.

5.3 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) (ISB 0011)

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

- <u>Clinical Risk Management: its Application in the Deployment and Use of Health IT</u> <u>Systems (ISB 0160 Amd 38/2012 Version 2)</u>
- <u>Clinical Risk Management: its Application in the Manufacture of Health IT</u> <u>Systems (ISB 0129 Amd 39/2012 Version 2)</u>
- 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.

6 Accessible information standard summary

Standard	
Standard Title	Accessible Information
Standard Number	SCCI1605 (ISB1605 - Amd 8/2013 Initial Standard)
Description	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).
	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.
	Accessible Information will require providers of NHS and adult social care to:
	 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	All providers of NHS and publicly-funded adult social care services, including, but not limited to:
	 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.
	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.
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	Organisations MAY begin to implement the Standard
Implementation	immediately upon publication of the Information Standards
Date	Notice (ISN).
Mandatory	By 31 July 2016, all applicable organisations MUST comply
Implementation	with the Accessible Information Standard in full (date of full
Date	conformance).

7 Strategic assumptions

- All applicable organisations will be compliant with the Accessible Information Standard by the published mandatory implementation date.
- Following SCCI1605 Accessible Information will become part of 'business as usual' for all applicable organisations.
- Many organisations will need some support to implement the Accessible Information Standard effectively.
- Organisations with systems which use the three recognised and supported clinical terminologies – Read v2, CTV3 and SNOMED CT – will have access to the four new subsets defined by the Accessible Information Standard and the codes associated with them.
- All organisations providing publicly-funded health and / or adult social care are subject to the 'reasonable adjustment' duties of the <u>Equality Act 2010</u>, and all NHS bodies and local authorities are further subject to the duty to 'advance equality of opportunity between those who share a protected characteristic and those who do not share it'.
- There is, and there remains, strategic and policy support for the Accessible Information Standard's core objective, that is that patients, service users, carers and parents with information or communication needs relating to a disability, impairment or sensory loss receive information in a format they can understand and any communication support they need to enable them to access services appropriately.
- The Standard is not developing, or leading to the development of, a data set or any central data return, collection or submission.
- Governance for implementation and beyond will be provided by NHS England.
- 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 eventual withdrawal of the Standard. Future developments might include:
 - o A data set or central data collection;
 - o Changes to the data items;
 - o 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.
 - o Standardisation of flow mechanisms and data formats.

8 Change required

8.1 Current situation – the 'as is' state

8.1.1 Process

The 'as is' state in the context of SCCI1605 Accessible Information refers to current practice with regards to the identification, recording, flagging, sharing and meeting of individuals' information and communication support needs. Assessment of the 'as is' state was completed through analysis of data recorded as part of engagement and consultation, testing and piloting of the draft accessible information standard. Further information about these activities can be found in the Report of Engagement, Report of Consultation, Test Report and Pilot Report respectively. Additional detail about the 'as is' state was also provided as part of less formal input from relevant professionals during the development process.

8.1.2 Overview of current practice

Current practice regarding identifying, recording, flagging, sharing and meeting the information and communication support needs of people with a disability, impairment or sensory loss varies greatly between organisations.

There are differences and inconsistencies within individual departments and services of the same organisation, between different organisations of the same type, as well as when different types of organisations are compared with one another.

This is a reflection of the fact that there is currently no consistent approach to the identification or recording of information and communication needs, something which the Accessible Information Standard aims to resolve.

At present, this lack of clarity means that even where an individual's information or communication needs are recorded with good intention by one clinician or staff member, the next individual involved in the person's care can be entirely unaware that such a record has been made – even if they are part of the same service or organisation. More frequently still, information recorded by one team, service or department is not shared with others involved in an individual's care due to a lack of process and guidance in this regard.

As such, needs are frequently not identified at all, or may be identified but not recorded, or recorded ambiguously, incorrectly or incompletely, or recorded but not shared or visible to other professionals involved in the person's care. Research as part of developing this standard has clearly demonstrated the problems inherent in the current lack of any standardised categories or processes.

Many organisations reported that, currently, they are not be able to ascertain communication needs until the point of assessment (i.e. when the patient or service user attended an initial appointment) by which point correspondence (in a standard print format) would be likely to have already been sent. Secondary care service providers reported that, although they received information about patients as part of the referral process, this often did not include information about communication needs. Many organisations have no standard questions or areas to record needs in either paper or electronic records, which increases the risk that a communication need would not be met even if it was recorded.

Organisations also highlighted issues with recording data about information and communication needs. In electronic systems, if fields for recording a communication need exist, the list of options on how to address that need is often limited. Many organisations record communication needs in a free-text area in the notes, which is unlikely to be checked by administrative staff. Many IT systems exist, even within the same organisation, and these often do not interact with other systems; this results in a lack of sharing of data about individuals' information / communication needs with other teams.

In many instances, the identification and recording of individuals' information and communication support needs is inconsistent and ad hoc, dependent on the personal commitment of individual staff members and the ability of individual patients to articulate their needs.

Local policies for meeting of individuals' needs also vary significantly, where they are in place at all. Even where they do exist, awareness amongst staff members as to what practical steps they should take in order to meet an individual's needs is often poor.

The process of developing this standard – and in particular, engagement and consultation – has led to an increase in the awareness-levels of NHS and adult social care provider organisations about the important role played by accessible information and communication support in enabling people with a disability, impairment or sensory loss to access services appropriately and independently, to receive high quality care and have a positive experience of care. It has also highlighted the importance of establishing and following a consistent process, and of having a comprehensive and well-publicised policy in place for meeting individuals' information and communication support needs. Many organisations have reported that they have already begun the process of reviewing and improving their own systems, processes and staff awareness in anticipation of the Standard's release.

However, it is recognised that a significant communications campaign is needed in order to continue to raise awareness, and, in particular to ensure that organisations who have not engaged with the Standard's development process are aware of their duties and able to implement the Standard effectively. A Communication Plan has been developed.

8.1.3 Overview of current record and data management systems

Applicable organisations use a diverse range of electronic patient / service user record, clinical management and administration systems.

Most GP Practices use a patient record / clinical management system from one of five major software suppliers, all of whom are part of the <u>GP Systems of Choice</u> (<u>GPSoC</u>) framework. This ensures that they have access to clinical terminology – enabling use of coded data items to record patient / service user information and

communication needs. However, in practice this is uncommon and recording – if it is undertaken at all – is as 'free text.'

In other settings, data about individuals' information or communication support needs may be recorded onto any of the available systems – noting current inconsistencies, ambiguities and omissions as described above. Some organisations make use of existing terminology to record needs, however, (often unstructured and ambiguous) 'free text' is more common.

It should be noted that a large number of applicable organisations still use paper records, including in particular dental practices and smaller, voluntary sector providers.

8.2 Migration – moving from the 'as is' to 'to be' states

8.2.1 Overview

In order to progress from the current or 'as is' state, to the future or 'to be' state (representing conformance with the Accessible Information Standard), organisations will need to:

- Develop and implement new or revised processes for the identification of individuals' information and communication needs;
- Reflect such changes by way of new or amended questions and sections in relevant documentation and online systems, for example new patient registration forms;
- Where systems use one of the three NHS terminologies, incorporate use of the codes associated with the four subsets of the Standard (as outlined in the Specification) as a routine element of patient / service user records / administration and management systems;
- Where electronic systems do not use any of the three NHS terminologies, or where paper based approaches are used, incorporate use of the 'human readable definitions' / categories linked to the codes associated with the four subsets of the Standard (as outlined in the Specification) as a routine element of patient / service user records / administration and management systems;
- Utilise or establish electronic flags or alerts or equivalent paper-based mechanisms – to ensure that, once recorded, staff are prompted to respond to individuals' information and / or communication support needs and / or automatic processes are triggered in order that needs can be met;
- Incorporate data about individuals' information and communication support needs as a standard, routine or automatic part of communication with other providers, including as part of referral, discharge and handover – this will include making adjustments to relevant templates and processes (whether electronic, paper, face-to-face or telephone);

- Develop and implement new or revised policies with regards to how individuals' information and communication support needs can be met, and support such policies with clear and well-known procedures for the arrangement or provision of formats or support required;
- Ensure that staff are aware of the implications of the Standard and are aware and able to follow local processes and procedures which have been put in place to ensure compliance. Such awareness SHOULD be achieved through signposting, supporting and facilitating the completion of NHS England's e-learning module and use of other resources developed to support implementation – see section 15.

8.2.2 Electronic systems

8.2.2.1 Overview

In the absence in the short to medium-term of a national integrated health and social care record, or single point of record access, data about individuals' information and communication support needs will need to be recorded in a number of different electronic and paper-based systems, by a range of different health and social care organisations. Such plurality of recording brings with it risks relating to duplication and currency, which must be acknowledged, however, resolution of which far exceeds the scope of this standard. The Standard therefore is required to be implemented in any and all systems currently used by providers of NHS and adult social care – in order that the outcomes are achieved. Such systems have a range of functionality and flexibility, and many are limited in their connectivity.

As part of the development of the Accessible Information Standard four subsets have been development, and SNOMED CT, Read v2 and CTV3 codes associated with them (as outlined in the Specification). To address identified gaps in terminology with regards to accessible information and communication support needs – and to introduce greater consistency and clarity into recording practices – new codes were authored and released within the three terminologies as part of the biannual release in October 2014 and April 2015. These codes are now available to use, and indeed the Standard mandates their use (where the terminologies are used in applicable systems). Additional codes will also be released in the future (see section 12.3 and the Specification).

8.2.2.2 GP patient records / clinical management systems

All GP practices using a patient record / clinical management system from a supplier who is part of the <u>GP Systems of Choice (GPSoC)</u> framework (more than 75% of practices) – and others using one of the three standard clinical terminologies – already have access to the data items associated with the four subsets of the Standard. They are therefore able to record individuals' information and communication support needs in line with the requirements of the Standard with immediate effect.

The Information Standards Notice (ISN) which is issued after Full stage approval requires software suppliers who are part of GPSoC to make the necessary changes in order that they comply with the Standard. In this instance, the focus will be on

ensuring that recorded information and communication support needs are 'highly visible' including through the establishment of flags or alerts, and facilitating the inclusion of needs as part of data sharing processes, specifically as part of referrals. Engagement with the GP Systems of Choice (GPSoC) user requirements team has already commenced, and a paper including a preliminary outline draft of the Standard was presented to a meeting of the GPIT New Requirements Group (NRG) on 01.05.14 as part of the test phase.

8.2.2.3 Patient Administration Systems (PAS) including NHS Local Service Provider (LSP) IT Systems

The Standard will require NHS bodies to make or direct changes to their PAS systems in order that they are able to comply with the Standard.

The Standard clearly specifies the outcomes which must be achieved as a result of implementation, however, it is recognised that the specifics of how local implementation is achieved using existing systems and processes will vary, including based on existing functionality and arrangements for upgrading / adjusting systems.

8.2.2.4 Summary Care Records

"The Summary Care Record (SCR) provides important medical information to clinicians in emergency, urgent or unplanned care to support patient safety and quality of care. The value of the SCR is further increased if other relevant clinical information is added, particularly to support 'anticipatory care' including patient preferences, care plan information and legal statuses.

Basic functionality for adding information to the SCR already exists in GP systems. However, the mechanism involves manual addition of information on an 'item-byitem' basis and is not widely used.

GP suppliers and HSCIC are developing improved functionality (in SCR v2.1) to make it easier for GPs to create SCRs with <u>additional information</u> for those patients that need them most."

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).

GP system suppliers are currently working to obtain full rollout approval for \underline{SCR} <u>v2.1</u>. It is currently supported by TPP SystmOne, with deployment in EMIS Web and InPractice Vision expected by autumn 2015.

Once the system used by the GP practice supports SCR 2.1, this means that if any of the codes are included on an individual's GP patient record – and the patient consents to additional information being included on their SCR – then the code will be added to their SCR. It will then be automatically visible to any health or care professional accessing their SCR in future. Patients with online access can view summary information from their detailed GP record, allowing them to confirm correctness and relevance over time.

The communication campaign associated with the implementation of the Standard (as outlined in the Communication Plan) will include awareness-raising and promotion of the use of SCR to make data about individuals' information and communication support needs available to other professionals and services who may be involved in their care in the future, particularly in urgent and emergency situations.

8.2.2.5 NHS e-referral service

From 15 June 2015 the <u>NHS e-Referral Service</u> replaced Choose and Book.

The <u>NHS e-Referral Service Vision</u> includes proposals to improve and update communication with patients, including through offering a wider range of information formats:

"Modern technology will allow the use of mobile phone Apps, e-mails, text reminders etc., to support different ways of communicating appointment-related information to patients and system alerts to professional users."

"Patients will be able to opt to receive booking information and updates in a number of different formats. Paper copies of referral / booking instructions will still be available, but other electronic media will be used to book, confirm and update appointments and send appointment reminders."

8.2.2.6 Local authority records (adult social care)

The Standard will require local authorities to make or direct changes to their service user record / administration systems in order that they are able to comply with the Standard.

The Standard clearly specifies the outcomes which must be achieved as a result of implementation, however, it is recognised that the specifics of how local implementation is achieved using existing systems and processes will vary, including based on existing functionality and arrangements for upgrading / adjusting systems.

8.2.2.7 Dental practices

Dental practices use a wide range of patient record and administrative systems – both electronic and paper-based (and combinations of the two). The implementation of the Standard by dental practices will therefore vary significantly. In all cases, dental practices will, as other applicable organisations, be required to make or direct changes to their systems to enable compliance with the Accessible Information Standard. This will include making changes to relevant registration and other forms such that information and communication support needs can be captured in line with the Standard, and staff are alerted to these needs when contacting the patient / when the patient next makes contact with the service.

8.2.2.8 Pharmacies

The <u>Electronic Prescription Service (EPS)</u> is being rolled out across the country. It enables prescribers - such as GPs and practice nurses - to send prescriptions electronically to a dispenser (such as a pharmacy) of the patient's choice. Following Full stage approval of the Standard, work will take place to explore the potential for including data recorded in line with the Accessible Information Standard as part of that shared with / available to pharmacists. In the meantime, pharmacies will be

required to implement the Standard using existing electronic / paper-based systems as outlined above.

8.2.3 Paper-based systems

Feedback indicates that a significant proportion of smaller providers, and in particular providers of adult social care, care in a nursing or care home setting, and voluntary sector providers of NHS care, rely in whole or part on paper records and paper-based approaches to patient / service user administration and record-keeping.

The Standard's Requirements are deliberately intended to enable – and direct – implementation of the Standard in paper-based systems, with lack of an electronic system posing no barrier to achievement of the fundamental steps and objectives of the Standard. The principles of routine identification, consistent and unambiguous recording of individuals' needs are entirely possible within paper based systems, and flags or alerts may be introduced using an appropriate colour scheme or affixing a sticker or other symbol as a prompt to staff to take action. It is likely that the implementation approach followed by organisations reliant on paper-based systems will be bespoke, and the Standard allows for such flexibility, whilst being clear as to the required outcomes.

8.2.4 Human behaviour

In addition to requiring changes to be made to electronic (and paper-based) record and administration systems, the Standard will require – in some cases significant – changes in 'human behaviour'. That is, many organisations will need to amend the processes followed by staff as part of interacting with patients / service users, arranging appointments, preparing and sending correspondence and providing information – and other activities – order to implement the Standard.

Further information about the practicalities of implementing the Standard is included as part of the Implementation Guidance, and resources to support implementation (including very specifically to support and enable human behavioural change in line with the Standard) will be made available as outlined in section 16.

Post-approval, engagement with Health Education England and with relevant professional oversight, curricular-setting and membership bodies – including royal colleges – will be undertaken with a view to embedding the Accessible Information Standard as part of appropriate training and education, as well as accreditation and revalidation.

8.2.5 Primary care interpreting services

The provision of interpretation in primary care – including for people who are d/Deaf or do not speak English as a first language (i.e. including people with a need for foreign language interpretation) – is being considered as part of a separate workstream being taken forward by NHS England, in partnership with North of England Commissioning Support (NECS).

Following research and engagement activity, "The themes have been used to develop a draft Quality Standards Framework for Interpreting and Translation Services. The draft Quality Standard Framework will be used to develop service specifications and commission models for delivering quality interpreting services..."

Work is ongoing as at summer 2015. Further information about this project is available on the <u>NHS England website</u> or by emailing <u>interpreting@nhs.net</u>

9 Success criteria

- All applicable organisations identify the information and communication needs of patients, service users, carers and parents with a disability or sensory loss at the point of first contact with the service. Relevant documentation and forms include a specific question about and section to record individuals' information and communication needs in line with the Standard.
- All applicable organisations routinely record the information and communication needs of patients, service users, carers and parents with a disability or sensory loss using the SNOMED CT, Read v2 or CTV3 codes associated with the four subsets of the Standard or (where these terminologies are not supported by electronic systems / where paper-based systems are used) using the 'human readable' definitions / categories.
- All applicable organisations have a policy in place, supported by necessary system functionality, to attach flags, alerts or prompts to the records or notes of individuals with information and / or communication support needs which relate to a disability or sensory loss. Such alerts prompt staff to take action in order that those needs may be met, and / or automatically trigger actions necessary so that those needs are accommodated, for example auto-generation of correspondence in an alternative format.
- All applicable organisations 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 is either formatted in line with relevant SNOMED CT, Read v2 or CTV3 codes or using the associated 'human readable' definitions / categories.
- All applicable organisations have an 'accessible communications policy' in place, and publicly available, which outlines how they comply with the Standard, including how individuals' needs will be met. Internal communication ensures that staff are aware of the Standard and of local policy and procedure to ensure effective implementation.

10 Implementation plan

10.1 Implementation approach

Successful implementation of the Standard requires changes to:

- Organisational policy, procedure and paperwork;
- The human behaviour of staff and their interactions with patients, service users, carers and parents;
- Electronic systems, clinical / technical architecture and terminologies.

The implementation approach will therefore be to provide:

- Advice, guidance and tools to support effective implementation of the Standard by organisations and their staff;
- SNOMED CT, Read v2 and CTV3 codes associated with four subsets listing all available terminology to be used in recording individuals' needs as part of the Standard;
- Support and direction for 'system-wide' / national changes needed.

10.2 User acceptance testing

Evidence of stakeholder engagement and input into the design and development of the Standard from health and social care professionals, organisations and representative bodies may be found in the Test Report, Report of Engagement and Report of Consultation.

Piloting (including live testing) of the draft standard took place between January and March 2015, and the outcomes are detailed in the Pilot Report. In addition, two 'effective implementation' workshops took place in March and April 2015, involving a range of key stakeholders and applicable organisations – the outcomes of which can be seen in the Report of Implementation Workshops.

10.3 Full implementation

The Standard allows for flexibility in implementation approaches, subject to successful achievement of the stated requirements and outcomes. In all cases, applicable organisations MUST have implemented the Standard such that they are fully compliant with all requirements by 31 July 2016.

10.4 **Timetable for implementation**

The proposed timetable for implementing the Standard is set out below, this outlines dates when applicable organisations MAY and MUST implement the Accessible Information Standard.

Organisations MAY begin to implement the Accessible Information Standard immediately upon publication of the ISN (Information Standards Notice).

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

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

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

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

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

11 Accessible information standard adoption

All applicable organisations are required to implement and comply with the Accessible Information Standard in line with the timescales and milestones detailed in section 10.4.

Nationally, it is anticipated that GP practices are likely to implement the Standard in advance of other services / settings due to their direct and immediate access to the data items associated with the four subsets of the Standard and to appropriate electronic flags or alerts. Early uptake of the Standard by GP practices will assist secondary care organisations (in particular) as information about individuals' information / communication needs should begin to be accessible to them via referrals and Summary Care Records (see section 8.2).

It is also anticipated that organisations involved in piloting the draft standard will act as 'front runners', as they will have already undertaken much of the preparatory work needed to effectively implement the full / final standard.

Locally, the adoption process will vary significantly depending on the current state of systems and processes for identifying, recording, flagging, sharing and acting upon the information and communication support needs of patients, service users, carers and parents in each organisation. It will also vary based on the organisation's level of involvement in the process of developing the Accessible Information Standard and level of awareness.

12 Project work streams

The main project workstreams are set out below.

12.1 Governance

Robust governance and project management is required to ensure that the Standard is successfully approved and implemented, and remains 'fit for purpose'. Following approval and release of the Standard, NHS England will continue to have the overarching lead role, with the existing advisory group (which includes membership from the Department of Health, Professional Records Standards Body and the voluntary sector) continuing to oversee the programme through implementation and subsequently adopting a maintenance role. The membership of the Advisory Group will be reviewed following approval of the Standard at Full stage, and may be revised as appropriate.

12.2 Communication, engagement and support

This workstream addresses the known issue of lack of awareness amongst professionals working in health and social care settings about the importance of meeting individuals' information and communication support needs, and how best to do so, as well as the specific actions required in order to implement the Accessible Information Standard.

The Communication Plan outlines in detail the proposed activities in order to raise awareness of the Accessible Information Standard amongst key target groups, including applicable organisations, and section 15 of this Implementation Plan details the implementation mechanisms / support which such communications will promote.

The bulk of the work lies in:

- Ensuring that applicable organisations are communicated to effectively in order to understand the Requirements of the Standard;
- Raising organisational and staff awareness of the challenges faced by people with information and communication support needs relating to a disability, impairment or sensory loss, and of steps which SHOULD and MUST be taken in order to identify, record, flag, share and meet those needs in line with the Standard;
- Continuing to build and develop the necessary working relationships to support effective implementation of the Standard including through facilitating the sharing of good practice, peer support and advice, and access to external sources of guidance.

The implementation methodology is focused on:

- Communications to get the key messages to the right people via the most appropriate channels;
- Provision of guidance and support to promote consistency and promote best practice;

• Establishment of working relationships and external support for the Standard.

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 including being incorporated into activities as outlined in the Communication Plan.

12.3 Clinical architecture and terminology

The Standard has defined four new subsets, listed within the <u>Data Dictionary for Care</u> (dd4c), with associated data items available in SNOMED CT, Read v2 and CTV3 (as outlined in the Specification). These codes MUST be used where electronic systems use / refer to any one of the three clinical terminologies. In electronic systems which do not use SNOMED CT, Read v2 or CTV3 codes (and in paper-based systems), 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'.

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 October 2015). 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.

Consideration has also been given as to how this standard relates to work around standards for the structure and content of patient records, and in particular the 'special requirements' heading, as outlined in '<u>Standards for the clinical structure and content of patient records</u>'. Engagement with the Royal College of Physicians and the Association of Medical Royal Colleges 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. Further detail is included in the Specification.

12.4 Conformance monitoring

12.4.1 Conformance criteria

The Specification for the Standard defines a number of conformance criteria or indicators of compliance with the Standard. These conformance criteria SHOULD be used by applicable organisations to assess and ensure conformance, and MAY be used by commissioning organisations to assess and ensure the conformance of organisations providing commissioned services.

Note that commissioners MUST seek assurance from provider organisations of their compliance with this standard, including evidence of identifying, recording, flagging, sharing and meeting of needs.

The conformance criteria MAY also be used by other organisations, for example local Healthwatch and voluntary organisations, to assess the performance of local health and adult social care providers, however, additional, targeted information and resources will also be developed in this regard.

It should be noted that no national audit of compliance is proposed, as the Standard is not establishing a national data return or collection.

12.4.2 External stakeholders

Many external stakeholders have shared their plans to support implementation – including as outlined in section 15.9 – and also to hold organisations to account on behalf of their members / people they support. Communications and resources to support implementation will include materials aimed at local Healthwatch organisations and voluntary groups – as well as at service users themselves – to raise awareness of the impact of the Standard and what should be expected as part of compliance.

Given the level of interest in this standard, organisations should expect, and are encouraged to be receptive to, approaches by local Healthwatch and voluntary organisations seeking to support and expedite implementation and compliance. Organisations embracing such external assistance are likely to find the process of implementation and compliance more efficient and potentially less expensive (given the wealth of expertise about accessible information and communication support that exists within the voluntary sector) and to see the 'added value' of relationship building and an enhanced reputation amongst disabled people in their community (in particular).

Organisations should be aware of the risk of complaints, investigation, negative media coverage and / or legal proceedings should they be unable to demonstrate their compliance with the Standard.

The Standard includes requirements for organisations to publish or display an accessible communications policy which explains how they will follow the Accessible Information Standard, and an accessible complaints policy. The inclusion of these requirements is intended to support ease of compliance assessment by interested organisations, and to ensure that people with information and communication support needs are able to provide feedback to organisations about their experiences.

12.4.3 Care Quality Commission

The Care Quality Commission (CQC) recognises the role of the Accessible Information Standard as an indicator of high quality care for people with particular information and communication support needs, and has provided the following statements:

- "Health services: As part of our inspection work, CQC will look at evidence of how services implement the Accessible Information Standard when we make judgements about whether services are responsive to people's needs.
- Adult social care services: As part of our inspection work, CQC will look at evidence of how services implement the Accessible Information Standard when we make judgements about whether services are responsive to people's needs and whether they are well led."

12.4.4 Patient-led assessment of the care environment (PLACE)

It is intended to include assessment of conformance with the Accessible Information Standard as part of the <u>PLACE programme</u>. This will be further explored following publication of the Information Standards Notice (ISN).

13 Roles and responsibilities

13.1 NHS England

NHS England will:

- a) Through the Information Standards Notice (ISN), direct amendments to nationally commissioned IT and administrative systems to facilitate implementation of the Accessible Information Standard, as appropriate.
- b) In addition to detailed Implementation Guidance, make available advice, materials, tools and templates for health and social care organisations to support them in implementing the Standard.
- c) Increase the availability of 'generic' health and social care information and / or standard templates in alternative formats via its website and / or via NHS Choices.
- d) Develop materials and advice for regulatory and assessment organisations, patient groups and local Healthwatch, to support them in assessing, monitoring and supporting compliance with the Standard.
- e) Provide support, such as recognition, for organisations going beyond minimum compliance.
- Provide governance, including via the ongoing management of the Standard Setting for Accessible Information Advisory Group, to oversee implementation and maintenance.
- g) Oversee and implement the Communication Plan, with support from the Advisory Group.
- h) Manage queries, concerns and feedback.

13.2 Department of Health

The Department of Health will provide:

- a) Policy leadership for the Accessible Information Standard.
- b) Support for the development and implementation of the Standard from the social care policy directorate.

13.3**HSCIC**

The Health and Social Care Information Centre (HSCIC) will provide expert advice, support and guidance from subject matter experts as to:

- Development methodology for Information Standards;
- The GP Systems of Choice Framework and GP IT more widely;
- Information modelling;
- Terminology and coding including the NHS Data Model and Dictionary, SNOMED CT, Read v2 and CTV3 codes.

14 Legal, strategic and funding position

14.1 Legal position

Although introducing consistency and clarity, via specific requirements, the Accessible Information Standard is building upon existing legal duties which public sector bodies and all service providers are already obligated to follow, including as set out in the Equality Act 2010.

The <u>Equality Act</u> 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 <u>disability</u>.

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. <u>Guidance</u> 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.

14.2 Funding position

There will be no specific funding made available to organisations to support the implementation of the Standard. This reflects the fact that the Standard clarifies and supports organisational compliance with existing legal duties (as outlined above), rather than introducing a 'new burden' and is intended to support direct patient care. There is no national collection, data set or secondary use of data proposed. It also reflects the fact that although there will be initial costs to implement the Standard, this initial investment will lead to a range of identified benefits – for both organisations and patients – including the generation of cost savings in the future. Further information about the benefits associated with this standard is included in the Specification.

However, for the 2015/2016 financial year, NHS England has identified a small budget to support implementation of the Accessible Information Standard, in addition to staff costs.

The majority of the dedicated budget has been identified to support implementation of the Standard as outlined below, that is, for:

- Development of an e-learning module;
- Arrangement and hosting of learning and implementation events;
- Establishment of a 'peer champions' network;
- Development of advice, guidance, tools and other materials to support implementation;

- Peer-to-peer events;
- Organisational support to enable organisations to take a lead role in particular aspects of implementation, for example sharing best practice, hosting or cohosting events.

Funding has also been identified to support the production of information about the Accessible Information Standard in alternative formats. This is primarily to support patients, service users, carers and parents with information and / or communication support needs relating to a disability, impairment or sensory loss to understand the impact and scope of the Standard. It is also intended to support voluntary and community sector organisations working with disabled people to work with local health and social care organisations to inform effective local implementation of the Standard.

14.3 Strategic position

The Accessible Information Standard has been set in the context of a wider workstream being taken forward by NHS England, with the stated aim to ensure that: "Everyone can find and is given the high quality information they need to have greater control of their health and wellbeing and associated decisions. This information is available when needed and in a format that is accessible and reflects individuals' needs and preferences. They receive support from health and care professionals who communicate effectively, are compassionate and inclusive and who listen and respond to the whole person, not just their symptoms or medical conditions."

This programme considers and seeks to develop and promote the role of high quality, accessible information as a key driver in ensuring that patients are able to be active participants in their own health and care. In addition to the Accessible Information Standard, the programme includes:

- Ongoing delivery and development of <u>The Information Standard</u> (the quality assurance kitemark for health information).
- Building a national collaborative model around health literacy.
- Scoping and developing proposals around levers and incentives within the commissioning system and how they could be applied to support the information agenda.
- Building partnerships both internally and externally to support the development of the information agenda.
- Developing a communications strategy, building a clear narrative and evidence base to underpin the significance of high quality accessible information as a necessary underpinning element of good, equitable person centred care.
- Building a suite of guidance and resources to support producers and providers of health information.

15 Support for health and social care organisations

15.1 Overview

As part of supporting effective implementation of the Accessible Information Standard, and minimising the burden of implementation upon applicable organisations, NHS England has committed to making available a suite of resources and offering a range of other opportunities to support awareness-raising, professional development and efficient implementation by organisations.

15.2 Resources, tools, advice and guidance

The following resources will be developed by or on behalf of NHS England and made available to support effective implementation of the Standard during 2015/16 (where relevant guidance or resources are already in existence, organisations will be signposted accordingly):

- Sharing of patient identifiable and other data with interpreters, translators, communication support workers and advocates (including information governance considerations);
- Communicating with patients via email and text message (including information governance considerations);
- Legal duties to meet individuals' information and communication support needs;
- Different types of accessible information and communication support and who may need them;
- The benefits of accessible information and communication support;
- Ensuring and assuring the accuracy of data recorded about individuals' information and communication support needs;
- Supporting mental health service users with communication needs;
- Ensuring the accuracy and quality of translated or transcribed information;
- Ensuring and assuring the competency of interpreters, communication support workers, translators and advocates;
- Using assistive technology, virtual, remote and web-based solutions to support people with information and communication needs;
- Achieving value for money and 'added value' with regards to accessible information and communication support;
- How to locally assess compliance with the Standard and staff knowledge / awareness;
- Effective 'easy read' information;
- Inclusive communications reducing the number of alternative formats needed by improving the accessibility of 'standard' documentation;
- Inclusive communications how staff and services can support everyone with communication needs;

- Inclusive communications specific advice about supporting people with particular information and communication needs, for example people with hearing loss, dementia or aphasia;
- Inclusive communications web accessibility and usability.

The following tools or templates will also be made available:

- Accessible communications policy;
- Registration form;
- Service user 'help' card;
- Communication 'passport';
- Tools to enable internal audit of preparedness and compliance;
- Posters, statements and other prompts which may be used to encourage people to inform the service that they have any information or communication needs.

In addition, short, concise introductory and reference documents will be developed, including: 'top tips;' myth busters; quick guides; and a glossary of terms / definitions.

The Communication Plan provides further detail on specific awareness-raising activities, and ways in which available resources will be promoted.

It is intended that all of the resources will be made freely and publicly available online, and that relevant resources will be developed in partnership with other organisations with relevant expertise, including from the voluntary and community sector and professional representative bodies. In addition, communications will signpost organisations to other sources of support.

15.3 E-learning module

In recognition of the identified need for greater awareness and education of health and social care staff to enable them to confidently, sensitively and effectively implement the Accessible Information Standard, NHS England will make available a free-to-access e-learning module.

The 'accessible information' e-learning module will support organisations and staff in implementing the Accessible Information Standard through raising awareness of the needs of people with information and communication disabilities, putting the Standard in context (both legal, strategic and policy), and including practical examples and scenarios which demonstrate actions which can and should be taken by health and social care staff to support people with information and communication needs.

The overall focus of the module will be on effective implementation of the Accessible Information Standard in practice, and promoting equality through accessible information and communication.

Steps will be taken to ensure that the module is as interactive and engaging as possible, including exploring the use of video content such as 'talking heads', for example service users sharing their experiences of good and bad practice,

challenges and solutions. A short test to assess understanding will be included at the end of the module, with staff gaining a mark of 80% or above receiving an e-certificate of achievement.

The e-learning module will be made freely available online, with a specific location to be determined, although likely incorporated as part of an existing suite of professional resources / e-learning content, such as the <u>Embedding Informatics in</u> <u>Clinical Education and Practice (eICE)</u> online programme. The possibility of incorporating the module as part of mandatory equality and diversity training will also be considered.

15.4 Learning events

A series of learning events will be held during 2015/16 to support implementation and provide an opportunity for the sharing of solutions and good practice. It is anticipated that between six and eight such events will take place across England during quarters two and three of the 2015/16 financial year.

It is hoped the events will be co-hosted or hosted by health or social care organisations demonstrating best practice in the field of accessible information and communication, perhaps in partnership with a relevant organisation from the voluntary and community sector.

The arrangements for these events will link into other implementation support approaches outlined in this section, for example they will provide opportunities to showcase best practice and for people working in health and social care settings to learn from 'peer champions', and receive practical advice to support effective implementation.

15.5 Peer champions

As part of supporting the effective implementation of the Accessible Information Standard, NHS England will facilitate and support the identification of 'peer champions' for the Accessible Information Standard, and for accessible information and communication more widely. There are two aspects to this:

- 'Professional champions': people who work in NHS or adult social care settings who are committed to working in ways which promote accessible information and / or the effective provision of communication support, for example GPs, nurses, social workers;
- 'Service user champions': people who access NHS or adult social care services who are committed to supporting access to accessible information and communication support.

Both types of champion could support their peers, for example a GP 'peer champion' could support a GP who was concerned or struggling with a particular aspect of the Accessible Information Standard, and a d/Deaf 'service user champion' could support other d/Deaf people to understand what the Accessible Information Standard means

for them. In addition, 'service user champions' could support health and social care professionals and organisations to effectively implement the Standard.

15.6 An online community

NHS England will establish a virtual 'community of interest' for the Standard, as part of which stakeholders and professionals from applicable organisations can share queries, solutions and good practice using an online platform. This community will connect into wider work to identify and share good practice, will include the peer champions, and link to available resources associated with the Standard.

15.7 Promoting good and best practice

The importance of promoting or publicising good and best practice in the field of accessible information and communication support is acknowledged as an important way to support implementation of the Accessible Information Standard by organisations. NHS England will support the identification and promotion of good and best practice though:

- Proactively inviting organisations to share examples or case studies;
- 'Hosting' examples of good practice online;
- Recognising (in some way) those organisations that are excelling;
- Publicising examples via existing communication channels;
- Showcasing examples of good practice as part of learning events and documentation associated with the Standard.

15.8 Peer-to-peer events

In addition to the implementation events outlined above, and the events to be hosted by voluntary sector strategic partners, outlined below, NHS England will also arrange a number of smaller events specifically aimed at bringing peers together to work through implementation challenges, share learning and good practice, and identify solutions, including where solutions may be shared or co-commissioned across organisational boundaries. It is anticipated that these events will be hosted / cohosted by voluntary sector organisations.

15.9 Support from external organisations

15.9.1 The voluntary sector strategic partner programme

15.9.1.1 Overview

The Department of Health, NHS England and Public Health England Voluntary Sector Strategic Partner programme brings together expertise from the voluntary and community sector to work with system organisations on key aspects of health, social care, and public health policy on behalf of patients, service users and the wider public. There are currently 22 partners, with extensive reach into the many thousands of local charities and voluntary organisations in England. Each year, each partner agrees a funded workplan. For the 2015/16 financial year, specific activities to support the effective implementation of the Accessible Information Standard are included as part of the workplans for:

- The Win-Win Alliance (which is made up of Disability Rights UK, Shaping Our Lives and CHANGE);
- The Disability Partnership (which is made up of the Royal Mencap Society, National Autism Society, Sense and Scope);
- Voluntary Organisations Disability Group (VODG), National Care Forum (NCF) and Sue Ryder Care.

15.9.1.2 Implementation support from CHANGE

"A key part of the methodology will be the employment of people with lived experience of learning disabilities, autism and / or sensory impairment as Accessible Information Standard Champions. The work will be carried out through large-scale, national awareness events, training sessions for professionals on compliance with the Standard and improving communication with people with learning disabilities, autism and / or sensory impairments, as well as training and workshops for individuals to raise awareness of their rights to information.

The Accessible Information Standard Champion(s) will work with self-advocacy groups to train individuals on quality checking accessible information and will support links with local organisations to aid in the creation of a network of user-led quality checking services.

<u>CHANGE</u> will employ two co-workers on this project for the next 12 months, one with a learning disability and one without. They will work in partnership with a representative(s) from Sense to champion the Accessible Information Standard. Together with NHS England we will identify local areas to target for professional and user-led training. The purpose of the training will be to increase awareness for health and social care professionals nationally and improved professional styles, thus removing barriers to accessing care and support to achieve a reduction in health inequalities.

The Win-Win Alliance and The Disability Partnership will work together to deliver six national events for health and social care professionals and users of services. These events will raise awareness of the Standard, highlighting both professional obligations and service user rights.

In addition, CHANGE will support Sense in the delivery of easy read documentation to enable individuals to know their rights under the Standard. CHANGE will continue to produce easy read information for NHS England and other organisations as part of the ongoing rollout of the Standard.

Outcomes:

• Ensure health and social care organisations are aware of their obligations following the approval of the Accessible Information Standard to improve access

to health and social care and promote greater choice and control for people with learning disabilities.

- Support better commissioning and reduced inequalities in health by supporting professionals and service providing organisations with the information, tools and experience necessary to comply with the Accessible Information Standard.
- If the Accessible Information Standard, is applied correctly, people are informed of their rights to receive the care they need in ways they understand.
- By training 'peer champions' in local areas information can be disseminated quickly and more widely, encouraging partnership-working and co-production and enabling people with learning disabilities to be employed in meaningful roles."

15.9.1.3 Implementation support from Sense

"<u>Sense</u> is committed to supporting NHS England with the continuing development, launch, promotion and implementation of the Accessible Information Standard.

Key elements of activity will centre around the development of implementation materials for providers and service users including a glossary of information formats and communication methods and a communication passport to enable service users to know their rights and indicate their needs under the Standard. As a member of The Disability Partnership we will work collaboratively with CHANGE and the Win-Win Alliance to design and deliver national and regional events and training for professionals, providers and service users.

In addition to providing external support to the Standard, Sense will promote the Standard to its service users, members and staff and seek to embed knowledge, understanding and support of the Standard in the organisation as a whole.

Opportunities to promote the Standard further will be identified including referencing to it within internal and external publications, providing relevant information on the Intranet and Internet, briefings and attending user forums, services, staff training and members events."

15.9.1.4 Implementation support from VODG, NCF and Sue Ryder Care

As part of their 2015/16 workplan, Voluntary Organisations Disability Group (VODG), National Care Forum (NCF) and Sue Ryder Care will work with NHS England to "...provide input in to our networks and events to enable providers to have an understanding of their responsibilities with regard to the Standard." Activities will include:

- Publishing information in weekly briefings to members of NCF and VODG;
- Inclusion of a workshop about the Accessible Information Standard at the Annual Managers Conference;
- Inclusion of presentations about the Standard at Managers Events;
- Providing access to more senior staff through member network meetings;
- Supporting NHS England to produce advice / guidance / tools to support implementation.

15.9.2 Other specific support from organisations who are part of the Advisory Group

15.9.2.1 Action on Hearing Loss

"As the largest UK charity for people with hearing loss and deafness, <u>Action on</u> <u>Hearing Loss</u> are a major source of information and support around hearing loss. Once the Accessible Information Standard is published, we will offer our expertise and support to patients and professionals who need advice on how to ensure communication and information needs are met and that people with hearing loss and deafness get the best outcomes from health and social care services.

We plan to promote the Accessible Information Standard and provide information and support to people with hearing loss through our website, information line, social media, magazine and newsletters, as well as through networks of other patient groups and charities, and health and social care organisations and professionals. We would look to share good practice through these networks as well as through our website and through the media, and raise awareness as well as encouraging compliance with the Standard. We will integrate the Information Standard into two projects we have planned for 2015/16 – the <u>Our Health in Your Hands campaign</u> and the development and dissemination of a 'How Life Should Be' resource, both of which work to encourage people with hearing loss and deafness to know their rights to accessible health and social care, ask for their communication and information needs to be met, and to complain if these are not met."

15.9.2.2 Care Quality Commission (CQC)

Once the Standard is approved, the <u>Care Quality Commission (CQC)</u> will support implementation and awareness-raising through targeted communications, including:

- Internal communication with CQC staff using existing mechanisms such as the intranet, webinars and inclusion of articles in staff bulletins, and incorporation of information about the Standard into internal training for relevant staff;
- External communication with providers using establishment mechanisms such as bulletins and newsletters;
- Raising awareness through the 'equality and human rights network' and using contacts with EDHR (Equality, Diversity and Human Rights) leads to share and cascade information;
- Development and publication of guidance about accessible information for inspections, including focusing on the Accessible Information Standard as part of a future <u>GP and Out-of-Hours 'mythbuster'</u> topic.

15.9.2.3 The Royal National Institute of Blind people (RNIB)

"<u>RNIB</u> is planning to support the implementation of the new NHS information standard in two ways outlined below, as part of a wider priority campaign to promote accessible NHS information to blind and partially sighted people.

Firstly we're launching a major country-wide communications campaign aimed at blind and partially sighted people, to raise awareness of the importance of accessible NHS information and to encourage everyone to notify their local NHS provider of their required accessible format. Second, we'll provide targeted support to NHS organisations aiming to implement accessible information for blind and partially sighted people, particularly where those organisations have a strategic influence to other NHS services. We at RNIB are well placed to assist in addressing the practical understanding of what patients with sight loss need and in the translation of these needs into processes."

15.9.3 Other external support

15.9.3.1 Statements of support

A number of organisations have formally endorsed the Accessible Information Standard and a series of letters or statements of support have been received. Many of these organisations have also offered to provide implementation support for the Standard, including awareness-raising, advice in their particular field(s) of expertise, and support for particular groups of service users. 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, Sense, SignHealth, the Royal National Institute of Blind people (RNIB), 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.

15.9.3.2 Support from professional representative bodies / royal colleges

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 06.05.15. 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.

15.9.3.3 Support from the Joint Health Strategy Group

At their meeting in London on 14 November 2014, the Joint Health Strategy Group (of library organisations who have health interests) "...concluded that we would be able to offer the following support and would work with the implementation team to see how we might make best use of the resources that the Group has to offer from its constituent stakeholders." Identified support included:

"Dissemination of information about the new standard using our constituent member networks to enable awareness throughout the professional library and knowledge community.

Help in creating briefing sheets which would encompass best practice on how to make publications and web sites accessible."

16 Post-implementation maintenance and review

Once the Standard has been implemented, NHS England will continue to have strategic oversight and operational ownership. NHS England will also provide governance for future developments including periodic review of the Standard, changes and future development of the Standard.

As outlined in the Maintenance Plan, there are two reviews of the Standard planned, in September 2016 and April 2017. These proactive reviews will assess the Standard for currency and validity, with any indicated changes being assessed using the documented change process and in line with the established governance approach. Evidence of achievement of anticipated benefits associated with the Standard will also be considered as part of both of the scheduled reviews.

The Maintenance Plan also outlines anticipated 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. Changes may be requested by contacting NHS England by emailing <u>england.nhs.participation@nhs.net</u> with the subject 'Accessible Information Standard'.