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National Guidance
• NHSE guidance https://www.england.nhs.uk/ourwork/patients/accessibleinfo/

Commissioning Responsibilities
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.

NHS England Responsibilities
NHS England will retain oversight and strategic responsibility for the Accessible Information Standard.
Overview

Five basic steps make up the Accessible Information Standard:

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

2. **Record**: record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record / administrative systems / documents.

3. **Alert / flag / highlight**: ensure that recorded needs are 'highly visible' whenever the individual's record is accessed, and prompt for action.

4. **Share**: include information about individuals' information / communication needs as part of existing data sharing processes (and in line with existing information governance frameworks).

5. **Act**: take steps to ensure that individuals receive information, which they can access and understand, and receive communication support if they need it.
Tips for printed communication

1. Use a minimum font size of 12 point, preferably 14 (which is readable by a significantly greater number of people).

2. Use a clear, uncluttered and sans serif font such as Arial.

3. Align text to the left margin and avoid ‘justifying’ text.

4. Ensure plenty of ‘white space’ on documents, especially between sections. Avoid ‘squashing’ text onto a page and, if possible, include a double-space between paragraphs.

5. Print on matt and not gloss paper.

6. Use page numbers.

7. If printing double-sided ensure that the paper is of sufficient thickness to avoid text showing through from the other side.

8. Correctly format Word documents and PDFs using styles and accessibility functions / checks. Ensure a correct and consistent heading structure, and that the cursor can move throughout all text.

9. Use descriptions (‘alt. text’) to explain diagrams or photographs.

10. Consider making all ‘standard’ printed letters / documents ‘easier to read’ – using plain English, highlighting important information, and supporting text with diagrams, images or photographs.

11. Keep track of the electronic originals of documents you print out so you can reprint in larger font or convert to an alternative format when required.

12. Further advice about creating accessible documents, including for users of assistive technology, will be made available as part of the suite of tools to support implementation of the Standard.
Step 1 - Ask
One of the fundamental principles of the Accessible Information Standard is that patients, service users, carers and parents should be asked to self-define their information and / or communication support needs, and it is these needs (and not their disability) which should be recorded.

Individuals MUST be asked about any information or communication support needs by a member of staff upon their first or next interaction with the service.

In addition, individuals MAY be asked to advise the service of their communication or information needs via inclusion of a request in a ‘generic’ letter. For example:

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

We want to know if you need information in braille, large print or easy read.

We want to know if you need a British Sign Language interpreter or advocate.

We want to know if we can support you to lip-read or use a hearing aid or communication tool.

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

Thank you.

Text from Anytown Surgery: We’re improving how we communicate with patients. Please tell us if you need information in a different format or communication support.
It would be considered good practice to include a ‘standard line’ as part of all correspondence to encourage people to contact the service if they have any information or communication needs, for example:

“If you would like this letter or information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call us on xxxxxxxxxx or email xxxxxxxxxx.”

However, organisations are not required to undertake any retrospective search (or ‘trawl’) of registered patients / service users to identify their needs as part of the Standard – although this would be considered good practice.

If an individual is known to the service and known to have a learning disability, it would be appropriate to offer support and prompts to support the individual in accurately identifying their needs.
An illustrative example follows:

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

Patient: Ok.

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

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

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

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

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

Patient: Yes, I think so.

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

Patient: Yes.

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

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

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

Patient: Yes.

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

Patient: Ok, thank you.

The organisation, service, team, department or ward SHOULD agree one or more questions, which they will use as standard, this will support consistency.
Feedback from patients and patient groups indicates that use of the term ‘disabled’ or ‘disability’ should be avoided wherever possible.

It should be noted that this standard does not impact upon the recording of patients’ diversity monitoring / protected characteristic strand affiliation, the collection of which is covered by separate guidance. However, organisations may wish to be mindful that people without any disability, impairment or sensory loss, but who do not speak or read English – because they use a different language – are not included in the scope of the Standard.

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

- Do you have any special communication requirements?
- How do you prefer to be contacted?
- What is your preferred method of communication?
- How would you like us to communicate with you?
- Can you explain what support would be helpful?
- What communication support should we provide for you?
- What is the best way to send you information?
- Do you have any communication needs?
- Do you need a format other than standard print?

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

- Do you have difficulty hearing, or need hearing aids, or need to lip-read what people say?
- Do you have difficulty with memory or ability to concentrate, learn or understand?
- Do you have difficulty speaking or using language to communicate or make your needs known?
The above questions, and other advice contained within the MHLDDS guidance with regard to identification of disability, are based on the document ‘Have you got a learning disability? Asking the question and recording the answer for NHS healthcare providers’ by Improving Health and Lives: The Learning Disabilities Observatory.

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

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

Two illustrative examples follow:

**Scenario 1**

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

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

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

Patient: *No.*

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

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

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

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

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

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

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

Receptionist: *Ok.*
**Step 2 – Record (SystmOne)**

So how can SystmOne help organisations to meet that?

In the patient details screen a contact method can be recorded.

In the contact method screen, a method can be selected for communication with the patient. If necessary, it is possible to override this method if a specific communication method is required.

Spine contact preferences can also be set from the Spine Details branch.
When recording the patient's language the following can be recorded:

- Using Makaton sign language (XaJPI)
- Using lip-reading (Xa4A6)
- Using British sign language (XaIILE)

In the Registration screen you can also record a correspondence address (e.g. for those patients whose correspondence needs to be read by a carer/relative)

When sending a letter to a patient you can use the patient address merge field with the constraint of correspondence address to add this to the letter.
Any letters generated via integrated Word can have their font size increased using the standard Word formatting icons.

**Recording coded data to share between clinicians and organisations**

There are also Read codes for conditions mentioned in the standard. These codes can be recorded in the care record, searched for, reported on and shared with other organisations. Ensure you capture the patient’s explicit consent to share the record.

Most of the codes required are found in the **Patient information status (XaCFw)** branch.
<table>
<thead>
<tr>
<th>Information status</th>
<th>Administrative statuses</th>
<th>Administration</th>
<th>Read thesaurus</th>
</tr>
</thead>
</table>

**Patient information status (XaCFWj)**

- Uses personal audio recording device to record information (Xad9e)
- Requirements for attendance (Y0fd4)
- Requires third party to read out written information (Xad9Y)
- Requires healthcare info recording on prsnl audio recording device (Xad9W)
- Requires contact via carer (Xad6e)
- Requires speech to text reporter (XacYA)
- Requires deafblind haptic communication interpreter (XacJI)
- Requires deafblind block alphabet interpreter (XacJG)
- Requires deafblind manual alphabet interpreter (XacJF)
- Requires tactile alert (Xac5Q)
- Requires visual alert (Xac5P)
- Requires audible alert (Xac5O)
- Requires lipspeaker (Xac5N)
- Requires manual note taker (Xac5M)
- Requires information in electronic downloadable format (Xac4f)
- Requires information on USB mass storage device (Xac4L)
- Requires contact by email (Xabsb)
- Requires contact by letter (Xabsd)
- Requires contact by short message service text message (Xabsc)
- Requires information in uncontracted (Grade 1) Braille (Xabsb)
- Requires information in contracted (Grade 2) Braille (Xabsa)
- Requires information in Makaton (XabsZ)
- Requires information in Moon alphabet (XabsY)
- Requires information in electronic audio format (XabsX)
- Requires information by email (XabsW)
- Key contact informed in advance of discharge (XaafR)
- Declines information about services for carers (XaZd3)
- Home access information (XaYR5)
- Requires loud verbal communication (XaY0j)
- Requires slow verbal communication (XaY0g)
- Requires deafblind communicator guide (XaYB3)
- Requires information in Easyread (XaYB0)
- Requires contact via telephone interpreting line (XaYAy)
- Requires contact by text relay (XaYAu)
- Requires information on audio cassette tape (XaYAB)
- Requires information on compact disc (XaYA5)
- Requires information on digital versatile disc (XaYA2)
- Requires contact by telephone (XaYAO)
- Declines to reveal benefit status (XaXSfH)
- Declined to give details of registered general practitioner (XaXBM)
- Patient declines to state family origin (XawYg)
- Declined to receive test result by telephone (Xab88)
- Requires written information in large font (XaPSp)
- Requires information verbally (XaPSq)
Adding alerts to the record

Alerts for patient can be recorded in several ways.

- **Reminder**: Reminders can be added to the record so that they show on appointment booking – reminders will be shared between organisations provided the record is shared.

- **Protocol**: A CCG wide protocol exists to flag any patients coded as above and will appear like this on the home screen

Online Access

SystmOne now allows registered or non-registered relatives of patients to be given online proxy access to the patient’s online services.
Recording carers and family members

Use the existing relationships functions to add family members and carers
Note: While communication format and contact method can be recorded here, it has no impact on a letter being created and does not alert the sender (this may change in a later release.)

Accessible Information Sheet Sy
Step 3 – Alert/Flag

A record of communication and / or information needs MUST be flagged or otherwise highlighted / made ‘highly visible’ to relevant staff when the individual has subsequent interaction or contact with the service (to enable appropriate actions to be taken to meet those needs).

‘Highly visible’ is defined in the Specification as follows:

“A recording of an individual’s information or communication support needs must be ‘highly visible’ to relevant staff and professionals. In the context of this standard ‘highly visible’ means:

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

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

Once data is recorded about individuals’ information or communication support needs, systems MUST prompt for, and staff MUST ensure that, such data is regularly reviewed and if necessary updated.

The purpose of review is essentially two-fold, firstly to identify if the individual’s needs have changed (for example due to a change in their level of sensory loss) and secondly to identify if the most appropriate methods of meeting those needs have
changed (for example due to advances in technology / a change in an individual’s access to particular tools or technology).
Step 4 – Sharing of needs
Organisations MUST ensure that information about individuals' information and/or communication support needs is included as part of existing data-sharing processes, and as a routine part of referral, discharge and handover.

All applicable organisations should include information about individuals’ information and communication support needs as a routine part of referral and handover communication, and as part of other data-sharing processes with other professionals and services involved (or soon to be involved) in an individual’s care.

All information-sharing as part of this Standard should utilise existing data-sharing processes, including following existing information governance protocols and processes for the obtaining and recording of patient/service user consent.

Information about individuals’ information and/or communication needs should be included as part of referrals both within and between organisations, including (but not limited to) referrals from primary into secondary care, transfers and handovers between wards or units, and discharge from an inpatient setting into the community.

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

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 SCR v2.1. It is currently supported by TPP SystmOne.

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.
Step 5 – Meeting Needs

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

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

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

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

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

1. Accessible Information - requires specific contact method. This category relates to the need for services to provide accessible methods or mechanisms...
which individuals with information and / or communication needs are able to use to contact the service, and which the service uses to contact them. This may require adjustment to current systems or processes. For example, many service users, including those who are d/Deaf or have some hearing loss, will not be able to use a telephone to, for example, book an appointment or receive test results. Alternative communication / contact methods which may be accessible to individuals with information and / or communication needs include email, text message, telephone and text relay. Organisations MUST ensure that an individual’s need to use or be contacted by an alternative communication method is flagged and / or highly visible to staff to enable appropriate action to be taken.

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

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

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

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

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

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

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

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

4. Accessible information - communication support. This category relates to the provision of support to enable effective communication / conversation, for example by the provision or use of aids or equipment, or by health or social care staff adjusting their behaviour. It is recognised that staff may need training or other awareness raising in order to effectively provide some of the types of support / adjustments indicated. Further advice is included as part of section 6.4.2 and in appendix d, and will be provided as part of resources to support implementation (as outlined in the Implementation Plan). The scope of the Standard includes accommodation of an individual’s need or requirement for a longer appointment to enable effective communication / the accessible provision of information. Applicable organisations should ensure that systems and processes for scheduling and managing appointments enable this flexibility.

Where a patient or service user has an identified carer, a discussion should take place to identify whether their carer has any information or communication needs. The same principles and requirements apply where one or more parents of a patient / service user have information or communication support needs – they should be identified and recorded as part of the child’s records / notes.
Use of email and text message

**ISB 1596 Secure Email Specification**


Health and care organisations MUST operate their email service to a level appropriate to the security risk assessment, and at minimum BS ISO/IEC 27001.

Health and care organisations SHOULD set policies and procedures for the use of secure email using mobile devices and ensure the email service enforces them.

Communication between NHSmail @nhs.net addresses and GSI systems is secure.

Secure systems will necessarily need to communicate with other untrusted email systems, for example when emailing the private sector (e.g. lawyers), other parts of the public sector (e.g. school nurses) or patients. If the patient has not consented to sharing their information without appropriate security controls then the information should be encrypted.
1. **Secure email using NHSmail to NHSmail**

Personal confidential data should only be processed using NHSmail to NHSmail ([name.surname@nhs.net](mailto:name.surname@nhs.net)). Verified safe haven email addresses in Nottinghamshire are included from page 16 in the appendix of the [Safe Haven Additional Guidance](#).
2. **Secure email using NHSmail to Government Secure Intranet (GSi) email addresses**

Below are examples of GSi secure email addresses:

- [name.surname@cjsm.net](mailto:name.surname@cjsm.net),
- [name.surname@eu-admin.net](mailto:name.surname@eu-admin.net),
- [name.surname@gcsx.gov.uk](mailto:name.surname@gcsx.gov.uk),
- [name.surname@gse.gov.uk](mailto:name.surname@gse.gov.uk),
- [name.surname@gsi.gov.uk](mailto:name.surname@gsi.gov.uk),
- [name.surname@gsx.gov.uk](mailto:name.surname@gsx.gov.uk),
- [name.surname@mod.uk](mailto:name.surname@mod.uk),
- [name.surname@pnn.police.uk](mailto:name.surname@pnn.police.uk),
- [name.surname@scn.gov.uk](mailto:name.surname@scn.gov.uk).
3. **Secure email using NHSmail to non-secure Gmail, Hotmail, CCG/GP email, SFHFT, NUH email addresses**

Non-secure email addresses include (but are not limited to):

- .gov.uk
- .nhs.uk (gina.holmes@mansfieldandashfieldccg.nhs.uk, name.surname@sfh-tr.nhs.uk, name.surname@nuh.nhs.uk)
- @btinternet.com
- @gmail.com
- @gp-cxxxxx.nhs.uk
- @hotmail.co.uk
- @jigsawmansfield.org.uk
- @KPMG.co.uk
- @mansfieldcvs.org
- @nottsc.gov.uk
- @nottshc-chp.nhs.uk
- @ntlworld.com
- @outlook.com
- @psytest-solutions.co.uk
- @uk.pwc.com
- @yahoo.com

This allows the recipient (non-secure email address from the list below) to respond in a secure manner without the use of an NHSmail/GSi email address. Please see guidance on how to set up this feature using your NHSmail email account and what the recipient needs to do when they receive a secure email in their un-secure email address i.e. Hotmail.
4. Guidance for recipients of an encrypted NHSmail email
http://www.mansfieldandashfieldccg.nhs.uk/images/i/Governanceandpolicy/NHSmail%20encryption%20guidance%20for%20non-NHSmail%20recipients.pdf
Appendices

Appendix a – Table of benefits

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

<table>
<thead>
<tr>
<th>Enabling functionality</th>
<th>Result</th>
<th>Description of benefit</th>
<th>How valued</th>
</tr>
</thead>
</table>
| Patients receive information from health and social care organisations in formats that they can understand. | Patients are able to make informed decisions about their health and care, and to better manage their own health, due to increased knowledge, skills and confidence. | More appropriate use of services including increased use of primary / routine care and services.                                      | • Reduction in missed appointments (‘Did Not Attends’ (DNAs)).  
• Reduction in inappropriate attendance at A&E / urgent care use / emergency admissions.  
• More appropriate use of primary care.  
• Improved patient outcomes: Right Care, Right Place, Right Time.  
• Improved patient satisfaction and experience – reduced complaints and litigation.  
• Reduction in premature death and increased life expectancy (especially for people with a learning disability). |
|                                                                                       |                                                                        | More patients take up screening and prevention opportunities (e.g. NHS Health Checks / immunisation).                       | Improved outcomes for patients due to increase in take-up of immunisations, earlier diagnosis and treatment. Resulting in reduction in time off work, increase in time individuals able to be active in their communities and reduction of health and social care costs. |
| Increased ability of patients to recognise signs and symptoms of disease / injury / illness at an earlier stage. | Improved outcomes for patients due to seeking appropriate intervention / treatment at an earlier stage (e.g. increased cancer survival rates / improved outcomes following a stroke). Resulting in reduction in time off work, increase in time individuals able to be active in their communities and reduction of health and social care costs. |
| Better support to make healthy lifestyle choices. | Improved health and wellbeing amongst patients due to not smoking, drinking alcohol in moderation and maintaining a healthy weight. Resulting in reduction in time off work, increase in time individuals able to be active in their communities and reduction of health and social care costs. |
| Better support to self-care and self-manage long-term conditions. | - Reduction in inappropriate attendance at A&E / urgent care use / emergency admissions.  
- Reduction in unplanned admissions and readmissions.  
- More appropriate use of primary care.  
- Shorter hospital inpatient stays.  
- Improved patient satisfaction and experience – reduced complaints and litigation. |
| Improved compliance with treatment programmes / medical advice / medicines. | - Reduction in operations / procedures cancelled due to patient being incorrectly prepared (resulting in improved usage of facilities / surgical time).  
- Improved patient safety and reduction in adverse incidents / harm caused due to patient’s non-compliance with advice / incorrect taking of medicines.  
- Improved outcomes due to increased adherence by patients to long-term medication and other clinical advice.  
- Improved patient satisfaction and experience – reduced complaints and litigation. |
| Improved privacy and confidentiality for patients. | Improved patient satisfaction and experience, improved knowledge and confidence.  
- Reduction in complaints and litigation.  
- Increase in patients’ ability to play an active role in their community due to improved confidence and autonomy. |
| Patients receive support to communicate with health and | Patients are able to participate in decision-making about care.  
- Increase in patients’ ability to play an active role in their community due to improved confidence and autonomy.  
- Improved patient satisfaction and experience – reduced complaints and litigation. |
| Social care organisations / clinicians / professionals. | Pathways and treatments. | Patients participate in decisions about, and take an active role in, their health, health care and treatment options. | • Increase in patients’ ability to play an active role in their community due to improved confidence, autonomy and outcomes.  
• Cost savings due to reduction in A&E attendance, planned and unplanned admissions, and outpatient admissions due to greater involvement of patients in the management of their long-term conditions.  
• Improved health and wellbeing of patients due to better understanding of their condition and increased ability to self-care. |
| --- | --- | --- | --- |
| Clear and consistent systems and processes for recording and referring to patients' information and communication support needs, and for the provision of information in alternative formats / communication | Health and social care staff and clinicians are able to improve the quality and efficiency of care they provide to patients. | Improved ability of clinicians and other health and social care professionals to communicate effectively with patients. | • Improved outcomes for patients and patient experience due to:  
  o high quality care in line with the ‘6 Cs.’  
  o increased efficiency and accuracy of diagnosis and adherence to advice / treatment regimens;  
  o reduction in misdiagnosis and delayed diagnosis.  
• Increased ability for patients to provide informed consent to treatment, and to receive treatment (or not) in line with their wishes.  
• Improved patient satisfaction and experience – reduced complaints and litigation. |
| | | Reduction in overrunning / late clinics due to ability to allow additional appointment time for patients with communication needs | • Costs savings for health and social care organisations due to reduction in wasted staff time and more efficient use of equipment / facilities |
| Support. | Reduction in duplication of effort and time wasted due to lack of knowledge of patients' information and communication support needs and/or actions to be taken to meet those needs. | • Cost savings for health and social care organisations due to avoidance of duplication of effort and double-booking/incorrect booking of communication support.  
• Reduction in staff time spent identifying, understanding and acting upon patients'/service users' needs (due to there being a clear and consistent process in place as part of business as usual). |
Appendix b – Assessing the information governance and privacy impact

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

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

1. Will the project involve the collection of new information about individuals?
The Accessible Information Standard is not proposing to establish any new national data set or collection.

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

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

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

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

As such, information collected as part of the Standard will only be made available to organisations or people who already have a ‘legitimate relationship’ with that individual and as such already have access to their patient or service user records. Note that the Standard is only concerned with the use of information as part of direct patient / service user care.

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

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

It should be pointed out that the information will be recorded with the explicit consent of individuals, or if they lack capacity, in line with the Mental Capacity Act 2005 Code of Practice.
4. Are you using information about individuals for a purpose it is not currently used for, or in a way it is not currently used?

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

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

No.

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

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

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

By improving disabled people’s access to accessible information, it will improve their privacy through reducing their reliance on a family member or carer to read information on their behalf.
7. **Is the information about individuals of a kind particularly likely to raise privacy concerns or expectations?** For example, health records, criminal records or other information that people would consider particularly private.

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

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

No.
Appendix i – Initial IG Checklist

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

New Information Standard: SCCI1605 Accessible Information.

1. **Does your proposal involve using information about patients?**

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

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

   Yes, but see explanation in response to question 1.

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

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

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

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

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

   Not applicable.

6. **Whether the patient information is directly identifiable or not, can you please set out which organisations or types of organisation will be using this information.**
The information will be used by service providing organisations (NHS and adult social care bodies, and providers of NHS and adult social care) directly to support patient care / the service user experience.

7. **How will the information be transferred between organisations?**

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

8. **Where will the information be stored?**

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

9. **How will the information stored?**

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

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

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

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

To support the development, appraisal, approval and release of this new information standard. To provide specialist advice as required. To support integration of the Standard into existing data sharing processes and records.
Appendix c – List of stakeholders involved in developing the Standard

Advisory group member organisations

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

Note that the group also includes two Patient and Public Involvement (PPI) members. For further information about the Advisory Group visit the NHS England website.

Organisations participating in the consultation

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

- Action on Hearing Loss
- Bart's Health NHS Trust
- Be Heard (Bracknell)
- Books Beyond Words
- Brent Mencap
- Comet Group
- Cyrenians
- Doncaster Speak Up
- East Sussex Community Voice / Speakup Countywide Forum
- Health Matters
• Healthwatch County Durham
• Healthwatch East Sussex
• Healthwatch Islington
• Healthwatch Redcar and Cleveland
• Healthwatch Waltham Forest, Waltham Forest Vision and Waltham Forest Deaf Forum
• Inclusion London
• Involvement Now
• Just Advocacy
• Leeds Teaching Hospitals Trust Blind and Partially Sighted Advisory Group
• Macmillan Cancer Support
• Medical Defence Union
• Moorfields Eye Hospital NHS Foundation Trust
• National Deaf Children’s Society
• National Federation for the Blind (Leeds Branch)
• Newcastle Society for Blind People
• Newcastle upon Tyne Hospitals NHS Foundation Trust
• National Community Hearing Association and British Society of Hearing Aid Audiologists
• NHS Enfield Clinical Commissioning Group
• NHS West Hampshire Clinical Commissioning Group
• People First (Self Advocacy)
• Pharmacy Voice
• PiF (Patient Information Forum)
• Race Equality Foundation
• Reach
• Royal College of Speech and Language Therapists
• Sense
• SignHealth
• Solent NHS Trust
• South London and Maudsley NHS Foundation Trust
• SpeakEasy N.O.W. Health Checkers
• The British Academy of Audiology (BAA)
• The British Medical Association (BMA)
• The Communication Trust
• The Joint Health Strategy Group (of library organisations who have health interests)
• The Optical Confederation
• The National Registers for Communication Professionals working with Deaf and Deafblind People (NRCPD)
• Thomas Pocklington Trust
• UK Council on Deafness
• UKAAF (UK Association for Accessible Formats)
• VISION 2020 UK

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