

Accessible Information Standard

Identifying Information and Communication Needs

The first step in the successful implementation of the Accessible Information Standard is based on 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.

Overview of requirements

Communication and / or information needs **MUST** be identified at registration / upon first contact with the service or as soon as is practicable thereafter. This initial question may be asked over the telephone, face-to-face at a reception desk, as part of a registration or admission form or through an alternative process.

In addition, communication and / or information needs **MUST** be identified proactively and opportunistically – the next time an existing patient / service user makes contact with / is seen by the service – but not retrospectively.

There is no requirement for a retrospective search or 'trawl' of records to identify already registered patients with needs, although this would be considered good practice.

Following identification of the existence of a communication or information need, the specific nature of the support and / or format required **MUST** also be identified.

Note about consent

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

Methods for identifying needs

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. There is a clear rationale for this, in that the aim of the Standard is to ensure that an individual receives information in a format that they can understand and any support which they need to communicate.

Recording that a person is 'deaf', for example, does not explain whether they are able to read written English, if they use British Sign Language (BSL) or are a lipreader and / or hearing aid user. Assumptions about communication support or alternative formats required, or any recording of needs, must not be made without consultation with the

individual themselves and / or, where appropriate, their carer or parent.

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. This could, for example, be over the telephone when calling for an appointment, results or repeat prescription, or face-to-face. Where the conversation is held face-to-face a private room or area should be offered and made available as appropriate.

As a minimum, individuals should have two options or ways in which they can identify or explain their needs: a face-to-face conversation in a private room; and an online / paper form or similar document. One of these methods is likely to be suitable for many people, particularly if relevant members of staff have had appropriate awareness training in supporting people with communication needs.

If questions are included as part of an online or paper form, for example a new patient registration form, many individuals will be able to read and complete such a form unaided or without professional assistance (particularly if relevant documentation is in line with 'tips for printed communication' (section 6.4.3 of the implementation guidance) and websites are accessible (see appendix e). Data may then need to be manually entered onto patient record or administration systems by administrative staff, or, in the case of online entry, it may automatically be uploaded into the patient's record.

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 such as an invitation to attend a 'flu jab' clinic, newsletter or via posters or onscreen information in a waiting area, or via contact by email or text message. Patients with such needs may then be prompted to speak to a member of staff, and may feel more confident or comfortable in doing so. 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 lipread 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 xxxxxxxxx or email xxxxxxxxxxxx."*

Note that print-ready templates for letters and posters will be made available as part of resources to support implementation (as outlined in the Implementation Plan).

Consideration should also be given as to how to identify the information and communication needs of people who are unable to read a letter or information on a poster, for example people who are blind or deafblind. Staff knowledge of individuals known or considered likely to have needs should be utilised as a way of targeting those individuals who are most likely to benefit from the Standard, but may also experience barriers to alerting the service to those needs. For example, they could be contacted via telephone to discuss their needs. A range of approaches should be used.

It would be appropriate – and considered good practice – to use existing data held about individuals which indicates that they are more likely to have information or communication needs to proactively target such individuals to identify and record their needs in line with the Accessible Information Standard. For example, lists or records of patients who are d/Deaf or databases of patients with a learning disability. In a general practice setting, it would be appropriate to refer to the [register of patients with learning disabilities \(QOF LD 1\)](#) or ['health check learning disabilities register'](#), where available. Suggested Read v2, CTV3 and SNOMED CT codes which MAY be used to identify individuals likely to be affected by the Standard (sometimes known as 'picklists' or 'cohort lists') will be made available as part of resources to support implementation.

Individuals identified as likely to have information / communication needs (from existing records, including clinical diagnoses) MAY be flagged to prompt / prioritise a conversation or contact to ascertain and record their needs in line with this standard.

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. It may also assist organisations in understanding current levels of 'unmet need' for accessible information and communication support, as part of preparing to implement the Standard.

Local authorities should make use of their record of deafblind people in their catchment area (as held under a requirement of the [Care and Support for Deafblind Children and Adults \(Department of Health, 2014\)](#)) and, as part of their duty to maintain up to date records, ensure that communication and information needs have been included in existing records. In addition, on first addition to the record, individuals should be asked about their communication and information needs.

These needs should then be included as part of the record, on other appropriate databases, and included in relevant local information sharing protocols (with the service user's consent).

Local authorities should also consider liaising with their Sensory Team to identify, contact and update the records of people known to have experience of sensory loss, including registers of people who are severely sight impaired (blind) or sight impaired (partially sighted).

It is important to recognise that many people with information and / or communication needs may find it difficult to articulate or explain what those needs are. There is the obvious challenge of being able to communicate your needs effectively when you have a sensory loss, learning disability or other condition, impairment or disability which can make it harder for you to communicate. Some individuals, particularly those with more significant needs, will be unable to read or complete a written form or to converse with staff unaided, and will need support.

In addition, many people with sensory loss, especially people who have been affected by sensory loss later in life, do not consider themselves 'disabled' and may not have a good understanding of the types of alternative format / communication support available. Prompts can be very helpful in these instances and good practice would be for services / key staff to familiarise themselves with the more common types of format and support which may be needed by individuals with particular disabilities, impairments or sensory loss – including as outlined in appendix d.

An individual may need support from an interpreter or other communication support professional in order to accurately identify their needs and, therefore, for them to be accurately recorded. In such instances, it would be prudent to use the next occasion when the individual accesses the service with the support of such a communication professional to support a conversation to identify and record the individual's needs.

Where difficulties are anticipated or experienced, services would be advised to identify available local expertise and make contact with relevant specialists who may be able to support or assist with identification and assessment of needs, and increasing understanding / putting plans in place to meet those needs effectively and efficiently in future. For example speech and language therapists and specialist learning disability nurses. The individual and / or where appropriate their carer or parent may be asked

whether they have had a comprehension assessment or other assessment of their communication support needs, and whether the outcome is documented in a 'communication passport' or elsewhere.

Many people with a learning disability (and some people with other communication needs), have a 'communication passport' 'communication book' or 'hospital passport' or similar document which includes a detailed record of their communication needs and preferences – this can be a very useful source of information and advice where available (and staff would be advised to proactively ask individuals if they have such a document where communication difficulties are experienced).

If an individual needs information in an alternative format or communication support because of a learning disability the conversation may take longer as greater explanation and examples or prompts may be needed. For example, the individual may not provide any details of communication support needs when asked an initial question, but, if prompted, may explain that they need written information in easy read. 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.*

Questions and prompts to identify needs

Some individuals may offer information about the detail or type of their needs proactively following a positive response to a question about whether they have any communication needs (or not); others may need support or prompting, including follow-up questions, to enable accurate identification of needs.

This question MAY be asked alongside recording of contact details and / or demographic data.

The initial question or questions will need to be sufficiently generic and easy to understand that it can be asked of any / all patients or service users, and their carers or parents where appropriate.

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, in order to maximise response rates and reduce stigma. It should also encourage staff to ask the question of all patients – including those who they do not perceive to be 'disabled'.

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.

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. This is because recording that a person is 'disabled' as part of diversity monitoring does not indicate their information or communication support needs – if any. That said, questions to identify information or communication support needs MAY be asked alongside recording of protected characteristic strand affiliation, for example, following a positive answer to the question, "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? This includes any issues or problems related to old age" (or similar) and indication of a disability relating to vision, hearing, learning or concentrating or remembering, mental health, or social or behavioural issues.

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 communication needs?
- Do you need a format other than standard print?
- 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?

Where appropriate, use may also be made of the Detailed Data Item Guidance associated with Table 50 (Protected Characteristics – Disability) of the [Mental Health and Learning Disabilities Data Set \(MHLDDS\) \(SCCI0011\)](#) which relates to identification of disability. Of note, this suggests that staff should, "Use professional judgement to provide guidance and give examples as appropriate to the client to ensure their understanding and so assure accuracy of their response." This is also highly relevant in implementing the Accessible Information Standard.

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. Staff may find this a useful source of onwards reading with regard to identifying the communication needs of people with a learning disability.

With regards to recording of the specific types of information format and communication support required, it is anticipated that multiple categories will be selected for many individuals.

Whatever the format used, communication and information needs MUST be recorded using the data items associated with the subsets defined by the Accessible Information Standard or their human readable definitions / categories. Detail is included in the Specification.

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?*

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.*