

SCCI 1605

Accessible Information

Glossary of information formats and communication types

This glossary, produced by Sense, is intended to be an accompanying resource to the official Standard documentation released by NHS England. It highlights some of the different information formats and communication methods that those in scope of the Standard may benefit from and includes case study examples for how services could and may wish to meet needs.

Introduction

With partners, NHS England has developed a new 'Accessible Information Standard'. The aim of the Standard is to make sure that people who have a disability or sensory loss can access information in the right format for them, as well as any support they need to communicate. The Standard tells organisations that provide NHS or adult social care services how they must do this.

This document is intended to be a guide to providers and users of services about different types of information formats and communication support that exist. It is not intended to be an exhaustive list but a guide to support the implementation of the Standard.

It is important to note that there may be scenarios where multiple information formats could be applicable, or a different format may provide the solution that the individual requires. To highlight this, a number of examples have been provided. These are for example purposes only and we encourage providers to discuss all options with service users to ensure that their needs are appropriately met.

Please note: where a definition name is followed by ✓ this indicates that there are SNOMED CT and Read V2 / CTV3 code(s) associated with this information format or communication type. A full directory of these codes (used in certain patient record systems) is available **online**.

Key terms used in the Standard

Accessible information: Information that can be read or received and understood by the individual or group for which it is intended.

Alternative format: Information provided in an alternative to standard printed or handwritten English, for example large print, braille or email.

Communication support: Support that is needed to enable effective, accurate dialogue between a professional and a service user to take place.

Who does the Standard apply to?

People using services

The scope of the Standard includes ‘individuals (patients and service users, and where appropriate the parents and carers of patients and service users) who have information and / or communication support needs which are related to or caused by a disability, impairment or sensory loss.’

Disability: The Equality Act 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.’

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.’

Impairment: The Equality and Humans Rights Commission defines impairment as, ‘A functional limitation which may lead to a person being defined as disabled...’

Sensory impairment: A hearing and/or sight impairment. People may refer to their sensory impairment using a variety of different terms, which are defined later in this document. These include deaf, hard of hearing, deafblind and blind. Sensory impairments can be congenital (i.e. present at birth) or acquired (presenting after birth – at any age).

Groups of people likely to be affected by the Standard

The following definitions are intended to support understanding of the groups most likely to be affected by the Standard, to support preparation and planning around how needs can be met. All of the below groups are within the scope of the Standard, although the list is by no means exhaustive, and you may wish to expand the list for your own service. It is worth highlighting that more than one definition may apply to a person who is accessing your service.

It is important to be aware that, as part of the Standard, it is an individual's information/communication needs that must be identified, recorded, flagged and shared (as well as being met). The Standard does not direct any recording of a person's disability, impairment or diagnosis.

Aphasia: A condition that affects the brain and leads to problems using language correctly. People with aphasia find it difficult to choose the correct words and can make mistakes in the words they use. Aphasia affects speaking, writing and reading.

Autism: **The National Autistic Society** defines autism as a, 'lifelong disability that affects how we communicate with, and relate to others. And it effects how we make sense of the world around us. Lots of things that people take for granted like body language and metaphors can be confusing and alienating.'

Blind: A person who is blind is someone with limited or no functional vision. They are likely to be registered as being **severely sight impaired**.

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.

Deaf: 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: A person who is deafblind has both a sight and hearing impairment, which causes difficulties with communication, access to information and mobility. Deafblindness can be congenital or acquired and doesn't necessarily mean that someone can't hear or see anything. Depending on the cause and onset of the hearing and sight impairment, deafblindness may also be referred to as dual sensory loss (usually relating to acquired deafblindness in older people) or multi-sensory impairment (usually relating to children who are born deafblind). More information is available **online**.

Hard of hearing: This term is used by some people to refer to an acquired hearing impairment, usually in later life. Other terms include hearing impaired and deafened.

Learning disability: People with learning disabilities have life-long development needs and have difficulty with certain cognitive skills, although this varies greatly among different individuals. Societal barriers continue to hinder the full and effective participation of people with learning disabilities on an equal basis with others.

Sight impaired: Someone who is sight impaired has vision loss. This includes people registered as being **partially sighted**.

The Standard also includes people with information and/or communication needs relating to different types of disability or sensory loss, for example following a stroke or brain injury, and/or a mental health condition that affects their ability to communicate.

Services and organisations

The Standard applies to all providers of publicly funded health and adult social care. If you are not sure whether the Standard applies to your service, please refer to Section 5.3 of the **Standard Specification**. If an organisation isn't included with the Scope of the Standard, there is nothing to prevent other providers or commissioners of services from implementing the Standard as best practice.

Types of accessible information and communication support

Overview

The Standard says that people with a disability or sensory loss should:

- Be able to contact, and be contacted by, services in accessible ways
- Receive information and correspondence in formats they can read and understand
- Be supported by a communication professional at appointments if this is needed to support communication
- Get support from health and care staff to communicate.

Information formats (also known as 'specific information formats')

Under the Standard, services **must** provide information in accessible formats for those who need them. This applies to all information given to the patient or service user that relates to their care, for example an appointment letter or information leaflet about managing a health condition. For more information on what information needs to be accessible, please refer to the **Standard documentation**.

There are many steps you can take to make your standard documents more accessible to a wider audience. For tips on this please refer to Section 6.4 of the Standard **Implementation Guidance**.

The below are examples of information formats that may be requested. Please note this is not an exhaustive list and that some formats such as text and email have not been included. It is important to be aware that some individuals may need prompting or support to identify which formats they need. People's needs may change over time, especially as technology progresses and new formats become available.

Audio ✓: This is where the information is presented in an audio format instead of written. This could be a recording of someone speaking or synthetic (computer-generated) and stored on to cassette tape, CD (compact disc) or electronic file, such as MP3. Transcription companies are able to provide audio recordings of documents, and/or many people with vision impairment will have **screen reader software** on their electronic devices, which converts text to speech. It may also be appropriate/possible to record information directly onto a device owned by the individual, such as their smartphone, tablet or dictaphone.

Braille ✓: A tactile reading format used by some 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. Transcription services are able to convert documents into braille. Braille printers are also available. There are a number of **different versions of braille** so it is important to ask the individual which they require.

British Sign Language (BSL) video ✓: A recording of a BSL interpreter signing information that may otherwise only be available in written or spoken English. A BSL video may be made available on DVD or via a website. This may be required by someone who is Deaf and has BSL as their first language, as the grammatical structure of written English is different from that of BSL and may not be understandable to the Deaf person. An example of a BSL video is available **online**.

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. Self-advocacy groups and other accessible information providers are able to convert documents into Easy Read. It is good practice to ensure that people with learning disabilities are involved in the creation or checking of Easy Read information. An example of information in Easy Read is available **online**.

Large print ✓: Printed information enlarged or otherwise reformatted to be provided in a larger font size. It is a form of accessible information or alternative format that 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 that needs to be larger and not the paper size. Some visually impaired people may have **assistive magnification equipment** to read documents, magnifying apps on their smartphones and/or **specialist software** on their electronic devices to increase the size of documents. Accessible 'large print' font sizes can range from point 14 to point 28 (and beyond), and individuals should be asked what size is accessible for them.

Moon ✓: A tactile reading format made up of raised characters, based on the printed alphabet. Moon is similar to braille in that it is based on touch. Instead of raised dots, letters are represented by **14 raised characters** at various angles. Transcription services can create Moon versions of documents.

Alternative communication methods (also known as ‘communication professional’)

The Standard specifies that services must arrange for support from an appropriate communication professional where this is needed to enable effective, accurate conversation. This section outlines some of the communication methods that people may use and professionals who may be required to enable effective communication of the method that best suits the individual.

Sign language is a visual-gestural language and way of communicating that is used by some d/Deaf people. Deafblind people may also communicate using sign language in England. There are two main grammar structures used in sign language:

- **British Sign Language (BSL)** ✓: 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.
- **Sign Supported English (SSE)** ✓: A visual-gestural language that uses the signs of BSL but follows the grammatical structure of English.

Deafblind people may need the following adapted versions of sign language:

- **Visual frame** ✓: An adapted form of sign language where the interpreter ensures they sign within the visual field of someone who has a restricted visual field.
- **Hands on** ✓: A tactile form of sign language where the individual places their hands over the hands of the signer, so that they can feel the signs being used.

Sign language interpretation **must** be provided by a qualified and registered **BSL interpreter** ✓ who can interpret between BSL and English. The **NRCPD** (The National Registers of Communication Professionals working with Deaf and Deafblind People) holds the registered list of interpreters and provides an online search function. For more information on who can and can't provide sign language interpretation, please refer to Section 11.4.4 of the Standard **Implementation Guidance**.

If the individual uses adapted versions of sign language it is important to ensure that the interpreter you book is competent and confident in this specialty.

In some scenarios, the use of BSL interpretation via a remote service may be applicable:

BSL video remote interpreting (VRI): Also known as video interpreting, remote interpreting or virtual interpreting, this is an online service in which a BSL interpreter interprets via video software. It works using a computer and webcam, a smartphone or tablet. Provided through contract or on demand by a range of organisations, it enables a direct connection to an interpreter so that the d/Deaf person can sign to them what they want to say. The interpreter then speaks this to the hearing person (via video link) and signs back their (spoken) reply. The **NHS 111** service uses BSL VRI as a way for people to contact them.

In addition to sign language, other communication methods may include:

Block: ✓: The **block alphabet** is a tactile form of communication in which words are spelled out on to the palm of the deafblind person's hand by 'writing' the letters with a finger.

Deafblind Manual: ✓: The **deafblind manual alphabet** is a tactile form of communication in which words are spelled out onto a deafblind person's hand. Each letter is denoted by a particular sign or place on the hand.

Non-verbal communication: ✓: This form of communicating **without using speech** uses gestures, pointing or eye-pointing instead.

Tadoma: ✓: Tadoma involves a person placing their thumb on a speaker's lips and spreading their remaining fingers along the speaker's face and neck. Communication is transmitted through jaw movement, vibration and facial expressions of the speaker. This is a type of communication that may be used by a deafblind person.

In addition to sign language interpreters, the other professionals that may be required include:

Advocate ✓: A person who supports someone who may otherwise find it difficult to communicate or express their point of view. Advocates can support people to make choices, ask questions and to say what they think.

Communicator guide ✓: A professional who acts as the eyes and ears of the deafblind person, including ensuring that communication is clear. A deafblind person may have a **communicator guide** provided by a charity, through a personal budget or by their local authority.

Deafblind interpreter – deafblind manual alphabet ✓: A person skilled in interpreting between the deafblind manual alphabet/block alphabet and English.

Deafblind interpreter – block ✓: A person skilled in interpreting between the deafblind block alphabet and English.

Intervenor ✓: A professional who provides one-to-one support to a child or adult who has been born with sight and hearing impairments (congenital deafblindness). The **intervenor** helps the individual to experience and join in the world around them. A deafblind person may have an intervenor provided by a charity, through a personal budget or by their local authority.

Lipspeaker ✓: A person who repeats the words said without using their voice, so that others can read their lips easily. A professional lipspeaker may be used to support someone who is d/Deaf to communicate.

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. It is also possible to use braille displays or other assistive technology to enable people to access the information displayed on the screen in other formats.

Speech to text reporter (STTR) ✓: A STTR types a verbatim (word for word) account of what is being said and the information appears on screen in real time for users to read. A transcript may be available and typed text can also be presented in alternative formats. This is a type of communication support that may be needed by a person who is d/Deaf and able to read English.

Translator ✓: A person able to translate the written word into a different signed, spoken or written language. For example, a sign language translator is able to translate written documents into sign language.

Contact methods (also known as ‘specific contact method’)

The Standard stipulates that services must contact individuals (and be contactable) in accessible ways. This could include, for example, providing information over the telephone, by sending a text message or enabling someone to book an appointment via email.

An example of a service that people may use is Text Relay:

Text Relay ✓: Text Relay enables people with hearing loss or speech impairment to access the telephone network. A relay assistant acts as an intermediary to convert speech to text and vice versa. British Telecom (BT)’s ‘**Next Generation Text**’ (NGT) service extends access to the Text Relay service from a wider range of devices including via smartphone, laptop, tablet or computer, as well as through the traditional textphone.

Aids, equipment and adjustments to support communication (also known as ‘communication support’)

There are a number of additional aids, equipment and adjustments that people may use to support communication, including:

Communication passport: Sometimes referred to as a communication book or ‘hospital passport’, this document contains important information (usually) about a person with learning disabilities that helps staff to meet those needs. It will include a person’s likes and dislikes, and outlines ways in which they communicate. Many hospital trusts provide communication passports to people with learning disabilities. Examples are available **online**.

Communication tool/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.

Hearing loop system: A hearing loop or ‘audio frequency induction loop system’ allows a hearing aid wearer to hear more clearly. It transmits sound in the form of a magnetic field that can be picked up directly by hearing aids switched to the loop (or T) setting. The magnetic field is provided by a cable that encloses, or is located close to, the intended listening position, such as a reception desk. The loop system allows the sound of interest, for example a conversation with a receptionist, to be transmitted directly to the person using the hearing aid clearly and free of other background noise.

Lipreading: A way of understanding or supporting the 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.

Voice Output Communication Aid (VOCA): This is also known as a speech-generating device (SGD). An electronic device used to supplement or replace speech or writing for individuals with severe speech impairments, enabling them to verbally communicate.

Case study examples

The fictional case studies below are intended to illustrate the steps that providers could take to meet the needs of those accessing their services.

Barbara has macular degeneration and needs information provided in audio format on a CD, so that she can listen to it at home. Her GP has identified a provider who can convert information into audio format for her but it takes three days to process and once she missed an appointment because an audio version of the letter wasn't available in time. On discussion with Barbara, her GP practice has agreed that they will ring her to inform her of any appointments rather than arrange for them to be converted into audio format. They will continue to provide audio versions of other information that she needs – for example, they have just converted an information leaflet on how to manage diabetes with a healthy diet for her.

Thomas was born blind and uses Grade 2 braille to access information. He is a keen user of technology and has screen reader software on his laptop and an external braille display. Following a discussion with his local sensory team, he has suggested that they email him any information he needs as he can then use his laptop to convert it into braille. He prefers this to receiving printed braille as it means he can access it quickly and search within the document to find the section he wants.

Sally is Deaf and has BSL as her first language. She uses hearing aids to help her access environmental language and visits the audiology department on a regular basis. Sally has an annual review of her hearing aids, which is booked in advance, but sometimes if her hearing aids break down she needs an emergency appointment to repair them. It can be hard to find an interpreter in time for an emergency appointment so the audiology department has suggested that they use a VRI service on these occasions. Sally is happy for this to take place as it means she can still communicate in her first language. She would still prefer a 'real' interpreter where possible so the department has agreed that they will continue to book interpreters for her scheduled appointments and use VRI for emergency appointments, if an actual interpreter isn't available at short notice.

Sam has a learning disability and needs information in Easy Read so that he can understand it. His social worker wants to give him some information about sex and relationships but doesn't have it available in Easy Read. When he looks online at how to get it converted into Easy Read, he discovers that a version of the information in Easy Read is already available to purchase, which is cheaper than paying for it to be converted. He checks that the information is factually accurate and good quality, buys it and gives Sam a copy at their next meeting.

A local authority has some information about personal budgets. The **local Deaf club** has requested that they create a BSL video version of the information so that they can share it with their members. The local authority works in partnership with other nearby local authorities, so contacts them and together they commission and fund the creation of a joint BSL video. They host it on their website so that other local authorities can link to it.

Bernard has a sight impairment and can no longer read information in standard print size. His GP asked if they could email him information instead so that he could read it using assistive equipment. However, Bernard doesn't use email or assistive technology, so his GP has therefore agreed that they will provide all information for him in large print.