



**Making health and social care
information accessible**

**Consultation document summer /
autumn 2014**

NHS England INFORMATION READER BOX**Directorate**

Medical	Operations	Patients and Information
Nursing	Policy	Commissioning Development
Finance	Human Resources	

Publications Gateway Reference: 02004

Document Purpose	Consultations
Document Name	Making health and social care information accessible: Consultation document summer 2014
Author	NHS England, Patients & Information
Publication Date	12 August 2014
Target Audience	CCG Accountable Officers, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, Directors of Adult SSs, NHS England Regional Directors, Allied Health Professionals, GPs, Communications Leads
Additional Circulation List	Engagement partners
Description	NHS England is developing a new accessible information standard which will make sure that people can understand the information they are given about their health and care. Now NHS England is undertaking a consultation with organisations and the public on the draft standard. This document explains more about the standard and describes how to participate in the consultation.
Cross Reference	N/A
Superseded Docs (if applicable)	N/A
Action Required	N/A
Timing / Deadlines (if applicable)	N/A
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Document Status

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Making health and social care information accessible

Consultation document summer / autumn 2014

Version number: 1

First published: August 2014

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1 Introduction

NHS England's main aim is to improve people's health. We want to make sure that people can understand the information they are given about their health and care. We also want everyone to be able to get involved in decisions that affect them. We know that some people need information in a different format, or help to communicate or explain what they think.

We are going to write a new guidebook for health and social care organisations across England. The guidebook will be an 'Information Standard' which is a set of rules which organisations must follow.

The guidebook will tell organisations how they should make sure that patients and service users, and their carers and parents, can understand the information they are given. This includes making sure that people get information in different formats if they need it, for example in large print, braille, easy read or via email.

The guidebook will also tell organisations how they should make sure that people get any support with communication that they need, for example through having a British Sign Language (BSL) interpreter or an advocate with them.

During winter 2013 / 2014 we asked people about their experiences and opinions through surveys and workshops. We used their views to help us to write the draft standard. You can read a full report about the engagement activity on our website www.england.nhs.uk/accessibleinfo

Now, there is a consultation on the draft standard. We would like to know what you think about the draft standard we have written, before the standard is final. This document explains more about the standard and tells you about how to have your say as part of the consultation.

More detailed information about the standard is included in the Specification. The Specification is a technical document which is difficult to read so we have explained the important facts in this consultation document. Health and social care organisations and professionals will want to read the Specification as well as this document as they will have to follow exactly what the Specification says.

You can find out more information about this work and about other ways to have your say on our website www.england.nhs.uk/accessibleinfo

If you have a question about this work you can email us at england.nhs.participation@nhs.net or telephone 0113 825 1324.

The consultation closes on Sunday 9th November 2014. All responses must be received by then.

2 Who is this document for?

This document is for everyone who is interested in accessible information and communication support. It is for people who want to have their say as part of the

consultation on the draft accessible information standard. We think that this will include:

- People who work in health and social care organisations, especially people who work in patient records, information governance, patient experience, equality and diversity, and communications.
- People who provide IT systems to health and social care organisations, including electronic patient administration and record systems.
- People who need letters in a different format, for example large print, braille, easy read, or via email.
- People who need support to communicate, for example through a British Sign Language (BSL) interpreter, deafblind manual interpreter, or from an advocate.
- People who are blind, deaf, Deaf, deafblind, or who have a learning disability, and carers.
- Voluntary organisations and self-advocacy groups that support, work with and / or are led by disabled people and people who need support to communicate.

3 What is the vision for the standard?

We have a vision for the accessible information standard. Other words for a vision are ambition or goal. It describes the difference that we want the standard to make.

Our vision is that: “Patients and service users, and where appropriate carers and parents, with information or communication support needs relating to a disability, impairment or sensory loss have those needs met by health and social care services and organisations.”

In more straight forward words, our vision is that: *“Health and social care services give disabled people information that they can understand and communication support if they need it.”*

4 What will the standard do?

NHS organisations, and organisations that provide NHS and adult social care services, will have to do what the standard says.

The standard will tell organisations that they should ask people if they have any information or communication needs. Organisations should ask questions about information and communication needs when they see a patient for the first time, for example it should be on registration forms. If organisations already know the patient, they should ask them if they have any information or communication needs the next time they see them.

If people have any information or communication needs, we want organisations to find out what those needs are. For example, they should ask people if they need information in easy read or large print or braille or by email. They should ask if people need an advocate or a British Sign Language interpreter.

We want all organisations to record or write down people's needs in the same way. This should mean that other organisations and other staff can understand what people's needs are. It should mean that when someone goes to a service they have been to before, they already know about their needs and can make sure that they meet them. If possible, we think that organisations should share information about people's needs with other organisations involved in the person's care. They may need to ask for the person's consent to do this.

We want organisations to make sure that if someone has information or communication needs this is very clear on their notes or records. We think that this should be highlighted in some way, or it should flag up so that staff know they need to do something.

As part of the standard, we want organisations to make sure that people get information that they can understand. We want organisations to send people letters that they can read, for example in braille or large print or via email or in easy read.

We want organisations to help people with communicating, for example if they lip read or use a hearing aid. We want organisations to make sure that people can have an advocate, British Sign Language interpreter or deafblind manual interpreter if they need one. We want organisations to give people with communication needs more time at their appointments if they need it.

5 Who will have to follow the standard?

NHS and adult social care bodies will have to follow the standard.

This includes clinical commissioning groups (CCGs) who make most of the decisions about local NHS services. It also includes Foundation Trusts, who run hospitals and community NHS services.

Adult social services departments at local authorities will have to follow the standard as well. This includes local councils.

Organisations that provide NHS services will have to follow the standard. This includes dentists and doctors.

Organisations that provide adult social care services which are paid for by the Government will have to follow the standard. This includes some care and nursing homes.

Organisations that provide IT systems which manage patients' or service users' records or send out communication to patients will have to follow the standard too.

6 Who and what does the standard include?

The standard includes:

- Patients or service users of publicly-funded health or adult social care, or their parents or carers. Publicly-funded means that the service is paid for by the Government through money from tax payers. This includes all NHS services.
- Information or communication support needs because of a disability, impairment or sensory loss. This includes support for people who are blind, d/Deaf, deafblind, have had a stroke, or have a learning disability.
- Providing information, such as patient leaflets and letters in different formats such as large print, braille, via email, in an audio format or in easy read.
- Supporting people to communicate through using a hearing aid, lipreading, or using a communication tool.
- Arranging a professional to provide communication support or to be an interpreter. For example a British Sign Language interpreter, deafblind manual interpreter or an advocate.
- Support for appointments, for overnight stays in hospital, and for long-term care such as at a care home.

We have decided that some things should not be included in the standard. This was a hard decision. We need to make sure that the standard does the things that it should do. Other things should be part of different work.

The standard does not include:

- The needs of staff (except if they are a patient, service user, carer or parent as well);
- People who need a different language to English but not because of a disability;
- People who would like to get information in a different way but who can still read information in a standard letter. This could be called a 'preference' and not a 'need.'
- Help that people might need because of a disability which is not to do with information or communication. For example the standard does not include having a ramp or allowing a guide dog into a building.

- Help that people might need because they cannot make decisions for themselves. This might be called lacking mental capacity.

The standard also does not include what health and social care websites should be like. There are lots of other guides about how to make websites easy for people to use. The standard will say that if a service wants a person to look at some information on their website, they must make sure that they can find it and read it. If they cannot then they will have to give them the information in a different way.

7 What will organisations have to do?

The standard has three stages that organisations and staff will need to follow. The stages are:

- Stage 1 – identification and recording of needs. This means finding out if someone has any information or communication needs and recording them if they do.
- Stage 2 – sharing and referring to recorded needs. This means passing on information about someone's needs to other people who are looking after them. It also means seeing that they have needs the next time they come to the service.
- Stage 3 – provision of support / meeting of needs. This means making sure that the person's needs are met, for example sending them information in the right format or providing the communication support they need.

There are actions which will have to be taken as part of each of the stages. These are explained below.

Stage 1 – identification and recording of needs

- Health and social care organisations must find out if a patient or service user (or their carer or parent) needs information in a different format or communication support because they have a disability, impairment or sensory loss.
- Organisations should find out about someone's needs when the person registers, or when they first contact or are cared for by the service. If this is not possible straight away, for example because it is an emergency, then organisations must find out about the person's needs as soon as possible. If organisations already know the patient, they should ask them if they have any information or communication needs the next time they see them.
- Organisations can find out about people's needs in whatever way they think best. This could be over the telephone, face-to-face at a reception desk, as part of a registration or admission form or in a different way. If someone needs support to explain their needs then organisations should make sure that they get it.

- If someone has communication or information needs, then organisations must record or write this down. Organisations must also find out about what type of needs they have, and record or write them down clearly.
- Information should also be recorded about the communication or information needs of a person's carer, if they have one, or their parent if they are a child.

Stage 2 – sharing and referring to recorded needs

- Organisations must make sure that when they write down someone's communication or information needs it is very clear and stored in a place where all staff know to look for it. If information is included on a paper document then it should be on the front cover, highlighted or at the top of the page. If it is recorded on a computer it should flash up or be included on every page of a person's notes or file.
- It is important that information about someone's communication or information needs is very clear so that organisations can make sure that they can meet their needs next time they come to the service.
- If possible, organisations should share this information with other organisations who are involved in the person's care. They may need to ask for the person's consent to do this.

Stage 3 – provision of support / meeting of needs

- Organisations must make sure that people with communication and information needs can contact them easily. They must make sure that they contact the person in a way that they can use. Different contact methods which will work for some people but not others are telephone, email and text message.
- Organisations must provide information to patients, service users, carers and parents in a format that they can understand. This includes sending letters out in different formats such as large print, braille and easy read, or via email. It includes providing information leaflets in different formats too.
- If organisations use a computer system to send out letters then they must make sure that it sends a letter out in a different format if this is what someone needs. If the computer system cannot send letters out in different formats then it must send an alert to staff so that they can send a letter in a different format instead.
- If someone needs support from a communication professional such as British Sign Language interpreter, deafblind manual interpreter or advocate, then organisations must arrange for this professional to support the person. This includes making sure that they have this support at appointments, so that they can use services, and to support them to make decisions about their health, care or treatment.
- Organisations must support patients, service users, carers and parents to communicate. This includes making sure that staff support people to use hearing

aids and communication tools. Staff should also support people to lipread and to use different ways of communicating. Organisations should give people with communication needs more time at their appointments if they need it.

- Organisations must provide communication support for people using outpatient and inpatient services, including long-term care, and for people who live in a nursing or care home.

8 How will organisations write down or record people's information or communication needs?

As part of the standard, there will be a list of types of communication support and information format which people need. Organisations will need to use this list to record people's needs. This is to make sure that everyone records things in the same way.

We think that organisations should record people's information or communication needs, and not their disability.

We think that the list of needs should include four different types of need. These could be called headings:

1. Requires specific contact method
2. Requires specific information format
3. Requires communication professional
4. Requires communication support.

We think that different categories should come under each of the different headings, as follows:

1. Requires specific contact method

- Email
- Letter
- Telephone
- Text message
- Text relay

2. Requires specific information format

- Audio cassette tape
- Audio MP3 file: by email; for internet download; on a compact disc (CD)
- Braille
- British Sign Language video: on a digital versatile disc (DVD); for internet download;
- Compact disc (CD)
- Digital versatile disc (DVD)
- Easy read
- Email: no attachments; Word document attachment(s); PDF document attachment(s)
- Large print: point 16 Arial font; point 18 Arial font; point 20 Arial font; point 22 Arial font; point 24 Arial font; point 28 Arial font
- Memory / data stick
- Moon

3. Requires communication professional

- Advocate for people with a mental health need
- Advocate for people with learning disabilities
- BSL interpreter
- BSL interpreter (hands-on signing)
- BSL interpreter (visual frame signing)
- BSL interpreter Sign-Supported English (SSE)
- Deafblind block alphabet interpreter
- Deafblind communicator-guide
- Deafblind haptic communication interpreter
- Deafblind intervenor
- Deafblind manual alphabet interpreter
- Deafblind manual interpreter
- Learning disability communication support worker
- Lipspeaker
- Notetaker
- Speech-to-text reporter (STTR)

4. Requires communication support

- Needs a longer appointment to support communication needs
- Needs a visual alert (for example to be able to read their name on a screen instead of having it called out)
- Needs an audible alert (for example to be told to go through to an appointment room)
- Needs communication supported by written notes
- Uses a hearing aid
- Uses a learning disability passport
- Uses electronic note-taking equipment

- Uses lipreading
- Uses Makaton
- Uses non-verbal communication
- Uses personal communication tool or aid
- Uses Tadoma
- Uses Voice Output Communication Aid

We think that it should be possible to pick more than one type of support under each heading, if that is what the person needs.

9 How quickly will organisations have to provide information and support?

Organisations must make sure that people get information in the right format for them and any communication support they need as quickly as possible. However, we know that it can be hard to get communication support in an emergency or to provide information in some formats straight away.

When thinking about accessible information and communication support, we think that health and social care settings can be split into three categories:

1. Routine care including appointments which are booked 48 hours or more in advance and ongoing or regular social or community healthcare.
2. Urgent care including walk-in centres and same-day appointments.
3. Emergency care including emergency admission to hospital setting, 999 ambulance calls and emergency social care.

For routine care, we think that organisations should make sure that people can get communication support and information in an accessible format with no additional delay in accessing care or treatment. This means that they should not have to wait longer than a person without any information or communication support needs.

For urgent and emergency care, we think that organisations should make sure that people can get communication support and information in an accessible format as soon as possible after they have contacted the service.

We think that there are two good reasons why organisations might not be able to provide information in a different format or communication support quickly. One reason is that there are not many communication professionals who have the right skills, for example deafblind interpreters. The other reason is because the information that the person needs is long, difficult or not used very often.

We think that organisations must still try their best to meet people's needs. If there is a time when they cannot meet someone's needs then they must find out why and make sure that they can help them next time. We think that organisations should use computers and the internet to help meet people's needs more quickly.

10 Will the information and communication support be good quality?

It is important that information provided to people by health and social care organisations is correct and of a good quality. This includes information which is in a different format such as audio, braille and easy read.

It is also important that professionals providing communication support, interpretation and translation have the right skills, knowledge and qualifications.

We think that British Sign Language interpreters and deafblind manual interpreters used in health and social care settings should have:

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

In a medical setting, we think that British Sign Language (BSL) interpreters used to provide interpretation should be qualified to Level 6.

We think that organisations should check to make sure that communication support and alternative formats provided to patients, service users, carers and parents is good quality. It would be good if they worked with patient groups to do this.

We think that it is sometimes acceptable for health and social care staff to act as interpreters but only if the person agrees and they have the right skills, knowledge and qualifications. Health or social care staff should not be used as interpreters whilst they are also providing care to the patient or service user.

We do not think that organisations should use family or friends as interpreters. This is because everyone has a right to privacy. It is also because they might not have the right knowledge, skills or qualifications so they might get the information wrong.

11 How will the standard be put in place?

We will use what people tell us as part of this consultation to write the final standard. We will look at people's comments to see if we should make changes to the draft standard and to other documents we have written, such as the Implementation Plan and Implementation Guidance.

The Implementation Plan explains how we will put the standard into practice. We know that there will need to be technical changes in IT systems and documents used for patients' records so that they follow the standard. We also know that health and social care organisations and their staff will need to do things differently because of the standard.

We are planning to have a pilot when some health and social care organisations will test out the standard during autumn 2014. There is more information about the pilot

on our website www.england.nhs.uk/accessibleinfo The pilot will help us decide on the final standard.

We have also written Implementation Guidance which should help organisations to understand the standard and follow it correctly. It includes advice about the types of information and communication support people need. Before we write the final guidance we are asking for your views on what it should include, this is explained in the next section, number 12.

12 What advice will you give organisations about the standard?

As part of Implementation Guidance, we want to help organisations to follow the standard by providing advice, guidance, and tools. We think that we should provide advice about:

- Sharing people's information with interpreters, translators, communication support workers and advocates;
- Communicating with patients by email and text message;
- What the law says about meeting people's information and communication support needs;
- Different types of accessible information and communication support and who might need them;
- Making sure that information recorded about people's needs is accurate;
- Supporting mental health service users with communication needs;
- Making sure that translated or transcribed information is of a good quality;
- Making sure that interpreters, communication support workers, translators and advocates have the right skills, knowledge and qualifications;
- Getting good value for money when paying for accessible information and communication support;
- How an organisation can check if they are following the standard properly, and see if staff know about the standard;
- What makes good 'easy read' information;
- Making standard documents easier for people to read;
- How staff and services can support everyone with communication needs;
- Specific advice about supporting people with particular information and communication needs, for example people with hearing loss, dementia or aphasia;

- Inclusive communications – web accessibility and usability.

We are also planning to write and share some tools and templates which organisations can use. These will include templates for an accessible communications policy, a service user ‘help’ card, and example questions or statements to encourage people to tell the service that they have information or communication needs.

We also plan to write some short introduction documents which staff can use, including ‘top tips’, myth busters, quick guides, a glossary and telling them where to find more information.

13 How will you make sure that organisations are following the standard?

We think that organisations should publish or display an accessible communications policy which explains how they will follow the accessible information standard.

We think that organisations should support people to provide feedback about their experience of receiving information in an appropriate format or communication support, including having an accessible complaints policy. We think that this should be part of the standard.

We are talking to the Care Quality Commission (CQC) and looking into the Place Led Assessment of the Care Environment (PLACE) programme to see how they might be able to help check that organisations are following the standard.

We think that local Healthwatch organisations, patient groups and charities will all want to encourage organisations to follow the standard.

14 When will organisations have to follow the standard?

We are hoping to have the draft standard approved by the Standardisation Committee for Care Information (SCCI) at their meeting in August 2014.

The Committee know that we are having a consultation on the draft standard and that the final standard might change because of what people tell us.

After the consultation, we will write a report about the consultation including what people told us about their views. We will also use everyone’s views and the results of the pilot to help us to write the final standard. The final standard might be different to the draft standard which is what we have consulted on.

We are planning to get the final standard approved by the SCCI in spring 2015. Once it is approved, we think that organisations should have 12 months to make changes so that they follow the standard.

15 How to have your say and contact details

We would like to know what you think about the draft standard that we have written.

You can do this by completing a survey on our website
www.england.nhs.uk/accessibleinfo

This consultation document and the survey is also available from our website in easy read, British Sign Language (BSL) video (with subtitles), and audio formats. You can also ask for a copy of this consultation document or the survey to be posted to you as a hard copy, in large print, easy read, on CD, on DVD or in braille.

We will also be holding some workshops to hear people's views on the draft standard. There is more information about these workshops on our website or you can contact us to find out more.

If you would like a copy of this consultation document or the survey sending to you, or if you have a question or concern, please contact us:

- By email to england.nhs.participation@nhs.net
- By telephone on 0113 8251324.
- By post to Sarah Marsay, Public Voice Team (Accessible Information), NHS England, 7NE, Quarry House, Quarry Hill, Leeds, LS2 7UE.

For updates about the development of the accessible information standard please visit the NHS England website www.england.nhs.uk/accessibleinfo

The deadline for responses is Sunday 9th November 2014.

Responses received after this date will not be counted.

Thank you for taking part.