

## **Making health and social care information accessible**

### **Consultation workshop hosted by Sense in London on 28.08.14**

#### **Notes**

##### **Introduction**

The event was attended by three participants, three communication support staff and four members of Sense staff. Sarah White, Policy Officer at Sense, welcomed everyone to the workshop, and Sarah Marsay, Public Engagement Account Manager at NHS England, introduced the accessible information standard. Following this, participants asked questions around the mandatory nature of the standard, whether or how it would apply to voluntary sector providers, whether children were within the standard's scope, organisational awareness of the standard and responsibility for compliance. Additional support to the discussion was provided by Kerry Uttley, Project Coordinator at NHS England.

##### **Note on participants' views**

Where participants' views are recorded below, they appear "in speech or quotation marks," and they do not necessarily represent the views of NHS England. The notes are not a verbatim record, rather they are an attempt to present the key points made by participants in order to inform the consultation on the draft standard.

##### **Discussion about the aim and scope of the draft standard**

Sarah Marsay talked through information about the aim and scope of the draft standard, including what it is intending to achieve and aspects which have been defined as in and out of scope at this stage, before inviting participants to respond to three key questions.

##### **1. Overall, do you agree with what the standard is aiming to do?**

- "Generally yes, but I wonder if the standard goes far enough, especially for people with multiple disabilities including communication difficulties. In my experience, staff need training and there is a need to change the culture of the NHS and of staff who work in the NHS. I think that staff need training on how to ask people if they have any communication needs, for example when they come into hospital. Staff also need to be aware of how to respond to someone with communication needs, especially someone with a learning disability. Staff need to know not to 'jump in' and start giving care to a patient without communicating with them first."
- "Everyone with communication needs does not fit into the same box. Often, I find that in the care of my son, him having a learning disability means a tick in one box, autism another, a sensory impairment another, and it seems like staff only

know about one box, but communication crosses all boxes and aspects of care. This is especially important when people have a learning disability and / or autism and a sensory impairment which means they need an interpreter. I am concerned that much of the information given by a clinician is 'lost in translation' and not received by the patient."

- "I have an example of excellent communications practice. The doctor tells everything to my son, who has additional needs, and then provides time for me to explain it to him too. This gives me confidence and provides assurance."
2. Do you agree with what the standard includes?
  3. What types of information format and communication support should be included on the standard's list?
- "I think that the scope should include information in British Sign Language (BSL) on DVD for d/Deaf people."
  - "The scope needs to include support from a deafblind intervenor and other types of professional support."
  - "I have concerns about the exclusion of family and friends from a role as an interpreter, although I understand the rationale for this in many cases. The problem is when someone has more complex communication needs – in this instance their parent or carer needs to be included. My experience is that staff often do not listen to parents."
  - "I think that additional needs, for example difficulties in processing information as well as a sensory impairment, need to be included in the scope of the standard. Where an individual has a sensory impairment and additional needs such as this, I think that the standard should state that the person's parent and / or carer must be involved. For example, my son needs a BSL interpreter and my support as his parent to communicate. As a basic rule, I think that the standard should state that if someone cannot explain their needs then their parent / carer must be involved. In my experience, it can be appropriate sometimes for a person's parent / carer to communicate for them. It is important to remember that a BSL interpreter interprets exactly what the doctor or other clinician / staff member says. When someone has additional needs as well as being d/Deaf then their parent / carer needs to also support understanding especially where the language used by the doctor is at a high level or complex. I think that the standard should state that 'where the person has additional needs, for example a learning disability, autism and / or difficulty in processing information, then their parent and / or carer must be involved.' It should be recognised that there are differences in understanding and in people's ability to communicate."

- “With regards to the scope, I think it is correct that it states that the person themselves and / or their parent or carer should be asked to explain how they need information to be delivered to them.”
- “What about staff who are supporting the person, they may be d/Deaf themselves. Are their needs included in the scope of the standard? I think that they should be.”
- “Training of staff is vital. Accessible information should be part of staff training.”
- “d/Deaf patients often receive letters from the NHS stating that we must contact our GP by telephone within seven days, but this is not appropriate when you cannot use a telephone.”
- “In my experience, my doctor will not pay for a guide when a deafblind person requests an appointment, for example for an examination, so the doctor visits the person at home without a deafblind manual interpreter. This means that the patient still does not get the care they need (in this instance an examination).”
- “I think that the standard needs to influence training, including for staff in key contact roles, such as receptionists. Receptionists can be key in good or bad experiences. Training must include doctors and nurses but also support and administrative staff.”
- “Information about sensory awareness should be included as part of NHS induction processes for all staff, this should be face-to-face. In my experience, currently training and awareness is inconsistent. It should be included in induction and in yearly e-learning.”
- “I know of an organisation who are currently writing their interpreting policy – this needs to link into and reflect the accessible information standard. The policy includes interpretation for d/Deaf and deafblind people.”
- “In my experience, I have to keep explaining my needs and re-referring myself to, for example audiology, which is frustrating. Last time, I could just manage to read the letter I received about my appointment with my magnifier. I emailed for an appointment and got a response within the hour – I was impressed that I could use email as a communication method with the service. I got an email with details of the appointment, but also a standard printed letter.”
- “I wonder about how the standard will influence inpatient stays in hospital. I think that an interpreter is needed during someone’s stay as an inpatient and not just at admission; it is needed for cooperation and consent and to support ongoing

care. An interpreter is essential when the doctor is doing their rounds; however, in my experience often communication support is seen as an extra. When my son was in hospital he needed someone with him 24/7, the hospital should allow someone's parent / carer to stay with them."

- "In my view, a little bit of training can go a long way, for example teaching a nurse some basic signs used by people for example for 'toilet.' I think that what really makes a difference is the willingness of staff to try and communicate."
- "I think that nursing students should learn some basic signing."
- "All patients need to be able to alert staff to their needs when in hospital; this is not just about nursing it is about other things such as mealtimes too."

### **Discussion about the detail of the draft standard**

Sarah Marsay provided more detail to participants about specific elements of the draft standard, including timescales for meeting individuals' needs, quality considerations, and implementation, before inviting participants to respond to four key questions.

#### **4. Do you agree with what the standard says about how quickly people should get accessible information and communication support?**

- "With regards to the type of communication support and information format, producing information in an audio format can take some time. In my experience it depends on whether or not an organisation has a contract in place. It can take up to three weeks for my local authority to provide a single letter in audio. Sometimes it is quicker, but it depends on the type of audio format needed, for example audio CD. On one occasion I was sent a computer disc instead of a CD so I still could not access the audio information. It is important that organisations are very clear on a person's exact needs – and this must be based on information from the person themselves. There are lots of different audio formats! In my experience, the timescale depends on the backlog of work and the type of information. The turnaround time can be quicker for information in an audio file sent electronically rather than on CD. In my experience two weeks is the minimum turnaround time – but I think that this is still too long."
- "I think that people should receive information in a format which is accessible for them at the same time as other people receive information in a standard format."
- "Sometimes there is a six week assessment to treatment pathway, so it is essential to get the information in time to do something with it. What about cancer patients and the two week wait deadline? In my area I think that the Any Qualified

Provider (AQP) audiology service is seven days to treatment – how would this work for a patient who needs information in a different format?”

- “It is important to think about the fact that, often, there is also a need to organise / request communication support at an appointment, so the patient needs to receive accessible information in time to book an appointment far enough in advance so that arrangements can be made.”
- “I know that some hospitals have systems which auto-generate correspondence, but could they not also automatically generate an email or a telephone call instead if that is what the patient needs?”
- “I find that turnaround and response times for different formats varies depending on whether it is a routine appointment or an emergency.”
- “We need to get information in enough time to process and action it, for example if there is a choice of providers we need a letter in an accessible format and accessible information about the different providers. We need to get the information in enough time to process it and make an informed choice without delaying our treatment.”
- “I think that the required timescales for different types of information should vary, for example five working days to receive information in an audio format is fine if it is not urgent, but if the information / action is urgent then the turnaround time should be maybe 48 hours.”
- “I think that organisations should have to demonstrate that they have the systems in place to respond to people’s needs promptly.”

5. Do you agree with the quality considerations?

- “With regards to deafblind manual interpreters, I understand that Signature is currently working on a qualification. As I understand it, currently there is no such thing as a ‘qualified deafblind manual interpreter’ – there used to be a qualification and under the old system there are about 13 registered professionals in the whole of the country. So therefore, it is not currently possible to specify that a deafblind manual interpreter is ‘qualified’.”
- “I think it is important that the standard recognises that people with some disabilities and communications needs might need different kinds of BSL interpretation, even if it is not possible to specify in the standard how this should be provided.”

- “I think that it also needs to be recognised that some BSL interpreters specialise in a particular area, for example court or hospital environments. This means they are experienced with the terminology for example. It should be possible to stipulate that a BSL interpreter has experience / skills in a particular area or subject matter, and / or in supporting people with particular needs for example people with a learning disability who are also d/Deaf.”
- “In my view, advocacy is also critical. It is important that organisations source advocacy support from professionals with expertise in particular areas, for example supporting people who communicate nonverbally.”
- “I think that the contract which organisations have with communication / interpreting agencies needs to be specific about types of skills / professionals they are able to provide, for example a BSL interpreter who is skilled in supporting / interpreting for people who need simpler BSL.”
- “NHS staff should see patients’ friends and family as experts in their needs too.”
- “I would suggest that one important type of support is Total Communication. This means the use of any and all communications systems which people may use, and using any / all / bits from each.”
- “I think that there should be consideration given to how a person could challenge if an interpreter is no good.”
- “My view is that the standard needs to include direction to organisations to liaise with a person’s friends / family / staff where they have additional needs / where this is their preference. However, at the same time, services must not put pressure on parents and carers to interpret in place of a professional, even if they have a role in supporting communication with the person.”
- “The standard should leave the patient with some choice as to where to get support from, for example a preferred interpreter.”
- “The standard should include signposting organisations to sources of advice, for example about deafblind manual interpretation.”
- “It is important to include older deafblind people as part of the standard. For example, people need awareness of their condition in order to best decide how they wish to be communicated with, they also need skills. Older people can often be less likely to ask for help too. There is lots of information in Sense’s publication, ‘Enjoy Life’.”

- “Organisations and staff need to understand that seeing someone for the first time can be very hard to understand, and they often position themselves incorrectly which makes things even harder.”
6. It is proposed to give organisations 12 months to implement the standard. What do you think about this?
- “There might need to be a staggered approach. For example an organisation might be able to provide large print sooner but need to set up new contracts for audio and braille. Perhaps different aspects of the standard should be prioritised?”
  - “I think that it will be important for people to know that they have a right to information in an accessible format. Hospitals should be required to inform people, it should be printed on letters and in leaflets.”
  - “12 months seems reasonable to me.”
  - “There needs to be monitoring of implementation during the 12 months, for example milestones of actions at three month points and / or reporting on progress.”
7. What do you think about plans for making sure that organisations follow the standard?
- “I think that it should be a requirement that organisations have an Implementation Plan for when and how they will comply with all aspects of the standard, for example x by y date.”
  - “What about the Equality Act 2010? Can this support compliance with the standard?”
  - “There should be a monitoring group to make sure that the standard is being met. This should be a national group which ensures that the standard is being implemented.”

## **Close**

Sarah Marsay thanked all of the participants for their contributions and thanked Sense for hosting the event. The consultation closes on 9<sup>th</sup> November, and those present were invited to encourage others they knew to have their say by completing a survey online at [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo) or in an alternative format.