

Making health and social care information accessible

Consultation workshops hosted by the Royal National Institute of Blind people (RNIB) in September 2014

Summary of comments made as noted by RNIB staff

1. Introduction

In total 30 delegates attended the three workshops which were held on 15th September in Newcastle, 19th September in London and 23rd September in Birmingham.

In the report below, participants' views have been recorded and summarised by the RNIB, who hosted the consultation events. The points made below do not necessarily represent the views of NHS England. The notes are not a verbatim record, rather they are an attempt by the RNIB to present the key points made by participants in order to inform the consultation on the draft standard.

2. Overall do you agree with what the standard is aiming to do?

Everyone was in broad agreement with the standard's aims. Words used to describe the overall aim of the standard included 'laudable', 'ambitious' and 'good'. Many raised the point that the standard only tackled what the Equality Act 2010 and previously the Disability Discrimination Act (DDA) had required for well over a decade and so it was "about time" that a standard was developed. But even so, many feared that the standard itself would be too big a challenge for the NHS to deliver, although desperately needed.

All groups felt that an unwritten aim of the standard was to ensure that all NHS and adult social care staff were disability aware and confident about communicating with disabled people. It was strongly felt that this should be an explicit aim of the standard. It was felt that so much of the standard was prescriptive about what had to be done (and rightly so) that it lost this key aim of empowering staff to be aware and confident in how they meet disabled people's communication needs. It was strongly felt that this needed to be addressed.

Many felt that aim of the standard should also mention the use of advocates - the current aim focusses on written formats, interpreters, and extra time at appointments.

Others felt that it was vital that the overall aim of the standard included developing a central uniform system (including an IT system) for recording and accessing people's needs across the NHS. It was felt that this is implicit within the standard's detail but should be spelt out upfront. There was a fear that if this was not the case, then local hospitals, clinics and GPs surgeries could just develop their own systems for meeting the standard which would not be compatible with each other.

As outlined in more detail below, participants raised issues about website accessibility and signage which are currently out of scope – many felt that the aim of the standard was not right if these two aspects are not covered. Many accepted that these could be covered in separate standards but felt that they had to be addressed somewhere.

3. Do you agree with what the standard includes?

Everyone agreed with what was already included in the standard, so there was nothing that they felt was unnecessary or should be removed. There were however many things which it was thought should be added:

a. Experts to take the standard forward

Most want the standard to include a requirement for health and social care services to appoint and train members of staff as “accessible information experts.” In Newcastle they wanted this to be taken a step further and for every service to have a visual impairment nurse or specialist (a role that currently does not exist). This would be similar to learning disability nurses and champions, which have been introduced in many health settings. It was felt that these experts would train other staff, keep up to date with developments in communication and take responsibility for the provision of accessible information.

All felt that the standard should include something far stronger on the need for staff to be trained, not only in the delivery of the standard but in disability equality and awareness.

b. Working with blind and partially sighted people

There should also be a “must” requirement for all health services to work with disabled patients including blind and partially sighted people, to ensure that the standard is implemented properly (note further detail on this point below).

c. Promoting the standard to patients

There needs to be more in the standard about health and social care providers needing to tell patients about the standard. It needs to be promoted to all patients so they know about it and can identify as needing communication support. There needs to be a date set for when all patients must have been contacted about the standard and whether they have communication needs.

d. Websites and electronic communication

Websites and other electronic communications need to be included in the standard. There was much debate about how it needed to be added. In Birmingham there was much discussion about this. The group agreed that the standard should not include specific instructions on how to make websites accessible. Instead it was felt that there should be a specific requirement which would read something like this: “All NHS and adult social care websites should meet accessibility standards W3C or the Government Digital Service standard.”

It was felt that as the W3C and GDS standards already exist there was no need to rewrite these in this standard but that health and adult social care providers needed to be directed to follow them. NHS Choices was mentioned as being a very accessible website and the standards they followed should be the benchmark for all health and social care websites.

On the issue of other electronic communication devices, like touch screen check in terminals, it was felt that these were a real problem and the standard needed to be very clear that these were not acceptable unless there was an equally convenient way for blind or partially sighted people to sign in.

e. Communication needs unique to blind and partially sighted people

Another really huge area of communication need which the standard struggles to cover are issues relating to communication with blind and partially sighted people that do not fall neatly into alternative formats or needing extra time. All of the workshops talked about this at great length.

The general consensus could be summarised as, “the standard needs to include something that compels staff to consider what visual information in their environment must be communicated to blind and partially sighted people to ensure that the patient has full access to the environment and the care given there.”

A number of examples below illustrate the types of communication needs that were discussed in this regard:

The standard currently mentions the need for audible announcements to alert blind and partially sighted people that it is their turn to see a health professional. However blind and partially sighted people frequently face situations where a doctor or nurse calls their name but does not actually collect them and guide them to the room they are to be seen in. Other frequent examples given were that:

- Blind and partially sighted people ask for directions and staff just point;
- Staff do not introduce themselves (and seem to assume that everyone can read their name badge);
- Staff do not tell patients when they leave the room;
- Staff do not explain to patients how long they are likely to wait when this information is written for others to see;
- Staff bring patients medicine or food but do not explain what they have brought or where they have left it;
- Staff begin an examination but do not explain what they are doing or are about to do, this can be very frightening if you cannot see what the nurse or doctor is doing;
- Staff do not help blind or partially sighted people to orientate themselves on a hospital ward;
- Staff do not provide important information that is displayed visibly such as opening time changes, patient surveys, staff and clinic changes.

These are all examples of where staff need to modify the way they communicate with blind and partially sighted people about the services they are providing or the care they are giving.

Many also thought that sighted guides should be covered in the standard. There needs to be an understanding that a sighted guide is not there for purely navigation purposes but to provide vital visual information to the blind or partially sighted person. If the provision of guides specifically could not be included then staff at least needed to be trained in how to guide and provide this type of information to blind or partially sighted people.

f. Mirroring the Equality Act 2010

Closely linked to the point above is the need for the standard to mirror the Equality Act in ensuring that the service provided to blind or partially sighted patients is as close to the

service provided to everyone else as possible. It was felt that this key principle needed to be included.

g. Signage

It was strongly felt that signage should be referred to in the standard. It was understood why the standard could not cover everything, but signage is so important and often so poor that participants felt that it needed to be mentioned in the standard.

It was believed that there is separate guidance on signage which needs to be looked at and updated. There was a concern that if the guidance around signage is poor then it should not be linked to within the accessible information standard but that something has to be said about the importance of signage as a form of communication.

4. What type of communication support and information format do you think should be included on the standard's list?

There was agreement with the categories / support types included in the consultation document, with some additional categories / support types also being suggested.

a. Readers

Participants in the Newcastle workshop were keen for “readers” to be included, meaning a person should be provided to read information to blind and partially sighted people at appointments. However, participants in the London workshop were very concerned that if readers were offered then there would be no incentive for health services to provide accessible formats.

b. Dictaphones

It was suggested that a category that stated something like “uses a Dictaphone to record information” could be included, particularly for situations like medication details. This would mean that either the patient could record the nurse or doctor explaining how to take the medicine or the patient could repeat what they had understood into the recorder making sure the doctor or nurse could check they had recorded it correctly.

c. Audible announcements not enough

Participants felt that the support category of “needs audible announcements” should be added to. It must include “needs audible announcements and guiding to the room or treatment area.” Audible announcements are not enough information.

d. Formatting of written materials

As well as mentioning font size it should also be included that all fonts need to be sans serif and preferably Arial.

Something should be included about format of emails - that there should not be lots of images or moving images in the email and that the email needs to be written in correct English punctuation so that a screen reader can read it back accurately.

Similarly text reminders are great for those with accessible mobile phones but they have to be formatted properly so a phone screen reader can read it correctly. Examples were given of when text messages did not have punctuation and could not be understood as all the words ran into one another.

e. Talking labels and equipment

Talking labels need to be added as a format.

Equipment that communicates, for example talking blood sugar readers, should be mentioned as well. Also testing kits are often inaccessible – both the kits themselves and the information that tells you how to use them and whether you have used them correctly should be accessible.

f. Hierarchy of choices

All groups mentioned that patients should be able to select what they needed in a kind of hierarchy. For example someone's first choice might be braille but where that proves difficult they would accept email, the bare minimum they would accept is for a person to read the information to them before sending accessible information later (in braille or email). There are further points made in this regard below.

There needs to be a clear way to update your format request and to check that it is correct.

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

All groups felt that for appointments where a health or social care provider had more than two weeks' notice all communications needs should be met.

All groups strongly thought that there needed to be a different approach to appointments with less than 2 weeks' notice which was more along the lines of:

- Communications support which must always be provided, i.e. support which could be provided even in an emergency, including follow up information by email, spending extra time with someone, sending a text message, telephoning, providing someone to read information, and large print.
- Communications support which could take longer to provide, for example braille where opinions differed between an 'acceptable timescale' of between seven and 14 days. Most people felt that an 'acceptable timescale' for audio information was 48 hours.

There was also discussion about how the nature of the information would dictate what someone's requirement might be. So for example someone who needs very large print of 28 point might have a recorded requirement as follows:

- For important medicine or treatment information please provide in 28 font;
- For information that is longer than 2 pages of A4 or is not urgent please provide by email.

All groups agreed that to do nothing was not an option and they felt that current wording made it appear that that was acceptable as long as lessons were learnt. This is where the hierarchy of needs was important so if an interpreter or braille could not be provided

straightaway, something else had to be provided. That might be to spend extra time with the patient or to send an email or to record information on to a Dictaphone for patients, either way it agreed that it was not acceptable for an organisation to say that they cannot do anything.

6. Do you agree with the quality considerations for the standard?

All groups believed that one of the best ways to ensure quality was to involve blind and partially sighted people in the design, delivery and evaluation of the standard in local settings. It was suggested that each Trust and clinical commissioning group (CCG) should work with a disability access group to ensure they got things right.

Other ideas mentioned at all workshops were:

- Building quality control into contracts with accessible communications providers;
- Carrying out 'mystery shopping' and spot checks;
- Surveying patients;
- Carrying out yearly audits;
- Building the accessible information standard into PLACE assessments [Patient Led Assessments of the Care Environment] to ensure quality;
- That responsibility for the standard had to rest at a very high level of the organisation and they should be accountable if provision was poor.

Again the Equality Act 2010 was seen as a good tool to determine quality, for example quality could be assessed by considering how close the information / service received by people with disabilities is to what people without disabilities receive.

Similarly it was felt that the check list used in the Equality Act 2010 Code of Practice to assess whether an adjustment is "reasonable" should be used by hospitals, for example:

- Does the accessible information meet the patient's needs?
- Is it fit for purpose?
- Is it efficient?

All groups said that quality checks involving patient feedback that were put in place must be accessible. So surveys must be accessible, complaints procedures must be accessible and they must be promoted in an accessible way.

Many also pointed out the importance of being able to give positive feedback as well when services got it right. There is also a need for this good practice to be shared easily amongst health providers.

In London participants listed some of the most common "quality issues" they faced with accessible information. It was suggested that a check list of common mistakes should also be provided to help services meet people's needs. Issues listed included:

- Poor quality paper for large print and braille;
- Braille and large print being provided on A3 paper (instead of A4);
- Audio not being formatted properly;
- Staff attitudes which in effect rendered any accessible information useless. For example, giving someone an audio signal that it's their turn by announcing that 'the

doctor will see you in room five' but without any other information or assistance to find room five.

7. It is proposed to give organisations 12 months to implement the standard. What do you think about this?

Many felt that 12 months was about the right amount of time. There was a lot of concern that many providers might not be ready by then but it was felt that giving them extra time could just lead to them putting it off for longer. It was felt that an ambitious time frame would spur some into action.

Others were concerned that 12 months was not long enough, but did not want to give health and social care services too long to implement either.

In Birmingham there was strong feeling that a longer pilot phase was needed. It was suggested that before the 12 month implementation deadline was issued a full 6 month pilot needed to happen. That pilot would then identify both problems and good practice which could be used to develop resources to aid others in implementing the standard. If this extra 6 months was added to the time frame then it was suggested that a staggered approach to implementing the standard could be introduced. So providers would have to start responding to what they could straight away.

Many felt that during the 12 month implementation period providers must be directed to deliver training in meeting the standard to staff.

All groups agreed that the standard had to be mandatory by 31st December 2016.

8. What do you think about plans for making sure that organisations follow the standard?

The publishing of accessible information policies was welcomed but many thought that these policies needed to be scrutinised, not by NHS England necessarily but by patients and disability groups. If all health services had a disability access group then they could assist with this.

There were grave concerns about NHS resources in terms of both staff and computer systems. There was a wide feeling that NHS computer systems were not up to the job and that a new system would need to be put in place. Similarly that staff did not have the time or the expertise to deliver at the moment so training and support are essential.

Disability access groups could assist with implementation if they are set up as part of the standard implementation phase.

There need to be experts in every setting especially those who are experts in disability equality not just the standard.

There needs to be a robust way to hold those that fail to meet the standard to account. Ideas for how to do this included:

- The Care Quality Commission (CQC) to have responsibility for inspecting organisations' compliance with the standard, and to 'name and shame' those that fail to

comply. However, some participants had concerns about the CQC's ability to do this effectively.

- PLACE assessments to include assessing the standard. However for this to be effective there would need to be more training of assessors with regards to access needs and more blind and partially sighted assessors.
- Easy ways for patients to make complaints and a clear accessible complaints process.
- Introduce a 'three strikes and you are out approach,' for example one complaint is investigated, two complaints leads to an inspection, three complaints leads to some kind of action such as fining the provider.
- Positive targets need to be set on providing accessible information.
- Health professionals should be reported to their regulators if they fail to provide accessible information.

Local Healthwatch were seen as being organisations that needed to be involved in implementation of the standard. However many highlighted the significant variation in the approach taken and priorities identified by local Healthwatch across the country. It was felt that Healthwatch England needed to be worked with so that they could support local Healthwatch to take this up as an important issue.

Lastly that resources and training needs to be provided to staff and that local services need to be supported in how to do this and get it right.

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