

Making health and social care information accessible

Consultation workshop hosted by Bradford Talking Media and Bradford Strategic Disability Partnership Friday 3 October 2014

Notes

Introduction

The event was attended by approximately 30 participants.

Sue Crowe, Managing Editor at Bradford Talking Media (BTM) welcomed everyone to the workshop and covered housekeeping matters.

Sarah Marsay, Public Engagement Account Manager at NHS England, introduced the accessible information standard. Following this, there was an opportunity for participants to ask questions about the standard.

Additional support for the discussion sessions was provided by Kerry Uttley, Project Coordinator at NHS England, Sue Haddock, Community Engagement, Development and Equalities Officer at Bradford Strategic Disability Partnership and Joanna Ingham from BTM.

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. Participants then split into three groups to discuss three key questions.

1. Overall, do you agree with what the standard is aiming to do?
2. Do you agree with what the standard includes?

Group 1 – facilitated by Joanna Ingham

- "I think it is important to make the standard as easy as possible for people with disabilities to understand."
- "The standard should include everybody."

- “When I was unwell, I did not understand the information I was given from the NHS. I think the standard needs to include providing accessible information about what treatment to expect.”
- “If one communication method fails then I think services should try another. For example, I know of an experience where a patient was sent a text message from their GP surgery. The patient did not respond but they were not checked up on. In this instance it turned out that the patient was seriously ill and has since died.”
- “It would be good if appointment letters included more information, not just a time and a place.”
- “Keep information simple and to the point – do not use jargon.”
- “I think the standard should include displays and signage in GP surgeries. The text is often not clear for those with a visual impairment or signs are too high for people who use wheelchairs to see clearly.”
- “Some disabled people might not get support when they go to GP – will the standard improve this?”
- “Are pharmacists covered by the standard?”
- “Information should be accessible but not patronising. For example, I usually receive easy read letters from my dentist but the last one I was sent was really childish.”

Group 2 – facilitated by Sarah Marsay

- “How will people be asked if they have any communication support needs? Will staff be trained? It is really important that staff ask people about their needs in the right way.”
- “There are certain things which services have to do, will the standard be a ‘must do’ or a ‘should do’? Will it make a difference?”
- “Will there be any budget made available to provide training needed by staff?”
- “If I go to my GP Practice, I might be looking for information, how will someone know I’m d/Deaf and need information in a different format?”
- “In my opinion, staff awareness is needed – training must happen. Funding is an issue.”
- “Who is responsible for GP training? Is it the responsibility of the service provider or the commissioner to make sure people have access to communication support?”
- “I am concerned about what it says in the draft standard about health and social care staff potentially being used as interpreters. I do not think that the document is clear that anyone providing interpretation in a medical setting must be appropriately trained; they must have attained an appropriate British Sign Language (BSL) interpreting qualification – this is essential. Consideration also needs to be given to the appropriateness of staff being used to interpret, even if they are appropriately qualified, and I do not think that it is appropriate.”

- “I agree, health and social care staff should not be used as BSL interpreters, even if they are qualified, as it would not be appropriate. I would also have concerns about them not being appropriately registered or signing up to a relevant (interpreting) code of conduct.”
- “In my experience, delays in getting a BSL interpreter are due to hospital commissioning processes and not because there are not many BSL interpreters.”
- “I know that people are entitled to access to their patient records. What about if I need it summarised or in easy read? Will the standard cover this?”
- “Will the standard be included / incorporated into [the GP IT system] SystemOne?”
- “I think that the standard must be embedded into NHS computer systems.”
- “In my view, the voluntary sector should be used to support people to be more confident and assertive in asking for support.”
- “When people receive information they often have more questions. Just providing a BSL DVD or video is one-way communication. I think that this should be followed-up by forums or opportunities for d/Deaf people to ‘drop in’ to their GP surgery to ask questions and to discuss the information, supported by a BSL interpreter. This could be advertised as a ‘Q&A’ session in a GP surgery for d/Deaf people, with a BSL interpreter.”
- “I think that it all comes down to budget.”
- “There needs to be more partnership working to support increasing access. For example Local Healthwatch, a charity, a GP practice – they could all work together towards a long-term goal and take a joint approach / develop new ways of supporting people. Different organisations can contribute different things; it is not all about money.”
- “Will NHS England be developing tools for clinicians to use as part of consultations to make appointments and care more accessible? It is important that the whole consultation process is accessible, for example being able to describe and manage symptoms. Services need to be more imaginative in involving people with accessibility needs throughout the process.”
- “It is important to remember that lots of people find it hard to describe their views and feelings, this can be even more difficult if you have a communication need too.”
- “I think that there should be a flag on your records which shows that you have information needs. It is essential that the information recorded is accurate, and consideration needs to be given to who records the information too.”
- “I have some feedback on the webpage used for the consultation. The picture which indicates BSL should link to the BSL version of the consultation document, but it does not. Also, I think that the consultation section is too far down the page, it took me ages to get to it and it should be at the top.”

Group 3 – facilitated by Sue Haddock and Kerry Uttley

- “Yes, we agree with what the standard is aiming to do.”

- “I think that foreign languages should be considered in this standard. It is especially important in Bradford where there is a lot of diversity. Sometimes a person has a disability but their friends and family do not speak English.”
- “If foreign languages are not included, it will be important to have some reference to other standards or legislation regarding foreign language needs.”
- “Children with learning disabilities that are transitioning into adult services sometimes have parents with foreign language needs and that can make the transition more difficult.”
- “It would be useful to understand how to apply the standard with the complication of foreign language needs.”
- “I think that websites should be in scope, as it is very important that websites are accessible. It is important to future-proof the standard for technology developments.”
- “We have a lot of trouble with the information which is on screens in the waiting rooms at hospital and GP practices; plus some people cannot read a visual prompt or hear a spoken prompt.”
- “I understand that mental capacity is not included in the standard, but it would be useful to understand how this standard and the Mental Capacity Act guidance work together.”
- “This standard relies on people self-reporting needs – some people do not consider themselves to have a communication need although they might actually have one. Organisations need to consider the way in which questions about information and communication needs are asked.”
- “Some types of disability change over time, like hearing worsening. Organisations should review the needs with a patient or service user from time to time.”
- “In terms of providing support, I think that it would be helpful to refer explicitly to ward / inpatient situations, and support at appointments and home visits, and to very clearly include social care.”

3. What types of information format and communication support should be included on the standard’s list?

Group 1 – facilitated by Joanna Ingham

- “Information needed by carers is important; the patient might not have needs but the carer might.”
- “Does it cover the way the GP talks to you, for example, not in a patronising way?”
- “Are people with dementia included in the standard?”
- “If a d/Deaf person is prescribed medication for the first time they might need a longer appointment with the doctor – supported by a BSL interpreter. But in my experience the interpreter has often not been booked for long enough and therefore has to leave.”

Group 2 – facilitated by Sarah Marsay

- “BSL interpreters.”
- “Easy read information.”
- “Information in BSL, for example booklets on BSL DVD and BSL videos on the internet, especially so that you can access information independently, from home.”
- “Contact method is also really important, for example letter, text, email.”

Group 3 – facilitated by Sue Haddock and Kerry Uttley

- “We have not heard of some of the formats and professional support types. They need to be defined.”
- “Patients might not know what types of support they can ask for. Organisations should think about how patients are made aware of their options.”
- “There should be an option for plain text with no punctuation or capital letters, as some screen-readers spell the whole lot out.”
- “There should be a category for ‘advocate for people with autism’, as it is not the same as advocacy for people with learning disabilities.”
- “I think that there should be a ‘special print’ option, with a free-text space to say what that is, for example no bold or coloured text, or printed on coloured paper.”
- “I think that the current list of ‘communication professionals’ is too detailed. I have concerns that many people who are required to record individuals’ needs will not understand the detailed list of different professionals, or know how to arrange for such a specialist to provide support. I think the list should be simplified to include BSL interpreter and deafblind communicator/guide, plus deafblind manual interpreter. I think that there should also be a relay interpreting option (for people who use BSL but also need someone to explain the BSL in easier terms). Also, I think that somewhere the standard should acknowledge that some people will not know what their communication needs are – the standard needs to provide advice on what organisations should do in these instances. For example, I know of someone who was really struggling to understand her consultant, but had not heard of a lip speaker and did not know such a person existed.”
- “The standard needs to try and build in the need for people to check information recorded about individuals’ needs is still correct. It should not be an ‘ask once’ option, people’s needs change.”
- “It is really important to ‘future-proof’ the standard.”

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. Participants then split back into their three groups to discuss four key questions.

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

Group 1 – facilitated by Joanna Ingham

- “If a d/Deaf person has an appointment and an interpreter has been booked, then the appointment is changed by the health care provider, whose responsibility is it to let the interpreter know and rebook them? This might mean that there is a delay.”
- “I think that in urgent care settings there should be staff with basic BSL skills who can support communication with d/Deaf patients until an interpreter can attend.”

Group 2 – facilitated by Sarah Marsay

- “In my view, the phrase ‘as soon as possible’ is not clear. The expectation and timescale needs to be pinned down. ‘As soon as possible’ is potentially an infinite amount of time. It should be clear that we need to get accessible information in advance, but also it needs to be clear that we need to get it sufficiently in advance to be able to read it before we need to make a decision / be informed. For example, if I have an appointment in two months’ time I should not receive the information the day before.”
- “People need to know what to expect in terms of timescales, so they can chase things up if need be.”
- “The lack of some professionals, for example deafblind manual interpreters, is used as an example of a ‘good reason’ for not providing support in a timely manner. However, if it is acknowledged as an issue then I do not think that it is acceptable to just accept that there is a gap – the gap needs to be addressed. In my view, the issue is a lack of support for people to qualify. If the issue has been highlighted, as it has, then the next step is to identify how to tackle the issue. It is not fair just to say it can take extra time for some communication professionals – this is not okay.”
- “In my experience it takes two or three weeks to get an appointment with a BSL interpreter, so the time taken to get a routine appointment is extended. The timescale depends on the situation, for example an acceptable wait would be different for a GP appointment or when going to A&E.”
- “If it is an urgent situation, then I think that the standard should say that it is not acceptable for an organisation to delay getting a BSL interpreter or cause extra delay to a patient receiving care due to their processes, for example because of their procurement processes.”
- “I recognise that there are legal requirements around consent.”
- “I have a concern about emergency admissions to A&E. Although my communication needs are important, I would not want an ambulance not to come for me because there was no communication support in place!”
- “What about capacity issues? How would information in accessible formats be produced? Has any consideration been given to the capacity of NHS

organisations to produce information in alternative formats? This needs to be factored in when determining timescales for delivering information.”

- “There should be different timescales set for different information formats and for different communication types.”

[Facilitators’ prompt, what do people think about remote BSL interpreting?]

- “I have seen it but not used it myself. People I know do not like it as it is not face-to-face, you do not know the person doing the interpreting and there could be problems with different BSL dialects leading to misunderstandings.”
- “I agree, I would not want to use remote BSL.”
- “I have seen some academic research which shows that there are more interpreting errors when BSL is interpreted remotely versus face-to-face BSL interpretation.”

Group 3 – facilitated by Sue Haddock and Kerry Uttley

- “We agree in principle, especially with regard to letters and other regular correspondence.”
- “It could be difficult to avoid a delay when booking professionals, as they might not be available.”
- “It is really important that a person’s confidentiality is respected. It might not be appropriate to send a detailed letter to an outside agency for transcription or reformatting into alternate formats.”
- “The timescale might not be realistic for some formats; there will need to be procedures for staff to follow.”
- “I am concerned that it might be completely unlikely to get the right communication in urgent care situations. We might be setting organisations up to fail.”
- “Who will ask the questions, who will respond to the needs?”
- “Are finance and resources being considered for organisations?”

5. Do you agree with the quality considerations?

Group 1 – facilitated by Joanna Ingham

- “Who is going to make sure that people are producing good information?”
- “Will people have training in how to produce ‘easy read’ information? Will people be consulted before ‘easy read’ information is sent out to make sure it is fit for purpose?”
- Some d/Deaf people in the group did not understand the BSL video on the NHS England website about the accessible information standard.

Group 2 – facilitated by Sarah Marsay

- “Organisations should use the [National Register of Communication Professionals working with Deaf and Deafblind People] NRCPD register to check the qualification of BSL interpreters.”
- “I think it is important that feedback is considered. A d/Deaf person might have a hospital appointment supported by a BSL interpreter – they should be asked for their views on the interpreter and on the experience. There should be a few simple questions asked on a form, this would encourage people to leave feedback. People should be asked for feedback on BSL interpreters, deafblind manual interpreters and advocates.”
- “One issue is in gaining final organisational approval for materials in alternative formats, for example patient information leaflets in easy read. It can be very difficult to get approval to publish, especially clinical input / approval. There should be some advice on processes to be followed.”

Group 3 – facilitated by Sue Haddock and Kerry Uttley

- “Currently it states that BSL interpreters in a health setting should have Level 6, but professionals should also be required to have experience in medical terminology.”
- “Professionals need to know that they have to maintain confidentiality at all times.”
- “I support the idea that patients and people who access social care are involved with checking the quality of formats and support, but I do not like the term “patient groups” as it is too ‘medical’ and I also do not like the term ‘service user’. Maybe you could use ‘user group’ or ‘members of the public who would be using that service’.”
- “I think that the qualification requirements for lipspeakers should be added / included.”

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

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

Group 1 – facilitated by Joanna Ingham

- “I think it will be harder for smaller GP surgeries to implement.”
- “What if people do not implement it, what happens?”
- “Is there any funding available for people to implement it?”
- “What if services or organisations say they cannot afford to implement the standard?”
- “Clinical Commissioning Groups (CCG’s), the Care Quality Commission (CQC), local Healthwatch and service users should all help to enforce the standard.”

- “When is the PLACE [Patient Led Assessments of the Care Environment] programme going to start? It does not seem to be being used in Bradford.”

Group 2 – facilitated by Sarah Marsay

- “What do you see as the role of Local Healthwatch?”
- “The standard should be included in Quality Accounts published by NHS Trusts, Local Healthwatch are required to respond to Quality Accounts prior to publication. It should also be included in the work of the Care Quality Commission (CQC).”
- “I think that a 12 month implementation period will be a challenge. A series of facilitated networking events bringing health and social care organisations into contact with smaller voluntary, user-led and grassroots organisations that could support production of information in alternative formats and communication support would help with implementation of the standard.”
- “Staff working in health and social care settings need to know how to book an interpreter, for example GP practice receptionists, they need to know how to commission an easy read version of a document or BSL translation for example.”
- “The question is, will there be a carrot or a stick to ensure that organisations follow the standard?”
- “My GP refuses to use email or text message to contact me, will this change?”
- “Once the standard is approved and released, say an individual does not get the support they need, where do they complain to?”
- “In my view, it is NHS England’s standard so it is NHS England’s responsibility for making sure that it is followed – it is not up to Local Healthwatch or anyone else to do this.”
- “One option would be for people to complain to PALS [the Patient Advice and Liaison Service], but there are concerns that PALS staff are employed by the NHS and so not impartial.”
- “I think that when the standard is launched NHS England needs to tell the community about what to expect and explain about the complaints procedure if they do not get their needs met. It needs to be meaningful. A culture change is needed, and this can only happen with a meaningful complaints procedure. The information for patients needs to be clear – organisations have 12 months to deliver this, these are your rights under the standard, this is what to do if your needs are not met.”
- “Organisations must have accessible complaints procedures.”
- “The CQC should check that organisations are following the standard.”
- “What about a national media campaign to support the launch of the standard? Information needs to get out to people who do not come to meetings or belong to groups. Will people be sent letters telling them about the standard?”
- “People need to know that the standard is coming.”

Group 3 – facilitated by Sue Haddock and Kerry Uttley

- “I think that 12 months is reasonable for urban hospitals and GPs, but rural settings might not be able to provide some of the communication support professionals listed as they might not be available.”
- “I think that if the implementation period is any longer than 12 months organisations will forget about it until it is too close to the deadline to make a difference.”
- “Organisations report to local Healthwatch and other organisations, so I think that a question should be built into these reports. Perhaps the standard could be included in local Healthwatch “enter and view” reports.”
- “Organisations should be required to report on the standard in any quality reporting that they have to submit.”
- “It is important to be ambitious with the standard. Organisations might not get there within the first year, but we want to describe the ideal situation.”
- “I think that you need to strengthen the sentence, ‘it would be good if they worked with patient groups to do this’ and also it needs to be clear that this covers all organisations and not just hospitals and GPs. Could the standard say something like ‘evidence of working with the public on producing information will be expected’?”
- “I understand the difficulties associated with monitoring compliance with the standard. My suggestion would be that you try to influence / add to questions to existing surveys and quality assessments, for example CQC, Adult Social Care Survey, Carers Surveys, and guidelines for performance-monitoring of commissioned services. It is important to join things up. I also think that there may need to be ‘guide’ questions to support assessment of compliance with the standard – these need to be accessible and surveys should evidence they have reached a diverse population including those with access needs (I recognise the challenges associated with this). Consideration also needs to be given to the role of different groups and organisations in monitoring, for example local Healthwatch could include the standard as part of their ‘enter and view’ visits and there could be a role for Local Health and Wellbeing Boards (LHWBBs). My suggestion would be for an item tabled yearly at meeting of the LHWBB indicating how well both health and social care were performing against the standards and highlighting the gaps and difficulties. Is there something included in the Health and Social Care Act 2012 about compliance?”

Close

Sarah Marsay thanked all of the participants for their contributions and thanked Bradford Talking Media and Bradford Strategic Disability Partnership for hosting the event. The consultation closes on 9th 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 or in an alternative format.