# Making health and social care information accessible

## SignHealth Workshop Bristol 11.02.14 (afternoon session) – Notes

### Introduction

Participants were welcomed to the workshop by facilitator Lynn Stewart-Taylor of SignHealth.

A brief introduction to the ‘making health and social care information accessible’ project was outlined.

Following this the nine participants took part in discussion around their personal experiences and to offer views to shape the standard. All questions and answers were delivered directly in British Sign Language (BSL).

The questions posed were those asked in the ‘making health and social care information accessible – your views’ patient, carer and service user survey.

### Workshop 1 – your experiences

#### Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?

Always = 8 Most of the time = 1

### Comments

* In my experience, there seems to be a lack of d/Deaf awareness from reception staff as well as from medical professionals such as GPs. For example, receptionists do not seem to understand initial requests from d/Deaf people to book an interpreter.
* GPs seem to assume that [all] communication difficulties have been overcome due to the presence of an interpreter.
* GPs often give out written information and documents that are not accessible. There is no support in translating these to BSL, for example from the interpreter or via social services.
* Issues can arise due to the lack of skills or competence of the interpreter. This can lead to the d/Deaf patient not understanding the translation of what the doctor has said.
* I worry that the interpreter has not correctly interpreted what I have said, given the doctor’s response.

#### Do you usually get the communication support you need when you use NHS services?

Always = 1 Sometimes = 6 Not very often = 2

### Comments

* A number of participants shared experiences of requests for an interpreter from the d/Deaf patient not being met. Therefore although they would like to have help via an interpreter this has not happened, sometimes as a result of an interpreter not being booked or not turning up to the assignment.
* I worry that receptionists see me – as a d/Deaf patient – as a ‘problem’ because an interpreter is required for me to access my appointment. I recognise that the process of looking for and booking an interpreter adds to the workload of the receptionist.
* I am frustrated by delays in getting an appointment. It can take two weeks for the interpreter to be booked
* Having to continue with the appointment without an interpreter is very difficult because of the communication barrier between patient and doctor. This creates stress.
* In an emergency it can be difficult for the hospital to source an interpreter.
* An example was shared of an apology being made to a d/Deaf couple because of a complaint made due to lack of access during a medical emergency.
* There seems to be a lack of d/Deaf awareness from GPs and hospital services, for example of the need and importance of ensuring an interpreter is provided. On one occasion I only received partial information about what was happening and what was wrong due to having to rely on short written notes between my partner and the medical professionals.
* It can leave you feeling disempowered. For example because no interpreter was provided at A&E my hearing partner took control of communication with the doctors and relaying the information. Therefore there was no direct contact and dialogue between me [the d/Deaf patient] and the doctor.
* Without an interpreter d/Deaf patients are not able to express themselves in full. I worry that this means I might not be effectively diagnosed by the doctor.
* There can be issues with medication. It is hard to direct questions to a doctor or pharmacist without an interpreter.
* I feel that, because my GP does not take notice of my list of ‘preferred interpreters,’ I have to take responsibility to book the interpreter directly.
* I do not think that doctors giving printouts of information is an acceptable alternative to an interpreter. The information remains inaccessible due the amount of medical jargon.
* I find it difficult when the assumption is made that I can lip-read to access what the doctor says. Also this is not fair as I then have no way to respond to the doctor.

#### Do you usually get information in a format you can understand when you use NHS services?

Not very often = 9

Comments

* I understand some of the information, for example that a medication has been prescribed. However, the details of when to take it are not explained clearly, for example how many times to take the treatment, when to take it, whether it should be taken with food or not.
* Information is often not completely clear, so the d/Deaf patient has to seek clarity.
* In my experience, printouts of information are given but this inaccessible due to the level of English and jargon used. Participants estimated that only 30% of the information given by the doctor is understood by the patient.
* Examples were given of requests for documents to be written in plain English not being met.
* Participants shared accounts of themselves or other d/Deaf patients taking medication ‘blindly’ as they do not know what is in it because it has not been explained in a way that is understandable to them.

#### Do you think there is any information you are missing out on when you use NHS services?

I miss out on most of the information = 9

Comments

* Several participants shared examples of patients having to clarify information with family members after the appointment.
* I had to take information given by my doctor to my workplace interpreter to ask them to translate – I know this is not right, but I felt that this was the only option.
* I often have to check things in a dictionary afterwards or research information online
* A number of participants mentioned that they have to ask others for clarification.
* I go to social services and ask them to explain, but it is not really within their remit. It is very frustrating and upsetting for me.

#### Do you usually get the communication support you need when you use social care services?

I do not use social care services = 9

Comments

* One example given about a participant’s friend who lives in a care home. The first appointment with social services was cancelled and the d/Deaf person had to insist that an interpreter was booked for the rescheduled appointment.
* Participants shared feelings that austerity measures and associated funding cuts are often used as an excuse for services not booking interpreters for meetings with d/Deaf service users.

#### D**o you usually get information in a format you can understand when you use social care services?**

I do not use social care services = 9

Comments

* Although this question was not directly applicable to the participants themselves, examples were given of other d/Deaf people’s experiences, including:
	+ Documents being ‘text heavy’ and therefore not appropriate for d/Deaf people who do not have English as their first language.
	+ Receiving information packs, forms and documents that are technical, not easy to read and difficult to complete.
	+ Situations when interpreters were required and requested but not provided.

#### Do you think there is any information you are missing out on when you use social care services?

Not applicable as the participants do not use social care services.

#### If health and social care organisations always gave you information in a format you could understand and if you always got the support you needed to communicate, what difference would this make to you?

Comments

* When you get the right information and communication support you feel fully satisfied and happier as you have access.
* Having an interpreter lessens the frustration.
* When information is given in the right format my confidence is improved and therefore so is my general state of health without the unnecessary worrying about accessibility issues.
* I think it is really important to have BSL interpreters - it would mean I could go home and switch off, safe in knowledge that I knew what was happening to me and why.
* When receiving letters I try to read the information given to me but cannot understand some of the wording. This means that I have to ask a support worker to explain using clearer and plainer English so that I can access the information.
* I can read a little bit but I like to have an interpreter available too to ensure I understand the nuances in the written English.
* If I had the right information and communication support I would feel more confident in going to the doctors. At the moment I am reluctant to go as I cannot guarantee an interpreter will be there.
* The difference in having good communication support is resolving health issues sooner. I think that this would mean fewer d/Deaf patients would end up in hospital.
* It would mean that you understand things properly rather than just having to put up with not having access.

#### If you have any other comments you would like to make about your experiences of getting the support you need from health and social care organisations, please tell us.

Comments

* Sometimes d/Deaf awareness is needed too as having an interpreter there is not the only solution.
* I would like the opportunity to have a BSL/English Interpreter to interpret for me at appointments plus be available to translate written documents for me.
* Health and social care services could consider making use of remote video relay interpreting services. The NHS could considering signing up for online interpreting, to allow access for d/Deaf patients in emergency situations or for last minute doctor appointments, when an interpreter is not available to attend in person.
* It would be beneficial to the d/Deaf patient to have time with the interpreter after the appointment to reiterate the information in sign language. Or even better there could be a drop in service at the hospital with someone who signs, like an NHS Support Worker so they can explain these things to you.
* The Deaf Health Champions are a good initiative that works well [in the North West SignHealth has advocates supporting patients who are d/Deaf]. They provide information and ensure d/Deaf people are aware of what their rights are – this encourages d/Deaf people to be more confident and aware of what is happening with their health.
* At NHS Walk-In Centres there should be a BSL health point available which is linked in to a live interpreter.
* The idea of having d/Deaf Support workers was favoured by the majority of participants present.
* In an ideal world the doctor would be a fluent BSL user and so appointments could happen directly between patient and doctor in a shared language.

### Workshop 2 – getting the right information and communication support

####  We think that your doctor, care worker or a receptionist at a hospital should ask everyone if they need any support. We want to write a question for them to ask, so that everyone is asked the same. What do you think about the question below?

**“Do you find it difficult or do you need support to see, to hear, to speak, to read or to understand what is being said?” Is this a good question?**

It is really not a good question and should not be used = 9

Comments

* The participants were unanimous in their response to the posed question. They felt that it implied that they had a problem, when the problem is actually that the professionals do not know BSL – this creates the communication barrier with patients.
* It would be better for the question to be simple and straightforward, such as, “Is there anything you need to access your appointment?” Then an interpreter could be requested in response.
* There could be a BSL icon on the desk at reception, something visible so that when the d/Deaf patient arrives it could be pointed at and the receptionist would understand that they are a BSL user.
* There should be a form to indicate d/Deaf / blind communication support needs. A BSL user could state that they are d/Deaf and request an interpreter, support worker, d/Deaf advocate or lip-speaker and include their preferred method of communication. If this is in a user-friendly format, say bullet points, then it can be easily completed and the GP could keep it on record.
* Where I work we have a hospital passport that gives information about how the d/Deaf person would like to communicate with the doctor, their preferred method of communication, for example whether they use finger spelling or BSL.
* A sign language hologram would be amazing.
* When you arrive at the GP surgery, there is sometimes a check-in screen; this could be extended to ask the question of whether the patient needs an interpreter. This system could also be implemented in hospitals.
* Information about patient access needs and preferences (for example a male or female interpreter) should be shared by the GP with the hospital.
* With online booking, it would be nice if the BSL option was available, a patient could request a BSL interpreter, or health support worker.

#### How do you think we should ask people about their information and communication support needs?

Email = 5 Face-to-face = 8 Letter = 5 Online form = 5 Text = 9

Other = 1

Comments

* I think face-to-face is fine, if that person has d/Deaf awareness. They need to know to be clear when a d/Deaf person is trying to lip-read and understand the importance of maintaining eye contact.
* Face-to-face should also include a BSL interpreter.
* Letter – but only if it is in plain English and therefore easy to read.
* Text is good; although I feel text should be a two way option as currently I cannot reply (it says ‘do not reply to this number’).
* An alternative would be a ‘letter’ which has content in BSL format, a DVD which is a translation of the paper letter.

#### What should organisations do to make sure that you can get communication support and information in the right format quickly?

General comments

* If an interpreter not available then a remote video interpreting service is the best option.
* Qualified BSL/English in-house interpreters based in hospitals so that they are always available for d/Deaf patients.
* Some people have suggested a GP surgery that is exclusively for d/Deaf people – although others have said that they would not want this due to privacy concerns.
* Alternatively there could be hubs or particular GP surgeries where d/Deaf people could go for accessible GP appointments.
* Hopefully NHS England could be the change we need for the future and will prioritise communication support and accessible information.
* For emergency situations all participants agreed that services which enabled d/Deaf people to communicate remotely using online platforms / technology and video relay services could be utilised in the interim whilst an interpreter is sought.

Comments on actions which could be taken in advance

* BSL translations of printed documents should be available on DVD for d/Deaf people.
* There could be a website with BSL content so that information is available on a central site.

* I would like to be able to access a fully translated version of the NHS website.
* It would be very useful to have a health app to translate all information in BSL. This could be a national provision, something available to everyone.
* The NHS England website has lots of different illnesses and diseases described - there should be a BSL version of these as well.
* All participants agreed that it would be good to have a website with pictorial information displayed with the function to zoom in and also select the references in simple English and BSL.
* Hearing people have masses of information that they have access to. If we had everything in BSL about how the body works then we would fully understand our health.
* Health announcements, current information, news announcements about pandemics such as bird flu should be sent out in BSL; otherwise the health of d/Deaf people will not be as good as that of hearing people.
* In GP surgeries or in waiting rooms the TV screens should be on a loop with BSL content, it could be with current information, or generic health issues.

Comments on consideration in an emergency situation or late at night

* All staff should be d/Deaf aware and have some knowledge of BSL.
* Staff should know how to book an interpreter quickly for a d/Deaf patient.
* The ambulance should have responsibility for informing A&E that there is a d/Deaf person on the way, rather than waiting until you arrive. This would enable the hospital to be responsive and prepare a video relay, or be sourcing a face-to-face interpreter.
* There should be a way of alerting the hospital that there is a d/Deaf person on route so that the person’s file and communication preferences are immediately accessible to the professionals.
* I would like to think that a doctor could sign, that would be a quick way of explaining things, and they could basically know what was wrong with me. I think that would be important and beneficial to both the patient and the medical professional.
* Paramedics, doctors, nurses and all other medical staff should take some basic sign language training as part of their qualification requirements.
* I think that all ambulance drivers and paramedics should have some basic sign language, as a fundamental aspect of their role and part of their job description.
* All hospital staff should be required to attend a refresher course every year to learn sign language and about how to work with d/Deaf people. I think that this is really important. It should be part of their professional development to have regular tests to keep up their sign language skills.
* Using family members as interpreters is not appropriate, they may not know the medical jargon, they may not interpret properly and they may be selective about what they interpret.

#### Is there anything else that we should think about when finding out about people’s information or communication support needs?

Comments

* There should be an online booking system so that d/Deaf patients can select their communication methods / preferences and trigger a response. For example if a person indicates that they are a BSL user and require an interpreter then at the time of them booking an appointment the surgery / hospital begins the process of booking an interpreter.

#### Is there anything else that we should think about when recording or sharing information about people’s information or communication support needs?

Comments

* Ensure d/Deaf patients’ communication needs and preferences are kept on record and that this information is passed on to wherever the d/Deaf patient is referred to and is flagged up to the next department and / or service.

Close and next steps

The workshop closed with all participants being thanked for participating and sharing their views.

For more information and updates visit [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)