# Making health and social care information accessible

## Sense Workshop London 22.01.14 – Notes

### Introduction

Liz Ball, Campaigns Involvement Officer at Sense, welcomed everyone to the workshop, and a round of introductions followed.

Richard Kramer, Deputy Chief Executive at Sense, highlighted the need to improve deafblind people’s experience of health and care services and improve the provision of accessible information which enabled people to make choices. He pointed out that professionals often talk about ‘hard to reach people’ when really the focus should be on why organisations are ‘hard for people to reach.’

Sarah Marsay, Public Engagement Account Manager at NHS England, welcomed participants to the workshop, and talked through an introduction to the ‘making health and social care information accessible’ project.

A question and answer session followed, with the opportunity for those present to query anything which was unclear or on which they wanted further detail.

Following this, the 6 participants took part in discussions around their personal experiences and to offer views to shape the standard. The workshop was facilitated by Sarah Marsay from NHS England, and Sarah White, Policy Officer (Health) at Sense.

Participants’ comments and queries are noted below.

### Workshop 1 – Discussion about personal experiences

1. **Thinking about when you use NHS or social care services:**
   1. **Do you usually get information in a format you can understand?**
   2. **Do you usually get the communication support you need?**

* I have had a good experience with my doctor’s surgery. I get a taxi to the surgery, the driver takes me to reception then one of the reception staff take me to the waiting room. Then when it is my turn, the doctor takes me to my appointment and when this is over, escorts me back to reception. One of the reception staff will then order me a taxi.
* It is possible to have a good experience with hospital appointments – but only if I am able to contact the organisation beforehand and if they are able to support me with a communicator guide at my appointment. I have been independent for many years but I did not realise how much I was missing out on until I started being supported by a communicator guide. Now, someone from the support organisation can contact the hospital to discuss my needs and get this put in place. This is at no cost to me – the cost is met by the NHS for communication support.
* I have a list of things, but I will pick a few. I do not have any positive experiences at all. I will give an example: at the moment I am going through a section 7 social services assessment. I have being trying to meet with a member of staff for over a year but there have been a number of problems with this. For instance, I requested information before the meeting so that I could read it through and I asked if the timescale / graph could be put into text, however I have not received this yet. I went back and requested the information via email but was told that they could not do this as they were ‘not allowed.’ They eventually agreed that they would give me a memory stick with the information on it, but when I received this a password was required and they still have not given me this. Then I received the password twenty minutes before the meeting – so I could not prepare. This problem is ongoing. Then another meeting was set up but there had been a change in policy – and this was not on the memory stick. They said that they would give me a paper copy but that they would have to remove the names from this. I am still waiting for this. I have been waiting over twelve months for a baseline assessment – there have been financial cuts in social care during this time, but I should have received a care package by now. I will get fewer hours of support now due to the delay – this is not fair. This is still unresolved.
* I have issues with the hospital transport service. The hospital transport service picked me up, this was difficult to arrange as it involved two different care trusts, but the main problem was that although they picked me up they did not provide a communicator guide so they could not communicate with me. This group [hospital transport providers] do not seem to have been targeted for awareness-raising around the need to provide a communicator guide, or more generally about how to make this service accessible.
* On a related issue, some transport services will allow a [guide or assistance] dog, but not a dog and a person. I have been told that this is because space is limited. But I need someone to support me with communication.
* My local hospital tried to resolve problems with communication. I have a medical condition which can need urgent treatment, so I carry information about what to do if my condition deteriorates, for example how to book an interpreter. However, I am lucky if the paramedics look for this information, often it is missed. At my local hospital, I have an agreement and they have a book / file about me so they have information about me and what to do. But in my experience staff do not find it quickly enough so when I am admitted I do not know what the nurses are saying or doing. My major concern is that I have an allergy to latex – staff need to know this before they start any procedure. I panic about this – despite the hospital having this information about me on file. I am not trying to cause trouble; I am trying to save myself from illness or injury. I have had a number of meetings with the hospital but things have not improved. Sometimes I refuse to go to hospital due to my experiences – I feel like I cannot cope with the situation any more.
* My experience is mixed. Most of the time the hospital do not book interpreters, which means I have to arrange and pay for my own interpreters. This is bad enough when I am seen as an outpatient but it is ridiculously expensive if I need an inpatient stay. The hospital booked an interpreter for two hours when I had a week-long stay on the ward. I was only told this two days before I was due to be admitted. I had to rely on colleagues to interpret for me in hospital. This is completely unacceptable. On rare occasions an interpreter is booked, this is often a BSL signer not a deafblind manual interpreter – clearly this is no good for me. When they have booked a deafblind manual interpreter they have not been registered or up to the job – and I have had no assurance of confidentiality. This is also not acceptable. Interpreters must be professional.
* I have also had a good experience with my old GP practice, which was excellent. After my first two appointments, the GP suggested that he would do home visits when I needed to see him so we could use my laptop with its deafblind display. It was his idea and he deserves some credit!
* I almost always get information in print so I cannot read it. This is manageable if it is in a suitable format for scanning, but often it is not. One hospital sends appointment letters out with the date and time highlighted, but this is blanked out when scanned in.
* Braille is my preferred format. Once I received information I had requested in braille so late that I had to rearrange my appointment.
* I have had lots of bad experiences and some positive. When I had my children I had four registered interpreters – this was probably my best experience. When I got my diagnosis, which was a really important thing, I asked for an interpreter and a note taker. It was a three hour consultant meeting but no interpreter or note taker was provided, despite their being eight professionals in the room, and lots of information.
* The interpreter arrived late for an appointment with my daughter, who is five years’ old, and who was going to have an operation. The nurse asked my daughter to interpret for me as the interpreter was late. I refused this.
* Often services do not provide qualified interpreters at appointments. When they do provide an interpreter it can be anyone of the hospital’s choosing. Often I get a male interpreter when I would want a female for a sensitive appointment.
* We received a letter from the hospital which said that they had “tried ‘phoning” my son. He is deaf and it says so on his notes.
* I had an appointment with the nurse at my GP surgery. Afterwards I received an automated telephone call; it was very difficult to understand the voice. I still do not know what the message was. There was no information given to me about the organisation or the appointment. I am likely to miss out on any information from a service which tries to contact me by telephone.
* I receive letters in a format I cannot access, and if I did not have the assistive technology to scan them in I could go to the wrong hospital.
* If you have seen a consultant and you need to make another appointment, they often write the details on small card or they say at the desk that they will send a letter out to you. I carry a large diary with me to write the information down. I feel that services / staff question why I go to appointments on my own. They do not seem to be able to book support for me as I am oral. Services need to look at their processes, for example it took time for my GP surgery to understand that I was not able to use the visual display. They seem to have ‘got it’ now but sometimes they forget and another patient ends up taking me to the room.
* Sensory awareness is needed for staff. I spoke to the practice manager at my GP surgery about this but she said it was not needed as it was ‘just common sense.’ I feel that services are not open to dialogue. They seem to think that if you have a guide dog they can do everything for you!
* I think one problem is that there is no compulsion for GP surgeries to do sensory awareness training, especially when they have lots of other demands on their time. I have never come across a registration form which includes communication needs – there should be a standardised form. At my practice we have a staff member who signs, and a named receptionist for people who need support.
* Deafblind awareness is needed. Some people do not think that they need this, because they do not think that they meet deafblind people. There is a need to change attitudes.
* I have a specific issue with interpreter support – I cannot see interpreters properly if they have dark skin. Clearly this is hard to mention when they are there, but I should be able to request an interpreter that meets my needs. Currently I use fax to communicate, but I know that I need to find an alternative method. It would be much easier if organisations would email me, but my GP practice and my local hospital will not.
* When my husband or children are in hospital it is really hard to contact the professionals involved in their care as they will not allow contact by text message.
* On one occasion an ambulance came to take me to hospital but the paramedic did not read the papers about my deafblindness and how I communicate which were in my bag. He took my glasses off, then took my jumper off and started putting a needle in my arm. I thought I was being assaulted. That is how bad the experience was. But I cannot complain as the complaints procedure is not accessible so the situation has not been resolved or investigated.
* When I was in hospital, there was an alarm system to get a nurse to attend to you, but it rarely seemed to work and I found it hard to get a response. I needed to go to the loo but I was attached to needles and so I could not. In the end I had to text my mother who rang the ward to get them to take me to the loo – my catheter was full. This happened repeatedly. When you have things attached to you and you cannot see what they are you are ‘trapped.’ It is very upsetting.
* It is hard to access A&E – there is often no interpreter and it is very hard to communicate meaningfully with anyone.
* Letters for hospital appointments often say, ‘if you have any difficulties call us’ but telephone is the only option, and I cannot use it.
  1. **Do you think there is any information you are missing out on?**
* Leaflets come through my door, for example with health advice, I would be interested in this, but I live with my [sighted] sister and she throws them away. Sometimes my neighbours talk to me about things they have read.
* I always receive GP or hospital appointment letters in print. My preferred communication format is audio CD or telephone. I do not use email.
* We miss information sent to us as we cannot read it. Some people have scanners or screen readers, I am waiting for a scanner, I have not been able to read anything for about a year.
* We miss out on general information, for example about ‘flu jabs; we just do not get this.
* Hearing and sighted people are passive recipients of information all the time, but deafblind people are not and we have to rely on others to decide if information is important or not.
* It is obvious that screening letters come from a range of different organisations – not necessarily your GP. There should be a system to indicate someone who needs a different format – this could just be mail merge. Computer apps are the future. There is also clearly an issue for people who need information in a foreign language too.
* Sometimes I have been told by other patients in the GP surgery about posters in the waiting area, for example about a flu jab clinic. But I only find out about things like this through word of mouth or from other patients. There should be information about your format needs on your records and this should flag up the need for a discussion about clinics or other things which might be relevant to you.
* The key thing is that I do not know what information is out there. I do not know what I have missed out on. There is so much information and so many situations which we are unaware of – so it is hard to respond to the question. It is easy to say if you do not receive information you are expecting or have requested, for example for a flu jab, but there might be a new support group for my condition – I would not know about it.
* All of the information I receive at home is not in large font so I cannot read it – I miss out on it all.
* Thinking about hospital visits or hospital care, if an interpreter is not arranged I can miss out on very fundamental things. For example, on one occasion I was in hospital overnight with no communication support and the hospital performed an invasive test on me without me understanding what they were doing. It was really frightening. A deafblind person cannot even see what is happening, for example if someone is about to put a needle in your arm.
* During one of my hospital stays I had a colleague visiting to provide communication support; however when they popped out the doctor could not communicate with me at all. Apparently he had said that I could go home but I did not find this out until three hours later.
* If there is no communication support then I have no clue what is going on.
* When you are in hospital you do not know that there is a drink or food on your table – they just put it down. This can mean that I do not eat during my stay.
* When I have been in hospital I too have missed meals, and sometimes missed medication as they put it on the table – I cannot see them. This could slow my recovery.
* One thing we are missing out on is the complaints process – it is not accessible.
* I was given a prescription. I was told how to take the tablets but I only received this information verbally. It is hard to remember all of the detail. All of the written information about medicines is in very small print. I try to talk to the pharmacist but sometimes I cannot remember all of the questions I want to ask. This is a concern – for example I worry about different medications interacting with each other, or with other things I might eat or drink.
* There is some information about medicines online – so you can adjust the font – but not everyone uses the internet, and this information is not personal to you.
* If you ask the pharmacy about how to take your medication they can put this on tape for you, I think.
* You can also miss out on the detail of how to take your medication, for example about the correct way to take particular eye drops.
* If a doctor decides that you need an operation, they do not automatically register that an interpreter is required. This is a big issue.

1. **What difference would it make to you if organisations always gave you information in a format you could understand and if you always got the support you needed to communicate?**

* Less stress.
* Extra independence.
* Everyone wants to be independent, in control, able to self-manage their own conditions.
* Accessible information would mean choice and control, less need to access services, more personal responsibility.
* It would make a big issue a small issue – it would mean equality and respect.
* If I knew I was receiving all the information I needed in a format which was suitable for me, and if I knew that communication support would be there, then when I arrive at a service I would behave in a way which matched their expectations, for example when arriving at hospital for a test. But when I arrive I do not know what to expect and I display my emotions – my upset – this is a response to uncertainty. If I had the right information and communication support it would make the professionals’ jobs easier as problems would be resolved and everything would be much quicker. Deafblind people expect to receive a lower standard at the moment – this is wrong. We expect to go to hospital and have problems. We should expect equality.
* It would mean that I can access the health service and get the treatment I need. Currently I have not been to a GP for over a year and I am not taking my medication as I could not get a GP appointment with an interpreter. I would be able to see my GP when I need to and access treatment when I should be.

### Workshop 2 – Discussion about improvements

1. **How should organisations find out about your information or communication support needs?**

* Services need permission to share people’s information. There should be one piece of paper where all your communication requirements are noted down – and this could be updated. It should be your GP surgery who records the information and shares it with other services with your permission, for example your local hospital. We need to be asked about all of our different types of needs, not just about interpreters, but also lip speaking, clear speech, if we have an assistance dog and so on. There should be a flag on each of these things so that it is highlighted on paper / on the computer.
* If people who are born deafblind then this information should automatically be on their GP records. It is slightly different if it is acquired – but it should still be put on your notes so that you do not have to explain your needs every time you go to hospital.
* When you get an appointment letter it should have a barcode on it which links to information about your communication needs stored somewhere on the system – so you would take your letter with you and staff at the hospital could scan the bar code and this would bring up all your communication and access needs on their screen. Information about your communication needs should be available to all parts of the NHS including A&E.
* On one occasion, I got to the front of a queue of people and spoke to reception staff. It was a sensitive issue but the staff said ‘I’ll ‘phone the support worker’ – they assumed I needed a support worker and breached my privacy. This made me really angry. There should be a way of sensitively asking if I need assistance. They should offer me a private space to discuss my needs – away from reception but with a member of reception staff – they should acknowledge that there is an issue and take simple steps to resolve it.
* Different methods will work for different people. For me, if I get to the face-to-face point it is too late. I need to communicate with services beforehand, preferably by email. Services should not wait until the appointment / I arrive to ask me about my communication needs – and they should not expect me to make a telephone call.
* They should ask at the doctor’s surgery when you arrive at reception. There should be a special screen to check-in. Although this might need to be adapted for people who cannot use a screen.
* Develop an iPhone app where people could log-in, update details about their access needs and get this sent directly to the system or by email to the relevant service.
* Some people might have had a section 7 assessment. The NHS could do something similar and record your communication needs – this would then apply to all medical situations so your access needs would already be known.
* What about an ‘access to health’ scheme, similar to ‘access to work’?
* When you have an assessment there should be money in your personal health budget or similar support package to meet your immediate needs – the idea is to put patients in control. So patients should be able to book their own interpreter and pay for it out of their personal budget. Or there could be a central NHS ‘pot’ to call on and use for this.

1. **What questions should they ask?**

* “What are your communication needs?”
* When you first meet a member of staff, “What can we do to help you?” This question allows people to respond individually, and recognises that their needs may be broader than communications, for example mobility.
* “Do you have any special requirements?” Then there should be a follow-up question to identify what support you need.
* It needs to be an open question. The danger with multiple choice answers is that you can often only choose one box – so I can only select ‘blind’ or ‘deaf’ – I am deafblind. If it cannot be an open question then there needs to be lots of options and multiple selection must be possible.

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

* It should be a seamless service from first point of contact to the end – so the information needs to be provided to the service in the first place.
* Technology is the answer. There should be equality of choice whatever your preferred means of communication. Your preferred format should be recorded, for example email. This information is recorded on forms but it needs to be flagged up, for example if it is ticked that you are severely hearing impaired. The system must pick up on all of the key information recorded on the form.
* The computer screen in your doctor’s surgery should underline your preferred communication format, for example telephone or audio. It is important to recognise that not everyone uses IT.
* I think that there needs to be a change in attitude so people at the reception desk, consultants, and social service staff expect people to have different needs. This is about attitudes and behaving flexibly. Staff should expect to need to do something different. There is a need to go back to initial training, and include diversity training as part of the professional training of all doctors and nurses. Awareness of needs should be embedded.
* The key thing is early training of all medical staff and receptionists. At one university all medical students had to learn British Sign Language (BSL). This is just one example of how awareness can be embedded. This would not meet everyone’s needs but it sets the scene for students around meeting people with different communication needs – it starts the awareness process and the development of the right attitude.
* There should be a minimum of deafblind awareness training as part of professional / clinical training.
* Check if people have anything on their person / in their bag which indicates any communication needs that they have.
* Every organisation, for example every hospital, should have details at hand of a local interpreting service – they should already be prepared so they do not panic when someone arrives. They should have things in place in advance.
* One major issue is that there are only 12 registered deafblind manual interpreters in the UK.
* Services need to know how to get an interpreter, and then get this process underway as soon as possible. They should be flexible and have a print and braille alphabet card, and use people’s own technology to communicate. The message needs to get out that it is okay to be flexible. Often the response is, ‘we are not allowed to use that’ even when using my own technology would enable communication.
* Language based communication might not be possible, but often gesture or objects can be used to gain some understanding of the situation.
* Staff need the confidence to try something different [to communicate] whilst waiting for a properly qualified interpreter to arrive.
* There is a service where you can access a BSL interpreter on screen – this would overcome some of the difficulties in getting an interpreter quickly. It is something I have previously used.
* Service should think about using a remote interpreting service.
* Every hospital should have someone who can communicate with deafblind people, including at the weekend. There should be at least one dedicated member of staff.
* There needs to be deafblind awareness training – having someone on standby 24/7 is not practical.
* There needs to be a team offering support which is available to every hospital – an umbrella organisation for other organisations to call on for urgent help.
* There should be teams in hospitals to support people with communication needs, and staff should be aware of patients with tactile communication needs. There needs to be investment in training of deafblind manual interpreters. There should be a strong training policy and funding to enable staff to expand on their knowledge too – there is a need for specialists.
* A&E departments can be very frustrating for anyone. The extra frustration for deafblind people is that if their partner or support person is not there it is a really confusing environment and not deafblind friendly.

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

* When organisations share information it must be accurate, for example about what type of interpreter or communication support you need. We need to be able to check the information before it is shared.
* Patients need to have the ability to update their information and retrieve it, even if they are classed as ‘case closed’ [by social services].
* I have had an assessment, but because I will not get a local authority service my case has been closed. This means that my details have been deleted and I have to start again from scratch if I go for another assessment.
* Consent is important. Organisations should ask people if their information can be shared. They should also ask before information is deleted or removed.
* I have been to a number of different hospitals for appointments – I do not understand why information cannot be centralised so I do not have to repeat it over and over again. It should be kept centrally. Information should then be shared with other services to support care and treatment – including communication needs.
* Everything some be held centrally. I should be able to access my own information.
* When you get a repeat prescription, you are asked to go back and see your GP after so long, to talk about your medication. Your communication information could be updated at the same time as your Medicines Use Review.
* I have a regular problem when contacting my GP as it is an automated system which is incompatible with Typetalk. So I have to email the practice manager and ask them to book me an appointment. The problem comes when booking an urgent appointment as this process causes a delay. When I go to the GP I am allocated a 10 minute appointment but if you have communication needs you need an extra-long appointment. A good GP recognises this and is accommodating.
* When booking a GP appointment, there should be an online system where you can reserve a longer appointment slot.

Close and next steps

On behalf of NHS England, Sarah Marsay thanked everyone for participating and sharing their views, and thanked Sense for setting up the workshop.

The engagement period will continue until 21 February 2014, providing lots of opportunity for people to have their say. Three surveys aimed at recording views from different individuals and groups, as well as more information and updates are available at [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)

Sarah White thanked everyone for taking part and noted the power of hearing personal experiences first-hand. Liz Ball also passed on her thanks, and added that she hoped to see improvements as a result of the standard. The session was closed by Richard Kramer of Sense.