**Making health and social care information accessible**

**Royal National Institute of Blind People (RNIB) Workshop Wallsend 19.11.13 – Notes**

Introduction

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 8 participants took part in discussion around their personal experiences and to offer views to shape the standard. The workshop was facilitated by Sarah Marsay and Lucy Dixon (RNIB Regional Campaigns Officer, North East).

Workshop 1 – discussion about personal experiences

1. **Thinking about when you use NHS and social care services:**

**a. Do you usually get information in a format you can understand?**

**b. Do you usually get the communication support you need?**

**c. Do you think there is any information you are missing out on**?

Most of the communication received by participants from health and social care organisations was not in the correct format. Examples given included:

* Receipt of letters from the hospital’s eye unit in standard print, despite the patient’s GP being aware of their communication needs when making the referral.
* Repeatedly asking for correspondence in a different format but being passed from department to department without a satisfactory outcome – despite asking for specific correspondence in a specific format, it was not delivered.
* Requesting a telephone call to confirm appointment details, or a letter in Braille, but receiving a letter in standard print and no telephone call.
* Concerns about older people who may not be as comfortable in speaking out about their needs and difficulties.
* Some reminders are better than they used to be, for example text message reminders are really useful.
* My GP is really good; I can telephone for an appointment and receive the results of any tests over the telephone – which is my preferred format.
* With Choose and Book, you only get a short time frame in which to make an appointment following referral, however, this is not possible if the correspondence comes in standard print and you cannot read it.
* Sometimes I arrive at the hospital and there are no records at all.
* At the hospital, I asked for a telephone call rather than a letter, but despite the receptionist recording this, I still received a standard print letter.
* There are problems with the screen in the GP surgery – it displays patients’ names so that they know when it is their turn, but I cannot read it and there is no audio. The receptionist should go over and tell you it is your turn – and not tannoy your name as it is embarrassing when this doesn’t happen to everyone.
* I have missed appointments in the past because I have not known it is my turn, for example if my name appears on the screen and I cannot read it, and there is no member of staff to come and get me. Sometimes other patients have read my name on the screen and, seeing no-one get up, asked ‘is xxx you’?
* I was recently a hospital inpatient and everything was in standard print – correspondence, the menu, all the information about my diagnosis and condition. Plus, I had a joint replacement and I would have liked to be able to feel what was going into my body – as other patients had the chance to see it and ask questions.
* In GP practices, where they have a screen to display your name, a member of staff should come and get you and show you where to go for your appointment, this would support independence.
* Currently my family read all of my mail for me, as it arrives in standard print – I am planning to get a scanner and some software so that my mail can be ‘read’ to me by my computer. This will increase my independence.
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?**
* Confidence
* Confidentiality
* Self-esteem
* Independence
* Respect for my human rights
* Privacy / being able to keep things private
* Improved patient safety

Workshop 2 – discussion about improvements

1. **How should organisations find out about your information or communication support needs?**
* Three ways – face-to-face, telephone and email.
* The information needs to be passed on from your GP.
* Upon registration as blind with your local authority they should signpost you to other health and social care bodies, and notify all agencies that you are blind.
* The GP has the key role – they should make sure that all organisations are aware of your needs.
* On registration with your local authority or GP they should pass this information on to the local hospital and other NHS organisations.
* The information about your needs should be disseminated from the local authority or your GP to adult social care and NHS bodies.
* If you are already registered with the local authority then this dissemination should go from your GP, your communication needs should be linked to your NHS number.
* The local authority should share information about people who are blind with NHS organisations, such as your GP. There would need to be an alternative route for people who are not registered with their local authority too.
* It should start from your GP, via a face-to-face appointment or over the telephone, or via the reception desk.
* Everyone involved in your care should know your communication needs.
* Staff need training in how to ask questions about someone’s communication or information needs, and awareness-raising, I have been asked ‘how bad is your sight?’ when it was not relevant, and also that does not tell you what format works best for me.
* All health and social care staff need to be aware of your needs.
* There should be a standard procedure and a standard question to ask about communication and information needs.
1. **What questions should they ask?**

Suggested questions from participants were:

* Do you have any alternative information requirements?
* Do you have any alternative communication requirements? If so, please state…
* Do you need a format other than standard print?
* How would you like us to communicate with you?

Comments and suggestions from participants were:

* The question should link to other access needs, for example accommodating an assistance dog.
* There needs to be a prompt and then tick box options.
* There is a need for explanation of terms, for example, about what ‘large print’ means.
* There should be a known approach and policy, the involvement of all administrative staff is key.
* It could be linked to the diversity monitoring ‘disability’ question. For example, do you have a disability? Is it sensory?
* If asking people if they are blind and so on, there needs to be a follow-up question and options to record communication support needs. In general, people know if they are blind or partially sighted.
* Organisations need to get the information right at the start, for example when you first register with a GP or attend hospital they should record your needs.
* If your communication or information needs change, you should be able to ring reception and have your records updated.
1. **What should organisations do to make sure that you get communication support and information in the right format quickly?**
* There should be other contact options if you need to be contacted quickly, including telephone, email and text. Many people have assistive technology these days.
* Make all condition / diagnosis / advice leaflets available on the internet so that administrative staff can alter the format and send them out to you.
* There should be a question about your preferred format but also about what your ‘second best’ option is, for example in an emergency.
* Email is good but not everyone has it, and emails can get lost. A telephone call should always be an option.
* There should be follow-up after a telephone call too, and patients should be asked if it is ok to leave an answerphone message or not (for example it may not be private).
* Use text messages.
* There is a need for future-proofing. In 20 years’ time everyone will have a mobile ‘phone and assistive technology. There are currently concerns about older people but this will change.
* There is a scheme where you can buy a basic tablet computer and have it set up with emails, reminders and appointments. It is important to consider new devices.
* The over-arching governing bodies of the NHS need to liaise better with each other and with other agencies such as the Department for Work and Pensions, for example over prescriptions and registrations.
* Some hospitals send out an automatic text message shortly before your appointment.
* Text message is useful.
* The dentist is different again, I am verbally told my appointment, but this is easy to forget.
* Local Healthwatch information should be available in different formats.
* There needs to be an inexpensive way for organisations to provide audio, Braille, large print and other formats in-house. Suggest using e-readers, MP3 players and synthetic speech – as this means that no-one is reading your personal information.
* Need to record if people have technology which can assist them, for example software which converts text into speech on a tablet computer.
* There should be as many options as possible.
* There is a role for NHS England nationally and regionally in making information available in alternative formats.
* There should be guidance for Clinical Commissioning Groups (CCGs) and others about inexpensive options for providing communication support and information in alternative formats, for example working with a local charity or collaborating with the local hospital trust.
* What about parents and carers? It is important to ask them about their information and communication support needs, and to record them appropriately.
1. **Is there anything else that we should think about when recording or sharing information about people’s information or communication support needs?**
* People with learning disabilities need simplified language and no jargon; information should be available in Easy Read.
* Keep communications as simple as possible, get straight to the point.
* Be open to feedback so a patient feels they can say if something’s not working and it can be addressed. Otherwise, your confidence can be knocked and you might not go back to that service.
* Do not ask me about my sight condition when I come to see you about something unrelated.
* Consider availability of prevention information, for example about stopping smoking, for blind and partially sighted people. Often information is in a poster and leaflet format – very visual – so blind and partially sighted people would not even know it was there. Your GP should make such information available, for example if they know you are a smoker, or a receptionist could draw your attention to it. Given the nature of the information you might not ask for it proactively.
* There should be audio information to back-up that presented visually, especially in departments such as audiology.
* When staff come and get you for your appointment, they need to physically come and get you, and show you where to go – not just call your name.
* Could there be a ‘meet and greet’ role in hospitals? This would help with signposting and navigating.
* What about volunteers helping you to navigate in hospital when you cannot see the signs?
* For Out of Hours services, your information needs to be shared via IT, including with walk-in centres.
* Sometimes getting to the right department, to A&E or admitted onto the ward is the hardest part as it is not easy to find where to go. What about talking signage where you press a button and it tells you where to go? Tactile maps would help too.
* There should be a checklist for hospital staff. If you have a patient who is blind or visually impaired, these are the things to do / ask…For example the RNIB has created a checklist. Often staff just do not know what to do, so a checklist would help.
* Improving communication is critical.
* Need to make sure that people know how to complain and what the different stages and processes are, for example the Patient Advice and Liaison Service (PALS), the role of the Care Quality Commission, Local Healthwatch.

Close and next steps

On behalf of NHS England, Sarah Marsay thanked everyone for participating and sharing their views, and thanked the RNIB 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, will be launched shortly.

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