**Making health and social care information accessible**

**Royal National Institute of Blind People (RNIB) Workshop London 27.11.13 – 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. General comments from participants at this stage included:

* Concerns about organisations’ resistance to adopting ‘local good practice’ due to cost.
* NHS England should look at best practice across the country and then decide on what they should recommend or put in place.
* Often, it does not seem to be the system that is the problem, it is the professionals that use the system.
* There should be a standardised format for recording communication needs that aligns across the health and social care system.
* NHS England should take advice from the private sector as some private companies are really accessible.
* Sometimes what the public want (in terms of accessible information) is not going to have a massive cost implication.
* Sometimes looking at electronic or digital ways of communicating is easier and more cost effective than traditional means of communication – but there often seems to be resistance to this, and I am not sure why.
* Many of the ‘check in’ and information systems in GP surgeries cannot be used by people with a visual impairment.
* Information about your information or communication needs should be shared between professionals and organisations where they have a legitimate need to know it.

Following this, the 9 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 Nasser Quhill from NHS England, with support from Dan Pescod and Hugh Huddy from the RNIB. 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?**

Most of the group said ‘no’ categorically. Comments from participants included:

* Very occasional if we do.
* No, more often than not.
* With GP’s yes if you ring them up.
* You do not know when a format is available in the first place.
* My GP will email me when I request it; however certain forms are not accessible online and are only available in hard copy. This is a problem for me because I will need support in completing the hard copy or someone else will need to complete it for me.
* A lot of people do not receive support, particularly people who are not known to social services. There are also those who are known to have a visual impairment but who do not like to trouble the doctor.
* Often organisations have to use agreed suppliers – large companies – for providing alternative formats. But sometimes there are skills in-house, or local organisations are cheaper and more responsive than corporate providers.
* It is a challenge for organisations to convey messages that different people will understand – there is not enough resource to get messages to people with, for example, learning disabilities.
* There needs to be a completely new approach to communication and information provision which incorporates language, clarity and cognition across health and social care.
* GP surgeries do not record what my communication needs are, and if it is recorded this is not transferred to where I am referred.
* No electronic systems are in place, I am reliant on the receptionist to sign me in.
* Are GP’s resourced to meet my communication needs?
* When you go to the hospital, you get a hospital number – details about your communication or information needs should be attached to this, and on the database that GP’s and other practitioners use.
* For every request I make, I always seem to hear the same response….’we haven’t got the resource.’
* As service users we know there is a cost implication, but there are also some cost effective ‘quick wins.’
* Once the national standard is released, what authority will NHS England have to make GP’s and other providers conform?
* It is not easy to meet the needs of people with complex, multiple needs. Their needs will need to be addressed individually.
* It is important to think through the impact of providing different formats. For example, if you have an appointment at the hospital they ask you to bring your appointment letter with you when you attend so that they can log you in. But if I got my letter in the format I wanted – on a CD – it would not do much good if I gave this to the receptionist!
* It is about ‘us’ asking for the information we need, but it is also essential that staff are trained in disability awareness to be able to meet and understand our needs.
* Sometimes correspondence or statements are hand written by professionals, which makes it difficult for other organisations to understand the content and have it reformatted.
* NHS Choices is really good – if information online is given to that standard, then that would be excellent.
* To a screen reader user NHS Choices is really good.
  1. **Do you think there is any information you are missing out on?**
* When I am at a GP practice I cannot read the posters, leaflets and other information advertised, I miss out on health messages.
* There are issues with communication between hospitals and GP practices. Patients very rarely receive any correspondence or communication in terms of referrals or treatment received – which is an information gap. In the event we do get correspondence that is great, but only if it is in a format that we can use.
* I do not understand why communication needs were not taken into account when touch screen systems were introduced into GP practices. For example, mine was installed in 2009 and is not accessible at all.
* Why is there still bad practice in accessible information, when there are so many pockets of good practice?
* Current local GP systems need to reviewed and GP practices should get patients involved in the development of local systems and services.

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?**

* It would help me get to appointments on time.
* It would make navigation easier to new premises that you need to visit, it would also mean that people will be expecting your arrival.
* Effectiveness should be measure through the eyes of the service user – the impact on individuals should be considered. If the right changes are made we would have more energy and more time.
* Remember that blind people cannot see facial information. There is a lack of awareness or ‘sight fascism’…if you do not experience it, you do not value it.
* If service users get information in the right format, it could be the difference between keeping your sight and losing your sight, for example glaucoma patients.
* The Information Standard should also apply to inpatient settings as well as outpatient.
* The right information would give us control and the ability to make the right choices and help us manage our lives…knowledge is power!”
* We need more key workers.

Other comments from participants included:

* Look at the VILD (Visual Impairment and Learning Disability) programme as a model of good practice.
* You cannot legislate for people skills. How do you address the ignorance of many health and care professionals?
* How can I avoid having to tell every individual health professional I meet that I’m blind? I often end up having to wave my white stick!
* Ophthalmologists understand everything that there is to know about eyes, but they often do not seem to have a clue about the practical side of living with blindness.
* Are certain procedures, such as eye tests, really necessary when someone has been blind for 30 years?
* Can there be a stick as well as a carrot? There should be consequences for professionals if they ignore or neglect their duty towards us.
* Do doctors get information via email? If, as I suspect, they do, then why do they not send it to us by email?
* I have not always expected to get access to my information, but now I think is it necessary for me to do so. Will that lead to information overload? The information we receive should be targeted information.
* None of the issues presented today are impossible to address or find a solution for. It is challenging but not impossible to find ways around sharing information for example.
* In terms of patient information, is email procedurally possible?
* There is a need to address problems with communication between professionals in terms of language used and other barriers.
* I think NHS Choices could be used as an example of good practice, it is nicely laid out and easy to navigate.
* When I take my white stick to the hospital it could spread infection – yet no-one has ever asked to clean it or wipe it with the anti-bacterial gel. Also, we often do not know that we should be using the hand gel when we enter wards for example as we cannot see the dispensers and no-one draws it to our attention.
* The system needs to be able to accommodate change.

Workshop 2 – Discussion about improvements

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

* It should be driven by what the patient wants.
* A combination of face-to-face, including asking the patient for consent to disclose access needs to other organisations, and information sharing via email.
* Access and communication needs should be included in referrals and patient records
* Through PPG’s (Patient Participation Groups) and patient networks.
* Include a section on communication needs on GP database systems, so it is on your record.
* There is a need to distinguish between disability and communication needs as the two are sometimes used interchangeably but tell you different things.
* Is there a role for people who are blind or visually impaired to support their own need to access information, for example purchasing a CD player so that they can understand information presented in audio format, rather than be completely reliant on the system to meet their needs? We need to think about what we can do to help ourselves too. Would it be helpful to wear a badge in hospital or have a symbol on our notes to indicate our needs?

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

Suggestions from participants were:

* How do you want to be notified? Then give a choice of a number of options.
* Do you have any communication needs?
* Do not ask, ‘what format do you want?’ as people may not realise that this includes email or text for example.
* A tick box style approach with options would work well.
* Everybody should be asked the same question(s).
* If you do not ask patients about their disability, and someone asked to be communicated with by email, then organisations would not know they were blind and so would not know that they may need other adjustments. This needs to be thought through.

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

* Make use of smart phones and technology including text messages and emails (many blind people have text spoken to them by their mobile devices).
* The use of technology by small companies, for example taxi firms, shows up larger firms. Smaller firms are far more effective and proactive in their approach.
* There is a need for a regional transcription service – somewhere central where the information comes from. Having a regional transcription service may also get over barriers in relation to confidentiality.
* If you use text or email the onus is on the patient to keep their records updated with the healthcare services they access.
* NHS systems should be able to share up-to-date (and updated) patient data to the entire system (one system for all).
* Communication needs should be included in Summary Care Records.
* Colours or symbols should be used to identify your communication need on your folder or records.
* Your communication needs should be discussed and recorded when you first meet your GP or nurse. This information should be recorded on the registration form.
* When you are registered blind (with your local authority), your GP should receive a copy of the statement and this should trigger a review of your communications needs.
* An extra field on patient records should be included to incorporate communication needs, if this section is left blank this should trigger a review (via an alert and prompt).
* Patients should record their condition or disability in their ‘medi-box’ or First Aid ‘message in a bottle’, for example that they are blind. GP’s should automatically give out these boxes to patients with disabilities.
* There should be systems for quick contact via email, text and telephone.
* It is essential to receive and acknowledge the patient once they arrive in the building – so that I know I am in the right place and being attended to.
* Produce a standardised sticker for use on notes to identify communication needs or disability.
* There should be basic staff training and awareness raising around accessibility and supporting disabled patients.
* Simple housekeeping would help – like telling you where the toilets are.
* Staff should act with a little humility and compassion toward our needs. That would make a big difference and it does not cost any money.
* It is about nursing practice. We need a compassionate model of nursing, based on care and common sense.
* The NHS needs to look at our needs and put them in the context of a thousand other needs that staff need to include as part of procedures.
* Does NHS England produce guidance on NHS procedures?
* When a patient is admitted to hospital, staff should ask about sensory impairment or disability, often they do not.
* Whatever questions are asked of patients at the beginning to record their needs must be specific, for example do you have a physical disability, are you blind? Some of the new definitions are confusing.
* Resources still seem to be a problem, in terms of the cost of meeting communications needs.
* Development of mechanisms to share information.
* Put in place ramifications for not adhering to the policy.
* Consider terminology – I do not like being called ‘site impaired,’ I prefer being called blind. I am not even sure what ‘severely sight impaired’ means.
* Build on a patient’s recorded communication need, for example if my communication need says I need audio, it should lead to me being asked if there is anything else I require help with.

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

* If you agree to be referred to other parts of the NHS, then your communication needs should travel with you as part of the referral – it should be seamless.
* Information should be given in a timely fashion and not after the visit.
* Disability awareness training should be given as part of medical training.
* Communicating with social services is difficult because they do not seem to like using email. It should be a requirement for social services to use the communication format suitable for the service user, including email.
* Email may be my preferred format but it does not denote anything – it does not signal communication need on its own.
* Providers need to know minimal print size for anyone who wants print, text or email.
* Patients should have access to NHS secure mail somehow.
* Communication concepts should be built around core communication channels, as a minimum these should be designed around phones.
* You should be allowed more than one communication option.
* Follow the example of banks as they communicate well.
* You should get a text notification to inform that you have received a letter or email, so that you can check you have received the correspondence, and it is in the right format.
* Email or letter as a minimum, just in case one goes missing or does not come through, the other will act as a backup.
* A format, for example, a letter that can be shared is useful as different people will need to see the same information.
* We need a description in text of where they want us to go instead of a map – see also the Department of Transport’s online route planner ‘Transport Direct.’

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, as well as more information and updates are available at [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)