



Making health and social care information accessible

**A report on five national consultation events held with
people with learning disabilities, October 2014**



**Erin Fahey, Shaun Webster, Catherine Carter,
Craig Bricklebank and David Charlton, CHANGE**

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An easy read summary of this report is available.

1. Introduction

NHS England wants to ensure that everyone can understand the information they are given about their health and care. They also want to make sure that everyone is able to be involved in the decision making process about their care as much as possible.

Since spring 2013, NHS England have been working on an 'Accessible Information Standard' which is a framework of requirements and recommendations which all publically funded health and social care organisations will have to follow.

The 'Accessible Information Standard' will tell organisations how they should make sure that patients, service users and carers can understand the information they are given. This includes making sure that people get information in different formats if they need it, for example in large print, braille or easy read. The Standard will also tell organisations how they should make sure that people get any support with communication that they need, for example through having a British Sign Language (BSL) interpreter or an advocate with them.

NHS England wanted to seek as many different views as possible before writing the Standard and last winter invited people to have their say through surveys and a series of workshops. These views and experiences were used to inform the draft 'Accessible Information Standard'.

Before the Standard is finalised, NHS England wanted to know what people thought about the draft and whether any changes or additions should be made.

The consultation phase of the project ran from 13 August until 9 November 2014. All of the views recorded as part of this phase will be used to inform the final Standard, which is due to be published in spring 2015.

Visit www.england.nhs.uk/accessibleinfo for more information.

2. Background information

CHANGE, a leading UK based human rights organisation working to promote the rights of people with learning disabilities, were asked by NHS England to lead on seeking the views of people with learning disabilities on the 'Accessible Information Standard.'

CHANGE ran a series of national focus groups with people with learning disabilities in November and December 2013 to record their views and experiences to inform the draft Standard.

It was agreed by NHS England and CHANGE that the consultation process should take the form of a second round of focus groups in order to provide the most effective opportunities for people with learning disabilities to input their views. Focus groups facilitate people being able to speak out, without the barriers inherent within written surveys.

CHANGE worked with four other user-led organisations across the UK, running in total a set of five focus groups (one was run directly by CHANGE). The choice of groups – based in different parts of the country – enabled a fair cross section of views to be obtained. The organisations involved were:

- Grapevine, Coventry
- CHANGE, Leeds
- Manchester People First, Manchester
- The Elfrida Society, London
- People's Parliament, Darlington Association on Disability, Darlington

Further information about the organisations involved is contained in **Appendix Two**.

Working with known groups was seen as a cost-effective use of resources, as these groups already have established networks of people with learning disabilities who they could readily bring together. It also ensured that those consulted were supported by others who are skilled in advocacy, self-advocacy and empowerment work so that people with learning disabilities were fully able to give their views in a safe and inclusive environment. This process meant that there could be confidence that the feedback obtained was clear, well-informed and reliable. It was also agreed that so far as possible, those involved should have been involved in the original set of focus groups to ensure that the same people were involved from the start to the finish of the consultation process. Visiting two new groups also enabled us to seek fresh ideas and views on the Standard.

3. Overview of work undertaken

In keeping with CHANGE's co-working model, two project workers worked closely together on this project, one person with learning disabilities and one without. This way of working facilitates the maximum involvement of the person with learning disabilities.

Due to availability, four workers with learning disabilities ran the five consultation workshops together with their non-disabled co-worker Erin Fahey as follows:

- Grapevine and CHANGE; David Charlton and Craig Bricklebank.
- Manchester People First and The Elfrida Society; Shaun Webster.
- People's Parliament; Catherine Carter.

CHANGE worked with NHS England to design an easy read consultation document, which sets out the content of the draft Accessible Information Standard including what it is anticipated will and will not be included.

This document was made available online via the NHS England website to accompany an easy read survey for those who wished to take part in this way.

The easy read document formed the basis for the five consultation workshops. CHANGE were provided with a set of comprehensive facilitator notes by NHS England, however having made the initial plans for the running of the groups, it was agreed by the co-workers of CHANGE that the easy read document would be used in the workshops to allow everyone to understand the content and participate fully.

The project workers from CHANGE worked with the partner organisations to set up all the necessary arrangements for the consultation groups. This included liaising with partners to ensure that necessary consent procedures were in place. Each group ran from 10am-2pm or 11am-3pm, with a break for lunch. The project coordinator without learning disabilities recorded as accurately as possible the individual, anonymised comments of focus group attendees. These are included in **Appendix One**.

4. Consultation workshops

Each consultation group followed the same format to ensure that the information presented was consistent between groups.

The agenda included:

- Welcome and ice breaker exercise
- Setting ground rules
- An Introduction to the Draft Accessible Information Standard
 - Introduction to the project
 - Developing the Standard
 - Aim and scope of the Standard
 - How will organisations write down or record people's needs?
- Discussion exercise about the aim and scope of the Standard
- More information about the detail of the draft Standard
 - Will people get information and support quickly?
 - Will accessible information and communication support be good quality?
 - When will organisations have to follow the Standard?
 - How will people know if organisations follow the Standard?
- Discussion exercise about the detail of the Standard
- Summary and next steps

After each group were presented with information about the content of the Standard, they were asked the same seven questions in order to establish their views.

The sessions were interactive and participants reported that they had found them enjoyable. Given the amount of information to be presented about the Draft Standard, it was decided by the co-workers at CHANGE that the seven questions would form a discussion exercise, in order to allow all attendees to participate. The questions put to the groups were as follows:

1. Overall, do you agree with what the Standard is aiming to do?
2. Do you agree with what the Standard includes?
3. What types of information and communication support do you think should be included in the Standard's list?
4. Do you agree with what the Standard says about how quickly people should get accessible information and communication support?
5. Do you agree with the quality considerations?
6. Current plans are that organisations will have 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?

The first three questions were asked to the whole group in the morning session. Each participant was given a voting card to vote whether they agreed or disagreed. Those

who disagreed to each question were then asked for their reasons why, in order to generate further discussion within the group.

In the afternoon, the groups were split into two, with each team being given two questions to discuss. They presented their views on a flipchart and presented these to the whole group for discussion. Splitting the groups into smaller teams enabled those with less confidence to speak in a large group to participate and make their views known.

5. Findings

Throughout all five of the consultation groups there were a number of key themes which were raised by all of the groups. There were particular concerns that many organisations would not properly implement the Standard and there were calls by all of the groups for greater accountability and more robust sanctions for organisations that do not follow the Standard. All groups were also keen for service users to be involved in the quality checking both of the accessible information itself and of the services after the Standard has been implemented.

The key findings of each individual session are included in **Appendix One**. This section attempts to draw together the common themes from across the five sessions, which the participants felt were most important.

Question 1: Overall, do you agree with what the Standard is aiming to do?

All of the participants across the five consultation groups agreed with the overall aim of the Standard. Concerns were raised within some of the groups that the Standard would not be properly implemented by all organisations and they sought reassurance from NHS England that there would be a robust implementation process to make the Standard work.

There was also a concern about the security of people's personal information when shared between organisations. Participants requested that they be able to opt out of information sharing, and also wanted reassurances that their information would be secure when shared.

Question 2: Do you agree with what the Standard includes?

There was agreement across all of the groups that other disabilities and autism should also be included as part of the Standard so that clinicians can have a full picture of the person. The same also went for those lacking capacity which the participants requested also be included.

A common theme throughout all five of the groups was that signage within hospitals and GP surgeries should be included in the Standard. All of the groups were in agreement that signage is often difficult to understand for those who find reading difficult. Participants came up with a number of suggestions for improving signage, including having easy read words in brackets after medical department names, using pictures as well as words and simple colour coding. It was also suggested that guides should be available in all hospitals to assist people in finding the right department.

A number of participants also requested that accessible buildings be part of the Standard.

The issue was also raised around the omission of those whose first language is not English. One particular participant highlighted that some individuals with a learning

disability may require their information in another language but also in easy read and that this should be available if requested.

Question 3: What types of information format and communication support do you think should be included on the Standard's list?

There was a common theme across the groups that there should be a set of rules, or a standard, on how easy read information should look. All organisations should use the same format for their easy read material so that there is a recognised standard across organisations. The groups also felt that organisations should work together with user-led organisations for people with learning disabilities to both quality check and produce their easy read information.

Many individuals raised concerns around the way they are called to appointments. They requested that a number of options be available, such as names on screens, Doctors coming out to collect patients and people being called into their appointment more than once.

All of the groups agreed with the proposals put forward by NHS England as to the types of information format and communication support which will be included on the Standard's list.

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

All groups were of the view that some information should be available immediately and that there should not be a wait for it. This included all easy read information, appointment letters and prescriptions. One participant made the point that just because information is in easy read format does not mean that it is understandable to everyone, and that staff should spend time helping the person to understand the information they have been given.

There was also concern across the groups that information and support would take longer in an emergency, which the groups felt was the most important time for the right information and support to be available.

It was commonly accepted in all of the groups that it was reasonable for support such as advocacy and interpreters to take slightly longer to be available.

Question 5: Do you agree with the quality considerations?

All five groups agreed that those working with people should have the right qualifications, but also the right experience. It was highlighted that an interpreter may have a high level of qualifications, but little experience and so would have difficulty in supporting a person appropriately.

The groups felt that the most important factor in ensuring that the Standard is implemented properly is compulsory training for all staff in communication. They also felt that at least one member of staff in each GP practice should be skilled in supporting people with learning disabilities and mental health conditions.

As set out above, the groups also suggested that all easy read information should be quality checked by people with learning disabilities to ensure it is truly easy read. They also requested a set standard for easy read to ensure consistency across organisations.

Question 6: Current plans are that organisations will have 12 months to implement the Standard. What do you think about this?

This question brought up mixed views across the five groups. It was the general view that the implementation of the Standard should not be rushed. However, all groups were in agreement that some things could be implemented sooner than others, and reasonable adjustments should be made straight away. This included longer appointment times and asking people their needs and how best to support them. All of the participants agreed that in order for easy read information to be of good quality it would take time to produce.

It was suggested that NHS England devise a list of priorities for organisations as to what should be implemented first, giving specific timescales for this.

Question 7: What do you think about plans for making sure that organisations follow the Standard?

All of the groups were concerned that organisations will simply ignore the Standard and not face any sanctions if they do not implement it properly. Participants wanted to see clear sanctions for those who do not follow the Standard. A number of suggestions were made by the groups, including having 'mystery shopper' patients who go into organisations to see if they have implemented the Standard.

It was also suggested that organisations should report to NHS England on a regular basis, and that one person within each organisation should have responsibility for ensuring that the Standard is properly implemented, and be accountable if it is not.

One participant said that the Standard should be given more weighting to ensure that organisations follow it.

6. A final thanks

CHANGE would like to thank the following organisations for working in partnership with us on this project:

- Grapevine
- The Elfrida Society
- Manchester People First
- The People's Parliament

We could not have undertaken this piece of work without your invaluable support and contributions. For further details on these organisations and CHANGE see **Appendix Two**.

Erin Fahey, Shaun Webster, Catherine Carter, Craig Bricklebank and David Charlton

October 2014

Appendix One – Notes from consultations

Notes from Focus Group A held at Grapevine, Coventry on 8 October 2014

Ten participants took part in the Focus Group.



Question/Area	Comments
<p>Question 1</p> <p>Overall, do you agree with what the Standard is aiming to do?</p>	<p>All participants agreed with the overall aim of the Standard, however some made additional comments:</p> <p>“They have got to make it better”</p> <p>“They don’t tell you what they [NHS England] are going to do to make it work”</p> <p>“Need to see the same Doctor more than once to make sure needs are always met”</p> <p>“It is good that everyone will follow the same Standard so that all documents are of the same Standard”</p> <p>“If they stick to it, it will work”</p>
<p>Question 2</p> <p>Do you agree with what the Standard includes?</p>	<p>All participants agreed with what is already included in the Standard.</p> <p>“Using guide dogs should be included in records”</p> <p>“People who can’t make decisions should be included too”</p> <p>“Should include physical disability and/or autism and other needs such as guide dogs so you get the full picture of the person”</p>
<p>Question 3</p> <p>What types of information format and communication support do you think should be included on the Standard’s list?</p>	<p>“Audio format is very important”</p> <p>“Text messages are a good idea”</p> <p>“Easy read letters with bigger print”</p> <p>“Everyone should have a learning disability passport”</p> <p>“Should have rules on easy read to make sure everyone’s easy read information is the same. This should include font size, type face and pictures that match the words”</p>

<p>Question 4</p> <p>Do you agree with what the Standard says about how quickly people should get accessible information and communication support?</p>	<p>“Not good enough to have to wait” “Information should be on hand” “There needs to be more money to make things accessible” “Doctors and Nurses should have training in communication skills”</p>
<p>Question 5</p> <p>Do you agree with the quality considerations?</p>	<p>All agreed communication professionals must have the right qualifications and experience.</p> <p>“Hospital passports need to be good quality to help quality of services” “New staff should have compulsory training”</p>
<p>Question 6</p> <p>Current plans are that organisations will have 12 months to implement the Standard. What do you think about this?</p>	<p>“This is too long to wait” “Will the staff have ‘time’ to follow it” “Will they keep it up?” “Will they just ignore it?” “Should be 6 months for things that cost money and take time” “Reasonable adjustments must be made immediately, such as longer appointments/asking people’s needs”</p>
<p>Question 7</p> <p>What do you think about plans for making sure that organisations follow the Standard?</p>	<p>“NHS England should make a policy to follow” “They should have ‘secret shoppers’ who go in and ask if they do easy read and report it if they don’t” “They should be closed down or get the sack if they don’t follow it”</p>

Key Themes

- Participants agreed that all the things already included in the draft Standard should be included.
- There was a concern amongst participants that staff will make excuses that they do not have the time to put things in place to make their services more accessible.

- The Standard should include people with physical disabilities and autism or other support needs, which should be included so that practitioners can get a full picture of the person.
- Participants felt that they should not have to wait twelve months for some things. Reasonable adjustments should be made immediately such as longer appointment times and asking people's needs.
- All participants thought that easy read information should be available straight away; they should not have to wait for it.
- The participants were also concerned that there is not enough money available to make the Standard work.
- The group felt that organisations should be quality checked by people who the Standard applies to (such as people with learning disabilities).

Notes from Focus Group B held at CHANGE, Leeds on 9 October 2014

Seven participants took part in the Focus Group.



Question/Area	Comments
<p>Question 1</p> <p>Overall, do you agree with what the Standard is aiming to do?</p>	<p>All of the group agreed with what the Standard is aiming to do.</p>
<p>Question 2</p> <p>Do you agree with what the Standard includes?</p>	<p>“Signage in hospitals should also be in easy read”</p> <p>“Tactile signs”</p> <p>“Easy read maps”</p> <p>“Not too high up”</p> <p>“Use easier words and pictures on signs”</p> <p>“Should be assistance from a person to get around a hospital”</p> <p>“Should include websites”</p> <p>“Should include whether lacking capacity”</p> <p>“People whose first language is not English”</p>
<p>Question 3</p> <p>What types of information format and communication support do you think should be included on the Standard’s list?</p>	<p>All agreed with what is already included in the Standard’s list. In addition:</p> <p>“Adjustments in the GP surgery, should have lowered counters and touch screens should be lowered and made easier to use”</p>

<p>Question 4</p> <p>Do you agree with what the Standard says about how quickly people should get accessible information and communication support?</p>	<p>“Should get easy read information at the same time as appointment letter, shouldn’t have to wait”</p> <p>“Should get advocate for all appointments”</p> <p>“Support needs to be in place in case of emergency and when visiting your GP”</p> <p>“1 week seems okay for some things – depends on the information and what’s wrong with you”</p> <p>“1 day/24 hours”</p> <p>“It’s different if need help from your support worker or if you need the NHS to arrange support”</p>
<p>Question 5</p> <p>Do you agree with the quality considerations?</p>	<p>“Compulsory training for staff”</p> <p>“Need to check everything is in the right format”</p> <p>“Privacy is important, for example with interpreters: confidentiality”</p> <p>“Quality checking by people with learning disabilities to make sure easy read is good and all information you need is included”</p> <p>“Have a group of different people to quality check the information”</p> <p>“Specialist agency should be used for advocates”</p> <p>“Advocates should have training and assessments all the time so they’re up to date”</p> <p>“Should work with organisations like CHANGE”</p> <p>“What about self-advocacy and peer to peer support to help people read information?”</p> <p>“What is ‘good quality’? Needs to be more specific and have set standards”</p>
<p>Question 6</p> <p>Current plans are that organisations will have 12 months to implement the Standard. What do you think about this?</p>	<p>“12 months is too short”</p> <p>“Should take it step by step, some things can be done sooner”</p>
<p>Question 7</p> <p>What do you think about plans for making sure that organisations follow the Standard?</p>	<p>“Organisations should be quality checked by people with learning disabilities”</p> <p>“Buildings should be accessible”</p> <p>“Local CCG’s [Clinical Commissioning Groups] should make sure organisations are following the Standard”</p> <p>“GP’s should submit regular reports to show that they’re following the Standard”</p>

Key Themes

- All of the group were keen for hospital and GP signage to be included in the Standard. They suggested that easy read signs should be used; ideas included tactile signs, having easy words in brackets next to the medical name, and using pictures. They also wanted colour-coding and lower signs.
- The group also thought that hospitals should have guides to give assistance to people to get to the right department.
- The group were keen that people with learning disabilities, or those who are included in the Standard, quality check both the easy read information and whether organisations are following the Standard.
- The group also felt there should be a set Standard for what is 'good quality' information.

Notes from Focus Group C held at Manchester People First on 14 October 2014

Twelve participants took part in the Focus Group.



Question/Area	Comments
<p>Question 1</p> <p>Overall, do you agree with what the Standard is aiming to do?</p>	<p>All participants agreed with what the Standard is aiming to do. They felt that longer appointment times would be particularly helpful and that more training generally around mental health and learning disabilities is needed within organisations.</p>
<p>Question 2</p> <p>Do you agree with what the Standard includes?</p>	<p>“Risk assessments should be carried out”</p> <p>“Additional needs should be included”</p> <p>“If English isn’t your first language and you have a learning disability, you would need information to be in easy read in your own language”</p> <p>“Signage should be included, and hospitals should have greeters”</p> <p>“Shouldn’t try to be too clever with signage, for example using lots of different colours”</p> <p>“Easy read maps”</p> <p>“All impairments should be included on file”</p> <p>“Security of information – if sharing [people’s confidential information] services must make sure unauthorised people can’t access it – there needs to be an ‘opt out’ option. Information also needs to be accurate and regularly updated so there are no mistakes”</p> <p>“Health passports should be person owned and regularly updated”</p> <p>“Need a regular update system in place for the patient and their GP”</p> <p>“Needs to be support for people who do not have regular support, for example people who live independently, as they can miss appointments”</p> <p>“Not everyone can access technology”</p> <p>“Everyone could benefit from better information and signage”</p> <p>“More training is needed”</p> <p>“Capacity should be included”</p> <p>“Websites should be included”</p>

	<p>“Help to get to appointments” “Should be accessible facilities”</p>
<p>Question 3</p> <p>What types of information format and communication support do you think should be included on the Standard’s list?</p>	<p>“Buzzers when being called into the GP surgery” “More options to send people out to you” “Letting named carer know someone has been contacted – there should be a note on your records giving permission”</p>
<p>Question 4</p> <p>Do you agree with what the Standard says about how quickly people should get accessible information and communication support?</p>	<p>“May need longer for support workers and advocates, can’t always be available straight away” “Why can’t everything be in easy read? All information should be jargon free” “How will it be funded?” “Easy read should be available for all, all of the time” “Staff need to be better understanding” “Should be available within a few hours” “Some things could happen quicker or straight away, need to spend more time explaining” “Not always understandable just because it is easy read, needs to be explained to people not just handed out”</p>
<p>Question 5</p> <p>Do you agree with the quality considerations?</p>	<p>“Need experience as well as qualifications” “Staff should have training in communication and support needs, including all doctors, nurses and chemists” “Staff should be trained in learning disabilities and mental health” “It should be the patient’s choice who advocates for them, they should have the chance to make the choice independently. Liaison nurses should be used more” “Service user/patient quality checkers – their views should be taken seriously” “Questionnaires asking people what is good quality” “Needs to be more skilled support staff in hospitals”</p>
<p>Question 6</p> <p>Current plans are that organisations will have 12 months to implement the Standard. What do you think about this?</p>	<p>“Can’t be rushed” “All staff have to properly understand it” “12 months is okay for organising the service” “Concern about cost, where will the money come from?” “If it doesn’t work it will be a waste of NHS money” “Some things like longer appointment times could be quicker” “Should get the easy things out of the way first”</p>

<p>Question 7</p> <p>What do you think about plans for making sure that organisations follow the Standard?</p>	<p>“Charities and advocacy groups should keep an eye on it”</p> <p>“Good checking on pilot schemes would help”</p> <p>“Good idea for Healthwatch to report it”</p> <p>“Having an Accessible Communications Policy is a good idea and people with learning disabilities should be involved in writing it”</p> <p>“Organisations should ask for feedback through patient experience”</p> <p>“Ask CQC [the Care Quality Commission] to check accessibility of information as part of the fundamental standards”</p> <p>“Will CHANGE be helping with drafting easy read leaflets?”</p>
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Key Themes

- The group as a whole were concerned that funding was not available to make the Standard a reality and that if funding was not available it would be a waste of NHS money.
- One participant in the group said that everyone would benefit from easy read and more accessible information, not just people with learning disabilities or additional communication needs. The group agreed that accessible information should be available for all, all of the time.
- The group thought that services should be quality checked by patients and that an Accessible Communications Policy should be introduced which is co-written by people with learning disabilities.
- The group also suggested that there should be feedback questionnaires for patients to see how the Standard is working.
- The group requested that signage and accessible buildings also be included as part of the Standard.

Notes from Focus Group D held at The Elfrida Society, London on 15 October 2014

Thirteen participants took part in the Focus Group.



Question/Area	Comments
<p>Question 1</p> <p>Overall, do you agree with what the Standard is aiming to do?</p>	<p>All of the participants agreed with the overall aim of the Standard.</p>
<p>Question 2</p> <p>Do you agree with what the Standard includes?</p>	<p>“Doctors should come and get you from the waiting room” “Should be quicker appointments” [shorter waiting times] “Should introduce sensory devices to call people to appointments” “Should be bigger writing on prescriptions” “The Standard should include private healthcare” “Needs to be confidential” “Should include people whose first language is not English as they may still have a learning disability” “People who lack capacity should be included” “Should include people with other disabilities and support needs” “Should include signage and accessible buildings” “Guides in hospitals”</p>
<p>Question 3</p> <p>What types of information format and communication support do you think should be included on the Standard’s list?</p>	<p>“Number options when calling for appointments can’t be used by people with communication difficulties – could there be a special number they could use?” “Should be longer opening times for phone calls” “More people with learning disabilities should work in health”</p>

<p>Question 4</p> <p>Do you agree with what the Standard says about how quickly people should get accessible information and communication support?</p>	<p>“Easy read should already be there”</p> <p>“Care plans and health plans should be in easy read”</p> <p>“Appointment letters and prescriptions should be accessible all the time”</p> <p>“Being called to appointments should always be accessible”</p> <p>“Staff should always give extra support”</p> <p>“Accessible information and support should be there in an emergency”</p> <p>“Should have a database with everything in one place”</p>
<p>Question 5</p> <p>Do you agree with the quality considerations?</p>	<p>“All interpreters and staff working with disabled people should have DBS [Disclosure and Barring Service] checks”</p> <p>“Advocates should have the experience and the right attitude”</p> <p>“Doctors and medical staff should have communication training”</p> <p>“Should be an agreed set of standards for easy read information”</p> <p>“People with learning disabilities should be involved in checking the quality of services, and get paid for it”</p>
<p>Question 6</p> <p>Current plans are that organisations will have 12 months to implement the Standard. What do you think about this?</p>	<p>Organisations should prioritise the following in less than 12 months:</p> <p>“Clearer and easier ways of making an appointment and rearranging them”</p> <p>“Making sure longer appointments can be made”</p> <p>“Everyone should have a health passport automatically when you join a new GP practice”</p> <p>“Should be easier and simpler to complain about your local GP or hospital”</p> <p>“Need clearer information about an appointment, including reminders such as clear phone call, text messages and informing support workers or advocates when an appointment has been made”</p> <p>“Better signage in hospitals is needed”</p>
<p>Question 7</p> <p>What do you think about plans for making sure that organisations follow the Standard?</p>	<p>“Should have a learning disabilities board which the NHS is accountable to”</p> <p>“Standard needs to be clear so it is accessible for everyone”</p> <p>“More people with learning disabilities need to take part or lead in meetings or training”</p> <p>“Need good communication, updates or a newsletter about progress”</p> <p>“Spot checks or ‘mystery patients’ to see how they are doing”</p> <p>“Support organisations to help each other and share best practice or problems”</p>

Key Themes

- Doctors and medical staff should have communication training as standard.
- There should be an agreed set of standards for easy read information.
- People with learning disabilities should be involving in checking the quality of services and get paid for it.
- There should be a “Learning Disabilities Board” to which the NHS is accountable.
- Organisations should share best practice or problems to support each other.
- The group echoed the views of the Grapevine group that support workers and advocates should be contacted with the patient’s permission to be notified when an appointment has been made to avoid missed appointments.

Notes from Focus Group E held at People’s Parliament, Darlington on 20 October 2014

Eleven participants took part in the Focus Group.



Question/Area	Comments
<p>Question 1</p> <p>Overall, do you agree with what the Standard is aiming to do?</p>	<p>All of the group agreed with the overall aim of the Standard.</p>
<p>Question 2</p> <p>Do you agree with what the Standard includes?</p>	<p>The group agreed with what the Standard includes but felt it should include websites, and the onus should not be on the patient to have to ask for accessible information.</p>
<p>Question 3</p> <p>What types of information format and communication support do you think should be included on the Standard’s list?</p>	<p>“Peer to peer support” “Signs should be more accessible, pictures or easy words next to medical words” “Guides to help you around the hospital” “Should be monitors outside GPs rooms to call people in” “Sign-in screens don’t always work – they should be easier to use” “You should be able use a sign-in screen with your voice” “Should be included in notes how best to call you to appointments e.g. taken to rooms, information about delays” “Different seating sections in A&E depending on what is wrong with you” “Appointments need to be at more convenient times – can’t use bus pass until after 9.30am”</p>

<p>Question 4</p> <p>Do you agree with what the Standard says about how quickly people should get accessible information and communication support?</p>	<p>“Should be more frequently” “Depends how often you see them” “You should get information beforehand over the phone or by email” “Some information should be given straight away such as easy read and large print” “Test results – information should be available straight away to take with you” “The Standard should include more specific timings” “You should get information more than once to make sure people understand the information” “Disabilities team and staff should be trained to work with people to help them understand”</p>
<p>Question 5</p> <p>Do you agree with the quality considerations?</p>	<p>“Person to change jargon and put things into simple words” “Need experience and qualifications” “Peer support/person centred support” “Need to ask the person what works for them” “One GP should be trained in how to support people with disabilities” “Need to be more learning disability liaison nurses to talk you through things like operations” “Need someone with you before and after appointments to help understanding” “Doctors should speak good English and understand disabilities” “Should be told if you’re going to have a change of Doctor”</p>
<p>Question 6</p> <p>Current plans are that organisations will have 12 months to implement the Standard. What do you think about this?</p>	<p>“Should be shorter” “Longer appointment times should be straight away” “The Standard should prioritise what should happen when, some things should be done straight away” “Should have longer to make information accessible” “Communication support should be available sooner than 12 months” “Changing ways of calling you into your appointment should be straightaway. They should call your full name, call you more than once and show you who you are going to see” “12 months is a long time”</p>
<p>Question 7</p> <p>What do you think about plans for making sure that organisations follow the Standard?</p>	<p>“Need quality checkers to see if they are following the Standard” “Should have disciplinary action if not following it” “Named person should be accountable and make sure following Standard” “NHS England and the CQC [Care Quality Commission] should make sure organisations are following the Standard and being punished if not – someone needs to take ownership” “NHS England need to follow up the policy to make sure it happens” “Send questionnaires to patients in easy read format”</p>

	<p>“Needs to be easier to complain” “Should name and shame organisations” “Report to the GMC [the General Medical Council]” “Extra support for organisations, they should support each other” “Groups and charities could help develop training” “More weight should be given to the Standard, then people would stick to it”</p>
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Key Themes

- Participants think that patients should quality check organisations to make sure they are following the Standard.
- The group wanted signage and websites to be included as part of the Standard.
- The group were keen that someone should be accountable for ensuring their organisation follows the Standard. They also wanted NHS England or the CQC to take ownership of making sure organisations are following the Standard.
- One of the group suggested that as part of the Standard, NHS England should prioritise when different things should be introduced, rather than having a 12 month blanket implementation time.
- The group also wanted more learning disability liaison nurses in each area to help people understand medical procedures.

Appendix Two – Organisations involved in the consultation

CHANGE, Leeds

CHANGE is a leading UK based human rights organisation led by Disabled People. CHANGE empowers people with learning disabilities by actively campaigning for equal rights and inclusion. CHANGE undertakes project work on issues that are important to people with learning disabilities such as enabling the transition from childhood to adulthood, promotion of health equality, access to housing and combating hate crime. CHANGE is a fully engaged partner within the Department of Health, NHS England and Public Health England Strategic Partnership Programme with the Health and Care Voluntary Sector. CHANGE delivers training and produces a wide range of accessible information. People with Learning Disabilities are involved in developing every aspect of the work. CHANGE promotes innovative employment models and has experience of employing people with learning disabilities on a proper salary for over 21 years. www.changepeople.org

Grapevine, Coventry

Grapevine helps people with learning disabilities to get the life they want – to make their own choices and be part of the community. Grapevine wants to reduce the isolation that so many people with learning disabilities experience. Grapevine helps people with learning disabilities make connections and have a life in the ordinary world. Grapevine runs a number of different projects, including the “H Team”, who train around 200 health professionals each year. The “H team” were winners of a 2014 NHS England Excellence in Participation Award. www.grapevinecovandwarks.org/

The Elfrida Society, London

The Elfrida Society is a leading charity based in Islington, London, for adults with learning disabilities. The Society’s aim is to make it possible for people with learning disabilities to manage as much of their lives as they want and feel able to. The Elfrida Society has several projects relating to the arts, health, advocacy, sport and parenting support. The access to health project supports adults with learning difficulties to access health services and provides essential support to understand complex conditions or procedures. The project also encourages local health services to become more accessible, through providing health advocacy, information, promotion and training. www.elfrida.com/

Manchester People First, Manchester

Manchester People First was established in 1992 and has over 500 members. Run by learning disabled adults and independent of services, Manchester People First give training and support to learning disabled adults and professionals and campaign for disabled people's rights. Projects include making information accessible, and independently inspecting and quality checking services for adults with learning disabilities across Manchester. <http://www.manpf.org/index.html>

People's Parliament, Darlington Association on Disability, Darlington

The People's Parliament is a user-led group which aims to be a voice for people with a learning impairment in the Darlington area. Using this voice, the People's Parliament tell people and organisations what they really think and feel about local and national issues. Members discuss important issues like health and social care, jobs, housing, anti-social behaviour, training and other issues. The People's Parliament promotes and supports choice, control and independence for people with a learning impairment. The Peoples Parliament also has an active role at Darlington's Learning Disability Network. Darlington Association on Disability supports the group, with the aim that they become fully independent in the future.

<http://www.darlingtondisability.org/dadinformationbooklet/dadinformationbooklet.htm>