Accessible Information Toolkit

A toolkit produced by local Healthwatch, for local Healthwatch

V1: July 2016

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1 Introduction

Welcome to the Accessible Information Toolkit. A toolkit produced by local Healthwatch, for local Healthwatch.

1.1 Who is this toolkit for?

This toolkit has been developed for local Healthwatch.

1.2 Why has it been developed?

A collaborative group of local Healthwatch with a particular interest in accessible information identified a need for more support on this topic.

It has been created to support and inform local Healthwatch activity around the provision of accessible information.

This includes a methodology for undertaking Enter & View visits that support adherence to the Accessible Information Standard.

2 The Accessible Information Standard

People with a disability or sensory loss have rights in relation to the information provided by services. From the 1st August 2016 some organisations must follow the Accessible Information Standard by law.

NHS England have created the Accessible Information Standard which the NHS and adult social care services are legally obliged to meet.

Whilst there are clear benefits to local people of other organisations adopting the standard (e.g. local Healthwatch and children's social care), there is currently no legal requirement for this.

As part of the Accessible Information Standard, organisations that provide NHS or adult social care must do five things.

They must:

- Ask people if they have any information or communication needs, and find out how to meet their needs
- Record those needs in a set way
- Highlight a person's file, so it is clear that they have information or communication needs, and clearly explain how those needs should be met
- Share information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so
- Make sure that people get information in an accessible way and communication support if they need it

"... there are clear benefits for local Healthwatch that adopt the standard ..."

Many of these rights are already enshrined in law. The standard makes these even more explicit, includes guidance for providers and adds a requirement to ask about and record information or communication needs. The existence of the standard also increase awareness of these rights amongst commissioners and providers.

More information about the standard can be found on the NHS England website and is available in the original, easy read, BSL and audio formats.

3 Five reasons to work on accessible information

There are some very good reasons for local Healthwatch to be working on improving the provision of accessible information.

Here are five reasons the collaborative group working on this toolkit felt were particularly important:

Empowering people

Accessible information is, in essence, about empowering people. People need information to make decisions about their health and care services. If an individual does not get information in a way that they can process, they are unlikely to be involved in the services they are accessing.

> "Accessible information… is about empowering people."

Reduce health inequalities

The nature and complexity of some information makes accessibility an issue for everyone. However there are some groups that are particularly disadvantaged by the lack of accessible information and good communication. Removing these barriers by providing accessible information, tailored to specific needs, is a key enabler for people to access health services. By doing this providers will be supporting reductions in health inequalities.

The Confidential Inquiry

The Confidential Inquiry into premature deaths of people with learning disabilities found that men with learning difficulties die on average 13 years sooner than other men; women with learning difficulties die on average 20 years sooner than other women.

Barriers to people with learning difficulties accessing health services include problems with understanding and communicating health needs and failure to make 'reasonable

adjustments' to services so that they can be used easily and effectively by people with learning disabilities.[1]

A shared endeavor

Getting good access to information has emerged as a common theme amongst a collaboration of community, voluntary and faith sector organisations within one local Healthwatch area (VOICE Network in Surrey). This may be a key concern for the beneficiaries of local community and voluntary organisations in other areas.

This topic has the potential to become a shared cause that can bring together disparate groups to work with and advocate the views of local people. Working collaboratively on this issue could be particularly effective at amplifying voices that are seldom heard.

Alignment with Quality Statements

Accessible information contributes to the 'informing people' Quality Statement, developed by the local Healthwatch network and Healthwatch England. Those statements identify the provision of advice and information about access to local care services, enabling choices, as a key part of the local Healthwatch role.

A tested method, delivering impact

An Enter & View methodology developed by local Healthwatch is available (Section 5). It supports the adoption of the Accessible Information Standard and has had demonstrable success in achieving impact for local people.

> "An Enter & View methodology … has had demonstrable success in achieving impact …"

[1] Hoghton, Turner & Hall (October 2012) Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)

4 FAQ's - what local Healthwatch want to know

During the development of this toolkit a number of frequently asked questions have emerged from the local Healthwatch network.

The nine most frequently asked questions have been addressed as directly as possible below for quick reference.

Why is accessible information important?

This is explored in Section 3 of this toolkit 'Five reasons to work on accessible information'.

What can local Healthwatch do to help?

There is no exhaustive list that can be provided; particularly as each local Healthwatch will have its own strengths, activities and focus.

It is clear that through its relationships and presence local Healthwatch is well placed to promote the existence of the Accessible Information Standard amongst people that will use services, commissioners and service providers.

Some local Healthwatch have achieved impact (described in Section 6: Enter & View: Impact on Accessible Information) by undertaking Enter & View visits using the methodology described within this toolkit (Section 5: Enter & View: Accessible Information).

Other local Healthwatch are adopting the Accessible Information Standard in the services that they provide to people.

What is the Accessible Information Standard?

This is explored in Section 4 of this toolkit 'The Accessible Information Standard'

Who does the Accessible Information Standard affect?

All organisations that provide NHS care and / or adult social care must follow the Standard. Commissioners must also support them to comply.

What should people with a disability or sensory loss should do if a provider is not meeting the standard?

Providers have a legal duty to comply with the Standard (section 250 Health and Social Care Act 2012) in full by 31st July 2016, and then ensure ongoing conformance thereafter.

If patients, service users and carers find that NHS provider organisations are not complying with the Standard by failing to meet their accessible information / communication support needs, they should follow the NHS Complaints Procedure.

If the issue concerns a provider of adult social care services, each local authority is responsible for arrangements for dealing with complaints, so people should contact their local authority for a copy of its complaints procedure. Under the statutory complaints system, you should complain to your local authority in writing or verbally to the complaints manager within 12 months. The local authority should acknowledge it has received your complaint within three working days. It will inform you of how long your complaint is likely to take to investigate. The local authority must respond fully within six months, unless a different time period has been discussed and agreed with you.

What has been done to promote the standard?

NHS England published an Implementation Plan and a Communication Plan in July 2015 to support implementation and awareness-raising about the Standard. Activity has included issuing press releases and publishing articles in a range of bulletins, including NHS England's NHS News, the CCG Bulletin and the Foundation Trust newsletter as well as regular social media coverage.

There has also been direct communications to CCGs, NHS Patient and Public Involvement and Communications leads, Directors of Adult Social Services, Commissioning Support Units and members of clinical reference groups (amongst others).

For patients, voluntary and community sector organisations including Action on Hearing Loss, CHANGE, the RNIB, Sense and SignHealth have raised awareness with

their members and networks both nationally and locally. Communications have also taken place with local Healthwatch organisations.

Between January and March 2016, NHS England conducted a series of regional implementation workshops which raised awareness of the Standard and also led to follow-up communications directly to provider and commissioner organisations.

Are service providers and commissioners aware of the Accessible Information Standard?

The majority of providers the collaborative group have engaged with in the course of this project, particularly primary care and adult social care providers, are not aware of the standard; the majority of commissioners are also unaware. This was supported by participants in an Accessible Information Standard workshop at the Healthwatch National Conference in June 2016.

> "NHS England would like to note that in their view many service providers and commissioners are aware of the Standard, and are working towards implementation, although they accept that there are likely to be some gaps at this stage."
>
> Kevin Aston, Project Manager - Accessible Information Standard, NHS England (July 2016)

Does the Accessible Information Standard apply to our local Healthwatch?

There is no legal requirement for local Healthwatch to meet the Accessible Information Standard, although you may consider it good practice and will in any case need to provide your services in a way that is compliant with other disability, discrimination and equalities legislation.

Why carry out an Enter & View focusing on Accessible Information?

The lack of awareness about the Accessible Information Standard identified by local Healthwatch so far in this project, combined with the communications issues faced by some communities, mean that people are unlikely to be aware of their rights. Consequently there is less challenge for providers to meet them. Local Healthwatch can provide this challenge and share good practice through its use of Enter & View by observing, experiencing and hearing from people how providers meet individual communication needs.

5 Enter & View: Accessible Information

An Enter & View methodology has been created, tested and refined during eight Enter & View visits between February and May 2016 by Healthwatch Redbridge, Healthwatch Suffolk and Healthwatch Surrey.

The methodology outlined below should be considered alongside existing guidance provided by Healthwatch England on effective Enter & View and applied in accordance with local policies and guidance e.g. guidance notes for Authorised Representatives (see Resources section 8.4: 'A guide for visiting team members, Healthwatch Surrey').

It is a tool which builds upon existing guidance and which can be tailored to specific needs.

It includes a purpose, strategic drivers and a method including a series of prompts and questions for Authorised Representatives to use during visits.

Whilst is has been informed by the Accessible Information Standard, and seeks to support adherence to that standard, this methodology includes other important accessibility matters that we know are important to people with disabilities and sensory impairments.

> "… a tool which builds upon existing guidance, which can be tailored to specific needs."

5.1 Purpose of the visit

- To engage with people who use the service, and those involved in their care, to understand how their communication needs have been responded to.
- Identify examples of good working practice related to the Accessible Information Standard and communication.
- Observe residents and relatives engaging with the staff and their surroundings.

5.2 Strategic drivers

- Implementation of the NHS Accessible Information Standard
- Seldom heard groups and the way in which they are supported to communicate are of particular interest to local Healthwatch

5.3 Methodology

The visits are announced Enter and View visits.

It is important to consult with local people that have experience of the type of service and/or any specific communication needs you are focusing on in order to tailor your approach to gathering evidence.

Service providers are contacted in advance of the visit to agree the logistics of the visit. At least five working days prior to the visit a final confirmation is sent to the service provider. This will include any materials that the service provider needs to promote the visit amongst people using the service, and their families, as agreed.

The logistics include reaching agreement with a member of the management team at the service provider location, prior to the visit, how the three stages of the visit will be undertaken:

1. **Observation of working practice**
2. **Engaging with Service Users**
3. **Questions for front-line staff**

During this discussion a lead professional is identified to support the visit and the Enter & View Evidence Gathering Tool (Section 8) is shared with the service provider.

Authorised representatives attend a briefing prior to the visit, during which a lead Authorised Representative is identified.

On the day of the visit the lead Authorised Representative and their team seek out the lead professional before speaking to anyone at the service.

The first task is to seek advice on whether anyone using the service should not be approached due to their inability to give informed consent, or due to safety, privacy, dignity or medical reasons.

Initial feedback is provided to the service provider during a meeting with the lead professional at the end of the visit.

5.4 Prompts and questions

Prompts for the Enter & View team

Things to look for:

- Sufficient & clear signage to the premises being visited
- Accessible parking close to the service
- Clear access to main entrance
- Ramp/lift available or working assistance bell
- An appropriate fire alarm system (audio/visual/other)
- Fire exits clearly signed in various formats
- Interaction between staff and service users; are they facing service user whilst talking to them using body language to communicate as well as verbal communication, is plain language used
- Staff treat service users as an individual and address their needs; they aware of how to access assistance in order to make communication easier and clearer
- Staff are easily identifiable; uniforms and name badges
- Good written communication in accessible formats
- Clear legible signs and pictures on bedrooms, lounges, dining rooms, toilets, bathrooms, offices, kitchens, etc.
- Clear legible signs in corridors guiding service users, visitors & staff to different parts of the building
- Complaints/compliments information is available in alternative formats

Questions for representative of the service

- Are residents\carers\next of kin asked about their communication needs when they first arrive at the service?
- How are these needs recorded if they have any?
  - Are they recorded on a database?
  - Are they recorded on care plans?
  - Or any other means?
- Are resident's communication needs 'flagged up' on your system automatically?
  - If yes, what system do you use?

  - If there is no system in place can you explain the reasons for this?
- Is there a process in place to ensure that all staff are aware of the communication needs of the residents before they start to interact with them?
- Please can you provide details of this system?
- What training is provided to support all staff to communicate effectively with the residents? E.g. Deaf awareness training, communication training, dementia awareness, easy read training.
- Is information available in different formats to make it accessible to all residents and are residents aware of this? e.g. large print, Easy read, Braille, Audio.
- How and when would you be able to access BSL (British Sign Language), Signalong (based on BSL) and MAKATON (a language programme using signs and symbols to help people to communicate) interpreters?
- If the next of kin had any communication needs is information provided to them in a format that is accessible to them?

Questions for other members of staff

- Have you been provided with training on how to support residents with sensory impairments & learning disabilities on a day to day basis?
  - Visual impairments: blind & partially sighted
  - Hearing impairments: profoundly deaf & hard of hearing
- How would a resident that has a specific need be identified? i.e had hearing impairments, visual impairments or learning disability?
  - Would it be in care plan
  - Electronic system
  - Sign on bedroom door or unobtrusive signage
- Are you aware of the ways that information could be provided for people with hearing impairments, visual impairments or a learning disability? If yes, what are they?
  - Hearing impairments –British sign language, induction loop, subtitles on TV
  - Visual impairments – Large print or audio
  - Learning disabilities – Easy Read

- If there was an alert (e.g. fire, emergency, announcement) do you know if there is an appropriate method for those with hearing impairments? If yes, what is it? If possible, can you show us?
  - Flashing light
  - Member of staff with responsibility for providing a different cue to an individual
- Has there been a fire drill and if yes, did it flag up any problems?
- Is there anything you would like to share with Healthwatch?

Questions for people using the service

- When you arrived at this service for the first time, were you asked if you had any hearing problems, problems with your sight or needed information in a particular format?
- Do you know if all the staff that interact with you here are aware of your needs?
- Do you feel the care staff here understand how to help you?
- What, if anything can be done to improve the way information is provided to you? i.e large print, audio (spoken/recorded information), easy read
- Is there anything else you would like to talk to us about?

6 Enter & View: Impact on accessible information

From just eight Enter & View visits using this methodology, some significant impact has been achieved.

The Enter & View methodology has been developed drawing upon the experiences of Healthwatch Redbridge, Healthwatch Suffolk and Healthwatch Surrey visiting the following locations:

- North Middlesex University Emergency Department, Thursday 18th February 2016
- Whipps Cross University Emergency Department, Wednesday 2nd March 2016
- Royal Free Hospital Emergency Department, Monday 14th March 2016
- Homerton University Hospital, Thursday 17th March 2016
- Newham Hospital Outpatient Department, Friday 18th March 2016
- Worplesdon View Care Home, Surrey, Thursday 24th March 2016
- Cranleigh Medical Centre, Surrey, Friday April 15th 2016
- Hazeldell Care Home, Suffolk, 27th May 2016

These visits have led to the publication of eight Enter & View Reports which have been shared with the providers, commissioners and Care Quality Commission.

A total of 54 recommendations have been made, which have influenced a number of changes in practice.

Focus on: Whipps Cross University Emergency Department, Wednesday 2nd March 2016

The visit undertaken by Authorised Representatives at Healthwatch Redbridge to Whipps Cross in March achieved some particularly positive outcomes. Some key findings and the provider's response to these are highlighted below.

- Written information available in the ED is in standard format. There isn't any information available in large print, braille or audio. The Practice Development Nurse was not aware of Accessible Information Standard.

Trust Response

Bart's Health has procured Hero Docs via EnabledCity (http://enabledcity.com/) which is a product that acts as a national repository for Easy Read Information (particularly aimed at people with a Learning Disability, although not exclusively so). This development by EnabledCity is being supported by NHS England. The repository is still being developed and Trusts or public bodies who have bought in are able to deposit easy read material they have developed, and take out any information, and utilise this in their own organisations.

The easy read material covers anyone with an impairment or disability who have communication needs and is able to improve communication with a lot of our patients.

This is currently a work in progress as the repository is still being developed.

- Staff said that they usually write things down. The Authorised Representatives mentioned the importance of having an interpreter during an appointment because some deaf people might not be able to understand the clinical information, as English isn't their first language. Staff said that "they have never come across a deaf person who cannot read".

Trust Response

The reception staff have access to interpreting services. The Trust will ensure that all staff are aware of this service and it is utilised fully. The Trust will monitor and audit usage of this service periodically and take remedial actions as required. The Trust will review usage of interpreting services annually and is happy to share the information with Healthwatch.

- Signage from the main hospital to the emergency department (ED) was poor and confusing.

Trust Response

This is an issue that the Trust is aware about. A working group has been set up to look at signage across the hospital including A&E.

Although patients and carers are part of the working group; no members have a sensory impairment or learning disability. The Trust is working towards rectifying this to ensure full inclusion.

It is envisaged that the scoping exercise and implementation plan will be completed by end of September 2016.

- There is an 'A&E X-ray' sign that doesn't state that it is a staff only entrance. We asked a porter who told us the passageway was for staff. We continued down the corridor on his instruction and the visually impaired Authorised Representatives had difficulty seeing the archway signs for A&E. They also found it difficult to identify the stairwell that led outside to the street. The sign was considered too low as someone could be standing in front of it. Luckily a volunteer was posted at the top of the stairs and directed us.

Trust Response

Until the work on redesigning signage has been completed, the Trust are using the volunteers to provide support to patients and visitors in directing them to the correct place. We anticipate this work to be completed by the end of the summer 2016.

All of the visits generated a commitment to change and positive comments from the providers involved.

"Master copy of resident literature is in 14 font and all future documents will be printed in this font."

"Following your visit we have already purchased three BSL symbol books which will be held in reception, majors and our clinical decision unit, but available to all staff."

"…thank you for highlighting this, I think we have been able to take the system further."

"…we have asked a patient to test [induction loop system] regularly for us. We have also purchased an addition mobile induction loop unit… added larger posters with the logo on … We will also add the loop system logo and information onto [waiting room] screens…"

"…read through the report and found it very positive. Thank you."

7 Next steps

The role of local Healthwatch around accessible information will continue to develop as people share their views and experiences on the way local services communicate with them.

This toolkit provides a footing from which to begin local discussions and activity on improving the accessibility of information for people. The experiences, views and knowledge of the 152 local Healthwatch will provide a rich source of expertise from which to further develop this and other support tools.

A number of recommendations follow which seek to further support local Healthwatch to be able to make a difference locally on the accessible information:

- Healthwatch England to promote the existence of this toolkit
- Local Healthwatch to share examples of work on accessible information via Yammer
- Local Healthwatch to share their experiences of using this toolkit via Yammer
- Healthwatch Redbridge to provide leadership for further development of this toolkit
- Healthwatch England to investigate governance arrangements for local Healthwatch toolkits

8 Resources

8.1 Health inequalities

Confidential Inquiry LD link: https://www.youtube.com/watch?v=hQXzcDbaVxc

8.2 Accessible Information Standard - for patients

A short overview: https://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-upd-er-july-15.pdf

8.3 Accessible Information Standard - resources for professionals

Resources available from NHS England:
https://www.england.nhs.uk/ourwork/patients/accessibleinfo/resources/

E-learning module (open access): http://www.e-lfh.org.uk/programmes/accessible-information-standard/open-access-sessions/

8.4 Enter & View: Accessible information visit tools

E&V - Focus on accessible information - Report template

E&V - Focus on accessible information - Prompts and Evidence Gathering

E&V - A guide for visiting team members

8.5 Enter & View: Accessible information report examples

Worplesdon View Care Home, Surrey:
http://www.healthwatchsurrey.co.uk/sites/default/files/uploads/worplesdon_view_-_accessible_information_-_2016.pdf

Cranleigh Medical Practice, Surrey:
http://www.healthwatchsurrey.co.uk/sites/default/files/uploads/visit_to_cranleigh_medical_practice_2016_-_accessible_information.pdf

Chestnuts Care Home, Redbridge
http://healthwatchredbridge.co.uk/sites/default/files/chestnuts_care_home.pdf

Cranvale Care Home, Redbridge:
http://healthwatchredbridge.co.uk/sites/default/files/cranvale_care_home.pdf

8.6 Further information on communication methods

People with dual sensory impairments:
https://www.sense.org.uk/content/methods-communicating-people-who-are-deafblind

9 Appendix 1: How has it been developed?

Healthwatch Surrey led a collaborative group of local Healthwatch to develop this toolkit.

The local Healthwatch that developed this toolkit are:

- Healthwatch Bristol
- Healthwatch Redbridge
- Healthwatch Suffolk
- Healthwatch Surrey

A significant contribution has been made by volunteers and community groups within these localities during conversations, meetings and events initiated by Healthwatch.

The toolkit has also received support from NHS England, Healthwatch England, The Alzheimer's Society, Surrey Coalition of Disabled People, Sight for Surrey, NHS Coastal West Sussex CCGs, Barchester Healthcare and Cranleigh Medical Practice.

The collaborative group provided opportunities for every local Healthwatch to be involved and benefited from the contribution of twenty four local Healthwatch via a consultation and a workshop at the Healthwatch England national conference.

A total of nine Enter & View visits were undertaken using the methodology at different services including GP services, Care Homes and Hospitals (Outpatient and A&E).

10 Appendix 2: You said, we did – involving the Healthwatch network

Twenty four local Healthwatch participated in the consultation which was a critical contribution to developing the toolkit.

A number of changes have been made as a result of involving the local Healthwatch network through the consultation and through a workshop hosted by Healthwatch Surrey at the networks annual conference.

These include:

You said	We did
The way you have used images in the toolkit is not appropriate for people with visual impairments	We spoke to people with visual impairments who confirmed the text was difficult to read with the photo. This has been amended.
More guidance is needed about how services ask people with additional communication needs what support they need	This feedback has been passed to NHS England.
None of our providers or commissioners are aware of the Accessible Information Standard	This feedback has been passed to NHS England.
Accessible information and plain English is for everyone	The wording in parts of the toolkit has been updated to reflect this.
What about braille on medication instructions from pharmacies?	The methodology remains generic enough to be applicable across service locations. We have updated the methodology to include involvement with users when planning visits in order tailor specific Enter & View programmes.
What about people with dual sensory impairments?	This toolkit now includes reference to resources that support communication with people that have a dual sensory impairment.
You could include more examples and questions for Authorised Representatives	We have sought to strike a balance between a number of competing priorities when deciding the structure of the tool.

Too many prompts and questions	These include; clear guidance required for lay people, diversity of needs, reasonable visit times for volunteers and providers, translating observations/conversations into clear and compelling reports for providers. Whilst the method has achieved positive results, we recognise that the structure will need to be refined as it is tested in more areas, service locations and with different Enter & View teams.
On page 11 I think the 'with your consent' will confuse people	We have updated the wording and tested this with Authorised Representatives.
Is it worth asking whether services have an induction loop for hearing aids and whether this is operational and promoted	We have now included this as a prompt.
We've heard people missing appointments because they don't hear their name being called. Do we need to include something that looks at alternative ways of alerting people with, say, a hearing impairment	We have now included this as a prompt.

In addition to these contributions, the consultation provided an opportunity to identify the appetite amongst local Healthwatch for undertaking activity on accessible information and their associated support needs.

Of the 17 local Healthwatch that participated in Healthwatch Surrey's workshop on the Accessible Information Standard at the networks national conference, the majority (12) intended to carry out Enter & View visits looking at accessibility of information in the next 12 months, all (17) 'believe there is a need for support tools to deliver effective Enter & View' however only six 'currently have all the support tools' they need to deliver the Enter & View programmes they have planned.