healthwatch Cambridgeshire healthwatch Peterborough

Accessible Information Standard

People's experiences of obtaining accessible information from local NHS Services

Peterborough: Part I

2017

About Us

Healthwatch Cambridgeshire & Peterborough***** are an independent consumer champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

We find out what people want from health and care services and advocate for services that work for local communities. We also act as the eyes and ears on the ground, listening to what people think and say about local health and social care services. We use the information and our statutory powers to ensure the voice of the public is strengthened and heard by those who design, commission, deliver and regulate health and care services.

Contents

*   This project commenced October 2016. Healthwatch Cambridgeshire and Healthwatch Peterborough merged 1 April 2017.

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Key Findings

- There are low levels of public awareness of the NHS Accessible Information Standard, and the benefits it provides service users with a sensory and/or learning disability.

- People with a sensory and communication impairment are getting some level of accessible information support, but not everyone is getting this support and even those getting some support are not getting all the support they need.

- The lowest level of provision was identified within GP practices. However further research is required to confirm this finding.

- The most popular resource needed was an advocate. However, our findings show this is mostly provided by family members or support workers, rather than through NHS providers.

- People with a sensory and communication impairment highly value accessible information services when they are in place.

- Telephone calls and emails to patients have improved communication to this group of service users regarding appointment dates/reminders.

- Staff attitudes are positive but training should be offered to frontline NHS staff, to increase public awareness and take up of this service.

- Communication between NHS providers could be better, to ensure service user requirements are captured and shared.

- Healthwatch can use its statutory 'Enter and View' tool to ensure NHS providers are complying with AIS.

Throughout this project, Healthwatch Peterborough has been actively promoting and supporting use of Assessible Information Standards at events, within our work streams, and with key stakeholders and local health leaders.

Understanding the issue

The Accessible Information Standard was introduced by NHS England to "make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand and with support so they can communicate effectively with health and social care services.

The standard was introduced after a confidential inquiry into premature deaths of people with learning disabilities (CIPOLD[1]) was undertaken in 2013. This inquiry showed that there was a further need to:

"identify people with learning disabilities in a healthcare setting, and to record, implement and audit the provision of 'reasonable adjustments' to avoid serious disadvantage[2]".

In July 2015, the Accessible Information Standard (AIS) was approved to ensure people with a disability, impairment or sensory loss can access information and communicate effectively with health and care services.

The AIS is important because it aims to reduce the disparity between care provided to people without any disabilities and people with sensory and communication impairment.

This document looks at what local people with sensory and communication impairments in Peterborough have been saying to us about their experiences over the last eight months. It contains information gathered by Healthwatch

Health and social care providers were given a year to implement the new standard and have been legally required to follow the AIS from 1 August 2016

Cambridgeshire & Peterborough after the implementation of the AIS. More intelligence is being shared with us all the time and we will actively pursue this. We hope this report provides a useful insight to local commissioners and service providers.

What we did in brief

A survey was produced to find out people's view (**appendix 1**) and we have incorporated the views of 35 individuals with a sensory or communication disability collected from eight engagement events and presentations. We gained cooperation from five organisations who support relevant service users, distributing and promoting the survey to their client group.

The 15 Step Challenge at Peterborough City Hospital (PCH) incorporated the AIS for the first time, following a request from Healthwatch Peterborough, using the Healthwatch England AIS toolkit.

For the full report on this event see **appendix 2.**

Healthwatch Peterborough also carried out an observational review at PCH around the level of promotional material on display.

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[1] https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/finalreportexecsum.pdf

[2] https://www.england.nhs.uk/ourwork/accessibleinfo/

What people told us

The disabilities stated by those surveyed were: learning disability, visual impairment, blind, deaf, hard of hearing and deafblind.
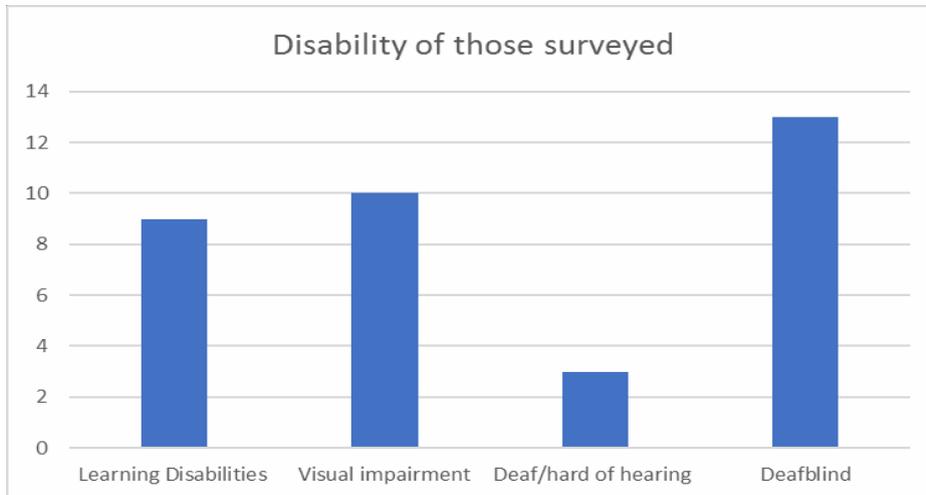

Chart 1.1 data from those surveyed about their relevant disability

Most people surveyed did not know about the AIS and had not been asked by an NHS service about their access and communication needs.

However, some people reported accessible information/communication support was available in the form of phone calls/text messages/Large Print letters and advocates.

Within GP services 29% of people reported they did get accessible information and communication support whilst 71% said they did not.

Within dental practices 36% of people reported they did get accessible information and communication support whilst 63% said they did not.

Within optician services 41% of people reported they did get accessible information and communication support whilst 58% said they did not.
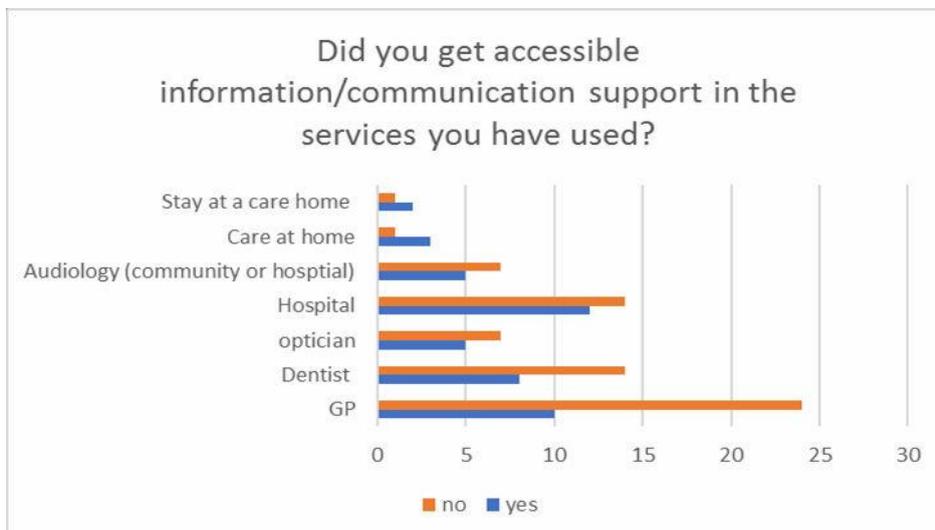

Chart 1.2 shows where those surveyed received, or did not receive, appropriate support when accessing a range of NHS provisions.

Within hospital services, including departments/wards and clinics, almost half of those surveyed reported getting accessible information and communication support.

One surprising finding was that only 41% of people reported they received accessible information and communication support from their audiology department.
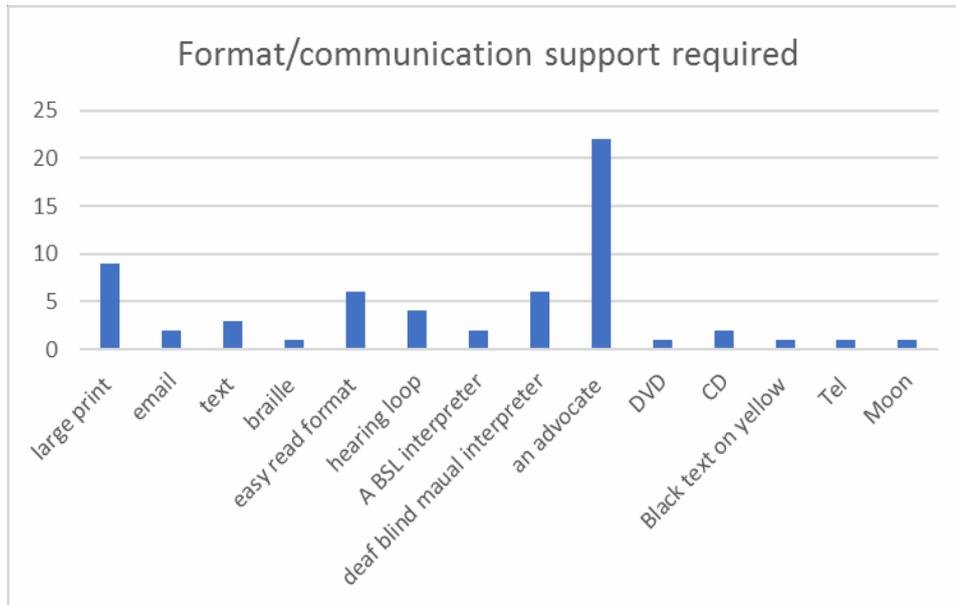

Chart 1.3 shows wide range of formats and/or communication support required by respondents to understand information given to them (total is greater than the 35 surveys completed, as some people used more than one support format).

An advocate was clearly the form of support required by the greatest number of respondents. However, it should be pointed out, that nearly all of those who identified advocates as a communication need said they were provided by either a family member or as part of their personal support/care package. Advocates were not usually provided by the NHS. Further investigation is needed to confirm this finding.

Large print letters (font size 14 and above) was also a popular need (15%), followed by easy read format (10%) and Deafblind manual interpreters (10%)

The percentage of BSL interpreters, identified as a requirement, was low, (3%) this reflects the people surveyed, rather than the real need for this support. Further engagement with Deaf and deafblind people could therefore be undertaken.

15 people surveyed identified two communication needs (e.g. a written format and a verbal communication need).

Five people identified three communication needs (e.g. a written format, an advocate and an interpreter). This was related to their complex communication needs and can be attributed to people who are either deafblind or have a LD.

Signposting and Information Officer, Heather Lord communicated with many of those surveyed using deafblind manual (pictured).
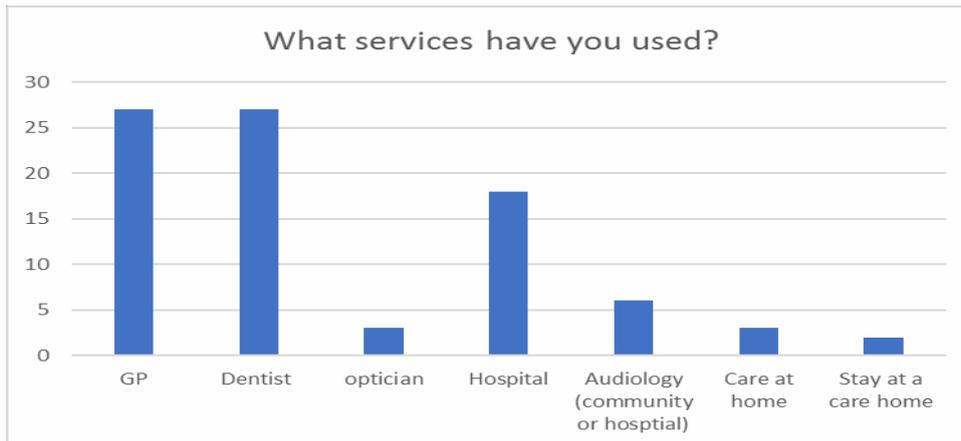
What services have you used?

Chart 1.4 Highlights the range of local NHS services that those surveyed have accessed (note: more than one option could be selected by those surveyed).

Comments from people surveyed

From people who require a hearing loop: 'I do ask a lot questions and ad lib - sometimes I get things wrong but I am getting better.'

'My husband can't hear things very well even with his hearing aids he misses things, I always go with him.'

From people who require easy read format: 'I don't like it if I can't read things for myself. My dentist and Optician phone me when I have an appointment.'

'I get frustrated when communication doesn't work. Easy read format and an advocate would help as I don't get to know people properly'

From people who require an advocate: 'I have a learning disability and require text messages, easy read and an advocate. I get an advocate from the Volunteer Centre, I find this very useful, it kept me calm when I had to have an injection, I can't always understand things. I get phone calls from the hospital when I need an appointment.'

'I am visually impaired and I would like an advocate – I could then hear it more than one time so I know what is going on.'

'My son acts as my advocate and reads my letters for me.'

'I always have to have a family member or my support worker with me.'

From people who require a BSL interpreter: 'I have had to wait longer for appointments until a BSL interpreter can do my appointment. Having an interpreter explaining results has helped me.'

> *'I need Large print and an advocate, it is an invasion of my privacy not to have these services. I feel odd and left out. If they were provided I would get more privacy and independence.'*

From people who require large print: 'It is a relief to be able to read things for myself otherwise my daughter has to read this information for me.'

Other evidence collected
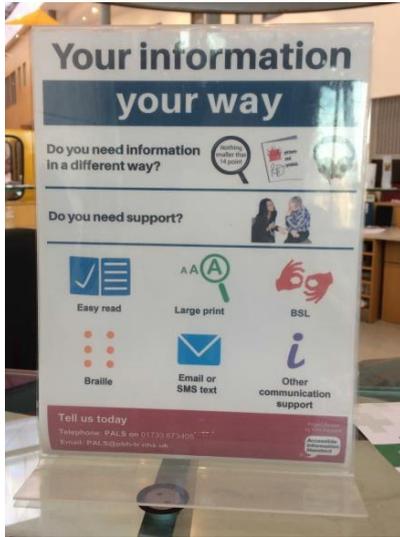
Peterborough City Hospital (PCH) has publicised information on the AIS with posters in the main reception/in lifts and in clinics and on the PALS desk (pictured).

Following a request from Healthwatch Peterborough to undertake a review of AIS provision at PCH, the Trust agreed to include an adapted survey as part of their 15 Step Challenge in October 2016.

Healthwatch Peterborough's findings:

Identification of needs: NHS services are required to ask people if they have any information and/or communication needs, and find out how to meet their needs - we were told this is being undertaken and there was some evidence to support this – but consistency/reliability/understanding of information made be an issue.

Recording of needs: NHS services should do this in an agreed way – we were told the information is recorded in a set way – but this was not the case on the Pipa Boards. We would expect both verbal and written communication needs to be recorded – this needs to be verified.

Flagging of needs: NHS services are required to highlight needs on a person's file, so it is clear to staff that they have information and/or communication needs, it should also clearly explain how those needs should be met –we were told this information was kept on page 3 of the Pas/E-track system – we questioned whether this was a 'visible' position and felt consideration should be given to putting this on page1. Inconsistencies in the use of symbols/understanding were evident on the wards we visited.

Sharing of needs: NHS services are required share information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so - there was some evidence that some sharing of information goes on i.e. between GPs and the hospital but again consistency was an issue.

Meeting of needs: NHS services are required to make sure that people get information in an accessible way and communication support if they need it. - we could not verify this as the service users identified were too ill to speak to us.

Note: The data from the 15 Step Challenge activity was collated from a very small cohort. The full report appears in **appendix 2.**

What should happen now?

It is evident from the comments made, that providing accessible information is of value to and valued by disabled people. It is also evident where it is not provided both communication and understanding is reduced, and that family members play a vital role in supporting people with sensory and learning disabilities by filling the gaps in service provision.

Most of the experiences shared by local people suggest the standards are not well known about. We recommend NHS providers look at both, levels of promotion and effectiveness.

Consideration could be given to more specific training to ensure front line staff, can talk confidently and knowledgably about the AIS. This would also improve implementation.

Healthwatch Cambridgeshire & Peterborough will review undertaking a follow up 15 Step Challenge including the AIS and report back on their findings.

Healthwatch Cambridgeshire & Peterborough will undertake a number of Enter & View visits to GP practices in the coming year. These will include questions on accessible information. The finding will be shared with the service providers with recommendations on improvements where appropriate.

We would also recommend ongoing/periodic peer reviews/self-assessment that could be prioritised within existing work schedules, where appropriate, for the leads for Equality & Diversity. This should include an assessment of the implementation process in line with the five requirements of AIS.

A review of the impact of how well AIS has been integrated, and is being delivered, across Cambridgeshire and Peterborough.

Background

In reflection of local data on those with a communication disability, Healthwatch Peterborough proposed to review the implementation of AIS with local NHS providers.

In October 2016 Healthwatch Peterborough adapted the 15 Step Challenge survey to cover the five key requirements of AIS. This survey was used, with support from Peterborough City Hospital, to review current implementation, with a view to make recommendations and return to evaluate improvements where needed.

In January 2017 Healthwatch Peterborough created a survey to establish AIS implementation and understanding in the community. In February 2017, in conjunction with Healthwatch Cambridgeshire, a joint survey was approved to use at public engagement events. This survey would increase awareness of the accessible information services now available to people with a sensory and learning disability and to find out what difference it is making to their experience of health and care services. And finally, to find out how it was being introduced at a local level across health and social services.

Healthwatch Peterborough wanted to include the views of those people the AIS is aimed at supporting. We therefore identified the following key service users, and user groups, to engage with in order to provide a focus for the work and make it meaningful:

People who have a learning disability or visual impairment or who are blind, deaf, hard of hearing or deafblind.

Thank you

Firstly, we would like to give special thanks to those service users and their carers and/or family members who completed our survey and provided us with a wealth of information and experience as feedback.

Healthwatch Peterborough were grateful for the opportunities to attend the following events and stakeholder Boards; making presentations on AIS and utilising the survey to establish people's views on the issue:

- Peterborough City Council Learning Disability Partnership Board (LDPB)
- Peterborough City Council Carers Partnership Board
- Peterborough Association for the Blind
- Deafblind UK's Rainbow Club
- Two Hampton Disability & Community events organised by Inspire Peterborough
- Two Peterborough City Hospital engagement events, run in conjunction with Healthwatch Lincolnshire

Many thanks to the following organisations who circulated the surveys for distribution:

Appendices

Appendix 1

Accessible Information Standard
Survey – 2017

In July 2016, a new Accessible Information Standard was introduced across the NHS and Adult Social Care. This means that people with a disability, impairment or sensory loss should get information in a way they can access and understand, and any communication support that they need. This applies to patients, service users, their carers and parents.

This survey aims to:

- Make you aware of the changes that are taking place

- Find out what difference it is making to your experiences of health and care services

- Find out how it is being introduced across health and social care services locally

All answers are completely anonymous.

You can find out more about the Accessible Information Standard at: https://www.england.nhs.uk/ourwork/accessibleinfo/

If you want to tell us more about your experiences of health and care services, or find out more about your local Healthwatch please contact us:

Healthwatch Cambridgeshire www.healthwatchcambridgeshire.co.uk
    Tel: 01480 420628 (for residents who live in Cambridgeshire).

    Healthwatch Peterborough www.healthwatchpeterborough.co.uk
    Tel: 03451 20 20 64 (for residents who live in Peterborough).

If you live in another county simply look up Healthwatch plus the name of your county.

    Please provide your email if you would like to sign up for our respective
    e-newsletter:

    Your email:
    _____

If you have not used any health or care services since August 2016, then you do not need to continue with the survey.

If you have, then please carry on with the questions.

Accessible Information
Standard Survey - 2017

1. Do you need information in an accessible format or communication support?

   ☐ Yes   ☐ No

2. What format/communication support do you require?

☐ Large print (font size 14 and above) ☐ Email   ☐ Text ☐ Braille
☐ Easy read format   ☐ Hearing loop   ☐ A BSL interpreter
☐ Deafblind manual Interpreter ☐ An advocate   ☐ Other

If 'other' please state what it is.

> [blank box]

3. What services have you used since the beginning of August 2016?

☐ GP surgery   ☐ Dentist   ☐ Optician   ☐ Hospital

☐ Audiology (community or hospital) ☐ Care at home

☐ Stayed in a care home   ☐ Other

Please tell us the name of the services you have used, for example, which hospital department/clinic or which GP surgery?

> [blank box]

4. Did you get accessible information/communication support in each service you have used?

	Yes	No
GP Surgery (name)		
Dentist		
Optician		
Hospital (dept/clinic)		
Audiology (hospital/community)		
Care at home		
Stayed in a care home		
Other (please state)		
Other (please state)		

5. Can you give a recent example of where **NOT** getting the information in an accessible format or communication support you need has been a problem?

6. Can you give a recent example of where getting the information in an accessible format or communication support you need has made your health/care experience better?

7. What county do you live in? _____

8. What is the first part of your postcode? (eg PE1/CB1)

_____

Thank you for completing this survey.

Appendix 2

The 15 Step Challenge including the AIS at PCH was held on 3rd October 2016: Prepared By HL

Whilst the 15 step challenge was very much led by PCH team including a well organised presentation by Jo Bennis. I think it is fair to say that the Accessible Information Standard was identified as being supported by Healthwatch Peterborough.

The questions were devising by HW P from the AIS toolkit and the 15 Step Challenge toolkit. In this way, we were able to follow the format of the 15 Step Challenge but introduce issues relating to the AIS.

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.

The 15 step Challenge questions covered the following headings;

- Welcoming
- Safe
- Caring and Involving
- Well organised and calm

We looked to ask questions from the following people;

- Representatives of the service; We spoke to Lesley and Natalie
- Other members of staff; We spoke to a lead nurse on each of the Units visited
- People using the service; We were not able to speak to any service users (see note below)

Note: On each unit an appropriate person was identified – ie a partially sighted person and a person with hearing loss. However medically they were not well enough to speak to us. So the information on AIS was not verified by people who use the service.

The team asked to consider this issue consisted of;

- Lesley Crosby –Deputy Chief Nurse
- **Natalie Craner, Equality and Disability Advisor**
- Peter Smith – volunteer from HW Lincs
- Heather Lord – Signposting and Information Officer

We were taken to the
- Cardiac Ward
- Ward A15 – short stay surgery ward

Overview;
Awareness: Staff identified VI, HI without difficulty, dementia was included as was mental health, however LD and D/B were not – and staff had to be prompted. But staff did have a good understanding of what needed to be done to assist these people.
Training: We were told induction training included reference to these topics. And annual training also includes refreshers on these areas. We felt the information on what to do to support people was born out of experience rather than training although there was no proof of this it was rather

the manner in which staff explained issues – rather slow with prompts required. – scrutiny of the induction and annual training packages would verify this.

Recording of information: was included on the PAS system, E-track, Pipa Boards (magnetic Boards on the patients beds – symbols used to identify different impairments/disabilities) and in 'hand-overs', admissions process and 'passport information' for People with LD found on lockers/in Notes. Comments were made about the reliability of this information. 'our information is only as good as that provided by GPs'. We felt there were issues relating to accessibility and understanding of symbols used on the Pipa boards. One member of staff was not familiar with the symbol for LD although the Chief Nurse informed us that all staff were familiar with this. Ward A15, the short stay surgery ward only had Mobility/HI symbols available. We felt this was an area that required more scrutiny (we would have like to look at the PAS/E-track system) and was an area for improvement.

With regard to the five AIS referred to above I would make the following comments;

1. Ask people if they have any information or communication needs, and find out how to meet their needs- *we were told this is being undertaken and there was some evidence to support this- but consistency/reliability /understanding of information may be an issue*.

2. Record those needs in a set way –*we were told the information is recorded in a set way – but this was not the case on the Pipa Boards*. ***We would expect both verbal and written communication needs to be recorded – this needs to be verified.***

3. 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 –*we were told this information was kept on page 3 of the Pas/E-track system – we questioned whether this was a 'visible' position and felt consideration should be given to putting this on page1.Inconsitanccies on use of symbols /understanding were evident on the wards we visited*.

4. Share information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so- *there was some evidence that some sharing of information goes on ie between GPs and Hospital but again consistency was an issue*.

5. Make sure that people get information in an accessible way and communication support if they need it.- *we could not verify this with patients as we did not speak to any service users*.

Note; please be aware this is information was collected form a very small cohort -we visited two wards and spoke to four people –No service users were included.