

healthwatch

South Tyneside



Check the Pulse

The accessible information standard two years on...

Healthwatch South Tyneside September 2018

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Healthwatch South Tyneside – who we are, what we do:

Healthwatch South Tyneside (HWST) is one of 148 local Healthwatch organisations across England launched in April 2013 to give users of health and social care services a powerful voice.

As set out in the Health and Social Care Act of 2012, HWST has the following statutory activities:

- Promoting and supporting the involvement of local people in the commissioning, the provision and scrutiny of local care services.
- Enabling local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved
- Obtaining the views of local people regarding their need for, and experiences of, local care services and importantly to make these views known
- Making reports and recommendations about how local care services could or ought to be improved
- Providing advice and information about access to local care services so choices can be made about local care services; and
- Formulating views on the standard of provision and whether and how the local care services could and ought to be improved.

As an independent Community Interest Company (CIC), it is a dedicated consumer champion, working with users of local National Health Service (NHS) and social care services to hear about their experiences, identify any issues or problems and help generate improvements. HWST has the power to enter and view services; can influence how services are set up and commissioned by having a seat on the local Health and Wellbeing Board (HWB); and provide information, advice and support about local services. It can also produce reports which influence the way services are designed and delivered and shares information and recommendations to Healthwatch England (HWE) and the Care Quality Commission (CQC).

Context

The Accessible Information Standard (AIS) was implemented by NHS England in 2016 under Section 250 of the Health and Social Care Act 2012 and strengthens The Care Act 2014 & The Equalities Act 2010 regarding reasonable adjustments, accessible information and advice for individuals who have a learning disability, sensory impairment or sensory loss. It requires information to be available in alternative ways, for them to understand what is being said and to communicate their needs.

There are five steps professionals must follow to ensure the AIS is applied properly, and by imbedding these five steps into working practice empowers patients to take control and make informed decisions over their own lives more effectively because they have information delivered in the appropriate way. If patients are able to understand what is being said because they have been provided with the right kind of resources to meet their needs, trust can be established between patient and practitioner.

The 5 steps that must be followed are:

1. **Identify** by asking all patients if they have understanding and/or communication need(s)
2. **Record** what the communication needs are to ensure they are met
3. **Flag** the communication needs so that this is highlighted as soon as their file is opened both electronically or paper formats
4. **Share** an individual's communication needs – with consent from the individual
5. **Meet** the communicational needs appropriately and continuously with all interaction, correspondence and also at appointments, planning in advance if necessary

For the standard to work efficiently information needs to be offered in a variety of alternative formats and according to NHS England *'individuals should be able to contact or make contact, receive information in formats they can read and understand, be provided with support from an interpreter within appointments, get support to communicate their needs better through use of hearing aids for example...'* As a minimum, individuals should have two options or ways in which they can identify or explain their needs: face to face conversation in a private room; or an online/paper

form or similar document. One of these methods is likely to be suitable for many people, particularly if relevant members of staff have had appropriate awareness training in supporting people with communication needs' (NHS England: 2016).

Rationale

The purpose of this report is to determine whether the delivery of accessible information from health and social care providers to patient's who resided within South Tyneside is coherent and sufficient. This research was undertaken after a telephone call made to HWST by a member of the public who actively supports her neighbour by reading aloud his written correspondence from his hospital and GP surgery, as he is unable to do so independently. She questioned the barriers she faced when asking for correspondence that would empower her neighbour to understand and communicate independently.

An initial telephone request to the surgery was made but the patient's neighbour was advised this may not be possible with their IT equipment. A follow-up conversation led to the GP practice secretary reluctantly re-doing the letter in a larger font but stating that further correspondence would not be in Large Print. A signed letter asking for Large Print in future was then delivered to the surgery. Another request to a different member of reception staff resulted in a similar uncertainty but eventually the difficulty was resolved. The decision to contact HWST arose after his neighbour felt uncomfortable reading private and confidential information within the letters, due to the sometimes-personal nature of what was enclosed.

HWST were able to advise his neighbour that the surgery should be listening to his requests and delivering information in the format he required to understand what is being said and to communicate his needs. Following our conversation his neighbour contacted the GP practice again and reiterated what we had advised. The GP practice now have an 'on screen' alert and provide information in large print although there are still problems with other health departments.

When further referrals for the patient were made, for example to X-Ray or other departments in the health service, his neighbour reports that correspondence/ appointment letters are also not in Large Print. The patient has communication difficulties after having a stroke and is not able to relay his requests for Large Print by telephone. This adds to the frustration suffered with his speech problems. The

Patient's neighbour reports that happily, following a verbal request, the patient's prescribing pharmacy now ensure the patient gets information in Large Print.

Following on from the above, HWST wanted to design an online survey and try to make it as user friendly as possible for individuals who may have had a sight impairment but wanted to participate and share their experiences of health and social care services. We did this by taking guidance from the following websites; NHS England and RNIB and liaised with Bliss-ability, Sight Service and Your Voice Counts (YVC). Following the guidance HWST found we needed to change our own font colour, font and font size to 18 Arial and keep the wording left aligned. Furthermore, the background colour was changed to support those who may have had a sight impairment and also included an optional box for participants to share their views and experiences at the end of the survey.

HWST delivered a group session with individuals from Your Voice Counts, a local advocacy charity for adults with learning disabilities, who welcomed this survey, with staff supporting members of the group they answered the questions and shared their experiences of accessible information. HWST also received feedback from individuals who attend The Deaf Club in South Shields after holding a presentation and having the support of a British Sign Language (BSL) interpreter from Northern Sign.

HWST promoted the survey through Health-Net, Sight Service, South Tyneside Talking Newspaper, and by distribution of email to organisations and groups across South Tyneside; advertising a direct link to SurveyMonkey from our HWST Twitter, Facebook, website and word of mouth.

Findings

This survey was undertaken to identify whether residents of South Tyneside are receiving information that meets their communicational needs and if so, how satisfied individuals are with the process of receiving their information. Analysing the respondent's comments there seems to be a recurring feeling of frustration because of:

1. having to either repeatedly request correspondence to be delivered in alternative formats or
2. because their communication needs have not been recorded or shared with other professionals accordingly.

HWST also identified within the responses that respondents appear to depend on family members, carers and/or neighbours to communicate their confidential information because they are not currently receiving information in a way that meets their understanding and communication needs.

Complications that may arise of relying on others could be: -

- a) information may be misinterpreted by the reader (for example not regarded as urgent)
- b) correspondence opened too late resulting in missed appointment or health needs not being met appropriately at that point in time, leading to further related health problems that could have been prevented
- c) the pressures placed on the carers, family members or neighbours to undertake this role and relaying personal information that they may find upsetting or uncomfortable.

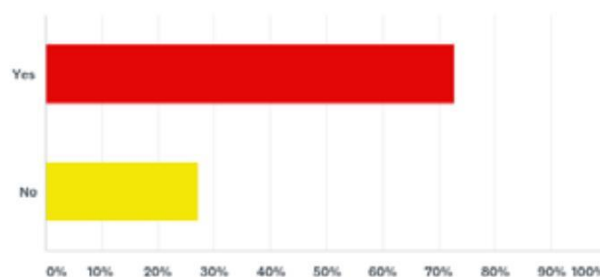
The survey identified not all health and social care providers within South Tyneside are following the AIS as they must legally adhere to; HWST can only speculate whether this is due to lack of awareness, lack of staff training or due to financial costs. However, by not complying with the standard and failing to follow the five steps of recording and sharing information to support patients' needs, service providers are in breach of the standard and can be penalised.

This report has also identified there are numerous individuals living in South Tyneside who have a hidden disability. This is particular true for the ageing population whose

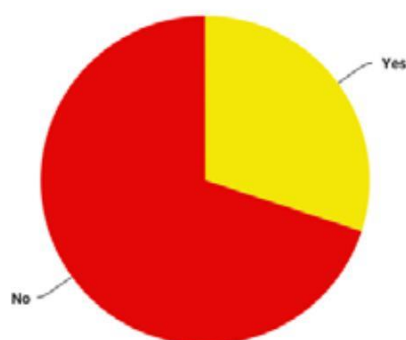
eyesight and hearing begin to deteriorate over time and although this may seem acceptable among society, record keeping must be updated regularly and the questions asked in a way that they are understood to ensure adjustments are recorded.

Survey questions and results

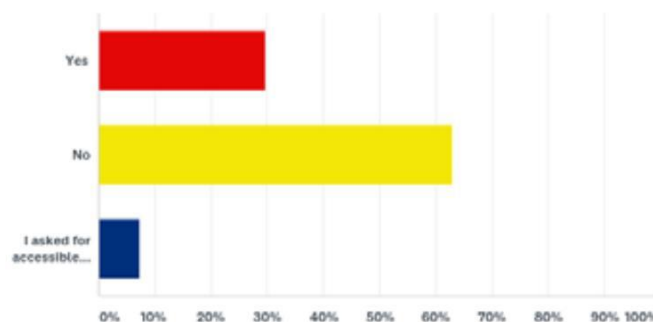
Q1 Do you need information to be delivered in a way to understand what is being said and to communicate your needs? For example; large print, braille, audio, British sign language or easy read format, access to an interpreter.



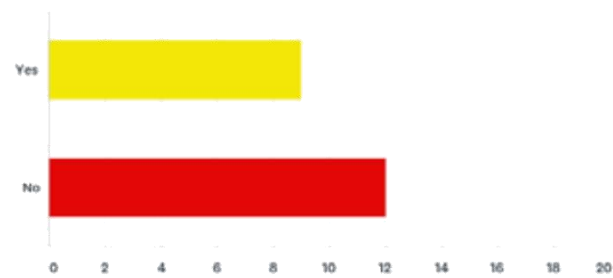
Q2 Do you receive accessible information?



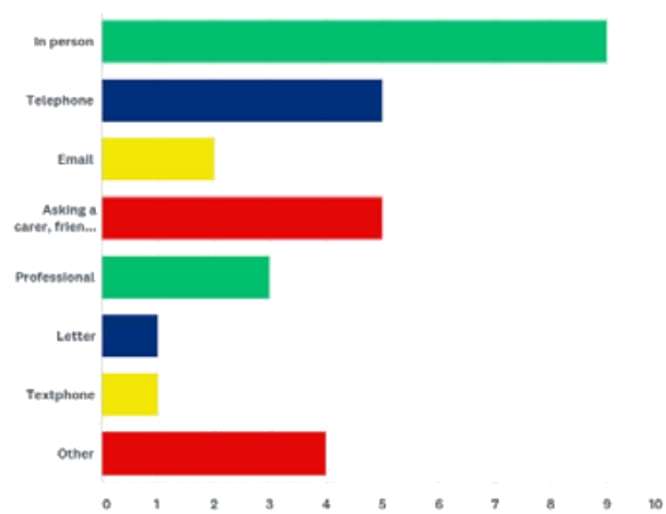
Q3 Did your G.P or local health and social care service ask if you needed accessible information?



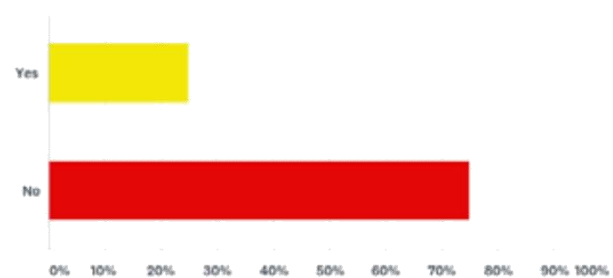
Q4 Has your request for accessible information been easy?



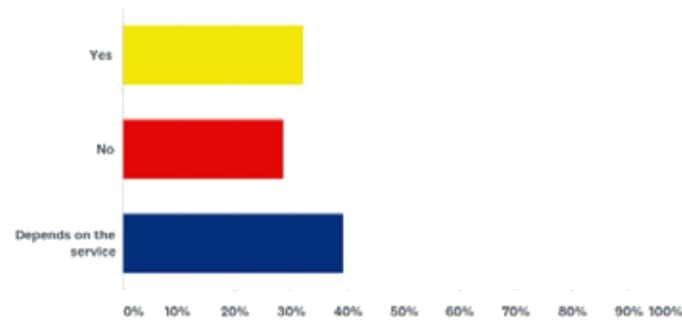
Q5 How did you ask for accessible information? (if applicable)



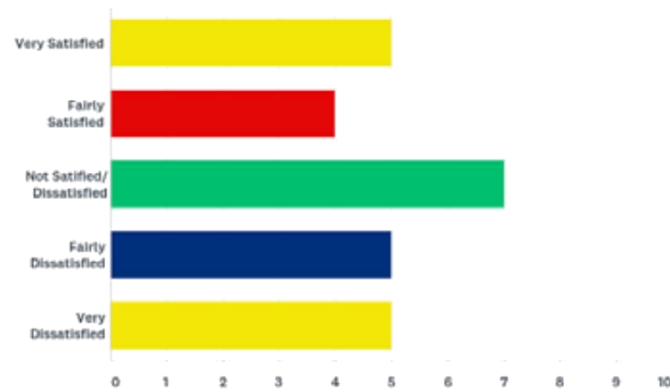
Q6 Has your request for accessible information been shared with other healthcare services you access?



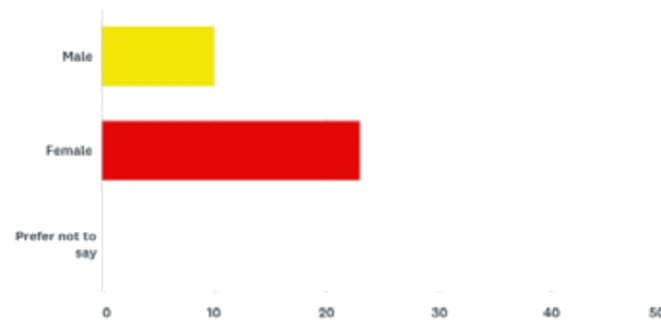
Q7 Do you now receive information in a way you can understand and communicate your needs?



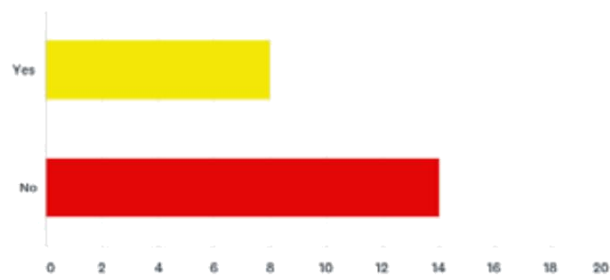
Q8 Overall how satisfied are you with your request for accessible information?



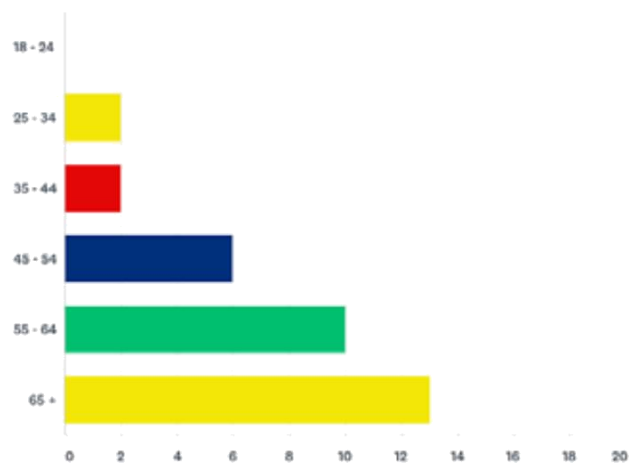
Q9 What is your gender?



Q10 Did you need support to answer this survey?



Q11 What is your age?



Q12 What is your postcode?

NE32_{NE31} NE34 NE33

Respondents' comments

"I have not been asked or requested accessible information - I would like to have been as I find normal print difficult"

"Can the information I gave at my assessment of needs not be used across the local authority departments automatically?"

"All needs met (Not sure if alternative information is shared?)"

"I haven't (asked) because I can manage" (Requires large print)

"I have not asked (for A.I) My husband reads all of my correspondence"

"I have not requested any other format than the usual - but I need to"

"Have not requested any alternative accessible information as yet, as wife reads all correspondence"

"Information isn't always available in Easy Read (for a person with learning disabilities) and if it is it's always after everyone else"

"A and E is the worst service for Accessible information. Often arrive in A and E and there should be an alert on patient file to inform staff of communication needs"

"This was done initially and then removed, so now when there is an admittance to A and E, staff are clueless, and shout and think patient can understand them, but the patient has "Nodding Dog Syndrome" which is where they will respond positively to any queries even though he will be suffering negatively. Doctors and Dentists are great, as they contact the BSL agency, who then send the Interpreter booking letter to the patient, alongside the NHS appointment. A and E is the worst service, as well as the ward service. Unable to book Interpreters in a timely manner and doctor does the rounds with the patient without the appropriate communication support in place, which is illegal, but this is ignored. Outreach services are fantastic, but A and E and wards need to improve hugely before even being thought of somewhere where information and communication is easily accessed"

"for a person with serious disabilities South Tyneside and the council provide no services this survey only serves to be yet 1 more box ticked!"

“Being deaf I am unable to use telephone but every organisation seems to require contact via phone. They will then not allow my husband to speak on my behalf due to data protection! Everything takes so long to do”

“Asking for this is difficult as I have had a stroke and can't communicate well”

“While I don't have access issues myself I have in recent years been a carer for a person with a visual impairment, he had no problem getting large print information from his bank and was dealt with sensitively by DWP (however it was three years ago!!) and particularly by HMRC. Other than appointments being in Ariel 12 black on yellow, no recognition was made for his disability. Fortunately, he had an electronic reader, but it was cumbersome to use and he did express frustration at the lack of large print he was not to my knowledge offered large print information by either the hospital, community services nor by Primary Care”

“My GP surgery provide me with information by email only when I specifically request it. Otherwise they still send me letters in print so there is obviously no logic applied”

“It really helps to have information provided in a way that is more accessible- it can make potentially stressful situations easier to deal with - great strides made in recent years but work still needs to be done across ALL services”

“I think one of the things that struck me about access to information is that patients often have more than one ‘ailment’ so all sections of health provision need to be updated about a person’s individual requirements and if it is added to health records then even people admitted urgently at A & E for example will be helped”

“Sunderland Eye Infirmary should improve, with appointment letters and the most important sections on such letters are which specialist/ department, date & time of appointment and telephone contact as appropriate, these details should all be in bold font and a very minimum of size 16. Patients with a known sight impairment in *any* health-related correspondence should be asked which size font they prefer. (Ariel is clear lettering and always upper and lower-case lettering, size 18 font)”

“The 111 service relies on patients providing details over the phone. If (like my friend), you’ve had a stroke and can’t communicate easily, you may find the

process too difficult and just call 999 in when anxious/ frustrated? Is this happening and could be avoided?"

An example of good practice

North East Ambulance Service (NEAS) do offer a range of ways to contact 111 and 999 services advertised on their website and they have engaged with numerous deaf and disabled groups raising awareness over the last 18 months and continue to raise awareness.

After contacting NEAS direct HWST would like to add that more than half of their call-handlers are dual-trained on 111 and 999 and use the same systems and support mechanisms to meet patients' specific communication needs. They will continue to provide access to the service for those that might experience difficulty using a telephone through both Text SMS and British Sign Language relay services and give front line staff access to other tools such as their Communication Support Guide to assist people with specific communication needs.

NEAS also undertakes community engagement activity to reach out to individuals and connect with those who are socially isolated however they recognise this is difficult. They attended over 120 organisations last year raising awareness of the different options available to contact NEAS in an emergency/ non-emergency situation and promote their services.

The Deaf Club, South Shields - Group Session

HWST held a group session with the support of two interpreters from Northern Sign which is a local independent British Sign Language/English interpreting service in the North East of England. Approximately 30 individuals attended the session to share their experiences of overcoming communication and understanding barriers with their local GP practice and hospital services they access.

The deaf community sincerely feel that their understanding and communication preferences are being ignored. It was obvious that the group felt frustrated and had concerns a serious incident may happen because local health and social care providers offer inadequate services to meet their needs. The group were able to demonstrate this by providing some first-hand experiences, with regards nursing staff not knowing how to communicate in BSL, lack of staff awareness of interpreters and assumptions made because of hidden disabilities.

The group are disappointed that they have little choice on which interpreter service is used to support them when attending hospital appointments, this is because hospitals commission a particular private interpreter service and did not include service users in decision making regarding this contract and as each hospital commissions a different provider the quality of service varies. Individuals said

1. they had no confidence in certain providers because of their own experiences of miscommunications when interpreting (this was pointed out by a family member present within the appointment),
2. non-attendance of interpreters to pre-booked appointments and no explanation given why they did not attend or the double booking of interpreters meaning two interpreters would need to be paid for their services.

One individual identified that when you are deaf and attend the hospital as a patient you are placing your trust into the nursing profession to treat the illness. However, when you cannot understand or communicate your health needs to the doctor or nurse the trust can be misplaced.

The group were unaware of the standard and did not know about a registration form that could record their needs and improve their experiences as a patient. They feel the system is failing them and one gentleman did not believe such a system is in place, following the admittance of his deaf mother to A&E as it took the hospital over 6 hours to contact him as they did not realise she was deaf.

We discussed the use of the Text Relay service as an alternative way of communicating, however the only criticism identified was not all deaf people can read the English Language so this can be a barrier for BSL users. An alternative to this is VLR, however, again the use of this facility also comes with concerns around confidentiality and the credentials of an interpreter, as a medical diagnosis maybe misinterpreted because of different regional dialects.

The concerns raised are not unfounded and as we advance forward with technology, all of this will need to be considered to understand what would meet specific individual needs best, therefore the group would welcome an invitation to influence policy and changes at a strategic level.

GP Surgery telephone questions around communicational needs and information delivery 09/07/2018

HWST undertook research with GP receptionists to identify their understanding of accessible information. We contacted 27 out of 30 GP practices in South Tyneside by telephone and only said who we were when asked.

We asked 4 quick questions around the delivery of accessible information, and it was clear the majority of receptionists understood and felt they complied with the standard.

However, approximately one third of the receptionists forwarded our call to the practice manager who answered the questions enthusiastically. A few of the receptionists seemed reluctant to speak with us, or had to ask a colleague to support them with their answers.

These brief conversations suggested not all reception staff knew what the AIS was and were unsure if there was any signage within the waiting areas to inform patients of their rights to receive information in different formats.

Are patients asked if they have a communication need that requires additional support	Is information advertised around surgery	Is there a Hearing loop/sign in practice	Access to a Sign language interpreter or an advocate
unsure	Yes	No	Yes
unsure	No	No	Yes
Yes	Yes	Yes	Yes
No	Yes	unsure	Yes
Yes	Yes	Yes	Yes
Yes/ unsure	unsure	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	No	Yes
unsure	Yes	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	No (did an audit)	Yes
Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes
Yes	unsure	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	No	Yes
Yes	Yes	Yes	Yes
Yes	Yes	No	Yes
Yes	Yes	No	Yes
Yes	Yes	Yes	Yes
Yes	Yes	Yes	Yes
Yes	Yes	Amplifier	Yes
No – should be on file	No	No	Yes

Conclusion and Recommendations

A significant proportion of individuals said providers of services are not asking them if they have a communication and/or understanding need(s) that require information to be delivered in an alternative format to make informed choices. The findings from the survey do contradict the findings from the GP receptionist telephone survey that suggested patients are asked if they have any communication needs that require additional support.

HWST would recommend practitioners ask for feedback from people who are *experts by experience* and would encourage them to hold workshops with local service user groups to increase awareness of barriers, to ensure the right changes are implemented and get their views considered in strategic planning.

HWST recommends more awareness of the responsibilities within staff roles when recording and updating all patient records to ensure that they are conforming with the standard, (to not just ask patients who 'they think' might have an accessible information need, but to ask everyone). Information provided in the right way would lower missed appointments and be more cost effective in the long term.

HWST recommends that ALL information is produced with a **minimum** of font size 14. (given the high number of people aged over 65 – the majority of whom will have some level of sight deterioration)

A common trend identified was that people who are receiving accessible information often only received this when a third party asked for this on their behalf. HWST recommend promoting the AIS to all patients (perhaps by customising the right-hand side of prescriptions with the question '**Do you need information in a different format?**' with a tick box). This would enable patients or carers, family, friends to update patient communication needs promptly. This information could then be uploaded to the computer system and discussed at their next appointment or online if websites support this.

- HWST did ask a local pharmacist if they are able to input this information into their database when the patient goes for their prescription. However, she said they were unable to access patient data, although they all use the same system

- it may be possible in the future to incorporate a link within database so they can share this need without accessing patient files.

HWST recommends regular testing of hearing loops within waiting areas. This would ensure those who need this assistive equipment are able to use it and any faults dealt with promptly - HWST would be happy to support with the checking of hearing loops if requested.

HWST recommends reports in EasyRead be ready for publication and released at the same time as regular reports as good practice; currently the latter is only available to read months later.

HWST recommends that all health and social care staff be trained in the procedure on how to plan and book an interpreter, not just a select few who may not be on duty when a patient is admitted. It is everyone's responsibility to understand communication and understanding needs of patients no matter ability.

We recommend that many more NHS, GP and social care staff to be encouraged to undertake sign language training and become approved registered members (so reducing the need to bring in outside interpreters and the delays in doing this).

Providers should actively listen to patients wishes when booking interpreters, as it was identified within the group session that deaf people were not given the option of who they wanted to interpret, individuals were told they had to use the service commissioned by that specific hospital or GP practice.

Technology needs to be user friendly (accessible) to enable patients who want to make an appointment through an online bookings system.

GP and hospital computer systems need to become fully integrated to ensure patients' communication and understanding needs are shared and identified at the point of accessing necessary services. This will alert front-line staff of patient needs and improve the delivery of care and support needed to ensure needs are met within a reasonable time.

HWST recommends service providers look at the North East Ambulance Service (NEAS) website as NEAS excels in the way they present and communicate information to individuals with specific communication needs. They have an excellent website that demonstrates this at <https://www.neas.nhs.uk>. The NEAS website is easy to navigate around and offers; RNID text relay service, Recite-Me as well as an NHS 111 BSL service for example. These allow patients to communicate with health advisors and obtain information that suits their communication needs and preferences. This service is at the front-line of how accessible service providers can be and is a good opportunity for other services to learn from and improve their own websites accordingly to meet patient's communication needs appropriately.

Statistics from Public Health England

People aged 18-64 registered with a learning disability, sensory loss or impairment.

Compared with benchmark

Better
Similar
Worse
Lower
Similar
Higher
Not compared

Indicator	Period		England	North East region	County Durham	Darlington	Gateshead	Hartlepool	Middlesbrough	Newcastle upon Tyne	North Tyneside	Northumberland	Redcar and Cleveland	South Tyneside	Stockton-on-Tees	Sunderland
Learning disability: QOF prevalence (Persons, All ages)	2016/17		0.5	0.6	0.6	0.6	0.6	0.7	0.7	0.7	0.7	0.6	0.6	0.6	0.4	0.7
People aged 18-64 registered blind or partially sighted per 100,000 (Persons, 18-64 yrs)	2013/14		214.1	240.2	263.6	293.7	240.6	268.7	263.0	212.4	274.5	169.0	201.4	264.1	143.4	320.3
People aged 65-74 registered deaf or hard of hearing per 100,000 (Persons, 65-74 yrs)	2009/10		620	1037	692	829	1708	2233	1206	1199	1071	365	1109	257	2111	1292
People aged 75+ registered deaf or hard of hearing per 100,000 (Persons, 75+ yrs)	2009/10		3089	4780	3015	3339	8981	-	6202	6304	5994	1063	5160	403	9433	5707
People aged 18-64 registered deaf or hard of hearing per 100,000 (Persons, 18-64 yrs)	2009/10		172.8	253.4	219.8	204.5	342.2	433.0	391.5	198.8	288.4	132.2	332.4	79.2	410.7	263.4
People aged 65-74 registered blind or partially sighted (Persons, 65-74 yrs)	2013/14		569	638	676	664	780	859	610	644	597	518	576	748	367	774
People aged 75+ registered blind or partially sighted (Persons, 75+ yrs)	2013/14		4255	4057	5126	4286	4041	2777	2846	4360	5696	2911	3632	3256	2662	4517

Eligibility under the Accessible Information Standard to receive information in different formats or have their communication needs supported through the use of an interpreter of sign (BSL or SSE) or an advocate for individuals who have a learning disability:

- Learning Disability
- Deaf and hearing impaired
- Blind and visually impaired
- Deafblind
- Aphasia
- Autism
- Mental Health
- Some people with long term conditions
- Parents/ carers

Appendices

- Bliss-ability <http://www.blissability.co.uk/>
- BSL British Sign Language <https://www.british-sign.co.uk/>
- North East Ambulance Service <https://www.neas.nhs.uk/>
- Northern Sign BSL Interpreter <http://www.northernsign.co.uk>
- Royal National Institutional of Blind People <https://www.rnib.org.uk/>
- Sight Service South Tyneside <http://sight-service.org.uk/>
- Your Voice Counts <https://www.yvc.org.uk/>
- <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb1605-accessible-information>
- <https://www.england.nhs.uk/ourwork/accessibleinfo/>
- <https://www.england.nhs.uk/wp-content/uploads/2017/08/accessilbe-info-specification-v1-1.pdf>
- <https://www.england.nhs.uk/wp-content/uploads/2017/08/implementation-guidance.pdf>
- <https://www.england.nhs.uk/wp-content/uploads/2017/08/implementation-guidance.pdf>
- <https://www.nhs.uk/NHSEngland/AboutNHSservices/Emergencyandurgentcare/services/Pages/NHS-111.aspx>
- NHS England Accessible Information Standard;
- Section 250 of the Health and Social Care Act 2012

E-Learning

<https://www.e-lfh.org.uk/programmes/accessible-information-standard/>

Resources

Free product catalogue for assistive technology products – Action on Hearing Loss

HWST would like to thank the following organisations for support and guidance to complete this report:

Action on Hearing Loss

Bliss-ability

HealthNet

NEAS

Northern Sign BSL Interpreters

Public Health Intelligence South Tyneside

Sight Service

South Tyneside Talking Newspaper

The Deaf Club

WordsWorth EasyRead Design Service

Your Voice Counts

To all GP practices across South Tyneside who participated

AND most of all thank you to the lady who contacted HWST regarding the barriers she faced when trying to receive information in an accessible way for her neighbour and to all of the individuals who took the time to share their personal experiences of health and social care services to make this report happen...

THANK YOU!!

This report is available in large print, braille or Easy Read on request



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