healthwatch
Shropshire

'Your Care Your Way'-Meeting Communication Needs

Progress in implementing the NHS Accessible Information Standard in Shropshire

A report into service users experiences

Survey period 2022
Report published 27 March 2023

Contents

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About Healthwatch

Healthwatch Shropshire is your local health and social care champion

If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. We are independent and have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need.

We work to make your voice count when it comes to shaping and improving services. We use a variety of methods to find out what people like about services, and what could be improved and we share these views with those with the power to make change happen. Our reports go to:

- the organisations who provide services
- the commissioners who pay for services (e.g. Shropshire, Telford & Wrekin NHS Integrated Care Board, Shropshire Council)
- service regulators (the Care Quality Commission, NHS England)
- our national body Healthwatch England to let them know how local services are working in Shropshire.

We are not experts in health and social care and surveys are just one of the methods we use to put a spotlight on services and ask people to share their views with us.

We are very grateful to all those who took the time to share their experiences with us. If you have an experience to share about the issues raised in the report please do not hesitate to get in touch.

Context

Clear, understandable information is important to help you make decisions about your health and care and get the most out of services. With fewer NHS appointments taking place face-to-face and more people managing their conditions while waiting for treatment, clear information that you can understand and act on is more important than ever.

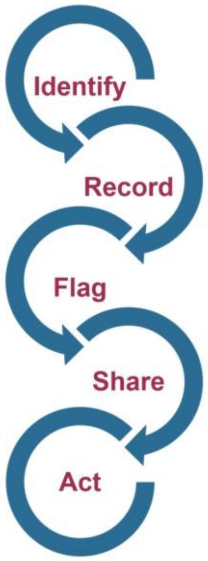
We all expect to be involved in decisions about our health, treatment and support. But information can be complex, and if you don't get clear and understandable information, you might not make decisions that are right for you.

Some people have communication needs that require support. They might need to use assistive technology, a British Sign Language Interpreter or information in a format like Braille, Easy Read or large print.

- Do you understand what your treatment or support involves?
- Do you know the risks and benefits?
- Are there any alternatives?
- Do you know what might happen if you are unable to follow the advice of doctors, nurses, and other care staff?

You can only answer these questions and make choices that suit your needs if you get information in a way you can understand.

> 'I feel for people who are not fighters.'
>
> **Carer for an elderly father**



Since 2016, the NHS Accessible Information Standard (AIS)[1] has given disabled people and people with a sensory loss (e.g. sight or hearing impairment) and carers the legal right to get health and social care information they can understand and communication support if they need it. By law, all publicly funded health and social care providers must fully comply with the Standard.

In 2017-18 Healthwatch Shropshire completed our first piece of work to find out how GP practices were using the Standard. We visited nine GP practices across Shropshire and spoke to 82 patients and 23 staff. Our main findings included:

- Most patients, carers and Patient Participation Group members had not heard of the NHS Accessible Information Standard at the time of our visits and did not know how it might affect them.
- Practice Managers had a varying degree of knowledge about the Standard and they were not all aware of the training available for staff.

To see our full report: NHS Accessible Information Standard Summary Enter & View report 2018 | Healthwatch Shropshire

Since February 2022 Healthwatch England have worked with a group of charities, such as RNIB, RNID, Mencap and SignHealth to identify improvements and actions to help services meet the legally-binding requirements and understand how it should be used. The AIS was first revised in 2017 and NHS England have recently reviewed it again, and will publish a review of the Standard taking Healthwatch England's recommendations on board. You can find out more about Healthwatch England's Campaign and recommendations here: NHS Accessible Information Standard – our recommendations | Healthwatch

As a part of their 'Your Care Your Way' Campaign, Healthwatch England submitted Freedom of Information Requests to all NHS Trusts across the Country, including

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[1] https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/NHS Accessibleinfo/

Shropshire. Accessible Information Standard – findings from our Freedom of Information requests | Healthwatch

It was found that local NHS trusts are not consistently meeting the legal rights of disabled people and people with a sensory loss to accessible information and Local NHS trusts are only partially meeting their legal duty to help people with additional communication needs. Shropshire residents who have sight loss, hearing loss or have a learning disability are not being given all the support they should by local health services because of their communication needs.

This failure puts services in breach of their duty under the NHS Accessible Information Standard, and so we wanted to gather experiences of people locally, raise awareness of the Standard within the local community and shine a spot light on the impact on people who's communication needs are not being met.

Health and Social Care services should

1. Ask if you have any communication needs and how they can meet them.
2. Record your needs and highlight them in your file or notes, so staff are aware and know how to meet them.
3. Share information about your communication needs with other care services when you give your permission.
4. Deliver information in a way you can access and understand, with the option for communication support if you need it.

To watch a video that explains the NHS Accessible Information Standard, please follow this link:

NHS Accessible Information Standard - Bing video

We will also be publishing an Easy Read version of this report soon and we will publicise this as widely as possible.

What we did

We produced a survey based on Healthwatch England's 'Your Care Your Way' survey but used more open questions to allow people to describe the detail of their experiences.

Our survey could be completed either online or by calling us and we then completed the survey over the phone. This gave us the opportunity not just to gather feedback, but also to explain to people what the NHS Accessible Information Standard is whilst on the phone. We were able to answer any questions people had, further raising awareness of the Standard. This also allowed us to gain a deeper understanding of people's individual experiences.

If you have a disability, impairment or sensory loss you have the right to be told about your health and social care in a way you understand

We want to hear from you if you have struggled to access health and social care information in Shropshire

Tell us your experiences today and help make a difference

Visit: www.healthwatchshropshire.co.uk

Or ring us on 01743 237884

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We tried to talk to as many people as possible, as we were aware that completing a survey either online, on paper or over the phone would not be possible for everyone.

We:

- carried out a focus group with Headway Shropshire
- visited groups in the community including sight loss groups, macular groups, hard of hearing groups, and carers groups to tell them about people's rights under the NHS Accessible Information Standard and raise awareness
- attended various public and system meetings to raise awareness of the NHS Accessible Information Standard wherever possible
- attended the online Learning Disability Partnership Board and Autism Partnership Board to tell them about people's rights under the NHS Accessible Information Standard and raise awareness

Raising awareness around the NHS Accessible Information Standard and people's rights under the Standard has been a key focus of our work. In the hope that people with communication difficulties and carers in Shropshire are aware of their rights and are able to ask for information in an accessible format or for communication support from their health and social care providers.

We wanted to find out how people are being affected if they are not receiving information in a format they understand, or their communication needs are not being met. We tried to make sure that we made the survey easy to complete. We had an online survey on our website as well as a paper version that we shared with other professionals who then shared within their networks. The Learning Disability and Autism Champion for Shropshire, Telford and Wrekin focusing on Autism, helped us to reword and review our paper survey and promoted this for us.

To further promote our survey, we posted about our campaign on social media to try to encourage people to complete our survey and find out more about their rights under the Standard.

Social Media Tiles

healthwatch Shropshire

We want more people to be aware of their right to information in different formats.

Tell us your experiences today #YourCareYourWay

Visit: www.healthwatchshropshire.co.uk

Or ring us on 01743 237884

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If you have a disability, impairment or sensory loss, or are a parent or carer of someone who does, you should expect:

1. To contact and be contacted by services in ways you find accessible

2. Services to give information and correspondence in formats you can read and understand

3. To be supported at appointments if needed.

4. Health and care services to support you to communicate.

Tell us your experiences today #YourCareYourWay

Visit: www.healthwatchshropshire.co.uk

Or ring us on 01743 237884

The people we heard from

We spoke to eight groups face to face and two online, to tell them about the NHS Accessible Information Standard. We carried out one structured focus group with people with an acquired brain injury involving four people. We then had three discussion groups: one with carers for adults with learning disability involving five people, a carers group of six people, and a hard of hearing group with 13 people. We also spoke to a community group for older people with learning disability.

Eighteen people completed our online survey, 12 were women (67%) 2 men (11%) and 4 preferred not to say (22%).

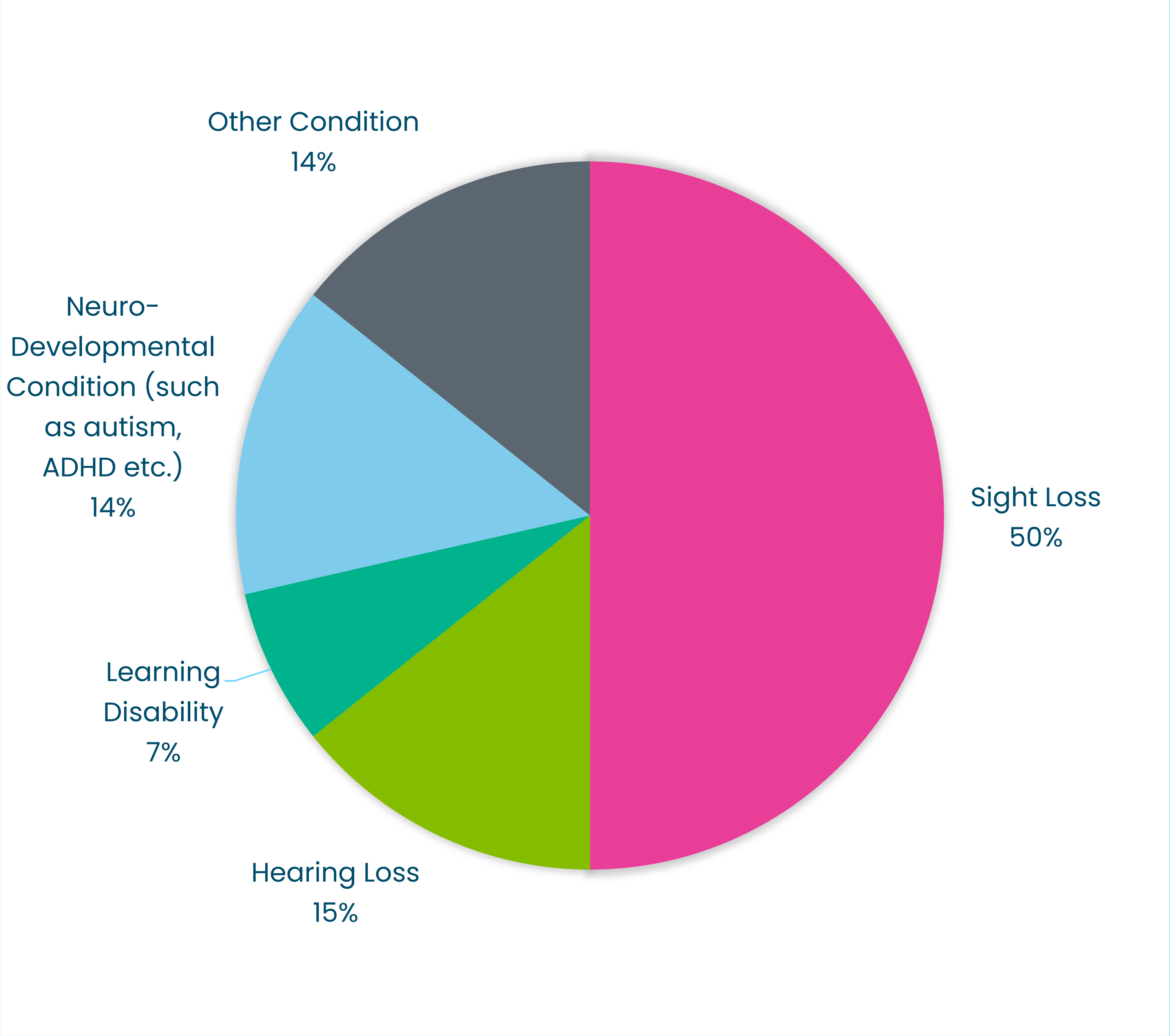
- 3 people were 80+ (17%)
- 4 people were 65 – 79 (22%)
- 6 people were 50-64 (33%)
- 2 people were 25-49 (11%)
- 3 preferred not to say (17%)

The focus group was more structured than the discussion groups and followed set questions, listed in Appendix B – focus group. This group consisted of people who had an acquired brain injury, that affected their communication skills. Their conditions included:

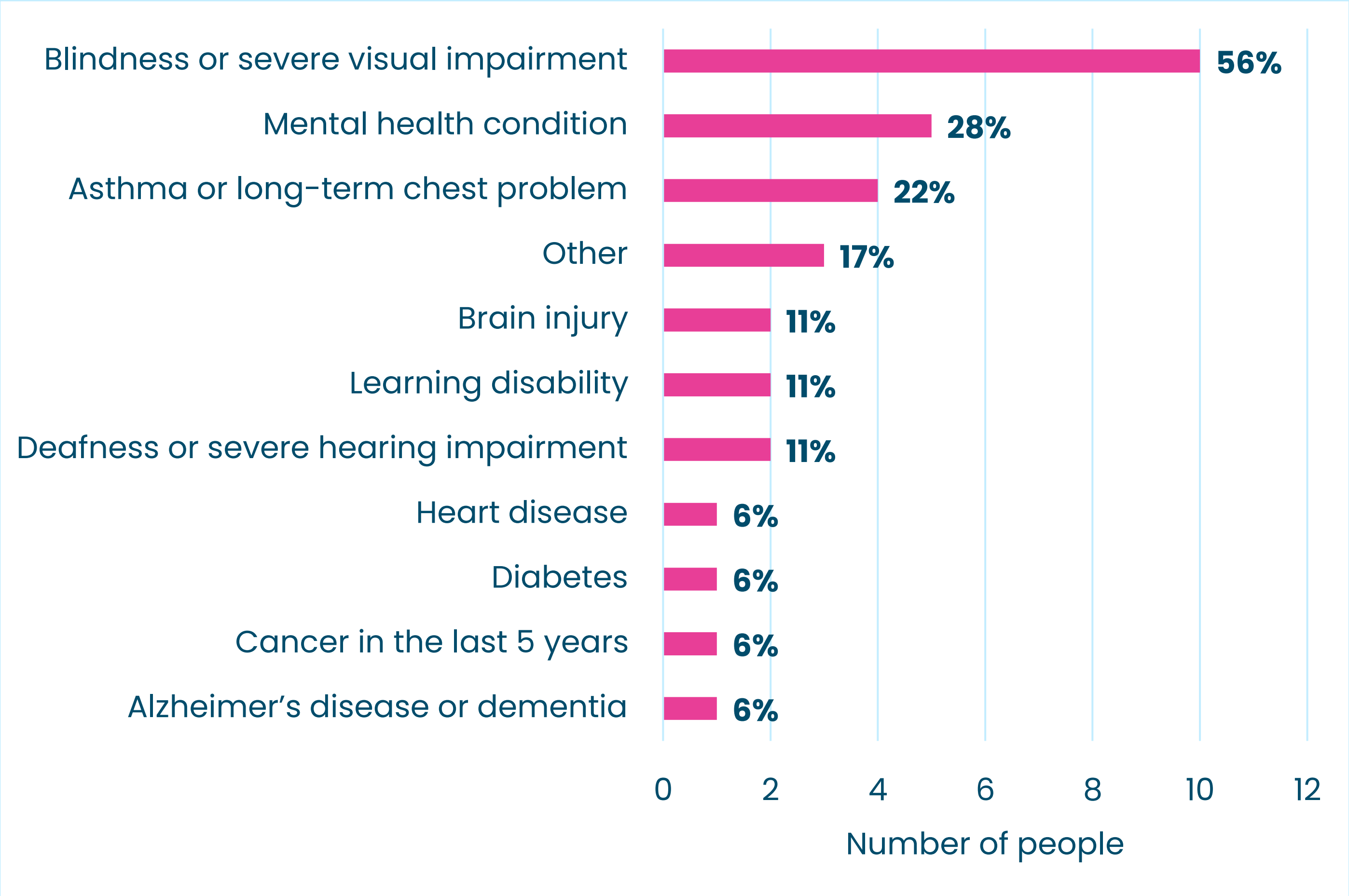
- Acquired sight loss, balance, and memory loss
- Memory loss, mobility difficulties
- Hearing loss, memory loss,
- Mental Health condition, depression
- Difficulty communicating verbally
- Short term memory loss

The people who completed our survey had various conditions that affected the way they communicate or understand information.

Do you have any of the following conditions which may affect the way you communicate or understand information?



Do you have a long-term condition?

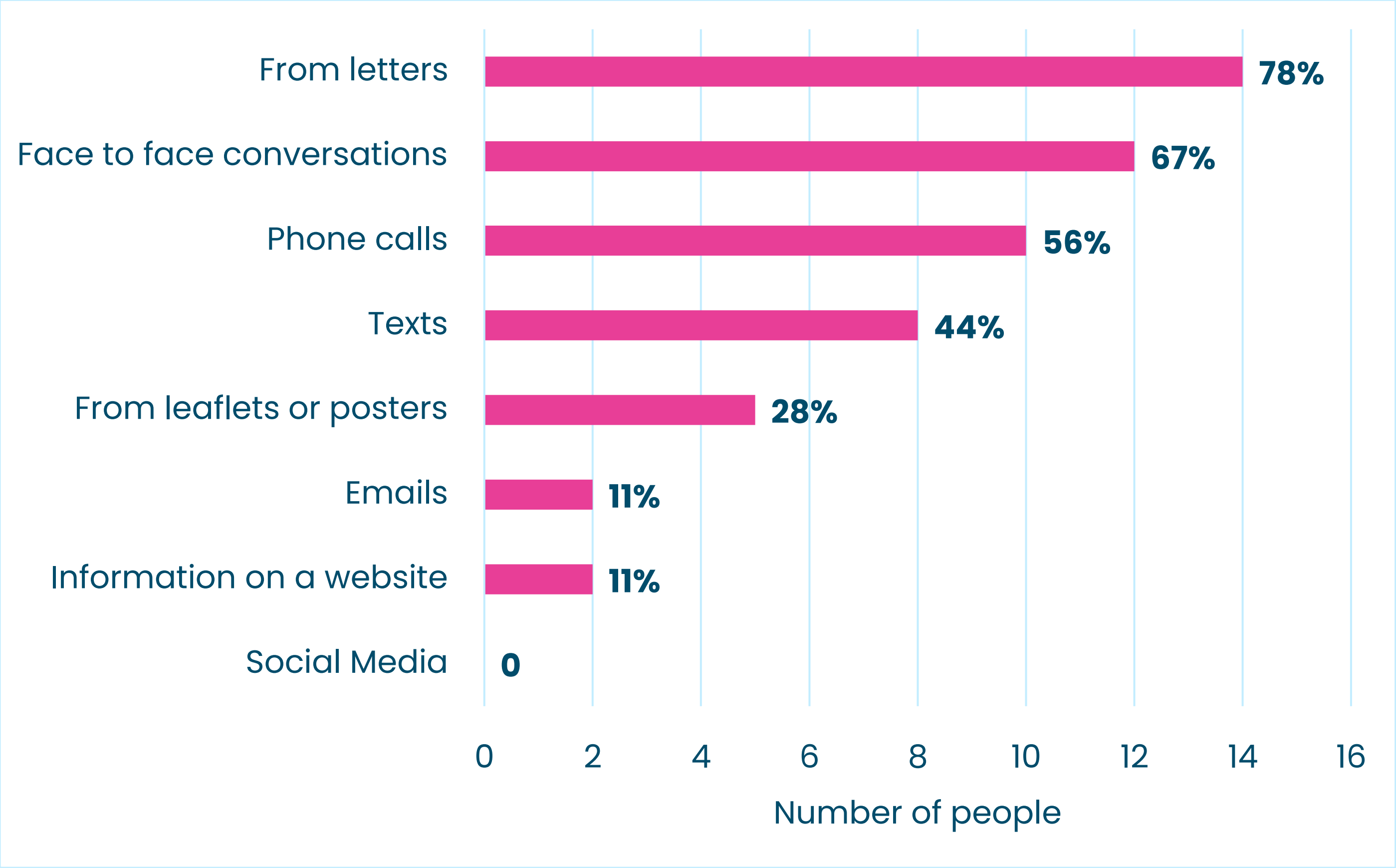


A full demographic breakdown is available in Appendix A

What people told us

The survey responses.

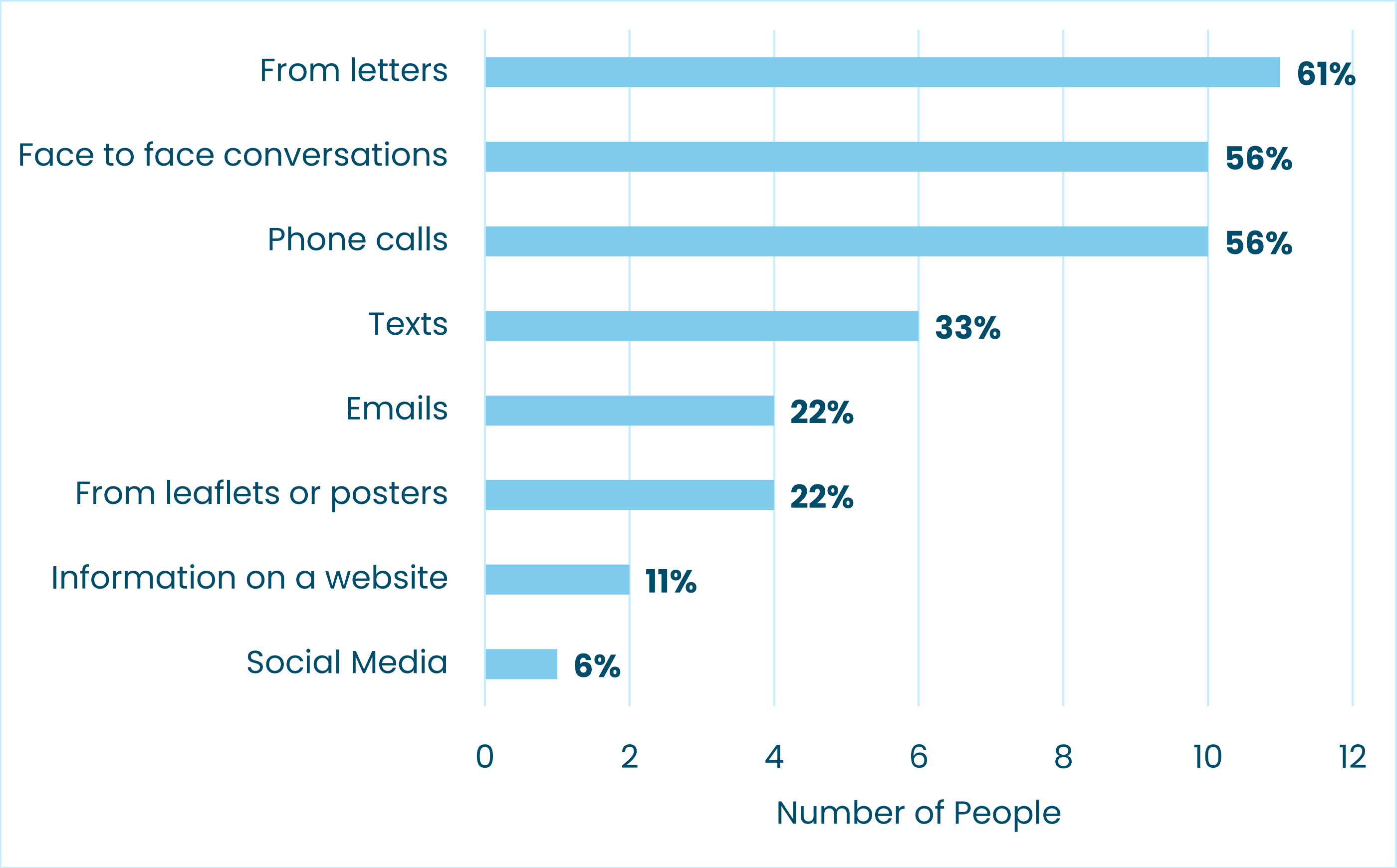
How do you receive information about your health and/or social care from different services? (Please select all that apply)



The majority of people (78%) said that they received information from letters, followed by 67% who received information from face-to-face conversation and 56% from phone calls.

No one told us that they used social media to access information about health and social care services.

Do you feel that you can understand the information available to you about your health and/or social care from different services? (Please select those you understand)



The feedback suggests that people do not understand all of the information they receive or do not receive information in a way that meets their needs.

- Letters

  10 people told us that they received their information from letters and understood the information received in this way.

  Four people who received letters told us that they did not understand them.

> ‘My wife reads letters for me as I can not’. (Person with sight loss – survey)

> ‘The Eye Hospital letters do come in large print but if you get referred to other services then they don't do it.’ (Person with sight loss – survey)

- Face-to-face conversations

  10 people said they receive and understand information from face-to-face conversations.

> ‘…been very kind at the clinic. They took time to explain everything through.’ (Person with sight loss – survey)

> ‘Face to face is best - you take cues from people face to face and can ask questions.’ (Carer for elderly mother with sight loss – survey)

  Two people did not understand information they received this way and so heath and care staff should check people’s understanding during appointments.

> ‘I always make sure I go in as originally, he went into appointments by himself and when he came out, he would not have a clue what was said to him. (Carer for husband with mixed dementia - survey)

- Phone calls

  Seven people told us that they receive and understand information given to them over the phone.

  Three people said they do not receive their information over the telephone but feel they would understand it if they did.

- Texts

  Six people told us that they receive information via text messages and understand the messages they receive.

  Two people receive text messages but feel that they do not understand the information they receive this way.

> ‘…I have experienced getting texts from the GP on my mobile and I struggle to understand how to get into my phone to reads texts..’ (Elderly person with sight and hearing loss – survey)

- Emails

  Two people said they receive and understand information via email.

  Two people told us that they do not receive their information from emails but would understand information via email. This would particularly support people who use assistive technology.

> ‘I have a free phone app I can use if there is a lot of text called Seeing AI from Microsoft… The app photographs whole document and reads it to me.’ (Person with sight loss – survey)

- Leaflets and posters

  Three people who received information leaflets and posters understood them. Two people did not understand information from posters or leaflets. One person did not receive information this way but felt they would understand information in a leaflet or poster if they did.

- Websites

  One person told us that they received information from websites and understood it. One person told us that they have received information online but did not understand it.

- Social media

  No one told us they received information by social media but one person said they would understand it if they did. This suggests that although social media is not used to give Health and Social Care information, some people may prefer to receive information this way.

The difficulties people have understanding the information they receive, highlights the need for services to:

- make sure they always ask people and their carers about their communication needs
- record this information in their records so it can be shared with other professionals
- act upon each individuals needs in a consistent way

This would ensure that people always receive their information in a format that they can understand.

We asked if information was provided and you did not feel you could understand it, how did this effect you?

Effects of not understanding health or social care information	Number of responses	Percentage
I did not take the right dose of my medication	2	11%
I could not understand how to take the medication I was given	3	17%
I was prescribed or given the wrong medication	3	17%
I missed my appointment	4	22%
I was not able to contact the service	4	22%
I missed out on information I felt was important about my health & social care	5	28%
I was not able to communicate with health or social care staff	5	28%
It affected my mental health and/or overall wellbeing	6	33%
I felt I was misunderstood	8	44%

Other effects were described:

When we asked people if information was provided and you did not feel you could understand it, how did this affect you, 8 (44%) of respondents described the other effect this had on them.

> ‘Labels being put over Braille in the pharmacy at my GP practice. I need to know the boxes and I make sure I have the right ones by using the Braille. I told the pharmacy that they shouldn't do this and they said they would put a note on my file. I said that you should never put labels over Braille, and I said not to put it on in the first place’. (Person with sight loss – survey)

> ‘Letters are always in small print from the GP and hospital so I can sometimes miss information. I am not one to ask for help, so I could miss things’. (Person with sight loss – survey)

> ‘I am finding it harder to see the medication I am taking, so I might need to ask the pharmacy about blister packs soon’. (Person with sight loss – survey)

> ‘With medication my mum needs me or dad to explain how to take medication. Mum has missed out on information as dad is elderly and can miss information sometimes’. (Carer for elderly mother with sight loss – survey)

> ‘My husband cannot be left alone end of story and if he didn't have my help all of the above would affect him. He only wants to tell people his view and doesn't listen to what he is being told so cannot communicate with healthcare staff. He has been given someone else's medication but luckily I

> noticed'. (Carers for husband with mixed dementia – survey)

> 'Only thing I have experienced is getting texts from the GP on my mobile and I struggle to understand how to get into my phone to read texts as I only use phone to make and receive calls. I ask my son to read my texts for me'. (Elderly person with sight and hearing loss – survey)

This highlights the wider effect of not being able to understand healthcare information has on people and the reliance on family members, friends or carers to support them, which can mean a loss of independence and privacy.

Lack of awareness and knowledge of the NHS Accessible Information Standard

We asked people, 'Have you ever been asked about your communication needs or how you communicate with others?'

Most people we spoke to told us that they have never been asked about their communication needs, and it also became clear that a lot of services in Shropshire do not know about the NHS Accessible Information Standard or what people's rights are. Also, communication preferences are not being shared between services. Issues of privacy and independence are also highlighted here.

> 'No never been asked. In the 3 years attending the Stroke Clinic at Princess Royal Hospital never asked, it felt more of a tick box exercise…' (Person with sight loss and acquired brain injury – survey)

‘I rang my GP and told them about the Accessible Information Standard and it was as if they hadn't been told about it. I asked for large print and they agreed to it as I told them it was the law….’ (Person with sight loss - survey)

‘I can not remember, I have had the condition for over 20 years. No one has asked me recently. People just assume you are blind.’ (Person with sight loss – survey)

‘Never been asked about communication needs. Never had any need to as all I do is ask my daughter or son to help me.’ (Elderly person with sight and hearing loss – survey)

‘The Eye Hospital letters do come in large print but if you get referred to other services then they don't do it.’ (Person with sight loss – survey)

‘No never been asked. Letters in large print would help with what little sight she has got. Dad reads letters for mum but the biggest thing sight loss has done is take away her independence.’ (Carer for elderly mother with sight loss and aquired brain injury from stroke – survey)

‘ You have to tell them they that the person you are caring for won’t understand.’ (Carer for person with learning disability – group discussion)

Some people told us that other providers, e.g. gas companies, had asked about their needs.

> ' Not from Government services only from Gas providers where they have asked whether I would like larger print…' (Person with sight loss – survey)

> 'Letters are always in small print from the GP and hospital so I can sometimes miss information. I am not one to ask for help, so I could miss things. I do get large print from my utilities, they asked me…' (Person with sight loss – survey)

Digital inequalities

Six people told us that they struggle to use technology, or don't have access to it at all, meaning that some ways of receiving health and social care information are completely inaccessible to them. They spoke of struggling to read texts and operate mobile phones, often having to ask someone else for assistance. The importance of asking people what their communication needs are and how they would like to receive their information are highlighted here:

> '…I cannot use email or social media as I am awaiting support from the sensory team to use accessible apps. I have been waiting 11 months for my assessment.' (Person with sight loss – survey)

> 'Only thing I have experienced is getting texts from the GP on my mobile and I struggle to understand how to get into my phone to reads texts as I only use phone to make and receive calls. I ask my son to read my texts for me.' (Elderly person with sight and hearing loss)

'…We don't use the internet or mobile phones so no texts. I always make sure I go in [to face-to-face appointments] as originally, he went into appointments by himself and when he came out, he would not have a clue what was said to him. Now I go in and ask the questions and listen to what's going on.' (Carer for husband with mixed dementia - survey)

'Call from hospital to make appointment and there are lots of buttons to press and appointment went as not quick enough. It is a machine' (Person with hearing and memory loss – focus group)

'I prefer face to face as my hearing has worsened but the GP often says let's try a phone call first. Sometimes I can't hear very well on the phone.' (Person with sight loss – survey)

'I can read letters, but need help to understand. I need easy read, the pictures help me. Phone calls are hard for me, face to face conversations are much better.' (Person with learning disability – survey)

'I can use the internet but find it hard to understand.' (Person with learning disability – survey)

Privacy issues

When information is not provided in a way that is understandable to a person with communication needs, it creates issues around privacy as people may have to ask a friend, family member and/or carer to access and understand the information on their behalf. The people we heard from told us that this can limit independence. People told us that they would like clear and understandable information so that they do not have to ask other people to read their sensitive and private information. People are not aware of their communication rights and so don’t ask for their information to be in a clear understandable format or for communication support.

> ‘… Letters in large print would help with what little sight she has got. Dad reads letters for mum, but the biggest thing sight loss has done is take away her independence.’ (Carer for elderly mother with sight loss and aquired brain injury from stroke – survey)

> ‘Mum had two strokes and lost her sight and her processing skills are not what they used to be and phone calls are not always understood - mum often passes phone to dad. Face to face is best as she needs someone to remind her. Mum has never been told staff cannot help her as she has never asked as she is unaware of her communication rights.’ (Carer for elderly mother with sight loss and aquired brain injury – survey)

> ‘Are they for me or for the carers to look at or support worker? I want the letter to be addressed to me but then have a bit where it says, ‘show this to the carer’. Letters should be clearer. “It’s addressed to me but to hand over to carer or support worker”’ (Person with acquired brain injury – focus group)

> ‘Takes your privacy away and carers know everything about you’ (Person with acquired brain injury – focus group)

> ‘I want to read my result letters myself and I don't want to ask for help’ (Person with sight loss – survey)

Supportive staff

Many people told us that staff were helpful, kind and accommodating with their accessibility needs, particularly highlighting the importance of staff taking the time to explain information.

> ‘…people are extremely helpful when they know about my sight. At the pharmacy if I need to sign something I point my finger where the box is, and the staff will help.’ (Person with sight loss – survey)

> ‘…A nurse has helped me with meal choices because there are no pictures on the list. I was given leaflets from Taking Part that are easy read. Royal Shrewsbury Hospital has been very good.’ (Person with learning disability – survey)

> ‘… been very kind at the clinic. They took time to explain everything through. Receptionist rang for taxi to help.’ (Person with sight loss – survey)

> ‘Pharmacy are very kind and helpful too with any questions I have.’ (Person with sight loss – survey)

> ‘They always need to involve us we can then explain. My Dr is very good with me [Plas Ffynnon, Oswestry]. I’ve been at the surgery all my life and my daughter.’ (Carer for daughter with learning disability – discussion group)

> ‘Went for a colposcopy at Royal Shrewsbury Hospital. Dr was very good explained the process and showed her the screen. She was very excited to see her ‘parts’ on the screen.’ (Carer for person with learning disability – discussion group)

> ‘She [tried] every dentist until one showed her everything and what it did. It went really well.’ (Carer for person with learning disability – discussion group)

> ‘…I am now at St Martins Pharmacy and they are very good and they are very helpful and community minded.’ (Person with sight loss – survey)

> ‘…Only help has been finding seat at the outpatients department where people have been so supportive, even describing if the chair has a back on it. Good support for movement around departments from reception staff and Doctors…’ (Person with sight loss and aquired brain injury)

We heard from one person who had a positive experience of a community support group. This shows how important community services are and offers the opportunity for people to seek advice and support face to face:

> ‘ …The sight loss club helped so much and we only discovered it by chance. It has been a massive help to us. This has made mum's life more bearable, and she is with other people who are the same as her. She was told about audio books there and now she gets lost in her audiobooks. Mum now cooks, bakes, and cleans.’ (Carer for elderly mother with sight loss and aquired brain injury – survey)

Unsupportive staff

Some people felt that staff were unsupportive and had not provided information in an appropriate way. There appears to be a breakdown in communication between staff and patients and their carers and also highlights how carers felt they should be consulted more.

> ‘Feels that she is very easy to 'fob off', or could be that she asks things she doesn't need to know. The consultant wouldn't tell her what had actually happened to her when she asked (and) what she had, that wasn't actually a stroke.’ (Person with sight loss and acquired brain injury- survey)

> ‘My daughter aged 37 was at the dentist. The dentist said it was my daughter’s choice not mine. She didn’t know what she was talking about. I should be allowed to make those decisions.’ (Carer for daughter with learning disability – discussion group)

> 'When I went to the eye clinic (enquiries advised me to go there) to say I was losing my vision then told me they couldn't help me and to go to A&E. They couldn't help me there. I went to my GP who emailed Welshpool, when we arrived they hadn't seen an email. I then received an appointment for the eye clinic at Royal Shrewsbury Hospital and received good support. However, they refused an injection (has Macular degeneration). My daughter

> contacted PALS and I was given the injection.' (Person with sight loss – survey)

> 'She fell off a pony, had a spinal abscess. Dr told her all the details including 50/50 chance of recovering. Had to move the Dr out of the room and tell him I will explain in a way she understands. She couldn't feel pain, I knew when she was ill, she didn't.' (Carer for person with learning disability - discussion group)

Unsupportive services

A lot of people felt that the way services are run is not supportive for individuals with communication needs. One area that people really felt needed to be improved was in providing support for families and carers of people with additional needs.

> 'Well I have certainly come out of consultation and try to remember what I was told, this was more to do with the disorientation of a diagnosis and not because I didn't understand what was being said. It's probably more due to the shortness of appointment times rather than communication style. If I need to know something further, I would look at the NHS website and probably not go further!' (Person with sight loss – survey)

> 'There is no specific support given to any different cohorts of Carers, despite the Carers sometimes being at risk themselves, and no attempt by any other signposting organisation such as MPFT to challenge the lack of a service they are directing people to! The Carers Support Staff have not had the detailed training that was promised or had any interaction with specific carers to better understand their stresses, difficulties

and even dangers! This statutory service is failing Carers at a critical time and no-one cares! Care for the Carer if you don't want services to be overwhelmed with demand!' (Carer with Neuro-Developmental Condition – Survey)

'I can't stress enough how my mum's mental health has been affected from losing her sight. First stroke mum lost 40% of her sight and second stoke 50% and fell into a deep depression… Mental health is overlooked and nobody ever talks about feelings with sight loss and mum could not get out of bed. The best thing the GP said was that it is Ok to feel depressed. There needs to be a support group for families too… There needs to be better communication with people with sight loss to help with mental health.' (Carer for elderly mother with sight loss and aquired brain injury – survey)

What people want from services

People generally told us that they prefer face-to-face conversations and need clearer communication from services.

People (including carers) need to be asked:

- about their individual communication needs so that they can receive information in a way that is clear and accessible to them.
- if they need communication support during appointments to help them to communicate and understand, e.g. a British Sign Language Interpreter.

'I can read letters, but need help to understand. I need easy read, the pictures help me. Phone calls are hard for me, face to face conversations are much better.' (Person with learning disability -survey)

'…I would always ask them to explain it to me. I went into hospital about my eyes and the doctor had a strong accent and I had to ask them to explain more clearly so I could understand. I prefer face to face as my hearing has worsened but the GP often says let's try a phone call first. Sometimes I can't hear very well on the phone.' (Elderly person with sight and hearing loss – survey)

'When you ring the Dr and they ask how you are doing it is hard to describe over the phone. Face to face is easier.' (Person with hearing and memory loss – focus group)

'Aren't they going to put it all on a website? It should be flagged.' (Person with acquired brain injury – focus group)

[Name comes up on screen at Bishop Castle GP practice.] 'So simple to have a screen where your name comes up.' (Person with hearing loss – discussion group)

'Would prefer face to face – I get appointments easier than my husband because of my condition.' (Person with acquired brain injury – focus group)

'…Letters in large print would help with what little sight she has got…' (Carer for elderly mother with sight loss and aquired brain injury – survey)

> 'There are many eye conditions and you can't assume everyone wants large print and I wouldn't suggest departments send out large print for everyone. Some people may be happier to have their stuff read by their family or may use a scanner that is better on normal print. Large print isn't for everyone and some people don't want help and some have not accepted and come to terms with what is happening to them' (Person with sight loss – survey)

> 'I always go with my husband – I do find it difficult with his Alzheimer's - he is aware of what is going on. I find it hard talking in front of him and wish I could have a separate appointment' (Carer for husband with Alzheimer's – discussion group)

> 'They don't give enough thought of the person caring – whether they are coping or not' (Carer for elderly father – discussion group)

Community group for older people with learning disability

We also heard from a community group in Shropshire about their recent experiences of accessing information and communication in an accessible format from local services. These comments reflect ongoing issues with a local GP practice and local services in general. The difficulties in accessing services for people with communication needs are highlighted here.

> '[Getting through the receptionists] You'd find it easier getting an appointment with the Pope than a doctor at [my GP practice]. They give you a list of numbers to choose from on the phone and if you've got a learning disability or

dyslexia or autism you're going to get wound up and confused before you have spoken to a receptionist.’

‘They gave me a telephone appointment to ask about my hearing problems!’

‘They don’t have any easy read stuff, not just for people with learning difficulties but elderly people too’

‘There is no ease in understanding where to go - if you don't know where you're going the signs are not easy to read and are very inaccessible’

‘Doctors using medical speak unless you stop them and ask them what they are talking about and it is very hard to understand. On a Friday afternoon they tend to speed things up and it’s very confusing’

‘Two appointments and two letters for the same appointment but at different times. Very confusing’

‘I have a trouble with receptionists when explaining I have a hidden disability. They assume you haven’t got it but then they go really quiet and strange when you say you have a learning disability. I didn’t realise people were looking down

> on me. Talk to you as if you're a child and you have to explain all your problems'

> 'Hospital doctors tend to talk over you with another person that it's in the room, but not to you'

Our recommendations

Having heard from a range of people with communication needs and their families and carers, we received several suggestions to improve services, including:

- Consider print size on letters
- Display patients' names on a screen when they are called up for an appointment
- The choice to have information provided via face-to-face appointment
- Slightly longer appointment times for those with communication needs
- Staff knowledge of who in the room to provide information to, and what level of detail is appropriate to give

Healthwatch Shropshire made the following recommendations in 2018 to all GP practices in Shropshire and what people have told us demonstrates that there is more work to be done by some practices:

All practices should:

- Review their approach to meeting the Accessible Information Standard and check that they are meeting the implementation criteria, including having an Accessible Information Policy (supporting information is available on the NHS England website) and gaining the necessary consent from patients to share their personal information outside the practice.
- Ensure all staff are familiar with the term 'Accessible Information' and the five steps to meeting the Accessible Information Standard.
- Ensure that all staff complete Accessible Information Standard training and this is regularly reviewed.
- Develop a systematic approach to identifying if existing patients are carers and / or have a communication need and asking them how they prefer to be communicated with.
- Find a way to ask patients / carers if they have a communication need that does not rely on them being able to read a poster or access the 'Accessible Information' page on the website.
- Consider appointing a member of staff as Accessible Information Champion, so that someone in the practice is responsible for ensuring written information is accessible and the communication needs of all patients are met by the practice, including checking the hearing loop is working.
- Consider making the practice environment more learning disability / Dementia friendly
- Consider involving the PPG in ensuring information is accessible for patients, e.g. letters, leaflets and posters are easy to read and understand.

To see our full report: NHS Accessible Information Standard Summary Enter & View report 2018 | Healthwatch Shropshire

Some broader recommendations for the Shropshire, Telford & Wrekin Integrated Care System:

- Work to raise awareness of the NHS Accessible Information Standard to help ensure both service users, carers and staff are aware of their rights
- Ensure it is standard practice to ask people about their communication needs
- Ensure that carers are asked about their communication needs and are fully supported in their caring role
- Direct people to clear information about the NHS Accessible Information Standard that is all in one place including links to relevant support services/groups (e.g. webpage)
- Consider the impact on the mental health and wellbeing of people and their carers when they are unable to understand information from health and social care services
- Recognise that access to information digitally (e.g. websites, social media, email, text messages) is not an appropriate option or available for everyone

Suggestions from Healthwatch England: Healthwatch England – Our Recommendations

- Services should be checked more often by the government to ensure they follow the NHS Accessible Information Standard
- Every health and care service should have an Accessibility Champion to take the lead in ensuring information is provided in an NHS Accessible way
- IT systems should be improved so that patients can update services with their communication needs e.g., on the NHS app
- People with communication needs should be involved in helping to design better services
- Training on the NHS Accessible Information Standard for all health and social care staff should be made mandatory

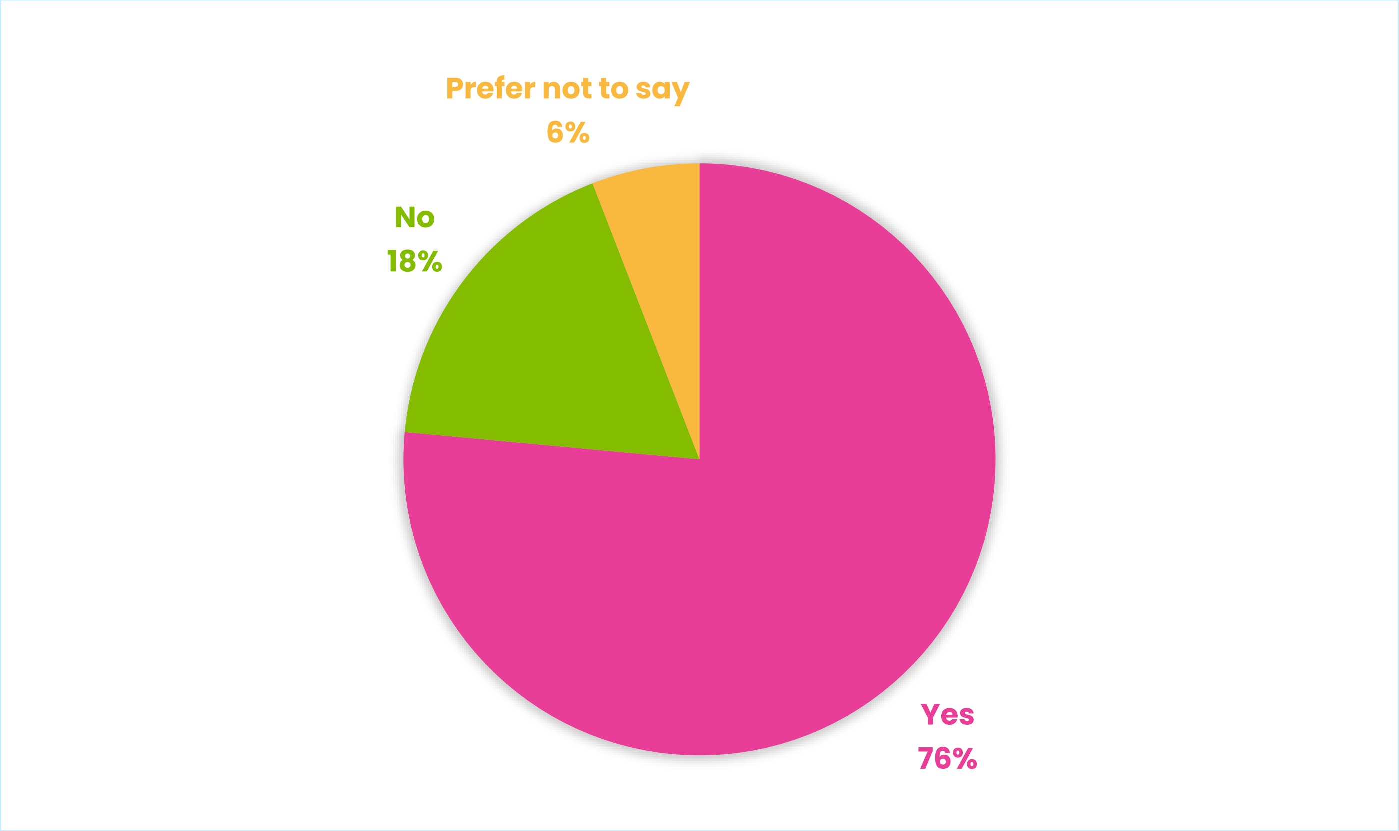
Response from Service Providers

Due to system pressures we have decided to publish this report without a response from providers and commissioners across the Shropshire, Telford & Wrekin Integrated Care System (including health and social care).

We will add responses as we receive them. Please check back to see what they have told us they are doing to support people with communication needs.

Appendix A – Demographic Information

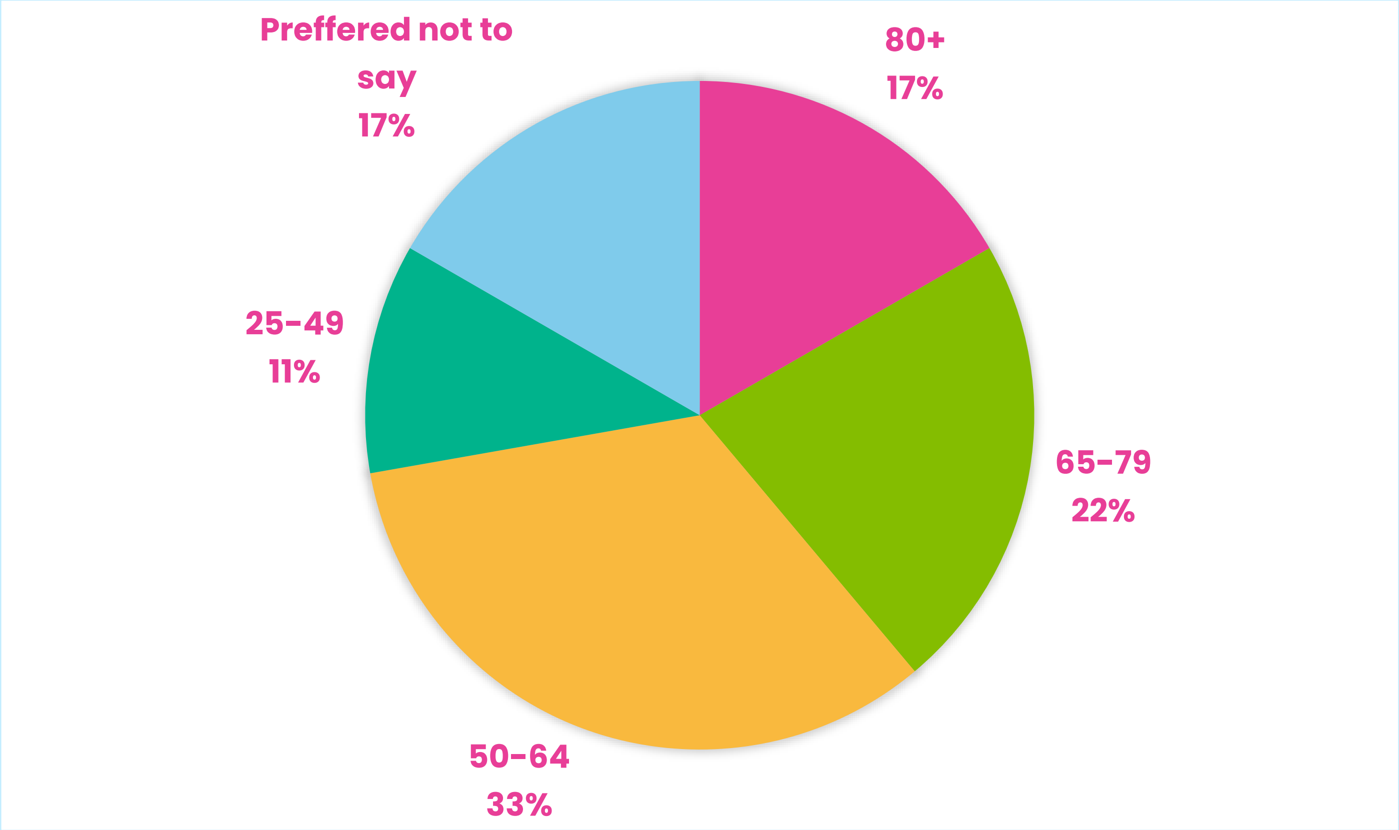
Do you have a disability?



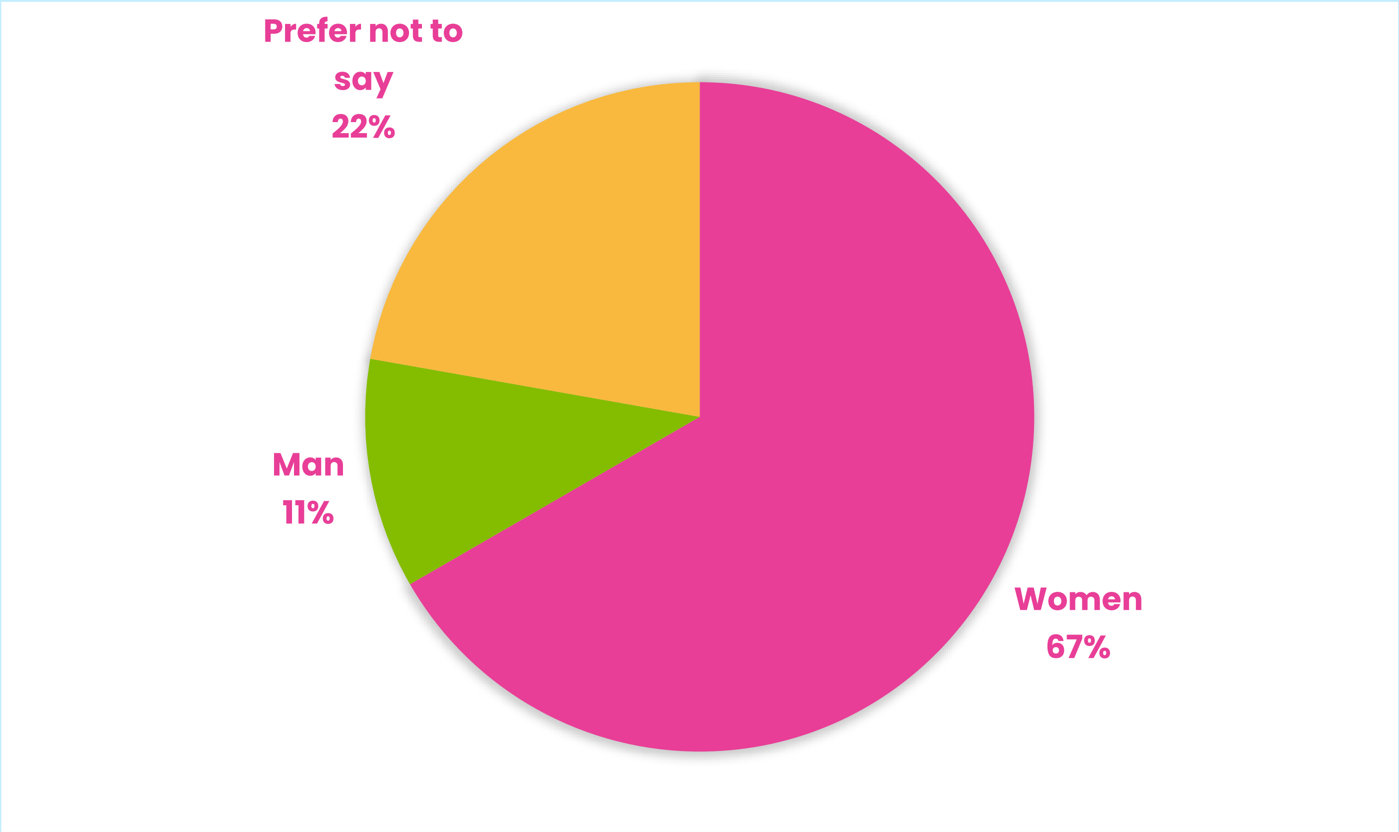
Other long-term conditions people had:

- Autism
- ME & Allied conditions
- Possible ASD

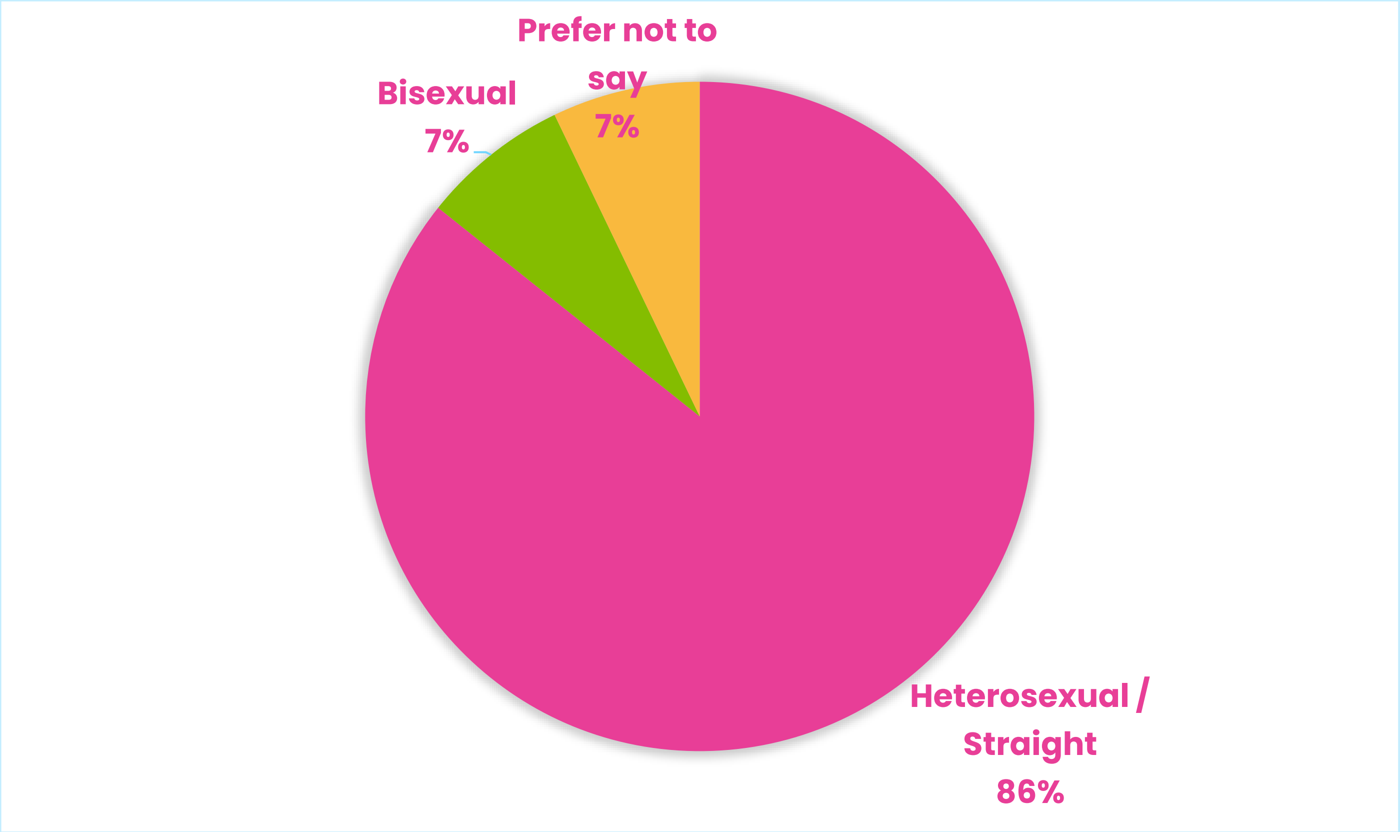
Please tell us your age



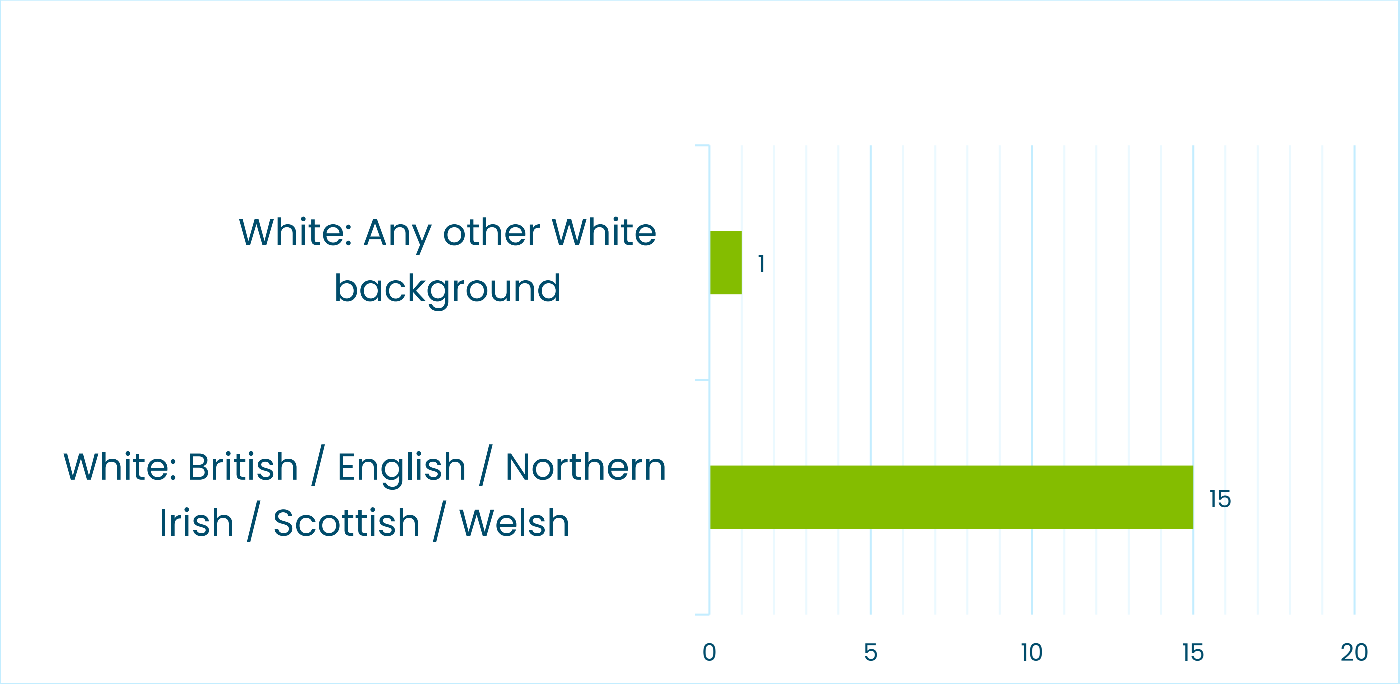
Please tell us your gender



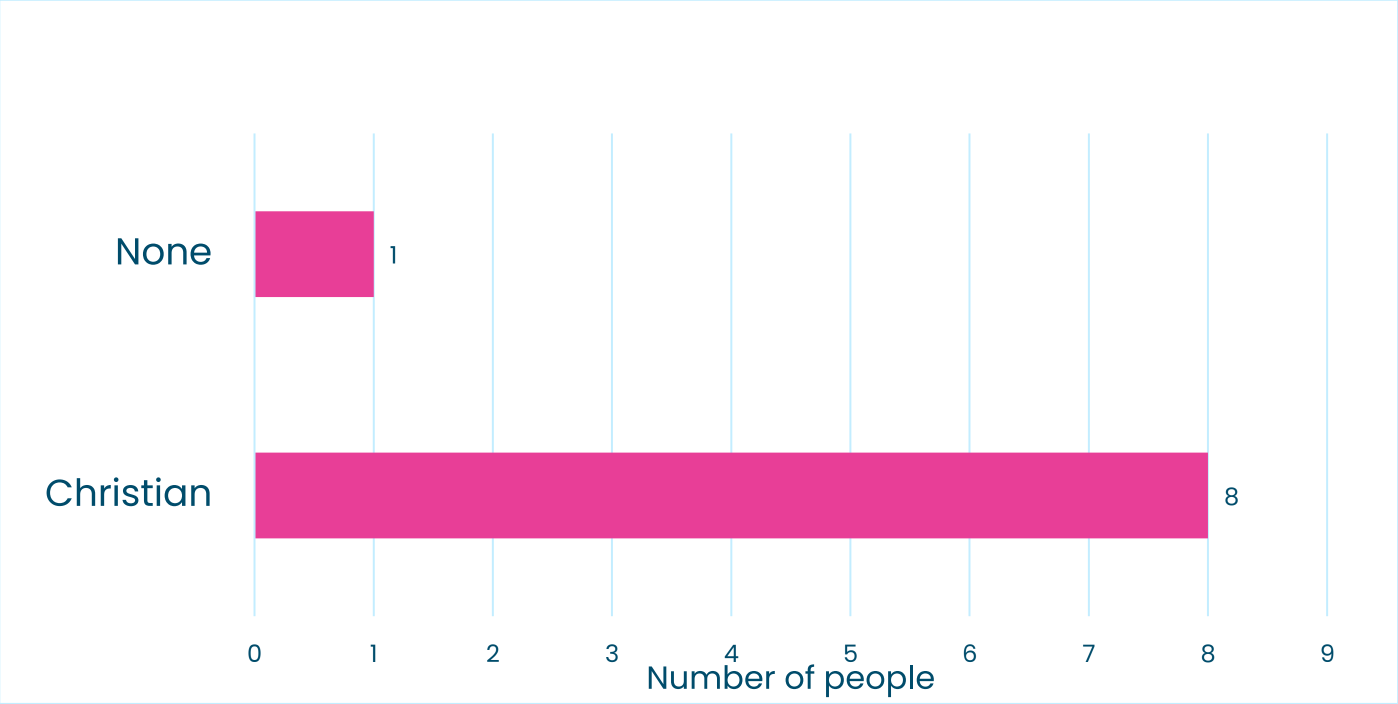
Please tell us your sexual orientation



Please tell us your ethnicity



Please tell us your religion or belief



Appendix B – All Feedback

Have you ever been asked about your communication needs or how you communicate with others?
No never been asked. In the 3 years attending the stroke clinic at PRH never asked, it felt more of a tick box exercise. Only help has been finding seat at the outpatients department where people have been so supportive, even describing if the chair has a back on it. Good support for movement around departments from reception staff and Doctors. Has mentioned she has memory loss at appointments, but often told not to worry about additional details.
Not from Government services only from Gas providers where they have asked whether I would like larger print. I get letters and text reminders from the eye clinic at the Copthorne Centre where I have had injections in my eyes. The text is slightly larger and date is in bold. I prefer font 11 or 12 and I use a magnifying glass. This works better on smaller text than larger text and Arial is better than Roman. I have a free phone app I can use if there is a lot of text called Seeing AI from Microsoft. I find if there is a lot to read then it is tiring. The app photographs whole document and reads it to me. I have not been to the doctors in such a long time and try to stay away from the hospital. When I went for my Covid jab at Gobowen I had my white cane and this is a good indicator to people that I need assistance. I don't want my sight loss to define me and I prefer to say I don't see very well instead of" I am blind."
I rang my GP and told them about the NHS Accessible Information Standard and it was as if they hadn't been told about it. I asked for large print and they agreed to it as I told them it was the law. The breast screening letter did not come in larger print and I expect to get my results in larger print and I told them they would be breaking the law if they do not send it in this format. I want to read my result letters myself and I don't want to ask for help. I can use my electronic magnifier on small print but it is annoying as it should be sent in the right format. The Eye Hospital letters do come in large print but if you get referred to other services then they don't do it. 5 years ago I attended

a Rapid Improvement Week at Shrewsbury hospital where they have different departments looking at things and we looked at appointment letters. Lots of patients we asked with sight loss did not want large print and said "what do I need that for?" There are many eye conditions and you can't assume everyone wants large print and I wouldn't suggest departments send out large print for everyone. Some people may be happier to have their stuff read by their family or may use a scanner that is better on normal print. Large print isn't for everyone and some people don't want help and some have not accepted and come to terms with what is happening to them. Sight loss is like grief where you are grieving the loss of your sight. Some people at the start of their sight loss journey have their confidence knocked and it is very sad as they feel they cannot do things for themselves anymore like reading their letters. I have been blind all my life so I am used to it.
No never been asked officially.
No
No
Sometimes
I can not remember, I have had the condition for over 20 years. No one has asked me recently. People just assume you are blind.
Yes, if hearing. I tell people that I have Learning Disabilities. I need people to explain things to me, for example, what the plastic curtains are for, why people are wearing face masks. A nurse has helped me with meal choices because there are no pictures on the list. I was given leaflets from Taking Part that are easy read. RSH hospital has been very good. PRH has not, they asked me what I came in for and told me to take a taxi home (I need E-Zec transport). I was only given tea and toast when I had a 3 hour wait. I was given an easy read leaflet for COVID that I understood. If there had been one about my mole removal it would have been less frightening for me. I can use the internet but find it hard to understand.
No never been asked. Letters in large print would help with what little sight she has got. Dad reads letters for mum but the biggest thing sight loss has done is take away her independence.

Never been asked about communication needs. Never had any need too as all I do is ask my daughter or son to help me.
Not really. I just say do it through me!

Have you ever been told by members of staff that they cannot help or support you to understand any information you have been given?
Well I have certainly come out of consultation and try to remember what I was told, this was more to do with the disorientation of a diagnosis and not because I didn't understand what was being said. It's probably more due to the shortness of appointment times rather than communication style. If I need to know something further, I would look at the NHS website and probably not go further!
Feels that she is very easy to 'fob off', or could be that she asks things she doesn't need to know. The consultant wouldn't tell her what had actually happened to her when she asked what she had that wasn't actually a stroke.
No, people are extremely helpful when they know about my sight. At the pharmacy if I need to sign something I point my finger where the box is and the staff will help.
No most staff are usually Ok and quite helpful.
No, been very kind at the clinic. They took time to explain everything and through. Receptionist rang for taxi to help.
Pharmacy are very kind and helpful too with any questions I have. I can't see texts now so I don't use a mobile phone.
No. If I don't understand something I will ask them to speak in plain English, not medical words.
When I went to the eye clinic (enquiries advised me to go there) to say I was loosing my vision then told me they couldn't help me and to go to A&E. They couldn't help me there. I went to my GP who emailed Welshpool, when we arrived they hadn't seen an email. I then received an appointment for the eye clinic at RSH and received good support. However, they refused an injection (has Macular degeneration). My daughter contacted PALS and I was given the injection.

No
Indirectly
YES!! There is no specific support given to any different cohorts of Carers, despite the Carers sometimes being at risk themselves, and no attempt by any other signposting org such as MPFT to challenge the lack of a service they are directing people to! The Carers Support Staff have not had the detailed training that was promised or had any interaction with specific carers to better understand their stresses, difficulties and even dangers! This statutory service is failing Carers at a critical time and no-one cares!! Care for the Carer if you don't want services to be overwhelmed with demand!!
No
I can read letters, but need help to understand. I need easy read, the pictures help me. Phone calls are hard for me, face to face conversations are much better. No, Always helped when I explain I have Learning disabilities. I find it hard to read names from Drs from different ethnic groups, I find it hard to understand them when they are talking, but they are very nice and helpful.
In addition to above list of questions - Phone calls: Mum had two strokes and lost her sight and her processing skills are not what they used to be and phone calls are not always understood - mum often passes phone to dad . Face to face is best - you take cues from people face to face and can ask questions. Sometimes during face to face meetings mum doesn't understand but face to face is better. Mum always wants someone there to help as she is very aware of her limitations and needs someone to remind her. Mum has never been told staff cannot help her as she has never asked as she is unaware of her communication rights.
In addition to above list of questions - Phone calls: Mum had two strokes and lost her sight and her processing skills are not what they used to be and phone calls are not always understood - mum often passes phone to dad . Face to face is best - you take cues from people face to face and can ask questions. Sometimes during face to face meetings mum doesn't understand but face to face is better. Mum always wants someone there to help as she is very aware of her limitations and needs someone to remind her. Mum has never been told staff cannot help her as she has never asked as she is unaware of her communication rights.

Letters: My husband would only understand the first few lines of a letter as they are not easy to understand for him. Leaflets and posters: No, he wouldn't understand or bother with them. We don't use the internet or mobile phones so no texts. Face to face conversations: I always make sure I go in as originally, he went into appointments by himself and when he came out, he would not have a clue what was said to him. Now I go in and ask the questions and listen to what's going on.
No but I would always ask them to explain it to me. I went into hospital about my eyes and the doctor had a strong accent and I had to ask to explain more clearly so I could understand. I prefer face to face as my hearing has worsened but the GP often says let's try a phone call first. Sometimes I can't hear very well on the phone.

Any other Effects?
I have minimal contact with the health service so the above doesn't apply to me
Labels being put over Braille in the pharmacy at my GP practice. I need to know the boxes and I make sure I have the right ones by using the Braille. I told the pharmacy that they shouldn't do this and they said they would put a note on my file. I said that you should never put labels over Braille and I said not to put it on in the first place. I moved pharmacies as they kept doing it. I am now at St Martins Pharmacy and they are very good and they are very helpful and community minded.
Letters are always in small print from the GP and hospital so I can sometimes miss information. I am not one to ask for help, so I could miss things. I do get large print from my utilities, they asked me. NHS leaflets can be hard to understand as I can't see blue writing on white backgrounds. It needs to be black print on white or yellow, yellow is much better. I have started to use google home for the internet which is useful. I am finding harder to see the medication I am taking, so I might need to ask the pharmacy about blister packs soon. The pharmacy are very helpful and if I am worried about which medication to take they will always help me. I have no family close by so I do need to ask sometimes.
I have not been effectively supported in what is a very demanding role.
I can’t do weekend appointments because there is no E-zec.

With medication my mum needs me or dad to explain how to take medication. Mum has missed out on information as dad is elderly and can miss information sometimes. I can't stress enough how my mum's mental health has been effected from losing her sight. 1st stroke mum lost 40% of her sight and 2nd stoke 50% and fell into a deep depression. We took her to the GP and got help and the first year of depression was devastating. That's the other thing with sight loss caused by strokes - processing skills are not what they were and short term memory is effected and she easily forgets conversation and needs things explaining to her. She needs information simplifying. Mental health is overlooked and nobody ever talks about feelings with sight loss and mum could not get out of bed. She was only retired for 6 years before the strokes. The best thing the GP said was that it is Ok to feel depressed. There needs to be a support group for families too. The sight loss club helped so much and we only discovered it by chance. It has been a massive help to us. This has made mum's life more bearable and she is with other people who are the same as her. She was told about audio books there and now she gets lost in her audiobooks. Mum now cooks, bakes and cleans. There needs to be better communication with people with sight loss to help with mental health.
My husband cannot be left alone end of story and if he didn't have my help all of the above would affect him. He only wants to tell people his view and doesn't listen to what he is being told so cannot communicate with healthcare staff. He has been given someone else's medication by Rowlands Pharmacy in Harlescott before but luckily I noticed.
Only thing I have experienced is getting texts from the GP on my mobile and I struggle to understand how to get into my phone to reads texts as I only use phone to make and receive calls. I ask my son to read my texts for me.

Focus Group

Have you ever been asked about your communication needs or how you communicate with others?
All: No
Asked can’t you come on your own but I said no.

When you ring a Dr and they ask how you are doing it is hard to describe over the phone. Face to face is easier.
I would prefer face to face – I get appointments easier than my husband because of my condition.

Have you ever been told by a member of staff that they cannot help or support you to understand any information you've been given.
All: No

Have you asked for someone else to help you (or have been offered help) when you have attended appointments or talked to staff from healthcare services?
All: No
get their quickly due to mobility issues
Takes your privacy away and carers know everything about you
Would prefer to be able to understand the information
I have missed appointments
Call from Hospital to make appointment and there are lots of buttons to press and appointment went as not quick enough. It is a machine
Are they for me or for the carers to look at or support worker. I want the letter to be addressed to me but then have a bit where it says 'show this to the carer'. Letters should be clearer. "It's addressed to me but to hand over to carer or support worker"
Husband wouldn't ask to have meds put in blister pack so he needs to ask. If I had no help I would end up taking it all.
My husband puts my tablets in my blister pack for me
My husband is my registered carer
Pharmacists are not good; they get it wrong. I am on blood thinners.
Pharmacist told my husband that if 'I am on this and that' it can lead to heart damage (medication was reviewed)I am on blood thinners too

What would you like to happen?
Something clearer for me
Aren’t they going to put it on a website? It should be flagged

Hard of Hearing Group

Name comes up on screen at Bishop Castle GP Practice. So simple to have a screen where your name comes up.
When they call you from behind the door it makes it impossible sometimes.
Isn’t it better to have name up instead of Dr calling name?
Doctors always call your name.
Sometimes they just call you on your mobile phone and you can’t hear them.
When appointments are made, why can’t they be closer to where we live? If they give you another Telford Appointment you should ring the secretary to rebook.

Carers of Adults with Learning Disabilities

My daughter aged 37 was at the dentist. The dentist said it was my daughter’s choice not mine. She didn’t know what she was talking about. I should be allowed to make those decisions.
We come here three days a week. Some pay more than those who come 5 days a week. I have raised this. They use you minimum income guarantee. (A discussion about paying for the time at the activity center).
Went to colposcopy at RSH. Dr was very good explained the process and showed her the screen. She was very excited to see her ‘parts’ on the screen.
She fell off a pony, had a spinal abscess. Dr told her all the details including 50/50 chance of recovering. Had to move the Dr out of the room and tell him I wil explain in a way she understands. She couldn’t feel pain, I knew when she was ill, she didn’t.
She tried every dentist until one showed her everything and what it did. It went really well.

They always need to involve us we can then explain. My Dr is very good with me (Plas Ffynnon, Oswestry). I've been at the surgery all my life and my daughter.
Every time at Dr I see a different Dr have to go through his history every time. Have to take anyone that is available.
When you talk on the phone its not the same.
I had a 7 minutes phone call from the hospital then referred back to the GP (this was after being under the hospital for support, phone call was them assessing and discharging)
My GP surgery will make you a face to face appointment
I prefer to do it the old fashioned way
As long as they will speak to you, only one dentist that wouldn't
You have to tell them they [person they are caring for] won't understand
There was an article in the paper by a journalist whose daughter has Downs Syndrome who said once his daughter was 18 it was harder to get consent. You need to use common sense.
We know our child the best. I never had support, in the end I couldn't move her. She never had rest-bite, they couldn't handle her. Only diagnosed 7 years before she died. If known earlier, we could have supported her better.

Carers Group

Always go with my husband – I do find it difficult with his Alzheimer's - he is aware of what is going on. I find it hard talking in front of him and wish I could have a separate appointment
I feel for people who are not fighters
They don't give enough thought of the person caring – whether they are coping or not

Appendix C – Paper Survey

NHS Accessible Information Standard Survey Questions

1. **Do you have any of the following conditions (which may affect the way you communicate or understand information):**

- ○ Sight Loss
- ○ Hearing Loss
- ○ Mental Health Condition
- ○ Learning Disability
- ○ Neuro-Developmental Condition (such as autism, ADHD etc.)
- ○ Other Condition

2. **Are you also a carer for another person? (This may be unpaid or provided informally)**

3. **Have you ever been asked about your communication needs or how you communicate with others?**

4. **How do you receive information about your health and/or social care from different services? For example:**

   (Please select all that apply)

- ○ From letters
- ○ From leaflets or posters
- ○ Information on a website
- ○ Phone calls
- ○ Emails
- ○ Texts
- ○ Social media
- ○ Face to face conversations

5. **Do you feel you can understand the information available to you about your health and/or social care from different services? For example:**

   (Please select those you can understand)

○ From letters
○ From leaflets or posters
○ Information on a website
○ Phone calls
○ Emails
○ Texts
○ Social Media
○ Face to face conversations

6. **Have you ever been told by members of staff that they cannot help or support you to understand any information you have been given?**

   (Please give examples if you are able to do so).

7. **Have you asked for someone else to help you (or have been offered help) when you have attended appointments or talked to staff from healthcare services?**

   (Please give examples if you are able to do so).

8. **If information was provided and you did not feel you could understand it, how did this affect you?**
   (Please select all that apply)

○ I was not able to contact the service
○ I missed my appointment
○ I was prescribed or given the wrong medication
○ I could not understand how to take the medication I was given
○ I did not take the right dose of my medication
○ I was not able to communicate with health or social care staff
○ I felt I was misunderstood
○ I missed out on information I felt was important about my health & social care
○ It affected my mental health and/or overall wellbeing

Another effect (Please describe below)

9. **What service(s) does your experience relate to?**

Please select all that apply

○ Royal Shrewsbury Hospital
○ Princess Royal Hospital
○ Robert Jones & Agnes Hunt Hospital
○ Community hospital (please specify)
○ Community Health Services (e.g. District Nursing or Health Visitors)
○ Hospital Mental Health Services
○ Community Mental health services
○ Ambulance Services
○ GP service (please specify)
○ NHS Dental service (please specify)
○ Pharmacy service (please specify)
○ Optician (please specify)
○ Social Care services
○ Care home service (please specify)
○ Home care service (please specify)
○ Clinical Commissioning Group
○ Other (please specify)

Healthwatch Shropshire would like to understand where we get our comments from so please share your postcode

Postcode: Date:

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