



**Accessible
information report**

June 2022



“Ask me what helps me, and do something about it.”



Contents

Introduction	2
Principles	3
I want to be independent	4
Inaccessible information makes me feel: frustrated, sad and angry	7
Organisations need to listen and respond	8
It is not just about format, it is about the whole experience	11
Organisations should learn from good practice	13
Organisations need to get experts involved to find solutions	15
Recommendations and actions	16
Appendix one	18
Appendix two	19

Introduction

Everyone has the right to receive information in a format they can access and understand. To ensure this happens, from August 2016 all organisations that provide NHS care or publicly funded adult social care have been legally required to follow the Accessible Information Standard¹. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

Many people have been fighting for accessible information for decades and although the Accessible Information Standard has been a legal requirement for six years, unfortunately, for many people things have not improved and they still do not receive information in a format that is accessible to them.

“Why is being disabled so difficult in the 21st century, 26 years after the introduction of the Disability Discrimination Act?”

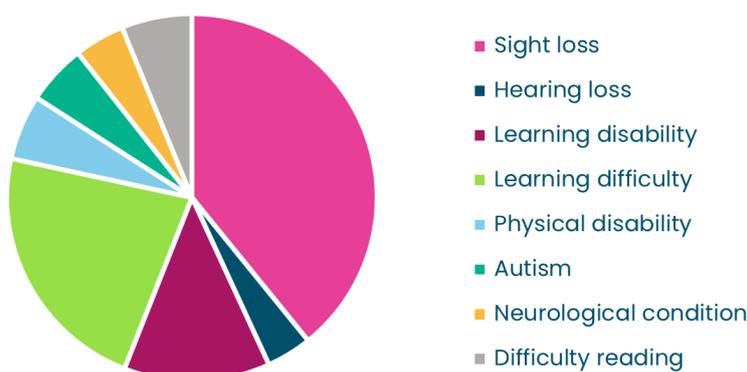
“Since I was diagnosed with a sight impairment I have had to fight for large print format, [it’s taken] three letters to CEOs over two years before I’ve largely succeeded, but [it] can still be hit and miss. I worked for 30 years as CEO of a charity for sight impaired people so I’m aware of [the] requirements. Although retired for 10 years I continue the fight not only for myself but for others and I will not give in, I will keep at them until I get it done”.



Through surveys, focus groups and conversations with 329 people and 10 organisations across North Yorkshire and York, we have gathered feedback about whether people get information in a format they can access and understand, and have developed a series of principles and actions based on this feedback (see appendix for demographic details of the sample and for the list of organisations). This was a partnership project between Healthwatch North Yorkshire and Healthwatch York. North Yorkshire County Council supported us in speaking to forums and groups with whom they engage, and is undertaking its own internal project to ensure good practice in accessible information is embedded within the organisation and it provides information in appropriate formats to local people.

We heard from people with a range of different information and communication support needs, as illustrated below.

Why respondents need information in a different format



*Note that some respondents have a mix of different needs.

Healthwatch England has also recently published a nationwide evidence review on this topic², which reinforces the issues raised in this report and further highlights the need for organisations to consistently produce information and communication in an accessible way. Alongside this evidence review, Healthwatch England has produced a set of recommendations to support the implementation of the Accessible Information Standard across the country³.

Principles

These nine principles are based on the feedback we received and provide a guide for what organisations can do to make sure in another six years' time, no one is still having to fight to get information in a format they can access and understand.

1. Ask what helps and do something about it. Put the user first.
2. Make Accessible Information an organisational priority from the top down and ensure everyone knows why it is important. Have understanding, committed staff championing this at all levels.
3. Ensure that you ask people about their preferred format. Record this and use that information to provide information in a person's preferred format. There is no point in having a flag on a record which is ignored.
4. Once identified, share people's information needs across organisations. Information about people's needs should only have to be recorded once for people to get the right format from all parts of that organisation.
5. Involve people with lived experience to help find pragmatic answers.
6. Provide choice. Don't assume that everyone with a particular issue needs information in the same format or that everything is accessible. Digital is not the solution for everyone.
7. Each organisation should have one contact or team who works across that organisation to find solutions to accessible information needs quickly and effectively.
8. Seek and share good practice. Providing information in accessible formats isn't always easy, but lots of organisations are trying. Share progress and challenges so that things are constantly improving.
9. Review what you're doing to make sure it is working and learn from what is and isn't going well.

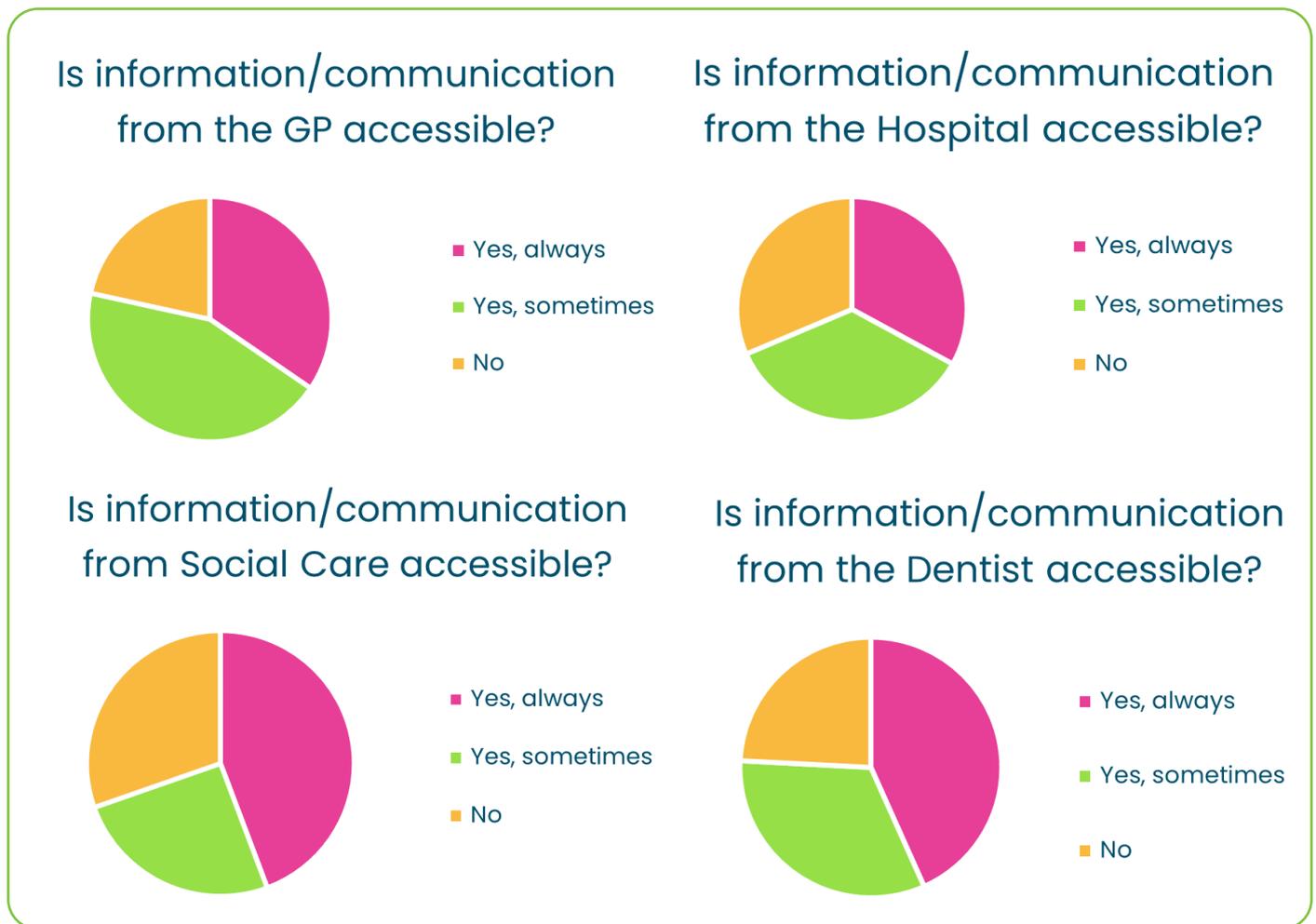
Healthwatch North Yorkshire and Healthwatch York would like to work with organisations to encourage the development and delivery of action plans based on these principles to ensure accessible information is produced as standard.

² [The Accessible Information Standard findings from our evidence review February 2022 \(healthwatch.co.uk\)](https://healthwatch.co.uk)

³ [Your Care, Your Way Campaign Full Recommendations \(healthwatch.co.uk\)](https://healthwatch.co.uk)

I want to be independent

A large majority of survey and focus group respondents said they want to be independent but feel deprived of their independence as a result of not getting health and care information in a way they can read themselves. As shown below, in this sample, people who need information in an accessible format do not get it regularly or consistently from health and care organisations, who are legally obliged to do so.



In our sample, 59% of respondents said if they do not get information or communication in their preferred format this means someone else has to tell them what it says and someone else may find out private information about them. Many organisations send information in a standard letter format and only offer a phone number for queries, to change appointments or to book follow up appointments.

However, some people with sight loss, learning difficulties or other conditions cannot access or understand a standard print letter and rely on others to read it out to them. Similarly, some people who are D/deaf, people who are neurodiverse, or have speech issues cannot always use the phone. With no other option to contact services, they have to rely on someone else to have conversations on their behalf.

Over half (65%) of respondents also said if they do not get information in the right format this can mean they miss out on information or appointments. This is not only stressful and disappointing for the person but also costs organisations time and money.

What happens if you do not get information/communication in your preferred format?



We all have rights in health and care. Most of us take for granted that we are the first people to know the news about personal health or care issues. This is not the case for many people who need information in a different format. Having to rely on somebody else means people are being deprived of their independence, privacy and control over their care. Respondents said this loss of independence makes them feel frustrated, invisible and like a second class citizen.

“It’s frustrating. My husband is quite capable of managing things for himself if it’s in the right format. It’s very annoying when it isn’t as I have to help which is time consuming for me and limits his independence”.

“[There are issues with] leaflets covering hospital procedures, or pre/post procedural measures to aid recovery. [It is] never even considered that the patient needs them in a format that is comfortable for them to understand, allowing them the independence they desire and crave, without having to go through unnecessary fretting, worrying, fussing from loved ones or friends. There are things a patient would like to keep private within their personal control”.

“I would like them to have Video Relay Service for British Sign Language (BSL) so I can ring them anytime I want to discuss things for myself by myself!”.



The case study below from Ian further reinforces the profound impact not getting information in an accessible format has on people's independence and privacy.

Ian, who lives in Whitby, has Motor Neurone Disease which has affected his speech so email is his preferred format. He can read letters sent to him, his issue is about how he can respond if needed as almost always the only option is a telephone number. Ian said: "Many people who do not use telephones are still able to manage their own administration. It may be a financial issue that the disabled person does not want to share with carers; it may be a personal health or personal care issue which again they don't want to share. Quite simply why should I ask, and pay, a carer to do anything for me that I can do myself?"

Ian feels all health organisations need to better understand the impact on disabled people having to fight the system to get accessible information and services. It is the emotional impact (frustration, anxiety) of going to an appointment not knowing if what you need will be provided. Will there be an interpreter if you need one, a quiet room if you need one, support etc. Too many people go to appointments not knowing if they will be able to express themselves or understand what they are being told or asked. It also costs money, as not sending information in an appropriate format means people will miss appointments (that they do not know they have) and that will financially impact the NHS.

Ian's GP surgery pre Covid gave a lot of excuses about not providing information in the right way for Ian. However, post Covid, Ian now has a GP's email address and the generic practice email he can use.

When organisations do not provide alternatives that enable Ian to communicate, Ian has challenged them. Some organisations are receptive including North Yorkshire County Council who are trying to find solutions. Ian's biggest frustration is with hospital trusts he is in touch with for appointments, where he has been told communication by email is impossible.

Ian added: "It is amazing in the 21st century that these issues are still there. The system doesn't anticipate that not everyone can use the phone. It is a legal requirement of the Equality Act that NHS Trusts make reasonable adjustments by providing alternatives to use of a telephone."



Organisations need to listen and respond

It is essential that organisations ask people what format they need and then act on this information. In the survey we sent to organisations, 82% of the organisations who responded (mostly GPs and hospital trusts) said they do ask people what format or communication method they would prefer and note their needs in some way. However, if this is happening it is not always consistent as 67% of the individuals who responded to our survey said they had not been asked by any organisation about which format they need information or communication in.

Unfortunately, on many occasions, the responsibility is still on the person to ask for information in their preferred format. However, even when it is raised many times, respondents said their needs are often still not taken into account. Some respondents said they know their medical notes include information about not phoning them up, but still the default is for them to get a phone call or to be told to phone up. Others said that they cannot read or access text messages, but appointment updates are still sent by text, meaning they can miss appointments or turn up to appointments that have been cancelled.

This highlights the need for organisations not only to ask people what format they require, but also to act on this from the outset. To ensure this happens, IT systems need to work effectively to flag the issue and staff also need to note and consistently act on the information stored on the system.

“For seven months I’ve been finding it very difficult to get a GP appointment. The receptionist always offered phone call appointments with a GP. This [is] a nuisance as I am profoundly deaf and it is not a good way to communicate. I’ve always found it challenging to get a face to face appointment. I chatted to the GP in March about this problem and they raised it with reception. Still no improvement. I come to get an appointment booked again as the same problem still around. Once again offered a phone appointment. Ridiculous. I eventually got [a] GP appointment but had to wait a week”.

“Hardest thing for me by far is being texted re important things -i.e. from doctors who I keep telling I cannot see texts”.

“My husband asked the doctors to phone on the landline as he can’t use a mobile. They did once and now they ring on the mobile again”.

“I would like them to ask me once, and then receive everything in large print thereafter”.



Some respondents expressed particular frustrations they have with receiving inaccessible information from eye clinics and hearing clinics. One respondent said they have been given important instructions about what to do after an eye operation in standard print which they could not read. Information should be accessible in any healthcare setting, but it should be the default for certain settings such as eye and hearing clinics.

“You would think all eye clinic patient letters would be defaulted to large print...[The] issue with [the] eye clinic is that at the end of an appointment, the professional provides a leaflet with printed information which can't be read. When you ask for them to email a pdf/word version it is as if they have never heard of that as an option. Why can't they have accessible versions available through the hospital or another website, so all they have to do is say, you can find a copy in x to download or print to the right size. Or they could take your details, pass them on to an admin person and ask them to email you an appropriate copy”.



“Getting a discharge letter after having a cataract operation, given instructions about what to do, in standard print. Need to think in advance and provide larger print and/or have the option to email it to the patient later”.

It is also important to note that the same format does not work for everyone. Respondents were clear that assumptions only lead to problems and not every person with a particular condition wants information in the same way; choice is key. Similarly, whilst some people are keen on using technology for information and communication, for others, digital is not the most appropriate or accessible option meaning it should not be the default.

“It should be a standard question asked at the start of any process: ‘What is your preferred means of communication.’ Please do not assume”.



“[Organisations] need to understand that not everyone has a smart phone or can use the internet well. There should always be an option - often this is not the case”.



This case study from Alex highlights the need for organisations to listen and crucially, to act on what people say is their preferred format of information or communication.

Alex, who lives in Craven, has autism which has had a negative impact on his senses as he has got older meaning he finds using the phone very difficult. He says it is like watching television with the volume at two, so you know people are speaking but have to concentrate extremely hard to work out what they are saying.

While no health organisation has asked Alex about his preferred format, he has continued to let his GP and hospital know not to use the phone for the past four years. With help from his social worker (who emails) 'no phone calls' is now on his notes, but often it is ignored.

He added: "Medication reviews are particularly difficult as the pharmacist telephones and only leaves a message on the third unanswered call to say that they have tried to call and as you did not respond you cannot order a repeat prescription. There is no non-phone option."

Airedale Hospital generally sends information by post, but a phone number is the only option for queries or to change appointments. Alex's hospital record also says not to phone, but when the GP referred Alex for an x-ray, the hospital phoned him to arrange a time. To do this, they would have had to go onto his record to get the phone number, which is next to a note saying 'don't phone'!

Alex has found some good practice. When he had Covid and had to rearrange a face to face appointment with the Memory Clinic, he was able to arrange an online appointment using Microsoft Teams (the admin person had to check whether Teams was available at the Outreach Clinic!). It wasn't easy to arrange, but worked for him and the consultant.

Leeds GIC care coordinator is good at using email but the video software used by the consultant 'Attend Anywhere', is a mystery to the consultant when it comes to enabling Alex's Support Worker to join the meeting which Alex has been told is doable, so Alex ends up having to attend the appointment on his own and struggles to remember what was said.

Leeds Sleep Clinic has updated the technology that monitors sleep apnoea so it can be read remotely. Reviews are offered by phone or by filling in a form which works brilliantly for Alex if there is nothing to discuss. However, if Alex needs to talk to someone, they do not offer a video option, so he has to go to the hospital (an 84 mile round trip) to see someone face to face.

Alex feels: "there is an assumption that everyone has someone who can help them if needed. By not listening or reading my notes, healthcare professionals are saying I do not matter and my needs are a nuisance."

It is not just about format, it is about the whole experience

A number of respondents in the survey and particularly in the focus groups highlighted that it is not just the format of the information or communication that needs to be accessible, the content also needs to be easy to understand and the experience at the appointment itself must take people's needs into account.

Unfortunately, services do not always provide information in a way people can easily understand; wording can be complex and is not always in Plain English. Respondents also said Easy Read is not always formatted correctly, sometimes Easy Read information is just pictures added to existing text, with wording that is full of jargon.

Any information sent electronically by health and care organisations should also be able to be accessed by the technology someone uses. Some respondents with sight loss said the screen readers they use cannot always read a pdf so Word documents should be used, with any images having a written explanation.

“Letters should be formatted in an easier way to understand, not just bigger print. A letter with an appointment has most of the important information – time, place etc. – in just one sentence. It would be better if it could be in bullet points”.



Services also need to ensure people's needs are met when they attend an appointment. For example, someone with sight loss should not be asked to respond to visual information. One respondent said doctors often call out the name of a blind or visually impaired person and then walk away, expecting them to follow without any problems. Similarly, someone who is D/deaf cannot be expected to hear when their name is called out in a waiting room. Accessible information extends to providing BSL interpreters when people need them. Plus, having the skills to talk to all people and make sure they understand what is being said in any health or care environment.

“Doctors call you in the waiting room and then you don't know where they have gone”.

“In waiting rooms, not everyone can see a screen or hear a name being called. People need to read the notes and provide additional support if needed. If you're not sure, ask”.



This case study from Marnie further reinforces the importance of both the format and content of information being accessible.

Marnie is a student at Henshaws College in Harrogate and is blind. Her preferred format is Braille, but she is able to access email and some documents thanks to her Brailliant, a Braille keyboard which can translate text into Braille and vice versa. Marnie is really clear about how people should send information: "I need information in the body of the email or in a Word document. I cannot access pdfs. If pictures are included, they need a caption or description to explain what the photo is showing. Wording should also be in Plain English."

"I want information in my preferred format so I can understand what it says and no-one has to explain it to me, I won't miss any appointments and no-one else will see private information about me."

Unfortunately, Marnie's GP, social worker and dentist all send printed letters.

If Marnie were speaking to the Prime Minister, she said: "I would explain why information should be in accessible formats. I would tell him that excuses about cost are not good enough and that if it is difficult, it does not matter. People need information in the right format for them."



Organisations should learn from good practice

When asked whether getting information in their preferred format has improved over the past five years, a quarter of respondents said it has got better which shows some progress has been made and highlights that there are some examples of good practice within the health and care sector.

Has getting information/communication in your preferred format improved over the past 5 years?



It is important that organisations work together and work across departments to share good practice, learn from each other and best support their service users. It is likely that each organisation will face similar challenges, so it is logical for organisations to share ideas and possible solutions.

In the survey we sent to organisations, all but one organisation said they had an Accessible Information policy and most said they are asking and recording what format people need information and communication in and are providing some formats on request. However, available formats varied among organisations, with some only providing large print, and others providing a full range of formats. Only two organisations said they provide BSL, audio and Braille and only three said they provide Easy Read, which suggests even though some efforts are being made to support people with communication needs, many organisations still have work to do.

The case study below provides an example of good practice, where the respondent's GP always sends information in an accessible format. The respondent also suggests a way NHS services could work better together to ensure accessible information is available across all services.

One respondent from York is blind. Her preferred format is email as she can use screen reader technology to read the information sent.

She has asked her GP practice to send information by email and they do this and it generally works really well so she can access the information herself and does not have to ask her neighbours or home visitors for help.

She does have an app (Seeing AI) on her phone which can scan and read letters, but has difficulty in pointing the camera in the right direction to get the information she wants. Usually she can use it to understand if the letter is important and then ask for help.

While her GP has addressed her information and communication needs Covid tests and screenings are difficult. She hasn't been anywhere she needed to show a negative Covid test as she cannot do them without help. She feels that if they sent the test instructions by email, she could do most of the test herself, but would still need help to see the result. She also tried to do her bowel cancer screening herself, but did not know if she got the sample in the right place.

She thinks the NHS should work better together about accessible information: "It would be better if the health service joined up its information. Why can't your accessible information need be linked to your NHS number, so every part of the NHS has the information and can act on it. That would be so much easier."

While there are examples of good practice, as illustrated, this is not happening consistently across organisations or across all departments within organisations.

An example of inconsistent provision was given by one respondent who said when clients ask for information or communication in a different format such as BSL interpreting or translation into BSL video clip the responses have been "hit and miss". They said they could have BSL interpreters at one meeting but no interpreter booked for the next one. It is also concerning that, within our sample, only one organisation said it had audited its accessible information provision and developed an action plan as a result. This suggests organisations need to do more, by providing training opportunities for staff and regularly auditing their provision to ensure consistent good practice.

"I would like organisations to have training on how to make things Easy Read and accessible for disabled people".

"Many organisations do not realise how easy it is to produce email and large print".

"[Social] care plans are in written English but they book a BSL interpreter to go discuss it with me. I don't get a BSL video to explain the plan - I ask for this and they won't provide it".



Organisations need to get experts involved to find solutions

People with lived experience and organisations who support these people can help find simple and practical solutions to ensure information or communication is accessible to all. More than 300 people shared their experiences with us, many of whom would be willing to be part of the solution and help if organisations are struggling to provide information in a particular format. It is important that every organisation listens to and involves people with lived experience in developing and delivering action plans that lead to improvements.

“Services need to engage directly with their users who have lived experience of needing accessible communication”.

[Organisations need to] communicate better internally and externally, be patient focused/patient-led to be more efficient and effective for good outcomes. Improve feedback systems to improve outcomes”.



It is also important to recognise that there are challenges for organisations when it comes to accessible information, for example due to inflexible computer systems and technical difficulties. However, no matter what the challenges are, organisations should always try to find a way to ensure everyone’s needs are met.

There are many organisations across North Yorkshire and York that support people with a range of different needs. They are working to find ways to communicate effectively with their service users and members. Such voluntary organisations and charities could share their learning and provide support to help health and care organisations overcome the challenges they are facing to provide information in a range of accessible formats.

“There are technical difficulties where systems don’t talk to each other and different departments in a council or hospital use different databases and save someone’s information in a different way. But in the 21st century there should be ways to address this”.

“Have a designated representative assigned to these questions and queries who care, show willingness to help, and feedback with positive response i.e. your letters, pdfs, leaflets will now be sent by email – if you do not receive something in this way, please email or contact me. Thus enabling further dialogue, and not prematurely closing the door on people without a satisfactory conclusion”.



Recommendations

The feedback we received has highlighted a number of clear principles. Alongside these we have recommended a number of actions to follow in order to achieve these principles. If these are followed, we are confident that if we ask people in another six years, they will be getting information in the right format and will feel positive, independent and empowered as a result.

Healthwatch North Yorkshire and Healthwatch York are committed to supporting these changes and would welcome an opportunity to work in partnership with organisations to help make this happen.

Principle	Action
<p>Ask what helps and do something about it. Put the user first.</p>	<p>Organisation: ensure there is a policy of asking every person if they have a communication need as part of a wider accessible information policy or strategy and action plan. Staff and volunteers: ask if your organisation has an accessible information policy/action plan. If not, ask why not and urge it to do so.</p>
<p>Make Accessible Information an organisational priority from the top down and ensure everyone knows why it is important. Have understanding, committed staff championing this at all levels.</p>	<p>Organisation: promote the accessible information policy and ensure that it has champions at every level and a regular agenda item for appropriate meetings. Staff and volunteers: Read and follow the policy and challenge any behaviour which is not delivering the policy's principles.</p>
<p>Ensure that you ask people about their preferred format. Record this and use that information to provide information in a person's preferred format. There is no point in having a flag on a record which is ignored.</p>	<p>Organisation: ensure a person's information needs are clearly recorded on a person's record and that all staff are aware of this and know where to find the information. Staff and volunteers: check if a person's record highlights any information or communication need and act on it.</p>
<p>Once identified, share people's information needs within organisations. Information about people's needs should only need to be recorded once for people to get the right format from all parts of that organisation.</p>	<p>Organisation: ensure information is shared across the organisation, either through a central IT system or another means so that a person only needs to tell you their information needs once. Staff and volunteers: ensure someone's information need is on their record and that the information is shared with or highlighted to others you are working with.</p>

<p>Involve people with lived experience to help find pragmatic answers.</p>	<p>Organisation: ensure your accessible information policy and action plan includes ways to find solutions if these do not already exist. Ensure the organisation will not condone an answer of 'that is not possible' without exploring a range of alternatives.</p> <p>Staff and volunteers: be clear who in your organisation can help you to find a solution if someone needs something and you do not know how to provide it. Also work with the person to identify alternatives as appropriate.</p>
<p>Provide choice. Don't assume that everyone with a particular issue needs information in the same format or that everything is accessible. Digital is not the solution for everyone.</p>	<p>Organisation: make sure you offer and can deliver a range of alternatives and this is clear to service users and staff and staff know how to access the formats.</p> <p>Staff and volunteers: make sure you know what your organisation is offering and how to provide that.</p>
<p>Each organisation should have one contact/team who works across that organisation to find solutions to accessible information needs quickly and effectively.</p>	<p>Organisation: identify someone to take the role of central contact for accessible information and ensure they have all the support, training and information they need to deliver this. Ensure the rest of the organisation knows about the role and works with them.</p>
<p>Seek and share good practice. Providing information in accessible formats isn't always easy, but lots of organisations are trying. Share progress and challenges so that things are constantly improving.</p>	<p>Organisation: identify and learn from good practice and what is not working. Share information across organisations and between organisations.</p> <p>Staff and volunteers: share good practice with colleagues, managers and others. Also let people know when things are not working so they can be improved.</p>
<p>Review what you're doing to make sure it is working and learn from what is and isn't going well.</p>	<p>Organisation: regularly review your policy and action plan to ensure things are improving. Update your policy and action plan to reflect changes and improvements.</p>

Thank you to everyone who worked with us on this project, responded to our survey or attended one of our focus groups and contributed feedback.

A particular thank you to the people who provided case studies and to North Yorkshire County Council, Key Ring, Leeds Society for Deaf and Blind People, MySight York, Sight Support Ryedale, The Wilf Ward Family Trust and its Jigsaw group, Vision Support Harrogate District and Yorkshire Coast Sight Support.

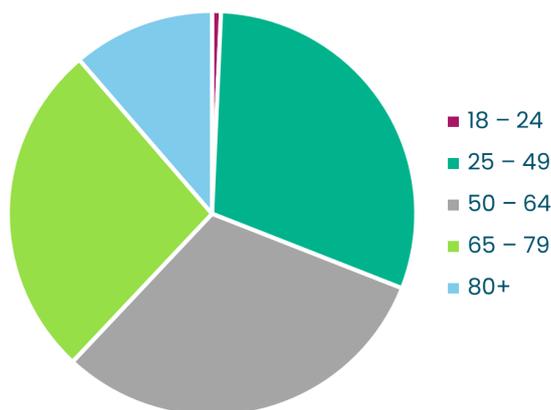
Your voices help inform and shape health and social care services in North Yorkshire and York. The more feedback we receive the greater chance we have in influencing change – so thank you for sharing your experiences with us.

Appendix one

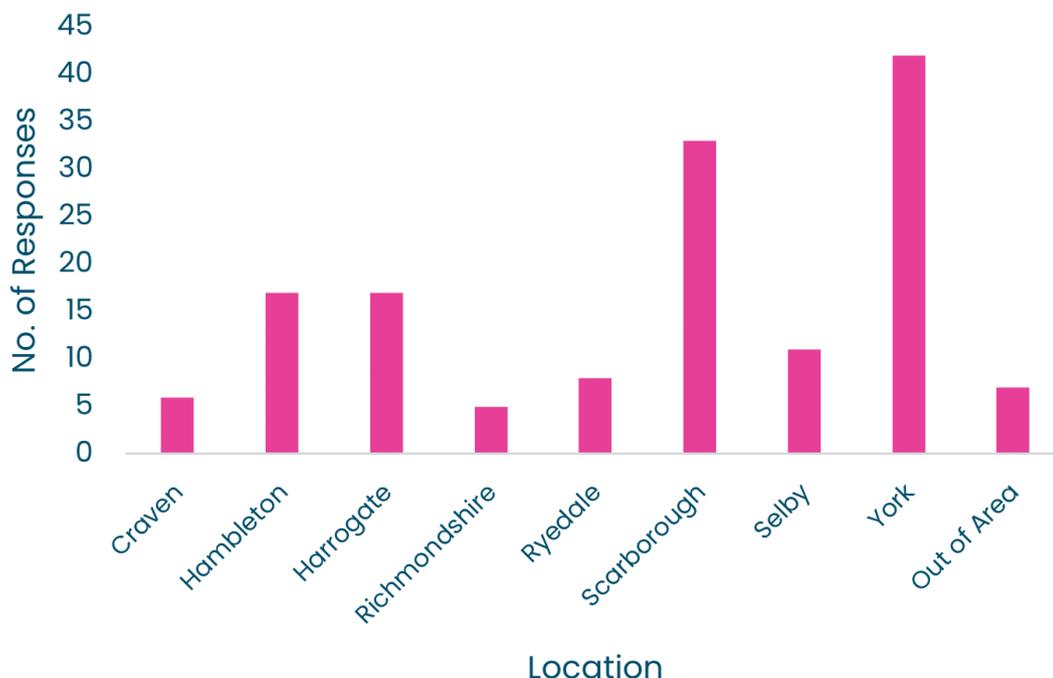
Demographics

Our survey sample included, 66% female and 30% male (4% preferred to use their own term or would rather not say). The majority of respondents were aged between 25–79, and a large proportion (93%) were White British (3% were Asian, Black or from mixed multiple ethnic groups and 4% said they were from other ethnic groups/ would prefer not to say). The geographical location of the survey respondents is illustrated below.

Age of respondents



Geographical location of respondents



Within the focus groups there were a mix of ages, but generally those with sight loss were over 60. There was also a mix of male and female participants from a range of different geographical locations.

Appendix two

Organisations

Our survey was shared with all health related Trusts and Clinical Commissioning Groups (CCGs) across North Yorkshire and York. Through the CCGs we aimed to circulate the survey to all Primary Care Networks and GP practices. The organisations who responded to our survey are listed below.

- NHS Vale of York CCG
- Communities and Prevention Team - City of York Council
- Humber Teaching NHS Foundation Trust
- Stillington Surgery (Hambleton district)
- Ampleforth and Hovingham Surgeries (Ryedale district)
- Pickering Medical Practice (Ryedale district)
- Dyneley House Surgery (Craven district)
- York and Scarborough Teaching Hospitals NHS Foundation Trust
- Leeds Road Practice (Harrogate district)
- Danby Surgery (Scarborough district)

healthwatch

North Yorkshire



Thank you to everyone who gave their feedback - we will continue to call for improvements on health and social care across North Yorkshire, and the more feedback we receive the greater chance we have in doing so - so thank you for continuing to share your experiences with us.



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