



Your Care, Your Way

Access to health and care for people with
visual impairments

Published May 2026



**Knowing
Works®**

Delivering your local Healthwatch service



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About Knowing Works CIC

Knowing Works is a large-membership social enterprise working to independently include people's lived experience in the shape and design of businesses, services, and strategies across sectors.

Over a decade of development in...

engagement, partnerships & collaborations, research, communication, service evaluation and authentic co-production. We deliver projects with an understanding of the challenges faced by those who commission us, bringing to the fore lived experience and compelling evidence, that changes minds and brings about sustainable change.



200k

Almost 200,000
experiences
analysed



Tens of thousands
of people engaged
in communities



Demonstrable impacts
for commissioners,
providers & the public



A catalogue of
published insights



Valued partnerships
across sectors



About this report

Your Care, Your Way campaign

'Your Care, Your Way' (YCYW) aims to influence standards of accessible information and support from NHS and social care services by:

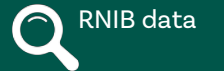
- raising awareness of people's rights to accessible care;
- discovering and highlighting lived experiences;
- challenging services and commissioners to improve.

This report presents findings of a survey and follow-up interviews completed with people living with a visual impairment in Suffolk. The survey was co-produced with people who have lived experience of visual impairment, helping to ensure it was accessible for those using screen readers and other assistive technology.

The survey explored how well local services were meeting people's needs and compliance with the NHS Accessible Information Standard (AIS). The AIS requires services to provide information and support in formats people with disabilities or sensory loss can access.

Explore Your Care, Your Way insights

For more information about people's rights, and to explore more of our insights, visit
www.healthwatchesuffolk.co.uk/your-care-your-way



In Suffolk (2023)

31,900 living with sight loss (est.)

3,390 registered as blind

Expected to increase by **24%** by **2032**



Nationally

One person
every six
minutes begins
to lose their
sight
x6



Every day
250
people start to
lose their sight
in the UK.
That's **one person every six minutes.**

**Who took
part?**

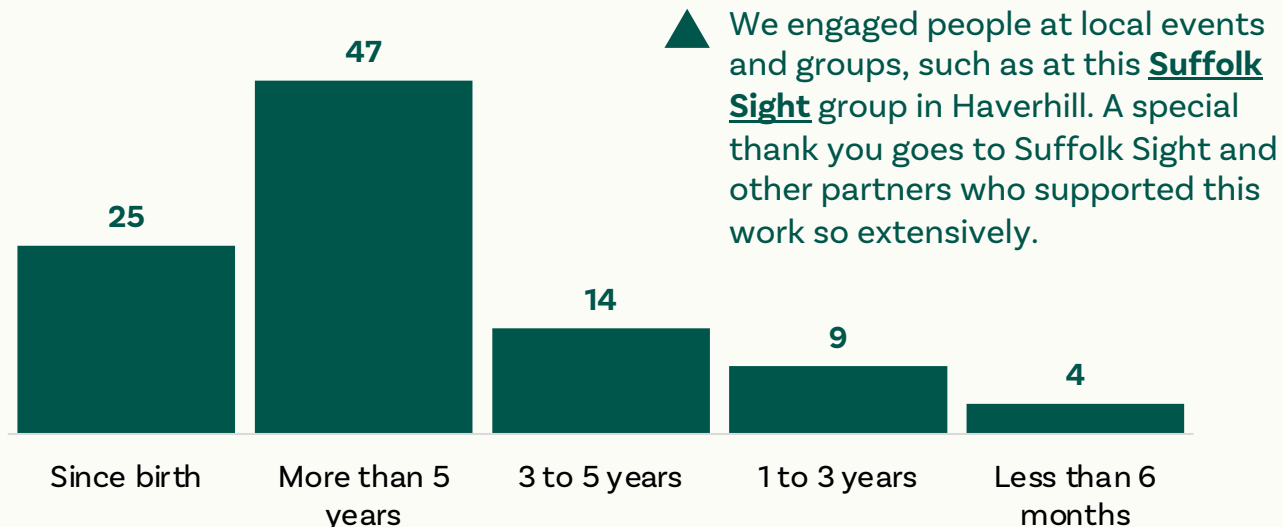


Demographics

There were **101** responses to the survey shared online and in the community by the Healthwatch team and other local partners (such as Suffolk Sight).

- When asked about ethnicity, most people (**97%; 98 people**) selected 'White', while two chose 'Mixed/Multiple ethnic groups', and one preferred not to say.
- Of 69 respondents who had registered as visually impaired, **37 (54%)** were registered as '**severely sight impaired**', while **32 (46%)** were registered as '**sight impaired**'.
- A total of **99** people told us how long their sight had been affected by their visual impairment. **Nearly half (47%)** had been living with sight loss for more than five years, while **a quarter (25%)** had been affected since birth. Around **a quarter (27%)** had experienced sight loss within the last five years, including **4% in the past six months** (see graph right).

In addition to the survey responses, we also held more in-depth conversations with some participants to gain a deeper understanding of their experiences. You can read more about these on pages 9 – 20, with snippets also featured across the report.

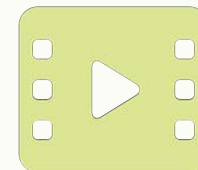


▲ Respondents had lived with their visual impairment for varied amounts of time.



Meet Simon

“Navigating through signposting can really be hard when you have to try to remember so much more as a visually impaired person.”



Watch our videos with Simon

“There is life after sight loss. I found it.”

Sixteen years ago, Simon received a diagnosis of a visual impairment that would change his life completely.

Together with his guide dog Ollie, Simon kindly participated in a series of short videos to highlight some of the ways his life had been affected by the loss of his sight, including the ways he can access health care and support. Follow our links below to discover what he told us.

- Life after sight loss - [click here](#)
- Inaccessible information - [click here](#)
- The importance of access equality - [click here](#)

Watch more of our videos with Simon - [click here](#).

Meet Heather



“I’m lucky as my husband does things for me, like the shopping and reading letters. I manage quite well compared to some people, but I find the loss of independence frustrating.”



Heather was diagnosed with age related macular degeneration around 10 years ago, a condition that affects central vision. Her condition affected both eyes, leaving her vision predominantly black and white and blurred.

Heather has experienced several bleeds and has undergone a vitrectomy to remove and replace the fluid within her eyes. She attends her local hospital for regular eye injections.

Heather is registered as sight impaired and lives in west Suffolk with her husband.

In addition to her visual impairment, Heather is an insulin-dependent diabetic. She also lives with coeliac disease, has arthritis in her hands and experiences mobility difficulties, for which she uses a walker or mobility scooter to support her independence.



Heather's experience

Heather described inconsistencies in the support she has to manage her **diabetes** while living with visual impairment. Despite securing access to a Freestyle Libre (a continuous Glucose Monitoring System, that avoids the need for finger prick tests) because of her limited vision, she has recently been asked to complete a daily written record of her blood sugar levels.

“Three or four years ago, I asked [the diabetes nurse] about a Freestyle Libre because I can't easily do the finger prick test. I can't get the actual test bit to match up with the blood because my sense of perspective has gone. She said ‘it's really only for type 1 diabetics’ and I'm type 2. I explained about not being able to use the glucometer very well and, in the end, she got me a Freestyle Libra for that reason. She's now left and a new nurse, who is very nice, told me I had to have a new photometer because the other one had stopped working. She didn't bother to show me how to use it and they're all slightly different. Then she wanted me to record my blood sugars four times a day for a week. She gave me a little book to write them in. Having seen that I've got a Libra because of sight loss, she's given me a book that I can't even read. So, my husband's having to fill it in.”

Heather felt staff at her GP practice could show greater awareness of her visual impairment. Despite wearing clear visual prompts, she was not always readily offered assistance.

“I have needles to dispose of, so I have a sharps box. I used to be able to just take it back to the doctors and they gave me a new one straight away. The last couple of times, I've handed the box over and the receptionist has said ‘you've got to fill this in’ and given me a form. I didn't know whether it was upside down or not. I couldn't see it. I said ‘my husband will have to fill it in for me’. They looked at me, and looked around, and said ‘oh as it's not too busy, I can help you’. That's a bit frustrating. I had a coat on with a badge saying I'm partially sighted, you know, standing right in front of them with that badge on. And I just thought it was ridiculous.”

Heather was frustrated by the lack of information in the appointment letters sent by the Eye Clinic, which would help her plan appropriately.

“[I find the letters from the Eye clinic are] not very specific. It says who you're visiting, like the consultant's name or one of their team, but it doesn't say whether you're going for an injection or just a review meeting and that makes a difference to me. If I'm going for an injection, I need to be prepared because, once I've had it and I come home, I can't see to do anything at all. If I know I'm going to have one I can think about meals and things in advance and sort everything out. But they never say and it's really frustrating.”



Meet Fiona

“The hardest part is that people don’t know what to do with you. They don’t understand and they don’t know what to do with you.”



Fiona lives in west Suffolk and is registered as severely sight impaired.

Fiona first had problems with her sight years ago, when she experienced a pain in her eyes. An optician made an urgent referral to Addenbrookes where she was diagnosed with Optic Neuritis (swelling of the optic nerve). Overtime, this led to a loss of vision in one eye. She was, however, still able to continue to work, drive and move about independently.

In 2019, Fiona suddenly lost the sight in her other eye, leaving her ‘completely black’.

“I kept thinking ‘there’s something wrong’, [but] I carried on. I woke up, and it was completely black. I actually said, ‘they’re making a lot of noise this time of the night’... it wasn’t until [a housemate] said ‘it’s 8 o’clock in the morning’. I just burst into tears.”

In addition to her visual impairment, Fiona also has a rare form of MS affecting her hands. This means she has difficulty using a computer. However, with the assistance of two support workers, Fiona continues her work supporting other people living with a visual impairment.

Fiona's experience

Fiona's experiences highlighted a widespread **lack of awareness of visual impairment** among both healthcare staff and the public. Assumptions about her capabilities often led to inadequate support, undermining her dignity and limiting her independence.

“[When I was in hospital I needed to go to the toilet, the nurse] just put me inside the door and shut the door. Well, I don't know where the toilet is. I don't want to feel all around the room. She came back and said, ‘Are we finished?’. I said ‘No, I want some help’. She had no idea of what my needs were, totally oblivious.”

“People think [my support worker] is my husband, but he's not. [While I was in the hospital I had to go] to the toilet. And when I came back, I said, ‘Oh, there was a form you wanted filling out’ and the nurse said ‘Oh, it's alright, your husband's done it’. That's wrong. I didn't want to cause a fuss, but I thought, ‘You're out of order’. Okay, he probably knows 99% of the questions. But it's my call... It made me feel very small.”

“I could hear the [receptionist] behind the glass. She said, ‘Can I help you?’ So I said my name and she said, ‘Well, there's a board there [for signing in]’. I said, ‘But I can't see’. I came in with my stick, so immediately, she should have thought ‘this lady may need help’. I'd have wanted her to not embarrass me. Some people with a visual impairment might have been able to do it, but don't assume everybody can... She didn't even help me to a chair. I had to feel my way and say, ‘excuse me, is anybody there?’, because I could have sat on someone's lap.”

Reflecting on what could be done better Fiona said.....

“The first thing that came to my mind was helpful assistance, observation. They need to train people in observation. Looking to see who needs help. It's very simple.”

In her interview, Fiona highlighted another worry she faces receiving information by text – a concern about whether contact is a scam or not.

“I have had texts (from my GP surgery) but I'm obviously scared. I had one the other day. It did say the time of my appointment, but sometimes I worry it is a scam, so I don't answer it. I think, if in doubt don't touch it. You never know if there could be a link behind the link.

“I know someone who was sent a link, that's how they got her.”

Meet Gary



“One of the issues about vision impairment is that people assume if you've got a guide dog or a white stick, you're totally blind and if you haven't, you're fully sighted. Neither is the case.”

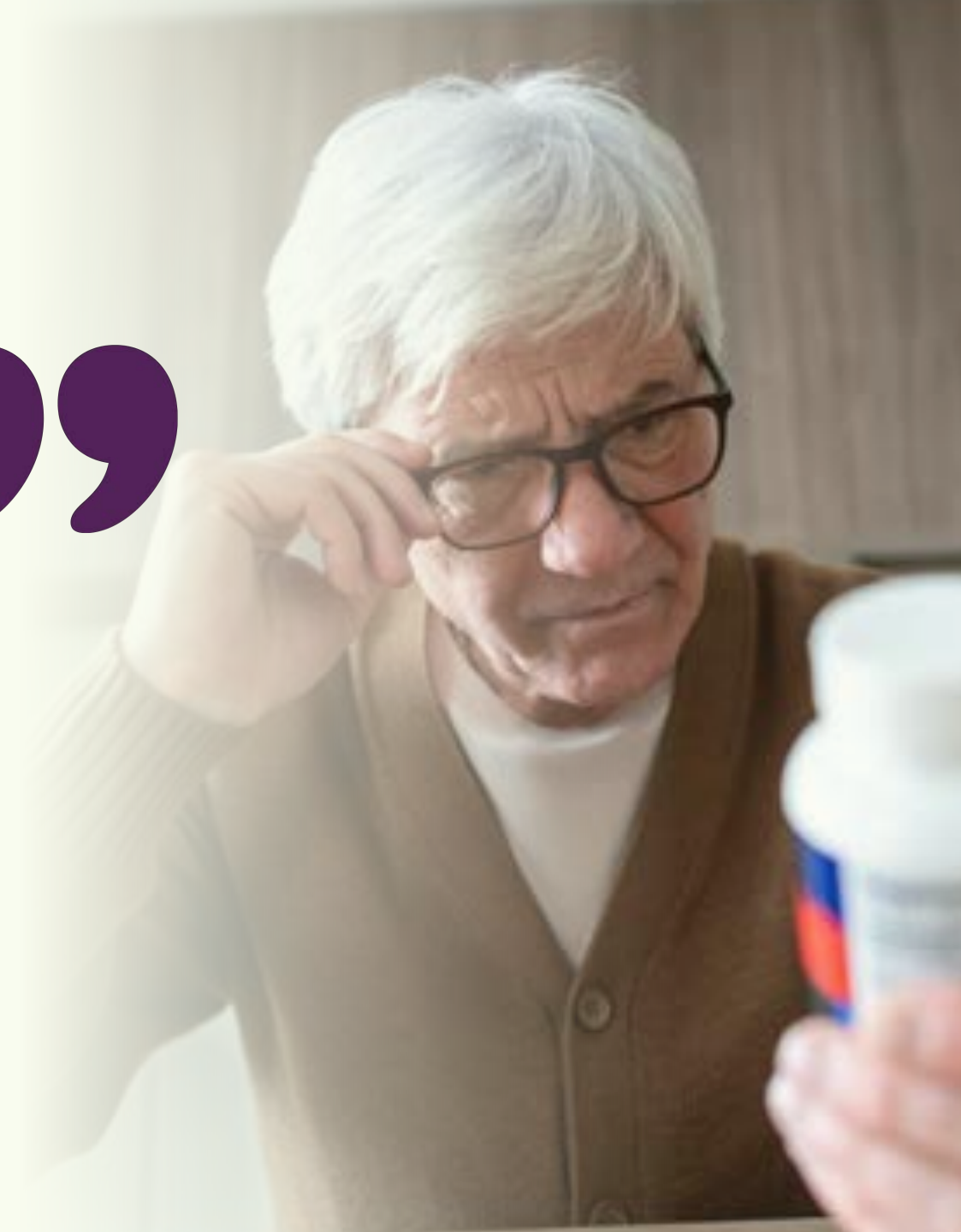
Gary's visual impairment, which he has had since a young child, is the result of damage to the optic nerve caused by a brain tumour. It means that his sight is very limited.

“I've just got a bit in the middle. I can't see down here, or up above, and I can't read. I have to use a strong magnifier to read.”

Gary recalled that, as a child, people often made judgments about his abilities because of his visual impairment.

“When I was a child, and I couldn't see like a notice board or bus timetable, and I used to ask my mum what it said, people thought I was illiterate, they thought I couldn't read. People just assume you must be a bit stupid.”

Gary worked as a computer analyst until a second brain tumour forced him to give up work. For the last 10 years he has helped as a volunteer advice worker supporting people with benefit claims and debt problems.



Gary's experience

Gary has multiple health conditions and takes several prescribed medications. Having experienced a 'near miss' with his own medication, he highlighted the need for clearer and more accessible information about medication for people with a visual impairment. He suggested pharmacists could do more to support patients by providing accessible information, such as directing them to reliable websites or offering clear, readable written guidance.

"I take lots of replacement hormones every day and sometimes I've been prescribed antibiotics which you shouldn't take with those things, and I only found out by doing a Google search. If you get a new prescription, so a new drug like antibiotics, you get a tiny little leaflet inside which you can't read - important things about side effects and what you shouldn't take it with. Even the information on the label on the front of the box, like the expiry date, I can't read that. I don't see why pharmacists can't give out maybe a website to find more, or just a piece of paper, because they haven't got time to explain to people all the different information on the leaflet, and something that's quite important, like what you should take it with or without... In fact, you think the pharmaceutical company would actually put a QR code on the package, wouldn't you?"

Gary felt there had been a lack of response from his GP practice to practical suggestions that would make the building more accessible for people with a visual impairment. Furthermore, he felt that staff lacked general awareness to the needs of people with a visual impairment.

"[Staff at my GP practice] don't seem very aware [of visual impairment]. If I was in the reception of the GP, and I saw someone coming with a white stick, I'd know straight away they wouldn't be able to see - or I'd assume they wouldn't be able to see the screen, and I would say, 'Well, don't worry, take your time, I'll let you know, when it is your turn'. Even if I tell them, they don't seem to realise I can't see the screen."

"Twenty years ago, my doctors asked me to go down to talk about disability awareness training. I had all the doctors and all the nurses there, all the staff talking about loop systems, about wheelchair access, about things like good contrast, stickers on glasses. There's about 6 steps up to the doctor's surgery, that are concrete set, the same colour, and I had real trouble trying to find the edge of the steps, and I commented they should put yellow strips on the edge. Here we are 15, 20 years on and they still haven't done anything about it. So, I'm always worried about whether people are actually going to do anything about it."



“

Meet Pat

“If there was anything that I wanted, I'd probably get my partner to look at it. But I think my medical stuff is private. It's even private between spouses. Plus, I want my partner to be my partner, not my carer.”

”

Pat has type 2 diabetes. They were diagnosed with diabetes related retinopathy with neovascularisation and macular oedema around five years ago.

“[My vision is] pretty blurry. I can see high contrast, but I've lost detail and distance is poor. Anything in just less than perfect lighting conditions is difficult.”

They are registered as sight impaired.

Pat highlighted inconsistencies in the availability of accessible information across health and care services.

“The hospital eye department now sends appointment letters in large print. All other letters do not come large print. And the reports that your GP receives after every surgery or major consultation, they're never in large print either. So even though everybody knows that I need large print, I don't always receive letters that way.”

Pat's experience

Pat has medical related PTSD, resulting in an intense and all-encompassing fear of any medical intervention. As a result, Pat has disengaged from several medical services, including routine screening programmes. Pat was grateful for the support offered by the team at the hospital eye clinic. They felt their concerns had been heard and that reasonable adjustments had been made to accommodate their needs. They felt they would not have been able to access services without this support.

“[I said] ‘I don't know how I'm going to access [the eye clinic], it just seems impossible to me. And I asked if I could just visit to get acclimatised and [the ECLO] arranged that. She's been by my side ever since. I believe they've really taken on board the fact that I am terrified, and I have been accommodated. So, for instance, I don't ever sit in the waiting room. I can't bear it. It's the waiting that will kill me because I will then run away because I've waited long enough. And it's not about being impatient. It's about trying to keep my panic at bay enough so I can access the service. So, it's exhausting... [To put it into context] I've stopped screening, of any sort, and I won't ever have any screening ever again because I've decided that I can't cope with it. I think if I didn't have access to a really good ECLO, my sight would probably have disappeared by now. This is the thing. This is not normal for them. This is an exceptional case, and they have taken the time and effort to accommodate me.”

Pat uses a magnifier to help read hard copy information such as letters and leaflets. While this allows them to access information that would otherwise be unavailable, they explained the effort required is significant. Reading demands intense concentration and can be mentally exhausting, as they have to work hard to avoid misreading or misinterpreting text.

“I've got to use a magnifier and I find it really, really tiring to read any great lengths of stuff because I have to concentrate so hard. My brain pattern matches words it thinks it's going to read and of course sometimes I'm reading things that are not there or I read things that are incorrect because my brain is just trying to do some of the heavy lifting. But, if I'm concentrating really hard, I'll try not to misinterpret it. That's tiring.”

Pat further highlighted that, as someone with a visual impairment, the need to remember information was far greater, as it is not always easy to go back and check information such as directions on medicines packaging.

“I check with my magnifier as much as I can to make sure the box and dosage is right. But the little labels they apply, I can't read those even with a magnifier. They're much, much too small and that has been a big frustration when I've had a one-off medication. I have to really remember how I've been told to use it because I can't read what it says.”

Meet Richard

“

“It is the small frustrations, but there are quite a lot of them. They are not the end of the world, but they make life that bit harder.”

”

Richard worked as a mechanic, but now owns and runs a business selling spare parts for construction equipment.

“One of the reasons I own and run a business is I’ve had difficulty working for other people... Working with visual impairment for others is sometimes tricky. It’s not what you can do, it’s what your employer perceives you can’t do, which is the issue.”

Richard has had blue cone monochromism since birth. It’s a genetic disease that means he has a deficiency in red and green cone receptors, affecting colour perception. Richard also has a nystagmus – an involuntary, rapid, and repetitive movement of his eyes, which he felt is ‘the worst part’ of his visual impairment. He said his visual impairment is ‘not such a big deal in many respects, because I don’t know anything else. I haven’t had great sight and then lost it - you don’t know what you haven’t had’.

Richard is concerned about the future and fears he could become isolated once he retires.

“I am past retirement age, I enjoy what I do and have no desire to retire now, but that decision is partly influenced by the lack of options open to me once retired. I don’t want to become dependant on my wife all the time, but the inability to drive severely limits what I will be able to do. My fear is that I become somewhat isolated”



Richard's experience

Richard shared his experiences of changes to the checking in process at Ipswich hospital, which had made it harder for people with a visual impairment to use. He was frustrated that a previously accessible system had been replaced, meaning he now must rely on staff for help.

“They've changed the reception area, at entrance six times over the last couple of years. Both times they've made it much harder for visually impacted people, which seems incredulous to me when that's where the main eye department is. So, I can no longer check myself in very easily at all, because they've made the machine so much more difficult to use visually... To be fair, there are often helpers. But it's frustrating to me that the system that was incredibly easy to use and functional has been made difficult, so I have to ask for help.”

Further changes to the waiting process for the eye clinic had also created challenges. Richard reported that patients are now required to wait in reception before being called into the department, however a lack of audio announcements, makes it difficult for patients with a visual impairment to know when it is their turn.

“What I used to do was just walk around to the eye department, but they don't do that anymore. They ask you to sit and wait until you're called to the department. But the audio part of that calling is usually turned off. So, you have to look for your number on the screen, which is great if you can see it. Otherwise, it isn't... The helpers always say, 'Don't worry, we'll help you', but to be blunt, they can't because they're helping other people. So, what I tend to do is walk around to the eye department and take the flack from the receptionist there. I think the whole point of the system is to try and keep the eye department itself a little bit clearer. Obviously, if they're very busy, they just don't want you there. Sometimes there's no comment, just 'yep, take a seat' and other times they've said 'no, no, you have to go back'. I've tried to argue and sometimes you win, sometimes you can't. I'm not saying anyone's unpleasant because they're doing their job, but it can be frustrating.”

Richard described how he uses technology to make information more accessible, while also highlighting the limitations he experiences.

“Technology is great, but tech also makes it more difficult because as it gets more fancy, it probably has more features and more bits to it, and that makes it harder... I use a handheld reader thing that will change the colours of the text for me. It's called Ruby, but like everything else it's a struggle. If you had an A4 piece of paper with text on it, you would initially look at the whole thing. You could see the whole page and your eyes would follow the text down. When you have to either blow the text up or change the contrast, then you've got a very small segment of text to read at any one time, which means you're moving the reader all the time. That makes it harder to read documents.”

Key findings





“I ask for email responses... **they often phone or message my husband instead.**”



Eye conditions

Respondents selected the eye condition(s) they live with. Most (66%) reported living with one eye condition, while 16% reported having two and 15% reported three. The remaining respondents did not specify their eye conditions.

The most reported conditions are shown below.

- Glaucoma - **25%**
- Dry age-related macular degeneration - **20%**
- Macular degeneration/dystrophy - **15%**
- Age-related cataract - **14%**
- Diabetic eye condition - **10%**
- Retinitis pigmentosa - **7%**
- Wet age-related macular degeneration - **7%**
- Congenital cataract - **6%**

Other reported eye conditions included:

Aphakia, Uveitis (incl. Behcet's), Hemianopia, Diplopia, Retinal detachment / vitreous issues, NAION, Optic atrophy / optic nerve damage, Nystagmus, Retinal vasculitis, Retinoblastoma, Myopia (non-degenerative), Pigment dispersion syndrome, Choroiditis, Blepharospasm, Microphthalmia, Ischemia, Stroke-related vision loss, and Corneal ulcer blindness.



▲ **42%**

of respondents lived with a form of macular degeneration, which can begin with a blurred or distorted area. If it gets worse, people might struggle to see anything at all in the middle of their vision.



Receiving accessible information

All organisations providing NHS or adult social care services are required to ensure information and care is accessible to everyone accessing services.

The NHS Accessible Information Standard (AIS) provides a framework that services and commissioners can use to ensure they are delivering services with due regard to people's rights and needs.

This section is about people's experiences of receiving accessible health and care, including how they were affected when information or care was not provided in a way that was accessible to them.

The AIS – six things all services must do to meet people's needs

- 1. Check**  You should be asked about your needs.
- 2. Record**  Your preferences for communication should be recorded in your notes.
- 3. Visibility**  Your needs should be flagged to staff when they communicate with you.
- 4. Share**  If you are referred, your needs should be shared with other services.
- 5. Meet Needs**  Your needs must be met. The service should be communicating about your care, your way.

6.

Services should make sure that people's information and communication needs are kept up-to-date in their records and systems. For example, IT systems can remind staff to check people's recorded needs are still correct when they update other information.

For more information about the AIS, please visit:

www.england.nhs.uk/accessible-information-standard

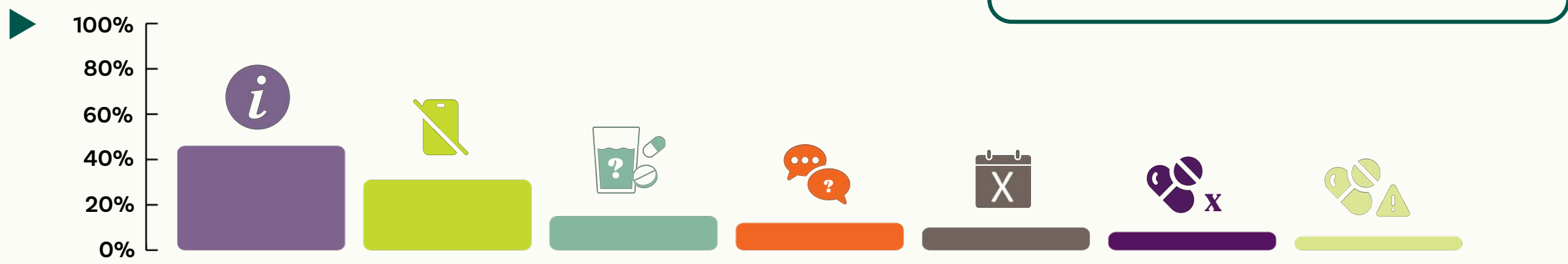
The impact of not receiving accessible information or care

Over half of respondents (52%) reported a negative impact because they had not received information in a way they could understand.

Amongst the 52 people who reported a negative impact:

- Most experienced one negative impact (35 people), however eight had experienced three or more.
- Of the 47 respondents who did not report a negative impact, 32 always received accessible information and support from services. Fifteen said receiving information in a format they could not access did not have an impact. For many, this was because they had access to the support of a partner, friend, or relative.

The top three most frequently selected impacts were missed appointments (24 people), not being able to contact a service (16 people), and difficulties with medication (14 people).



Key

-  Missed important information (46%)
-  Could not contact a service (31%)
-  Not knowing how to take medication (15%)
-  Could not communicate with staff (12%)
-  Missed an appointment (10%)
-  Got the wrong medication (8%)
-  Took the wrong dose of medication (6%)

Ratings across services

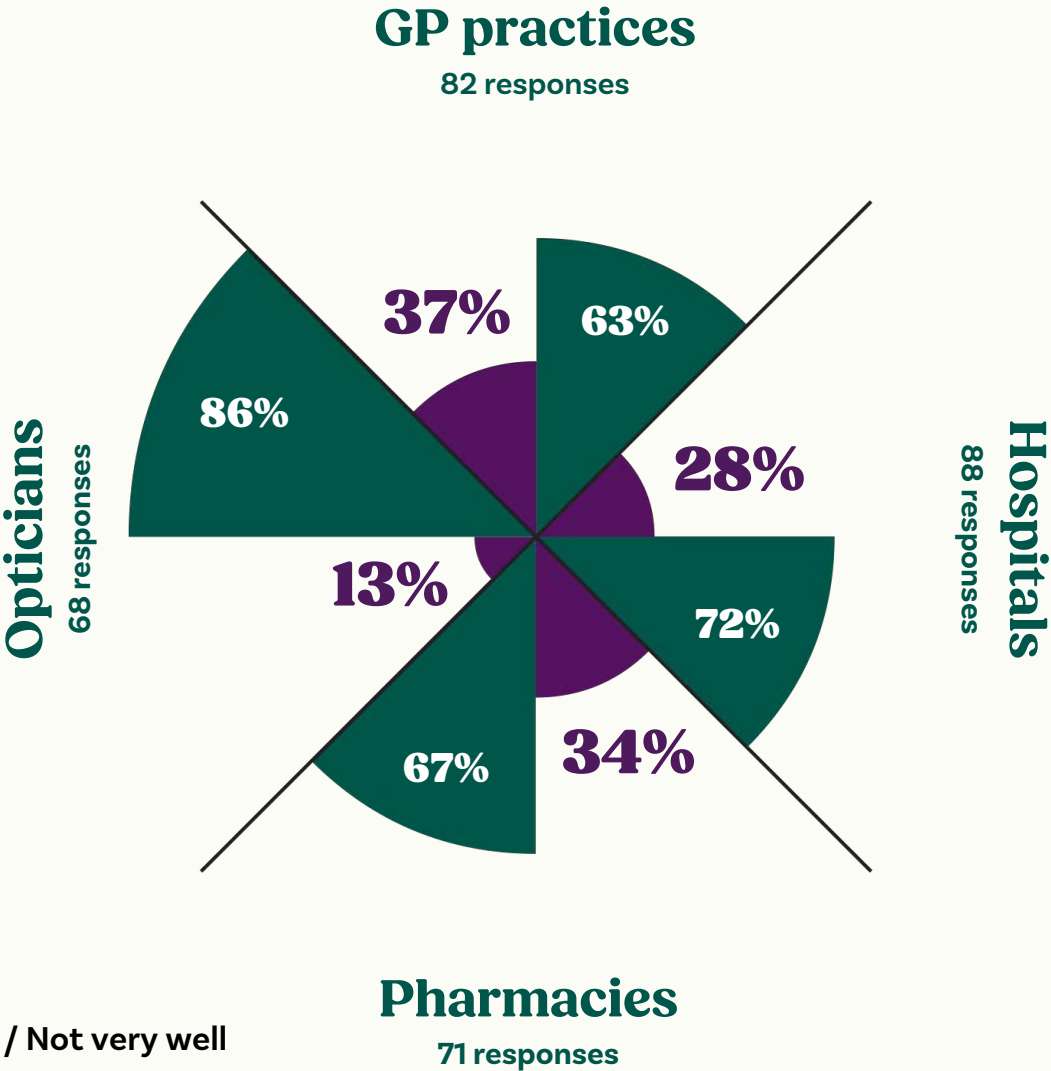
We asked people to tell us how well services ensured the information they received was clear and usable, ranging from ‘very well’ to ‘not very well’.

People were more likely to be positive than negative about the information they received across all services.

Over a quarter of people gave negative ratings for receiving information from GPs (37%), pharmacies (34%) and hospitals (28%), compared with just 13% at opticians.



- Not at all / Not very well
- Quite well / Very well



Qualitative responses

People described their experiences of receiving information from services and suggested improvements.

People had their own ways they liked to receive information, but many praised texts, emails, or phone calls over paper letters. Some used apps, but they could be difficult for others.

Most challenges people faced were associated with letters, leaflets and certain parts of online systems or apps.

For example, one participant highlighted that the NHS app is not compatible with screen readers when downloading images, limiting access to health information for users who rely on assistive technology.

“

“The hospital have sent through appointments in audible format which is fantastic, but any **after care information is still provided in a leaflet**. I think this should be improved.”

“The hospital has finally moved over to using email notification, which is so much more usable (being expandable and readable for the sight impaired), secure, as well as being able to always find any letter as it can be located in a folder instead of losing the ‘hard copies’.”

“

“They always **text me, which is great because I can enlarge the text**”.

”

“My GP does well on providing appointment information via text or email accessible using a screen reader. However, any test results are left for me to find out using the NHS app, which is always very difficult to navigate using the screen reader and sometimes not accessible at all due to the download of letters, etc. These do not get read out, it just says image.”

“Nothing in large print, so someone has to read and explain them to me. I have a learning disability too, so I would like things in easy read - **but it doesn't happen.**”



“I have constantly asked for all documents or appointments to be sent via email and not text as I can enlarge emails to be able to see them.”

”

“Things change and suddenly you have to get prescriptions a different way. Everyone assumes you can just do stuff, read stuff, and sign things. It’s a nightmare to know if you’re doing it right.”

“I keep asking for phone calls rather than emails directing me to the AskMyGP app. It’s frustrating to have to keep asking every time I need help.”

“My practice has never asked me if I would like information in a different format”

“

”

“

“Texts and messages are sent on the assumption that you can see clearly.”

”

Some people were unhappy with how information was shared and wanted more choice better suited to their needs.

Fourteen people were unhappy with the way in which they received information. Some were never asked about their preferred format, felt their needs were overlooked, or reported that requests for alternative formats were not acted upon.

Comments highlighted a need to avoid assumptions and provide information in formats tailored to individual needs.

“When they need to phone, they always use my mobile rather than my landline, which I prefer as I don’t carry my mobile around with me and I can’t see it well.”

Many people experienced problems with print size and readability of letters, leaflets, and other information.

While eleven people said large-print information was provided, 25 said requests were not always fulfilled. Suggestions included improving font size and layout, especially for key details like phone and reference numbers, and offering alternative ways to access information, such as phone calls. Print-size preferences should be recorded and applied consistently to avoid repeated requests.

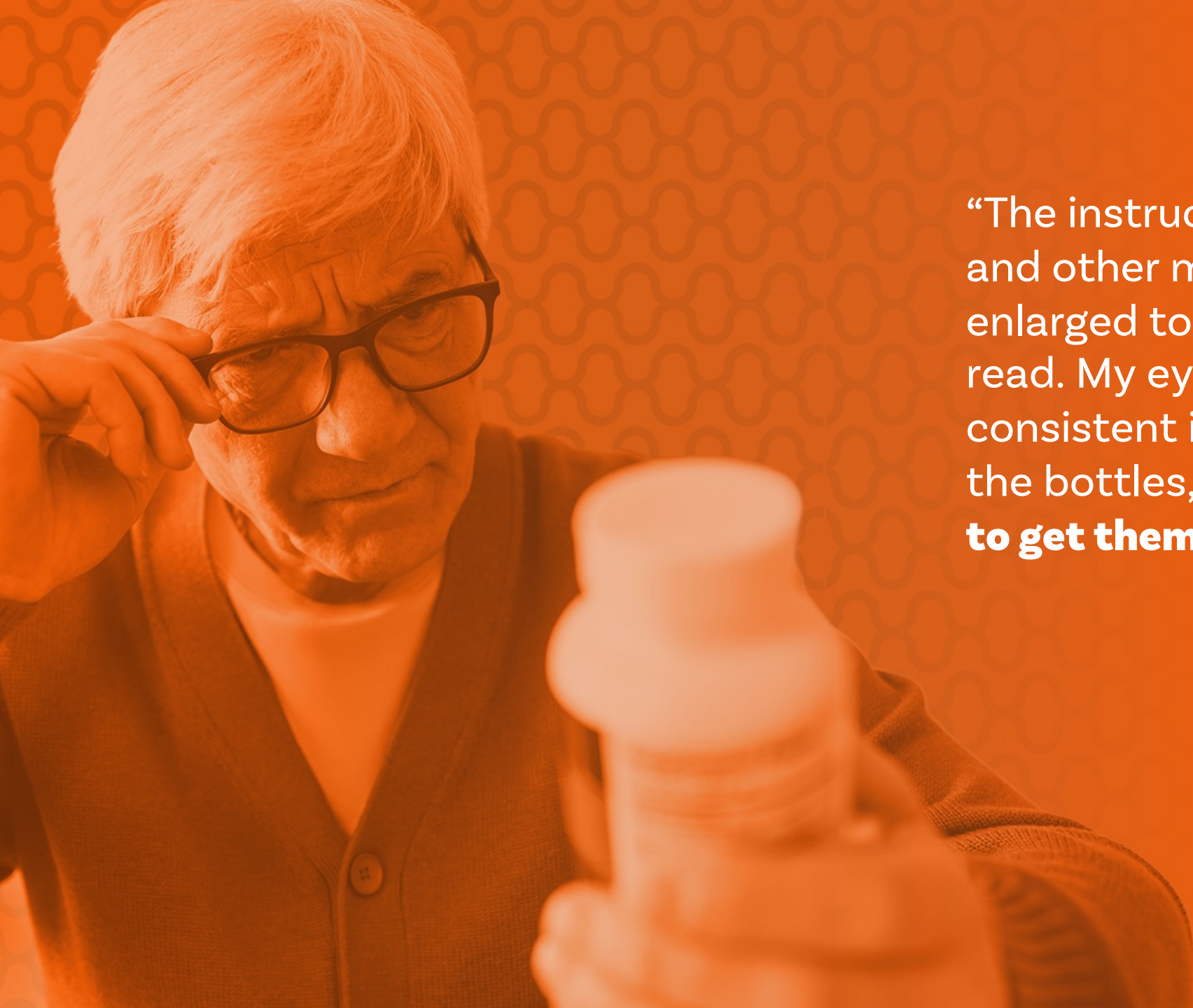
Thirteen people reported difficulties with print size on medication, which sometimes led to confusion or uncertainty about the correct way to take them. Some relied on support from others at home, but not everyone had this help. Suggestions included providing large print or alternative access, such as a QR code linking to a website that can be read aloud or zoomed in.

One person praised receiving information in an easy-read format, while two others said they would like this but had not received it.

“If I do receive printed letters, they are always in standard type and relatively small font size. More thought should go into size, layout, especially phone and reference numbers which are often small.”

“I think that information in the stickers on drugs boxes should be in large print. I can’t read any of them, even with my magnifier. Patient information leaflets are never accessible. They should be supplied in large print.”

“I have always had the same problem with new medications. The important information about dosage and side effects etc is in tiny, unreadable print. This information is obviously very important, and I can’t believe a way hasn’t been found to provide this in an accessible way.”



“The instructions on eyedrops and other medication is not enlarged to make it easy to read. My eyedrops are not consistent in the colours of the bottles, so **it is very easy to get them mixed up.**”

Qualitative responses

People described their experiences of receiving information from services and suggested improvements.

Some people rely on others to access information, which can affect independence and privacy.

Eight people said they had to rely on someone who is sighted to read information. Some felt this reduced their independence and affected their privacy, as they could not access their health information confidentially. One person said it made them feel like they were 'missing out.'

Five people also highlighted a lack of staff support to help them read and understand information, especially if they did not have sighted support at home. However, nine people shared positive experiences, saying staff explained information clearly, checked if they could read it, helped with medication instructions, and were approachable for questions or follow-up support.

“I use paper prescription renewal requests and I'm **not sure how I would cope with this were my wife not available to assist.**”

“Currently my spouse is able to support me, but they also have macular degeneration so this may change.”

“I cannot see information or posters that are all around. So, I have to wait until someone tells me the information there and if it applies to me. **I often don't know about things or miss out.**”

“The pharmacy don't read out instructions on medication that is handed out. [Medication] is in a sealed bag when handed over, so I have to rely on somebody at home to read the instructions for me.”

“Everyone expects me to rely on a sighted person to read and explain information to me.”

“If I need help with letters (the staff) assist me and I can always call the clinic to check anything.”



“One of the worst things any service provider can say to me is, well, haven’t you got someone who can help you?”

If people cannot get information about their healthcare they understand, it can have a profound impact on their mental or physical health. This may lead to missed appointments or a lack of understanding of important information about their care that can have a long-term impact on their lives and wellbeing.

However, fundamentally, ensuring accessibility in services is about equality. As Simon puts it, ‘having the freedom that everyone else enjoys of listening to my own medical information’.

Watch our videos with Simon

- Watch a short video about why equality matters – [click here](#).
- Watch more of our videos with Simon – [click here](#).



People suggested a range of other accessibility improvements for receiving information.

On top of large print and easy read text, several people offered other ideas to make information easier to access and understand.

One person suggested that offering all content in dark mode would improve readability for them. Others recommended providing information in alternative formats, such as audio or Braille.

Another person highlighted the need to improve the quality of printed letters, noting that some were very faint and difficult to read. These suggestions emphasise the importance of offering information in multiple ways to accommodate different needs.

“Bigger print or information in audio format”.

“All online content in dark mode easier to read please”.

“It would sometimes be good to have patient information and leaflets sent in Braille so that it's easier to refer back to”.

“

“More thought should go into size, layout especially phone & reference numbers which are often very small”.

”

“I don't see why pharmacists can't give out maybe a website to find more [about your medication], or just a piece of paper, because they haven't got time to explain to people all the different information on the leaflet, and something that's quite important, like what you should take it with or without... In fact, you think the pharmaceutical company would actually put a QR code on the package, wouldn't you?”

“They have sent through appointments in an audible format, which is fantastic, but any after care information is still provided in a leaflet form which is very strange, I think this should be improved”.

Struggling to get your test results, you need support with the app. The information comes via letter in small print. I suggest that I get phone calls with my test results.

“

“This information [on medicines] is obviously very important and i can't believe a way hasn't been found to provide this in an accessible way. Even a link to a website would suffice”.



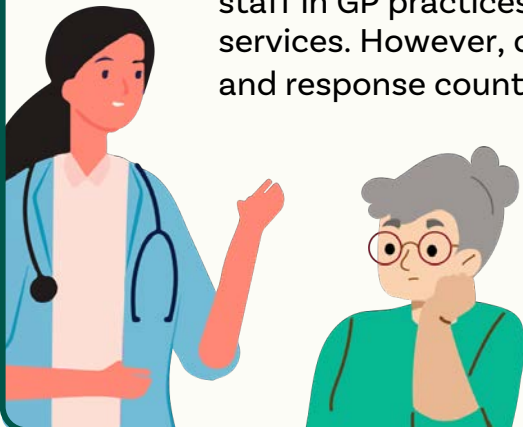
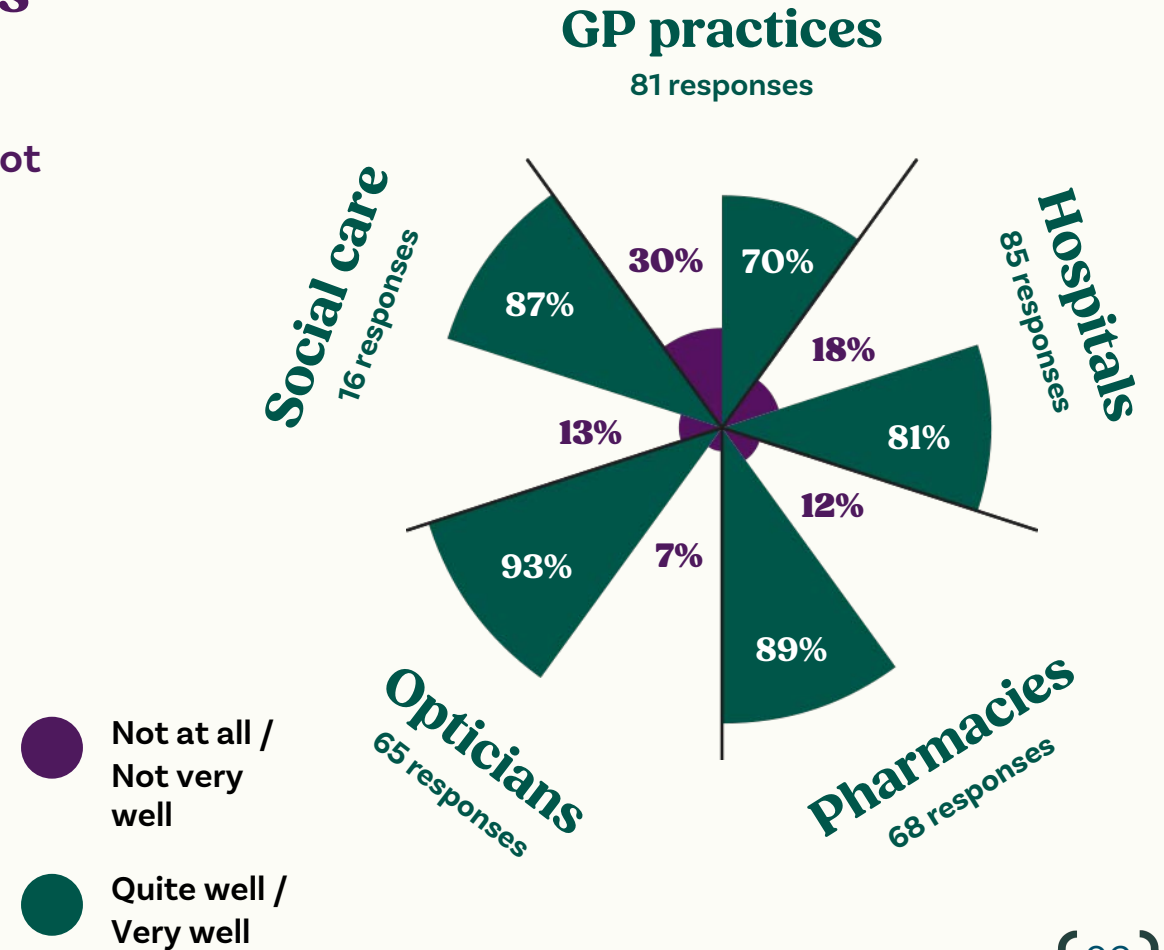
Staff in services

Ratings for staff across health services

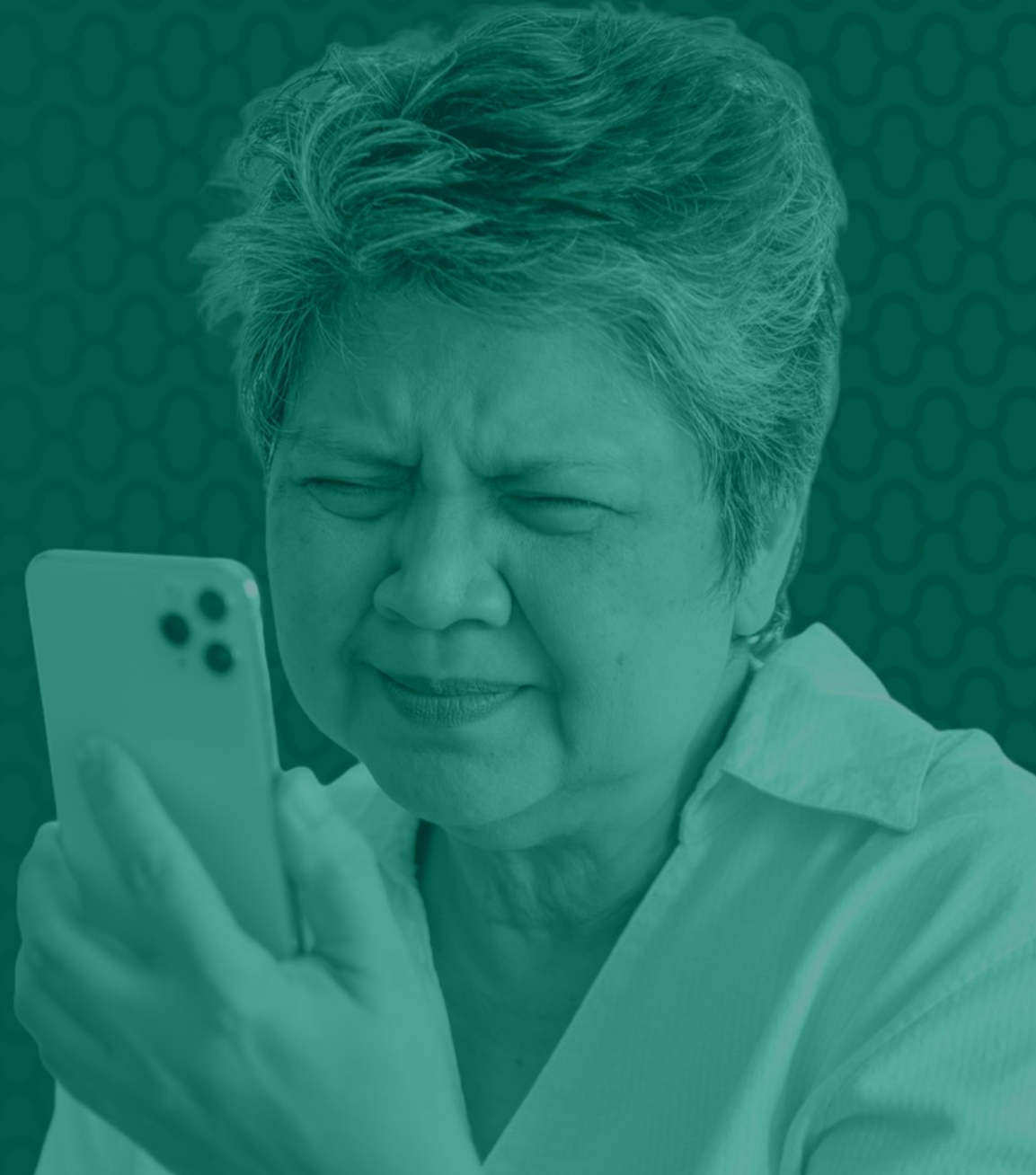
We asked people to tell us how well staff supported them when using healthcare services, ranging from 'very well' to 'not very well'.

Across all service types, people were more likely to rate their experience as 'very' or 'quite' well rather than 'not very' or 'not at all' well.

People were most negative about the support from staff in GP practices and hospitals, compared to other services. However, differences were fairly marginal and response counts varied across service types.



“As sight problems are hidden, all aspects of care relating to sight are only achieved if the staff delivering this care are given the highest quality training... if care is not delivered properly, it is due to low quality training and understanding of eye conditions.”



Qualitative responses

What did people say about the support they got from staff in health and care services?

Most people praised staff for being helpful and caring, though a few raised concerns about attitudes.

Among comments on staff attitudes, 38 people shared positive experiences, noting that staff were helpful, understanding, caring, attentive, and friendly.

People particularly appreciated staff who were outgoing and talkative, willing to spend time assisting with tasks (such as completing forms), and proactive in recognising and supporting people's needs.

Seven people reported negative experiences, describing staff as dismissive, impersonal, cold, or unhelpful. One individual described feeling dehumanised, and others highlighted a lack of understanding regarding accessibility needs.

“They are always understanding of my needs.”

“Huge variation between staff. Some are extremely kind and empathetic, then **there is the odd one who is very impersonal and cold who makes me feel dehumanised.”**

“Staff are always polite and helpful.”



In her interview, Heather shared a time she wasn't listened to and was interrupted by a member of staff:

“I'd just had a run of three monthly injections in my eyes and he looked at the scans and he said, ‘You've got to have three more monthly ones now’. And I said, ‘In that case, I've got a problem’ - and before I could even say what the problem was, he sort of stepped at me. He said, ‘Yes, you've got a problem. If you don't have them, you'll go blind’.”

“

“Staff are pretty good and direct me to a seat carefully, so I don’t sit on the floor. It is infuriating when I ask for a specific direction or piece of furniture and am told ‘over there’.”

“When looking for the toilet I was told it was around the other side, this was quite difficult.

When waiting in the queue the receptionist does not always ask you to come forward so you don’t know when it’s your turn.”

“In the clinic, I find that they tend to come out of their room, call your name, turn their back and walk away. I think that they should come up to me and take me through to the room.”

“

“The staff are very helpful at showing me where to sit and opening the door wide for my dog and I.”

Many people valued staff who provided clear and accessible guidance, but others struggled when support was unclear or unavailable.

Twenty-six respondents gave examples of helpful guidance, where staff supported them in navigating the service in ways they could understand. This included showing people where to sit or wait, opening doors, collecting patients from the waiting area, and providing verbal information about who they were seeing. One person specifically praised volunteers who escorted patients to the required department, though noted this support was not always consistently available.

Fifteen people reported negative experiences where guidance was insufficient. Examples included vague verbal instructions such as “the toilet is around the other side”, non-verbal gestures like waving forward, or not being offered support to know when it was their turn in a queue. Some staff assumed patients could read screens to find their appointments, or, if staff did call them, some would immediately turn away instead of waiting to ensure the patient could follow.



“Your call to the GP or nurse comes through on a screen which just pings by sound... I wish they were more proactive in coming out.”

Simon has noticed that some services have got better at meeting his needs, including his hospital in Ipswich and local GP practice. But he feels some things could still make his life easier when he visits them.

At the GP practice, this included supporting people with check-in procedures that can be inaccessible to people with visual impairments and staff offering proactive support to reduce anxieties.

Watch our videos with Simon

- Experience when visiting the GP practice - [click here](#)
- Watch more of our videos with Simon - [click here](#).



Some people rely on family or carers, but staff support remains crucial for those attending alone.

Ten people explained that staff support was not relevant to them because they are accompanied by family members, carers, or support workers.

Several highlighted that they would face significant difficulties without this help, and one person expressed uncertainty about the support they would receive if their family member was not with them.

Similarly, six people stated that they do not necessarily need assistance from staff because they can manage independently, though they felt confident help would be available if requested or necessary.

Together, these experiences underscore the need for ensuring staff support is available and accessible for patients who attend alone or may need help unexpectedly.

“Staff are always friendly and courteous though I am not sure how much assistance I would receive if my wife were not there.”

”

“Not really relevant, but I have confidence they would respond when necessary.”

“I always have a sighted person with me. I cannot imagine managing it alone.”

“I always take a carer with me. I am not confident that I could be independent or receive the help I need. Staff are always helpful once they see I need assistance getting around, but **they don't seem to be aware of my visual impairment prior to the appointment.”**

“

“

“I am fiercely independent, but I am sure if I asked the staff would help.”

”

“GP asked me to make another appointment at reception; receptionists told me to book an appointment online as they do not book appointments anymore. It took me about 6 weeks to book an appointment.”

“They will offer me extra time if I need it”

“I think my ‘partially-sighted’ pin-on badge means I get help when it looks like I need it.”

“No adjustments that I know of. I wish they could take the time to explain my medication to me.”

“They don’t seem to be aware of my visual impairment prior to the appointment. It would be helpful if my visual impairment was noted along with my name at every information point, so it is always obvious.”

“Might be useful if the receptionist was aware the patient is visually impaired and may require additional help as always need to explain on arrival.”

“Hard to get support as don’t realise I have sight issues unless I carry a white cane.”

“I use a cane. They don’t help as much as they could. They should be more aware if someone is on their own and needs help. They’d help if I asked.”

“

“All too busy to notice and mostly too proud to ask. So partly my fault.”

Staff awareness and support for visual impairments varied. Some needs were recognised and accommodated, while others were overlooked.

Sixteen people reported a lack of awareness, noting that staff did not recognise their visual impairment, particularly when patients do not use physical aids. In contrast, seven people shared positive experiences, mentioning strategies that helped staff recognise visual impairment, such as wearing ‘partially sighted’ pin badges, staff familiarity through regular visits, or assumptions based on attendance at services like the eye clinic.

Fourteen people reported that, even when staff are informed of a person’s visual impairment or when there are clear indicators (such as a white cane), staff do not always offer support. Examples included limited flexibility in booking processes and continuing as usual without adapting. One person felt staff overlooked their needs because they were perceived as managing well, while another felt their reluctance to ask for help may contribute to this.

Eight people described positive accommodations, such as staff ensuring they understood information, assisting with completing forms, and checking if help was needed.

Most people were positive about social care staff, though experiences varied depending on carers and service coordination.

Eleven people shared positive experiences with staff in social care services, including supported living, homecare, and residential care.

They note that the quality of care could depend on which carer was on shift, that departments did not always coordinate well, or that social workers had not met their needs.

“

**“I have
24/7 care from
Leading Lives
which are 1000%
brilliant.”**

**“Four social workers, five
complaints. Still no help that I
requested. Services being cut
needs not being met.”**

**“Support workers are
aware of my eye condition
and enable me to live
independently.”**

**“They just shove tiny print prescription
paperwork and say, ‘sign here’. I have no idea
what I’m signing.”**

“

**“I wish they could take the time
to explain my medication to me.”**

**“When a staff member is interacting, it would be useful if
they explained their role e.g. reception staff, optometrist,
dispenser...”**

”

**People sometimes need staff to take extra time to
explain information, particularly regarding
medication and documents.**

Five people reported negative experiences when receiving information from staff. While some acknowledged that staff were under pressure, they emphasised taking time to communicate clearly was important for understanding and confidence.

Some people felt overlooked when staff spoke to others or made assumptions about their abilities.

Four people described experiences where staff bypassed them and spoke directly to a sighted companion instead (e.g. family member, carer), rather than addressing them. In addition, one person reported feeling like a nuisance after staff made assumptions about what they could or could not do and attempted to redirect them to an alternative service more stressful for them to navigate.

These experiences highlight the importance of staff communicating directly with patients and avoiding assumptions.

“They speak to whoever is with me...not to me.”

“They assume my carer will do everything, including answering questions which I can do myself.”

“I think other visually impaired people would agree at times we find ourselves being talked about to our sighted partner rather than directly to us.”

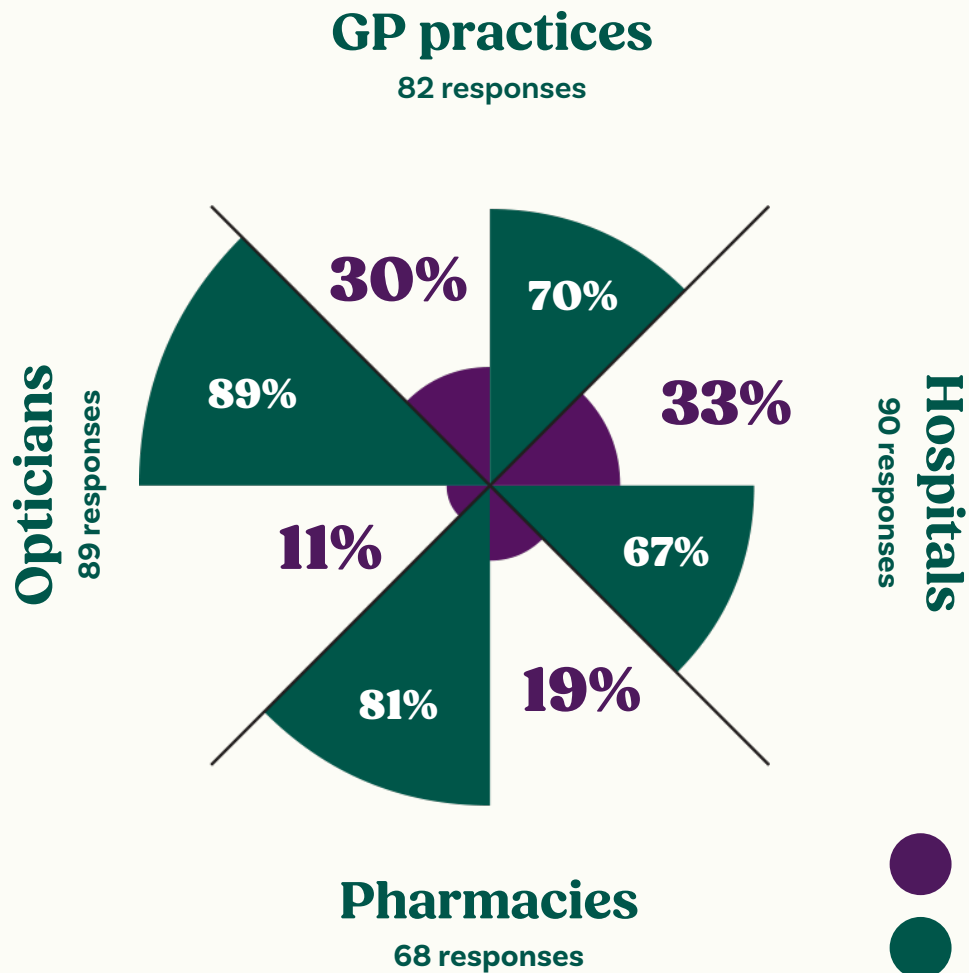
“I had an upsetting experience when planning an appointment for a breast screening. I made staff aware of my visual impairment prior to my appointment in the mobile screening lorry. They did not want me to go there and tried to make me go to Ipswich hospital instead. I explained that I was physically perfectly able to climb up the steps and had never had a problem previously accessing the service in the lorry, and in fact, Ipswich hospital would be far more stressful for me to navigate, and I didn’t need any special help beyond awareness and consideration from staff. **They reluctantly agreed, but I was left feeling like a nuisance and a problem.**”



In her interview, Fiona reflected that she had been made to feel ‘small’ when staff approached her support worker to complete a form instead of waiting for her to return from the toilet.

“A lot of people think [my support worker] is my husband, but he's not. [while I was in the hospital I had to go] to the toilet. And when I come back, I said, ‘Oh, there was a form you wanted filling out’ and the nurse said ‘Oh, it's alright, your husband's done it’. That's wrong. I didn't want to cause a fuss but I thought, ‘you're out of order’. Giving it to [my support worker] to fill out. Okay, he probably knows 99% of the questions. But it's my call. Just because I can't see, you give it to him. You could have asked me. It made me feel very small.”

Service environments



Ratings for environment across health services

We asked people how easy they found it to navigate and use facilities when visiting healthcare services, with responses ranging from 'very well' to 'not very well'.

Across all service types, most people rated their experience positively, selecting 'very' or 'quite' well rather than 'not very' or 'not at all' well (see graph). However, a significant proportion reported difficulties in certain settings. Around one third of respondents found hospitals difficult to navigate, and 30% reported similar challenges in GP practices. This is notably higher compared with pharmacies (19%) and opticians (11%).

Qualitative responses

What did people say about navigating services?

Many people described ways staff helped them to navigate services, particularly valuing proactive support. However, a small number highlighted inconsistencies in this support.

Thirty-three people reported positive experiences. This included general comments about consistently receiving assistance, staff being willing to locate patients and take them where they needed to go, and being checked in by staff rather than relying on self-service screens. People particularly appreciated staff that were proactive in recognising when someone might need support. Volunteers were also praised for their assistance.

Eight people reported negative experiences. Some said that although they rely on someone coming to collect them for appointments, this does not always happen. Others noted that volunteer services are not always available during the daytime, and people who need help are not always recognised or approached by staff.

“There are sometimes volunteers on the front desk who will take you to the department you need. This is a great service, but it’s not always available even during the daytime. I find it quite tricky to find my way around the hospital alone. It would be fantastic to always have a volunteer available to take you to your department, it’s easier to find your way back to the exit“

”

“I always have to ask someone to take me to clinic. They're always kind and helpful.”

“Not all the time, but sometimes I feel that I can be lost when people call me, but they do find me and take me to the relevant doctor or Hospital rooms. However, I think that there could be a device, especially in hospitals whereby they can navigate people with GPS and use turn by turn directions.”

“Not big enough when lots of people are there. There is too little seating and those needing help are not noticed. The service once you get to the desk is fine.”

“Need to be guided but whilst in hospital I can honestly say that only one nurse had any understanding”

“



"The receptionist tells you to go to area A, B, C or D. They are labelled, but it takes me a long time to find the labels, and I normally have to ask another patient. This is quite embarrassing."

"Signage is far too small or not the right background colours. Notices around the pharmacy are unreadable."



"Signage is often above eyeline. Visually impaired people are checking for obstructions and are not looking up to find signage."

"The surgery is well signed with large numbers on them."



In his interview, Richard described difficulties he faced when navigating a local hospital.

"In the hospital, there's signs everywhere and it's a really massive place to get lost in. When you walk down the corridor, maybe 100 metres or something away from a sign, you'll read what it says and you know you've got to go left at the next turn. I have to walk up to the sign to read it and sometimes it is very high, which doesn't help."

Some struggled with signage, citing small text, poor colour contrast, and placement issues that made navigation harder.

While seven people described signage in healthcare services as clear and easy-to-follow, twenty-nine people described difficulties.

They described signs as being too small or having text that was difficult to read, using background colours that reduced visibility, or, in some cases, not being present at all.

One person also highlighted that signs placed above eye level are particularly challenging, as people with visual impairments may be focusing on potential obstructions and are less likely to look up. Several people also described being completely unable to follow signage and therefore rely on other ways to navigate around.

People experienced difficulties with screens in healthcare services, describing unclear displays, hard-to-use touchscreens, and a lack of audio or alternative check-in options.

Eighteen people reported difficulties using screens in healthcare settings. Common issues included displays that do not announce patients' names or destinations, leaving them unsure if they had been called, and touch screen check-ins which have small text or are hard-to-use.

People suggested improvements like adding audio announcements, placing screens closer in the waiting area, enlarging text, improving contrast, and allowing alternative check-in methods, like using the NHS app, especially when staff are busy or the screens are challenging to use.

“Logging in for an appointment is on a touchscreen! This can be quite tricky and would be impossible for some people.”

”

”

“

“The information system in the waiting area where people's name are shown, it would be good to have some form of audio to say the name and where to go, especially when the receptionist are busy.”

“In terms of the GP, they have a call board, which is on a television screen. And they just silently put your name up and where you've got to go to see whoever is running the surgery at the time. So, I can't see that. If I remember, and if I'm on my own, I asked the receptionist, 'Can you just tell me when my name comes up, please?' And, if they remember, they do. If not, I've found that people who are in the waiting room have helped me out.”

“I am unable to use the checking in computer. I cannot see the screen that tells patients when it is their turn, and which room to go to.

“I always need to take someone with me.”



“

“If they change shelves or move things around it makes it harder for a person with visual impairment to navigate and find items independently.”

“In a familiar place I’m OK if nothing is changed. In a strange place, I need a sighted guide.”

”

“Know the layout and staff provide sufficient guidance. Might feel different if first visit and severely sight impaired.”

“

“If the clinics change or there’s a diversion, I would find it difficult to find my way.”

”

Familiarity with healthcare settings help some people navigate easily – but new patients or those encountering layout changes, diversions or blocked walkways find it harder.

Thirteen people said they can get around healthcare services easily because they were familiar with the layout from regular visits. However, five people said they found it harder when they were in new places, when the layout had changed, when there were diversions, or when walkways were blocked.

This shows the importance of providing extra help to new patients, and to make sure people are guided whenever the way around a service has changed.

While some people found the layouts of services clear and easy to navigate, others described confusing, maze-like spaces, long walks, obstacles and poorly marked pathways which made moving around difficult.

Eleven people reported positive experiences with the layout of healthcare services, describing spaces as clear, simple, and easy to navigate. They highlighted practical features that made moving around easier, such as clinics located on the ground floor, wide straight corridors, single-level layouts, automatic doors, and reception desks positioned in obvious, accessible locations.

In contrast, nine people described layouts that made navigation difficult or stressful. They mentioned long walks between areas, maze-like corridors, sectioned-off or cluttered spaces, and poorly defined pathways. One person also highlighted an issue with rope barriers, noting that because the rope is above a guide dog's head they do not always see this as a barrier.

A further seven described challenges with space, such as narrow corridors and busy environments. This left some feeling unsafe due to uncertainty about how to move around. In contrast, five people reported positive experiences, noting wide corridors reduced the risk of bumping into things, and that smaller settings, such as pharmacies, were sometimes easier to navigate.

“

“I find it hard to walk through the hospital on my own as people fly about with hospital beds and wheelchairs and expect me to get out of the way. Even though I have a white cane, I still have near misses.”

“They offer a downstairs room but its really small for my power wheelchair, so sometimes I miss out. Physically moving about is difficult.”

“It can be hard as most opticians are very cluttered. You do have to really concentrate on moving around. Chairs and small desks are always around you.”

“

“Everything is laid out clearly.”

”

“Moveable barriers (the type where there are two stands and a piece of rope between them) are a pain. I cannot see them and neither can my assistance dog because the rope is above his head. He does not see this as a barrier.”

“To gain access to my GP surgery there are a series of concrete steps with no contrast. Despite being promoted many years ago that yellow edges would be painted on them, this has never happened.”

**“Tight squeeze in my wheelchair.
No accessible WC.”**

“When I have to go upstairs it’s frightening or scary.”

“I find the lighting in the practice to be harsh fluorescent lighting that affects my vision.”

“Lighting is the main problem. It’s usually spotlights that point in a direction that dazzles you.”

“Good clear lighting.”

“Lighting is usually very strong and glaring.”

Some people reported accessibility barriers such as lack of ramps, limited space, insufficient accessible facilities and poor lighting.

Seven people reported positive experiences relating to accessibility in services, highlighting features like lifts for wheelchair users, accessible toilets, and adjustments made by staff, such as offering ground floor rooms when stairs were difficult to manage.

However, four people identified barriers, including steps at entrances without ramps, cramped spaces that were difficult for wheelchair users to navigate, and a lack of accessible toilets. These issues made it harder for some to access and move around services. An additional four people felt using stairs could be intimidating, noting that a lack of contrast made it hard to see where steps begin and end.

Five people had issues with lighting describing it as poor, harsh, glaring, or dazzling.

These experiences highlight the importance of considering accessibility in building design, providing ground floor rooms where possible and improving the visibility of stairs through high contrast markings or paint.

Some faced difficulties travelling to and from healthcare services due to unreliable transport and limited guidance, while others praised hospital transport.

Three people reported difficulties getting to and from healthcare services, highlighting unreliable public transport and a lack of support in navigating from the bus stop to the facility, with one also describing challenges moving between different areas of the hospital. Additional support for patients was recommended, such as introducing a golf-cart or similar transport to assist people, or scheduling appointments around the same time to avoid multiple visits.

Meanwhile, two people praised hospital transport services, noting that drivers were helpful in guiding people to their appointments. Two people also highlighted the benefits of home-based healthcare options. They appreciated when GPs visited them at home instead of requiring a trip to the practice, or when medications were delivered directly.

“As I live on my own, I am dependent on public transport. It can take me all day to get to the hospital and back home again to my village with very poor bus service. During the past 5 years, I have twice had to find my way over to the hospital pharmacy on my own after a consultation. Add eye drops that seriously affect vision to the unfamiliar route from the clinic to the pharmacy and then the journey getting to the bus stop, this can all get very challenging in low light conditions with an eye condition. I have noticed that there are often volunteers within the clinic, perhaps if there was an electric ‘Golf Cart’ type vehicle that could be location outside the clinic to be used in these circumstances to transport patients back to the bus stop or other on-site locations.”

”

“I have personal experience of trying to navigate my way from the eye clinic to hospital pharmacy. I receive eye drops (during my consultation) that dilate the pupils and impairs my sight further. This makes the journey to the pharmacy an obstacle course with extremely poor signage. This continues from the pharmacy as I attempt to make my way to the bus stop.”

“Getting to the opticians is difficult. Too far away from the bus station.”

“Hospital transport take me to hospital and also escort me to my appointment.”

Apps and digital services

What did people say about digital services?

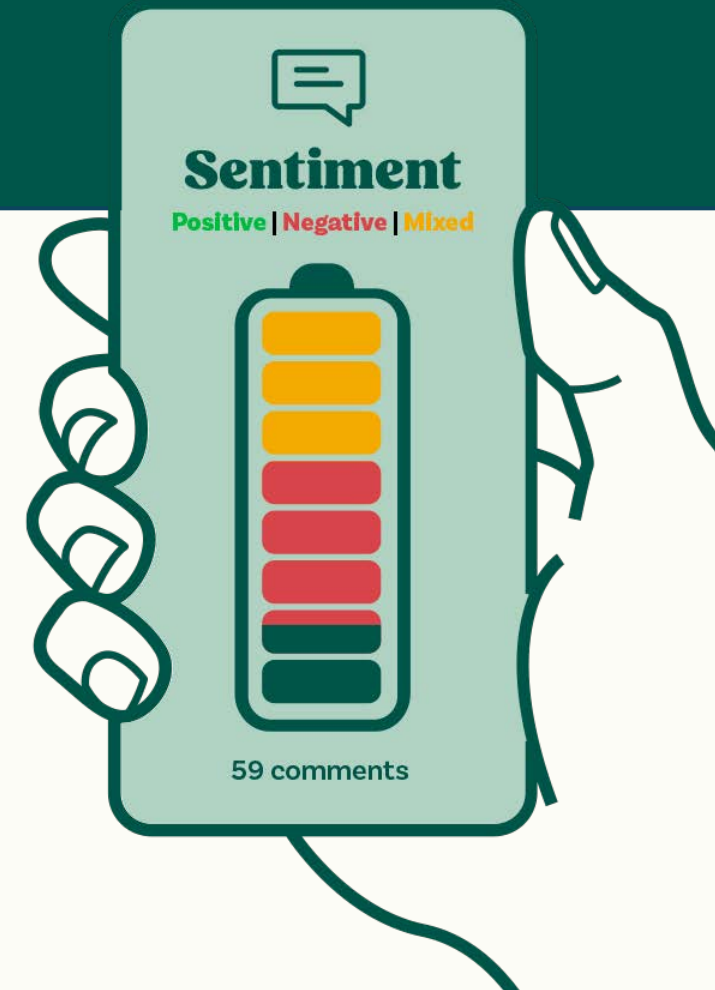
Apps and patient management systems are often used to access and manage healthcare, including booking appointments, viewing test results, and ordering prescriptions.

We asked people which apps they used and to describe their experiences of using them. The most common apps used were the NHS app (65 people), AskMyGP (18 people) and eConsult (11 people), followed by Anima and MyChart.

- Some people could access apps using screen readers or voiceover, but this was inconsistent. Key barriers included text presented as images that cannot be read aloud using screen readers, poor compatibility with assistive technology, and a lack of built-in accessibility features such as contrast settings or font adjustment.

“Needs a little more testing for assistive technology.”

“There are no accessibility options.”



Current digital developments by the NHS and services are not always accessible

“I use the NHS app for repeat prescriptions and eConsult to make doctor’s appointments. They can be difficult to use with a screen reader particularly if they have taken photographs of letters and uploaded them. The same applies to the Employment Support Allowance.”



- **Some struggled with tasks like booking appointments, navigating test results, and completing online forms.**

For example, one person described needing to zoom in to read text in long forms, which then made it difficult to scan ahead or know where they were supposed to enter information. Some also found apps clunky to use, with difficulty moving between sections and problems with scrolling. Logging in was also a barrier because passwords were hard to manage and apps often did not remember user details.

“Logging in to the app is clunky. Scrolling through is also difficult.”

“Using technology, remembering passwords, etc, makes me very anxious.”

“Checking reports, test results is very helpful. Moving from one section to another is very clunky requiring going back several times.”

“I find eConsult difficult to use. The questions are quite repetitive. Also, because I have to enlarge the screen to read the font, it means I cannot scan down the page for questions that are going to come up. **This means that I type in information in the wrong sections, not knowing that a question is going to be asked further down.**”

- **Some reported positive experiences with ordering prescriptions, managing medication, and checking basic information. Apps such as MyChart and the NHS app were sometimes described as easy, helpful, and usable.**

“Managing my medication using the NHS app has worked well and means that we don't have to drop the prescription off to the surgery.”

“I much prefer digital information, as I can use my own accessibility software to access it.”

“**All very accessible using voiceover.**”

- Some shared that they were required to use online systems and no longer able to book appointments by phone. This was difficult for those who could not use apps easily, or at all. Many relied on help from carers or family members to access apps, reducing privacy and independence.

“I have to get someone else to access for me. Difficult as you have to use online rather than ring them.”

“As a visually impaired individual, I find it increasingly difficult to access services now as the only route to access a GP consultation seems to be online via the app or website. This is an obstacle for many, but particularly for the elderly and visually impaired.”

“I can't do this independently I need a carer to help + I'm unable to get my prescription via the chemist (I used to be able to do this over the phone) it now has to be online.”

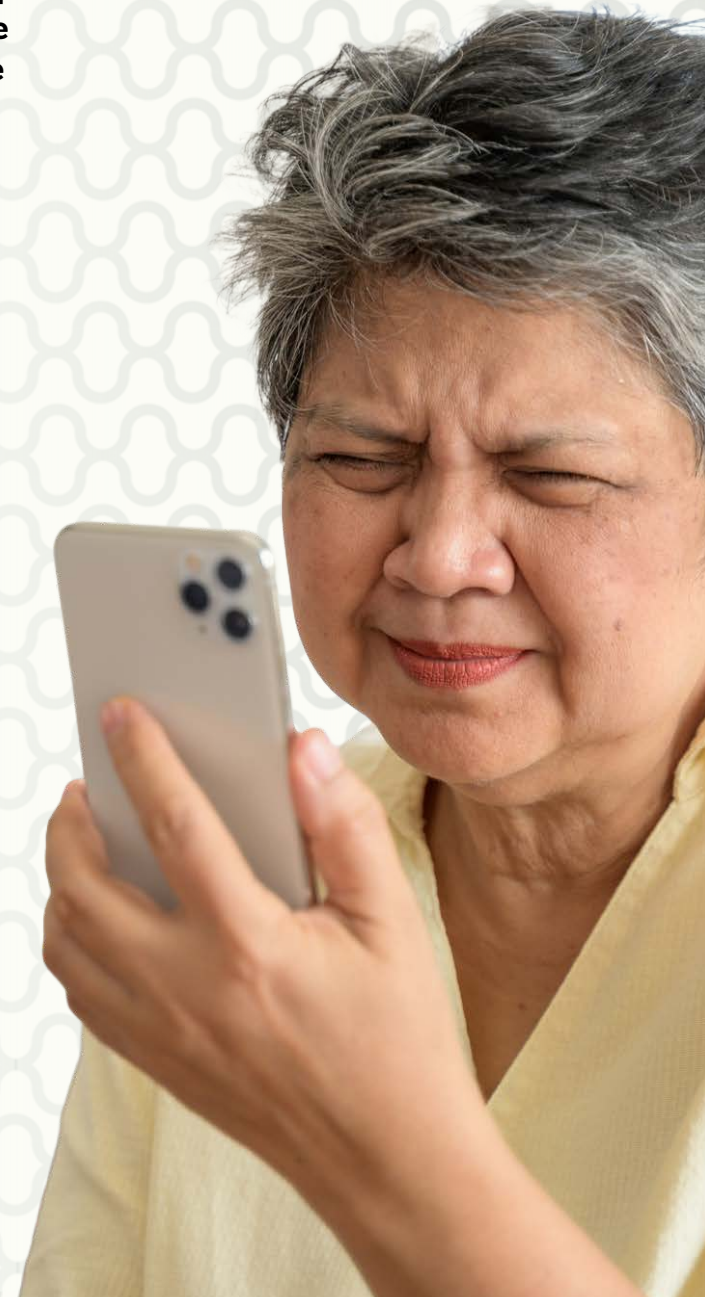
- Experiences of apps differed between platforms. People were generally positive about MyChart, whereas more negativity was shared about eConsult and Anima. The NHS app and AskMyGP received mixed feedback.

“I have previously used the ask my GP app, which worked well. However, this was replaced by Anima which didn't work at all well.”

“Anima is useless. My Chart is really good, informative and easy to navigate.”

- Overall, while some people were positive about using apps, others experienced significant barriers and frustration. This reduced independence, made tasks more time-consuming, and highlighted the importance of providing choice in how people access healthcare services.

“I've got to use a magnifier and I find it really, really tiring to read any great lengths of stuff because I have to concentrate so hard. My brain pattern matches words it thinks it's going to read, so sometimes I'm reading things that are not there, or I read things incorrectly because my brain is doing some of the heavy lifting. But if I'm concentrating really hard then, I'll try not to misinterpret it. That's tiring.





From interviews...

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“I use [the NHS app], but that in itself has its problems. I do it on my iPad. The page where you log in is fine because I can expand the box for where I put in my e-mail address and my password, fine. No problem. Then you get onto the actual page and the writing is so small, and that page does not expand. None of them do. The prescription page or, you know, if you want to look at your health records, your GP health record or whatever, you can't expand that. You can't expand any of them.”

“I used the thing called System Online, which my Doctor uses for requesting medication, which I still use. When I looked about requests on the NHS app, some of the medications are not down there. So, there's going to be this discrepancy between the NHS app and my My GP's app or the system online website. Some medications are missing. Also, I had to go to the hospital about my bad knee. I had to wait six months, six months back in March. And on the NHS app, it shows you your waiting, your referrals and wait time. But now I'm waiting for another appointment in six months' time, which it should have been in September, I've not heard yet. and it's just totally disappeared off the system.”

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“My practice uses Ask My GP as their preferred method of communication, and I can't really use the app because I can't make it big enough for me to type using my phone. So, I have to telephone. But what happens is, if you telephone, the receptionist will fill out an 'Ask my GP' request form, and then, unless I'm really, really explicit, and sometimes if you're ill, you forget to tell them that you need to be telephoned back. I can't have an e-mail come through to say, click here to go to 'Ask my GP' for a response to my enquiry. So that is frustrating. It's not the end of the world. I'm quite used to it. But I have to try and remember to say, please, can you ask somebody to telephone me back to tell me the answer? Don't just assume I can access something online because I can't.”



What it's like to live with visual impairment

What else did people say about life with a visual impairment?

Several people gave general examples or lists of the challenges they face because of their visual impairment. This included how it affects their social life, and ability to carry out and participate in certain activities and tasks.

“The insidious nature of glaucoma affects everyday living in increasingly significant ways, such as driving, mobility, reading, cooking, social activities. You learn to adapt to these changes, knowing that some of them can be ameliorated by the likes of technology, but appreciating that the primary function of the specialist services is to manage the condition and adjust treatment. The social consequences are down to the patient.”

“I can't work out which side to open a door and weirdly, I often can't tell where a toilet door is. I stand there thinking, 'has someone removed the door?'. When I am assisted into a theatre or cinema, I have to ask which direction the stage or screen is, because I am so disorientated by the change of light. It's very hard to see a bus coming. Find a train door. Put shoes on the right feet. Get a coat the right way up. Not being able to find something I have just put down – I have a warped sense of humour, thankfully, and I swear in frustration too.”



In her interview, Fiona described how helpful awareness would be when moving around public places like shops.

“I mean when you said what would be most helpful walking into a shop, the first thing that came to my mind was helpful assistance. Observation. They need to train people in observation. Looking to see who needs help. It's very simple.”

“Everyday stuff is just difficult. You always need to be aware of where you are and what you are doing. It is very difficult to suddenly change to doing something different.”

Some people described specific issues relating to transport.

Eight people reflected on their experiences with public transport, with most describing poor provision and limited bus services. This often meant relying on taxis, making longer or more time-consuming journeys, or facing difficulties getting to work and attending appointments.

One person noted that moving to an area with better transport had improved their situation after sight loss. Others experienced ongoing challenges. In addition, two people said being unable to drive affected their confidence and independence and made everyday life more challenging.

In the survey, we asked whether people faced any financial barriers when accessing eye care or support for their visual impairment. A total of 18% of respondents had faced financial barriers when accessing eye care or support for their visual impairment. The cost of transport to healthcare services and appointments was a common concern.

“Getting about is a nightmare. There are no bus services. There is the occasional bus, not enough to amount to calling it a service. It’s shameful. I live an 8-minute car journey from where I work, but it is one hour 15 minutes and 2 buses by public transport. It’s just not viable.”

“I feel completely isolated and alone. It costs too much to get taxis and community transport takes ages. I mainly stay in the house...”

“Having a visual impairment affects my confidence and will start to impede my freedom. I already feel less confident driving longer distances and driving at night.”

“My recent experience of bus travel has a lot to be desired. Twice this year I have been left behind when the driver has not stopped or not finished the journey, no reason or apology. Suffolk County Council were unhelpful and communication from them is non-existent.”

“Public transport is very poor in my area and non-existent in the evening.”



“It is difficult to get to hospital appointments as not able to drive after having eye drops or injections. I can sometimes use the bus, but it is a very limited service and not ideal, risk of infection after treatment. I can afford a taxi but one two-way journey costs me £100.

“My treatment is less frequent now but for many people this would be way beyond their budget. I used a voluntary driver service in the early days and gave a donation.”

“As my sight has deteriorated significantly, it is much more difficult to navigate the outside world. Shopping, using cash machines, reading product information, signage, carrying shopping bags and baskets.”

“It feels frustrating as there are lots of things that I now need help with that I used to be able to do – such as ordering prescriptions and shopping.”

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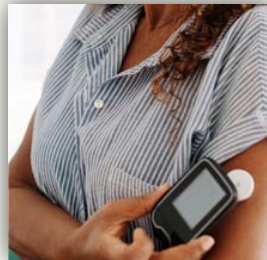
“Extremely difficult to operate electrical equipment such as the oven, TV, other kitchen appliances. Simple DIY jobs take 3 times longer than normal. Cannot see coins or operate cash points.”

Many people said sight loss made everyday tasks harder.

This included things like using cash machines, getting prescriptions, reading signs, cooking, cleaning, and carrying out other routine errands.

“I need to know where everything is so I can easily find what I need, say on a shelf or in a cupboard.”

“I try to do my housework as best I can. Cooking is hard. I have a spouse, and they used to cook, but they are too ill now. I do the best I can. I would like someone to come and show me how to cook now that I am visually impaired, as it is much harder.”



In her interview, Heather described how packaging design is often a barrier to independence.

“Colours on packaging, why do they print it in red on a black background? People don’t seem to realise that these colours just do not show up. Small type on packaging. I find reading cooking instructions hard.”

“I’m lucky because I’ve got my husband and he does things for me. He does all the shopping, reads me letters, reads everything for me that I need to have read. So yeah, so I do manage quite well really compared to some people. It’s just frustrating because it’s the loss of independence.”

Several people also described the psychological impact of their condition.

This included worries about their condition progressing or worsening over time, as well as anxiety related to attending appointments or being seen or treated for eye conditions.



In her interview, Fiona described how uncertainty about the future and the impacts of living with a progressing impairment made her feel.

“It is scary. You're unsure, you don't know the future. What's going to happen to me, why me, get all the emotions. It might take a year. I know a lady, she wouldn't accept it for six years.

”But you need support, having the right support at the right time makes all the difference. A lot of people just shut down. For myself, I couldn't work, couldn't see, lost my job. You worry about the financial side, what am I going to do? How am I going to live? I've still got the bills. It's really, really scary, really scary but just with a little bit of support....”

“[Visual impairment] doesn't affect just the person. It affects all the family.”

“I'm finding it very scary as my sight is getting worse.”

“Having only been severely sight impaired since 2020, it's the unknowing of what is happening to me with my condition. Reading booklets or articles is hard going, just as no one tells you just how isolating and restrictive that life can become. Feelings of vulnerability and at times helplessness can creep in, not knowing if I'm about to face total blindness or if there will ever be a medical intervention that can alleviate my condition.”

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“I remain with floaters in my eye after cataract surgery that don't improve. I'm concerned about low vision in my left eye and anxious to be seen and treated.”

“Awful. Very frustrating. Makes you cry.”

“I go to clubs, but I don’t feel I can mingle as much as I’d like to because of my visual impairment.

“I feel I am in a bubble because everything is blurred. I would like a bit more support with mixing with others.”



In his interview, Gary reflected on the assumptions people make about people living with visual impairments.

“I think one of the issues about vision impairment is that people assume if you've got a guide dog or a white stick, you're totally blind. Or if you haven't got a white stick or guide dog, you're totally fully sighted. Neither is the case, you know.”

Many people highlighted that others could make incorrect assumptions about them, including a lack of understanding of how visual impairment affects daily life.

They also noted a general lack of awareness that people may need adaptations, adjustments or patience.

“Because I am independent, people don't realise I need these adaptations.”

“I wear vari-focal glasses and people simply assume that my eyesight is poor. They do not understand visual impairment and its limiting effects on all aspects of daily life.”

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“Most people think you can either see or you can't, there's no inbetween.”

“It's hard going when you look normal but struggle everyday to function. But it has always been like that for the last 67 years so you get used to it.”

“Because my impairment isn't visible people assume I don't need help.”

“Not enough people are aware of what it is like to live with double vision.”

“I look like I am ‘normal’, so I learnt to lie to get work and be ‘normal’, whatever that is. It will be a struggle until I die.”

Five people described negative experiences accessing healthcare services.

This included a lack of follow-up, limited support, and not receiving the care they felt they needed.

“Once the hospital tell you your diagnosis it’s scary and you feel so alone and get left to find yourself any support.”

“Mental health team were supposed to be sending emails to assess my needs. I have not received any since August 2025 despite leaving messages via phone. As usual, it’s like banging your head against the wall, waste of time and money, etc.”

“On initial registration I had very helpful contact, but it all happened within a few days and it’s difficult to know who came from what agency. Perhaps a follow-up months down the line would be appreciated and not felt abandoned.”



In her interview, Fiona reflected on feeling dismissed by the hospital when she reached out after losing vision in her second eye, having already been blind in one.

“I rang West Suffolk Hospital and I said, ‘I need to see somebody straight away. I’ve got up this morning and I’ve gone completely black’, and the lady said ‘oh, that’s not an emergency.’”

“The eye dept at Ipswich seem to ignore my condition. There is no cure and they seem to have no interest in tracking my diminishing vision. I have never had routine checks only when referred by my optician.”

“It is vital to get urgent treatment for visual problems to improve positive outcomes of saving and even improving sight loss. The services at BSE are overstretched and in my case were below the Gold Standard Framework of giving treatment at 4 weekly intervals for 4 months. In my case, it varied from 5 to 7 weeks intervals. Staff shortages, holidays, and that the service was overstretched due to lack of investment and a surge of new patients over the past 10 years due to ageing population were all reasons given to me.”



Suffolk Sight

Praise for support

Suffolk Sight is a community-based charity supporting children and adults living with sight loss in Suffolk. They provide a range of services to help individuals promote and maintain their independence, such as home visiting, befriending, advice, and clubs.

Three people reflected positively on their experiences with Suffolk Sight, praising the advice, meetings and support they received throughout their journey.

“Suffolk Sight has been very helpful to me through the whole journey. I recommend anyone who has a sight impairment to contact them for help and support groups.”

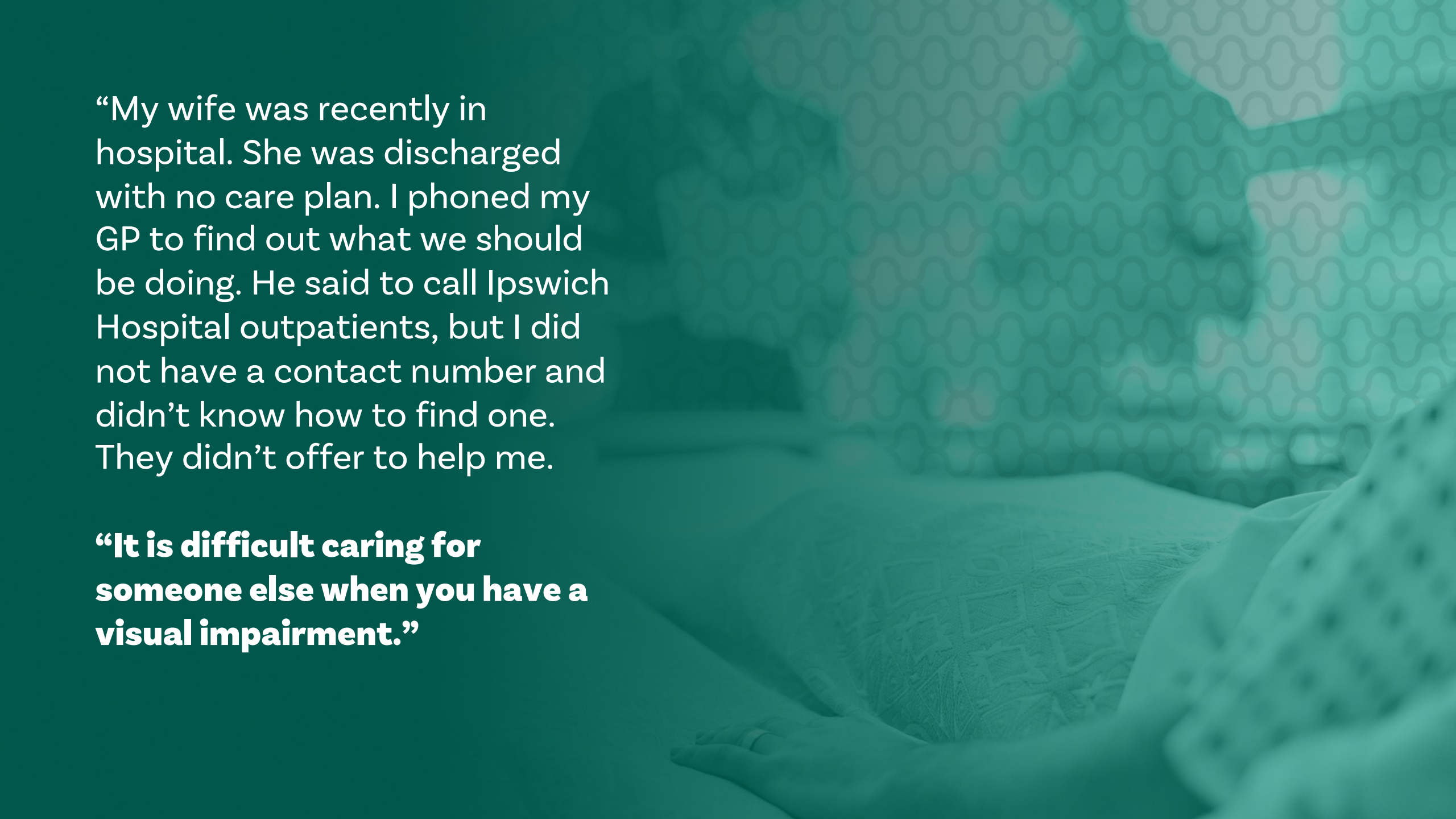
“I am very grateful to Suffolk Sight. I go to their monthly coffee mornings, which are lovely.”

“Suffolk Sight provide an incredible service and advice which has improved my social life through monthly meetings and drama group which I heard of via Suffolk Sight. Also, very helpful with technical advice.



Heather found Suffolk Sight to be an excellent source of support, helping her fill in forms for attendance allowance, providing equipment, putting bump stickers on her cooker etc. She found out about Suffolk Sight through the Eye Clinic Liaison Officer (ECLO) at West Suffolk House. She says the peer support she gets from groups is very important to her.

“We have our monthly meetings and there's always a part of them about being social, you know, we can chat. I mean, [one of the other members] is totally blind. I occasionally ask him a question because I have trouble with some things like getting toothpaste onto my toothbrush. And I said to him, How do you do it? And he told me what he does. And the other couple of ladies were saying they have trouble with ring pull cans because the ring breaks off and I've had that a lot. I've got a little gadget that lifts them off. And so, I took mine in to show them and show them how I use it and how best to do it.”

A photograph of a person lying in a hospital bed, partially covered by a patterned blanket. The image is overlaid with a semi-transparent teal filter and a repeating geometric pattern of interlocking circles. The text is positioned on the left side of the image.

“My wife was recently in hospital. She was discharged with no care plan. I phoned my GP to find out what we should be doing. He said to call Ipswich Hospital outpatients, but I did not have a contact number and didn’t know how to find one. They didn’t offer to help me.

“It is difficult caring for someone else when you have a visual impairment.”



Knowing Works®

Thank you for reading this report

This report has been produced to standards of accessible health and social care. It will be shared widely with commissioners and providers of NHS and social care in Suffolk.

Knowing Works is a social enterprise delivering insights to include people in shaping projects and services that help them. For more information about our services, please visit www.knowingworks.co.uk or reach out to our team at info@knowingworks.co.uk.

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