



# How can Gloucestershire's health and care services communicate better to improve care?

A patient and public perspective

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May 2023

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# About us

Healthwatch Gloucestershire is the county's health and social care champion.

We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared.

Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.



## Introduction

### Background

We know from public feedback that good communication makes a positive difference to people's experience of health and social care services, and that good care requires good communication.

We believe everyone has a better experience if the professionals caring for them communicate effectively with them, those supporting them, and other services involved in their care. This is likely to impact not only people's understanding of their health and care pathway, but also their level of engagement with services and professionals, and even how they feel about themselves.

In recent years, we have regularly heard from people who have experienced poor communication, especially while on referral from one service to another. We therefore decided to explore in greater depth the communications that people receive from medical professionals and services.

We asked the public to tell us more about their experiences to help us build a fuller picture of what is working well and what isn't, so that we can help services to understand how to communicate better during the referral process and to improve care.

### What we wanted to find out

We wanted to understand how satisfied people in Gloucestershire are with the communications they receive; whether they feel they are kept well informed and in regular contact with their GP, consultant, and other health and care professionals; and whether they consider the various services they access to communicate well with each other in order to provide them with joined-up care.





## What we did

We conducted this project during January and February 2023, actively engaging with people across the county during a three-week period to gather their feedback.

### Group discussions

During the three-week engagement phase, we visited sessions run by the Alzheimer's Society, Longfield Hospice, and the Gloucestershire Parent Carer Forum, where we held group discussions with **55 people** about the topics being explored.

The first session was attended by people living with Alzheimer's/dementia and their unpaid carers. The next included unpaid carers and their loved ones living with conditions including Parkinson's, dementia, and COPD. The final group consisted of parent carers whose children regularly access a combination of health and care services.

### One-to-one conversations

We invited people to share their experiences by phone or email if they preferred, or in addition to completing our online survey; we received one phone call and one email providing more detailed feedback.

### Engaging with service providers

We also visited service providers in person to gather their input, speaking with the Centre Head of Maggie's in Cheltenham, Health Delivery Lead of the Community Wellbeing Service (Forest of Dean), members of the PPG Network, Manager of Headway Gloucestershire, and CEO and Clinical Manager at Kate's Home Nursing.

### Online survey

We devised an online survey which was available through our website and possible to download in Easy Read format. To ensure that no one was digitally excluded from contributing their feedback, we also offered a printable version of the survey, and delivered hard copies upon request. **103 people** completed our survey.

### Raising awareness

We raised awareness of the project and promoted the opportunity to be involved by:

- Sharing the survey through local networks such as Know Your Patch
- Promoting the survey on our social media platforms
- Including information about the project in the January edition of our e-bulletin
- Directly sending a poster, survey link, and more detailed information to approximately 50 established contacts involved in the running of local support groups and organisations
- Speaking to the public while running a stand at a Time to Talk Day event.

# Key messages

- Services and departments do not communicate well with each other or reliably share information, meaning service users have to continually chase, repeat and correct information.
- There is no central point of contact that can be easily and directly reached with concerns or questions, so most people don't know who and how to contact for reliable information, advice, and signposting.
- Information packs giving people relevant, up-to-date details on their condition/injury and their expected health and care pathway are not provided.
- People often receive little to no advice about financial assistance, social care options or local support that is available to them and that could make a considerable difference to their wellbeing.

# What people told us

## Group discussions, one-to-one conversations and service providers

A number of recurring themes were established throughout our conversations. These included: an apparent lack of communication between services; people not knowing who to speak to and being passed 'from pillar to post'; service users feeling 'lost and abandoned' due to the lack of information and communication following their diagnosis, discharge or referral.

Because I'm a curious and proactive person, I ensure I find the contacts I need, but I pity anyone who waits to be informed and directed by healthcare professionals alone.

You're given lots of verbal information but you're not taking it in; you're in shock and you're feeling overwhelmed. You need some written material to be able to take away with you and look at when you feel ready.

I haven't known where to turn for help. I've sat on my floor and cried sometimes because I don't know what I need. It feels as if there's a lot of help out there, but no one knows where it is.

People want to help themselves, but they don't know how.



## Survey

103 people completed our survey to tell us about their experiences of communications within or from health and care professionals and services.

### Demographics:

We received responses from people living across 22 of the 27 Gloucestershire postcodes, all of whom were aged 18 to 80+.

Of those who declared their gender, 65 were women, 32 men, one identified as non-binary and one as intersex. There was representation of the transgender community and of numerous sexual orientations (see Appendix).

The majority of respondents stated that they live with a disability and/or long-term health condition and a fifth considered themselves to be a carer.

93% of respondents were White British/English/Northern Irish/Scottish/Welsh or Irish; one person identified as Asian/Asian British; one as Caribbean; one as Mixed/multiple ethnic Black African and White; and one as Black/Black British.

Most respondents (72) had been referred by a GP, 38 by a hospital/consultant, and 19 by other medical professionals such as nurses and clinicians. These were to a wide range of services and specialists, predominantly: hospital, physiotherapy, mental health, adult social care and dermatology.

The survey asked respondents to rate the extent to which they agreed with 17 statements about communications between health and care services and between services and service users. The answer options were: strongly agree; agree; neutral; disagree; strongly disagree. Text boxes were provided after each question to allow further comment, and these generated a considerable volume of feedback (see Appendix).

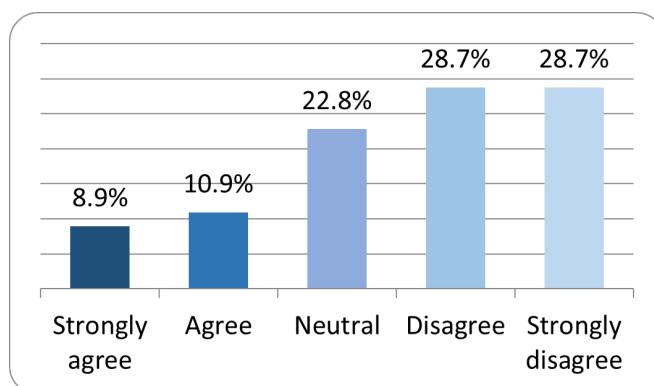
For the purpose of analysing the data, establishing which areas are working well and which require improvement, neutral responses have been accounted for in all calculations but omitted from the following discussion, agree/strongly agree have been combined, as have disagree/strongly disagree.

### Areas that require the most improvement

Several survey statements received a negative response overall, with many people saying they regularly feel the need to check, chase, and repeat information, that referral waiting times seem unreasonable, and that departments and services often fail to communicate with each other.

Over half of respondents disagreed with the statement '**Departments and services communicate with each other to provide joined-up care**', while just one in five agreed.

A key objective of the recently formed One Gloucestershire Integrated Care System (ICS) is to deliver more joined-up care to service users, the comments made in this section are particularly relevant to improving communications and delivering higher quality and more collaborative care.





I feel there is a distinct lack of understanding within teams in the NHS/social care system of who else is actually in the system and how to appropriately communicate.

It's exhausting having to repeatedly tell different people about my medical history, when if it were recorded properly I wouldn't have to.

A main problem seems to be the use of different software by different Trusts. How much thought and money goes in to designing such systems?

As a patient you have to be very alert and aware. Be prepared to oversee all of the communication of your care, as the information is not often relayed correctly.

I'm disgusted and appalled at the lack of support, knowledge, communication and coordination of services.

The statement that received the highest level of disagreement was '**Waiting times for referred services seem reasonable**', with 68% of respondents disagreeing and fewer than a fifth agreeing. Many people commented that they appreciate the level of pressure the NHS is currently under, but expressed concerns that the longer someone is waiting for a referral, the more likely it becomes that their condition will deteriorate and that they will develop further health problems. Lengthy waits for services such as neurology and mental health were mentioned, stretching beyond months into years.

Early intervention and prevention is key to better health outcomes. Long waiting times for referrals often result in a person developing several other conditions on top of their original condition/illness purely because they've been made to wait too long.

Physio early intervention prevents acute injury becoming chronic, such a delay means mental health suffers too.

Of those who responded, two thirds said that they feel the need to '**chase information**', over half that they need to '**repeat details numerous times**', and just under half that they need to '**check that correct information has been passed on**'.

People mentioned how helpful it would be to receive copies of the correspondence between GPs and consultants, to have their information stored and shared reliably between compatible IT systems and checked by medical professions ahead of appointments, and to feel that it is OK to question/challenge incorrect information.

I do not trust the communication often and I feel the need to constantly be chasing things up.

I feel I have told my story a million times and each time it traumatizes me.

It is always necessary to chase information and to check promised action has actually happened.

I have had the wrong information written, they have changed what I have said, and in some cases I have even had someone else's paperwork mixed in with mine.

After time you become exhausted and cannot continue repeating yourself.

I always have to check because too often information isn't sent on. I have to do their job for them sometimes.

Every time I see someone new, I have to give my whole case history again.

## Areas that are working better

Other survey statements received a more positive response overall, showing that some areas of communications within the system are working better than others.

Most people said they know how to ask questions and who to contact, and that they are asked how they would like to be communicated with. Just under half of respondents told us they receive information according to their preferences, that clear communications avoid confusion, and that they are provided with relevant guidance leaflets. Around half also agreed that they feel listened to. However, at least one in four participants disagreed with each of these statements, showing that there is still room for improvement.

Over twice as many respondents agreed as disagreed with the statement '**I know how to ask questions and who to contact**', although some commented that this is only because of a background in health and social care or research, and many stated they've had to be curious and proactive to find this out for themselves.

I would go around in circles and often get told to contact the person I have just spoken to who then tells me to call the person who told me to call them.

I know, but I feel for someone with limited capacity or a barrier it would be challenging for them to gain the information required.

Though just over half of respondents agreed that they are '**asked how they would like to be communicated with**', one third disagreed, and many people stated that they have never been asked about communication preferences.

They usually ask this... it's very important.

Can't remember when I was last asked, I'm retired now and reckon the surgeries should seek this info more than once in a lifetime.



Following on from being able to state a preferred method of communication, nearly half of respondents agreed that they then **'receive information according to their preferences'**, but one in four disagreed. A number of people commented that they receive calls to their mobile when they've stated a preference for landline calls, or vice versa, and others reported that they receive many letters when they have said they would prefer emails.

It would be good to ensure Deaf people have access to information in their first language, BSL.

Once a preference has been given, the communications have been sent as requested.

My wishes are not always listened to and they use their preferred method.

Only 49% of respondents agreed that they **'feel listened to'**, while 26% disagreed. Some people said that to feel listened to they have to be assertive and even 'difficult'. Others said they have felt like a 'nuisance', an 'irritant', and 'a number on a conveyor belt' when visiting medical professionals.

On most occasions, but sometimes even a 'do you want to draw attention to anything else/tell me about...'  
would be helpful.

I make sure I am listened to.

I feel like I am processed in and out as quickly as possible by the majority of consultants.

Just under half of participants agreed that **'Relevant guidance leaflets are provided that I can read when I am ready, outside of appointments'**, while nearly a third disagreed. Many people commented that when leaflets are provided, they are out of date, and that they often resort to looking up information on the internet. People also stated the importance of providing information in accessible formats such as Easy Read and BSL.

Sometimes. Area diabetic clinic did this well.

They may be relevant, but many are woefully out of date.

In reaction to **'Communications are of an appropriate level to avoid confusion'**, almost half of respondents agreed, while nearly a third disagreed. A few people said they regularly experience 'crossed wires' and 'mix ups', and some said written communications tend to be too long and complicated, while others considered them too brief and ambiguous.

Sometimes yes, sometimes no. Depends on where from and the media it is coming in.

Many people do not have great reading skills – many of the letters feel very full of text.

Too basic and not enough even when asked.

## Mixed response

The remaining statements received a mixed response, with a similar number of people agreeing as disagreeing that communications are efficient, consistent, clear and detailed, and that referral processes and waiting times are well explained. Responses were also varied when it came to people feeling that they are treated holistically, as an individual.

In response to the statement '**Communications are efficient**', 38% agreed and 35% disagreed. People commented that this is inconsistent as it varies between services, and that communications are often significantly delayed because of a reliance on 'snail mail'.

Q Communication via the post advising of an appointment is sometimes after the actual appointment.

Q Local surgery is superb at this. Other primary care services do communicate but seldomly in an acceptable timeframe. Departments in hospitals vary.

Q We have had many letters and texts during the vaccination periods when we had received duplicate reminder letters and texts when we had already received that dose. This is quite inefficient and confusing to those who are less able.

There was a similar divide in response when it came to communications being '**clear, appropriately detailed and consistent**.' People described communications from professionals as full of 'medical jargon, ambiguous, cause anxiety and spasmodic'.

Q Often specialist to GP and patient letters are written with medical terms and no consideration of whether the patient will understand them. This can make a patient feel they are not an individual being properly respected.

Q I frequently (usually) have to ask for clarification.

Q I never know what's happening.

Q There isn't consistent communication between my consultant and GP. I am fearful that any changes in my condition will be missed and not followed up. I have to regularly check that both GP and my consultant have received results.

To the statements '**The referral process is well explained**' and '**I am prepared for how long I will be waiting for a referral**', around a third agreed while another third disagreed. Many people said that this varies between referral pathways and that the undetermined wait time can cause further anxiety. It was suggested that a visual depiction of the referral pathway could help service users to understand the process.

Q Rarely explained. You need to know the right questions to ask.

Q Some kind of explanatory notes of why a certain service is recommended and for what reason would be helpful.

I rarely have any idea where I am being referred, who is dealing with the issue, who to contact about it, etc. I just wait to receive a letter then turn up when I'm told. This doesn't feel like good care.

It's easy to feel lost in the system as the weeks and months go by.

If I'd known that a referral for mental health would take up to 18 months I could have gone to seek help elsewhere at a much earlier stage, which would have prevented a prolonged period of ill mental health.

Finally, while 40 people agreed that they are '**Seen as a whole person, not a diagnosis or set of symptoms**', almost the same number disagreed. Some people said they are 'divided' by their various conditions which are treated in isolation despite being related, and others said they feel their illness is not taken seriously. A number of people commented that medical professionals have too little time to offer individualised care.

When you eventually get into the hospital you are treated exceptionally well. All other services treat you as an irritant and put you into a number crunching exercise.

As times have changed over the years, hospital doctors and surgeons have developed a kinder approach and a more approachable bedside manner.

Dependent on service - physio exceptional!

I feel each consultant looks at each set of symptoms and never holistically even though they are related.

Doctors and health care professionals need to take a more holistic approach to their patients. Mental health, diet and many physical conditions are all interlinked.

## Other issues identified from people's feedback

- Many people living in rural areas have limited mobile and Wi-Fi signal, making it difficult to efficiently communicate by mobile, text, or email.
- People with visual and/or hearing impairments find certain forms of communication inaccessible and require appropriate alternatives.
- People who access health and care services across county (or country) borders face additional difficulties in terms of communication between services, especially regarding the variety of IT systems in use.
- Many people receive duplicated communications and have routine face-to-face appointments when the information could be delivered by phone or in writing; this can be a waste of resources.
- As consultants cannot refer patients to other consultants, the GP becomes an intermediary and the process is further complicated and delayed. GPs and consultants often fail to keep each other updated and 'pass the buck'.

Many respondents acknowledged and appreciated the current pressures on the NHS and all staff within the health and care system at present, but believe action is needed to improve communications between services, and between services and service users.



**This is a really important area of work, thank you for looking at it. I feel that so much of the confusion and distress I have experienced with medical issues in the past could have been avoided with clearer, more timely communications from and between healthcare professionals.**



## Recommendations

We believe that health and social care providers can best improve services by listening to people's experiences. Having analysed what people told us and what we discovered about the communications between services in Gloucestershire and between those services and the people who use them, we recommend the following actions to improve health and care in this area.

- Departments and services should communicate efficiently with each other.
- Establish service users' preferred methods of communication and adhere to these.
- Provide a central point of contact who can be easily reached.
- Provide information packs with up-to-date details on service users' condition and expected health and care pathway, including details of financial assistance, social care options, and support available locally.
- Ensure communications are clear, detailed, and written with laypeople in mind.
- Maintain regular contact with service users; routine communication to provide updates, manage expectations, and provide reassurance.
- Allow service users more access/input into their own medical records.
- Align IT systems across services to allow efficient sharing of medical records.
- Work together to move away from silo working and separate diagnoses, towards a holistic approach that values the whole person.

## Stakeholder response

**Suzie Cro, Deputy Director of Quality,  
Gloucestershire Hospitals NHS Foundation Trust**

"Thank you for sharing the final report. We see feedback as an important improvement tool that supports the fundamental principle that people who use NHS services should have the opportunity to provide feedback on their experience. Listening to the views of our patients helps identify what is working well, what can be improved and how.

"We have read Healthwatch Gloucestershire's key messages within your report and would like to thank you for the opportunity this report brings. Also, we would like to work with you to take your nine recommendations and codesign our improvements with you. We, like you, believe that we will best improve services by listening to people's experiences. Thank you once again for providing us with these insights and we look forward to codesigning an improvement plan for the recommendations."



**Gloucestershire Hospitals**  
NHS Foundation Trust



“Thank you to Healthwatch Gloucestershire and the 50+ individuals\* who got involved and took the opportunity to share what matters to them about communications between us and the people and communities of Gloucestershire.

“We really want to make sure people have the information they need to make decisions about their lives and those of their families and communities. We have recently made good progress with getting to know and grow trust within some of the diverse communities across the county and our Patient Advice and Liaison Service (PALS) teams are always a good place for people to start.

“We look forward to working with Healthwatch Gloucestershire over the coming year to identify innovative ways to enhance our communications; by using the findings in this report, which tell us about some of the things people want to know about; together we can develop the best ways to share that information with them.”

**\*Note:** In addition to the 55 people we talked to face-to-face, 103 people responded to our survey.

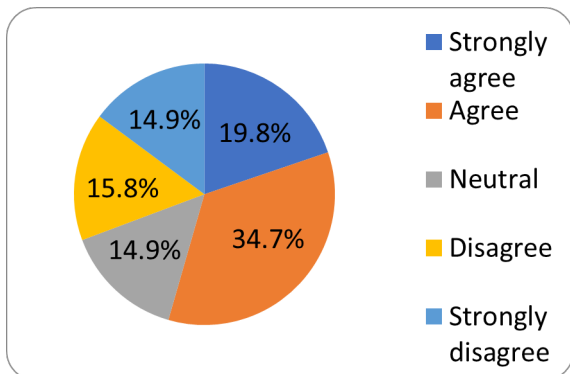
## Thank you

Thanks to everyone who took the time to tell us about their experiences, and to everyone who helped to promote this project. We can only do what we do because local people give us their feedback. Particular thanks go to the organisations who welcomed us to their group settings.



# Appendix: Survey data

## 1. I am asked how I would like to be communicated with (phone, email, text, letter)



“They usually ask this... it’s very important.”

“GHC physio ask this question. Not offered by any other service involved with.”

“This is dependent on who you speak too and what service your trying to access.”

“While I am asked how I am communicated with, I am not asked how I would prefer to communicate with professionals. For example accessing GP appointments can really only be done via the website and this is not always easy to navigate.”

“Only offered a telephone call, staff reluctant to use email. This holds all the power with staff.”

“I am asked, but that doesn’t mean it happens.”

“If in regular contact with an organisation it usually has phone and email information. Rarely is one asked for preference.”

“No one has ever asked how I would like to receive communications.”

“Can’t remember when I was last asked, I’m retired now and reckon the surgeries should seek this info more than once in a lifetime.”

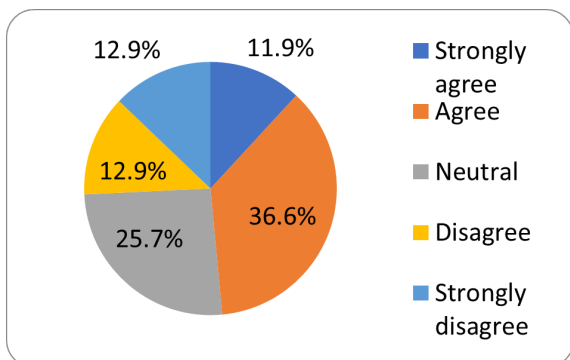
“I provide all my communication details but have poor digital broadband access and almost non-existent mobile signal therefore I request use of the landline for communication that needs conversation, confirmation etc. It almost never happens, calls are almost always made using the mobile number, which just end up with a missed call message that I receive when I go out into an area where I get a signal. This often results in missed appointments.”

“I am visually impaired and hearing impaired and I have to constantly ask for accessible formats.”

“I have been asked if I want to receive SMS reminders of appointments and that works well, but I have seldom asked how I want to be communicated about other things. I get called in once a year to monitor one chronic clinical condition and less regularly for another chronic condition. I receive that by letter, when I should be happy with an email, or SMS, which would be cheaper for my GP and more reliable.”

“Yes it is important that the method of communication meets the person’s needs.”

## 2. I receive information according to my preferences



“Text yes, email rarely.”

“My wishes are not always listened to and they use their preferred method.”

“I’m often told that I’ll be sent a letter but no other options given.”

“I get more post than I feel is necessary - I would be happy to get more by email.”

“Nope, they keep mailing letters that take two weeks to arrive; what I would really like is emails backed up by snail mail.”

“I get texts so guess I asked for that.”

“Sometimes I do, such as advice about surgery opening times, but then other times I don’t. I’m supposed to receive a text or email for my flu jab, but I often don’t receive them so have to phone up the surgery.”

“Hospital always calls home phone rather than mobile which I have given as my preference.”

“Only sometimes.”

"Even the ophthalmology department that diagnosed my visual impairment never send large print when corresponding."

"Yes but only if phone or mobile phone."

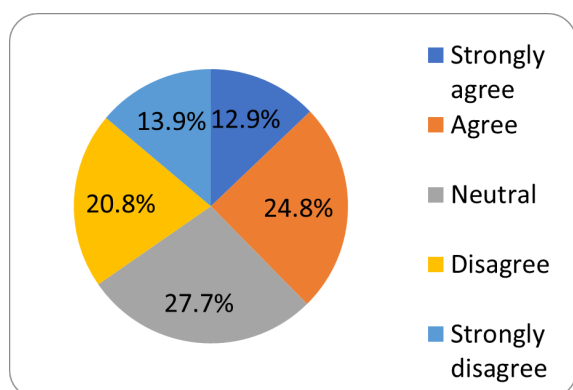
"Hit and miss. Home delivery for medication from hospital used to phone me to arrange delivery, then they stopped and sent emails, which I didn't even know about. Now they keep sending me a text to download an App to order medication. It seems the system doesn't really think about the illness that are catering for. People have dexterity problems, eye sight problem with my condition MS, yet the easy communication of a telephone call has been scrapped. I don't have room for all these Apps. I forget to order, another symptom of MS. I don't like the new service, also you get a text late at night when your delivery is coming, you can't talk to anyone if you have a problem, as the text comes out of office hours."

"It would be good to ensure Deaf people have access to information in their first language, BSL."

"Information is not always received according to my preferences, but the majority of the time it is."

"Once a preference has been given, the communications have been sent as requested in the past."

### 3. Communications are efficient



"Coming from the Drs by text, yes. Trying to get an appointment or follow up from the hospital, no."

"Communication from the hospital is appalling, miscommunication at its best. Stop using post and start using email as much as possible. Communication via the post advising of an appointment is sometimes after the actual appointment."

"I have had to chase up communications, and in some cases beg to get my information from them, or beg for appointments."

"Some good examples of communications from some teams, but equally some examples of poor communications. It isn't consistent. Plus trying to navigate websites and mobile Apps is always a challenge! Do you design these digital solutions with people who will be using them?"

"Varies - have received two appointment letters after the appointment. No clear pathway/info to further support."

"Telephone calls from staff are always to suit them. Calling in to services is a nightmare."

"More use should be made of email by GPs and others."

"Much needs to be done. Living near the county border, cross-county border comms, particularly with Bristol hospitals seems non-existent at times. Comms from GP don't always work (text message sometimes aren't sent, and SystemOnline doesn't always show made appointments and sometimes differs with info on its App)."

"Local surgery is superb at this. Other primary care services do communicate but seldomly in an acceptable timeframe. Departments in hospitals vary."

"Two weeks for letters to be delivered. We once figured out that after the letter leaves the secretary's office it sits in the mail room for a week. That is not efficient. And this was before the mail strikes!"

"Some are better than others. Still waiting for a reply to a referral made mid-November."

"There is some work needed from my local surgery around sending their text messages and emails. They are too intermittent."

"I have had letters lost in the post on more than one occasion and letters which have not gone out, emails that have not been replied to for several weeks."

"Secretary needs regular reminding that I would like to receive a copy of clinic letters."

"Delays in making contact after enquiries."

"During the last postal strike, there was no back up notification from NHS resulting in users missing appointments etc - more emphasis re online notification and telephone if required."

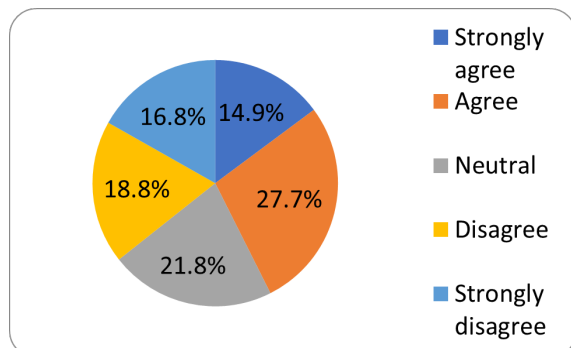


"If I receive a message from my GP, it either comes as a text message that I can't reply to, or via an email directing me to an online portal that I have to sign in to access."

"We have had many letters by post and texts during the vaccination periods when we had received duplicate reminder letters and texts when we had already received that dose. This is quite inefficient and confusing to those who are less able."

"Yes. They should be."

#### 4. Consistent communication ensures I am kept updated



"It would keep me updated if it was consistent! It is very spasmodic."

"Communication only by consultant within GHNHSFT, none received from other professionals."

"I have recently (in last 4 months) had tests and X-rays and have had no update from GP; will have to chase myself."

"Where digital systems are in place the onus is on you to keep checking. Not all are digitally proficient."

"There is no consistency to the communication. If there was, then I would be kept up-to-date, but there is no consistent communication."

"I would not be left in the dark as to what was happening. I would know where to go when referrals, etc. are not followed up."

"I never know what's happening."

"Communication between A&E and GP was slow; GP not made aware of new bleed on brain."

"If it actually happened."

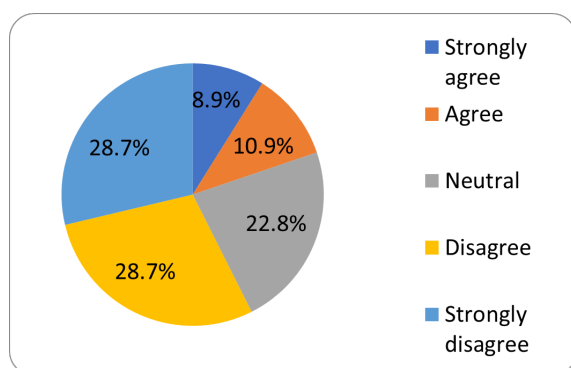
"It would if I received 'consistent communication', but as I don't always, it doesn't."

"No, doctors surgery do not get back to me when I email them. I am chasing blood test results, they never read them properly, they scan the first page and say yep all okay."

"For a long term condition I require consistent communication between my GP and consultant in an out-of-county hospital. I have regular monthly blood tests and monitoring but there isn't consistent communication between my consultant and GP. I am fearful that any changes in my condition will be missed and not followed up. I have to regularly check that both GP and my consultant have received results. For continuity of care, it is not helpful when I see a different GP every time at my surgery. In fact I couldn't tell you the name of my GP as I have never seen the same one more than once."

"I would always ask to be copied in to any health correspondence being shared between primary and secondary care."

#### 5. Departments and services communicate with each other to provide joined-up care



"I've been chasing a cardio follow-up consultancy for a couple of months now."

"Physio knew nothing about my son on discharge from hospital despite verbal communication this was to be actioned on discharge. We self referred to access help, only because of own knowledge I knew we could. GP unaware of recent hospital admission, five days later, so bounced back into A&E as GP informed us could not help."

"This is a challenge for the ICS."

"I have to repeat key information; there is no sense to me of a picture building."

"I frequently had to repeat information about my relative to different departments, e.g. physios, social worker, nursing staff."



"Discharge from hospital to needs assessment care or to privately funded care is chaotic."

"In my experience not ALL departments communicate with each other, however, I do feel it's just a case of being understaffed and things get missed."

"I have had to ask for departments to talk to each other or present what I have got and they have taken copies from what I have given."

"All departments use different IT systems; I am having to repeat myself more than once."

"Absolutely not, nothing is ever communicated between departments. Even between emergency services."

"The opposite is generally the case. Staff don't communicate and are often negative of other parts of the system. Staff openly criticise other professionals and give opposing opinions."

"Lack of communication can have, at worst, life threatening implications and at best be hugely inefficient. A main problem seems to be the use of different software by different Trusts. In a recent experience, 40 minutes of questioning by a SWAST paramedic was all painstakingly logged on a tablet for swift transfer of info, but on arrival at Cheltenham Gen the respective systems were incompatible and the info could not be read. How much thought and money goes in to designing such systems? You couldn't make it up."

"I live in South Gloucestershire but my GP is in Gloucestershire (two miles from home). There is a huge issue with IT systems cross-border that do not communicate and include info. For example, my GP can't see Southmead Hospital results. Totally inefficient. This is not a NATIONAL health service in my opinion."

"Never get joined-up care. If I tell a clinician that they are prescribing me a drug that is contradicted by a drug prescribed by a different silo, they just shrug. None of the consultants ever talk to each other."

"There appears to be significant variation. Most likely linked to service pressures. I feel there is a distinct lack of understanding within teams in the NHS/social care system of who else is actually in the system and how to appropriately communicate."

"I have two ongoing problems and the one department has no communication with the other."

"This is not true; none of them ever seem to know what's happening as part of care they rely on me to tell them."

"I have mental health issues and physical health injuries due to my Army service and being in a IED none of the consultants know about either."

"Communication between GP/pharmacy is poor; between GRH consultant and GP takes weeks."

"It's exhausting having to repeatedly tell different people about my medical history, when if it were recorded properly I wouldn't have to. I find it hard to keep track of all the different appointments and conversations I've had; I always worry I will miss something important out when someone asks me to summarise."

"Communication between my GP and hospital consultants appears to be patchy. Sometimes excellent, sometimes apparently non-existent."

"Hospital consultants pass the buck onto GPs about patient care, GPs don't have a enough knowledge in certain areas, e.g. gynaecology, dermatology."

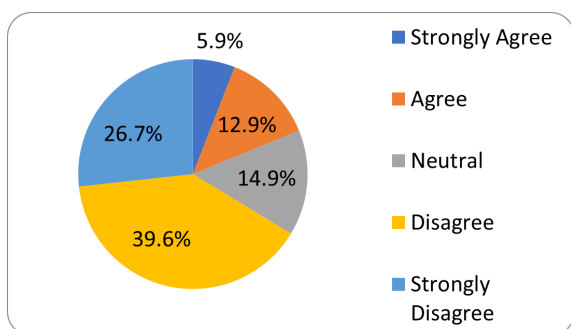
"Only if one party specifically asks for information to be passed on, rather than this being the default"

"Not had a positive experience of this yet in the two years I've lived here, for my children or myself in fact, it's awful."

"More work is needed for a joined-up approach."

"No, unfortunately on several occasions for different health reasons I have not received joined-up care between various hospitals and my GP. As a patient you have to be very alert and aware and be prepared to oversee all of the communication of your care, as often the information is not relayed correctly from one doctor to the next."

## 6. I never feel the need to chase information



"On the plus side - chasing information helps to keep my brain active!"

"I do not trust the communication often and due to the current situation with waiting times and shortages of staff I feel the need to constantly be chasing things up as things are inefficient in the NHS."

"There have been a few occasions that I have had to chase information or appointments; again I feel this is due to the huge strain that the NHS is under."

"It was extremely difficult to see a doctor or trained member of staff on the ward at the community hospital, despite leaving messages that I wished to speak to someone. I had to resort to telephone conversations on numerous occasions but these were not as satisfactory."

"I am always chasing up."

"Post BMT - constantly chasing results from tests."

"I always have to chase. For example my daughter has been on the CAMHS waiting list for an autism assessment for two years now! I had a letter after six months, but not heard anything since!"

"I had to chase follow on work like Next Steps exercise. Again this was four years ago so maybe different now?"

"It is always necessary to chase information and to check promised action has actually happened."

"Sometimes GPs don't pass on all information from consultants when this is needed. Why can't patients get a copy when a consultant writes to a GP? If email were used, this would not cost much or take much time."

"Test results!!"

"I am always having to chase up information, especially when it comes to appointments and requests for imaging or blood tests from secondary care."

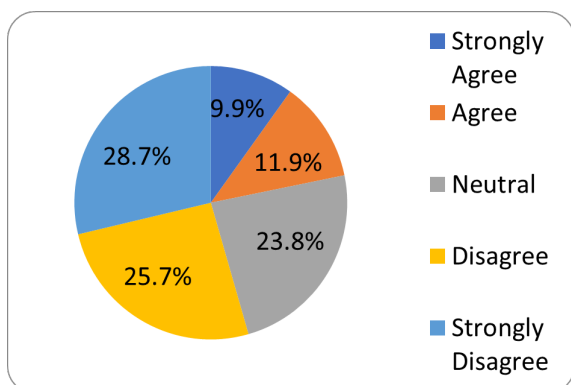
"My carer always has to chase and often remind the NHS of the Armed Forces covenant which most of the staff are unaware of."

"I wasn't sent an appointment several times and had to chase."

"Due to the problems set out above I always have to check the info needed is in place a few days before my appointments at the hospital."

"I don't have many tests, but when I do, I seldom get the results unless I chase them up."

## 7. I never feel the need to repeat details numerous times



"All the time I repeat myself, I do however understand some of the need for this."

"I find I am having to do this and it's distressing for me."

"Not one appointment where we didn't have to repeat each time."

"I think that it is important to repeat details numerous times, but what details are you referring to? I don't mind giving my name and date of birth, as a check to see if I am in the right department!"

"They don't listen to me or take on board what I am saying or what has been said by someone else in a different department, sometimes even what a colleague has said."

"Sometimes I do, and sometimes I don't. Sharing information between Bristol Haematology, Gloucestershire Haematology, GP and speciality services can sometimes be non-existent."

"I have to tell my story to different professionals, who all use different IT systems and different professional assessment tools."

"You have to repeat all relevant information to every department. There is absolutely no communication between any healthcare service."

"GPs and others do not always have the time to read records before an appointment."

"I keep having to repeat details all the time. Sometimes even to the same clinicians!"

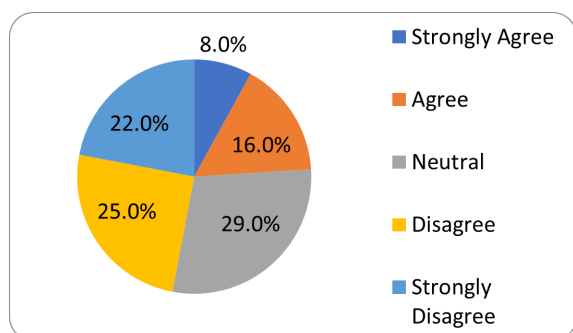
"I feel I have told my story a million times and each time it traumatizes me. But the NHS staff don't seem to care, instead of reading my notes or discussing, it's easier for me to tell it. They then don't provide any support after for me or my carer she is left to deal with the fallout."

"At surgery level have to be prepared to repeat everything."

"This is the worst part of it all. One story, six different people!! In front of my son who's disabled who really doesn't need to hear it six times how difficult his life has been/is."

"After time you become exhausted and cannot continue repeating yourself due to the shock, ambiguous loss and make do."

## 8. I never feel the need to check that correct information has been passed on



"I was often not convinced that messages had been passed on."

"I have had a recent experience of where a key part of what I shared was not passed on."

"You can't rely on anyone else getting it right."

"Often mistakes with information shared."

"I always have to check because too often information isn't sent on. I have to do their job for them sometimes."

"I have had the wrong information written, they have changed what I have said and in some cases I have even had someone else's paperwork mixed in with mine."

"The wrong information is often passed on and details not recorded correctly."

"My medical records are incomplete."

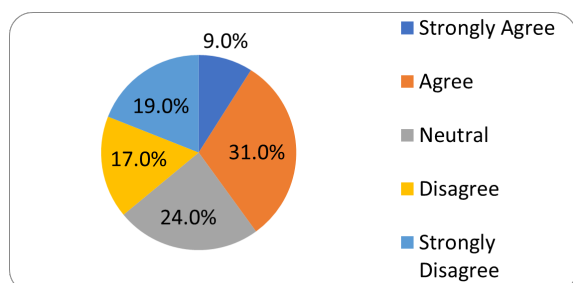
"I check because it's always wrong."

"I suspect that information is rarely passed on correctly, but in my experience it doesn't go down well if you question the way doctors do things. There is an assumption that a 'good patient' will do whatever they're told, so any display of agency/questioning of authority tends to be met with denial/dismissal."

"If two parties are involved I ensure the same information is given to both parties."

"I always thoroughly double-check everything!! In the past, I've received someone else's medication, had the wrong dose of medication put on my file, as well as received appointments in the post that have already passed before I've received the letter in the post. This is all due to admin errors."

## 9. Communications are clear and appropriately detailed



"Often specialist to GP and patient letters are written with medical terms and no consideration of whether the patient will understand them. This can make a patient feel they are not an individual being properly respected"

"Some letters are clear, but more often than not they are waffly without any clear indication of what the main message is."

"Totally disagree, I was told by my GP that my husband's case was far too complex and he could not comment or give any guidance to his medical needs."

"I frequently (usually) have to ask for clarification."

"Sometimes a kind of standard proforma is required."

"I can't count the number of times letters have contained incorrect information."

"Online results contain medical jargon; it needs clarifying and simplifying. Messages saying borderline pre-diabetic? Ambiguous and cause anxiety."

"Letters I receive from consultants are usually clear."

"I don't understand most of it."

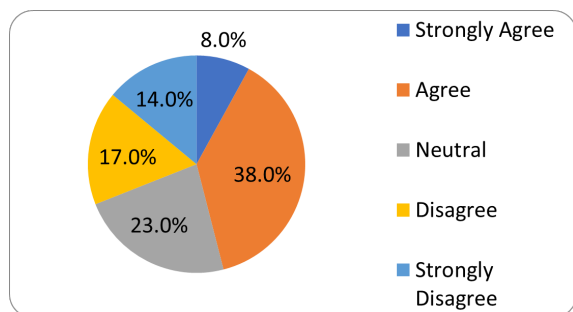
"If I can't get the correct format then I can't read it."

"It depends on the communication - letters are usually quite clear but routine communications (including face-to-face conversations) are often extremely unclear."

"Tend not to contain too much detail meaning you go searching 'Dr Internet'."

"Not really, basic at the most."

## 10. Communications are of an appropriate level to avoid confusion



"Only if reiterated by myself for confirmation etc."

"Wires seemed to get crossed quite regularly. I had two completely different accounts of my relative's abilities in terms of coping at home from the OT and nursing staff. Trying to pin down what would be needed in terms of home support took far longer than it should have as a result."

"Fine for me but may not be for everyone."

"I've had mix ups so often that I will ring to check they have the same appointment details as I have and that the information is correct."

"Sometimes yes, sometimes no. Depends on where from and the format it is coming in. For example text messages from the GP practice are really helpful and sometimes I look at them and think why did I need to receive this and why have I got the same message four times?"

"Largely OK but still think letters etc. could be improved with more simple language. I know when you get a cancer diagnosis it can be very scary and there is an even greater need to be clear. Similarly many people do not have great reading skills; many of the letters feel very full of text."

"Mostly but not always. Diabetic clinic at surgery never explained adequately."

"I suspect some (many?) patients would struggle."

"Letters dictated that come with spelling or grammar errors, while very funny, could also be very confusing."

"But I am clinically trained."

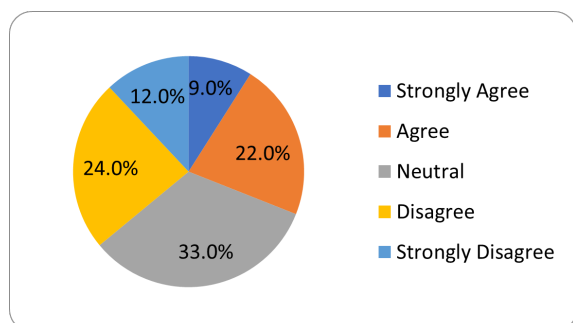
"No they are not."

"For me, yes but some people get very confused."

"Consultant using long medical words in letters."

"Too basic and not enough even when asked."

## 11. The referral process is well explained



"Sometimes, trouble is nurses and doctors forget to tell you things and when then order scans and forget to tell you, then this causes anxiety."

"Who is supposed to explain this? I have had to handle all my son's referrals myself. I even had to contact the CQC to get one referral sorted out. It can be a full-time job arranging referrals especially for carers who have to sort out referrals for themselves, as well as the person they care for."

"I am not sure if my GP knows what to expect either."

"No timescale or explanation given, only exception was paed's consultants who clearly communicate with each other."



"Rarely explained. You need to know the right questions to ask."

"Some referrals pathways are clearer than others. See previous comment about autism waiting time for my daughter."

"It's very well explained that your routine hospital appointment is delayed."

"No explanation about a referral to CHC or the change process within that."

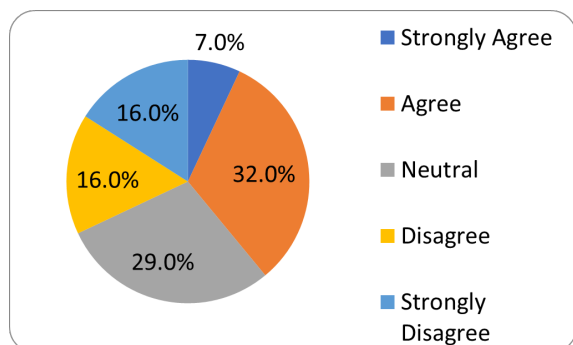
"Again it depends on who is referring and for what. Some kind of explanatory notes of why a certain service is recommended and for what reason, would be helpful."

"It really does vary per department or issue, but overall this is good."

"I rarely have any idea where I am being referred, who is dealing with the issue, who to contact about it, etc. I just wait to receive a letter then turn up when I'm told. This doesn't feel like good care."

"This needs more work and a visual pathway would help Deaf people."

## 12. I am prepared for how long I will be waiting for a referral



"Only in non-urgent situations."

"It seems no one knows things are changing all the time. I just expect to be waiting a long time for something non-urgent. Urgent care is good on the whole. I know staff are struggling and I feel sorry for them. They have too much to do and not enough resources."

"It's easy to feel lost in the system as the weeks and months go by"

"No idea, never explained."

"No, I am not prepared for the length of time waiting to receive a referral. I have already been to see a GP so they should be able to make sure that the referral is followed up promptly."

"Waiting times have got a lot longer over the years, it's very frustrating but again appreciate how understaffed and under funded the service is."

"As long as I have been told an expected waiting time but I have had to chase this up again."

"At one point my referral seems to have got lost so it took much longer to be seen – again five years ago, I had to chase."

"They don't tell you how long you will have to wait."

"Sometimes I have waited only to find I have been dropped off the waiting list."

"I am prepared to wait as it would be unreasonable not to, but GPs have literally no idea how long any referral could take."

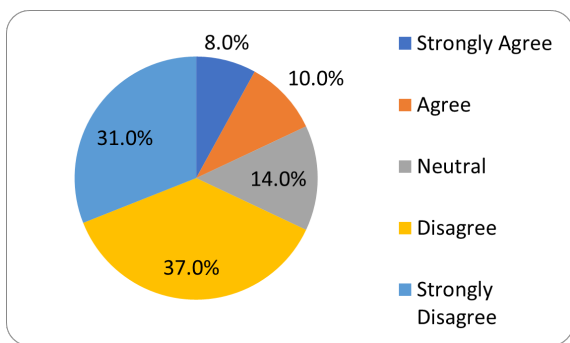
"I can't remember a time that I've been referred for something and haven't had to explicitly ask about waiting times."

"Certain areas not upfront on timescales; lack on information. SCAAS service in particular."

"Have no idea! Never told, or told very long waiting list!"

"If I'd known that a referral for mental health through NHS Let's Talk would take up to 18 months I could have gone to seek help elsewhere at a much earlier stage, which would have prevented a prolonged period of ill mental health. I felt extremely frustrated and let down by NHS services and not being properly informed at an early stage, being made to wait for ongoing assessment appointments."

### 13. The waiting times for referred services seem reasonable



“I know the NHS is under pressure – I think the waiting times are a big problem for us.”

“Not all waiting times are acceptable. However, if the conditions deteriorate when contacting the relevant department, in my experience, I have been seen sooner rather than later.”

“The waiting times are far too long and we need to get this down, but this means that everyone works together and people attend their appointments.”

“They are what they are.”

“My husband has been in hospital for three weeks, and likely to be there for a further number of weeks. All due to a simple minor operation being delayed.”

“I have heard from two people re their GP not referring for investigation soon enough.”

“Being asked to wait 12 months for a neurological complaint is clearly not acceptable.”

“For example, physio early intervention prevents acute injury becoming chronic, such a delay mental health suffers too.”

“The referrals are taking years at the moment! It makes me very concerned for myself and family if we have any serious health conditions in the future.”

“Waiting list times are a joke in some areas of the service. Hopefully it will improve as the backlogs built up during the pandemic are cleared.”

“Although not directly relevant to me, I do know quite a few people who are having to wait excessive times for relatively routine procedures (like hip and knee operations), sometimes a matter of months, or even years.”

“Our expectations are guided by what I see in the media of long waiting times.”

“Too long for child autism assessment.”

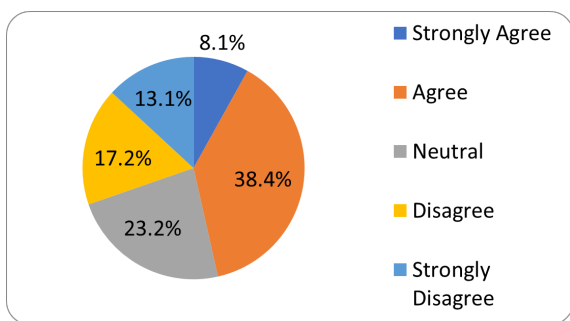
“Way too long, for kids even worse. I’m currently trying to get support for my child for incontinence and I don’t even have an idea of years? CAMHS been waiting 1 ½ years already, no idea of when even now.”

“Waiting a year is bad and then for that appointment to be cancelled eight months in advance with no other appointment, so you have to go through the whole process again. Two to three weeks to see the doctor to raise the issue. I know of people that have given up trying to the detriment of their health. So wrong.”

“Not at all. Early intervention and prevention is key to better health outcomes. Long waiting times for referrals often result in a person developing several other conditions on top of their original condition/illness purely because they’ve been made to wait too long.”

“For ophthalmology good.”

### 14. Relevant guidance leaflets are provided that I can read when I am ready, outside of appointments



“Leaflets & internet access are a godsend.”

“This is better.”

“Physio shared this type of information.”

“Often available but not actually issued.”

“I have been given the leaflets and am able to read them but I also do look on Google as sometimes the information is outdated.”

“Rarely offered.”

“Need more in Easy Read.”

"Important to have key info to take away as not always possible to hold onto all that is said, particularly if complex or emotional content."

"No additional information provided or signposted."

"Sometimes. Area diabetic clinic did this well."

These leaflets only come through relatively close to the appointment date."

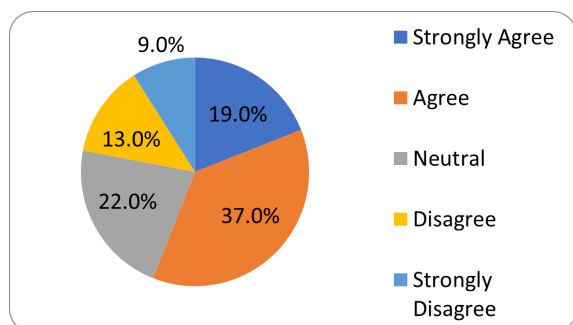
"Some of the leaflets are out-of-date, or for the wrong form of drug. For example, I was given a leaflet for oral methotrexate instead of a leaflet for the injections. For most other things there weren't any leaflets at all."

"They may be relevant, but many are woefully out-of-date."

"Referred to the web, the information is on there."

"Need to produce information in BSL."

## 15. I know how to ask questions and who to contact



"I know how to ask questions, but not always sure they are the right questions."

"I was fortunate to have a background in the NHS when trying to find things out."

"I know, but I feel for someone with limited capacity or a barrier it would be challenging for them to gain the information required, it's helpful if they take along a friend, carer or family member to ask the relevant questions."

"I know how to ask questions as I work in health and social care and understand the system. If I didn't then I would struggle."

"I guess I just go to GP. However, I have a first appointment with a nurse re PSA levels in some weeks so guess they may also be a useful point of call."

"Managed to track down email addresses in most cases."

"I do, but I bet most don't."

"Telephone numbers at the top of letters often don't have what the number is for. I never ask people in the NHS questions anymore, as an academic researcher I find the answers myself."

"That's because of my background"

"I know how to ask questions but not always sure where to go to ask these questions."

"For primary care I do."

"Only because I have had to find out."

"I would go around in circles and often get told to contact the person I have just spoken to who then tells me to call the person who told me to call them."

"I know this because I collect information and work out how to do this. Many people aren't confident enough to contact someone to ask questions. Many people aren't confident using IT or the phone."

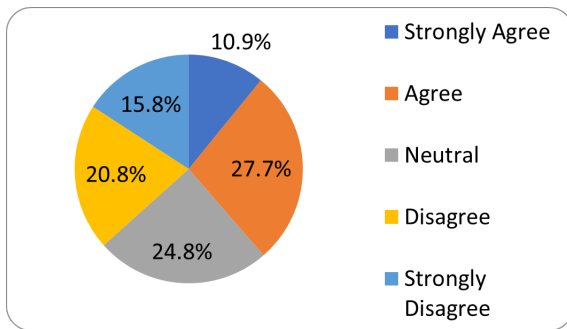
"With the exception of dental treatment, I know where to ask questions and obtain medical advice."

"Normally know how to ask questions, but there is not always a direct number to call for queries."

"This needs more communication."

"Because I'm a curious and proactive person, I ensure I find the contacts needed, but I pity anyone who waits to be informed and directed by healthcare professionals alone."

## 16. I am seen as a whole person, not a diagnosis or set of symptoms



"I trust that this is true even though I have various health issues."

"By some, not all."

"My GP sees me as a whole person - but the hospital appointments divide me by my conditions."

"Dependent on service; again physio exceptional!"

"Services rarely see me as a person and majority of the time see me as a diagnosis."

"For the majority of my care under the hospitals in Gloucestershire I have received outstanding care and treatment. However, on a few occasions, many years ago, I have been treated appallingly, made to feel very insignificant and not worthy of their time."

"I have been made to feel like I am not a person but just 'here is your diagnosis, now on your way'."

"I have ME. This comes with a complex set of symptoms and associated conditions. I feel this condition is viewed as a psychological condition and my worries/concerns are not taken seriously."

"When you eventually get into the hospital you are treated exceptionally well. All other services treat you as an irritant and put you into a number-crunching exercise. Social services within the Gloucestershire area are appalling. Thankfully the whole care system is supported by charities, otherwise the country would fall apart."

"My GP who sadly stepped down at Christmas, has been excellent. Oncologists seem to have too little time."

"I have had cancer and I don't feel the effect or impact of this is always appreciated when I have concerns."

"Not only do the clinicians not deliver personalised care, the system doesn't allow it. There are too many silos, no cooperation between them, too much wasted time (e.g. appointments running two hours late) and too much driving to hospitals miles away, when the CCG and now the ICB keep saying they want to deliver care closer to home. The core service that the NHS should be providing is medical services. No amount of social prescribers can do that."

"I think the NHS is under too much pressure to give a personal service right now."

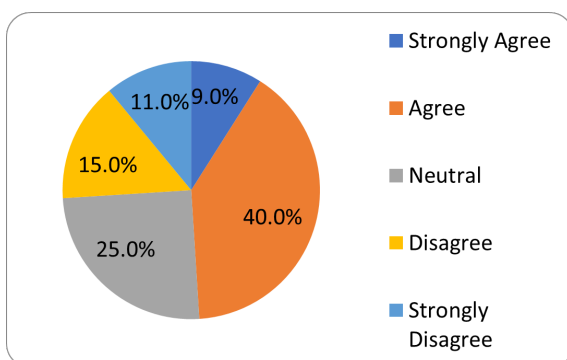
"Each consultant looks at each set of symptoms, never holistically, even though they are related."

"It feels like sometimes I am just another number in a ten minute slot."

"I have multiple conditions but they are treated in isolation from each other."

"Doctors and health care professionals need to take a more holistic approach to their patients. Mental health, diet and many physical conditions are all interlinked. Prescribing medications to mask symptoms will never produce the best outcomes for a person's overall wellbeing."

## 17. I feel listened to



"No! Due to a) clock watching, and b) people's tendency to group outward appearances/age into one category irrespective of cognitive ability."

"On the whole, yes"

"I felt that I was a nuisance to the staff. They didn't seem used to relatives or patients asking questions."

"I have been told that I speak like a robot, as I am not listened to or respected."

"I make sure I am listened to."

"I feel diagnostic overshadowing based on my history happens a lot."

"I feel like an irritant to my doctor, and social services sees everyone as a money saving exercise."

"Only listened to after being difficult. This is hard work and very distressing."



"Sometimes and other times oncology has been too busy or not interested in what else I am doing to improve health. There is often a dismissive or uninformed approach to integrative approaches, i.e. getting the best from conventional, lifestyle and complimentary. There are huge dangers from Google but there is now a mass of evidence (to varying degrees) of a whole range of approaches. Some oncologists seem more ready to embrace or at least accept than others. I like the campaign by the Patients Association for Shared Decision Making – that came out of a big research project in Scotland that showed one in seven people have post-decision regret. I think that was mostly ref surgery. A badge has been created for clinicians to show their support with apparently very positive feedback from patients."

"On most occasions, even a 'Do you want to draw attention to anything else/tell me about' would be helpful."

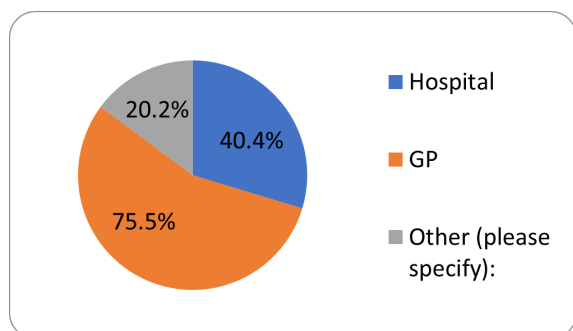
"I never feel listened to, either for my own medical conditions or for my son's. It took six years for us to get one referral for my son, because the GPs weren't listening. When we finally found a GP who did listen, the consultant running the service retired and they didn't have anyone else to run it so they referred us to London. If they had listened to us six years previously then that wouldn't have happened, my son would have got treatment for his condition."

"I feel like I am processed in and out as quickly as possible by the majority of consultants. If I see the same consultants privately this is a different matter, it's like seeing a different person. I was very impressed with a rheumatoid consultant, she is the nicest consultant I have ever seen in the NHS."

"Yes most times, but only if assertive on some consultations."

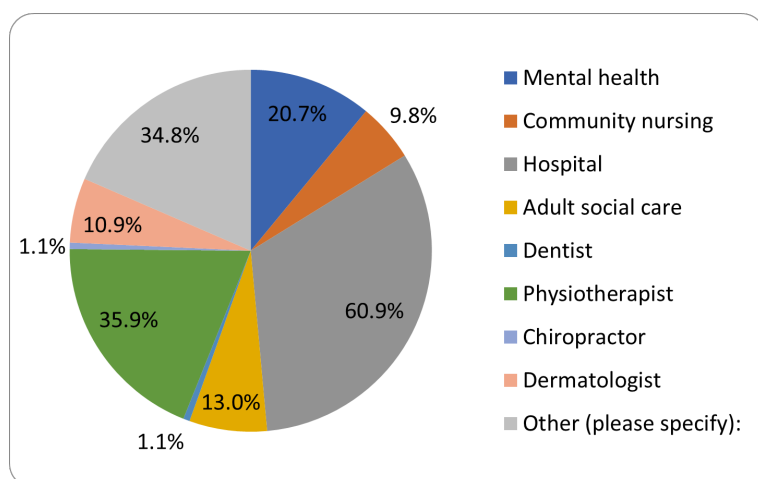
"Depends on the healthcare professional, but often it feels like you're just a number on a conveyor belt and many doctors behave just like robots."

### 18. I have been referred from:



- Nurse
- Day centre to ASC locality office
- Private health care
- Audiology
- Teens in Crisis
- Armed Forces
- Stroke Nurse (after six years) and chiropodist
- Dermatology
- By GP to hospital originally, and now by hospital clinic to cardiology

### 19. I have been referred to:



- Podiatry
- Cardiology
- Brain Injury Team
- Private eye clinic
- Haematology, skin specialist, X-ray, sleep clinic
- CAMHS, ME clinic
- Area diabetic clinic
- Pain clinic specialist
- Nephrology
- Rheumatoid, gastro, osteo, pain management
- Orthopaedic consultant

- Epilepsy clinic, Brain Injury Team, osteoporosis team, ophthalmologist
- Too many to list! Includes, ophthalmology, general surgery, ENT, orthopaedics and maxillofacial
- Neurologist, endocrinologist, oncologist
- Gynaecology
- Frailty nurse
- Hydrotherapy

## 20. Is there anything else you would like to tell us?

"The mental health services are atrocious. They have let myself and many of my friends down. The lack of communication between Wotton Lawn and outpatients is almost non-existent. Mental health services also never listen to what I want and what I want to say. Before I've gone into the meeting they've made their minds up. Most of the time there is no point in me being there."

"Cancer pathways seem very confusing to many of us; from talking to several people in the last couple of months there seems to be no clear referral to, for example, prehab and rehab. I am aware there are hopes to improve - they cannot come soon enough!"

"Cross county border, poor to non-existent comms is the key problem."

"Please make systems speak to each other."

"A GP spoke to me on the phone abruptly and rudely and then hung up."

Part of the reason, Gloucestershire NHS Foundation Trust is one of the worst performing Trusts in the country. There are some wonderful people working for the Trust but the mismanagement and poor communication is unforgivable."

"Not everyone has a mobile phone, nor has access to a computer. Our mobile reception in our village is non-existent. This should be asked about by the professionals rather than assuming that everyone can do things online or on a mobile phone."

"This is a really important area of work, thank you for looking at it. I feel that so much of the confusion and distress I have experienced with medical issues in the past could have been avoided with clearer, more timely communications from and between healthcare professionals."

"I do not like only having phone calls with my GP."

"It is high time that all health care systems can talk to each other. This is particularly important when calling an ambulance."

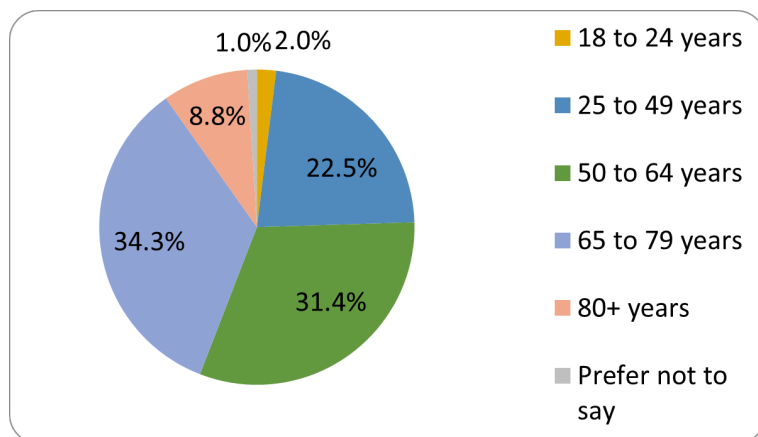
"We would love to continue to work in partnership to improve access for Deaf and hard of hearing people."

"Fully understand the current pressures on the NHS but the waiting times do seem to be very bad at present."

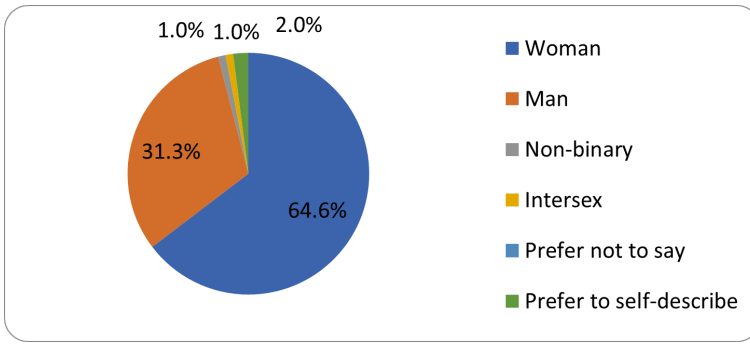
"After my husband's stroke, I was given no information regarding wellbeing, financial or his care. I'm now his carer on carers allowance and he receives full enhanced PIP. I would love to see a system where central point could give a package of information, not by listening and gaining help from neighbours, friends through ringing around. Headway, Help for Heroes - after two/nearly three years have helped tremendously."

## Demographic data

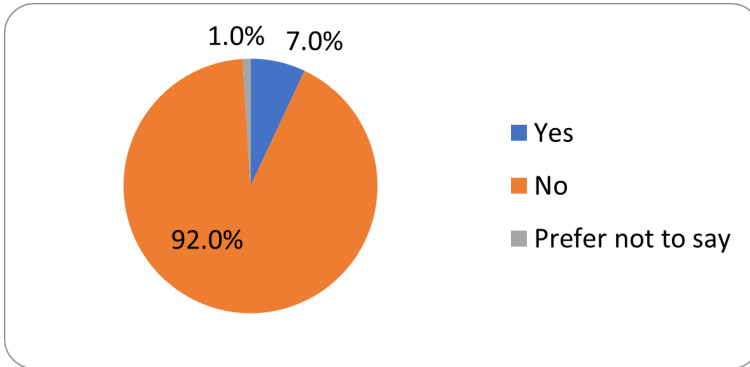
### How old are you?



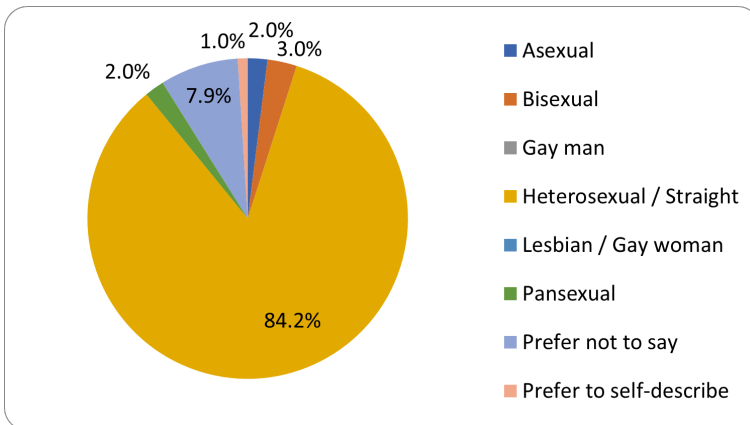
### What gender do you identify with?



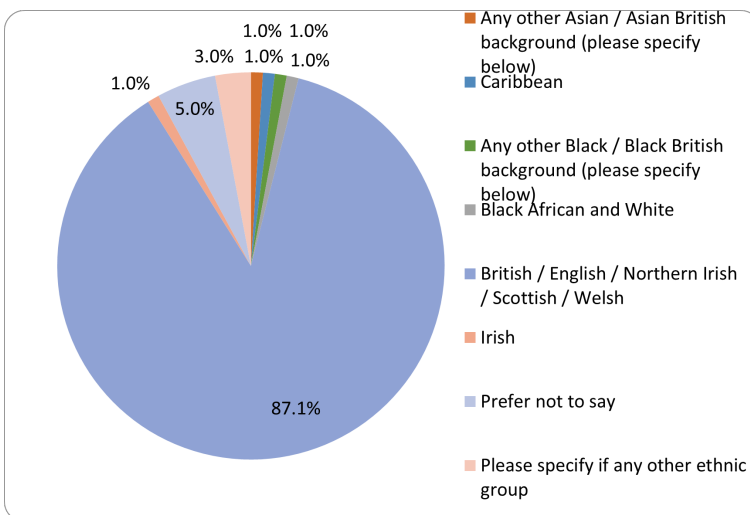
### Is your gender different to the sex that was assigned to you at birth?



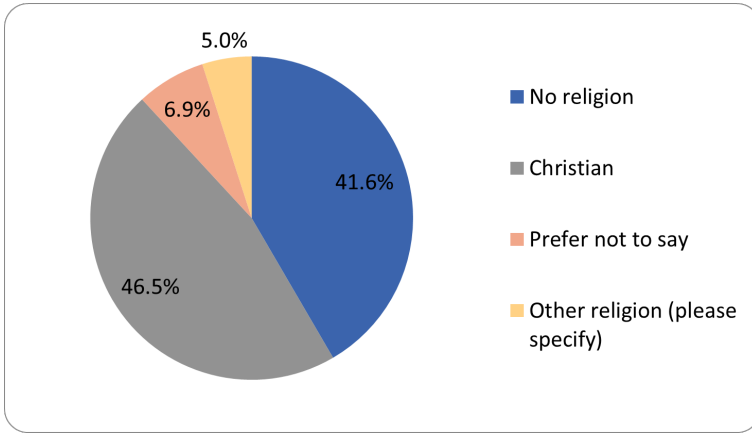
### Which sexual orientation do you identify with?



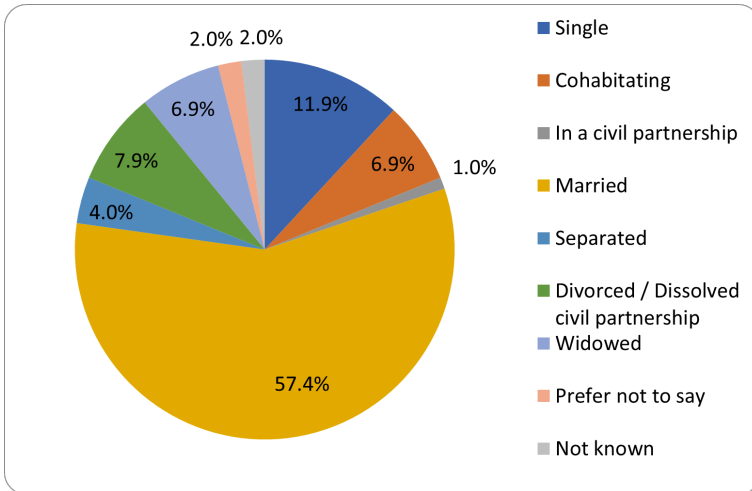
### What is your ethnic group?



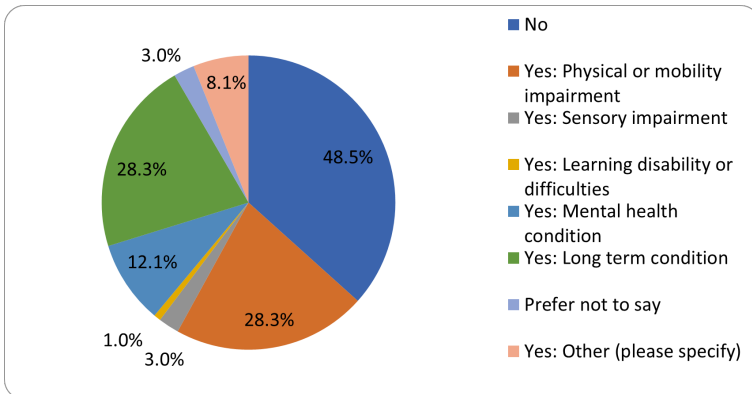
### What is your religion?



### What is your marital or civil partnership status?

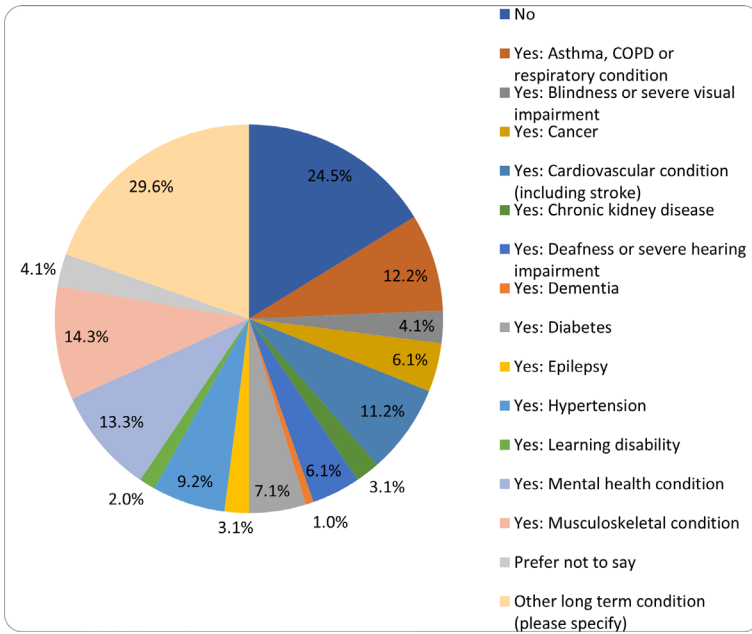


### Do you have a disability?

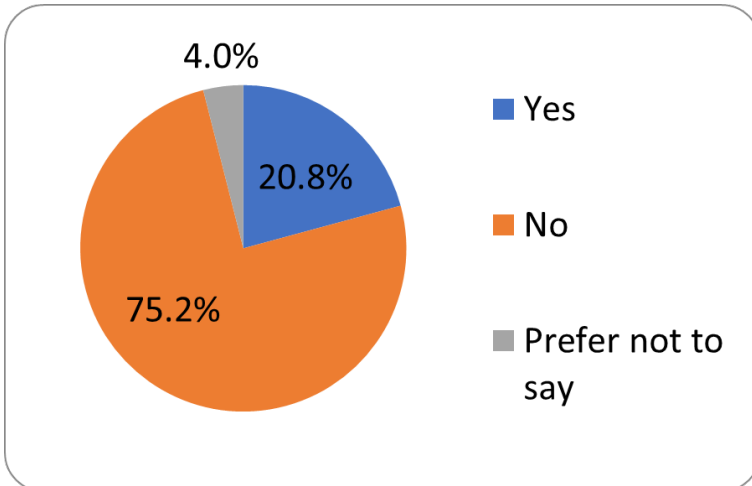




### Do you have a health condition?



### Do you consider yourself to be a carer?





# healthwatch Gloucestershire

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