



# Inclusion Gloucestershire Survey

January 2022

---

## Choice & Control Chapter 2

**INCLUSION**  
**GLOUCESTERSHIRE**

BIGGER DREAMS ► BETTER LIVES ► BRIGHTER FUTURES

# Contents

Introduction .....	Page 3
Who told us their ideas and opinions? .....	Page 4
What areas of life are worrying people? .....	Page 5
Key Messages about Choice, Control and Other Important Areas .....	Page 6
More information about what people said is worrying them .....	Page 11
Experiences relating to “Choice and Control” .....	Page 16
Other local research .....	Page 32
Recommendations .....	Page 33
What will Inclusion Gloucestershire do next? .....	Page 35
Thank you .....	Page 36

# Introduction

Inclusion Gloucestershire wanted to understand the areas of everyday life that are causing concern or worry for people in Gloucestershire who face disabling barriers.

In June and July 2021, we invited people who face disabling barriers to give us their opinions and experiences along with any ideas they have for improving things.

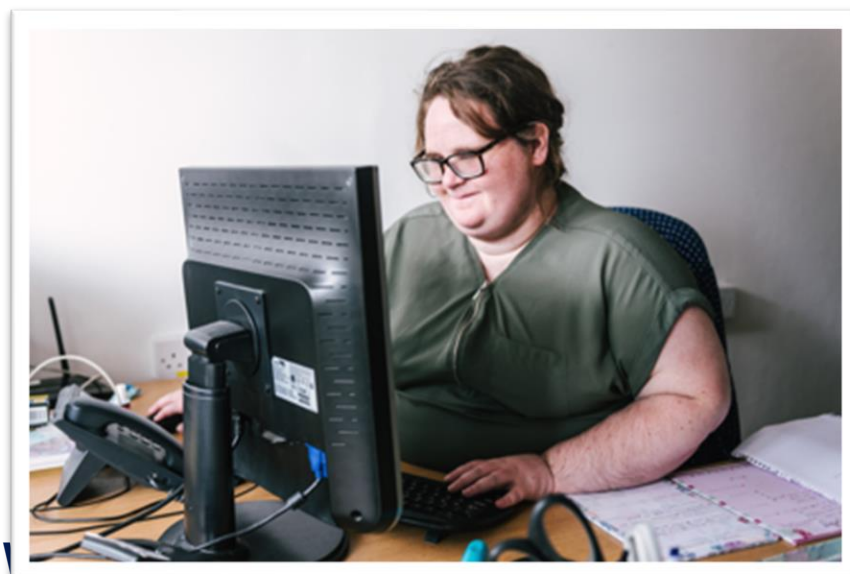
**We asked people who face disabling barriers, family and friends and paid staff members who support people facing disabling barriers.**

As a user led organisation, we want to make sure that our work is led by those who face disabling barriers and their families and friends.

We will use the information we have been given to guide our organisational strategy (big plan) for the next 3 years.

**For more information on how we found out about what people thoughts, please see our headline report at:**

<https://www.inclusiongloucestershire.co.uk/research-strategy-and-partnerships/>



# 135 People Gave Us Their Views!

There is more information about who gave us their views in the headline report but here is a summary:



- Most people identified themselves as female.
- Most people did not identify as transgender.
- Most people identified themselves as heterosexual.
- The largest group of people who gave us their ideas were in aged 55-64. The second largest group were aged 45-54, closely followed by people who were in the 35-44 age group.
- Nearly all people used English as their first language.
- Most people identified themselves as White British.
- The largest group of people who gave us their ideas have lived experience of a mental health condition. The closest group to this were people with learning disabilities and then people with a physical impairment.  
**Several people had more than one “type” of lived experience.**
- Most people live in Gloucester or Cheltenham, but there are still many participants who live in other areas in or near to Gloucestershire.
- Most people who gave their ideas are not members of Inclusion Gloucestershire at the moment.
- Most people have not used Inclusion Gloucestershire’s services in the last 6 months.

**For more information on how we found out about who responded to our survey, please see our headline report at:**

<https://www.inclusiongloucestershire.co.uk/research-strategy-and-partnerships/>



## What areas of life are worrying people?

We asked people who gave us their ideas and opinions to tell us how worried they are about 22 areas of life.

We asked people to tell us if they were:

- **Very worried,**
- **A little worried,**
- **Not sure,**
- **Not too worried,**
- **No worries or**
- **Whether the area does not apply to them.**



In most of our work we use a strengths-based approach but the reason that this survey used the negative concept of worries and concerns, was to reflect that people still face significant disabling barriers in society. We wanted to identify where there are issues and gaps so that something can be done to address them.

**One area that was causing people some worry was in a number of topics that we have called “Choice, Control and Other Important Areas” and this report is going to tell you more about what people have told us.**

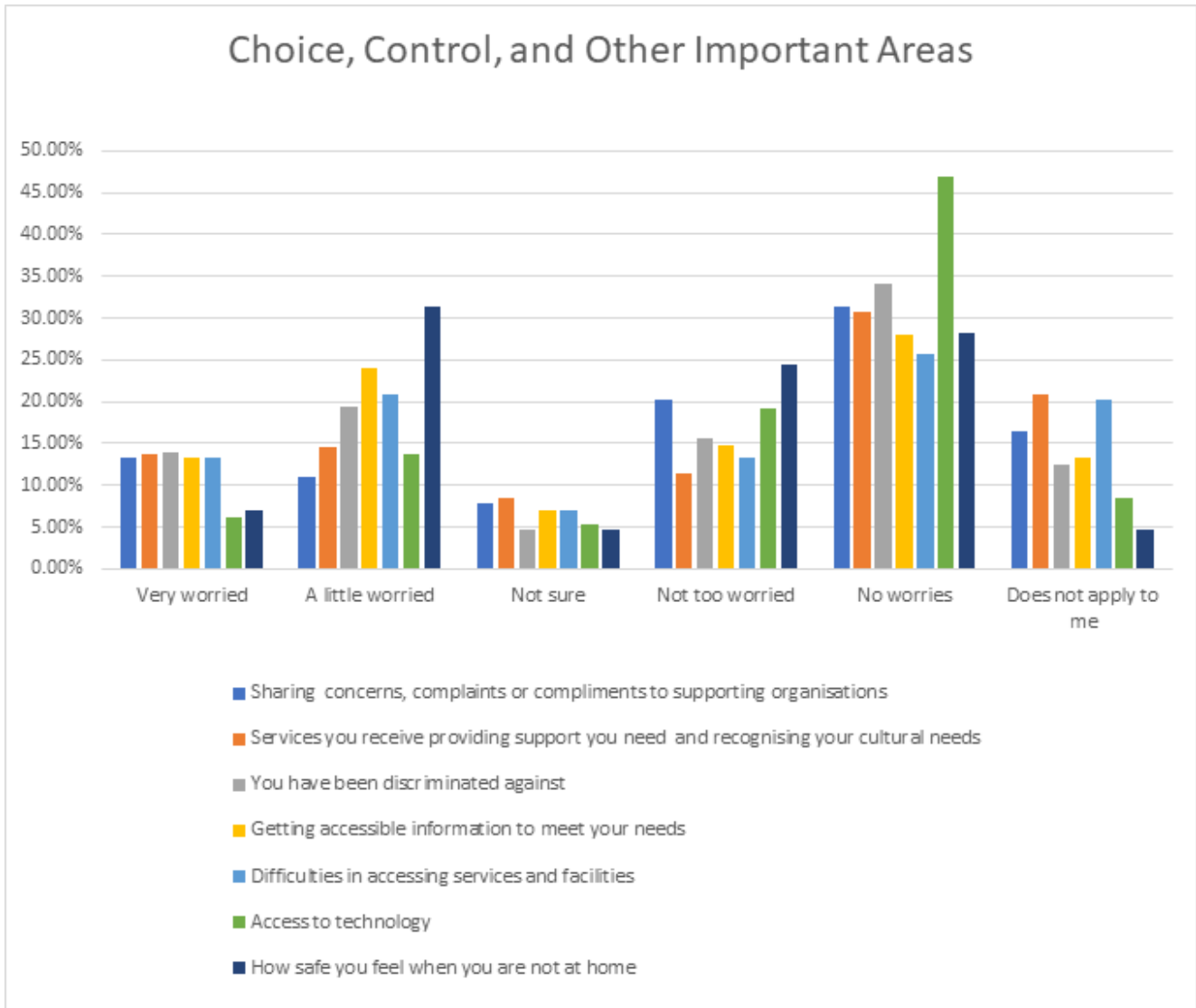
This report covers things like discrimination, making complaints, accessible information and services, cultural sensitivity, access to technology, and safety.

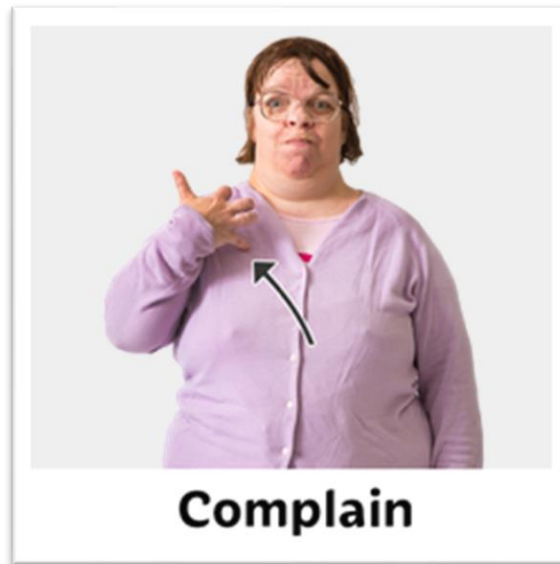
If you want to know more about the other areas we asked about, we will be writing more reports in the next few weeks and months, or you can see our headline report and our report about health on our website.

<https://www.inclusiongloucestershire.co.uk/research-strategy-and-partnerships/>

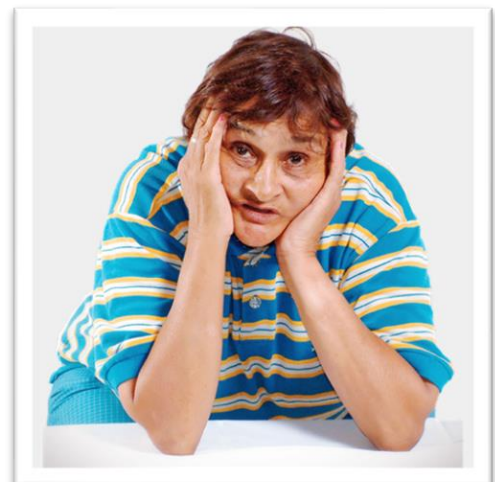
# Summary and key messages regarding choice, control & other important areas

This is a summary of the key information we found out about choice, control, and other important areas:





- A quarter of people were worried about sharing concerns, complaints or compliments with organisations supporting them.
- Some people have not felt that they were not taken seriously when voicing complaints or that they were seen as a “troublemaker” and their opinions were not valued.
- There were concerns about poor verbal and written communication and a feeling of not being listened to in feedback processes.
- Delays in responses or unhelpful responses when making complaints was also highlighted and resulted in frustration for some people.
- A small number of people were concerned about the impact that raising concerns might have on their support.
- A number of people voiced their positive experiences in resolving concerns or complaints.
- Culturally sensitive services were not identified by most people to be an area of concern, however the ethnic profile of the people who responded to this survey (91% of people were White British) is not reflective of the diverse communities within Gloucestershire and this is likely to have impacted on the findings.
- A small number of people were concerned about gaps in awareness and service provision, specifically in relation to Welsh



language services in England, and the needs of those with sight loss and their carers.

- A few people were concerned about poor staff and service responses to recognising and meeting cultural needs, and a feeling of frustration resulted from this.

**A third of people who responded were very or a little worried about discrimination in the last year.**



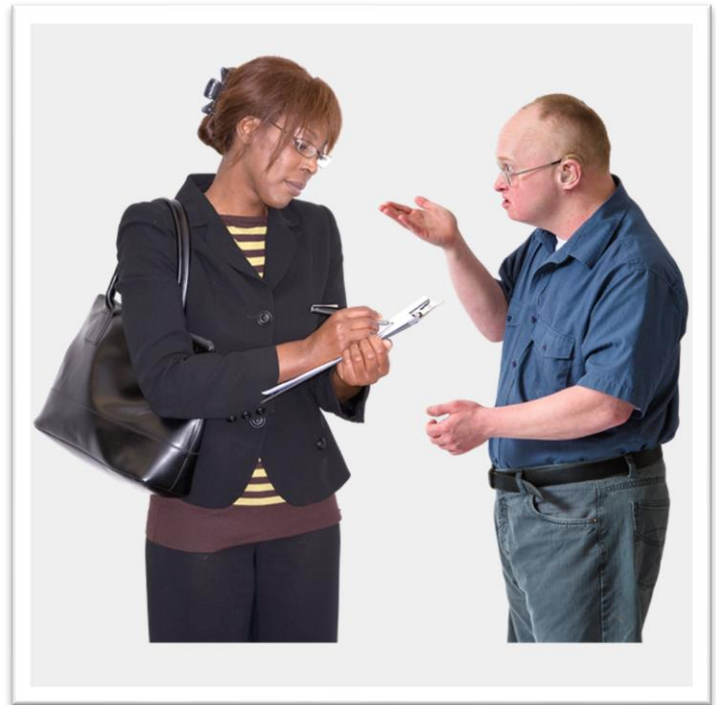
- People who responded to the survey had experienced hate discrimination, bullying, and discrimination in employment and these experiences were based on a range of protected characteristics including race; sexual preference; and religion.
- Other acts of discrimination were based on individual personal needs based on mental health, need for accessible venues or communication

preferences.

- A lack of reasonable adjustments and poor attitudes, assumptions and lack of awareness and understanding had contributed to the discrimination people have experienced.
- Almost two fifths of respondents, which is 50 individual people, said that they were worried about feeling safe when they were not in their home.
- Access to information was an area of concern for 37% of respondents, and this relates to a range of services and processes.
- Specific concerns were raised regarding the accessibility of information, both digital and paper based, for those who have sight loss.



- The amount of information available through digital means and the use of phones and texts to engage with people had caused difficulties for a number of people.
- Whilst relatively low numbers of people (20%) appeared to be worried about their access to technology in our survey, the extended use of technology and its impact on accessible information was an area of concern to some people who were not able to use some digital systems and processes without adjustments.



- A flexible and adaptable approach to information and the use of reasonable adjustments did not appear to have been the experience of a number of people.
- A lack of acknowledgement of communication preferences had left one person feeling they were discriminated against.
- People's poor experiences of gaining accessible information may be linked to a lack of understanding and training in relation to the varied communication needs that people may have.
- Just over a third of people (34%) said that they were worried about accessing services and facilities. This was 45 people.
- Venues being inaccessible for those who use wheelchairs and inaccessible transport, and difficulties with travel and pavements were highlighted.
- The processes in place to enable access to some services were a barrier.
- The difficulties that people face had negatively impacted on their individual confidence and experiences.



- Lack of awareness and understanding about the importance of access needs was concerning and highlights the need for ongoing education.
- Almost two thirds of respondents (61%) felt they had excellent choice and control in their lives (scoring 4 and 5 on a scale). This was 57 people.
- Positive experiences in relation to individual choice and control, and the support of others, were recorded by several people.
- Negative experiences in relation to “choice and control” were shared by a number of people, and these linked to lessening choice due to changing health needs, lack of support as a family carer and services not being supportive.
- The impact that this was having on people’s emotional well-being can be seen below, and includes low self-esteem, low feelings self-worth and frustration.
- A few people felt their choice and control was impacted by the attitudes and response of wider society creating barriers and are also concerned about government approaches to those who face disabling barriers.



## **Choice, control, and other important areas: more information about what people said is worrying them**

We asked people 7 questions about how worried they were about things to do with choice and control, and there were mixed views.

The questions we asked were:

- 1. Are you worried about sharing concerns, complaints, or compliments with any of the organisations who you are supported by?**
- 2. Are you worried about the services you receive, being able to provide you with the support you need and recognising your cultural needs?**
- 3. Are you worried that you have been discriminated against in the last year?**
- 4. Are you worried about getting accessible information to meet your needs?**
- 5. Are you worried about difficulties you may have in accessing services and facilities?**
- 6. Are you worried about your access to your technology?**
- 7. Are you worried about how safe you feel when you are not in your home?**



We also asked people to tell us how much choice and control they felt they had in their lives.

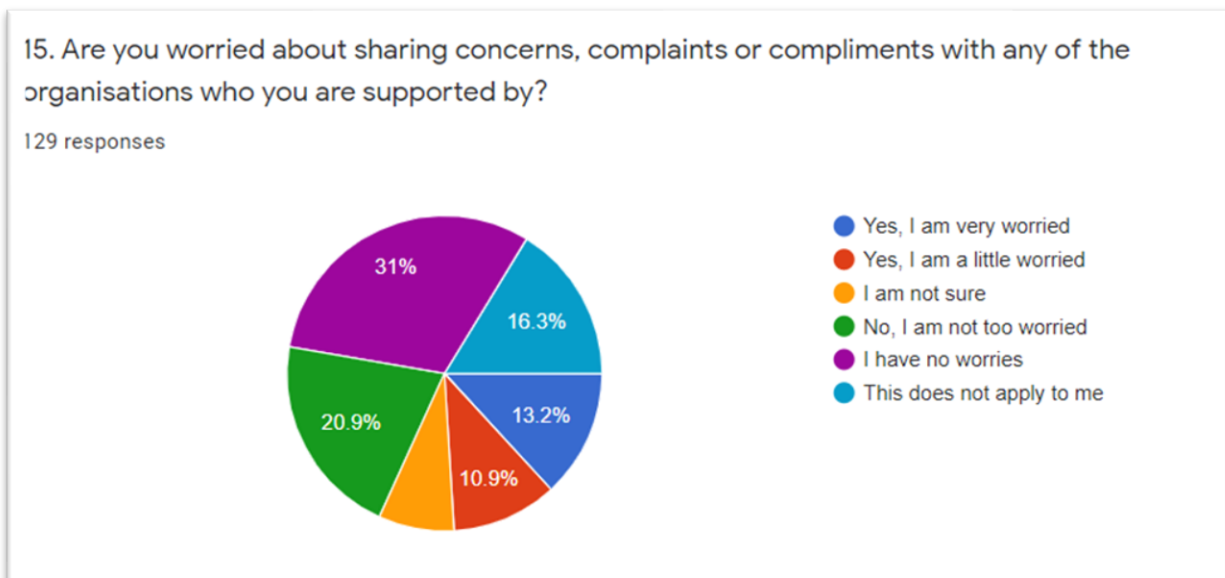
And then we asked people to tell us about their experiences in relation to various areas including:

- **Sharing concerns, complaints and compliments**
- **Having their cultural needs met**
- **Discrimination**
- **Accessing information**
- **Accessing services and facilities**
- **Choice and control**

We also asked people what the one thing was that was causing them most concern and how they think things could be improved and if this related to the sections of our “Choice and Control” chapter we have included them in this report along with any other information we were told about concerns in this area.

## What did people tell us?

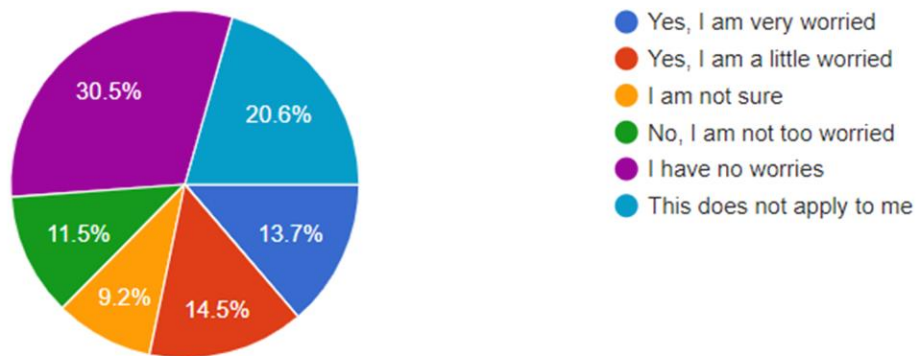
1. **Almost a quarter of people (24%) were worried about sharing concerns, complaints or compliments with organisations that supported them. This was 31 people.**



**2. Just over a quarter of people (28%) were worried about services being able to provide culturally sensitive support. This was 37 people.**

16. Are you worried about the services you receive, being able to provide you with the support you need and recognising your individual cultural needs?

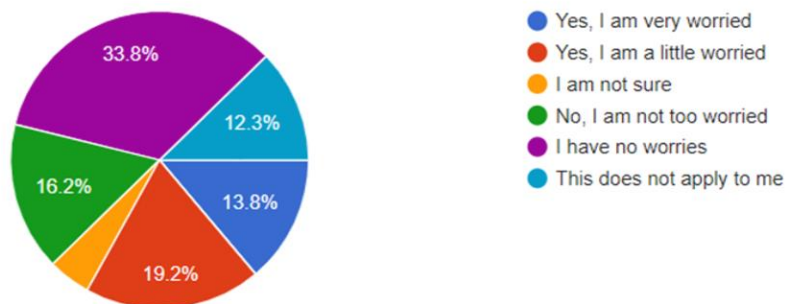
131 responses



**3. A third of people (33%) were worried about being discriminated against in the last year. This was 43 people.**

7. Are you worried that you have been discriminated against in the last year? Discrimination is if you are treated differently because of who you are. This may be because you are disabled or because of your sexuality or because of your culture or religion. It may also be because of your age or your gender or because you are pregnant. It may also be because you are married or in a civil partnership.

30 responses

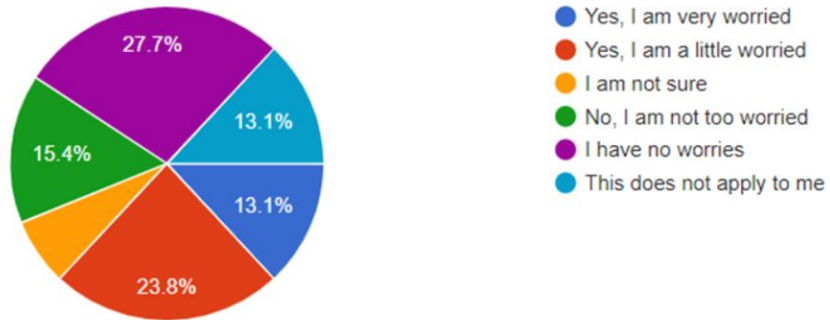




**4. Over a third of people (37%), were worried about access to accessible information. This was 48 people.**

18. Are you worried about about getting accessible information to meet your needs? This could be information from any organisations or services that you use e.g. councils, GP's, banks, leisure centres, buses etc.

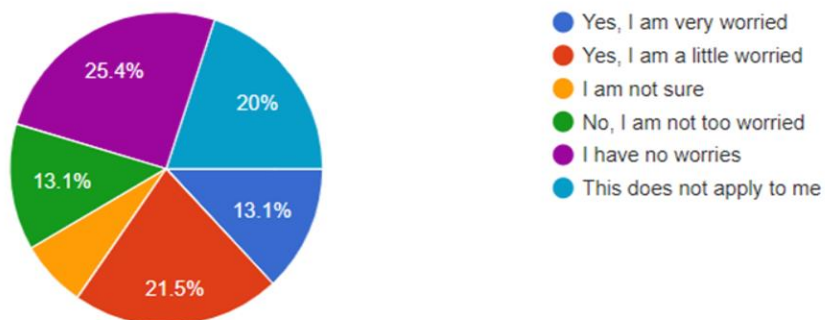
130 responses



**5. Just over a third of people (34%) said that they were worried about accessing services and facilities. This was 45 people.**

19. Are you worried about difficulties you may have in accessing services and facilities? This could be difficulties in getting into buildings, understanding the signs in buildings, lighting being too bright, no hearing loops etc. This could be any organisations or services that you use e.g. councils, GP's, banks, leisure centres, buses etc.

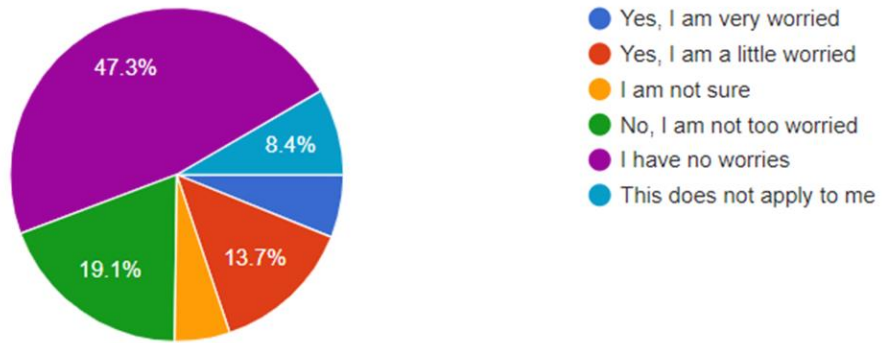
130 responses



**6. A fifth of people (20%) said that they were worried about access to technology. This was 26 people.**

20. Are you worried about your access to technology? This may be equipment like laptops, tablets and smart phones or it may be technology to help you be more independent like hearing controls that you can talk to.

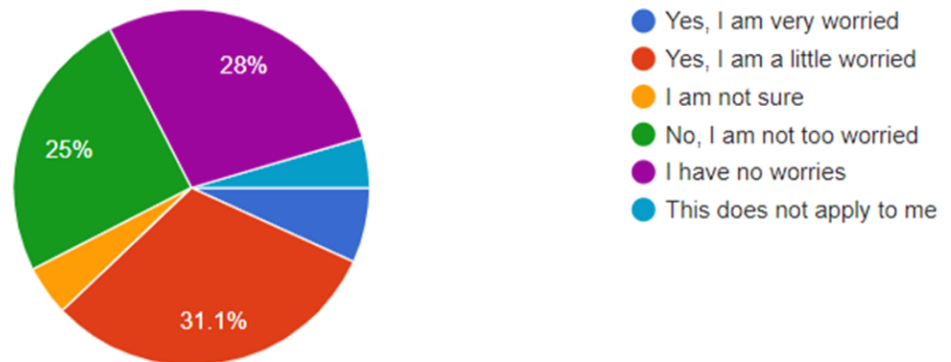
131 responses



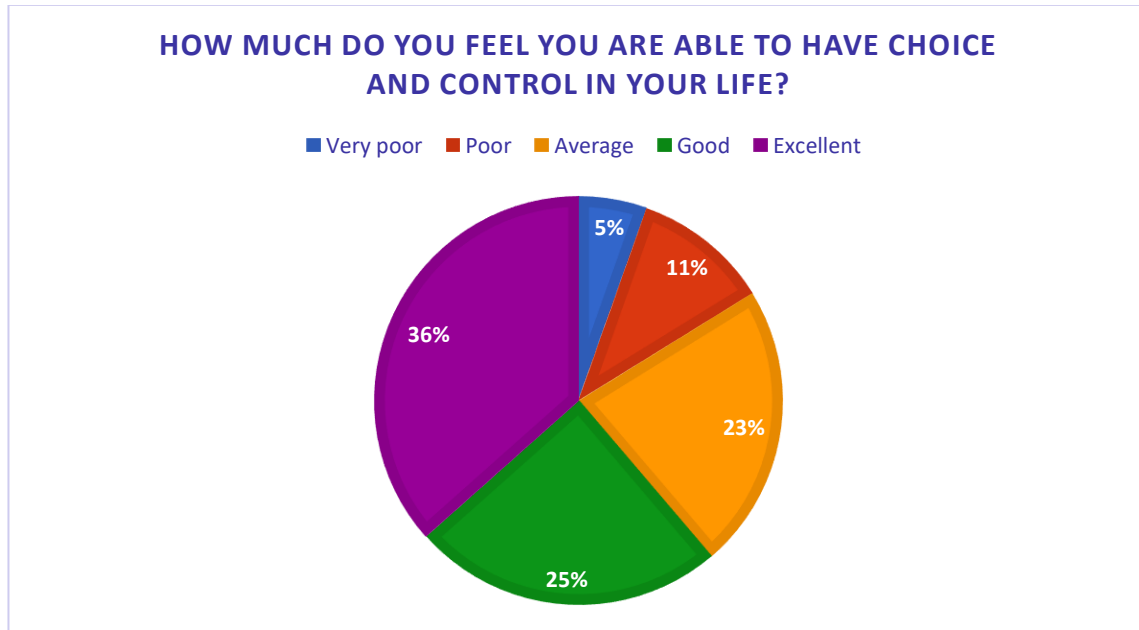
**7. Almost two fifths of people (38%) said that they were worried about feeling safe when they are not in their home. This was 50 people.**

21. Are you worried about how safe you feel when you are not in your home?

132 responses



8. In relation to the degree of control people felt they had in their lives. 16% of people felt they had poor choice and control (scoring on a scale of 1 and 2) and this was 15 people. Yet almost two thirds of respondents (61%) felt they had excellent choice and control in their lives (scoring 4 and 5). This was 57 people.



1= Very poor choice and control ..... 5 = Excellent choice and control

## Experiences of Choice, Control and Other Important Areas

People told us about their experiences in the areas of choice and control, and we have been able to use this information to explore which areas are common to several people. We discuss these further below.

### Poor responses when concerns are raised

For some people, they felt that they were not taken seriously when voicing complaints or that they were seen as a “troublemaker” and their opinions were not valued.

A number of people voiced concerns about poor verbal and written communication from those responding to feedback and this had resulted in a feeling of not being listened to.

Delays in responses or unhelpful responses when making complaints were also highlighted and resulted in frustration for some people.

24% of respondents were worried about voicing their views, and a small number were concerned about the impact that raising concerns might have on their support.

For a few others, they stated that they no longer have confidence in using feedback processes.

Several people voiced their positive experiences in resolving concerns or complaints, and these related to direct support providers, GP's, and mental health teams.



**“Meaningless obfuscation.....not being taken seriously when voicing concerns to GPs/surgeries.”**

**“Not being listened to – dismissed, belittled, discriminated, not being taken seriously when voicing concerns to GP's/surgeries.”**

**“It feels like you are a troublemaker.”**

**“Generally being quite vocal and willing to challenge things can sometimes see you as labelled as awkward.”**

**“...labelled as a troublemaker if you complain.”**

**“...labelled as difficult and a troublemaker.”**

**“No response was received. Any further support I have had to seek out for myself.”**

**“Not being listened to – dismissed, belittled, discriminated, not being informed or updated about what’s happening.”**

**“I often to not get a response or get brushed off.”**

**“...my opinions, along with the opinions of my family and friends were not listened to.”**

**“I was not listened to.”**

**“...judgemental comments and factual inaccuracies that have been recorded then go on to be read which in turn lead to pre-judgements from the next clinician. This has affected my treatment, along with misdiagnosis.”**

**“Everything taking a long time and having a negative affect...not being informed or updated about what’s happening.”**

**“...with denial or irrelevant tangential statements of “assurances”.”**

**“Feel sometimes that asking for equality is too much like expecting special treatment.”**

**“If I share things sometimes people can get annoyed.”**

**“I don’t feel confident to tell people things that don’t go well. I feel scared.”**

**“Worried about it affecting support going forward.”**

**“IT can sometimes be easier to let things go, especially around access when people hide behind the cost benefit of undertaking changes.”**

**“All been bad.”**

**“I don’t share, my experiences have largely been negative.”**

**“I don’t intend to either (share my views) as I will never put myself in the clutches of (named service) again.”**

**“Don’t voice anymore.”**

**“In the past it has not changed anything or moved things forward. I save my energy.”**

**“Issues raised only seem to get dealt with if it is an emergency.”**

**“GP seemed receptive to further information regarding changes to NICE guidelines.....”**



**“I have had good experiences regarding the above (making complaints) when speaking to my mental health team.”**

**“When things are not going well people who support me help me and make sure I am OK.”**

**“I had very good communication with my son’s school throughout lockdown.”**

**“..I have staff members and an advocate to make complaints on my behalf should I need to.”**

**“My team leader sorts out any issues that I may have, taking time to talk to me.”**

## **Cultural sensitivity**

For those people who felt this question related to them (114 people), fewer people (43) were worried about culturally sensitive services than were not worried about this aspect of their lives (65 people), and 6 people were not sure. However, the respondents for this survey predominantly identified as White British so this needs to be considered in the context of feedback received.

A number of positive and supportive experiences were shared in relation to services meeting cultural needs.

One person voiced concern about the ability of services to use peoples preferred language, and specific reference was made to a lack of Welsh language services in England. One person was concerned that access to faith-based facilities was not considered a priority. One person was concerned that the needs of those with sight loss and their carers is not recognised.

A few people were concerned about poor staff and service responses to recognising and meeting cultural needs, and a feeling



of frustration resulted from this. This also appeared to result, for some people, in a low expectation about whether their cultural needs would be met.

**“I think in general they are willing to help if they can.”**

**“Hands on frontline carers are amazing and go out of their way to meet cultural needs.”**

**“I have a support worker from (name of service). She respects my beliefs and is supportive when we talk about them.”**

**“Very happy with the services offered.”**

**“Support plans, policies, plans and relevant paperwork is in place to help staff know what is in my best interest and how to meet my needs.”**

**“There are no Welsh language services in England at all, but I expect that.”**

**“...not considered a priority for my son or I to be able to access church, but this is a high priority for me.”**

**“The needs of the blind and their carers are not there.”**

**“Services don’t meet my cultural needs.”**

**“Some staff make no attempt to meet cultural needs and have a “like it or lump it” attitude.”**

**“Do not get any support.”**

**“I do it (meet my cultural needs) myself.”**

## **Discrimination and safety outside of the home**

A third of people who responded were very or a little worried about discrimination in the last year.

Almost two fifths of respondents (38%), which is 50 individual people, said that they were worried about feeling safe when they are not in their home.

Additional information relating to feeling unsafe was not specifically asked for, but the experiences of discrimination some individuals have been subject to in the last year

indicate the pressure that some people who face disabling barriers are under when they leave their home.

Individual examples of discrimination that were shared were based on race; sexual preference; religion; personal needs based on mental health; need for accessible venues; or communication preferences.

People who have responded in the survey have experienced hate discrimination, bullying, and discrimination in employment.

Concerns have been expressed by a few people regarding a lack of reasonable adjustments and poor attitudes, assumptions and lack of awareness and



understanding.

One person is concerned that there is a lack of diversity within senior leadership roles; and a lack of awareness of cultural differences

**“People assume I do not understand just because of the colour of my skin and the way I dress.”**

**“People assume I am sexist because I am Muslim.”**

**“A GP refused to treat my Polycystic Ovary Syndrome as I was in a long-term relationship with a woman and therefore “shouldn’t be having children”.”**

**“I and my ex-girlfriend were being verbally abused by our neighbours, who would shout homophobic slurs at us and call us “crazy/freaks” on a daily basis. When we called the Police and explained this to them, we were told by one officer that if we were “normal and not mentally ill we would be able to cope with the situation.”**

**“I have been discriminated against in the workplace for having mental health issues.”**

**“Discrimination in the workplace and not being able to succeed because I am a woman of BaME origin.”**

**“Not using my communication preferences.”**

**“Being harassed when I leave my house.”**

**“Hate discrimination is a daily occurrence, because of the way you speak, you look or you move. There are some horrible bullies in the community and I don’t think it is my job to educate them.”**

**“I get bullied wherever I go. They find anything about me to bully. They bully me about everything.”**

**“(Been discriminated) mostly in applying for jobs.”**

**“I’ve been discriminated because I work full time.”**

**“I applied for a job with a prominent “disability confident employer”, disclosed my disability and applied under the guaranteed interview scheme. Naturally I did not get an interview. Naturally, they declined to comment on the case when I queried it. Naturally, such a scheme does not have any sort of accountability process. I cannot maintain an interest in seeking employment when this is what you can expect from the best employer.”**

**“(Been discriminated) in the workplace.”**

**“Refused a job interview because the recruiting officer had no idea their organisation was a two tick employer.”**

**“I don’t think she was willing to make the necessary reasonable adjustments for me.”**

**“(Lack of) reasonable adjustments – events at buildings with stairs, events at locations without parking close by.”**

**“Prejudice is everywhere, and people make assumptions all of the time.”**

**“Some people don’t understand autism and in the past when I’ve had an “autism meltdown” they just stare rather than helping.”**

**“When I feel I am improving myself and getting better, then people I know can be annoyed by this and don’t understand.”**

## **Access to Information and Digital Access**

Access to information was an area of concern for 37% of respondents, which is 48 people, and this relates to a range of services and processes.

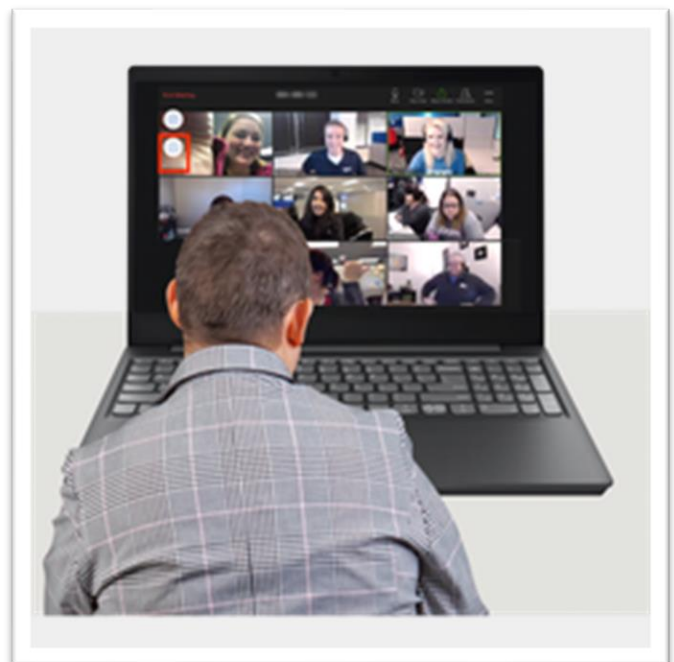
Some people found using complaints and compliments processes difficult, with concerns around knowing who to connect with.

Specific concerns have been raised regarding the accessibility of information, both digital and paper based, for those who have sight loss.

The amount of information available through digital means and the use of phones and texts to engage with people has caused difficulties for a number of people. Additionally, not having direct contact details of individuals or departments that people want to engage with is a barrier for people to be able to resolve their own queries and questions.

Whilst relatively low numbers of people (20%) appeared to be worried about their access to technology in our survey, the extended use of technology and its impact on accessible information was an area of concern to some people who are not able to use some digital systems and processes without adjustments.

A flexible and adaptable approach to information and the use of reasonable adjustments does not appear to have been the experience of a number of people. This resulted in people experiencing poor communication and information, leading to frustration and lack of help, particularly if people are not confident to make their





needs known and responded to. A lack of acknowledgement of communication preferences had left one person feeling they were discriminated against.

People's poor experiences of gaining accessible information may be linked to a lack of understanding and training in relation to the varied communication needs that people may have.

One person also commented on the fact that staff turnover impacts on information availability.

One person commented positively about their experiences of access to accessible information.



**“Getting to talk to the right person in a huge organisation.”**

**“I’ve been round and round in circles trying to access support.”**

**“Who do I complain to or contact for help?.”**

**“I don’t know where to go and my cognitive issues mean I rarely have energy left to do research.”**

**“I often don’t find companies and so on have got information available in Braille and although I do have a scanner and am learning to use the internet some paperwork doesn’t scan very well and some websites aren’t very accessible with screen reading software.”**

**“Not much out there for supporting a blind person and their needs.”**

**“It’s a struggle, I don’t use the internet so would benefit from being informed via groups. Everything is “online” or “go the website”. I find this very difficult.”**

**“Organisations phoning instead of texting options.”**

**“I ask for information in a letter.”**

**“People try to tell me over the phone. Also, they try to assess me over the phone. I prefer to be done in person, if I request it.”**

**“Not given a list of probable phone numbers, to conduct your own business with departments, e.g., finance.”**

**“Nothing appears to be easy anymore. We have all of the technology, but it has hindered rather than helped us. Also, not everyone is able to sue things like computers. Everyone assumes we can, plus I don’t like always giving my mobile phone number out – it is personal to me.”**

**“(It would be better if there is) public information on why some people may want to wear masks and not get close to others, even if this is allowed.”**

**“They don’t explain it.”**

**“Dishonest and lack of detail (in communication).”**

**“...only help I could get was to go privately (as unable to get information).”**

**“...have to be a strong advocate for yourself to access some services and make yourself heard to ensure you get support, this doesn’t feel fair, especially for people who find it difficult to advocate for themselves.”**

**“Not using my communication preferences (was discriminatory).”**

**“Lack of understanding and training.”**

**“You briefly have a social worker, then they have to leave you.”**

**“(Named Provider) are amazing at making sure I have all the information I need in a format I can access it. I don’t know what I would do without them.”**



## **Accessing services and facilities**

Just over a third of people (34%) said that they were worried about accessing services and facilities. This was 45 people.

People shared their experiences of difficulties accessing services in relation to places of worship, access to doctors, shops, cafés and places of entertainment. Also, general concerns in relation to venues being inaccessible for those who use wheelchairs, and concerns regarding inaccessible transport and difficulties with travel and pavements.

The processes in place to gain access to a doctor were thought by one person to be frustrating and an inappropriate use of skills and resources.

The difficulties that people faced had impacted on their individual confidence, and one person raised concerns regarding the approach and attitudes of some service providers and members of the public.

Lack of awareness and understanding about access needs and the importance of them was an area of concern, and the need for ongoing education was identified.

One person identified positive support they receive from a named provider.



**“Have lost confidence in going to church.”**

**“Doctor’s - How do you get past the navigator?”**

**“Not all places I visit have access suitable for a wheelchair.”**

**“Travel difficulties and knowing people. I won’t talk to people unless I know them.”**

**“Access issues and transport issues are the main things for me.”**

**“The biggest concern I have is around the poor pavements and building accessibility for me as a wheelchair user including access to buses, trains, taxi’s etc all of which contributes to my opportunities for independence being limited and restricted.”**

**“I have had situations of getting stuck on scooter in shops because of restricted room.”**

**“Today I was in John Lewis, a woman said, “you really shouldn’t be here, you are taking up too much room”, the staff were really nice but it makes me think I shouldn’t be here.”**

**“Accessing public spaces like shops, pubs, entertainment is very limited. Many shops in my town have steps or are too narrow, choice is very limited. Halls and entertainment places are often difficult to get into, requiring lots of phoning and planning beforehand, toilets can be difficult to access. Doors to shops/cafes etc are often heavy. Dropped pavements are often blocked or non-existent.”**

**“Also, online consultation – contacted my surgery using online service, emailed me back to say Doctor would call sometime on a certain date. That is fine but I would prefer to have a time as well, or at least say morning or afternoon. I spoke to my doctor who basically said I need to come in then he made me an appointment. What a waste of time and why are doctors taking on the receptionist’s role of making patient appointments when they are supposed to be overloaded at the moment. I knew I would need to see a doctor; I did not need one to phone me and tell me that - just seems a very backward and time-consuming way of doing things. Thought by letting them know by email and sending photos they would have just sent an appointment date and time.”**

**“Some service providers enjoy the power they have over people’s lives, others are just overburdened with work and worn out.”**

**“Big lack of awareness.”**

**“Try as we might we need to try and keep on educating people as much as we can.”**

**“(Named Provider) are a great help and I know I can always get the support I need from them.”**

## **Choice and Control**

Almost two thirds of respondents (61%) felt they had excellent choice and control in their lives (scoring 4 and 5). This was 57 people.

Positive experiences in relation to individual choice and control, and support of others, were recorded by a number of people.

Many of those who responded strongly advocated for the importance of choice and control and the fact that these rights should be there for everyone.

Negative experiences in relation to “choice and control” were shared by several people, and these linked to lessening choice due to changing health needs, lack of support as a family carer and services not being supportive.

The impact that this was having on people’s emotional well-being can be seen below and includes low self-esteem, low feelings of self-worth and frustration. Lack of available information also appears to have had an impact on people’s access to



services and supports.



One person commented on how people’s own financial situation can have a positive impact on access to services.

A few people felt their choice and control was impacted by the attitudes and response of wider society creating barriers and were also concerned about government approaches to those who face disabling barriers.

**“My life is good because I go to different places.”**

**“...freedom to engage in the community.”**

**“Educated, supported by intelligent husband and family who deal with whatever is needed.”**

**“My support staff are always around for me to talk to and to reassure me. They are always finding things for me to do and are very supportive.”**

**“I pretty much can control what I need.”**

**“I am happy with choice and control, when I want to go out I can go out.”**

**“My life is good because I go to different places.”**

**“Appreciate help from family to help make choices.”**

**“Feel confident that I can make choices and keep control of my life.”**

**“I’m independent.”**

**“I would feel empowered to make a difference.”**

**“This (Choice and control) is a good thing. People have a right for their own choice.”**

**“It (Choice and control) is important and necessary as we are all individuals and have our own needs.”**

**“Everyone is entitled to have choice and control in their lives. I am able to communicate this via my preferred communication method.”**

**“I think they (Choice and control) are very important to everyone!”**

**“Very important because you must be able to do what you like to do or not do.”**

**“I have very little speech but I do get choices offered to me.”**

**“I would like to get on with what I can do and what I am able.”**

**“This (Choice and control) is a good thing.”**

**“I like having choice.”**

**“(Choice and control) is poor because of my disease not because of my social situation. There are things I would like to do then I say “oh yeah fatigue and pain and can’t do them. No amount of support will help with that.”**

**“The need for support is frustrating, particularly when you can no longer do things that you used to take for granted. People can often fail to appreciate how having to ask for help can be so humiliating”**

**“Where I have choice and control in most areas of my life, I feel that my physical and mental health conditions (and the way that some people react to them) dictate other areas of my life.”**

**“I feel that choice, since becoming ill, is a luxury.”**

**“I would like to have control in my life or some control.”**

**“Holding down a job and caring for someone at the weekend is really tough. No support for weekend care.”**

**“I haven’t got choice or control over my life.”**

**“When I need support from mental health, not always there.”**

**“When I decided not to take prescribed medication for a supposed bipolar disorder I was asked “Are you really ill then? You’re probably not then if you won’t take them!” That shows you how much respect there is from the system for people who express**

**choice and control over their treatment. I didn't have bipolar disorder, I do though in fact have complex PTSD."**

**"I have no choice over where I live, services I can access or activities I can take part in. Life is now very limited and my world is very small."**

**"I don't really know what choices I have at the moment."**

**"My mental health is judged and controlled by GP's."**

**"I have to be back by 10pm."**

**"I always feel like I am doing wrong."**

**"I struggle with a belief that I am a burden to others."**

**"I am the one who has to search out help rather than the system knows I am of poor health and should search me down to offer what support is suitable for me!"**

**"I understand how "the system" works and where to go to get what I need."**

**"Our family are financially secure therefore we have much more control than people who depend on services. We can pay for things ourselves if and when we need them and don't have to rely on public services. This is especially true of health and mental health services."**

**"Some people still have the choice taken away from them because of disabilities/learning disabilities/difficulties/autism etc. Just because they do things in a different way, does not mean they should not get choice."**

**"These are nice ideals, but they are useless ideals without the resources and information (and the authority) to exercise them."**

**"When you are dependent on others your choice and control is limited."**

**"The one thing that is causing me most concern is the stigmatisation and labelling that has happened to me."**

**"(I am concerned about the) long-term effects of the pandemic on inclusion."**

**"(I am concerned) that disabled people have been at the bottom of the list of government concerns since 2010, and indeed have been in receipt of state antagonism which has gone unchallenged whilst high profile activism for others has been in the news."**

**"(I am concerned about) government incompetence."**

## Local Research and Data

Some of our findings in relation to choice and control are similar to other local research.

For more information, please see the following reports:

- 1) **Barnwood Trust, “Our Changing World: A report into disability and mental health in Gloucestershire during the COVID-19 pandemic” highlighted barriers to accessible services and technology.**

<https://www.barnwoodtrust.org/wp-content/uploads/2020/09/Our-Changing-World-Exec-Summary-v6.pdf>

- 2) **One Gloucestershire: “#BlackLivesMatters: Gloucestershire’s Mental Health Services” highlighted recommendations relation to culturally appropriate advocacy and interpreter services.**

<https://haveyoursaygloucestershire.uk/engagementhq.com/gloucestershire-s-mental-health-services>

- 3) **Kingfisher Treasure Seekers and Inclusion Gloucestershire in a report from last year (October 2020) highlighted concerns regarding discrimination – “Health Inequalities: accessing health services in Gloucestershire with particular focus on BAME communities”**

<https://www.inclusiongloucestershire.co.uk/research-strategy-and-partnerships/>

- 4) **Healthwatch Gloucestershire, in a recent report (February 2021) highlighted concerns and recommendations regarding communication methods and approaches – “Accessing care through GP Practices in Gloucestershire”**

<https://www.healthwatchgloucestershire.co.uk/wp-content/uploads/GP-Feedback-Report-FINALr-Feb21.pdf>

5) Inclusion Gloucestershire, Gloucestershire County Council and University of Gloucester in a recent report (February 2021) highlighted access and transport concerns. “Access for us all: Barriers to Mobility”

<https://haveyoursaygloucestershire.uk.engagementhq.com/gloucestershire-s-mental-health-services>

## Recommendations

- All organisations should review their feedback procedures and processes to ensure accessibility, frequent feedback to those using the procedures and introduce (if not in place) a process to seek feedback from those who have used the procedures to ensure continuous improvement.
- Further research is needed to understand people’s experiences of culturally sensitive services more fully from the perspective of a more diverse group of people.
- Increased awareness is needed in relation to the needs of those who experience sight loss and their carers and a local awareness campaign using local and social media may be beneficial.
- Organisations and services need to ensure they offer a range of communication methods and approaches to enable all people to engage with them.
- Additionally, organisations and services need to have an increased commitment to make reasonable adjustments to facilitate preferred individual communication methods.
- Increased awareness and further training is needed in relation to discrimination and poor attitudes and this could be developed with a range of key partners across Gloucestershire to ensure it is sensitive to a range of needs and lived experiences. This training should be co-designed and co-delivered.

- Further research is needed in relation to how safe people feel when not in their own homes, and what needs to be done to address this.



- All organisations should review the accessibility of their websites and processes for individuals to gain information and get involved in order to improve accessibility and offer a range of approaches.

- A local standard for accessibility of information should be co-developed with a range of partners, taking account of legislation and resulting in high profile publicity for those organisations who achieve this. This would include the need to have a personalised approach to communication which is responsive to individual need.

- Training and awareness raising linked to the local accessible information standard should be co-developed and co-delivered. This could also be extended to include wider access needs in relation to environments, processes etc.

- Accessibility of buildings, transport and pathways continues to be a challenge and investment is needed in improving feedback mechanisms so that issues are more easily identified

- Accessibility in terms of both physical access and processes and practices needs to be at the forefront of service design and planning.

- Existing good practice in public transport in other areas, such as spoken announcements at bus stops and on buses, should be rolled out across Gloucestershire, in partnership with transport providers and the Local Authority.

- The extent that people feel they have choice and control varies significantly and some people mentioned the importance of others advocating for





them. It is essential that advocacy services are available more widely to people facing disabling barriers, to empower them to have choice and control over important aspects of their lives.

- Many of the issues highlighted in this report could begin to be addressed because of new legislation (National Disability Strategy and National Strategy for Autistic Children, Young People and Adults 2021- 2026 and existing legislation - clear local governance processes to ensure this need to be established and be transparent in nature to ensure that local change will be achieved. The Health and Well Being Board/ICS Board should ensure this is in place.

## What Will Inclusion Gloucestershire Do Next

We will share this report with providers of health and social care services in Gloucestershire and with other local organisations and groups.

The report will be available on our website, publicised on social media and shared with individuals who were part of the survey and gave us their contact details.

We will ensure that in all forums in which we are involved we share the experiences and recommendations with decision makers. This includes connecting with the following workstreams and groups:

- **Learning Disability Partnership Board**
- **Physical Disability and Sensory Impairment Partnership Board**
- **Autism Partnership Board**
- **Carers Partnership Board**
- **Mental Health and Well Being Partnership Board**

We will continue to actively engage with people who face disabling barriers to seek their views and experiences in relation to healthcare via our Speak UP Groups; MHELO (Mental Health Experience Led Opportunities) Focus Groups; Inclusion hubs; our user led Quality Checking visits and our regional network of self-advocacy groups.

If you would like any information on any of the above activities, please visit our website or contact us on the email below:

<https://www.inclusiongloucestershire.co.uk/our-services/>  
[info@inclusion-glos.org](mailto:info@inclusion-glos.org)

We will implement the organisational specific recommendations highlighted above and work in partnership with others to achieve the system wide recommendations.

*And finally, thank you!*

We would like to thank everybody who gave their time to complete our survey and share their experiences with us.

We would also like to thank our small team of volunteers who have given their time and insight to enable us to present peoples experiences in this report.



@inclusionglos



Inclusion Gloucestershire



@inclusionglos



Inclusiongloucestershire

Find out more about us at: [www.inclusiongloucestershire.co.uk](http://www.inclusiongloucestershire.co.uk)