

Living with a long-term health condition in Covid-19

What local people told us



December 2020



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Background

Covid-19 has brought rapid change, emergency measures and a world that we could not have imagined one year ago. It has meant a different daily life for most of us as well as our wider communities. It has also meant rapid adjustments to health and care services, directing resources to priority areas, and changing the way things work to prevent the spread of infection.

Since the start of the pandemic we have been talking to people generally about health and care during Covid-19, but we wanted to understand the particular experiences of people in Gloucestershire living with long-term conditions.

A long-term health condition is a health problem that needs ongoing management over a long period of time. It usually means that the person is helped to manage their condition with the use of treatments, therapies and medication. They may also use social care services to help with daily living. People living with long-term health conditions tend to be regular users of health and care services and they may be particularly vulnerable to Covid-19.

For many people with a long-term condition, life became more limited during the pandemic as the focus was on safety and Covid-19. We wanted to understand how people's lives had changed. In particular, what aspects of self-care, health and wellbeing had been affected. We also wanted to find out how people's usual health and care services had changed and to hear their views and experiences about that.

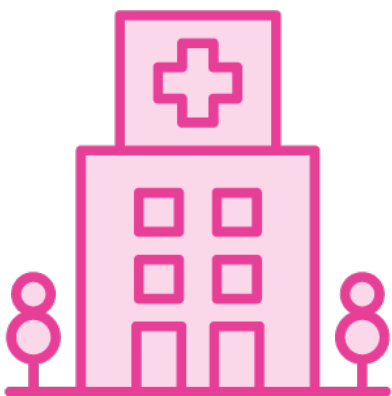
As we were hearing from people who may have been shielding, we also wanted to ask about their experience of isolation. The information collected during this research will form part of a larger dataset that we have been gathering over the months to form the basis of a focused report on social isolation in 2021.



What we did

Our approach was to work in partnership with key organisations working with people with long-term health conditions. Opportunities to work with charitable organisations were limited at this time however, due to the impact of Covid-19, for example some of their staff were furloughed.

We created an online survey that ran from the start of August until 16 October 2020. The survey questions are detailed in Appendix A.



We ran an online focus group with a local Stroke support group on Thursday 1 October 2020, and we also carried out structured interviews based on the survey questions.

We also worked with Gloucestershire Hospitals NHS Foundation Trust. They provided people who were attending outpatients with our engagement pack which explained the purpose of the project and gave them a range of ways to feedback about their experiences.

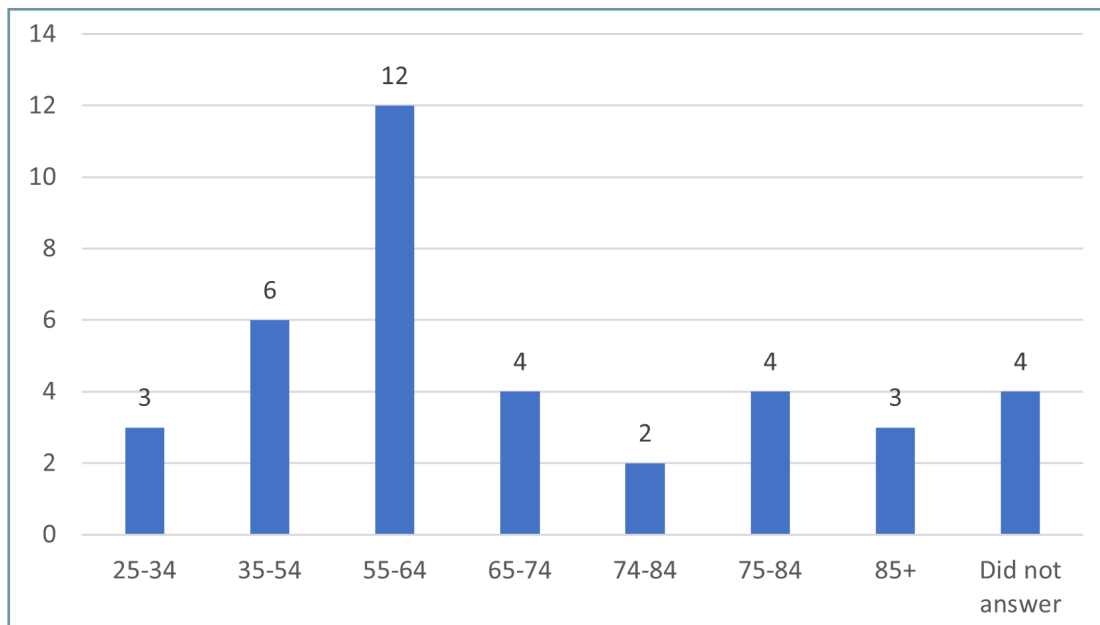
We promoted this project through our community sector network and through our regular communication channels including our e-bulletin, social media and website.

Who we spoke to

Twenty people completed our survey. We interviewed a further 16 people, two people completed diaries of their experiences, and three people took part in our focus group. The following is a summary of all those we spoke to during the survey, interviews and diaries engagement.

Age

Figure 1: Age groups



Gender

Twenty four people were female, 10 were male, and one person was transgender. Three people did not answer.

Sexual orientation

Twenty six people identified as heterosexual, two identified as lesbian, and one person identified as gay. Nine people did not answer the question.

Locality

A full geographical breakdown of those we spoke to is listed in Appendix B.

Condition

Many of those we spoke to had co-existing conditions. The most reported conditions were anxiety/depression, hypertension, and chronic obstructive pulmonary disease (COPD). A full breakdown of conditions can be seen in Appendix C.



Key messages

- People said their mental health had deteriorated.
- People found staying active in their day-to-day lives particularly challenging.
- Not being able to see friends and family has compounded a sense of isolation.
- Confidence to engage in outside day-to-day activities has decreased; people are still fearful of being around others.
- The fact that some usual health and community services were suspended had a negative impact on people.
- Some people welcome remote appointments, while others feel that face-to-face appointments work best - one size does not fit all.
- For some people facial coverings felt like a barrier to an effective consultation.
- People are largely carrying on as best they can while health and care services try to catch up and resume; some people were not sure what they could expect.

What people told us

Survey, interviews, and diary study

We asked people if the pandemic had affected their normal day-to-day life - 92% (35 people) said it had and we asked them to tell us how. The following is a summary of the most common themes which cut across all areas of life, community, health and care.

Accessing health and care

Many people talked about how their ongoing care and treatments had been disrupted by the pandemic.

For some, appointments had been cancelled altogether, with no indication of when they would be returning: ***“I was promised an appointment with the diabetic nurse but that was cancelled with no other date given.”***

Regular care had also been affected by the pandemic: ***“Getting his regular blood tests for his chronic condition is a sorry trial. We are no longer able to book these without first going through a GP. His six weekly tests have become three monthly.”***

There were broader concerns expressed: ***“Overall, my family are concerned that serious health conditions are no longer being managed effectively which will either mean earlier death, or the need for further NHS intervention that would otherwise not be necessary. None of my family feel positive about the future management of their health conditions and lack of treatment creates a poorer quality of life.”***

One person had even been advised to seek alternative treatment themselves: ***“No vitamin B12 injections were available. Advised to buy a spray or tablets - this has cost her money and had no effect. She has been feeling increasingly desperate.”***



For those who were offered appointments, these were often conducted via the telephone. For some, this was a welcome change: ***“It seems to be the way forward. I think it’s more efficient.”***

However, others found that there were limitations to this method: ***“This meant that when I developed a new rash, they couldn’t see it. This resulted in them not putting my rash in my medical notes, which meant that the consultant didn’t take it seriously.”***

“You can’t see people’s non-verbal expressions over the telephone, but my experience of a face-to-face appointment with the consultant was that we couldn’t see each other’s facial expressions anyway. So, it would have been much better to have a video appointment, but yet again, there was no capacity for a video appointment despite me requesting one.”

Some people described how services that had been cancelled were starting up again: ***“Outpatients was cancelled for a long time. When it started again, it was a bit chaotic. Running late. But it was all distanced and there was lots of sanitiser. Everyone wore masks and PPE, so it felt quite safe.”***

Getting out and about

Many people talked about how, since the pandemic, they were unable to get out as much as they used to, if at all, due to restrictions and shielding. They felt unable to exercise as much due to activities being cancelled and government restrictions which limited people going outside: ***“I am not taking enough exercise, so I am putting on weight.”***

Returning to normal

Despite restrictions having eased when our engagement work took place, many people spoke about how they still felt vulnerable and anxious about returning to normal activity. ***“[I] have found it challenging doing the normal things I used to do before lockdown. Confidence levels have dropped.”***

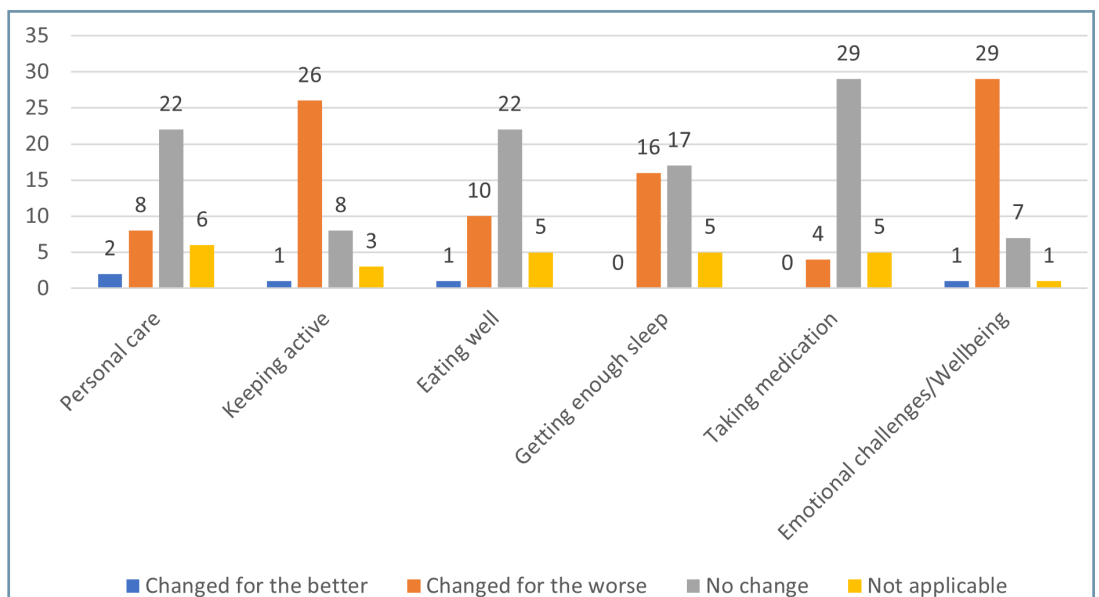
Seeing family and friends

Another change that was noted was not being able to socialise and see family and friends. However, some people saw their family more as they were helping with shopping and medicine delivery. Many people commented that they missed being able to hug one another: ***“...having to keep a distance. I like to hug people. So now I have to hug a tree.”***

Mental health

For many of those we engaged with, mental health had been adversely affected by the pandemic, with many people feeling symptoms of anxiety and depression: ***“My mental health has declined as I had little stimulation on a day-to-day basis.”***

Figure 2: How has the pandemic changed the way you manage the following aspects of your health?



Figures 3 and 4: Has the pandemic changed any element of accessing health, care and community services?



Isolation

68% (26 people) said they had felt more isolated/lonely during the pandemic. Eight people said there had been no change, and one person said they had felt less isolated/lonely. We asked people to tell us more about their experiences of loneliness and isolation.

Many talked about how they were separated from their friends and family, and how this had exacerbated feelings of isolation and loneliness: ***“I cannot see my friends and I live alone. One daughter lives a long way away and I haven’t seen her for months.”***

Even for those who lived with others, not being able to see people outside of their household had been difficult: ***“[I] didn’t see anyone other than my husband and our housemate for several months. I’ve not seen any of my family since last year.”***

Although contact via the internet had become a norm for many of those we spoke to, some felt that this was not enough and did not hold the same value as face-to-face meeting: *“I have felt somewhat more isolated. Although I have set up a regular link via the internet of a group I organise, there has been very little other communication. There would usually have been a number of occasions where I would have been able to meet up with others socially. But this general socialisation has not been replicated.”*

For one person, the lockdown restrictions easing had made them feel more isolated: *“It has also been more difficult as others have started to meet up – often when perhaps rules are being broken (although they are not crystal clear!) – and I am not in the position to do so, as I am still quite fearful of the consequences.”*

Case study: People living with the effects of a stroke

We talked with Cathy, David and Richard (names have been changed to protect privacy). They are all members of the Stroke Association. Cathy had a stroke in November 2018, David in September 2019 and Richard in August 2019. They were all living with the effects of a stroke and accessing health and care services before the pandemic began.

How life has changed since the pandemic

Life has been pretty much the same for Cathy. It takes her a long time to get up each day and she feels lucky because her husband is very understanding. During the lockdown, if the weather was nice, she would go outside and do a bit of gardening, which she enjoys although she cannot do more than about 10 minutes before getting tired. She also reads large print books, so she would do this too. She has missed just being able to go out. Since having a stroke, Cathy has been quite depressed and not being able to see family has been the hardest part for her. She feels frustrated about Covid-19 and is now terrified to go anywhere. Her husband does everything; on some days she is too tired to even peel a potato.

Both Richard and David rely on other people to do most things for them, so day-to-day life has remained largely the same for them during the pandemic. For David carers continued to come to his home to get him out of bed, dressed, and into his chair. His wife would go off to work early and when she came home, she would make a meal before the carers came back in the evening. Richard also found his life has carried on unaltered, although his wife is his fulltime carer. He did have carers previously, but his wife was not happy with them, so they were stopped.

How managing health conditions has changed

As all three had their strokes more than a year before the pandemic, they felt that not a lot had changed. Two of the three commented that they had been very disappointed at the lack of help they had received on discharge, as they were not able to stand, transfer or walk. All three talked about the lack of support offered by health and social care services. One said they were paying for private physiotherapy as nothing had been forthcoming, even before the pandemic.

Cathy has experienced more psychological problems than physical and says she feels very down a lot of the time. She also commented about an eyesight appointment that she had a while ago. The Occupational Therapist who sat in on the appointment was surprised to hear that Cathy had not been offered any support. She arranged for her to talk to someone which was useful, although the problems with her eyesight were not resolved.

How accessing health, care and community services has changed

All three felt that they do not usually receive much help from the health and care system and Covid-19 had not changed this. One of the group felt the pandemic had been a good excuse for services to hide behind and not offer any support. One of the group's private physiotherapist had tried to follow up a new wheelchair that had been promised months ago, but he is still waiting.

Richard told us that he has missed contact with the GP service. He likes to be seen face-to-face and does not like being asked to describe his conditions over the phone. Cathy identified a positive change with Zoom psychology meetings, which she is pleased with. Richard also said that having his prescriptions delivered is a great help.

This part of the discussion touched deeply on feelings, with a shared difficulty expressed about accessing services. All three became emotional and sometimes found it difficult to talk about their experiences.

Recommendations/considerations

- Recognise that some people will prefer remote appointments, and others will prefer face-to-face appointments - offer a choice where possible.
- Be clear about what people can expect - if there is a reduced or different service, then explain clearly and manage expectations.
- Consider extending appointment times to allow for the challenges of communicating effectively through PPE and enhanced infection control measures, so that people spend less time in waiting areas.
- Consider future plans to tackle the impact that Covid-19 has had on people, including issues of physical and emotional health, physical activity and isolation.

Next steps

Although the feedback gathered during this piece of work is not extensive, it echoes the data that we gather on an ongoing basis. We will continue to share key data with the health and care system in Gloucestershire and to distil the key messages. As health and care services navigate their way through Covid-19 and beyond, we will help them shape services that take account of this combined patient and public experience.

Thank you



A huge thank you to everybody who gave their time and energy to sharing their views and experiences. A particular thank you to those people who took part in our focus group and interviews - your insights bring us a greater depth of understanding.

Thanks also to Gloucestershire Hospitals NHS Foundation Trust's Quality Team and Outpatients staff for promoting this work, and to the Stroke Association for their support.

Stakeholder's response

NHS Gloucestershire Clinical Commissioning Group (CCG)
Becky Parish, Associate Director, Engagement and Experience

“NHS Gloucestershire CCG was pleased to receive this insightful report from Healthwatch Gloucestershire (HWG). The themes it identifies reinforce much of what we are hearing from local residents about their experience of health services from a variety of sources. We will continue to work with local residents, HWG and all partners across the One Gloucestershire Integrated Care System and beyond to learn from our collective experience of the pandemic, identifying where we can make improvements but also giving consideration to the positive elements of change we might want to retain and embed for the future.”



Gloucestershire Hospitals NHS Foundation Trust

“We welcome the insights shared in this report from people in our community living with long-term conditions during Covid, and we would like to thank everyone who took the time share their experiences.



“Throughout this year, as part of our response to Covid, we have continued to listen to, and learn from, the experiences of patients, carers and staff through a range of engagement and involvement activities, including our Friends and Family Test surveys, and the feedback we receive through our PALS team. We understand the effect that face masks and PPE has had in creating a barrier to communications as well as the broader impact that Covid has had on people’s day-to-day lives and sense of connection and wellbeing.

“We want our hospitals to feel as safe and calming as they can be and will continue to work in partnership with our colleagues, patients, communities and partner organisations to ensure that their feedback and experiences shape how we continue to respond to the healthcare challenges that Covid poses. The findings from this report will be used to inform our improvement programmes across our Trust, including how we communicate more effectively and support patients, their carers and our communities, to ensure that we can continue to deliver the best care for everyone during these challenging times.”

Gloucestershire Health and Care NHS Foundation Trust

“Gloucestershire Health & Care NHS FT welcomes the report and thanks the participants for being so candid. The feedback is consistent with feedback we also received in June 2020 through our ‘Caring during the Covid-19- your experience’ engagement approach - particularly around the sense of isolation and mental distress that Covid-19 has had on people’s lives. Having access to this level of insight in addition to our wider co-production activities is key to ensuring that we constantly strive to improve services in partnership with those with lived experience.



“In addition to other system, regional and national reflections, the report’s findings will be explored through the ongoing learning that we are engaged in as an organisation to ensure our services are the best they can be in light of Covid-19 and the challenges it poses.”

Appendices

Appendix A. Survey questions

1.	What long-term health condition/s do you have? (Please list the names only)
2.	Has the pandemic affected your normal day to day life? <ul style="list-style-type: none">• Yes/No
3.	What are the top three things in your normal day to day life that have been affected?
4.	Has the pandemic changed the way you manage the following aspects of your health? (Changed for the better/Changed for the worse/No change/Not Applicable) <ul style="list-style-type: none">• Personal care (washing, dressing etc)• Keeping active• Eating well• Getting enough sleep• Taking medication• Emotions/mental health challenges or wellbeing• Other (please specify) Please let us know more details about what has changed, and why you think this is?
5.	Has the pandemic changed any element of accessing health, care and community services? (Changed for the better/Changed for the worse/No change/Not Applicable) <ul style="list-style-type: none">• Getting an appointment with your GP• Getting an appointment with your practice nurse• Access to Urgent Care e.g. 111 / MIU• Access to Emergency Care e.g. 999 / A&E• Speaking with consultant• Accessing physiotherapist• Accessing Occupational Therapy• Accessing mental health nurse/team• Accessing social care• Assistance from volunteers• Assistance from charity or community organisations• Accessing the pharmacy• Carer support• Community spirit• Other (please specify) Please let us know more details about what has changed, and why you think this is?

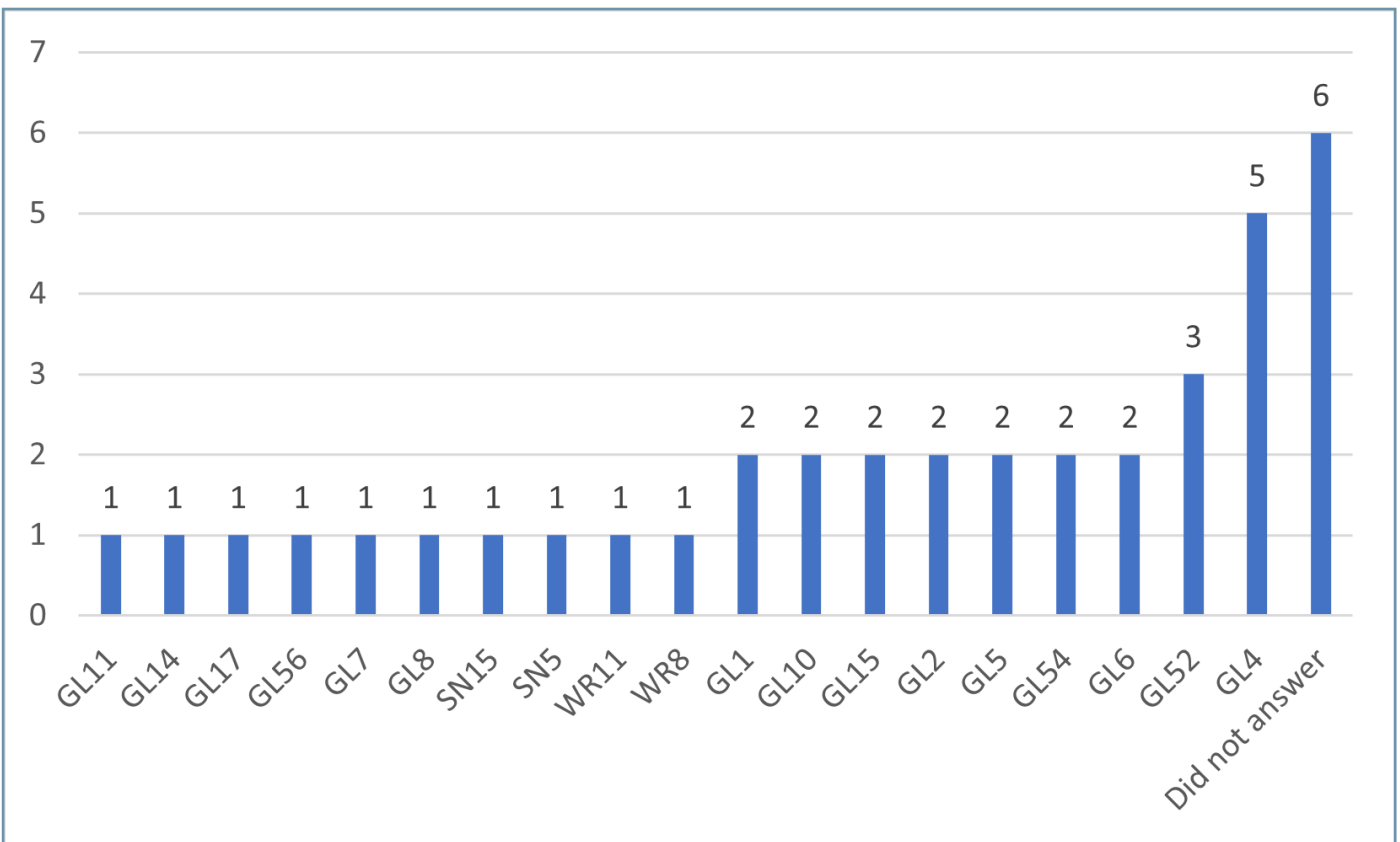
6. Have you felt more or less isolated/lonely at any time during the pandemic?

- More isolated/lonely
- Less isolated/lonely
- No change

Please tell us more

7. If there is anything else you would like to tell us about your life during the pandemic (Please write in the space below)

Appendix B. Breakdown of responses by postcode



Appendix C. Breakdown of conditions

Condition	Total
Anxiety/depression	7
COPD	4
Hypertension	4
Asthma	2
Osteoarthritis	2
Multiple sclerosis	2
Fibromyalgia	2
Stroke	2
Schizophrenia	2
Arthritis	2
Coronary heart disease	2
Not specified	2
Diabetes	2
Musculo-skeletal condition	2
Skin condition	1
Mild facial pain syndrome	1
EUPD (Emotionally unstable personality disorder)	1
Low mood	1
Gastroesophageal reflux disease	1
Polio	1
Asperger's	1
Cellulitis	1
Sciatica	1
Ehlers-Danlos syndrome	1
High cholesterol	1
Eczema	1
Crohn's disease	1
High blood pressure	1
Coeliac disease	1
Graves' disease	1
Glaucoma	1
Dementia	1
Dermatological condition	1
Frailty	1
Chronic fatigue syndrome	1
Thyroid problems	1
Acid reflux	1
Rheumatism	1

Why not get involved?



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