

pandemic patient experience

UK patient experience of health, care and other
support during the COVID-19 pandemic

September 2020

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Summary

The Patients Association wanted to get a better understanding of how patients and others are experiencing the COVID-19 pandemic. We wanted to know about both the experience of health and care services, and the experience of daily life – the things that make a difference to our wellbeing.

This is a report based on the findings from a survey to capture those experiences. The survey had four sections:

- Managing and accessing care for existing health condition(s)
- Experience of treatment and care for COVID-19
- Experience of end of life care and bereavement support
- Experience of services under lockdown overall.

It ran from May until August, and around 953 people responded to at least one section of the survey.

Key findings include the following:

- i. We asked about whether people had been included in the 'clinically most vulnerable' or 'shielding' group, and whether they had been happy with the process of finding out and accessing support. 38% of respondents told us they were not happy with this process. Some people told us about mistakes that had been made, about having to wait too long to be informed they were in the 'shielding' group, and about times when they felt they should have qualified but didn't. While some had found priority supermarket access and government food parcels useful, others struggled to make use of these, or were left without support because their condition or disability did not qualify them for it. A number of disabled people, chronically ill people and older people told us they felt left behind.
- ii. 67% of respondents had had health and care appointments cancelled as a result of the pandemic. 47% had chosen to put off accessing services and support. Many people told us that diagnostic services, GP appointments and dental services in particular were hard to access, as well as support for mental ill health. Some people said they wanted to know when and how services might restart, and that they felt they had been left in the dark. There was a mix of opinions about the benefits and drawbacks of virtual consultations – either online or over the phone. Many people said they wanted face-to-face consultations in person, and that continuity of care was made more difficult when contact was over the phone. Others felt remote consultations had some benefits, including for those who do not live close to their GP surgery, or who prefer to access services quickly online.
- iii. Our sample of people who had had COVID-19 was small – just 67 people – although there was considerable uncertainty among respondents who had been unable to access tests, so the true figure was probably higher. Those who had had the virus at some point often told us they had good experiences in the circumstances, but that they didn't always have access to the support and information they needed, especially from GPs, and sometimes from the NHS111 telephone line.

- iv. Some of those who had experienced a bereavement during lockdown told us about good experiences of compassionate care and support. There were some clear examples of failings in services, however, and people were not always able to stay in contact with their loved one at the end of life. Some people also raised long-standing issues with end-of-life care, including poor communication leaving relatives with inaccurate views of a person's condition, the loss of valuables in hospital or problems associated with the discharge process, which may have been exacerbated under the current circumstances.
- v. We asked respondents whether they felt their health and care needs had been supported overall during the pandemic. Over half told us they did not.
- vi. Just over half disagreed most or all of the time that they had been supported emotionally when receiving health and care services. Half said they hadn't been able to take part in cultural or faith-based activities. 49% disagreed all or most of the time that they had not had to wait too long for health and care services, 48% disagreed that they had had the right support to make them feel safe and address any fears, and 47% said that their care had not been well co-ordinated, with only a quarter agreeing all or most of the time that it had been. 47% disagreed all or most of the time that they had been able to access the services they needed.
- vii. Half of respondents agreed or strongly agreed that they felt more lonely during this period; 69% agreed they had found it hard not being able to travel; 50% said they struggled to keep a routine; and just over half said they found it difficult to motivate themselves. 75% disagreed that they found shopping easier now, 53% were finding it harder to do their job, and 73% were finding it harder to access leisure activities. 71% agreed they felt anxious about catching COVID-19 themselves, while 82% worried about others catching the virus.
- viii. 61% of respondents told us they felt more anxious or worried in general.

The survey provided some examples of good experiences; friends, family members and neighbours supporting one another, voluntary and mutual aid groups providing vital help, and caring, helpful health and care professionals. However, it also highlighted some clear failings. This pandemic is not yet over, and future crises are likely. We propose the following principles for ensuring all patients, disabled people, carers and others are able to have the best possible experience:



- Recognise from the outset that the impact of the crisis will fall hardest on those who already face discrimination and inequality, including Black, Asian and other minority ethnic groups, disabled people, carers, women and gender minority populations and those living in areas of high deprivation, and that these inequalities will affect some people in combination
- Maintain the principles and values of patient choice, shared decision making and voice, so that services are shaped by patients, disabled people and others who most need them
- Ensure there are fully resourced services available to help people maintain people's mental wellbeing, to treat mental ill health, and to ensure that no one is left isolated
- Ensure carers get the support they need, including emotional support, to continue to care for their loved ones
- Provide clear, concise and timely communication, updated regularly, about the impact of the crisis on support and services, what is available in the interim, and when and how services may begin to restart
- Ensure access needs are respected and met, including providing materials in different formats and languages, including signing, descriptions, captioning and transcription for all official visual content, and that people are able to access support offline if they do not have access to the internet
- Maintain compassionate end-of-life and bereavement support services, with clear communication between staff, patients and others, and the opportunity to be with friends and family members at the end of life unless totally impossible.

Introduction

The COVID-19 pandemic, beginning globally in 2019 and stretching well into 2020 so far, has radically reshaped many of the services we had previously taken for granted. The official period of 'lockdown', begun in March 2020, saw some support and activities familiar to day-to-day life suspended completely. Even at the time of writing, as lockdown is eased across most – but not all – of the United Kingdom, many businesses remain closed, services remain limited and futures remain uncertain.

During lockdown, communities have celebrated the NHS and the people who work for it en masse. We know that frontline health and care workers have continued to put their own health at risk during this pandemic, to deliver what services they can. However, we also know there have been considerable challenges.

The Patients Association wanted to get a better understanding of how patients, disabled people and others have been experiencing those services during the pandemic. We wanted to know about both the experience of health and care services, and the experience of daily life – the things that make a difference to our wellbeing.

To do this, we produced a survey, open to all, covering issues relating to healthcare for both COVID-19 and pre-existing conditions, how aspects of government support were working, and whether people felt they were getting all the support they needed. This included support at the end of life and after bereavement, for some.

Around 950 people responded to our survey. This report is about what they told us – their views and experiences, positive and negative, and their concerns for the future.

The report will begin by outlining what we know already about people’s experience of COVID-19, from other research. It will then present findings from each of the four sections of the survey:

- How are you finding managing and accessing care for existing health condition(s)?
- How have you found treatment and care if you have had COVID-19?
- If you have recently been bereaved, what has been your experience of care before and after the person’s death?
- How has your experience of health and care services been overall?

It will conclude with some suggested principles for planning support and services in the future.

Many people spent considerable time and energy sharing their experiences with us, and we would like to thank everyone who contributed.

What do we know already?

A range of groups and organisations have recognised the need to know more about how patients, disabled people, carers and others are experiencing the COVID-19 pandemic in the UK. National Voices has launched a website called [Our Covid Voices](#) to capture the voices and experiences of people living through the pandemic, and Scope is inviting disabled people to [share their experiences](#), for instance. Among an extensive range of academic research, the University of Manchester is co-ordinating a project to create a national collection of voices and stories documenting the impact and legacy of the pandemic, Sheffield Hallam University is exploring racism experienced by NHS nurses at this time, and the University of Oxford is leading research into ‘remote-by-default’ care, via video or phone.(1)

Much of this research is over the longer term, providing useful and robust research as services continue to develop. There are also already a number of reports highlighting vitally important issues for people trying to navigate health and care while COVID-19 continues to reshape our services. Our report sits alongside these as evidence of patient experience during the pandemic. The research and reports below help us to put the findings of our own survey in a wider context.

COVID-19 has highlighted existing inequalities

The COVID-19 pandemic did not create health inequalities, but it has drawn fresh attention to the extensive challenges and barriers faced by marginalised groups. 2020 marked ten years since the publication of the Marmot Review, which highlighted unjust and unnecessary health inequalities. A follow-up report this year found that, since 2010, life expectancy has stalled – and the more deprived the area, the shorter the life expectancy. Nearly half of those in poverty in the UK live in a household where someone identifies as disabled, and Black, Bangladeshi and Pakistani people face higher rates of poverty.(2) These are persistent issues of discrimination, racism and sustained under-investment in the poorest areas; the COVID-19 crisis has, unsurprisingly, followed similar patterns.

Reports and campaigns by the Race Equality Foundation, the Ubele Initiative, the Royal College of Midwives, the British Medical Association (BMA), government health bodies and others have already noted the impact of COVID-19 on bringing to light existing health and other inequalities in the UK relating to race.(3-6) The virus, like other health conditions, has had a disproportionately negative effect on those who already face discrimination within health services. The King's Fund points out some people from Black, Asian and other minority ethnic (BAME) backgrounds, including African Caribbean and South Asian people, may tend to have higher incidences of cardiovascular disorders and diabetes, which might complicate cases of COVID-19. The Race Equality Foundation also highlights certain groups with disproportionately older populations than White British people, including people from Irish and Jewish communities.(7) Some of these groups also include a disproportionately high number of low-paid, frontline workers, live in poorer areas and in more crowded households, and the impact of this on health risks, outcomes and incidences of ill health should not be ignored.(8)

Even if not directly affected by COVID-19, some communities will face additional – or compounded – challenges accessing healthcare as a result of the pandemic;. As the NHS Confederation highlights, some key services, such as translation and interpretation, are at risk of being withdrawn, or stretched further, during the pandemic. (9) Where professional services are not available, this risks the ability of some patients to articulate their needs, priorities and preferences. It also risks placing extra pressure on patients to have friends or family members take on this role, where this may not be appropriate or safe. Groups and individuals working on issues affecting Black, South Asian and other ethnic minority groups recently told Public Health England (PHE) that racism within health and care systems, and a related lack of trust, also prevented some people from seeking diagnosis, treatment and further support.(10)

The Kings Fund also highlights that 20% of NHS workers are from minority ethnic groups, and that some have experienced higher mortality rates than white staff; 64% of NHS staff known to have died from COVID-19 as of April 2020 were from an ethnic minority group. (8) The vast majority of these people were born in a country other than the UK, with Filipino staff representing the largest group.(11) An NHS Confederation report reported hearing from BAME NHS staff members who did not have the confidence to make demands for sufficient levels of personal protective equipment and testing in the workplace. There were also concerns expressed about PPE that did not take into account cultural considerations, such as head coverings and other religious requirements.(9)



The Government in England responded to emerging data pointing to these inequalities in April, announcing an inquiry to be led by NHS England, NHS Improvement and Public Health England (PHE). NHS England and NHS Improvement focused on the potential impact on BAME NHS frontline workers in particular, agreeing an action plan to protect staff and improve representation. This included stressing the need for risk assessments by NHS employers, taking into account ethnicity and age alongside other factors; engagement through staff networks; and a bespoke health and wellbeing offer for BAME staff. Public Health England published a review of COVID-19 and health inequalities in June. Its initial report, updated in August 2020, presented findings based on existing data collected by official bodies. It confirmed that 'the impact of COVID-19 has replicated existing health inequalities and, in some cases, has increased them'. Black people were most likely to be diagnosed, compared to other ethnic groups, and death rates were highest among Black and Asian groups. People of Bangladeshi ethnicity had roughly twice the risk of death than White British people.(12)

A second report brought in evidence submitted by organisations and individuals with an interest in BAME issues. These stakeholders stressed that inequalities were longstanding, and factors such as type of job, use of public transport, overcrowding, housing conditions, and the composition of each household might increase risk of exposure to COVID-19 (and other health conditions). They also stated clearly that racism is a root cause of poor health, risk of exposure and risk of worse health outcomes.(10) Further analysis of the same data by the Race Equality Foundation points out that deprivation has a compounding effect for working aged people, but not for older people, stressing the need for analyses that account for differences in age and location as well as racialised patterns.(13) Both PHE and Race Equality Foundation reports note problems with availability of data, either on some of the possible compounding factors highlighted, or for specific groups such as Gypsy, Roma and Traveller communities. Researchers from Bournemouth University have also highlighted the lack of data on Gypsies, Roma and Travellers, who have worse health outcomes overall and face significant challenges accessing health and other services.(14) The Scottish Government introduced a framework for supporting Gypsy and Traveller communities during the crisis, recognising additional risks.(15)

NHS England has committed to some action in response to PHE's reports. These include encouraging NHS organisations to better engage those who need most support, to restore NHS services inclusively including digital care pathways, to accelerate preventative programmes and provide better support for those with mental ill health, review patient ethnicity data and build better partnerships with local authorities and voluntary organisations. There is, however, no mention of funding to support work to combat health inequalities.(3) This work requires resources, and it is concerning that they are not yet in place. Neither of the PHE reports include mention of disability or Black, Asian or other minority ethnic disabled people; this is a major oversight, given the intersectional nature of discrimination faced by groups who are multiply marginalised, and the specific direct and indirect impacts of COVID-19 on disabled and chronically ill people.

Disabled people feel left behind

Inclusion London, a Deaf and Disabled people's organisation (DDPO), found that D/deaf and disabled people feel 'abandoned, forgotten and ignored' as a result of the COVID-19 pandemic.

This is in line with some of the responses to our own survey, discussed in more detail later. The organisation cites the Coronavirus Act as an example of dehumanising disabled people and curbing their rights, through marking them as 'vulnerable', and suspending local councils' duties to provide care and support. The interim report, based on survey results from over 300 people, found that 60% of disabled people had struggled to access food, medicine and other necessities, 35% reported increased levels of psychological distress, and almost half described inaccessible information, confusing guidance and a lack of advice. Disabled people reported facing cuts to care packages, delays to assessments and difficulty securing PPE for their care workers. Respondents had the impression that their lives were valued less as a result of requests to sign Do Not Resuscitate (DNR) notices, or fears that they would be denied emergency treatment because they are disabled or scored highly against official measures of frailty. Terms such as 'vulnerable', assigned without any choice, entrenched existing stigma and prejudice against disabled people, and employers, retailers and government services have failed to provide reasonable adjustments or accessible information, according to respondents.(16)

The findings of this survey were supported by a further survey by the Office for National Statistics (ONS), which found that almost two thirds of disabled adults said COVID-19-related concerns were affecting their wellbeing. Disabled adults were significantly more likely to report spending too much time alone, compared to non-disabled adults; one in ten disabled adults reported often or always feeling lonely in the last seven days compared to one in 20 non-disabled adults. One in ten disabled adults said they felt very unsafe when outside their home as a result of the virus, compared to fewer than one in 25 of non-disabled adults.(17,18) An additional report by disability charity Scope found that disabled people felt forgotten, resented being grouped together as 'vulnerable' while having little clarity on what support would be available to them, struggled to get food, essentials and welfare benefits, and were concerned about relying on public transport if the time came to return to physical workplaces.(19)

Some of these issues will be explored further in the analysis of our own survey data. While we have not been able to explore all of the impacts, challenges and experiences of different communities, our own findings can be added to this growing body of evidence, and the voices of people directly affected by the pandemic.



About our survey

The Patients Association wanted to hear from patients, disabled people, carers and others about their experience of health, care and other support during the COVID-19 pandemic. The survey was designed to record people's voices and opinions as the crisis continued to unfold, so that we could better understand its impact, what worked and what would need to be different in the future.

The survey had four sections:

- How are you finding managing and accessing care for existing health condition(s)?
- How have you found treatment and care if you have had COVID-19?
- If you have recently been bereaved, what has been your experience of care before and after the person's death?
- How has your experience of health and care services been overall?

Respondents were able to complete as many sections as were relevant. They were also able to decline to view questions relating to bereavement if they did not wish to do so.

The survey was available online from 6th May 2020 to the 17th August 2020. Respondents could request a copy in a different format, or to complete it over the phone by contacting our freephone helpline. However, it should be noted that the predominantly online format is unlikely to have reached those without access to internet or technology, or with low computer literacy, and these groups will be underrepresented

Who responded?

953 people responded to questions in at least one of the sections above. The majority of respondents identified as female (65%), were aged over 55 (74%, with 48% of those people in the 65-74 age bracket), were White British 84%, and were heterosexual (86%). All regions and devolved nations were represented, but only five respondents told us they were in Northern Ireland. The South East and London were overrepresented, with 19% and 13% of respondents respectively. 16% of people identified as carers. Half of respondents filled in the survey within 20 days of it opening at the start of May, while full nationwide lockdown policies were still in place.

We regret that we were unable to generate a more diverse profile of respondents. The Patients Association is committed to trying to widen its reach and its membership as it grows, learning and implementing lessons from projects such as these, to better represent all patients.

Quotes from survey respondents have been minimally edited for clarity and language, but care has been taken to preserve the original meaning.



Managing and accessing care and support

This section asked questions about people's experiences of managing their health condition or disability during the COVID-19 pandemic, including during lockdown.

Lockdown officially began in the UK between the 16th and 23rd March, when the general public were told that all unnecessary social contact should cease. Some people were identified as being at greater risk of severe illness from COVID-19 based on pre-existing conditions. Those who are most at risk – or 'clinically extremely vulnerable' – were placed on a list and told to 'shield' by avoiding any contact with those outside of their household. In England, people on this list had special access to services from government and other bodies, mostly via a government website, including food parcels, priority access to supermarket delivery slots, statutory sick pay as a result of being unable to work due to shielding, and help from NHS and local authority volunteers. There were slightly different processes, systems and rules in Wales, Scotland and Northern Ireland. People aged over 70 were also advised to shield, but age alone did not qualify someone as falling into the 'clinically extremely vulnerable' group. Neither did having other disabilities or health conditions that made leaving the house difficult.

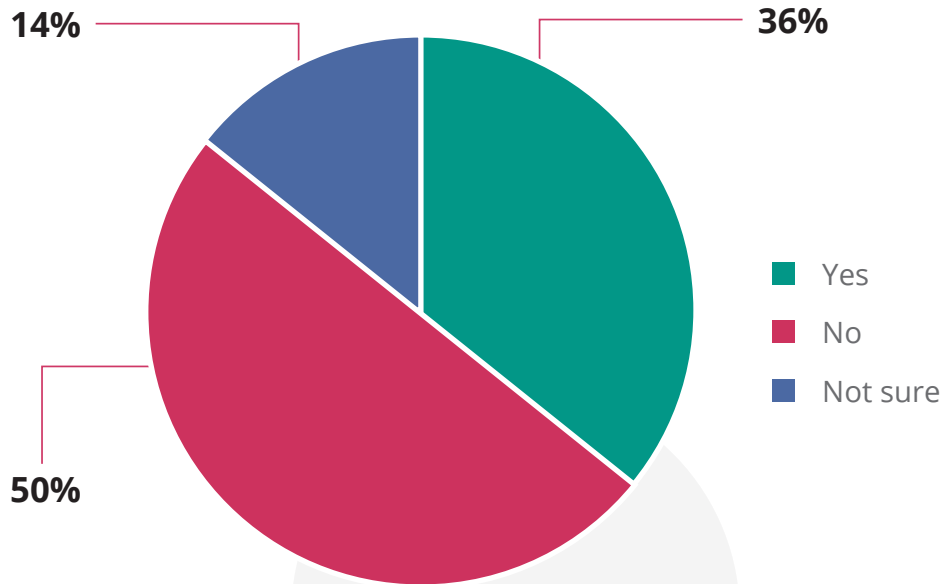
The first questions in this section explore whether people were or were not put on the shielding list, whether they were subsequently able to access support and services, and whether they were happy with how these processes worked. The survey then asked in more detail about people's experiences of health and care necessary for pre-existing conditions, including whether they had been able to get appointments or treatments, and whether they had any concerns about how the pandemic might affect their condition(s). Finally, it touches on what other support people felt they needed at this time.

Support for people shielding and with other needs

730 people told us whether or not they had been placed in the 'clinically extremely vulnerable' or shielding group, because their condition(s) meant they faced greater risk of serious consequences should they contract COVID-19. Of these, just over a third (265 respondents) reported that they were in this group, of whom 206 people had received a letter from the NHS or health and care services to confirm this. 50% were not in the group, and 14% were unsure. The survey did not directly explore how people ascertained what group they were in if not by letter, or how confident they felt about their understanding of this, although free text responses did occasionally indicate misunderstandings over the designations of 'clinically extremely vulnerable' and 'vulnerable' people, for instance in assertions that all people over 70 were advised to shield.

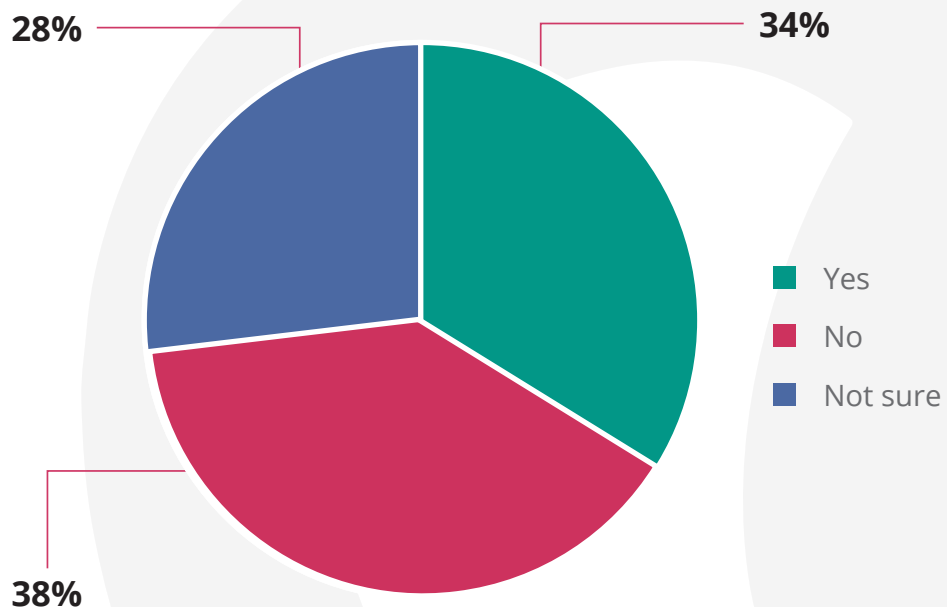


Figure 1: % responses to the question 'Does/do your condition(s) mean that you have been placed in the 'clinically extremely vulnerable' or highest risk group?' (number of respondents: 730)



Just over a third of respondents were happy with how this process had worked, but 38% were not, and a further 28% were unsure.

Figure 2: % respondents to the question 'Are you happy with how this process has worked?' (number of respondents: 661)



Comments from 346 respondents describe some of the problems – and good experiences – relating to the Government’s support scheme for people it identified as needing to shield. Comments were analysed to identify different themes, with some comments including multiple themes. Analysis showed that poor communication or a lack of communication were the most commonly raised issues, followed by descriptions of clinical needs that had to be met during the pandemic, confusion over the system, and lack of support. There were a number of comments regarding priority shopping lists, as well as government food parcels. Some people also highlighted where they felt mistakes had been made about whether they were or were not in the shielding group.

Good experiences

34 responses mentioned a good experience or good communication – around 10% of the total. Comments show that for some people the system worked well, and helped them to manage in the early stages of lockdown.

They proactively contacted me and arranged for support.

We were supported with essential food until we managed to get a supermarket online shop sorted.

The letter explained why I was in the serious risk category and I felt fully informed of the situation quickly.

Other respondents described how the system helped them access further support, or make decisions for themselves and their families.

Since receiving the letter and completing the form on the Gov.uk site within 3 working days I was contacted by my County Council informing me what they will do for me and whether I have any issues they might be able to help me with and they also advised me that I will be getting a free food parcel. Also within 3 working days [one supermarket] emailed me to inform me that they were giving me Priority Access to their online delivery service and within 5 working days [another supermarket] emailed me to advise me that I will be given Priority Access to home delivery slots... It's fair to say that I am impressed with how smoothly my experience of the scheme has worked to date.

Within the first week I had a letter from my consultant telling me to self isolate. This letter allowed my husband to work from home.

Promptly received a letter acknowledging the person I live with was vulnerable with advice on how we should live in the same house. Consequently we decided I should shield as well.

These comments demonstrate the importance of good, clear communication, at the right time, and with appropriate interim and follow-up support.

Confusion and poor communication

More people, however, reported poor communication compared to those with good experiences. 222 responses mentioned something relating to poor communication, lack of communication, lack of information or confusion.

Many of responses described letters or other communications that came weeks after lockdown began. This meant they were left without access to support, or even information about what support existed.

Government letter didn't arrive for eight weeks and so I didn't know what help was available or who to contact.

I only received the letter a couple of weeks ago... and a phone call last week to see if I needed any help. Only then was I told how I could get priority booking from supermarkets food delivery. [response date: 7th May]

I only received the letter after six weeks after Government said people would get such a letter - and it had only been written a day or two before I received same.

It could have been done quicker. We were already 3 weeks into lockdown when I was identified as extremely vulnerable - and that was from my health care professionals, NOT via a letter from the NHS.

It took four weeks for un-usable food box and five weeks to get a priority supermarket delivery slot. Had to contact the pharmacy directly to get help. My mother and brother-in-law still don't have priority food slots, even with letter.

Others mentioned confusion or mixed messages from different organisations and professionals, including contradictory advice and insufficient self-assessment processes.

I got letter from the Government putting me in the shielding group. Then eight weeks later a GP letter saying I wasn't. Very confusing.

I received a letter from my hospital rheumatology dept asking me to follow a flow chart and assess my own risk. The flow chart did not work for me. I emailed an address they had given for questions but received no reply. I don't think it's good enough to ask me to make a clinical judgement about my own vulnerability, and I need advice I have not been able to get.

Inconsistency: One of my hospitals classified me as extremely vulnerable, although after checking with one of my consultants he agreed with my GP [that I was moderately at risk]. Overall, it appears that risk categorisation should be more patient-centred for all patients.

My consultant said I would receive a letter at the start of lockdown. Nothing came. I filled in the government online form to apply - three weeks later the response was to contact my GP. I did this and two weeks later I received the letter - on May 5th!

My wife got a letter, saying she is vulnerable. Not even our GP knows why. I didn't get a letter but was contacted by some supermarket chains telling me I was identified as vulnerable. Two of my cousins, both undergoing cancer treatment, were not identified as vulnerable and had to jump through hoops to get some help!

Took a while to get the letter and seek clarity. Charities and societies did a better job at explaining risk levels than the NHS.

A small number of people highlighted important questions about the accessibility of information and communications from government. These were not appropriate for some

disabled people, and there were concerns expressed about support for people with spoken English as a second language.

The lady is a profoundly Deaf BSL user and has received no information in her first language - British Sign Language. All information has been sent in written format which the elderly lady struggles to understand. The Government, Department of Health and the NHS have not produced any information in BSL and have left it to charities to fill the void. The Government's daily coronavirus briefings have not included a BSL interpreter unlike Scotland, Northern Ireland and Wales. This means that Deaf BSL users have not had equal access to crucial information at the same time as hearing people, and have had to wait 24 hours for a charity to summarise the information into two minute videos.

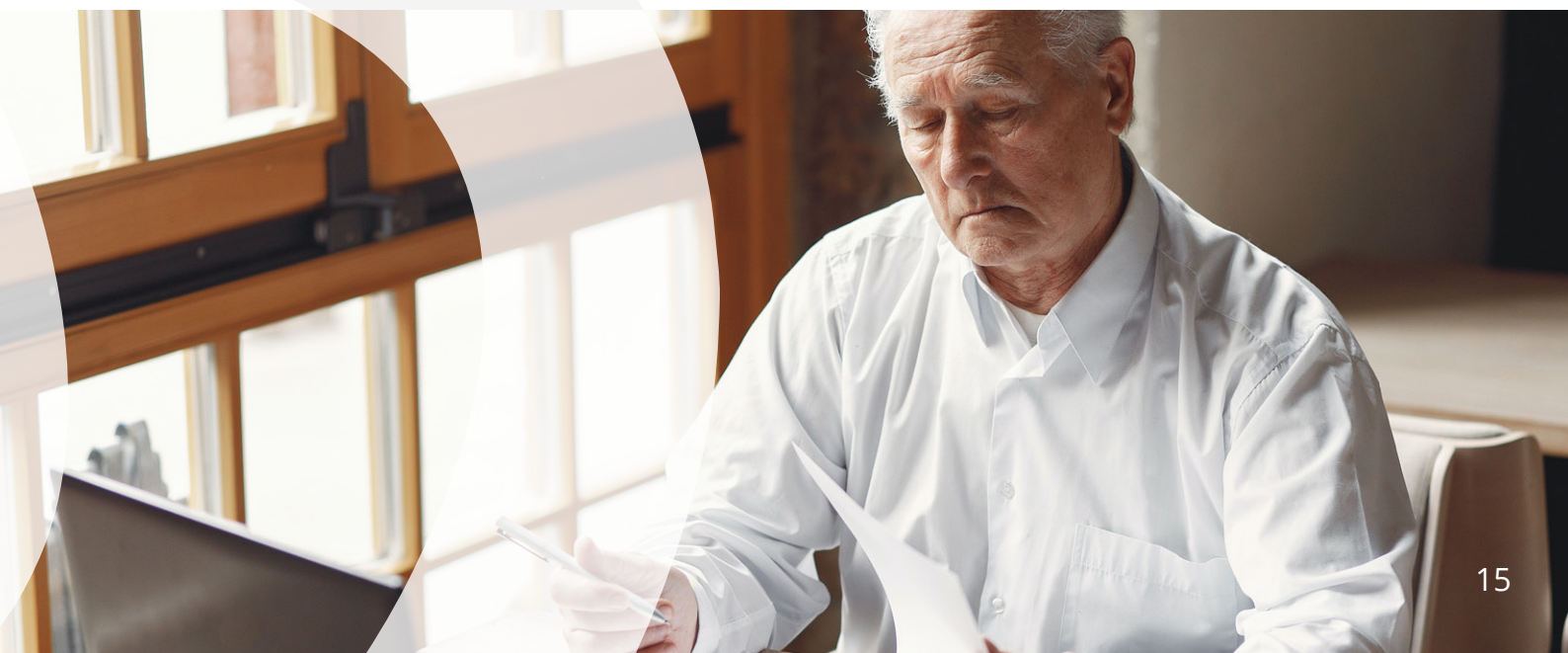
Not sure how well thought through the communication has been to people that do not speak or read English, as this letter would have been targeted at over 70s? Was there any follow up from GP practices in a culturally sensitive way?

For some, delays and lack of clear information had a serious impact on their own health and on the risks they unknowingly exposed themselves and others to.

It didn't arrive until three weeks after the initial shielding commenced for those over 70 [sic] and those with known chronic illnesses and/or co-morbidities. I am a nurse and by the time I had received my letter, I had already nursed COVID patients. I asked my GP if I should shield, who said categorically no, (using a tick box one assumes) then checked with two different assessment tools and reassured myself that I could continue working but with caution. Then categories of patients were assessed by individual consultants/specialist nurses and I was told to 'shield'.

I have not received a letter with information that I am on the shielded patient list. I have been informed [...] that I am on the shielded patient list and it was suggested that I should contact my GP with a request to reissue the letter... I did not receive a letter and contacted the surgery again, but despite what they said before they will not issue the letter or any confirmation of my vulnerability. I am a key worker and I had to return to work as without any letter I could not shield myself.

It took seven weeks before I received any letter or any help and by then I had had the virus.



Problems with the system

55 comments mentioned supermarket priority lists and government food parcels – key measures put in place to help those shielding, who might otherwise struggle to get essentials.

Some comments regarding food parcels were positive, with a small number of respondents noting that they were helpful, needed and welcome. However, others expressed a frustration with the system that required people to tick a box that meant they got a government food parcel, regardless of whether they wanted, needed or were able to use one, in order to get other support such as access to supermarket priority lists.

When you register with the government website you have to indicate if you need help or not. If you tick 'no', you get no further consideration and cannot even get a supermarket delivery to your home. I have had to collect this myself. However, if you tick 'yes' you get free food AND supermarket home deliveries. I need the delivery but not the free food, so get nothing. There should be an option where you can get the supermarket delivery slot only.

You can't just get supermarket deliveries, you have to say you need help then you get government food boxes delivered, which we don't need.

Government food parcel of no use - started late but full of processed food that I can't eat, as well as other foods I don't eat for religious / ethical reasons. Online food delivery priority still being sorted, horrendous.

Food parcels were also criticised by respondents in later questions, both in terms of their contents and the systems people needed to use either to access them or, in some cases, cancel them. Many people had struggled with supermarkets and other shopping too, although many reported good experiences of support from friends, neighbours and family members. As two of the comments below suggest, however, there were also positive views expressed about the food parcels, which had provided vital support to some people while they could not access a supermarket. Lack of access to supermarkets and disruption to supply chains has posed particular problems for those with special dietary requirements, which are also not well catered for by generic food parcels. The responses highlight the extent to which people are reliant on supermarkets for food supply, as very few comments related to other types of local shops. There were additional challenges for those not used to, or able to, use online ordering systems.

[I got a] food parcel for the first two weeks but then it was impossible to cancel the delivery. I took to Facebook and someone suggested contact the local Council office. Still the parcels arrived even though I sent one back with the delivery company.

Food parcels are useless for people with special dietary requirements. I didn't apply for one as a result.

Food parcels came weeks after not being able to get a slot online. I struggled to get fresh food for four weeks. The problem with the food that was dropped off is that 60% is tins of tomato soup or tomato sauces. I am not allowed these, with my renal diet. So I've left them in a box and a food bank is picking them up.

Food parcels have been totally inadequate. They are only for me, and since my wife is disabled she cannot go shopping. Contents were inadequate to make meals for a week. Having finally got priority online shopping I have tried four times to stop food boxes, without success, so am now overflowing with rice, pasta, baked beans and cereals.

Food parcels were not for diabetics. No pet food included. Arrived five weeks after shielding request. It was a large heavy box, left in the rain. Doorbell not used. Cancellation caused removal from supermarket home deliveries.

I have been helped by food parcels from two organisations: the food provided is a bit random and assumes that I cook in a kitchen, which I do not, so a lot goes to waste in the bin or is given away to a friend I care for.

Parcels are useful, but heavy to bring in and the delivery drivers often walk off before I can ask for help.

1. Food parcels do work. I'm grateful. But I can't stop them! I can manage with support from one of the charities I work with. I've said this and changed my needs online – but they keep coming. 2. I've given up on supermarkets. Not reliable. Minimum order costs. Limited stock of special diet stuff.

It was difficult to get a supermarket slot without also getting the food parcels. The food parcels just arrived and it was really difficult to stop them.

My husband and I are late 70s but have to shop in supermarkets and pharmacies. We have been unable to obtain even one online shopping slot. There is no help available.

Online supermarket shopping was quite a learning curve!

Many comments regarding access to shopping and deliveries focused on those who could no longer access delivery slots, as they were reserved for those in the shielding group, and the individuals had not been classed as 'clinically extremely vulnerable'. Others described problems accessing delivery slots at the start of lockdown, in part caused by delays in letters and communications to those in the shielding group. A number reported positive experiences, being able to access delivery slots and being supported with food packages in the interim. Finally, one respondent pointed out that this system did not exist in Northern Ireland, highlighting the fragmented nature of the UK response:

I have had extreme difficulty accessing food from the supermarkets. In [Northern Ireland] there was no priority listing for supermarket online delivery services. A system for people to register was not opened until 5 May 2020. I have registered on that date yet I have heard nothing. I was shielding yet until present I have [had] to leave my home and shop for essentials myself.

Based on the comments in this survey, food parcels and similar support can provide vital help to people who need it during crises, including as interim support while other services become harder to access. However, they need to be designed with people and households in mind, planned around nutritious meals, taking into account specialist dietary requirements and cultural needs, and with better systems for people to communicate their needs.

People in the 'wrong group'

120 comments made reference to individuals' specific clinical needs or conditions. Often people felt their needs or health conditions were not appropriately recognised or catered for. Others described clear mistakes that had been made (and in some cases respondents told us these had been later rectified), which had made securing support more difficult.

At the beginning of lockdown, I did not receive a letter as expected, even though my GP thought I should be shielding. I felt like I was in limbo – supposed to stay home but unable to access any government help or supermarket priority delivery slots. Didn't get a letter although I should have done. Behaved as if I were shielding. Had to apply online, so it was four weeks before I was entitled to a supermarket slot (but unable to get to supermarkets, or get any help).

I should have been on the list but neither GP, nor Public Health England nor my consultant had any influence or knowledge of this despite extensive records. It took two months to resolve.

I have type 2 diabetes controlled by insulin and tablets, COPD lymphedema periphedema with sensory ataxia, hyperhidrosis, diverticular fatigue. I think I should be in the highest risk group.

I have an autoimmune illness, receiving life-long medicine, and associated asthma. I am invited by my medical practice to attend yearly check-ups at their dedicated asthma clinic, yet I have not received any communication or advice from my GP or asthma nurse regarding self-isolating. I trusted my intuition and began self-isolating before official lockdown. My autoimmune condition has made me anxious. Just been left to manage alone. No shopping priority. Gone into survival mode: food and shelter. Not in the shielded group but high risk of dying. Just been left.



A small number of people were disappointed with the lack of information about why they had been considered 'clinically extremely vulnerable', or didn't feel they should have been. Some wanted more condition-specific information about their relative risk, while others questioned the benefits of being put in the group.

It didn't give guidance on why I was placed in this group and I had difficulty getting priority shopping deliveries even after phoning the local support line.

I live with HIV, the condition is a spectrum. The advice direct from the Government was a mess, third sector organisations and BHIVA had to help people decipher it. Then some people were told to shield when they didn't need to; if those people aren't connected to support services they'll be spending weeks in total isolation unnecessarily.

I do not consider myself bad enough to be labelled extremely vulnerable.
[Respondent indicated they had received a letter to notify them they were in this group.]

Left without support

48 comments described a lack of support. These comments came both from those in the shielding group and from others, but there was a dominant sense that those outside of the group had been left without support.

Many people told us they had existing chronic conditions or identified as disabled, but their condition did not pose any significant additional risk for COVID-19, and so they were not included in the 'shielding' group. This meant they were cut off from things like supermarket deliveries, where they had previously relied upon these.

I am unsure of my vulnerability status. I have had no confirmation and my GP practice was unable to help. I am blocked from enrolling with supermarkets because my name is not on the 'government list' so I can't get grocery deliveries. My GP practice knows nothing about getting on the 'list'.

I am housebound and very limited in my ability to move about but people in my position have seemingly been overlooked and find it difficult to get a delivery slot with any supermarket.

I'm disabled and housebound and don't qualify for the government list even though supermarkets used this to give slots!

Those with mental health problems have been totally ignored. These people find it hard enough to go out in 'normal' times. They are finding life very difficult to go out for food, and have not been included in the list of people who need extra help. Those with invisible disabilities have been ignored again .

I totally understand that there are extremely vulnerable people who could suffer medically if they were to contract COVID-19 and the process to ensure that they were identified and provisions made was necessary. But there are a whole group of people who are vulnerable at all times due to their disability/health condition, but they have been unable to access home grocery deliveries and were not

able to give any evidence to their employer of their status. This group has never been consulted or offered support.

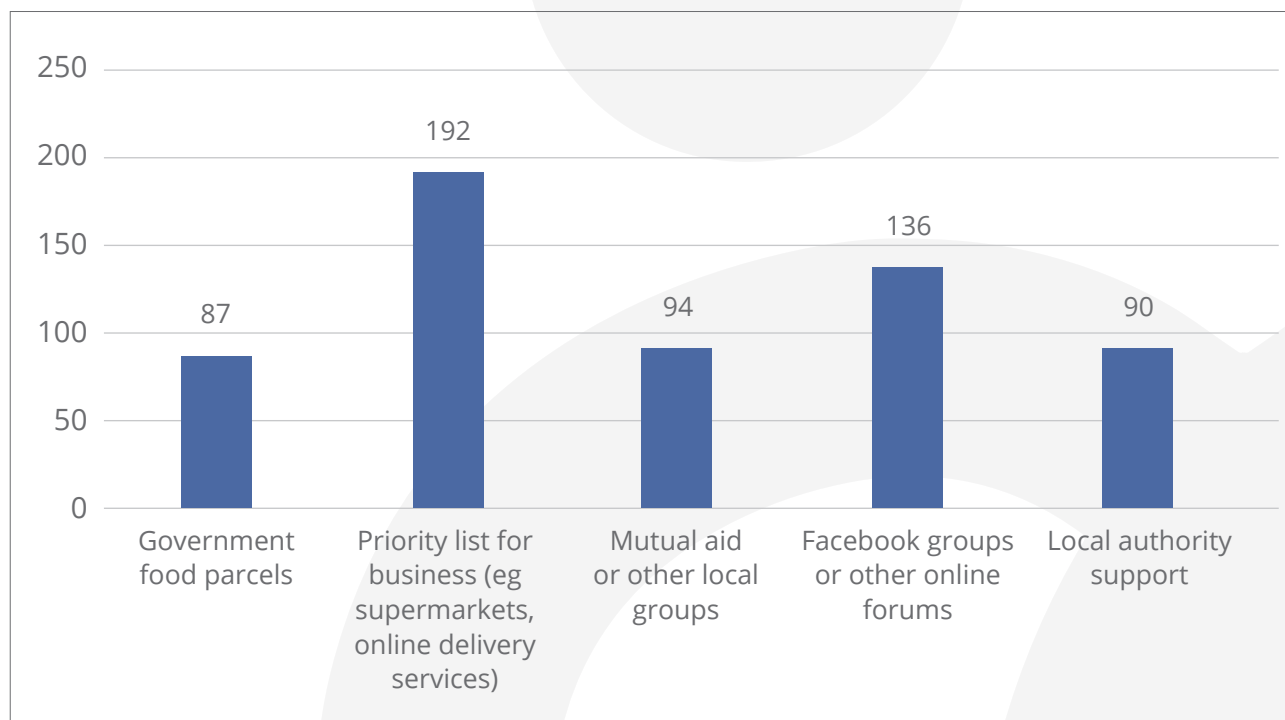
I feel vulnerable because I am deaf and I can't access healthcare without an interpreter.

As some of these comments indicate, these processes and problems have left many patients, disabled people and others feeling frustrated, abandoned and ignored. There is significant learning here for government and others about how to plan for better systems in the future. Most importantly, they must take the views, needs and experiences of those who most need support into account.

Services for day-to-day life in lockdown

We asked respondents which government and other services they had used as the pandemic continued, to help with daily life. Most commonly, people indicated they had used priority lists for businesses such as supermarkets. Facebook and other online forums were also commonly used, with comments referring to WhatsApp, Zoom and other online communication tools as well.

Figure 3: number of responses to the question 'Which of the following services have you used or received during the pandemic? (tick as many that apply)'



378 people provided additional comments about how they had found using these kinds of services, again, with good experiences and bad.

Support in the community

Many had praise for mutual aid, volunteer and charity organisations in particular, both new and pre-dating the pandemic, as well as the informal help received from friends, family members and neighbours.

A brilliant local mum set up a Facebook page and a system of street volunteers extremely quickly. The volunteers have now undertaken 1001 support activities, including 643 shops and 161 chats.

An already existing loose structure within the local community has been strengthened during the pandemic. It is now important to see how this can be sustained.

I am a member of a peer support group for people with long term health conditions through the local MS Centre. As well as the ongoing Brainfog Facebook group the centre quickly identified the need for additional online options for support, exercise sessions etc that would usually be held in the centre. These are now delivered through a dedicated online support Facebook group. I'm not sure how easy to find these would be for people not already in contact with the centre but group membership and engagement seems to be increasing overall. I've found this contact vital especially during the lockdown where the only person I engage with on a day to day basis is my husband. Being able to connect easily with people who have had a similar condition to share ideas, experience and do fun activities with has been a huge help. Even though my contact with them has been variable knowing they're there if I need them is really valuable.

The group most helpful to me has been my church which has been organised in house groups (those not normally part of a house group have been temporarily allocated to one) and group leaders are ensuring each person gets a call each week. I have found this helpful and supportive. I am a group member and I know my house group leader well. As someone who suffers serious mental illness I, on one occasion, talked for almost an hour about the something I was finding difficult to cope with; it was therapeutic just to have a sympathetic listener.

I have used both a COVID and ME support group on Facebook. These have been the only thing that's helped me feel less anxious as they have normalised what I'm going through. Otherwise support has been extremely lacking.

Local voluntary group is superb. They approached me, and deserve a medal.

A small number of people told us they did not know where to access this kind of support, however, or had not been offered it. In addition, online groups and services inevitably exclude those with limited digital literacy or access to the internet. While unfunded volunteer- and charity-led networks provide essential support to many, and should be supported and sustained in turn, they cannot be a substitute for other services.

Useful to find out what's going on, but a lot of friends in my age group don't have internet access. Even though I do I have been unaware of a lot of services, only finding out by accident and luck.

Health and care services during the pandemic

67% of respondents (of a total of 721) told us they had had appointments cancelled as a result of the COVID-19 pandemic. 48% (of 712) told us they had chosen to put off accessing services or treatments as a result of the crisis. Some comments in response to other questions suggest a reluctance for some to access healthcare services, especially primary care, to avoid either exposure to the virus or adding to health professionals' workloads. Others express a concern about how or whether they will be able to access services in the future, and a lack of information about when these might restart. Some others stated that while they had nominally chosen to postpone appointments, in reality there was no choice involved, as services had shut down.

Figure 4: % responses to the question 'Have you had any health or care appointments cancelled?' (number of respondents: 721)

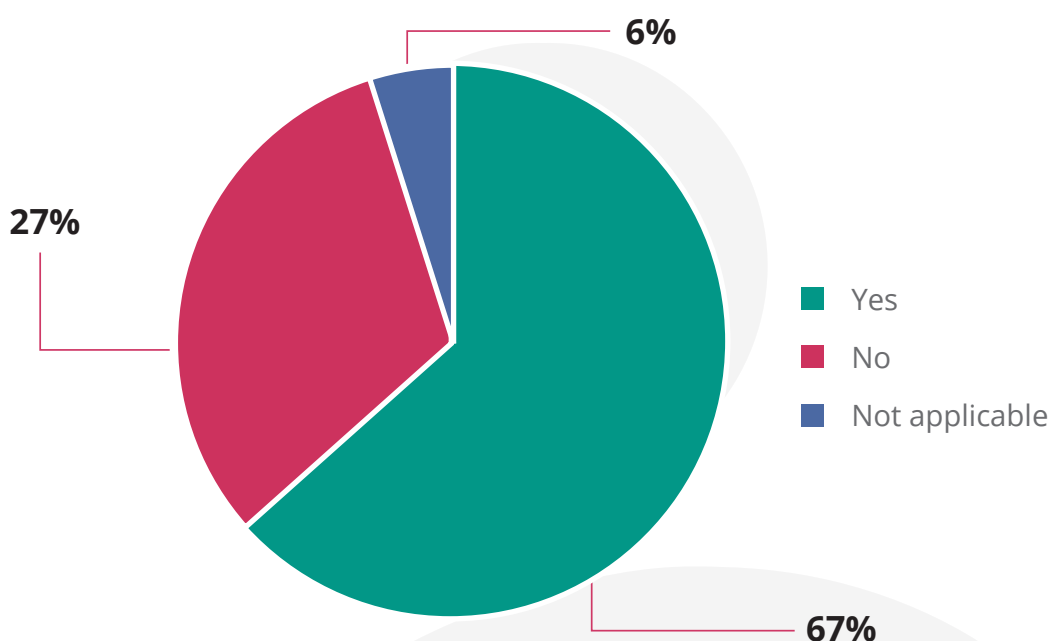
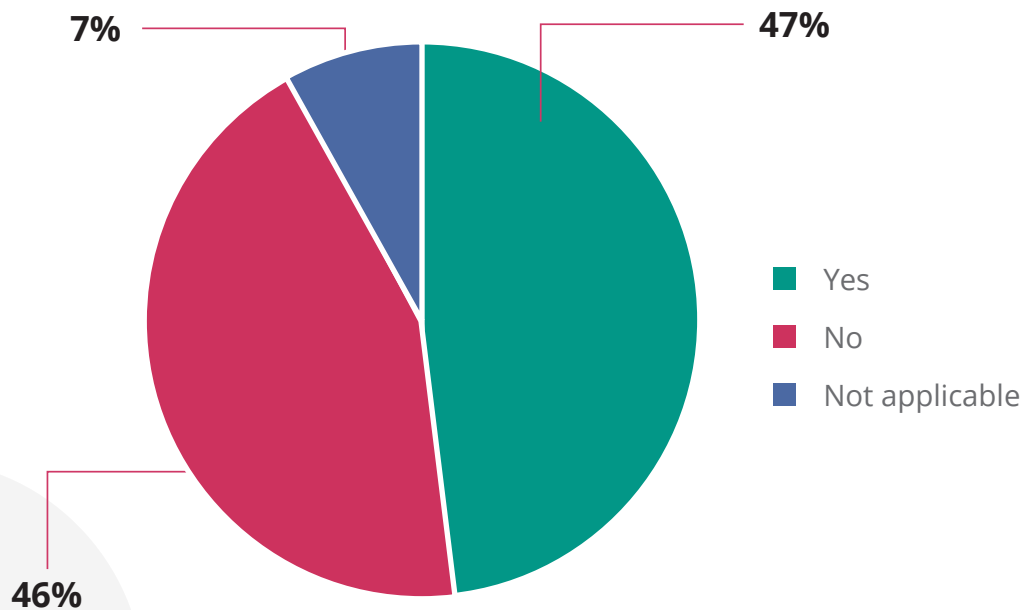


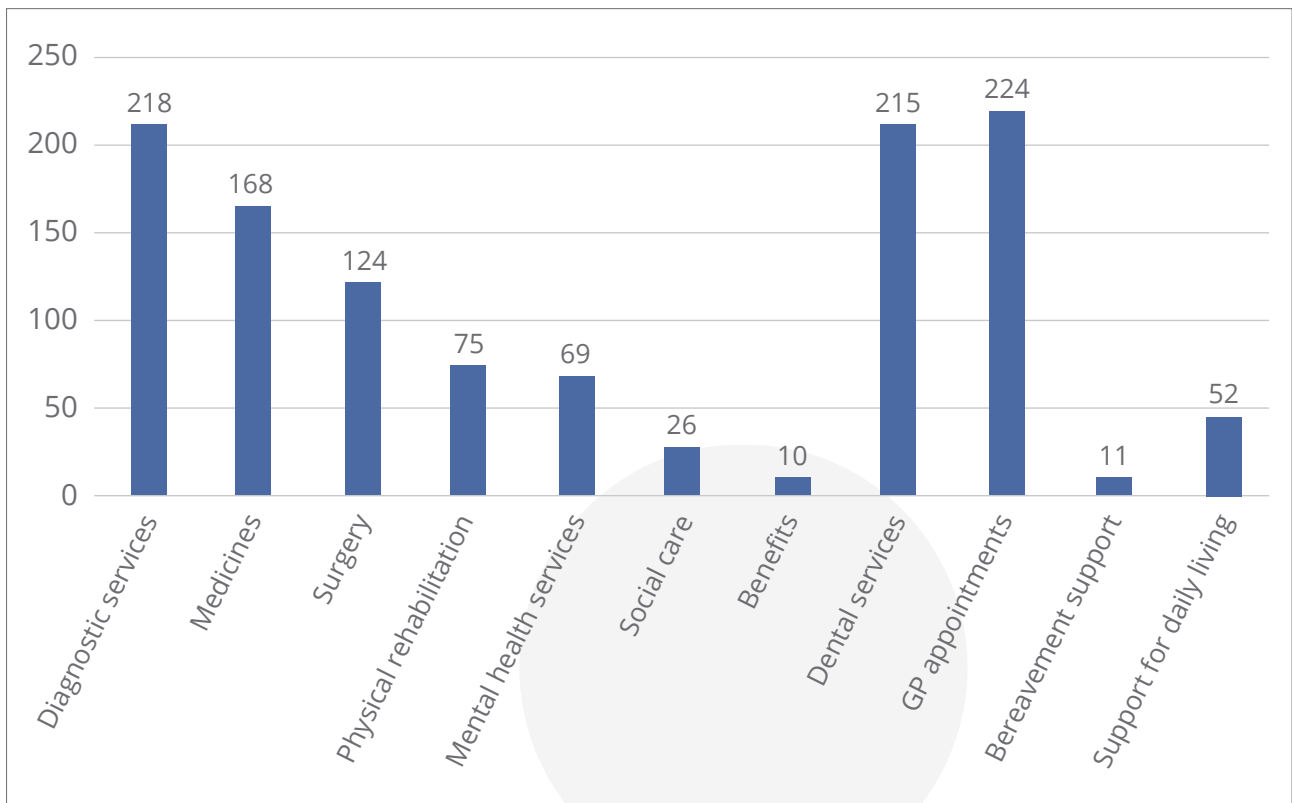
Figure 5: % responses to the question 'Have you chosen to put off accessing any services or treatments as a result of the pandemic?' (number of respondents: 712)



We asked patients whether they had had, or were having, trouble accessing specific health and care services during the pandemic. The results show that people were most commonly struggling to access GP appointments, diagnostic services and dental services, and the latter also received many comments from people who had significant needs for dental treatment. Over 100 hundred responses also indicated trouble accessing medicines and surgery, with slightly lower numbers struggling to access physical rehabilitation and mental health services, as well as support for daily living. Diagnosis and treatment for mental illness also came through in comments throughout the survey as an area that was being neglected during the COVID-19 pandemic. Small, but nevertheless important, numbers told us they were struggling to access social care, welfare benefits and bereavement support.



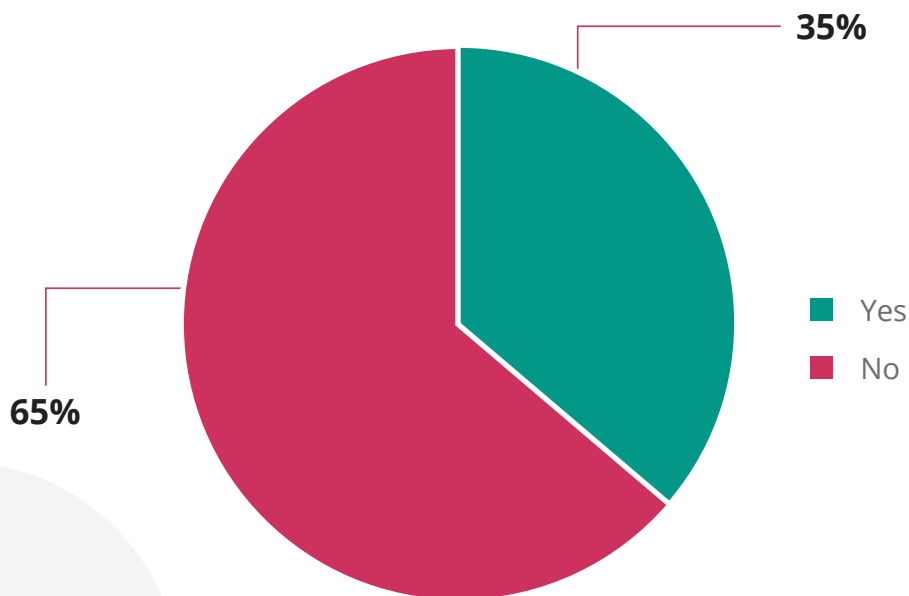
Figure 6: number of responses to the question 'Have you struggled to access any of the following services, either for new, changing or existing conditions, as a result of the pandemic? (tick as many that apply)'



Where respondents (124 in total) had needed to stay in hospital during the pandemic, for whatever reason, over a third reported that they had been able to stay in touch with friends and family, and many expressed satisfaction with how this had been arranged. However, almost two thirds had not been able to stay in contact. As will be discussed in a later section, this was particularly hard for those whose friend or relative died in hospital without having outside contact. The variability of this picture is concerning; patients should be able to stay in contact with those they wish too, regardless of which hospital they receive care from, but it appears that hospitals' approaches have varied considerably, with some getting it right and others getting it wrong.



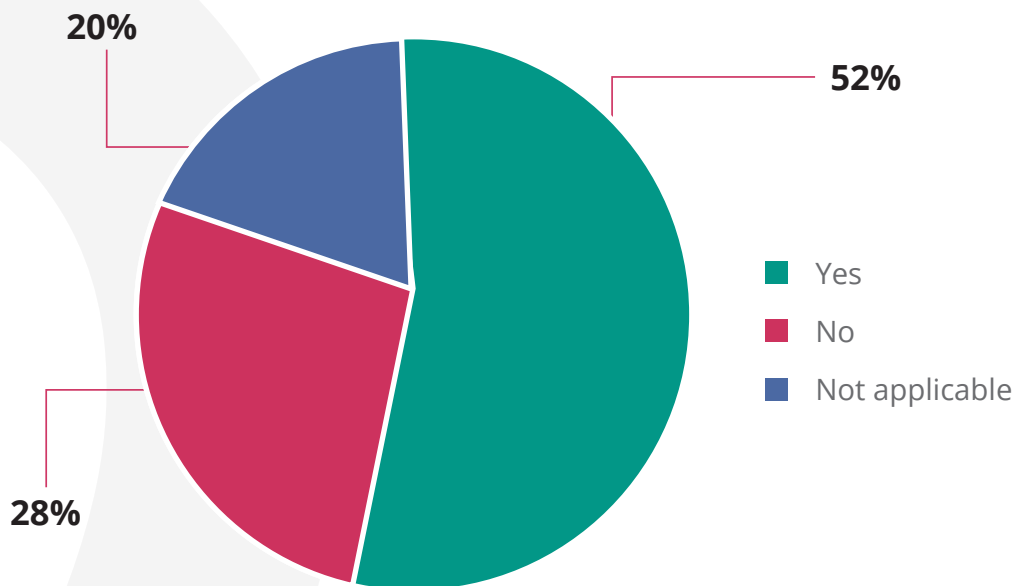
Figure 7: % responses to the question 'If you have been admitted to hospital during this time because of your condition(s), have you been able to stay in touch with friends and family?' (number of responses: 124)



We also asked people who had contracted the COVID-19 virus whether they had been able to stay in touch with friends and family members if they had needed an admission to hospital.

Restrictions on hospital visiting gave rise to many complex consequences, among which was an inability for relatives to keep track of what was happening to their loved one after they were admitted with COVID-19. Undoubtedly some hospitals will have managed to provide information to loved ones effectively, but we heard how distressing it could be for someone whose relative had been taken into a hospital system and then not heard of again for a sustained period.

Figure 8: % responses to the question 'Were you able to have contact with friends and family members while you were ill?' (number of respondents: 56)



Eight days of hell. No one phoned me and you could not get an answer. My wife was in four wards which I had to track down. When she was diagnosed positive no one called me. I tried to get through to the ward from 1000hrs to 2015 hrs: when I got through they told me admin staff don't work weekends. My wife could be dying and I would be the last one to be told. Disgusting.

Needs and concerns for the future

We asked respondents whether they had any worries or concerns for the future, as a result of the pandemic, and what other support they might need in place to help them better manage during this and future crises.

59% (from a total of 723) told us they were worried their current condition(s) might get worse as a result of lockdown and other policies during the pandemic. 70% (of 723) told us they were worried the services they needed would become harder to access after the pandemic.

Figure 9: % responses to the question 'Do you have any worries or concerns about how your current condition(s) might change as a result of lockdown and other government policies during the pandemic?' (number of responses: 723)

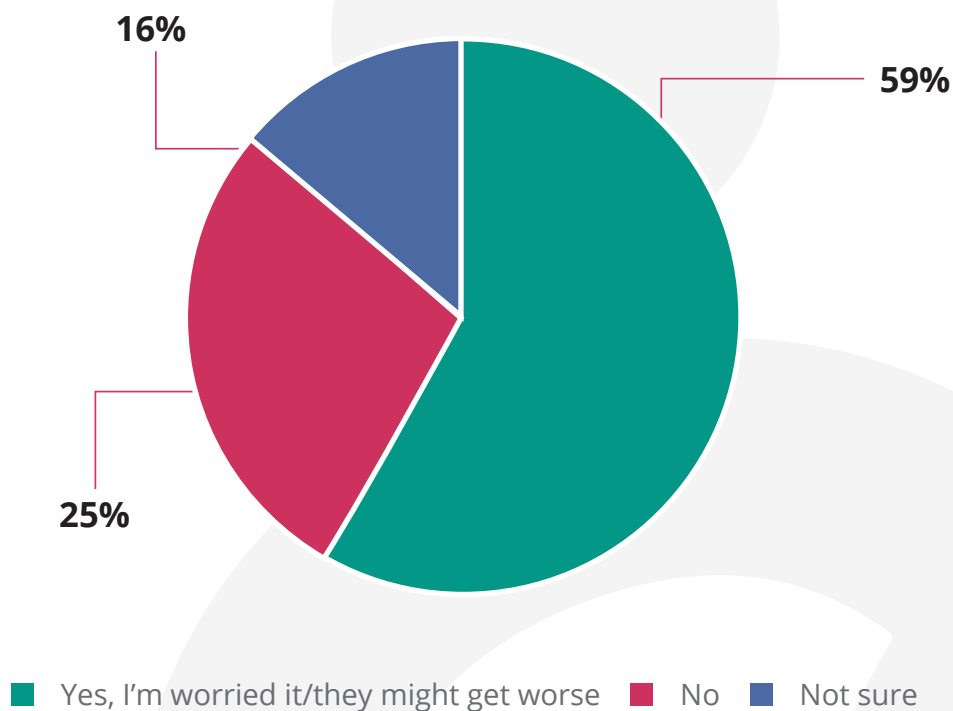
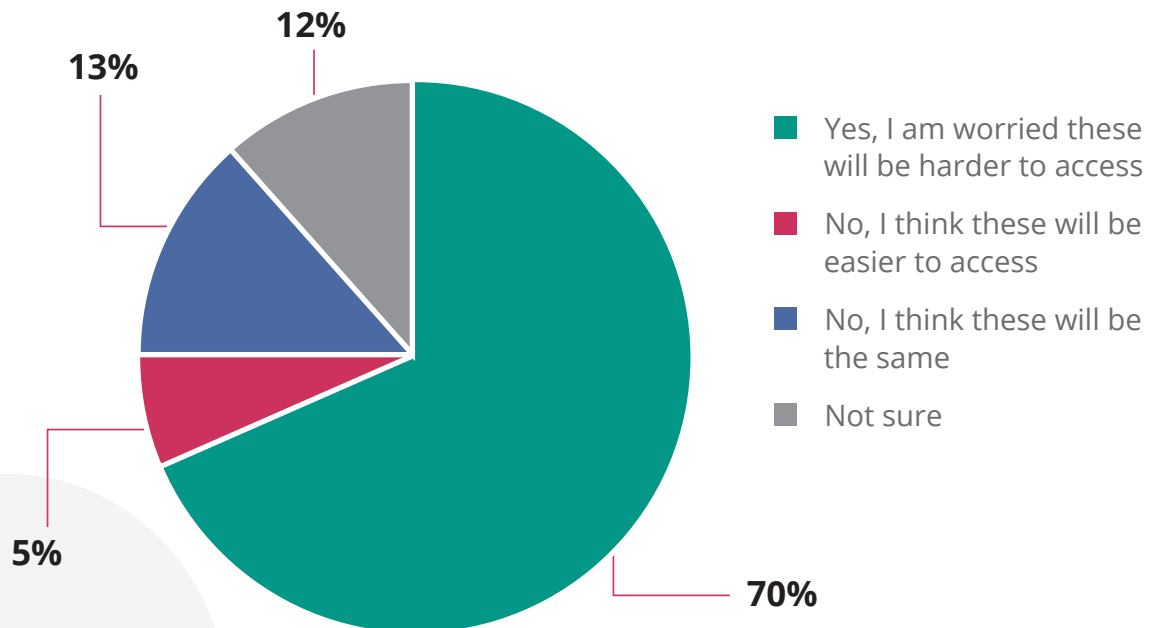


Figure 10: % responses to the question ‘Do you have any worries or concerns about how treatments, services or support for daily living will work in the future, after the pandemic?’ (number of responses: 724)



These results show a substantial need among patients for reassurance that they will get access to diagnostic services, treatments and other support services that have been put on hold due to the pandemic. Since many of the survey responses were submitted, the NHS has taken steps to restart many services, although they do not yet amount to pre-COVID levels of provision, and debates are underway about what learning to draw from the measures taken during the initial emergency period. The testimony we have gathered from patients shows that this restart work should include clear information for patients about what they can expect, and when. The restart must not be driven by the needs of the system, but must be driven by the needs of patients: it should recognise the impact of recent measures on patients, and involve meaningful work with patients to understand their needs and respond to them. This should include efforts to ensure an equitable approach, identifying those who have been most disadvantaged, as well as sensitive and effective communication with patients.

Improving and expanding support

468 people provided comments in response to the question ‘Are there any ways in which you think support for people with pre-existing conditions could be improved?’ Common themes included better support for specific clinical needs, more capacity in and funding for NHS services, and better planning of services for crises. This included ensuring easier access to healthcare services and professionals, and maintaining existing NHS services separately from COVID-19 treatment facilities. Others, again, highlighted the impression that those with chronic conditions or who are disabled but not in the ‘shielding’ group, had been forgotten. A small number of comments also related to access needs relating to these services, which some people reported had not been met. Several respondents raised the issue of lack of parity between mental illness and physical health conditions; treatment, rehabilitation and other services for mental ill health must have as much priority as those for other conditions.

The Government needs to put more money and resources into health and social care. So both, as they form part of the same care pathway to better patient outcomes. When you are admitted to hospital they should listen to you because you have had the condition for many years and it's very specialised.

Most medical services have worked round the clock to provide the usual level of care but my surgery tell me they have difficulty contacting specialists in hospital and obtaining pathology reports. Certainly my ongoing conditions have been less well monitored and we still cannot get advice about one condition from which I became and remain acutely ill.

Much more local support in the community, and allowing therapists to visit patients at home or in care homes.

Move more attention to existing conditions from COVID-19. We are in danger of causing more health problems in the future post-COVID.

For those of us who do not fall under the 'extremely vulnerable' category but who know that contracting COVID would put us in a potentially worse condition than others (I have autoimmune conditions) some additional help would have been useful. I feel we have been left out of 'help measures'. Instead I have barely been out of the house for the duration aside from walking the dog and keeping more than advised social distance.

For many weeks we have had a 'COVID-19 Care Service' and Emergency Care Service; we haven't had a National Health Service because it was basically stopped; my partner, who luckily had their heart surgery the day before lockdown, has had very little follow-up care and no rehabilitation. It has affected their mood and no doubt the delay will affect their recovery.

There was also a clear desire for a restart to begin, or at least for timescales to be provided, so that people could understand when they might be likely to resume their treatment.

Return now to normal appointments for pre-existing conditions and for screening. When 'routine' appointments are cancelled, a later date could have been arranged recognising that the revised date might have to be cancelled also. With no date, one is left 'in limbo'.

Please 'pick us up' where they left us before the pandemic started! Let us get back into treatment, the appointment we had, and so on.

People who [have a life-threatening illness] and who have not contracted COVID-19 should not be pushed to the back of the queue in accessing life-saving surgery. I think the urgent consultations should be expanded to necessary follow-on treatments as soon as possible to prevent less urgent conditions worsening.

My (NHS) dentist can treat people, and this involves getting really close to a stranger's mouth. My (NHS) podiatrist cancelled my appointment and said I could have one after I had developed an ulcer on my foot. My hairdresser can trim my beard, which is really close to my mouth. My podiatrist cannot trim my toenails, which are almost 6 feet away from my mouth. Why not?

Have plans for a return to usual services and communicate these to patients. A time frame need not be included but to know that monitoring will return eventually and that there is a plan for this would help. Annual diabetes checks is what I am considering.

Patients should have been involved in the decisions to make changes to the appointment systems, both the temporary ones during the lockdown and the restarting of routine care.

While it is crucial to ensure the resumption of services happens in a way that is safe, and minimises risk to patients and healthcare professionals, respondents to our survey clearly expressed their frustration about a lack of information, inconsistent practice, and concerns about conditions getting worse. This feedback portrays a relationship between the NHS and its patients that has been very seriously disrupted. Better communication and information, and clear, public plans for restarting services across different nations, could help to reassure people their needs have not been forgotten.

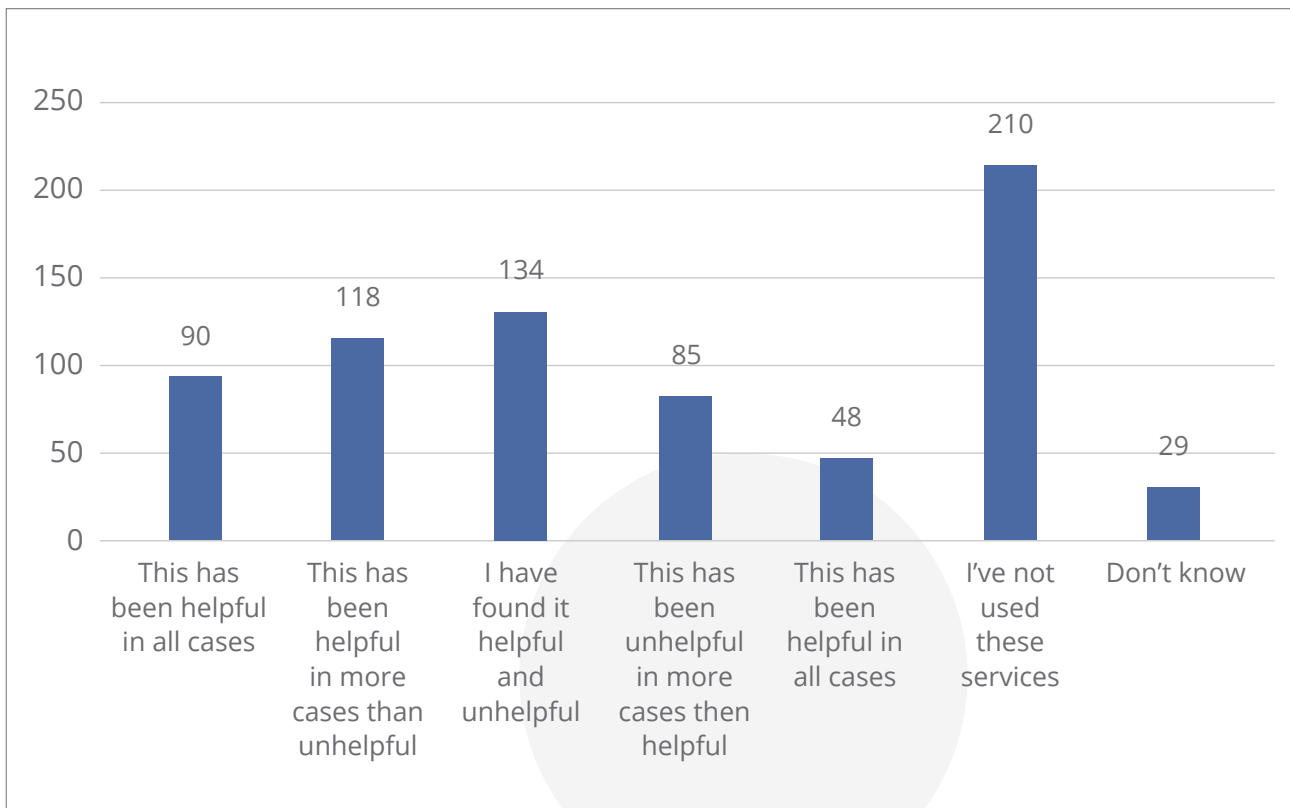
Virtual versus face to face

In an earlier question, we asked people how they had found the transition of many health, care and other services to online-only. Many, in fact, told us they hadn't used these. Of those who had, more people tended towards the positive end of the scale, although people most commonly reported they had had a mixed experience.

We did not ask any specific questions about the broader model of remote consultations, including online, video and telephone methods; this was an oversight. Many respondents referred to trying to access services over the phone, and told us about some of the challenges they faced in doing so. A small number also drew a distinction between voice and video calls, deeming the latter more useful.



Figure 11: number of responses to the question 'Many health, care and other services have moved online during the pandemic. How has this affected you?' (number of respondents: 714)



Overall, respondents had a mix of opinions about how useful video and telephone consultations were. Many said they wanted a return to face-to-face appointments, and some pointed out difficulties associated with remote consultations, including difficulties for diagnosis, and lack of a personal or consistent relationship. However, others found online and telephone consultations easier to use.

Provide telephone consultations for everyone and by all hospitals, GPs, etc, so all patients have access to a consultation still but via telephone no matter where they live, condition, hospital they are with or consultant they are under. Face-to-face consultations are one thing that can easily be done remotely via telephone as it is mostly talking so is able to be offered as a suitable alternative without compromising quality of care to the patient.

DEFINITELY face to face appointments with GP, not phone calls to reception or to a nurse. It is outrageous.

Far better follow up for people with multimorbidities is desperately needed. If telephone checks are going to be the way forward then they must be completed: it is no good making a call, getting no reply and then not following up.

Telephone consultations for most patients are of limited value - most important is medical/nursing observation of the patient. Patient needs to manage their condition in connection with the same staff, who get to know the patient. For chronic conditions nothing is worse that consulting with different staff each time.

I can only access my GP by telephone or letter. We have telephone consultations. Face to face in an emergency. I need to know that I can always speak to the GP who knows my (complicated) situation. I have been misdiagnosed over the phone more than once when another clinician returns my calls.

Easier access for face to face appointments: a stethoscope can't be used for an online consultation and invariably the GP needs to listen to your chest.

Face to face consultations should be resumed. Some conditions cannot be diagnosed remotely and older patients may not be not at ease or understand, so don't bother until it's too late.

Face to face contact (over internet) rather than telephone as people with mental health issues can sound OK but seeing them gives a different picture.

Give them more choice and control. Communicate better and involve them in decision making processes. Use digital services where appropriate.

Keep GPs available for face to face appointments. I'm quite tech-savvy and there are times when an online appointment would be fine but other times when it wouldn't. The decision to stop people seeing their GP scares me, partly for myself, but especially for so many other people - people with little internet knowledge or access, people with mental health conditions that may not be comfortable using phone or computer to describe symptoms, those people who present with one thing but the GP is able to realise that there are other things going on, people in abusive situations who may not be able to talk online or by phone, so many ways this is a terrible idea.

My son has cystic fibrosis and his own service has been amazing and I wish all specialities could offer this level of multidisciplinary service... He has regular videocalls from professionals/doctors/specialist nurses/ physiotherapists/ dieticians etc and home visits as required. They support me as his carer.

The pandemic has highlighted the weaknesses in the NHS in terms of administration and difficulties in communicating with patients. A quick way to improve this would be to move to 'digital by default' for communication with patients (only for those who are comfortable using digital) because it is quicker, easier and cheaper. It would mean my rheumatologist could have emailed me to explain my shielding decision within days rather than the weeks that it took to get the letters sent out.

Therapies should not have stopped. Online appointments should be the norm as many are far from their home and involve a lot of waiting for nothing.

Future policy and planning needs to take into account the range of needs and preferences patients have and, ideally, give patients a choice. Remote consultations will work very well for some people, but others will find them a considerable challenge. This includes many disabled people, who are less likely to have access to the internet than non-disabled people, those in rural areas without reliable connectivity, those with poor digital literacy, and those who lack the privacy necessary for sensitive conversations with health professionals. Digital consultation methods need to include ways of measuring patient experience, empowering patients and enabling shared decision making in their design. This will need to include meeting access needs of, for instance, disabled people who may need technology in appropriate formats, or people who need translation services.

Continuity and co-ordination

Some respondents expressed a desire for better co-ordination and planning of their health and care, and more continuity. Often this meant having a single, named professional such as a GP, with detailed knowledge of a person's medical history. As noted above, some people felt that the move to digital and telephone consultations had exacerbated problems with continuity.

Need to have access to someone who knows my medical history and can talk with me.

Being able to see the same doctor. This is not the case when getting a telephone appointment.

Continuity of care...CONTINUITY OF CARE! There is too strong a move to telephone and video consultations. I seriously believe and am very concerned that there will be an even stronger influence to reduce direct GP contact. Patients with long-term health conditions are NOT getting the essential services they need...and this is exacerbated by very rarely dealing with the same doctor.

A dedicated specific GP that is familiar with my chronic health conditions and isn't only treating symptoms that present on the day. I believe that increasingly primary care provision is only responding to the immediate issue and that the GP has little/no knowledge of the 'overall personal picture'.

If they were allowed to have a nominated health professional who they could get to know and would get to know the patient. There isn't any consistent follow-up.

Computer systems need to be linked so hospitals can access GP records and vice versa. I was being fast tracked for head and neck cancer and six months later I have not had my MRI Scan - so make this sort of thing a priority.

Why aren't we being identified by the NHS system? The whole system is fragmented into too many outsourced bodies and no one knows what the other is doing. It has gone from seamless to meaningless.

Always seeing one named GP who knows about you, with another kept up to date. Making sure the hospitals and consultants know the name of that GP. Making sure the GP understands the sum total of all your conditions and treatments. Routinely - even every 12 weeks - being phoned to check if all is well.

While this may not be a new issue, the pandemic may have brought new light to it, given the necessity of accurate health records for accessing support, and limited access to regular healthcare services.



Checking in

Many respondents, at different points of the survey, told us they wanted healthcare professionals to 'check in' with them, and with others who might need support or care. 51 comments in this section referred to 'checking in'. This did not mean addressing clinical needs, unless they became apparent, but rather making sure a person had what they needed, knew where to go for support, and did not feel forgotten.

A list of patients from the GP that need a call about their health, not just about shopping etc.. a check up call.

An occasional phone call to check how you are doing would be good, rather than feeling like everything has stopped.

Things had to change quickly which is understood, but normality is needed ASAP. GPs are aware of which patients are vulnerable and did what they needed to, however they also know about patients who need reassurance - those with mental health issues or autism maybe. It seems those people were forgotten which unfortunately I know has caused death.

Assertive outreach, stop allowing us to fall from the radar because your systems can't communicate. Phone us. Ask if we're OK. We'd really f***** appreciate to know you care about us.

I feel that what would really help is having a doctor that checks up on the patient. I have a diagnosis of COVID that's been ongoing from March. I no longer have the virus as I've since tested negative but I'm really struggling with the symptoms still, on top of having ME. I've found that it's my responsibility to call the GP when something new happens. I've been stuck like this for 17 weeks and have no one to talk to about it and my worries around it. I feel like I'm in limbo and I don't know if what I'm doing is helping or making it worse as my symptoms keep shifting slightly but not enough to call the GP for help. I feel like for those with ongoing symptoms and/or chronic conditions it would make the world of difference to have a doctor call me every now and then to see how I'm doing as it would give me a chance to talk about what's happening and my concerns, and I would know if I'm doing the right thing or if I should be going to get a check-up, so would help enormously with my mental health.

Just a letter from the GP saying they understood it was difficult at the moment and explaining how they could help?

This is an important call, and one that needs to be taken seriously as the pandemic continues, and in advance of future crises. While many people have extensive personal networks for support, others are less well-connected, and in a time of uncertainty and isolation there is a clear risk of increased loneliness and mental ill health. A form of support that recognises disability and chronic illness, but goes beyond to focus on wellbeing, could help some of those in the most isolated situations.

Experience of COVID-19

Who responded?

Identifying respondents who had had COVID-19 proved a methodological challenge, despite the inclusion of questions asking both whether the respondent had had the illness, and whether it had been confirmed by a test.

In part, this reflects the situation during the survey period, and particularly during the earlier part of the survey window, when the majority of responses were submitted (50% during the first 20 days the survey was open). Specifically, the lack of available testing at the height of the emergency period meant that many people who had been unwell were unsure whether they had had COVID-19 or another flu-like illness: in free text responses, some who said they were confident they had had COVID listed atypical symptoms; others described illnesses that matched widely recognised patterns of illness in COVID, but indicated that they were unsure of their diagnosis in the absence of a test.

The survey design was therefore, of necessity, something of a compromise, and has produced some complex data. Respondents who were not sure whether they had had COVID or not were allowed to complete the questions for those who definitely had, which on inspection enabled us to gather responses from some people who it seems fair to count as COVID-19 patients, even without a clear positive test. However, the operating logic of the online survey meant that it was not possible for people to indicate that they had had a negative COVID-19 test, only that they had not had a positive test.

We have therefore identified a sub-sample of respondents who we are confident in treating as having had COVID-19, as follows. People who self-declared they had had it are included irrespective of whether this was confirmed by a test or not, unless their free text answers provided a clear reason to exclude them: for example, one respondent indicated they had had COVID-19, and then explicitly stated that they had tested negative for it. Some respondents were not sure they had had it, but indicated they had tested positive; they were included. Otherwise, respondents who answered 'not sure' to the self-declaration question were included only when their free text responses offered a strong suggestion of their having had COVID-19, such as a description of symptoms that match it closely. This provides a sub-sample of 67 patients who can be treated reasonably confidently as having had COVID-19, although this is probably an underestimate: some of the 'not sure' respondents will also have had the illness, but it is not possible to identify them with confidence.

What did they tell us?

Good experiences under the circumstances

Many respondents who had had COVID-19 indicated they did not feel their experience could have been improved, although numerous of them attached caveats such as 'in the circumstances'. This suggests patients might have been willing to accept a difficult experience given the emergency situation, but that the same experience might not be acceptable in more normal times.

Detailed comment on the system and the professionals working in it was mixed: some respondents offered strong praise; others felt disappointed or let down by what they perceived to be a slow or poorly organised response, and at times one that did not take a patient's other health issues into account. Nor did the emergency period mean an end to some of the regular concerns that patients raise with us from time to time, such as unhappiness with the attitudes and approaches of clinicians and professionals.

Lots of ways, but not sure in the rapid timescale of things anything could have been much better, other than a more supportive GP environment which was and is woefully lacking.

I would have liked oxygen provision to have continued after the ambulance journey, rather than delayed for six hours of pain and distress.

My experience could have been improved if the nurses and doctors actually listened to me, heard me, took my pain seriously, and my very real concerns seriously. I found them to be cold, uncaring, dismissive, unkind, cynical and not able to relate to me as a human being.

Better care of people suffering with co-morbidities and long term conditions [would have improved my experience].

Testing

The most commonly identified thing that might have improved the experiences of respondents who had been unwell was testing: many people indicated they had not been able to access a test, and so were not entirely sure they had had COVID-19. This often caused uncertainty and frustration both during an illness, and when reflecting on it subsequently.

Testing was not available when I was first suspected of having it in March, so that would have been helpful to have had at the point. By the time it was available to me, it was mid-May. Greater support for those whose symptoms go on longer than expected [would also have improved my experience], as there's a great deal of anxiety that comes with this.

I became ill in early March, before the shielding lists were sorted out. Had I been formally identified as high risk earlier (I personally knew that I was, but that only helped so much) and given priority helpline access accordingly, I would not have had as narrow an escape as I believe I did.

We had a virus similar to COVID-19 - cough, shortness of breath, loss of taste and smell, totally fatigued for several weeks. We got better, but cannot get a test to see if we had it.

I had COVID symptoms in early May but I did not ask medical advice for three weeks as I worried that my cancer treatment would stop.

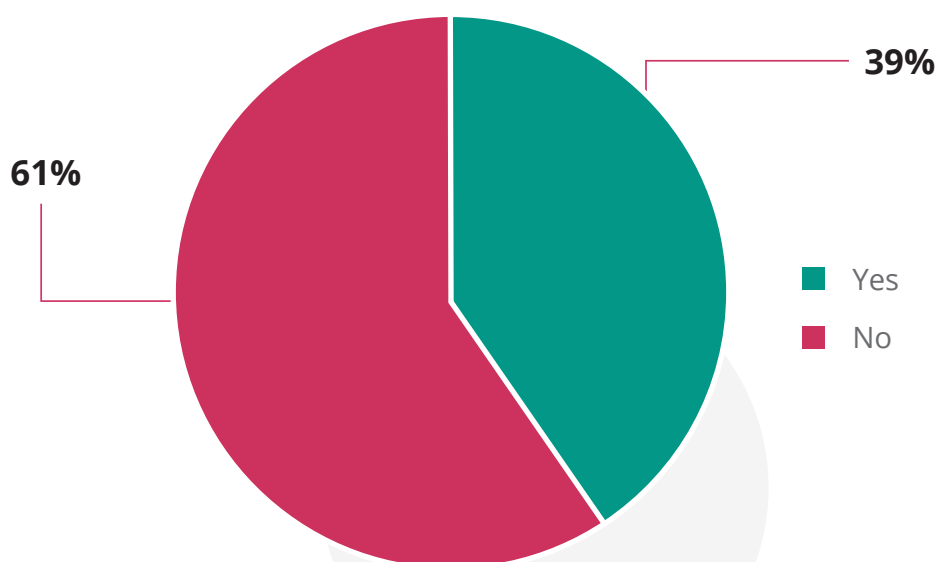
I am unsure if I have had COVID-19 as I has some symptoms before testing was available, so I don't know if I have had it or not.

Testing would have been appropriate and I was offered testing through the COVID-19 app, but unfortunately there were no available slots despite the fact that the website stated over 115 were slots available.

Where did patients turn?

61% of respondents (from 56 in total) told us they felt unsure about when to seek treatment for COVID-19. While this is a small sample, the results reflect a wider uncertainty described elsewhere in this report.

Figure 12: % responses to the question 'Did you feel confident making a decision about when to seek treatment?' (number of respondents: 56)



A theme running through the responses is that support from the NHS was quite often hard to access. Of course, this was by design during the lockdown period: the official guidance stated that anyone with symptoms should remain at home and not seek face-to-face medical attention, and access to primary care (whether sought because of coronavirus or for other reasons) was heavily restricted in order to reduce the spread of COVID-19. However, the net result for people who fell ill was that often they felt they needed help from the NHS but could not access it. Some respondents who reported having had COVID-19 told us they did not feel their other condition or conditions were taken into account when they did need to access healthcare services.

The two main routes for accessing support were GPs and NHS 111. Respondents' experiences of NHS 111 were mixed, but tended towards the negative. The most common complaint was that the advice it provided was either not useful or not practical; others indicated they had been unable to access the service at all. Some reported a positive and helpful response.

Patients often reported frustration in respect of GP services, though for a variety of reasons. Some succeeded in seeing their GP but found them unhelpful, while others reported that receptionists were performing their gatekeeping role with particular strictness, and blocking access to doctors. These experiences were not unique to COVID-19 patients, but reported by patients seeking care for other conditions.

Contacted 111 - no help. Advised to access a test 46 miles away when too ill to drive. Told to take paracetamol.

Difficult to get advice and support - left to make clinical decisions unsupported. 111 and GP services were almost inaccessible for several days because they only operated telephone services.

Rang 111 five times, but was told if I had no cough just to isolate.

A more responsive service when acutely ill. It sounds dramatic, but I could have died and got no return call from 111 or local health providers.

111 were understanding on the phone at day 10. Then a paramedic rang for a phone assessment. My husband had more symptoms than advertised on TV as he started on 13 March. With no underlying health issues he had to stay at home. I had to monitor his breathing and check for red patches on his skin. He has severe headache, cough, no taste or smell, diarrhoea, nausea, dizziness, fever and shivers. Our local doctor rang as well. So within 3 hours we had professionals on the phone. He has been left with breathing problems when walking.

111 is a very arduous experience with stupid questions, designed it appears to deter people from calling. It is a waste of money, time and stress for patients. As a social worker I avoided using it and would not recommend it to anyone but a buffoon.

All long term pre-existing conditions were totally ignored! GPs conspicuous by their absence! Receptionists acting like they were medically qualified!

It is sad that most GPs will not do home visits and one wonders how an accurate diagnosis or judgement of a patient's condition can be made via the telephone when one has never had any personal knowledge of that person and never even met them face to face.

Yes, [my experience could have been improved] if GPs made it easier to communicate with them, rather than letting the receptionists making decisions on their behalf!

The system was a mess. I first filled in a form on 111 which directed me to a GP, but the receptionist told me to ring 111. When I said I had been directed to them by 111 I was told a practise nurse would phone me. She was the person who said I must not go to the surgery and I didn't have COVID-19.



Experience of bereavement during the pandemic

Who responded?

Although more than one in three respondents consented to answer the questions on bereavement, only around half to two thirds of those went on to provide answers. In some cases, respondents were happy to provide consent, but then did not have any recent experience of bereavement to share. Only thirty people reported that they had bereavement as a result of COVID-19, so this discussion mostly considers people's experiences of bereavement during the coronavirus period, not specifically bereavement from coronavirus.

However, we can say that the small COVID-bereaved group are somewhat younger than the main sample – if they mostly lost parents, this might be expected. They are 90% female, and more than a third (13 people) live in London. Half of them completed the survey within the first nine days of it being open (compared to respondents overall, half of whom responded within 20 days of the survey opening). This is perhaps again unsurprising: numbers of deaths were high at this time, and numerous respondents will already have had experiences to relate by this point. The distribution of the remaining cases through the rest of the survey period seems, to be essentially random.

Experiences of death and bereavement during the pandemic

Overall, respondents offered mixed views on the end of life experiences of their loved ones, tending slightly towards the positive. Some respondents reported very high quality, highly compassionate care at end of life. That said, the 24% of respondents who reported what they felt was a poor or very poor experience is a substantial minority.

My friend was cared for well in the circumstances, but the support to the family was not as good as it would normally be. I can't see how things could be any better in these tragic circumstances

My mother was treated with respect and kindness in her final days and hours.

The 'carers' (longstanding home visits) were very good, as were the NHS (district) nursing team, but the actual GP was poor... Difficult to arrange a visit and then they seemed more interested in the existence of an 'end of life form' than any actual care or treatment.

The bereavement service at the hospital were excellent: the restrictions did not make it possible to do 'normal' things but the people in this department made every effort of normalise our loss if it were possible.

Nursing staff were really caring and made my father's last few days as comfortable as they could.

I got the feeling older people are expendable.

The care home staff did not leave my relative's side during the last 24 hours of their life; they made sure someone was with them at all times. The compassion shown was second to none.

Place of death

In respect of place of death, there was a noticeable difference between the wider cohort and the smaller cohort of COVID-bereaved respondents, the latter overwhelmingly reporting that death occurred in hospital or (in fewer cases) a care home; other respondents at times reported that the person died in their own home or elsewhere, in addition to those two settings.

Dying alone

However, it is clear that restrictions associated with COVID-19 exacted a heavy toll, in some cases, on the dying person, bereaved people, or both. Relatives being unable to visit and say final goodbyes was a prominent theme in the responses; many people expressed horror at the thought of their loved one dying alone, deep sadness at being unable to be with them, or both.

Two relatives in care homes contracted the illness and died alone. Their main focus during life was to care for their families, and they were denied the opportunity to say goodbye. The relatives, because they were in care homes, could not access hospital care or specialist care. This is inhumane.

Not being able to be with loved ones at the end is unforgivable.

It was my friend's mother that died in hospital. She was tested twice for COVID and each time showed negative. However she was left on a ward on her own for a week, terrified and lonely, and she died alone. The ward did not tell the daughter until a few hours after she had died. I could not believe they were so inhumane. The woman that died was in her mid-80s – it was so tragic that all the work about dignity of dying has gone out the window for COVID-19.

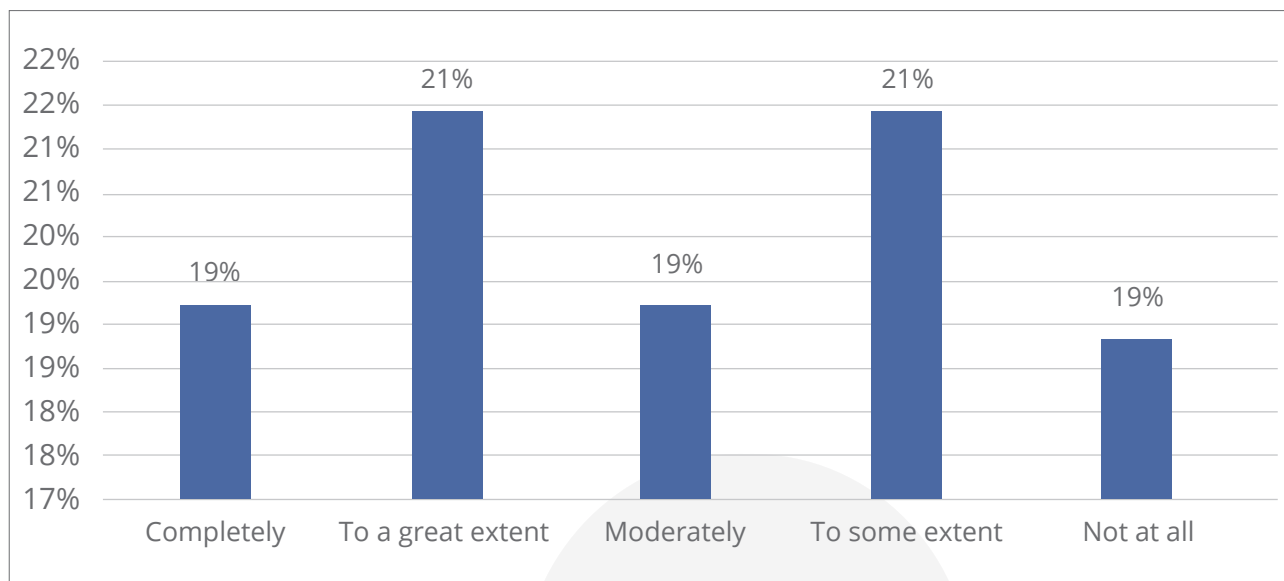
Visiting restrictions due to COVID-19 made my sister's last days/weeks terrible for her and our family.

Communication

Closely related to this were issues of communication: some people appeared to be unsure, even after the event, of the circumstances in which their loved one had died – particularly, whether they were alone or not. When asked whether they felt they had been kept informed about someone's condition during their final illness, respondents provided a polarised set of responses, evenly split between good and bad.



Figure 13: % responses to the question ‘Do you feel you were kept well informed during the last illness of your friend, relative or the person you cared for, prior to death?’ (number of respondents: 187)



The fact that it was so hard to contact the hospital made it very difficult for the whole family. Staff we spoke to were lovely but they had so little time and it was very hard to speak to anyone at all. My Mam has very limited speech so there was no way that she could keep in touch with us. It was upsetting seeing other hospitals put things in place to help, ie using ipads, when our hospital didn't have anything.

Governments always forget deaf people. We cannot communicate through phone, and must use an interpreter. We cannot lipread through masks. My English is not good, I cannot read letters. I need an interpreter for help.

The hospital maintained my parent was not dangerously ill and would be out in a couple of days. I went in to visit expecting to see them sitting up in bed and eating lunch; instead there were curtains round the bed, and I was physically restrained from going to the bedside by a nurse, as a doctor was 'working on the patient'. I was ushered into a side office, and a few minutes later the doctor came in and pronounced my parent dead! Dreadful experience - my parent died with no relative present; my siblings accused me of not advising them of how ill our parent was! The doctor left the hospital a short time later - it wasn't his fault, only one of two doctors working in the large hospital over the weekend and called in by ward staff far too late. Scandalous!

The person who died was a close friend of my late husband. His next of kin was his invalid brother and niece. His niece was most distressed that neither she nor the vicar could be with him when he died, although she understood that it was a government regulation. She can only hope that he wasn't alone.

Fear to seek help?

A slight theme emerged from the responses to these and other questions of people being worried about seeking help, and having their health worsen as a result: either because they

feared getting COVID-19; or they feared that treatment for COVID-19 would interfere with care they were already receiving. The possibility was also raised of signs of worsening illness, that ultimately led to death, being missed because of the cancellation of regular treatment.

A close friend died of a heart attack, frightened to go to hospital because of the COVID-19 infections in the local hospital.

They died of complications from chemo for cancer. But chemo and any hospital visits had been cancelled – could these complications have been spotted if people were still being seen?

Long-standing problems

By no means all of the feedback from respondents was novel: problems such as poor communication leaving relatives with inaccurate views of a person's condition, the loss of valuables in hospital or problems associated with the discharge process were all among the sorts of problems that could mark a bad end of life experience before the coronavirus period.

Hospital lost personal valuable effects.

Due to COVID they were not admitted to hospital soon enough and their infection was left to take hold, ending up with an emergency admission due to sepsis – they had no chance, but if they had been admitted seven days earlier things may well have been different. Paramedics were reluctant to take them into hospital due to the virus.

The pre-discharge care was poor, no consultation with me as the main carer by hospital staff meant little time to prepare. The social care assistance I received at home assisted me greatly in providing care for the cared-for person at home. The carers were amazing.

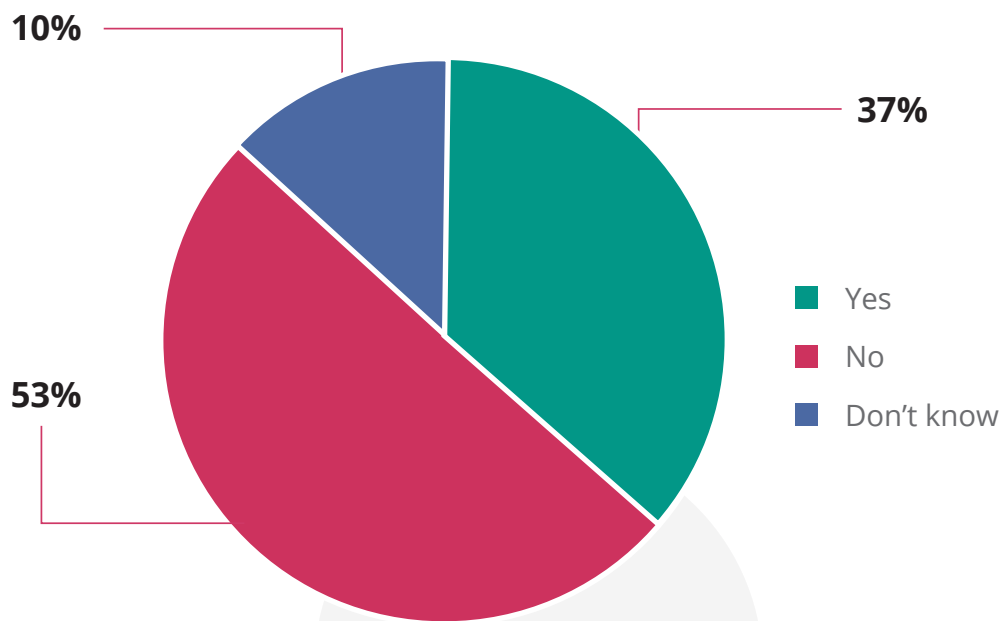
Overall experience of support and services during the pandemic

Measuring patient experience

We asked respondents whether they felt their health and care needs had been supported overall during the pandemic. Over half told us they did not.



Figure 14: % responses to the question ‘Do you feel your health and care needs have been supported overall during the pandemic?’ (number of respondents: 726).



We also asked some further questions about patients’ experience of support and care overall, either for pre-existing conditions or for cases of COVID-19. We did this by inviting respondents to tell us whether they agreed or disagreed with the following statements in relation to their care:

- I feel listened to
- I have been treated with respect
- I have been able to access the services I need
- I have been able to access the right information to care for myself
- I have been supported emotionally
- I have had the right support to make me feel safe and address any fears
- I have been able to take part in cultural and/or faith-based activities
- I have been able to stay in touch with friends and family
- My care has been well co-ordinated
- I have not had to wait too long for health and care services.

The chart on the following page shows how people responded in full.

From this chart we can see that three quarters of people (of a total of 710) agreed all or most of the time that they were able to stay in touch with their friends and family. 59% (of 653) agreed all or most of the time that they had been treated with respect. Almost half (49% of 693) said they agreed most or all of the time that they had been able to access the right information to help them care for themselves.

Some other results were more concerning. Just over half (51% of 610) disagreed most or all of the time that they had been supported emotionally. Half (of 386) said they hadn’t been able to take part in cultural or faith-based activities.

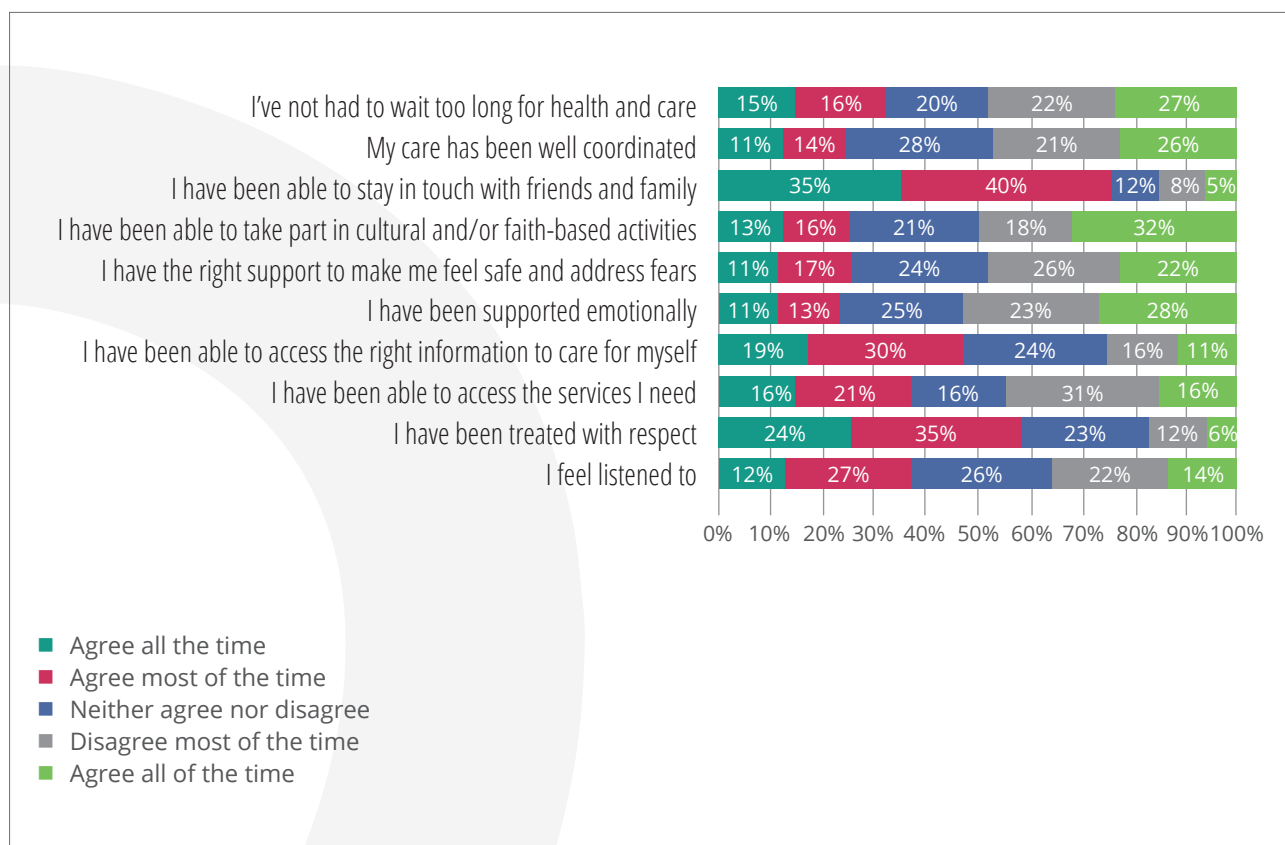
49% (of 618) disagreed all or most of the time that they had not had to wait too long for health and care services, 48% (of 653) disagreed that they had had the right support to make them feel safe and address any fears, and 47% (of 563) said that their care had not been well coordinated, with only a quarter agreeing all or most of the time that it had been. 47% (of 695) disagreed all or most of the time that they had been able to access the services they needed. Respondents were fairly evenly split between those who agreed they felt listened to, and those who disagreed (of a total of 650).

Even where overall results showed a good patient experience, there were significant minorities who did not report the same. 18% disagreed most or all of the time that they had been treated with respect, and 27% disagreed that they had been able to access the right information to help them care for themselves.

Some issues with access to services are, perhaps, understandable given the priority given to COVID-19 treatment during this crisis. However, patient voice and patient rights cannot be suspended even at these times. All patients must be treated with respect, feel as safe as possible, be listened to and be able to engage in the cultural and faith-based practices that matter to them.

As has already been stated, mental wellbeing at a time of heightened anxiety and isolation must be a priority, as must continuation of services for mental ill health. The results below suggest that this is not the case, and that people are not getting the emotional support they need.

Figure 15: % responses to the question ‘Thinking about your care and support during this pandemic, both in terms of any pre-existing condition(s) and COVID-19, to what extent do you agree with the following statements?’ (number of respondents varied)



Experience in daily life

As before, we asked respondents to what extent they agree or disagree with a series of statements about how life may have changed while living under lockdown, or as it begins to be lifted, in order to capture patients' and others' experience of daily life outside of healthcare settings. The statements were:

- I feel anxious or worried about catching COVID-19 myself
- I feel anxious or worried about others catching COVID-19
- I feel more anxious or worried in general
- I am finding it easier to access leisure activities
- I am finding it easier to do my job
- I am finding it easier to go shopping for the things I need
- I am finding it easier to stay in touch with friends and family
- I have struggled to keep to a routine in the way I would like to
- I have found it difficult to motivate myself
- I have found it hard not being able to travel
- I have struggled to find my own space at home
- I have felt more lonely during this period.

The chart on the following page shows these results in full. Our respondents were not, on the whole, struggling to find their own space in their homes. Just under a quarter of respondents to this question (662 in total) did agree or strongly agree, however, so it is still an issue for a significant minority. 54% (of 729) said they either agreed that it was easier to stay in touch with friends and family or that there had been no change. However, 35% still disagreed or strongly disagreed.

Other results brought further cause for concern. Half of people (from a total of 729) agreed or strongly agreed that they felt more lonely during this period; 69% agreed they had found it hard not being able to travel; 50% said they struggled to keep a routine; and just over half said they found it difficult to motivate themselves. 75% disagreed that they found shopping easier now, 53% were finding it harder to do their job, and 73% were finding it harder to access leisure activities. 71% agreed they felt anxious about catching COVID-19 themselves, while 82% worried about others catching the virus. 61% told us they felt more anxious or worried in general.

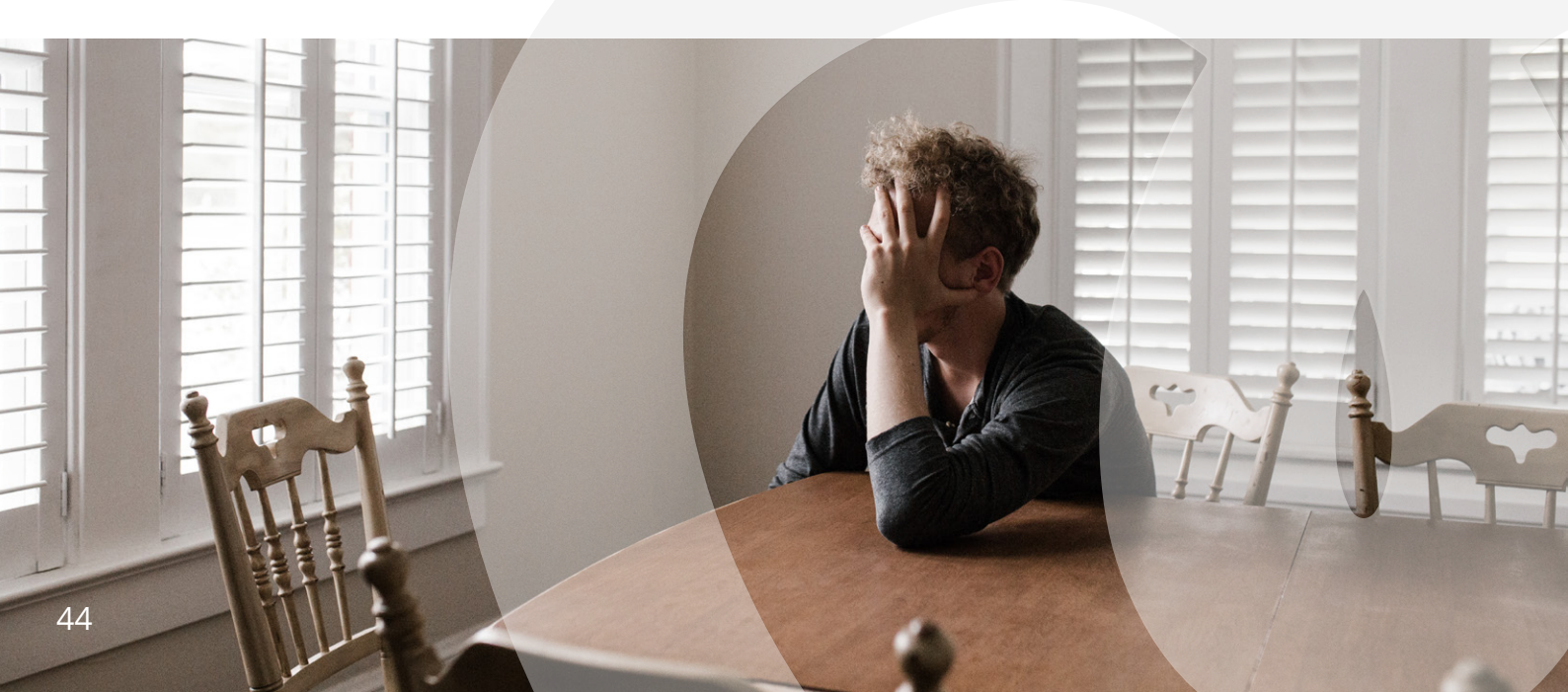
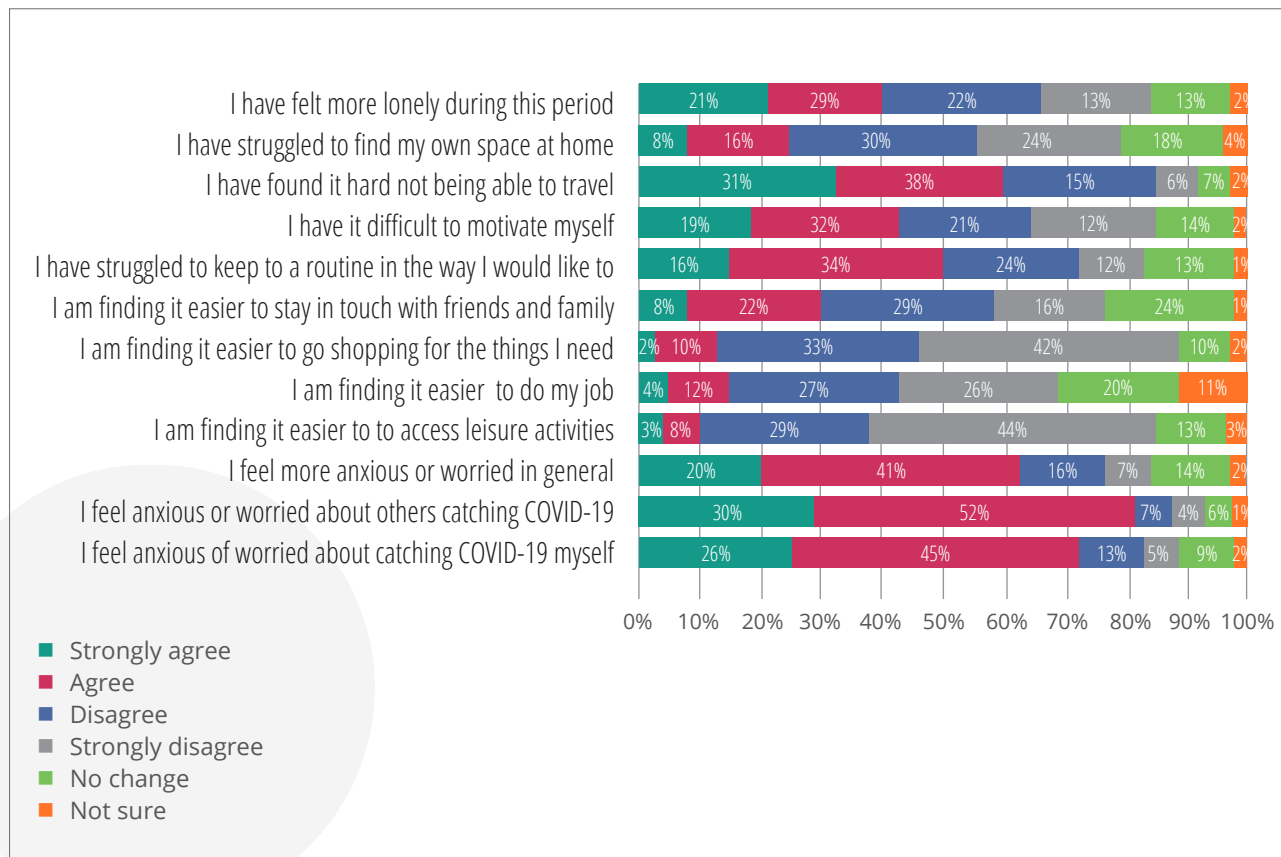


Figure 16: % responses to the question ‘To what extent do you agree or disagree with the statements below about the different ways daily life might have changed for you under lockdown?’ (number of respondents varied)



Other experiences

We gave respondents the opportunity to tell us anything else about their experiences of lockdown and of health and care services. There were a combined 861 comments across two questions in this final section, covering positive and negative aspects of health, care and experience of daily life.

Good experiences of care from services, friends and family

175 comments mentioned good experiences across the two questions, with 100 relating to health and care services and 75 to the wider experience of the pandemic.

As someone with a long-standing health condition, I appreciate how well I have been treated by so many medical professionals and by my family members. So given the seriousness of this insidious disease, I have little time than to be extremely grateful to those who still care about me and others like me.

GP service surreal but helpful when asked. One planned hospital visit was strange: no crowded waiting room, but reception, nurse and doctors all had more time for me as a patient in this unhurried atmosphere.

I think frontline services are wonderful and as a country we need to start appreciating charity orgs like Imago as the NHS would crumble without charities' support.

I think that the services I've received were wonderful and much better than normal, and I see this route as a way forward for better healthcare where 'hands on' examination isn't needed!

Impressed by the adaptability of GP surgery, although there might possibly have been a little bit more communication.

The services I access have responded really well, adapting protocols to keep me safe when I visit for treatment and to minimise my hospital visits. I have received support by email if needed.

Very good support from pharmacies.

However, some respondents noted a more mixed experience as they moved between different services, or at different stages of their treatment.

Hospital support as I concluded my cancer treatment at the start of the lockdown has been excellent and continues to be very supportive via outpatient services when required. Email and telephone access channels open as required. I worry for others who were in the early stages of diagnosis or treatment and how this would have affected their treatment and prognosis.

Home therapy nurse wonderful, very caring. I have lost confidence in the team that 'cares' for me most at the hospital.

I have had excellent nursing and medical care during two hospital admissions but have also observed others receiving poorer care and less respect.

My normal hospital Addenbrookes is first class. The one in Carlisle is awful. I realised I needed to isolate as much as possible to keep out of it.

My partner was taken ill, and despite COVID he has received excellent care from our local hospital and various teams of workers in the community. Confusing at times, rather than a well oiled machine it has been more like a rusted joint requiring TLC.

Isolation and lack of support

Isolation, loneliness and resulting fear or mental ill health have been key themes throughout this survey, and many respondents noted it here too. 93 comments (out of 446) in responses to the question about experiences of lockdown related to isolation and loneliness. 101 comments across both questions related to friends and family members; many of these were about the impact and anxiety of being separated from them, although a small number also noted the pressure of spending much more time in confined spaces with family.



Worried about single family members living alone, not seeing anyone.

The worst thing is missing being able to spend time and cuddle my little twin granddaughters.

The thing I miss most is contact with family and friends. I've managed so far but don't know how long I can continue to sustain it. I live with one small poodle, good company for someone who lives alone at the best of times but she's especially precious to me at the moment.

Not being able to see my friends who normally offer me emotional support. Being kept indoors with whole of family, causes friction and high anxiety.

My main mental concerns have been because I have not been able to visit my wife in a nursing home since 13th March and although government guidance allows for such visits now the homes themselves are mainly not following the guidance – they are continuing to stop visits.

My daughter has been unable to visit me, the nursing home imposed lockdown two weeks before the government lockdown. The only people I see are carers, they are extremely worried, and many are too scared to come to the nursing home – so we have lots of agency carers. They are not tested and I am really scared for myself, the other residents and the permanent carers – our health is being put in danger by this. The manager of the home does nothing to support the carers or myself as a resident. She never talks to me or the other residents: she only communicate with our relatives, I find this insulting – particularly as I'm paying £5000 a month to be in this nursing home.

I have lost close friends due to not being able to meet and their fear of contact because of their age or illness This has greatly distressed me and made a very difficult medical situation (new cancer diagnosis and treatment) much worse.

As a very healthy 71 year old I have found it very hard to be stuck at home and to have no contact with my grandchildren. I was widowed 18 months ago and this crisis has made me very aware that I live alone now in a way that I didn't feel before as I was active and travelled about quite a lot.

Despite many reports of good experiences, many others also told us about bad ones. While none are acceptable, some of these demonstrate exceptionally poor support.

As an unpaid carer, trying to look after two people who really don't get what lockdown means and what we have to do to stay safe, I am finding the stress levels grow daily. Trying to keep others happy and feeling safe is emotionally draining and there is no release valve.

All my long term care has been cancelled and not re-arranged. I feel unsupported and not able to access the care I need.

As a carer it is difficult not having a break.

The [paid] carers don't have enough PPE. The manager is also taking COVID positive people into the home, I am really scared because the room opposite me has just

become vacant because a resident died. I am so scared of catching COVID-19 from this person, as the carers don't have enough PPE, too many agency staff, and hygiene standards are not what they should be anyway. My hands are never washed and I don't have access to sanitiser, although I'm paralysed on my left side the carers never put this on my hands despite me and my daughter asking for this to be done regularly. The home don't have enough stock of sanitiser.

I was locked in my bedroom for the first two weeks as my lift stopped working. The carers then had the brainwave to bring my mattress from my bed downstairs to the lounge and with the cushions from the settees raise it up so I could get on it, now I am able to get a shower and see the garden, and watch TV - my only companion during the lockdown. Upstairs the carers could only give me washes and there was no TV; I was slowly getting angrier as the days progressed, now downstairs I am able to do some of my crafts and am so much happier.

Healthcare services during the pandemic have been appalling except for those in ICU in hospital. Older people have been sacrificed and their care has been non-existent. The situation in the nursing homes was inhumane. GPs appear to have made themselves superfluous to needs and the service needs to be rethought.

No dentists open. Chemists working a month behind. GPs expecting everyone to econsult. Dermatologists refusing to look at skin conditions. All periodical medical testing has been stopped. Hospitals appointments all cancelled. Hospital visiting of the sick and dying stopped. Cancer treatments stopped, including MRI Scans.

The NHS has let ordinary people down. It has been near impossible to communicate with doctors' surgeries. We have made to feel unwelcome when wanting to find out about our normal health needs. It us worrying to think that online consultations are going to be the norm. This is ludicrous. It appears that the NHS has told the hospitals not to do routine cancelled surgery, etc. on those who are 70 and over. This is not only ageist, it is unethical in this day and age. It is also extremely worrying that people in care homes are not being allowed to have visitors. This is inhumane.



Conclusion

The results of this survey have provided a picture of what it has been like, so far, to access services, healthcare and support during the COVID-19 pandemic.

It has provided some examples of good experiences; friends, family members and neighbours supporting one another, voluntary and mutual aid groups providing vital help, and caring, helpful health and care professionals. Government initiatives such as food parcels and priority lists have worked for some. Some people have also told us about good, compassionate care at the end of their loved ones' lives.

However, elsewhere this report offers bleak reading. During the period in which responses to our survey were being submitted, communities turned out for a weekly 'clap for carers', and 'thank you NHS' banners, flags and stickers appeared on buildings all over the country. For the NHS, it might have seemed like an affirming national celebration, at a time when as an organisation it faced enormous pressures.

But that is not a picture that emerges from this report: those sentiments are largely absent from what patients told us about how they experienced this period. Based on this evidence and much more besides, it increasingly appears that we may have to confront an uncomfortable picture of weak institutional responses to the pandemic at many levels, not just (or even mainly) the NHS.

Overall, we heard about major disruptions to the relationships between the patients and the health and care services they rely on. People told us of their frustrations in being cut off from the support that had previously been essential to their daily lives. Many have had treatments and other support postponed or cancelled; in some cases this may be understandable, but a lack of information about how services will restart has left people in the dark. Regular support that is essential for quality of life has also disappeared for some. There is a risk during crisis situations that the voice and experience of patients, including their relationship with staff, gets lost in the need to get things done; there is some evidence from this survey that this has happened.

In my local hospital I noticed very few staff at all levels wore any visible indications of their name let alone their function. When you can see only the eyes of a person caring for you, can't hear their voices, it was most frightening.

Disabled people and people who are chronically ill have told us they have been left behind. While priority lists have helped some, those with conditions other than those on the government's 'clinically most vulnerable' list have been left with little access or support, despite the necessity of this to daily life. People have told us that services for mental ill health have become even more difficult to access under lockdown, and that they do not feel mental wellbeing has been a priority for government services. Many have been cut off from friends and family members, and some are extremely isolated as a result of the pandemic, without anyone checking in on their health and wellbeing.

This pandemic is not over, and it is likely that further crises will occur in the future, whether related to health or other issues. While it can be difficult to predict and plan for such occurrences there are, nevertheless, lessons that can be learned and principles that can be taken forward. There will be considerably more research released about the COVID-19 response over coming months and years; the lessons must be taken on board.

Based on the findings in this report, we propose the following principles for ensuring all patients, disabled people, carers and others are able to have the best possible experience:

- Recognise from the outset that the impact of the crisis will fall hardest on those who already face discrimination and inequality, including Black, Asian and other minority ethnic groups, disabled people, carers, women and gender minority populations and those living in areas of high deprivation, and that these inequalities will affect some people in combination
- Maintain the principles and values of patient choice, shared decision making and voice, so that services are shaped by patients, disabled people and others who most need them
- Ensure there are fully resourced services available to help people maintain people's mental wellbeing, to treat mental ill health, and to ensure that no one is left isolated
- Ensure carers get the support they need, including emotional support, to continue to care for their loved ones
- Provide clear, concise and timely communication, updated regularly, about the impact of the crisis on support and services, what is available in the interim, and when and how services may begin to restart
- Ensure access needs are respected and met, including providing materials in different formats and languages, including signing, descriptions, captioning and transcription for all official visual content, and that people are able to access support offline if they do not have access to the internet
- Maintain compassionate end-of-life and bereavement support services, with clear communication between staff, patients and others, and the opportunity to be with friends and family members unless totally impossible.



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