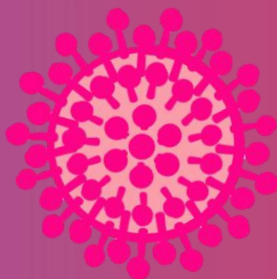




Knock-on effects of coronavirus on access to healthcare:

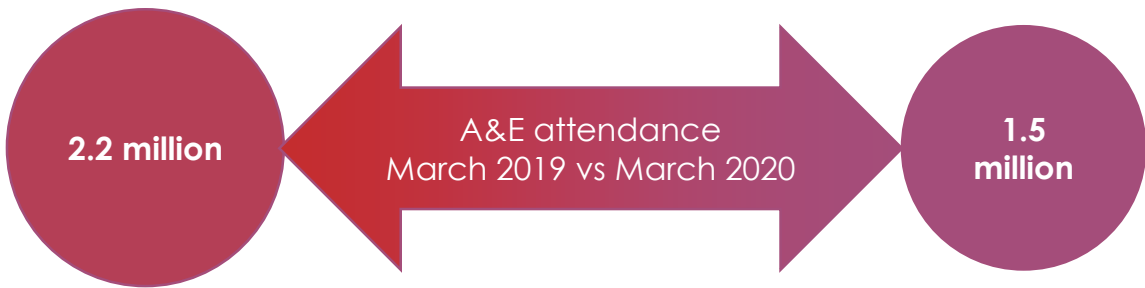
lived experience research



Impact of covid-19	Why lived experience	Why is care missed	Experiences of care	Recommendations
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The impact of covid-19: context for this research

Coronavirus has caused, to date, over 20,000 deaths in the UK alone. At the same time there is increasing evidence that non-coronavirus deaths are also above average for the time of year, suggesting a non-direct impact of the virus on the UK's health. Aside from the tragic loss of life we know that coronavirus, and measures to reduce its spread, is impacting on the health and wellbeing of millions of people in the UK, and changing the way they access care and support. National level data tells us that attendance at A&E has reduced significantly¹, 90% of GP appointments are done by phone or video², and reported diagnosis of conditions such as cancer have dramatically declined³.



There are a range of factors which contribute to this change in how people access healthcare. Some services cannot be delivered safely, because of the restrictions of lockdown, others because staff and resources have been reallocated. We also know that people are changing their behaviour, some people are nervous about accessing healthcare settings where the risk of infection with coronavirus is higher. Others feel that their problems are not important enough to merit treatment when there are other, more urgent, priorities for the NHS. Messaging from Government, scientists and the media have been clear about the need to Stay Home, Stay Safe, Save Lives and Protect the NHS. This messaging has shifted in recent days to 'Help us to help you', encouraging people to see care when necessary.



This research aims to add to the evidence base around the knock-on effects of coronavirus for health and wellbeing in the UK by understanding the experiences of people whose care has been disrupted.

1. <https://www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/ae-attendances-and-emergency-admissions-2019-20/>
 2. <https://www.bbc.co.uk/news/uk-england-52216222>
 3. <https://scienceblog.cancerresearchuk.org/2020/04/21/how-coronavirus-is-impacting-cancer-services-in-the-uk/>

Why a lived experience approach?

We create the world we live in. To understand our world we must learn from our experience of it. To do so we must be ready to hear from people about their lives and what matters to them. Through understanding lived experience we can explore choices and options and work together now to create the foundations for a healthy future.

“One cannot separate the health of the individual from the health of the family, the community, the society, and the world”
The Gesundheit Institute

We also know that the experience of telling our own stories can have a powerful effect, enabling us to process our experiences and make meaning from them, something several of our interview participants commented on was the value of telling a stranger about what had happened to them, without the social pressure to ‘make the best’ of things in the face of the pandemic. There is a lesson here for how we respond to the inevitable consequences of the coronavirus.

This project

Twelve people were recruited by professional market research agency Plus Four, to include a range of age, gender and ethnicity. They were interviewed in the week beginning 20th April, just after the second 3-week lockdown period was announced in the UK. Each participant had experienced disruption to their healthcare within the first three weeks of the lockdown, either because care was not available or because they had not sought it out. In most cases when we spoke to people it was a mix of the two, with individual stories revealing complex interactions with the health and care service.

Each interview was carried out over the telephone by an experienced social researcher and took between 30 and 45 minutes. Participants were assured that all data would be anonymous, that participation was voluntary, and that they would be provided with a link to the report when published so they could follow what happened to their input. The interviews focused on the experience of the individual, with the researcher inviting them to tell their story and reflect on the impact on them and those around them.

Life in lockdown

We started each interview by asking people to talk through their routines during the lockdown, and how they had changed. This helped to situate the interview in actions and experiences, but also gave us insight into how lockdown was affecting the people we spoke to:

“People are worse off, but it doesn't stop you feeling sad and down. I have felt very lonely since all of this happened.”

What we heard is consistent with the findings of the Mental Health Foundation¹ and others, the physical distancing measures are causing emotional distress for many people, and can make poor living situations much worse.

1. <https://www.mentalhealth.org.uk/news/almost-quarter-adults-living-under-lockdown-uk-have-felt-loneliness>

Asthma

Pregnancy

Obsessive
Compulsive
Disorder

Anxiety

Diabetes

Keratoconus

Cardio-
myopathy

Epilepsy

Graves
Disease

Depression

IVF
TreatmentUlcerative
Colitis

Cataracts

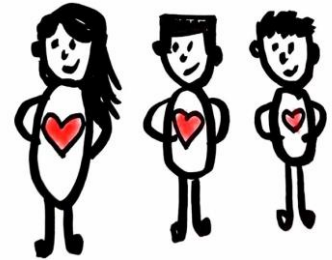
Complex
Regional
Pain
SyndromeEar
Infection

Stroke

Among the 12 people we interviewed we discussed a wide range of physical and mental health conditions, from chronic to acute.

Findings: are people avoiding or missing out on care?

Everyone understood and fully accepted why treatments had been cancelled or postponed or changed. There was no question for anyone that these are extreme circumstances and NHS staff are doing their best. This was true both for those whose care was cancelled, and those who avoided seeking it.



Choosing not to seek care: responsibility often trumps fear

For the people we spoke to, the primary reason for delaying care was to avoid adding to the burden on the NHS. Fear of contracting coronavirus was a significant, but usually secondary factor. Where people are anxious about attending a hospital they often talked about an existing dislike or fear of treatment being made worse.

People use a range of narratives to explain not seeking care, some talked about the NHS, or individual staff, being overwhelmed. Others talked about fairness, and the need to prioritise resources on those who are 'worse off'. They saw coping with their condition on their own as part of the collective effort to fight coronavirus.

"I didn't want to take time away from people who might need help just because I've got a headache... I rang the maternity unit, I felt like I was wasting their time."

"You don't want to ring the doctors because they've got so much to deal with. I just need to get through this time the same as everyone else [on your own], but that in and of itself is quite stressful."

For some participants this decision was a source of anxiety, especially where it wasn't clear what the alternative or follow up would be when they cancelled an appointment. Some participants were afraid that by following guidance to self-isolate and avoid risk, they would be discharged from services, or 'sent to the back of the queue'. This fear of being penalised for not following a set of inconsistent and often unknown rules left people feeling that they had little control, as one participant said "you're sort of at their mercy". Waiting times were a related concern, where people had waited months for an appointment they were afraid that any action on their part would mean a return to square one.

But fear does play a part

We heard some powerful stories from people whose concern about the risks to their own, and others, from contracting coronavirus were changing their behaviour significantly. One pregnant participant told us that part of her concern about asking for medical help was fear for her baby.

"I was anxious about them trying to get the baby out early, I can't keep it safe for those extra weeks whilst all this is going on. The longer I can hang on to the baby the safer it will be."

For those who chose not to seek care to reduce the risk of coronavirus existing conditions were often a concern. Others were influenced by a personal connection with coronavirus: several people reported that they knew someone who had contracted the virus while in hospital for another condition, a powerful anecdote.

What about care that's unavailable?

It's the not knowing that's the problem

For people whose care was cancelled or postponed we found that there was, again, huge understanding of the reasons behind the change, and a great deal of patience expressed. But it was also clear that the impact could be profound when treatment is delayed, changed or cancelled without a clear pathway forward.

"Absolutely soul destroying. It's been absolutely heart breaking. The situation is bad enough, but then well you feel abandoned by the hospital on top of everything else."

For some people the appointment that had been cancelled had been long awaited, for example a referral to a psychiatrist for someone with long term mental health issues. For these people the feeling of having built up to a potential resolution and having it snatched away was a source of disappointment, and where no timetable was available for it to be rescheduled, hopelessness.

"It's not their fault that this has happened. But it's taken me ages to get my head straight that I needed to get to this appointment. So it's put me back to square one."

For other people whose treatment was rescheduled to a different date and this was made clear early on, it felt reassuring or was a relief.

"In hindsight I was pleased. I was worried about going in. The locking down had started and everyone was suddenly not allowed to go out. Going into hospital on your own was worrying."

Concern about managing risks

One of the most common concerns from people whose care had been delayed or cancelled was how they could manage the risks to their health. This ranged from concerns about post-operative infections to uncertainty about whether to delay planned changes to medication. Participants tended to assume that the medical staff involved were acting in their best interests, but were often unsure whether they should be worried, or what to look out for and when to ask for help.

For one person we spoke to, the cancellation letter reassured them that their case had been reviewed by a consultant and could be safely postponed – they wrote to the hospital to follow up and were happy to receive a phone call to discuss their concerns. In contrast another person we spoke to had their appointment cancelled by text message. **Once again, clear, personal communication was the crucial factor.**



Experiences of care

The best care was the most human care

Many of the people we spoke to were complimentary about the care they had received, and grateful to the staff who delivered it. Positive experiences were often talked about as compassionate, considerate and human. People appreciated being informed at each step of the process, having the time to ask questions and where staff acknowledged the unique situation we are all in.

The same principles applied when recounting experiences of telephone or video appointments, starting with the call happening at the specified time to reduce waiting and associated anxiety. Several people reported confusion about whether appointments would go ahead over the phone or not, leading to appointments that they weren't prepared for, and so didn't get the most from. This was particularly true for patients with long term conditions, and pregnant patients, where services like designated nurses or midwives formed a cornerstone of their care:



"On the phone [with the nurse] it was very different. Normally, I tell her things you don't tell anyone else... But the phone call was a bit more matter of fact...I'm sure if I had brought it up, she would've spent the time, but I'm holding back. I wasn't prepared."

"Communication is very functional and like we have bigger fish to fry."

Restrictions on friends and family accompanying the patient were understood, but also caused concern. One particular example is pregnancy, the people we spoke to highlighted worries about being alone without the support of a partner. This was linked with a concern that disruption to the pre-natal process would mean going into birth unprepared, alone and in a medical situation where the goodwill of the staff alone wouldn't be enough to overcome resource shortages and allow them to support new mothers emotionally.

"I had felt like previous appointments a few weeks before they were really caring, now they just want you to have the baby to get you home again."



Person-centred care

Looking across the experiences of all the people we spoke to, we see a pattern of more positive experiences where people are contacting services that they already have a relationship with, rather than new services. Making best use of those contacts to address not just the issue at hand, but the person as a whole, can contribute significantly to a feeling of support.

In the hospital

Where people had eventually visited the hospital or another medical setting their experiences were often positive with elements of the surreal:

"They were lovely. They wore masks, it was very bizarre. A different reality"

Several people expressed concerns about particular hospitals, based on their previous experiences or what they had heard, suggesting that perceptions play a big part in how confident people are that coronavirus measures will be effective.

"If it is in hospital 'A' I would be phoning up to cancel it. I would have to go through the main doors. I am not ready for that. If it was hospital 'B', I would go."

A key concern for people who accepted that they would need to visit a hospital during lockdown was the practicalities. How would they get there? Should they wear a face mask or gloves? Would they be able to go straight to their appointment and maintain physical distancing? Waiting rooms were a particular area of concern, several people with regular appointments pointed out that the process often involved three or four waiting rooms, each with a different reception desk, other patients and risks.



Experiences of care: the practicalities

The most positive experiences reported were those where care was human, with staff acknowledging the situation, making it a shared experience. Clarity about the precautions to be taken were crucial – one participant described two experiences when she accompanied her father, who has hearing loss, to a follow up appointment that involved an MRI and a CAT scan. In one case the staff member explained what would happen in advance, the precautions that would need to be observed in terms of distancing, checked in that these had been understood by patient and carer, and then proceeded. In the other case there were mixed messages between the receptionist and technician about where she should stand for physical distancing, instructions given brusquely to her only with no check in with her father, and no explanation.

“The nurse was rude, I felt tearful for dad because he looked so little and vulnerable. Felt as though I was being told off.”

Remote care and technology: a mixed bag

Of the 12 people we spoke to all had some experience of remote care, either by telephone, video or through an app. These experiences ranged from those who were familiar with using technology in other aspects of their life and happy to adapt to something they saw as efficient, to those who struggled with the change.

“I phoned my GP, I am a technophobe, I phoned them up. They told me to download the app. I said sorry, what’s an app?? I need a prescription. She said she would help me as a one-off but I did get the medication.”

Apps

The use of apps was highly variable, sometimes within one case. For example one pregnant participant had been recommended three separate apps to access different information, but still managed to miss an appointment until the day after when a letter arrived in the post to say it had been cancelled. Where staff are uncertain about how the technology works this adds to the confusion. In many cases telephone calls were strongly preferred, because they allow for questions, which is both practically and emotionally valued.



Video and telephone appointments

Again, there were mixed views from the people we spoke to about how useful remote appointments are. For some participants it added little to no benefit over a telephone call, and in some cases neither approach was able to make the assessment their condition needed. In contrast one participant who had post-stroke physio via video call found it invaluable. The therapist could show the exercises, watch them be carried out, and comment. However the main reason this experience was so positive was actually the approach of the staff member, who explained everything that has happened, asked for consent at each stage and was 'human'.



In contrast, another carer reported the experience of someone with a learning disability of a telephone appointment. The appointment wasn't scheduled for a particular time so the carer wasn't able to be there, and it wasn't clear that a shared understanding had been reached about changes to medication: the carer googled the tablets afterwards to find out what they were for.

"Afterwards he knew that his tablets are being changed but not why. When he's on his own he downplays things, either because he doesn't understand or doesn't want to make a fuss."

The answerphone

One of the most frequently mentioned remote communication tools was the answerphone. Everyone we spoke to had an experience of automated messages, either before the phone rings, or when it rings out. These messages have a strong influence on both people's behaviour and their experience of care. This varied from messages telling people to go online unless their condition was urgent, which put them off asking for help, to confusion as answerphone messages were out of date. These messages are the first point of contact for many people, so their importance can't be underestimated.

Recommendations and next steps

1. Setting expectations about the right level of demand for the NHS

Our research, and the population level data, tells us that people are avoiding or being prevented from accessing the care that they normally would. Some of this disruption will be harmful and have negative long term consequences for physical and emotional wellbeing. On the other hand we also find that some interactions work well remotely, and some appointments may not be necessary. At the individual level people need enough information to make confident decisions for themselves about their care. At a societal level a meaningful public conversation is essential to balance the level of demand the NHS can meet with the expectations of the citizens.

2. Understanding the consequences of messaging

Messaging from the NHS has a significant impact both on behaviour and on people's experience of care, from the macro level of advertising campaigns to the micro level of answerphone messages which set the tone for an experience. Our research shows that some people are hearing that the NHS is on hold, and not asking for help is the best way they can contribute. Not everyone has the tools to interpret these messages in a way that keeps them safe and well, and we need to understand this inequality and how it can lead to actions that are ultimately harmful.

3. Focus on person-centred care, clear communications and managing uncertainty

All our participants gave us the same message about what makes a positive care experience, and it's not a surprise. In a time of uncertainty people just want to know what to expect and when, to be treated as an individual, and have space to be heard. This message may not be new, but understanding how to achieve this in a time of resource constraints is more of a challenge.

4. Health is more than a set of symptoms, and care is more than a series of interventions

Some of the most distressing accounts we heard were from people with existing mental health conditions, and pregnant women. For these groups continuity of care was crucial to their wellbeing, and was the aspect most disrupted by covid-19. Their care didn't feel unsafe because the infrastructure was in place to manage crisis, but it didn't meet their longer term health needs.

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