Citizen Experiences of Accessing Healthcare during the Covid-19 Crisis

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& Healthwatch Surrey

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Executive Summary

The Covid-19 crisis and the associated government enforced lockdown and social distancing measures have drastically changed the way the general public have lived their lives during the pandemic. This project aimed to understand the effects of these changes on how citizens have been able to access the healthcare that they need, and how their help-seeking behaviours may have been influenced by news and government guidelines surrounding Covid-19. In addition, the project investigated how citizens' lifestyles may have changed while adapting to the crisis and what effect this may have had on both mental and physical health. Finally, this project aimed to uncover what news sources citizens accessed and gaps they may have noticed, which would benefit from being addressed for a potential future pandemic.

Regarding accessing healthcare and changes in help-seeking behaviours, the main findings are as follows:

- Accessing medication for long-term health conditions has mostly been straightforward, especially when support had been offered by family, friends, neighbours and volunteers
- Non-urgent appointments that needed to be postponed or rescheduled were largely not automatically rescheduled, leaving it up to the patient to follow up
- In-person appointments that took place during the crisis were carried out to a high standard, with appropriate safety measures (such as PPE) in place
- Citizens responded well to a more digital approach to accessing healthcare (phone, video, app consultations), with many finding it more convenient and preferable to accessing in-person care. Although there are flaws that could be addressed to make this run smoother, it was largely recommended that digital options be offered as standard going forward
- Participants have delayed seeking help during the crisis, mainly because they have wanted to avoid going to healthcare settings where they may contract the virus; worrying that the NHS is under too much strain already and not wanting to exacerbate that, and a shift in mindset which left citizens no longer seeking help for minor ailments which they usually would seek medical attention for
- Many citizens have left health queries unaddressed which have escalated their conditions. This may cause a spike in urgent care need when services resume as usual. Another reason that there may be a higher demand when services resume is due to some gaps in services, which have left some patients without the appropriate support, causing them to deteriorate during this time

Additionally, citizens reported wide-ranging reactions to the lifestyle changes caused by lockdown restrictions. The main findings are as follows:

- Many have reported enjoying the some of the consequences of the lockdown: no longer having to commute, more time spent with family and less obligatory socialising
- Others found this lack of routine difficult to cope with, as well as feeling trapped indoors as public spaces and non-essential services had been closed
- Lockdown revealed many easily-accessible, free online resources to aid keeping fit and healthy. Many participants reported relying more on these resources for advice and inspiration, especially with gyms and sports centres closed

- Keeping in touch with loved ones has been largely digital due to social distancing measures. Those who have struggled to use digital means for various reasons (such as age, no access to technology, struggling to navigate the technology) have relied on phone calls, which they found to be a suitable substitute
- Participants reported worrying for the safety of others during this time. Specifically, people conveyed concerns for the victims of the reported increase in domestic abuse; charities struggling to meet their fundraising targets and healthcare professionals working without sufficient PPE, as reported in the media. Participants mentioned also worrying about those who are put at increased risk as a result of others having ignored social distancing rules
- There has been much more focus on mental health since lockdown started. This emphasis on mental health has reportedly come from the workplace, on social media and community groups. Participants explained that acknowledging mental health more has been a welcome change and many believed it should become standard practice to talk more about mental health
- Lockdown restrictions have driven a sense of community which people have enjoyed, taken pride in and relied on to create a sense of hope during lockdown

Regarding the government response to the crisis, the main findings are as follows:

- Local resources (the Local Council guidance, letters from GPs) were considered helpful and welcome
- The NHS website was considered not detailed enough and could have benefitted from a live chat feature, a FAQ section or signposting to further resources, such as 111
- The criteria detailed to meet the threshold for the shielding lists may have left a target group of people with chronic long-term conditions without the appropriate advice or support, as only those with hollow organ transplant, currently undoing cancer treatment, currently using immune-lowering drugs like chemotherapy or those who have a respiratory disease had been considered
- Citizens felt that lockdown happened too late and that the response should have been quicker and now are worrying that the easing is happening too quickly
- Citizens have acknowledged that the learnings from this situation should contribute to helping leaders make meaningful decisions about how health, care and support are provided to people in a more effective way for any potential future crisis

This project examined the implications that lockdown had on the Surrey Heartlands population, showing which aspects of life were made easier, more challenging, which services worked well and where there were gaps. Based on participant feedback, some key recommendations included, but are not limited to:

- Create a clearer and more straightforward process that will automatically rearrange any appointments that need to be rescheduled or postponed, without putting the onus on the patient
- Signpost and raise awareness about other NHS resources and services such as 111, LIVI and the NHS website and continue to encourage the public to explore these first for any non-urgent medical matter, as a rule of thumb. This could also help to avoid a build-up of issues for when services resume

- Offer patients alternatives to in-person appointments as standard procedure and allow digital appointments where physical examinations are not necessary
- Risk assess patients to understand what kind of additional support they may need. Put safeguards in place and provide them with coping mechanisms to ensure they are not left without access to any care
- Support third sector organisations to address some gaps in healthcare services where appropriate, which may alleviate demand and pressure on those services
- Allow local GPs to recommend which patients should be shielded on a case-by-case basis rather than apply generic criteria which may leave someone vulnerable and needing additional support
- Acknowledge the inextricable link between mental and physical health and continue to emphasise the role of mental health in leading a healthy lifestyle
- Create more localised communications campaigns so populations are more aware of news and statistics that are relevant to them
- Proactively plan to ensure strategies and procedures are in place to ensure a reduced, but effective, service is able to run during periods of emergency

Background and Aims

The Covid-19 crisis has had an effect on the lives everyone in the UK, particularly when it comes to accessing healthcare services. With the NHS under greater pressure than ever before and in order to minimise risk of contracting the virus, multiple services have had to be delivered via different means, such as phone and online consultations, while others have had to be discontinued indefinitely.

In addition to behaviours changing around accessing healthcare, lockdown restrictions have impacted the everyday routines of the population due to social distancing measures: from managing a work-life balance from home, to doing the weekly shop and exercising. Social distancing has made it challenging to take part in community activities, to see friends and relatives and to maintain a healthy and balanced life during lockdown. All of these changes may have implications on the mental and physical health of the population.

The aim of this project is to gain insight on how lockdown has affected the way citizens usually access healthcare services. There has been evidence of an increase in non-Covid-19 related deaths and this project aims to gain insight on reasons for this. Specifically, the project investigates whether the public has delayed seeking help due to fear of going into a healthcare setting or perceiving their condition not to be severe enough.

Additionally, the project aims to identify whether any healthcare problems not dealt with during this time will become urgent in the near future; whether essential services were postponed or cancelled; whether participants still obtained the support they need; what has worked well and where any gaps may have been. Moreover, the project aims to investigate areas of healthcare that could be addressed and improved in case there would be a second peak or a future pandemic.

This project also aims to understand how exactly the restrictions imposed by lockdown have affected the general population's health and wellbeing; what aspects have become more challenging, and what aspects have become easier.

Lastly, the project aims to identify how the public accessed information regarding Covid-19 and their experiences using these sources; whether they were thorough, easy accessible, widely known and where any gaps may have been.

Methodology and Approach

The data collection method was semi-structured interviews. This method was chosen as it allows themes to be explored in-depth while also allowing for participants to raise new themes and ideas. Interviews were conducted remotely or in a socially distanced way in order to comply with government guidelines during Covid-19. Programs such as Zoom and Skype were used, as well as interviews conducted over the phone.

Recruitment was conducted by Citizen Ambassadors from Healthwatch Surrey, using convenience and snowball sampling methods. Specifically, participants reached out to their connections with third sector organisations, referrals from friends and by targeting relevant groups on social media.

Citizen Ambassadors conducted the fieldwork and summarised key findings. The summaries were collated, coded thematically and analysed using Computer Assisted Qualitative Data Analysis Software (NVivo) by a member of the Research and Insight Team in Surrey Heartlands Health and Care Partnership.

Workstreams and Participant Profiles

Five Citizen Ambassadors conducted a total of 24 interviews for their corresponding workstreams. The workstreams are as follows: Cancer, Prevention, Women and Children's, Mental Health and Digital.

Participant Type	Cancer	Digital	Mental Health	Prevention	Women and Children	Total
	5	5	6	3	5	24
BAME			1			1
Disability			3		1	4
Carer		1				1

Of the 24 participants:

- 1 identified as BAME
- 4 identified as having a disability
- 1 identified as a carer

Of the experiences spoken about, some participants spoke not only about their own experience, but also on behalf of that of their families. This included more experiences of people with disabilities and long-term health conditions, although these people have not necessarily been interviewed themselves.

Findings: Accessing Healthcare during the Crisis

The themes in this section correspond to questions participants were asked about their experiences in the accessing healthcare services they regularly would, how this may have changed during the crisis and the effects of changes on the participants.

Although each Citizen Ambassador was instructed to probe for issues related specifically to their workstream, due to the nature of the Covid-19 crisis, it was expected that participant accounts would intersect with themes related to Digital and Mental Health.

Finding 1: Varied Experience in Accessing Medication

During the Covid-19 crisis different aspects of accessing healthcare services have been affected. One of these has been accessing medication for ongoing long term health conditions. For some participants, this process had been negatively impacted. For example, some medications were in high demand, causing GP delays in prescribing them. While some repeat prescriptions, such as contraception, were reportedly easy to source, more specialised medications, for example for epilepsy, have been difficult to access as these are often supplied directly by the hospital a patient attends. For those who filled prescriptions in person, participants reported that social distancing measures caused long queues at pharmacies, making the process more difficult. However, they generally understood why these measures were necessary and agreed with them.

Others reported facing logistic issues in the newly adapted process of accessing medication. One participant reported that their GP surgery wouldn't allow online requests for children's prescriptions, although they did for adults. This led to them having to go to the pharmacy in order to obtain this necessary medication, despite the fact that they were shielding. In a similar vein, another participant reported that their GP surgery was reluctant to share information about their child's medication because the document authorising confidential information sharing was 10 years old. Although this was eventually solved, this revealed a gap in preparedness for an emergency situation such as Covid-19.

Other participants reported that they did not face any challenges in accessing medications as they only required off the shelf medications, which were easily obtained. For accessing repeat prescriptions, participants used a range of different services such as ordering them online and opting for different courier and delivery services, which eased the stress of having to collect in person and potentially expose themselves to the virus.

Some participants reported an improved experience with accessing medications than before the crisis, as they had received supplementary help from their community. For some, loved ones, neighbours or volunteers offered to collect and drop off medications for them. One participant reported that their doctor dropped off cancer medication on their way home, to ease the process for the patient.

Finding 2: Largely, Cancelled Appointments were not easily rescheduled

In order to stop the spread of the virus and redeploy staff to help with the Covid-19 response, many scheduled appointments for various health conditions had to be cancelled or postponed while lockdown restrictions were enforced. Of the appointments that participants reported had been rescheduled, these tended to be non-urgent appointments. For example, orthopaedic elective surgery or dental appointments which had been postponed to a point where risk of virus contraction would be considered lower.

Other specialist procedures due to take place such as cancer diagnostic tests or appointments designated to take place in London hospitals had also reportedly been rescheduled for this purpose. While the patients affected by this were understanding of why their appointments had been postponed, how they were informed of the appointment cancellation and the level of ease involved in rescheduling greatly affected whether they had a positive experience or not.

Appointments that weren't automatically rescheduled to a later date caused an unnecessary hurdle for patients, as it left the onus on them to follow up and ensure a new date was provided. One participant reported that a wrist scan had been postponed and in order to reschedule it, they had to rearrange via their GP, convoluting the process unnecessarily. Another participant reported that to reschedule the appointments in hospitals was challenging as the phone lines had been too busy. Additionally, admin staff were restricted from working onsite so there were fewer people available to answer queries, as well as minimal to no communication for some patients about changes to their appointments.

There was variance in how patient responses to automated messaging, or lack thereof, was handled. For example, one patient reported forgetting to respond to texts that prompted them to schedule a blood pressure test. However, after they didn't respond, there was no resulting follow up, leaving this unaddressed. Another patient reported not responding to an invite for a phone interview, which resulted in their GP threatening to close their file, despite ongoing, serious health issues. This caused emotional distress and a complaint to Patient Advice and Liaison Service (PALS).

Further, participants have reported that their rescheduled appointments could have been handled better. One participant reported that an urgent podiatry appointment was cancelled with no information provided regarding an alternate approach to treatment. This left the patient feeling despondent and disappointed, not aware of to how to proceed. Similarly, one patient undergoing cancer treatment reported that all subsequent check-ups had been postponed, causing them to feel uneasy and to experience anxiety about their prognosis. In addition, the clinic was shut and the patient received minimal contact in the time following their treatment, which could have been handled better. All in all, postponement of non-urgent appointments were met with patient understanding. However, the process used to reschedule appointments could have been more straightforward.

Finding 3: Satisfaction with Urgent In-Person Appointments Continuing

Appointments that were deemed sufficiently urgent or requiring an in-person examination have continued as usual during the Covid-19 crisis. One participant who took their daughter to the GP for unresolved pain explained that the GP conducted an examination in full PPE, in the GP surgery car park. This participant reported being greatly satisfied with this experience as they felt the same level of care had been provided by the GP, who was very thorough. They felt safe knowing precautions using PPE had been taken, as well as not having to go inside the building where they may have been at risk.

For most patients requiring a face to face appointment, at least some part of that process has now become digitalised. For example, one participant reported that their initial consultation took place over the phone and following this, a community nurse came to the house to take bloods when this was deemed necessary. This participant considered this approach successful and effective as it avoided any unnecessary exposure and still resulted in an efficient service, with blood test results arriving the next day.

Finding 4: Digital Alternatives have been effective and should continue

During the period of lockdown, as well as rescheduling and postponing appointments, multiple services have also been delivered via different digital means, such as phone and video consultations. By and large, the public response to accessing digital alternatives to healthcare has been positive.

Participants reported feeling satisfied about receiving phone and video appointments in lieu of in-person appointments. Overall, phone and video appointments were regarded as quicker and easier than in-person appointments as patients did not have to deal with travel and waiting times for the appointment. In addition, they circumvented the problem of visiting a medical centre and potentially unnecessarily exposing themselves to the virus.

Regarding quality of care provided during digital appointments, most participants reported feeling satisfied and did not consider the appointment to be any less effective than a face to face appointment. One participant following radiotherapy cancer treatment commented that her online appointment was conducted by a registrar, who had excellent knowledge and understanding of their cancer.

Treatments such as CAMHS appointments have also taken place online where possible, which one participant reported as working much better than physical appointments, owing to their son feeling more relaxed at home and being able to drop in and out and take breaks as needed. As this alternative has seemed to work much better for the participant's son, they would opt to continue with remote video consultations even after lockdown has ended.

Participants reinforced the opinion that lockdown has improved the service provision and many reported that phone and video methods were preferable to face to face appointments.

> ***"In many respects, the service is even better than it was before, with all the options like telephone or video appointments. I think the GPs are able to be more productive because they're not waiting for patients to arrive, or to walk slowly down corridors, and because they aren't having to do so much paperwork to do with routine things which have been cancelled. They are able to triage things really quickly."***

One participant with autism explained how video consultations help to avoid the stress of unfamiliar surroundings or becoming overwhelmed by the sensory overload of the hospital environment. In addition, having this appointment from the comfort of her own home helps her to communicate more effectively as she is more able to think clearly in a familiar environment and not exhausted by the journey and wait time in clinics.

As well as allowing a patient to see the face of the healthcare professional they are talking to, it also allows their name (or names in the case of multiple professionals) to be displayed on screen throughout so patients know exactly who they are talking to. Especially for the participant with autism, this was considered better than a face to face appointment.

While the feedback regarding digital alternatives to appointments have been largely positive, participants also expressed facing some challenges using these methods. For example, one participant recalled having a phone consultation with a healthcare professional who had not read up on their patient notes prior to the call. This participant believes that the Covid-19 crisis has exacerbated an ingrained culture of quick and rushed appointments. They felt there was less pressure for a clinician to feel as prepared as they might in a face to face appointment, and was unsatisfied with their experience on this occasion.

Relying on virtual means for conducting appointments has caused other problems for patients. For one participant whose allergic reaction was assessed over the phone, they expressed that they would have felt more at ease had a professional examined it in person. Another challenge patients expressed when using Zoom and other video-capable technology was that it was difficult to absorb all the information provided via these methods. One participant noted that the healthcare professional they spoke to was 'quite wordy,' causing them to feel overwhelmed with the process.

> ***"I would have preferred to have a face to face appointment with the doctors – I think I would have taken in more information that way. Zoom is great, but it's not the same as sitting across from someone. We've lost out on that during the lockdown."***

Overall, while some preferred to speak to a healthcare professional in person, the same participants explained that virtual consultations were sufficient as a compromise, especially during the crisis to avoid unnecessary exposure to the virus. Other participants, however, considered the virtual consultations even more effective, efficient and preferable than an in-person one. It was suggested that after the lockdown restrictions are lifted, the various different options should be offered to patients as standard protocol so they may choose which best suits them and their lifestyle.

Finding 5: Participants have delayed seeking help during the crisis

The pandemic has had an effect on the public's help-seeking behaviour as multiple participants explained that they, or their loved ones, had delayed seeking help for a medical query that they usually would have pursued medical attention for. The two main reasons given for this were unwillingness to put extra pressure on NHS resources and feeling frightened to attend medical settings where they may risk exposing themselves to the virus.

Another reason given by participants for delaying seeking help which they regularly would have was feeling that the condition they had was not severe enough to warrant medical attention. In two cases, for a wisdom tooth infection and for a swollen foot, participants reported waiting for their condition to worsen in severity before eventually seeking help. In other cases, participants decided either to self-medicate at home or seek help via other methods available, rather than visiting a healthcare professional in person.

One participant explained that delaying seeking help is a positive consequence of the crisis because it caused themselves, and other people they know, to think twice about whether they were in genuine need of help before defaulting to rushing for medical advice. During lockdown, some participants have been learning to handle minor ailments themselves, while others have been exploring other avenues of accessing help, which they usually would not have

considered. One such method that was mentioned multiple times was LIVI, an app which provides video access to a GP via smartphone or tablet for consultations and prescriptions.

> ***"I think [my husband] is much more likely to use this service than to make a face to face GP appointment, actually – no having to take time off work to go to an appointment, no sitting in the waiting room for an hour because they're running late. It's so much easier."***

Overall participants reported being satisfied with this service as it provided prompt access to a healthcare professional with minimal effort.

Finding 6: Lack of joined-up care may cause a spike in demand for services

Over the last few months people with long-term health conditions have required treatment unrelated to Covid-19 and there will likely be a backlog when normal healthcare practices resume. One reason for this could be, as previously mentioned, that some citizens have wilfully delaying seeking help, allowing their conditions to worsen in severity in the meantime. This may lead to conditions becoming urgent once lockdown restrictions have eased.

Another reason that healthcare problems could become exacerbated and may require urgent medical care could be due to lack of thorough or joined-up services, allowing certain patients to fall through the cracks. One example is of a participant, whose son attended a school that provided 1:1 support prior to lockdown. He also benefitted from the sensory garden therapy, equine therapy, occupational therapy and speech and language therapy they provided. This stopped suddenly in line with lockdown, with no alternative in place. Shortly before lockdown, their son was referred for CAMHS treatment and offered a consultation via a video conference. However, their son has been terrified of this option as he is uncomfortable receiving treatment in this way and it would likely aggravate his symptoms. As no suitable alternative had been identified or offered, the family are waiting until traditional methods resume to pursue these, meaning that their son has been left without support indefinitely. The abrupt stop to support with no alternative in place may have caused unnecessary distress and deterioration until the appropriate support is offered.

Similarly, another reported gap in care is the lack of equipping patients with the knowledge of what to do in an emergency. Although some participants reported that they did receive this information, this was not consistent, leaving many participants unaware of where to turn. Emergency processes seem to have been provided more for patients with specialised conditions. For example, a participant receiving cancer treatment explained that his Health Centre made it clear at the beginning of lockdown and throughout, that they were contactable if he needed any help. In addition, he had the contact details of the Macmillan Nurse for any cancer-related concerns. This shows an example of third sector organisations supplementing the support provided by healthcare services, and potentially addressing a gap in those services.

Another example highlighting issues in emergency protocol was in the area of mental health. A family referred their adult son, who was experiencing a mental health crisis, to the Crisis Team. They believed this to be related to the disruption to his support structures and healthy routine caused by the pandemic. This participant was told that a community psychiatric nurse would visit the following day (Saturday). When this didn't happen and they weren't contacted, the

participant called again and was told that they don't provide a service on Saturdays. The crisis team failed to provide a prompt intervention to avert the escalating crisis, leading their son to have an acute relapse which will likely take months to recover from.

These examples illustrate how a lack of joined-up services caused patients to fall through the cracks and exacerbated their conditions, which may require urgent medical care once regular practices resume.

Findings: Changes in Lifestyle during the Crisis

The themes in this section correspond to questions participants were asked about how lockdown and social distancing measures affected their day-to-day lives and that of their families. Participants explained how they have attempted to adapt to a new way of life, finding alternative and creative ways to work, socialise and stay active.

Finding 7: There was a varied response to lockdown measures

Although daily routines have changed drastically due to lockdown measures, some had found this to be a positive and refreshing change. Participants whose regular lifestyles involve staying indoors and having less interaction with others have reported enjoying lockdown. One participant who is on the autistic spectrum explains it has been enjoyable that being socially distant and not engaging with others has become socially acceptable.

> ***"This is part of my being autistic; I quite like being on my own, I quite like it being quiet. It's been great for the last three months, because I've not had to make excuses about why I don't want to be there, and what I might be doing instead. And because nothing is happening, I don't feel like the odd one out because I'm not joining in."***

For participants who had busy schedules pre-lockdown and have since had to adapt to working from home, avoiding the commute or school run, the ability to work to their own timelines has been a welcome change of pace. Participants have also acclimated to this change by developing a new daily structure and created new routines to adhere to, which has allowed them to remain 'mentally levelled.'

In addition, participants report experiencing less stress in general as juggling work and home care commitments were easier when confined to one location. In particular, participants with families have reported benefitting from having more time to spend together and being able to provide emotional support for each other.

> ***"In a way, lockdown has been a really positive thing for us as a family. We were all so busy all the time with work and school and activities, and this has forced us to slow down and spend more time together as a family. It's been great, and brought us even closer together."***

Conversely, there have been many participants who have found the changes challenging to adapt to. Some participants who have had to work differently, or stop work altogether, report that this caused them to lose all sense of routine. Furthermore, participants reported feeling 'trapped' at home due to lockdown restrictions and feeling anxious or stressed on the occasions they have gone out, due to worries about social distancing and catching the virus.

With schools closed and childminders no longer able to work closely with children, lockdown also posed a unique set of challenges for parents who faced newly acquired home-schooling and childcare duties. This required families to learn how to balance routines and resources in the home during lockdown. One participant, for example, detailed having to schedule access to laptops for two adults working, four children trying to complete online school and college classes and creating allocated slots to keep in touch with friends.

Similarly, lockdown restrictions have created challenges for people who are carers. One participant recounts the challenges they face as the carer for their brother and mother who are shielding together. The restrictions meant that their brother was no longer able to attend the day centre that he would usually visit three times a week. This change has led to challenging behaviours as he is unable to fully understand what the crisis is or why he is required to shield.

Moreover, for people at higher risk of contracting the virus, or those who had been advised to shield, commonplace activities such as food shopping had become a burden. Some participants faced a trade-off between risking going out and not having the essentials they required. Many have had to rely on relatives or volunteers to do this for them as online delivery slots were scarcely available.

Finding 8: Keeping fit has become largely digital

With gyms closed and social distancing measures in place for public spaces, participants explored various other ways of staying active. Common activities amongst the participants have been daily walks, running, walking the dog and cycling as a means to keeping fit since the crisis.

Digital resources have played a significant role during lockdown as many participants reported exploring digital alternatives like apps, and accessing online resources such as gym classes conducted via Zoom. The lockdown revealed a range of different, cost-free and easily accessible apps for people of different ages and abilities. For example, multiple participants reported their children joined in on Joe Wicks' exercise classes on TV. Specialist classes were also available, such as 'Fit 4 Life', which features chair-based exercise for people with disabilities. Other participants have reported using social media apps to gain inspiration of how to keep fit during lockdown, such as learning various dance challenges on TikTok or looking up workouts on Instagram.

With extra time available in the day and more energy from more sedentary work patterns, most participants claimed they had been more active than usual. Of the participants who reported that they had been less active than usual, this was mainly due to two reasons, the first of which was a reduction in social care provision, meaning that the support needed to remain active was no longer available. The other reason given was having no access to, or disliking, digital means of staying active and consequently avoiding these apps. The participants who reported a decrease in activity would have usually accessed face to face

fitness classes, gone to sports centres or gone out of the house to be active. However, as this was not possible, this resulted in a decrease in overall physical activity.

Finding 9: Keeping in touch with loved ones has become largely digital

Another area where digital accessibility played a significant role was to do with keeping in touch with loved ones. As social distancing restrictions prevented people from socialising with anyone they didn't live with, participants reported relying on phone calls and text to catch up with loved ones. A common theme mentioned was the use of multiple social media apps such as WhatsApp, FaceTime, Houseparty and Facebook, all of which have video call capabilities. Technology had been instrumental in helping participants to stay connected, especially for participants' whose loved ones are abroad.

Multiple participants have explained that connecting with loved ones has been invaluable during lockdown and helped them to cope during this challenging time.

> ***"You think your friends are important to you, but it's perhaps only when something like this happens and you're denied that access to them, that you realise how much of a support they are. You realise how important they are to you when that's taken away."***

As using technology has been the main substitute for in-person contact, people who do not have means to connect digitally, or those they do not feel technology-capable have faced challenges in that regard. Contacting older loved ones has involved using more traditional means such as the phone, as one participant whose mother is 102 years old, explained. Similarly, another participant described holding online family quizzes, which have been successful, although their grandad with dementia had struggled with this. By the same token, one participant whose son had autism also struggled to cope with a group video call due to overstimulation.

Since the partial relaxing of social distancing measures, some participants have explored seeing loved ones in person at a safe distance and socialising remotely. This easing had been the source of worry for many participants, who fear that lifting the restrictions too soon may lead to a second peak.

> ***"I know the government are now saying that we're allowed out, but that doesn't mean that we have to go out."***

Finding 10: Worries and fears were mainly about others

In a similar vein, when asked what worries and fears the public faced during lockdown, many participants responded that their main concern was lockdown ending too soon and the general public not heeding government advice and consequently making the situation harder, and potentially life-threatening, for others. These concerns are mainly on behalf of their family members who are high-risk due to being older or having serious medical conditions. Participants acknowledged that the actions of a few irresponsible people may have a significant impact for others.

While some older or high-risk people may want to take advantage of the easing of restrictions, they are advised to avoid doing so as they are high-risk. This has been challenging for them and a source of worry for their loved ones who believe they do not understand the gravity of the situation. Participants believe that some people may have had a flippant attitude to restrictions because some public figures were shown to not be following the government advice.

Participants also reported having concerns about other vulnerable people, the increase in domestic abuse, charities struggling to meet their fundraising targets and healthcare professionals working without sufficient PPE, as reported in the media.

Finding 11: Mental health has been significantly affected

The media has played a significant role in influencing participants' mental health, with many claiming that watching the news has resulted in them feeling worse. One participant explained that consuming the statistics around infection rate and death toll daily had caused huge anxiety.

For many others, it was the consequences of the lockdown restrictions and the implications they had that were a source of worry. For example, many people were unable to work during lockdown for different reasons and reported facing financial difficulty. One participant explained they were no longer able to continue work as they were advised to shield. Another reported that their business was considered non-essential work and subsequently closed, causing financial pressure for themselves and the six staff they employ. This situation, facilitated by the enforced lockdown, caused a great deal of stress for multiple participants.

Another consequence of lockdown has been the suspension of regular healthcare services, which has caused health anxiety for some participants. For example, one participant reported being incredibly anxious following a surgical procedure to determine whether cancer was present or not. The lockdown has caused a delay in the test results, which has left the participant upset while waiting for the biopsy results.

Moreover, the social distancing measures exacerbated the feelings of anxiety and upset caused by the crisis. Non-essential travel and social distancing has prohibited family members being able to provide moral support in person. For example, one participant described not being able to attend the funeral of two family members, which although necessary, was difficult to come to terms with.

In general, participants have reported their emotions fluctuating often and experiencing greater highs and lows than usual.

> ***"To start with, I was really up and down, my friends have found that, as well – we call it the 'Coronacoaster.' But then it's been harder to cope with things, and little things can make you quite teary. You find yourself reacting to things that you wouldn't have, previously."***

Accordingly, participants report exploring new routines and coping mechanisms to manage these difficult emotions. Some new hobbies reported have been: reading books, weekly pamper sessions, trying out new baking and cooking recipes, using colouring books and puzzles, taking part in online courses, learning to play the ukulele, compiling photo albums for distant family members, taking part in art club on Channel 4, meditation and more.

Although the situation has caused mental strain, participants reported that it had helped them to appreciate the simple things in life much more. Many claimed that they'd previously taken for granted being able to go for takeaway coffees or having a garden and now find themselves savouring the quieter roads, the sound of the birds singing and the stillness. Others have found that the rare occasion to drive somewhere feels like an event to look forward to and they find themselves looking forward to simple things like a planning a meal.

Since Covid-19, there has been much more awareness around the effects of being confined indoors on a person's wellbeing. Moreover, the pandemic has revealed that vulnerable populations that have been prioritised during the crisis tend to be overlooked in regular circumstances. One participant, who identifies as disabled and relies heavily on adult social care services explained that for the last two years, service provision had been scaled back drastically, only providing support for personal care.

> ***"At the moment there is so much awareness of people that aren't going out, that might not be as well off as you; all these vulnerable people have existed for years, it's just that no one cared about them because they were trapped behind their own front door. I'm quite enjoying that other people are beginning to appreciate what it's like to live in the same four walls and stare at the bedroom ceiling all day. Because maybe when this is all over, they may just be a little more understanding as to why, when you're asking to go out of the house for two hours a week, that's not unreasonable."***

Although the new focus on mental health is welcome, the participant explained that it should not have taken a pandemic to empathise with what many vulnerable people endure every day. As we ease back into normal life, participants acknowledged that they would benefit from more education and regular conversation about aspects of a person's lifestyle that may impact negatively on mental health. Many emphasised that this awareness should be promoted and maintained.

Finding 12: A Sense of Community has been created

Another common theme that emerged during interviews was an increase in the sense of community that has developed locally and the positive impact that it has had on participants' wellbeing. Multiple participants reported looking forward to the Clap for Carers as it increased their sense of hope and increased their sense of pride. Participants reported feeling comforted knowing that they are not alone in facing this crisis.

"One positive that's come out of it is that the road that I live on has developed a really nice community. We now have a WhatsApp Group for supporting each other, and doing shopping for people who can't get out, sharing plants and books. That's been a real positive – the development of local community groups."

Of the participants interviewed, there have been both people who have volunteered to help and people who have been the recipient of the help offered. Both have reported that volunteering helped as a coping mechanism during lockdown. For the former, it was useful to feel like they were making meaningful impacts on the lives of people who needed it. The latter benefitted from the services and feeling less isolated as a result of these acts of kindness.

Findings: Areas of Improvement for a Future Pandemic

The themes in this section correspond to questions participants were asked about what could have been handled better during the crisis and what they would like to be addressed if a second peak or future pandemic were to take place. Areas of improvement included providing more consistent, factual and reliable information. Gaps in care were also identified that participants believed to be an oversight and should be addressed urgently.

Finding 13: Sources of guidance were inconsistent and confusing

Participants were asked which sources they relied on for advice about what can and cannot be done under the restrictions. For vulnerable groups that were advised to shield, information sources that they cited included: the local Council guidance, letters from GPs and the NHS website. Participants who accessed these sources of information found that they contained enough detail and were easily accessible.

Multiple participants who accessed the NHS website, considered the information provided there not detailed enough, specifically when seeking advice while presenting Coronavirus symptoms. One participant suggested that the site may have benefitted from a live chat feature or a FAQ section. It could have signposted to other services which provided accurate and reliable diagnostic information, such as 111. Some participants also stated that they were unaware of the range of services provided by the NHS and at times sought information via other (international) sources, whose reliability they doubted.

Sources that participants used to access up-to-date information about the crisis developments and changes in restrictions included the daily briefing, social media, news websites such as the BBC (et. al). The general feeling around the daily briefing is that the information provided has been unclear, inconsistent and unhelpful. Much of the government advice provided was considered ambiguous at times, for example, around what counts as essential travel, whether or not a face mask is mandatory in certain settings etc. This has meant some decisions have been open to interpretation and the public pick and choose which advice they should follow based on their own personal situations. One participant was unhappy with the guidance provided about vulnerable children, as it was claimed that most children would be fine. The participant considered this to be inaccurate as children with multiple health conditions, like their son, should be acknowledged as being at risk and advised to shield. Most participants reported ignoring the guidance and simply doing what they felt was safe for themselves and their families.

"What people don't seem to really be getting, is that the government are not making a rule for every individual and their personal circumstances; they're making blanket, general rules which everyone needs to think about and work out how it applies to them. People can't work anything out for themselves because they're so used to asking Google and getting the answer that they don't actually think for themselves. Just because someone says you can go out, doesn't mean that you necessarily should."

It was suggested that the NHS provide advice based on factual information to supplement the government briefing, which was considered confusing and contradictory. Additionally, it was suggested that the 'Questions from the Public' always take place with an NHS representative rather than an MP, to ensure the information was more clinically reliable and that health communications were kept separate from any political bias. Multiple participants explained that if this were the case from the start of this crisis, they felt the advice would have been taken more seriously.

Participants claimed that if there should happen to be a second peak or another pandemic in the future, it would also be beneficial for information to be provided based more on local statistics and information. This would make it more relevant and less intimidating for the residents.

Additionally, participants stressed that while digital means were working well, vulnerable groups or older residents may require more support in accessing the same information and measures should be taken to ensure the communication avenues are more accessible.

Finding 14: Shielding lists may have neglected some vulnerable groups

Another possible improvement for the future would be more consistency around categories for vulnerable groups and more prompt advice for people on the shielding list. Two participants who were on the shielding list did not receive letters to confirm this until around six to eight into the lockdown.

One participant reported not meeting the threshold to be considered for the shielding list, although they believed they should have been.

"I don't understand what vulnerability group I'm supposed to fall into. The government list is people who are extremely vulnerable due to having a hollow organ transplant, having cancer treatment, being on immune-lowering drugs like chemotherapy or you've got a respiratory disease… and I don't tick any of those four boxes. I have a lot of chronic health conditions, but I don't fit any of those neat four boxes so I didn't get a government letter to start with."

This participant's GP advised them to shield regardless. However, the categories of the shielding list meant they missed out on vital support that was offered to patients on the list, such as food boxes and medicine delivery. In any future crisis, it would be useful to allow local GPs (with access to patients' medical records) to recommend which patients should be included on the shielding list, rather than apply generic criteria which may leave someone vulnerable and needing additional support.

Finding 15: Learnings from this crisis should be used to prepare for another

Multiple participants reported that for a future crisis situation, they would feel safer if lockdown measures had been enforced more quickly. It was suggested that next time, the country could follow the example of other more successful countries, such as New Zealand, that acted quicker and consequently reported fewer overall cases of Covid-19 and deaths related to it. Furthermore, participants suggested that clearer, unambiguous lockdown restrictions should be agreed upon prior to enforcing them.

In terms of resources, participants believe that the country would benefit from designating certain buildings that would be converted into Nightingale temporary hospitals now to maximise the opportunity to treat patients as soon as possible. Another recommendation was to invest in PPE in preparation for another potential crisis. Participants felt that learnings from this first, unprecedented situation should be harnessed and used to better react to future crises.

Conclusion and Limitations

The analysis of participant experiences suggests that accessing healthcare during the Covid-19 crisis has been varied. Some citizens reported that certain aspects have been handled well, and seem to be even better than usual, such as: options of medication delivery and digital appointments alleviating pressure of in-person appointments. The crisis has also revealed gaps in care provision and lack of processes that have caused people to fall through the cracks such as: no alternatives offered when video consultations have been unsuitable.

Similarly, citizens have had varied experiences of the lifestyle changes caused by lockdown restrictions. While some enjoyed the change of pace, others struggled to maintain a sense of routine. There were positive aspects associated with staying home, such as more time with loved ones and a newly-found sense of community. However, at other times, the enforced lockdown has led to negative feelings related to feeling ‘trapped’ at home and not being able to do activities that many consider essential, such as socialising.

Although the government response to the crisis has been criticised by citizens, largely they believe that the learnings from this situation should be used to create a proactive approach in preparing for another possible crisis. Although the crisis has revealed gaps in care and unpleasant experiences for some patients, some valuable learnings about accessing healthcare have emerged and many citizens believe these should be incorporated into regular practice to optimise the service provision offered.

This project examined the effects of lockdown and social distancing measures on the Surrey Heartlands population, showing which aspects of life were made easier, more challenging, which services worked well and where there were gaps. The findings can be used in the short term to: inform Recovery and Restoration plans; to meet the healthcare needs identified by participants; investigate any gaps in care identified and begin to address these pathways by investigating avenues for implementing the recommendations in this report. The findings can also be used to provide appropriate support as lockdown measures begin to ease and put safeguards in place if there should be a second peak or a future pandemic. Furthermore, in the long term, the findings can

be used to contribute to creating a strategy on how to deal with crises in future, ensuring that decisions are based on understanding people's experiences during lockdown, their lifestyles, and how this affected their health and/or illnesses.

The limitations of the research findings from this project are that the recruitment method did not guarantee representation from certain demographics such as BAME groups. A greater representation of this perspective would have contributed to more valid and meaningful findings regarding experiences during the crisis as this target group has been disproportionately affected by the Covid-19 crisis.

Additionally, the nature of the recruitment method and data collection method may have disadvantaged those who are unable or uncomfortable accessing digital media.

The project focused on Surrey residents' perspectives on the system of care available to them during the crisis. These findings are not necessarily applicable to a wider (national) population as the research did not seek to determine how service provision in Surrey compares and differs to other regions. Furthermore, because this project used a qualitative methodology with a limited sample, the feedback will not necessarily be representative of all the opinions of patients', families or people who accessed care in Surrey during this time.

Recommendations

In light of Covid-19, the following recommendations, based on participant feedback, can be explored to optimise the offer of care.

Recommendations for improving the digital offer of care:

- Ensure there is a viable process to make online requests for prescriptions, for adults as well as children. Where this is not possible, create a straightforward and convenient alternate process and make participants aware of this.
- Ensure a regular check so that all documents required to allow data sharing (for example, to a parent about their child's medication) are up to date in case of an emergency.
- Check patients' contact preferences for automated messages and add a follow-up mechanism to ensure that the patient's needs are not overlooked if they forget to respond to the first prompt.
- Create a clearer and more straightforward process that will automatically rearrange any appointments that need to be rescheduled or postponed, without putting the onus on the patient.
- Provide any patient whose appointments have been cancelled with information on the process going forward, to reassure them they are not forgotten about. Also provide them with a contact number for any emergencies.
- Signpost and raise awareness about other NHS resources and services such as 111, LIVI and the NHS website and continue to encourage the public to explore these first for any non-urgent medical matter, as a rule of thumb.

- Offer patients alternatives to in-person appointments as standard procedure and allow digital appointments where physical examinations are not necessary.
- Create a process for phone and video consultations which allows for time before and after the appointment so that the healthcare professional has time to prepare (e.g. read up on the patient file) prior to the appointment and write notes after.
- Make it standard practice for the healthcare professional to send a summary of the meeting to patient afterwards, to eliminate any confusion that may have been caused by jargon or technical issues and to ensure that they have an up-to-date record of any decisions made about their healthcare.

Recommendations for addressing gaps in care:

- For patients who are not willing to have digital treatments, investigate other avenues to deliver this care so that they are not left unsupported.
- Equip patients with the knowledge of how to handle an emergency, especially if they are undergoing specialised treatment and may need a bespoke type of care.
- Risk assess patients to understand what kind of additional support they may need. Put safeguards in place and provide them with coping mechanisms to ensure they are not left without access to any care.
- Ensure that professionals are aware of the service provision they are able to offer, its limitations and any alternate routes they can offer to patients in the event of an emergency or crisis situation.
- Support third sector organisations to address some gaps in healthcare services where appropriate, which may alleviate demand and pressure on those services.
- Use patient complaints and feedback to identify further gaps in care.
- Ensure that processes are in place that allow vulnerable people who rely on social care, to receive this support – even if it is a temporarily reduced offer.
- Circulate information about volunteer organisations in the area that may be able to supplement the support offered and help patients meet their needs.
- Examine the possibility for local GPs to recommend which patients should be shielded on a case-by-case basis rather than apply generic criteria which may leave someone vulnerable and needing additional support.

Recommendations for culture changes:

- Acknowledge the inextricable link between mental and physical health and continue to emphasise the role of mental health in leading a healthy lifestyle.
- Create more localised communications campaigns so populations are more aware of news and statistics that are relevant to them.
- Proactively plan to ensure strategies and procedures are in place to ensure a reduced, but effective, service is able to run during periods of emergency.