



Life in ‘Lockdown’

Investigating the impact of a pandemic

October 2020

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1 Introduction

Living amidst a pandemic is a new and unsettling experience for many.

In March 2020, the country went into ‘Lockdown’. Services closed their doors to all but the most urgent cases and concentrated efforts on responding to the Covid-19 crisis. Residents were confined to their homes and it prompted a substantial shift to remote access to work, education, and care.

Covid-19 also presented an unprecedented challenge to front-line practitioners, managers, and policymakers.

In this context Healthwatch Camden worked with its partners and volunteers to understand the perspective of local people during this time.

Life in ‘Lockdown’

This report documents the experience and views of 1,590 Camden residents on life in the early phases of Covid-19. It provides an independent perspective which can help to improve understanding of:

- how services can communicate effectively
- how to mitigate the direct and in-direct risks Covid-19 poses to health
- the consequences of service changes during Covid-19

Through a survey and a series of in-depth interviews with a diverse group, people provided us with some clear messages.

Project Aims:

- Add to evidence on people’s experiences during Covid-19 of the quality of health and care services and the effectiveness of information / support.
- Identify gaps in support to help prepare for potential future Covid-19 waves or other health crises.
- Provide a channel for people to have a voice about the impact of Covid-19 on their lives.



2 Summary

What we did

We wanted to hear from local people about their experiences of the Covid-19 pandemic and life in ‘Lockdown’.

We were interested in how people were getting information to guide them and help them stay well. We were also interested in experiences of accessing health and care services under the new conditions and how people’s health and wellbeing was being affected.

To find answers, we adopted a two-part process to gather insight from people living, working or using services in Camden:

- A questionnaire conducted online and by phone - launched on 22nd April and running until 4th of June.

A second version of the survey running from 4th June to 31st of July which sought additional feedback on the ways people had managed to keep themselves well under lockdown and on levels of anxiety about the prospect of lockdown easing.

- In-depth weekly interviews over 6 consecutive weeks to gather detailed personal stories from 8 residents about life under lockdown and how they were coping. Extracts of these case studies have been used through the report. All names have been changed to protect identities and all participants have given permission for their stories to be published. Full case studies can be found in the Appendix (section 12.3).

We also participated in online focus groups and community meetings to discuss the experiences of different community groups, targeting those who are seldom heard.

Through all of these mechanisms we learned about the range of different ways Covid-19 impacted people.

What we found

Finding information about Covid-19:

1. All groups relied most heavily on television (regardless of age, ethnic group or disability). Only small numbers reported getting information from the council, voluntary organisations or faith groups. There was an unmet need for information in accessible formats (e.g. languages, BSL, Large Print, Easy Read).
2. Although there were reported challenges of digital exclusion, use of WhatsApp groups by young and old alike challenges pre-conceptions about resistance of older people to communicating via technology.
3. Many people reported finding information about Covid-19 confusing and contradictory. People with long term health conditions or disabilities were more likely to report finding information difficult or very difficult to understand.

Changes to experience of health and care services:

4. The benefits of remote health services were embraced by the majority (across all ethnic and age groups). However, some reported serious dissatisfaction, including those with complex needs and mental health conditions.
5. Many people had routine or long-awaited appointments with NHS providers cancelled at the start of lockdown. People reported a subsequent lack of communication leaving many feeling they had been forgotten. People would have liked a phone call or remote appointments as an interim measure.
6. People have delayed accessing care they need for a range of reasons. Among those who hadn't used a health or care service, one in five people told us that they needed a service but felt their needs could wait amid the crisis, and 13% chose not to access care because of fear of contracting Covid-19.

Concerns during 'lockdown':

7. Levels of concern about Covid-19 were high among all people in Camden. However, Asian¹ respondents were significantly more worried about catching the virus (67%), and Black² respondents were slightly more worried (57%), compared to White counterparts (50%).

¹ Asian / Asian British / Southeast Asian

² Black / African / Caribbean / Black British



8. Black respondents were significantly more **concerned about job security** (33%) compared to White (22%), Asian (20%) and other respondents (24%).
9. Those under 65 reported higher levels of every Covid-19 concern other than catching the virus, compared to those 65 and older.
10. People with disabilities were more likely to report **concern about being lonely and isolated** (54%) than the general population (31%).

Impact on health and wellbeing:

11. There is strong evidence of a significant negative impact of the Covid-19 crisis and lockdown on the general wellbeing of people in Camden. Sixty-eight percent of people reported a deterioration of mental health. Eighty-eight percent of 25 to 34-year-olds reported a detrimental impact on mental health.
12. A deterioration in mental health was reported by both those who were living with pre-existing mental health issues prior to the Covid-19 outbreak and those who had no history of mental health problems.
13. Increased use of open green spaces, exercise, reductions in travel and staying local were all cited as positive impacts. However, working from home while caring for school age children was a significant cause of stress for parents.

Transitioning out of ‘lockdown’:

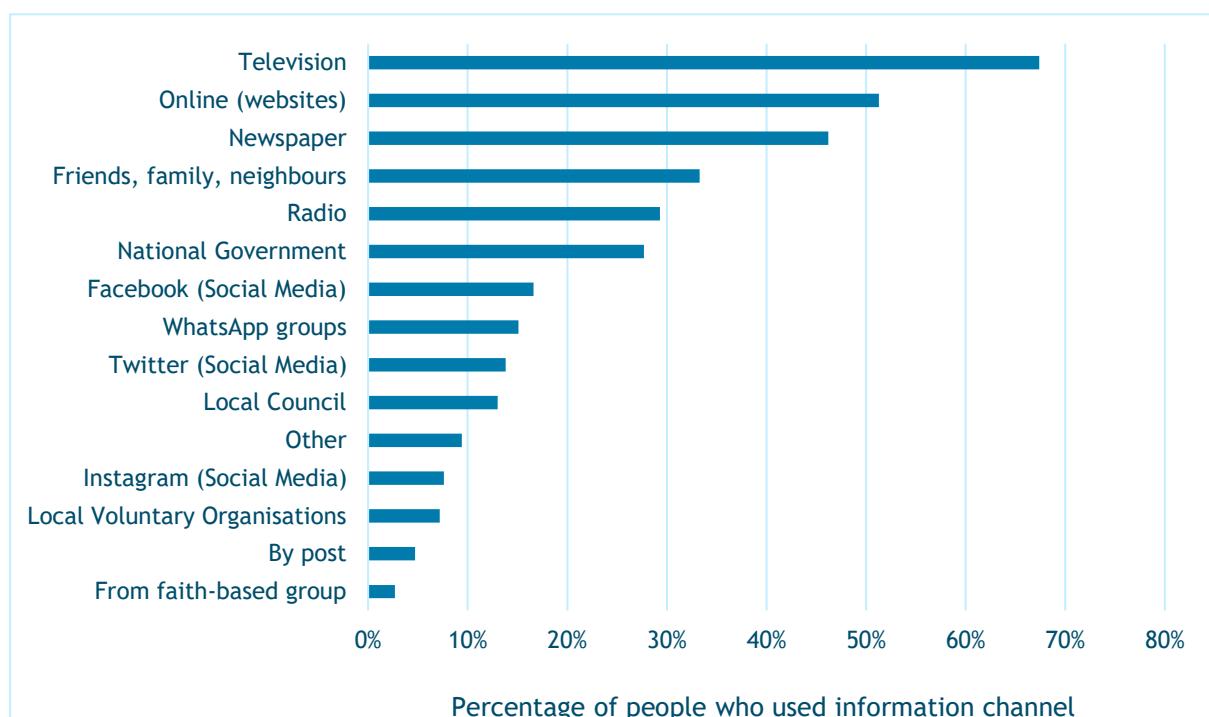
14. Four in ten felt lockdown was easing too soon or that it would trigger a second spike. Many people reported a lack of confidence in returning to work, school and other activities, some of whom were choosing to continue self-isolation.
15. One in four survey respondents were keen to see lockdown lifted.
16. A higher percentage of Black respondents looked forward to lockdown easing (53%) compared to other groups. In contrast, only 15% of Asian respondents said they were looking forward to lockdown easing.

3 Information about Covid-19

Use of information channels

People accessed Covid-19 information in a variety of ways and the majority of people did not rely on just one channel for information (see Figure 1).

Figure 1. Where do people get information about Covid-19, changing government guidelines, and how to stay well?³



Overall popularity of channels

Television was by far the most popular channel with over two-thirds (67%) of respondents reporting they watched television for Covid-19 information. Approximately half (51%) found Covid-19 related information online or through websites. Slightly less than half used newspapers.

One-third of respondents relied on friends, family, or neighbours as a channel for information. A smaller proportion of people got information via Facebook, WhatsApp, and Twitter.

Very small numbers of people reported receiving information via local voluntary organisations (7%) or faith-based groups (3%). Despite the Covid-19 communication campaign undertaken by Camden Council, including a letter from the leader sent to

³ 1559 people provided answers to this question and were invited to ‘tick all that apply.’



every household, only 13% of survey respondents reported accessing information or advice from the local council. This low figure may be partly explained by the blurring between information source and information channel which may also explain the surprisingly low numbers ticking national government (28%).

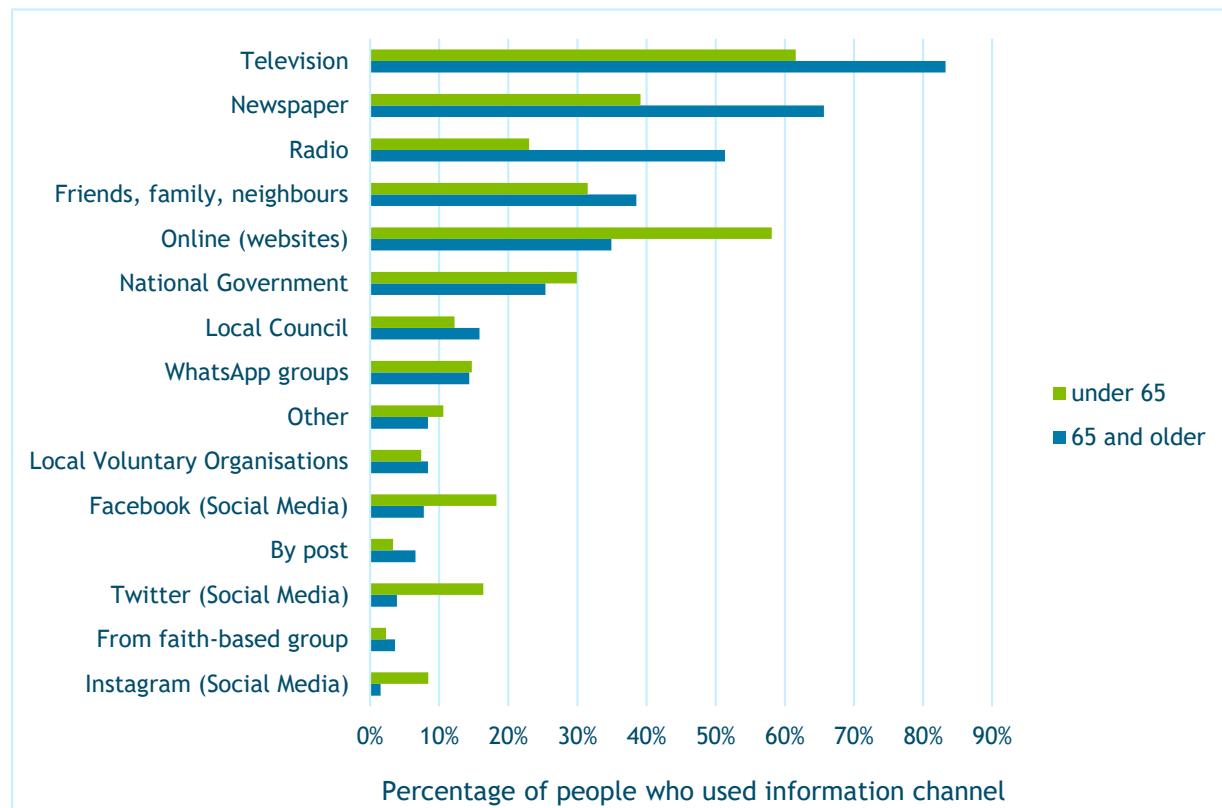
The survey also explored whether there was variation in use of information channels between different groups of local people (see Figures 2a, 2b and 2c).

Popularity of channels by age

Respondents aged 65 and older relied more heavily on traditional information sources including newspaper (66%), radio (51%) and friends and family (39%), compared to those who were under age 65 (39%, 23%, 32%, respectively) (Figure 2a).

In contrast, younger people relied more heavily on online websites and social media including Twitter, Instagram, and Facebook. However, it is interesting to note that an equal percentage of older and younger respondents reported using WhatsApp groups (14%). This may suggest that the emergence of Covid-19 community mutual aid groups, using WhatsApp as a platform, has encouraged older people to embrace this new digital platform.

Figure 2a: Channels for Covid-19 information by age⁴



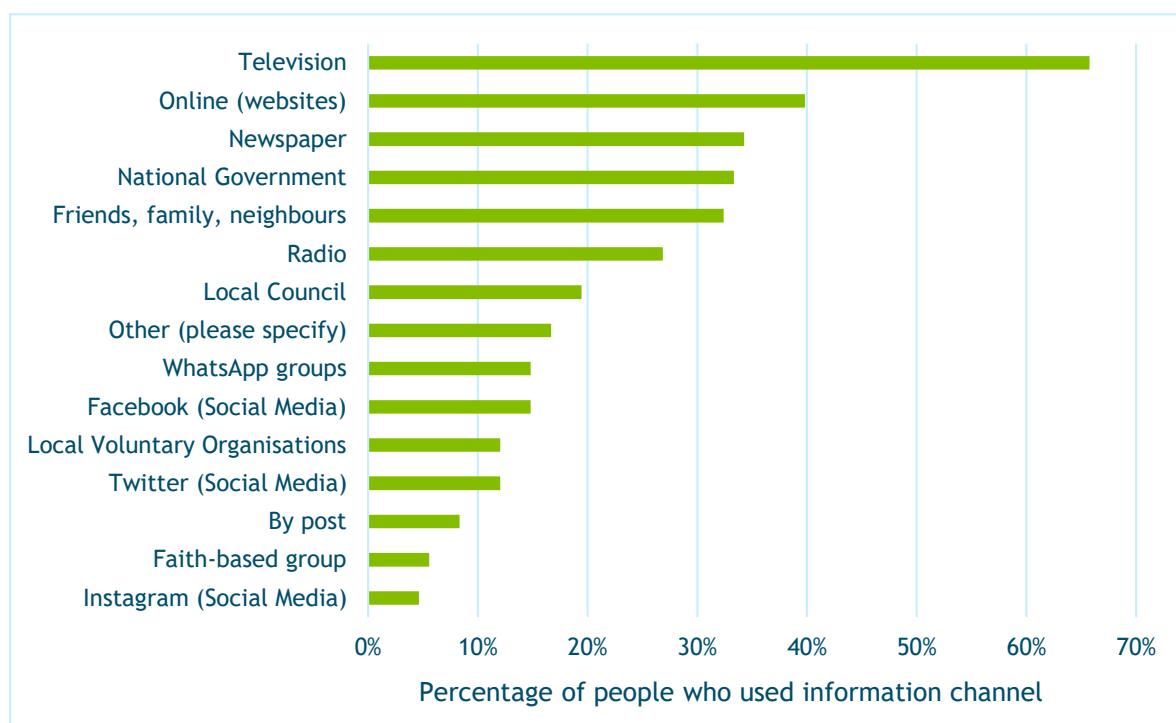
⁴ 335 people aged 65 and over, 921 under 65, answered this question.

Popularity of channels among people with disabilities

In general, the responses from people with disabilities showed little variation from those of other survey respondents, such as the heavy reliance on television. However, there is evidence of higher use of information from local voluntary organisations (12% disabled respondents ticked this box compared to 7% of the total respondents).

Disabled people also used information from Camden Council slightly more than the general population (19% compared to 13%). This finding suggests that local people with particular support needs are more likely to seek and use information and advice that is locally tailored. It may also indicate an increased likelihood of disabled people having a pre-existing connection to local support networks providing information and advice.

Figure 2b. Channels for Covid-19 information among people with disabilities⁵



Popularity of channels among different ethnic groups

There was a slight variation in the information channels used by different ethnic groups. There was slightly less use of websites among Black/African/Caribbean/Black British responders. There was slightly more use of WhatsApp among Asian (25%), Black (27%), and other ethnic group responders (20%) when compared to White (11%) and mixed/multiply ethnicity (12%) responders (Figure 2c below).

⁵ 108 people with disabilities answered this survey question.



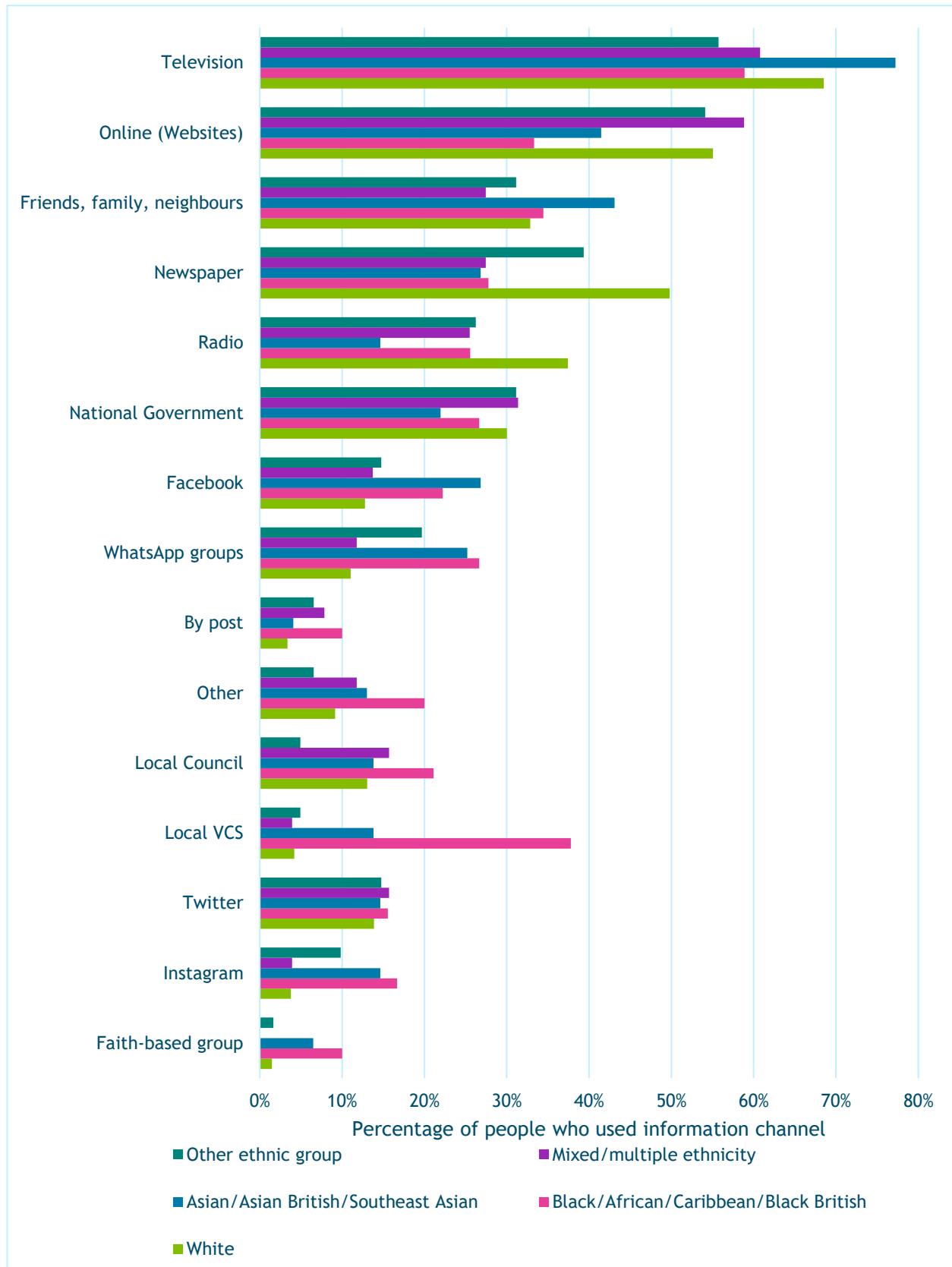
The very high use of television by responders identifying as Asian/Asian British and Southeast Asian is also notable at nearly 80%. Although this survey did not explore further, anecdotal evidence suggests this may be explained by the high popularity of Bangladeshi TV and other channels broadcasting in mother tongue minority languages.

“Most of time I watch the news on Chinese channel, so I can understand easily.”

Harry's story

Harry is living in a student block so finds it hard to isolate as he shares a kitchen and toilet. *“All the social distancing information assumes you are in a home of your own. There’s nothing to advise people like me who are sharing a toilet with 15 others. The security guards are on edge. We are fighting in the student union for more clarity on what the university should be doing for us. It would be nice to have an advice page on a website for students self-isolating in halls.”*

For Harry's full story, see section 12.3 in the Appendix

Figure 2c. Channels for Covid-19 information by ethnic group⁶

⁶ Among those who answered this question and identified their ethnicity, 743 people were White, 123 were Asian/Asian British/Southeast Asian, 90 were Black/African/Caribbean/Black British, 61 were other ethnic group, and 51 were Mixed/multiple ethnicity.

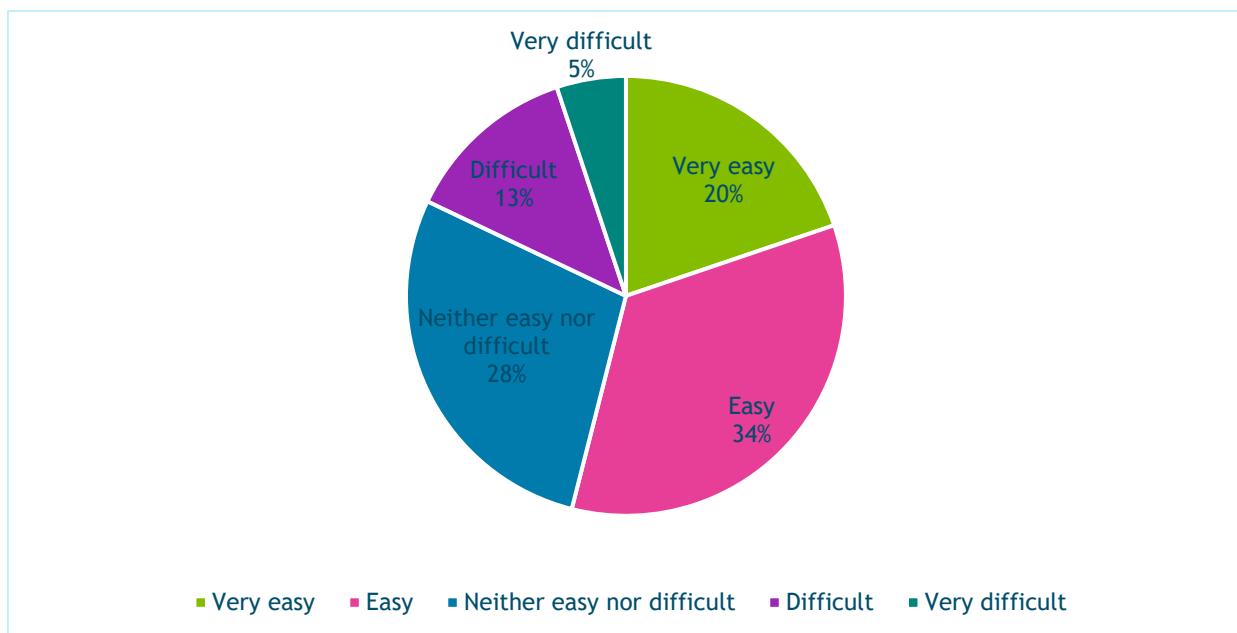


4 Effectiveness of information

Clarity of Covid-19 information

Overall, over half of survey respondents found Covid-19 information and guidance easy or very easy to understand. However, a significant minority of 18% found it difficult or very difficult. There were no significant differences in age between those who found it easy or difficult. In other words, some people of all ages found information difficult to understand.

Figure 3. How easy has it been to understand information and guidance around Covid-19 and how to keep well? ⁷



Closer analysis of the characteristics of people who said they found Covid-19 information and guidance ‘difficult’ or ‘very difficult’ to understand reveals a disproportionate number who had a disability or long-term health condition.

“It's not easy to keep well because we don't know how to keep safe.”

⁷ 1,551 people provided an answer to this question.

How Covid-19 information could have been made easier to understand

Of the 401 people who provided suggestions on how to make information easier to understand, sixty five percent said they found information to be confusing and contradictory. They also said that advice and guidance changed too often which made it confusing and difficult to follow.

Those reporting that information was confusing and contradictory included people across all groups of respondents and, notably, also included people who had earlier replied that information was easy to understand. It is worth noting the possible connection between the use of a wide range of information channels and the people finding information inconsistent.

People said they wanted information to be clear, precise, and simple to understand. They wanted it to be honest, factual, backed by data and science, and delivered by experts.

[It would help to] have more experts, not politicians, delivering the important messages in a clearer manner.”

Criticisms of the national government

A significant number of comments criticised national government for a failure to communicate effectively with the public and 36% of respondents made comments that expressed concerns about national government performance including mistrust in the government's intentions, explanations, or regulations.

“Too often the information seemed to be driven by political considerations rather than health and wellbeing considerations.”

“Government seems to make up policy as it goes along and information or statistics they produce are often declared unreliable or wrong by other bodies.”

“They lack consistent clear guidance and government staff publicly don't follow it anyway – total mess. Everyone I know is making their own sensible decisions – the government has been too muddled.”

The role of media

Some people also criticised the media and its involvement in invoking fearmongering and spreading false news and confusing headlines.

“Two days ago the media claimed that a stomach rash was a new potential symptom. The NHS has neither confirmed nor rejected this. Quick responses to such press claims would be great as the NHS would be my primary choice for trustworthy information.”



Accessibility of Covid-19 information

Nearly 8% of survey respondents reported barriers to accessing information. Respondents cited a lack of accessible information for people with communication support needs including British Sign Language for d/Deaf people, Large Print for people with sight loss and Easy Read for people with a learning disability. A lack of information available in non-English community languages was also reported as well as a lack of information for people who were not online.

“[There should have been] instant links to numerous other languages.”

“Drawing picture to make it clear.”

“[It would have helped to have] leaflets with important information delivered to houses for people without internet.”

“Why was there no BSL signing at government daily briefings?”

However, the fast-changing nature of the Covid-19 pandemic, scientific knowledge and government response was a key factor underpinning the public's experience of inconsistent and confusing information and advice.

5 Changes in use of health services

The switch to an emphasis on remote care

Among those who had used a health or care service since April most had accessed that service remotely, either online or over the phone. There were many more mentions of people accessing care over the telephone than through other remote means. Only 9% of people who accessed a health or care service had accessed it in person (including A+E visits).

Nearly 500 people went on to further elaborate on their experience with the online or remote health or care service. Sixty four percent of respondents mentioned at least one positive aspect about the telephone or online health or care service. Positive comments ranged from being satisfied to saying that remote access had exceeded expectations. There were many benefits listed with the most frequently mentioned being speed and efficiency, convenience, and not having to travel long distances or take time off work. Some respondents reported early resistance about shifting to remote access but subsequent satisfaction.

There was reporting of positive online and telephone experiences from a diverse range of local people, including older people who might be assumed to be more resistant to change. For example, 66% of respondents ages 65 and older mentioned at least one positive aspect of the switch to digital.

One elderly patient told us:

"I rang the GP surgery and the receptionist said a doctor would call me back which he did - within an hour. He was very helpful on the phone and we decided I didn't need to go in to see him."

Jane, who lives with multiple long term and debilitating conditions, said:

"My issues are recurring so it's usually very daunting and a physical strain to get to the GP. I often put off going as I don't have the energy to get there. But this time they did everything over the phone. It was really quite liberating not to have to go in person - it's made me feel like I've got a little bit of control back over my own care. I wasn't expecting that."

A teenage boy reported:

"I just rang up and they said I could go and collect my prescription from the chemist. I didn't have to make an appointment or anything. I couldn't believe how easy it was!"

Other residents said:



“I had a consultation over the phone. It’s actually better than before! Now I don’t have to go and wait around - and it’s a long way on the bus.”

“It really really worked. I was amazed.”

However, 21% of respondents mentioned at least one negative aspect about the telephone or online service. Among these comments we heard that the experience was not satisfactory, that the way the service was provided had changed for the worse, or that the service user preferred face-to-face.

“It was utterly inconvenient and impersonal.”

“It was much worse [than a face to face appointment]. I have been misdiagnosed several times.”

“Online is no replacement for face to face doctors.”

Some people reported feeling excluded and intimidated by the need to perform tasks online when they are not confident using a device or the internet.

“I couldn’t show the hospital the scans as they were on a disc and I don’t have the programme to open it.”

Some people live with communication support needs that make it harder to use some technologies. For example, we were contacted by a d/Deaf patient who pointed out that a call back from a GP is no good if you cannot hear the phone ring.

“When I needed to see my GP, I was not able to reach because the notice on GP door advised me to phone. How do I phone when I am deaf?”

There was evidence that remote access can work better for some services and some people than for others. There was very high positive reporting for online ordering of repeat prescriptions. Ten percent of survey respondents had ordered a prescription online and the majority said this worked well and was convenient.

“Using the new Dr IQ app made ordering a prescription much easier.”

However, people told us that remote does not work for all ailments and diagnoses, particularly those that require physical touch and or are more serious. A significant number of responses commented that remote services are not adequate for people seeking mental health support or for those with complex needs.

“There’s been Zoom groups and telephone calls to replace mental health day services but they’re only twice a week and it’s too hard to keep well, worse than normal much worse.”

“For children with severe disabilities, video or phone consultations cannot replace face to face ones.”

“Had online appointment with a doctor and it was fine. But they couldn’t do everything they needed to because they couldn’t touch my body or run tests.”

Jamila’s story

As the weeks went on, the challenges of caring for her disabled son became more overwhelming for Jamila. *“I’ve had a bad time. My son is in a bad way. He cannot drink. A lot of crying. He is not well. We haven’t slept for two nights,”* she says. Jamila contacted the GP and had a telephone consultation. *“Normally they would examine him. It takes four people to hold him for a physical examination so this time it was just guesswork.”*

For Jamila’s full story, see section 12.3 in the Appendix

We also heard complaints and queries about why more services had not been able to adapt to an online or telephone offer. Some people questioned why more routine hospital appointments for long term conditions could not have been conducted remotely rather than being cancelled indefinitely.

“A phone call or an online meeting was all I needed. Instead my next appointment has been moved from 1 April to September.”

Many patients have been willing to adapt to different ways of getting support whilst the current situation demands it, but they wanted to make it clear that the quality of service was not the same.

“I have been seeing my therapist using online video calls rather than in person. I have got used to it, though it is certainly not the same as being there in person.”

“Not the same but better than nothing.”

Others said they hope that the option of a remote appointment would still be available once things had returned to normal.



“I had a phone consultation with my GP. It was a positive experience. I'd like this to be offered even after the lockdown for minor health issues.”

Figure 4. Positive and negative experiences of remote access health and care service by ethnic group⁸

	% of people who reported a positive online/telephone experience	% of people who reported a negative online/telephone experience	% who did not report on remote access of health or care service
White	48%	14%	38%
Asian/Asian British/Southeast Asian	43%	24%	33%
Black/African/ Caribbean/ Black British	48%	14%	38%
Mixed/Multiple ethnicity	59%	14%	27%
Other ethnic group	50%	13%	37%

All respondents, regardless of ethnic group, were much more likely to report a positive experience of online access to a health or care service than to report a negative experience (Figure 4). Furthermore, the survey findings show that the level of positive feedback was similar across all groups regardless of ethnicity (around 14%). The exception is a noticeably higher reporting of negative experiences by respondents who were Asian (24%).

⁸ Among those included in this chart, 403 were White, 63 were Asian/Asian British/Southeast Asian, 21 were Black/African/Caribbean/Black British, 29 were Mixed/Multiple ethnicity, and 24 were Other ethnic group. Percentages above are based on these numbers.

Reasons for not accessing care

Well over half (62%) of respondents had not used a health or care service because they reported that they did not need to (Figure 5). Others had their appointments cancelled or found their services were closed. However, over 20% replied that their needs could wait or were not a priority amid the Covid-19 crisis and 13% chose not to access a health or care service because of fear of contracting Covid-19. These responses are evidence of the significant impact of the Covid-19 situation on the health-seeking behaviour of people in Camden.

“I feel worried about my health I’m not feeling well but I’m scared to go to the hospital.”

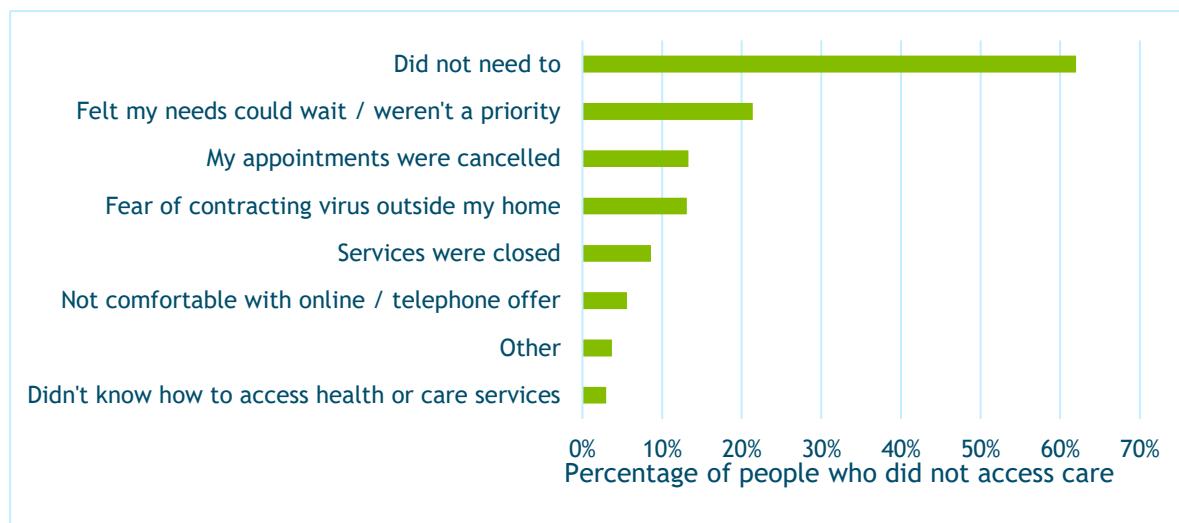
“I have been waiting for eye surgery and treatments for my disability which are now indefinitely postponed.”

“There was lack of medical services for me due to lock down. I was not able to get support for my heart pacemaker.”

There was also some evidence of confusion about the availability of services. For example, one Camden resident wrongly believed that her GP practice had been closed throughout lockdown.”

“I received a text from my GP to advise that they would be open on bank holiday Friday. So I will wait until then and try to call [because they have been closed since the start of lockdown].”

Figure 5. If you haven’t used a health and / or care service, why not?⁹



⁹ We gathered data from 429 people who had not used a health and or care service since Covid-19. This question was in survey version 2 (timeframe for responses was from 4 June - 31 July 2020). This question was ‘tick all that apply’ and some people stated multiple reasons for not accessing care.



Jane's story

Jane is disabled and lives with long term health conditions. Jane reported high levels confusion around advice and support services available. As a regular user of NHS services, Jane had to contend with very significant changes to the support she receives. All her regular monitoring appointments were cancelled.

“They haven’t offered me anything online or by phone. I’ve been left completely in the dark. Because of the nature of my condition this could have serious implications for my health,” she says.

“I know my condition well enough that I could self-manage but I cannot feel comfortable doing that unless I have a specialist I can communicate with for support. But all communications with the hospital have just completely stopped. I don’t want to go to the hospital - I just want some communication. I had one phone call from the secretary of a consultant from one of the clinics I attend who just cancelled my appointment and again there was no offer of a telephone or skype consult - I asked and they said they are not doing them. No date was given for re-arrangement.”

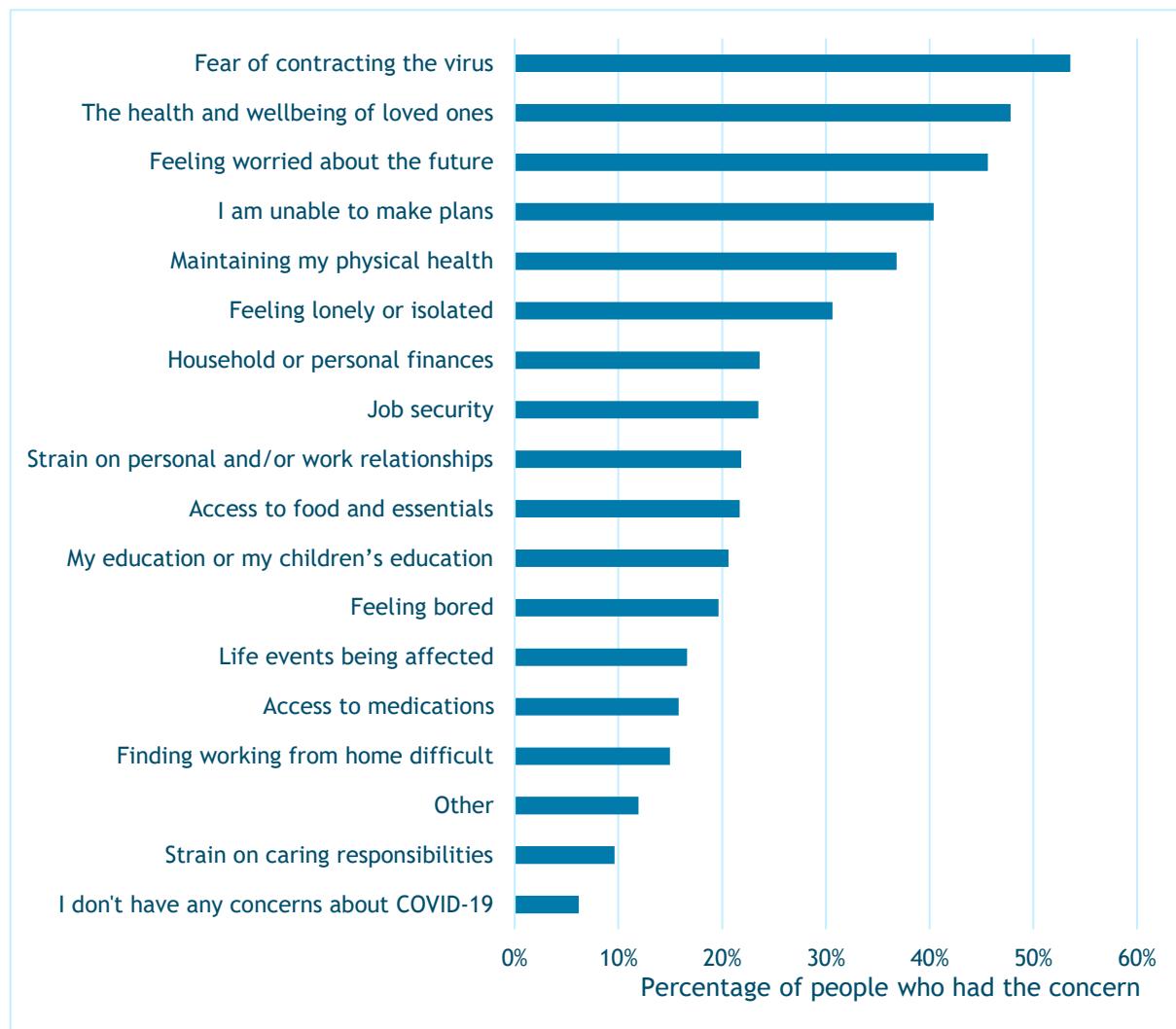
For Jane’s full story, see Appendix section 12.3

6 Concerns about the pandemic

Survey respondents reported a wide range of concerns about the Covid-19 pandemic with most ticking more than one major concern in their answer (Figure 6).

Of those who answered this question, over half were fearful of contracting the virus. Nearly half were concerned about the health and wellbeing of loved ones. Over 20% were worried about getting food and other essentials. Concerns around livelihood, finances and job security were high on the agenda for many. We heard about the strain on relationships and difficulties of working from home.

Figure 6. What concerns you most about the Covid-19 pandemic?¹⁰

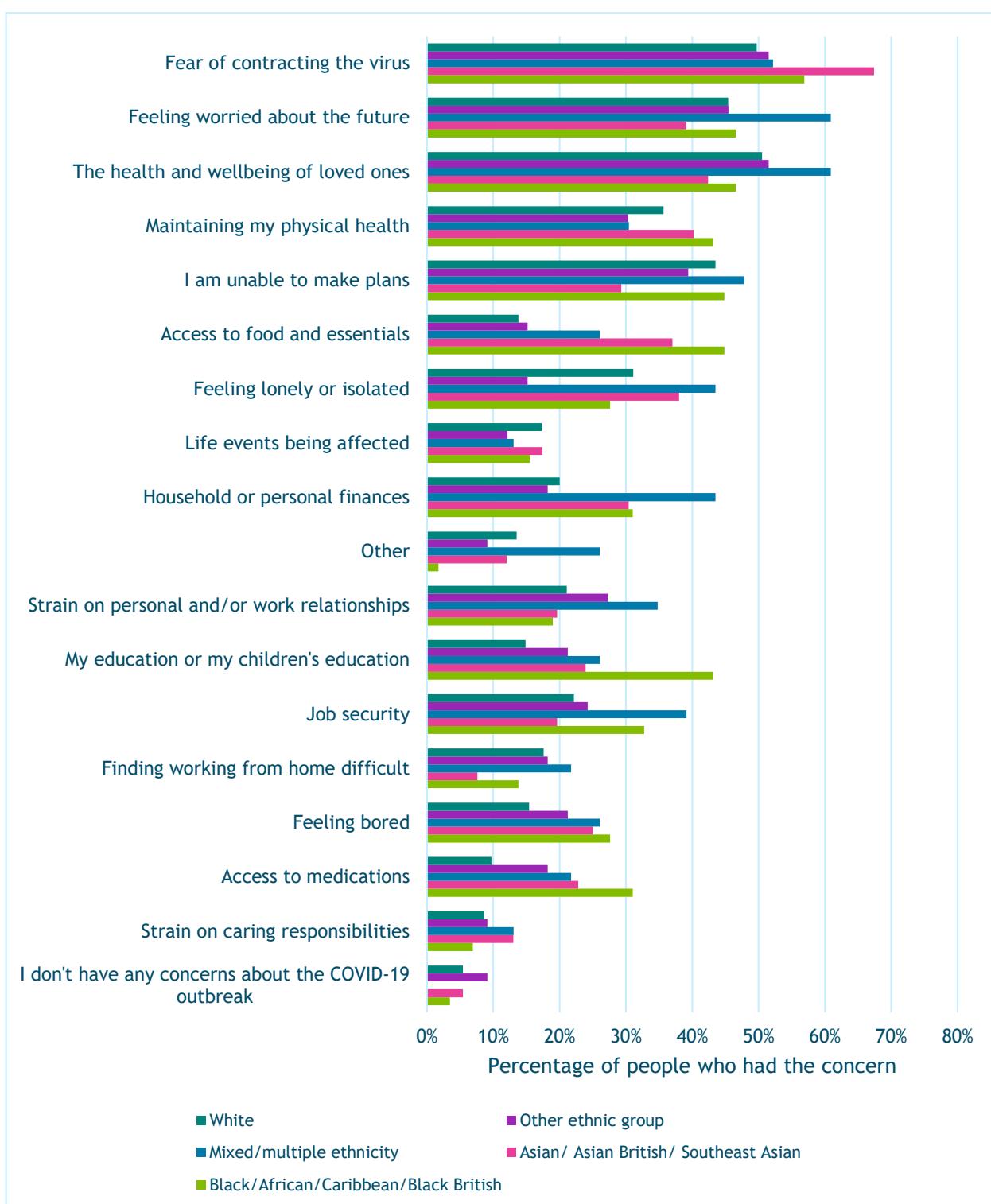


¹⁰ 728 people answered this question. This question was included in version 2 of the survey, meaning the timeframe for responses was 4th June - 31 July 2020. People were asked to 'tick all that apply.'



The following Figures (Figure 7a and 7b) explore whether there was variation in what concerned people most between different groups of local people.

Figure 7a. Concerns about the Covid-19 pandemic by ethnic group¹¹



¹¹ 58 Black/African/Caribbean/Black British, 92 Asian/Asian British/Southeast Asian, 23 Mixed/multiple ethnicity, 370 White, and 33 Other ethnic group respondents provided answers to this question. Percentages above correspond to these numbers.

Figure 7a shows that Asian respondents were significantly more worried about catching the virus (67%) and Black respondents were slightly more worried (57%) compared to White counterparts (50%).

People of mixed/multiple ethnicity reported higher concerns on several measures not directly related to health such as job security, personal finances, strain on relationships, the health and wellbeing of loved ones and feeling worried about the future. Black respondents were significantly more concerned about job security (33%) compared to their White (22%), other (24%), and Asian counterparts (20%).

Black respondents were notably more concerned (45%) than other groups about access to food and essentials. This difference is especially stark when compared to White respondents where only 14% were concerned about access to food and essentials.

“I am working from 7 am till 8pm at night looking after children, I tripped and fell chasing children. As a mother we have been ignored and not prioritised. The local charities don’t allow us access to food parcels.” - Black respondent

Black respondents were also more concerned about access to medication (31%) compared to White counterparts (10%).

Bernadette and Karim’s story

Karim needs to take care what he eats and uses dietary supplements such as vitamins which have been difficult to obtain. “*Not being able to go out freely to purchase the foods necessary for my wellbeing makes life difficult.*”

For his mother, Bernadette, caring for her son while isolating is difficult. In particular, she finds it very distressing not to be able to prepare the healthy foods that she says are instrumental to her son’s wellbeing. She is also distressed by the withdrawal of routine support services.

For Bernadette and Karim’s full story, see Appendix section 12.3

Higher numbers within this group also reported concerns about their education or the education of their children (43%) compared to White counterparts among whom only 15% reported being concerned about education.

“I am worried if I become jobless” - Black respondent

“I’m very anxious I don’t like going out and am scared of getting Covid-19” - resident of a mixed/multiple ethnic group background



Figure 7b. Concerns about the Covid-19 pandemic by age group¹²

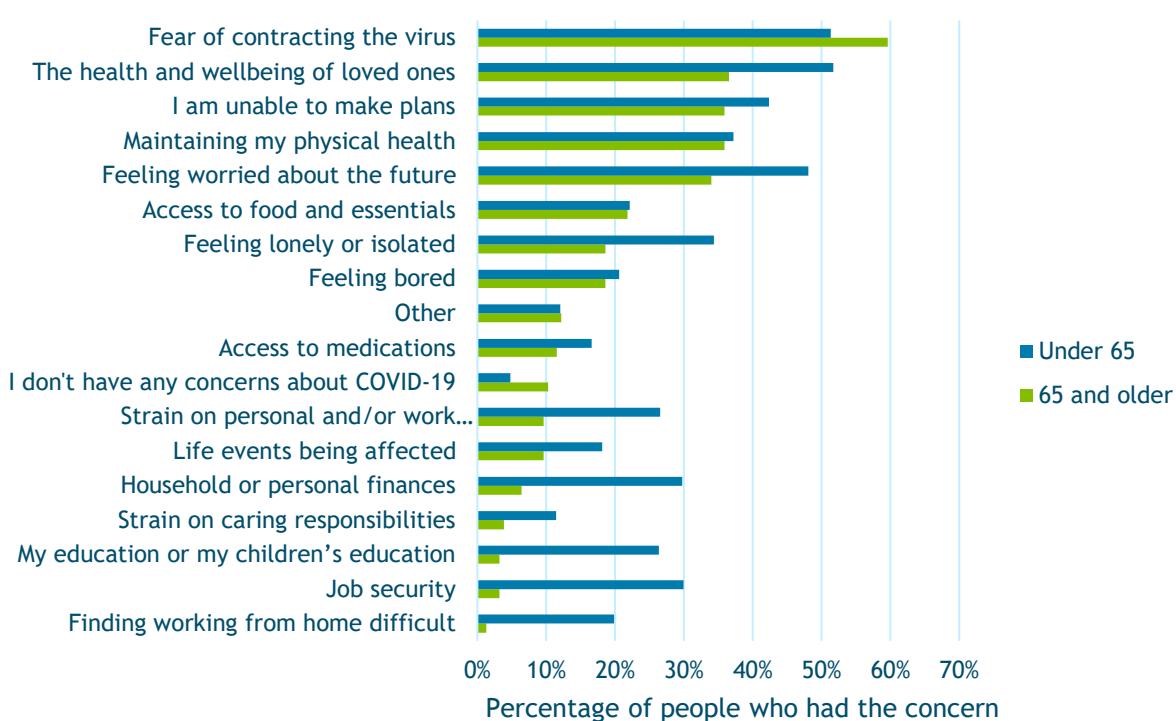


Figure 7b reveals higher levels of concern about Covid-19 among those under 65 than among those 65 and older across every type of concern other than catching the virus. Moreover, people under 65 are only slightly less likely to report fear of catching Covid-19 than those aged 65 or over. The survey classification of age is insensitive to further distinctions between middle aged, young people and older age. But the extent of concern about the wider impact of the pandemic on livelihoods among all people in Camden is clear.

Abreshmina's story

Abreshmina's husband is in a care home and she has been unable to visit him during lockdown. *"In a way I am happy that his brain doesn't work because otherwise he would miss me and be unhappy. Instead it's me that misses him and is unhappy. I wish I could still be taking care of him but it was too difficult after I had my fall. But he is alive. And when this thing is finished we will go to visit him – me and my daughter – and we will buy him ice cream which he loves very much."*

For Abreshmina's full story, see section 12.3 in the Appendix

¹²156 respondents were ages 65 or older, and 524 were under 65.

Fifty-two people answered this question who also identified as having a disability. Their concerns differed little from those of others but, notably, people with disabilities were more likely to report concern about being lonely and isolated (54%) than the general population (31%).

“Cannot get food deliveries for weeks. Delivery people won’t bring them in and I am too disabled to pick them up.”

Fifty-nine people who answered this question were formally shielding. These people reported similar concerns to all other respondents. However, among those shielding there were more reports of concern about access to food and other essentials and to medications and they reported feeling more bored.

Those who were shielding were slightly less concerned than others about household or personal finances, about the difficulties of working from home, job security and their education or their children’s education. Among survey respondents who were shielding, less than half were over 65 years old. This goes against the common perception that nearly all people who are shielding are elderly, when in fact a significant amount are under 65 and vulnerable for other reasons.

Marjorie’s story

Marjorie is resigned but fed up. *“I am very bored and very stiff. I am getting very restless. I’ve managed to do my household chores. I am getting bored with TV and movies. I miss the people that I usually see. My friends ring me a lot. On the whole, I am managing. I am not ill or disabled, but I’ve had long periods when I had to be indoors.”*

For Marjorie’s full story, see section 12.3 in the Appendix



7 Impact on health and wellbeing

Lockdown's impact on mental health

In total, 716 people submitted additional comments about how the pandemic has impacted them in various ways. Very high numbers (68%) of these reported a negative impact on their mental health including mentions of increases in depression, anxiety, loneliness, and stress.

The reporting of a deterioration of mental health was common (50% or over) across all the different groups of people who responded to the survey – whether older, younger, BAME, white, able bodied or disabled or shielding.

However, mental health was mentioned more often by respondents who were aged between 25 and 44 years-old. Among 25 to 34 year-olds, in particular, 88% reported an impact on mental health (see Figure 8 below). Many reported feeling overwhelmed, near breakdown, or in need of help or support. The additional demands of caring for children and working from home clearly had an impact on this age group. Figure 7b shows the many concerns that this age group had which likely had a compounding impact on their health and wellbeing.

“I gained weight, not enough exercise therefore body in very poor shape; feeling very low mentally: overwhelmed by home schooling added to other responsibilities.”

“I am now in debt and rely on my partner to provide financial support which is a strain on our relationship.”

Figure 8. Reporting of impact on mental health by age group

Age	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75+	I'd prefer not to say
% who said Covid-19 had negative impact on mental health	67%	67%	88%	79%	59%	62%	63%	50%	75%

A deterioration in mental health was reported by both those who were living with pre-existing mental health issues prior to the Covid-19 outbreak and those who had no history of mental health problems.

“[Covid-19] exacerbated the anxiety and depression I already have.”

“For the first time, I’m considering accessing mental health services. Totally lost motivation to do anything productive.”

Mental health concerns represented a spectrum spanning from reports of increasing stress and anxiety to more serious issues that warrant specialist intervention.

“As someone who suffers from severe mental health it has massively affected my agoraphobia even more as being told to stay inside for 12 weeks (due to pregnancy and high risk) I haven’t stepped outside once. My anxiety is so much worse which then triggers my depression and due to my personality disorder I am unable to handle my emotions.”

“Been feeling down and crying often, mainly because I am unable to meet family, friends and colleagues in person for such a long time.”

“Fear of spreading virus and death made me panic and depressed.”

Harry's story

Harry is a student at the University of London and is living in student accommodation in Camden. He is transgender and lives with a disability. He also lives with mental health issues.

Harry struggled with the impact of lockdown which confined him to his student room, bringing back memories of a period earlier in life when he suffered from severe depression and anxiety.

“It feels like I’ve gone back years to when I’d dropped out of school due to bullying and gender identity issues and was living in my bedroom. Before lockdown I was starting to recover something of an adult life. Now it feels like I have lost everything I had achieved and am back just to living in my room,” he says. “During the first couple of weeks I felt suicidal – I felt what is the point of having made the progress I have?”

“My early experiences of mental health services meant I lost trust. So now I don’t want to reach out to any services other than things I really need. Instead, I have learnt a lot of self-care techniques.”

For Harry’s full story, see Appendix section 12.3



Other impacts on health and wellbeing

In addition, 17.2% of people mentioned the pandemic's impact on their physical health including frequent mentions of lack of exercise and weight gain. Many also mentioned experiencing fatigue and difficulty sleeping.

"Anxiety and enforced inactivity...I am a 24/7 carer for a physically and mentally disabled elderly parent and my already limited life has become much more difficult due to shielding."

"Constant heightened stress, which is affecting my sleep, due to full time caring responsibilities and working more hours than I normally would due to work demand."

7% of people mentioned the negative impacts of not being able to access health or care services. This included complaints about the difficulty getting to see doctors or other health and social care providers including dentists. People with long term health conditions reported increased challenges around managing their condition without the usual support and concern about symptoms getting worse.

Many respondents also had Covid-19 or suspected they had it and were still suffering the lingering effects of the illness.

"I had the disease in March and there was no help forthcoming from anybody so I just suffered at home."

Lockdown's impact on the health and wellbeing of disabled people

Eighty-four people with disabilities answered this question on Covid's impact on health and wellbeing. Among these, 69% mentioned a negative impact on mental health including anxiety, depression, and loneliness. Nineteen percent of people with disabilities mentioned the impacts of not being able to access health or care services (compared to 7% overall). This shows that the impact of services being closed was felt more greatly by those with disabilities who are likely to be more heavily dependent on routine services and appointments.

Positive impacts of lockdown

A small percentage of people reported positive changes in their lives or lifestyles since the Covid-19 outbreak. This was most often in the form of increased exercise or people enjoying not commuting to work every day and spending more time with children and family.

"Improved my quality of life (less stress commuting to work and more time spent with my children)."

"Healthier, due to more relaxed lifestyle & taking early morning exercise on Hampstead Heath!"

For some people with mental health conditions, the effect of lockdown was to reduce some contributors to stress.

"I am autistic and badly dyslexic. I have extreme anxiety and any change in my schedule is hard for me to deal with. On a plus note, the social distancing is amazing and I feel safer going shopping as people don't get into my personal space and don't try and talk."

"I have Asperger's so this has been a positive experience for me...everything has become quiet, no traffic noise, my senses get very over stimulated because of my autism so I have been happier and more relaxed and content since lockdown. I also have mental health problems which I think have improved since lockdown."



8 Keeping well

The second version of the survey which ran between 4th June and 31st July asked participants what they were doing to stay well.

More than half who answered (59%) said they were staying in touch with family and friends remotely (using telephone or online). Exercising both outdoors and indoors featured strongly along with watching films and cooking. Almost one-third of responders also said they were doing more reading, limiting how often they listened to or watched the news, and spending more time with the people they lived with (See Figure 9.).

In free response (rather than tick box) answers, many people also talked about the importance of keeping in touch with others through a variety of networks beyond family.

Figure 9. What are you doing to help you stay well during this time?¹³



¹³ 723 people answered this question.

Razia's story

Razia lives in Somers Town with her husband and four young children. The family is tight on space in their 2 bedroom council flat so normally Ravea spends as much time as possible with the children outside. Adapting to full days indoors has been a challenge. But Razia has tried to make the best of it.

"I am feeling really well", she says. "I am trying to look at this in a positive light. Before lockdown I was so busy and my husband works as well - it felt like I was in a relay run every single day. Just concentrating on doing the basics - eat, sleep, drink, wash - has made me realise that we rush around keeping busy and cause ourselves so much stress."

"We are in the month of Ramadan and we normally have family gatherings which we cannot do this year. But actually being just with my husband and children has been nice. Normally my husband would be out at work but because of lockdown we have the chance to prepare the food all together as a family. We can have time to reflect on our religion and because there is no school in the morning we're allowing the children to stay up with us. It feels quite spiritual. We are working together as a team."

Razia's full story, see Appendix section 12.3



9 Views on easing ‘lockdown’

As lockdown began to ease, we asked people how they were feeling and what would help them to make the transition out of lockdown.

Twenty eight percent of people felt that lockdown was ending too soon, felt confused, worried or anxious about the easing of lockdown, or felt their health and safety was being put at risk.

“I feel it's all too quick. I think people are underestimating it.”

In addition to those who felt it was too soon, 11% of people feared that the ending of lockdown would trigger a second spike in cases of Covid-19.

“The virus has not gone away. I am worried for everyone.”

Some people reported feeling that restrictions were being lifted for the “wrong reasons” giving priority to economic over health concerns.

“There is a rush to help the economy but not sure that's safe yet.”

“I think it's far too soon. I don't trust the governments intentions. It feels to be driven by economic reasons rather than safety.”

The level of distrust of government decision making was high among survey respondents. Some people (11%) also said they did not trust that the public, including friends and family, would comply with new post-lockdown guidelines including social distancing. Those who were vulnerable or shielding had particular concerns.

“I am highly concerned for risks to my physical health - my asthma and other demographic factors put me at higher risk. Am concerned that a spike in infections may happen. Am concerned that friends relatives and colleagues do not seem motivated to stay within regulations and are already in daily breach of these. Transition would be helped if I was confident that others will comply with guidelines.”

For some people who were either formally shielding or felt themselves to be vulnerable, the easing of lockdown contributed to further pressure on their sense of wellbeing as the collective public effort of “all being in it together” gave way to a division between those who were getting back to some sort of normality and those who were still forced to isolate.

Ten percent said that, despite the easing of restrictions, they will continue to be cautious and continue to stay at home or work from home and take other safety measures. They also said they intend to use their own judgement when considering changing their behaviours and not rely on government advice.

“I will wait a few more weeks before changing my new habits.”

“I will not be easing my personal lockdown.”

“Opening of all services can bring back virus. I am concerned about my children’s school. I am not giving my children to school maybe September... depends on safety measures.”

One major concern people had was about using public transport. Many said they would continue to avoid public transport even after lockdown ends and instead choose to work from home or cycle.

“I’m very anxious about my children travelling to school on public transport in September.”

Twenty six percent of respondents were either looking forward to the end of lockdown, or at ease with the prospect. They often mentioned the economy and the need for people to get back to work and school. Those who felt good about restrictions lifting also looked forward to returning to ‘normal life’ again and doing things they couldn’t during lockdown. Some were looking forward to the end of lockdown so that they could resume their care routines and get access to health and care services again.

“I think easing is a good thing - if done systematically and in a way that makes sense to the public. Some of the decisions seem strange and based around politics rather than facts. Need to get the children back to school.”

“I feel happy. The last three months wasn’t living, it was surviving.”

“I am feeling great for the country and economy to get back to normality.”

“I will go to my dentist and visit my doctor to check the diabetes. I would like to go the community centre meeting friends and do exercises.”



When asked what would help them to feel safe to transition out of lockdown, only a very small number (5%) mentioned having an adequate test and trace system in place and an even smaller number (3%) mentioned needing access to a vaccine. Sixteen percent said they needed clear guidelines from government about what this phase means, what people are allowed to do, and how the rules will be enforced. This included assurances of mask wearing and social distancing.

“Don’t feel that this is based on science. I wish people were mandated to wear masks and that social distancing requirements were clearly stated.”

“Happening too quickly, more government control of crowds and increased emphasis of importance of social distancing. More encouragement to wear masks.”

Many had mixed feelings about the easing of lockdown, and agreed that it was a difficult decision with many pros and cons.

“Can see the benefits to the economy, mental wellbeing and children. But important to balance how we protect residents from Covid-19.”

“I am cautiously pleased.”

Some mentioned they will need more support in the form of mental health or other health and care services.

“To help me transition it would be really helpful if low cost antibody tests were available for all or a proper track and trace system. There’s not much help out there to psychologically prepare you for the new normal, it’s just assumed you’ll keep calm and carry on.”

Among those who were shielding, many had similar concerns as the general public about the easing of lockdown. However, a greater proportion of people shielding said they would continue to be cautious after lockdown was lifted and either stay home or take other precautions to stay safe (21% compared to 10%). Seventeen percent of those shielding feared a second spike and 34% felt that restrictions were being lifted too soon (both higher than among respondents who were not shielding). Only 17% of those shielding were looking forward to restrictions being lifted (compared to 25% of total respondents).

Figure 10. Attitudes to easing of lockdown by ethnic group. % of that ethnic group who had the view of lockdown.¹⁴

	Asian/ Asian British/ Southeast Asian	Black/African/ Caribbean/Black British	Mixed/multiple ethnicity	Other ethnic group	White
Too soon	38%	12%	36%	8%	27%
Looking forward to it	15%	53%	18%	31%	24%
Continue to be cautious	7%	18%	14%	8%	10%
Mixed feelings	10%	10%	5%	12%	6%
Fear second spike	6%	10%	9%	4%	11%
Mistrust the public	9%	4%	14%	8%	15%
Mistrust the gov't	6%	0%	9%	23%	16%

Figure 10 (above) shows the differences in attitudes to the easing of lockdown by ethnic group. Interesting variation emerges, particularly between the relatively high percentage of Black respondents who reported looking forward to lockdown easing (53%) compared to other groups. In contrast, only 15% of the 82 Asian respondents said they were looking forward to lockdown easing. Those most likely to report feeling lockdown was being eased too soon were Asian and Mixed/multiple ethnic respondents (38% and 36%, respectively). Among those that were Black, not one mentioned a distrust of central government.

¹⁴Percentages are based on the number of people who answered this question and provided their ethnic group. There are 82 Asian/Asian British/Southeast Asian, 49 Black/African/ Caribbean/Black British, 22 Mixed/multiple ethnicity, 26 other ethnic group, and 363 White respondents included.



10 Next Steps

The national and local context of the Covid-19 pandemic is fast evolving. These findings represent an important point in time during the first six months of the UK response. The scale of the response to the survey may be indicative of the level of concern felt by local people about the Covid-19 pandemic and their desire to support health and care services through the crisis.

The sixteen key findings presented at the beginning of this report provide insight for the health and care system to inform preparedness and responses to future pandemics.

They also inform some suggestions for how things might be done differently and better if, or when, Camden faces a similar situation to that encountered in March 2020. It also informs some next steps for action and investment that will enable people who live and work in Camden to be more resilient to public health challenges in the future.

Since the survey's launch in April 2020, Healthwatch Camden has been proactively sharing emerging findings with various stakeholders in order to regularly feed resident experience into the coordination of the Covid-19 response. For example, we presented emerging findings at the June 2020 Health and Wellbeing Board and at Camden Council's inquiry into the disproportionate impact of Covid-19 on BAME communities. We also published 16 blogs which were either directly informed or inspired by what we were hearing in the survey responses.

Going forward, we plan to share the findings of this report widely across Camden, North Central London and beyond so that it has the greatest potential for impact. We will write a tailored and unique cover letter for each stakeholder and share insights and relevant suggested next steps and improvements.

In Spring 2021 we will publish an 'Impact Report' which will showcase each unique cover letter and set of suggested next steps, with a corresponding update on how this report has inspired changes and improvements.

11 About Healthwatch Camden

Healthwatch Camden is an independent organisation with a remit to make sure that the views of local service users in Camden are heard, responded to, taken seriously, and help to bring about service improvements.

Our duties (which are set out under the Health and Social Care Act 2012) are to support and promote people's involvement in the planning, running and monitoring of services; to gather views and experience and to make reports and recommendations for improvement based on those views; to offer information and advice on access to services and choices people can make in services; and to enable local people to monitor the quality of local services.

Our remit extends across all publicly funded health and social care in the borough. It includes statutory powers to enter and view any publicly funded health and social care service and to call for a formal response from the relevant bodies to any of the recommendations we make.

Healthwatch Camden has a seat on the Health and Wellbeing Board and contributes directly to strategies to reduce health inequalities across the borough.



12 Appendix

12.1 Methods

This report is the result of two versions of a survey created on SurveyMonkey. The first survey was used in the beginning months of the Coronavirus pandemic, between 22nd of April and 4th of June 2020.

By June, we realized the world was in a different place than when we first launched our survey. Covid-19 was more established and people were feeling the effects of long-term lockdown and change. People began to plan for the easing of lockdown restrictions. The second version of the survey was used from 4th of June through 31st of July 2020.

The two surveys had overlapping questions, and we combined the data from these questions for the analysis and this report. Surveys had additional, unique questions which resulted in a smaller number of responses, which are also included in this report. The exact number of responses obtained for each question are outlined in the report above.

The surveys used a combination of multiple choice, tick all that apply, and open-ended questions about experiences during Covid-19.

The surveys were accessible online and primarily were self-completed by residents. At the outset, the survey promotion included advertising on Twitter, Facebook, Healthwatch Camden website, and Healthwatch Camden newsletter (approximately 380 subscribers at the time). Other online outreach channels included local Mutual Aid WhatsApp groups, Instagram, NextDoor and mailing lists of the community partners, e.g. Visually Impaired Camden, Royal Association Deaf People, Camden Carers, Voluntary Action Camden, Special Parents Forum, CCG newsletter, and others.

The survey outreach was a multifaceted, collective effort between many Camden-wide organisations and contacts. The survey also had strong support from Camden GPs and hospitals. Between May and June, Healthwatch Camden partnered with four GP practices in Camden to send the survey link out via their text messaging system to entire GP patient lists. The four GPs were chosen based on previously established working relationships with Healthwatch Camden and based on which GP patient lists were more closely matched the demographic of the borough. While we couldn't ensure an accurate representation of Camden through the GP text messaging methodology, we could ensure that the opportunity was at least presented to a diverse and vast group of people.

Cholmley Gardens Medical Centre text messaging resulted in a 2.5% response rate (10,000 patient list), Kings Cross Surgery had a 1.8% response rate (7,000 patient list), Somers Town Medical Centre had a 2.0% response rate (5,000 patient list), and Adelaide Medical Centre had a 6.6% response rate (6,500 patient list).

The successful text messaging campaign produced a survey sample that was much larger than we had envisioned and which can be, with caveats, seen as representative of the Camden population in terms of its size. It should be emphasized here that the survey was not originally meant to be representative. Rather, the initial focus was on patients with ‘protected characteristics’, e.g. a disability. Therefore, no deliberate effort was made to create a ‘traditional’ probability sample, where participants are selected randomly.

In an effort to make the survey accessible to those who are not online, the survey was also offered over the phone. Healthwatch volunteers and staff would answer phone calls and proactively call those who were digitally excluded or not online who were interested in taking the survey. Conducting surveys over the phone took about 15 minutes per survey. Many other local groups and people helped get the word out about the survey to their networks. We are grateful to Age UK Camden for putting printed flyers about the survey into food delivery parcels for those who were shielding and who might not have been online. Healthwatch Camden volunteers also conducted outreach online and through printed flyers posted around Camden.

Additionally, Healthwatch Camden (with the assistance of Camden and Islington Public Health) commissioned two Camden voluntary and community organisations (Kings Cross Brunswick Neighbourhood Association and African Health Forum) to administer surveys to their Black, Asian, and minority ethnic service users via the phone.

The survey was both quantitative and qualitative in nature. Quantitative data was analysed through SurveyMonkey and Excel. Qualitative data was analysed by a team of Healthwatch staff and volunteers who used qualitative theming methods to read through and theme all qualitative answers and develop insights.

We collected demographic data in this survey. All demographic questions were optional and many chose to skip various questions. For analysis purposes, we excluded 71 responses from people who answered ‘No’ to both ‘Are you a Camden resident?’ and ‘Do you use health and or care services in Camden?’ We still read and considered these answers but chose to leave them out of the final report in order to create a specific report that serves Healthwatch Camden’s remit. This left us with a total sample size of 1,590 for analysis.

All questions in this survey, including demographic questions, were optional which left some people leaving questions blank. In the report above, the sample size of



each question is listed for accuracy. See Appendix A for demographic breakdown of survey respondents.

We received resident feedback that standard ethnic groupings used on other surveys do not represent how local people actually identify and therefore provided participants with the option to self-identify in a free-text response.

For the purposes of our report, it was important for comparison reasons to group respondents into the different major ethnic groups used by Camden Council and other bodies. We wanted to evidence which groups were further impacted by the pandemic and might need more support going forward.

Black/African/Caribbean/Black British includes those who self-identified in our survey as any of the following: *Black, Black British, African, Black Caribbean, North African, East African, Somalian, and West Indian British*.

Asian/ Asian British/ Southeast Asian includes those who self-identified in our survey as any of the following: *Asian, Asian British, Chinese, Hong Kong Chinese, Indian, Filipino, South Asian, Southeast Asian, Bangladeshi, British Bangladeshi, Pakistani, and Sri Lankan*.

Mixed/multiple ethnicity includes those who self-identified in our survey as any of the following: *Mixed, Mixed Race, Multiple Ethnic groups, Mixed British and Asian, Mixed Arab, Black/White British, Mixed European and Asian, mixed White British and Black African, White/Black Caribbean, Russian/Jewish/African*.

Other ethnic group includes those who self-identified as any of the following: *Latin American, Arab, Arabic British, other ethnic group, Mediterranean, Jewish, Brazilian, Sephardic, Greek, Hispanic, Latina/o, Turkish, Russian, Chilean, Persian, Middle Eastern, European, Spanish, Australian, and South American*.

White includes those who identified as any of the following: *White, White British, White European, White other, Irish, White UK, White US, Caucasian, White Australian, Scottish, White English, Pakeha, Northern Irish, and White French*.

See Appendix section 13.1 for demographic breakdown of survey respondents. The survey sample broadly represents the demographics of the Borough of Camden. 30% of our survey responders were from Black, Asian, and Minority ethnic backgrounds compared to 34% in Camden. However, those aged under 18 and 18-24 were slightly underrepresented in our survey, when compared to Camden as a whole. Our survey also had an overrepresentation of females to males, when compared to Camden as a whole. One hundred and eight people, or approximately 7% of our survey responders had a disability and 20% had a long-term health condition. This is compared to 14% of Camden residents who have an illness or disability which affects their day to day life.

12.2 Demographics

Figure 11. Age of survey respondents¹⁵

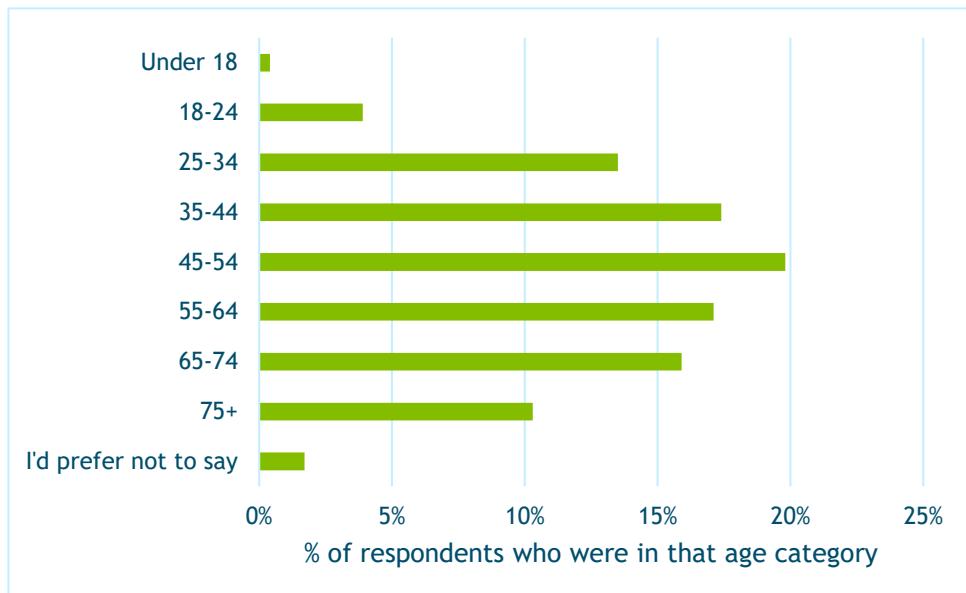
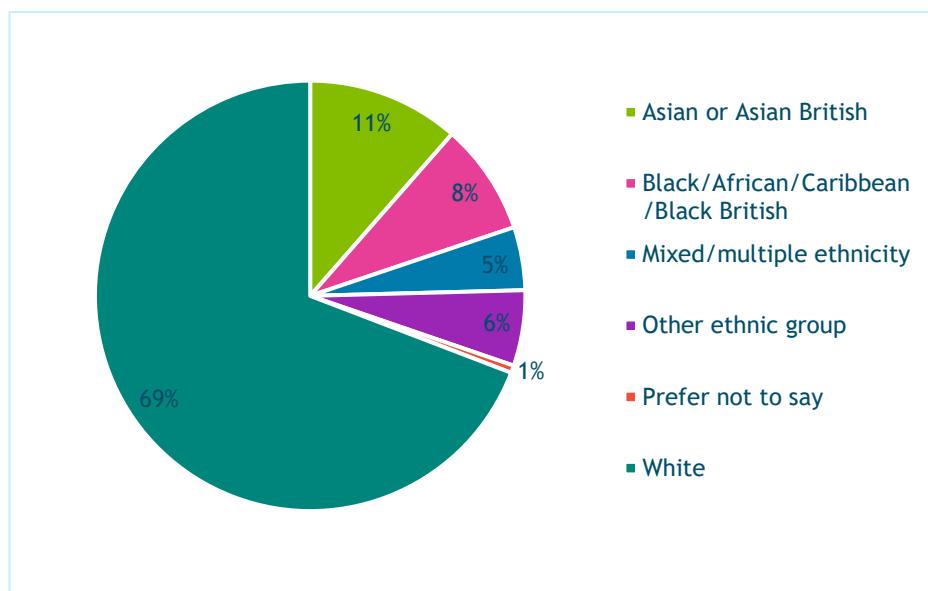


Figure 12. Ethnic groupings of survey respondents¹⁶



¹⁵ 1278 people answered this question and 312 people skipped.

¹⁶ 1,074 people answered this question and 516 skipped



Figure 13. Gender of survey respondents¹⁷

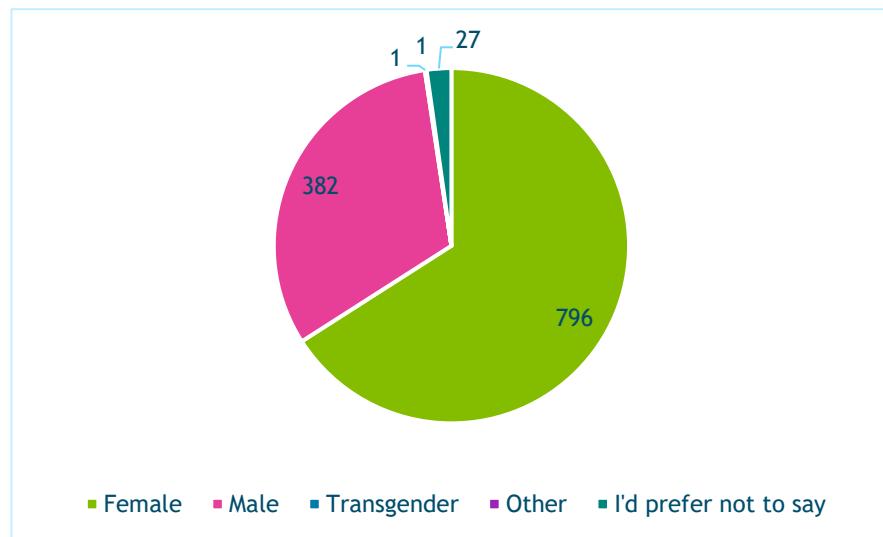
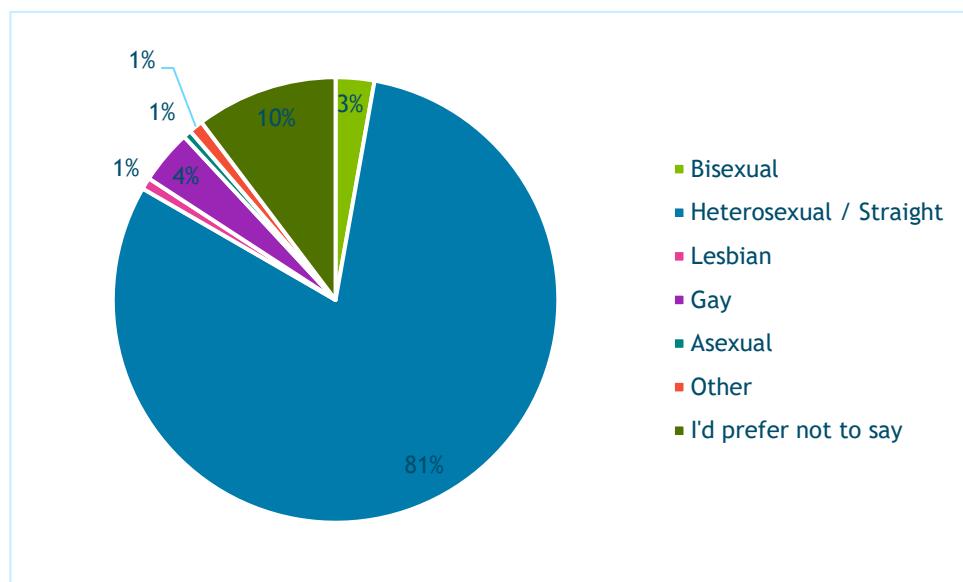


Figure 14. Sexual orientation of survey respondents¹⁸



¹⁷1207 people answered this question and 383 left it blank

¹⁸1,176 people answered this question and 414 left it blank

Figure 15. Other characteristics of survey respondents

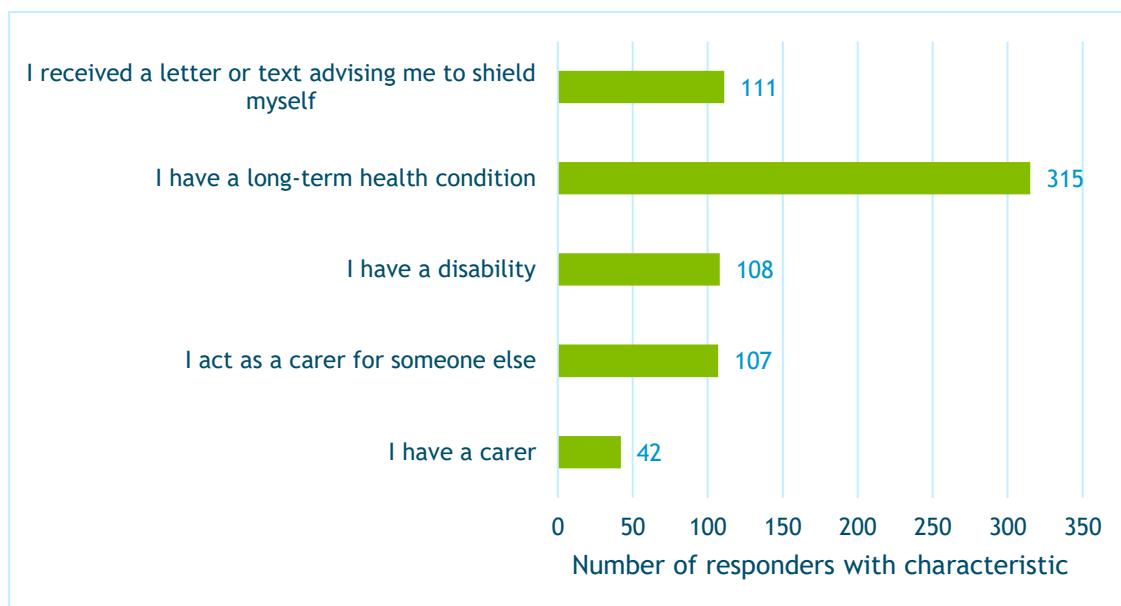
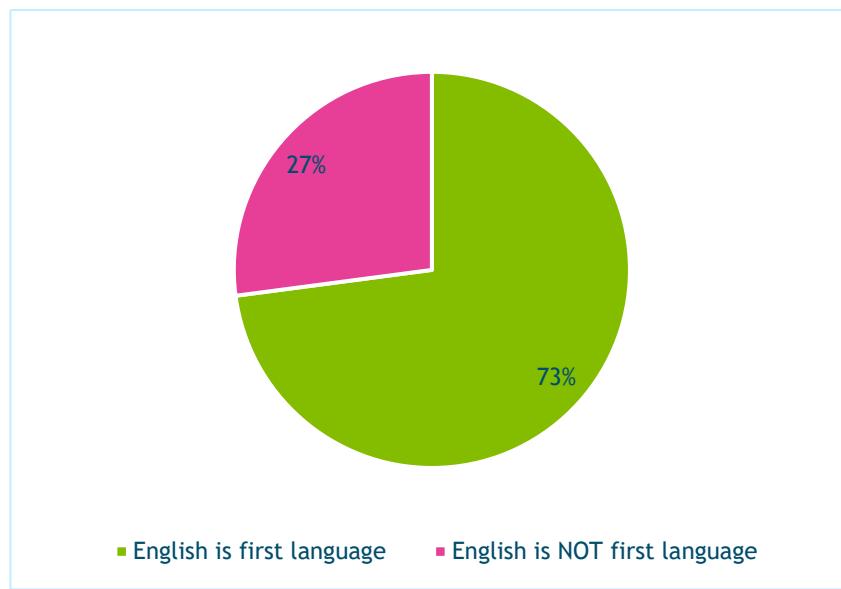


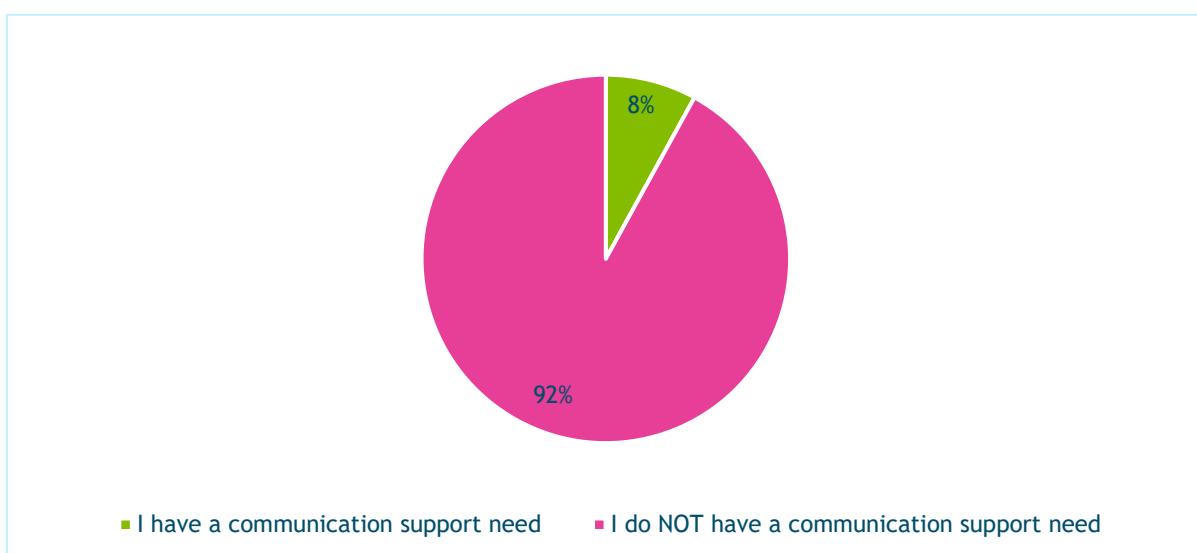
Figure 16. Is English your first language?¹⁹



¹⁹ 1270 people answered this question and 320 skipped



Figure 17. Do you have a communication support need?²⁰



Of those who answered yes to this question, many went on to describe that they required British Sign Language, had visual impairments, need Easy-read documents, use Braille, audio, or large print, need information in another language, lip read, needing extra time with materials, need an interpreter or translator, or have autism.

²⁰ 1263 people provided an answer to this question and 327 skipped



12.3 Personal Stories of Life during Covid-19 Lockdown

Eight Camden residents (one mother-son pair) were invited to participate in the Healthwatch Camden work to collect case studies about life under lockdown. The participants were identified through both personal and local network contacts and were selected to represent Camden's diverse community. Each individual agreed to be interviewed once a week over six weeks so that we could hear whether and how things changed for them as the weeks of lockdown continued.

During an introductory interview of about 45 - 60 minutes, we gathered information about the circumstances of each individual and asked how their life was different during lockdown. We went on to ask about use of local services and changes to the way each participant was accessing services. We also gathered information on the ways in they were getting the information and advice they needed and finally we asked them how they were feeling. Over the following six weeks we returned to the same interview questions so that we could track changes over time.

Although each individual reported different experiences, several common themes emerged from the case studies. Most importantly, the negative impact on general health and wellbeing was evident. For some of the participants, resilience was severely eroded as the weeks went on.

All the participants reported enjoying the process of the weekly conversations which gave them a chance to reflect on their experiences.

All names have been changed to protect identities and all participants have given permission for their stories to be published.



Personal Story 1: Razia

Razia lives in Somers Town with her husband and four young children. Razia has a job at the local primary school so, like many, has been forced to make the shift to home working and home schooling.

The family is tight on space in their two bedroom council flat so normally Razia spends as much time as possible with the children outside. Adapting to full days indoors has been a challenge. But Razia has tried to make the best of it. She is dealing with the overcrowding by getting organised and making as much space as possible to play with the children.

“I am feeling really well”, she says. “I am trying to look at this in a positive light. Before lockdown I was so busy and my husband works as well – it felt like I was in a relay run every single day. So not having to do my hair or even get out of my pajamas is relaxing. Just concentrating on doing the basics – eat, sleep, drink, wash – has made me realise that we rush around keeping busy and cause ourselves so much stress.”

“We are in the month of Ramadan and we normally have family gatherings which we cannot do this year. But actually being just with my husband and children has been nice. Normally my husband would be out at work but because of lockdown we have the chance to prepare the food all together as a family. We can have time to reflect on our religion and, because there is no school in the morning, we’re allowing the children to stay up with us. It feels quite spiritual. We are working together as a team.”

The local primary school has been a huge source of practical and moral support – providing information and advice to families, providing free school meals and making efforts to enable the children to be in touch by seeking written permission from parents to share contact information and setting up video conferencing.

The family case worker who provides mental health support for Razia’s husband has continued to be in touch and checks they are all okay but this is all done virtually on a smart phone. “*Just knowing someone’s there helps,*” says Razia. As the weeks went on, several other local groups and individuals reached out to make contact via newsletters and emails, including the Ward Councillor and local volunteers.

“Technology has made all the difference. If this had happened ten years ago we would have been totally cut off!” As time went on however, Razia started to report emerging challenges.

By week three, the issue of access to schooling for her children was high on Razia’s mind. The family has one laptop and two smartphones between them so they are sharing devices to enable the children to do online school work.

The eldest child is at secondary school. She often cannot do her work until the evenings when one of the phones or the laptop is free. The situation improved when the school provided the family with an additional laptop so that the children could do online lessons.

Razia takes some regular medications and, as time passed, she realised she would need a repeat prescription. “*I had a text message from the GP saying they are open on Friday which is the Easter bank holiday. So I will call them on Friday.*” As this text was the first communication she had received from her GP, she had not been aware that the practice was open before that. But when she did ring, she found it very convenient to have a telephone appointment instead of going in and her new prescription was sent direct electronically to the pharmacy.

By week four, financial difficulties were starting to bite. “*I am thinking of applying to the Somers Town crisis Covid relief fund because my husband’s earnings [as a self-employed taxi driver] have gone right down. No one is taking taxis and he has to pay for the lease and insurance on the car even if no money is coming in. I don’t understand why he doesn’t qualify for the government’s self-employed income support scheme.*” The application form for financial help from the crisis fund looked daunting and the number of questions was off-putting. It took Razia three days to complete.

By the following week there was a new worry – about returning to school. “*Boris Johnson’s announcement was very confusing and we are all worried about the risks of having to go back to school.*” On the bright side, Razia was starting to feel more relaxed about going outside with the children and had been enjoying the sunshine, seeing local people at a distance and teaching her son to ride a bike in the local open space that, in normal times, would be busy with people and cars.

However, by the following week, the taste of being outside and the enjoyment of more social contact was making it harder to be inside again. “*Before, when we knew we couldn’t go out, it felt okay as we knew we didn’t have a choice. But now the kids are nagging to be outside.*”

The Eastman Dental Hospital had been in touch. Razia’s daughter was disappointed at the cancellation, due to lockdown, of her appointment to remove her braces. But they had heard nothing since until a phone call to offer advice about continuing to care for her teeth. “*They said they would give her a new appointment as soon as it became possible. It was nice to know they hadn’t forgotten about us.*”

The free school meals for which the family is eligible had changed from food packages to meal vouchers. “*I think food packages are still needed as a lot of us don’t want to go out to do shopping,*” says Razia. “*Camden is offering a service to help people with shopping- it’s about knowing who to contact in these situations.*” At the time of our final interview, Razia had not heard the results of her application for emergency financial support.



Personal Story 2: Jane

Jane is disabled and lives with long term health conditions. She was advised by her doctor that she was at high risk from Covid-19. So she began shielding even before lockdown and she withdrew her children from school. However, her husband is a self-employed plumber with no recourse to government financial support. He has no choice but to continue working at a building site which, they feel, is putting the family at risk. “*It’s a massive strain on our physical and emotional health in the household and me and my daughters are not leaving the house,*” says Jane. Paying their housing cooperative rent is going to be a challenge and their requests for a rent break have only resulted in a referral to potential benefits they could claim. Finding somewhere else to live while shielding is not an option.

During our first interview, Jane reported her confusion around advice and support services available. As a regular user of NHS services, Jane had to contend with very significant changes to the support she receives. All her regular monitoring appointments were cancelled. “*They haven’t offered me anything online or by phone. I’ve been left completely in the dark. Because of the nature of my condition this could have serious implications for my health,*” she says. “*I know my condition well enough that I could self-manage but I cannot feel comfortable doing that unless I have a specialist I can communicate with for support. But all communications with the hospital have just completely stopped.*”

Jane did get contacted by her GP to notify her that she has been registered with the Government as shielding and would therefore be entitled to register for support with food provision. But she also has concerns for her daughter who has asthma and her mother who was recently diagnosed with a serious condition. “*It’s confusing because children with asthma haven’t had any communication about being vulnerable while adults with asthma have.*” “*My mother was missed off the shielding list as she was only diagnosed just before lockdown. So we had to chase the GP to get her registered.*”

Access to food was a challenge in those first weeks. Supermarket delivery slots were all taken and Jane struggled to get the priority she was entitled to as someone formally shielding. “*My husband took my shielding letter to try to gain early entry to a shop but was turned away as he was not the named person shielding. But if you are shielding you can’t go to the shops!*”

“*There are some great social media groups that tell you which shops are delivering but for many it’s hard to find support as everything is online,*” she says.

Jane said she had not received the letter that was sent to residents from Camden council about support and advice available. Jane took action. “*I set up a local mutual aid group on social media but it’s been a struggle to reach vulnerable people to let them know support is there.*”

“The information has been quite good for me – I’ve been communicated with about how to protect myself but the lack of communication has been about my ongoing care and my continued health. That’s the part I’m struggling with.”

By the time of our second interview Jane was starting to face considerable challenges managing her complex conditions. *“I had a phone call from another of the clinics I attend at the hospital to cancel my appointment. I asked if I could have a telephone or skype consultation but they said they are not doing them. No date given for re-arrangement. I’m falling between the cracks.”*

The health gains Jane had been making were being undermined by the sudden halt to her regular swimming and physiotherapy sessions and by the interruption to her regular medicines monitoring. She also faced difficulties with her supply of some regular non-prescription medication with deliveries interrupted.

As time went on, the challenges started to mount up. By our fourth week interview the family was finding things more difficult on every level. *“Financially, emotionally, physically things are getting worse for all of us,”* says Jane. *“One of my children is struggling to cope and hasn’t been sleeping.”* There was a limited therapy offer from school of 15 minute free appointments but these all got booked out fast so Jane had to resort to private therapy support which has been helpful.

On the bright side, by week four there was some progress with access to food. *“Iceland and ASDA have now added me to their list so finally the fact I am on the shielding list has filtered through. Before I had been getting in touch with shops to ask for this entitlement and the shops hadn’t been informed – even though I had got the letter. But they said the government hadn’t told them yet.”*

Jane also reported a good experience with her GP who had spoken to her on the phone. *“It’s normally such a strain to get there – it’s daunting and exhausting so I’d often put off going as I don’t have the energy,”* she says. *“This time my GP rang me. Instead of having to have tests they just went on my judgement which was quite liberating. It’s made me feel like I’ve got a little bit of control back over my own care. I wasn’t expecting that. When you are dealing with so many different doctors you start to feel totally out of control of your own body.”*

By the following week Jane’s health had improved and she was trying to take a more relaxed approach to the challenges of home schooling to ease the pressure. This coincided with the first stage of easing of lockdown.

“The lack of clarity from the government has had a huge impact on how we are behaving. My family are still inside due to me shielding but the world outside feels like it’s going back to normal but nothing in place for school or work. It makes those of us who are shielding feel like we are forgotten about. The more the world goes back to normal the less safe I feel to be able to engage in anything. It means we have to be even more cautious and there’s no longer a sense of everyone being in it together.”



By our final interview, Jane had decided that the positive benefits of venturing outside with her children outweighed the risks. A gated community garden nearby has provided a safe environment for her children to run around with plenty of space for Jane to protect herself by staying distanced. “*My daughter was really struggling but this has made a real difference. And I have had enough. When it started it felt okay because we felt we needed to just get on with it and cope for 12 weeks but now we realise that for vulnerable people like me it won’t be over anytime soon.*”

A problem with her teeth had presented a new challenge. “*I lost a filling. When I called the dentist, the answerphone referred me to 111. They do have an emergency service where they are wearing full PPE but I am supposed to be totally shielding and not go out of the house. It’s not that the service isn’t there – it’s whether I have the confidence to feel secure doing that because it goes against the advice I have been given to shield.*” “*I am only just about finding the confidence to step outside my front door. They have suggested I can give myself a temporary filling getting the product on Amazon! So maybe I’ll try that.*”

As we said goodbye after six weeks, Jane reflected: “*I think I have accepted that I am in limbo and that my health is not going to be looked at until I don’t know when. Our family life for the past few years has been totally dictated by hospital appointments and constantly thinking about my health and all that has suddenly stopped. In a way it’s actually quite nice.*”

Personal Story 3: Karim and Bernadette

Karim is thirty-five years old. He is registered disabled and suffers from sickle cell disorder making him highly vulnerable to Covid-19. He lives with his mother, Bernadette, who cares for him and they are shielding together.

Lockdown has had a big impact on him, including making it difficult to go to hospital for his regular blood transfusion on which he depends to stay well. The risks involved in leaving their home and travelling to hospital for the treatment made them both very anxious. On top of this, the new Covid-19 related restrictions at the hospital meant that Bernadette could not accompany her son in a taxi and stay with him during his transfusion as she usually does. Instead, he had to rely on hospital transport which was difficult to organise in the early days of lockdown.

“My mood and depression has deepened and I am anxious most times because of the unknown,” he says.

Karim reports receiving a letter from his GP in the very early days of lockdown which he and his mother found very reassuring. They also received some information from the ministry of housing and from Camden Council informing them where to seek help and offering advice. *“However, the information was general and I would of expected a follow on from an office closer to home, addressing needs and some form of assurance.”*

Because of his long-term health conditions, Karim usually has regular contact with different health and care services. He is coping with big changes. *“The lockdown has made all services very difficult to reach. Most of my appointments were cancelled and I was not able to talk to clinical staff.”*

Karim also needs to take care what he eats and uses dietary supplements such as vitamins which have been difficult to obtain. *“Not being able to go out freely to purchase the foods necessary for my wellbeing makes life difficult.”*

For his mother, Bernadette, caring for her son while isolating is difficult. In particular, she finds it very distressing not to be able to prepare the healthy foods that she says are instrumental to her son’s wellbeing. She is also distressed by the withdrawal of routine support services.

“There has been changes to all of the services that I depend on for my son. Appointments have been cancelled and changed. Some clinics followed through with calls whereas with some there were no calls – no information on who to call on if an emergency arises.”

“Besides going online and registering Karim, I did not know what to do and was very worried in case ifs and buts occurred,” she explained. However, before long, a social care team member called. “She was very instrumental in I becoming less anxious about things. I was able to get people to assist me.”



Bernadette stresses how important it is to have a person offer guidance rather than depending on finding information online. “*Having physical people to point the way made it much easier to assist in meeting the needs,*” says Bernadette. “*It would be better, I think, for one of these professional persons to make contact and be able to discuss and outline a more personal plan for the individual.*”

When asked how she is feeling, Bernadette is honest. “*Am always on high alert, tense. I’m okay but it is very lonesome, being stuck indoors with an ill family member.*”

A week later, she was feeling more upbeat. “*I feel more hopeful about Karim’s care and I am finding more time for myself and being able to proceed with my projects. I am more relaxed,*” she says.

Feeling better supported was a significant factor in this change in mood. “*I got a call from Camden transport enquiring about help Karim may need in the future. They have logged the date and time he will need their services and this has taken away any stressful feeling regarding his next trip to the hospital. I also received a text from a local volunteer, asking about myself and Karim’s wellbeing and reminding me that I can call on him anytime.*”

Nevertheless, being very vulnerable means life is proving very difficult for Karim. He hasn’t been able to go out to participate in any activities and being stuck inside and feeling frightened is taking its toll. As time went on, Karim’s mood worsened. “*I am bored and more grumpy and I haven’t been able to get the food I requested from Camden,*” he said in the fourth week of interviews.

Bernadette’s mood is also affected. “*I feel saddened about Karim’s situation. It’s very difficult to separate my feelings from his.*”

A trip to the Whittington hospital had felt very daunting although hospital transport had been provided and the service had been prompt and reliable.

Thing got harder as the weeks went on. Karim began to report that he was “*feeling terrible. I can’t go out and it’s exacerbating my moods.*” “*I’m now in fear of the second wave and this is leading to more stressful tendencies and stressful behaviour,*” he says.

Other ongoing health issues such as his eyes also start to give him problems. “*It’s frustrating to know what to do or who to call, except finding a way to get to Moorfield eye hospital.*”

In her final interview Bernadette reports that she is getting increasingly concerned about her son’s mental health. “*From experience, I believe Karim needs an input of counselling support. And because of the current situation it’s difficult to get the help. That gets me frustrated and sad,*” she says.

Personal Story 4: Jamila

Jamila lives with her two sons aged five and six. Her younger son, Hamza, is severely autistic with learning disabilities that mean he is non-verbal and incontinent. He has been under medical and social care since birth.

The impacts of lockdown on this family are extreme. With school closed and social care provision on hold, Jamila is faced with a huge challenge to care for her boys on her own in their small flat.

"I live in a prison with Hamza always, but Covid-19 lockdown has made it worse," she says. *"He self-harms when in distress. Since the start of lockdown, we have him for 3 weeks screaming and neighbours banging on the walls. It's also difficult for my other son. He is at home all the time with his brother screaming and headbanging and having a meltdown."*

Ensuring Hamza gets the right food is a problem because there are many foods that he won't eat. *"At the start I had a letter from the government to say we are very vulnerable. But we don't seem to have got any help as a result,"*, she says. Jamila was not able to get any supermarket delivery slots. *"They said if you have not had a letter from GP or NHS you need to contact them to request that you could be included on the shielding list. The health visitor refused to register him but the social worker helped - she brought nappies and some food."*

After some time, Jamila managed to get some of the right foods. *"The rationing has eased up but the shops have not accepted us to be on the vulnerable list."*

Jamila is very anxious to protect herself and her children from Covid-19 and fears that venturing outside with Hamza is too risky. *"Normally he loves to go outside but the problem is that he grabs things and he licks everything."*

In normal times the family relies on a lot of support including a health visitor, an occupational therapist, a dietitian, a social worker and a paediatrician from the Royal Free Hospital. But much of this has been affected by the lockdown. *"Hamza has a carer 4 hours a day. She has still been coming but it's not safe for her to come inside or take him outside. Instead she's been standing in queues at shops to get food, nappies, and medicine. It ends up taking up all her time."*

The play provision that Musa, her other son, normally attends is also closed. *"The paediatrician has called and sent the medicine. The occupational therapist has spoken to the dietitian and has been in touch trying to support. The social worker came on her free day and brought some cereals that Hamza will eat as well as nappies and paracetamol that I need for him."*

Another form of support has been the local mutual aid WhatsApp group. *"They told us about the food hub close by and gave me contact details for a volunteer but I haven't really followed up on that,"* says Jamila.

"There is lots of information on social media and family and friends have passed on information to me. I speak Somali but I don't need information in languages other than English. I have a cousin in Sweden who sent us food."



With some of the issues around access to food easing up over the first weeks, Jamila felt slightly better. “*I’m a bit better than last week – as long as I can manage with the food. We couldn’t find food for him – it was terrible. Having a child screaming from hunger is unbearable.*”

However, the stresses of being stuck inside had not eased. “*The neighbours have been banging on our walls and on our door and now they are calling the police because of his screaming. His behaviour doesn’t normally affect them so badly because they are not at home all the time,*” she explains.

As the weeks went on, things did not improve. “*I’ve had a bad time. My son is in a bad way. He cannot drink. A lot of crying. He is not well. We haven’t slept for two nights.*” She had contacted the GP and had a telephone consultation.

“*Normally they would examine him. It takes four people to hold him for a physical examination so this time it was just guesswork.*”

“*Because he can’t go out it’s so much worse. There is no distraction now from the crying.*” Jamila asked the social worker if they could organise some respite and they offered to arrange a session for Hamza at a play centre. But Jamila felt she could not take up the offer, as there was no safe way to travel there due to her son’s tendency to grab and lick things where he comes into contact.

“*I called the social services line this week but no reply. They know how to hide when they want to. They know us. They wanted me to meet with a new social worker but why start with a new person during the pandemic just meeting her through the phone? What’s the use?*”

Another problem is that Hamza breaks things in the home such as the safety locks in the kitchen. “*I usually get a handyman to mend stuff once a month or so but I can’t get him now.*” To add to her difficulties, the special wheelchair buggy that she needs in order to take Hamza outside is broken and can’t be mended in the lockdown circumstances.

Better weather had improved Jamila’s mood the following week. “*Well it’s nice weather – we are okay. I am going to try to go out and take the children out with the carer because they really need to go out.*” The heat also brought challenges. “*He has a special bed which is waterproof and fixed to the floor. It’s sweaty in the hot weather. He hasn’t slept. I was planning to get a handyman to get air conditioning on the ceiling to help but I can’t do that because of lockdown.*”

Jamila is also growing more concerned about the impact on her older son of missing school. “*My computer is not working. The school sends some work on paper. But his brother rips it up. So we wait until Hamza is asleep and then Musa can do his homework. They said that a child who has a social worker can get a laptop for the children to do homework.*”

The Child and Adolescent Mental Health service had called about doing an assessment and had offered a therapy session online to help Hamza calm down. But without a device to access the internet this was not possible. In a positive development, the social worker had been liaising with the housing officer to intervene with the neighbours and ask them to be more tolerant. Also, Hamza had been offered sessions at the Greenwood Centre. Jamila is frustrated. “*We must take two buses to get there! And other passengers complain at Hamza’s behaviour and get angry which makes it hard for me. When I told them we can’t get there they said that’s the only thing they can offer. So I guess then they tick a box that says I have turned it down.*”

The following week Jamila’s resilience was weakening. “*I’m worn out,*” she says. “*I am physically and mentally tired and the children are tired of it all too. Hamza has been very difficult. Not everyone can follow these lockdown rules, especially if you have a child like mine. He is scratching and eating the wallpaper and throwing things through the mailbox. This lockdown has really affected him. We need a chance to recover.*”

This week Jamila had been trying everywhere to get help. She had even called Islington social workers who told her they couldn’t do anything for her because she was from Camden. She had asked the Camden Early Years team whether she might be entitled to a short break for respite but they explained it was very difficult to offer during lockdown.

“We celebrated Eid alone and a friend brought some sweets to leave at the door.”

Another issue facing the family is the return to primary school for Musa. “*I won’t take that risk,*” says Jamila. “*There is nothing that this government is telling us is believable. It’s not clear and I am following my instincts which say no it’s too soon. You have to follow your instincts sometimes as a parent.*”

Although Jamila is in contact with a wide range of services, she feels that none of the support offered is appropriate for her and her family’s needs. “*I didn’t agree with the Education, Health and Care Plan and we are waiting for mediation,*” she explains. “*They all say we cannot help and with each new service they have to start over again with assessments and they twist the words and give you false hope. I am willing to pay myself. I just need help to find things that will help.*”

Meanwhile, the stress of lockdown and the prospect of having to continue to isolate while others start to return to school and other activity is taking its toll.

“I don’t want to do something desperate but it’s just total burn out for me now. What’s the exit? I have no support – nothing. If I get sick who is going to look after my two boys?”

At her last weekly interview, Jamila reported that things continued to be tough but there was some good news.



“The only good news is that McDonalds re-opened yesterday. We got delivery and he ate two happy meals in one sitting and he was so happy.”

They had also ventured outside. *“For the first time I took both boys out for a little walk close in the area when it was quiet at 7pm. It is very challenging but baby steps..... just a few minutes out.”*

In another step forward, it has started to feel safe enough for the carer to come inside. *“She is very careful. She puts on face mask and gloves and shoe cover. She cannot risk working with Hamza but she took Musa out for a while so he got some respite,”* Jamila explains. Also, arrangements were being made for them to receive a laptop from Camden so that Musa could connect with school and the family could access some online services.

However, this week they also had to cope with a serious incident. Jamila explains: *“Hamza’s behaviour changes. In the first month we had the screaming and head banging. Next, we had picking and breaking things and drinking out of the toilet and putting everything through the letterbox. Then he was eating the wallpaper. He puts everything in his mouth and destroys everything. It’s very dangerous. Now he’s obsessed with the door.”*

The kitchen door must remain shut for safety reasons as Hamza has no awareness of danger and is a risk to himself and others. This week the door got stuck. *“The medicine was shut inside as well as my phone so I couldn’t call for help. After two hours trying to get it open I had to knock on my neighbour’s door to get help and use the phone. I called the police – I had no choice. The officers came and got the door open for me. It was very embarrassing and I am ashamed to have had to disturb the neighbour – I’ll have to send a thank you.”*

Reflecting on what might have helped her cope better with lockdown, Jamila says *“I think it would have helped if we could have had a bit more warning that lockdown was coming so we could have better prepared the vulnerable. I hadn’t got stock in of the special things I need to look after my son. And, if I had warning, I could have made arrangements for my other son to go to stay with relatives so he wasn’t locked in with his brother screaming all the time and could do his homework. I wish I had been able to prepare.”*

With all that she has to cope with, Jamila still manages to keep a sense of humour. *“You have to laugh or what can you do?”*

Personal Story 5: Harry

Harry is a student at the University of London and is living in student accommodation in Camden. He is transgender and lives with a disability. He also lives with mental health issues.

At the time of his first interview, Harry was struggling with the impact of lockdown which confined him to his student room, bringing back memories of a period earlier in life when he suffered from severe depression and anxiety.

"It feels like I've gone back years to when I'd dropped out of school due to bullying and gender identity issues and was living in my bedroom. Before lockdown I was starting to recover something of an adult life. Now it feels like I have lost everything I had achieved and am back just to living in my room," he says. *"During the first couple of weeks I felt suicidal – I felt what is the point of having made the progress I have?"*

"My early experiences of mental health services meant I lost trust. So now I don't want to reach out to any services other than things I really need. Instead, I have learnt a lot of self-care techniques. The support in Camden might be good but I am hesitant to reach out because of my bad experiences."

Lockdown also presented Harry with some immediate practical challenges in maintaining his regular treatment. *"I have an NHS prescription for hormone replacement therapy from a gender identity clinic but some GPs refuse to fulfil the prescriptions for me or challenge me on it. GPs often don't know anything about transgender people at all. I had to change my GP practice 3 times because of being refused treatment. So now I've signed on to GP at Hand. I have a regular injection prescribed through GP at hand which I collect from a pharmacy then go and have it injected at a separate place. During Covid-19, the pharmacy to which my prescription is normally sent was closed. So I had to go back via GP at Hand and get it sent elsewhere. In the end I was able to get the hormone injection at a clinic that was open. But it was a disruption to the process I thought I had finally got sorted so it was very worrying. I have to rely on a chain of GP, pharmacist and clinic so there are three things that can go wrong."*

Harry is living in a student block so finds it hard to isolate as he shares a kitchen and toilet. *"All the social distancing information assumes you are in a home of your own. There's nothing to advise people like me who are sharing a toilet with 15 others. The security guards are on edge. We are fighting in the student union for more clarity on what the university should be doing for us. It would be nice to have an advice page on a website for students self-isolating in halls. I think student halls are an area that's been very neglected."*

Harry is not too worried about getting the information he needs although he thinks the government advice is confusing and contradictory.



"It would be good to have more information about what's open and available in terms of services – for example, dentists. But if I really need something I will search the internet." He has joined the local mutual aid WhatsApp group as a volunteer. *"But there are hardly any people who need help compared to the number of volunteers!"*

He does, however, have worries about his studies. *"It's been really hard to find out what the new arrangements are for course work. I need advice on how to adapt my dissertation to the circumstances. The University didn't have comprehensive and clear advice on what should be happening. But my biggest worry is that I might find my mental health getting worse because of this. I am more anxious than before and not seeing people and having activities to go to is affecting my mood."*

By the following week, Harry was feeling better. Linking with Extinction Rebellion protesters had been fun, connecting him with other people and giving him a sense of doing something for a good cause. *"Today I'm actually feeling really good,"* he says. *"I am part of a protest. We are occupying an area under a tree to save it from being cut down. We are sitting carefully apart with deck chairs wearing masks and hand sanitising and limiting the number of protesters on site at any one time."*

Harry found that getting outside had been positive in many ways. *"I've actually found I've been so much more productive with my course work because of getting out under the tree. I don't deal with change well at the best of times so dealing with the sudden and unwarranted change has been hard. I am on the autistic spectrum and have ADHD which I think has made it harder for me to adapt – to keep up with the hardest aspects of everyday life like having a sleep routine, shopping, food and study while I can't do the fun things that keep me going like socialising, visiting museums."*

To help support himself, Harry had explored an online Cognitive Behavioural Therapy course offered free by the university but had decided it was not suitable for him. However, he welcomed a wellbeing email that had been circulated to students. *"Usually it's just telling us there are counsellors available but now it's got better at offering links to resources. This is good. I wish they'd been doing more of that before. Getting their act together."*

Harry reported that he had ventured to travel by bus. He found the experience interesting. *"It was weird because it was a combination of politeness and hostility. Everyone eyeing up – don't come closer. I normally find physical contact difficult but find that being close together is easier on public transport because, strangely, there is no social aspect to the touching or acknowledgement of personal space with everyone just shoved close together. But now suddenly that self-consciousness about personal space has come onto the bus too."*

By the time of his next interview, Harry had big news to report. *"I'm really happy because I'm moving out of student halls into a flat. I'm lucky that I was able to figure out online ways to flat search. The properties I looked at had been empty for quite a while. Because of Covid-19 you can't view when people are in."*

He has also made good progress with his studies. “*I finished my last course work essay so now I’m getting on with my dissertation. I prefer using online resources so not being able to use the library is not a problem for me.*” He’s also been accessing some university meetings that had been shifted from live to an online platform and using the phone to follow up on things like career advice. “*Something that is interesting about lockdown is that I’m not so anxious about phone calls anymore because I’m having to do so many of them.*”

Harry has been using outdoor spaces more and more. “*I can go to the park and work. I can be more productive than when I’m sitting in my student room. I am so depressed sitting inside the room and I feel safer outside.*” The Dominic Cummings affair had also had an impact on his thinking. “*It’s made me wonder why I’m bothering to observe anything. I’m not happy with one rule for them and another for us. I feel as long as I am taking infection control measures – keeping distance, washing hands – I shouldn’t have to restrict my activities anymore.*”

Life moves fast when you’re a student and by the following week there were more new things going on for Harry. “*I’ve been on the Black Lives Matter protests and my samba band is starting to get back together. We’ll practice at a distance in the local park and break into smaller groups.*”

“*I have definitely been feeling better – not trapped and aimless anymore. It really does feel like there will be an end to this. At the start of lockdown it really felt forever. Now it doesn’t feel such a long time anymore.*”

He’s also been busy sorting out arrangements to move into his own rented flat. “*It’s involved lots of online stuff and I’ve had to talk my mum through everything in terms of sending me documents and she doesn’t do online so that’s been difficult. Everything is harder when you are not digitally fluent.*”

Harry does have some concerns about the easing of lockdown. “*I feel worried about what easing is going to mean for the general population. I am not worried about my own health. My living conditions mean I can’t realistically self-isolate anyway so I am resigned and I’m not in touch with people who are particularly vulnerable. I know I shouldn’t be getting lazy about infection control but I find I’m just not thinking about it so much which is not good. But then I know it’s so much better for my mental health to get out. This is what has changed in the last couple of weeks. People are now prioritising things other than the pandemic.*”

At the time of the final interview Harry was about to move into his new flat.

“*I feel like my life is getting back to normal. I was worried that the usual activities that I am involved in would never start and it might be the last time I would see my friends from University. Some of them are graduating and so there is a feeling of loss. It could have been an amazing summer. It’s been the first time I felt like a normal functioning adult and Covid-19 took that away from me. But it could have been a lot worse.*”



Harry is very aware of the different trajectories being experienced by different people. “*I realise for me it’s going to be a lot faster to get back to normal than for some groups of people.*”

He’s having to make changes to his future plans for doing a PhD. “*I should have been going to India but I can’t do that because of the situation. So now I have an alternative PhD plan about how we use music in activism and working with the activist Samba community which is much closer to what I really want to do. So, in fact, the Covid-19 situation has been an opportunity to step back and think about what my priorities are.*”

“*I think I’ve stopped paying attention to government information. It feels arbitrary and irrelevant now. I know what I can do to protect myself and others and we just need to follow the lead from community and friends about what we need to keep safe and look after each other.*”

Personal Story 6: Abreshmina

Abreshmina is an Iranian born creative writer. She is 81 years old, highly independent and, until recently, was a fulltime carer for her beloved husband of 60 years. Despite struggling with her own aches and pains in her neck and back, Abreshmina washed him and tended him when he woke which was often two or three times at night. Eventually however, managing his dementia became too challenging and he now lives in a nearby care home where, until lockdown, she would visit him every day. Being unable to visit her husband has been the greatest tragedy of the Covid-19 restrictions.

"I will do anything for him because I know how wonderful he is and I know he would do the same for me. Now I can't even see him. On the telephone he sometimes doesn't know me so now I can't communicate with him at all and it breaks my heart. I am thinking about him all the time." Abreshmina is supported by her daughter who lives close by and calls her every day. But she likes to get out.

"I was an independent lady. I used to go out every day because my flat is small. I used to go a walk and do my shopping. Now, because of the situation, I must stay home. It is horrible for me. I am sitting on my own. I cannot be sociable. I am not talking to my friends or phoning them because I don't want to tell people about my sadness. This morning I felt ready to die."

Abreshmina knows that help is on hand if she needs. Her daughter has ordered her shopping online. Neighbours are also on hand. *"The neighbourhood has made a small army to help and they have told me I can let them know if I need,"* she says. She is also in contact with Camden Carers who have called her to check she is managing. But for this independent lady, depending on others is not her style. *"I like to be able to choose my own things from the shelf and I like to have a reason to go out to get something for myself. So I am going out to get my shopping. I wear a mask and gloves. People let me go in and not wait in the long queue."*

Abreshmina's health is not good and she hasn't been able to visit her GP in the way she normally would. *"I have a swollen foot and my allergies are back,"* she says. *"I phoned the GP and the doctor phoned me back. He made a prescription and told me to phone the pharmacy and they would deliver it to me. It worked okay over the phone. I got the prescription. Doctor was very kind. But he couldn't do anything for my foot because I need an examination and in this situation I cannot go. My daughter said don't go to hospital because it is dangerous for you."*

Isolation and loneliness are already taking a toll. Abreshmina explains from the perspective of a poet. *"If I can write a poem there should be a tingling to my brain otherwise I can't write. I feel my brain is completely blocked because I feel sad and hopeless. I used to be very active but now I am like a bird in a small cage. Life has become so much smaller – I feel I am suffocating. But today, doing this interview, I have talked myself out of my sad mood!"*



The following week, Abreshmina was in better spirits. “*It’s a sad time but I feel a little bit hopeful. I went out and I bought my fruit and milk.*” Undaunted, she had been travelled by bus to the shops but was taking precautions with careful hand washing. She had also been contacted by Age-UK to offer support.

The week had involved complications around getting her prescription and anxiety seemed to be affecting her day to day management of practicalities. “*I didn’t contact the doctor’s surgery because now they don’t answer the phone and you get a long lecture from an automatic voice... Instead, I phoned the pharmacy but unfortunately I forget things my memory is a little bit funny. I feel more anxious than usual so I find I am forgetting things completely. For example, my pills for cholesterol –suddenly when I finished them I realised I didn’t have any more.*”

“*Thank god yesterday they delivered my prescription to me. I said they should put it in a carrier bag and hang it on the door handle but they put it on the door mat – lots of germs – so quickly I opened the door and took it with gloves. And twice I changed my gloves.*”

She reported that new information had arrived although much of it seemed to be confusing and some was inappropriate. “*I have had letters with information from Waitrose and John Lewis and from British Gas. Lots of different information. I get some funny letters – for example I got a letter about the TV license in my husband’s name saying my TV license will finish but I wanted to phone them and say what are you talking about my husband is in a care home!*”

Abreshmina has continued to be defiantly independent. “*My daughter tries to convince me not to go out to buy food and I know that if I need anything she will organise it. But I decided myself, because I am very independent, I believe I should go out and if I want to go again I will.*” She has, however, started to avoid public transport. “*Before I was taking the bus but now after the rule change the bus is too crowded. I can’t walk very far without sitting down. From my flat to the shops there is nowhere for me to sit down but I can sit on the bench at the bus stop.*”

She has also been active online, getting in touch with friends and family. “*Always I am sitting by my laptop and my mobile. One of my cousins (who lives in Canada) sends me lovely videos to make me laugh and another cousin in Los Angeles phones me. And I listen to the news.*”

The best news of the week was that she had been able to speak to her husband at his care home over the phone and was reassured that he was well. Talking about her husband makes Abreshmina very emotional and she becomes tearful as she speaks of her love for him.

By the following week, there had been a significant breakthrough in communicating with the care home.

"It was wonderful," says Abreshmina. "I saw my husband using video on Facetime. They are taking care of him and he was clean and shaved. So I am happy about that." She had also spoken with the manager and was very grateful to him for making this contact possible and very complimentary about all the staff at the home. *"They say I can do Facetime anytime but usually I just phone to hear his voice."*

Abreshmina had also been busy socialising over the phone with lots of calls from friends in Iran and elsewhere. *"I've had a good day,"* she said.

In her final interview, Abreshmina expressed mixed emotions. She was feeling hopeful that there may be an announcement that lockdown was easing and she could go out more. The saga of getting medical attention for her swollen foot and adjusting her blood pressure medication was continuing. *"I phoned the surgery with lots of difficulty and they made an appointment for the doctor to call me back. The doctor called me but the first time I didn't hear the phone. I called them back to say I was waiting and why didn't I get the call and they said he phoned but you didn't reply. I am a bit deaf."* Eventually, however, she did speak with the doctor who was able to make a good diagnosis over the phone. A new prescription had helped reduce the swelling. Nevertheless, Abreshmina's anxiety about her health was clear. *"I am not scared of death but I am frightened of falling or something and dying here alone in my flat without anyone knowing."*

The care home had made a short video with her husband. *"They took him into the garden and he was drinking coca cola or something and eating a lolly but he didn't like that he likes ice cream but I was very happy because I saw my husband. They sent the video to my daughter and she sent it to me and I was able to watch it on my phone."*

She went on: *"Today I phoned my husband. There was good news because they did a Coronavirus test and my husband was negative. Physically he is in better shape than me but his brain is out of work because of the dementia."*

"In a way I am happy that his brain doesn't work because otherwise he would miss me and be unhappy. Instead it's me that misses him and is unhappy. I wish I could still be taking care of him but it was too difficult after I had my fall. But he is alive. And when this thing is finished we will go to visit him – me and my daughter – and we will buy him ice cream which he loves very much."



Personal Story 7: Marjorie

Marjorie lives alone in her flat in Somers Town. Despite her ongoing health conditions, she lives an active and busy life which belies her 84 years. Because of her age she is shielding during the Covid-19 lockdown which has involved a dramatic change to her life.

"I'm never normally on my own," she says. "I'm out and about. But now I am alone. I can't see my friends. I ring them but it's not the same. I'm lucky to have a balcony so I can get some fresh air and I try to structure my day. I have an exercise programme for my joints – if I'm not careful they seize up. Normally I go to a gym, but it's not possible now. It's very quiet and boring although I don't mind being on my own. I watch a film in the afternoon."

Despite living alone, Marjorie feels well supported by those around her. *"I live in a block of flats. I'm fortunate that everyone wants to help because they know me. I have neighbours who have been very helpful. People get things for me and leave them at my door."* She's also received various communications with information and advice and offers of support while shielding. *"I've had the letter from the Prime Minister and two emails from the NHS telling me not to go to the GP surgery. Instead I must ring 111 if I'm in trouble. I've had several text messages telling me to stay indoors."*

However, all her routine appointments have been cancelled. *"My dentist emailed me to cancel my appointment. And I have to get my regular medications through the pharmacy. I can ring up my pharmacy and they order them for me. My neighbour collects them or the pharmacy delivers."*

Marjorie is well informed and has embraced the opportunities of communication technology and the internet. *"I have a background in health and care, and I can get online so I can find the information I need. I use the NHS website which is quite good. I follow the news quite carefully. I use my iPad to look it up and I have a cup of coffee and read the papers online."*

But Marjorie is concerned that others are unlikely to be managing as well as she. *"Lots of older people haven't got the technology. I wouldn't cope if I didn't use my iPad. I don't know how on earth some people are getting the information. Camden Council could deliver paper-based Covid-19 information to every door but then people can get suspicious of people knocking on the door."*

"When this is over, they need to think about communicating with vulnerable people. Someone should know who they are and how to find them. GPs should know them and have them on their databases. Age UK is doing good work."

By week two, Marjorie reports becoming increasingly bored and is busying herself with domestic tasks. *"I did all the chores last week so I'm not going to scrub the floor again. This week I'm going to cook more."*

She'd received food deliveries from the supermarket but found lots of items missing, particularly fresh goods. So she had searched online and found a place in Covent Garden that would deliver fresh fruit and veg. "*I phoned them up and ordered online and it arrived this morning,*" she reported.

"I've also got some new books, some from my neighbour and some from the bookshop. I try not to watch too much television," she says.

Marjorie has continued to pursue her interest in keeping well informed about Covid-19. "*I receive information through the Covid app. They ask you to answer a couple of questions every day. They will remind you if you didn't check in. They give you lots of information if you want to read it, all about their new survey, about the research they are doing. I learned about the app from an older people's charity.*"

As time went on, Marjorie decided to take matters into her own hands. "*I decided to rebel! So I've been out today. I walked along the canal, which is very different from when people would sit down and drink. I enjoyed it. Just sitting around is not good, I am going to do a walk every day. I don't want to go too far or take a bus. I am happy to be seeing people.*" She also went to the pharmacy. "*They were very nice and asked me how I was. They all wear masks and only let one person in at a time. I was in and out in a flash.*"

Marjorie says she's been eating well "*too well*". She's also pleased because her cleaner, who has been having to stay away, returned this week to help her. But she's still not able to get her hair done. "*I'd love to go to the hairdresser. They sent me a video on how to care for my hair.*"

By the next interview, Marjorie was feeling increasingly confident to go out and about. "*I had a lunch in a garden in Muswell Hill. It was a beautiful day. I got a cab. They separate the driver and the passenger, and I wore gloves. It felt safe.*"

However, she's feeling increasingly bored. She's been putting her time to good use sorting out her wardrobe and doing her filing. But overall she describes "*the same old boring week.*"

By the week of her final interview, Marjorie is resigned but fed up. "*I am very bored and very stiff. I am getting very restless. I've managed to do my household chores. I am getting bored with TV and movies. I miss the people that I usually see. My friends ring me a lot. On the whole, I am managing. I am not ill or disabled, but I've had long periods when I had to be indoors.*"

She continues to appreciate the advantages she feels she enjoys. "*I do everything online, shopping, banking. I am blessed that I can move around and use the computer. My neighbours are very helpful, the young people are very good about asking if I need anything.*"



There is one significant positive to lockdown which concerns her hay fever. “*This time of the year is usually miserable for me because of pollen and poor air quality but this year has actually been better because there’s no traffic so less fumes.*”

Marjorie is continuing to contribute to Covid-related research efforts. “*I got an email asking to subscribe for regular surveys, I think it was from Kings College London Geriatrics Department. I’ve done this for three days. They asked questions about age, weight, ethnicity, questions about pills. Today they asked if I wanted to sign up for the tracing app.*”

Television and books continue to provide entertainment. “*I’ve been looking at thrillers, there’s a good one on Channel 5. I am trying to make it exciting when it isn’t. I am reading The Mirror and the Light by Hilary Mantel.*”

However, this is not a life she enjoys. “*My usual boring Covid week,*” concluded Marjorie.

13 Acknowledgements

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