

May 2021

Unlocking the Digital Front Door: the keys to inclusive healthcare

Personal Narratives



Listening to people's experiences

We have worked with three partners, the Abbey Centre in Central London, the Centre for Seldom Heard Voices in the South West and Change People who have interviewed 27 people between them about their experiences of accessing healthcare.

We wanted to fully understand the barriers to good care, particularly from the perspective of people with high burdens of ill health and who are affected by inequality.

In this report, we share the reports from each organisation, which feature short introductions and first person accounts.

Interviewers shared question prompts and encouraged participants to tell their own story.

Introduction:

Abbey Community Association is a registered charity located in the heart of Westminster. Having delivered services since 1948, we continue to fulfil our original objectives of supporting the communities of south Westminster to improve their quality of life. The south of Westminster is characterised by households living in concentrated areas of acute deprivation in close proximity to some of the wealthiest households in the UK. This diversity presents unique challenges for our communities, expressed in perceptions of low community cohesion and access to affordable food, services and housing. We work towards social justice by delivering projects to improve health and wellbeing and running socio-economical projects for local vulnerable residents and families. Our projects are shown to increase inter-community and generational understanding and connections.

Methodology:

The Head of Community Programmes has overseen, which was managed by the Community Champions Project Coordinator and the Community Champions Outreach Worker led the delivery of the project. We hired two bi-lingual sessional workers, one of whom speaks English and Bangladeshi (MS), and the other one speaks English and Arabic (AD) to conduct the interviews. The interviews with participants were conducted during 1st December 2020 to 31st January 2021. During February and March, the audio recordings were written, and the report was completed.

National Voices provided the “Brief and Materials’ Pack” for the ‘Digital Front-Door’ initiative, which were given to the sessional workers, at our initial meeting, in December 2020. This included Bournemouth University’s National Voices Digital Front-Door Project Field Work Briefing Pack and Conversation Prompts, Participant Information Sheet, Participation Agreement Form (PAF) (compulsory) and Photo Consent Form (optional) which were provided to the participants to sign and return to us. The Bangladeshi sessional worker agreed to interview eight clients, and the Arabic speaking sessional worker agreed to interview seven clients.

At the time of delivering this project, we went into the second Covid-19 Lockdown. During this period, one of the sessional workers contracted Covid-19, so on her behalf, we arranged the delivery of the forms to some of the participants’ home address to be signed and returned to us in the “Stamped Addressed Envelope” we provided. A “WhatsApp Group” with the sessional workers was created, so we could easily communicate with each other, especially during Lockdown.

A total of 15 PAFs, 6 photo consent forms and photos of the participants, who agreed to have their photos taken, were received and emailed to Sam Hudson. Bearing in mind we had to follow-up on some of the forms to be signed and returned to us, including the completed audio recordings which the sessional workers sent to us via WhatsApp. AD used a smart phone to speak to her clients and record the interviews. The only challenge AD experienced was that one of her clients spoke very quietly. MS used a laptop for her 1:1 Zoom meetings with her clients to explain the project before the clients did voice recordings of the interview.

Before the end of January 2021, the audio recordings received via WhatsApp were transcribed in a draft format. One of the drawbacks with audio interviews was that some recordings were not clear, and inaudible as participants spoke softly, even with volume on high when transcribing so it was difficult to transcribe fully plus some recordings were a bit longer than others. In addition to

the language barrier which one of the sessional workers helped to translate from Arabic language to English.

The audio interviews involved two males and 13 females, three of whom spoke of their own experiences as well as their spouses. Their ages were between mid-20s to early 60s and the ethnicities are different including Black African, White & Black African, Arab, Bangladeshi, and Spanish. Health conditions experienced by the interviewees include diabetes, cancer (one with pancreatic cancer), hypertension, very bad back problems, thyroid, epilepsy, Irritable Bowel Syndrome (IBS), arthritis, asthma, high cholesterol, high lymphocyte count, joint problems, gallstones, knee replacements, anxiety, depression, food allergies, and dealing with grief.

Table 1 – participants’ demographic data

Client Initials	Age	Gender	Ethnicities	Languages spoken	Post codes	Health conditions
DM & spouse	37	Female Male	Black African	Arabic and English	SW1P	DM: IBS Spouse: hypertension, diabetes
KM & spouse	44	Female Male	Arab	Arabic and English	SW1P	Spouse has long term health condition, very bad back pain, broken foot.
AU	60	Male	Bangladeshi	Bengali and limited English	SW1V	Diabetes, high blood pressure, high cholesterol
AC	51	Female	Spanish	English and Spanish	SW13	Diabetes, thyroid condition, arthritis, on gluten-free diet, food allergies. Suffer sometimes from depression and anxiety and grieving as lost few close people recently.
AK	61	Female	Bangladeshi	Bengali and English	W1F	Diabetes, cholesterol, high blood pressure, arthritis. Spouse has cancer.
BK & spouse	60	Female	Arab	Arabic and English	SW1W	High blood pressure, arthritis, overactive bladder husband: pancreatic cancer
SS	25	Female	Bangladeshi	Bengali and English	SW1P	Irritable Bowel Syndrome (IBS)
SB (Mrs)	42	Female	Bangladeshi	Bengali and English	SW1V	

SB	28	Female	Bangladeshi	Bengali and English	SW1V	No relevant health conditions.
AA	53	Female	Arab	Arabic and English	SW1P	Problem with blood - high lymphocyte count. Last year, had gallstones which affected the liver and now taking medication and has long-term thyroid.
AI	58	Female	Arab	Arabic and English	W2	Very bad back pain, high blood pressure and asthma
KS	59	Male	Arab	Arabic and English	SW1P	Joint problems. at high risk of having diabetes.
ML	65	Female	White & Black African	Arabic and English	SW1P	Two knee replacements, severe asthma, epilepsy, severe health condition, at the top list of the vulnerable list and advised by the doctors and GP to shield.
HK	54	Female	Black African	French and English	SW1V	Cancer
NB	52	Female	Arab	Arabic and English	SW1P	Asthma, diabetes, arthritis, and anxiety.

Source survey December 2020 - January 2021

Personal Narrative 1

DM is a 37-year-old Black African female, originally from Sudan, and has been living in London for 10 years now. She worked in her country as a doctor.

DM's recent experience during Covid-19 as a patient: She had IBS symptoms and had an appointment with the doctor who did an investigation and said it was something related to her liver, so she had to do an ultrasound and had to wait for this. "This is normal, happens all the time but I have been waiting for about 4 months and every time I phone them, they say you need to wait because of Covid-19. I am not comfortable at all. All this is uncomfortable, stressful, and really affects my life as I have children and husband at home. Nobody cares about this. There are new regulations about Covid-19, which is understandable but still at the end of the day they will have more cases with another issue."

DM's first appointment was digital then they booked another appointment for her. According to DM, digital appointment is fine, it is quicker, it is easier but for DM, she is not convinced because hiPersonal Narrative and examination are important to have a diagnosis or to make any diagnosis. "Virtual examination via screen is fine, you do not need to go to a doctor. Some people have a language barrier, some people are afraid. So how you can manage all that? Imagine if it is something urgent, something chronic. I'm not talking about myself but the other people."

DM's husband is living with diabetes and has hypertension. "He spoke to the GP that he needed a blood test. This happened before the Christmas holidays and because of the new regulation that you need to wait outside then they will let you into the GP surgery, this made a delay in time but after that he missed the appointment. And this is not his mistake that he missed his appointment. This is their mistake. And, unfortunately, they didn't give him the test and they did not give him his medication and he could not have all this medication during the holidays for two weeks."

"First GP speak to me virtually then I have the appointment with them, but it took a long time and I'm not happy at all about this. Not happy about not seeing them face-to-face as this is only history, but no examination, they do not ask about other symptoms, they delay everything. The investigation and your symptoms get worse, and this is more stressful because you have condition, you have the symptoms, and nobody care about your health, others, and my husband's as well. It is not something positive at all."

And, unfortunately, they didn't give him the test and they did not give him his medication and he could not have all this medication during the holidays for two weeks.

In terms of support, "Need more data - people need to know about the things that happen around us. Because all the things that they do they make us feel "fear", to go even to the hospital. If you have something urgent, you have this "fear". I will not go to the hospital (because of this "fear"). And if you speak to them, only they explain now because everything is closed, you do not have to go, this is something "denied", but I need to see someone. Okay I do not want to go to the hospital, but I need to be seen by anyone before I do anything. Not only virtually, but this will also not help.

It will help people like having more data, more explanation, appointment – the time of the appointment if they have long time to explain not only 10 minutes on the phone and even if you speak to the receptionist, but they also say the doctor will speak to you. I spoke to the receptionist



at 8 o'clock in the morning and they speak to you at 10, 11 o'clock after few hours, you have been waiting.

For me that is fine (enough data/credit on phone) but some people have this as a problem. They do not even have credit on their phone. This is really an issue and a big issue for all the people, for the vulnerable.

Language barrier (English) – this is a very important thing; we must keep an eye on that. We need people to interpret”.

Personal Narrative 2

KM is 44- years old. She is originally from Kuwait and has been living in Westminster with her husband and four children for nearly 13 years now. She does not have any health conditions, but her husband has a long-term health condition.

KM's experience for trying to access health care: KM struggles with this because it is difficult to make an appointment for her husband to see a doctor.

"If my husband needs any appointment, they take a really long time. It is difficult to phone the doctor, and it is difficult to have a face-to-face appointment. My husband always needs a face-to-face appointment, but we are always waiting for the doctor to call us back and sometimes they do not call us back. Other times when we call to make an appointment, they keep us waiting for a long time. One day I needed to make an appointment for my husband for his back problem and it took us nearly a month to get an appointment. So, when the time came, I forgot about the reason I was calling for that appointment for my husband because he has more than one issue including a very bad back pain.

There is no face-to-face appointment so we cannot see a doctor. It is difficult to see a doctor. It is difficult even when we see the doctor. The first thing they need to know is if we have coronavirus, but if there is any other health issue or condition, they put you on hold. You need to wait for the doctor to call you back so it's really difficult that one."

My husband always needs a face-to-face appointment, but we are always waiting for the doctor to call us back and sometimes they do not call us back.

Making appointment for KM's husband: KM called to make a physiotherapy appointment before Christmas for her husband and was sent a text message with an appointment on Boxing Day. "They called us yesterday (Thursday) and they said they would charge us because we did not attend the physiotherapy and when I told them 'Sorry you gave me that appointment on that day and when I called to cancel or see if that was a mistake or something, no-one was there because it's Christmas Day/Boxing Day and New Year'. It is difficult when they (Receptionist) tell you "yeh", we charge you for that." I spoke to the physiotherapist after that, and the £18 fee was cancelled.

It is very difficult now, because of Covid-19, to access the health care or hospital. If there is an emergency there is no ambulance, you need to use your car or bus or go by cab. It is difficult because my husband has a lot of problems and he needs support. He needs someone to help him to just walk but they told us 'no, it's not allowed and it's just one person because of the situation'.

It is not easy because I had a situation. I twisted my foot which resulted in a fracture. At that time there was no ambulance, so I went with my daughter in a cab to the hospital. They did not ask me anything but told me to go to Emergency which was far as the cab dropped me off a long way from there. When I reached the Emergency door, they did not let my daughter go in with me because she is not a translator and I can speak English. I just walked by myself, with the stick with difficulty, just jumping on the ground. It was a really hard time, there was no chair, no one help me with a chair, when I sat on a chair, they left me in the corridor, and I think they forgot about me. I sat there for 4.5 hours from 5 o'clock. The doctor saw me at 9:30 pm, did an x-ray and let me go at 10 pm, jumping on my stick and left foot at that time. There is no support. At that time, I told my



daughter to go home because I think I will stay for a long time there. So, it was a very, very difficult time.

You spend a very long time there but more so now because there are not a lot of doctors or nurses so with the lengthy time spent at the hospital, you really feel more tired, so I prefer to stay at home, take anything or any tablets if something is not serious like the 'flu'. I just try to do what I can but with my husband's situation I need to be there with him. It is like there is no other solution, but this really takes very, very long and it is difficult to be in a health care or hospital or any place.

The difficulty I am facing is about my husband's medication which I need to order monthly. When I speak with the receptionist they say 'no let us just send it to the doctor to see', so it is difficult, there is no face-to-face to talk with the doctor to see my husband, to see his blood test, to understand if he needs to raise the medication or not, and they told us just to email, not text but email the request or wait for a doctor to call you to see if he needs to raise the medication. Everything really put us down and puts us off.

In my husband's situation with his back problem, it is difficult when they cancel a lot of his appointments which are important. The hospital cancelled his appointments that he needs twice every year, but they cancelled treatment for his blood, circulation for his blood, and even the operation for the disc for his back and neck. They cancelled his appointment for an ultra-sound for his neck/leg. They cancelled a lot of appointments and they do not even tell us when they will make a new appointment for him. No-one sends a letter or even asks him to go to the GP just to see if he is ok or not. Nothing on the health care is positive, all very negative for me.

I think it is very important to have access to free calls because some places or hospital charge us."

Personal Narrative 3

Mr AU is a British Bengali citizen and aged 60 years old. He has been living in the UK since 1978 and living in Pimlico, London with his wife and 6 children. He has high blood pressure, high cholesterol, and diabetes.

He often finds it difficult to access health care and is not fluent in English, so he finds himself unable to explain his health issue. It is also very hard to get hold of a doctor and to ask in GP and hospital and he finds himself waiting for a long time. It is also hard for him to make an appointment because of this.

“Last week I was on the phone talking to the receptionist at my GPs to get appointment regarding my high blood pressure and booking for another check-up of my blood. And today, after the check-up, the doctor advised he will call me to discuss the blood pressure and tell me the result.

I did see my GP recently and I did not have to fill any form or anything else.

The last time I made it to access to urgent or out of hour care was for my son as he was feeling unwell.

We called 999 and they came. There was also high traffic. When we arrived at the hospital, we waited for four hours and the queue was too long which made us want to leave.

My wife experiencing severe arthritis and her pain was very bad. We had to send email to the GP which was sent to doctor. It was difficult to take the picture. As we are not a doctor, we do not know what is specific enough. We also had telephone appointment regarding Covid-19 system.

It was very hard accessing health care, not being able to speak English properly. I find it difficult to understand what the doctors are saying. GPs are always busy, so it is difficult to make appointment. Doctors are rarely free. Waiting time is very long. I had to wait 4 hours, the last time. I barely find time as I have 6 children, some are in education and I work full time.

It is difficult to use digital health care as I am not knowledgeable with the computer, so I barely know how to use it. I cannot fully explain my symptom or how I am feeling as well. The shift to digital health care does put me off with accessing the service.

Digital health care – negatives: I still must go to the GP for my physical appointment such as blood pressure, blood test due to personal health issues. It is difficult to articulate how I am feeling and explain my symptoms.

It is difficult to use digital health care as I am not knowledgeable with the computer, so I barely know how to use it.

Digital health care - positives: I can be at home and still be with my children even if I must work. Save some transportation cost, less time in the waiting room and less chance of catching Covid-19 or any illness that may harm me.

What will help and support me to access digital health care: Free phone call and data and broadband/Wi-Fi. Bengali interpreter will be beneficial to me. Tablet and good phone that allow



me to take clear picture for doctor are useful. I find it scary to go outside and take walk for exercise as I could catch the coronavirus.

I had diabetes's complications as last week my blood sugar level was too high which was too risky and harmful to my health."

Personal Narrative 4

AC is originally from Spain. She is 51 years old and lives in Westminster, Victoria and has been in the UK for the last 20 years or more. AC is living with diabetes. She was diagnosed with thyroid condition. AC also has arthritis and must have a gluten-free diet as she is sensitive to many foods and allergies. She sometimes suffers from a diagnosed depression and anxiety and finds it difficult grieving, having lost a few close people recently.

“I was going to have a face-to-face appointment with a health professional just before the Lockdown. They keep changing the appointment, and a few days before the Lockdown they decided not to have any patients. So, I have been waiting for a referral for a very long time. And I was quite disappointed because they changed the doctor it took long, and they just refused to see anyone a few days before this Lockdown. Then I have a phone conversation with another doctor and I just said, “listen I am quite emotional, quite unwell right now, I need to see someone face-to-face, sometimes I am not very good over the phone.” I am talking about my personal circumstances, so I was refused to have a face-to-face. Recently I was referred to see a doctor face-to-face. I was helping people in a care home and I just said I am quite anxious because of Covid-19. I feel much better now but needed to see someone face-to-face and the NHS medical professional (psychologist) was shielding at the time.

I tried to access out-of-hours/urgent health care recently and was put through to a call centre and referred to another place and another call centre with music and was waiting for the professional to call me back all day. I called 0800 0234 650 for mental health trust regarding my crisis. I was given two different numbers for the same situation. It was a waste of time, especially as I was finding it difficult to breathe. It was making everything worse. I was expecting someone to call me back, but it never happened. I have not seen anyone face-to-face, professionally.

I do not have a smart phone or computer so I cannot access virtual health care and rely on neighbours and friends or libraries, but they are unavailable now.

I am unable to communicate verbally as it is emotionally difficult to express over the phone. I prefer to see someone face-to-face. And if it is for something physical, go to the doctor if quite unwell. I find it very unfair. I have used 111 in the past. They ask so many questions and want your details where you are, where you are calling from. I prefer the NHS direct, conversation with GP/doctor. I find that it is about engaging with someone so if you are talking to someone over the phone and it is something emotional that person must have good skills over the phone and try to reassure the person. It makes things worse for you if you do not have someone that is warm and supportive or for physical health if someone really knows how to engage with that person. It is more about the human kind of engagement. I do not feel like it is like the human kind of engagement. I have come across people who have had their own agenda and rushing you through.

I do not have technology, I have a simple phone and feel a good advocate would help sort things that are basic, which would be important, as sometimes I am not managing. Perhaps a free course that would help with finances, as I am really struggling with paying bills. Sometimes feel I need to see someone face-to-face and sometimes can deal with over the phone. Feel a bit weary

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speaking to someone over the phone. 'Record this conversation for training purposes', I have no choice. I would like to have a choice and make my own decision at the time.

In terms of getting my medication or sometimes a support worker when I need it, I do not always need it but sometimes my situation where my health deteriorated, and I probably need someone to help me through for a couple of weeks or to deal with calls or hospital appointments or to have access someone to help me.

With Diabetes UK's good website, I, managed to get a lot of information over the internet, I have a good friend who is a nutritionist, I try to find alternatives. I know exercise is good but if you are not well, mentally, it is hard to keep up with the routine. So, sometimes I need someone to just give me a push and help and support.

Support at home – Last social worker support was just a waste of time. Just taking notes and they were going to help get me a card but that never happened. Felt like it was 'ticking the box' game. But in the past, I have had very good support. Not sure what is going on now, maybe I've just been unlucky."

Personal Narrative 5

AK is a 61-year-old British Bangladeshi female who lives in Central London. She came to England in 1976. She is married with two children who were born and brought up here. For the last 6 – 7 years her health condition has not been very good. AK is living with diabetes, high cholesterol, high blood pressure and arthritis.

“In my experience since March’s lockdown started, I can’t go to my GP. When I phone to speak to GP, receptionist ask what the reason and she explains. Then she says the Dr will call you back. I do not know when the GP will call back. Later, when the Dr phone called, some of the things I forgot. I cannot explain properly. It is very difficult. If it is face-to-face, I can talk openly, and GP can see and check up properly and patient get satisfied.

For myself it is ok but for other patients, they do not know anything - some people cannot speak English at all. They must depend on another person, like their children, to do the work. In the meantime, they cannot phone call to the GP. It is very difficult. On the other hand, some of the surgery need to fill the form online and between 48 hours, GP will call them. It is really, difficult for the sick patient. When call come, they forgot what to say.

My other experience, I had a rash on part of my body. I spoke to the Dr, she said take the picture and send by email. I could do it but sometimes I find it difficult to do. If I see face-to-face, I do not have to do all this thing.

The positive thing is in this situation, Dr continue to look after us with the remote service and prescribe medicine, thanks for that.

And the negative things when we cannot see the face- to- face Dr, we are not satisfied and happy.

My opinion in the future, if the Dr sees the patient like a video call or facetime, it is good.

My other point is the government should support everybody with free broadband, Wi-Fi and with the winter bill because we are always home and using the heat, with too many bills coming. The government should support that. Also, the 60s and over 60s people cannot receive any extra money using the benefit, they cannot receive extra money until their pension age. The government should support those people as well.

And with people living with long term-health conditions such as cancer, diabetes, kidney problem – now the hospital is so packed up, it is very difficult. Sometimes the ambulance also could not come. In this situation if it is possible, they can get treatment at their own home; I think it is good for them and good for the staff as well.”

Personal Narrative 6

BK is a 60-year-old British citizen who has 3 children. She has been living in the UK for 22 years and is experiencing health conditions including high blood pressure, arthritis, and an overactive bladder.



“I was finding it very difficult during the lockdown in March when I had to fill a form to make an appointment with my GP. When I phoned my GP, maybe he could not understand me, or I did not explain as I was not face-to-face explaining what happened to me. I had so many symptoms, like I could not sleep and felt some pressure around my head. The GP thought that it was mental but realistically it was not like that until I went to the Accident and Emergency (A and E). My blood pressure was high and not coming down. When I went home, I could not sleep, I took a tablet. I was phoning every week and the doctor could not understand. My eye was dry, he prescribed some eye drops, it was not helping because I had pain around my eye and when I tried to sleep, I could not because of the pain. So, many things were happening to me, then I had to go back a second time during the pandemic, to A and E. It was very dangerous to go to the A and E during Covid-19. I was crying when I went there. I told them to send me to do MRI during this investigation about my head. Either this pain was causing my headache, or my neck was, they did not understand.

Finally, the A and E department wrote a letter to the doctor asking him to send them a referral for me to have an MRI because the hospital will not do an MRI without the doctor’s referral because of the medical process/system. And the system will not let my doctor do something himself, like in my case. They think it is not serious. So nearly 3 – 4 months from this situation, because of a lack of communication with the surgery, when I phoned, it was so difficult to get to the doctor. I was suffering, I was hoping for the doctor to listen to me. I had forgotten what my suffering was about when the doctor called 3 – 4 hours later – e.g., when he said he was going to phone at 10 am and he phone called around 1 pm. It would have been easier if they gave me a monitor to monitor my blood pressure at home. So, many things happening so many times, I had to open the video call and keep repeating my situation, each time. I went through a difficult period. In the end, the doctor said I have got blood pressure that is causing me all these symptoms.

So, this is my Personal Narrative ending with the high blood pressure, dry eye, and angina. It may be better to deal with when these things happen at the time. When people go twice to the hospital emergency in this pandemic that means something is more serious. It must be investigated like with a face-to-face appointment, wearing a mask, or have a video call or send me to have a blood test with Personal Protection Equipment (PPE).

I was phoning every week and the doctor could not understand.

I am a carer for my husband because he has prostate cancer. He went through radio therapy treatment so I must be patient with him and attend with him before I can do most of our household shopping, so it was a very stressful time. In my opinion, during this pandemic, when people have a serious illness – e.g., my husband with prostate cancer – which needs to be reviewed every 6 months, they cancelled the appointments, and they could not do the blood test to see whether the cancer is the same or changing. It is important to consider that to do a blood test either they send a health professional to the home, with PPE, to take a blood sample to see if it is okay or if it is not okay to consider taking a treatment. We finally had an appointment which was good, but it needed to be reviewed in February as well. It was difficult to go to the hospital for my emergency appointment. We went by bus at the time as there was no car. Going by taxi would have been better.



Other options to phone – have a free phone, phone provider to put some free number, as changing appointments takes hours, you must consider this. One time, I phoned 111 and waited on the line for 1 hour before the doctor was available.

There is another thing that has to be addressed about the patient who has got cancer because in the pandemic they cannot go to the hospital. They are struggling financially – so should provide in this environment at home – e.g., give them free Wi-Fi or tablet or give them facility to monitor the patient's health to know how their health is, until the pandemic is finished or over because the patient needs to be monitored and to have volunteering nurse to check on them, check bloods and visit them from time to time. These needed to be addressed during the pandemic. Also, the people looking after the patient were good. Cancer is so stressful and puts my family under pressure. They need to have counselling sessions and provide free Wi-Fi to listen to them on their laptop or iPad. They also need to provide some care relief for the time being. So, to me this thing has to be addressed as well as to relieve the pain, suffering by providing treatment for that.”

Personal Narrative 7

SS is a 25-year-old working full-time. In terms of health conditions, last year she picked up an infection abroad and has post infectious Irritable Bowel Syndrome (IBS) that she has been seeing the GP for the whole of last year to get treated.

“In terms of difficulty to access health care, it has been difficult for GPs to be transparent on how to book online. I still do not know how to do that, and I still call for my appointments. Other things, I have had doctors call me for appointments, but I have missed those calls because they do not call at set times.

With my recent experience I went to the GP today because I needed to pick up a stool sample but prior to that, where I have had test results from other stool samples the doctors have phoned me. Again, I have missed those appointments. Recently, as well, because of the Lockdown I had a hospital consultation with the doctor and the appointment had to be switched from face-to-face to telephone which was quite convenient because it was a quick diagnosis and quite helpful.

I tried to see my GP recently. Again, I had to go in and pick up the stool sample but then the appointment before that was online because of the recent Lockdown and it is quite nice as well with text reminders. I was not given the option of in-person or virtual health appointments. It was just told that way and again that was to do with the Lockdown and the current crisis where it is too risky to have an appointment. I feel like my go to is 111 to access health services.

I feel the waiting times for accessing health care are very ridiculous but obviously when you want to know what you

I had a hospital consultation with the doctor and the appointment had to be switched from face-to-face to telephone which was quite convenient because it was a quick diagnosis and quite helpful.

have, like when you need urgent care you will wait but just the lack of communication, just feeling like you are not an actual patient. You just feel like ‘oh no I’m just wasting the resources but that sort of makes me feel like ‘oh no, do I actually need to see a doctor for this?’ when I actually have had to see a doctor.

In terms of remote digital care models, because I am quite young, virtual is fine, but it is more for the older generations that I would be worried about.

With regards to the shift to virtual health care, I feel like it can be convenient for certain situations when you see doctors. Honestly, I think it is better especially if you have got something infectious, like back in the day I thought it was ridiculous like you were sick, and you would go into the GP and it was just a bunch of sick people all together. So, I think it is better in that respect but when testing needs to be done, again for certain conditions, you know people need to be diagnosed and the equipment is there and ready in the GP, then that is better. So, I do not think it has put me off, I think it is an improving system and a system that needs to move forward. I have experienced virtual appointments – so positive, again convenient, I do not have to travel, I do not have to pay money to travel, also you realise you do not even get that much time with the consultant and so it feels like face-to-face you might have 15 minutes but that might be better on the phone.



On the negative side, you just do not feel as important. If testing needs to be done then you have to go in a later date whereas with some appointments you can just go in, get your blood test, then and there, so it really depends on the entirety of the condition.

In terms of what help, and support are needed to access virtual health care – I think phones and tablets – not everyone has one, unfortunately, so giving this to those who are vulnerable would be great. Free data and Wi-Fi, I think, are very crucial. Also access to free phone calls, even an interpreter as loads of Bangladeshi parents would benefit from that because normally, they would be bringing their children, with them to the appointment, to help them understand what is going on. But in terms of what would support me, I would say having the option of virtual face-to-face appointments would be nice. I think free data and Wi-Fi would be useful because of financial problems.

Unfortunately, I do feel like the virtual ways are still not there, they need to be communicated clearly and may have like leaflets, booklets, very clear information of what you need to do, how you need to register and currently, I am just getting telephone calls. I do not know if there's actual webcam calls or anything. Wi-Fi connection can be bad, having that support would be good.

In a nutshell, I think that the practical ways to support people would be nice because right now there is just the feeling of isolation for everyone. I'm thinking more about how the older generation would feel – like even myself if I feel isolated, I feel like I'm not actually considered or cared for and nurtured back to health."

Personal Narrative 8

Mrs SB is a 42-year-old British Bangladeshi who has been living in this country for the last 23 years. She has 3 children who were born and brought up in England. All her husband's family here are British and so are some of her relatives.

"I want to say my last experience with health care service was not as good as I thought it would be. I called the GP surgery, which took some time to answer. When I spoke about my serious problem, they gave me a 3-day course of antibiotics, instead of 7. I needed to call again, multiple times, to get another prescription. This was also my last GP experience which was a few days ago.

It was difficult for me to find access to health care because I have children at home with no support from anyone who I can trust to look after them while I am away because my husband is at work during the day. He goes early in the morning and comes back in the evening, so I cannot leave my children at home. I could drop them off at their cousin's house, but this would take a long time. Because of the time being wasted, it is difficult to access health care. At first it was a phone call, then we arrange for some antibiotics. Since that prescription did not help me, I had to call again for a new prescription but this time they told me to give them a urine sample. I took that sample then I went in and gave it.

Another barrier that would stop me from accessing any good health care would be travelling. I do not have a car which means I would have to take public transport which would be taking a bit longer, another barrier maybe a lot of traffic ahead on bus route. I do not have very good English. I can understand, I speak also but sometimes some words are difficult for me. So digital health care service adds extra challenge for me because if I have an infection somewhere, they will need to do a check up on me in person, but with online it is difficult. It would be more difficult for them to examine me. Switching to virtual health care has been challenging for me because I am not used to having my appointment online before, so it is very difficult for me to understand.

The positive of having virtual session is I do not have to travel anywhere so my legs do not start hurting. Sometimes my leg hurts if I walk for a long time.

The negative is that it is harder to have my check-ups because online is not as easy as with in-person appointment.

I want to say another thing – the older people that are 60 plus with long term illnesses need more financial support with heating and hot water especially during the Winter months. The people living with cancer or diabetes need to have an ambulance come for them but sometimes they would need a taxi to go to the hospital and may not be financially stable enough to pay for it so the NHS should be able to cover that expense. The NHS should check up on those with cancer that have been in contact with coronavirus – like one patient is at home, and another person in the same house has coronavirus and as the health care can't see the cancer patient that session could be with a built-in camera for a nurse to come in and check up on them regularly – e.g. their food, health, that everything is okay and they are eating properly because his family member with coronavirus can't see or feed him. That is how (cancer) patients who cannot be transferred to the hospital should be serviced at home.



Elderly people with long-term illness including diabetes, arthritis, high blood pressure or high cholesterol should have free medicine and free medicine service with having it sent to their home. They will also need to be monitored at home, if they can't be monitored at the hospital after the surgery."

Personal Narrative 9

SB is 28 years old and lives in London. She is of Bangladeshi background. Her father needs a lot of support for mental wellbeing and physical illness and her mother takes care of him. Both her parents are from Bangladesh. SB does not have any long-term health conditions, nor does she have any reasons as to why she might find it difficult to access health care.

“In terms of my recent experience for needing and accessing health care, most recently I went to see my GP but was unable to see him face-to-face, so I had to call the GP practice to arrange an appointment and then the GP called me, and I had a phone consultation instead. It was an easy process; it was not difficult, and it was fine speaking to the GP over the phone. I do not have any issues and it was helpful as well. I have not tried to access urgent or out-of-care services recently, but my husband had to go to A & E a few weeks ago and he found the experience fine. He did not have any issues with it. He just had to wait a couple of hours whilst in A & E, which is normal and apart from that it was fine. The service ran as expected.

For my GP appointment, I was not given the option of whether I could go in person or if I had to do it virtually. I had to have a phone consultation.

It was an easy process; it was not difficult, and it was fine speaking to the GP over the phone.

Now there is nothing that would stop me from accessing health care. The only concern I would have is that with Covid-19. As the Covid-19 rates are high now, I would not want to go to hospital or like to have any in-person visits at the GP. I would prefer to have them virtually.

For myself, remote virtual digital health care models do not pose any additional access challenges and I am quite familiar with using technology, but I do suspect that it would cause many challenges for people who are not as familiar or have availability to technology, Wi-Fi and laptops – so, for example, it might be a bit more difficult for my Dad who has long-term health conditions to access digital health care by himself but luckily, we are able to help him. My Mum’s also able to help him so if he did have to have any virtual visits or anything like that it should be okay because he has people to support him.

With regards to the shift to virtual health care putting me off accessing services - no, for me, I think it is fine even having phone consultations or face-to-face kind of facetime meetings with the doctor. If I had any concerns say, for example, if I had a rash and I can have a consultation even by phone where I can see them like over a facetime meeting then I think that is fine and that is not a problem for me.

My overall experience with a virtual appointment was positive. It was quite quick and easy so with my phone consultation it meant that I did not actually have to leave the house to travel to the GP. And again, because my consultation was during the time of Covid-19, it made me feel more comfortable to have a phone consultation as I do not want to go to the GP Practice for fear of maybe catching Covid-19.

Having the equipment provided, such as a phone and free data, would help with digital health care. Also, you would, need Wi-Fi, otherwise you cannot connect or be able to speak to someone, or even to use the phones and tablets, to be able to do anything if you do not have any Wi-Fi. I think

another thing that might help would be to have maybe one application that does everything – so maybe you can do a GP appointment through it, you can go to speak to someone at A & E, like all through just one application rather than having to call different numbers to go through different people.”

Personal Narrative 10

AA is a 53-year-old who has a problem with her blood – she has high lymphocytes. Late last year, she had gallstones which affected her liver and now she is taking medication. She also has long-term thyroid and takes thyroxine.

“Recently because of Covid-19, my appointment has been mostly by phone. It did not work well for me as the Rheumatology, not GP, was from Chelsea Hospital. I was so disappointed because the doctor said he would do it by phone, so I could not show him where the pain was or how it felt and I could not ask him about the summary, on the test he sent me to do, which was different to what he told me over the phone. So, I asked him for a face-to-face and I have been waiting. I hope I will get that face-to-face appointment. But my appointment with GP has mostly been by phone, like if I need medication the doctor has spoken with me, asked me questions and I give her the answers. I prefer face-to-face because if I have something on the face or on the body, they tell me to send a picture, but I prefer to see the doctor to show her the body, because sometimes it is sensitive.

There is no option given to contact the GP. They said they will put me on the list and the doctor will call back. We do not know when they will call back as they do not give a specific time. It could be in the morning or afternoon. We need to wait all day.

When the doctor speaks on the phone, he does not give 100% care - maybe it is 70%.

Sometimes I do not like to say what it is, but the receptionist asks, ‘what’s your problem?’.

Another negative thing when we contact the GP is, we first speak with the receptionist who asks what the problem is. Sometimes I do not like to say what it is, but the receptionist asks, ‘what’s your problem?’ and we have to say what it is so the receptionist can put us in emergency or not. It is a private matter and is not acceptable, the doctor should know the problem. If I call the GP, it is because it is urgent. I am not calling the GP to have fun there or just to speak. But if I need an appointment that is not urgent, I want to tell the receptionist it is not urgent, that I do not mind waiting for the appointment even if it could take a month before I can see the GP. But if I call, I have an urgent issue, and the message should be passed onto the doctor to call me that I have something urgent.

I do not think it is a good idea to have virtual appointment because there are not good with language, there are elderly people, people are not good with technology or do not have it. It will be a big problem, I think. Smart phone, personally I do not like it. It will affect everything, like expensive if you take a package. You need to pay a lot of money to get the data.”

Personal Narrative 11

AI is 57 years old and is of Arabic background. She has been a UK resident since 2017. She has had 5 back surgeries – 3 were done in Dubai and 2 in London.

“When I first came here my life was very difficult. I was shifted from family to family by the Red Cross because the Home Office did not give me accommodation. My health was very bad at that time and it was very cold with so much ice here. This gave me more pain and my mobility became very weak. I suffer from very bad back pain, high blood pressure and asthma.

After my back surgery, the pandemic happened, and it was so difficult to see the doctor face-to-face. I was not given any options regarding my GP appointment. I always spoke to the lady on the counter, not even to the doctor. It is not easy to access health service in general and is the most difficult thing in the UK. If I want to have an appointment, it is very difficult for me to get it as soon as I like especially when I have so much pain. Most of the time the doctor is not there. It stops me from using the health service. I keep calling and talking to them until they give me an appointment.

I do not like seeing the doctor on video call or something like that. Talking to the doctor would be much better. The difficult thing that is not good for me is I used to see different doctors. This is the third time, and they give me different GPs. This is not good because my main GP knows everything about me but with the new one, I have to tell again and again, start my Personal Narrative from the beginning.

I do not need free data but if they have strong Wi-Fi that is fine. My phone/tablet are okay. I would like some advocacy. After I had my surgery, then coronavirus pandemic happened, and everything finished – like nobody to talk to, only every two or three months the doctor asks, ‘how are you?’, like that. They contact me by telephone. I have nothing - only pain killer, pain killer, pain killer.”

Personal Narrative 12

KS is a 59-year-old male living in London and is of Arabic background.

“I am suffering from joints problems and recently my GP warned me to take care of my health because I am at risk to develop Type 2 diabetes because my mother and two of my siblings have it. My experience with my GP is good, the last time I saw her was face-to-face appointment. But I am not happy with the E & A when I had an accident two weeks ago.

They made me wait for more than four hours and then they scheduled me to see the dentist outside my area. And the emergency dentist was not helpful at all. He told me to buy a pain killer from the pharmacy to stop the pain and make an appointment with my dentist. I was very angry and decided I will never go the E & A again.

Although my last visit to my GP was face-to-face, and that was because they wanted to check my blood pressure. However, before this I had a telephone appointment, which was so difficult. I struggled to understand what the doctor was saying, and I was alone because my sons were outside, and my wife was not at home when the doctor called. I was so angry and did not even follow what she said. It was not positive at all. This happened with me twice and I decided not to call my GP unless they ask me to come for check-up.

I hope they do not introduce this type of service (virtual health care) in the UK, especially for people like me whose English is not their first language. But if there is no choice may be to have interpreter, and smart phone, free data and good Wi-Fi will help.”

Personal Narrative 13

ML is a 65-year-old White and Black African female who lives in London.

“I have had two knees replacement, severe asthma and epilepsy. My health condition is severe, serious, and vulnerable. I am at the top of the vulnerable list and the doctors and my GP have asked me to shield.

I like to see my GP face-to-face as I have lots to tell him, and I am not confident with talking to them on the phone.

The last time I had an appointment with my GP was by telephone, which started since the beginning of coronavirus. I found it very hard because they cannot understand me.

When I spoke to the receptionist, they gave me a telephone appointment straight away but sometimes not in the day. I have not called them since last March because I am shielding. The last time they sent me a letter to shield. I am afraid to go to them even if I need help, because I am afraid, they will make me wait and I might catch Covid-19.

I do not need an interpreter, but I do not feel comfortable at all. I had a telephone appointment at St Thomas’s Hospital, with the physiotherapy, for my hands. It was very difficult, and I could not understand what she was saying because the conversation was long. My hand was in pain; therefore, I could not focus on what she was saying. Also, the physiotherapist did not see me, she kept telling me ‘do this, do that with your hand’. If she saw me, she would have realised that I was in severe pain.

To be honest, I do not want this type of virtual health care service. But maybe support with reading because I do not have problems with free data or smart phone.

I have a carer visiting me every day.”

Personal Narrative 14

HK is a 54-year-old Black African female living in London and can speak French and English.

“My name is HK and I’ve struggled during this period of Lockdown because I have cancer treatment and then I had an MRI appointment that has been cancelled but it is also difficult when you call the GP, you cannot see the GP because you have to speak on the phone and having this type of health issue you sometimes need 1:1 and sometimes when you call the GP to book an appointment they do not give you the same day. You can wait sometimes 24 hours or 48 hours for telephone call and when they call you, if you just miss that call then that is it. Your time is gone, you have to call again and if you are ill, it is very difficult. You call 111, they send you to the GP, you call the GP it is very, very difficult, especially for us.

My recent experience trying to access the health care I wanted to see the doctor and because I was calling no-one was picking up. When I called them, they said the doctor was going to call me in the morning. I waited all morning, but the doctor did not call. I went there around 2 pm and they said for me to wait until the doctor call me. I waited and when the doctor called, I did not see the phone call and then I called back they said to wait and that day passed by and then I went again myself there to talk to them they said you must call, they cannot see you. Then they made me wait for three days and with my repeat prescription I waited for one week which they told me go to the chemist to get your medication. I went there, my medication was not sent. I do not know what is happening. It was really, difficult.

Recently I have not accessed A & E because I am not allowed to go to those areas, which means when I call, they tell me when I need to go. Then if the doctor needs to see me, he is not available then I cannot access there. But my husband has been there, he called, they told him to wait. He waited until morning, he called in the night. They gave him the appointment, I think 6:20 early morning but he called during the night. They told him not to go, to wait at home but to go there at 6:20 am. Then he has to wake up around 5 am.

They have the option to go online but I have tried that one and it was also the same. Because sometimes when you put in the detail, it is not bringing you to the next level then I decided to stop the online. So, if the system is broken, it is not working properly.

GP do not want people to go there, they say ‘don’t come here’. When you call, they say do not come here, unless we tell you to come. And when you speak to them, they will tell you that nobody is coming here. They speak with you over the phone, but they do not see anybody. I want to see my GP, but my GP says he cannot see me.

English is not my first language so if you make just one mistake with an online appointment then everything is not going

English is not my first language so if you make just one mistake with an online appointment then everything is not going to work for me.

to work for me. They will keep sending you back, they will keep sending you back, they will keep sending you back, it is so difficult. So, my experience with virtual appointment health care is not helpful at all. They need to train people to show us what to do. They need to keep calling people to go there to train them. We need them to explain or to send a letter that when you go online, click here then after here when you have this, they need to show it on letter, so we practise. This is



also one of the reasons I cannot be doing this because you need to put data on your phone, without internet you cannot access.

English is also a barrier because it is not my first language. It is important they need to bring the interpreter back. If they bring the interpreter and I talk to them and the doctor speak I can understand the medical terminology. Need advocacy, like somebody to advise me/making decisions, it is also important. Like when I had the sickness, I had to go with my advocacy to tell me how the treatment has to happen. That saves me a lot of executive decision because I did not understand everything in the first place. They have to get me an advocacy and an interpreter for me to understand all the terminology and everything they are going to do because the health is important. You cannot go and decide something then after you did not want it to happen like that.

Cancer health care experience: That experience was not good - that you call, that you want to talk to the GP, you cannot see the GP and you want to talk to him when they said you have to talk to the GP then you cannot get him on that day only for phone call, you can wait even for 48 hours. That is not good.

No home-based treatment / help offered. Missed many appointments for hospital specialist because of Covid-19. They rebook when they change the date, it has been so difficult. You cannot feel good because you know that you have been in a situation with a sickness that is life threatening and you must know what is happening in your body. Must know if this sickness went completely or if there is still something there. All this you must know.

The doctor sends you a letter that you cannot go outside, you are vulnerable, you need to be in the house, whatever. The Government sending you letter and is forgetting to tell us about our health condition, what we are going to do, what the priority is for us. Because of that, they should also put us in priority appointment, especially for those at high risk – cancer/diabetes.”

Personal Narrative 15

NB is a 52-year-old female who lives in London. She speaks Arabic and a little bit of English. NB has asthma, diabetes, arthritis and suffers from anxiety.

“My experience seeing my GP wasn’t pleasant, as they didn’t give me one-to-one, but a telephone appointment which stressed me. English is not my first language and I found it very difficult to explain what my problems are or even to understand what the doctor was saying.

The last time I went to E & A I stayed more than four hours and at the end they did not give me any medication. It was not a happy experience.

Digital health care models are very stressful for me. They enhance my anxiety. Digital health care puts me off accessing services because I want somebody to talk to face-to-face, a doctor that can treat me like a human being.

I would need help and support to access virtual health care – like a smart phone, an interpreter, and an advocate, because I might need somebody to explain to me what they ask me to do. In general, I do not want this type of service. I want to have one-to-one appointments.”

Discussion

The research was conducted during the second lockdown, where the interviews were carried out virtually. This has affected the quality of the recordings as some participants spoke quietly or not clear where the sessional workers and the project leads spent some time to go back to the participants and asked for clarification or for more information. Also, some participants spoke in their own languages where the sessional workers translated their recordings into English languages, and this has its limitation.

The findings indicated that interviewees missed doctor appointments and medications during the lockdown and particularly during the Christmas holidays. Participants were not happy about the virtual appointments with their GPs and there were "fear".

Participants experienced barriers to access digital health care services during the lockdown including not having digital equipment and skills, internet data, and language (English is not their first language).

Because of the language barrier patients do not understand phone conversations with their GPs. "I found it very hard because they cannot understand me".

Patients do not like to speak to their doctor on video calls "I do not like seeing the doctor on video call or something like that". Talking to the doctor would be much better". "When the doctor speaks on the phone, he does not give 100% care - maybe it is 70%".

Participants prefer face-to-face meetings, where they can express themselves. This indicates the important of the body languages." It makes things worse for you if you do not have someone that is warm and supportive or for physical health if someone really knows how to engage with that person. It is more about the human kind of engagement. I do not feel like it is like the human kind of engagement. I have come across people who have had their own agenda and rushing you through".

When patients phone called their surgeries, the receptionist says the doctor will phone call back without indication what time. Patients wait for long time to receive their calls and when they received it, they either missed it or forget what to say. Participants did not find speaking to the receptionist is helpful. "Sometimes I do not like to say what it is, but the receptionist asks, 'what is your problem?' and we have to say what it is so the receptionist, who can put us in emergency or not. It is a private matter, and it is not acceptable, the doctor should know the problem".

The issue of not using the digital equipment and not having the skills were mentioned. One patient said "It is difficult to use digital health care as I am not knowledgeable with the computer, so I barely know how to use it. I cannot fully explain my symptoms or how I am feeling as well. The shift to digital health care does put me off with accessing the service". "I do not have technology; I have a simple phone".

Participants are from the BAME communities where English is not their first language and they have communication issue.



“English is not my first language so if you make just one mistake with an online appointment then everything is not going to work for me”. They will keep sending you back, they will keep sending you back, they will keep sending you back, it is so difficult”.

Participants mentioned the need to train them on how to use this new system. “They need to train people to show us what to do. We need them to explain or to send a letter that when you go online, click here then after here when you have this, they need to show it on letter, so we practise”.

When people got infections, it was difficult to access health services as they need face-to-face appointments to be examined or do some blood or urine test in- person.

Patients do not like to see different doctors every time they contact their GPs “The difficult thing that is not good for me is I used to see different doctors”. This is the third time, and they give me different GPs. This is not good because my main GP knows everything about me but with the new one, I need to tell again and again, start my Personal Narrative from the beginning”.

They talked about the long time to get an appointments and cancellation of appointments. Some GPs asked patients to send their request only by email there was no phone options.

Referral from GP to hospital take long time and patients suffered during this long time waiting and their conditions might get worse.

Participants struggled to take picture as they do not have smart phones, or they do not know what exactly to take photo from. Or they do not feel comfortable to take picture and send to their GPs.

Participants living with long- term health conditions including, cancer, diabetes and poor mental health struggled to manage, and they did not have support from health professionals at home. They did not find calling 111 is helpful due to the long waiting and the many questions they asked people to answer and for people who cannot speak English language is difficult. Their experience visiting A&E there was long waiting time average of 4 hours and there was no ambulance service.

Deprived people cannot afford to hire taxi to visit hospitals for emergencies.

Participants spoke about how they suffered from social isolation during the pandemic.

Participants who are living with long -term conditions were living in the same house of people who contracted coronavirus that put them at risk. There was no checking on them during the pandemic where their family members were sick.

The positive about the digital health care services mentioned including the following:

Although there were many issues with accessing digital health care service during the pandemic but there were some positives things mentioned. Patients said “I can be at home and still be with my children even if we are working. It did save some transportation cost, less time in the waiting room and less chance of catching Covid-19 or any illness that may harm me”.

What will help and support people to access digital health care service?



Participants mentioned number of things including “Free phone calls and internet data (broadband/Wi-Fi). “Bengali interpreter will be beneficial to me”. Tablet and good phone that allow me to take clear picture for doctor are useful. “I feel a good advocate would help sort things that are basic, which would be important, as sometimes I am not managing. Perhaps a free course that would help with finances, as I am really struggling with paying bills. Sometimes feel I need to see someone face-to-face and sometimes can deal with over the phone. Feel a bit weary speaking to someone over the phone. ‘Record this conversation for training purposes’, I have no choice. I would like to have a choice and make my own decision at the time”.

“Practical ways to support people would be nice because right now there is just the feeling of isolation for everyone. I’m thinking more about how the older generation would feel – like even myself if I feel isolated, I feel like I’m not actually considered or cared for and nurtured back to health.”

Participants spoke about their need for support to get their medication delivered to them and other home- based support. “sometimes my situation where my health deteriorated, and I probably need someone to help me through for a couple of weeks or to deal with calls or hospital appointments or to have access to someone to help me”.

Diabetes UK’s website resources was found useful, “I, managed to get a lot of information over the internet, I have a good friend who is a nutritionist, I try to find alternatives. I know exercise is good but if you are not well, mentally, it is hard to keep up with the routine. So, sometimes I need someone to just give me a push and help and support”.

Support at home – “Last social worker support was just a waste of time. Just taking notes and they were going to help get me a card but that never happened. Felt like it was ‘ticking the box’ game”.

Young people can access the digital health care services, but they said “Unfortunately, I do feel like the virtual ways are still not there, they need to be communicated clearly and may be to have like leaflets, booklets, very clear information of what you need to do, how you need to register and currently, I am just getting telephone calls. I do not know if there’s actual webcam calls or anything. Wi-Fi connection can be bad, having that support would be good.

Recommendations and Conclusion:

We recommend during such circumstances in the future for “people living with long term-health conditions such as cancer, diabetes, poor mental health, and kidney problem as the hospitals were so packed up, it is very difficult for them to get treatment or follow up. Sometimes the ambulance also could not come. In this situation if it is possible, they can get treatment at their own homes.

Elderly people with long-term illness including diabetes, arthritis, high blood pressure or high cholesterol should have free medicine and service for delivering their medications to their homes. They will also need to be monitored at home, if they can’t be monitored at hospitals after surgery.

Adopting schemes of communal Wi-Fi at housing estates, libraries, and community centres in addition to providing digital equipment for deprived people and IT training would help people to access digital health care service. Having one application that does everything would be helpful as GPs are using different systems or Apps.



GPs surgeries to understand their patient's demography and their needs, so they can provide interpretation and advocacy services where are needed.

People living with long term illness to be given appointments as priority especially for those at high risk – cancer/diabetes.

In conclusion the target participants had experienced many challenges during this pandemic to access the primary and secondary health care services. That was due to the lack of digital equipment and IT skills, internet data and languages and cultural barriers.

Personal Narratives from The Centre for Seldom Heard Voices

The COVID-19 pandemic has led to changes in the ways that people are able to access healthcare services and has accelerated a move to digital models of care. For some, this has created opportunities for easier access, but it has also highlighted barriers for people and a digital divide.

The Bournemouth University Research Centre for Seldom Heard Voices brings together a range of academics across different disciplines including social sciences and social work to engage with marginalised communities and to amplify often excluded or silenced voices. We have a strong track record of developing collaborative partnerships with communities and key stakeholders and for using participatory and co-created approaches. Our aim is to apply our research to real-world challenges to maximise societal impact. Our research includes collaborations with looked after children, youth in the developing world or conflict areas, rough sleepers, substance users, stigmatised and threatened minorities, immigrants and trafficking victims, older people, carers, disabled children and adults and many more. Impact includes contributions to child and adult social care practice, influencing policy, theoretical contributions to conflict resolution and community engagement and empowerment in the UK and globally including Kosovo, Malaysia and Costa Rica.

Aim

The aim of this piece of research, which commenced in November 2020, was to gain an insight into how the new digital measures being introduced by NHS England could impact those at risk of exclusion and what could help them to maintain their access to quality care. It explored the ways in which digital services could be adapted to meet the needs of and support those who might find it difficult to access digital health services and address the barriers to accessing good care.

Population

The target sample of this research were the following groups that the NHS Digital (2019) identified as more likely to be digitally excluded, such as:

- older people
- people in lower income groups
- people without a job
- people in social housing
- people with disabilities
- people with fewer educational qualifications, who were excluded from school or who left school before the age of sixteen
- people living in rural areas
- homeless people
- people whose first language is not English

Sample

This report contains 11 lived experience narratives documenting the potential impact of the introduction of a 'digital front door' to the NHS on people who are socially excluded or at risk of being excluded as a result of the digital technology measures being introduced by the NHS. The narratives include a variety of experiences, including those who may be at further risk of



marginalisation with new measures, for a multitude of reasons. It also includes the experiences of people that have diabetes and those who have had experience as a cancer patient.

Recruitment

Contact was made with organisations that represented people from these groups as it was recognised that it could be difficult to reach those who were at risk of digital exclusion, through digital means. Potential participants were sensitively sampled, to consider as many groups as possible.

Methodology

Participants consented to being audio recorded and to having their own words quoted anonymously in this report. They were then asked to participate in semi-structured interviews, which included a series of open-ended questions focussed on their personal circumstances, their past and current experiences with accessing healthcare, and what barriers they may experience to accessing and using digital means.

Personal Narrative 16

Hannah is deaf and has a thyroid problem. She uses sign language to communicate, is a parent of two hearing children and is the director of communication and fundraising at a charity: Sign Health.

The voice of deaf people is so often forgotten, and we are marginalised, especially when policies are being made and technology is being considered. Deaf people suffer more with obesity, diabetes, and other health conditions and this is largely because information for deaf people is inaccessible.

My daughter has Coeliac disease and with my thyroid problem, we have regular hospital appointments and the burden is on us to call the hospital to remind them to book an interpreter. They should automatically book one: the Accessible Information Standards (2016) puts a duty on health providers to make services accessible but there's anxiety as to whether my needs will be met: will I understand happens to my daughter? Always the same pre-emptive strikes - have you booked an interpreter? There's complicated medical information and jargon I've got to translate - a lot of interpreters are trained in medical terminology but as a user I need to access that information as well, for my health and for my child, so: is the system geared up to meet my needs and will an interpreter provide for me?

My in-laws are deaf and recently, they've felt cut off, largely because everything became telephone based and for people who can't hear on the phone, that's difficult. We realised the system had to change so we used our reserve funds to set up BSL Health Access, to provide remote interpreting services and over 30,000 have found this a lifeline to communicate with GP's, hospitals etc. Without this, deaf people would have been much worse off. It's not an answer to everything, the system needs to be rolled out to the whole NHS so professionals can contact interpreters rather than putting the onus on the patient, imagine sorting that when you're poorly, not feeling with it. There's huge anxiety and risk to well-being. Also, if I was talking to my GP about something sensitive online, my family would know, some people are private and in abusive households... if a victim wanted to report to the GP, they couldn't do that discreetly. There are black people requesting a sensitive racial mix and people have a right to ask for and access that but less than 10% of interpreters are BAME. If someone requests a specific interpreter, will that make the queue longer waiting for one to come up? Face to face interpreters resolve a lot of issues. In health care terms, there is a limited supply. To become a qualified interpreter is prohibitively expensive and there is nowhere you can go to be immersed in the language so it takes a long time and sign language is not the same everywhere, it looks physically different, different words are different signs so it's more challenging to become a good interpreter because you have to recognise that. It's not just a case of hearing it, there is the consequence of accents of being able to interpret effectively and accurately for all. Training to become an interpreter should become cheaper, enabling more people to become interpreters.

There are limitations because if a deaf person doesn't know what's wrong or can't explain it well and there's questions coming from professionals to get more understanding and using inaccessible language, there could be emissions or misinformation, even a misdiagnosis.

There's nothing like face to face, Zoom depends on WIFI connections and on buffering, there's no substitute for the real thing. I'd like to continue to see someone face to face and for the continuity



of real life and those incidental conversations, human contact, it's part of the culture of the language. This new age of technology can't replace what we had. I went to the GP for my boy last year and there was a long wait, the doctor couldn't wait for the interpreter to come online so we resorted to writing notes, so new technology is no substitute for the real thing, it is not like face to face. Many would rather not have an appointment so there will be issues of neglect and ignorance of our needs, it's an issue throughout the community, felt by many. Please NHS consult with end users, you know you can get information, we don't have that at all, we only get what we physically see. We live an isolated existence anyway, so consult with us, we know our needs. We are happy to share our knowledge and expertise with you to make decisions based on good information rather than lacking information because you could miss a whole section of the community including us.

Personal Narrative 17

Angela is in her mid-60s and is profoundly deaf.

The doctors do phone or video now and I think oh god I've got to find a room... it's all the set up involved and making sure I'm in an environment where I can hear. I get antsy; I need to use this phone because it's the one I can work with my hearing aid, but they insist on having a mobile as your main number. I'm telling them I can't understand, I can't hear, it's on full volume so the neighbourhood can hear but I can't. I struggle to get information, there's a lot of feedback on my mobile because few newer mobiles work with my loop systems, which are made especially for me. My iPhone doesn't have a jack, how am I supposed to use my loop system? Covid hasn't helped with video conferencing, things go wrong and with my loop on, I still have no idea what they're saying. If I can see them it's easier, it's a two-way process. People tend not to talk to you, same as in hospital, they look at what you're looking at and they're speaking but I've no clue. Also, I need someone who speaks without an accent, they say that's not equality, but you need to provide for me.

Weight Watchers use Zoom but I know there's conversations going on because I see so many people on my screen, but I don't know who's saying what. I had a doctors' appointment on Zoom and everything went wrong, for half an hour he was trying to link to me, he eventually gave up and did it on the phone, we had 10 minutes for what should have been half an hour. When we moved here, my hearing aids had broken and I hadn't registered with a new hospital and I was told it was simple so we phoned and they said to go to your doctor and I was really upset because my husband was talking to them, I just couldn't and eventually I was in tears so he phoned the doctor but there are things I would not talk about in front of my husband, I've always been independent, totally private about myself so there is a risk. I'd be more concerned with anybody in any sort of abuse, they need somewhere safe to go and the danger of losing that if we go the triage route, there is nowhere for them to go. Years ago, there were loads of places.

I couldn't hear so my husband was talking to them and to me and feeding back to the doctor, it's so frustrating. I deliberately come up here without anybody listening and when I talk to the doctor I come and close myself off because it's personal and my health is my business.

Age is a factor as well. My husband is completely tech phobic and when he's told to go online, he loses it, there is no way he can deal with it and he has had appointments with the doctor online and he gets really nervous and agitated. I've got to tell him what to say. Plus, there's an assumption that everybody has access to IT. People across the board are losing contact they should have and that relationship because they don't have the equipment. Once, I went to get my hearing aid repaired in the hospital and the girl was talking to me and I had no idea what she was saying. In the end I said you've got to look at me and she said phone this number and I said you're dealing with people that are severely deaf and you're telling us to phone. So she said to email and I said I didn't have a computer and the attitude was it's tough. I got angry about that for all the people younger and older than me, who haven't got the confidence to go online but have been told to deal with it. That's not how disability works, the support should be there to enable you to live life as normally as possible. I do find that the attitude is well you're old, but I've lived with it all my life,

It is very important that no matter how far we move forward with modern technology we don't leave anybody behind, and we don't leave any unable to get what they need.

I've been under the NHS for this for 50 years, really makes me cross because there's an assumption that goes along with the age but you've got young people who have various levels of disability or learning difficulties.

I've always been reticent about this. It's a problem if you don't have out of hours service, my husband suffers a mental health problem, it's quite bad and he needs to be able to get someone and so triage does not work for him. He is very vulnerable, he needs somewhere to go so to take those services away would be wrong, people are going to be lost, probably that need the help the most. It would not be accessible for my husband it wouldn't at all, he won't touch a computer. He doesn't care, he just doesn't want to do it which means if I die tomorrow he's got a huge problem everything is online, our banking is online everything is done online and he is one of those people who, in his circle of friends I don't think anyone would be confident to use a computer, their wives or kids do it. When I go my husband won't even have a phone, he'll just have an ordinary land line. Years ago his work brought in a systems, a little iPad and he was so stressed during the day, he would come home in a dreadful state because he was forced to use it, I thought it was going to push him over the edge, it was worrying and there was nothing I could do to help I couldn't even talk him through it. My husband can't even access apps on the TV, he doesn't understand the concept of them so I imagine there will be huge problems and they need to think about it carefully. My husband is not the only one like this, who would be totally lost.

When we moved we had to contact everyone to let them know that we'd moved and every single issue we had we went online, we couldn't do it, we couldn't change the gas, electric, home insurance anything. My husband doesn't like dealing with it but I think I need a rest from this, 2 hours on the phone is too much for me to cope with. It's absolutely draining, exhausting by the end of the day.

Training would be ideal but I can imagine the training would be online so you've hit a snag before you even start, it would be great if the BBC had programmes to do it, they do a range of bitesize programmes for education, there's no reason why they couldn't develop something for adults that would be interesting. Maybe a local library could invite people who want to know how things are going to change, it's a huge task and it's not going to be easy and I can't see training happening. You've got the assumption that people will have the equipment at home, but thousands of people don't have access to a computer through choice or they can't afford it.

Personal Narrative 18

Robert and Helen are husband and wife and are both over 75. Robert has been involved with Dorset County Hospital as a research ambassador, with an interest in how people are treated from the age of 55 by social services and the NHS, in particular how they cope with the needs of people who are less able to deal with things for themselves and with technology. Helen runs a group via the WI.

R: This is an essential thing to think about and a group that needs most help are largely over 65 who haven't got the capabilities or financial capabilities of having proper technology to help them.

H: What concerns me most is not if they've got access or whether they can afford it but the fact that after a certain age, when they come to it late, technology panics people and it's very difficult for anyone over

H: I think the big problem is the people who it is least likely to help are possibly the most vulnerable in society.

65, and I'm well over 75, to deal with something when they've got to deal with technology as well without a lot of help and training.

R: I have a godmother who is 96 who is feisty and still full of her own marbles, driving etc but she cannot cope with any technology, she only just manages a telephone. Technology, unless you're brought up with it, it's something that passes you by and it worries you because the number of things in life where you become dependent on technology is getting out of hand. She can't pay bills unless she has a card, can't use a card unless she can get into a machine, doesn't know how to use a machine and she panics of how she can cope with her life and needs. She makes phone calls to the agencies for gas or a problem and has the same difficulty as many people in not understanding those with loss of hearing and finds listening to them difficult.

H: It's real problem, my experience running a group via the WI who are mostly elderly, actually accessing them by telephone is hard enough but for them to access me by telephone is much harder and it's partly a question of they were brought up that you don't ask for help.

R: Our surgery is fairly difficult to get hold of, getting through to people through the switchboard system can be difficult and explaining how triage works becomes a problem and they have particular difficulties with a backup of calls. When you ring 111, it is difficult to understand that the initial questions they have to ask don't appear relevant if you're going through an emergency issue. The difficulty is that you've got such a wide range of people in the age group with different capabilities and access to different systems and opportunities, we forget that no two people are the same in terms of what they have and how they deal with simple technology in an emergency.

H: One of the big problems to the very elderly and an example is my husband's aunt who had awful trouble accessing her television service, she couldn't work the handset and time after time we showed her a simple way of doing it and by the evening she had forgotten and that is the problem for the older generation and they are probably most in need of reassurance and care which is almost impossible to give via technology.

R: One of the essentials is that training for those who are at the giving end i.e the people who are running the technology, they have got to be carefully trained in how to make certain that patients understand fully and simply what they have to do and how they have to do it. Training in accepting the call and taking them properly has to be given. We've got to look at when people have carers popping into their house to look after them, that they are given enough training to be able to help those people they are looking after.

H: Even in our village I know of two or three people who if they need to make an emergency call, they haven't got a landline and have to walk to the bottom of the garden to get a signal.

H: I would add that accessing via the telephone is more difficult because if you are in a house with more than one person, everyone knows when you are on the telephone and if the doctor rings back everybody knows if the wrong person picks up and it could well be a deterrent if there is something embarrassing.

R: We've touched on training of the staff and that a patient has got to be supported so they feel they have control of a situation but that only goes so far in terms of capabilities as they age, they don't want to be dependent but they inevitably are more and more. The other thing is that how do we deal with the homeless? And those with dementia because the dementia numbers out there are



huge. We forget too often that we need to look downwards as opposed to upwards all the time. And there are extremely good reasons for it because the cost of the technology in itself, whether it be a simple telephone, by the time you've put costs together people literally can't afford them. So what you could do is develop a system whereby you install a line into somebody's house, I know that's got to be paid for somehow, that you can have a blocking factor on it so it can only be used for A,B or C. How many people who are subject for instance to balance problems wear devices around their necks or on bracelets which they can press if they have a fall and call somebody but that requires a phone link?

Personal Narrative 19

Elaine helps care for her husband, who has a heart condition. He had a heart attack in 2013 and then an emergency aortic aneurism repair in 2014. He then had a spontaneous pneumothorax, which left him with reduced lung function. In 2016 he was diagnosed with bowel cancer.

My husband couldn't have an operation for his bowel cancer, so he's just finished radiotherapy so we're waiting to hear the results, but he does not have the best quality of life. What I found in the last year is it's so difficult to see a GP, we've had a very good GP in the past who knew my husband well and knew all his problems, it was easy to access her if we had any problems, but that's gone now, the most we can ask for is a telephone consultation, which isn't always the best. Sometimes we want a face to face chat, the e-consult should be followed up with a consultation, but it hasn't been. One thing I found particularly bad over the last year is that if you have a problem, they want a photograph, everything is done with the e-consult and photographs. Well, it's not always easy: I fell down the stairs and they wanted a photo of my ankle and my husband got a lump on his eye and they wanted a photo, it isn't easy to get photographs and send them; it's much easier to see you. I'd rather be face to face. It's easier just to talk, you can see somebody's expression, they can see yours, you can't tell that with just the voice, seeing somebody face to face would be preferable to telephone consultation.

I guessed it would become permanent because it works well from their point of view, so I wasn't surprised. I don't feel good about it because it's not nice to think you're not really going to have easy access to a GP anymore. I think that's very dangerous [to triage for A&E] I really do, there are a lot of elderly people who just don't feel comfortable doing that because it takes a long time sometimes. I've been told by my GP and also by the paramedics and doctors at Dorset County Hospital because of my husband's health, if I need treatment for him I've got to dial 999 and I think that's what people will do but it's going to clog up the service. I feel this is going to put a terrific strain on A&E because I think people are just going to use A&E because they cannot walk into a doctor's surgery anymore.

It's one way of getting rid of us old people who are just a drain isn't it, because we won't bother with it anymore.

From day one with our surgery we said we want to allow the other person to access our medical records and talk about each other because we didn't want a situation where a doctor would say 'we can't give you that it's confidential', so we made that agreement but there might be people who don't want that and have got children around and don't want to discuss their mental health or medical condition or what have you and that could be a real problem and it could put people off and they won't bother. I can think of people who it certainly would affect.

Giving a tablet or device to elderly people, as long as they can be taught how to use it would be brilliant, obviously just making sure they're going to the people that will actually be able to use it.

My husband has something called a telehealth tablet which he has to record his blood pressure, temperature and his stats every day and they get sent in to the nurse and when we first asked about it we had to go along to a meeting with lots of other people and they had to determine whether he was going to be able to use it because not everybody can use technology so yes for older people, if they can be taught how

to use a tablet that would be ideal, if they felt comfortable. It's never going to take away from the personal face to face, that's the real bug bear for me. You're going to have a lot of people with



learning difficulties, a lot of people who are homeless and a lot of people who are just not comfortable with technology who will not be able to access the NHS and what will happen with those people I dread to think.

If they were to be made permanent and to be made sort of the only option it does worry me, it does really worry me. Yes it is a real worry and not only for people who are like us but for people who are really not able, that's the real concern, I can kick and fight and scream and get attention if I need it but there are people who just can't and they're the ones who are going to fall through the crack and there could be a lot of people.

Personal Narrative 20

Maria has varied health issues, including chronic obstructive pulmonary disease (COPD) and she has also developed diverticulitis, a very painful abdomen condition.

My health conditions make life very difficult at this time because I am a high-risk individual. Since everything has become digital, for people of my age it is very difficult: a lot of us are not computer savvy, we're too old now, our brains are already full up. We've lived for nearly 70 years, some even longer, and you get to the stage where you get too tired to learn and a lot of older people cannot afford computers, a lot are living on their pensions. I'll send an email, but it takes me a hell of a time and for some, they don't know where to start and they couldn't afford it anyway. It sounds pathetic but I'm not going to last much longer, I don't need to know it and that's how a lot of us feel. I would say people are put off before they even start, thinking 'oh this is going to be so difficult that I can't be doing with it' and it is hard work for us oldens, we don't know where to start. It sounds ridiculous, if I tell my friends to go on an app then they'll say 'well, what's an app?' and I'll say 'well, I don't know if I know what an app is'. They expect too much of us, they're not making allowances for our age, a lot of people don't have anybody to teach them so that's very sad and you're always being forced to do something you don't want to; I would much rather speak to somebody in person who can answer questions. If you could see them face to face, one would feel happier. A lot of it is so complicated, you need a young mind to get your head around it because you've been brought up with it.

It doesn't come easy, they'll tell you to click on the app and you think 'well, what is an app?'.

Also, if you're doing something you don't like, you can't take it in and you're not going to get anywhere and that's what happens to me. When you like something, you can become good at it but when you don't want to do it, it becomes a chore. If I didn't have my daughter to do online prescriptions, I don't know how to get to it. She can do it within a minute, and I could be resting at that time. I would get it wrong and with this autocorrect, I sent an email once about a man and it changed it to 'Amanda'! This is technology gone bonkers, why does it do that? If I hadn't read it through, it would have said 'Amanda', so technology and I do not get along. I could not complete an online form, I couldn't do it, I wouldn't know how to access the app in the first place or how to put an app on an iPad, I wouldn't know where to start. I seem to get in a muddle but if I had to do something out the ordinary ie access and fill in an online form, I wouldn't be able to do it.

We're from an age where you didn't even have a calculator at school, houses didn't have telephones, and this is what we're stuck in and we've been around so long that our brains are overloaded and don't want any more technology.

With phoning, there's nothing more irritating than trying to contact somebody and you get 'if you want more information visit our website' or 'all our lines are busy, you can visit this' and it cuts you off, the line goes dead. You think: what do I do now? Once it took 52 minutes before a woman came on and I said 'I'm shielding and it says are to let you know' and she said 'but why?' and I said 'I don't know why' and she said 'there's no reason for that' but it was on the letter, it's unbelievable. I thought I had to but it turned out they didn't. You can't speak directly so you do what you think you must but then you don't have to at all. Next time, that could put you off doing something you should be doing because you never know where you stand. I had an allergic reaction to some vitamin B tablets and my eyes swelled up and it was awful, so we asked if they do a Zoom meeting,



but I really don't like them, and I won't do anymore. It's very difficult to describe something over the telephone to a doctor because unless they can look at you it's difficult and I sound a little bit vague about things, do you see what I mean? So they catch me on the hop because you're thinking ooh I didn't think of that. I would rather go back to seeing people face to face.

If people are in a very bad situation and are feeling very unwell, they are not going to be capable of making a phone call? The majority of people only go to A&E if they are in a desperate situation, if you've got a kiddie that's fallen down a flight of stairs you're going to be in such panic, you're not going to be coherent on the phone when you're trying to describe your child's injury and it's wrong, no I don't like that idea at all, it worries me because I think you need somebody there, I had a gardener and he nearly cut his finger off so I bundled him in the car and took him to A&E... if that hadn't been there what would I have done? I think we are very, very lucky to have A&E and it would be dreadful if it went. People will just get worse and worse and some people will even die because they won't know quite what to do, if you're having a heart attack you can hardly pick up a telephone and say can I come in.

Personal Narrative 21

Paul has had Type 2 diabetes for 18 years. He is also visually impaired and has an ongoing melanoma in his right eye. He was also a carer for his father who had liver and lung cancer.

Until this last year, I had no problems accessing healthcare at all... when I've needed an appointment at the doctors, it's been fine. This year I had everything cancelled because of Covid. I have nerve damage which means I have very little use of my fingers in my right hand, I've been down twice now to have electrodes etc put on my arms. I'm also awaiting an operation for a cataract, because of melanoma in my eye they were going to try and rush me through, but we went back into lockdown. No contact since August. I have appointments in London in January which are dependent on whether I have that done and the treatment I've had for the melanoma caused radiation retinopathy which is fluid build-up at the back of the eye so I have 5% sight in that eye and about 25% in my other eye so I'm reliant on family, friends or buses and taxis.

I was able to have a face to face with a doctor but that was only after a phone appointment and he said it's a waste of time on this call, I can't see your hand over the phone and I need to have a face to face with you. So I went and he saw my hand and I told him about some lumps on my hand which confirmed what he had said but then I told him I had very little movement in my fingers in the right hand and my finger was numb and he referred me to the hospital to have some tests to see the reactions and it's come back with serious nerve damage through diabetes but he said there is only one thing we can do about that, which is to operate to find out what's going on with the nerves in the elbows. I must admit... phone conversations with the doctors, there would be a problem, trying to diagnose something over the phone, sometimes you do need to have that face to face so they can see the mark on the face or the lumps on the hand or whatever.

I try and avoid online forms if I can, if I was on my own and had to do it on my laptop... If the forms were to come as paper, what I can do with post is photograph it and then enlarge it or I have apps that will read it for me but as for form filling, if I was sent a form I could photograph and enlarge it and then write the answers down in the relevant boxes after I've looked at it the photo... I need to use something to help me fill out forms.

I don't tend to do online forms, my wife is registered as my carer, she has to help me.

Some form of training like a video on YouTube or something that you can access, that would guide people like me with sight problems through the process. The only other thing, I know a lot of people who are vision impaired through Dorset Blind, they would need a person to fill out the form for them, some have no vision whatsoever. They would need their carer to talk them through the form, fill the form out for them, unless it came in a braille format or an audio format. The NHS would have to make sure that there's an education programme making sure everybody knows the system, whether it be postal, technical ways but then you've got the OAP's, the people who have less contact with technology. My wife is, as much as she's doing at the moment, she sometimes does struggle so she has days where she

With the sight issues, we are still trying to be fiercely independent. I battle a lot to try and keep my independence because if I was to give up on things I do now, even though I can only just about do them, it will start affecting my mental health.



goes out and just to get herself out a bit but she's lost her independence because she has to look after me. If I had no sight problems, I'd be able, but we're stuck in each other's pockets all the time. She'd have more of time of the day to herself.

There would need to be letters in the post, educational leaflets in the doctor's surgeries, YouTube videos. I think most families or most OAP's that have less access to technology in the past, they may know somebody who can show them YouTube videos. The doctor's surgeries take on a couple of people just to go round just do a phone call or door knock, to make sure everybody knows what to do. Education is really important because when somebody breaks an arm or something, I had a friend who fell down steps, broke his leg which released fatty tissues into his blood, and he died of a heart attack. It is the side effects from that break may have further, on your health, so if you break a bone 111 what do I do? It's making sure people know, even if it comes out on a card or something you keep by your landline phone of what you have to do. People who don't know what to do will just dial 999. To be honest if I was in the position I was home alone, and I needed urgent care I would ring 999 it wouldn't be 111.

Personal Narrative 22

Carol is 96 years old. She has no serious health issues but lives alone and does not have any online access.

I see my daughter about once a year, I do my own housework and cooking and what have you. People tell me I am amazing. I have tablets for high blood pressure which are the only tablets I have and once a year they ring me up. My daughter in law makes an appointment and goes in with me because of my hearing problems, I can't always hear them and they're always in a hurry.

I haven't a computer, I've never been interested in it. I haven't even got an email; I prefer books and music and what have you. So that's not something I would feel comfortable dealing with myself. It's just what you feel interested in. My daughter in law is 40 years younger than me and even she struggles with her phone. I just don't want to. I've always been a rebel, but the more people tell me I should be online, the more I'm determined I will not go online. It is a problem, I think. It would be a last resort for me, I would have to have people come and help me, but I wouldn't do it unless I really, really must.

I'm not online at all, my grandson offered to buy me a computer, but I said 'no, thank you', money wasn't the problem, it was me.

I live on my own as my husband died 23 years ago so it's more or less a normal thing for me to be in the house on my own but I feel sorry for people with no support because I think there's a lot of them. I don't see the answer, there's no one there for them. I have a mobile phone that I take everywhere with me, one for the desk, it's not an elaborate phone, I carry that around with me. It has an emergency number, I have never had to use it touch wood but if I hadn't got help, I really don't know. There would be no one to come if I hadn't got my son and daughter in law. I haven't had any visitors or anything, I would be in a very dire situation if I didn't have my family.

I don't think setting all that up at my age, I shall be 96 in February... I'm not expecting to be here that long. It's my choice, I could sort it out and what have you, I'm sure my grandson would think that was good anyway. I just don't think at my age that it's necessary to go on broadband or Bluetooth and all the rest of it. I don't think I've that amount of time left, although one never knows.

I think possibly older people will be left behind. I feel as regards digital stuff that I have been left behind, mine is through choice but other people might want it that can't get it. If it progresses, there's going to be an awful lot that will be left behind, there will be a lot that won't be able to cope with it. I couldn't even be able to do a video call on this phone. It's just a landline... I'd probably have to put a sticker on the window with 'help' on it. I've got some friends at 80 and they're of the opinion they can't wait, they don't think that this country or the people in it can wait to get rid of their age group. It's a dreadful attitude quite frankly but that is how they believe.

Quite frankly, I don't think we exist anymore, they can't wait to get rid of us.

They have tried, those people, they have got a computer and all the rest of it but they're not very clever with it; my son is always going and helping them and they make a mess of it but



the bank that they belong to put them onto paperless, they are determined to get everybody online banking.

The teacher actually called my grandson out when he was at school to help her with her computer, they've been brought up with it so it's easy for them, a lot of people have been brought up with it so it's just people onwards from their 50's that haven't and we're the ones that are going to be left, well we have been left behind. If I hadn't got help, I don't know where I would go to get an appointment with a doctor, but if they are going to stop doing the little things, we won't be able to get to them anyway. It is worrying yes; you don't know what the future is going to hold with this.

Personal Narrative 23

Pam was diagnosed with breast cancer and after having a mastectomy in January 2013, was left with lymphedema in her arm and hand. She is currently the chair and secretary of the Bournemouth and Poole lymphedema and lipoedema support group.

In May, I had dreadful pains in my toes, so I rang the surgery and they said to send an email with photos of my foot for the doctor... but the camera makes the photos too big to put on the email and I'm not any good at trying to reduce a file to send it. Then I had a call back and was diagnosed with gout in my toes so I spoke with the doctor, who said 'just take anti-inflammatory's and if it flares up again contact us', so I had that whole consultation without any face to face, just telephone. My surgery has just been taken over by another surgery, I already don't know the doctors and sometimes when you do a face-to-face they can see you're not looking quite right, you can't do that on the phone. Even repeat prescription, that's a nightmare in that the website didn't work and there were technical issues, so you take the repeat prescriptions to the surgery anyway. You need to be able to ring the surgery and ask for an appointment rather than trying to do it online because I'm never sure they've got it. You end up ringing and asking if they got the request anyway. So I'm in a loop of ringing the chemist and they go no we've had nothing and you ring the doctor, no the doctor hasn't signed it off yet, so you're in that.

THE PROBLEM IS UNLESS YOU SEE THE PERSON, THERE MIGHT BE OTHER THINGS GOING ON WITH THEM THAT THEY WOULDN'T PICKED UP ON THEMSELVES.

If you're more elderly, some ladies in our support group haven't got a clue and they're in their 70's or 80's, so they personally would struggle with trying to do a repeat prescription or try and get an appointment online. We tried in the group to do a basic IT computer course with Access Dorset and a lot of them struggled with that, even just the logging on and getting the menu, so they're not going to do it. It's a lack of knowledge because we weren't brought up with computers, when I first started work, we were still on paper legers. And it's down to who's teaching you, the person knew what they were doing and wasn't able to get across, you really want an idiot's guide, step by step: login, click this, do that, need something like that for people that are not that confident with computers. Something they could read like a recipe with all the ingredients, and the other issue is not everybody's got a computer, I've got a handful of members where I have to post to them because they don't do laptops, computers, iPads or anything like that. I have had Zoom calls on my pre-diabetic program but you've got the same problem with trying to log on to access zoom calls.

The other issue now: dementia is such a big thing, if you've not got a Power of Attorney in place some GP's are reluctant to talk to you because of data protection and their privacy and all that. It depends what's happening with the person medically, it's meant to be between you and your GP and you have to ask is anyone able to listen in?

The NHS out of hours helpline: last year we rang the number, you get asked a load of questions, which symptoms, what's happening etc and they decide if you need to see somebody and make an appointment for you to go down to A&E at a specific time to see the out of hours doctor, but then they were getting overwhelmed, you were waiting hours for the out of duty doctor to ring you back and that can go on. In October, I fainted and one



of my friends thought I was having a stroke and called 999 and I ended up in A&E which was interesting because I went in about quarter to eleven at night and didn't see a doctor until ten to seven in the morning, that's how long and then I got discharged at half past seven.

If people have got family or friends that could help them that's fine but I think the first step for those who are not 100% is doing an instruction sheet on how to, because people send links out and tell you to log onto the website and you've got to make a password up but some people may not know how to make a password up, I've had that or it's not a strong enough password and they sometimes forget what they did. It sounds easy but say you've got somebody with a hand condition and they're not able actually to press the keys.

Of course, all these things cost money, don't they? But you can't leave a certain group out of society out of it if they've not got access.

Personal Narrative 24

Lisa is visually impaired and lives alone. She previously cared for her children, who are now grown up and she is currently an expert by experience with Dorset HealthCare and works as an elected governor with them. Lisa has also had experience with domestic violence.

Last year, I had a personal infection and I can't see, so they went with what it could be so I got some cream. I ended up ringing and getting stronger stuff but then I had another issue, so I finally went in for both things. I got an examination and was told it's not an infection so I had been putting steroid cream and all sorts I didn't need on it, which they would have known if I had seen them like I used to, but that was a lot of medication on my skin. When I did go in, that was a lot better. We had a long chat, my full ten minutes. I felt like we went through everything that was wrong, checked my drugs and it was really pro-active, probably the best one I've had. If they take face to face away, there will be a lot of down sides. One of my blind friends had an appointment with his doctor and it took 55 minutes to get connected, he wasted the appointment trying to get through because he couldn't work it and people can't, zoom is different for every single device. Also, when having a phone conversation with the doctor at work because the doctor rings you back at any time so if you're working you can't just walk out. The first time I had a phone call like that I had to run away from someone to have it privately and... saying all those symptoms out in the middle of the street or on the bus, you're not going to. I've been in a domestic violence situation and I know if you don't document everything, each time you get hurt etc it's not viable in court, but I think some of that won't get documented anymore because they can't say it at home or in front of children. One idea we had, places like local hubs or in a library that you can go to that are soundproof, you can go for a phone call or even a video would be a way to go. It wouldn't have to be 24hrs but, it would help. It's basically the public telephone made safer in a hub.

Taking pictures is hard for a normal person but for especially for me. And they don't tell you who's going to see the picture or if it will be in your records. I just say I can't do it because I didn't know what I was sending the picture of. I wasn't even offered a video call from my doctors. I really struggle with forms too; I've had to fill in a load of different forms for different things and I'm not 100%. I'm 56 so I left before computers were in school, so forms I do struggle with. It's a real faff and you don't know you're doing the right thing. I've had a couple of forms that I've ended up sending to someone else to do because I couldn't figure it out, it's taken a week to just fiddle with a form. I also think why are they giving me a form to fill in, a blind woman, why? No, I'm not happy about it because I don't write brilliantly either, I've got dyslexia so reading back what I've written, I sound like a child. If you read what I write, I sound terrible. If you've got something urgently wrong with you but you can't use the right wording, then you can mean anything. I much prefer to talk to someone.

When taking a picture of something personal, would you really be happy to send that to your doctor?

People are suffering and all the things we have fought for, it's going backwards. I can't use a mobile phone when I've suddenly gone blind for different reasons, which does happen a lot... Then you can't access a doctor so it's up to the partner to phone the doctor and if the partner says no then they can't access them. When they

There's no safe space that's accessible for all and everyone knows about. A&E is somewhere we've always been able to run to, you need to be able to go there and ask for help for whatever reason



could have physically just gone round... With A&E as well, sometimes you've got to gather your child up and run to A&E but if you've got to phone that's an extra thing to do. If you think you're having a miscarriage and nobody knows you're pregnant, what are you going to do? Turning up at A&E is an easy thing anyone can do, even anyone that is abused, if they get out the house... you're not allowed in the police station, you can't go to the hospital or to the doctors, where do you go if you need help? In a violent situation where do you go? With mental health, you can walk in to A&E and say I'm going to kill myself or whatever or if you can drag someone in who is really struggling and they can get help... if you've got to ring first you just can't do it, they're gonna run, they're gonna do something. If you've had mental health issues, that's where you would go because that's all everybody knows, you are brought up from young to go to A&E if something is wrong but if you can't and someone is displaying behaviour that you're terrified, you wouldn't know what to do.

The other thing, there's a lot of people that can't afford or don't want smart phones. A lot say I'm not doing any technology and that is it. My Mum is 89 and hasn't done emails. There's lots that just don't want to start a phone. It's all just another bill to her. With equipment, that's really hard because not everybody can use it. My Mum suffers, some of it is she doesn't know what she's doing but a lot of it is that she hasn't got a lot of power in her hands because of her polio and her eyes too. For me, trying to get apps for the Samsung to read out emails, all these emails from the health authority, I can't read them when my dyslexia kicks in, the top, middle or bottom sort of goes sometimes, it's giving me too much information.

Personal Narrative 25

Josephine is in her 80s and cares for her husband who has recently been diagnosed with dementia and has had a heart bypass.

Both my husband and I have got health conditions. I have a leaky heart valve and blood pressure problems and I need Thyroxine, a thyroid drug which I've been taking since I was about 30. My husband, initially he had stents, and then had a heart bypass about 6 years ago and he's just been diagnosed with dementia. It is frustrating that you have to wait a long time to get answered on the phone and then you've got to make arrangements with the doctor if they have to make a decision whether they need to see you or not.

It is frustrating not being able to access the doctor as normal but we're fortunate in respect that we've not had to badly. My husband had an issue a couple of months ago where he had to call 111 and they referred him to the hospital, and they said they were going to keep him in overnight and so I went to bed. Next thing I know it was gone 12 o'clock, there was a ring on the door and it was my husband, they just said you can go home. I was annoyed about that so we went up to the hospital the following day and I was referred to the phone so I phoned them on the hospital phone and got an answerphone to say we will get back to you, but nobody got back to me so I wrote them a letter. I said it wasn't good enough, you knew he had dementia. We're quite a way away from the hospital and fortunately he had some money in his pocket to pay the cab to get home. So the people at PALS said do you want me to take this any further and I said it needs to be, somebody needs to be told about it so they said that they would speak to the people in charge. We know how A&E is in such desperate needs at the moment so I didn't want to go and sort of make a great big issue of it but I needed it to you know be dealt with.

I'm not IT perfect and I only use it for social things, I don't use it much at all, I don't even bank online cos I don't like banking online.

A straightforward email I don't mind but apart from that I find it pretty difficult and my husband would have no idea.

I wouldn't like A&E to become via triage very much, I'm not too happy about it but it just depends. The ideal thing is to go straight there.

I use my iPad for social reasons, if I have to use it for you know more important things, I'd have to learn a lot. At the moment I could cope but who's to know what the future brings. I've still got my faculties so that's fine but when they go it's another question, isn't it? My husband wouldn't be able to cope, my husband wouldn't be able to cope at all. His memory goes on up to date things and it could get worse, he wouldn't be able to cope with any IT.

The fact that you don't contact the surgery as much as you might have done before simply because you think oh no that's alright, that'll go away sort of attitude. Which is not comfortable but I don't think it's going to change, I think that's going to be the routine for it in the future, you've got to phone up and you might get a response, you might not. It's all the potential worries in the future.

Personal Narrative 26

Simon describes himself as an addict, who has been in recovery since April 2020. He was previously homeless and very isolated from society until he went into the care of a charity.

I COULDN'T USE A COMPUTER, NEVER HAD A SMARTPHONE, AND DIDN'T EVEN KNOW HOW TO USE ONE.

Last year, I went into the care of a charity which accommodates homeless people in churches; they managed to secure me accommodation. I'd been shut away from society by my drug use and coming out of the drug world, I realised some challenges I face to be part of main stream society: I had no phone for many years, really shut away and isolating. My work had been cash and it's been a struggle even going to the benefits office, not knowing how to use a computer because you can't get access to stuff, even in the doctors now you go to the screen. When I was under the care of Faith Works, they said someone had heard my Personal Narrative and wanted to help, I was suspicious, but I was lucky, and they bought me a smart phone. When I got the smart phone first, technology unsettled me where I couldn't do it, so I kept going back to my old basic £10 phone. A lot of people are happy not having technology, people just want a simple life, cos it hurts your head believe me at first, if you're not used to it, it hurts your head.

I used to have one to ones with my doctor, who helped me massively. The doctor saved my life, it was that serious, I was falling apart. I was overweight and without that face-to-face, I would have died by now; there is no way I would have survived and there's lots of people like me, loads of us, not necessarily drug addicts or alcoholics but people who just aren't digitally minded. I speak to people daily, try to give them Bourne Digital's number, because I realise the importance of it. There must be a way that if you haven't got a computer you can still get access, it's unfair if everything's 100% on computers, it's totally unfair.

THE RESULT OF ALL THIS WILL BE MORE DEATHS AND MORE ILLNESS, THAT IS THE END RESULT, THAT'S WHAT WE'RE TALKING ABOUT HERE: LIVES. THE VULNERABLE, THE FORGOTTEN, THE HIDDEN, THE ANONYMOUS.

I just want equality really; it's the drugs and alcohol that change things, take that out of the equation and we're just normal people trapped in addiction. I've had to do a digital CV because everything's on the internet and I actually cried 6 months ago, felt like I'd come out of jail, I've come out in this world that I'm not part of? I ain't got a

clue.

With the signal all over this country: there's little places down at the bottom of hills, it's quite a rural country, there's a lot of little villages, all walks of life out in country parks, in the mountains. And there's just too much movement behind technology, too much momentum, it's a digital juggernaut and it isn't stopping and you can't beat them so it's got to be mass, mass, mass promotions to get people like me hooked up at every opportunity, a real push. A promotional campaign in every town, city, village. We're talking life and death, that's what it comes down to. If you are totally cut off and no confidence, it'll come out in a few years' time that they could have done a little bit more, they could have protected people more.



A&E is just amazing, you were always able to just go in there and save your life. It just wouldn't be totally practical, would it? What do you do if you've done something to your finger or something, then you've got the person on the phone and all that awkwardness and asking you all the questions, and you're in shock and you need to get to A&E as quickly as possible. It's back to the confidence and not knowing.

I didn't understand broadband and getting a telephone; there's lots of addicts out there with children and a lot of addicts haven't got bank accounts to set up to pay for broadband. Kids use school computers but when they go home there's nothing there. We're all dependent, I never wanted to be dependent because this is a loan laptop and the dread was getting used to it, then it's gone. Luckily they have extended the loan as I'm doing a Maths and English course and I can keep it until Summer but I'm dreading it because I'm broke, I get basic benefits and have no credit rating to get things.



Change People.

Change People is a human rights organisation, led by Disabled People, working to build an inclusive society where people with learning disabilities are treated equally.

Personal Narrative 27

I am a British father, a grandfather and a husband. I live in South Yorkshire. I have a learning disability. I have dyslexia and short-term memory issues. I live on my own, I work two jobs and I am a geek. I like sci-fi, horror shows, movies and I like music from the 80s; blues, jazz, rock and reggae. I don't like clowns or spiders. I have asthma, eczema, high blood pressure and type 2 diabetes.

Tell us about your recent experience needing and trying to access healthcare.

My recent experience of needed and trying to access healthcare was when I was trying to get healthcare around my hearing. I wanted a face-to-face meeting with the doctor, but they don't do that at the moment. I said what is the point in that. I tried to get on it, but I don't have the patience to get on it. I don't like meetings online about my health, it's not personal enough. People need a choice, not everyone is confident enough online. I know I am not. I might be old fashioned, but I like face-to-face. Online is not real enough. I am confident online working, but not confident enough around my health. I feel like they will miss something or when my internet is weird, they won't hear.

I tried getting online to see my doctor, but I couldn't do it. I lost the patience; it was stressing me out. I phoned my doctors back and said I need a face-to-face meeting. A telephone call won't do anything, I wasn't being awkward, I just needed a face-to-face meeting because telephone calls don't work with me. They said at the moment it isn't possible. They told me to get some olive oil and cotton wool. Some wax came out but not enough. They need to be syringed properly. He said this is for now.

I tried to access out of hours about my ears, but I found getting through a doctor hard. You have to ring back loads of times. It wakes 3hrs sometimes or ask me to call back later. Sometimes I speak to a machine. It is not easy at the moment to access services; you have to ring up early and you can't get through. You have to time it. Hard to judge best time to ring them up. When you are working it is difficult. They only make an appointment when you are working as mine is not open on weekends.

I was only offered virtual health appointments. I rung them up to make appointments, but it is very difficult. They are always busy. It is frustrating. I walk up to the doctors, sometimes I can book in advance, it depends on who is on the desk. For my ears, I had no other options than online.

Things that would be a barrier for me accessing care would be digital, if you don't read very well and information is online, it can be hard to read it. It puts me off going on it. I can't rely on my support worker because they can't come into the house and my mum lives far away. I sometimes send my mum a photo if I need help reading. Sometimes I have no other option. The information isn't in easy read. The colours on the internet, white, I can't look at it. It

makes me feel physically sick. Because I have dyslexia, the black writing on white background is difficult.

Remote/virtual/digital care models make it is a lot more difficult now. You feel pressured to do remote, I don't like it. I try to do phone calls instead of online now. I got a text about my covid jabs, that was good. I get texts about my appointment and that is fine, it took me 3 years to get that. Before they used to send me letters, I couldn't read and kept missing my appointments, they would get mad at me. I only got it because the receptionists changed. My hospital appointments are still paper form and I send this as a photo to my mum or my wife to read, or my support worker.

Shifting to virtual healthcare puts me off. Yeah. It makes me more isolated and puts my health at risk. Not everyone is online and not everyone has the confidence to use online services. Another thing, passports. Health passports, keep talking about it, but I have never seen one.

The information isn't in easy read. The colours on the internet, white, I can't look at it. It makes me feel physically sick. Because I have dyslexia, the black writing on white background is difficult...

I have never done a virtual appointment, couldn't get on it. I didn't have a guide to know what to press. If you don't read well, it can be very confusing. I tried to do it myself, I don't like to rely on people all the time. It makes you rely on people, and it takes my confidence away. If things are going to be online, they need to talk to people with learning disabilities and make easy read guides.

I would need help and support to access virtual healthcare. I wouldn't need equipment such as phones/tablets. I already have them. I have an iPad too. Free data would make a difference. It costs money in long-term getting in touch with them. Broadband/Wi-Fi would help. Yeah, because it would be less stressful, so many different Wi-Fi companies. Sometimes it is difficult to understand people at call centres as they talk fast and I can't keep up, the language is hard too. I moved from TalkTalk to Plusnet, because they talk slower and clearer. They also don't pressure me to buy stuff. Free phone calls would be good, because if you have an appointment it helps. I don't need an interpreter. But sometimes people don't understand what I am saying because of my speaking problem. Over the phone makes it worse, I get more nervous and stutter. I have got an advocate. I have one at the moment because of covid-19. They just talk to me online, not face to face. It's like putting a plaster on a giant cut. It doesn't cover everything I need.

I normally get support with reading, but not as much because of covid. We do it over video chat. Sometimes she can see it and sometimes she can't.

It's like putting a plaster on a giant cut. It doesn't cover everything I need.

In the end I take photos and post it on my phone to hers. Information about results can sometimes be ok by phone, for small stuff. Big stuff face to face. I prefer face to face for appointments. Get my ears done properly by a nurse not olive oil. I don't know how much to put in my ears. I worry I might hurt my ears more. I have eczema in my ears, sometimes it blocks them. I think there should be step by step easy read guides on how to use stuff.



In the past I went for diabetes check-up. One doctor used to talk to my mum and not me. Second one was better as she asked my permission if she didn't understand me, could she ask my mum. I have not had a diabetic check up in the last year. I have not had an eye test for a long time too. I don't have a mixture of remote, home or hospital treatments. I do my injections at home.

National Voices

National Voices is the leading coalition of health and social care charities in England. We have more than 170 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

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Making what matters to people matter in health and care