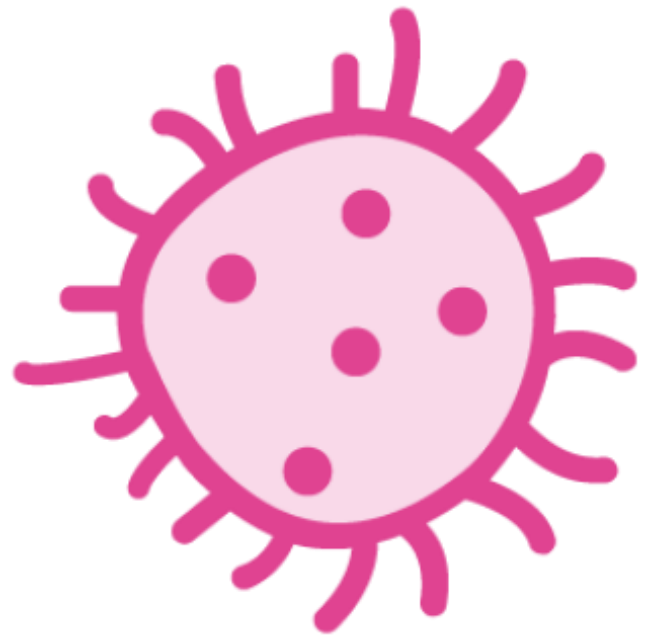


healthwatch Hertfordshire



Digital Exclusion Case Studies: Covid-19 Patient Experience

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Executive Summary

Background

During the Covid-19 outbreak, Healthwatch Hertfordshire carried out three online surveys to better understand the public experiences of mental health, shielding and health and social care services more generally. To ensure that we also heard from those who do not have access to, or do not feel competent using the internet we carried out this additional piece of work to speak to those who are digitally excluded about their experiences during the coronavirus pandemic.

Our aim was to find out the reasons behind digital exclusion as well as how being digitally excluded has affected people's experiences during the pandemic.

What we did

We placed an advertisement in our volunteer newsletter encouraging people who considered themselves to be digitally excluded to contact us.

We used qualitative case study methodology. In doing so, we conducted six, one to one in depth telephone interviews between 24th August and 7th September 2020. This approach meant we could investigate people's experiences in depth and within its real life context, as well as showcase the uniqueness of individual experience.

What we found

Barriers to Digital Inclusion

- Two of the people we spoke to told us that their main barrier to digital inclusion was the cost as well as a mistrust of online platforms and services, notably online banking and social media.
- Two people told us that they lacked the skills to use their devices to get online.
- For one person we spoke to, their medical condition prevented them from using electronic devices for extended amounts of time.
- One person told us that they were not interested in using the internet.

Experiences during Coronavirus

- The people we spoke to shared experiences of missed healthcare appointments, increased feelings of isolation and loneliness and expressed frustration at confusing Government messages regarding the coronavirus pandemic.

Digital Inclusion

Amongst the people we spoke to, motivations for getting online included:

- Being able to keep in contact with friends and family more easily
- Being independent, and not relying on help from family members
- Being able access more information

1. About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

2. Introduction

The Coronavirus Pandemic

In March 2020 the World Health Organisation (WHO) announced the Covid-19 outbreak as a global pandemic. In response to the crisis, on 23rd March 2020 the UK Government enforced a national lockdown which saw much of the support and activities familiar to day-to-day life completely suspended, with more reliance on remote support in place of face to face. As the outbreak developed, there were ever changing messages and information broadcast by the Government, which signposted the public to online platforms for further information. Moreover, the restrictions put in place meant that people who live on their own were more vulnerable to loneliness and social isolation as a result of Covid-19, which may be heightened by digital exclusion if they opt out of getting online.

What is 'Digital Exclusion'?

Digital exclusion is the inability to access or use online products or services. In 2018 the Office of National Statistics stated that there were 5.3 million adults in the UK, or 10% of the UK population who were non-internet users. Digital exclusion can result from multiple factors, which include but are not limited to:

- **Affordability** - some people may be digitally excluded as they cannot afford devices which can be used to access the internet, or may not be able to afford an internet subscription
- **Accessibility** - some people may be unable to use digital platforms as they are not designed to meet all user's needs - including those who use assistive technology.
- **Skills** - digital exclusion may result from lack of knowledge or confidence in using electronic devices and online services.
- **Trust** - some people may avoid using the internet due to fear of online crime and lack of trust of online platforms.

Digital exclusion is more likely to affect people in lower income groups, people in social housing, people with disabilities, homeless people, and people whose first language is not English (NHS Digital, 2020). Studies have also shown that digital exclusion is more likely to affect those with mental health issues, who then cannot access self-monitoring apps and web-based therapies (Greer et al., 2019). In these cases, digital exclusion is often linked with social exclusion and therefore impacts the wider determinants of health (Greer et al., 2019).

During the Coronavirus (COVID-19) outbreak the digital divide may be accentuated as updates, information and resources are published online. Digital skills and access also allow people to stay in contact more easily with friends and family.

3. Aims

Through a qualitative case study approach, we aimed to:

- Better understand the barriers that people experience to digital inclusion and the context surrounding/reasons behind digital exclusion.
- To understand how being digitally excluded has affected experiences during the coronavirus pandemic.
- To assess how digitally excluded people have found information and advice during the coronavirus pandemic.

4. What we did

During the Covid-19 outbreak, Healthwatch Hertfordshire created three surveys to learn more about people's experiences. One focused on the affect Covid-19 has had on mental health, one focused on the experiences of those who had been shielding during the pandemic, and the last focused on health and social care more generally.

Although there was the option to request the surveys in an alternative format, all respondents completed the surveys online. This indicated that all of the respondents not only have access to online technology, but they also felt competent using it, or were able to rely on someone who did.

To ensure that we heard from people who do not have access to the internet and/or do not feel comfortable using it, we conducted this separate piece of work to engage with those who are digitally excluded. To do this, we placed an advertisement in our newsletter encouraging those who do not use the internet to contact us. We then arranged to have one to one in-depth phone interviews with the participants, which were held between 24th August and 7th September 2020.

We carried out this research via a qualitative case study approach in order to gather an in-depth and highly detailed picture of the experiences of digitally excluded people in Hertfordshire during the pandemic. This approach is particularly useful to understand contextual conditions or reasons behind actions or views, as well as showcasing the uniqueness of individual experience.

The criteria for inclusion was:

- No access to devices that can be used to access the internet OR
- No access to the internet or data connectivity OR
- Limited use of electronic devices due to mistrust or lack of skills to use them

5. What we found

We interviewed 6 people in total and spoke to them about barriers to digital inclusion, how they have been experiencing the pandemic and their motivation for getting online.

Due to the nature of our discussion, there are some similarities between the case studies highlighted in this report, as well as some differences resulting from the individual circumstances of those we spoke to. It is important to note that due to the methodology chosen and sample size, generalisable inferences or conclusions cannot be drawn.

5.1 Barriers to Digital Inclusion

Firstly, we asked the people we spoke to about the reasons behind their digital exclusion, and any barriers they experience to digital inclusion. Discussions covered the financial cost of electronic devices and broadband subscriptions, lack of trust of online platforms as well as lack of skills to use devices and disabilities and medical conditions which restrict computer usage.

Financial

For two of the people we spoke to, one of the reasons for their digital exclusion was financial. They commented that the expense of buying a device to use the internet, as well as paying for a broadband subscription, was too great for this to be a feasible option for them. For one person, who sometimes has help from their family members to purchase electronic devices, this was compounded by not wanting to create any additional financial burden for them.

Mistrust

Another prominent theme, mentioned by three of the people we spoke to was a mistrust of online platforms and services, notably online banking, stemming generally from an awareness of online scams. There was also mistrust of the information available on social media platforms, and the reliability of the information available online specifically relating to coronavirus.

“When I hear what people are paying monthly, I mean, that’s put me off, but I would think it would be a no-go for a lot of people.”

“I think it’s mainly cost because I’d have to get a BT phone...it would mean a router and wiring.”

“To begin with there were a lot of, not scares exactly, there were scams and people getting into your emails and to begin with it was all rather scary really and I didn’t think I wanted it.”

“I’m nervous to do anything financial on it because of the several experiences of friends who’ve had people who’ve gone on to their computer and done all sorts of things.”

Stories from Hertfordshire...

Julia* lives in assisted living and does not access the internet due to a lack of trust in digital platforms and the misinformation spread online. She wants to get online, but sees this more of a necessity in the modern world than something that she really wants. In order to get online she would like more information about what devices are available that would be suitable for her.

She says that she has not been feeling too lonely as a result of the lockdown due to the fact that she is able to see the people who care for her. Her concern is that as an older person, the coronavirus pandemic may go on too long to allow her to go back to her life as normal.

“Talking about...Covid-19, I mean, there can be an amazing amount of misinformation on social media.”

“I haven’t been able to see my friends or go out for a meal...and when you’re older, you think, are we ever going to.”

Skills and Confidence

For two of the people we spoke to, although interested and motivated to get online, they felt that they lacked the skills either to use their device or navigate the internet.

Stories from Hertfordshire...

Emily* lives with her husband and owns a laptop, she considers herself to be digitally excluded mainly due to the fact that she lacks the skills to use the laptop she owns. She would mainly like to use her laptop for looking up more information, as this is something she has needed help from family members to do during the pandemic. Emily does not want to use the internet to access online banking as she does not trust the bank and would rather visit in person.

“We haven’t got online banking...we don’t trust the bank.”

“I have no training to use the internet, I don’t know how to use a laptop.”

Accessibility and Preferences

An additional reason for digital exclusion of the people we spoke to raised was around their medical condition and disability which prevent them from using devices to access the internet. This means that although they have the means to find information and read mail online, hard copy was preferred. This individual also noted a need for voice recognition software but could not afford it, also affecting their ability to get online. Lastly, for one person, the main reason behind their digital exclusion was a lack of interest in using the internet, and a preference for going out and doing things such as shopping and banking in person.

Stories from Hertfordshire...

Glen* used to work for an organisation using computers which caused him to develop certain medical conditions that meant his doctors recommended that he minimise his computer use. Despite the use of assistive technology to assist him with typing and making the mouse use easier, he prefers to receive information via the post to read it in hard copy. This has become increasingly difficult as fewer and fewer organisations provide catalogues, favouring email communication.

“As a result of being forced to work with user-hostile software, I developed supraspinatus and bicipital tendinitis. My orthopaedic surgeon and my GP recommended me to avoid computers, so I try to avoid computers.”

5.2 Experiences During the Coronavirus Pandemic

We also wanted to find out how the people we spoke to had been experiencing the Coronavirus pandemic, and whether or not they thought that their digital exclusion had affected their experiences in any way. We discussed loneliness and isolation and how this could be impacted by being unable to use online services such as Facetime and Zoom, as

well as changes to medical appointments and how they have been finding information and advices regarding the pandemic.

Loneliness and Isolation

A common theme amongst the experiences of those we spoke to was a feeling of increased isolation and loneliness during the coronavirus pandemic. Two of the people we spoke to told us that it was the social interaction that they were deprived of during the lockdown that had the most significant effect on them. They felt that this feeling was worsened for them by being digitally excluded, as they were not able to use online methods of communication such as Facetime and Zoom.

However, this was not the case across the board, with two other participants feeling that being digitally excluded did not affect their feelings of loneliness over and above people with access to the internet. Four of the people we spoke to emphasised that the most important thing to them was being able to go out and see their family and friends, although despite the lifting of lockdown restrictions, this still caused anxiety for some.

“It’s mixing with people and being friends with people and socialising, that’s what affects you more than anything.”

“Well it’s caused the frustration because obviously I’ve got the television and I watch every broadcast and also the discussion in parliament on the parliament channel and communicated, I have a next door neighbour...without conversation from them I think I might have gone crackers with the isolation.”

“Our church has been doing Zoom, but amazingly, I can get it on my landline which is fantastic.”

“It’s wrong really, but for someone who is registered disabled I still had a life, and I feel as an older person...it’s cut my social life and my retirement into little pieces and I really have to force myself to do anything.”

Stories from Hertfordshire...

Maddie* was bought a tablet by her children and likes to use it to check the weather and occasionally check Facebook although doesn’t know how to use all of its functions. Although her children often tell her to get online, she prefers going out to do things such as meet up with friends, grocery shopping and going to the bank. Since the Coronavirus outbreak, Maddie has not been able to go out to the shops and has been relying on family members to bring her food. Maddie still does not really see the benefit of the internet but sees it more as a necessity in the modern world.

“Well I know a lot of people who get their shopping delivered. Really you could sit in the chair and not move out of the chair and everything would come to you. But I am a bit old-fashioned so I still like to walk to the shop... I could do without any of it really”

“When you stop doing it you forget all about it and you’ve got to start learning it again. I think that’s why my daughter got me the tablet because it’s easier to get around.”

Information and Government Messaging

A prominent theme that came through our discussions was related to the confusion caused by Government messages around the Covid-19 outbreak, which for two of the people we spoke to, was compounded by the inability to look up information on the internet. One opinion was that Government messages would be confusing across all platforms and access to the internet would not necessarily help to clarify them.

Amongst our participants, the most common source of information regarding the Coronavirus pandemic were the news on the television, radio, newspaper and friends and family. Although two participants felt that they had adequate information, three were left with additional questions and mentioned that they would have either liked to be able to access the internet to clarify information they had heard on the television, or they had asked family members to look up this information for them.

All the people we spoke to expressed their frustration at the fact that broadcasts and news relating to coronavirus often signposted to websites for further information, and phone numbers were not available.

“Well I think it was easy to understand the stay indoors but not really easy to understand as it eased up. So you didn’t know whether people could visit you or you could go to visit them. Then they said its one metre apart, next thing it’s two metres, it’s very confusing.”

“I think its people here find it terribly confusing what - who they can go and visit and how many they can go and visit and I think that’s terribly confusing for people, but I mean that’s - whether you get that online or from any other source, people just find all the advice terribly confusing.”

“with the virus, I wanted to know what the signs and symptoms were and I ask my daughter and she just looks it up on her laptop”.

“Everything is go to WWW... phone numbers are not given, so you can’t even phone anybody.”

Stories from Hertfordshire...

Gayle* has been shielding alone in her apartment and does not have access to the internet due to the cost. She has been supported throughout the pandemic by her son. Gayle received her shielding letter in April and this delay left her without help to get food for a couple of months. She eventually received her letter and help with food deliveries. Throughout the pandemic, Gayle greatly missed going out to spend time with her friends and being able to spend time with her grandchildren, and felt lonely and isolated. Alongside this, Gayle found the Government messages around Coronavirus confusing, and was concerned about not being able to look up more details on the internet. In addition, Gayle had increased worry due to cancelled medical appointments, and appointments moved over the phone. This has meant that although lockdown restrictions have lifted, Gayle still feels too nervous to go out. Gayle wants to use the internet primarily to stay in touch with her friends as well as to look up information and do online shopping.

“Just confirming what we’d heard on the television, but not being able to look that up in more detail is frustrating.”

Medical appointments

Two of our participants had appointments affected in some way by the Coronavirus pandemic, including appointments cancellations and appointments moved over the phone. This is in addition to one of our participants stating that they have avoided making doctor's appointments as they don't know how they would go about this within the new restrictions. These comments suggest that although these participants were impacted by changes to their appointments, their experiences were not worsened by digital exclusion.

Two of the participants also commented that although they have seen that video-call appointments have been made available, they do not see this as a feasible option, for themselves and other members of the population.

"There's been problems, there's been lots of cancelled appointments."

"They said they wrote to me telling me it was a telephone appointment and I hadn't got the letter, but it was lucky I answered the phone."

"I normally just go ring up or go in there and they give me an appointment, but I don't know what the procedure is now so I haven't bothered going."

"You see on the television, doctors contacting their patients over a computer and they can talk to them and see them. But to me that's in an ideal world, it isn't real. And probably speaking to a lot younger people and people like myself who are over 65, 68 upwards are not in the position these people are."

"You can't actually do anything else because you don't know when they're going to ring. So you can't do anything else that day or that morning."

5.3. Digital Inclusion

As part of our discussions with digitally excluded people, we asked: "If there were to be another lockdown, how could the situation be improved for those who are digitally excluded?" Responses included comments about ensuring that more information is provided in hard copy, providing training for people to help them get online and ensuring that phone numbers are available, as well as more information about what to do if you feel ill.

"I think there should always be a phone number that's an alternative to a www."

"Hard copy - communication - post is vital."

"The digital exclusion - the thing is if you haven't got a computer and you haven't got the facility for putting it in and there is another pandemic, it's not going to help you - you're without it."

“Better information on the television and the radio at a local level as well.”

“The only think which I feel that could help the situation is me to learn this computer.”

“You always feel as if you’re causing a problem if you ask for hard copy, but yes, I think you should have [information] in hard copy.”

We also asked the participants if they were interested in getting online, and if so what their motivation would be and what kind of support they would need to help them do this. Following this, we asked if they had heard of, or had interest in participating in any digital inclusion initiatives.

Two of the people we spoke to were not interested in getting online, preferring instead to use other methods of doing things, such as going out to the shops and contacting people via the telephone. For one person this was due to missing the personal touch you get from going out and speaking to people, rather than the impersonal nature of online platforms.

Another of the people we spoke to wanted to get online, but saw it more as an obligation for living in the modern world. Additionally, this participant felt that not being online was disadvantaging them. When asked about what information or advice they would need to help them get online they responded that they would like more information about what type of device would most suit them.

“It’s the personal thing, because you’re actually talking to a living person.”

“More and more the world just expects you to be online. I don’t want to do things like online banking, but I’d quite like to Google.”

“Looking up things and communicating with friends. All my friends they’re on WhatsApp and all these sorts of things.”

“It’s annoying when you can’t find answers to some of your questions and if you want to communicate with people and all they ever give you is a website.”

“When you’re asked for your email, if you haven’t got an email address, you’re at a bit of a disadvantage.”

Three of our participants were keen to get online and were interested in digital inclusion initiatives. Reasons for this included being able to feel more independent and not rely on friends and family, being able to stay in touch with friends and family more easily and being able to look up information using search engines.

Two of these participants were already aware of The Online Centres Network - a network ran by Good Things Foundation which is made up of over 5,000 grassroots organisations, all working to tackle digital and social exclusion by providing people with the skills and confidence they need to access digital technology. The participants knew of their local Online Centre, but had been unable to access support here due to closures caused by the coronavirus pandemic. Healthwatch Hertfordshire were able to signposting the remaining participant to their local Online Centre.

Stories from Hertfordshire...

Freddie* lives alone and has not been able to access the internet as he lacks the skills to use his laptop. His main motivation for getting online is being able to regain his independence and not rely on friends and family members to sort things out for him online.

Throughout coronavirus Freddie has had great care from Harpenden Care who have assisted him with getting food. Freddie has most enjoyed his opportunities to get outside and see his family members and friends.

“It would help greatly if I could learn how to do this and I could do it by myself, this computer, and there’s a lot of things now which - “it’s very easy to get in contact with us, just go to www” ...and I said “Yeah, I would do if I could do”

6. What next?

Thank you to the people who spoke to us and shared their views and experiences of being digitally excluded. Healthwatch Hertfordshire will use these case studies to inform future work, as well as share these case studies with Health and Care services, Councils and Voluntary and Community Sector Enterprises in the county so that digital inclusion initiatives can learn from the experiences and views expressed in this report.

*Please note, false names have been used throughout this report to protect the anonymity of the people we spoke to.