Digital Exclusion MHELO Focus group

Report on findings

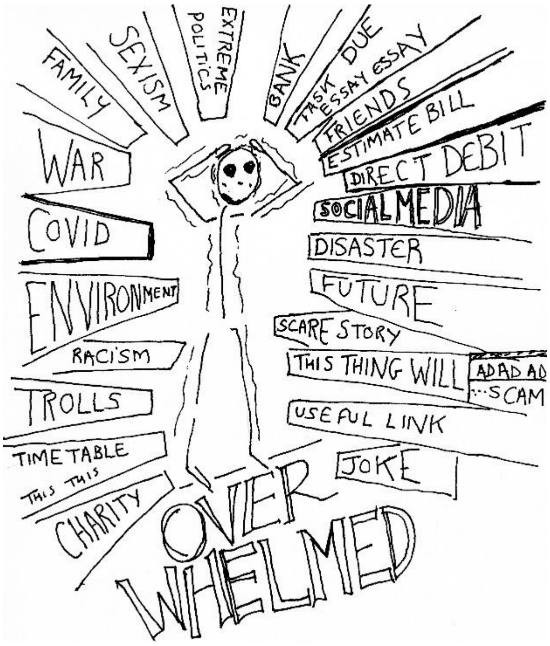
Introduction

The effects of the COVID-19 pandemic have been far reaching and have impacted many areas of our lives. One area which there has been significant and long-lasting impact is the rise of non-contact interactions and the increase of the use of technology in daily living.

MHELO members who have lived experience of mental ill health identified the area of the rise of the use of technology as an area for focus and exploration. We held one focus group and a survey to gain insight into how this area is impacted people in their day-to-day living and how there is a potential for the increase of people being excluded because of the use of technology. We wanted to focus on digital exclusion rather than digital inclusion because of this.

Case Study

“I just wanted to highlight to your group how difficult she (members daughter) is finding online study and accessing support for her mental health which is only available online. She is autistic and has really struggled with her mental health over the past few years. She gets overwhelmed by the volume of emails that she is receiving at university and lack of face-to-face contact in all areas of her life. This has resulted in her having sensory overload and literally shutting down when she cannot cope so she stops responding to emails and consequently misses out on important information. She is only young and all too often the assumption is that youngsters are ‘digital natives’, and although she is very competent with technology, it cannot replace the importance of face-to-face contact, especially for an autistic person who has real difficulties with her ‘executive function’ and ability to process information.”



The effects of technology on Mental Health

There was a concern raised that people didn’t consider how mental ill health is not considered throughout the process of accessing things online. There is an increased

Illustrations by Max Frances

anxiety and fear levels which surround change and people not being able to understand how to use technology and then not accessing a particular service because of that fear. We discussed some of the thing's areas which had affected people.

Person 5-

"Within the NHS, who is likely to be digitally excluded in their list, it doesn't include people with mental health issues or serious mental illness. People who have fluctuating mental health needs can be digitally excluded because of how they relate to accessing things digitally dependant on the state of their mental health.

For example, if someone is in a heightened anxious state and struggles to access thing online normally, they won't be able to access it if they are in this state. This could have a serious impact on them if they are trying to get support for their mental health."

Person 1-

"A lot of it is getting people over the fear of using computers. There's a thought that you will break something. It's about having confidence and getting over the fear that you can break it."

Person 6-

"You can't say to someone just play around with it to try and learn how to use it something. I don't want to play with it, it might explode, it might eat all my data. I don't even know how to play with it."

"Actually, typing is an issue. It takes me up to an hour to write a short email, and I can't type, and it makes me really nervous, and I delete half what I say. Social anxiety carries over into the internet for some people."

"I'm always afraid of anything I don't properly understand, I can muddle through with a bit of help. I didn't have an email address until went on a course in 2012 and had to have one to be able to sign up. If it wasn't for my father and brothers, who put me onto their home hub so I can visit in Tewksbury, I wouldn't have access to a computer."

Assumptions

Throughout the discussion it was evident that there were a lot of assumptions that people make which increase barriers for individuals. These assumptions can be directly from staff but also from people who design the systems which people use.

People assume that you have internet connection.

Person 2-

“In the forest, the digital connections not that great. Even if it says they have broadband, it doesn’t mean to say that you can actually access it.”

“When people did the BBC bitesize, people didn’t have the broadband to be able to access it.”

People make assumptions about people’s abilities.

Person 2-

“With young people- who make the assumption, that young people equals digital savvy. People don’t always have the access and have the resources.”

Person 6-

“I can’t use i-pads and things like that because I can’t use the touch screen. Disabled people and unwell people would have a really big problem with using a touch screen.”

“I don’t know how to look after a computer. I don’t know what’s true about the stuff they send you. I don’t understand that anti-virus stuff.”

Person 3-

“People don’t always know what internet safety is.”

Person 4-

“We set it a Facebook portal for my mum whilst she was in a care home so we could still talk with her. Staff said they would set it up for her, but she never got access to it. We then had to get her a tablet so we could allocate a time to speak to her. The OT just left her with it, and she couldn’t physically hold it, so she couldn’t see me and ended up crying over it and it was really distressing for both of us. All we needed was a stand or for someone to help her and hold it for her.”

People still assume that people do have access to technology.

Person 6-

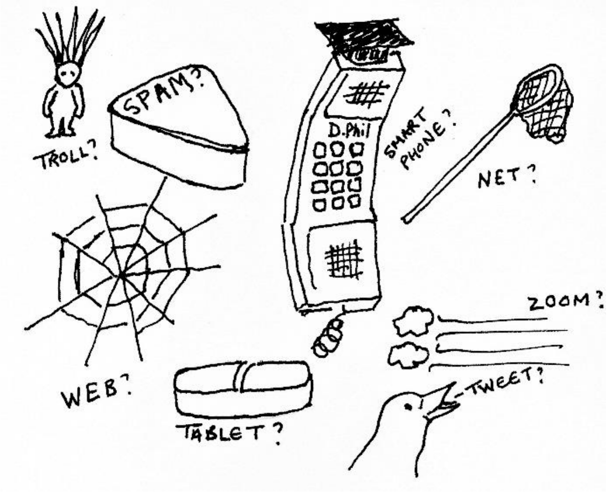
“There should have to be an understanding that people don’t have a computer or a smart phone. I don’t think anyone at my church does.”

“Without computers we had very little contact with anybody.”

Person 4-

“Throughout lockdown we lost half our churches home group because they couldn’t come online.”

People assume that everyone understands the same language about technology



Person 6-

“Something to do with familiarity with language. For me there is a language barrier. For my nan- I set up her set top box for her. A lot of the words just don’t make sense to her. She is very intelligent, but there is no way she would be able to set it up. She’s not had the peer group that speaks the language, so she doesn’t know it.”

“People need to know what to ask, and people have to understand what your level of knowledge is.”

“I make the point of using all the wrong terminology, so people understand how much I don’t understand it.”

Training and support

There needs to be an awareness that people need to be able to have not only appropriate training, but appropriate ongoing support and know how they can access this.

Person 2-

“Even when someone’s shown how to do it, it’s a one off, they need support for the support. They have the training, but people need ongoing support.”

“Even when someone was provided with a laptop, there wasn’t any training. Luckily another charity put on the training.

It’s often informal connections that offer support. For example, one person was trying to get onto something at 10pm at night, and they called me because there wasn’t anyone else who could help.”

Person 6-

“Some of us need written prompts. I need written instructions.”

Person 5-

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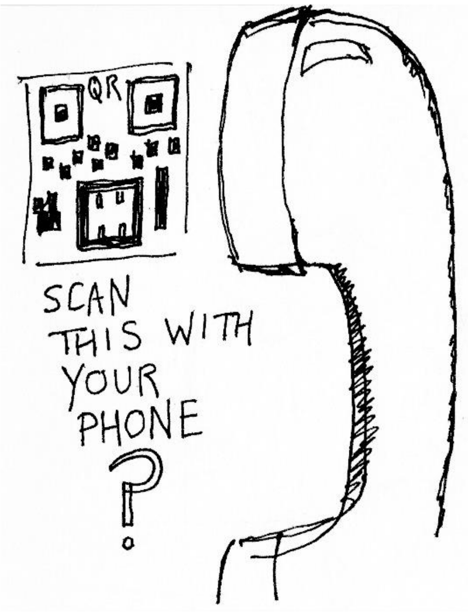
“Unless someone uses something all the time, like at work, then it’s really difficult to learn how to do something or use something new. If you attend one training on how to use something, it doesn’t mean you can then use it. People need ongoing support”

Person 6-

“People need to employ a tech person. Nurses and people work very hard, but they don’t always know and can’t always help. People need to have proper technical assistance.”

Person 3-

“If people use the internet, do they need staff support? It changes it if people need help because staff must do it for them. A lot of the time staff don’t even know what they’re doing. And it means that people can’t do things for themselves.”



Choice and Control

The biggest outcome of the conversations we had with individuals was around having choice and control within how they can access things. To be able to have increased understanding that people need different levels of support and need to be aware of how they can use an alternative is they are finding accessing services digitally was very important.

Person 6-

“You have to know to ask. The COVID tests- I would have to scan something in to be able to get the COVID tests on the internet and there wouldn’t be any way that I could do that. They had to order it for me, but they only did that because I knew I had to ask.”

Person 4-

“There has to be adjustments made. It’s not an all or nothing service. For example, with the GPs it can’t all be online, there has to be a way of making adjustments for people, but people need to know that they can make those adjustments”

Person 6-

“People need to know what to ask, and people have to understand what your level of knowledge is.”

Person 4-

"I think it should be a freedom of choice. I think the choice has been taken away from us. I don't know much about universal credit- but I think even that has got a journal online. If someone can't do that then they are at risk of not getting their money, which is drastic."

Person 3-

"If I don't answer the phone to universal credit, they can sanction me. I have to make sure I am somewhere where I have signal. I rely on that money."

Person 6-

"It should be automatically available if you don't have internet capabilities, groups like Inclusion Gloucester, should have the resources set aside to print and send relevant materials. Inclusion Gloucestershire and Artlift have been very accommodating. Other people less so."

Person 5-

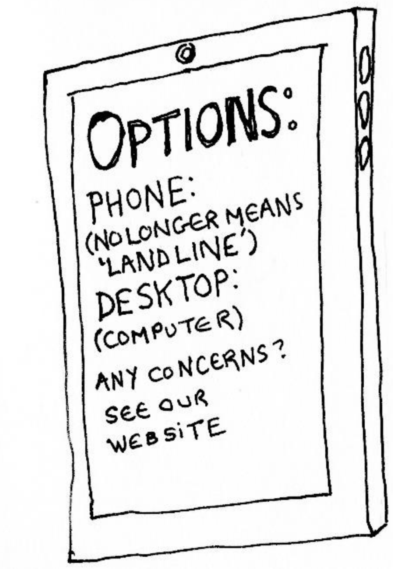
"There isn't the choice, it feels like they force you to go down the digital route."

Person 4-

"Trying to order online, a lot of places don't even give a phone number."

Person 2-

"Some of the websites are pushing you to email in rather than phoning in. Even if you can get onto the website, yes you can get these chats and they type it back, I don't feel comfortable with those. The phone number is all the way down at the bottom."



Person 5-

"There are some websites where there isn't even a number that you can get to speak to someone. You have to go through many different numbers to actually find out how to speak to someone. I've found this a lot on council websites. If you don't have an email address, how do you even get in touch with people?"

"There's no one solution, everyone has individual needs, there's no solution other than to support people with their individual needs."

Unconsidered impact

There are a lot of areas of our life which now rely heavily on digital access that there are further implications which haven't always been considered and make a big impact on people's daily lives. This impact is sometimes about people's ability to access services, but there are other wider and more personal implications.

Person 4-

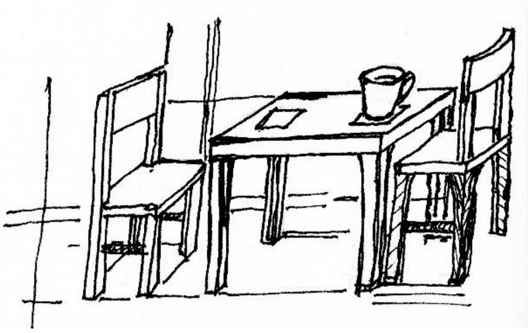
"For benefits- if I don't get it in on time then my benefits could be stopped, but it takes me so much longer to get the stuff together they need because I need to get things online. For example, trying to get my bank statements online I can't download them on my i-pad because it won't let me, I had to get someone else to do it. I couldn't go into the bank because it was closed."

Person 3-

"My local bank has closed down, I have to travel to the next town now to go to the bank. People assume that I bank online, but I can't I have to go into the bank."

Person 6-

"My partner panics with bills- they are all designed to be paid online and they want them paid tomorrow. It then means that there's more anxiety about getting it done on time. It also means that people can get late payments, and then that can affect their credit score."



Removing the human element

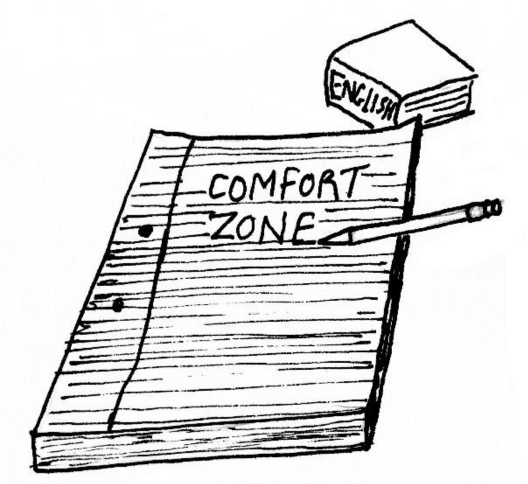
With the move into a digital access age, we are becoming more removed from the human element. We couldn't fully explore this area, but these are some of the comments people made in relation to this.

Person 4-

"Things like sorting out your benefits or accessing a doctor are quite emotive things. It's really hard to have that done in not a personal way."

Person 5-

“I’ve filled in the GP form because that was the option given to me. I didn’t know how to find the words to explain what I needed help with on an online form. You lost the body language and having someone trying to help you find the words.”



Person 2-

“Yes, you can get these chats and they type it back, I don’t feel comfortable with those.”

Person 6-

“People need to know what to ask, and people have to understand what your level of knowledge is.”

<u>Responses to our survey</u>

We launched a survey via google forms, which was also offered out to MHELO members, networks and Inclusion Gloucestershire staff and advertised on our Facebook pages. Paper copies were offered to individuals if they were unable to access the form digitally.

We identified similar themes within the responses to our focus group, with the main concerns being raised around accessing GP’s and services. There was a shared concern about the removal of choice in being able to access services, being able to speak out and be involved and that there would be an increased likelihood of individuals being excluded.

“I am afraid that it may become compulsory rather than just an access option.”

“Lived experience group (and many similar groups) - only done via Zoom and at a fixed time without a non-live mode of contributing and having dialogue. No voice for those not free at that time or who feel uncomfortable with Zoom.”

“Attempts to get help will simply be ignored.”

We had 3 responses to the survey and have shared the responses below.

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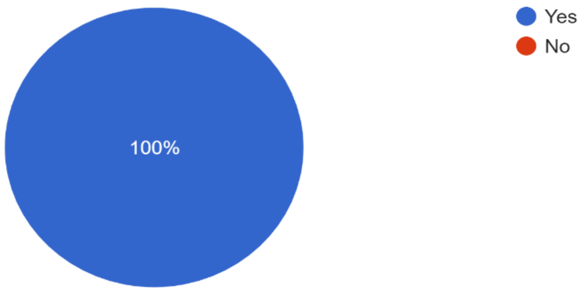
Have you accessed services online in the last year? This could be via webpage, webform, online meeting or anything outside of in person appointment or a phone call.

3 responses



If you have accessed services online, tell us about your experience.

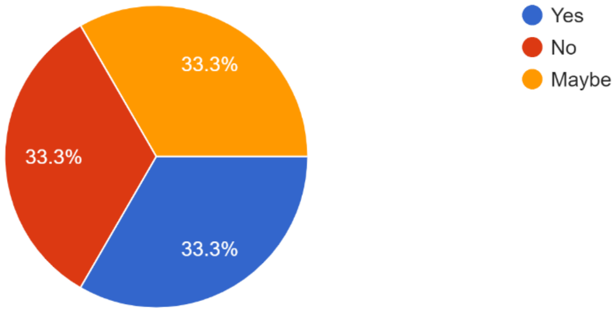
“I regularly use Zoom and Teams for online meetings with various organisations and friends. I find Zoom easy to use, but Teams is tricky.”

“Not good.”

“Doctor appointment- 300 character limit in online form, so I could not give all the relevant information or format the information I did give properly.”

Do you know of other people who haven't been able to access services online?

3 responses



If they haven't been able to access services online, why?

“No computer”

How have accessing service online been good?

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“It has kept me in touch with people when shielding and has allowed me to 'see' my GP more safely.”

“Not good no.”

“I can arrange things without worrying about using phone, or phoning only at the correct time, or needing to arrange lots of time to wait for a call centre to pick up.”

How have accessing service online been bad?

“GP rang me for a consultation and needed to examine my throat. He guided me through downloading an application on my mobile and then contacted me via the app. Using my phones camera (and after putting my phone in my mouth!) he was able to examine my throat and diagnose the issue. It would have been so much easier and less uncomfortable to have had a face-to-face appointment rather than having to swallow my mobile!
Online meetings can be overwhelming and everything said goes to everyone unless you are familiar with their chat functions.”

“Not good.”

What are the barriers to accessing services online?

“Some people are not technology literate they may not have access to a computer or smart device or just don't want to engage this way.”

“Need to see someone in person.”

“Online doctors services needing a visit to the surgery to set up.”

What are your main concerns around having to access support online going forward?

“I am afraid that it may become compulsory rather than just an access option.”

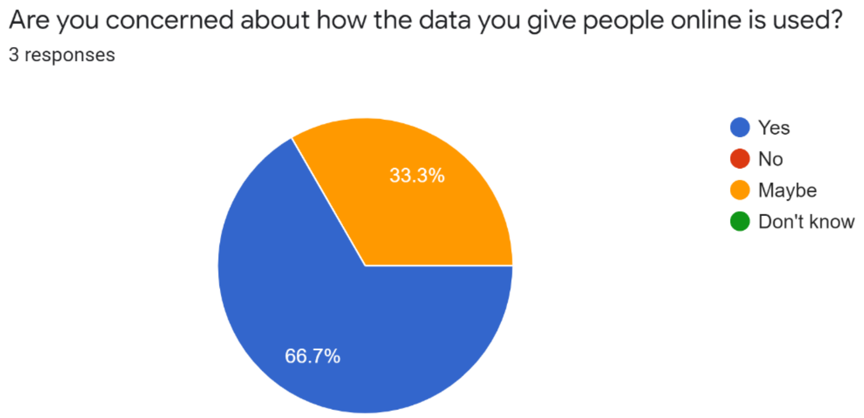
“Unable to fully see body language.”

“That attempts to get help will simply be ignored.”

What is the biggest impact for you about having to access services online?

“A bit 'swings and roundabouts', some good, such as keeping in touch and some bad such as the impersonal nature of online/telephone GP consultations.”

“Isolation.”


Are you concerned about how the data you give people online is used?
3 responses

If you are concerned about how the data you give people online is used, what are you concerned about?

“Over or under sharing.”

“Who has access to this.”

“If data leaks only once then it cannot be "unleaked", and even if organisations holding data were perfectly trustworthy (which they obviously are not) it only takes one case of human error or a single hacking attack for a leak to happen. There is no way of knowing what purposes such data will ultimately be used for.”

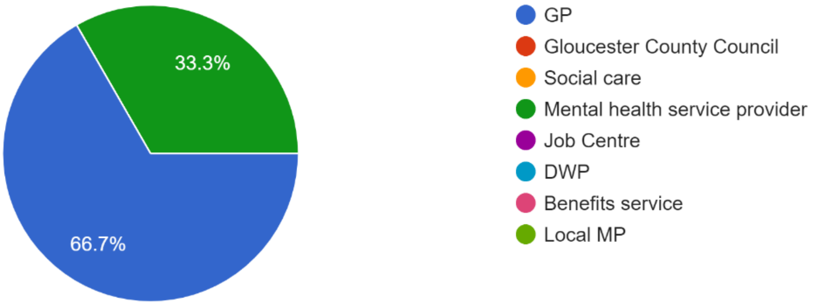
Is there anything else you would like to tell us about accessing services online?

“Lived experience group (and many similar groups) - only done via Zoom and at a fixed time without a non-live mode of contributing and having dialogue. No voice for those not free at that time or who feel uncomfortable with Zoom. With this exclusivity these groups seem to exist more for professionals working for local government or charities than for disabled people.”

Illustrations by Max Frances

Who needs to know about your experience of accessing services online?

3 responses



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