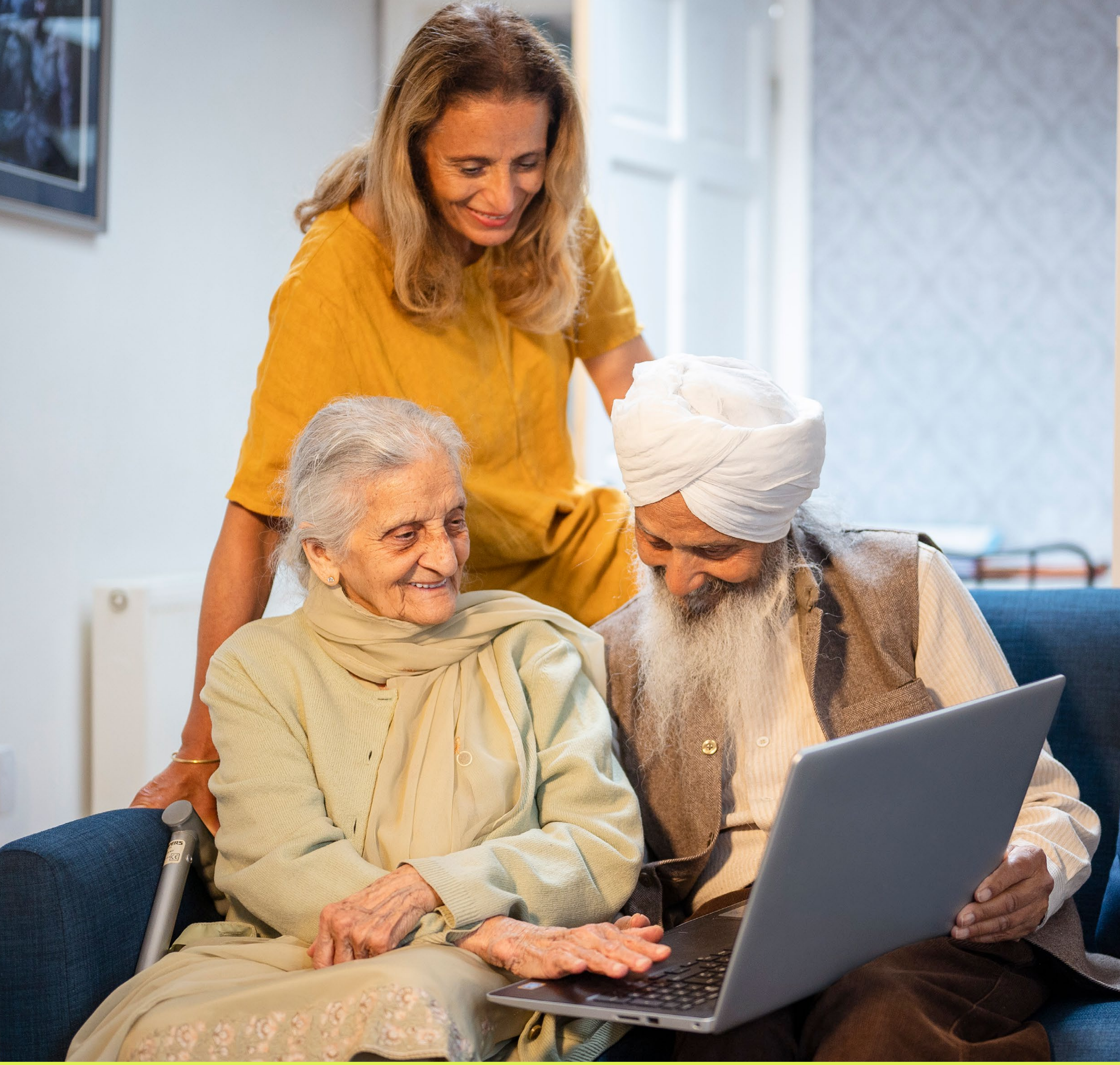


Digital exclusion and unpaid carers in South Yorkshire

Dr Kate Hamblin and Dr Rachael Black

Centre for Care
CROOK public service fellowships
University of Sheffield
CARERS TRUST Sheffield Carers Centre

BACKGROUND

Digital technologies and online services are increasingly part of our everyday lives. The COVID-19 pandemic saw a shift to the online delivery of a variety of tasks and amenities – both in the public and commercial sector – during periods of 'lockdown'. Banking, shopping, working from home, socialising and accessing health and social care services online all increased exponentially during the pandemic, and for many people digital remains a key part of their daily lives.

However, as highlighted by the '*Digital Poverty in South Yorkshire*' project conducted by colleagues in the University of Sheffield Information School, not everyone is able to easily access digital devices and online services. There is a 'digital divide' between those who can and cannot easily use digital devices and in turn go online to access services. For some, this is due to 'digital poverty' or 'digital exclusion' and there can be several underlying and interacting issues. A person might not be able to afford to go online due to the cost of digital devices or Broadband, or does not have access to a reliable internet connection. Skills, experience and the confidence to use digital and online services are also factors which contribute to digital exclusion. There are also *geographical differences*, with the Yorkshire and Humber region having the highest percentage in England of people who have not used the internet in the previous three months; in turn, there are areas within the region itself where digital exclusion is more acute. The Sheffield City Region in its 2020 *Renewal Action Plan* acknowledges the uneven access in the area to both digital devices and the internet, and the skills to use them. As such, 'digital upskilling' and 'digital assets' are two areas of focus in the Action Plan.

This is important as when more services move online, those who cannot access them are at risk of further exclusion and increased deprivation. Digital poverty is related to other forms of disadvantage- it makes socio-economic, educational, racial, linguistic, gender, and health inequalities worse and is made worse by them. This brief focuses on carers in the South Yorkshire region as a particular group identified as more likely to be digitally excluded due to the intersections between caring and factors that contribute to digital poverty, such as low income and poor health, and at the same time increasingly expected to access support and services online.

The need to explore the impact of the shift to online and digital services on carers is pressing. Just as the pandemic created change in terms of the provision and use of online or digital services, we also know that in this period there was an increase in both the number of people in the UK providing care and the challenges carers faced. Centre for Care partner *Carers UK* estimated that in June 2020 an additional 4.5 million people had become unpaid carers since the start of the pandemic in March 2020. Research by colleagues in the Centre for Care on the experience of carers during the pandemic found that in May 2020, 1.3 million carers reported feeling under *financial pressure*, with this strain affecting in particular women and carers aged 31-45. Related to these pressures, carers reported more hunger in their households and were *twice as likely to use food banks* when compared to people who did not provide care during the pandemic. Carers mental health and experiences of *loneliness* were also adversely affected during the pandemic. *Accessing services* also became more challenging, with data indicating that in April 2020, a quarter of all carers could not access the social care support they needed and were on NHS waiting lists- higher proportions than for people who did not provide care.

The aims of this brief are therefore to develop insight into the experiences of carers, underscore some of the benefits and challenges they encounter when using digital devices and services, and by exploring what they feel would help, make policy and practice recommendations.

METHODS

This project was a collaboration between Sheffield Carers Centre and the University of Sheffield Centre for Care and Information School. Funding from the *Crook Public Service Fellowship* scheme allowed us to conduct a series of focus groups with carers in the South Yorkshire Region. A total of thirteen carers took part, the majority of whom were female. Two thirds identified as White British and one third as Multiple Ethnicity-White British and Black Caribbean. Two participants considered themselves to have a disability. There was a spread of ages represented in the focus groups with one participant aged between 30-34 years, two between 35-39 years, two aged 45-49 years, four aged between 50-59 years and one aged over 75 years.

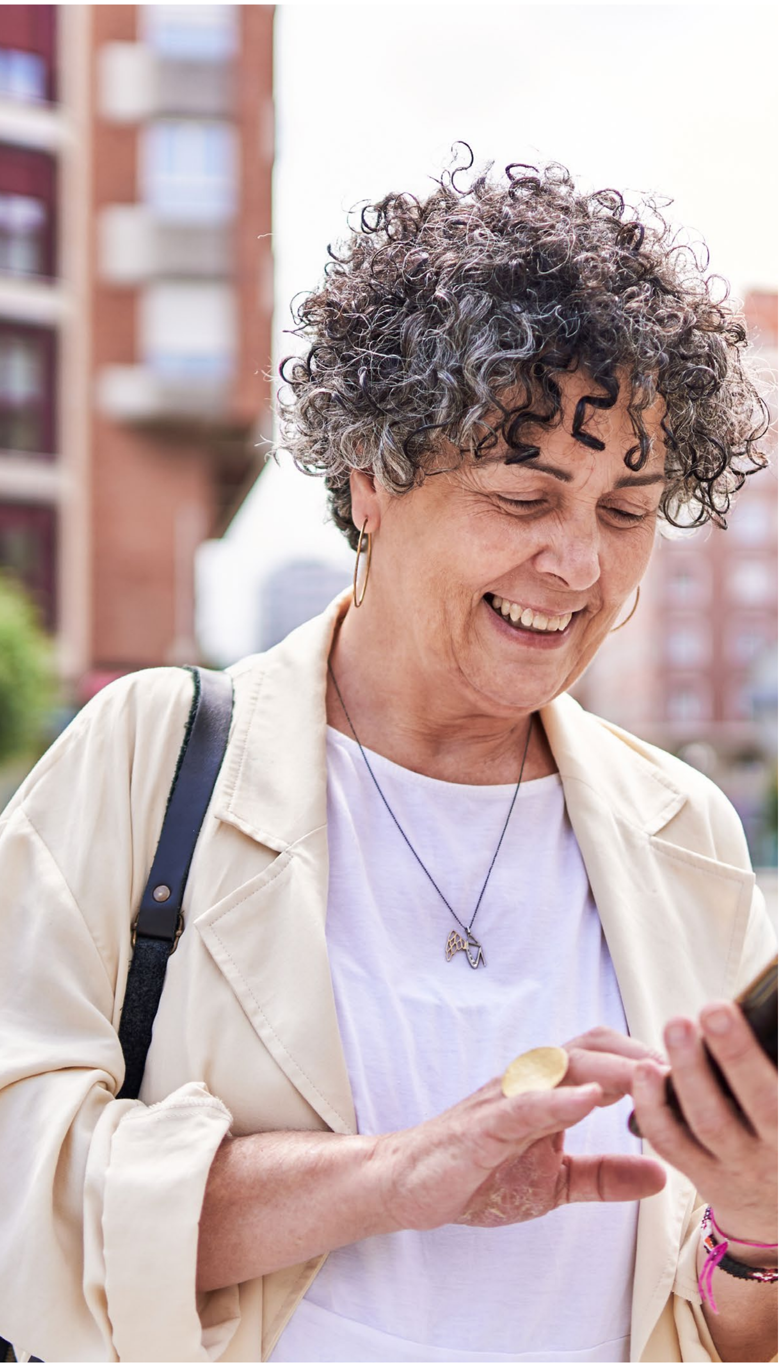
KEY FINDINGS

"Everything is online now"

WHAT DEVICES ARE CARERS USING?

The carers who participated in the focus groups used a mix of different digital devices for different tasks, some of which supported their caring role directly or more generally 'made life a bit easier'. All participating had a **smart phone, tablet or laptop**. Some had **smart speakers** or **smart doorbells** installed at home. There was limited use of digital **assistive technologies** in our sample. Only one carer had installed sensors around the home that would send an alert if the person they cared for (who had dementia) left the property late at night or had become disorientated as to the time of day (e.g. cooking a meal, believing 4 a.m. to be 4 p.m.). Prior to the installation of the assistive technologies, the carer had considered whether it was time for the cared for person to move into residential care, but they were able to remain in their own home with the devices in place.

We also asked about the digital devices the people the participants cared for used to go online. Several of the people we spoke to were carers for younger people with autistic spectrum disorders (ASD) and/or learning difficulties. For these carers, the people being cared for were more familiar with digital technologies and comfortable going online, using a wider range of devices such as consoles for **online video games** as well as smart phones and tablets. However, for those caring for parents or older adults, there was a resistance or reluctance of those they cared for to go online or use digital technologies. Some carers had encouraged the people they cared for to try **simplified smart phones** and tablets but with limited success. This then means that, as services increasingly shift to being available predominately online, some of the carers we spoke to now needed to **manage additional tasks** for the people they care for. In turn, those they cared for could sometimes then feel they were less independent and more reliant on those caring for them than they would like to be.



WHAT ARE THEY USING DEVICES FOR?

In the focus groups, we also explored what activities carers and those they support used digital devices for. For the carers of younger adults with ASD and /or learning difficulties, their use of smart and online gaming devices was **calming, for 'winding down' activities, as a means to socialise online and as a way to keep in touch with family members throughout the day.** They were therefore key parts of daily routines; conversely the parents and older people being cared for were described as being technology-averse by the carers in the focus groups, which they found at times frustrating when particular devices might be beneficial.

Reflecting on their own use of digital technologies, the carers we spoke to tended to use their smart phones for **communication** and quickly **searching for information.** Some also used their smart phones for **online shopping and banking,** either for themselves or those they cared for, while others used laptops and computers for these 'important jobs' or anything involving extensive typing as they could see the screens better and use the keyboards more easily. Online shopping was a key activity for carers who said they either lived too far away from shops and did not have their own transport, or if they could not leave the person they cared for on their own or bring them with them. The latter was the case for people caring for others who had sensory issues and for whom busy shops would be overwhelming. For these carers, online shopping was described as a 'lifesaver', particularly during the COVID-19 pandemic, though several who did use this service would have preferred to go in person but felt this was not possible. Banking too was something people went online to do to save time, especially when local branches had closed.

Laptops, tablets and smart phones were also used for **online appointments** which during the pandemic had become very familiar to the carers we spoke to for matters related to health, social care and education. School parents' and other meetings were held online generally via Teams or Zoom. Though not everyone had been familiar with these videoconferencing apps prior to the pandemic, all had experience of using them, as one carer remarked

> *"I don't think anybody knew how to use Zoom before the pandemic".*

Medical services too moved to the use of **online services to book appointments**, ask for photographs to 'triage' prior to an appointment or for video calls for the appointments themselves; some of the carers said these measures were introduced principally during the pandemic and many were still in place. The ability to book online or email regarding a non-urgent appointment was felt to be an improvement on previous practice which often involved people having to call on the morning to try and secure an appointment that day, which was not always successful or wanted for a non-urgent issue. Pharmacies had also introduced **online medication ordering** systems which one carer said:

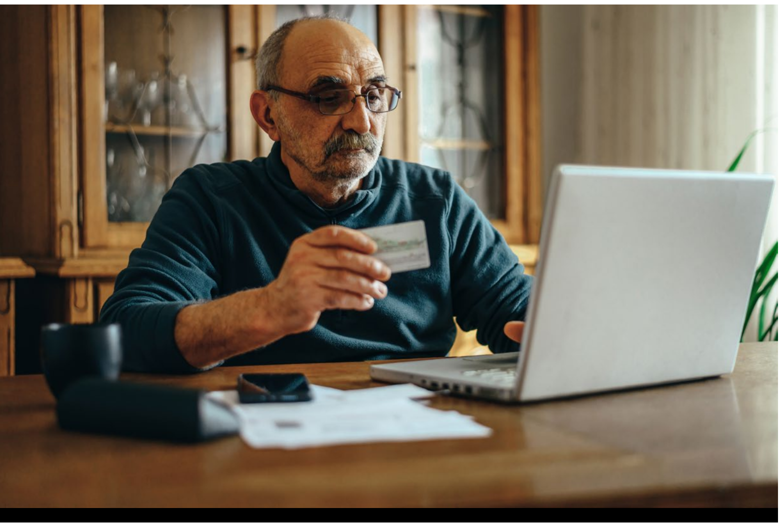
> *"it's a big help for me, ordering my dad's stuff and picking up so I don't have to keep trekking back and forth to the pharmacy because invariably they don't have all of it or they've only got one packet of this. But that is helpful."*

Carers who took part in the focus groups also explored the limits of online services in relation to health care. Though they felt the ability to book appointments and arrange prescriptions online were beneficial, online appointments to discuss sensitive issues or topics were felt by all carers to be inappropriate, with examples cited, of instances, where there had been distress or misunderstandings. One carer explained:

> *"I think that's where technology sometimes goes too far with medical and healthcare things. There's a lot for it to be said for it being face-to-face and a more personal approach… I do think technology is brilliant for doing online shopping, keeping in touch with people, for those who are house-bound or can't go out because they've got caring responsibilities but the actual healthcare issues which at the end of the day are the most important issues, I think it's gone too far. I think we do need to take a step back and think 'GPs do need to be seeing people' and get out and about to clinics rather than people saying 'oh I think it's this' over the telephone because you can't always read people over the telephone or even over a Zoom because it's stopping and starting and you can't judge what the unsaid messages are. Somebody's face can say something that their voice isn't".*

Other services had also shifted to online provision during the pandemic. Sheffield Carers Centre had opted to offer both in person and **online support meetings,** which was welcomed as one carer noted

> *"when you're caring for someone, you can't always get out, even though they have face to face meetings, it can be difficult to either leave them or take them with you".*



The carers were also familiar with video calling as many had used these apps to **stay in contact** with friends and relatives during the pandemic. Messaging services like WhatsApp were also mentioned as useful to keep in touch via messages, pictures and calls. A WhatsApp group of local carers had been set up, and others were part of neighbourhood groups which had been a good source of practical support. A carer explained how important this had been during the COVID-19 pandemic:

> *"WhatsApp kept us going through lockdown- it kept you going, being able to talk to other people in the same situation as you, caring like you".*

Researching online was another key activity the carers said was important- whether this was related to caring or to the condition of the person they cared for. One carer described how when her son was diagnosed with Autism Spectrum Disorder (ASD) she was not given any leaflets or written information but advised to search Google for more information. Some carers were also part of online groups on social media platforms such as Facebook, and used these as a way to find information. A carer explained:

> *"I don't go on Facebook just to have a nosy; I go on to because there's loads of information on there for us but nobody tells us- we have to go out and find it for ourselves".*

ADVICE & SUPPORT

We asked the carers involved in the focus groups about any support or advice they received about online services and digital devices. **Families and/or friends and neighbours** were cited as a key source of support and advice related to which devices to purchase and 'troubleshooting' any issues. Carers also described examples of "luck- you go somewhere, and you speak to someone and they say 'I've done this- have you?'" where by chance **conversations with other carers** resulted in finding out about new devices or online services. Some searched for information **online on forums or YouTube** for instructional videos but acknowledged this required a level of skill and confidence that others may find challenging. The carers also highlighted that organisations increasingly relied on emailing newsletters, which were a useful source of information, but potentially missing out carers who did not have an email address. Few carers were aware of organisations that could loan or provide devices that could connect to the internet and felt these could be more widely publicised.

CHALLENGES

We discussed the key barriers to using digital devices to go online with the carers. Several carers questioned what they felt was an implicit assumption that everyone was 'online' and able to access important services via the internet, with one carer remarking

> *"It is going to be an issue of health inequalities- this 'digital desert'. They assume everybody's gone digital but when you look at the mapping, actually loads of people haven't got access".*

The main barrier they cited was **affordability**- in terms of the equipment but also the access to the internet. Carers felt technology 'moved quickly' and devices often rapidly became obsolete or could not cope with software updates and needed replacing frequently. Some were not aware of the social tariffs offered by some telecommunications providers to people on low incomes or Universal Credit, with one carer highlighting the low take-up and the lack of signposting by organisations such as Job Centre Plus.

There was also a lot of discussion related to concerns about **online safety and security.** Some had been the victims or knew others who had been the victims of online scams, hacking or viruses where money had been stolen and regardless of direct experience, most carers we spoke to were concerned about the risks. Concerns were also raised regarding online safety of younger people with learning disabilities, with some carers increasingly worried about 'grooming' and cyber bullying. Though the carers concerned explained the risks to those they cared for, they were still worried and one carer remarked:

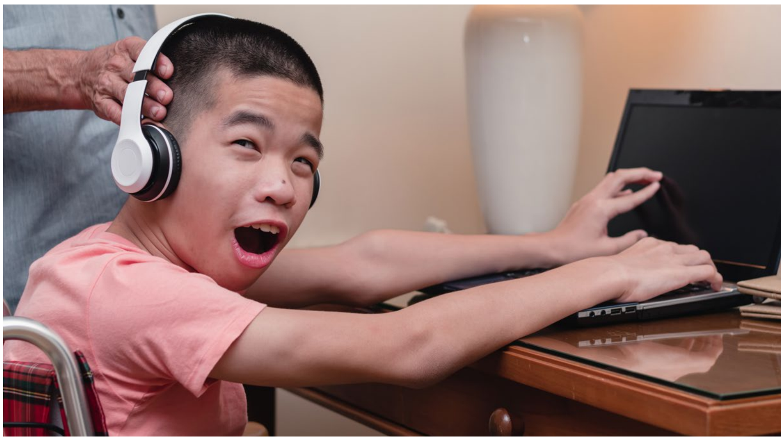
> *"I just want to be a mum... but we've just got that alert button on".*

Another related area of concern was **privacy.** Several of the carers were concerned about smart speakers as they felt they were "a bit spyish"; even those who had them in their homes were wary about discussing certain things in rooms where the smart speakers were.

Confidence was also cited as a barrier to going online, for both carers and the people they cared for. Often this was linked to being able to identify potential 'scams', but also to perceived levels of **skills.** Even for those who worked in roles that involved computers, using them 'socially' could be daunting. Carers who had either never worked in jobs that involved computers or had retired a while back felt they were being 'left behind' as technology moved on. The confidence of the people they cared for was also cited as a challenge, with some resistant to using technologies themselves, or to installing the internet in their homes to enable their carers to access online services with them. The **usability** of some devices was also explored by the carers, with small keyboards and text on smart phones considered problematic, as was the voice recognition abilities of smart speakers, which sometimes the people they cared for found frustrating. Some websites were also cited as lacking in terms of usability, and the reliance on 'chatbots' was a particular source of frustration.

Reliability was also a concern, with carers describing themselves as 'time-poor' and therefore unable to invest in technologies that would require a great deal of setting up and troubleshooting; some also struggled with good and **reliable internet connectivity** in their local area. Again, the speed of developments in technology meant that some carers felt that devices could suddenly stop working, or online interfaces could change and therefore require them to re-familiarise themselves with them, which was difficult when **lack of time** was an issue.

When discussing examples of where they had felt the use of online services had 'gone too far' regarding health care appointments, carers also questioned whether there was now an over-reliance on digital technologies and the internet more generally. There were discussions in the focus groups regarding the predicted **electricity blackouts** discussed in the media, and what this would mean for those reliant on various technologies and the internet. Those caring for people with cognitive impairments or learning difficulties described themselves as 'scared' by the prospect of blackouts and were worried about how they would help the people they cared for to understand what was happening. A similar point was made by the parent of a teenage boy with autism, as her fear was that when his tablet needed replacing, he would be incredibly anxious without it and would not understand how much time it would take to source a new one. He also struggled to understand that games, websites and apps accessed on one device could also be accessed on another.



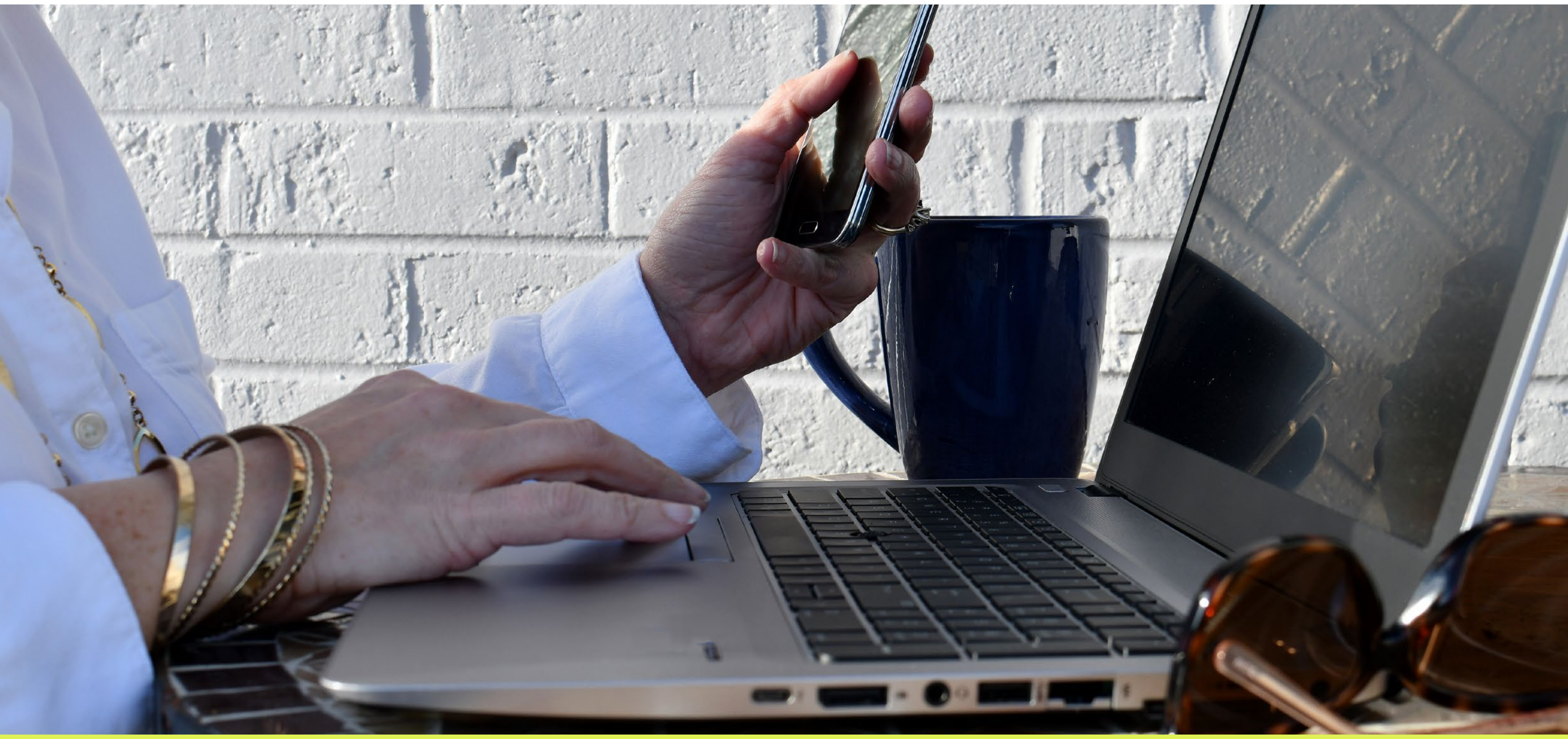
WHAT'S MISSING?

When exploring where carers looked for advice and support related to technology and online services, **finding information** was the key challenge cited by the carers involved in the project. Carers were frustrated with the amount of time they would spend looking for information and support online, and how frequently this information was out of date. The carers in the focus groups frequently mentioned a single point of access for relevant, up-to-date information that included resources from the local authority, carers centres and groups and condition-specific organisations would be helpful, as two carers explained:

> *"For me, the carers centre are great for information, but if you could have a single point of contact that was really up to date with the council, with everything feeding in. We're all really busy- every minute is important. If you've got half an hour, you want to get on the internet and find it because your dad will be shouting for something else. You haven't got time to ring up and be told 'oh we don't do that anymore- try this number'. We need clear signposting to a single point of contact with all the information that's up to date"*

> *"I think it would be nice to have one single point of contact, like a link that you can then go into with regard to different diagnoses or needs and then you can find your own as opposed to just googling stuff. You want to spend your time being a carer, not googling randomly stuff to try and find out what may or may not be there".*

The carers we spoke to also said hard copies of information easily became out of date, and were also increasingly difficult to find as most information was now online- this, they felt, was a particular challenge for those who did not access the internet.



KEY RECOMMENDATIONS

Based on the discussions with carers, key recommendations for policy, practice and service provision include:

- **Information and advice:** carers said finding information and accessing trusted and accessible advice on digital devices and services was a source of frustration. Information was rarely 'all in one place', was sometimes out of date and difficult to navigate. A single source of regularly updated, unbiased and easy to understand information and advice was felt to be needed.
- **Collaboration between different services:** there was also frustration regarding the lack of 'joined up thinking' around digital. GPs and Job Centres, for example, missed opportunities to signpost carers to support such as social tariffs for digital and other local support.
- **Digital by choice:** the idea that everything should be 'digital by default' was challenged by the carers. Some online services for specific tasks were felt to be useful and more accessible than face-to-face appointments, but for others, in person was preferred. The ability to choose was felt to be important, but also support to enable people to choose.
- **Device loans and repair schemes:** The cost of purchasing, updating, repairing and replacing devices was a key challenge for carers. The provision of loan and repair services (and publicity about these services) could support more carers to engage with digital and online services.
- **Practical support for skills and confidence:** Carers welcomed opportunities to develop practical skills and confidence, recognising that all those who had taken part in the sessions had some familiarity with digital devices. Support for those they cared for to develop their own digital capabilities was also felt to be important.

ACKNOWLEDGEMENTS

We would like to thank Emeritus Professor ADH Crook, and the ESRC and University of Sheffield Impact Accelerator Account for funding this project (Project number: X/014889). We are also grateful to Sheffield Carers Centre for their support and the participants for sharing their experiences and expertise. Our thanks also go to our colleagues in the University of Sheffield Information School (Dr Efpraxia D. Zamani, Dr Laura Sbaffi and Dr Sara Vannini) and Centre for Care (Dr Kelly Davidge, Sarah Givans and Professor Sue Yeandle) for their support during this project.

This project received ethical approval from the University of Sheffield Research Ethics Committee (Application Reference Number 046180), and received research governance approval from Sheffield City Council and was sponsored by the University of Sheffield (Application Reference Number X/014889-12).