



Digital exclusion and older unpaid carers: summary of findings

Dr Anastasia Rousaki, Dr Laura Sbaffi, Dr Efpraxia Zamani,
Dr Kate Hamblin, Dr Rachael Black



THE IMPACT OF THE TRANSITION OF CARE TO DIGITAL TECHNOLOGIES FOR UNPAID, OLDER CARERS

Unpaid carers play a crucial role in caring for individuals with chronic illnesses, disabilities, or other care-related needs. However, many services have now moved online; causing challenges that can lead to digital exclusion. It is mainly older adults who end up digitally excluded and many can struggle with factors like device costs, digital skills gaps, and privacy concerns. Digital exclusion can lead to many disadvantages including difficulties accessing support services, financial hardships, limited respite from caregiving, and challenges in staying in employment. To tackle these issues, we conducted group interviews with 48 carers, discussing issues related to digital exclusion, digital poverty, the digital transition of care and online safety. The group discussions took place in Leeds, Derby, Devon, Liverpool and Bath, as well as online, and thus cover a wide geographical context within the UK. In the present report, we briefly discuss our findings.

BEING PUSHED ONLINE, LACK OF AGENCY REGARDING DIGITALISATION

In discussions, carers criticised the dominant belief in equal online access, and often felt pushed into digital life. They challenged the assumption of security online, worrying about data privacy and unclear terms. They felt pressured to go digital for essential services, feeling they had no real choice. Concerns about privacy, cookies, and complex terms were widespread. Carers stressed the importance of knowing where their data goes and distrusted complex contracts and

requested support for those not tech-savvy. They criticised the lack of accessible help, especially for older individuals and suggested drop-in centres for assistance and community-based training to bridge the digital divide.

CONCERNS ABOUT ONLINE AGENCY, SURVEILLANCE AND SAFETY

Participants in the focus groups expressed widespread worries about online safety and surveillance. They described feeling unsafe online, with concerns about privacy and the potential for surveillance. Many were sceptical of new technologies and felt like their personal information was easily accessible, leading to a preference for phone transactions. Participants also feared scams, with some sharing experiences of being scammed online. They questioned the intentions of technology designers and called for greater accountability and democratic processes in technological interventions. Policymakers were criticised for prioritising profit over cybersecurity. As a result of these concerns, many carers and their loved ones chose to avoid using the internet altogether.

NEED FOR ASSISTANCE

Carers in the focus groups viewed the push towards digitalisation as overpowering and expressed concerns about their lack of technological knowledge. They felt guilty for not being adept and highlighted the need for formal instruction. Assistance was seen as crucial, especially with the decline of in-person support since COVID-19. Participants rejected the idea that providing free devices alone solves the problem, advocating for comprehensive support services. They critiqued

the lack of guidance in using digital tools and raised the reduction of helpful resources like libraries. The societal trend of leaving older individuals and carers to navigate technology alone was criticised, with a call for collective solutions and community-based training. Frustrations over limited help and costs were seen as excluding older carers from society. Suggestions included drop-in centres and helplines tailored for older individuals, emphasising the importance of accessible assistance and ongoing support.

LACK OF FUNCTIONALITY

The discussions among carers highlighted a significant issue with the lack of functionality and interoperability in both digital services and institutions. Participants described challenges such as prolonged phone calls and difficulties accessing essential services due to malfunctioning technology and bureaucratic processes. Digital services were often deemed unfriendly, with complex interfaces and a lack of direct communication options. The lack of interoperability between services (such as sharing records and information) had financial implications and made accessing services nearly impossible. Participants criticised the inflexibility of systems, especially for individuals with dyslexia or hearing loss, and suggested



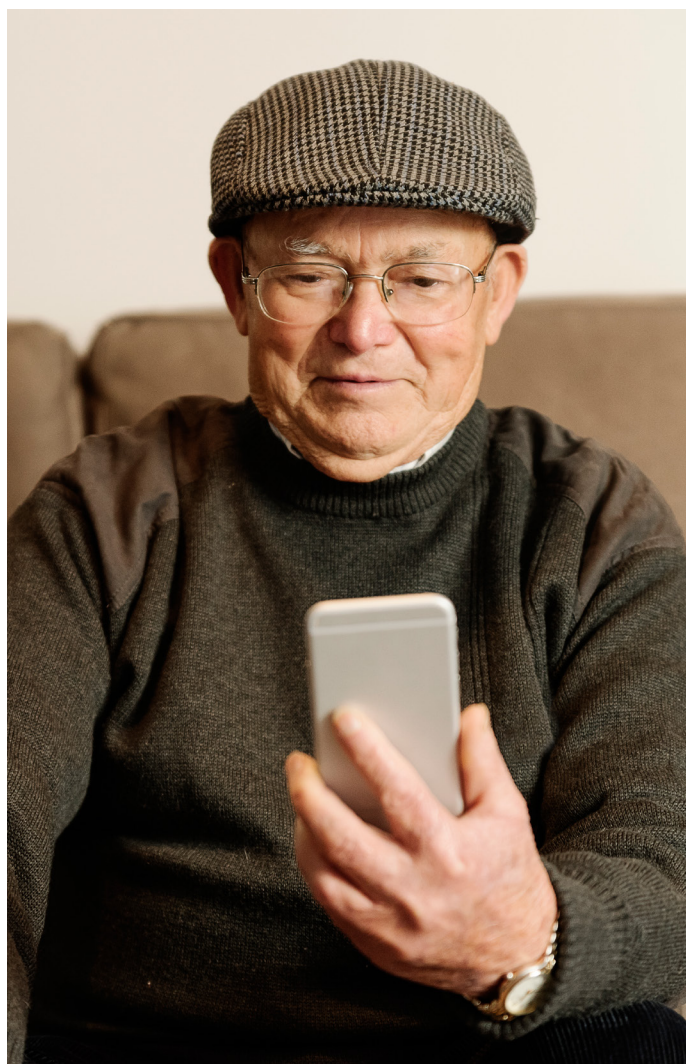
seeking assistance from trained personnel for benefit applications. Within the healthcare system, participants expressed frustration with helplines, online forms, and appointment bookings. They highlighted delays in addressing health conditions and difficulties in accessing services through various methods. The lack of functionality and interoperability exacerbated feelings of powerlessness among carers and underscored the ineffective implementation of technology within the healthcare system. Participants questioned the effectiveness of urging technology use while facing these challenges and advocated for simpler digital systems and more accessible services within the NHS.

DIGITAL EXCLUSION

Participants expressed a deep sense of digital alienation and exclusion, with technology exacerbating their sense of isolation. Participants struggled with the complexity of technology and felt blamed for any difficulties they encountered. Technology was personified as excluding carers, leaving them feeling unaware and left behind. There was a strong perception of societal neglect towards older individuals, with participants feeling like outsiders compared to younger generations. The rapid pace of technological advancement added to their sense of exclusion, with participants feeling overwhelmed and struggling to keep up. Despite the promise of benefiting from technology, participants felt it created barriers and deepened societal alienation.

LACK OF CONNECTIVITY

Participants expressed significant concerns about the lack of connectivity, particularly in rural areas, leading to extensive time spent on paperwork and frustration with digital platforms. This issue was particularly pronounced in Southern (eg. Devon) and Midlands regions of England. The lack of connectivity had tangible impacts on participants' lives, with some resorting to expensive mobile data to stay connected. It exacerbated financial and care-related challenges, such as difficulties with benefit applications. Participants described the mental toll of dealing with connectivity issues, adding to the burden of





caregiving. They emphasised the responsibility of internet providers in improving speeds and addressing connectivity issues. Slow internet speeds were seen as a barrier to accessing essential services, particularly for households on social tariffs. Participants expressed apprehension about the impending transition to an all-digital landscape, especially with the anticipated end of copper line operations by 2025. They raised concerns about the reliability of digital systems during power outages and the potential consequences for individuals dependent on medical devices. These discussions highlighted the complex challenges associated with the shift towards a fully digital communication infrastructure.

THE NEED TO MAINTAIN TRADITIONAL OPTIONS

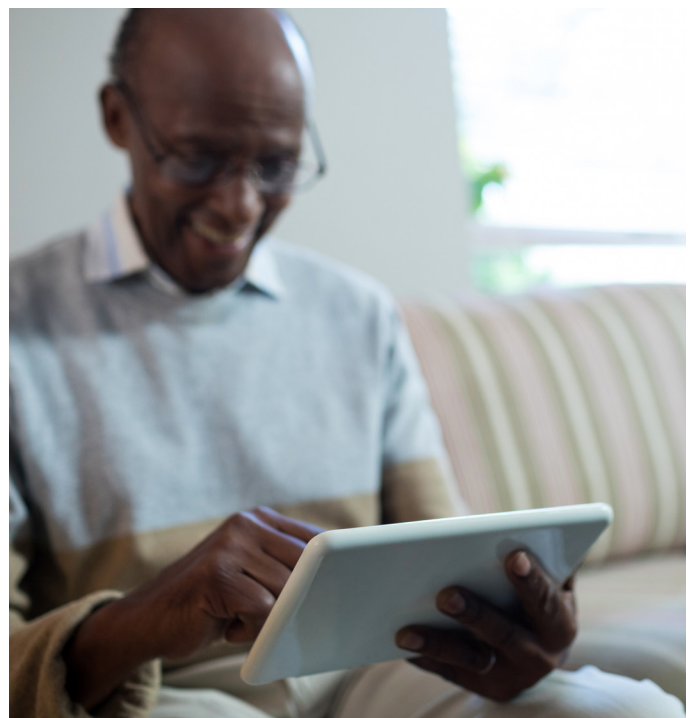
Participants expressed concerns about the decreasing availability of traditional support systems, particularly noting the lack of in-person and telephone options in the post-COVID era. They resisted the complete dominance of digitalisation and stressed the importance of having a contact number to reach a person who can promptly answer the phone. They found remote services challenging, with difficulties in reaching supervisors and navigating digital platforms for tasks and information previously accessible through conventional means. Participants advocated for the continued availability of paper options and stressed the importance of providing choices regarding online activities, emphasising that not everyone wants to learn new technologies. They highlighted the need for alternatives, such as in-person consultations, to maintain a “human” element. Participants suggested refraining from eliminating face-to-face interactions until future generations face similar circumstances. They called for round-the-clock helplines staffed by real people, stressing the importance of maintaining traditional elements and expressing a preference for speaking to real people over automated systems.

ACCESSIBILITY CHALLENGES

Participants highlighted the importance of addressing ableism and accessibility issues, particularly for both the individuals they care for and themselves as carers. They expressed challenges in using technology due to disabilities, such as concentration issues, memory problems, vision impairments, and hearing loss. Carers stressed the need for accessible devices and support services, sharing experiences of feeling isolated and unable to access essential information or assistance. They discussed a lack of support and recognition, calling for equality in policies and interventions for carers. Participants emphasised the importance of considering individual backgrounds, including disabilities and socio-economic factors, in digital training and interventions. They advocated for the development of assistive technologies tailored to specific needs, as well as greater research into disabilities to inform system design. Additionally, they highlighted the need for inclusivity in all policies and specific departments focusing on disabilities. Participants underscored the importance of local support and individualized assistance, particularly for those with mobility issues, and emphasised the need for simpler and more context-sensitive technological solutions.

THE COST OF TECHNOLOGY

Carers find technology and internet expenses daunting, especially broadband costs, impacting their finances. Bundled services limit choices, and phone contracts are expensive, with background apps draining credit. Technology is seen as costly, with laptops and associated expenses adding up. Affordability concerns lead to limited internet usage and reliance on pay-as-you-go options. Social tariffs are inadequate, leaving some





struggling financially. Navigating benefits online is challenging. Participants stress the need for internet access for research and finding deals but face financial hurdles and lack support.

THE NEED FOR FUNDING AND DEVICES

Participants highlighted the need for devices and funding to address digital inclusion, especially for carers. They emphasised the importance of making technology accessible through initiatives like distributing refurbished devices and allocating funds for community services targeting digital exclusion. Training also requires financial support, with participants urging funders to consider providing assistance for equipment and access. Carers framed their value in market terms, highlighting the financial surplus they create through their labor and the government's savings resulting from unpaid care; pronouncing the economic benefits of investing in their training and support. They stressed the health and economic consequences of systemic exclusion, advocating for funding to improve knowledge and skills, which they argued would benefit both individuals and the wider community.

CLAIMING AGENCY VIA RESEARCH AND CO-PRODUCTION

Participants expressed a desire for agency in addressing their needs and shaping policies and technologies aimed at them. They called for more research focused on understanding their experiences, emphasising qualitative methods and co-production. Participants advocated for robust carer representation in policymaking, highlighting the importance of including individuals from underrepresented backgrounds and continuously listening to carers' feedback. They stressed

the need for policies and technologies to be co-designed with carers, urging designers to consult with them and ensure that features align with reality. Participants emphasised collaboration with carers throughout the development process, recommending pilot studies and ongoing feedback to ensure the relevance and success of interventions. Overall, they called for a holistic approach that values the input and experiences of carers in shaping solutions for digital inclusion.

THE BENEFITS AND UNFULFILLED POTENTIAL OF TECHNOLOGY

Participants acknowledged technology's potential to improve their lives but highlighted challenges. They praised its assistance for disabilities and healthcare benefits like online appointments. Yet, they noted the exclusionary nature of such innovations, especially toward those without smartphones. Despite optimism, participants emphasised a gap between technology's envisioned benefits and current realities.

CONCLUSION AND POLICY SUGGESTIONS

The transition of care to digital technologies presents both opportunities and challenges for unpaid, older carers. Our research highlights the impact of this transition, including digital exclusion, concerns about online safety and privacy, lack of functionality and interoperability, and the need for continued access to traditional support systems. Moreover, participants emphasised accessibility challenges, the high cost of technology, and the necessity for funding and devices to address digital inclusion.



POLICY SUGGESTIONS

ESTABLISHING SUPPORT SERVICES

Polymakers should encourage and prioritise the development and implementation of support services tailored to the needs of older carers. This includes establishing drop-in centers, helplines, and community-based training programs providing ongoing assistance.

ENHANCED ONLINE SAFETY MEASURES

Polymakers should work towards enhancing online safety measures to address concerns about privacy, surveillance, and scams. This may involve increased regulation of technology platforms, improved cybersecurity standards, and greater transparency in data handling practices.

ENSURING ACCESSIBILITY AND INCLUSIVITY

Policies and interventions should prioritise accessibility and inclusivity, considering individual backgrounds, disabilities, and socio-economic factors. This entails investing in assistive technologies, providing tailored support services, and ensuring that digital training programs are designed to accommodate diverse needs.

FINANCIAL SUPPORT FOR DIGITAL INCLUSION

Government funding should be allocated towards addressing the financial barriers to digital inclusion, including the provision of devices, broadband subsidies, and support for training initiatives. Social tariffs and assistance programs should be expanded to ensure affordability and accessibility for all carers. This is particularly important in the context of healthcare and the NHS.

CARER REPRESENTATION AND CO-PRODUCTION

Polymaking processes should involve robust carer representation and co-production, ensuring that the voices and experiences of carers are central to decision-making. This includes conducting research focused on understanding carers' needs and preferences, as well as actively involving carers in the design and evaluation of policies and technologies.

MAINTAINING TRADITIONAL OPTIONS

Polymakers should recognise the continued importance of traditional support systems and ensure that a range of options, including in-person and telephone services, remain available alongside digital alternatives.