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Lessons from Lockdown

What next for online carer support?

Full Report
July 2021

 mobilise

In partnership with



About Mobilise

Mobilise is the tech startup that harnesses the collective knowledge, wisdom and expertise of unpaid carers and empowers those that care to thrive. We provide a range of online support services, grounded in research and tested with carers across the UK.

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About this Paper

This paper has been researched and written to assist commissioners and providers of carer support services as they consider how to build capacity for reaching and meeting the needs of carers in the future. The paper has been funded through the Government's modern industrial strategy by UK Research and Innovation.

Contributors

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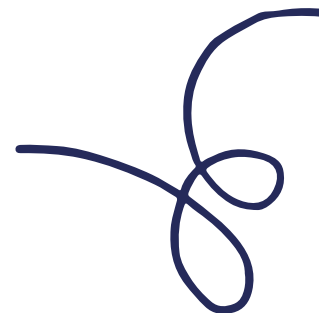
Dr Warren Donnellan is a Psychologist and Lecturer based in the Department of Psychology at the University of Liverpool. He is an internationally recognised expert in resilience and caregiving across the life-course.

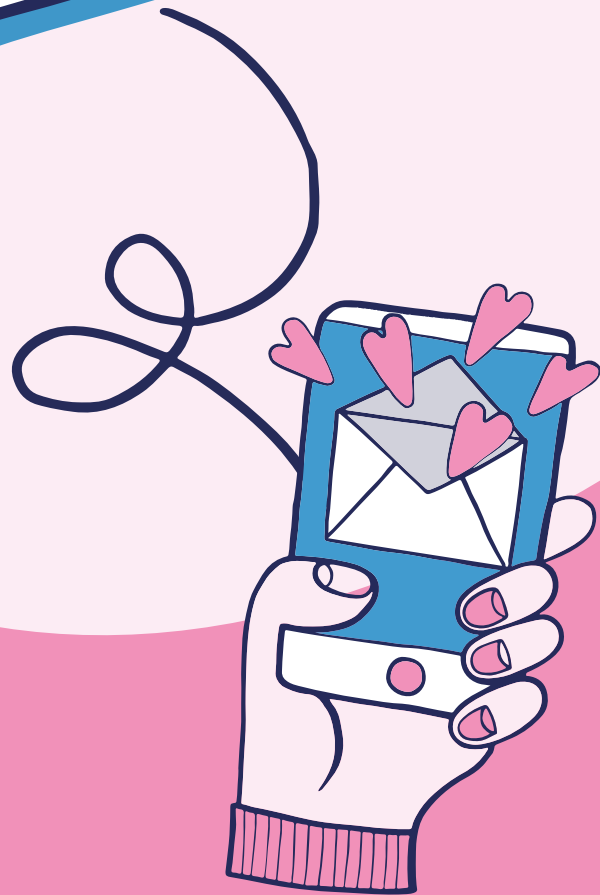
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Executive Summary

Too many carers struggle in their caring role because they are not being reached by support services. Experience over the COVID-19 pandemic has shown that well-designed online services can open up support to new groups of carers, helping them to thrive in their caring role.

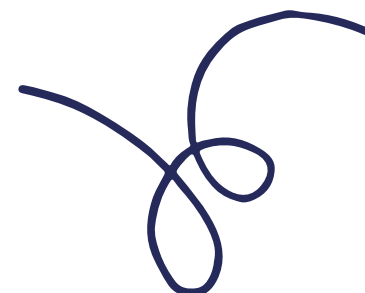
This report summarises relevant existing evidence about providing online support for carers - both from the social care sector and from a wider 'digital transformation' background - and introduces new evidence from the experience of carers leads and support providers through the pandemic.

Where online tools have been used out of necessity during lockdown to replicate offline support of existing audiences, behaviours will likely revert to pre-pandemic norms.

However, the experience of many providers has been that the move to online support has opened up support to significant new audiences. Looking ahead, these groups (younger, and more digitally engaged) are likely to represent a larger proportion of carers over the next five to ten years.

Commissioning and providing effective online support for carers will likely depend on:

- greater collaboration across local authority borders
- reimagining the shape of support to meet the needs of a different audience and the capabilities of online technology
- developing new digital skill sets - either 'in-house' or via commissioned providers
- investing in light-touch, preventative tools that can be deployed at scale
- Where online services are piloted and developed as part of a long-term digital strategy and integrated with existing offers, they have the potential to support significantly more carers to thrive.



Key Findings

1 Online services can increase numbers accessing support services

Experience throughout the ongoing COVID-19 pandemic has accelerated demand for online carer support services. Online tools were seen by those providing services as a cost-effective and accessible way to dramatically increase the numbers of carers accessing support - particularly those from traditionally underrepresented groups, and particularly as a preventative approach.

Six out of ten carers surveyed were already using online tools for day-to-day communication and services. Those who had used online tools to access support for their caring role were seeking to continue doing so in the future - particularly because they valued the accessibility of support which did not require them to leave home (either because of travel difficulties or because they did not want to leave the person they care for alone).

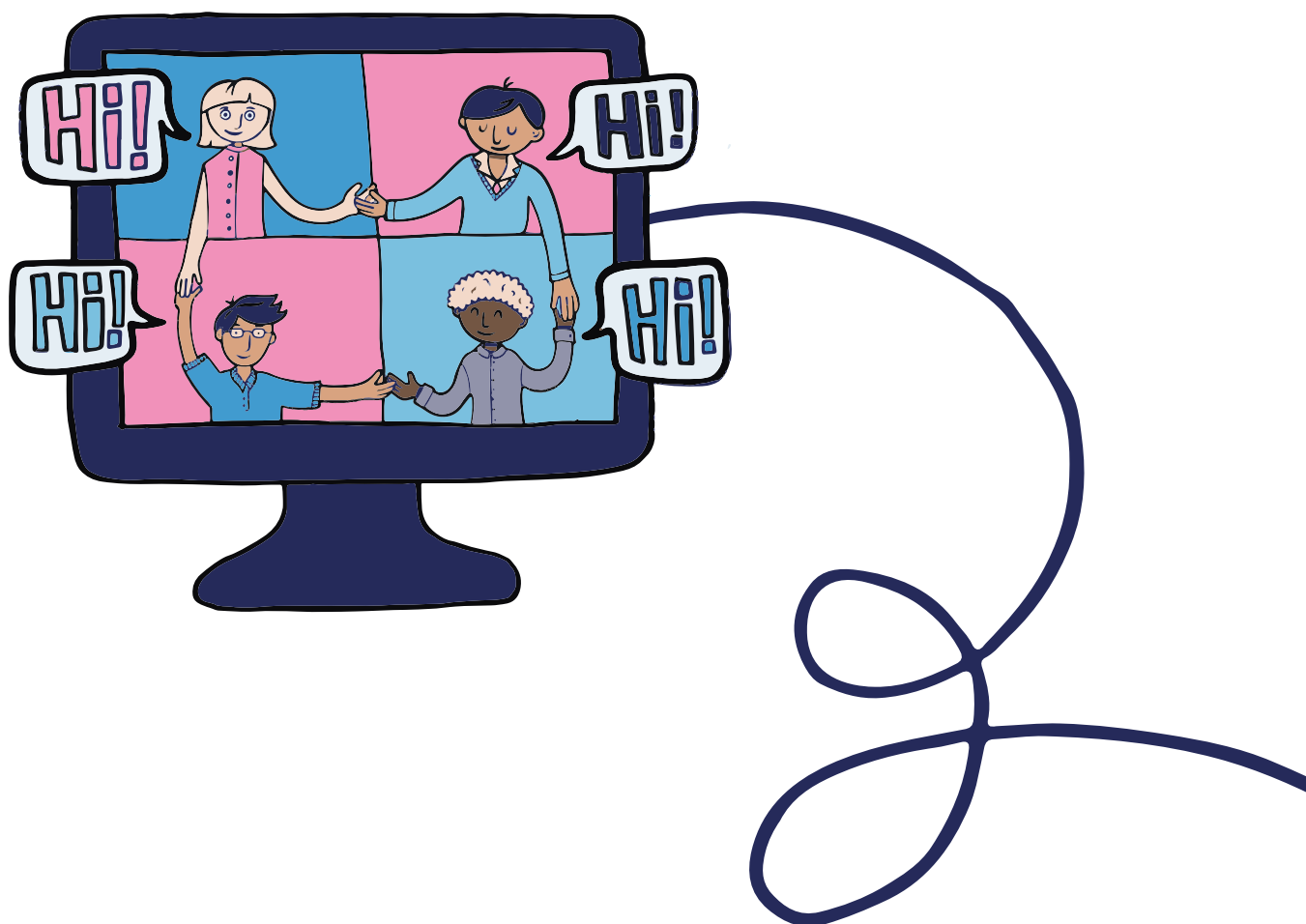
There are significant differences in online behaviours between different groups of carers - particularly in relation to age and gender. Looking to the next 5-10 years, a new generation of carers will increasingly turn to online channels to reach support for their caring role.

However, online support should be viewed as an extension to existing services rather than a replacement. Particular audiences will continue to prefer to engage offline, and certain support services require the intimacy of an in-person connection. Two themes coming out of the evidence were the importance of having support available for the person being cared for and enabling the carer to receive support separately (i.e. in another room).

2 Service design can drive increased engagement, and lower long-term costs

The importance of thoughtful service design was a consistent theme through the evidence. Although there is an 'untapped demand' for light-touch, preventative support services, access to these could be frustrated by clunky technology or overly-complex processes (particularly amongst older generations). Many of the challenges of a 'digital divide' can be addressed through investing in intuitive user experience design and imaginative use of simple technologies to meet the needs of carers.

Supporting carers to engage with complex technology can be labour intensive for providers, and is likely unsustainable at any substantial scale. This makes the importance of intuitive user experience even more compelling.



3 Successful online support will rely on partnerships and collaboration

Pressures on cost effectiveness and impact create a compelling case for regional and national collaboration in the provision of online support.

Duplication of content

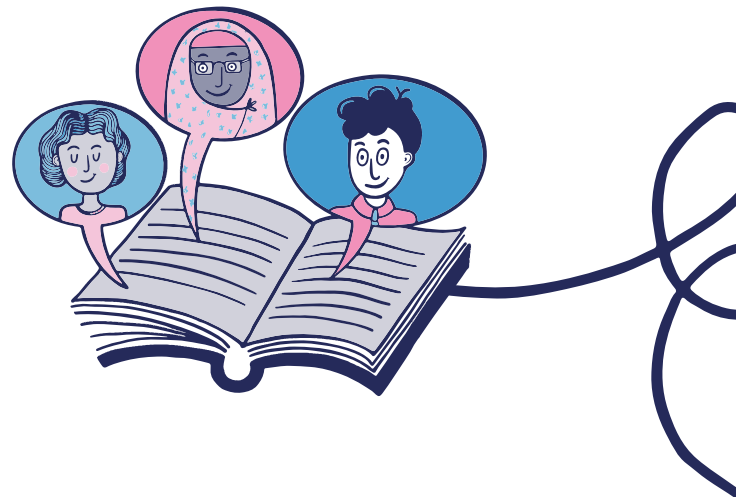
Many online services (e.g. virtual events, online guides and automated tools) could be delivered efficiently across local boundaries whilst freeing up resources for in-person delivery. Along with other providers, Mobilise has found an approach of 'create once, use many times' makes it possible to reach significantly more carers without a substantial increase in staffing.

Shared investment of resources

The development of online tools can require significant investment of capital and time if they are to be effective, accessible and scalable. A regional and national approach to commissioning services creates efficiencies of spending and improves the quality of the end product by accommodating a wider diversity of carers' needs.

Sharing of data and insights

A major challenge around designing support services to meet carers' needs is the limited data available. Online services can generate key insights to inform future planning. Where services are common across local authority boundaries, datasets can be used to drive national and regional benchmarking.



4 Online support works differently to in-person support

The shift to online support has worked best when the service has been designed with a clear purpose, and with the limitations and opportunities of the platform in mind. Simply trying to recreate an in-person experience in a Zoom or Teams call often ends in frustration.

New technologies open up a range of different possibilities for service design that have not previously been possible. Crowd-driven, peer-support platforms such as WeFarm could provide helpful models to draw on.

Although online group video calls work well for some groups of carers, other online approaches can be very effective. Men for example, sometimes feel more comfortable using automated tools rather than a person when addressing 'embarrassing issues'.

Online approaches seem to be most impactful for early-stage, light touch preventative support. Out-of-hours support is key to this, with up to 70% of carers coming to the Mobilise platform outside working hours.



5 Specific skill sets require training and recruitment

Staff training has played a key role where online services have been deployed successfully. This includes becoming familiar with how to use the technology itself, but also developing a more sophisticated understanding of the ways different groups may wish to use technology. Many teams have been surprised by the engagement of older people groups with mobile and video technology, for example.

Where organisations are seeking to deliver online support themselves, this requires developing additional skill sets such as human centred design and product development. An alternative is to partner with specialist organisations.

Lessons from Lockdown

Existing Evidence

This section draws together themes from existing evidence, which may help to inform decision-making for commissioners and practitioners. The evidence was collected by reviewing a range of publications published by carers' charities and social care bodies, as well as academic and industry-led research into digital transformation.

Context

Prior to the pandemic, support for carers faced profound challenges. Many of those challenges were exacerbated by the pandemic, and a significant proportion of carers took on more hours of more intensive care tasks as services were shuttered and family and community were unable to visit and help (Carers Week, 2020).

Many carer-supporting organisations worked extraordinarily hard to find new ways of providing support - not only online, but via telephone and in-person socially distanced visits where needed and possible. The intensity of the pace and need for innovation during the pandemic can offer valuable lessons for building an ecosystem of support for carers that meets the needs of the future.

Digitisation trends hastened by COVID-19

Social care services, and carer support in particular, should not be too easily 'lumped in' with healthcare services, but in the absence of enough social care data we can observe trends in healthcare as a form of proxy.

Those healthcare services that were not directly affected by COVID-19 were both forced and enabled by the circumstances of lockdowns to accelerate movement towards a "digital-first" primary care offer by 2023/24" (Hutchings, 2020, p3) that had already been laid out in The NHS Long Term Plan. GP practices triaged patients remotely, and at the pandemic peak moved 71% of appointments to remote, up from 30% the year before (Royal College of General Practitioners, 2020). Outpatient appointments delivered by video tripled compared to 2019, and use of online platforms to book appointments and request prescriptions soared.

Despite the many stressors of the pandemic, we can see through studying local authority websites that many carer support services managed to adapt; most commonly by moving assessments, counselling and advice services from face-to-face to online (Willis et al., 2021). While carers' centres and day centres were physically closed "peer support groups, training and social events" moved online.

Increasing reach & accessibility

Most carers are online

Most adults in the UK regularly use the internet. Although carers are more likely than the general public to face barriers to getting online (on average they are older and have lower incomes) the vast majority of carers used the internet to seek information, and pre-pandemic 79% reported using technology as part of their caring role (Carers UK, 2019). Data collected between January and March 2020 (i.e. largely before the impact of lockdown) indicated 54% of adults of 75 and over were recent internet users - a rapid increase since 2013 (ONS, 2021).



Further Reading

<https://www.goodthingsfoundation.org/fix-the-digital-divide/>

Design Matters

39% of the total time spent online by adult internet users in the UK in September 2019 was spent on Google and Facebook-owned sites such as YouTube, Instagram, WhatsApp and the Facebook app itself. These platforms invest heavily in designing easy-to-use interfaces which guide the user about how to navigate. Given that carers are pressured for time, intuitive and friction-free design is crucial for delivering online services.

When services face extreme budget pressures, and people seeking support report desperation and the breakdown of physical and mental health, usability may feel like a low priority. But even in high pressure, under-resourced situations, the NHS has found that investing in improved information for patients not only improves outcome, but improves staff wellbeing, efficiency and cost effectiveness.

A design-led approach that kept patients feeling informed and in control through long Accident and Emergency waits resulted in 75% of patients saying the wait was less frustrating, a 50% reduction in ‘threatening body language and aggressive behaviour’ from patients and a 21% drop in complaints. Staff reported feeling more empowered and more understanding of patients’ confusion and frustration. Overall, for every £1 spent on the design solutions, £3 was generated in benefits (Frontier Economics 2013).



Further Reading

The Government Digital Service service design handbook can accelerate any service going online with standard, well researched patterns and a library of ready made code to build easy to use services quickly and well: <https://www.gov.uk/guidance/government-design-principles>

Out-of-Hours Support is crucial

Mobilise has found that, depending on local variations, between 50% and 70% of carers are seeking support outside regular working hours (i.e. 9am-5pm, Monday-Friday).

This has particular implications for working carers, who are likely to be at work during the day. Although online support can never (and should not aim to) fully replicate face-to-face support, digital technologies can ensure that some form of support is available at 3am (when offline services are unlikely to provide very much). Carer usage data from the Mobilise platform indicates there is substantial activity throughout the night.



Further Reading

Digital public services: How to achieve fast transformation at scale
<https://www.mckinsey.com/industries/public-and-social-sector/our-insights/digital-public-services-how-to-achieve-fast-transformation-at-scale>

Information as a Service

Legislation sets out the provision of ‘information and advice’ for carers as a central part of local authorities’ duties. Research published in 2015 confirmed that carers used the internet as a key source of information relating to specific health conditions and carers rights, to access emotional support and keep in touch with one another (Tinder Foundation, 2015). A majority of carers were using the internet to seek information relating to caring leading up to the pandemic (Carers UK, 2019) and use of technology to stay informed and stay in touch increased over the coronavirus lockdowns (Carers UK, 2020).

In a context of constrained budgets, many Local Authorities have placed a “greater emphasis on information and advice as the preferred means of support for carers (as opposed to the provision of ongoing replacement care or of Direct Payments)” (Fernandez et al.,2021). The initial point of contact and hub for this information is often council websites.

But analysis has repeatedly shown that local authorities are not using websites effectively to support carers, and setting carers, staff, and commissioned service providers up for frustration, wasted time and resources. Lloyd and Jessiman’s study of local authority websites in 2016 found “conflicting information” (Lloyd & Jessiman, 2017). A repeat of the study in 2019 found similar issues alongside confusing information like making “reference to secondary NHS services rather than primary care – without noting referral criteria.” (Fernandez et al.,2021, p. 22). Analysis during the 2020 pandemic found that despite efforts across services to shift to digital provision critical information was still missing from many sites. Some “do not appear to have any services for carers according to their websites”, others “were hard to navigate” where “long series of links led to a dead end.”(Willis et al., 2021).

This is not simply an issue of convenience, or momentary frustration. Such “poorly signposted” (Pursch & Isden, 2018) information sets up carers and Local Authorities for a difficult relationship, where “Everything is a fight” (Carers UK, 2014) or a “battle” (Carers Trust, n.d.). Carers who are not finding out about their rights and the services available to them might lessen their use of services in the short term, but ultimately will undermine their capacity to care, to remain mentally and physically well, and to stay connected to the community and engaged in the workforce.



Further Reading

Carers UK Guides, tools and resources

Reimagining help: the right information at the right time - a resource for health services setting out processes for learning how to provide information in the most useful and impactful way. As yet no such resources are developed for social care or carers specifically but many lessons can be learned <https://www.nesta.org.uk/project/reimagining-help/>

Crowdsourcing

By shifting from a static website model with potentially out of date content to a crowdsourced model, local authorities and providers can unlock for their carers the benefits of a more dynamic and responsive approach.

Facebook groups, social media and even machine learning techniques make available to an individual carer the amassed wisdom, knowledge and expertise of millions of others carers who may well have experienced similar problems in the recent past.

One key advantage of this approach is that in addition to accessing practical information/advice, the carer is simultaneously able to build their network of 'similar' carers providing emotional support and advice into the future. Donnellan et. al. have flagged that these networks are a key driver of improving carer resilience (Donnellan, 2018).

This is particularly important when creating services that meet the needs of black, asian and minority ethnic carers. Some cultural groups find accessing support from a peer group more acceptable than seeking help from a statutory institution.



Further Reading

WeFarm is a platform where 2.4 million small-scale farmers are able to share detailed practical advice with each other to increase productivity

https://www.researchgate.net/publication/342013809_Farmer-to-farmer_digital_network_as_a_strategy_to_strengthen_agricultural_performance_in_Kenya_A_research_note_on_%27Wefarm%27_platform

Partnership across boundaries

Avoiding the reinvention trap

Those involved in commissioning, providing and receiving social care frequently complain that local authorities “re-invent every wheel” with a frustrating mixture of duplication and disconnection found between departments and between Local Authorities themselves”(Surrey Care Association, 2020). For carer support services, researchers have found this to be especially true (Willis et al., 2021).

Coming out of the pandemic it may be tempting for each local authority and commissioned provider to develop their own online support solution. Given the likely similarities between each solution, it may be much more efficient for regional networks (such as via ADASS Carers Leads groups) to commission a shared solution covering a number of areas.

Effective sharing

The rapid shift to digital provision during repeated lockdowns has sparked further interest in sharing resources and ideas. The “freedom to innovate” (Hussain, 2020) brought about by the pandemic has permitted experimentation and collaboration, which in turn has led people to speculate about how services could be structured more effectively.

Some of these changes are simple yet profound. Like other providers, Mobilise has been able to share the cost of providing content across different authorities by delivering online events on a national basis. This has greatly expanded the range, frequency and attendance at events without creating unsustainable demand on local resources.

These experiences can lead to shifts in perception about how carer support services can or should be structured. Researchers early in lockdown noted that carers engaging with Mobilise support were able to create connections with other carers across the country - enhancing and diversifying the level of support available (Donnellan & Lariviere, 2020)

Moving forwards

While drawing on what has come before is an important aim, reviews have repeatedly found a “paucity of apps and websites specifically developed for informal carers” (Papa et al., 2020). It must be admitted that there are relatively few examples and hubs of expertise to draw on.

But recognising that the space is relatively open leaves room to build connections and collaborations.

Effective digital collaboration which can make the most of resources, while avoiding disconnection or duplication, requires a culture of openness, alongside structure and intention. Rather than spending tens of thousands of pounds developing dozens of in-house apps, repeated assessments of generic tools, writing the same copy regarding carers rights and advice about technology, this work can be shared.



Further Reading

Explore the positive examples described in the joint ADASS TSA Commission report on technology in adult social care; many of these creative uses of technology were led by or impacted unpaid carers
<https://www.tsa-voice.org.uk/adass-tsa-comm/>

Data

Improving data collection and analysis capacity can lead to more effective decision-making, and ensure the needs of a broader range of carers can be understood and met. What is termed 'data' can include but is not limited to personal information (names, email addresses etc). A broad range of data, such as user behaviours (when different users access particular services, for example) can provide hugely valuable insights for commissioning and providing more effective services.

Identifying what data will be helpful

In the year prior to the pandemic calls for improved data in Adult Social Care had become increasingly urgent, bolstered by the publication of the Office for Statistics Regulation's review. They confirmed that of data in the fields of "economics, employment, health" it is "social care that stands out by far for its low quality or even absent data" (Office for Statistics Regulation, 2020). Attempts by researchers in the field have been hampered by "a frustrating lack of high-quality, comparable data" (Schlepper, 2020).

High quality data is crucial for commissioners and practitioners as well as researchers, because understanding supports decision-making. Reliance on fragmented, biased information and anecdotal evidence "means that policymakers, commissioners and providers are not able to make robust decisions to improve the lives of people who receive care" (Nicholas, 2019). For these purposes 'high quality' data does not have to mean intrusive surveys of every user - counting clicks and pageview times can also be extremely informative about what carers are finding helpful.

The carer population is increasingly diverse, with different needs, interests and experiences, different drivers to seek support and barriers to accessing services. Older carers, sandwich carers, carers from ethnic and cultural minorities, carers with different levels of income, education, digital skills and health literacy. Data is critical to working out what works for this complex population.

Data helps understand challenges, identify opportunities, choose and assess solutions. Services which collect less data may find it harder to build a business case for investments, or to draw attention to challenges or unmet needs; "We need parity of measurement to have parity of policy"(Office for Statistics Regulation, 2020).

Data-driven decision making

When investing time, effort and attention in improving the availability and use of data in services for unpaid carers it is critical to set out what that data is for, what the intention is behind collecting and using it, and how it will be analysed. Trying to rapidly fill the information void without careful consideration not only wastes resources and time, but can actively cause harm, as errors and biases distract us, distort decisions and leave those working in the service and using the service confused and frustrated.

Work on improving the technical side of data collection must be accompanied by attention to organisational culture. With little information available, the few numbers that are collected often become targets - in practice, even if not officially. Targets can help us focus attention and resources, provide transparency and hold us accountable. But targets which are not carefully balanced, frequently reviewed, and “informed by a nuanced understanding about how data reflects complex lived realities”(Nicholas et al., 2020) risk creating target culture that ‘hits the target but misses the point’ (Deakin 2015), with perverse incentives and distractions.



Further Reading

Health Foundation: Strengthening Social Care Analytics

<https://www.health.org.uk/funding-and-partnerships/programmes/strengthening-social-care-analytics>

Skillsets for delivering online support

The Open University's survey of 500 leaders and managers in adult social care in England found that despite difficult working conditions over the pandemic, in general staffing levels were manageable - only 6% reported understaffing - but 44% of respondents said they had "only the bare minimum of skills to operate, or lacked vital skills". They cited key areas of concern as digital (36%), leadership (33%), and technical (31%) skills with almost half (46%) looking for recruits "capable of adapting to future challenges in the wake of COVID-19". (Turner, 2021).

Commissioning, delivering and assessing digital support offers for carers requires skills and knowledge that may be in high demand, and therefore expensive and challenging to access. But making key decisions without these skills can lead to expensive mistakes, missed opportunities, and poor outcomes for carers.

Overcoming this skills shortage whilst also managing a budget shortage requires a careful balance - prioritising digital skills (or interest in learning) when possible in hiring, building in-house skills and confidence, drawing on outside expertise; and sharing costs, resources and learnings with other carers support services or local authorities.

Accepting that digital transformation is ongoing; there will always be new products and services becoming available, price changes to making new technologies accessible and security and privacy issues to consider. Adapting requires not just one-off training sessions, but a transition to a learning culture, which supports experiments, shares ideas, is willing to build-on and adapt tools and learnings developed by others.

The result will be an evolving mix, that draws on changing lessons about how to learn from data, improve information services, fix disconnection and duplication, and meet carers where they are.



Further Reading

Bath & North East Somerset:

<https://medium.com/digitalfund/finding-our-user-experience-journey-mapping-the-users-831c2b38d27b>

Digital Transformation Is About Talent, Not Technology:

<https://hbr.org/2020/05/digital-transformation-is-about-talent-not-technology>

Lessons from Lockdown

New Evidence

This section, written by Dr Warren Donnellan (University of Liverpool) and Dr Matthew Lariviere (University of Bristol), summarises primary evidence gathered in 2021.

The primary evidence draws on a poll of over 1,000 unpaid carers, and a survey and interviews with local authority carers leads and providers of carer support.

Poll of Carers

Dr Warren Donnellan



Methodology

A survey of 1000 unpaid carers between 22nd and 28th April 2021 was conducted on behalf of Mobilise by 3GEM, a market research agency.

It is important to note that the survey asked respondents if they look after or give any help or support to anyone with long-term physical or mental health conditions or illnesses. Whilst we use the term 'carer' throughout this section, not all respondents may identify in this way.

It is also important to note that whilst we do have the data to be able to conduct a vast array of analyses stratified by different demographic variables, this goes beyond the scope of this report. Here we aim to outline some general demographic trends seen in unpaid carers living in the UK.

Who were the carers surveyed?

The survey sample comprises a diverse and generally well-balanced group of unpaid carers living across the whole of the UK. However there are some interesting trends to be aware of. For example, the carers are almost entirely under the age of 65 with the most prominent group being aged between 25 - 34 years old. Carers of white ethnicity make up the majority of the group to complete the survey, although people of mixed, Asian, black and other ethnicities are also represented. Finally, it is worth noting that a significant majority of carers completing the survey are from the higher social grade categories.

Most of the carers in the sample have been supporting their loved ones for between one and five years, although some for much longer. Interestingly, almost 20% of the carers have picked up caregiving responsibilities since the first COVID-19 lockdown was announced in March 2020. Most carers are spending up to 34 hours per week providing care, with a small proportion providing over 50 hours of care per week. The majority of carers are looking after a partner/spouse, parent/step parent/parent-in-law or a child under the age of 16 and a decent proportion of carers spend time looking after other relatives. See Table 1 for full descriptive statistics.

These findings paint an interesting demographic picture of unpaid carers living in the UK, but some level of caution should be taken when interpreting the results as it is always possible that trends may in part result from online survey bias rather than a representative pattern. For example, it is possible that we overestimate the use of online tools because the poll was administered online.

Table 1. Respondent demographic characteristics

Respondent characteristics	% of sample (N=1000)
Age	
16-24	21.6
25-34	30.9
35-44	23.6
45-54	14
55-64	6.8
65+	3.1
Sex	
Male	46.5
Female	52.8
Other	0.7
Region	
North (including Scotland and N. Ireland)	35.2
Midlands	24.3
London and South East	27.6
Wales and South West	12.9
Ethnicity	
White	80.8
Mixed	7.7
Asian	8.3
Black	4.7
Other	0.8
Social grade	
Higher and intermediate managerial, administrative, professional occupations	40.8
Supervisory, clerical and junior managerial, administrative, professional occupations	22.9
Skilled manual occupations	13
Semi-skilled and unskilled occupations, unemployed and lowest grade occupations	22

Care duration	
Less than a year (since March 2020)	19.3
1-2 years	23.7
2-5 years	27.4
5-10 years	13.6
10-20 years	7.4
20+ years	2.5
Don't know	6.1
Hours per week spent caregiving	
Less than 9 hours	26.5
10-19 hours	22.1
20-34 hours	23
35-49 hours	11.7
50+ hours	6
Don't know	10.7
Care recipient	
Partner/spouse	33.6
Parent/step parent/parent-in-law	28.4
Child under 16	27.2
Child over 16	10
Other	21.8
Live with care recipient	
Yes	64.8
No	35.2

Are carers using online tools generally and do current approaches meet carers' needs?

The current support offer (largely offline) is not meeting carers' needs.

Existing support for carers was perceived as inaccessible or inadequate by carers, particularly those in the middle-aged 45 - 64 age group who had been caregiving for longer periods. For example, 20% of carers felt inadequately supported in their caregiving role, 14% felt that support was inaccessible to them, and 18% felt that support was provided in an unattractive way.

Older carers (over 65s) reported having more trouble understanding support whereas middle-aged carers reported having more trouble accessing support. Middle-aged carers wanted access to individual, accessible support and self-care more than the older group. This suggests there are age differences in what support carers want and how they wish to access it.

Lockdown has seen a significant increase in carers using online services, and many are hoping to continue using them.

Six in ten carers were already using everyday online tools to do things like manage their finances, order takeaway and shop online before the COVID-19 pandemic, and the same proportion intended to do so afterwards. Most carers use online social media to connect with family and friends and about one third use it to connect with caregiving communities. There is clearly a desire among carers to seek out advice, support and information about caregiving from existing online channels.

About one third of carers were accessing health and social care services, seeking advice from other people with caring responsibilities and booking health and social care services online prior to COVID-19 and this increased during the course of the pandemic. Carers accessing these services indicated a willingness to carry on doing so in the post-COVID-19 period, which suggests that they are satisfied with the services they are accessing. Additionally, about a quarter of carers indicated an appetite for online support services that they were not currently accessing that may have been unavailable prior to the pandemic; for example, whilst 17% of carers had used caregiving apps previously and wanted to continue using them, 21% had not used them but wanted to, and 23% had not yet heard of them.

Despite the significant jump in people using health and care services online during the COVID-19 pandemic, it is still not at the levels of people using the everyday online tools described above. There is an untapped demand and a need to promote online services to carers so that they can make more informed decisions about whether or not to use them.

Zoom/Microsoft Teams sessions are one effective method, but there is scope for a much more diverse online offer.

Prior to the COVID-19 pandemic, only 37% of carers had used video conferencing software such as Zoom and Microsoft Teams. Interestingly, 68% of carers reported using these platforms during the pandemic but only 57% planned to continue using them in the post-pandemic period. For many support services, one-to-one online services were perceived as positively as one-to-one face-to-face services. Furthermore, 77% of carers felt that speaking to a human when accessing support is important. This suggests that it is supportive human interaction rather than the mode of delivery that matters to carers.

Video calls are not the only way of providing carers with supportive human interaction. One-to-one support can be provided either synchronously, using telephone and chat exchanges using online discussion forums, or asynchronously, using blogs and videos. A 'suite' of services via different remote platforms and channels providing accessible, user-friendly human interaction is likely to have the most positive impact for carers.

There are barriers to digital inclusion, but these may not be insurmountable.

Age may be the most fundamental barrier to digital inclusion in carers. Whereas younger carers (under 35s) are most concerned about finding the time and private space, 35 - 64 year olds are most worried about data privacy and time. Older carers (over 65s) are less confident about using technology in general; they see online tools more for socialising and staying in touch with family and friends rather than accessing health and social care services. Therefore, extra effort may need to be taken to engage older carers in online support options; it may be that reframing the online support offer is necessary before attitudes can change.

Another important barrier is hardware compatibility. For example, 89% of carers report accessing the internet on a smart phone compared to just 33% who access it on a desktop computer. This means that online tools and supports need to be mobile compatible and easy to use on a smart phone. Devices also need to be internet enabled, whether that be through WiFi or data allowance.

Carers Lead & Provider Survey



Dr Warren Donnellan

Who took part in the survey?

19 people working as carers leads or providers of services across England and Scotland responded to a mixed method online survey between 5th April and 17th May 2021. Respondents worked across a mix of levels, from front line support workers and carer campaigners to higher level managers of care provider organisations and chief executives based within local authorities.

Respondents were asked a range of questions about their attitude towards in person and online carer support services. Respondents also had opportunities throughout the survey to provide typed qualitative responses to contextualise and enrich the quantitative data. It is important to be tentative in the conclusions drawn from this data in part due to the small sample size but also due to missing data across the survey. The findings are outlined below under thematic headings.

What approach (in person or online) do people working within carer commissioning services think delivers the most value and benefit to unpaid carers?

Respondents were asked to reflect on how existing carer support services should be delivered, on a scale of entirely in person to entirely online, based on existing human and financial resources within their respective organisations.

Respondents invariably preferred a blended, hybrid approach in the delivery of emotional/psychological support, information about resources available to carers and carers' rights, peer support, training in care skills and self-care, support with exercise and eating healthily, and identifying and reaching more carers, whereby services are delivered using an equal mix of in person and online modes of delivery.

While respondents felt that online support should not replace face-to-face support which will always be necessary for some people due to digital exclusion and deprivation, they felt that online support is more convenient and gives options/flexibility to carers who live busy lives and cannot always leave the house to attend in person appointments. Respondents also recognised that online support is often less time consuming which means that support workers can reach more carers more frequently, some of whom may not have been accessed previously due to infrastructural or accessibility challenges, e.g. so called 'hidden', hard-to-reach carers living in rural locations.

How confident and equipped are people working within carer commissioning services about digital technology support for carers?

Respondents were asked how confident, equipped and resourced they felt to make decisions about digital technology support and to implement and maintain this support for carers they were supporting. The vast majority of respondents felt confident and had the skills and expertise necessary to make good decisions about digital technology support and to implement and maintain this support for the carers they supported.

Funding and resourcing was generally perceived as a barrier but interestingly a greater proportion of respondents felt that this was a barrier to the implementation and maintenance of support than making good decisions about digital technology support. Perhaps this is unsurprising as implementation and maintenance of services carries a more direct cost than confidence in the capacity of an organisation.

What are the challenges facing unpaid carers of using digital technology support offered by carer commissioning services?

Next, respondents were asked to consider the challenges facing unpaid carers of using digital technology support in terms of how likely it is to prevent carers from accessing services and how costly it is to overcome.

All respondents felt that there were challenges facing unpaid carers in using digital technology support. Proportionately more respondents felt that carers' ability to afford necessary devices and data, carers' physical disabilities and/or access needs, and carers' concerns over privacy and security were slightly challenging in terms of preventing some people from accessing support or incurring some costs to overcome.

However, proportionately more respondents felt that carers' lack of digital skills and digital literacy, carers' lack of time and carers' lack of interest were seriously challenging in terms of preventing most people from accessing support or incurring very high costs to overcome.

What experience do people working within carer commissioning services have of piloting new digital technology support during COVID-19 and do they plan to continue using it post pandemic?

Respondents were asked about their experience of piloting new digital approaches during the COVID-19 pandemic and whether they planned to continue using these supports in the post-pandemic period.

All of the respondents had tried online peer support and online training and learning during the pandemic. The majority of respondents had tried online emotional and psychological support, online assessment services and online information about resources and rights for carers.

Interestingly, even for those respondents who had not tried these new digital technology supports, all were keen to try to implement them in some way. Indeed, more than half of respondents said that they intended to continue offering the same or a higher level of digital technology support for unpaid carers that they first piloted during the pandemic. In line with the first subsection above, the respondents explained that digital technology support offers a 'lifeline' to carers and greater flexibility and reach to new, previously unsupported carers than before.

This clearly demonstrates a willingness to try new approaches and an openness for new ways of working in the post-pandemic world. However it is important to note that a proportion of respondents did not know whether they would continue offering these services and some did not intend to at all. When asked to consider their reasons for these views, the respondents explained that maintaining the same level of service would depend on sufficient human and financial resources being made available post-pandemic which may result in digital support being offered at a slightly lower level than currently.

What do carer commissioning services need in order to sustain digital technology support for unpaid carers after the COVID-19 pandemic?

Finally, respondents were asked to rank a number of factors that they believed to influence sustainable digital technology support in order of importance from least important to most important. In line with the subsections above, the most important factor was funding, followed by: training and support for staff development; information about options available on the market; support and communication between services; support and guidance from leadership; and, finally, support and guidance from regulators at the least important factor.

Overall, the analysis suggests that there is 'no one-size-fits all' solution to support for unpaid carers. Indeed, there is a clear appetite among people working in carer commissioning services for a blended, hybrid approach as we move into a post-pandemic future. However, there a number of important lessons from piloting during the COVID-19 period as well as a number of tangible barriers, the main one being funding and resourcing, which would first need to be overcome in order to achieve the plans and ambitions described above.

Carers Lead & Provider Interviews



Dr Matthew Lariviere

To contextualise our findings of the commissioned services survey, the team carried out semi-structured interviews with 20 people involved in the commissioning and delivery of carer support services. This sample included commissioners, care leads, carer support workers, and technology providers from England and Scotland. By carrying out interviews, we hoped to elicit the views of stakeholders responsible for supporting carers within an increasingly digitised care ecosystem. Interviews were recorded and transcribed verbatim, then analysed thematically to identify shared and divergent patterns about participants' beliefs in how digital technology can work to support carers. Here we present the major thematic findings from this aspect of the study.

Why has digital support not worked?

Some participants believed that a significant minority of the carers they support would never engage productively online. Some of this perception came from direct feedback from carers, some was informed by changes observed in engagement, and some came from pre-existing perceptions, like a carer's age, as illustrated with the quote below:

“There’s a lot of people that are in the older sort of age range, and they’re very old fashioned. They don’t know what they’re doing.” (Carers Support Worker)

A few participants noted that digital simply did not work for some carers. These were generally carers who both lacked digital confidence and lacked the resources to develop that confidence- generally due to the demands of caring combined with their own physical and mental health issues. While this group did include more older carers, it was not exclusively older carers. Younger carers (carers aged under 65 years) could also lack both confidence and the resources to develop their confidence. People in this situation needed face-to-face intervention, support made more difficult to access during COVID-19 related restrictions and lockdowns.

“There’s definitely a demand and need for some, some of the face-to-face side of it and some things that haven’t been as effective in terms of in-person from that perspective. So, for example, being able to give carers a proper break from their caring role is much harder. If it’s just over a Zoom screen from [compared to] actual in-person.” (Carers Lead)

Several participants identified challenges with building relationships through digital platforms and telephones. These individuals highlighted the particular value they inscribed to body language, eye contact and sharing physical space to build ‘bonds’ or ‘trust’ to develop social relationships.

“They could be speaking to somebody different every time. They feel every bit of effort to see that person to sort of gauge what their body language. Things that are missing when you’re talking on the phone. There’s a lady recently having a terrible time with the anti-social behaviour team at the council. She feels that it would be better for her to physically go down to the office to see them.” (Carers Support Worker)

There was no consensus about how best to support carers. Some participants prioritised face-to-face support for carers. They noted how many carers had strongly supported face-to-face interactions, like described in the previous quote. Conversely, other participants reported how ‘sceptical’ staff had been proven wrong when carers participated in online engagements. This may link to what other interviewees noted: it was staff who were more hesitant about moving online, motivated by their own dislike of change and dislike of technology, rather than any belief strongly held by carers.

“My team manager who manages the [carer hub] for me. She was quite sceptical about what the uptake would be [of the digital support]. Whereas actually we’re seeing a constant increase in the number of carers taking part in the hub.” (Carers Lead)

This cultural preference for face-to-face interactions within care organisations may introduce biases against assessments for digital solutions. However, for staff interested in digital options, COVID-19 granted the organisational permission and resources to accelerate plans for digital solutions they already had in development.

How has digital support worked?

Some participants suggested online tools could increase accessibility of services for carers. Online tools can be accessed outside of working hours and eliminate the need to travel. This presented an opportunity for services. Carers who had previously been hidden from services because of the difficulty carers faced with travelling were now being engaged.

“[We have run] yoga, mindfulness sessions, and the feedback from our carers is that they helped. What made these better for carers was the fact that they didn’t have to travel to link into things.” (Carers Services Development Officer)

Digital tools seemed popular for drop-in information sessions and virtual ‘cafes’. It also enabled targeted work to reach underrepresented groups, for example, one participant discussed the development of a closed Facebook carers group for South Asian women.

“We’ve used [online tools] as a way of reaching out to communities who are quite often underrepresented. We’ve set up a closed Facebook group, specifically for female carers from the South Asian community, because they weren’t accessing support. It’s very early days, we literally set it up a couple of weeks ago, but we’ve got nearly forty women from the South Asian community to sign up to that as a way of getting information.” (Carers Lead)

These factors provided benefits from lower effort engagement, which gave several participants hope that it would prevent carers spiralling into crisis and requiring more intense face-to-face support. Instead, carers could access small amounts of support in ways that were relatively convenient.

“It’s really reaching more carers, which is brilliant, by providing a sort of preventative early intervention support for them through peer support and training information that’s all really useful. [...] I see digital is very much a sort of preventative, early intervention.” (Older People’s Services Commissioner)

What does it take for digital support to work?

Digital transformation has not evolved out of nowhere. Organisations that have met any measure of success with digital tools for carers have required resources and labour to achieve their goals. Participants noted several potential obstacles with implementing digital tools to support carers.

One such challenge is the affordability of devices, software/app licences, and data.

“We have been quite fortunate with the carers service having received money from [a devolved administration]. We’ve identified that that has been an issue on the whole, but we’ve been able to manage it.” (Carers Services Development Officer)

The process of helping people access online support involved substantial labour. Even when an organisation had funding to purchase devices and data for carers, dedicated staff were required to help carers through extensive technical struggles, especially if carers had relatively low digital literacy skills. This required organisations to allocate staff-hours to pre-existing staff or hire new staff with this new responsibility.

“We’ve spent three hours with the same person trying to tell them where the Zoom icon is. People didn’t know that you can click on a link to take you to the call.” (Carers Engagement Leader)

Participants also reflected on the limitations of technology implementation. It was not enough to make a ‘good’ product/service. Service leads needed to develop the right solution to the right people at the right time in a manner with which they were willing to engage. A facet of digital transformation that some services struggled to achieve. To complicate matters, several participants expressed confusion about why attendance was erratic, or why carers who provided great feedback did not return for subsequent online meetings.

“It is still quite hard to understand. We surveyed parents. We asked them what they wanted. We took things outside of the normal office hours, because this is what people said they wanted. The take-up was better, but it could not be described as good by any stretch of the imagination.” (Carer Support Worker)

Participants appreciated the drive to match services to carers' needs and their care context. One participant used the concept of 'empathy mapping' to describe this matching process to increase carers' adoption and uptake of digital services.

“Something quite common in the digital world is a user’s journey. [We create] a user’s empathy map based on how a user’s feeling and kind of linking [their user journey and feelings] together. Now we understand more about how the carer is feeling when they join us, and that they’re scared. We understand the language we need to use in order to encourage them into services.” (Digital Carer Support Lead)

Sometimes creative solutions led to successful outcomes. One participant described how they included the whole household in storytime and cooking to great effect.

“We streamed children’s stories. We bought in six online stories, like The Tiger Who Went to Tea, then we brought cook-alongs. These were healthy foods packaged and delivered that the children heard about in the stories. They would go ahead and make the food with their parent or carer – the mum, dad, whoever – after we streamed the story. They were massively well attended. They provided children’s entertainment and cooking together. It involved the full family. They were so popular. Whereas the carer groups or parent carers had just been about the adult, you know, parent-carer or the guardian with no child involvement, because they would be at school. But [the cook-along] was much more social.” (Carer Support Worker)

This case highlights the importance of adapting digital tools to meet the interests of carers and cared for people. Successful digital support tools do not constrain relationships and social connections, they attempt to reinforce and enhance them.

How did the transition to digital carer support work?

The sudden transition to a sole or dominant digital support for carers was experienced similarly by the participants. For most organisations, COVID-19 simply accelerated their digital transformation plans.

“The majority of services that moved were what you might call support and activities. We moved them online relatively quickly, and relatively simply, we’ve been thinking about doing this kind of thing already.” (CEO of Provider Organisation)

“[Digital support] was absolutely a priority [before the pandemic]. I think in terms of ‘when’ timescales wise, [the pandemic] just fast forwarded it significantly. Over the next one to three years using digital technology was a priority in our organisational business plan, but we definitely had not anticipated the speed at which it has happened.” (Carers Lead)

However, some participants expressed concern about the effect this rapid digitisation may have on organisations and the care sector.

“Covid has severely drained a lot of local authority and national resources. It’s unclear what [digital support] looks like in the future, as far as what their budgets allow or whether they have to prioritise basics.” (Carer Support Worker)

This highlights a potential future obstacle for local authority commissioners and care providers as they plan their future service offerings. After reallocating resources to accelerate digital transformation of their services, how will they ensure sustainability of these services in the future? How can they catalyse their investment in new technologies, support staff, and training to best effect for their organisation, workforce, and clients?

What are the plans for the future?

As the United Kingdom's four nations and other countries slowly experience eased restrictions, the inevitable question remains, 'how do services plan to support carers in the future?' Many participants suggested a 'blended' offering of digital and face-to-face support options.

“Carers have said to us that what they’re very keen to see is a blended service approach as we move back into wherever we’re going next. They don’t want to lose the digital. We were talking about 75 to 80% digital and 20% face-to-face.” (CEO of Care Provider Organisation)

“The expectation is that we would, to some degree, get out to see some people, but I think some of the telephone support or online support might continue for certain things. It might be a mixture of both going forward.” (Carer Support Worker)

Some participants hoped carers hubs would take more of a 'strategic champion', 'influential role' or 'influencer' position in the ecosystem of services, signposting carers to supportive communities, services, employers, and businesses that were 'carer-friendly'.

“I would like to see our carers hub taking much more of a strategic role, so they will mostly be like a strategic champion placing themselves in quite an influential role across [the locality]. I imagine the hub being the strategic champion. It will be a partnership response with all sectors and different parts of [the locality] behind it, but the hub will be leading it.” (Older People’s Commissioner)

Several interviewees expressed concern about managing a growing number of carers. Digital is a key part of their plans to cope. We have identified three key thematic areas for digital support:

Digital as preventative service. The aim for this approach is to keep people feeling supported and connected through peer-to-peer connections without needing to draw much (or at all) on face-to-face services.

Digital as extension to existing services. The aim here is to use less resource intensive modes by continuing to offer affordable and accessible online options, e.g., online drop-in sessions and information clinics.

Digital as connections to communities. Here the aim is for digital technology to foster and sustain carers' connection with services and peer communities outside of their local area.

What long term shifts can we anticipate?

The forced adoption of technology has accelerated plans and legitimised investment in the digital. It may change working practices, but the strong preference expressed by some staff to return to face-to-face suggests many want to return to the pre-pandemic status quo. Some digital shifts may persist despite these entrenched cultural preferences.

The shift to online carer assessments and form filling support may remain because it is more efficient for carer hubs. Staff may feel more comfortable working from home. Carers who prefer text or video contact will not want access to those services disrupted or discontinued. One crucial challenge for local authorities will be to develop a strategy to sustain digital transitions that have worked for their organisation, workforce, and carers they support rather than easily reverting to pre-pandemic behaviours.

We cannot predict how support for carers will continue to adapt as the pandemic subsides requiring new arrangements for carer support.

Digital technology has helped many people during this challenging eighteen-month period where many carers were confined to their home. This technology has served as a catalyst to extend the possibilities of carer support services, potentially prevented further crises for carers, and fostered new communities of carers across the UK and internationally.

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