



ROAD TO RECOVERY: COVID-19 SURVEY RESULTS

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Executive Summary

To understand how carers have been affected by the pandemic, Carers Tasmania released a survey titled *'Road to Recovery – COVID-19 Survey.'* With recovery in mind, carers were asked to complete a series of questions surveying the impact of COVID-19 on their caring roles, and what support may be needed as we transition out of the restrictions.

The survey featured three distinct sections – *'The person you care for'*, *'The impact of COVID restrictions on your caring role'*, and *'Looking forward to when restrictions are lifted'*.

A total of 400 survey responses were received – 214 online, and 186 being returned via return mail (hereafter referred to as hard copy). As Tasmania has the lowest data inclusion rate in the nation¹, it was determined to include a paper-based survey to engage carers that are largely shut-out from digital pathways.

The Road to Recovery survey results highlight a range of different experiences amongst carers, with some feeling little to no change due to introduced COVID restrictions, while many others were overwhelmed with stress and anxiety. Carers who felt relatively low levels of stress were typically older and often noted that they lived a more insular life pre-pandemic. The carers who felt the biggest burden were those who relied on family, support services, and schooling for their children.

Carers were not only impacted by their care recipients' risk of exposure to the disease, but just under half of carers reported being in a high-risk category should they be exposed to the virus. In line with the demographics of Tasmanian carers, more than half (59%) of care recipients were over the age of 65. The most common COVID risk factors for care recipients were *chronic conditions, frail age, and weakened immune systems* while 33% of carers reported having a diagnosed chronic condition.

Less than half of all carers reported having a contingency plan should they become ill, with the main barriers cited including *'There's no one who can step in'* and *'I don't want to be a burden on other people.'* This theme was consistent as just over 40% of carers reported having a family member that could assist upon short notice.

More than half of all carers reported caring for more than 60 hours a week pre-pandemic, with 40% said that the time spent in their caring role had increased throughout the COVID-19 restrictions. Likewise, 40% of carers reported increased expenses, including food, household bills, and fuel for transport had risen during isolation.

Carers reported changes to their sleeping habits, while also expressing concern for their mental and physical health. Thirty-nine percent of carers reported changes in their sleeping habits, and those who said they lost sleep reported an average loss of 3.4 hours per night. Likewise, 16% of carers said they were exhausted and overwhelmed thinking about their wellbeing, with a further 13% saying they were concerned and worried daily.

Just over 30% of all carers said that they had recently contacted their GP for support, while just under 60% of carers said that they had utilised telehealth appointments throughout the pandemic.

¹ https://digitalinclusionindex.org.au/wp-content/uploads/2019/10/TLS_ADII_Report-2019_Final_web_.pdf

Questions about technology usage displayed the biggest differences between the two survey cohorts (online and hard copy). When asked if they had used technology to connect with family and friends, almost 90% of online respondents said that they had, while under 60% of hard copy respondents said they had. When asked why this was the case, 17% of all surveys returned by mail indicating that the carer will not use the internet at all, while 12% said they just do not want to use technology.

When asked what would help them following the lifting of COVID-19 restrictions, carers provided valuable feedback. Nearly half of all carers indicated that there were some areas where they would like more skills or knowledge. When asked what would help them, the most common answers including *'Being connected to my local community'*, *'Having a better understanding of the services I can access'*, and *'Be connected to other carers.'*

The findings of this survey highlight the differing experiences of carers throughout the 2020 COVID-19 pandemic, with some carers routines seemingly not changing, while others struggled to keep afloat.

The results provide insight into steps to move forward beyond restrictions, and to the supports needed by carers in Tasmania.

1. Carers and care recipients

The first step was focused on gaining insight into care recipients, understanding COVID risk factors, and the availability of immediate support.

The most common conditions that carers reported for were those with *disabilities (57%)*, *medical problems (36%)*, and *mental ill health problems (29%)*. Results were consistent across the two survey cohorts (online and hard copy), however *has a medical problem* was 15% more prevalent amongst carers who filled out a paper survey [Graph 1].

The majority (59%) of carers provide care for someone who is over 65 years old. Carers who returned the survey via mail were almost twice as likely to care for someone over 75 years old than those who responded online. Likewise, online respondents were five times more likely to care for someone under 12 years old [Graph 2].

In total, 73% of carers stated that the person(s) they care for are in a high-risk category for contracting COVID-19 – while 49% of carers themselves are in a high-risk category. Differences between survey cohorts also arise in this question, with carers responding in hard copy 14% more likely to care for someone in a high-risk category, while they were 29% more likely to be in one themselves [Graph 3].

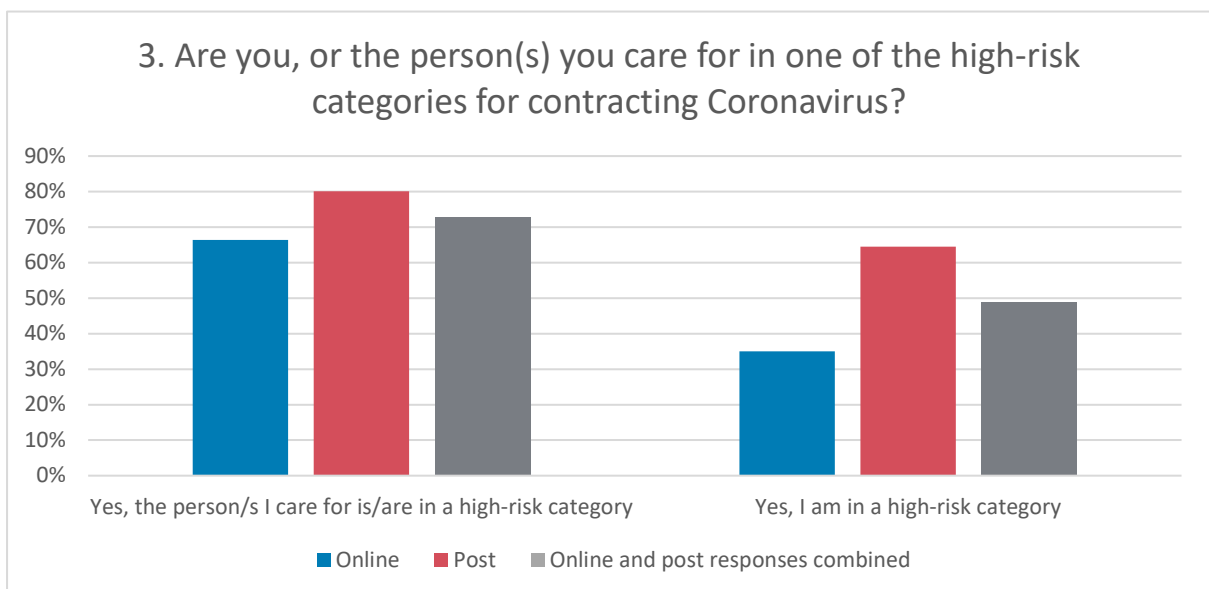
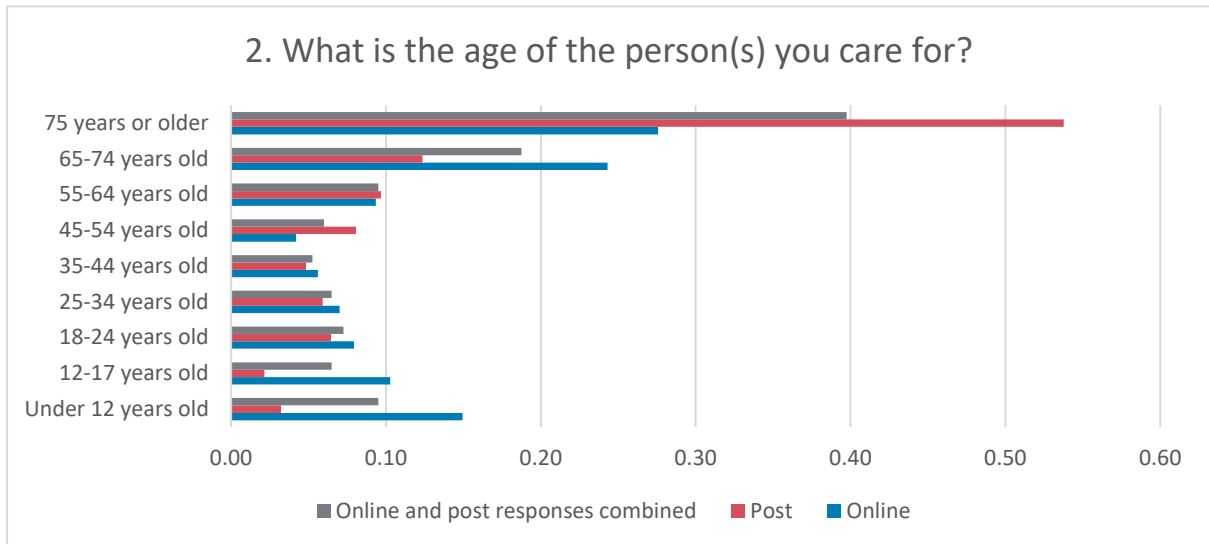
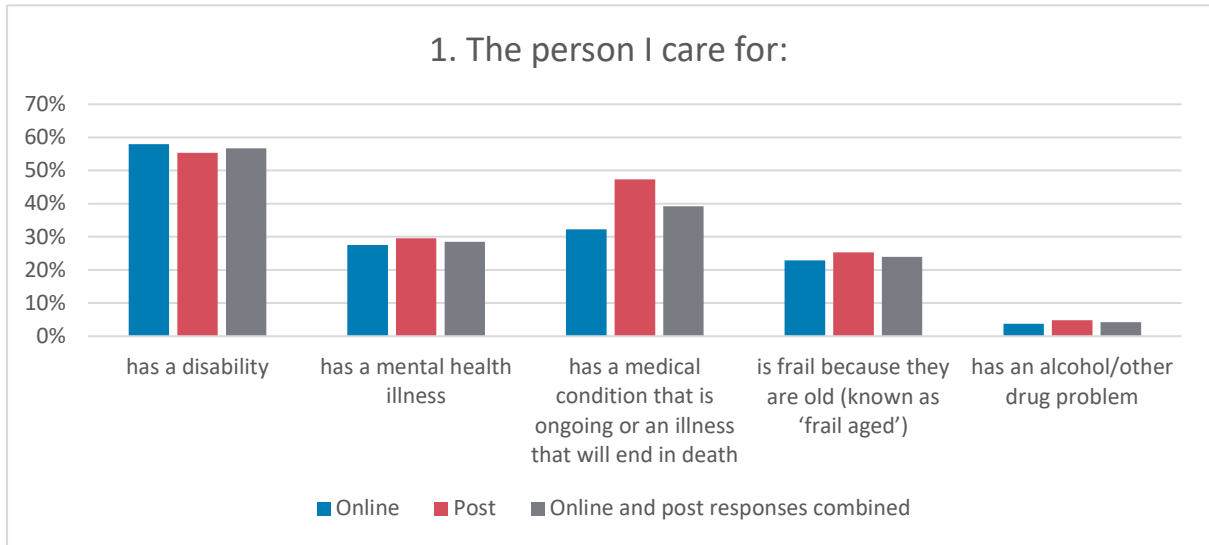
Care recipients risk factors were consistent across the two survey cohorts (online and hard copy). The most common risk factors were *diagnosed chronic conditions (48%)*, *frail aged (31%)* and *weakened immune system (31%)*. The only notable difference between the cohorts was that carers responding via post were 10% more likely to care for someone who is frail aged [Graph4].

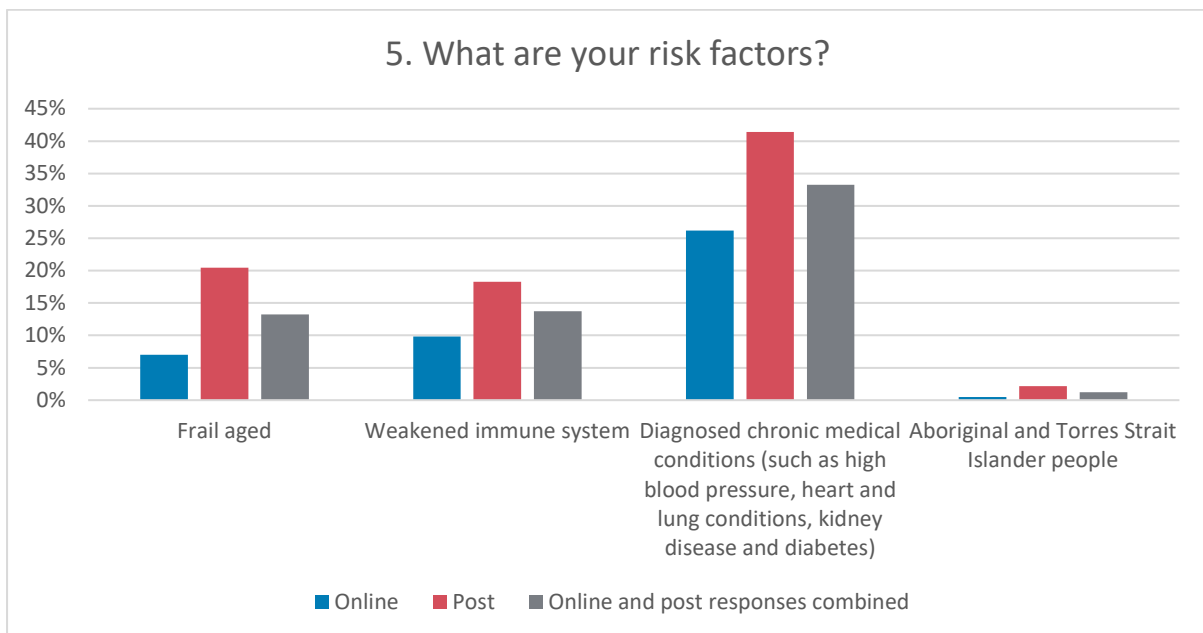
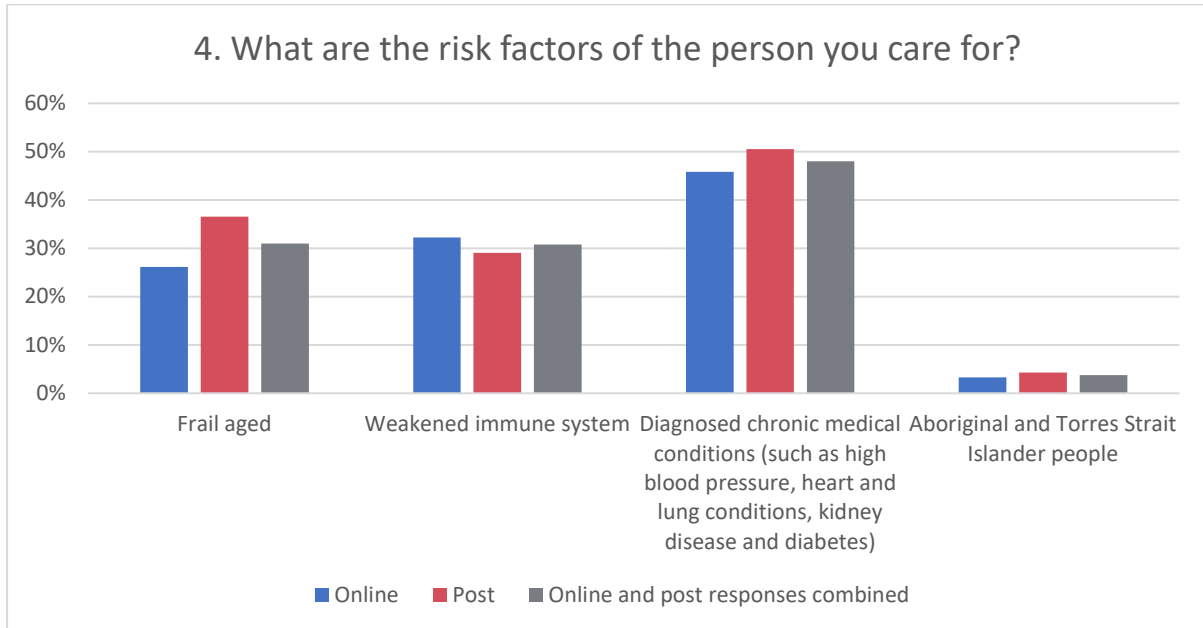
While the care recipient risk factors were relatively consistent, differences between carers were noted. Once again, the most common risk factor was *diagnosed chronic conditions (33%)*. Carers who responded by mail were more than twice as likely to be frail aged, and 15% more likely to have a diagnosed chronic condition [Graph 5].

“I have been working from home, caring for my two autistic sons, and taking video conferences every day...Some days are fine, but I am feeling a big strain.”

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"My husband usually only sleeps for one hour then is awake again. He panics if we have to go out."

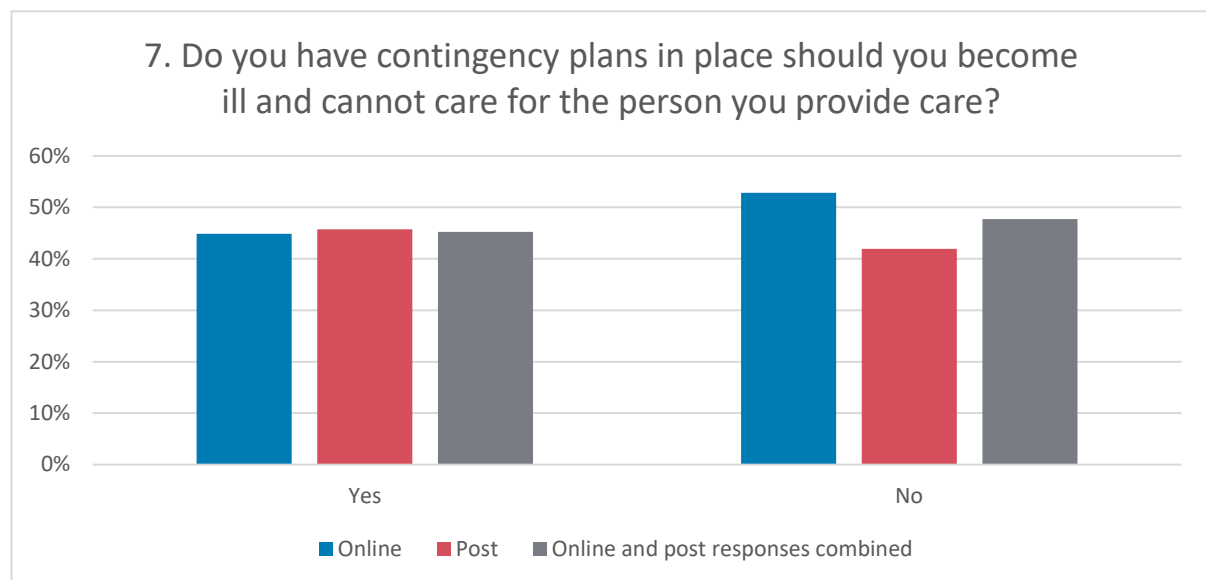
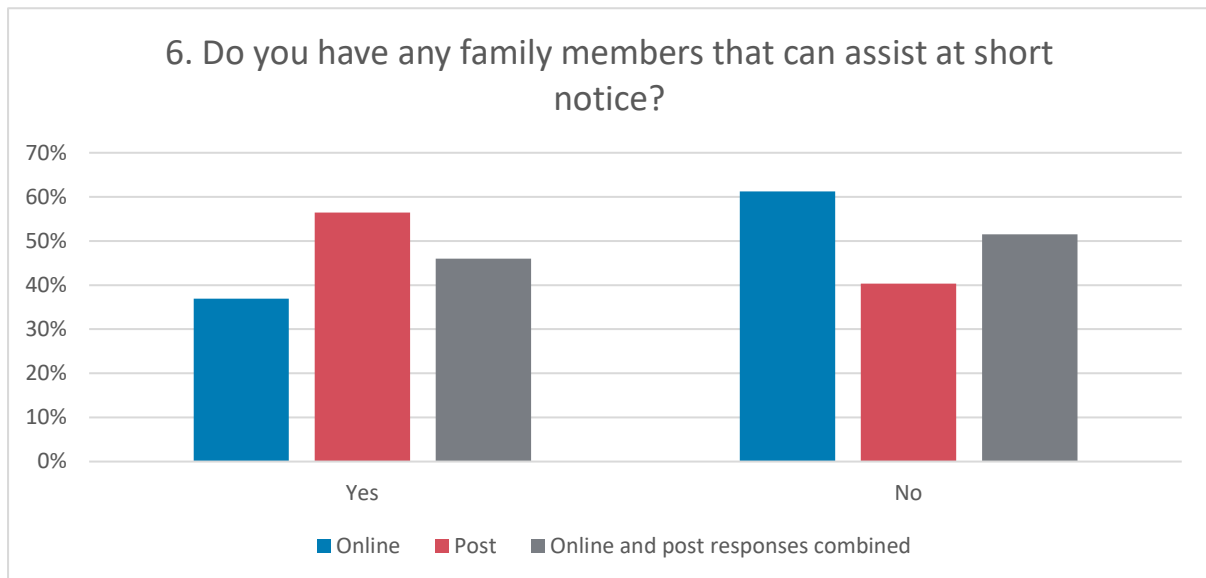


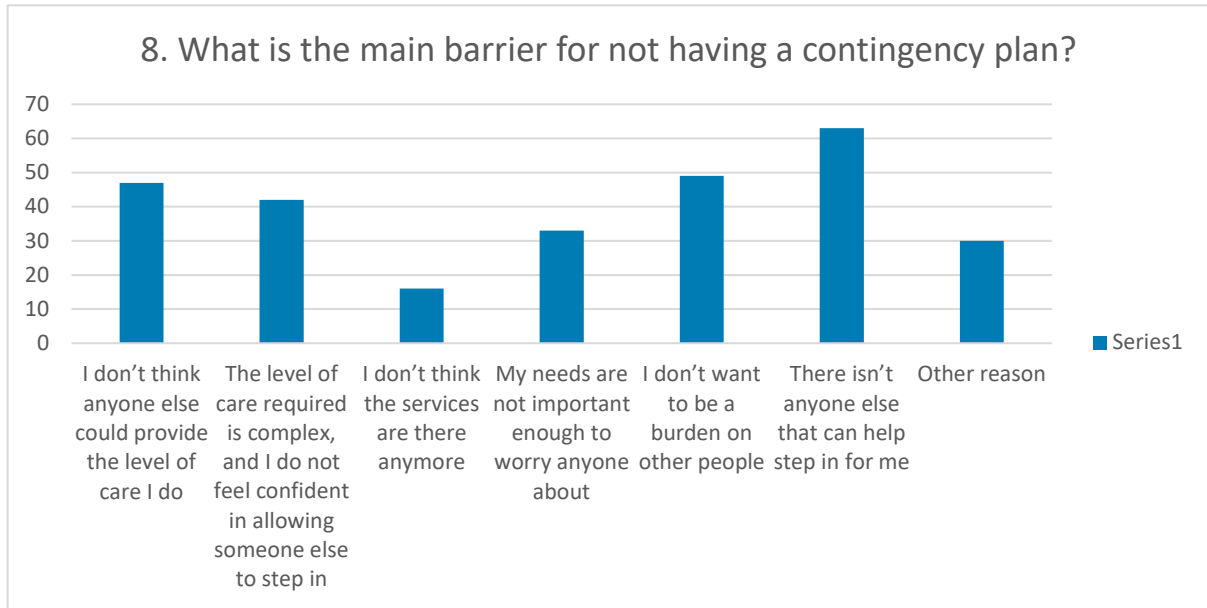


Support in the caring role

More than half of carers (52%) said that they did not have family members that were able to assist in their caring role at short notice. These numbers differed between online and hard copy – with carers who responded by post being 19% more likely to have a family member that could help at short notice [Graph 6].

When carers were asked if they had contingency plans in place, just under half (48%) of carers reported that plans exist should something happen. Numbers were relatively consistent between the online and hard copy responses [Graph 7]. When asked about the main barriers to having a contingency plan, carers answered most frequently *there isn't someone that else that can step in for me* (16%), *I don't want to be a burden on other people* (12%), and *I don't think anyone else could provide the level of care that I do* (12%) [Graph 8]





2. The impact of COVID-19 restrictions on the caring role

Time commitment

More than half of all carers (53%) reported that they had been caring more than 60 hours per week prior to COVID-19 restrictions. These numbers were consistent across online and hard copy responses, with several carers writing in that they care '24/7' and '100+ hours' [Graph 9].

Forty percent of all carers indicated that they had begun spending more time in their caring role following the introduction of COVID-19 restrictions [Graph 10]. The average increase in time reported was 24 hours a week amongst those for whom care had increased. The most common reasons noted for increased care were 'I find I am high alert to additional needs' (19%) and 'Local services have been reduced/closed' (16%). Twenty percent of all carers said that this increase in care had reduced their time for other family members.

International studies reinforce this finding. Siobhan O'Dwyer, University of Exeter² noted:

"Many carers were already struggling before the pandemic. Now with respite services cancelled, schools closed, nursing homes off limits, and access to food and medication restricted, the pressure is more intense than ever before. If we do not pay attention to the needs and experiences of family carers now, we may soon find we have another crisis on our hands."

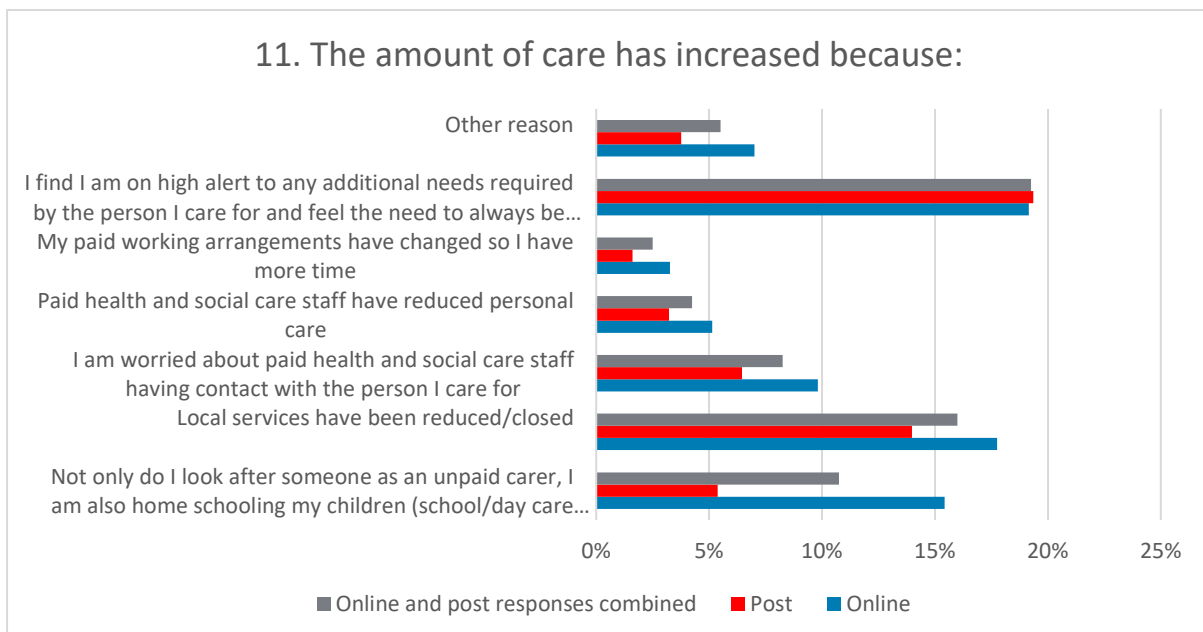
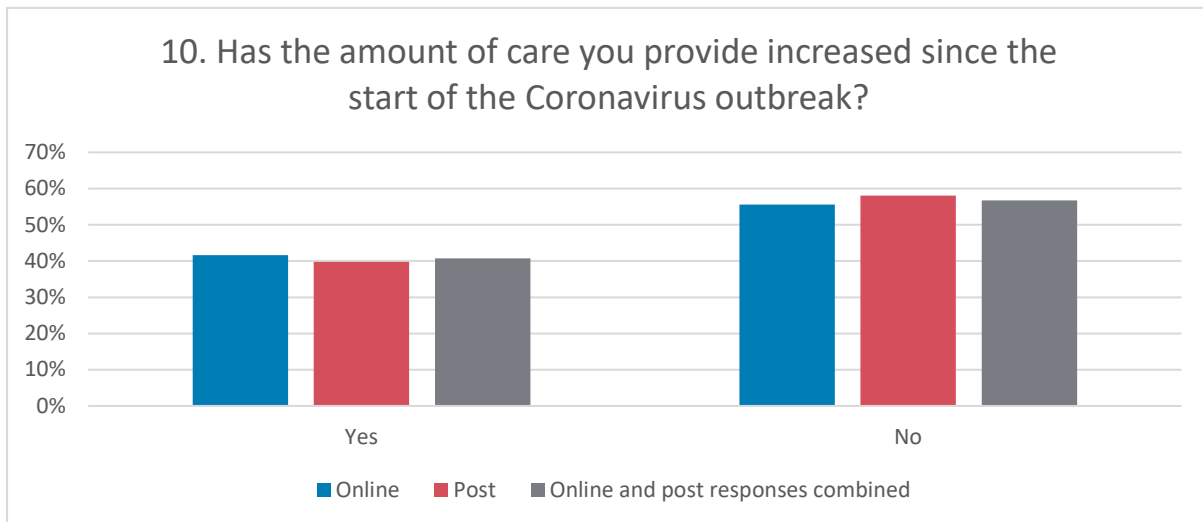
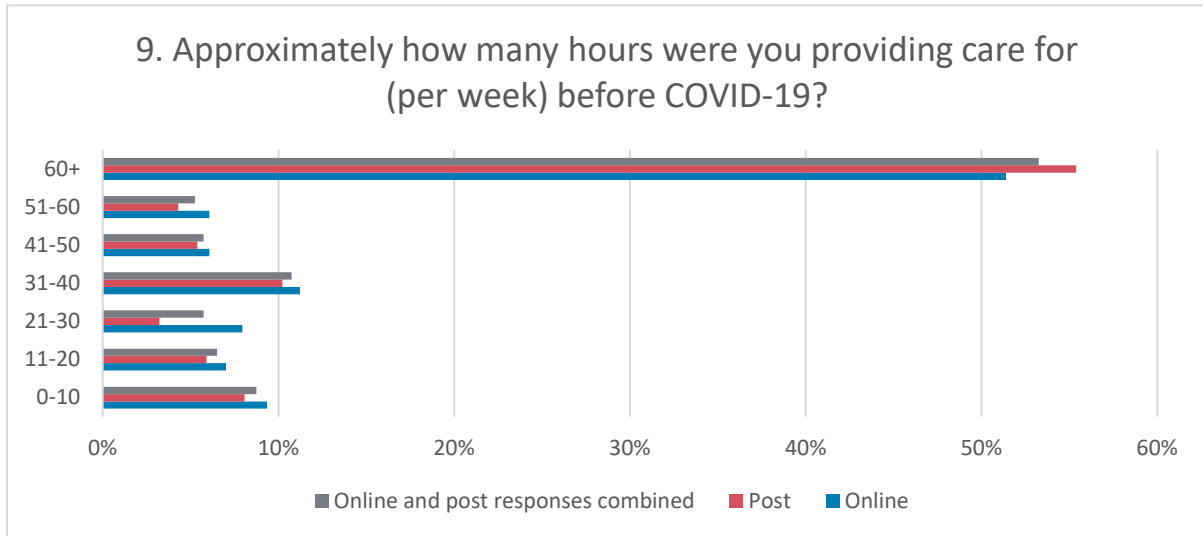
As previously mentioned, carers who participated online were far more likely to have school aged children. This was reflected by online participating carers being three times more likely than those who completed hardcopy questionnaires to cite home-schooling as a contributing factor to their increase in care [Graph 11]. When asked what types of care had increased, the most common responses were *emotional support, practical help in person, and motivation* [Graph 12].

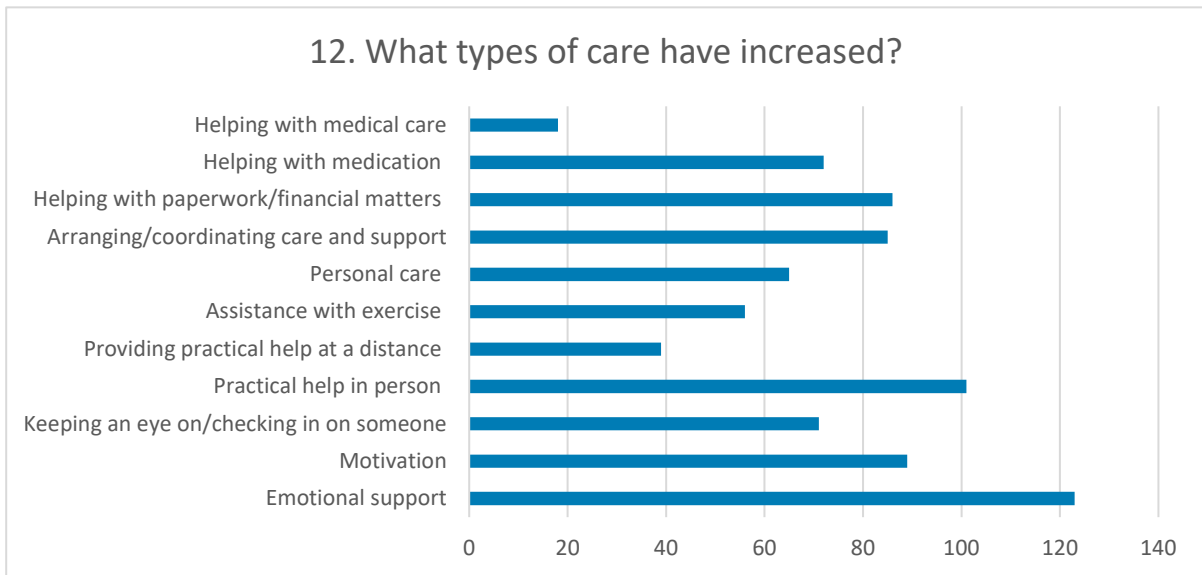
"I'm now caring for both my disabled daughter and elderly mother on a full-time basis. Due to the virus, my daughter cannot attend school, so I'm unable to have a break at all."

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"I am a single mum. I just don't get a break."

² <https://medicine.exeter.ac.uk/news/articles/researchtoinvestigateimpa.html>





Finances

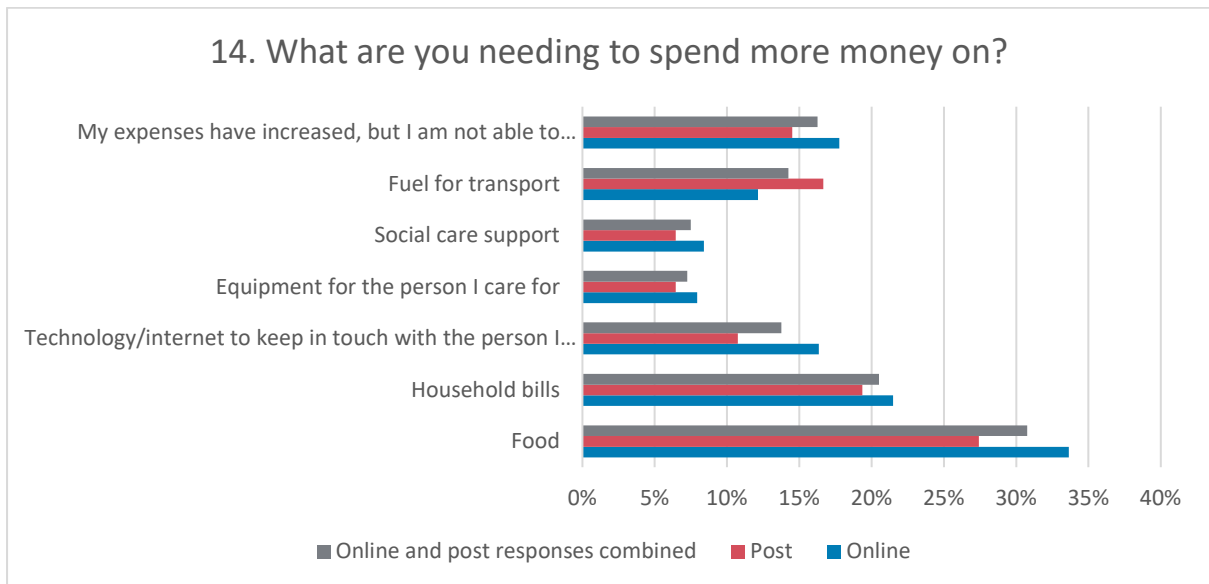
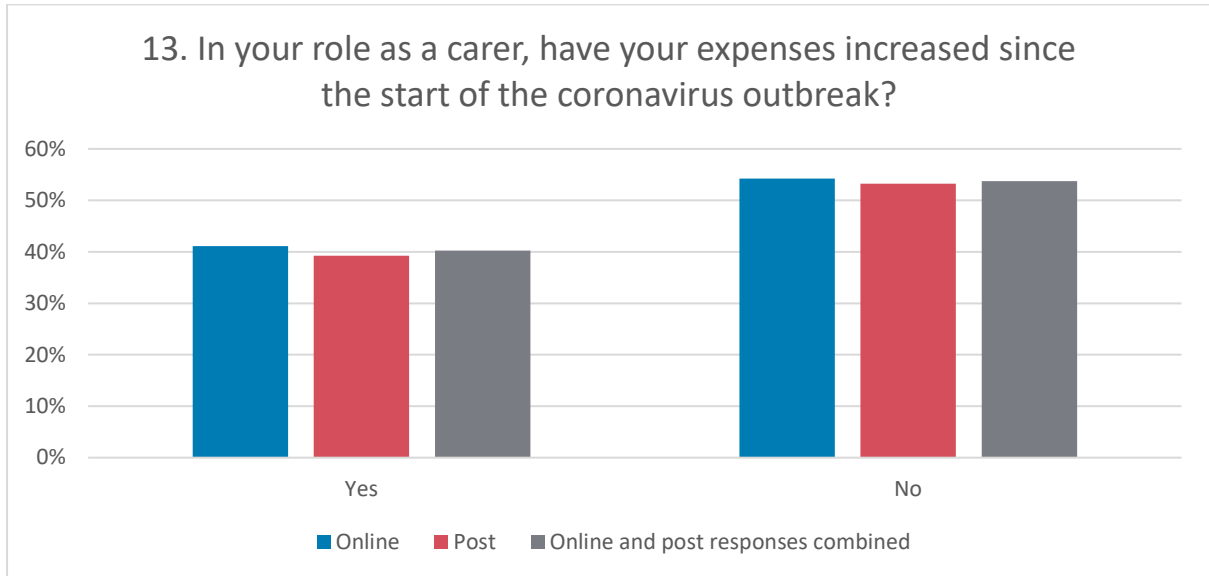
Forty percent of all carers reported that their expenses had increased since COVID-19 restrictions were put in place [Graph 13]. This matter was highlighted in the media, as carers were not given the coronavirus supplement that was given to other social benefits recipients. The most common causes for increased expenses were *food (31%) bills (21%) and fuel for transport (14%)* [Graph 14].

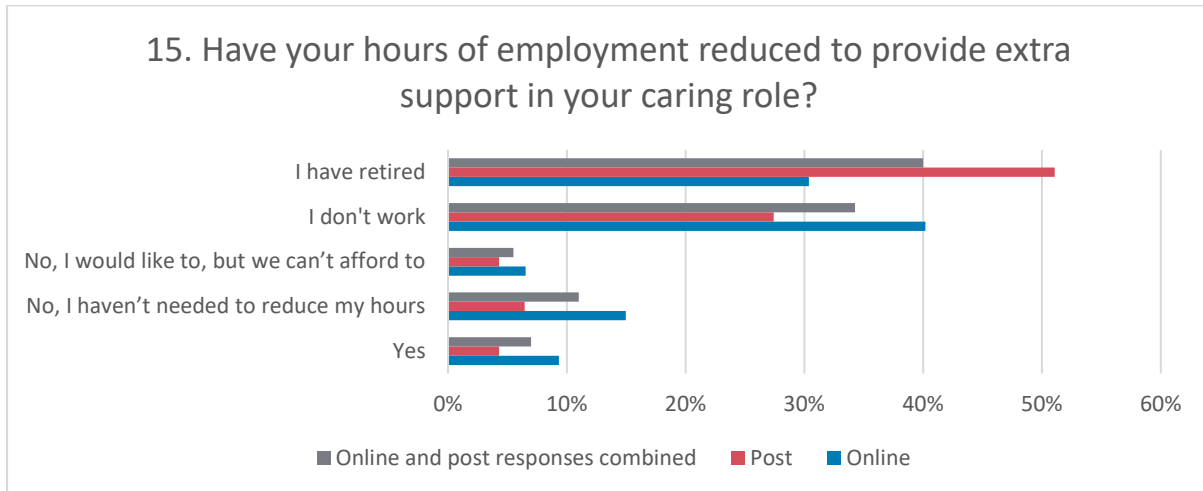
When asked if they had reduced their hours of employment to support their caring role, most carers (74%) indicated that they had either retired or do not work. Of those that stated they are employed, 7% of carers noted that they had reduced their employment (average of 9.95 hours), while a further 6% said they would like to but could not afford to [Graph 15].

“The cost and ability to access healthy foods and medication have become a concern. Vegetable prices have increased I’m unable to get many of our medications due to availability.”

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I chose to stop all paid supports for my daughter...after we experienced an outbreak in the NW. I stopped work for six weeks to be at home with [her].”





Sleep and wellbeing

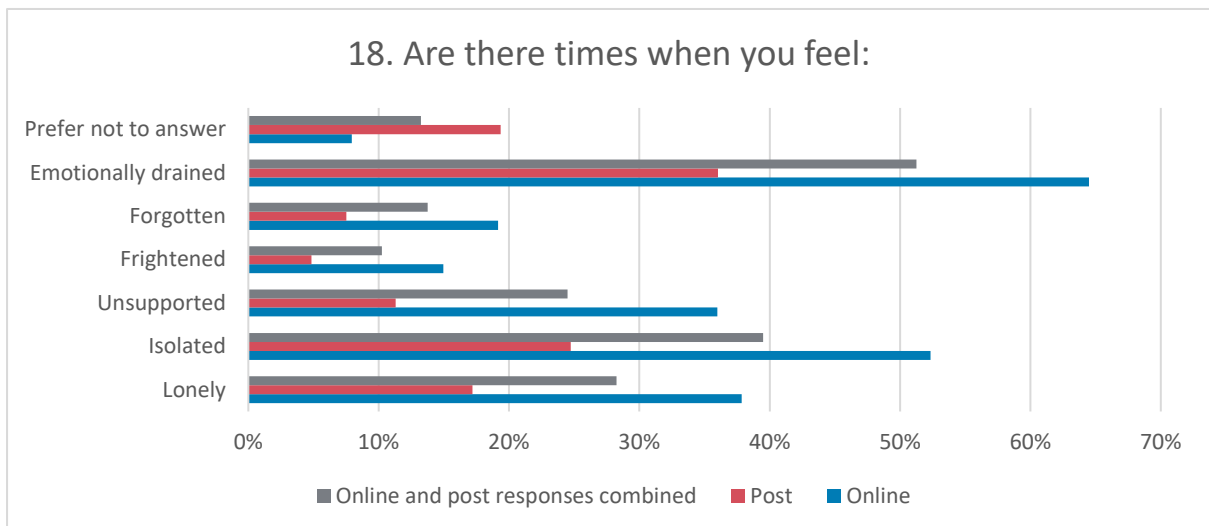
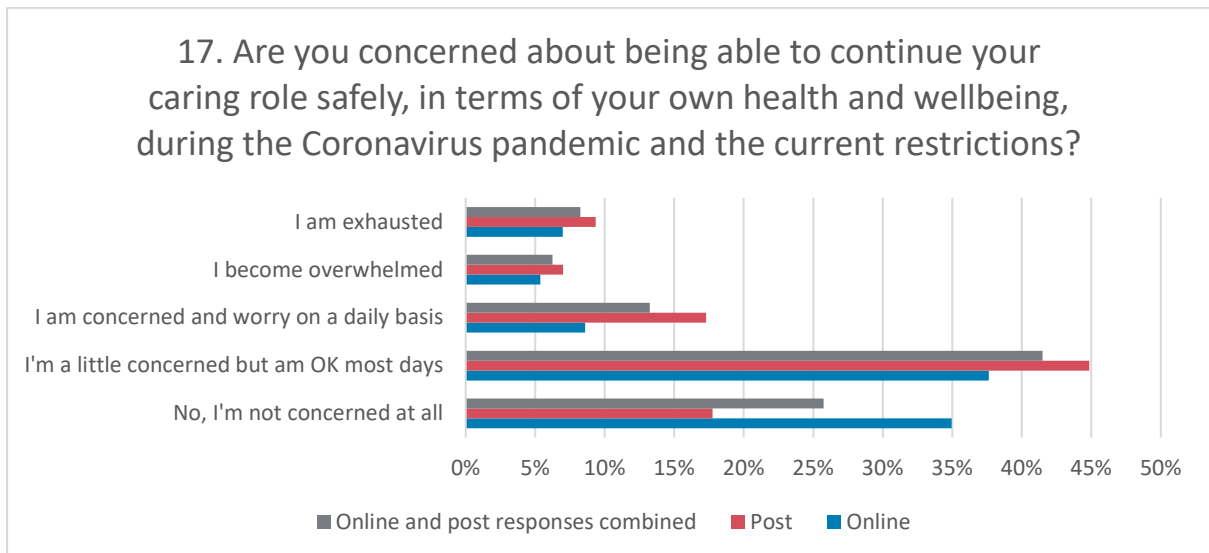
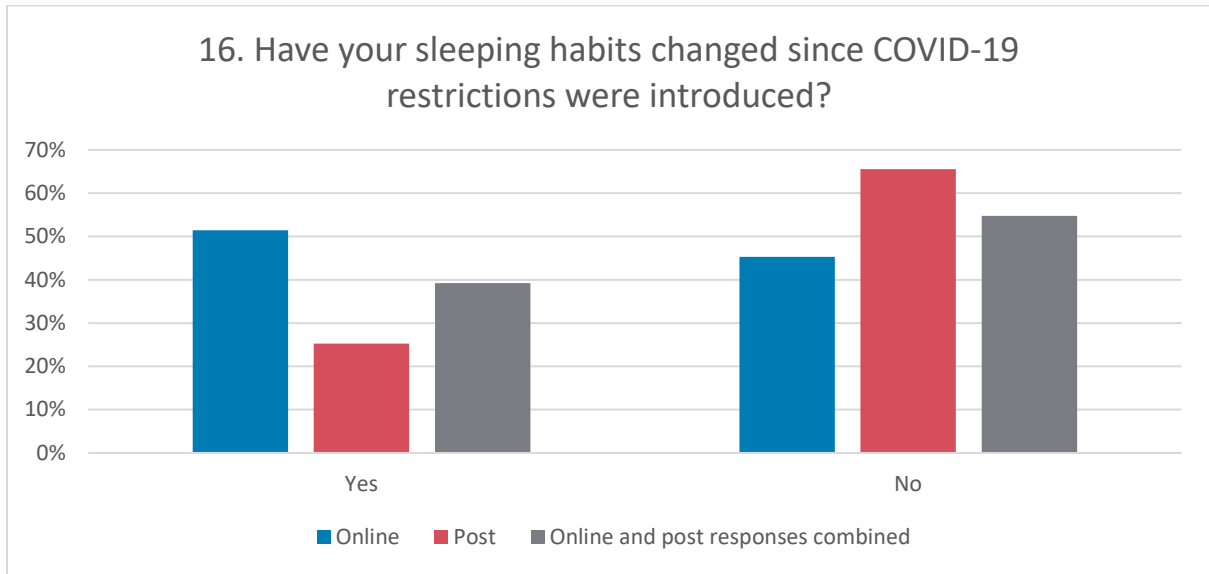
Sleeping patterns changed for 39% of carers. These responses were quite different between those that complete the survey online versus hard copy. Carers who responded online almost twice as likely to have reported a change in their sleep. Of those that reported changes, the average loss of sleep was 3.4 hours per night [Graph 16].

“My six family members all have additional needs. Having everyone at home with high anxiety levels has been extremely difficult.”

When asked if they were concerned about their wellbeing during the restrictions, carers had varied responses.

Twenty-six percent of carers said that they were not concerned at all, with carers who responded online twice as likely to not be concerned. While the most common response was “I’m a little concerned but I’m OK most days’ (42%), 16% of carers said they are exhausted and overwhelmed, and a further 13% said they were concerned and worried daily [Graph 17]. Fifty-one percent of all carers reported feeling emotionally drained at times (online 13% higher), while a further 40% said felt isolated [Graph 18].

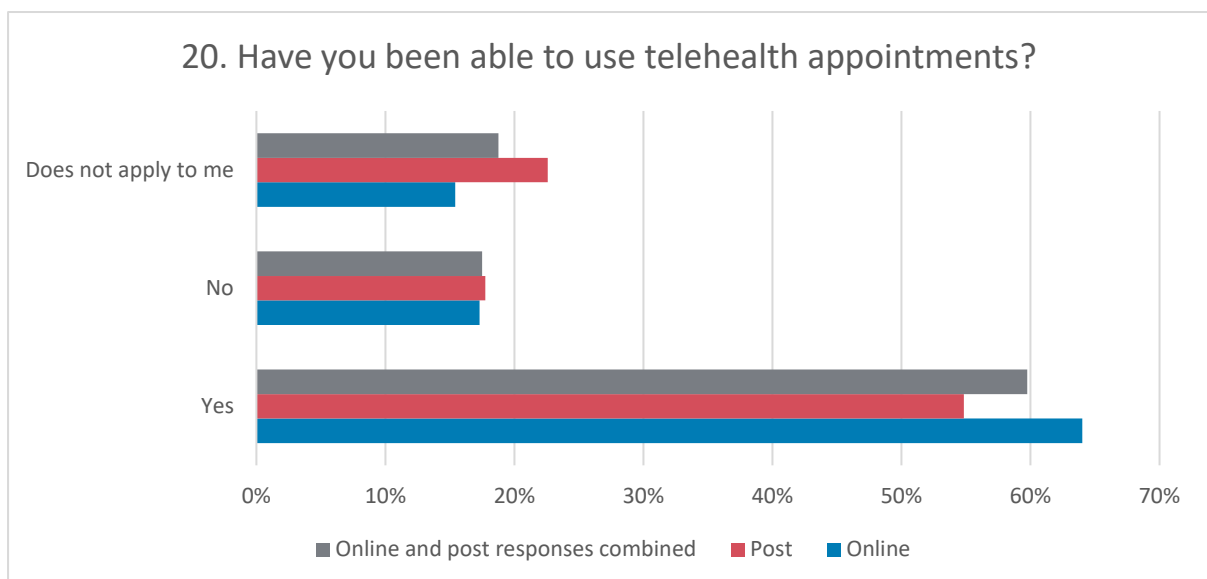
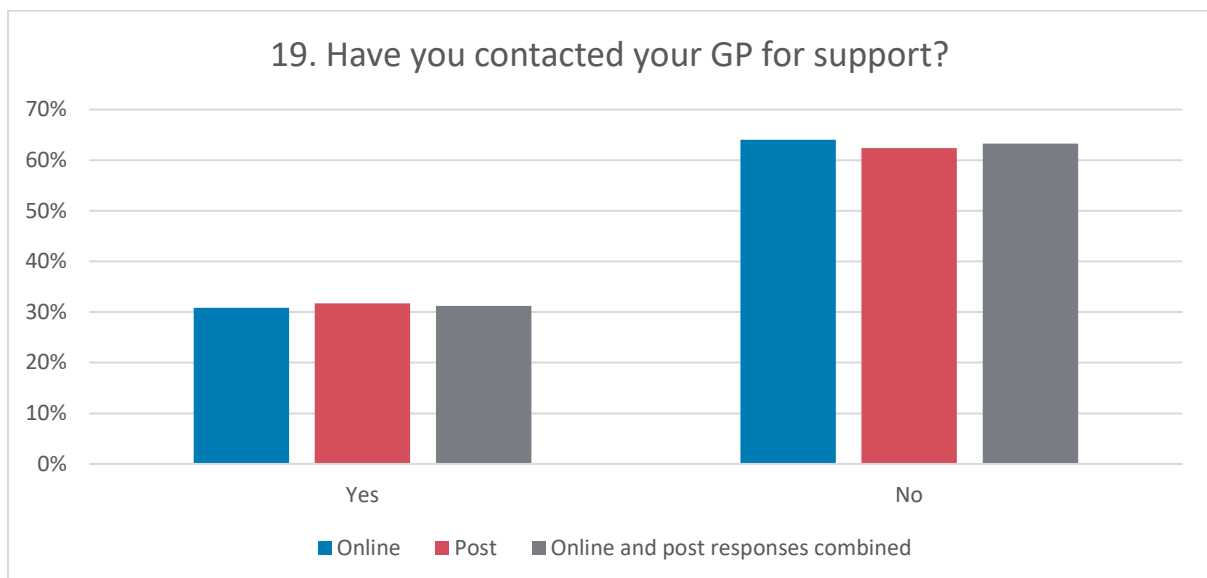
“I have gone from having my son attend a specialist school 5 days a week [...] Now home full time with all his needs needed to be met by me. It is very overwhelming, the days are long and my mental health has suffered.”

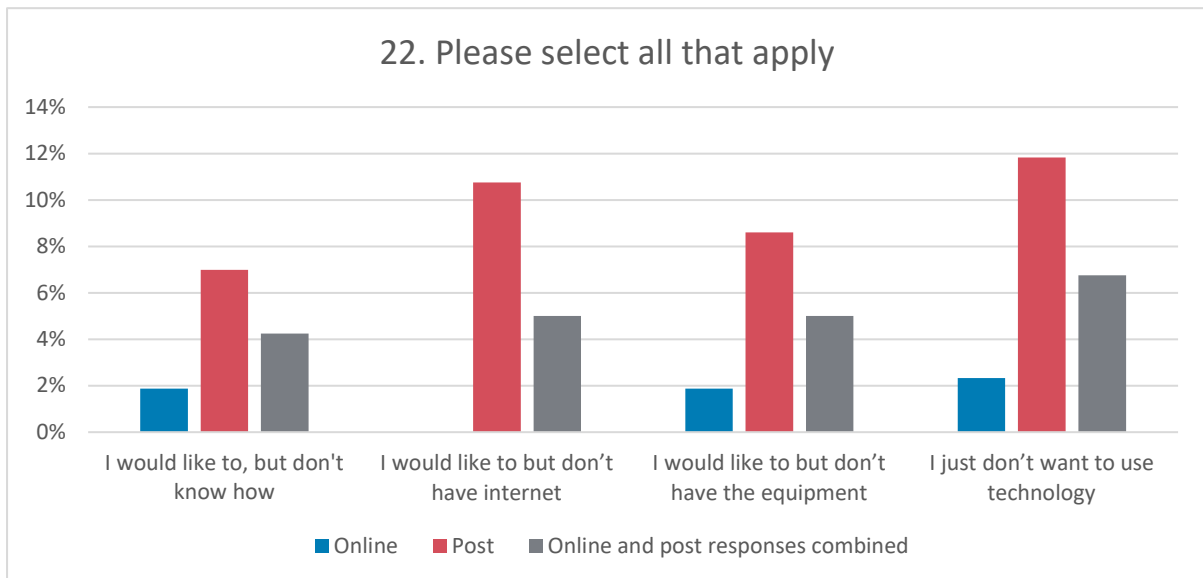
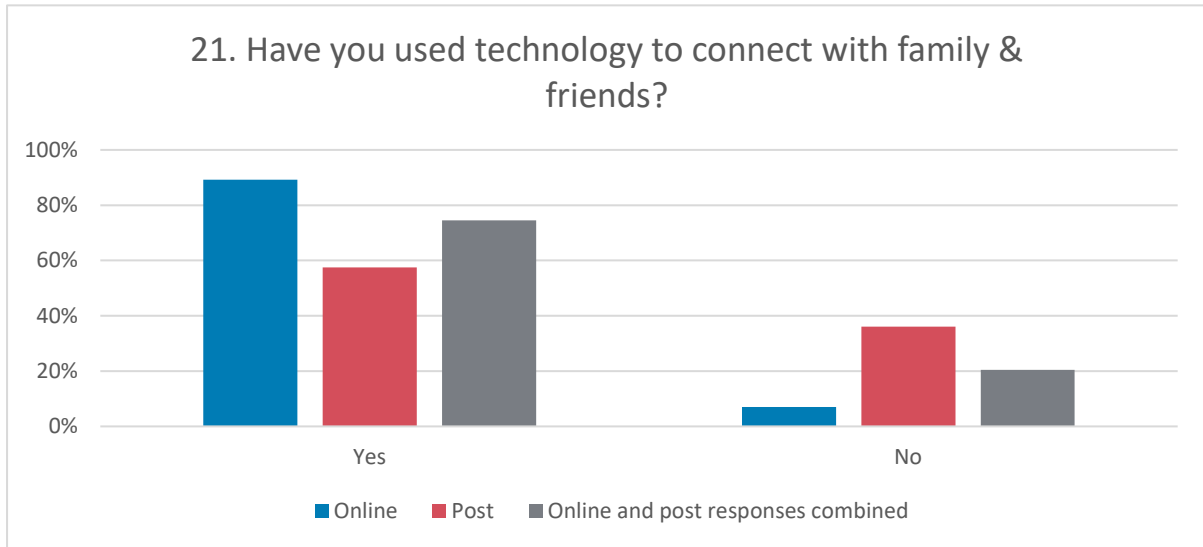


External engagement

Just 31% of carers said that they had recently contacted their GP for support [Graph19]. While 60% of all carers said that they had used telehealth appointments throughout the pandemic (9% higher with the online cohort) [Graph 20].

Three-quarters of all carers said that they had used technology to connect with either family or friends throughout the COVID restrictions. Carers who completed the survey online were 31% more likely to have used technology over the period [Graph 21]. Of those that didn't, the most common barriers to using technology were 'I just don't want to use technology' (7% of all carers, 12% of hard copy responses), 'I would like to but I don't have the internet' (11% of hard copy responses), and 'I would like to but I don't have the equipment' [Graph 22].





3. Looking forward beyond COVID-19 restrictions lifting

Useful resources

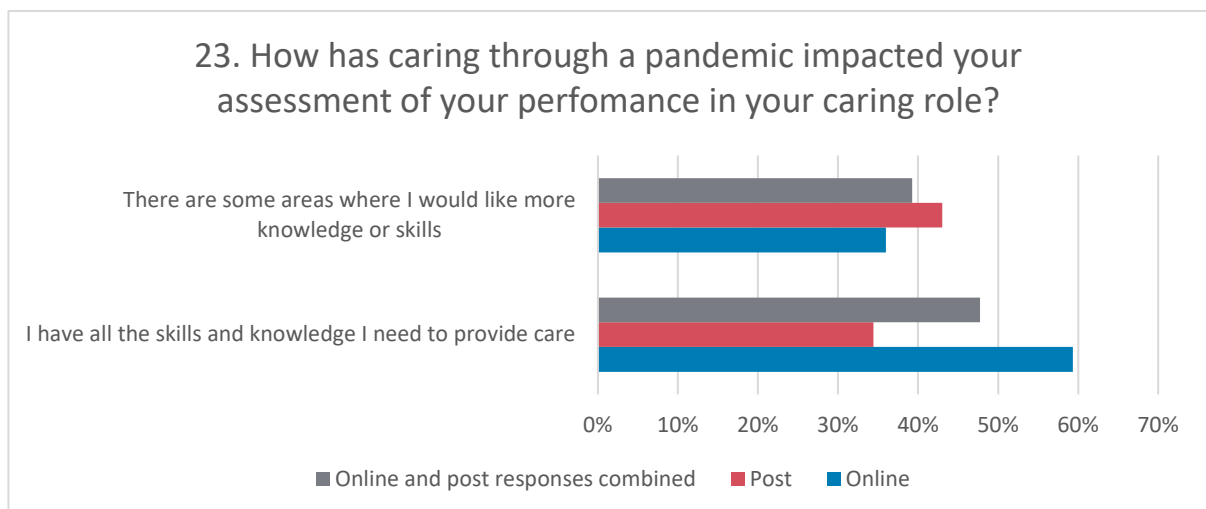
Looking beyond COVID restrictions, we sought to assess how comfortable carers felt in their role, and where they believed that they need some help. Thirty-nine percent of all carers stated that there were some areas that they wanted more knowledge or skills [Graph23]. When asked what would help best prepare them for the future, the most common responses were to *have a better understanding of the services I can access as a carer (46%), to be more connected to my local community (24%), and to have improved and inclusive communication processes in place between medical staff (20%)* [Graph 24].

When asked what would help them following the easing of COVID restrictions, carers most common answers were *confidence and reassurance that I can go out safely (40%), support to get services going for the person I care for (29%) and talking with a counsellor that understands the caring role (22%)* [Graph 25]

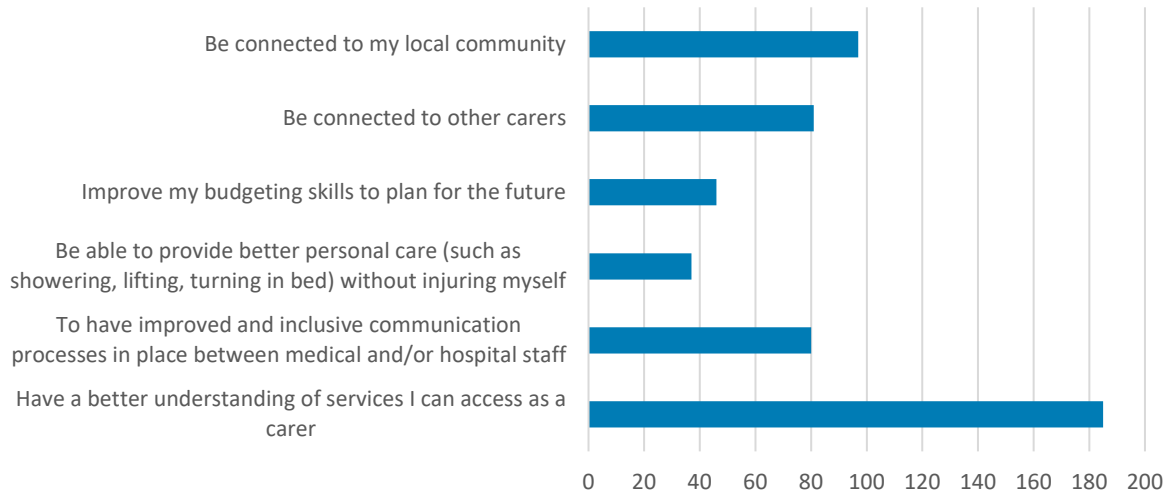
“I would love the opportunity to connect with other carers.”

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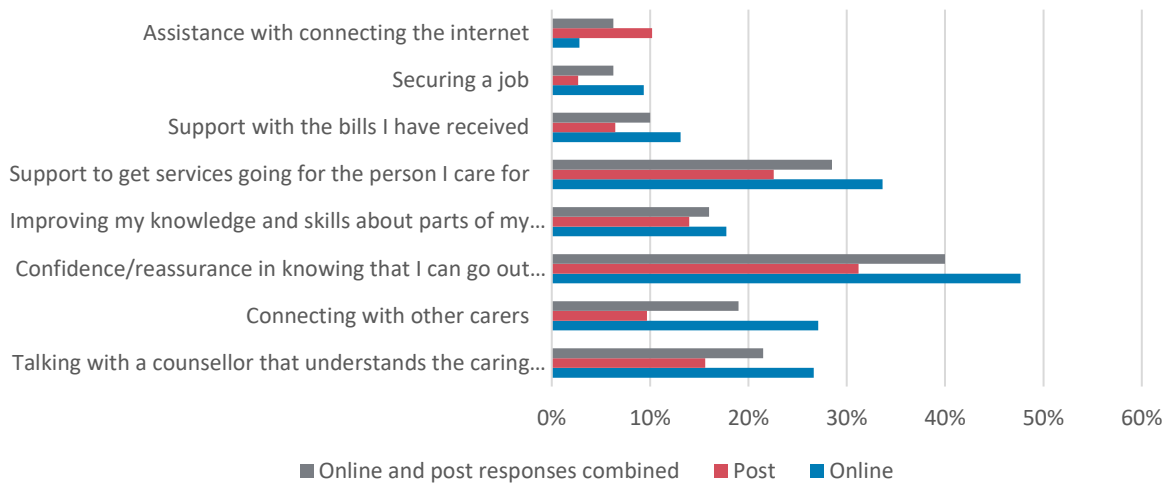
“Some don’t or can’t ask for help... We just battle through each day because that’s all we can do - even though some carers have their own health problems.”



24. To be prepared for the future I would like to



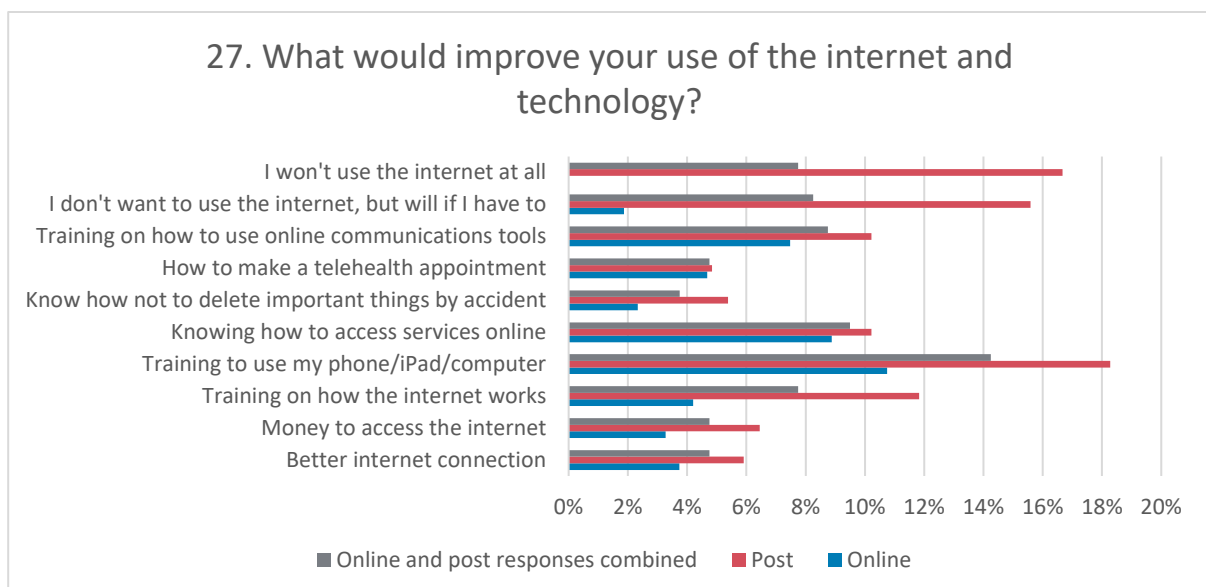
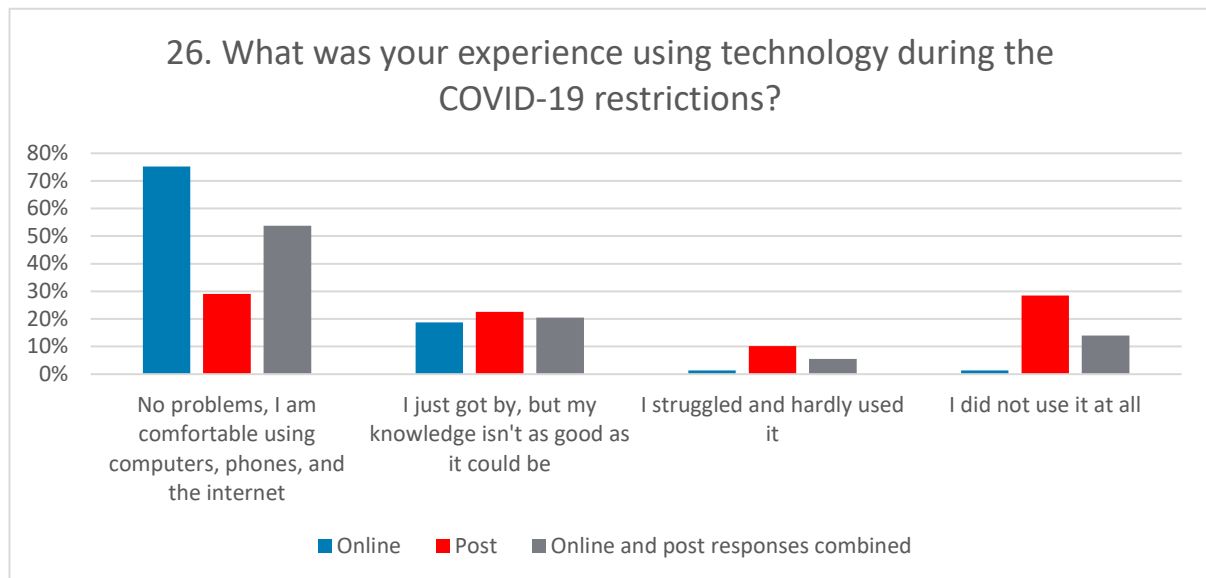
25. What would help you after COVID-19 restrictions lift?



Technology

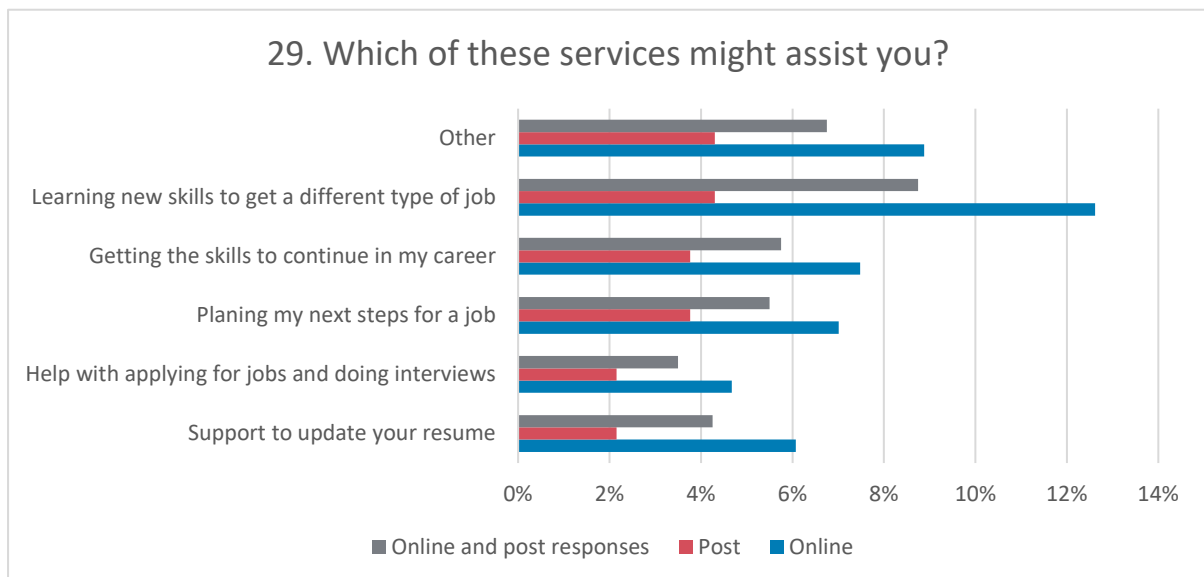
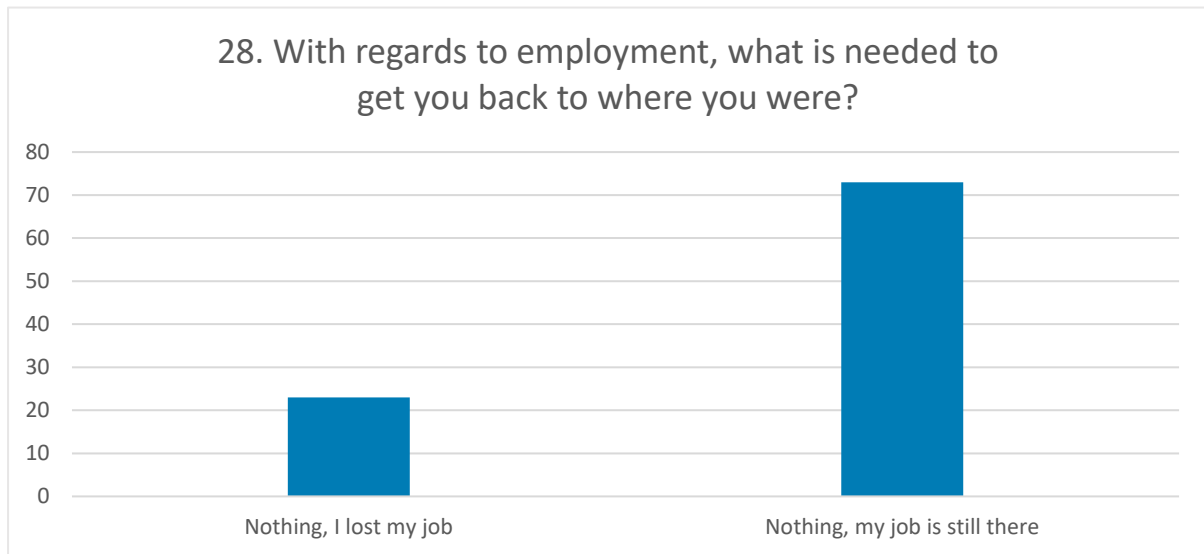
When asked to further reflect on their technology usage throughout the pandemic, the clearest differences between the cohorts were highlighted. Twenty-eight percent carers who responded in hard copy reported not using technology at all through the pandemic, while 10% said they struggled and hardly used it. These responses were both less than 1% in the online cohort. Likewise, carers who responded online were nearly three-times as likely to say that they had no problems with technology [Graph 26].

When asked what would improve their use of technology, some carers doubled down against technology. Seventeen percent of hard copy responses stated that they would not use the internet at all, with a further 16% saying they do not want to, but they will if they have too. The most common responses were *training to use my phone/iPad/computer (14%)*, *training on how the internet works (12%)* and *training on how to use online communications tools (9%)* [Graph27].



Employment

When carers were asked to further reflect on employment, and how long it would take them to get back to where they were 6% of all carers stated that they had lost their job. A further 18% said that their job was still there [Graph 28]. When asked what services may be of assistance, the most common responses were *learning new skills to get a different type of job* (9%), *getting the skills to continue in my career* (6%), and *planning my next steps for a job* (6%) [Graph 29].



Conclusion

The impact on family and friend carers has been significant during the COVID-19 pandemic and associated restrictions.

The load on many carers has significantly increased and carers have experienced loss of sleep, time with family, income, and support (both from family and external providers), together with increased stress, anxiety and expenses resulting from increased costs of living. Carers with school-aged children have had to juggle significant caring responsibilities with those of home schooling that has had an appreciable impact on their wellbeing.

The low data inclusion rate of the general population is reflected amongst carers with many simply not engaging with technology to establish or maintain social networks, family relationships, and other supports during the pandemic that underpin the ability to care for family members or friends.

Many continue to report on their anxiety and fear with re-engaging with general society, with most fear directed at the impact on the loved ones for whom they care.

The results indicate that carers would benefit significantly from services which facilitate extending and establishing social connections and networks. With many leaning on their pre-established network throughout the pandemic, service that facilitate connection should be a priority, particularly if further outbreaks/lockdowns were to occur. Contingency planning is a clear need.

Carers feedback also indicated that there is a noticeable gap in carers knowledge regarding the support and services that exist to help them in their role. Investing time and effort into educating, and re-educating carers on the services available should bridge this gap over time.

Whilst reluctance exists, particularly with older carers, to use and leverage technology, this is a clear need to both build resilience for further outbreaks and other disasters, but more broadly to have increased access to online services. This is a combination of skills, equipment, and the financial resources to obtain and maintain connectivity.