



The Scottish Parliament
Pàrlamaid na h-Alba

How has Covid-19 impacted on care and support at home in Scotland?

November 2020



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Background

As part of their scrutiny of social care in Scotland, the Health and Sport Committee at the Scottish Parliament carried out an online survey to receive views from people who provide, or receive, care and support at home.

The survey was created to understand the impact of Covid-19 on care at home services, and what issues the pandemic has highlighted, improved, or made worse.

The survey ran from 10 August 2020 to 7 September 2020 and the Committee received **723** responses.

Survey participants could also register interest in participating further in the inquiry, and **530** people indicated a wish to do so, including **125** who indicated they wished to participate in remote video focus group sessions.

In October 2020, the Parliament's Engagement Team ran two video focus group sessions in order to learn more about the findings of the survey and bring the all-important lived experience from those who receive care at home and those who provide care at home to the attention of the Committee.

The additional evidence compiled as part of these focus groups is included in this report to help place the survey results in context.

We wish to stress that participants were self-selecting, and the sample is unstratified, so the output of this survey is a means to provide a snap shot of experiences related to Care at Home during the COVID-19 pandemic in Scotland and are not necessarily representative of experiences as a whole.

Key messages

- We received over 700 responses to the survey, including 415 responses from family members of those receiving care at home and unpaid carers and 93 responses from individuals receiving care at home.
- A significant theme within the report is around the reduction of care as a result of the pandemic, and suggests many families felt they were 'left to get on with it' and that neighbours had to 'step in' to provide care and support. Some respondents told us that their care services were 'completely withdrawn'. The need for greater recognition and support for unpaid carers was made clear in the responses to the survey.
- However, we also heard praise for the hard work of care staff and that they need to be recognised for this, with respondents suggesting care at home staff do not receive the same support or recognition as NHS staff.
- Whilst the need for safety was highlighted by respondents as the most important issue in relation to the provision of care at home services during the pandemic, only a few respondents indicated that they chose to deliver care for family members for safety reasons. Instead, concern regarding safety mainly related to access to and appropriate use of PPE as well as testing and training of care staff.
- Ensuring continuity of care was the second most important issue to respondents, with concerns around quality and consistency of care as well as the need for designated carers to reduce the number of staff entering homes. Employers also expressed concerns about the difficulty to ensure consistency of care due to staff absences, self-isolation requirements and shielding. We also heard from respondents that this led to increased challenges in the recruitment and training of new staff, with some employers who responded telling us they were only able to take on people with previous experience in delivering care due to a lack of time available for training.
- Wellbeing and mental health was also a significant theme throughout the responses. We heard from many respondents that the reduction of visits and activities, and resulting loss of a routine, increased feelings of loneliness and isolation for those in receipt of care. Respondents also told us that additional pressure on unpaid carers due to closures of day-centres and respite services has resulted in increased feelings of anxiety, depression and mental exhaustion.
- With the reduction of formal care and formal additional support services respondents told us that non-formal means of care, such as faith groups, third sector groups and neighbour support, were crucial and had they not been present many would have struggled to cope.
- For staff, despite a reduction in care being delivered, many told us about their increased workloads, with new tasks required as a result of the pandemic such as additional staff training, increased staff meetings and increased paperwork. Many managers who responded told us that a move to home working also resulted in an

increase in hours, with less time away from work and additional pressure due to childcare and other family responsibilities.

- Respondents also felt that access to additional support and services was one of the most important things to consider within the context of the pandemic, to ensure the safety and wellbeing of those being cared for. This included access to food and prescription deliveries, access to activities and entertainment (and the technology needed to engage in these), and access to hospital, GP services and medical equipment.
- Whilst respondents largely praised the advice and information from the Scottish Government, it was felt that one to one communication between services and service users needed to improve.
- Finally, it was suggested that more needs to be done to listen to the needs of those receiving care and involve them in decision making. This includes more flexible spending of Self-directed Support (SDS). These are issues that have existed long before COVID-19 but which have been exacerbated since the pandemic began.

The summary of responses that follows was produced by the Scottish Parliament's Outreach and Engagement team on behalf of the Health and Sport Committee as part of an ongoing inquiry into adult social care in Scotland. The final report from the Committee is due to be published in early 2021.

Section 1: Who took part?

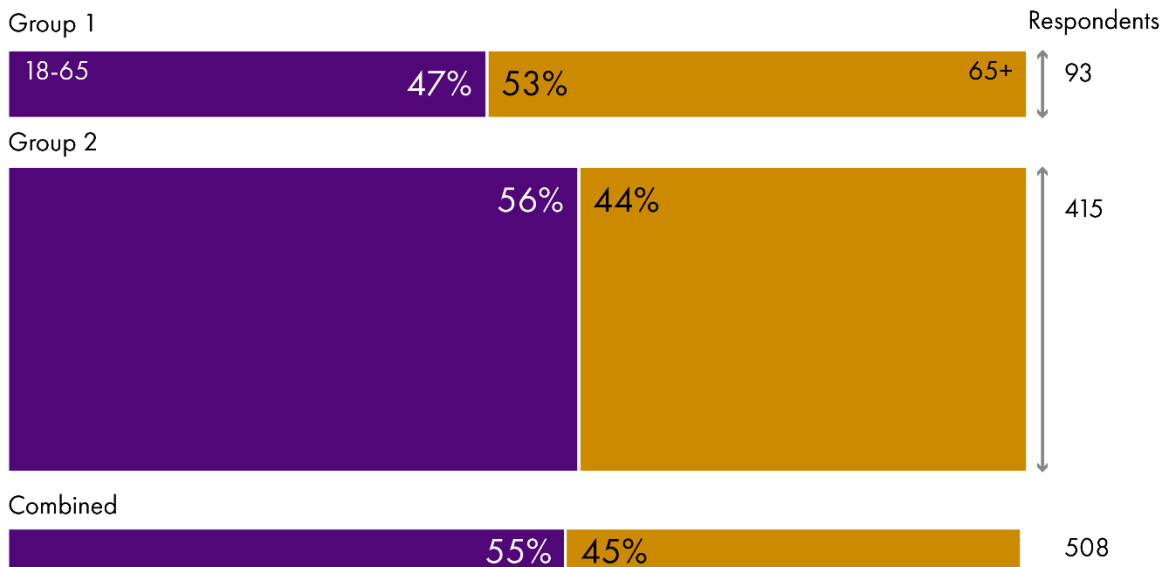
The Committee wished to hear from three groups:

- Group 1: individuals receiving care at home, receiving **93 responses**.
- Group 2: family members of those receiving care at home and unpaid carers, receiving **415 responses**.
- Group 3: staff, managers or owners of a care at home services, or personal assistants providing care, receiving **215 responses**.

About Individuals receiving care at home (Groups 1 & 2)

Age of those receiving Care at Home

We requested respondents from Groups 1 provide their age, and respondents from Group 2 provide the age of the person receiving care who they were responding for:

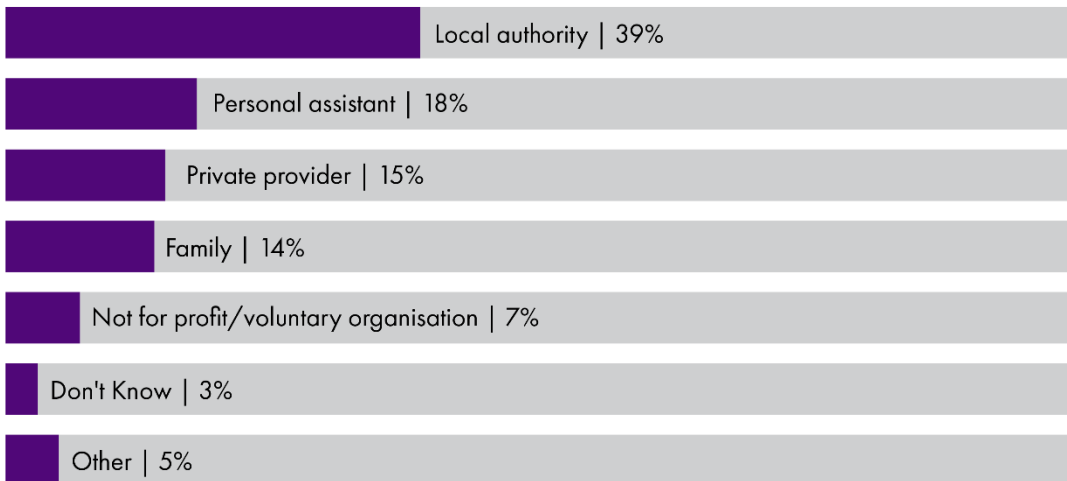


What is the age of those in receipt of care at home?

We received a good balance of responses from those receiving care aged between 18 and 65, and those aged over 65.

Who provides Care at Home?

We asked Groups 1 and 2 for information about who provided the care at home. Local Authorities was the most common response (39%) followed by Personal Assistant (18%), Private provider (15%), Family member (14%) and nonprofit provider (7%).

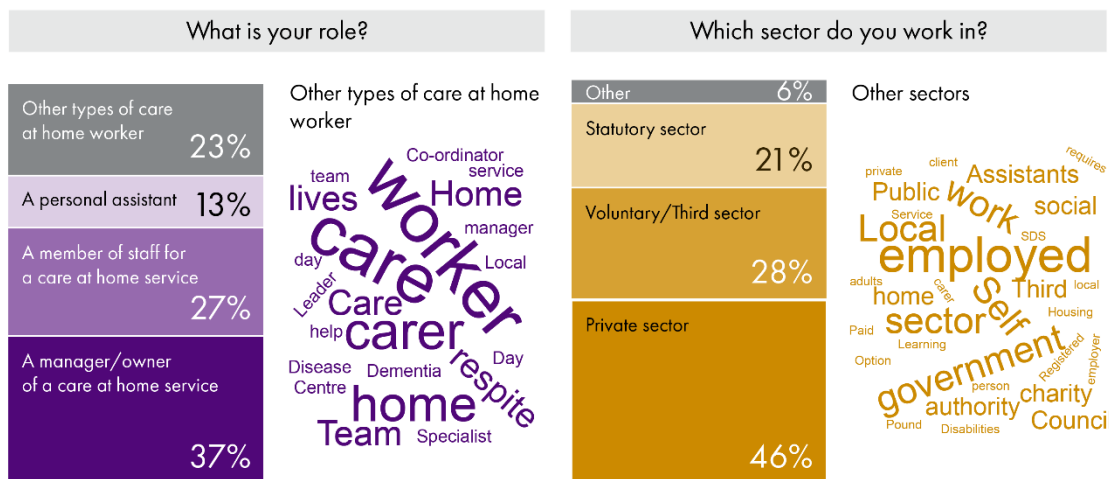


Who delivers care at home?

The data collected indicates a good sample (508) of people with lived experience of receiving care at home in Scotland.

About staff providing Care at Home (Group 3)

We asked staff providing (Group 3) care about the sector they worked in, their working pattern, and the role they carried out when delivering Care at Home.



Sector

From the 215 staff who responded (46%) worked in the private sector, 28% worked in the voluntary or third sector and 21% in the statutory sector. The remaining 6% of

respondents worked in 'other' sectors such as self-employed, a Personal Assistant paid through Self Directed Support (SDS) Option 1¹ or a paid family member.

Working Patterns

The vast majority of staff who responded (71%) worked full time, with 20% working part time, 4% on Zero Hours contract, 1% were self-employed and 'other' working patterns included occasional relief work, experienced staff who had recently retired or had reduced their hours, or a paid family member providing care '24/7'.

Roles

In terms of roles delivered by staff in the Care at Home sector, 37% of respondents were a manager or owner of a Care at Home service, 27% were a member of staff for a care at home service, and 13% were personal assistants. 23% of respondents indicated that they performed 'other' roles such as: social work; respite care; support work; specialist care in areas such as autism, dementia, Huntington's Disease or physical disabilities; middle management roles; and family members in a paid caring role.

One key thing this data tells us is the array of professional skills and roles that contribute to delivering Care at Home in Scotland.

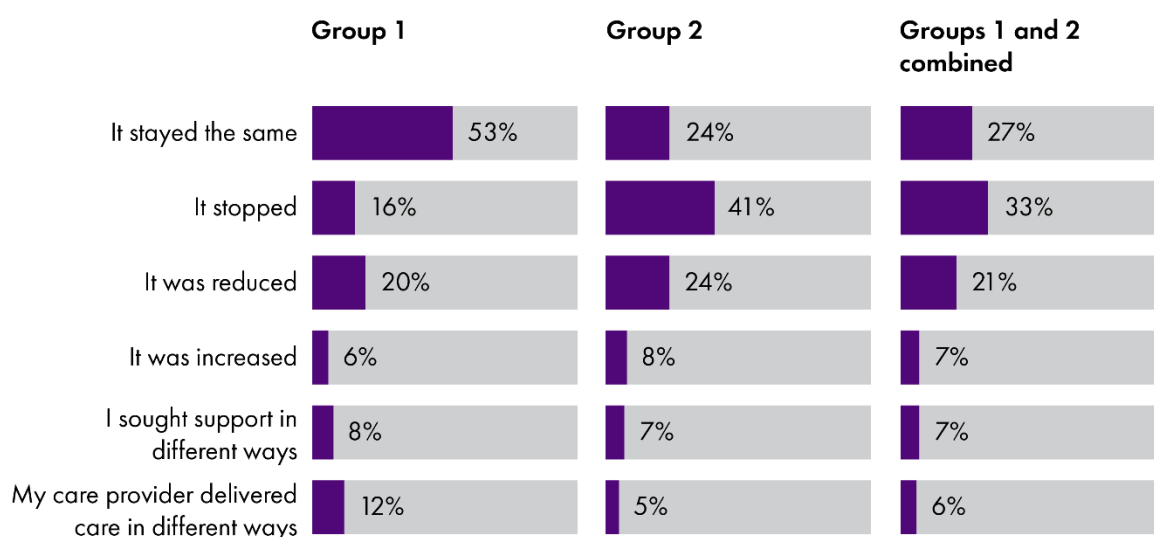
The relatively high number of respondents who perform a senior role (37%) may account for differences in experience between Groups 1 & 2, and Group 3 in the next section about changes to Care at Home during lockdown.

¹ option 1 - a direct payment, which is a payment to a person or third party to purchase their own support
[Options for Self-directed Support, Care Information Scotland](#)

Section 2: Changes to Care at Home

The experience of those receiving care: reduction in care

We asked respondents to share how their care at home support changed as a result of the pandemic.



How did care at home change during the pandemic?

Just over a third of respondents (34%) in Groups 1 (people receiving care) & 2 (family members or unpaid carers of people receiving care) reported their Care at Home support remaining the same (27%) or increasing (7%). **However, over half of respondents (54%) stated that their care at home support either stopped completely (33%) or reduced (21%).** The remaining 12% of responses indicated seeking or receiving support in different ways. The stark impact of care ceasing completely was testified to in the online session we held with people who receive care:

‘My care was completely withdrawn. This happened at exactly the same time as I asked for SDS. I had nothing for 6 months and even now it isn’t sorted. I’ve had to pay for a private carer out of my own pocket and I’ve spent thousands. I felt I was having to ask family members to risk their own safety.’

Of the 246 respondents who provided more information about the number of hours per week their care at home either increased or decreased, 191 comments (78%) related to care being reduced or stopped.

139 of comments relating to care being reduced or stopped clearly indicated the number of hours per week their care at home was decreased, the remaining 52 comments included phrases such as ‘it stopped completely’ or ‘totally withdrawn’ or ‘reduced to no hours’ meaning that while the reduction in care was significant there was no way of ascertaining the number of hours reduced.

Those respondents that did quantify the reduction in hours it ranged from a reduction of 30 minutes per week, to 61 hours per week of care not received during the pandemic with an average reduction of 20.5 hours per week.

There was a wide range in the reduction of hours of care



There was no marked difference between the level of reduction of hours in terms of the different Care at Home sectors with similar reductions seen in local authority, nonprofit and private sectors with around 43-44% of responses indicating care stopping and between 21-24% of responses indicating the level of care reducing.

However, from those who received care from Personal Assistants only 28% reported care stopping completely with around 32% reporting care reducing. **This suggests that some Personal Assistants were able to continue to provide some level of care to those in need.** The importance of having Personal Assistants and other carers who were able to be flexible and responsive in their delivery of care was stressed repeatedly when we spoke to people who receive care in our online session:

‘When I got out of hospital I couldn’t get up and down the stairs. I asked my carer to take washing basket upstairs and carer said she wasn’t allowed to do that.’

‘I don’t understand why carers can’t text or phone if they are running late. We are told they will arrive at 8pm so we plan our day around that and they don’t turn up until 10pm it is really disruptive. Why can’t they phone or text to let us know they are running late. If my hospital can call about appointments through automated systems then why can’t care providers do similar. I feel care providers aren’t embracing technology.’

‘I’ve not been allowed to go in my carers’ cars so this has made it difficult for me to do things like get to the bank and I’ve had to rely on the food train for deliveries.’

In what way had care changed?

Respondents were asked to provide further details of how care and support was sought, or delivered, in different ways.

Families ‘stepping in’ and ‘left to get on with it’

A key theme that came through was the large number of respondents reporting that family members increased the amount of care they provided, and the feeling that unpaid carers and family members were forced to ‘step in’ and ‘provide all the care’ ‘100% of the care, 100% of the time’ ‘left to get on with it’ and provide care ‘without any help or support’ as it was ‘assumed’ family members would provide care.

Some respondents said families provided care because 'no support was offered to them' and 'no contact' was received from care providers.

Other respondents said families chose to deliver care in order to 'reduce the number of people entering' homes for safety reasons.

This issue came up repeatedly during our online session with people who receive care:

'I feel like people were kind of left to get on with it. If I didn't have family then I don't know if I'd be here.'

'My daughter had to come from Glasgow in the first few weeks to bring me food, but I got that sorted eventually'.

The impact of care responsibilities on family members was also raised:

'I employ private support workers and also my daughter who lives with me. When lockdown started I furloughed the other support worker for the first 6 weeks (to have fewer people coming in to the house) but it was too much for my daughter to do alone so the support worker came back and worked as before.'

Some delivered care for their family member while they were 'working from home', others provided care while they were 'furloughed'. However, some were 'unable to work from home due to caring responsibilities'.

Day Activities reduced

Another key theme that emerged from responses was the major impact the closure of day centres and other respite activities had on people receiving care at home. Respondents noted that day centres and respite closing due to Covid-19, led to cared for being 'isolated' at 'home every day during lockdown' which raised concerns about mental health and wellbeing.

The closure of day centres and respite added to the strain of additional care provided by families and unpaid carers:

'my son's day care service closed... this left me as his mum and unpaid carer without any support care or even guidance, there was no alternative offered. I fully understand that we are in the midst of a pandemic but my caring role did not just stop it did in fact increase. I felt completely abandoned.'

The importance of day care centres and other external sources of support was raised in the online session we had with carers when a family carer told us:

'My husband attended a disability resource centre before the lockdown. The worker from there phoned us twice a week which was great. My husband was getting aggressive towards me because of frustration and they could calm him down. I do miss the contact. He needs stimulated/ motivated. We need to get the centres open again.'

Phone Calls

Some respondents reported 'minimal' 'support provided in telephone consultations' which 'has been difficult' and 'far from ideal'. Others reported phone calls 'to check we were okay' or to see 'how (they) were coping.' Some reported offers to 'assist with shopping or prescription collecting... (which) felt like a bit of support, most welcomed.'

However, some respondents had 'no contact or offer of support' and 'no one checking to see how we were coping', this further compounded the feeling of abandonment experienced by respondents. This issue came up in our online session with people who receive care:

'Surely GP's, Social workers, nursing staff (people who know you) should be communicating more about people's situation and whether or not they should isolate. Phone calls like this on a local level would be the answer. I really feel like GP's have had no role whatsoever in this, but they are the ones who know people best.'

Video Calls

Some respondents noted the use of 'video calls' to keep in contact with support services.

Some had 'video chats / activities daily, and this has been fantastic for our daughter as she can still see all of her friends and it breaks up her day'

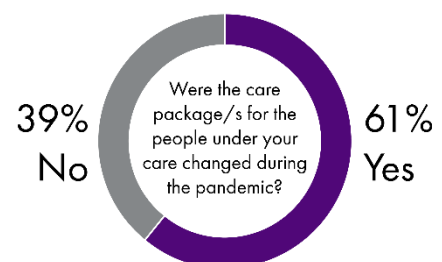
One mentioned being provided with 'daily online activities and live video links which allow the services users to keep in contact with each other while participating in various arts and crafts activities, baking, and virtual visits to outdoor activities centres, local zoos and farms.' Another said their day centre hosted 'video quizzes.'

Others used video calls to chat with personal assistants 'about the things (they were) finding difficult and stressful, this helped having someone who knew (them) to talk with.' Another family used 'video to link with personal assistants to visually keep an eye on my son whilst I had a video appointment for my work in a different room.'

The experience of staff providing care during lockdown

Reduction in care packages

We asked staff (Group 3) if the care packages for the people under their care changed during the pandemic. 61% of staff indicated that care packages had been changed, and 39% noted that care packages had not been changed.



Staff testimony confirms the experience of

service users outlined above as they report activities being cancelled, and a 'prioritisation' of care packages 'to identify those that required low and moderate support that could be provided in an alternative way' meaning that 'some (care packages) were suspended, some required different delivery and some carried on as normal.'

A paid carer told us: 'Many of the people I work with are older people and in the first 2 months of lock down their care packages were reduced to the bare minimum, it was allocated on higher risk assessment, everyone else was told to get on with it. Told it would be reviewed in 12 weeks time but that time has now passed.'

Some staff mentioned that prioritisation took place 'In consultation with service users and families, cases were reduced on a case by case basis, taking into consideration, capacity levels, health conditions, living alone or no informal caring arrangements.'

Staff who delivered face to face care for those considered most at need did this 'with appropriate PPE,'

But staff also confirmed that a lot of 'care and support stopped during the (lockdown) period... although zoom/internet and telephone contact was continued to sustain the package (from a distance) the impact on the person cared for was very significant.'

Reasons for reduction

Some views we heard from staff continued to support the view espoused by service users (groups 1 & 2) that many families were expected to 'get on with it.'

There is some evidence to suggest that prioritisation of care services led to services being cancelled in the assumption that unpaid carers will 'pick up the slack.' One respondent suggested that they were 'being refused support because there are 2 parents' present in their home. This point was echoed in our online session where a family carer told us, for example:

'The only communication I had was from XXX Council to let me know that the carer visits were being reduced...We put in place an emergency plan. Neighbours willing to step in.'

The main reason for reduction in care provided from a staff perspective was, understandably, 'safety' as staff 'could not go into people's homes safely' and there was a need to 'spend minimal time in people's homes to ensure everybody was safe.'

'As a manager I had to balance the health and safety of staff and the individuals we support. We tried to make firewalls. We got each team to support just one individual. Made provision for extra support where we could.'

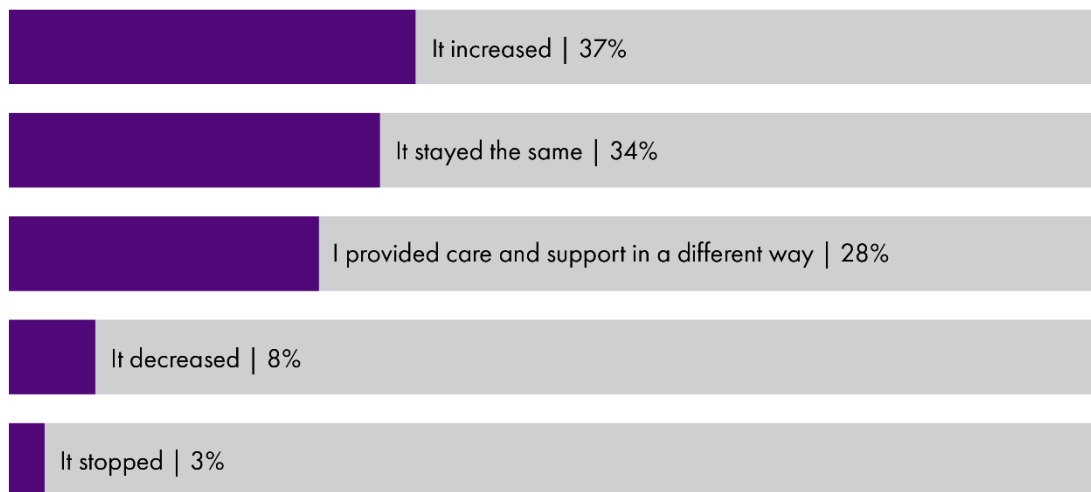
However, other reasons for a reduction in care at home services was a reduction in staff numbers 'due to a lot of staff members having to isolate due to health conditions' and 'staff on sick leave which affected the continuity of care.'

In some cases care at home reduced because 'staff were furloughed', or Care At Home providers had their funding 'reduced.'

Another reason given for reduction in care provided was due to 'service users cancelling their support completely due to having care from family members who were perhaps furloughed or lost their job due to the pandemic.' Staff reported that 'service users' packages were decreased where family could help' and 'some people cancelled their care due to shielding, or family members on furlough were at home to deliver the care.'

Changes to staff working patterns

We asked staff members (Group 3) about how their working patterns changed because of the pandemic. Their responses are listed below:



Did your working pattern change during the pandemic?

These responses are interesting as 71% of staff report their work patterns remaining the same or increasing despite the context of so many care packages being reduced, as outlined above.

However, this discrepancy could be due to the number of managers and owners responding to the survey 'working from home to support and help coordinate front line staff.'

According to staff while 'working hours stayed the same, work load increased significantly.'

Another staff member outlined examples of additional workload:

'Work generated included:

- Training Staff (in) PPE- infection control – COVID
- Increased staff meetings (Conference calls) to ensure workers were informed and also to promote positive wellbeing
- Completing and updating Risk assessment on individual's and service provision
- Developing recovery plans.

- Reporting, at time similar information, in different formats to Senior Managers, HR Care Inspectorate.

This list is not exhaustive and does not include the day to day running of services and support.'

Workload also increased due to factors outlined above that led to a reduction in staff for health reasons which led to additional pressure on existing staff meaning that their work 'increased due to staff being off.'

This issue of availability and turnover of care staff and its impact on recruitment of new care staff was mentioned by one professional care manager:

'We had to seriously adapt how we train new people. The induction when training new recruits usually includes manual handling, but we've had to do online training. This has included additional Covid-19 training which has been good, but not having the new staff in, you worry if they're confident when they go out there. We were only able to take on people who had previous experience because we couldn't offer the same in-depth training as we usually do, and could only have limited numbers in, so we were restricted on new recruits.'

Although not providing as much face to face care many staff felt they had an increased workload while working from home. One staff member stated that:

'I was working from home a lot more and therefore felt I was not getting a break from work, less structure and a lot of change for service users.'

Staff working from home also had to contend with pressures of 'childcare' and even 'unpaid home caring for elderly (relatives) who moved in... during lockdown.'

Staff also reported 'anxiety and stress levels throughout the workforce were heightened through the pandemic and subsequently the operational staff had to work more to offer support to staff in field based roles.'

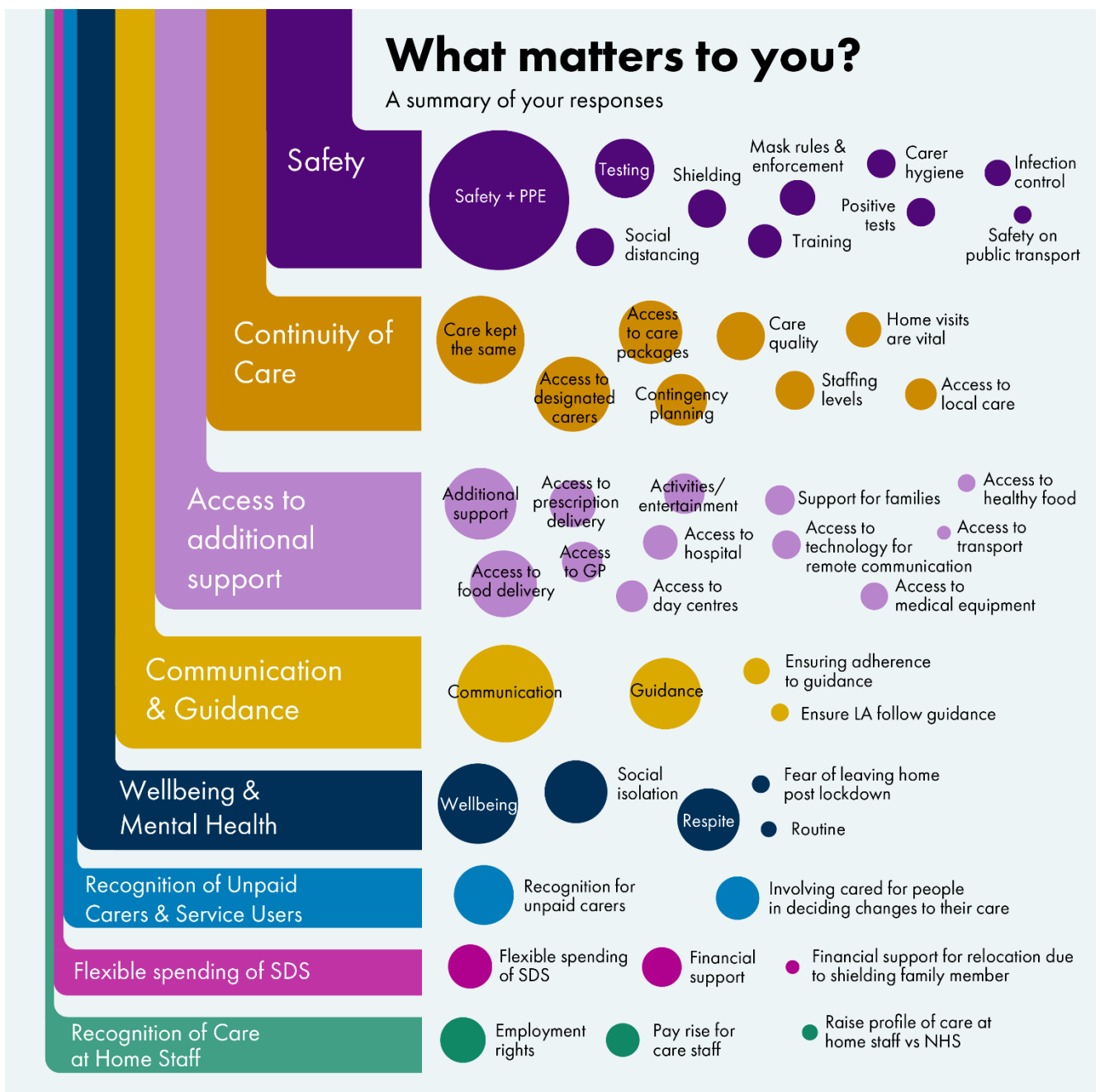
Many staff worked hard in difficult circumstances with one respondent noting that:

'My main motivation for picking up these extra shifts was to be able to provide consistent support to the individuals we support and to reduce risks that bringing an unknown agency worker into the service might bring.'

Section 3: What mattered most to participants

We asked all participants to tell us the two things that are most important to them (in the context of care at home services) if there was a second wave or further outbreaks. We received 1268 responses from 686 of the 732 participants. Every response was considered, tagged and grouped together into themes.

Below is a summary of the key issues that respondents highlighted as most important to them. Although their responses came from the context of the COVID-19 pandemic, we feel that the responses are also helpful to provide lessons for future delivery of care at home in Scotland.



Safety

The most important issue highlighted by respondents was the need for 'safety' as the 'safety of staff and people we support is paramount.' Many respondents just wanted to know that their family members were 'feeling safe and fully supported' and 'well cared for.'

Much of the comments relating to safety focused on 'consistent access to PPE for care staff' and ensuring 'carers have access to full PPE from the start', echoing views expressed in other parts of the survey about PPE.

Others were concerned about safety in terms of carer hygiene and appropriate use of PPE: 'currently not all carers are following Guidelines issued and are not wearing PPE'. Some respondents called for carers to receive 'sufficient training' in 'infection control', 'social distancing' and safety.

Others wanted to maintain safety via 'frequent testing for the staff and service users' and wanted reassurance of 'what would happen' if a staff member or person receiving care 'tested positive' or 'had to self isolate.'

Some respondents focused on 'shielding vulnerable individuals' keeping them 'well clear of others' with access to 'adequate protection and shielding facilities.'

A few respondents wanted to ensure safety in the wider community and 'on public transport. There was a call for 'better support and enforcing Government guidelines on protection' and 'making people follow the rules' to ensure those who are cared for are not 'put at risk' when out and about in the community.

Continuity of Care

Another major issue that was flagged by respondents was the need for 'continuity of care', 'that services are able to continue and not be closed again' and care services are 'not changed and my routine is kept as normal as possible' and 'the care service continues to be delivered according to the care plan - I would be in an impossible situation if this could not continue.'

Respondents were determined that 'we must not be forgotten about' and 'not to be left to manage entirely on our own' and called for care services 'not to be stopped' and 'that care packages for patients remain in place in the future'.

Our video sessions confirmed that continuity of care, and ensuring that the care package on offer meets the needs of the individual were still an issue of concern:

'My care plan has not changed at all in 2 and a half years but I feel my needs have changed, I've had no review from social work or care providers. They keep on promising to come and do it but they haven't ever got around to it.'

'It's very difficult to get hold of a social worker to actually do a review or even to speak to over the phone to be honest. I think the main reason is there aren't enough of them to deal with the work.'

'We were left to pick up the slack of the other services with little to no support. This should not happen again.'

Others were concerned with 'quality of care' and stressing the need to 'provide a consistent, reliable service'.

Respondents were keen that service users had 'access to designated carers so they aren't going from home to home' increasing risk to those receiving care and that there is a 'continuation of care from... regular carers' as 'it is not good to have various different people coming in you don't know' due to 'hygiene standards' and to maintain routine a familiarity for those receiving care.

This continuity of care is only possible if there are 'enough staff' and high staffing levels 'to cover those who will need to self isolate or quarantine.' Another key factor raised is the need for 'contingency plans for services include information from local authority (and other service providers) as to how support will come from them should a service be depleted of staff.' There was also a call for 'more substantial crisis plan from managers on how to deal with' future outbreaks' as it is important that 'carers and clients in services feel confident that we are prepared and are able to keep them safe and well informed'.

Wellbeing and Mental Health

Respondents had concerns about the wellbeing and mental health of those receiving care and those providing care.

There were requests to 'receive support for my mental health and wellbeing' as the situation was 'not doing mental health and wellbeing much good being stuck at home not seeing friends and family.'

Respondents raised 'social isolation' as a major factor, for example: 'the isolation for someone with dementia who lives in their own has devastating effects.'

Respondents talked about the need to preserve as much routine, and 'as many familiar carers and peers as possible is very important for mental health.'

Many respondents stated that they were 'mentally exhausted', 'depressed', 'anxious', 'mentally drained' and in some cases 'people are frightened to let staff back into their homes even although they are struggling' with their mental and physical wellbeing.

One respondent noted that the pandemic and lockdown 'affecting (service users') mental health and I'm worried if it continues that they will just give up on life.'

Unpaid carers stressed the need for 'respite' to help them have 'chance of a break' as the 'lack of respite has been very hard emotionally and mentally'.

'I had little space for personal recharge and found trying to get help during pandemic exhausting on many levels. I felt this was unacceptable and very frustrating.'

Access to additional support and services

Many respondents felt that access to additional support and services was one of the most important things to consider in the context of Care at Home services and the Covid 19 pandemic.

In order of most requested additional support respondents cited the need for:

- access to food delivery
- access to prescription delivery
- access to GP services
- activities/entertainment
- access to hospital
- access to day centres
- support for families
- access to technology for remote communication
- access to medical equipment
- access to healthy food
- access to transport

Communication and guidance

Another key theme was the need for quality communication so 'people are kept well informed of the situation' as there were instances of 'no contact' between some services and service users:

'There was absolutely no contact from social care for my mother during the pandemic. I had to contact them to ask for more support.'

'We had an overwhelming amount of information thrown at us from all angles. You wondered sometimes if people who wrote the guidance had spoken to anyone who works in home care.'

There was a call for 'clear concise guidance' so people are aware of the roles they need to carry out in future pandemics.

There was a call for 'clear, concise instructions separate to those of 'registered care homes' specific to care at home services' and a need for 'clarity – (as) the guidance we have from our employer and the government is contradictory. This is causing confusion between supported people, families and staff.'

The advice and information from the Scottish Government was largely praised by those in our online sessions, which reflects previous findings in the survey about how well-informed people felt:

'I felt as if Nicola Sturgeon was my best friend because I saw her every day. I think the Scottish Government advice was well communicated, especially in comparison to Westminster. I felt the science was explained clearly.'

A paid carer told us: 'We took most our advice centrally, from Scottish Government, COSLA, the unions, to gather as much information as possible. There are so many different strands to social care, home care, outreach. There was so much information. We needed a social care portal which spelled out just the basics for us. Clearer, easier to read information would be very useful.'

Recognition of unpaid carers

Another major theme that emerged from the survey was the need for greater recognition and support from unpaid carers, especially as unpaid 'Care at Home had to continue on as normal while other services (social work, GPs etc) practically shut down'.

There was a feeling that unpaid carers 'were left to pick up the slack of the other services with little to no support. This should not happen again!'... Unpaid carers should 'not to be left to manage entirely on (their) own.'

'I felt completely abandoned as an unpaid carer, I work full time to maintain the home my son who has needs lives in and give him a comfortable lifestyle. He does receive benefits but these are not enough to cover his costs so I work to cover them.'

There was a call for unpaid carers to have 'more support and financial help.'

Many unpaid carers mentioned that they were 'juggling caring full time and working full time' and that policy makers should 'think about the primary carer in the home who is doing everything out of love... there are no days off or respite breaks and ... working from home... as still need to earn a living.'

There was a request for 'support for unpaid carers to be put in place' so that they are protected from 'burning out' and 'not left to care 24/7 without a break.'

There was also a call for 'Unpaid carers (to) be recognised as the same' as other 'NHS carers' and be provided access to 'testing kits' and 'priority in supermarkets' during lockdown.

Some felt that unpaid carers with 'increased work load and should have received additional financial support' and that they 'need support with money. They need a full time wage. We are under seen and under valued.'

The issue of the professionalisation of care at home services came up in both our online sessions with carers and those who receive care. There was a strong feeling that the system needed to move towards a professional career model:

‘Carers on the ground are excellent, we need to professionalise that. We need a carer’s charter. Unpaid carers can’t / won’t cope, we need some kind of agreement, a charter, with rights and responsibilities on both parts.’

‘Use the unpaid carer’s knowledge. We should professionalise the sector, qualifications.’

‘Carers themselves are not treated well. They are underpaid and not given enough time to get to appointments’.

‘The care and support system needs to be put on a professional basis and carers need to be given a pathway where they can be given more respect and better conditions and will be valued more. Similar to nurses.’

‘I totally agree with a national care service’.

Involving people in their care

Some participants felt it is important to involve people and families in shaping the care they or their loved ones receive with more ‘consideration given to individual circumstances...’ ‘it should meet the individual need and not be service led.’

This point was raised partly as a reaction to some people having ‘care stopped’ without consultation and the decision taken ‘unilaterally by the care provider.’

There was also a feeling that service providers sometimes ‘ask for feedback and ideas’ to improve services ‘but then don’t reply (or) sort something out’ as a result of engagement with service users.

Others want ‘proactive’ discussion with service providers about changes to care services and stressed that carers and service users need ‘to be heard with regards to what they need and what is missing’ in the services they receive and for them ‘to be at the heart’ of decision making to stop people receiving care being ‘squeezed further to the edge of society.’

There was also a call for service users to be involved in ‘how services will resume and what they should look like.’

Recognition of staff

Another key theme that emerged was the need to ensure ‘that care staff are recognised for their excellent work and receive the right support from their employers’... ‘we owe a great debt to our managers and staff who have planned, delivered and reviewed support throughout this crisis, while battling personal and family concerns.’

There was a focus on employment rights of staff and ensuring that 'front line staff do not lose income if they are symptomatic' and that care companies 'support staff better' and protect staff wellbeing.

There was also a call to 'increase the hourly rate' of pay for carers who 'were so good and went the extra mile' and some service users would 'like to see better protection for carers and better pay and better recognition for their efforts.'

Staff and service users also felt care at home staff 'were not afforded the same support as NHS staff' with reports of staff being 'turned away from shops that provided priority shopping to' key workers.

One respondent noted that:

'There was an expectation that support workers would manage in the absence of these support mechanisms and a failure to highlight the pressures on care providers and support workers meant that even in local communities the public did not view our staff in the same way as NHS staff... Perhaps in view of a second outbreak of the pandemic, Scottish government can help to raise the profile of the support workers who care for the elderly in the community through advertising campaigns specifically about support workers. Or including support workers alongside NHS workers in current advertising campaigns.'

Flexible Spending of SDS

A final key theme that emerged from responses was the need to 'allow flexible spending of SDS' so that those receiving care can spend on care and support that is 'available' and 'meets needs' of those receiving care.

Some wanted more flexibility to buy additional equipment such as 'a tablet, or art supplies in lieu of workers being' available or use budget to 'pay a family member' when carers were not available.

Some reported local authorities being unwilling to be flexible on spending of budgets: 'they made my life a misery when I asked to use £300 to buy a piece of equipment.'

There was anger that SDS budgets could not be used on other care provision when usual care was not available: Why 'should I pay for 31 hours care a week (that) I am not getting for 5 months'? And respondents felt that they 'not have to pay for services not being used.'

The different approaches to care delivery based on SDS was commented upon in our online sessions:

'Although I have Direct Payments and SDS they are still asking how long I take in the shower and how many showers a week I am allowed. It shouldn't be about that now. It's supposed to be about outcomes now but they are still working on the old approach of how long things like showers take.'

'A few years ago when SDS came online I was involved in training social workers and it was very telling that only a few of them understand the concept of person centred care. The younger social workers understood it and the older ones who used to work that way years ago understood it but the ones in the middle who make up the bulk of them just couldn't understand it, they couldn't get away from this idea of counting the hours.'

'I think that local authorities don't like SDS and put barriers in the way to put you off applying. They're trying to make a one size fits all approach.'

Section 4: Safe, Supported and Well Informed?

We asked respondents how they felt during the pandemic, asking them how safe, supported and well informed they felt.

Safety

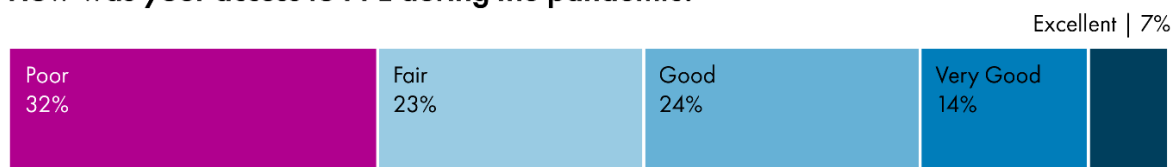
"I felt safe during the pandemic"



A third of respondents (33%) only felt 'slightly' safe or 'not at all safe', 43% felt 'moderately safe', while just under a quarter (23%) felt 'very safe' (18%) or 'extremely' safe (5%).

Part of the reason for lack of confidence in levels of safety could relate levels of access to PPE:

How was your access to PPE during the pandemic?



Just under a third of respondents found access to PPE to be 'poor' highlighting either a lack of provision having 'never been offered PPE' and PPE being in 'short supply at the beginning.'

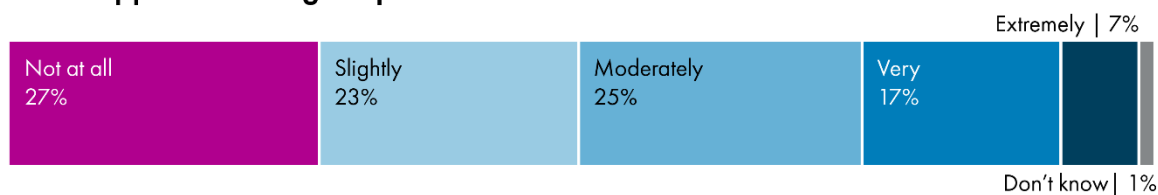
Many respondents had to 'buy our own PPE' but stressed dismay at price rises:

'The price we normally pay for PPE for use at home quadrupled in price during the lockdown, this left a very bad feeling.'

Those who had a positive experience with PPE (21% rating access as very good 14% or excellent 7%) praised 'triage services', PPE 'Hubs', third sector organisations and 'carers centres' who provided 'amazing' support. However, even those with a positive experience also highlighted the well documented issue that PPE access was 'initially poor at times' and 'it was challenging and but supplies improved later on.'

Support

"I felt supported during the pandemic"



Half of respondents only felt 'slightly supported' (23%) or 'not at all supported' (27%) during the pandemic. A quarter (25%) felt 'moderately supported' and a quarter felt 'very' or 'extremely' supported.

These findings further support previous findings relating to some service users of Care at Home services feeling 'abandoned' during the pandemic lockdown.

Well Informed

"I felt well-informed during the pandemic"



41% of respondents felt very or extremely well-informed during the pandemic. This is in part due to 'televised Scottish Government briefings' and 'information (being) very clear and well thought through'

However, respondents noted that there was 'room for more local responses' and communication during the pandemic. Some respondents reported Local Authorities not following government guidance which caused 'confusion.' Others felt a need for more specific guidance for certain conditions and the care at home sector in general:

'People who receive care at home services seem to have been forgotten about and everything is focused on care homes.'

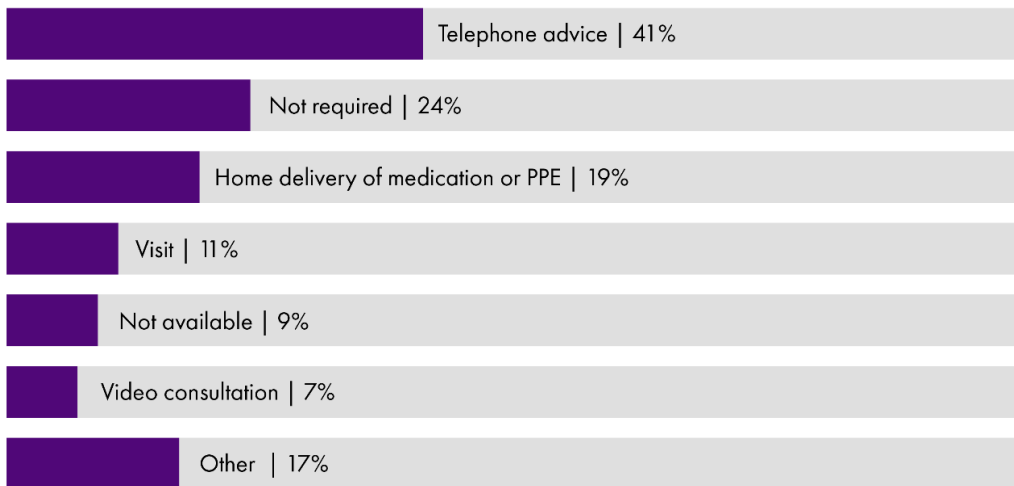
Clear and consistent guidance and information was an important issue for people we heard from in our online sessions:

'Government guidance was very good but lower down at council level and social work level it was non-existent. I got government advice through TV and Government website as well as personal messages.'

Section 5: Additional Support

We asked all respondents about their experiencing accessing additional support beyond their main care provider, in the case of Groups 1 & 2 (people receiving care and family members and unpaid carers of those receiving care), and employer, in the case of Group 3 (staff).

GPs and Primary Care Teams



What support did you get from the local GP/primary care team during lockdown?

Although many people received interaction with GPs and primary care teams over the phone, 151 respondents provided additional information that overwhelmingly suggested that ‘no support’ was available, ‘None at all. None offered. I don't know if it was available or not.’ with respondents seeking telephone advice having ‘some difficulty finding help as many departments closed and phones just rang out.’

This issue was touched upon by participants in our video session with people who receive care:

‘I got no help at all from GP’s or Social Work. I really feel like GP’s have had no role whatsoever in this but they are the ones who know people best’

‘It’s very difficult to get hold of a social worker to actually do a review or even to speak to over the phone’

The word cloud below highlights how little support survey participants felt was available from GPs and Primary Care teams.

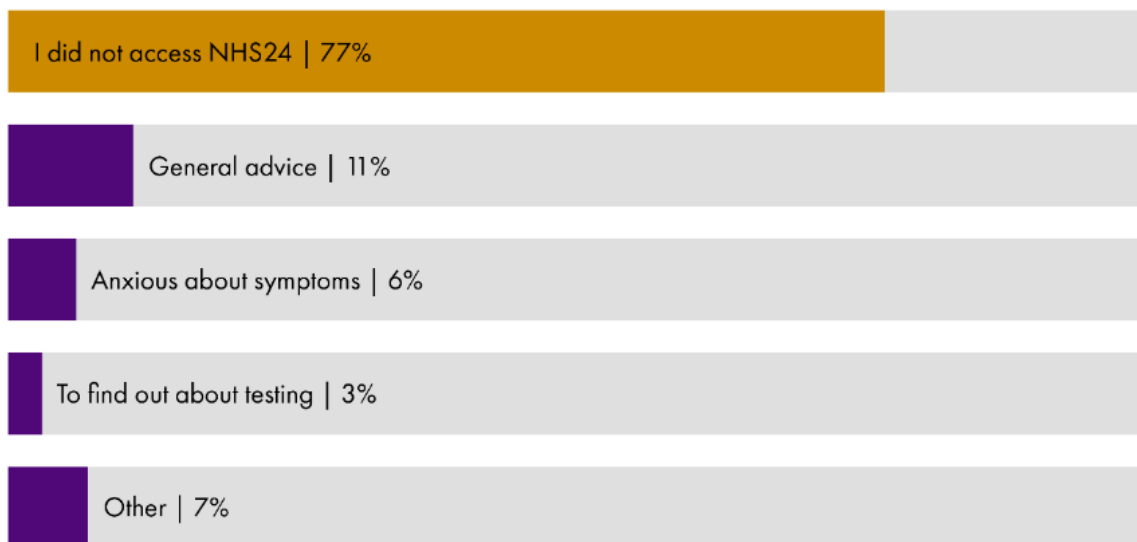


If you replied 'Other' please specify

NHS 24

We asked all participants if they used NHS24, and the reasons why they contacted the service.

Their responses are detailed below:



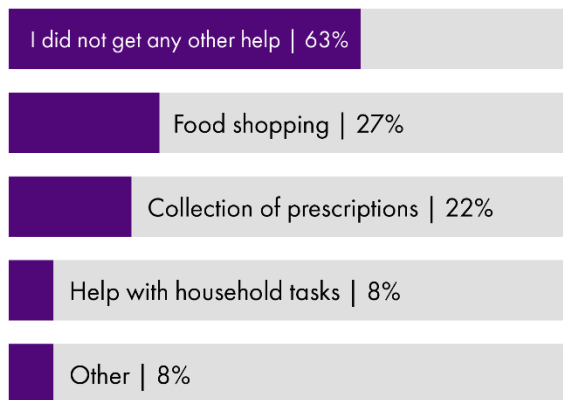
Why did you contact NHS24?

What is clear is that many did not access NHS 24 during the lockdown, although 20% of respondents did contact the service for issues relating to COVID-19. The 7% of respondents who answered 'other' contacted NHS 24 for a range of other medical reasons not directly related to COVID-19.

Forms of additional support

We asked all respondents about the forms of additional support they received and who provided additional support:

If you were able to get other help, for you or those that you support, what was it?



If you received additional help, where did this come from?



What additional support did you receive?

Key additional support received was delivery of food and medicine, however 63% of respondents ‘did not get any other help’ which further emphasises the feeling of ‘abandonment’ experienced by some people and families in receipt of care at home services during the lockdown period.

The most common other source of care identified was:

Family/friends



One of the most common sources of additional support came from friends and family with additional support also coming from voluntary organisations; local authorities, Neighbours and Community Councils. This issue of community-based support through informal ‘networks’ was echoed in our online session with people who receive care:

‘Pulling Together is a group in my area and they do things like deliver shopping for you but occasionally you’ll get a doorstep delivery with other things like a gift or some extra PPE etc. The Synagogue have been great as well. They’ve been delivering little gifts at every festival time. It’s great to get the little message that you are being thought of, it makes you feel good.’

It is clear that much of the additional support provided to those in need of care at home during lockdown came from unpaid volunteers or relatives, perhaps emphasising a level of community activism and neighbourliness during the pandemic.



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