

SCOTINFORM



VOCAL Carer Survey 2021: Midlothian

Purpose of the Survey

The VOCAL Carers Survey gathers the views of carers looking after people in Edinburgh and Midlothian. Its aims are:

- To obtain a profile of carers
- To understand the impact of caring more broadly, in three areas:
 - Health and Wellbeing
 - Money and Work
 - Time away from Caring
- To assess satisfaction with services currently offered
- To assess interest in other potential services and developments, including online support.
- To understand VOCAL's impact
- To understand which other agencies were supporting carers
- The findings are to be used to inform VOCAL's strategic planning and to assist with communicating with stakeholders.

The 2021 Survey follows on from surveys conducted in 2015 and 2017.

Methodology

- The survey was designed by Scotinform in consultation with VOCAL and its partner agencies.
 - Unlike in previous years, the questionnaire for Edinburgh and Midlothian was identical (the survey structure allowed us to filter responses according to the place of residence of the person being cared for).
 - An online survey link was distributed and shared by VOCAL on its social media and to its mailing list, as well as by partner agencies.
 - A paper version of the questionnaire was sent out to individuals for whom VOCAL did not have an email address. Paper copies were also available in the VOCAL offices and in the offices of some partner agencies. VOCAL staff and volunteers made themselves available to support respondents in completing the survey, either in person or over the phone.
 - Both versions of the questionnaire offered respondents the opportunity to enter a prize draw as an incentive.
 - Paper returns were inputted by Scotinform.
 - Thank you to VOCAL staff and volunteers for supporting the process.
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Responses


- 1,286 responses were received in total.
 - 826 of these related to somebody being cared for in Edinburgh, and 392 to somebody being cared for in Midlothian.
 - These figures are broadly in line with the number of responses achieved in 2017 (1,228 responses, with 915 in Edinburgh and 313 in Midlothian).
 - 171 paper responses were received, representing 13% of all returns. The response rate on the 1,414 postal surveys sent out was 12%, compared with 13% in 2017.
 - VOCAL has made significant progress in moving communications online since 2017, when 61% of returns were paper based. It is likely, however, that a paper format will be required in future surveys in order to ensure that they remain accessible to carers.
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Reporting

This report covers the data set for people caring for somebody living in Midlothian. Please refer to separate reports for more detail on:

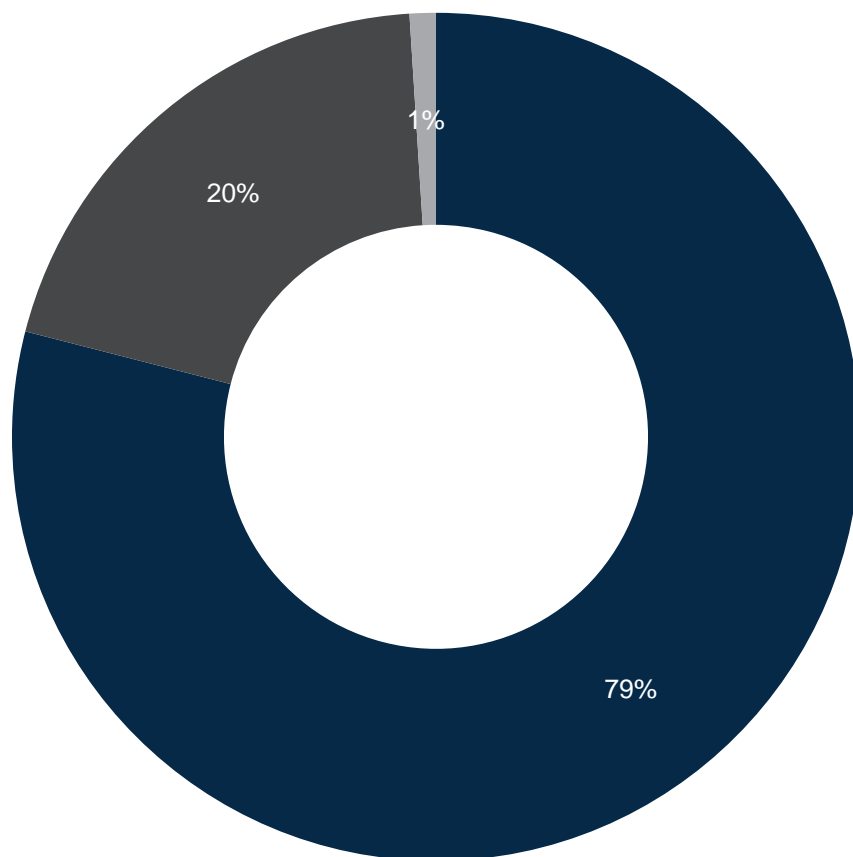
- The full data set
- Respondents caring for people living in Edinburgh
- Respondents engaged with VOCAL

Please note:

- Where percentages do not total 100% this may be due to non-responses and/or rounding
 - Where percentages exceed 100% this is due to multiple responses
 - Unless otherwise stated, the reporting base is all respondents caring for someone who lives in Midlothian (392)
 - Open-ended feedback is identified with 
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CARER CHARACTERISTICS

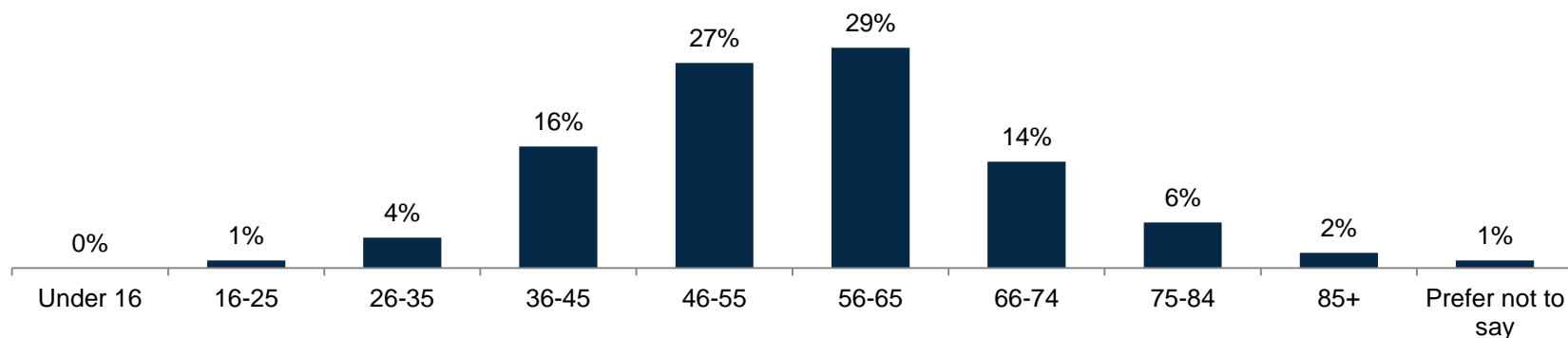
Carer Characteristics – Gender



■ Female ■ Male ■ Prefer not to say

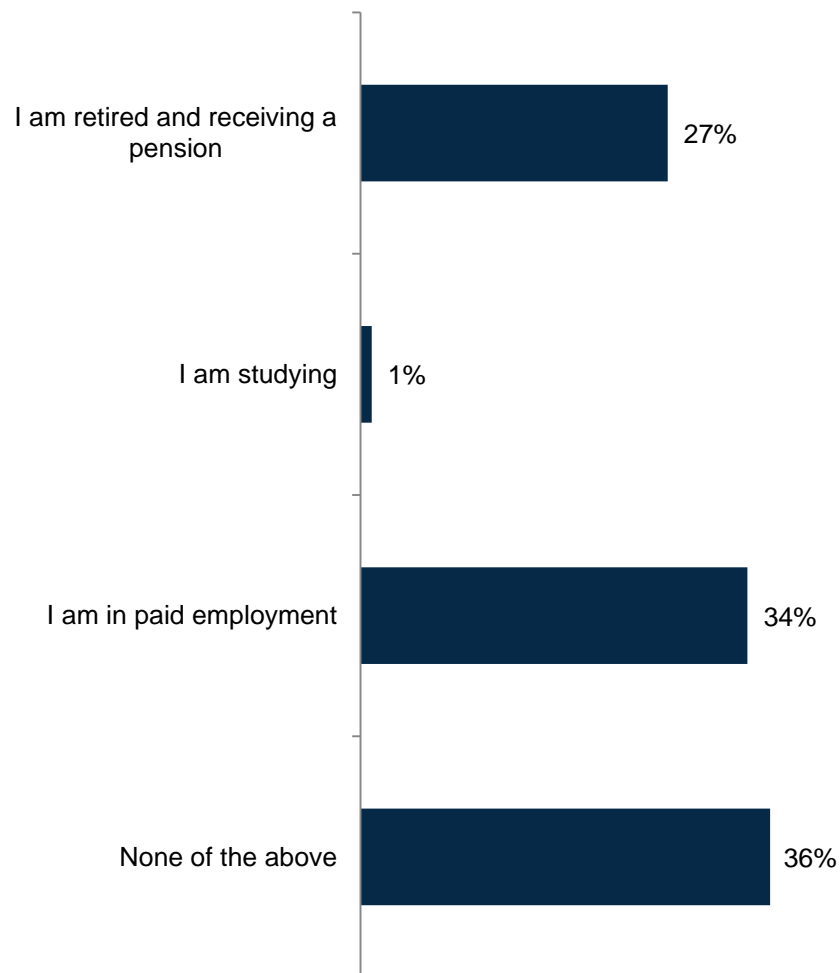
- Four in five respondents were female.
- This is slightly higher than in the 2017 survey (77%) and the 2015 survey (76%)
- The proportion of male carers was highest for respondents caring for a partner or spouse (32%).
- The proportion of female carers increases according to the length of time spent caring. 74% of those who been caring for 1-2 years are female, compared with 90% of those who have been caring for more than 20 years.

Carer Characteristics – Age



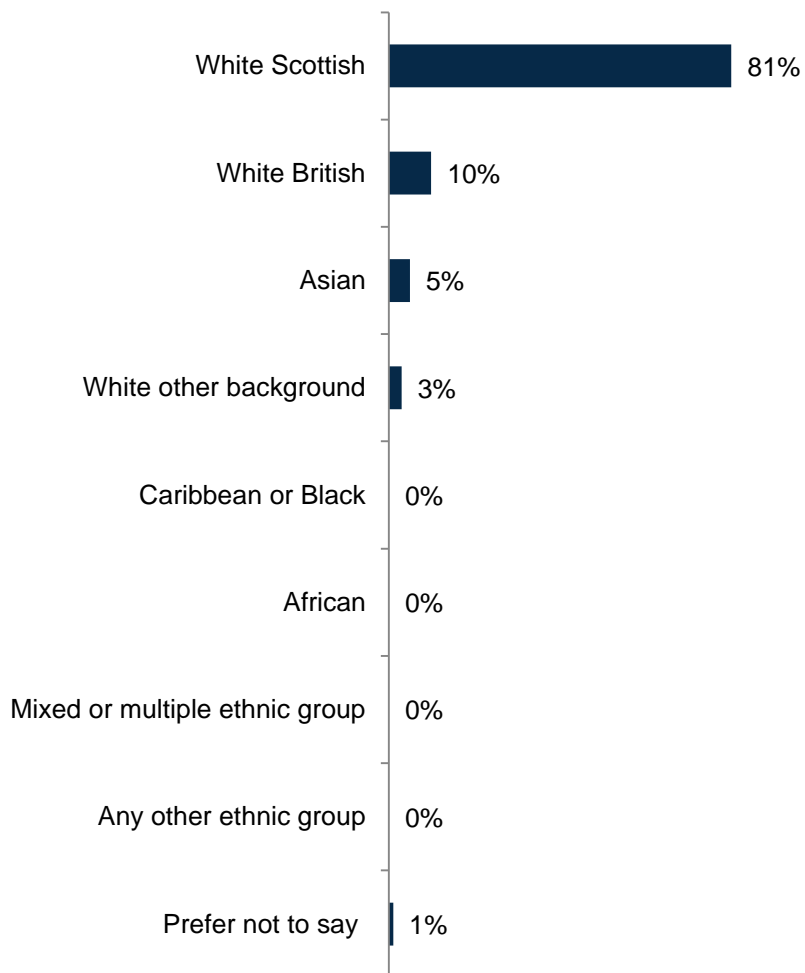
- The age profile of the sample has shifted downward, and is now generally younger than in 2017, with 77% of carers being of working age.
- In 2017, 34% of respondents were aged over 65. This time around the figure is 22%.

Carer Characteristics – Economic Activity



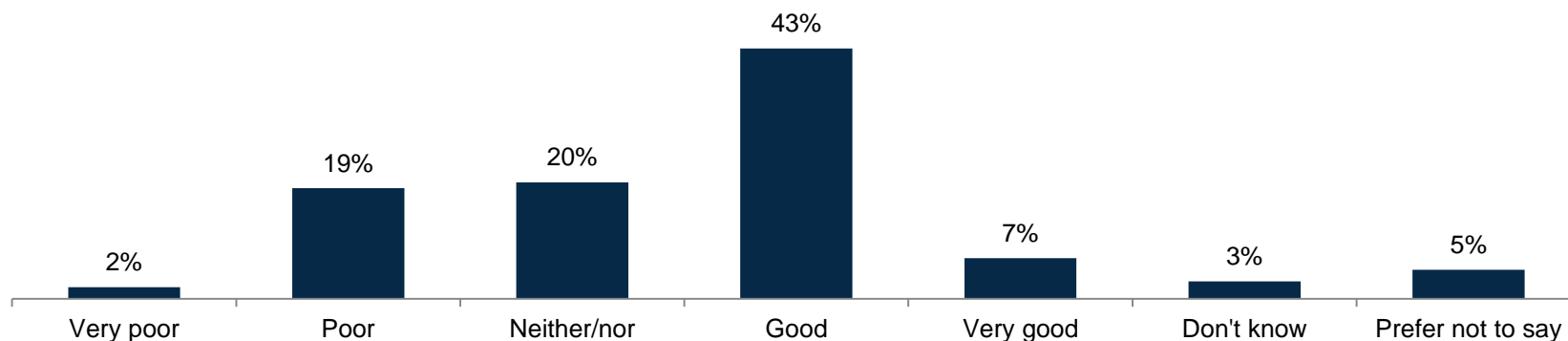
- Reflecting the younger age profile, the economic profile is also different in the 2021 survey.
- The proportion of respondents in paid employment has increased from 27% to 34% and the proportion retired and receiving a pension has declined from 42% in 2017 to 27% in 2021.
- Notably, the proportion of carers not in employment, education, or receiving a pension has increased from 30% in 2017 to 36% in 2021. The proportion of respondents in this cohort was higher for respondents caring for their children (50%), respondents caring for more than one individual, and respondents caring for somebody aged 25 or under (57%).

Carer Characteristics – Ethnicity



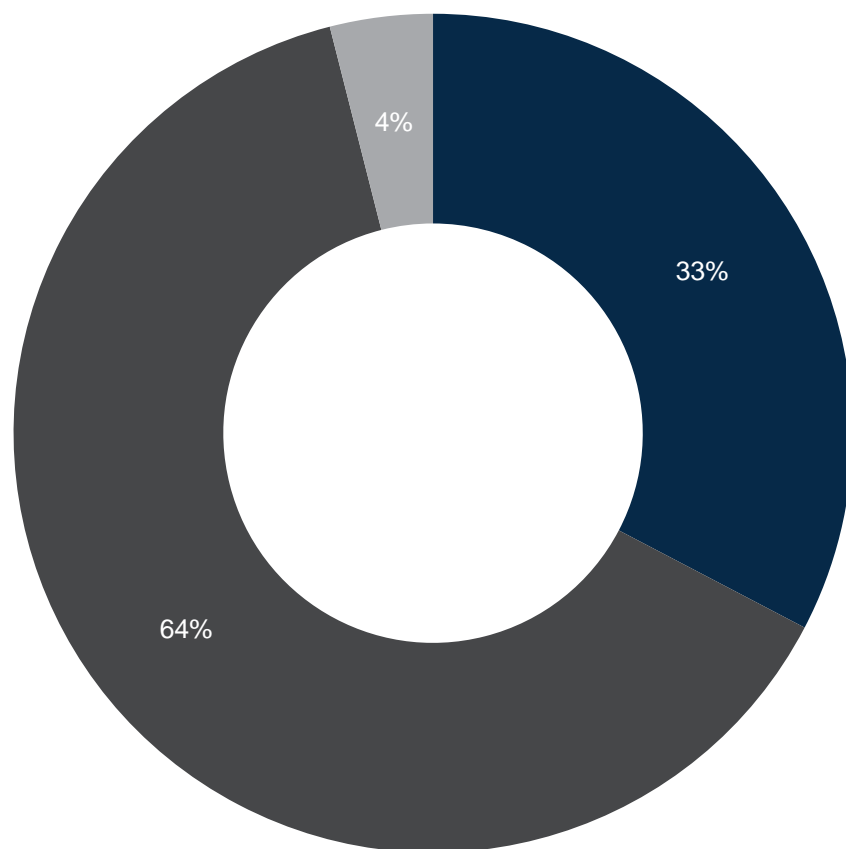
- 94% of respondents are white, down from 98% in 2017.
- 5% of respondents are Asian.

Carer Characteristics – Health



- In a new question for 2021, respondents were asked to assess the state of their health.
- 50% said that it was 'very good' or 'good', with 21% saying that it was 'poor' or 'very poor'.
- The proportion of those saying that their health was 'poor' or 'very poor' was higher for respondents who had been caring for over 20 years (25%). It was also higher for those not in employment, education or retired and receiving a pension (31%).

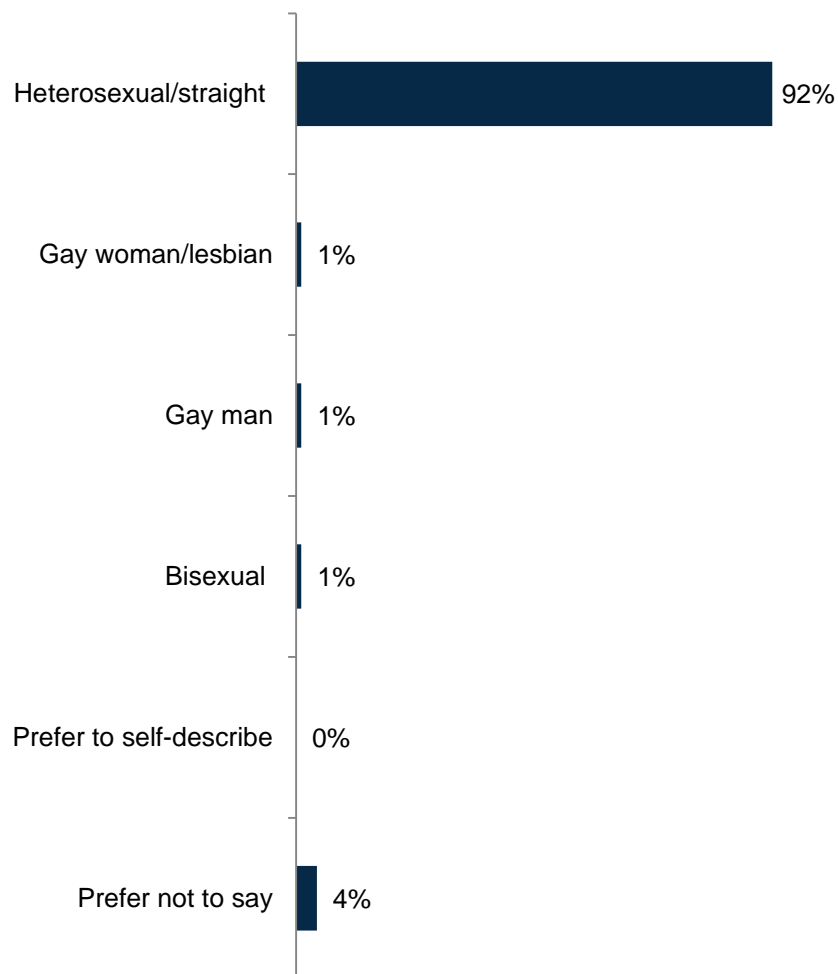
Carer Characteristics – Disability



■ Yes ■ No ■ Prefer not to say

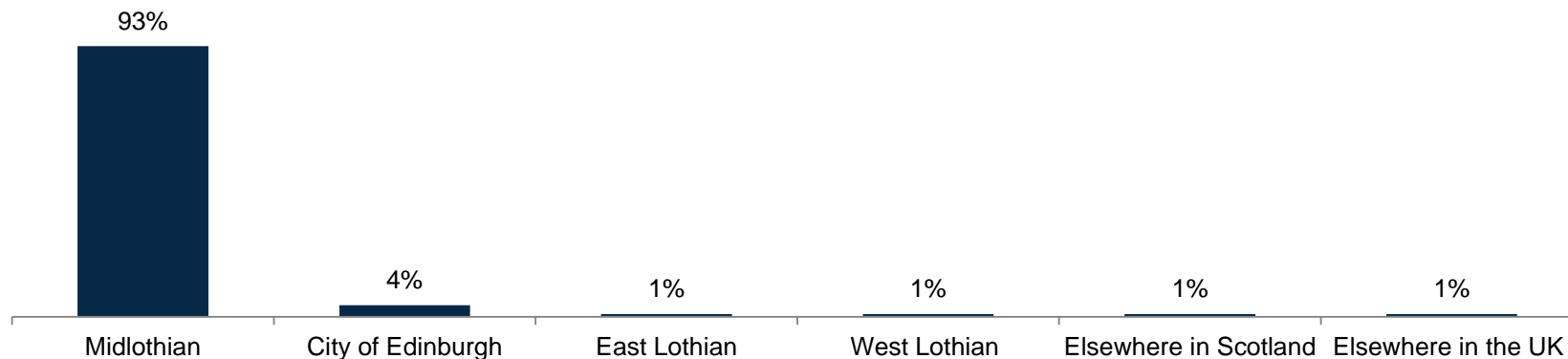
- 33% of respondents consider themselves to have a disability.
- The figure is higher for respondents who have been caring for over 20 years (38%) and respondents aged 75 and over (40%).
- The 128 respondents who consider themselves to have a disability were asked about its nature:
 - 53% reported a mobility disability
 - 45% a mental health disability
 - 20% reported a hearing disability
 - 10% a visual disability
 - 9% a co-ordination disability
 - 4% a learning disability
 - 3% a speech disability

Carer Characteristics – Sexuality



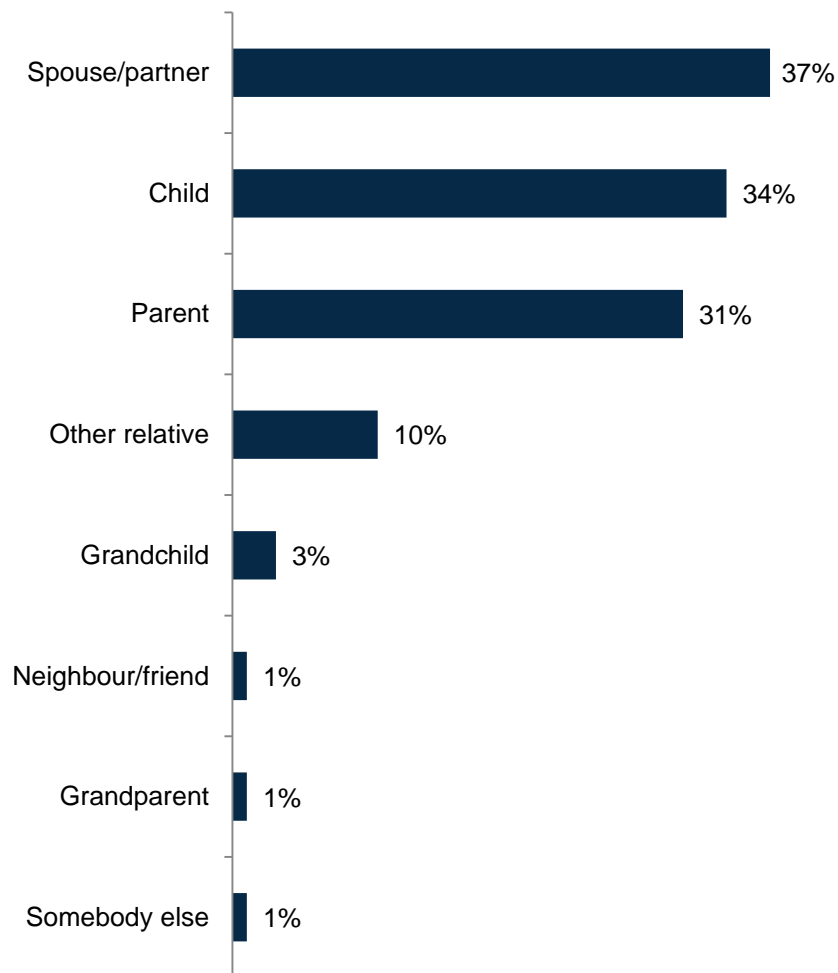
- 92% of respondents describe themselves as Heterosexual/straight, 1% as bisexual, 1% as a gay woman/lesbian and 1% as a gay man.
- This was a new question for 2021 so there is no previous data with which to compare.

Carer Characteristics – Place of Residence



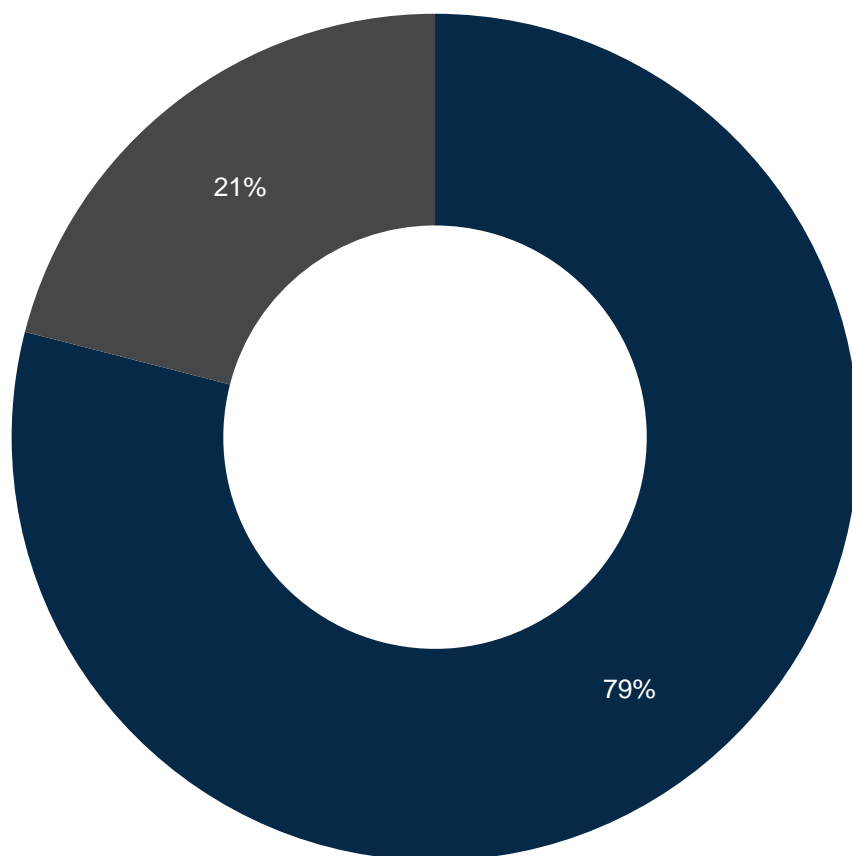
- 93% of respondents lived in Midlothian.
- 8% of respondents who care for somebody living in Midlothian live in a different local authority area (5% in Edinburgh).
- Living in a different local authority area from the person being cared for is likely to pose additional challenges, practically and financially and in terms of securing support.

Relationship to Person Being Cared For



- This was another new question for the 2021 survey.
- Respondents were fairly equally distributed across three main categories: caring for a spouse/partner, caring for a child (please note that this describes the relationship, not the age of the person being cared for), and caring for a parent.
- There is some evidence of multi-generational caring, with 11% of respondents caring for a child also caring for a parent.

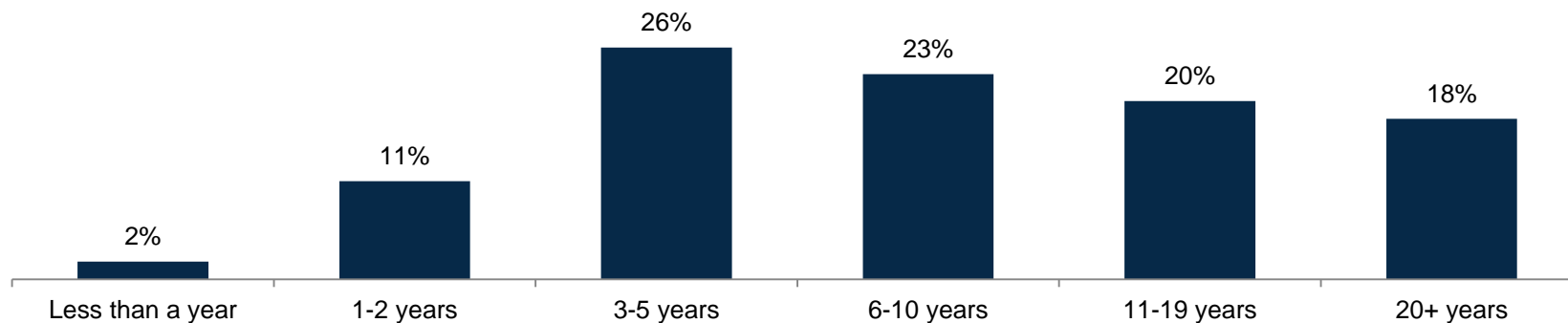
Living With the Person Being Cared For



■ Lives with them ■ Does not live with them

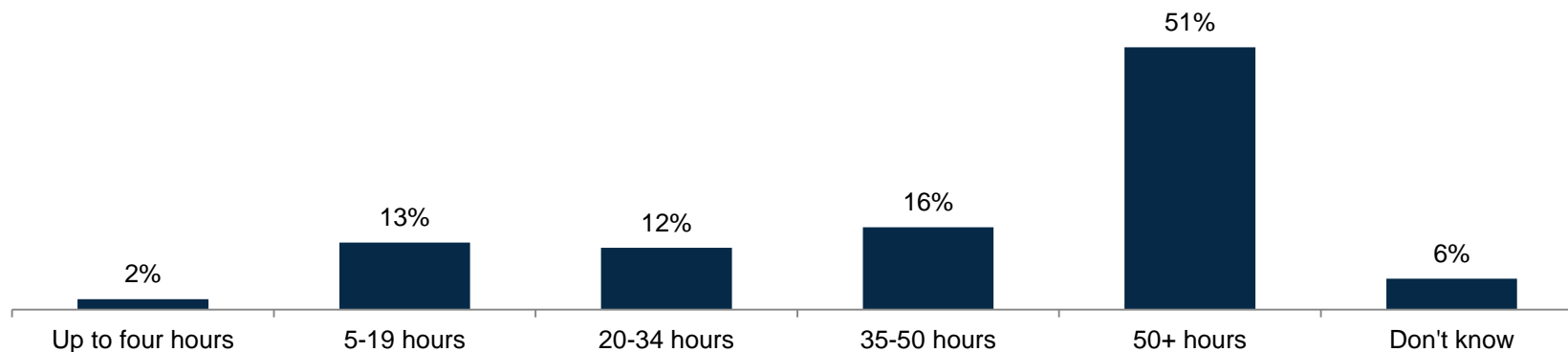
- 79% of respondents live with the person for whom they are caring.
- This figure is higher for respondents caring for their child (92%) or spouse/partner (97%), caring for someone aged 25 or under (92%), and those providing more than 50 hours of care a week (96%).

Duration of Care



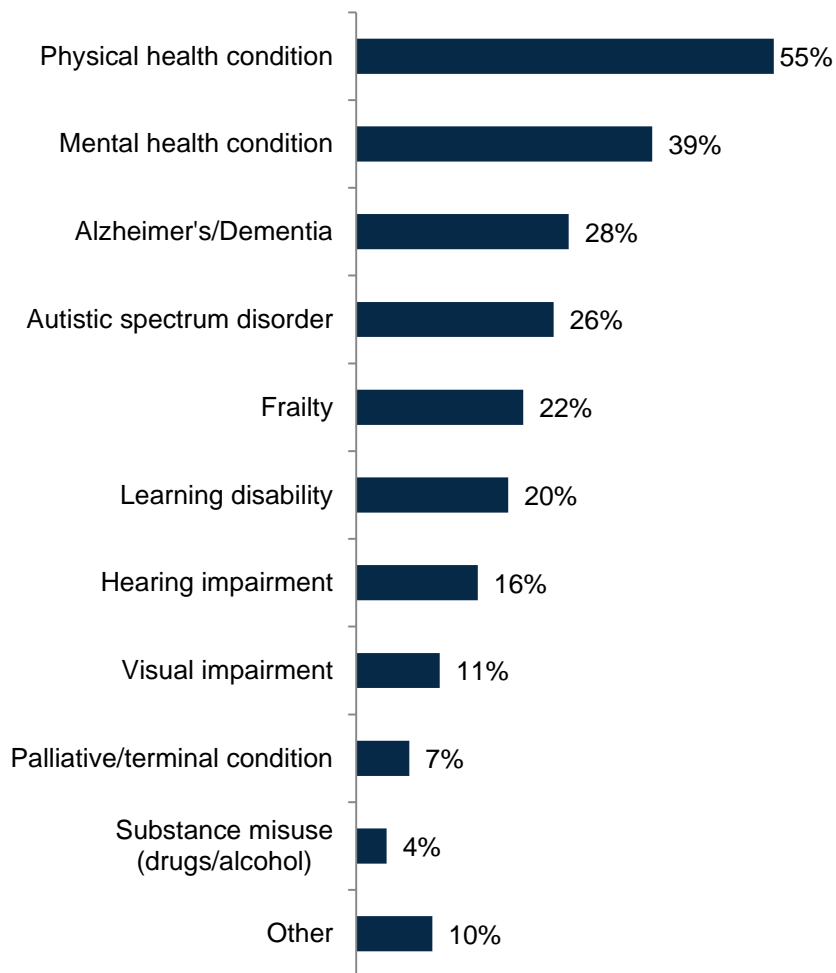
- 61% of respondents have been caring for more than 5 years. This is slightly higher than the figure in 2017 (57%).
- 18% of respondents have been caring for more than 20 years. This figure is highest for respondents looking after their child, 32% of whom fall into this category, and those caring for somebody with Autistic spectrum disorder (26%) or learning disabilities (46%). Respondents who have been caring for this long are more likely to be 56-65 (26%).
- More recent cares who have been caring for up to 2 years account for 13% of the sample overall. The figure is higher for respondents caring for a parent, (16%), caring for somebody with frailty (19%) Alzheimer's or dementia (17%), and who are aged 65-74 (17%).

Length of Time Spent Caring Per Week



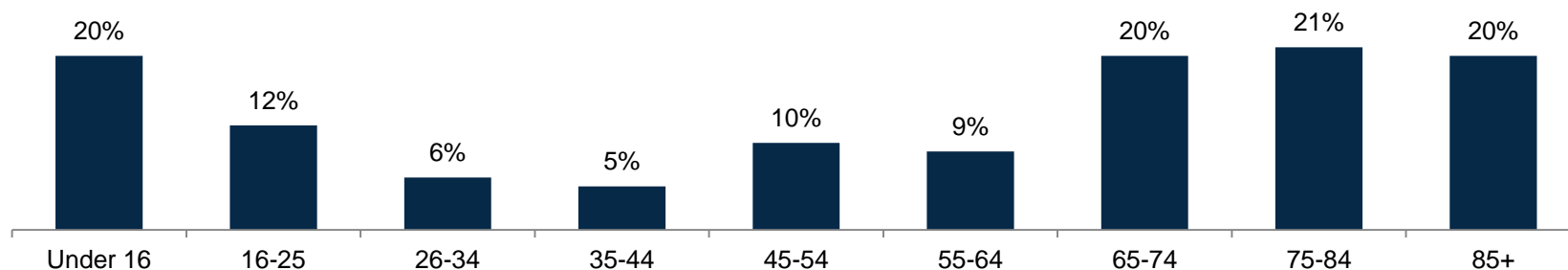
- This was a new question for 2021.
- 92% of respondents spend at least five hours a week in a caring role, with over half of them spending more than 50 hours a week.
- The proportion of respondents caring for more than 50 hours per week is higher if they live with the person they are caring for (64%), if they have been caring for more than 20 years (57%) and if they are caring for somebody under the age of 25 (65%).
- 89% of those who rate their overall health as 'very poor' and 59% of those who are not in paid employment, education or retired and receiving a pension are caring for more than 50 hours per week (note small sample size).

Conditions Cared For



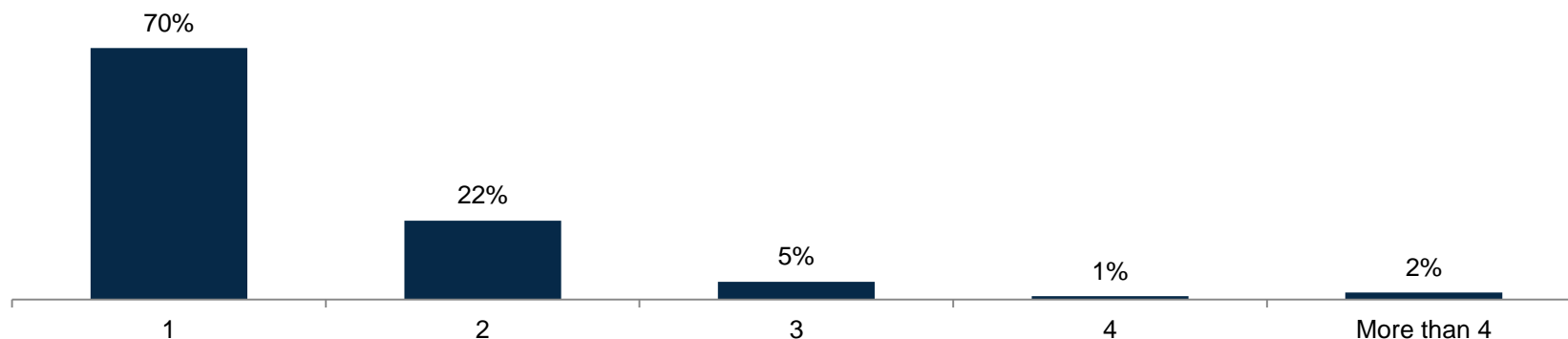
- Respondents were most likely to be caring for someone with a physical health condition, a mental health condition or Alzheimer's/dementia.
- The proportion of respondents caring for someone with a mental health condition has almost doubled, from 22% in 2017, and the proportion caring for someone with an Autistic spectrum disorder has increased from 15% to 26%. The proportion caring for someone with Alzheimer's/dementia or frailty has declined (37% and 32% in 2017).
- Some of these trends reflect the increase in respondents in the sample caring for their children.

Age of Person Being Cared For



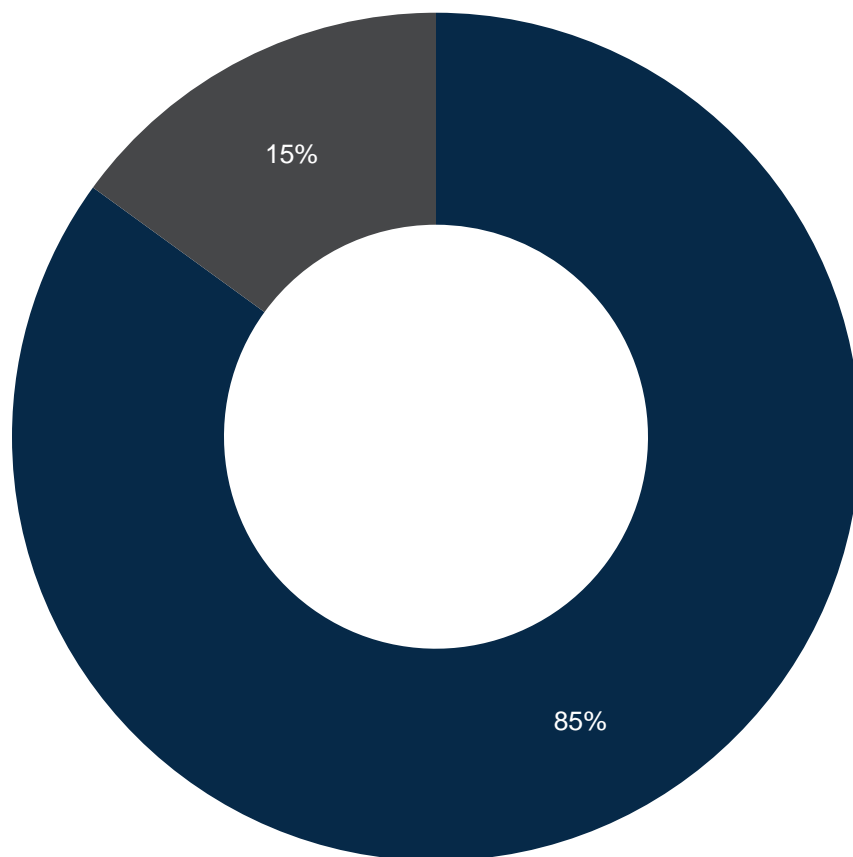
- 41% of carers are looking after somebody aged 75 and over. This is slightly higher than the 2017 figure (38%).
- The proportion of people being cared for aged over 75 is higher for carers who are looking after a parent (85%), have been caring 1-2 years (62%), do not live with the person they are caring for (83%) and are caring for frailty (89%) or Alzheimer's/dementia (83%). 84% of those aged over 75 are caring for someone in this age group (note small sample size).
- 32% of carers are looking after somebody aged 25 or under. This is an increase compared to 2017, when the figure was 23%.
- In contrast to the carers of people aged 75+, respondents are more likely to be caring for someone aged 25 or under if they are caring for their child (81%) or grandchild (100% - note small sample size), have been caring for 11-19 years (50%), are caring for someone with Autistic spectrum disorder (92%) or learning disabilities (69%). 41% of those who spend more than 50 hours a week caring are looking after somebody aged 25 or younger and they tend to be aged 26-55.
- These are two very different types of carers, perhaps with quite different needs.

Number of People Cared For



- 70% of respondents are caring for one individual – down slightly from 2017 (73%).
- 30% of respondents are multi-carers, caring for more than one individual.
- Multi-caring is more likely if the respondent has been caring for 20+ years (40%), and for respondents aged 36-65 (35%).

Engagement With VOCAL



■ VOCAL User ■ Non-VOCAL

- 85% of respondents have been supported by VOCAL in the past.
- There was no significant variation by carer characteristics or circumstances in the level of engagement with VOCAL.
- This figure is slightly lower than in 2017 (88%) but that may reflect the involvement of partner organisations in the survey this time around, which will have broadened the reach of the survey beyond VOCAL users to a greater extent than in the past.

Carer Characteristics: Key Findings (1)

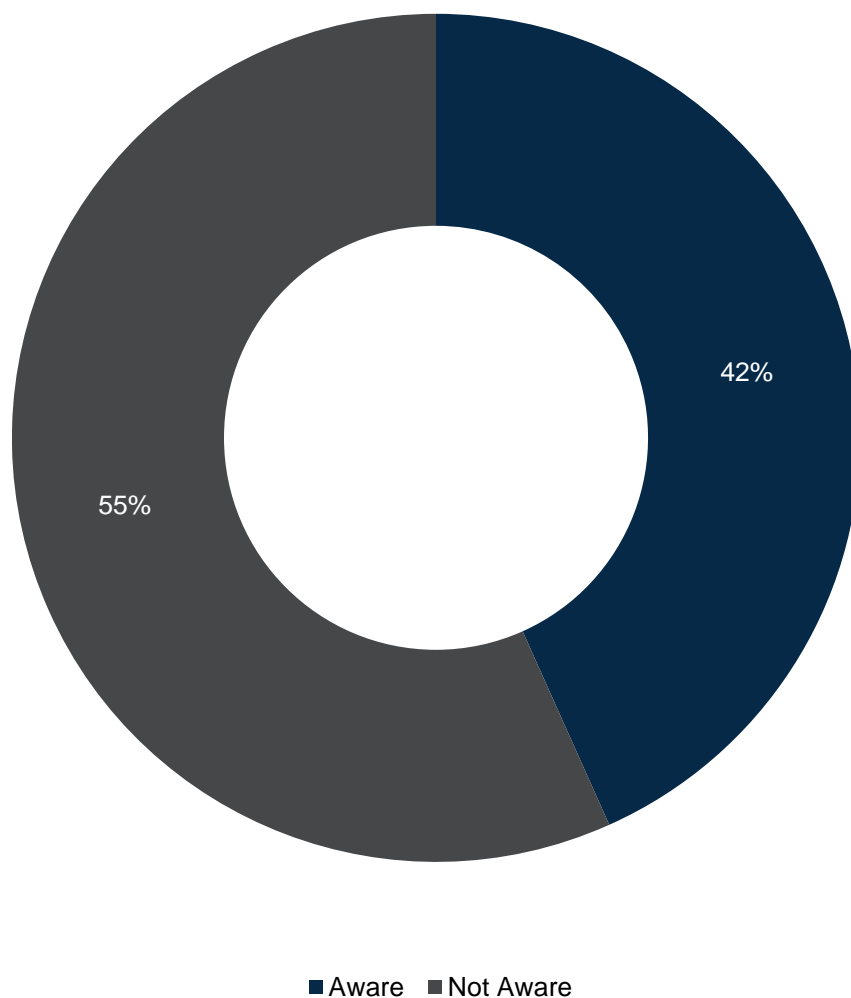
- As in the previous survey, approximately 4 out of 5 carers are female.
 - Compared to the 2017 survey, the profile of respondents has changed to include more younger carers. 77% of respondents are now of working age.
 - The proportion of respondents not in employment, education, or receiving a pension has increased since 2017.
 - Only 50% of respondents consider themselves to be in good health and 33% consider themselves to have a disability.
 - Respondents are equally divided between those caring for their spouse/partner, those caring for their parent and those caring for their son or daughter. 79% of carers live with the person they care for.
 - Nearly two thirds of respondents have been caring for more than five years; nearly a fifth have been caring for more than 20 years. The overall duration of caring activity has increased compared with 2017.
 - More than half of respondents provide more than 50 hours of care per week.
 - Nearly a third of respondents are caring for more than one person.
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Carer Characteristics: Key Findings (2)

- There have been increases in the proportion of respondents caring for someone with mental health conditions and Autistic spectrum disorders, and a decline in the proportion caring for someone with Alzheimer's/dementia and frailty.
 - 41% of respondents are caring for somebody aged 75 and over, slightly up from the 38% in 2017. The proportion of respondents caring for somebody aged 25 and under has increased from 23% to 32%.
 - There are differences in the caring experience depending on the age of the person being cared for; in general respondents looking after someone aged 25 and younger are more likely to be living with the person they care for, to have been doing it for longer, and to be caring for more hours per week.
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AWARENESS OF CARER RIGHTS

Awareness of Carer Rights

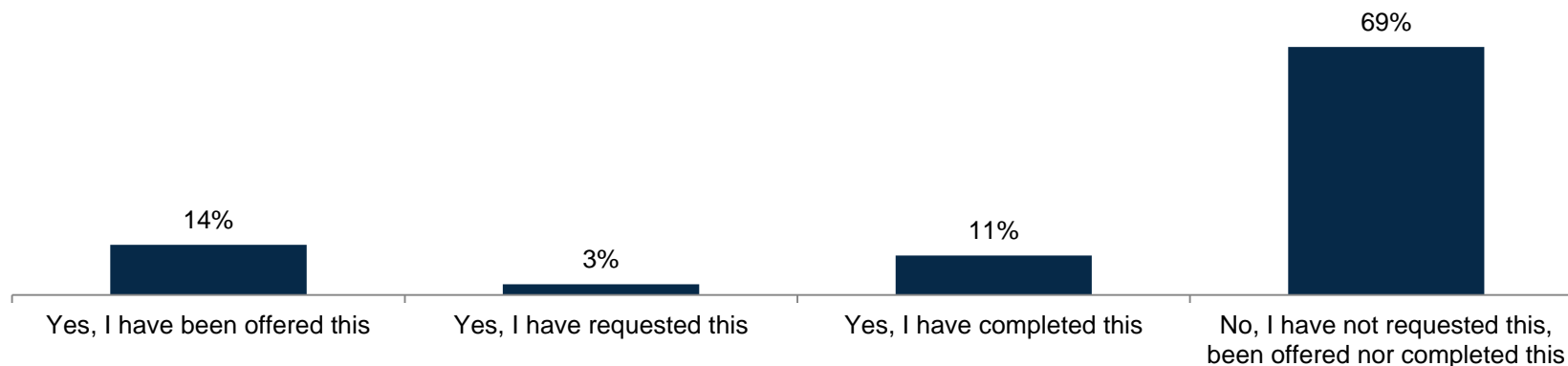


Respondents were told:
‘Since 2018, under the Carers (Scotland) Act 2016, every carer has a legal right to request support, known as an Adult Carers Support Plan or Young Carers Statement (for carers under 18). This captures information on your caring role and sets out how you wish to be supported as a carer.’

42% of respondents were aware of this fact.

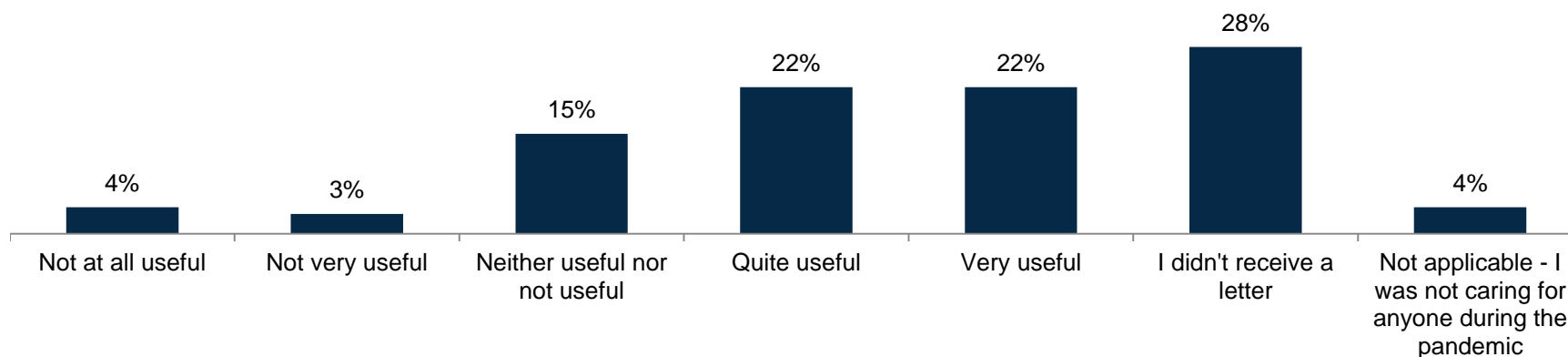
There were no significant variations in awareness according to carer characteristics.

Experience of Support Plan/Statement



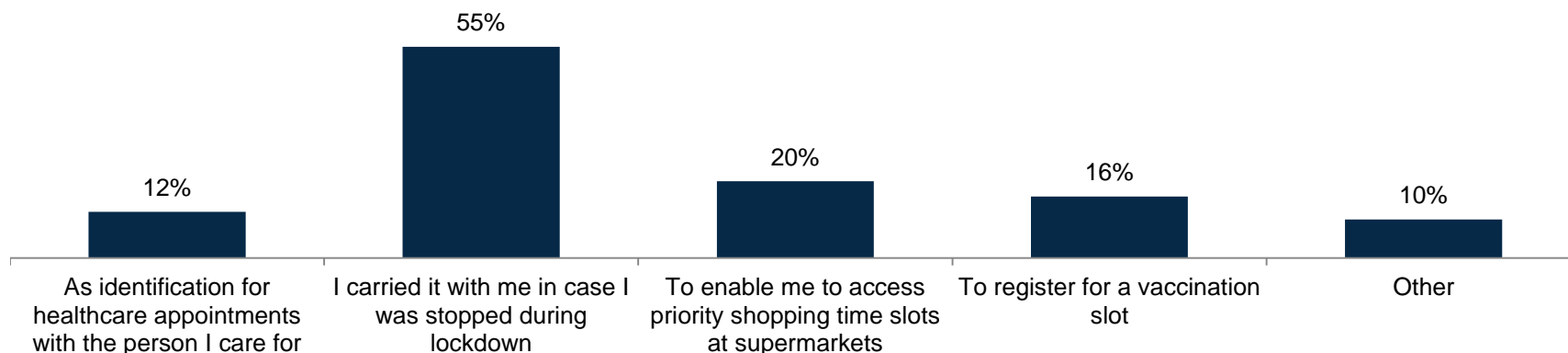
- 14% of respondents have been offered an Adult Carers Support Plan or Young Carers Statement. 3% have requested it themselves.
- 11% of respondents have completed this plan/statement.
- 69% of respondents – more than two thirds – have not requested, been offered nor completed a statement or plan. This is not due to recently becoming a carer; 71% of those who have been caring for 6-10 years report that they have no experience of a support plan.

Carer Identification During the Pandemic



- Respondents were asked how useful they found the Carers Identification Letter that was issued during the pandemic.
- Overall, 44% said that they found this 'quite' or 'very' useful.
- It is interesting to note that 28% of respondents report that they did not receive a letter. This figure was higher for people who have been caring for less than two years (42%) and those not engaged with VOCAL (37% - the figure for those engaged with VOCAL was 27%).

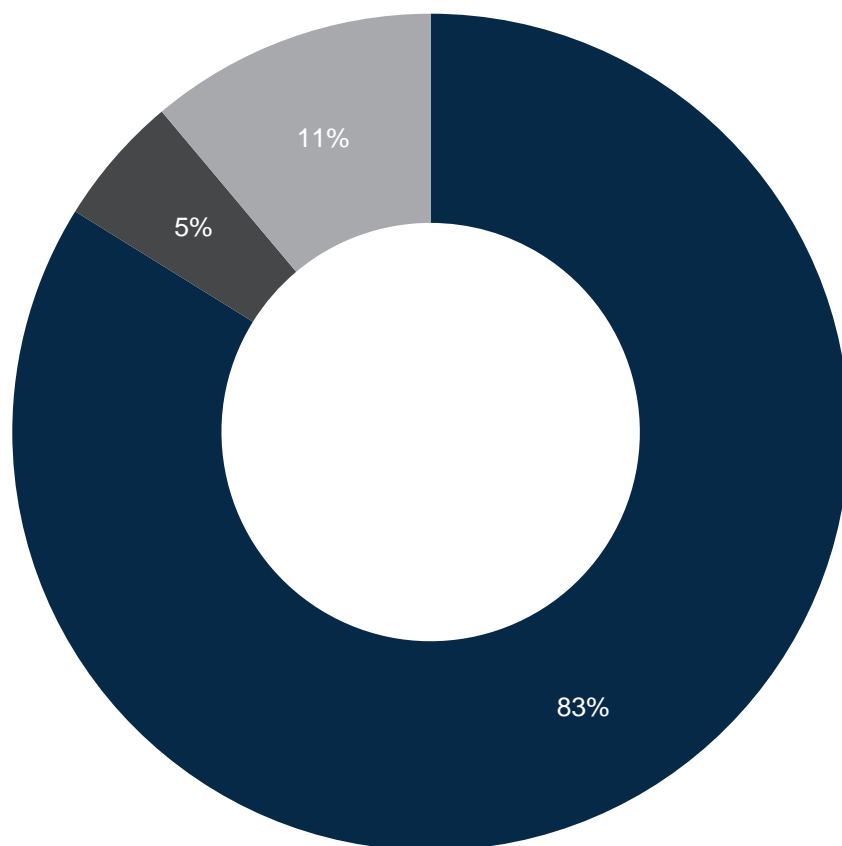
Use of the Carers Identification Letter



Base: All those who received the Carers Identification Letter (266)

- More than half of those who had received a Carers Identification Letter had used it as proof of status in case they were stopped during lockdown.
- 16% had used it to register for a vaccination slot and 20% to access priority time slots at supermarkets.
- 12% had used it as identification for healthcare appointments with the person they care for.

Interest in a National Carers Card

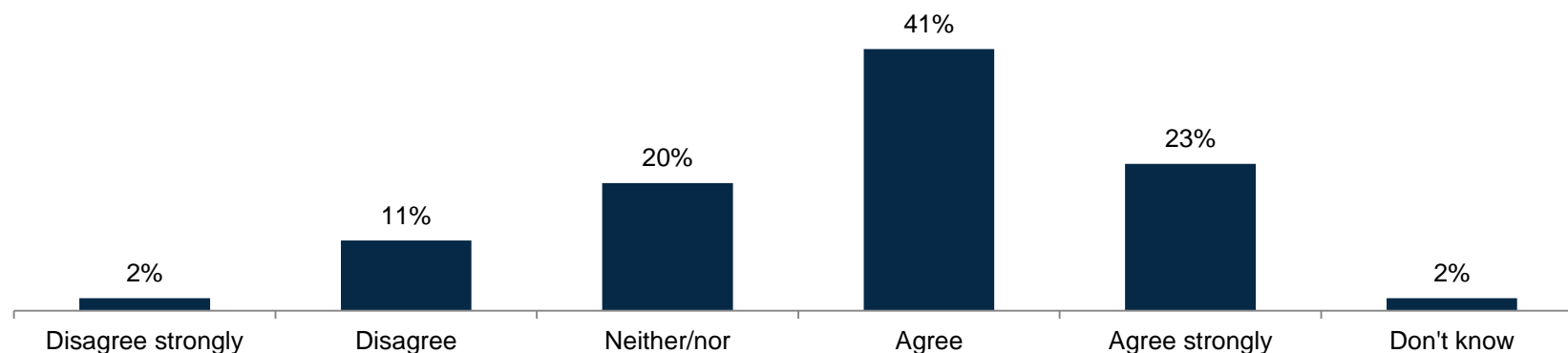


■ Would be interested ■ Would not be interested ■ Don't know

- 83% of respondents would be interested in a National Carers Card to identify them as having caring responsibilities and status.
- The 326 people who would be interested in having a National Carers Card were asked how they would use it:
 - 97% would use it as identification to show that they were a carer
 - 45% would be interested in using it to receive discounts at businesses and events
- The findings suggest strong support for this proposal.

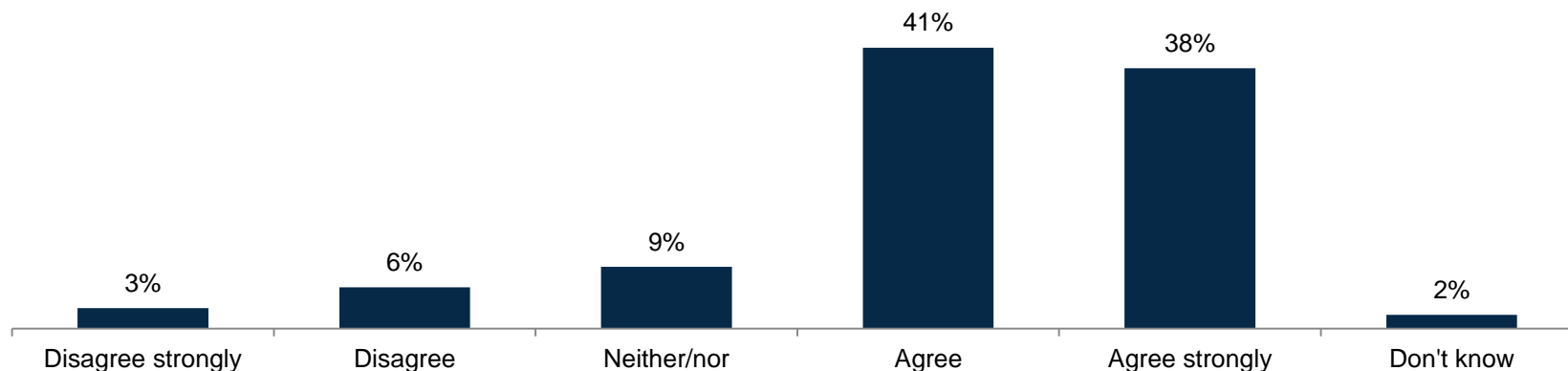
HEALTH AND WELLBEING

Health and Wellbeing: “Being a carer has affected my physical health.”



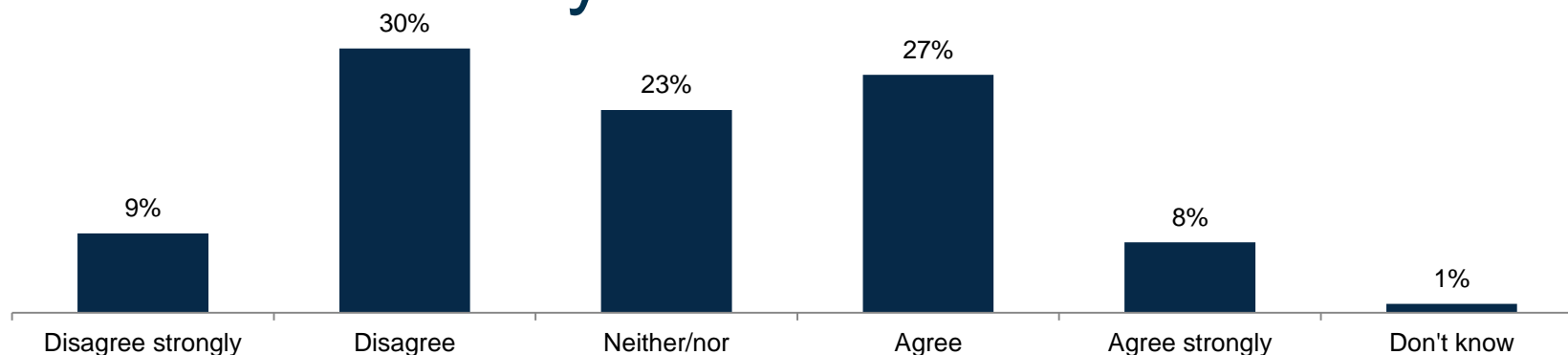
- 64% agreed that “being a carer has affected my physical health”. This compares with 55% in 2017 who agreed with the statement “being a carer has made my health worse.”
- As in 2017 there appears to be a relationship between the duration of care provided and the impact on physical health. 50% of those who have been caring for less than a year agree with this statement, compared with 67% of those who have been caring for 20 years.
- Nearly three quarters of those caring for someone under the age of 16 agree with this statement.

Health and Wellbeing: “Being a carer has affected my mental health.”



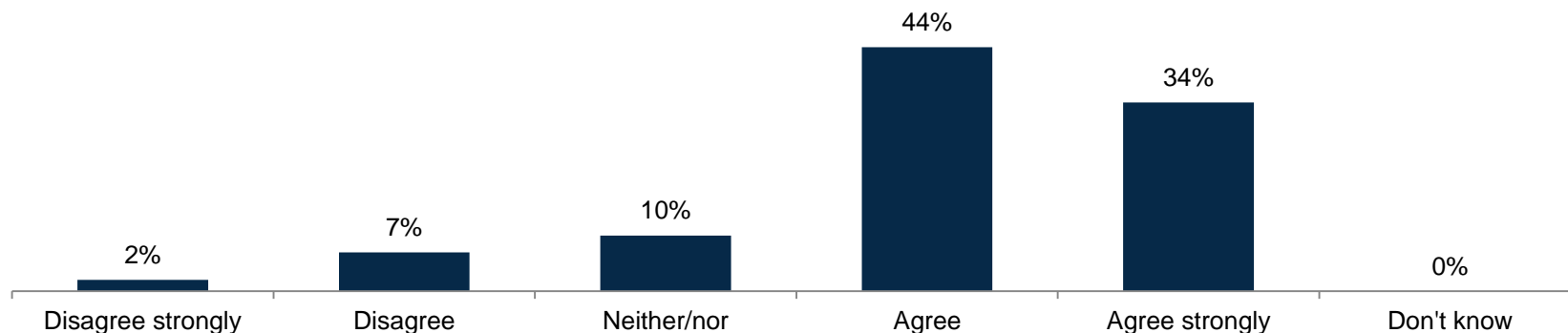
- 79% of respondents agreed that “being a carer has affected my mental health”, with 38% agreeing strongly. This compares with 55% in 2017 who agreed with the statement “being a carer has made my health worse.”
- The proportion of respondents agreeing with this statement is higher for people who are caring for more than one person (87%).
- Younger respondents are more likely to agree with this statement than older respondents: 94% of those aged 26-35 agree with this statement, compared with 17% of those aged 85 (small sample size).

Health and Wellbeing: “Since becoming a carer I have had more contact with health services about my own health.”



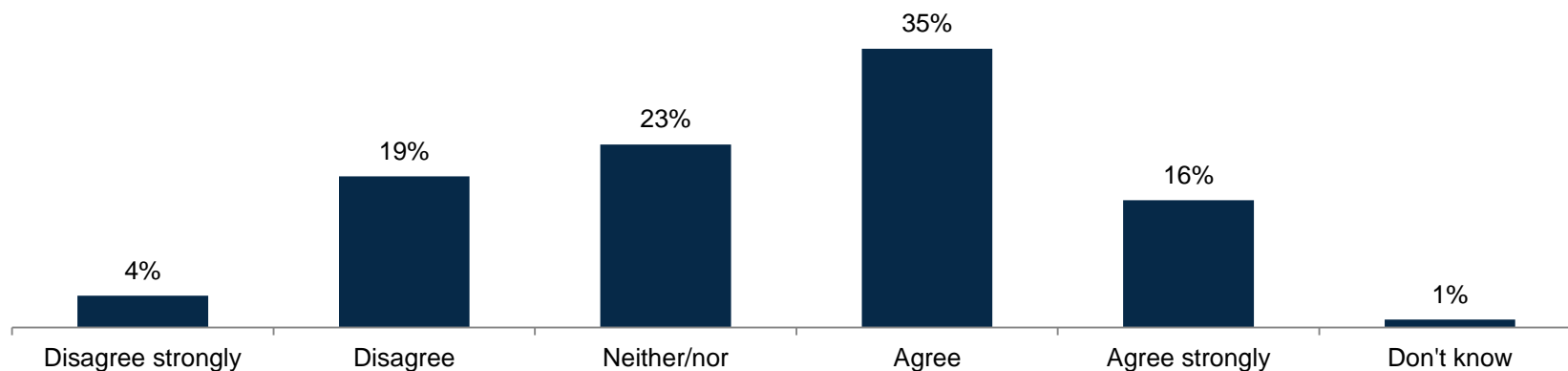
- 35% of respondents agree with this statement. This compares with 31% of respondents who reported an increased number of GP visits in 2017.
- Respondents who have been caring for more than 11 years were more likely to agree with this statement (40%), as were those caring for more than one person (42%), those aged 35-44 (47%) those in paid employment (41%) and those not in employment, education or retired and receiving a pension (40%).

Health and Wellbeing: “Being a carer affects the quality of my sleep”



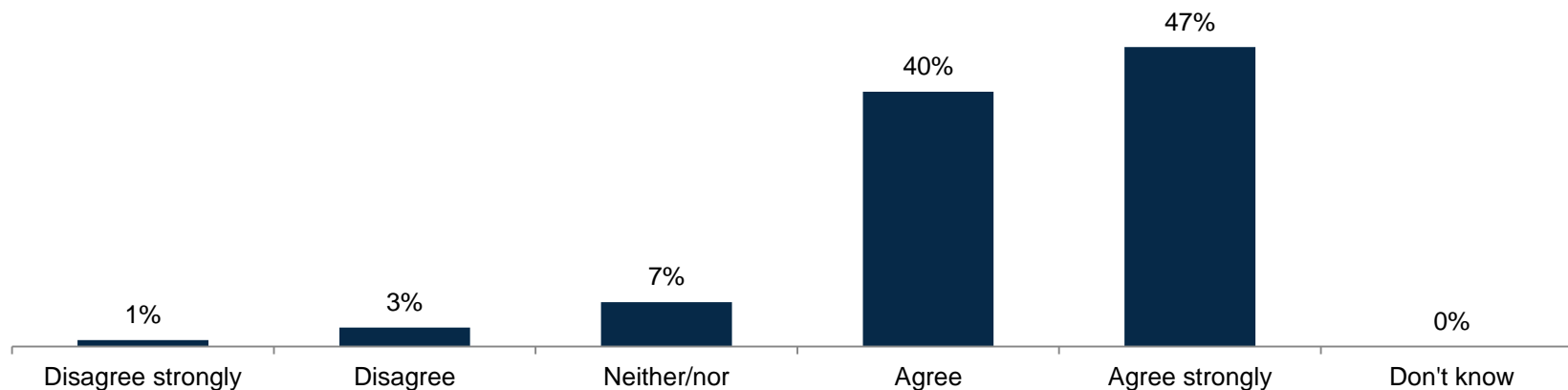
- 78% of respondents agree with this statement, a significant increase on the 58% figure from 2017.
- Respondents were more likely to agree with this statement if they were caring for someone with Autistic spectrum disorder (83%), Alzheimer's/dementia (84%), a learning disability (85%) or substance abuse (100% - note small sample size), as well as if they were caring for somebody aged 16-25 (85%).

Health and Wellbeing: “I feel isolated from family and friends”



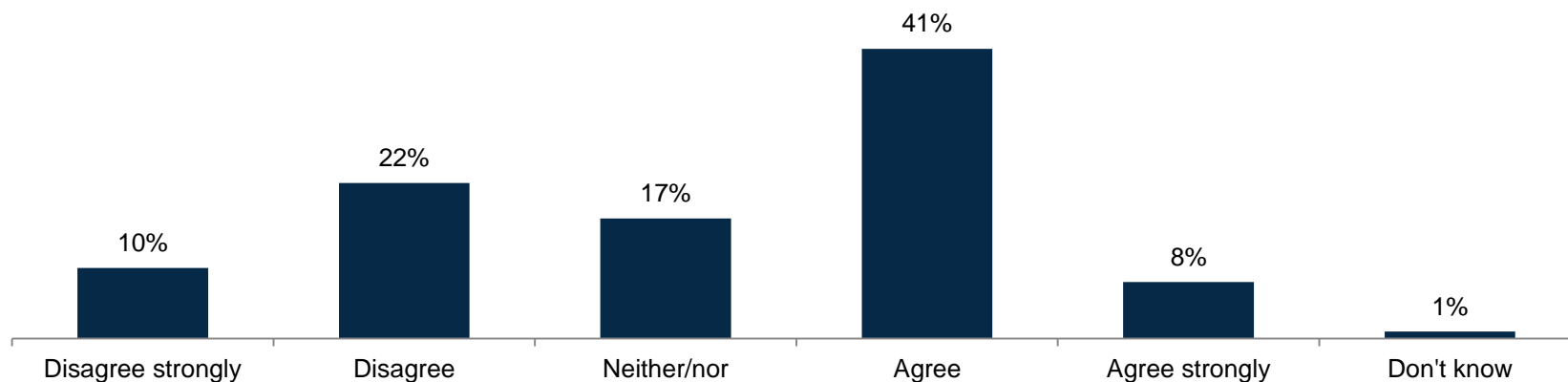
- 51% of carers agree that they feel isolated from family and friends, up from 42% in 2017 (the pandemic may have impacted responses to this question).
- The proportion of respondents agreeing with this statement is highest for people looking after their own child (59%), carers who have been caring for 11-19 years (62%) and carers of people aged 25 or under (64%).

Health and Wellbeing: “I worry about what will happen to the person I care for if I become ill.”



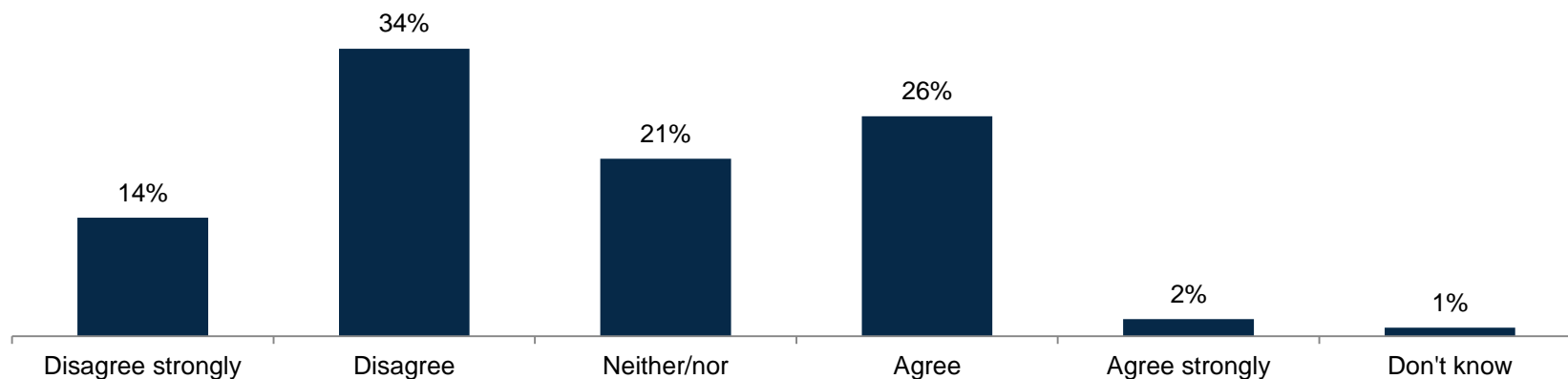
- 87% of respondents expressed concern about contingency planning, compared with 77% in 2017.
- The highest level of agreement to this statement came from respondents who live with the person they care for (90%), respondents looking after somebody aged 25 or under (94%) or 75-84 (91%), and those caring for more than 50 hours per week (92%).

Health and Wellbeing: “I have someone I can rely on for support in my caring role.”



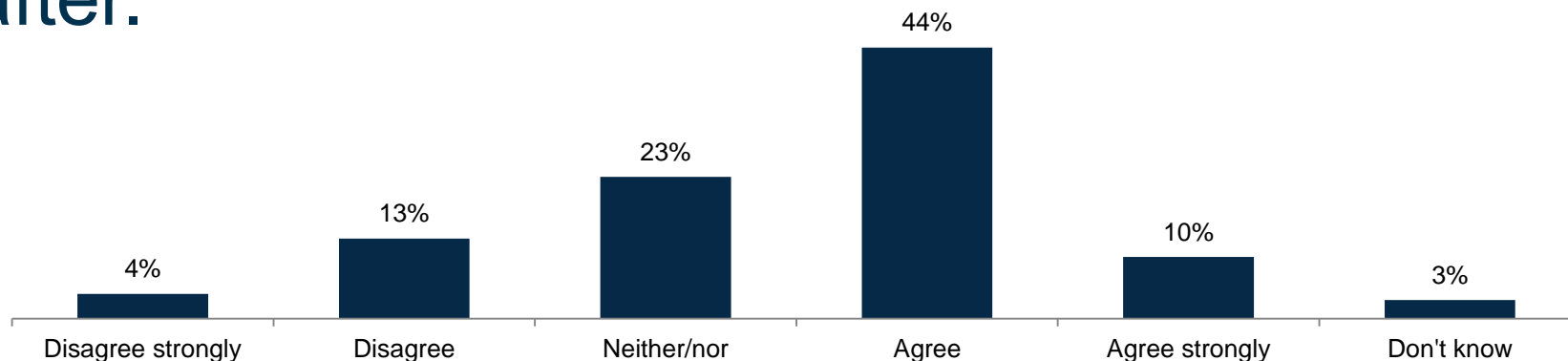
- Just under half (49%) of respondents felt that they had someone to rely on for support. This is slightly lower than the figure of 58% reported in 2017.
- 32% of respondents disagreed with this statement. This figure was higher for respondents who have been caring for 11-19 years (44%), those caring for people with mental health conditions (40%) and due to substance abuse (44%), and those caring for people aged 35-44 (47%).

Health and Wellbeing: “I have a good balance between caring and other things in my life.”



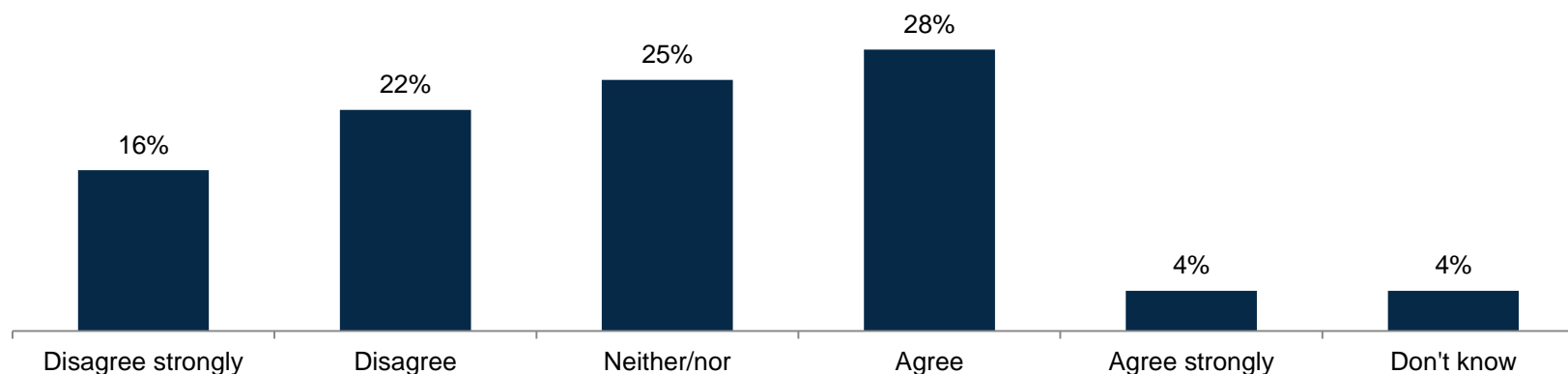
- 28% of respondents agreed that they were able to balance their caring role effectively with other things in their lives. 48%, nearly half of the Midlothian sample, disagreed with this.
- The proportion of respondents disagreeing was higher for respondents caring for their child (53%), or their spouse/partner (52%). Respondents caring for someone for more than 50 hours a week were also more likely to disagree with this statement (61%).

Health and Wellbeing: “I have a say in the services provided for the person(s) I look after.”



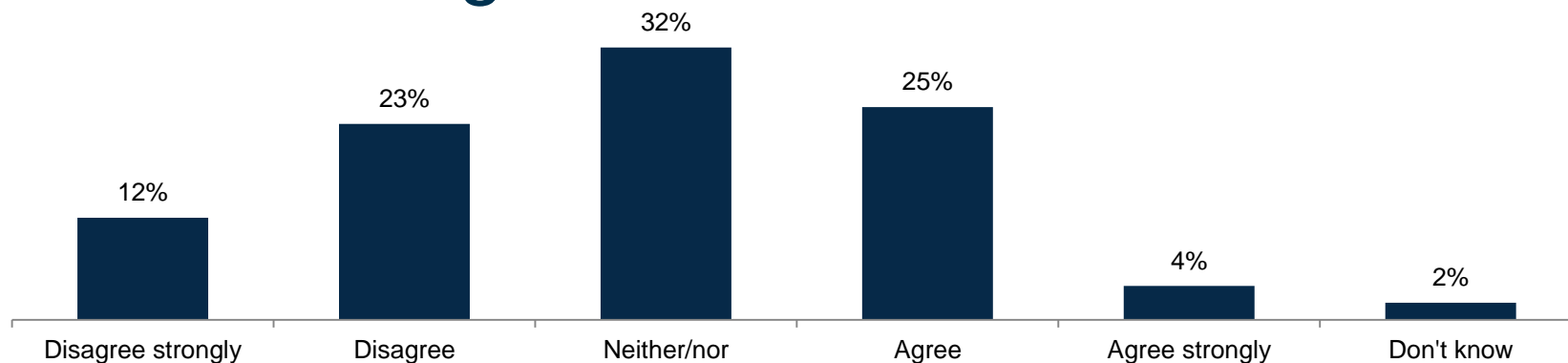
- Just over half of the sample agree with this statement, with 17% disagreeing.
- The level of disagreement was greater for those caring for someone due to substance abuse (31%) or visual impairment (26%) and those caring for people aged 16-25 (26%).

Health and Wellbeing: “Local services are well coordinated for the person(s) I look after.”



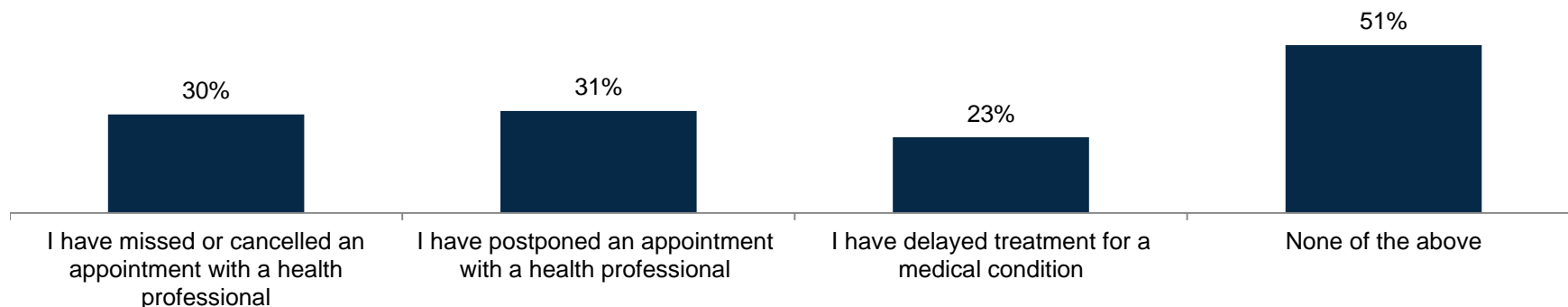
- 32% of the sample agree with this statement, with 38% disagreeing
- The level of disagreement increased with the time spent caring. 29% of respondents who had been caring for 1-2 years disagreed with this statement, increasing to 48% for those who have been caring for 11-20 years.
- Respondents were also more likely to disagree with this statement if they were caring for people with Autistic spectrum disorder (52%).
- Over half of people caring for people aged 16-25 and 35-44 disagreed with this statement.

Health and Wellbeing: “I feel supported to continue caring.”



- 29% of the sample agree with this statement, with 35% disagreeing.
- Respondents were most likely to agree to this statement if they provide care for 5-19 hours per week (37%).
- They were more likely to disagree if they were caring for a grandchild (70%), if they are caring for someone with a visual impairment (61%) or if they deem themselves to be in poor or very poor health (55%)

Health and Wellbeing: Impacts of Caring













- The responses to the survey suggest that respondents have experienced barriers to accessing care for themselves due to their caring role.
- 30% of respondents have missed or cancelled an appointment with a health professional.
- 31% have postponed an appointment with a health professional.
- 23% have delayed treatment for a medical condition.
- 49% of respondents say that they have experienced at least one of these impacts.

Health Impacts – Additional Comments (1)



153 carers made additional comments about the impact of caring on their health, many of which covered multiple issues.

95 respondents provided specific details of the impact of caring on their health:



-  *“It is a terrible strain on my life as I have to watch him all the time.”*
-  *“I am currently on antidepressants to help me in my caring role.”*
-  *“I feel completely exhausted. It has affected my sleep patterns I also have peripheral neuropathy which is harder to control as I have limited rest.”*
-  *“I feel burnt out and like I have no respite.”*
-  *“Significant mental health issues.”*
-  *“I have no room or time for appointments of my own right now as my role as a carer takes up almost all my time.”*
-  *“Suffer from anxiety, low mood, feeling of failure.”*
-  *“I am suffering from stress, anxiety, panic and confusion. I have physical conditions that I keep putting off for my own health care.”*
-  *“It's too easy to become focused on caring for someone else rather than looking after yourself.”*
-  *“I've been diagnosed with a overactive thyroid and I haven't been able to make a blood test in the past because I've been caring for my young child.”*

Health Impacts – Additional Comments (2)



18 respondents reported a loss of sense of self, or a lack of time to themselves to attend to health or social needs:

-  *“I have no time to myself. I do not prioritise myself enough.”*
-  *“I feel guilty taking time to do things for myself. I struggle to find the time to do things I enjoy.”*

13 respondents were concerned about the impact of relationships with other family members or with friends:

-  *“Losing touch with friends and family as I am very restricted in time away.”*
-  *“My marriage is under immense strain.”*

10 respondents mentioned financial worries and the impact that they have had on their health:

-  *“Just feel tired trying to hold down work and look after my family.”*
-  *“Trying to work but had to cut hours due to looking after my daughter. Worry about money and bills. Stress.”*

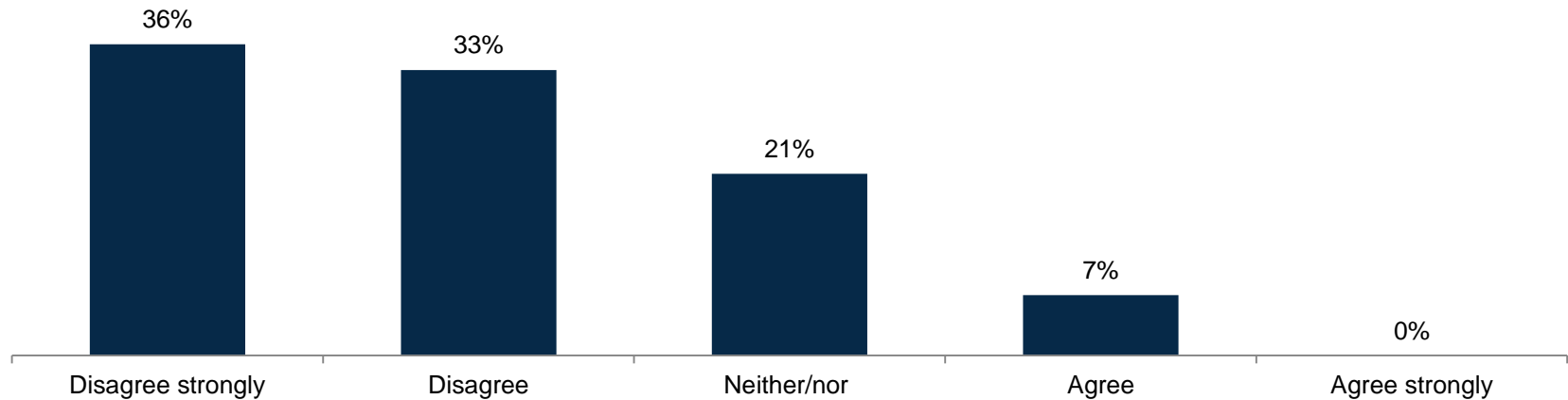
8 respondents reported feelings of guilt, anger and resentment, 6 talked about their fears for the future, 6 commented on the impact of the pandemic on closing services and creating barriers to accessing healthcare, and 5 talked about the additional stress caused by having to interact with agencies in order to secure support.

Health Impacts – Key Findings

- The responses to the health and wellbeing questions suggest that, across all measures, the health and wellbeing impacts of caring are more acute in 2021 than they were in 2017.
 - 64% of respondents agree that caring has impacted their physical health and 79% that it has affected their mental health.
 - Only 29% of respondents agree that they feel supported to continue caring. 32% feel that local services are well coordinated for the person they care for, and there is evidence in the open-ended comments that dealing with multiple agencies adds to the mental load for carers.
 - Almost half of respondents report that their caring role has resulted in missed or postponed appointments or a delay in treatment for their own health.
-

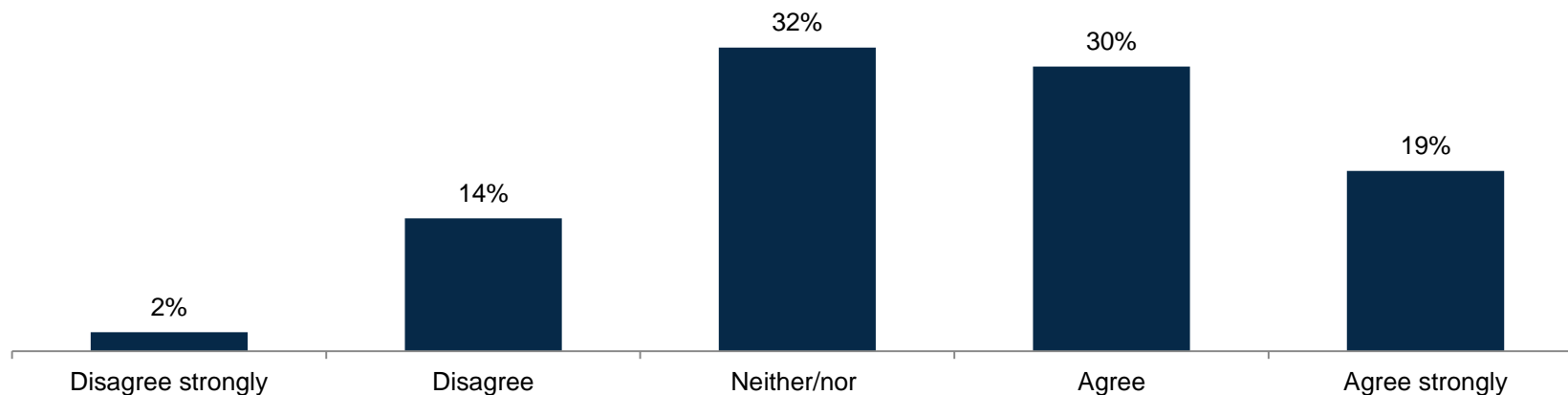
MONEY AND WORK

Money and Work: “Being a carer has improved my finances.”



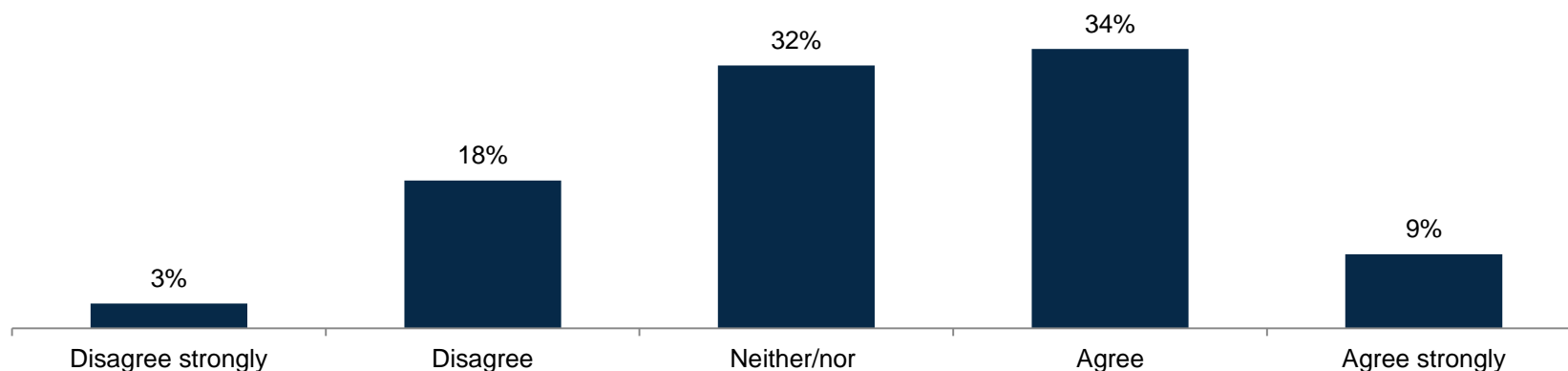
- Only 7% of the Midlothian sample agreed with this statement. 69% disagreed.

Money and Work: “Being a carer has negatively impacted my finances.”



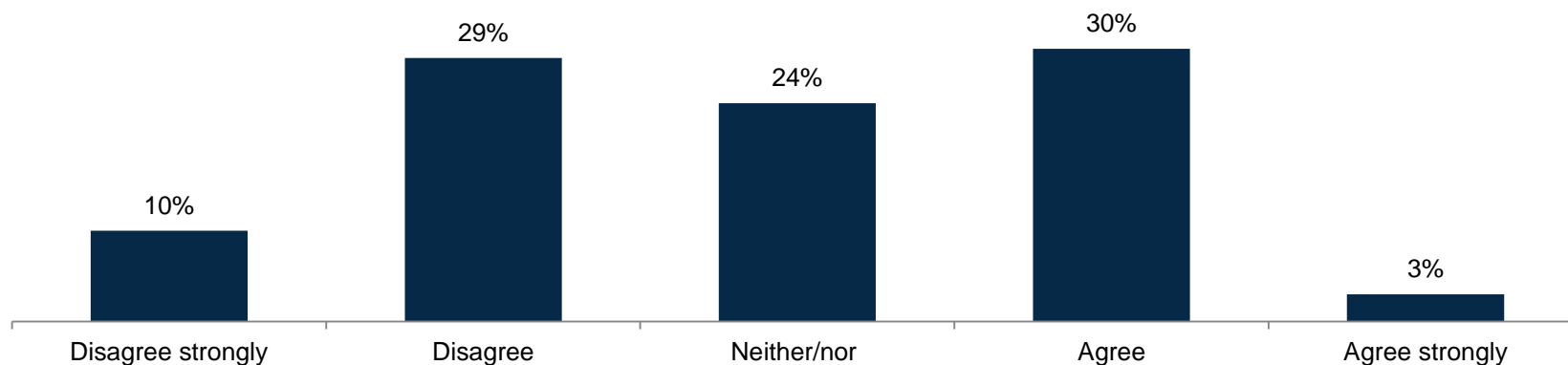
- 49% of respondents agreed with this statement, 19% of them agreeing strongly. This is in line with the 48% of respondents who agreed ‘being a carer has made money and finances more difficult’ in 2017.
- The level of agreement was higher for respondents caring for a child (55%), respondents spending 35-50 hours per week caring (66%) and respondents aged 55-65 (60%).

Money and Work: “I find it hard to talk about how caring affects me financially.”



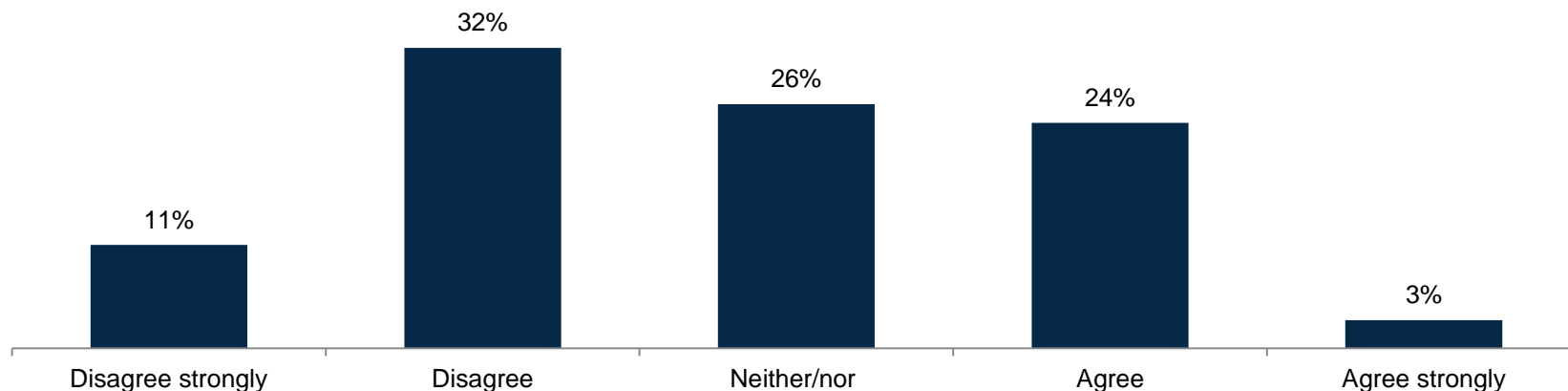
- 43% of respondents agreed with this statement, in line with the 2017 figure (42%).
- Respondents were more likely to agree with this statement if they were caring for somebody due to a mental health condition (50%) or substance abuse (82% - small sample size), or if they do not receive a salary or a pension (52%).
- There is continued clear evidence of stigma and emotional challenge associated with talking about the financial impact of caring.

Money and Work: “I know what financial support I can access.”



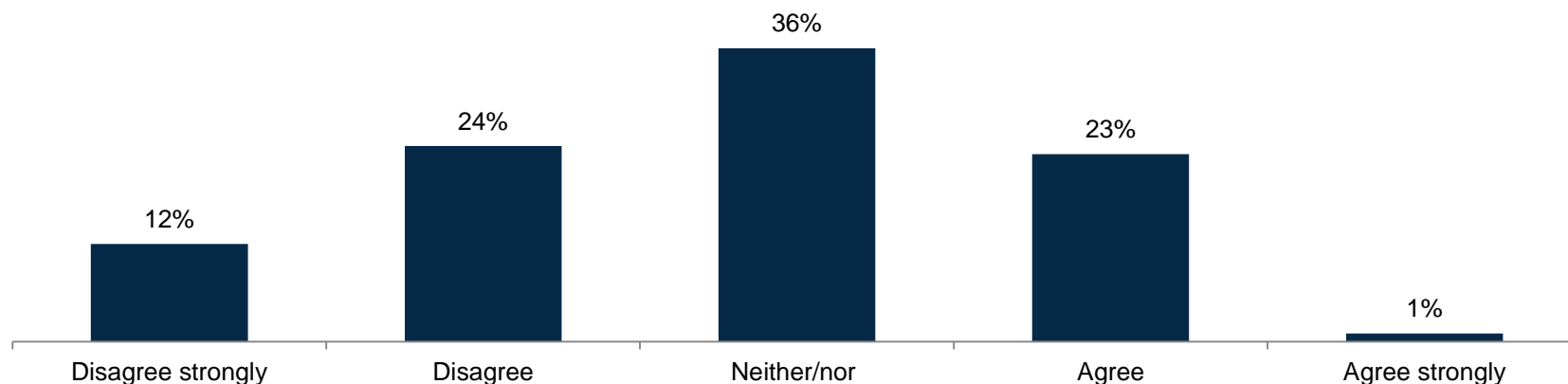
- 33% of respondents agreed with this statement, with only 3% agreeing strongly. This has dropped from the 2017 figure of 38%.
- Responses to this question were fairly consistent. There was some variation in terms of the conditions of the people being cared for, with 42% of those caring for people with Alzheimer's/dementia agreeing, compared with just 12% of those caring for someone due to substance abuse.

Money and Work: “I am confident in applying for financial support.”



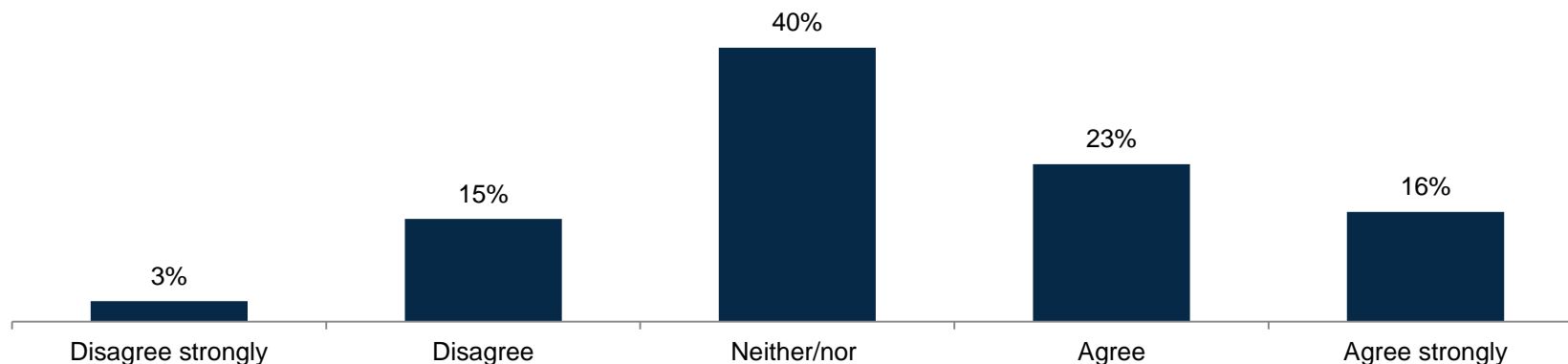
- Just 27% of respondents agreed with this statement, with only 3% agreeing strongly. This is slightly lower than the 2017 figure of 29%, where 3% agreed strongly.
- Agreement with this statement was notably low for people caring for individuals due to substance abuse (12%), again suggesting that there may be additional challenges for this group of carers (please note small sample size).

Money and Work: “I have enough financial support available.”



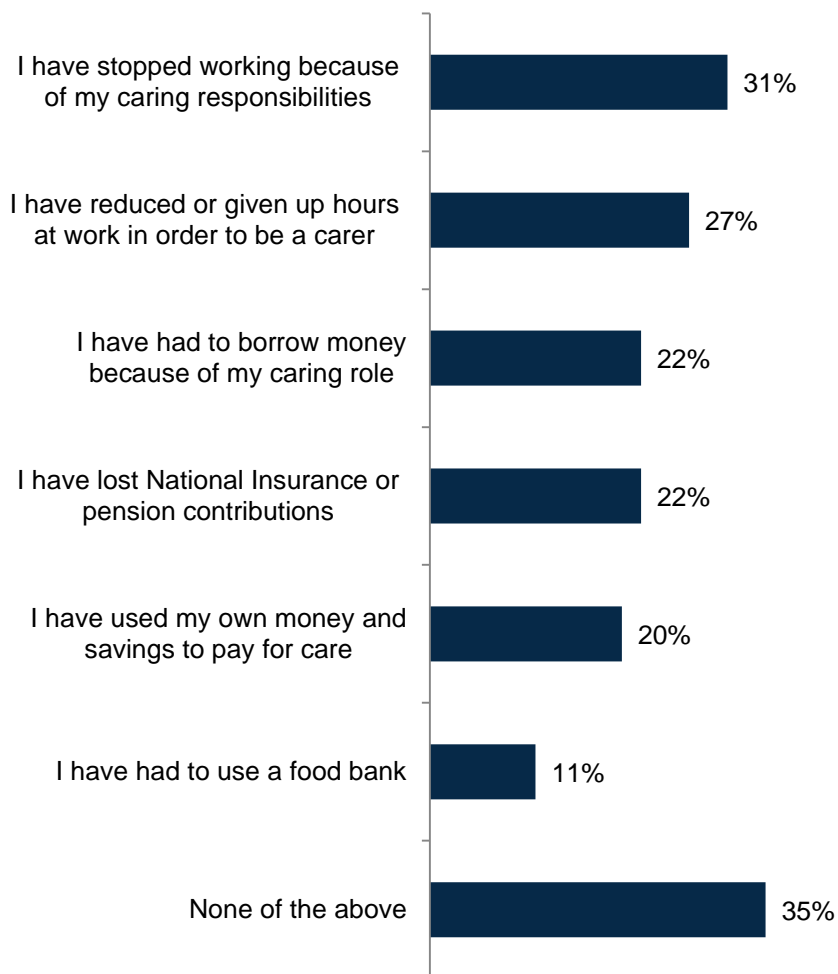
- Just less than a quarter of respondents (24%) agreed with this statement, down from 31% in 2017.
- 36% of respondents disagreed with this statement. The level of disagreement was higher for those who had been caring for 11-19 years (44%), respondents caring for people with mental health conditions (43%), learning disabilities (44%), substance abuse (56%) and visual impairment (45%).

Money and Work: “I worry about paying for care and/or care home fees.”



- 39% of respondents agree with this statement. This is higher than the 32% agreement level in 2017.
- Unsurprisingly, concern over this issue is highest (although not exclusively so) for those caring for older people. 43% of those caring for a parent are worried about paying for care, compared with 28% of those caring for their child.
- Reflecting this, respondents are also more likely to agree with this statement if they have been caring for 1-2 years (45%), are caring for somebody with Alzheimer's/dementia (49%) or a palliative condition (56%), and are caring for someone aged 75-84 (48%).

Financial Impacts of Caring




- 65% of respondents report at least one of the suggested financial impacts of caring.
- 31% have stopped working (up from 24% in 2017).
- 27% have had to reduce their hours (up from 22% in 2017).
- 20% have used their own money to pay for care. This is down on the 2017 figure of 29%.
- 22% have lost NI or pension contributions as a result of giving up work- this is much higher than the 11% figure from 2017 and is likely a reflection of the different demographic in 2021.
- In new questions for 2021, 22% of respondents have had to borrow money because of their caring role, and 11% have had to use a food bank.

Money and Work– Additional Comments (1)


75 respondents made additional comments about the impact of caring on their finances.

36 respondents provided specific details of the impact of caring on their financial situation:


 *“I use Visa cards and bank loans to help me get by.”*

 *“Its expensive! All the adaptations to the house and equipment and continence care add up. we are worse off than we ever were.”*

15 talked about the impact of reducing or giving up paid work:

 *“I have lost hours of work due to having to care for my grandson at short notice. I am unable to commit to a contract due to my caring roles therefore rely on short notice supply work when it is available and I am too.”*

8 talked about challenges with the benefits and funding system:

 *“I am on the top level of ESA and high level of PIP mobility and low level of care for myself. I have had to get a car to allow me to keep caring and I can't claim anything else.”*

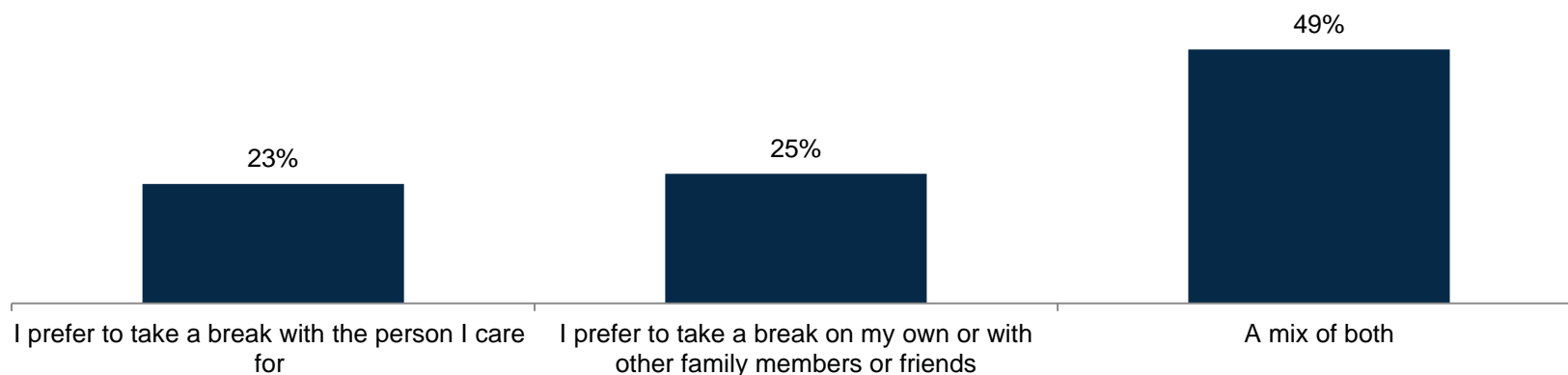
Other subjects (each mentioned by 5 or fewer respondents) were: concerns about planning for the future (5) and the impact of the pandemic in increasing financial concerns (1)

Impact on Money and Work– Key Findings (1)

- As with the health and wellbeing questions, the impact of caring on money and work appears to be more significant in 2021 than it was in 2017.
 - This may in part reflect the change in respondent profile, with more carers being of working age than in 2017. 31% have stopped working because of their caring role, up from 24% in 2017.
 - 49% of respondents agree that being a carer has negatively impacted on their finances and only 24% agree that they have enough financial support available.
 - There is continued evidence of stigma around this issue, with 43% agreeing that they find it hard to talk about the financial implications of their caring role.
 - 33% of respondents know what financial support they can access and 27% feel confident in applying for it.
 - 22% - nearly a quarter of respondents – have had to borrow money because of their caring role. 11% have used a food bank.
-

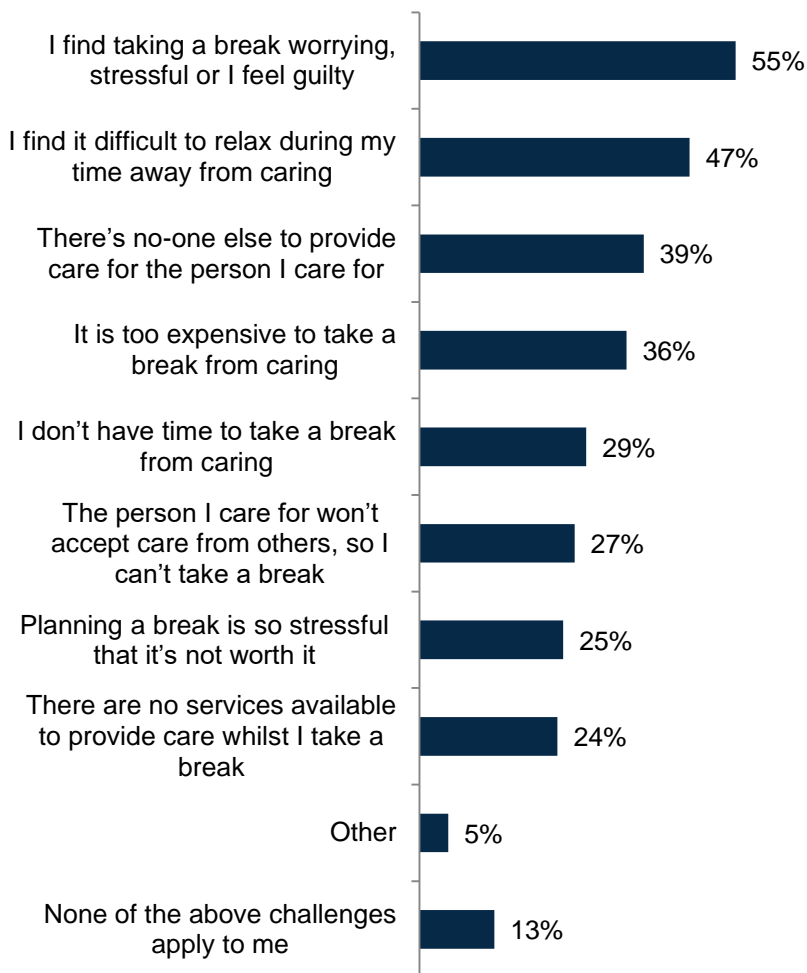
TIME AWAY FROM CARING

Time Away From Caring: Preferences



- 23% of respondents say that they would prefer to take a break from caring with the person they care for.
- 25% say that they would prefer to take a break on their own or with other family members or friends.
- Nearly half of the sample would like to do both.

Barriers to a break from caring



- Over half of carers find taking a break hard, citing feelings of stress, guilt and worry.
- 47% say that they find it difficult to relax whilst they are not caring – an increase from 28% in 2017.
- 39% say that there is nobody else to provide care, and 27% that the person they care for won't accept care from others (the corresponding figure for 2017 was also 27%).
- 36% agree that it is too expensive to take a break from caring – up from 19% in 2017.
- 25% agree that planning a break is so stressful that it's not worth it – up from 22% in 2017.
- 24% of respondents say that there are no services available to provide care whilst they take a break, and 29% that they don't have time to take a break.
- Overall, 87% of respondents say that at least one of these challenges applies to them. As in 2017, those caring for those aged 25 and under are more likely to have experienced at least one of these barriers.







Time Away: A Good Break (1)

Respondents were asked what a good break would look like for them. 320 respondents answered this question.







Responses covered some common themes, many of which reflect the findings of the previous slides:

- The opportunity to take a break from caring duties and their usual daily routine.
 - The ability for the carer to 'be themselves', and perhaps be looked after too (not have to cook, for example).
 - Being confident that the person they care for is also looked after, whether or not they are on the break with them.
 - For respondents with children or partners, the opportunity to spend time together as a family.
 - Peace and quiet were mentioned often, although a minority of respondents would like to go away with family or friends and have fun. All wanted to relax.
 - In terms of locations, countryside and seaside locations were mentioned most frequently, with many respondents saying that they found it relaxing being near water.
 - Some respondents pointed out that a break does not need to be an overnight trip; they would be content with a couple of hours knowing that they would be undisturbed.
-

Time Away: A Good Break (2)

-  *“Time out during the day for physical exercise or a weekend away to destress.”*
 -  *“Son being cared for even if it is one night away and we are at home doing nothing. but we would still worry about him being away, as he has never been to overnight respite.”*
 -  *“Peaceful, relaxing, nice food, weather and company.”*
 -  *“Spending time alone, in total peace & perhaps with the sound of the waves maybe on a beach or cliff top listening the crashing waves. Being near Water I find relaxing.”*
 -  *“My wife and I would like to have a weekend away. But we don’t have the abilities to send our daughter elsewhere to enable us to have a break.”*
 -  *“Regular opportunities to be on my own outside of work and caring. If I’m not at work, I am caring and it can be draining.”*
-

Time Away: A Good Break (3)

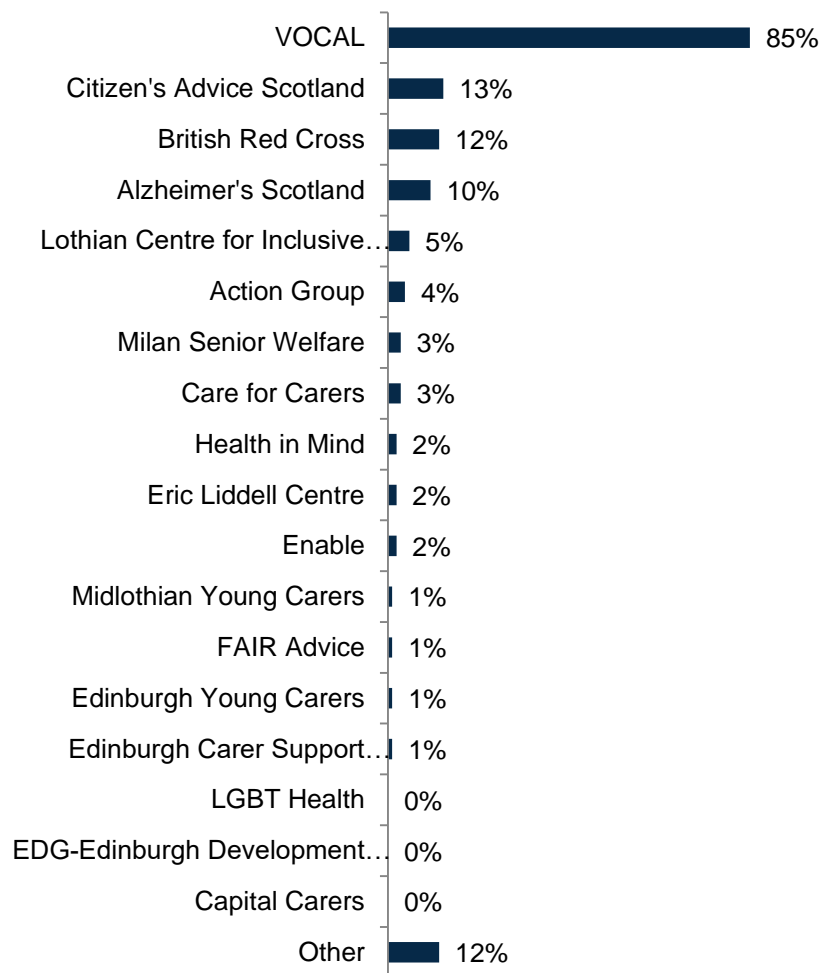
-  *“Myself and my kids away from the stress of our normal day to day life.”*
 -  *“A good break will be to go on my own or with other friends that are carers too and just relax. Sync ourselves with the landscape, go for walks, enjoy reading a book, and have a laugh with friends.”*
 -  *“Somewhere I can switch off from everything.”*
 -  *“Taking the people I care for away with me. Log cabin with hot tub, in the countryside.”*
 -  *“Time to relax for myself. Be a bit selfish. Not having to worry.”*
 -  *“Absolutely anything!! Even just a weekend in my own home would be amazing!”*
-

Time Away: Key Findings

- 23% of respondents would like to be able to take a break with the person they care for. 25% would like to go away on their own, or with other family or friends. 49% would like to do both.
 - 87% of respondents experience challenges when taking a break – and all of the barriers are experienced to a greater extent than in 2017.
 - The main barriers are the carers' feelings of stress, guilt and worry, resulting in them finding it difficult to relax, and a lack of support to look after the person they care for whilst they take a break.
 - When asked to describe a good break, respondents talked about a respite from their caring duties, an opportunity to 'be themselves' and being confident that the person they care for is well looked after, whether or not they are on the break with them.
 - A break does not have to be an overnight holiday – many carers would just like a few hours to themselves.
-

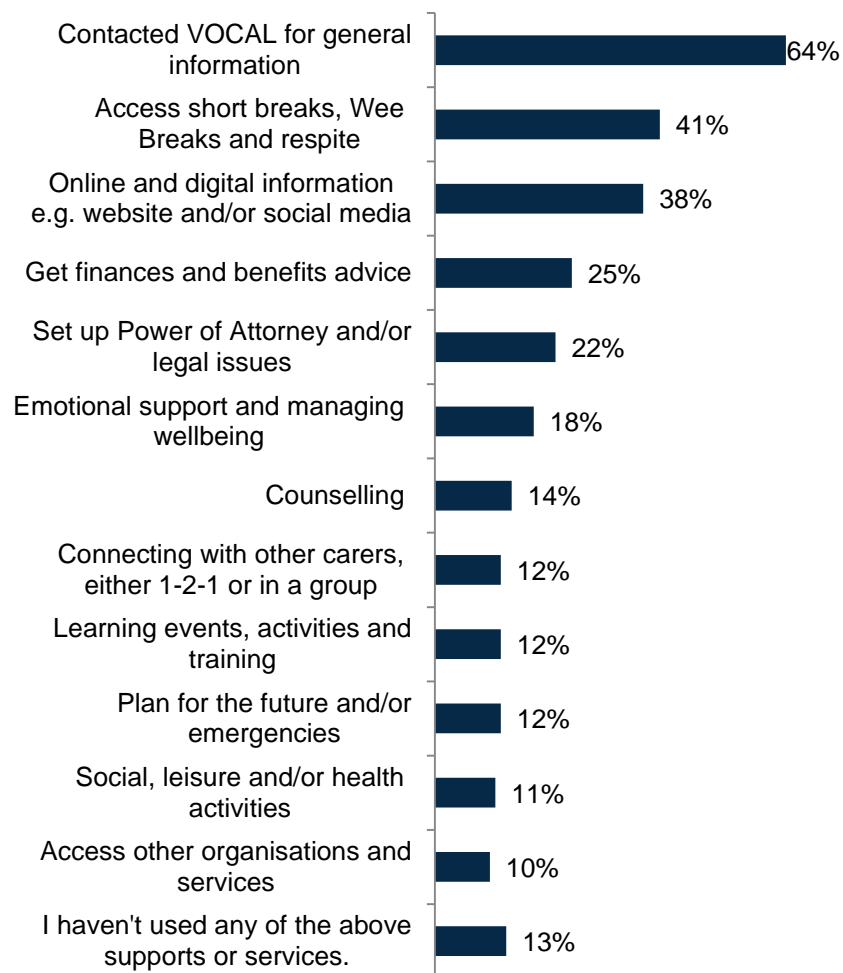
VOCAL

Agencies Used for Support



- Respondents were asked to identify which services and organisations have supported them in their caring role.
- As shown in Slide 22, 85% had engaged with VOCAL, making this by far the most engaged-with agency.
- Citizen's Advice Scotland, British Red Cross and Alzheimer's Scotland were the other agencies with the highest levels of engagement.

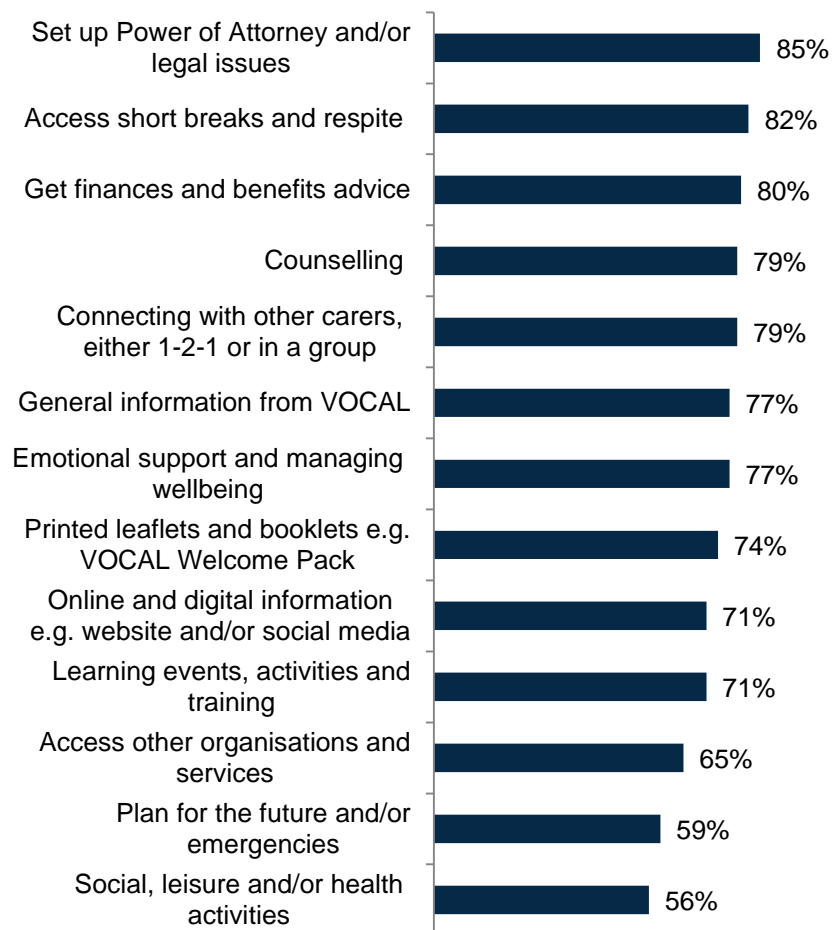
Uptake of VOCAL Services



- The most used VOCAL services were: obtaining general information; Wee Breaks and respite; and online and digital information.
- This underlines the importance of a multi-channel approach for engagement and support (see Slide 90).
- In terms of tangible support, respondents were most likely to attend get finances and benefits advice, set up Power of Attorney and/or legal issues, and access emotional support and managing wellbeing.

Base: All those who have engaged with VOCAL (335)

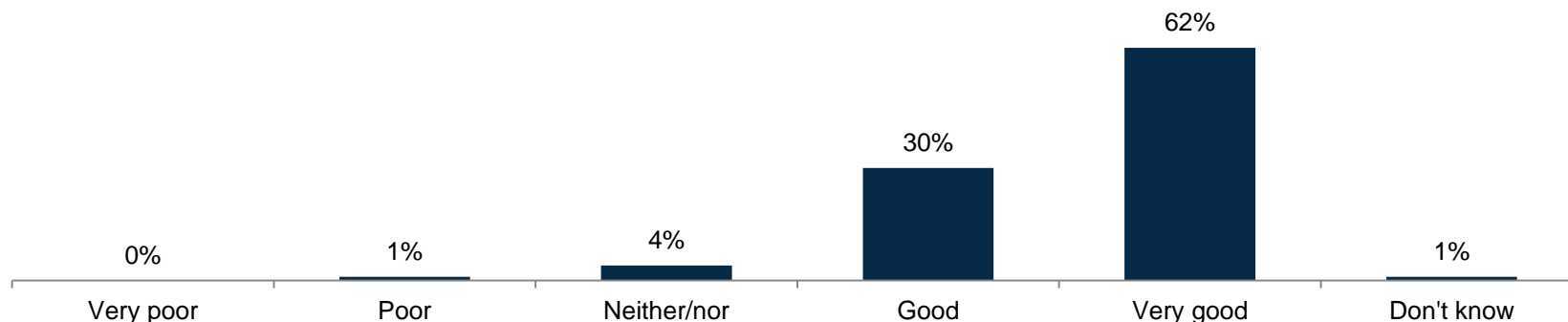
Value of VOCAL Services



- Respondents who have used each of the services were asked how useful they found them.
- Satisfaction ratings overall were very high, ranging from 85% for setting up a Power of Attorney and/or legal issues to 59% for planning for the future and/or emergencies.
- Social, leisure and/or health activities satisfaction was at 56%; it is likely that the pandemic will have particularly impacted on delivery of these types of activity.

Base: All those who have used each of the services

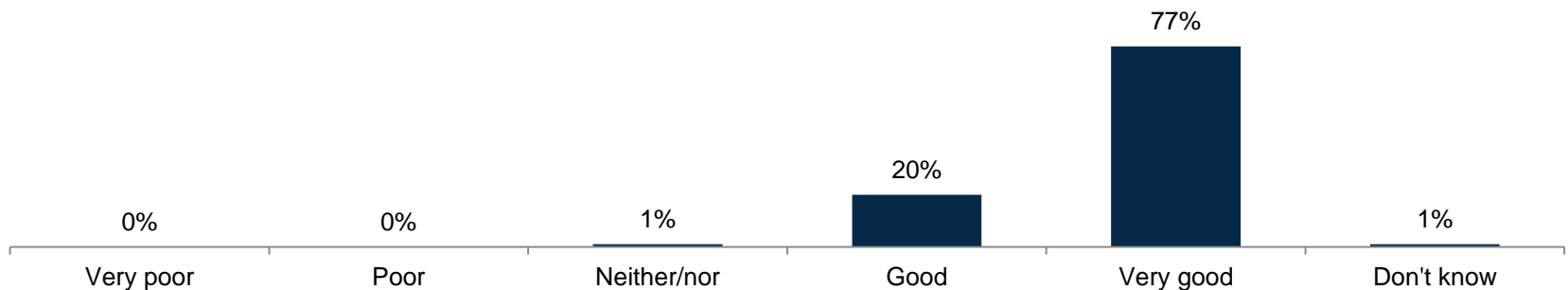
Satisfaction: Ease of getting in touch



Base: All those who have engaged with VOCAL (335)

- 92% said that this aspect of their experience was “very good” or “good”.
- This compares with 94% in 2017 (although in 2017 VOCAL had not experienced lockdown in the survey year!).
- There was very little variation across the sample for this question.

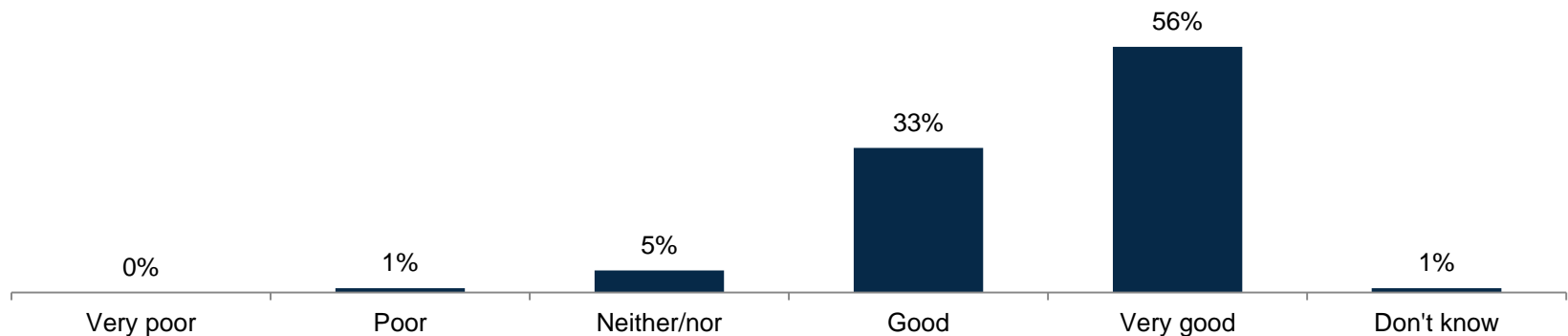
Satisfaction: Friendliness of Response



Base: All those who have engaged with VOCAL (335)

- 97% said that this aspect of their experience was “very good” or “good”, with more than three quarters (77%) choosing “very good”.
- This is higher than the figure for 2017 (94%)!
- Again there was very little variation across the sample for this question.

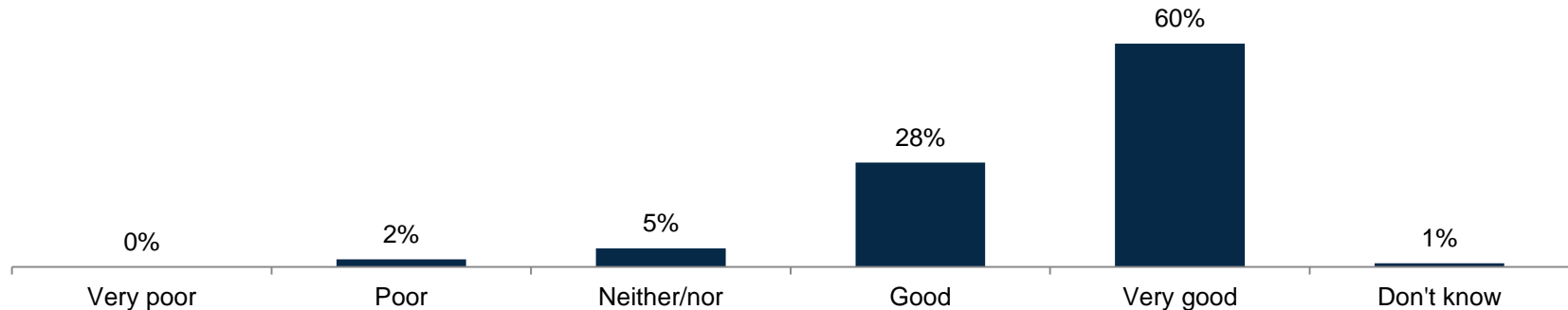
Satisfaction: Timeliness of Response



Base: All those who have engaged with VOCAL (335)

- This was a new question for 2021.
- 56% of respondents said that this aspect of their experience was “very good” and 33% that it was “good” – 89% in total had a positive experience.
- Again the response to this question was fairly consistent.

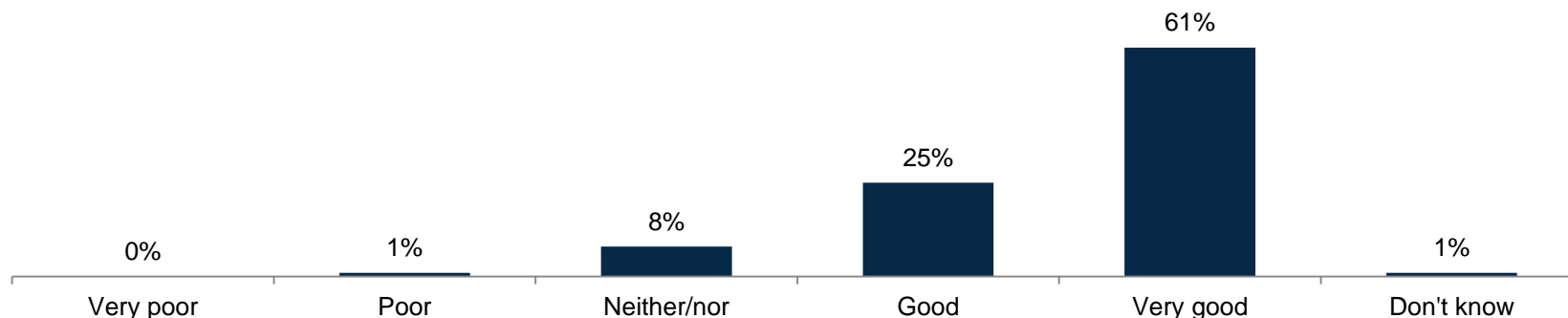
Satisfaction: Getting the Information and Support I Needed



Base: All those who have engaged with VOCAL (335)

- 60% of respondents said that this aspect of their experience was “very good” and 28% that it was “good” – 88% in total had a positive experience.
- This is in line with 88% positive feedback in 2017 to the statement ‘getting as much information as you needed.’

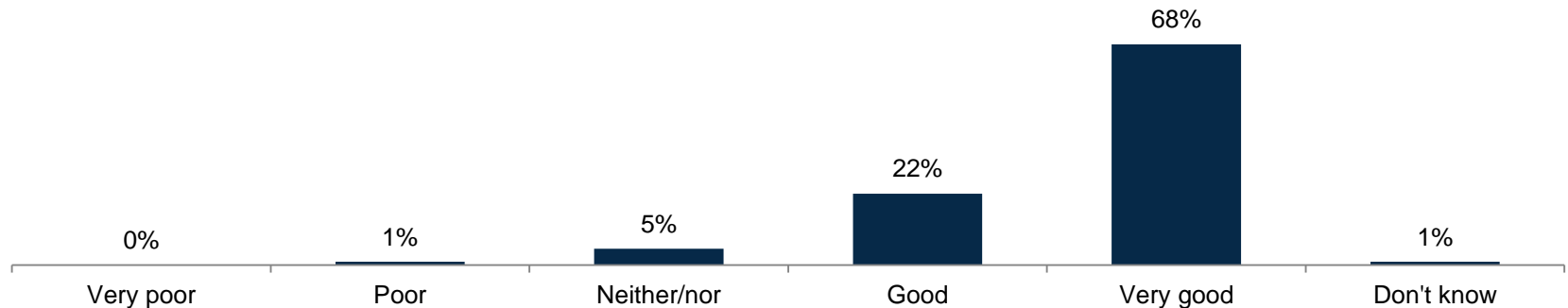
Satisfaction: Knowledge of Staff and Volunteers



Base: All those who have engaged with VOCAL (335)

- 61% of respondents said that this aspect of their experience was “very good” and 25% that it was “good” – 86% in total had a positive experience.
- This compares with a figure of 85% in 2017.

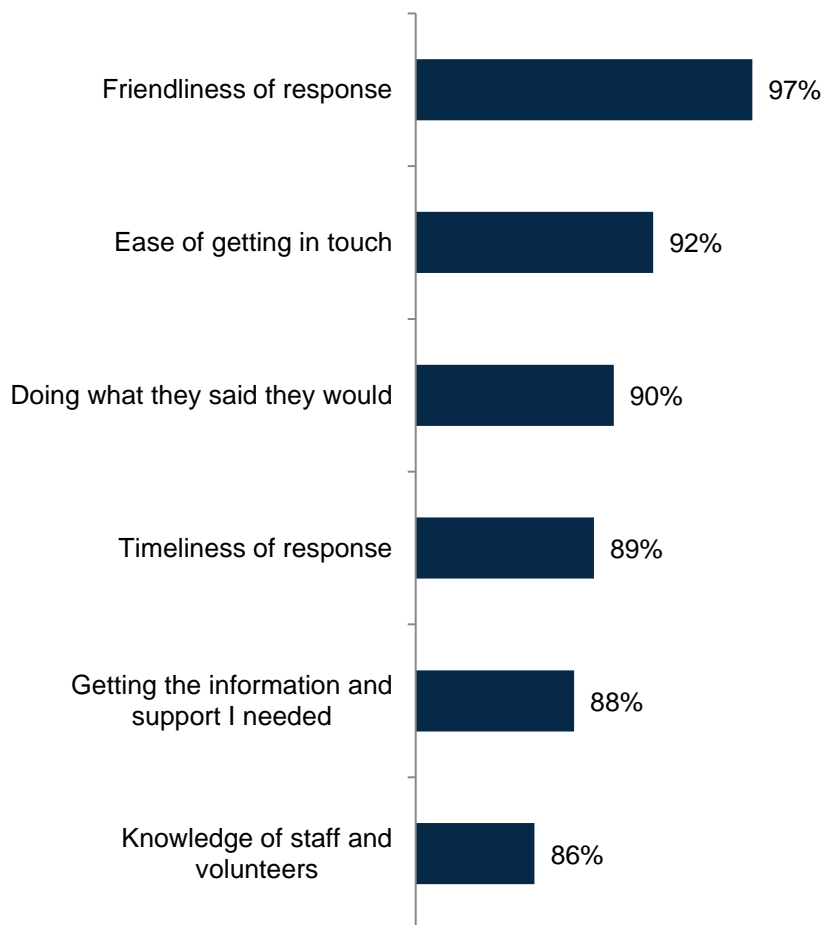
Satisfaction: Doing What They Said They Would



Base: All those who have engaged with VOCAL (335)

- 68% of respondents said that this aspect of their experience was “very good” and 22% that it was “good” – 90% in total had a positive experience.
- This is higher than the 2017 figure of 87%.

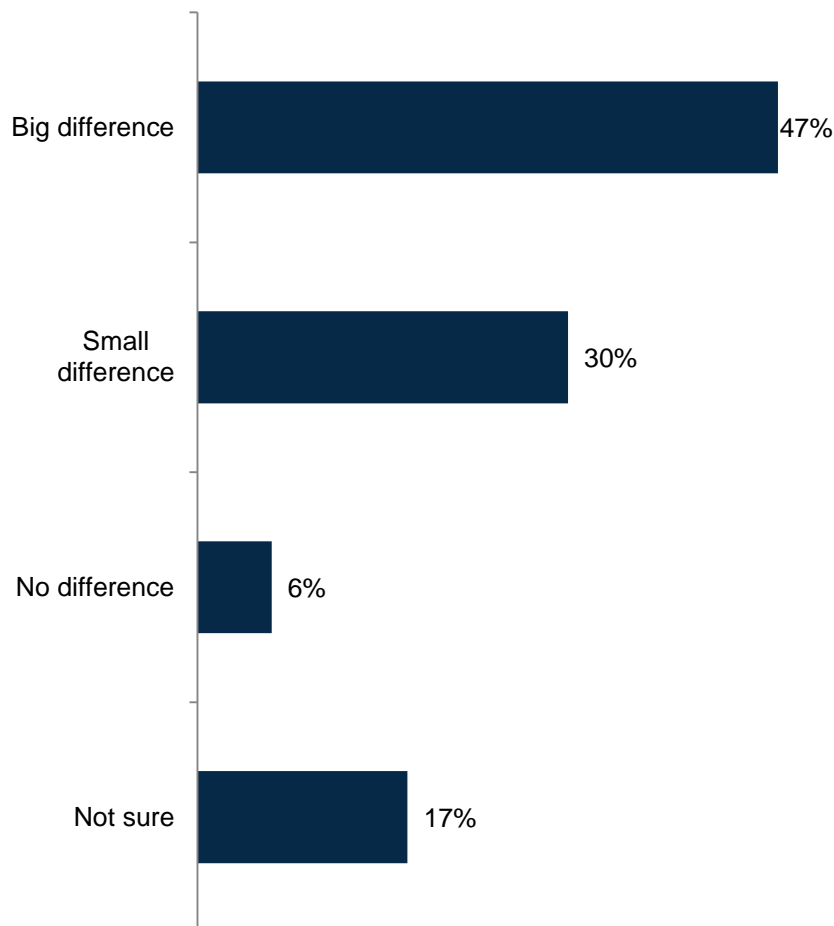
Satisfaction Ratings: “Good” or “Very Good”



Base: All those who have engaged with VOCAL (293)

- This would be regarded as an excellent performance in any year; to have achieved this in 2021 after the challenges of lockdown is particularly noteworthy.
- Satisfaction across all measures is in line or above the figures in 2017!
- As in 2017, the friendliness of the response is a particular strength, with 77% rating this as ‘very good’.

Impact of VOCAL



Base: All those who have engaged with VOCAL (335)

- Overall, 77% of respondents who have engaged with VOCAL say that this has made a difference to their experience as a carer.
- 47% say that VOCAL has made a big difference and 30% that it has made a small difference.
- In 2017, 89% of respondents reported that VOCAL had made a difference (75% a big difference and 14% a small difference).
- The perceived impact of VOCAL appears to have diminished slightly since the previous survey. Given that many of the health and financial impacts have got worse, it is likely to be increasingly challenging to do anything that addresses them.

The Impact of VOCAL

129 respondents described the impact of VOCAL, Midlothian.

Those who felt that VOCAL had made a difference fell into five main areas:

- 73 respondents identified positive health impacts (including feeling more confident and reducing feelings of isolation). There was also a strong sense of comfort in knowing that VOCAL was available, even if there was no immediate need to contact them.
 - 53 respondents cited that the impact arose through VOCAL's information or advice.
 - 37 respondents identified positive financial impacts, including securing Power of Attorney and help with applying for support.
 - 25 respondents identified benefits accrued through time away from caring (either by going away or by using Wee Breaks funding more flexibly during Covid when this was not possible).
 - 4 said that they had developed new skills that helped them in their caring role.
-

Health Impacts

“Knowing there is an organisation there to help with practical issues and emotional support who know how you feel was very important. I didn't feel so alone”

“At the time of need VOCAL stepped up for me.”

“Before speaking with VOCAL I didn't even know I was a carer even though I had been for a few years.”

“VOCAL is very focussed on the carer's needs to an exceptional level

“I could not have done it without their help.”

“Support when I was at my worst.”

“Helped with acknowledging my feelings.”

“They saw you first then your caring role, that's impressive.”

“If I didn't have VOCAL to get help I would feel totally lost in my caring role.”

“It has made me sit down and make time for me.”

Information and Advice

“Without them I would not have a care plan in place for my mother.”

“I know what is out there to support me if I want to access it.”

“From getting information and getting help with forms and processing through to ongoing support - life would not have been the same without VOCAL.”

“VOCAL is my first point of contact.”

“Very helpful on how to deal with problems, filling in forms and accessing activities.”

“Professional, experienced neutral guidance Advice what to do when. Who to contact. What to ask for.”

“Great at information giving and support.”

“They provided me with information I didn't know was available.”

Financial Impacts

“I was not even aware we were entitled to the benefits that VOCAL helped me apply for. .”

“I was given advice on how to access the higher rate of Attendance Allowance for my mum.”

“We were given help with filling in my daughter’s PIP form and appealing the decision. We found this help invaluable .”

“Valuable help with completion of benefits forms.”

“Filling forms out for blue badge and benefit forms as I would have filled out the wrong forms.”

“The help with the Attendance Allowance info as well as the filling out of all the forms was just amazing .”

“I am unaware of the benefits system and they explained it to me.”

“My mum was keen to have power of attorney set up to safe guard her in the future..”

Time Away From Caring

“One or two short breaks – both of which were great.”

“A new respite week for our child.”

“Wee Breaks were a massive help during the holidays.”

“Being able to access short breaks to help me recharge.”

“The support I received to achieve the break was positive and made a big difference to the person I cared for.”

“The respite break made a big difference to my wife and I.”

“Help with getting a garden table and chairs so I can sit outside.”

“I use my cricut machine which I got from funding from Wee Breaks. It helps me relax”

New Skills

“VOCAL have helped me have driving lessons every week plus afford my theory and practical test.”



“The dementia classes were so useful in helping me understand.”

“I am learning to show my daughter how to be mentally strong and cope with her condition.”




“The online crafts were really great, a space for myself when I needed it most.”

No Impact

Respondents who said that VOCAL had made ‘no impact’ were also asked to explain their answer. 20 respondents provided more information. One strong theme arising was less to do with VOCAL than with the fact that respondents felt overwhelmed by the magnitude of their caring responsibilities, and that there was little that could be done to reduce this impact on their lives:

-  *“Until services open up practically other than talking there is little anyone can actually do.”*
-  *“I feel overwhelmed with caring for a very disabled person, VOCAL got me access to some eat out vouchers but that is just the tip of the iceberg, we need proper trained support for him.”*

More practically, several respondents said that they were unable to access services due to work or caring commitments. There was a third cohort who acknowledged that they found it very difficult to ask for help and therefore were unlikely to experience any positive impact:

-  *“I joined during lockdown and I don’t have time with facing the kids all the time to join online meetings.”*
 -  *“I care for my mum but also have to work full time and cannot attend any meetings or events during the day.”*
 -  *“I’d say that it’s me that hasn’t accessed VOCAL enough, no fault of VOCAL.”*
-

Further Feedback on VOCAL Services (1)

Respondents were invited, in an open ended question, to provide further feedback on their experience of VOCAL's services. 126 respondents answered this question.

69 comments were made that emphasized the positive impact that VOCAL had made. These reflected the impacts in the previous slides:

 *"VOCAL has been a lifeline that I didn't know I needed."*

 *"My concerns were taken seriously and I appreciated the advice I got."*

21 respondents praised VOCAL staff and volunteers, with a further 3 highlighting the role of a specific staff member:

 *"Staff at VOCAL are brilliant, I had a very positive experience when VOCAL assisted me during a care crisis."*

 *"The person I spoke with was extremely helpful and made me feel comfortable and able to talk."*

Other positive feedback focused on: the quality of the training courses (3 respondents), staff proactively checking in on carers (3), support in emergency situations (1), attending events (1) and meeting other carers (1).

Further Feedback on VOCAL Services (2)

A comparatively small number of negative comments (10 in total) were made about carers' experiences of VOCAL:

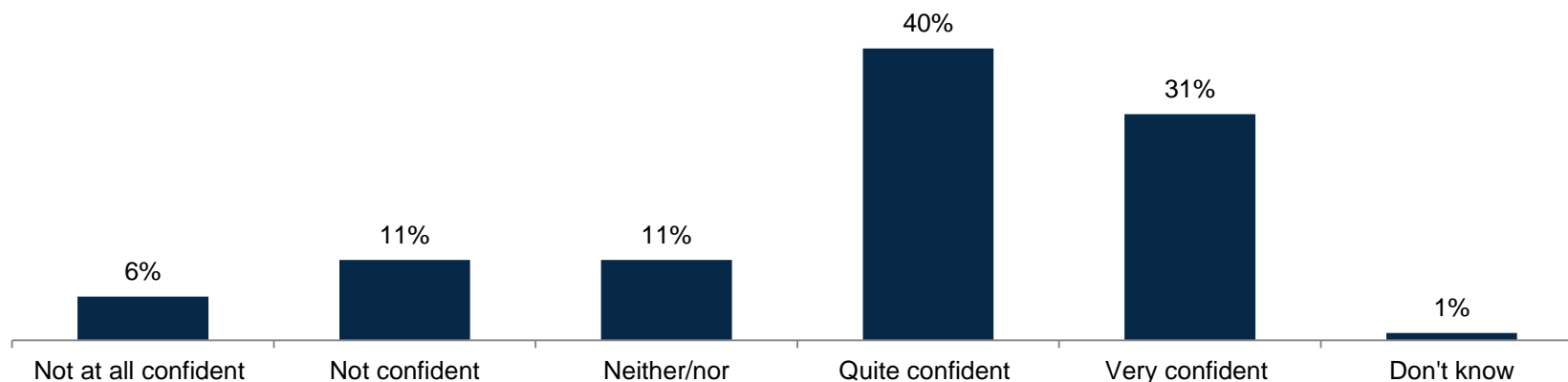
- 5 reported communication issues (eg a phone call not being returned).
 - No other type of comment was made by more than one individual. These comments concerned: requiring more support than VOCAL was perceived to be able to provide; an issue with a specialist providing advice/support; difficulties in mixing with other VOCAL carers; feeling overwhelmed with the volume of information provided; and the impact of the pandemic on service delivery.
-

Satisfaction with VOCAL – Key Findings

- Satisfaction with VOCAL services and support is in line with or higher than the 2017 response, with no measure rating lower than 86% ‘good’ or ‘very good’.
 - To have maintained these ratings through lockdown is incredible!
 - The friendliness of the VOCAL staff is a particular strength; 77% of respondents who used VOCAL services rated this as ‘very good’.
 - 47% of respondents who have engaged with VOCAL say that the organisation has made a ‘Big Difference’ to them, and 30% that it has made a ‘Small Difference’.
 - These figures are lower than the figures in 2017 (75% and 14% respectively).
 - Given the consistently high satisfaction ratings, it is reasonable to suggest that this lower impact is more to do with the magnitude of the challenge facing carers in 2021 rather than a reflection on VOCAL.
 - Respondents report a range of tangible and intangible benefits in relation to health, finance, and advice and support. VOCAL has clear authority and high levels of trust.
-

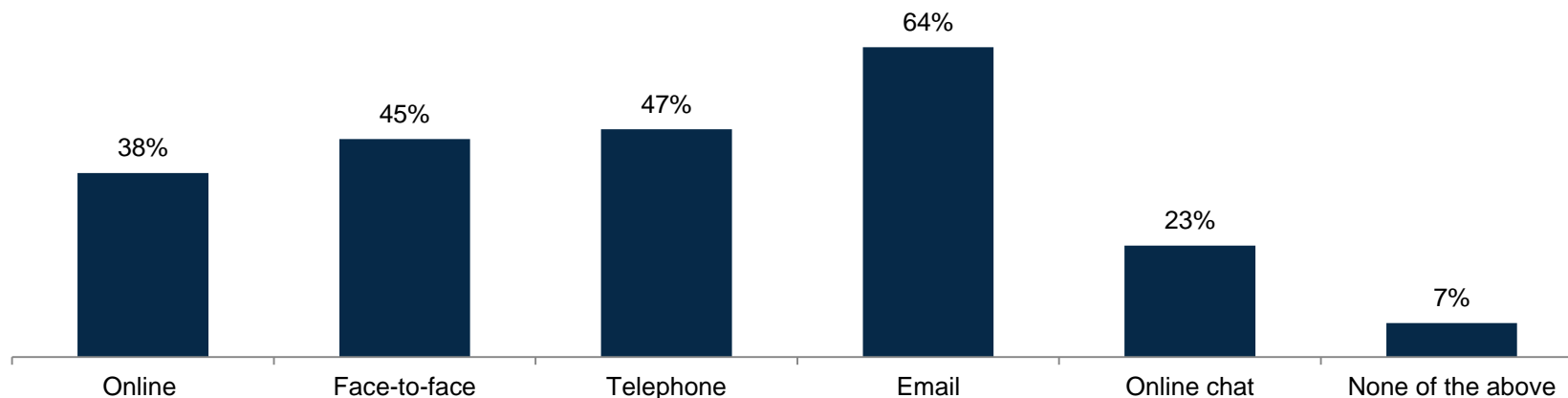
SHAPING FURTHER SERVICES

Shaping Future Services: Using Technology



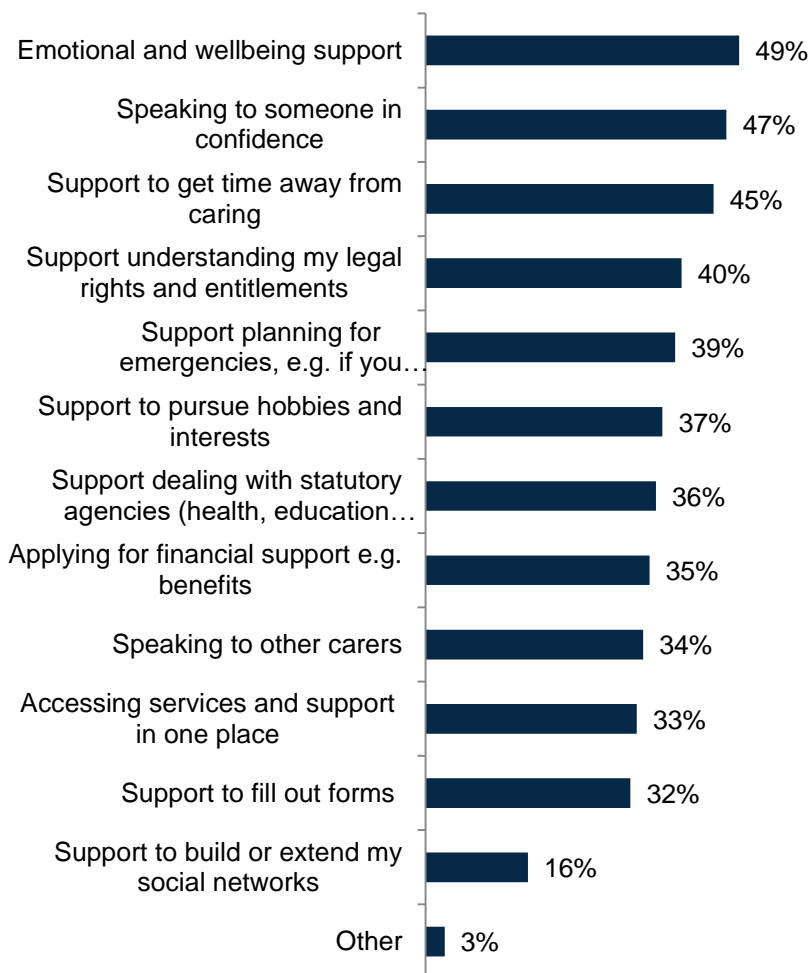
- 71% of respondents said that they were 'very' or 'quite' confident in using digital technology like the apps, internet and video calling. The corresponding figure for 2017 was 58%.
- This leaves 17% of the sample saying that they are not confident in using this type of technology. As in 2017 this figure increased with age; 11% of 16-25 year olds fall into this category, increasing to 22% of 66-74 year olds (caution: small sample size).
- Respondents who are in paid employment or education are more confident than those who are retired or not in any of these categories (87% for people in employment, compared with 61% of retirees and 68% of those not receiving a salary or a pension).

Future Support: Communication Preferences



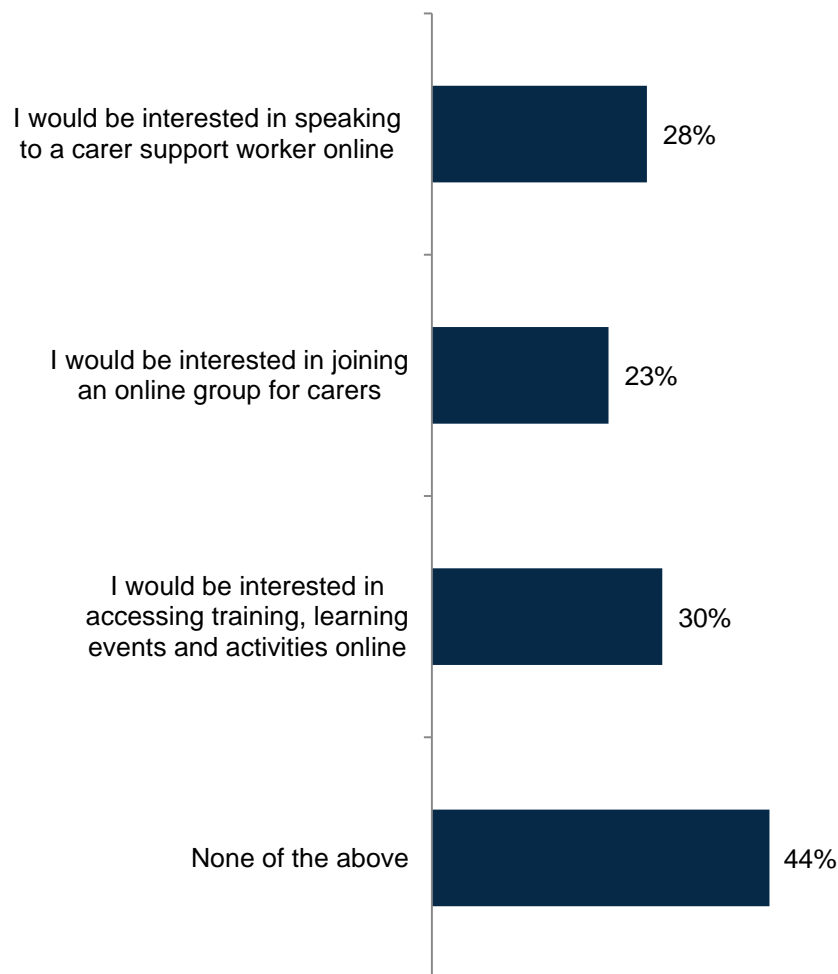
- Email is the most popular communication channel across the sample, with 64% of carers selecting this as the way in which they would like to receive support and information from VOCAL and other agencies.
- However, face to face and telephone support remains popular, underlining the importance of interpersonal support.
- The results underline the importance of maintaining a range of communications channels to support a very diverse group of carers and ensure equality of access.

Future Support: Interest in Potential Services



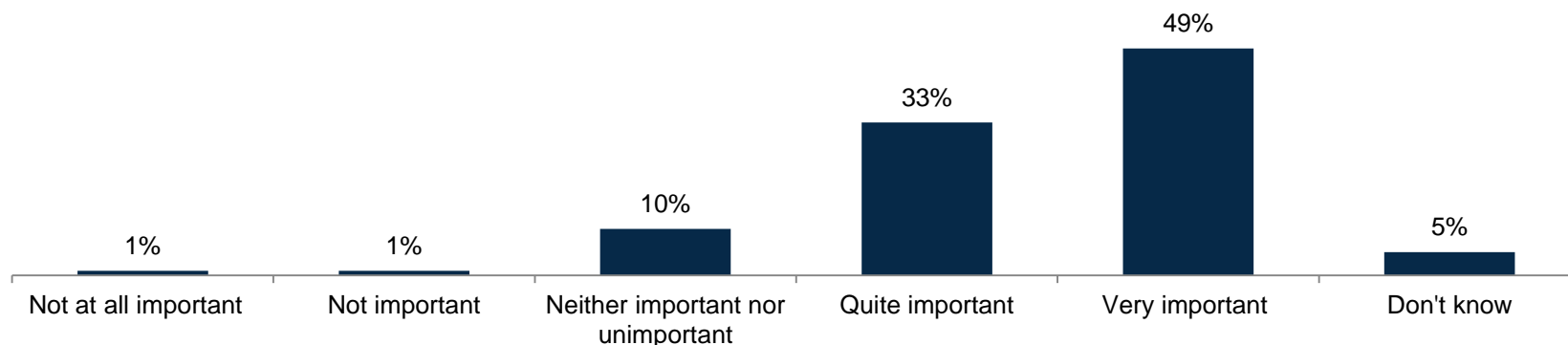
- Respondent preferences largely reflect the findings of the 2017 survey.
- The top three services: emotional and wellbeing support; speaking to someone in confidence; and support to get time away from caring, are very closely aligned to the things that VOCAL does well.
- Respondents who are not currently engaged with VOCAL are also interested in support dealing with statutory agencies, support to pursue hobbies and interests, and speaking to other carers – these might all be useful marketing messages for engaging new users in Midlothian.

Future Support: Interest in Online Services



- 53% of respondents would be interested in accessing services online.
- Interest in this type of provision declined with age; all of the carers aged 16-25 were interested in online services, compared with 33% of those aged 85+.
- However, interest across all age ranges is approximately double the level reported in 2017.

Future Support: Importance of Local Services



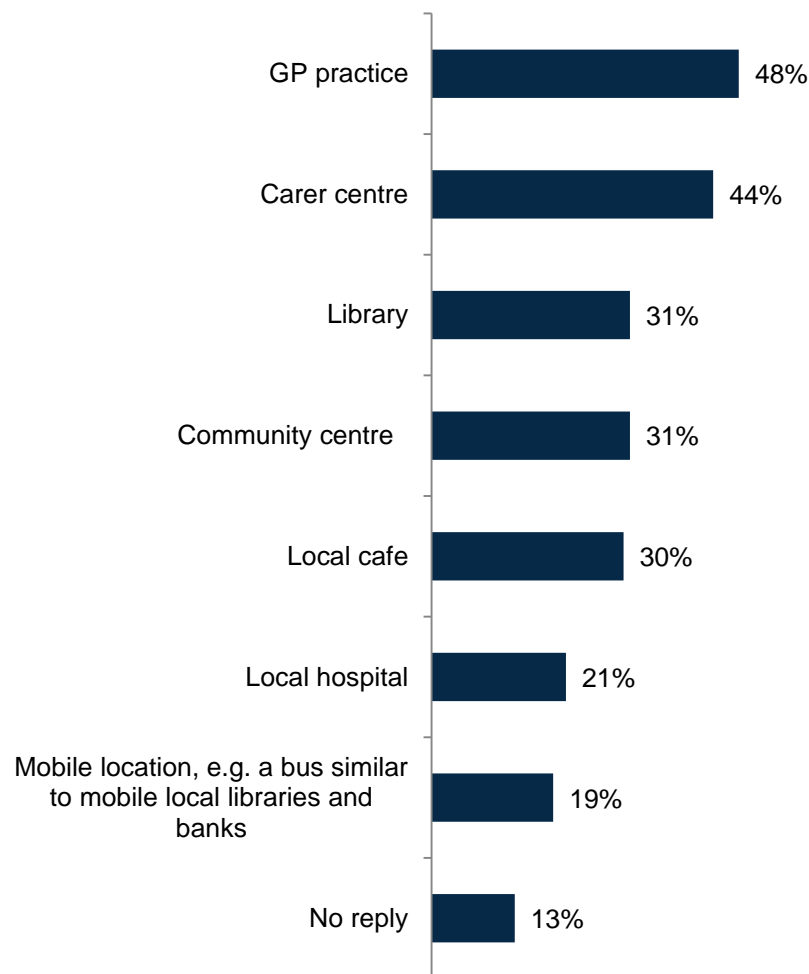
- 82% of respondents said that it was important that they had access to VOCAL services locally.
- Nearly half said that it was “very important”.
- This is slightly lower than in 2017, when 94% said that local access was important. This could perhaps be a consequence of adaptations due to lockdown, when even local services were inaccessible in the traditional way?
- As in 2017, carers of children and of people aged over 85 were more likely to say that access to local services was very important (56% in both cases).

Future Support: Location Preferences

Respondents were asked to identify particular locations where they would like to access support and services. The locations in Midlothian receiving 10 or more responses, mostly located to the west or south of the city, were:

Dalkeith (70)
Penicuik (61)
Bonnyrigg (40)
Loanhead (34)
Gorebridge (19)
Newtongrange (11)

Future Support: Potential Service Location



- Just under half of respondents would be interested in accessing support and services in their GP practices, whilst a similar proportion would like to visit a dedicated carers' centre.
- Using community spaces such as libraries and community centres appeals to approximately a third of respondents.
- Approximately a fifth of respondents would like to access services through a mobile location or a local hospital.

Ideas for Better Support in the Future (1)

Respondents were asked how they could be better supported by VOCAL and other agencies. 180 respondents answered this question.

- 74 respondents said that there was nothing more that could be done and that they were happy with the support received.
 - 26 said that they would like to continue to receive up to date information on a range of issues. It was felt that this was particularly important at the start of the caring journey.
 - 15 said that they would appreciate it if agencies could proactively check in on them on a regular basis.
 - 13 said that they would like to be able to access services closer to their own homes.
 - 8 would like help with respite care.
 - 7 would like face to face meetings to start up again, either in the community or at existing carers' centres.
 - 6 would like VOCAL to continue to lobby for better support for carers.
 - 6 would like a more individualised approach to support; tailored to their individual circumstances, perhaps with a named contact person.
 - 6 would like activities for the person being cared for.
 - 3 would like access to support, services and activities outside of working hours.
 - 4 would like drop-in activities
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Future Support

“Wish they gave us all the options at the start rather than us having to seek them and find out as we go.”

“Face to face again. Drop in centres outside working hours.”

“Regular check in would help. Just to see how things are.”

“More groups in my local area.”

“The main need I have is for legal and financial advice, particularly where there have been changes to legislation, so keeping up with this sector is important”

“Keep abreast of Council decisions and tell them the impact it has on carers.”

“Contact at least once a month just to see if you are OK.”

“How do I get homecare for my mother when I go on holiday? May as well not go anywhere and the thought brings me to tears..”

Future Support: Key Findings

- Email is the most popular communications mechanism and interest in online provision is nearly double what it was in 2017.
 - Despite this, the survey shows a requirement to maintain a range of delivery formats to ensure that VOCAL services are accessible to everyone.
 - 82% of respondents feel that it is important to be able to access services locally.
 - There is clear appetite for an enhanced geographical presence, both in terms of the local communities where you work and in the type of locations you might consider.
 - The continued supply of useful information (particularly at the start of a caring journey), being able to access services closer to home, and more proactive contact to check in with carers were the top three suggestions for developing VOCAL services in the future.
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Conclusions

- The challenges facing carers all appear to have increased since 2017.
 - Respondents report bigger impacts on their health and finances, and more barriers to taking a break.
 - The age profile of respondents has changed. The profile contains more younger carers, many of whom are caring for their own children on a long-term basis.
 - Within this challenging context, VOCAL continues to achieve very high satisfaction ratings – something made even more remarkable given the pandemic.
 - Respondents cite a range of health and financial benefits as a result of engaging with VOCAL, and are clearly reassured by the knowledge that they can get in touch if they have a problem.
 - There is evidence that VOCAL's impact has reduced due to the extent of the challenges faced by carers; as challenges increase more support will be required to deal with them.
 - Respondents would like to see more services in their local communities at a time that suits them – and for VOCAL to proactively check in with them on a regular basis.
 - Online communication and activity is a key part of the communications mix, but it is important to maintain face to face and written communication too.
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