

**SCOTINFORM**

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VOCAL Carer Survey 2021: Edinburgh

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# 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.

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# 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 Edinburgh. Please refer to separate reports for more detail on:

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

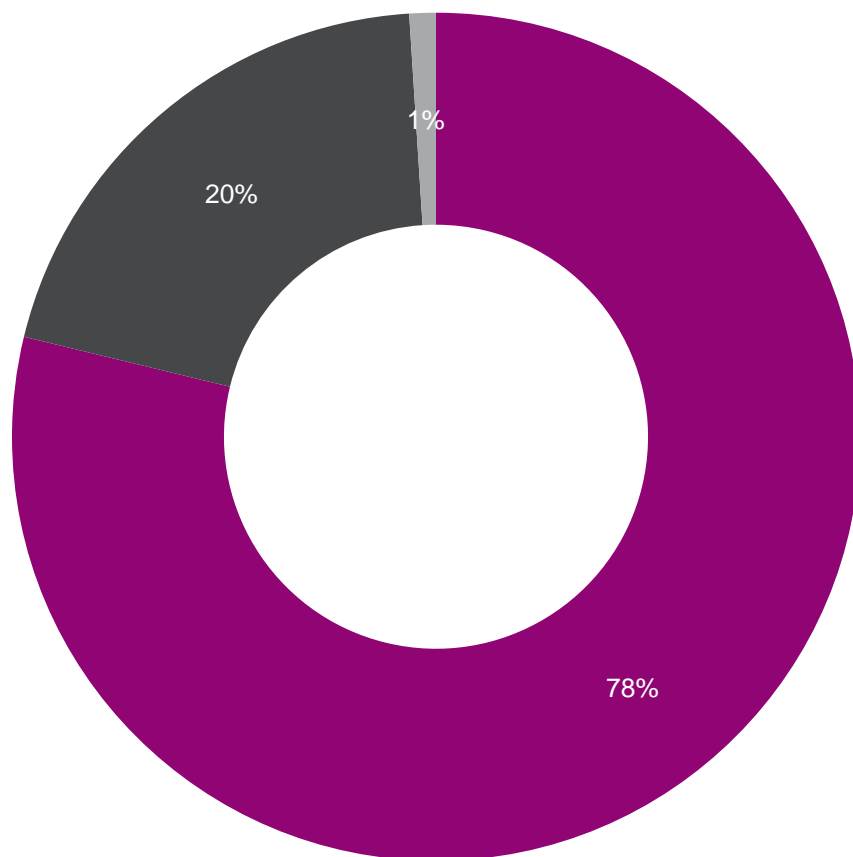
Please note:

- 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 Edinburgh (826)
- Open-ended feedback is identified with 

# CARER CHARACTERISTICS

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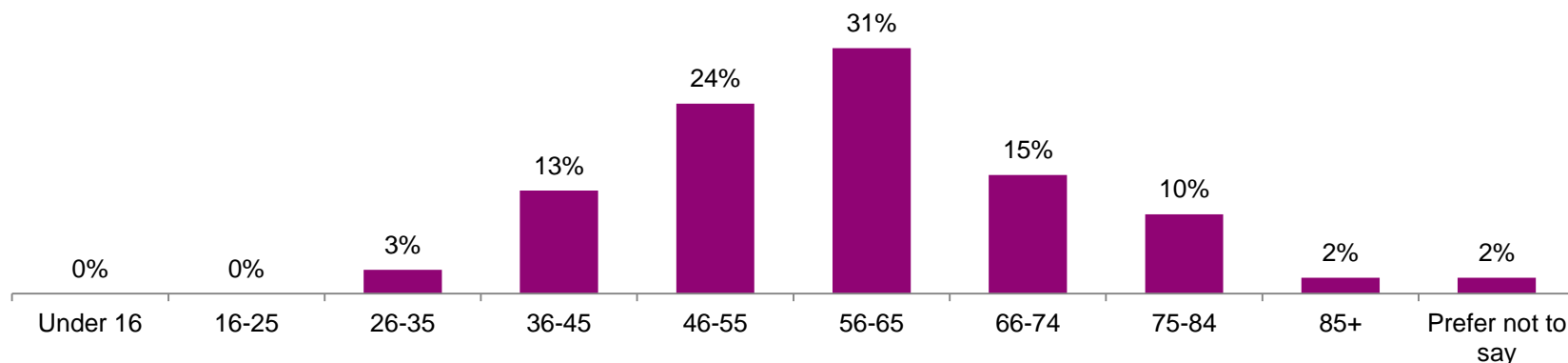
## Carer Characteristics – Gender



■ Female ■ Male ■ Prefer to self-describe

- Just over three quarters of respondents were female.
- This is consistent with the 2017 survey (76%) and the 2015 survey (77%)
- The proportion of male carers was highest for respondents caring for a partner or spouse (36%).
- The proportion of female carers increases according to the length of time spent caring. 67% of those who been caring for 1-2 years are female, compared with 82% of those who have been caring for more than 20 years.

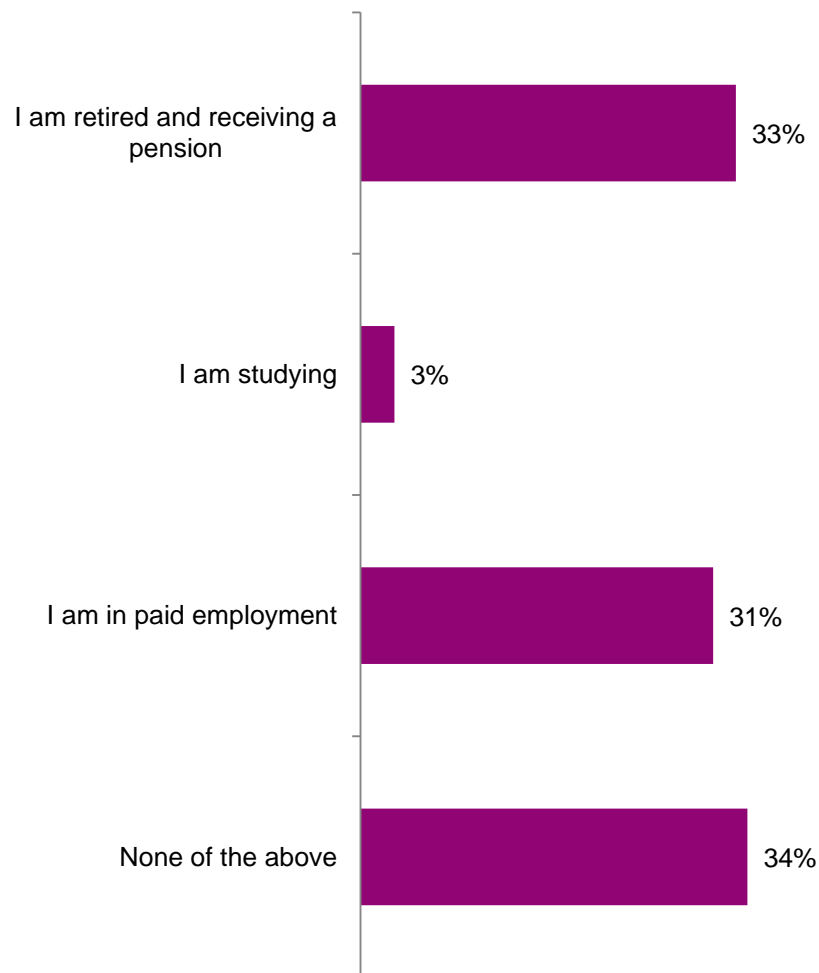
## Carer Characteristics – Age



- The age profile of the sample has shifted downward, and is now generally younger than in 2017, with 71% of carers being of working age.
- In 2017, 45% of respondents were aged over 65. This time around the figure is 27%.

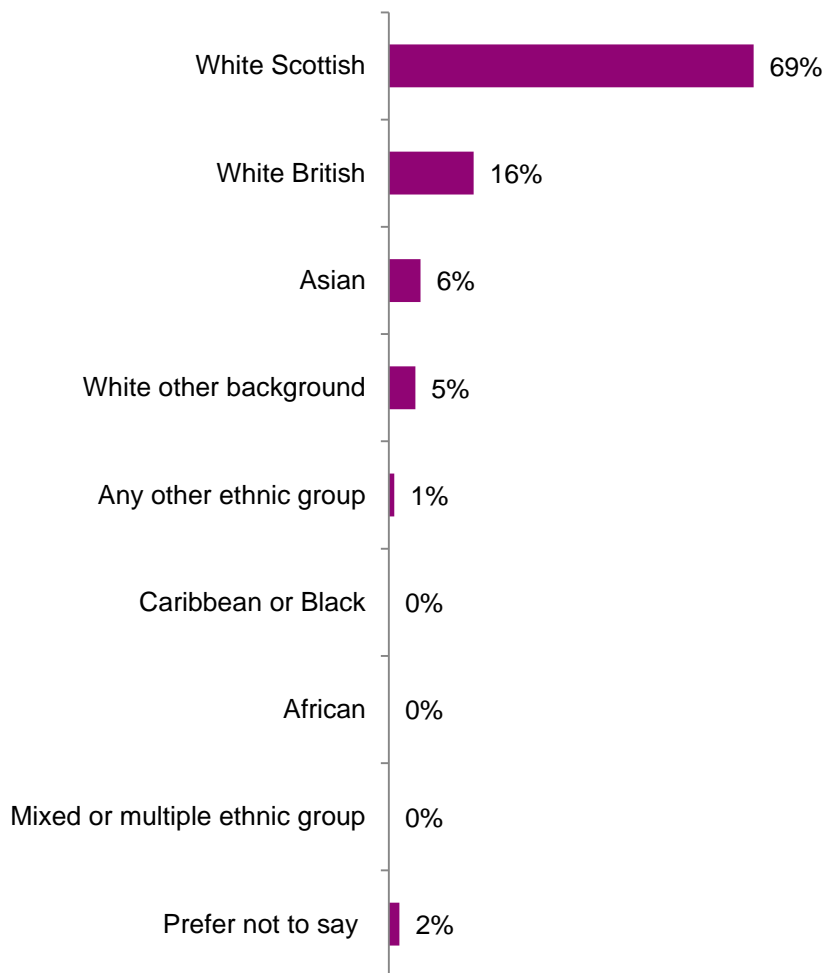


## Carer Characteristics – Economic Activity



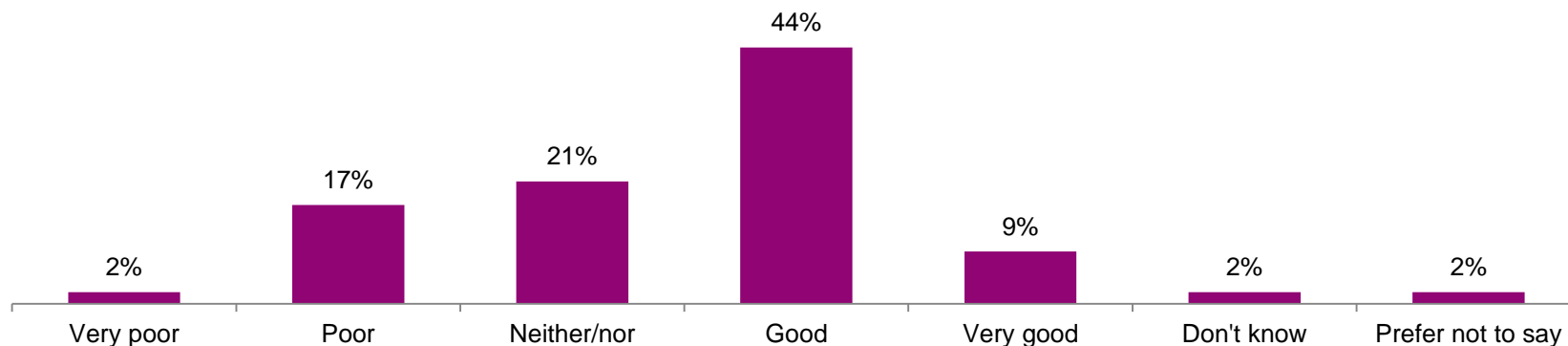
- Reflecting the younger age profile, the economic profile is also different in the 2021 survey.
- The proportion of respondents in paid employment has increased from 25% to 31% and the proportion retired and receiving a pension has declined from 50% in 2017 to 33% in 2021.
- Notably, the proportion of carers not in employment, education, or receiving a pension has increased from 23% in 2017 to 34% in 2021. The proportion of respondents in this cohort was higher for respondents caring for their children (45%), those who have been caring for 11-19 years (47%), respondents caring for more than one individual, and respondents caring for somebody aged 25 or under (52%).

## Carer Characteristics – Ethnicity



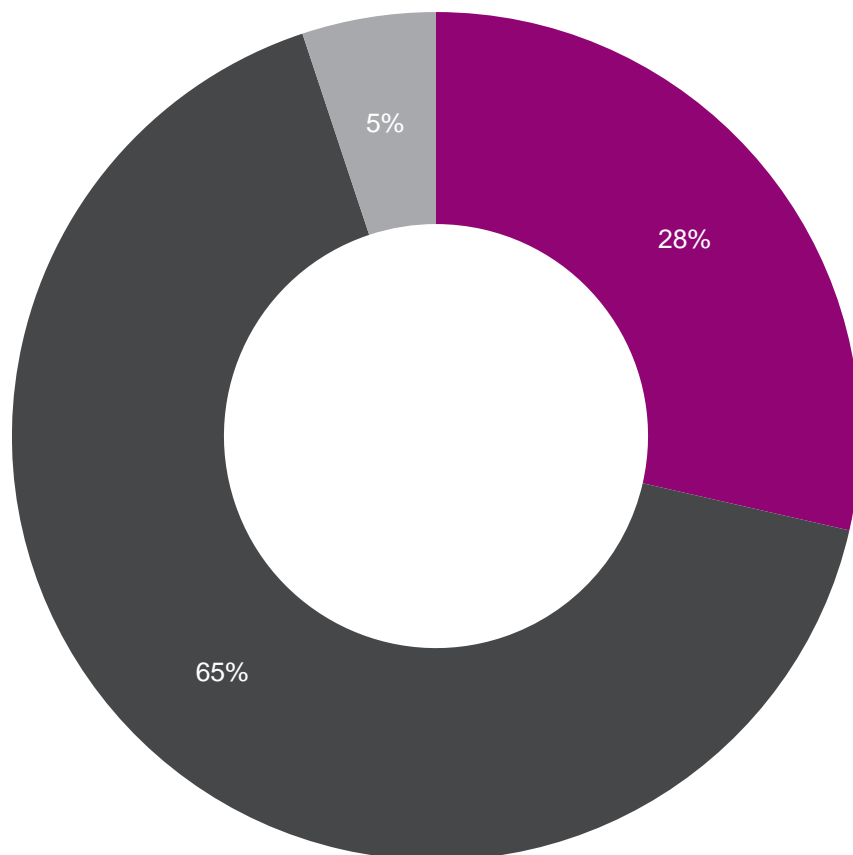
- 90% of respondents are white, down from 95% in 2017.
- 6% of respondents are Asian.

# Carer Characteristics – Health



- In a new question for 2021, respondents were asked to assess the state of their health.
- 53% said that it was 'very good' or 'good', with 19% 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 (29%) and respondents aged 85 or over (37%: caution, small sample size). It was also significantly higher for those not in employment, education or retired and receiving a pension (42%).

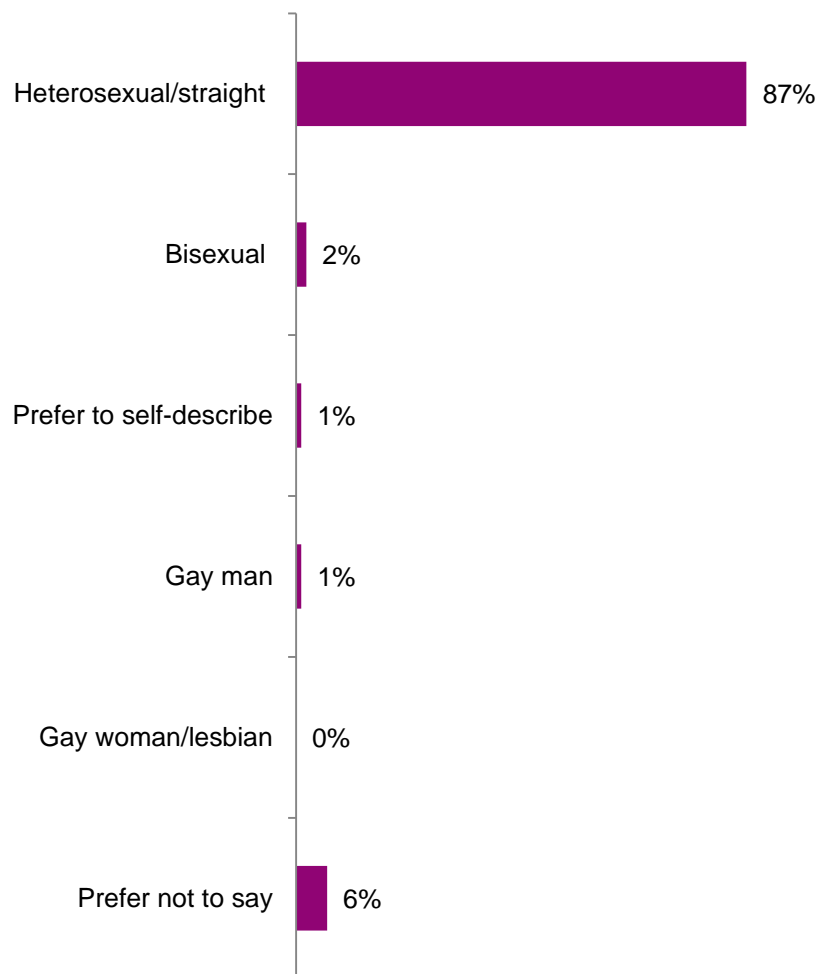
## Carer Characteristics – Disability



■ Yes ■ No ■ Prefer not to say

- 28% of respondents consider themselves to have a disability themselves.
- The figure is higher for respondents who have been caring for over 20 years (42%) and respondents aged 85 and over (50%).
- The 235 respondents who consider themselves to have a disability were asked about its nature:
  - 54% reported a mobility disability
  - 45% a mental health disability
  - 15% reported a hearing disability
  - 9% a visual disability
  - 8% a co-ordination disability
  - 7% a learning disability
  - 1% a speech disability

# Carer Characteristics – Sexuality



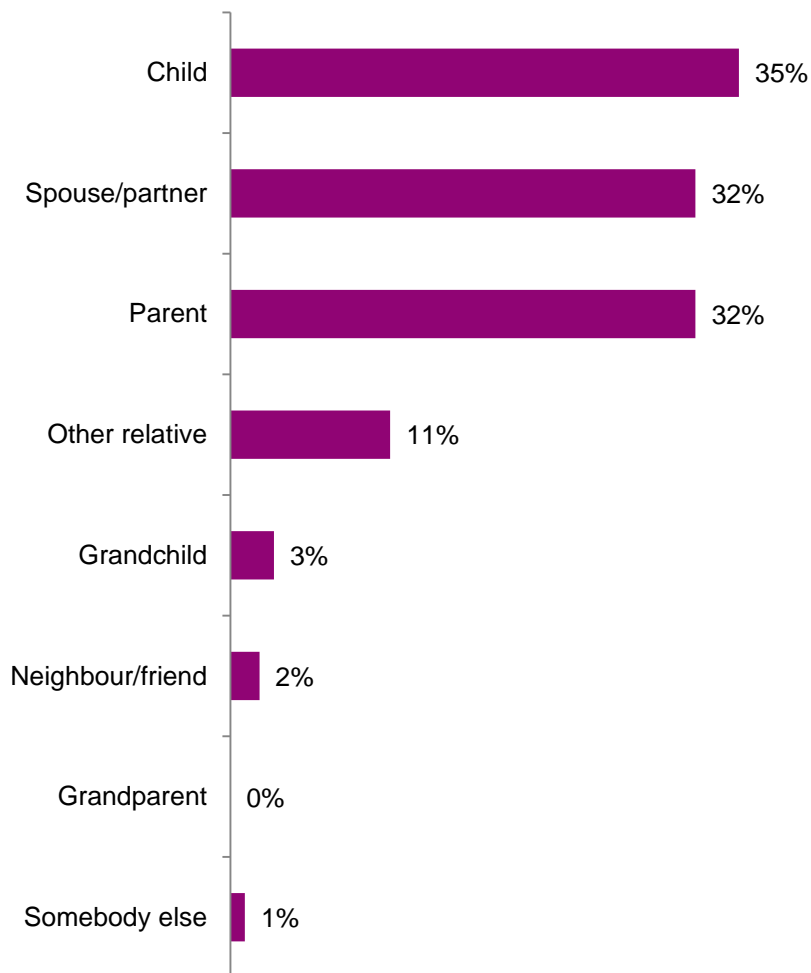
- 87% of respondents describe themselves as Heterosexual/straight, 2% as bisexual and 1% as gay. 1% preferred to self-describe.
- This was a new question for 2021 so there is no previous data with which to compare.

# Carer Characteristics – Place of Residence



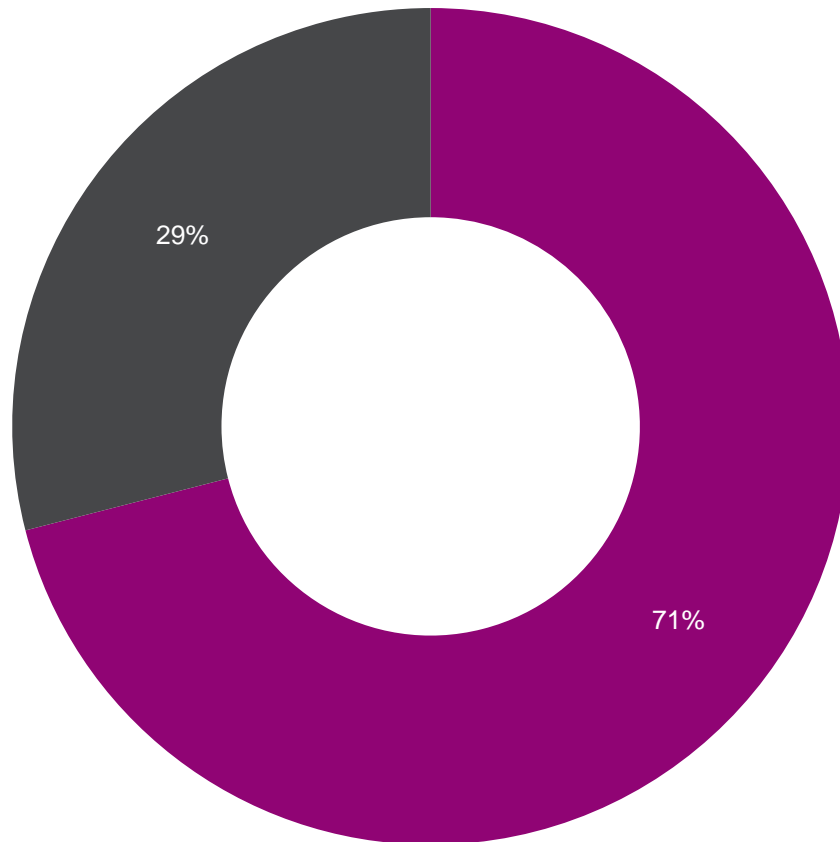
- 95% of respondents lived in the City of Edinburgh.
- 5% of respondents who care for somebody living in Edinburgh live in a different local authority area.
- Living in a different local authority area from the person being cared for is likely to pose additional challenges, practically and financially 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 child (please note that this describes the relationship, not the age of the person being cared for), caring for a spouse/partner 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

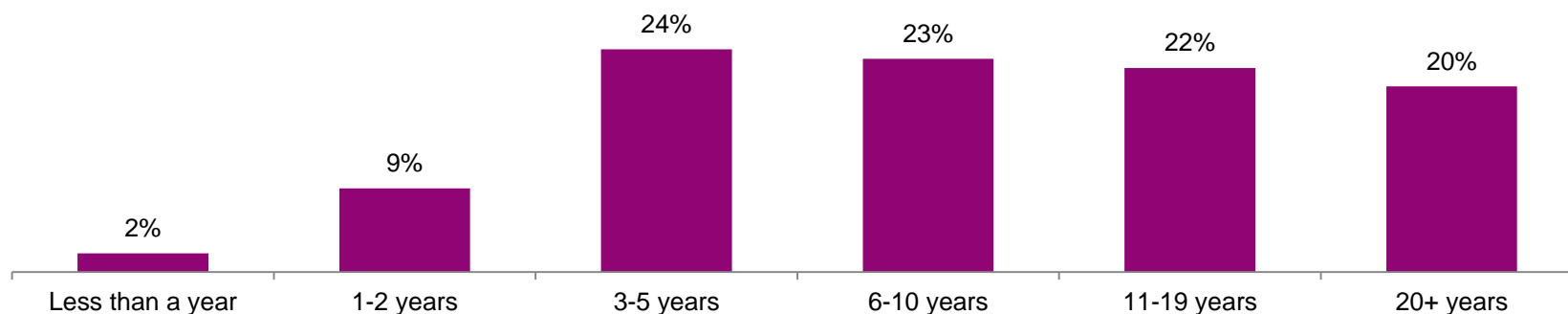


■ Lives with them   ■ Does not live with them

- 71% of respondents live with the person for whom they are caring.
- This figure is higher for respondents caring for their child (89%) or spouse/partner (92%), caring for someone aged 25 or under (92%), and those providing more than 50 hours of care a week (95%).

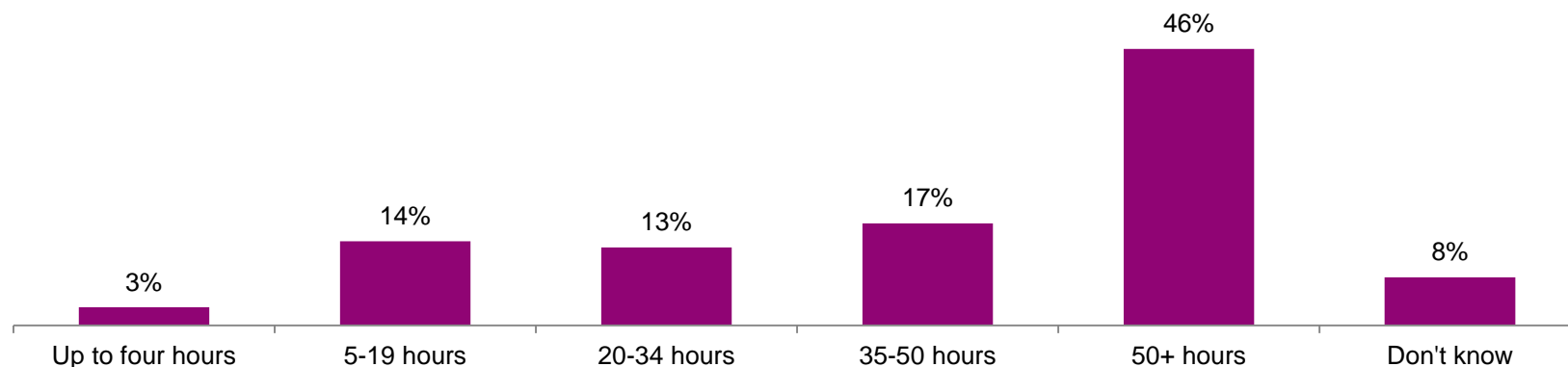


## Duration of Care



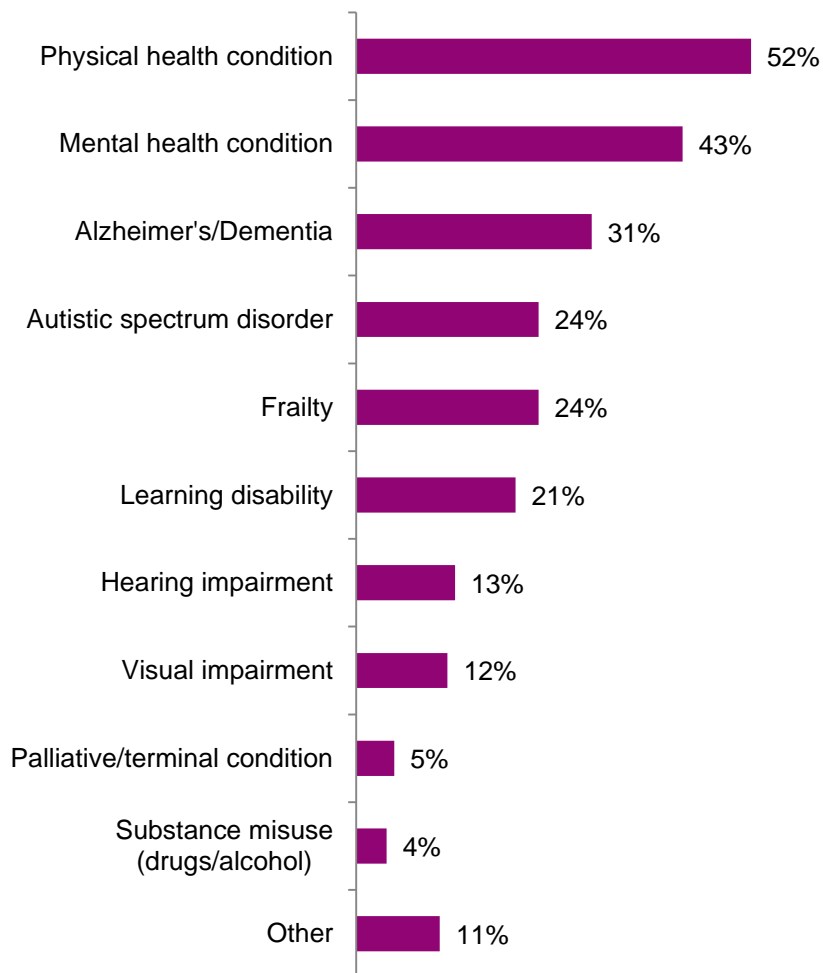
- 65% of respondents have been caring for more than 5 years. This is slightly higher than the figure in 2017 (58%).
- 20% of respondents have been caring for more than 20 years. This figure is highest for respondents looking after their child, 37% of whom fall into this category, and those caring for somebody with Autistic spectrum disorder (33%) or learning disabilities (45%). Respondents who have been caring for this long are more likely to be aged 66-74 (31%).
- More recent cares who have been caring for up to 2 years account for 11% of the sample overall. The figure is higher for respondents caring for a parent or partner/spouse (13%), caring for somebody with Alzheimer's or dementia (19%), and who are aged 65 or over (14%).

# Length of Time Spent Caring Per Week



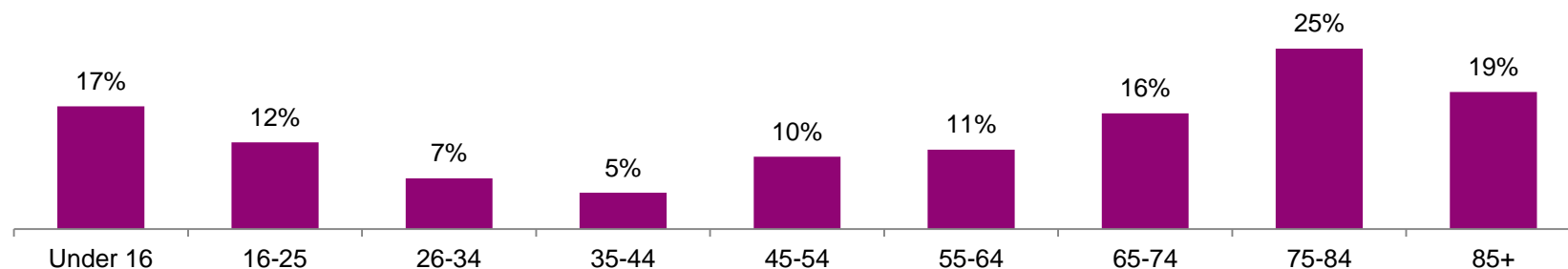
- This was a new question for 2021.
- 90% of respondents spend at least five hours a week in a caring role, with nearly half of them spending more than 50 hours a week.
- The proportion of respondents caring for more than 50 hours per week is higher if they live with the person they are caring for (61%), if they have been caring for more than 20 years (55%) and if they are caring for somebody under the age of 16 (67%).
- 53% of those who rate their overall health as 'very poor' and 56% of those who are not in paid employment, education or retired and receiving a pension are caring for more than 50 hours per week.

# Conditions Cared For



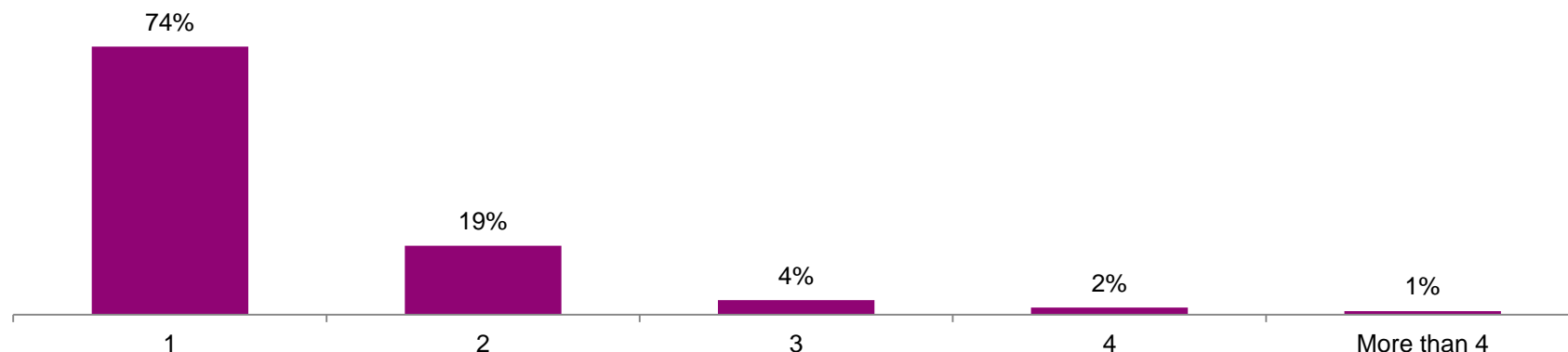
- Respondents were most likely to be caring for someone with a physical health condition, a mental health condition or Alzheimer's/dementia.
- The proportion of respondents caring for someone with a mental health condition has more than doubled, from 20% in 2017, and the proportion caring for someone with an Autistic spectrum disorder has increased from 14% to 24%. The proportion caring for someone with Alzheimer's/dementia or frailty has declined (42% and 36% in 2017).
- Some of these trends reflect the increase in respondents in the sample caring for their children.

# Age of Person Being Cared For



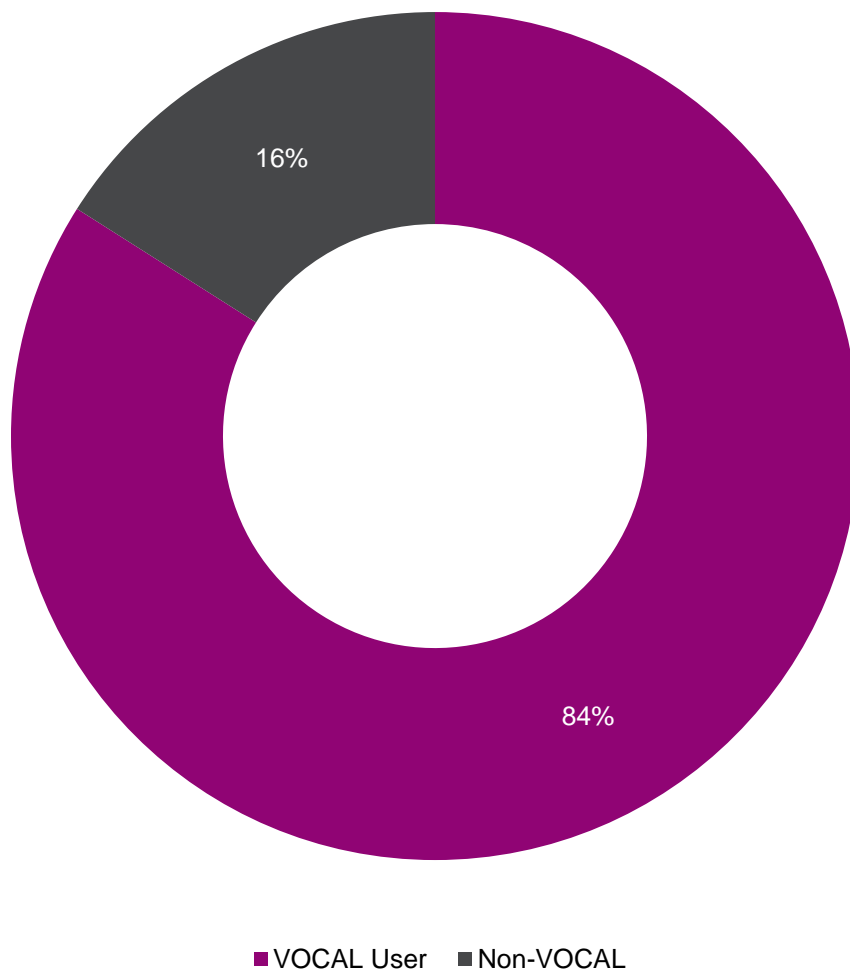
- 44% of carers are looking after somebody aged 75 and over. This is slightly lower than the 2017 figure (49%).
- The proportion of people being cared for aged over 75 is higher for carers who are looking after a parent (88%), have been caring 3-5 years (60%), do not live with the person they are caring for (68%) and are caring for frailty (91%) or Alzheimer's/dementia (82%). 61% of those aged over 75 are caring for someone in this age group.
- 29% of carers are looking after somebody aged 25 or under. This is an increase compared to 2017, when the figure was 19%.
- 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 (75%) or grandchild (100% - note small sample size), have been caring for more than 11 years (46%), are caring for someone with Autistic spectrum disorder (85%) or learning disabilities (67%). 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 26-65.
- These are two very different types of carers, perhaps with quite different needs.

# Number of People Cared For



- 74% of respondents are caring for one individual – up slightly from 2017 (72%).
- 26% 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 (36%), if they are caring for someone with Autistic spectrum disorder (44%) or related to substance abuse (50%) and for respondents aged 36-55 (33%).

# Engagement With VOCAL



- 84% 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 (87%) 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.
- The proportion of those who engaged with VOCAL was higher for people in paid work (87%), education (90%), or who are retired and receiving a pension (85%) than for those in none of the above categories (79%).

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# 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. 71% of respondents are now of working age.
  - The proportion of respondents not in employment, education, or receiving a pension has increased since 2017.
  - Only 53% of respondents consider themselves to be in good health and 28% 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. Nearly three quarters of carers live with the person they care for.
  - Nearly two thirds of respondents have been caring for more than five years; a fifth have been caring for more than 20 years. The overall duration of caring activity has increased compared with 2017.
  - Nearly half of respondents provide more than 50 hours of care per week.
  - A quarter of respondents are caring for more than one person.
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## Carer Characteristics: Key Findings (2)

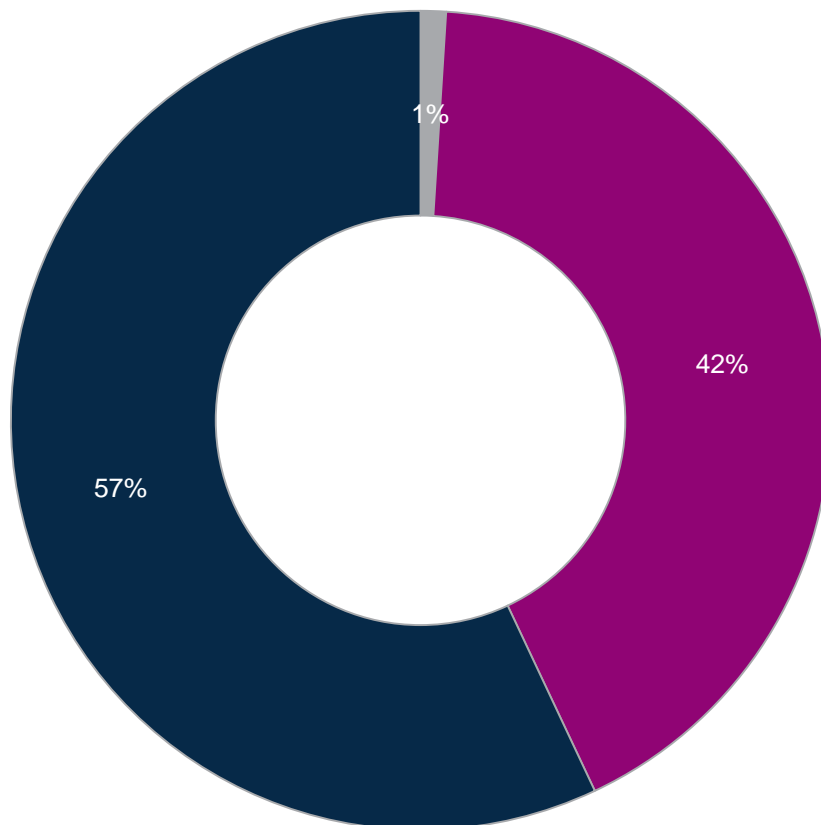
- There have been increases in the proportion of respondents caring for someone with mental health conditions and Autistic spectrum disorders, and a decline in the proportion caring for someone with Alzheimer's/dementia and frailty.
  - 44% of respondents are caring for somebody aged 75 and over, slightly down from the 49% in 2017. The proportion of respondents caring for somebody aged 25 and under has increased from 19% to 29%.
  - 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**

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# Awareness of Carer Rights



■ No reply ■ Aware ■ Not Aware

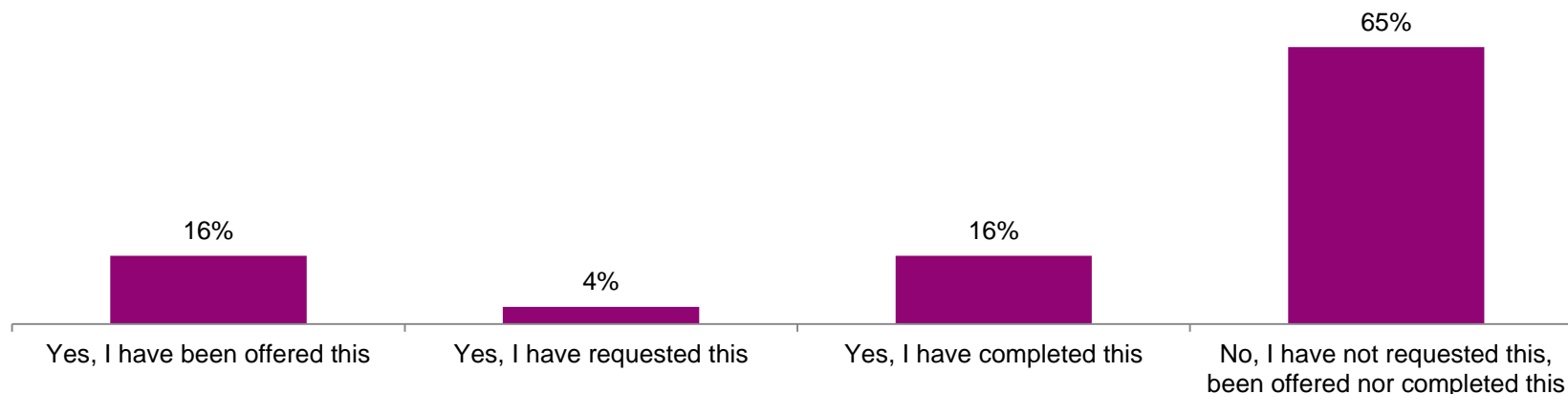
Respondents were told:

‘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.

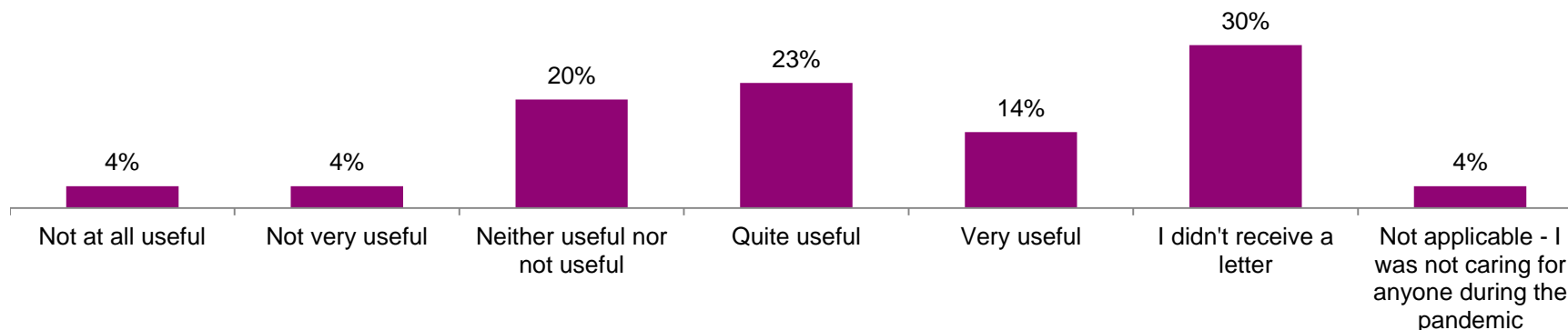
There were no significant variations in awareness according to carer characteristics.

# Experience of Support Plan/Statement



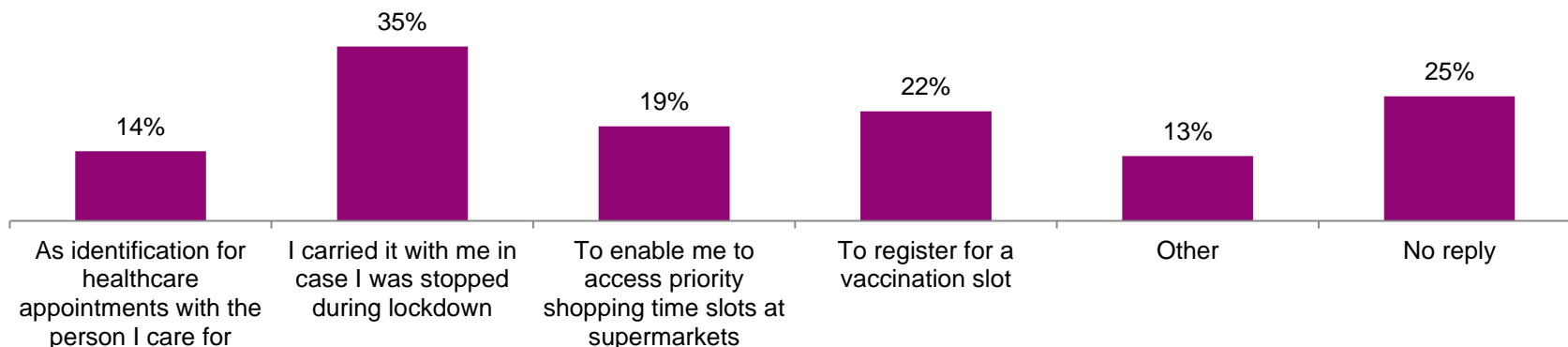
- 16% of respondents have been offered an Adult Carers Support Plan or Young Carers Statement. 4% have requested it themselves.
- 16% of respondents have completed this plan/statement.
- 65% of respondents – nearly two thirds – have not requested, been offered nor completed a statement or plan. This is not due to recently becoming a carer; 72% 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, 37% said that they found this 'quite' or 'very' useful.
- It is interesting to note that 30% 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 (37%) and those not engaged with VOCAL (52% - the figure for those engaged with VOCAL was 25%).

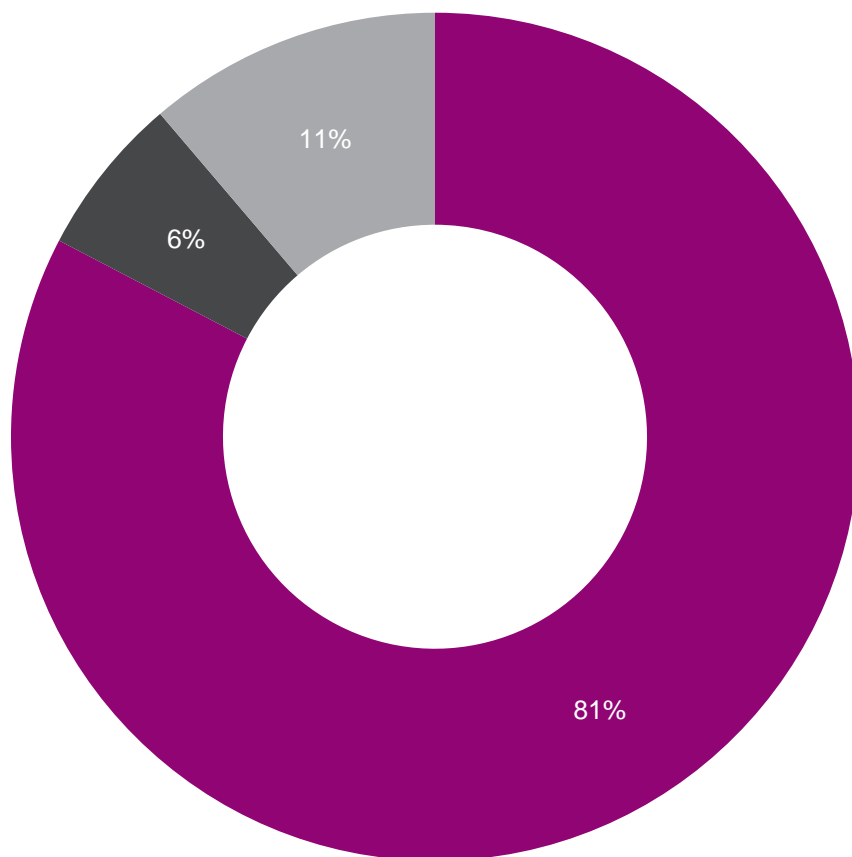
# Use of the Carers Identification Letter



Base: All those who received the Carers Identification Letter (545)

- Approximately a third of those who had received a Carers Identification Letter had used it as proof of status in case they were stopped during lockdown.
- 22% had used it to register for a vaccination slot and a similar proportion to access priority time slots at supermarkets.
- 14% had used it as identification for healthcare appointments with the person they care for.

# Interest in a National Carers Card



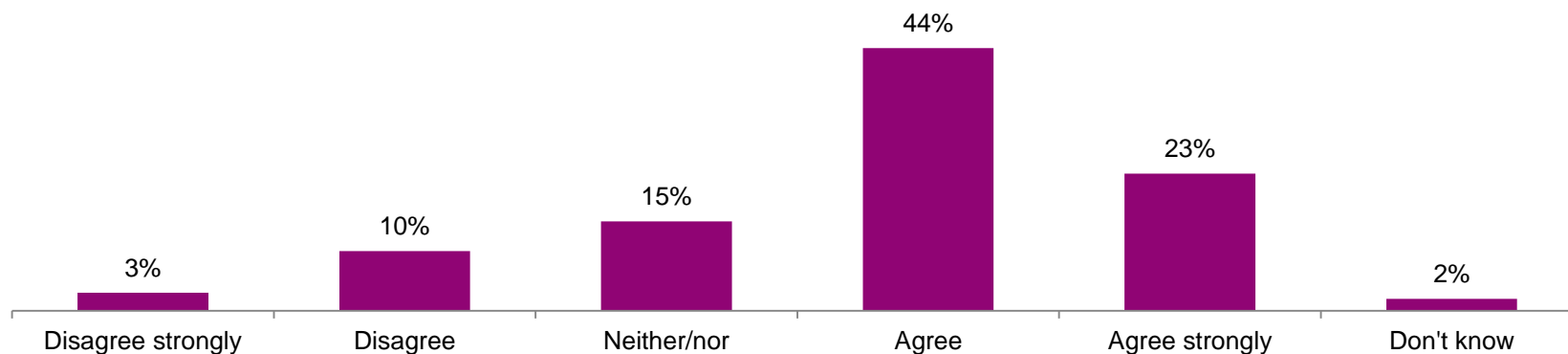
■ Would be interested ■ Would not be interested ■ Don't know

- 81% of respondents would be interested in a National Carers Card to identify them as having caring responsibilities and status.
- The 667 people who would be interested in having a National Carers Card were asked how they would use it:
  - 94% 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

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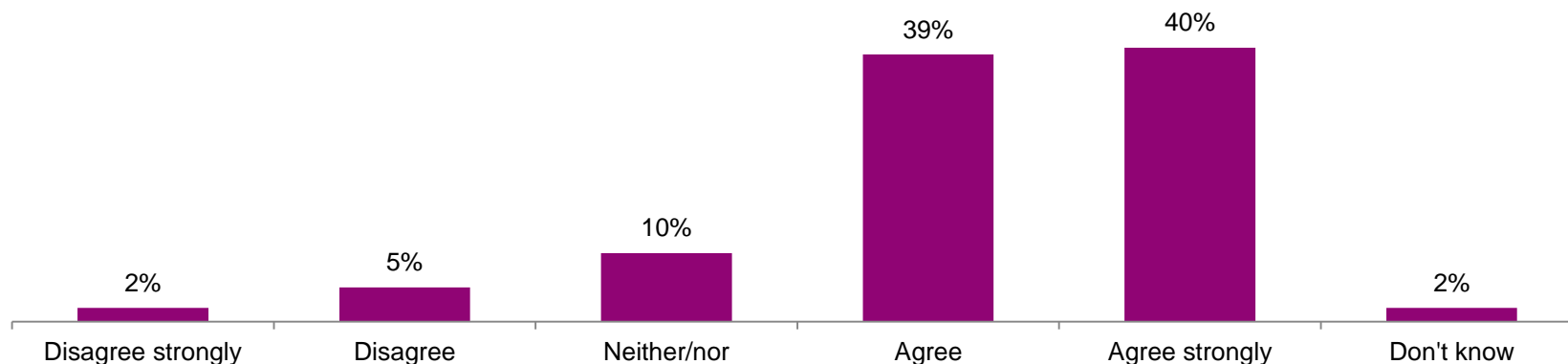
## Health and Wellbeing: “Being a carer has affected my physical health.”



- 67% agreed that “being a carer has affected my physical health”. This compares with 59% 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. 44% of those who have been caring for less than a year agree with this statement, compared with 73% 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.

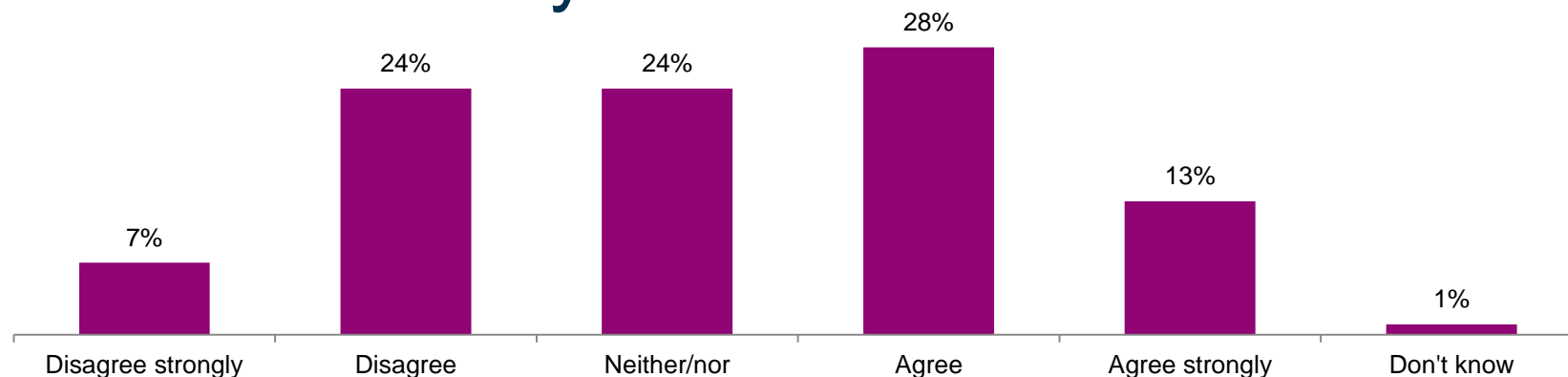


## Health and Wellbeing: “Being a carer has affected my mental health.”



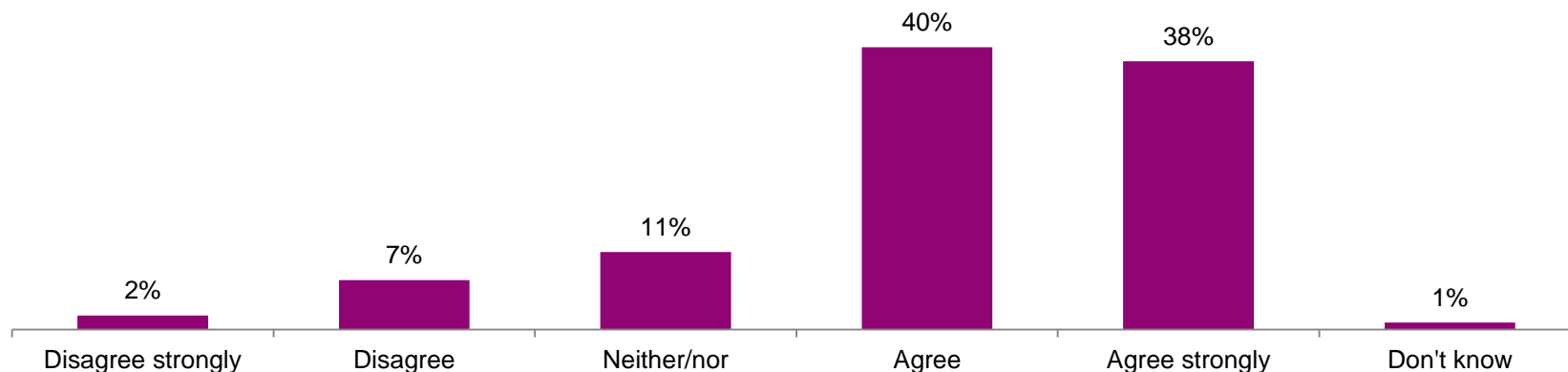
- 79% of respondents agreed that “being a carer has affected my mental health”, with 40% agreeing strongly. This compares with 59% in 2017 who agreed with the statement “being a carer has made my health worse.”
- The proportion of respondents agreeing with this statement is higher for people who are caring for more than one person (89%).
- Younger respondents are more likely to agree with this statement than older respondents: 87% of those aged 26-35 agree with this statement, compared with 50% of those aged 85.

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



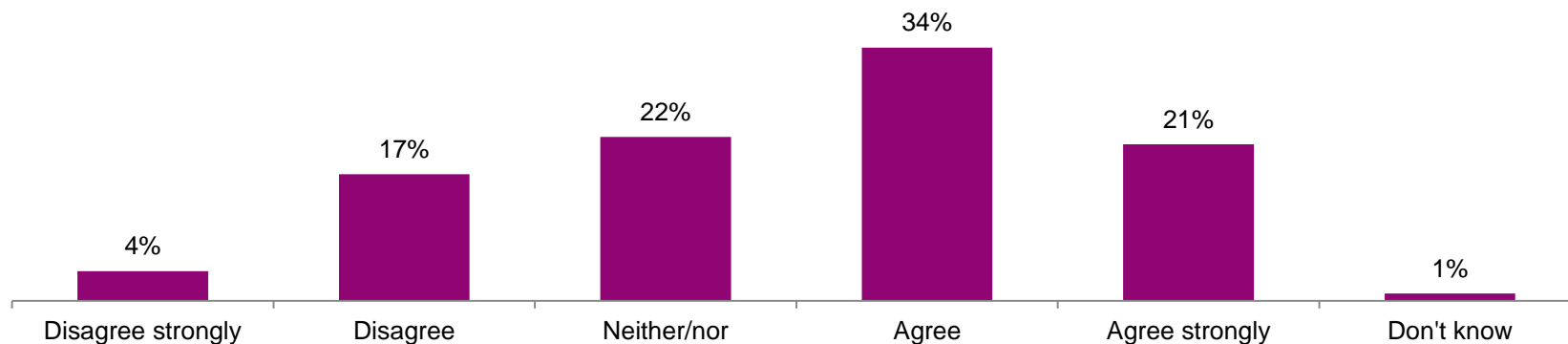
- 41% of respondents agree with this statement. This compares with 35% of respondents who reported an increased number of GP visits in 2017.
- Respondents who have been caring for more than 11 years were more likely to agree with this statement (48%), as were those caring for more than one person (51%), those aged 45-54 (56%) and those not in employment, education or retired and receiving a pension (48%).

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



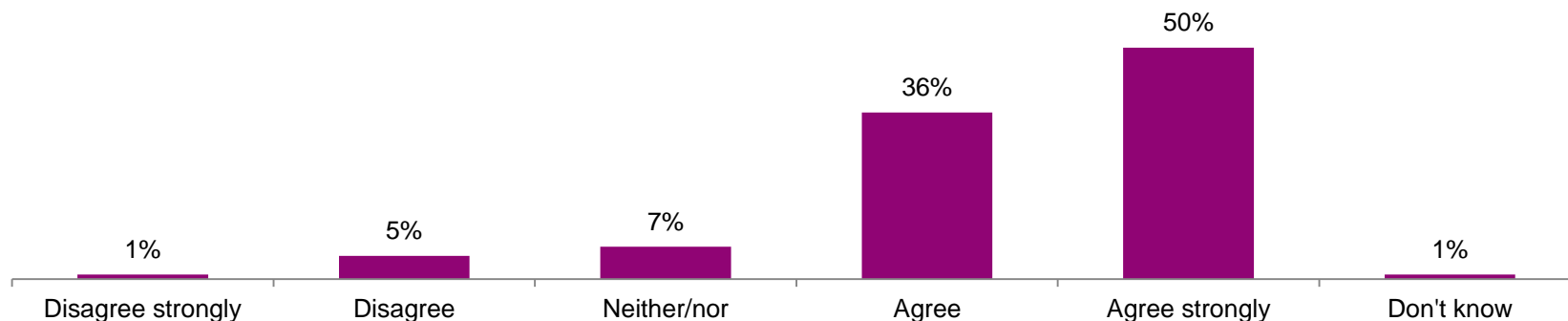
- 78% of respondents agree with this statement, a significant increase on the 59% figure from 2017.
- Respondents were more likely to agree with this statement if they were caring for someone with Autistic spectrum disorder (84%), a learning disability (82%) or substance abuse (87%), as well as if they were caring for somebody aged 16-44 (85%) or those caring for more than 50 hours a week (87%).

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



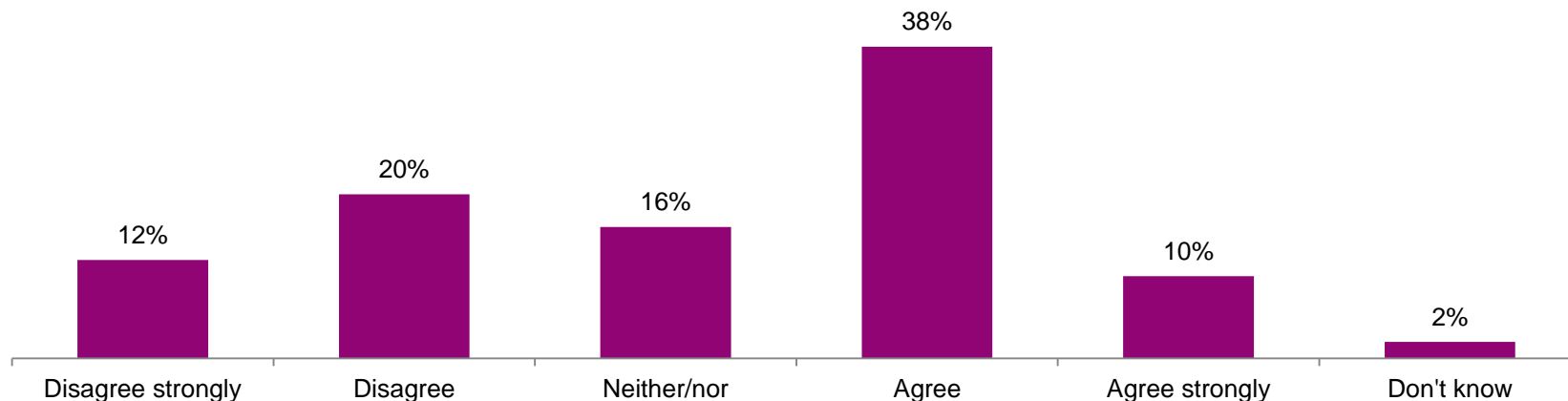
- 55% of carers agree that they feel isolated from family and friends, up from 44% in 2017 (the pandemic may have impacted responses to this question).
- The proportion of respondents agreeing with this statement is highest for people looking after their own child (64%), carers who have been caring for 11-19 years (61%), carers of people aged under 16 (73%) and respondents aged 36-45 (71%).

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



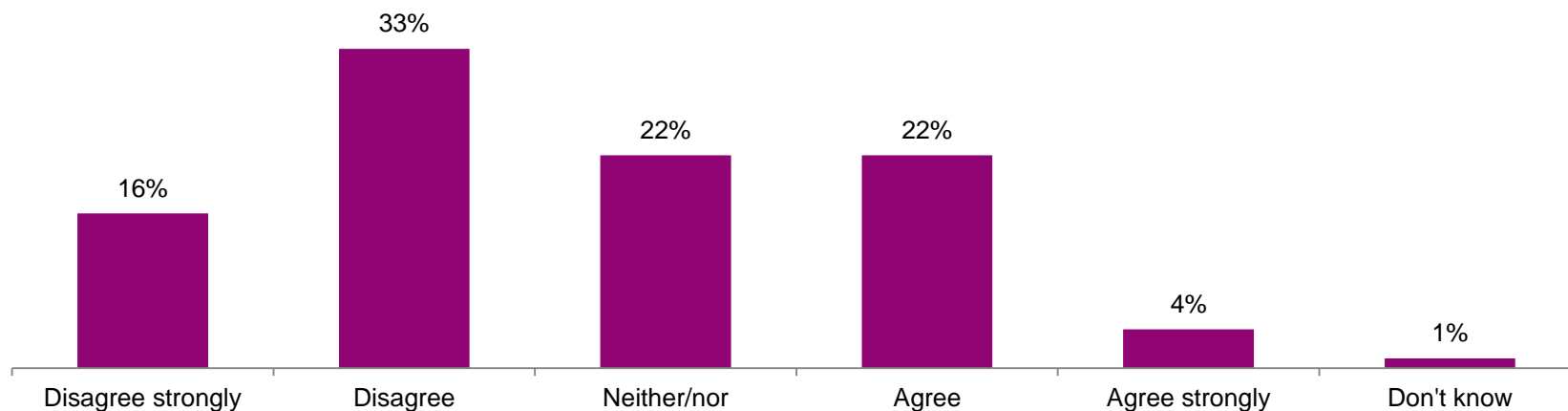
- 86% of respondents expressed concern about contingency planning, compared with 78% in 2017.
- The highest level of agreement to this statement came from respondents caring for their child (91%) or grandchild (100% - small sample size), those who have been caring for more than 20 years (90%), and those caring for those with Autistic spectrum disorder (93%) and learning disabilities (91%). Those who care for more than 50 hours per week are also more likely to agree (91%).

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



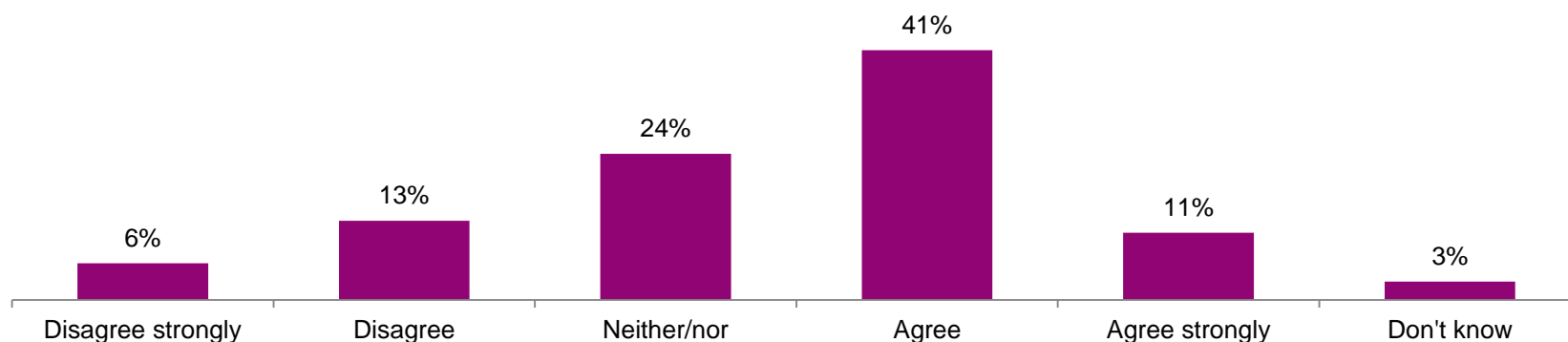
- Just under half (48%) of respondents felt that they had someone to rely on for support. This is slightly lower than the figure of 53% reported in 2017.
- 32% of respondents disagreed with this statement. This figure was higher for respondents caring for a spouse/partner (37%), those who have been caring for 11-19 years (41%) and those caring for people aged 35-44 (43%).

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



- 26% of respondents agreed that they were able to balance their caring role effectively with other things in their lives. 49%, nearly half of the Edinburgh sample, disagreed with this.
- The proportion of respondents disagreeing was higher for respondents caring for somebody aged under 16 (59%), or 16-25 (61%). Respondents caring for someone for more than 50 hours a week were also more likely to disagree with this statement (60%).

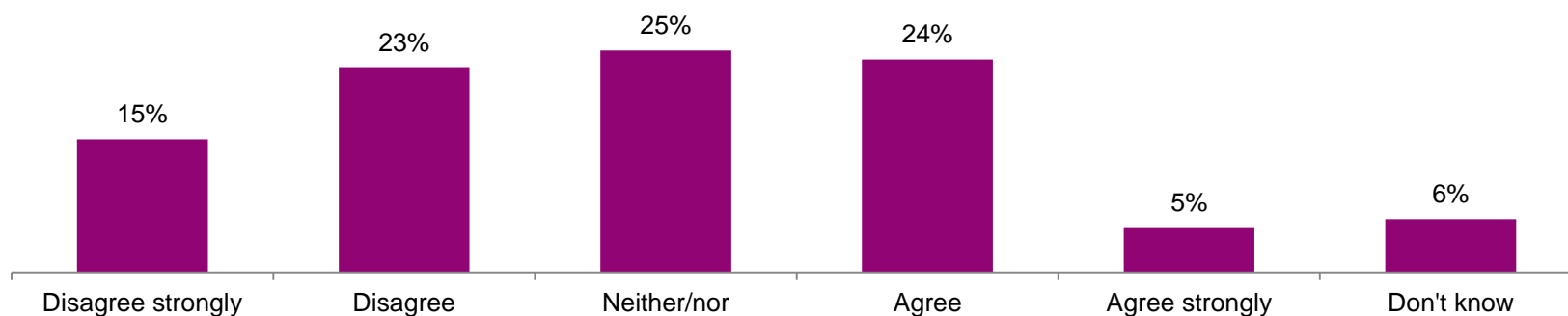
## Health and Wellbeing: “I have a say in the services provided for the person(s) I look after.”



- Just over half of the sample agree with this statement, with 19% disagreeing.
- The level of disagreement was greater for those caring for someone due to substance abuse (47%) and those caring for people aged 35-44 (34%).

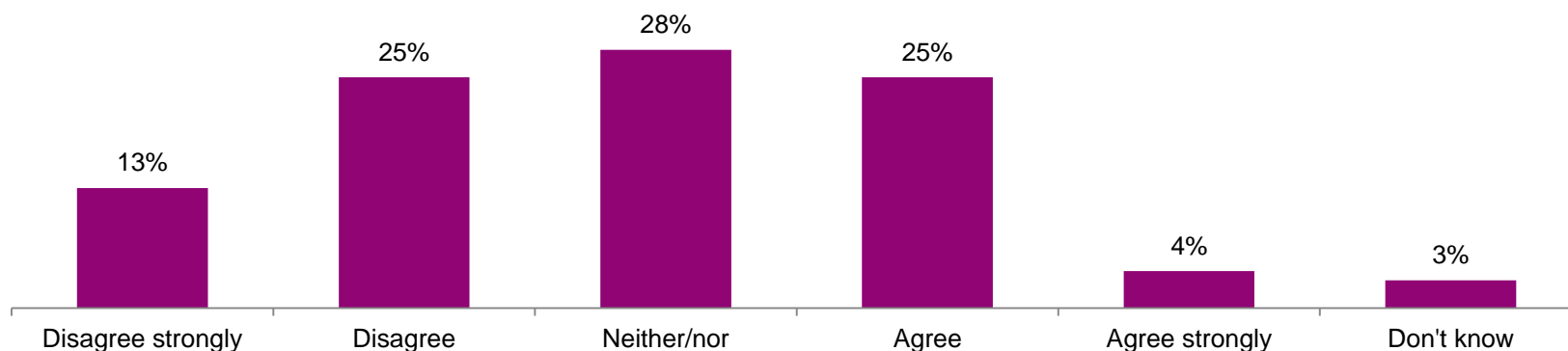


## Health and Wellbeing: “Local services are well coordinated for the person(s) I look after.”



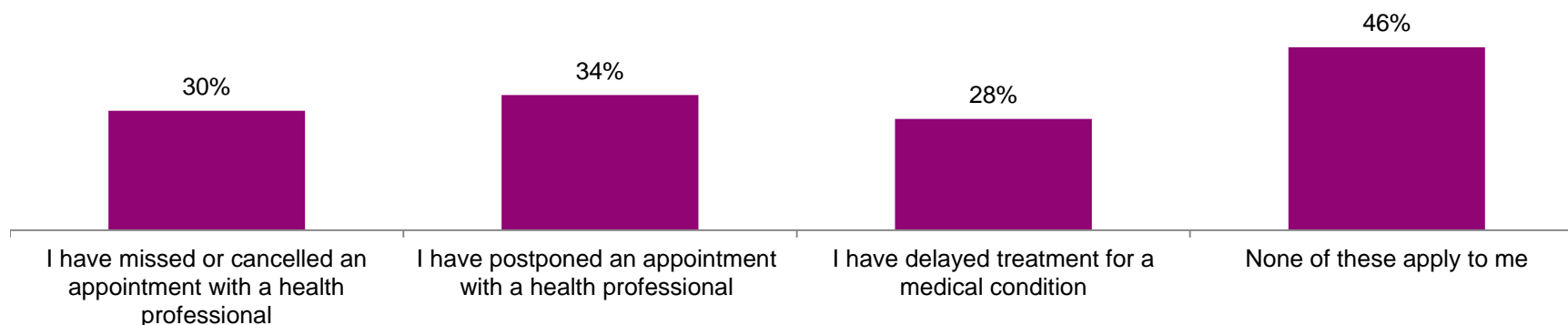
- 29% of the sample agree with this statement, with 38% disagreeing
- The level of disagreement increased with the time spent caring. 19% of respondents who had been caring for less than a year disagreed with this statement, increasing to 44% for those who have been caring for 20+ years.
- Respondents were also more likely to disagree with this statement if they were caring for people with Autistic spectrum disorder (51%), or a learning disability (48%).
- 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 38% disagreeing.
- Respondents were most likely to agree to this statement if they had been caring for less than a year (69%), if they care for up to four hours per week (56%) and if they deem themselves to be in very good health (46%).
- They were more likely to disagree if they were caring for a grandchild (48%), 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.
- 34% have postponed an appointment with a health professional.
- 28% have delayed treatment for a medical condition.
- 54% of respondents say that they have experienced at least one of these impacts.

# Health Impacts – Additional Comments (1)

358 carers made additional comments about the impact of caring on their health.

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

-  *“Completely exhausted and running on empty. I never feel rested, just depleted. I suffer with horrendous migraines and the doctors have told me to reduce the stress levels in my life, but how is this possible?”*
-  *“Three years ago I was diagnosed with cancer. I got no extra support and felt I had to leave hospital at the soonest possible time to get back to my husband.”*  
*“Could not cope as I was mentally and physically exhausted.”*
-  *“I am now suffering from anxiety and pretty bad depression. My own physical health has deteriorated in the past 13/14 years I have been caring. I often push myself beyond my energy levels as there is no one else, making myself ill.”*
-  *“My stress and anxiety levels are high and my sleep disordered. I am aware of this and do try to look after myself but the ongoing drone of my responsibilities takes its toll on me.”*
-  *“I have severe osteoarthritis in my ankle and have delayed getting it operated on as I feel I cannot be off my feet for any length of time as not sure how this would impact on the care I give my wife?”*
-  *“I don’t have the energy left to deal with appointments for myself so only make appointments if it’s urgent.”*

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## Health Impacts – Additional Comments (2)

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

 *“I practically help 24 hours a day, I have no time for myself.”*

 *“I sometimes think that I have no life of my own but I do get fresh air walking my dog.”*

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

 *“Difficulty with employment and their empathy towards my caring role.”*

 *“I have had to miss or rearrange work appointments – which impacts financially as I am self employed.”*

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

 *“It put a strain on my relationship and sadly it ended, that caused me more depression.”*

10 respondents reported feelings of guilt, anger and resentment, 9 talked about their fears for the future, 8 commented on the impact of the pandemic on closing services and creating barriers to accessing healthcare, and 8 talked about the additional stress caused by having to interact with agencies in order to secure support.

4 respondents completing the survey shared that they were feeling suicidal.

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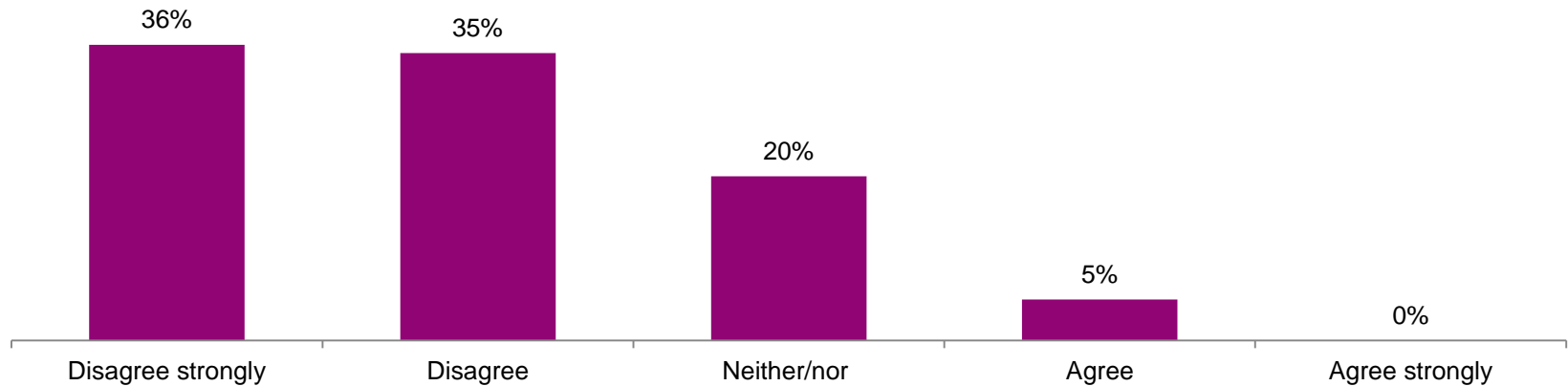
## Health Impacts – Key Findings

- 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.
  - 67% 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. 29% 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.
  - Over half of respondents report that their caring role has resulted in missed or postponed appointments or a delay in treatment for their own health.
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# MONEY AND WORK

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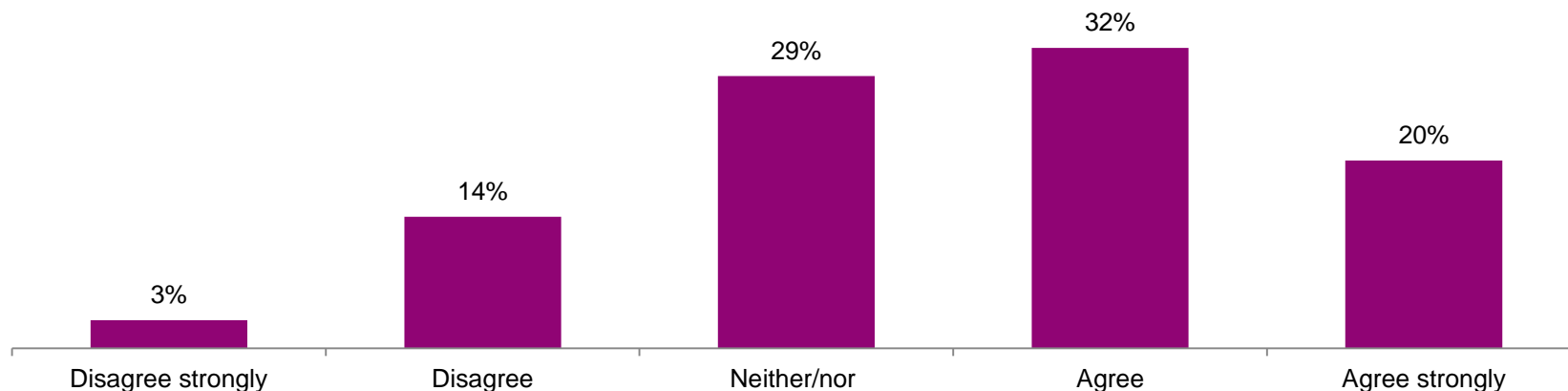
## Money and Work: “Being a carer has improved my finances.”



- Only 5% of the Edinburgh sample agreed with this statement. 71% disagreed.

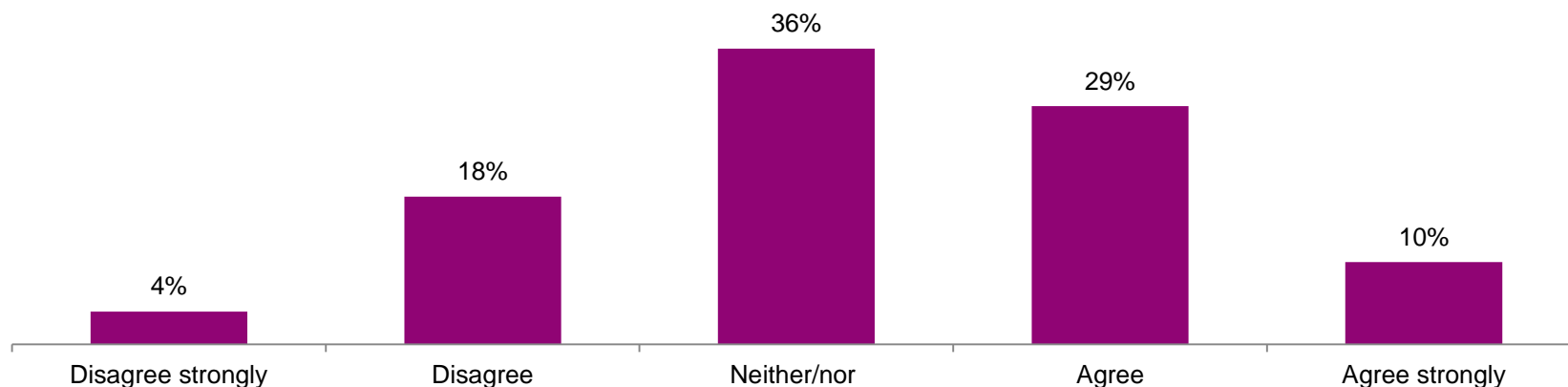


## Money and Work: “Being a carer has negatively impacted my finances.”



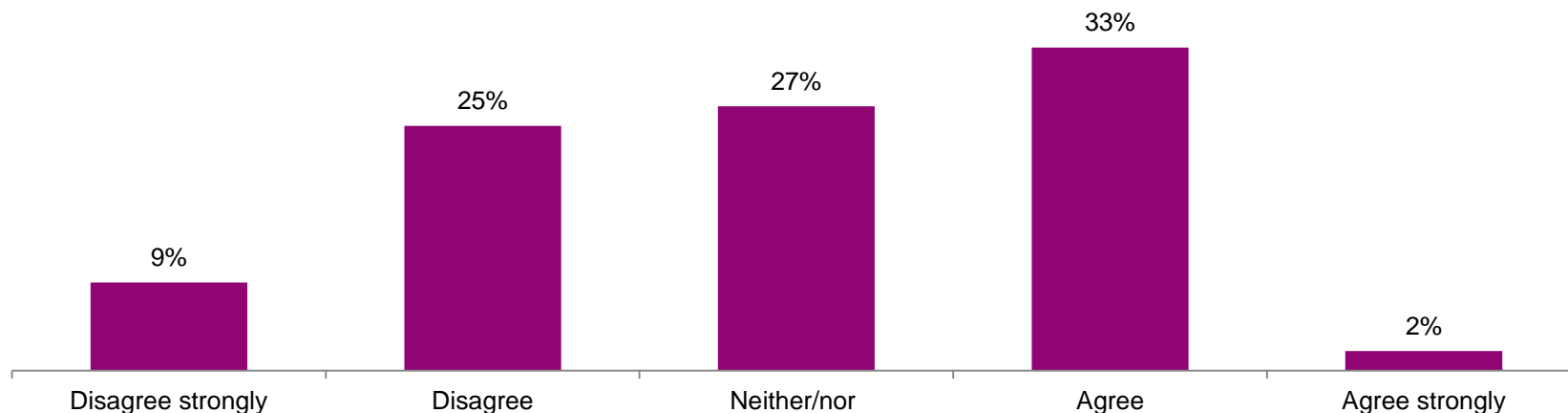
- 52% of respondents agreed with this statement, 20% of them agreeing strongly. This is slightly higher than the 47% of respondents who agreed ‘being a carer has made money and finances more difficult’ in 2017.
- The level of agreement was higher for respondents caring for a child (64%) or grandchild (85%), respondents spending 35-50 hours per week caring (62%), respondents aged 45-55 (64%) and respondents not in work, education or receiving a pension (65%).

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



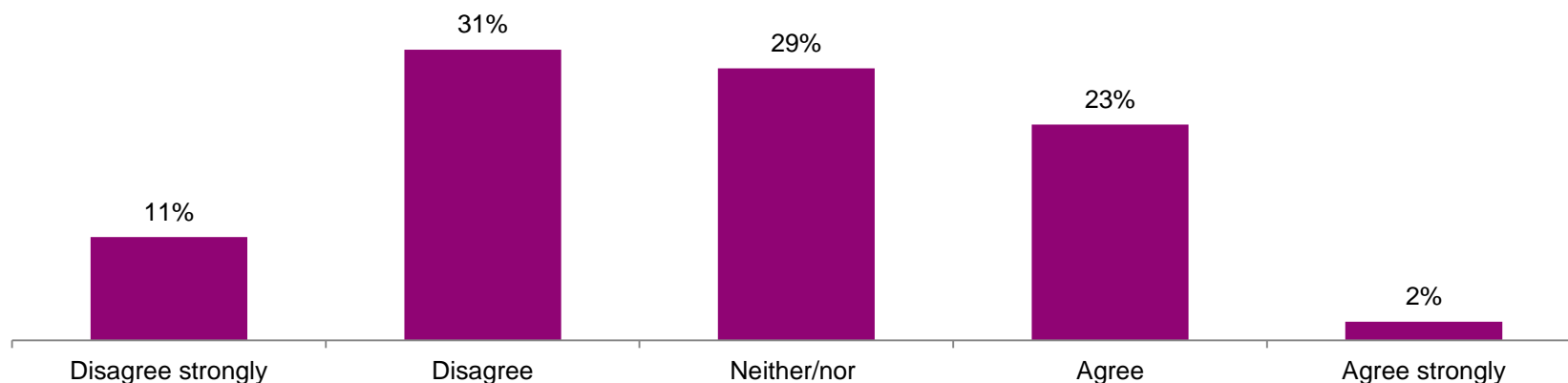
- 39% of respondents agreed with this statement, in line with the 2017 figure (40%).
- Respondents were more likely to agree with this statement if they were caring for children aged 16 or younger (60%), caring for adults aged 16-25 (49%) and were not in receipt of a salary or a pension (54%).
- There 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.”



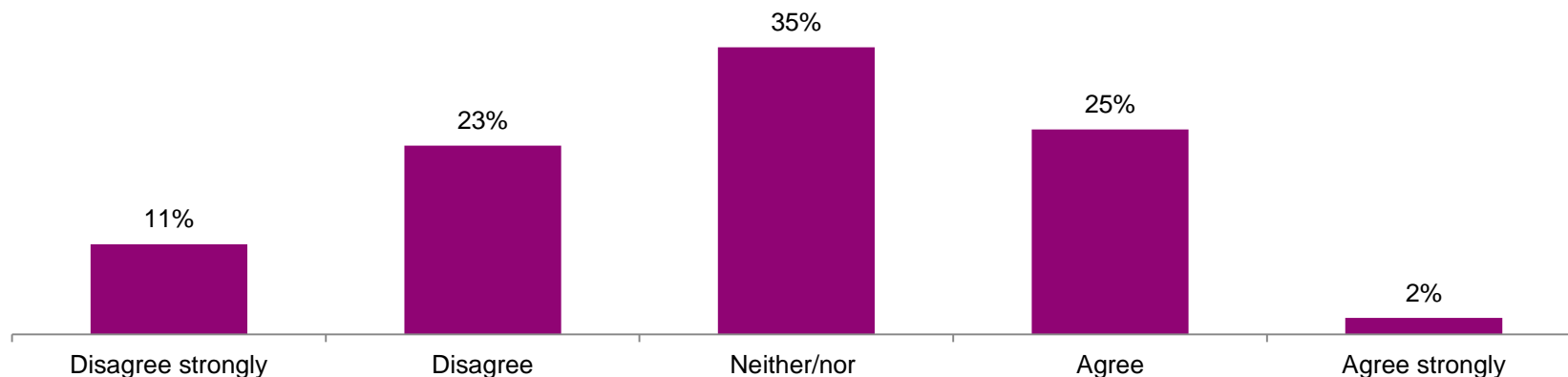
- 35% of respondents agreed with this statement, with only 2% agreeing strongly. This has dropped from the 2017 figure of 43%.
- Responses to this question were fairly consistent. There was some variation in terms of the conditions of the people being cared for, with 44% of those caring for people with Alzheimer’s/dementia agreeing, compared with just 16% of those caring for someone with substance abuse.
- Agreement was higher for respondents who had engaged with VOCAL (37%) than for those who had not (28%).

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



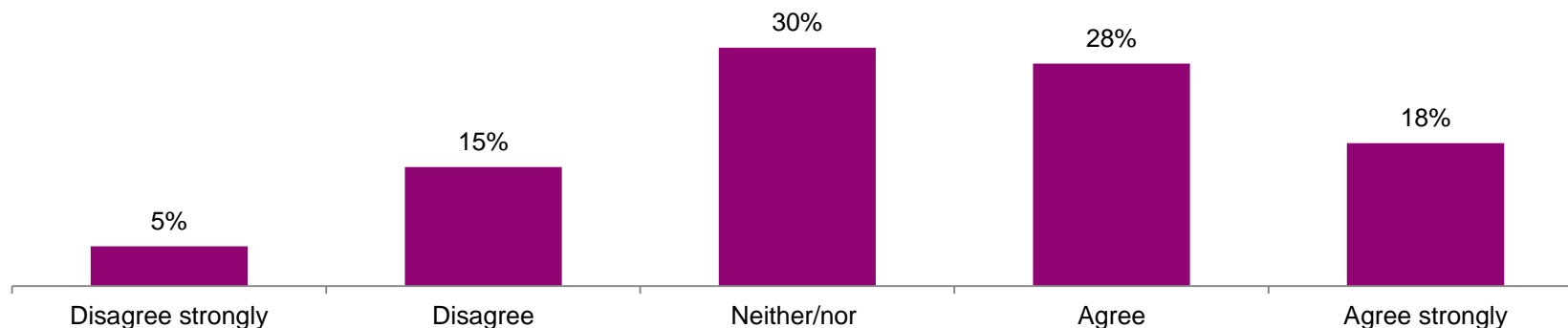
- Just 25% of respondents agreed with this statement, with only 2% agreeing strongly. This is lower than the 2017 figure of 32%, where 3% agreed strongly.
- Agreement with this statement was notably low for people caring for individuals with substance abuse (13%), again suggesting that there may be additional challenges for this group of carers (please note small sample size).

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



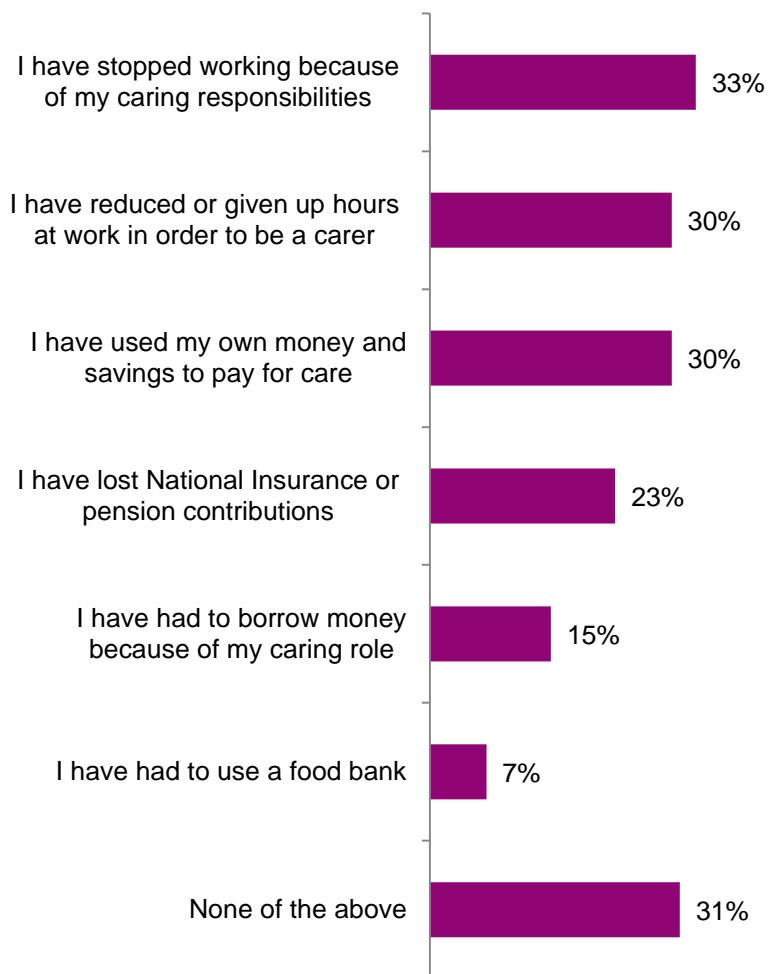
- Just a quarter of respondents (27%) agreed with this statement, down from 35% in 2017.
- 34% of respondents disagreed with this statement. The level of disagreement was higher for those who had been caring for 11-19 years (40%), respondents caring for people with mental illnesses (41%), learning disabilities (41%), substance abuse (57%) and hearing impairment (40%).
- Respondents who were engaged with VOCAL were less likely to disagree with this statement than those who were not (32% compared with 43%).

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



- 46% of respondents – nearly half of the sample – agree with this statement. This is higher than the 40% agreement level in 2017.
- Unsurprisingly, concern over this issue is highest (although not exclusively so) for those caring for older people. 58% of those caring for a parent are worried about paying for care, compared with 36% 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 (52%), do not live with the person they care for (55%), are caring for somebody who is frail (59%), with Alzheimer’s/dementia (59%), a hearing impairment (60%) or a visual impairment (59%), and are caring for someone over the age of 75 (82%).

# Financial Impacts of Caring





- 69% of respondents report at least one of the suggested financial impacts of caring.
- 33% have stopped working (up from 27% in 2017).
- 30% have had to reduce their hours (up from 23% in 2017).
- 30% have used their own money to pay for care. This is down on the 2017 figure of 34%.
- 23% have lost NI or pension contributions as a result of giving up work- this is much higher than the 13% figure from 2017 and is likely a reflection of the different demographic in 2021.
- In new questions for 2021, 15% of respondents have had to borrow money because of their caring role, and 7% have had to use a food bank.



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## Money and Work– Additional Comments (1)


192 respondents made additional comments about the impact of caring on their finances. 80 respondents provided specific details of the impact of caring on their financial situation:

-  *“I am now in my late 50s and I really never expected to be in this awful financial situation. It is embarrassing to have to regularly use food banks so we can eat.”*
-  *“In the last year I have got into debt and I have become depressed as a result.”*

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

-  *“I have had to give up my 12 year career as a chef resulting in a loss of about £2500 every month and double our costs of living.”*
-  *“I could be earning more if I wasn’t looking after my mum so there is an opportunity cost. I worry about what will happen if/when her money runs out.”*

32 talked about challenges with the benefits and funding system:



-  *“We are in receipt of a DP but I cannot use it to pay myself even though during the pandemic I have looked after Mum single handed. This is because I have Power of Attorney, which is a necessity taking care of someone with Alzheimer’s. The DP should support the carer who is doing a full time job.”*
-



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## Money and Work– Additional Comments (2)

18 respondents made comments about their worries and concerns for their financial situation in the future:

-  *“I am reluctant to spend money in case it is needed for care at a later date.”*
-  *“I do worry about my future finances, and the long-term financial needs of my son as he will need money to pay for his care when I am not here.”*

Other subjects (each mentioned by fewer than 10 respondents) were: the impact of the pandemic in increasing financial concerns (3) and the cost of care/care home fees (3).

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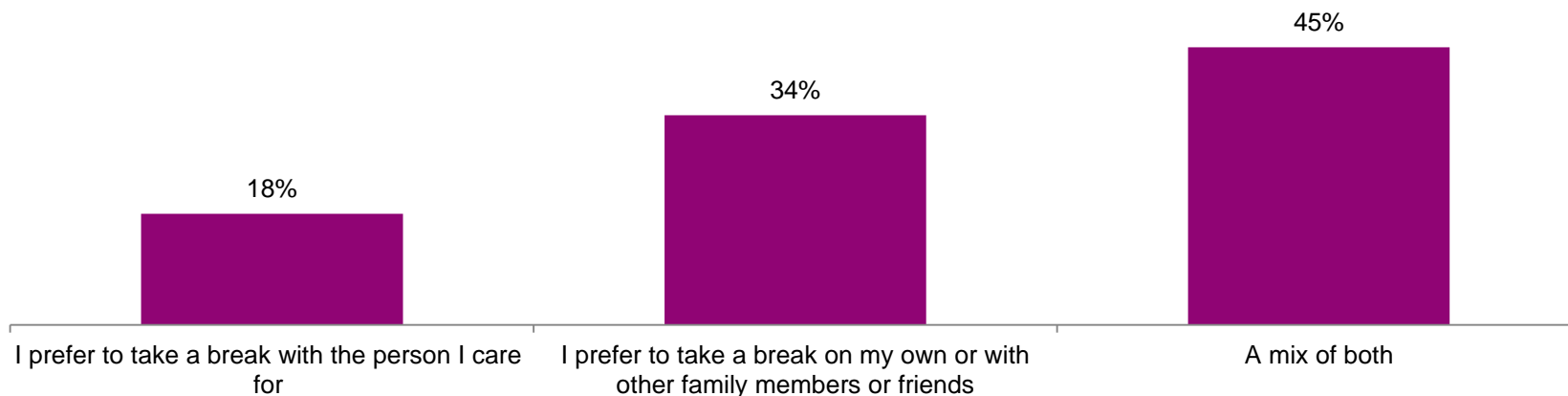
## Impact on Money and Work– Key Findings (1)

- 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. 33% have stopped working because of their caring role, up from 27% in 2017.
  - Over half of respondents agree that being a carer has negatively impacted on their finances and only 27% agree that they have enough financial support available.
  - There is continued evidence of stigma around this issue, with 39% agreeing that they find it hard to talk about the financial implications of their caring role.
  - 35% of respondents know what financial support they can access and 25% feel confident in applying for it.
  - 15% have had to borrow money because of their caring role. 7% have used a food bank.
-

# TIME AWAY FROM CARING

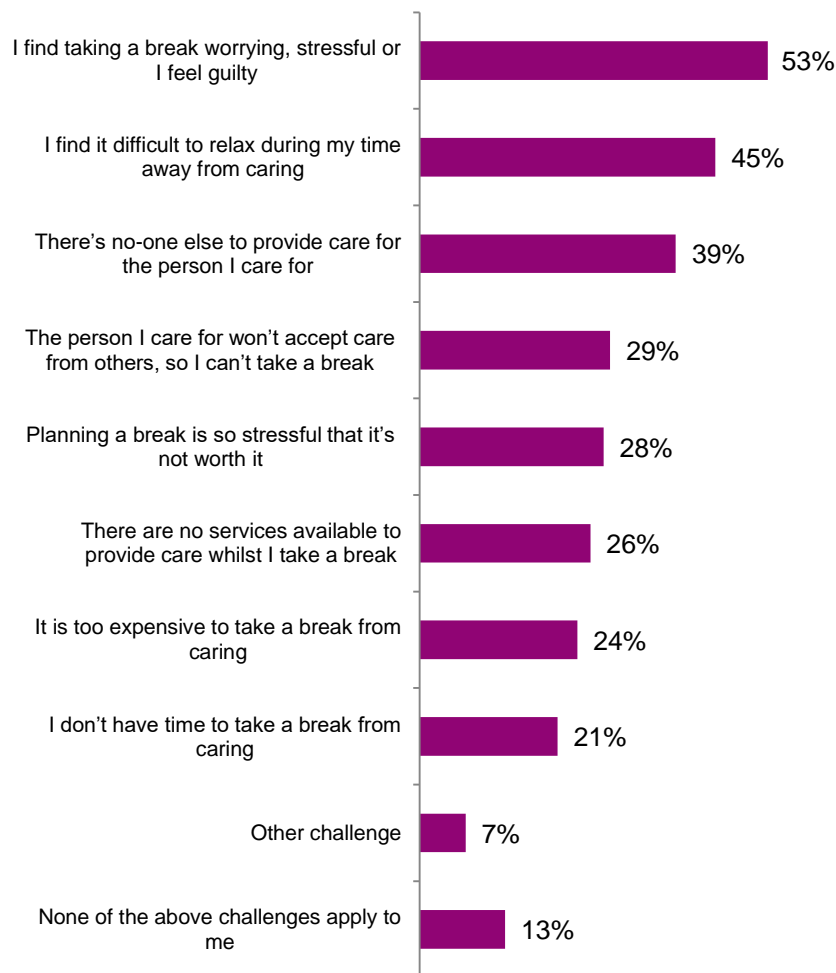
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# Time Away From Caring: Preferences



- 18% of respondents say that they would prefer to take a break from caring with the person they care for.
- 34% 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.
- 45% say that they find it difficult to relax whilst they are not caring – an increase from 34% in 2017.
- 39% say that there is nobody else to provide care, and 29% that the person they care for won't accept care from others (the corresponding figure for 2017 was 31%).
- 24% agree that it is too expensive to take a break from caring – up from 16% in 2017.
- 28% agree that planning a break is so stressful that it's not worth it – up from 22% in 2017.
- 26% of respondents say that there are no services available to provide care whilst they take a break, and 24% 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.

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# Time Away: A Good Break (1)

Respondents were asked what a good break would look like for them. 683 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)

-  *“Peace and quiet and the security of knowing that my partner is being well cared for and not unnecessarily sedated to convenience the care providers.”*
  -  *“Somewhere quiet, where I can just relax and have no demands on my time. Just to be able to be me and not someone’s carer.”*
  -  *“A chance to play golf on a Saturday.”*
  -  *“A week or two with money enough that i do not need to cook, somewhere warm with a calm sea, where my son can have fun and i can rest. he loves the beach.”*
  -  *“A weekend at the seaside with my fiancée, in summer..”*
  -  *“Somewhere peaceful and no housework or meals to make and maybe a bit pampering!”*
-

## Time Away: A Good Break (3)

-  *“A good break would be one where he was there for a while and I was on my own or with friends for a while.”*
  -  *“A change in my current role even if it’s just for a few hours without thinking that I need to be back to make sure the person I care for is all right.”*
  -  *“Being with other people. having fun and laughs.”*
  -  *“Somewhere warm as that helps my rheumatoid arthritis. No worries about the person I care for. But that won’t happen as there is no one else to care for that person.”*
  -  *“A retreat into Scottish countryside where I can look at water/trees/hills and just relax and do very little.”*
  -  *My husband and I having a holiday on our own. In 34 years we have gone away (7 days) once for our silver wedding anniversary. Next year is our 40th anniversary and would love for us both to go away for a week together on our own.*
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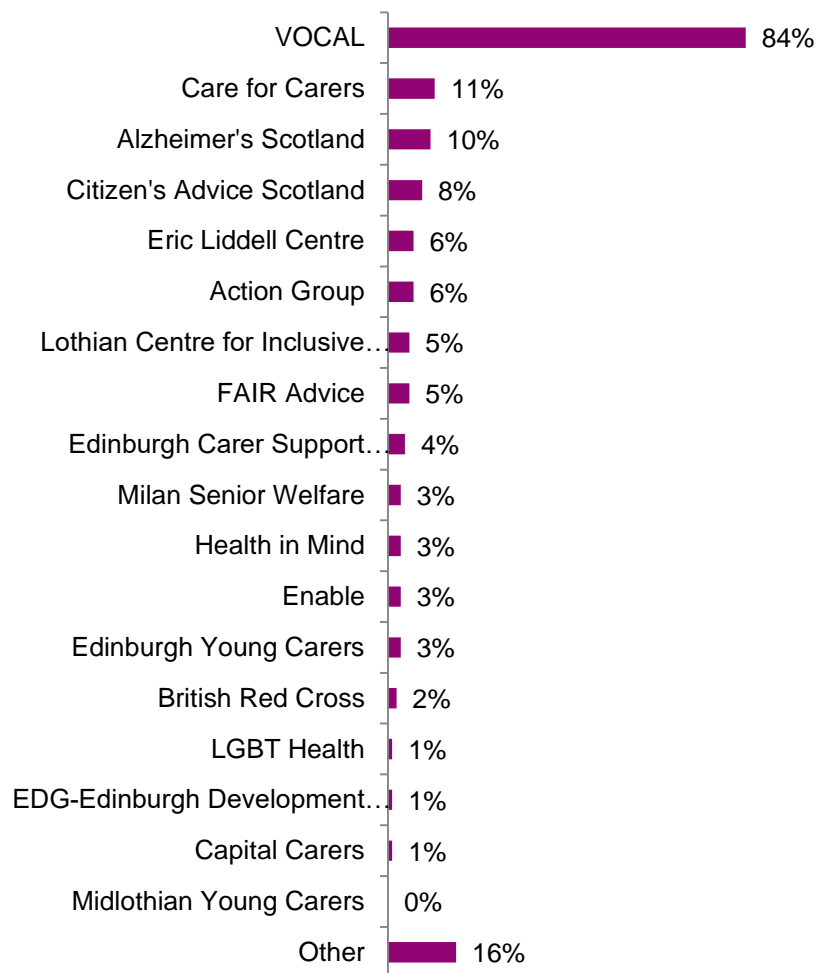
## Time Away: Key Findings

- 18% of respondents would like to be able to take a break with the person they care for. 34% would like to go away on their own, or with other family or friends. 45% 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**

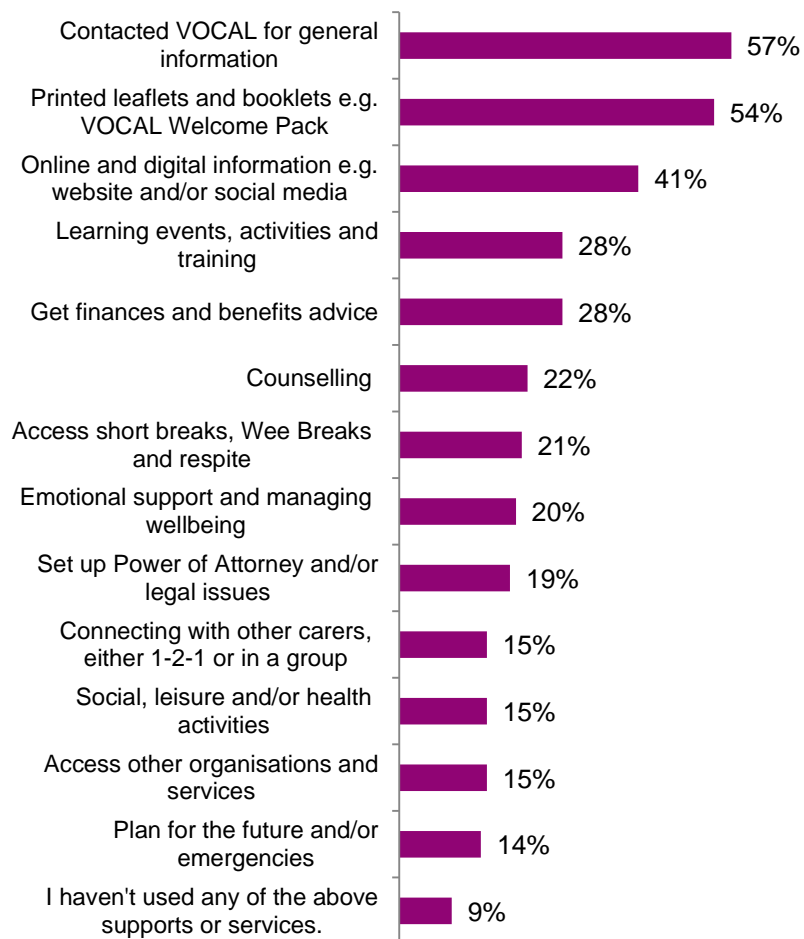
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# Agencies Used for Support



- Respondents were asked to identify which services and organisations have supported them in their caring role.
- As shown in Slide 22, 84% had engaged with VOCAL, making this by far the most engaged-with agency.
- Care for Carers, Alzheimer's Scotland and Citizen's Advice Scotland were the other agencies with the highest levels of engagement.

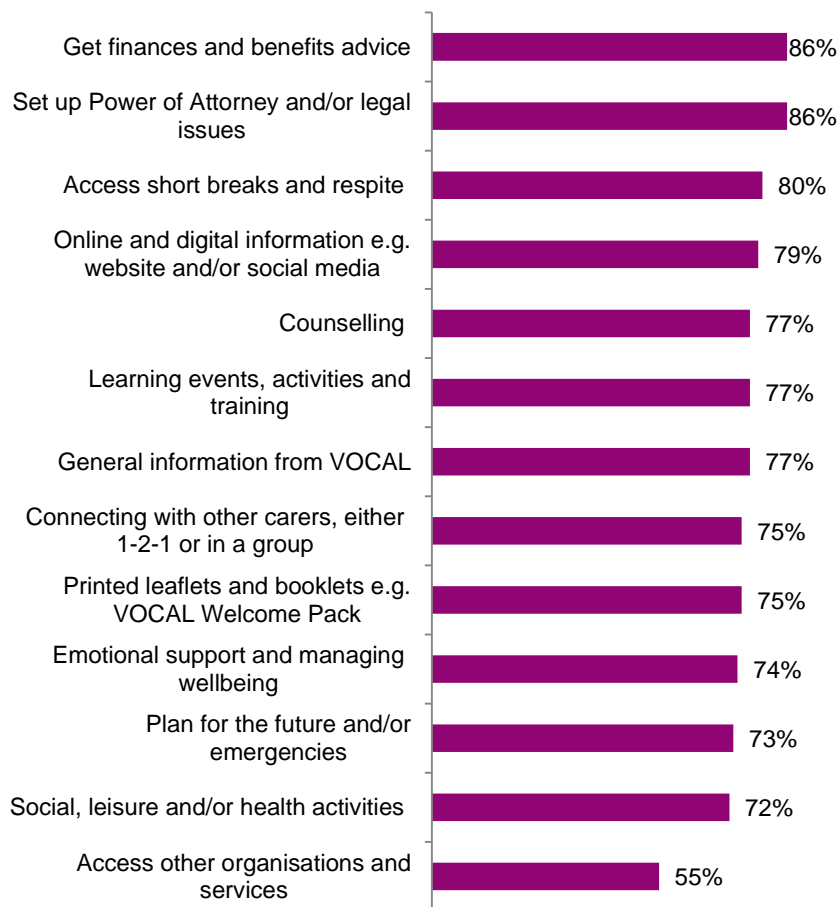
# Uptake of VOCAL Services



- The most used VOCAL services were: obtaining general information; the printed leaflets and booklets; 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 events, activities and training, get finances and benefits advice, and access counselling.

Base: All those who have engaged with VOCAL (691)

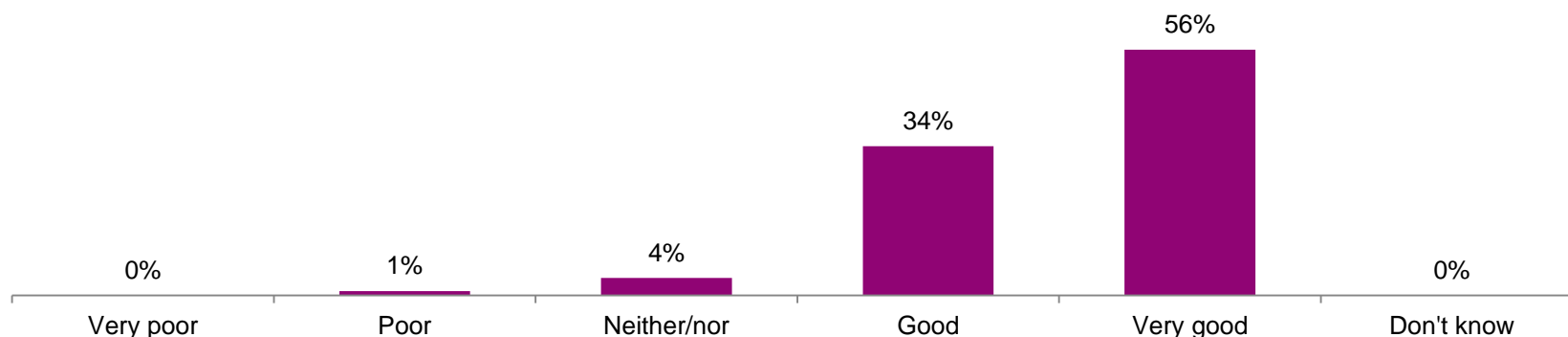
# Value of VOCAL Services



Base: All those who have used each of the services

- Respondents who have used each of the services were asked how useful they found them.
- Satisfaction ratings overall were very high, ranging from 86% for finance and benefits advice and setting up a Power of Attorney and/or legal issues to 72% for planning for the future and/or emergencies.
- 55% of those who had used VOCAL to access other organisations and services had found this aspect useful. It is not possible to know whether this was a reflection of the signposting itself, or of subsequent experience with these other services.

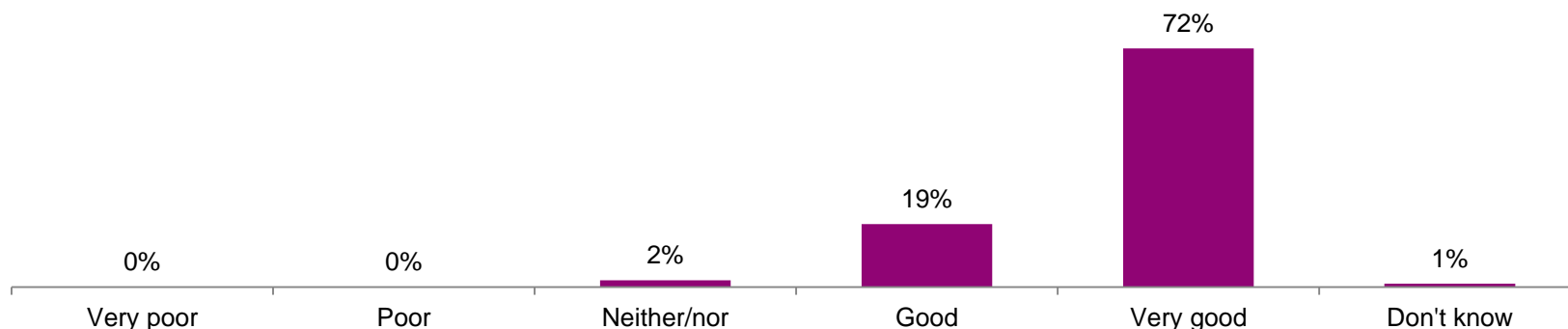
# Satisfaction: Ease of getting in touch



Base: All those who have engaged with VOCAL (629)

- 90% said that this aspect of their experience was “very good” or “good”.
- This compares with 92% 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.

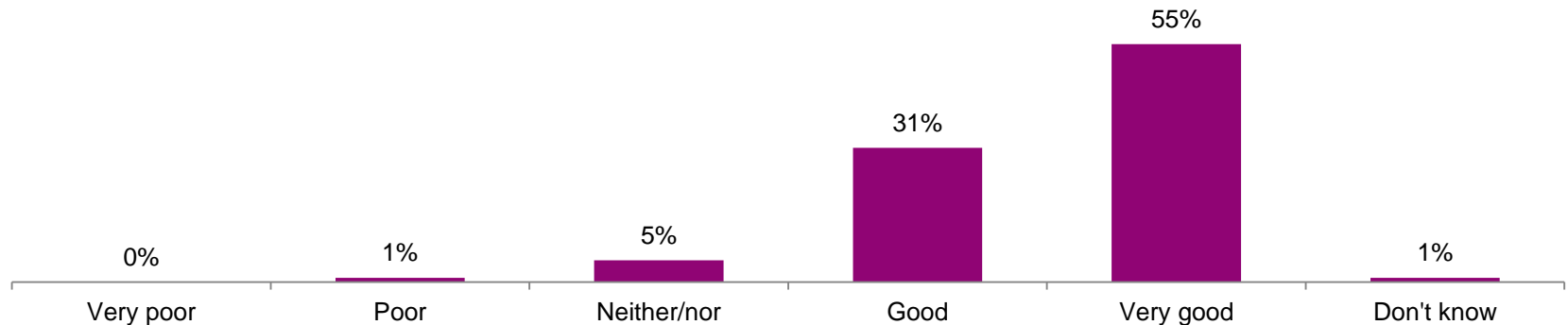
# Satisfaction: Friendliness of Response



Base: All those who have engaged with VOCAL (629)

- 91% said that this aspect of their experience was “very good” or “good”, with nearly three quarters (72%) choosing “very good”.
- This is consistent with the figure for 2017.
- Again there was very little variation across the sample for this question.

# Satisfaction: Timeliness of Response

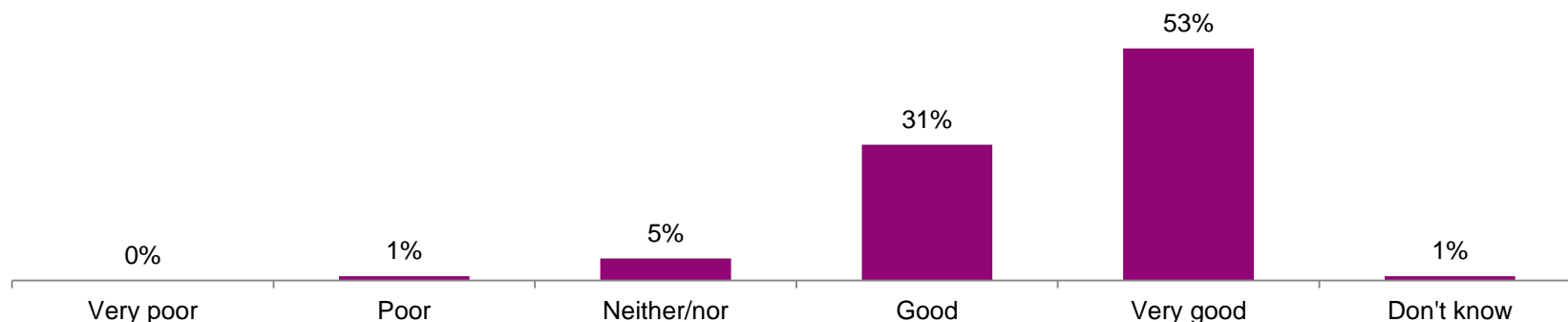


Base: All those who have engaged with VOCAL (629)

- This was a new question for 2021.
- 55% of respondents said that this aspect of their experience was “very good” and 31% that it was “good” – 86% in total had a positive experience.
- Again the response to this question was fairly consistent.



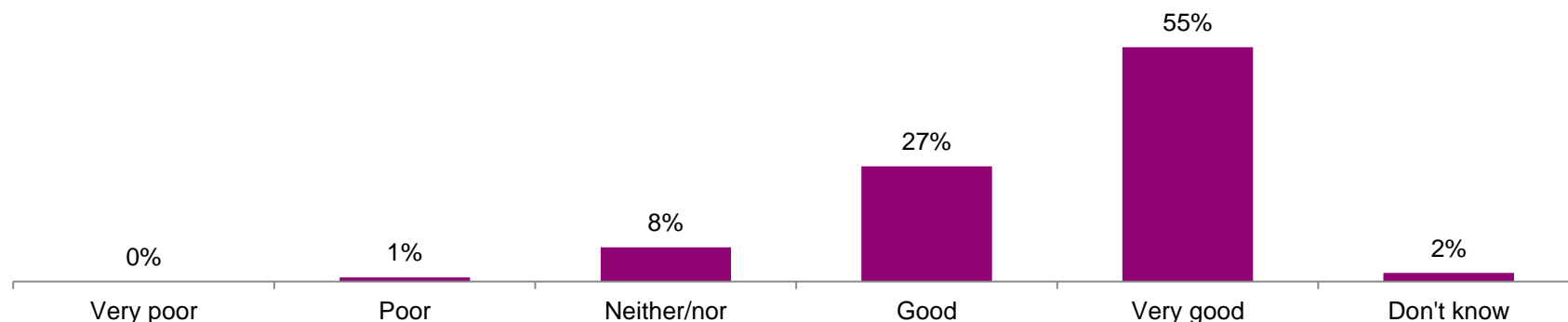
# Satisfaction: Getting the Information and Support I Needed



Base: All those who have engaged with VOCAL (629)

- 53% of respondents said that this aspect of their experience was “very good” and 31% that it was “good” – 84% in total had a positive experience.
- This compares with 88% positive feedback in 2017 to the statement ‘getting as much information as you needed.’

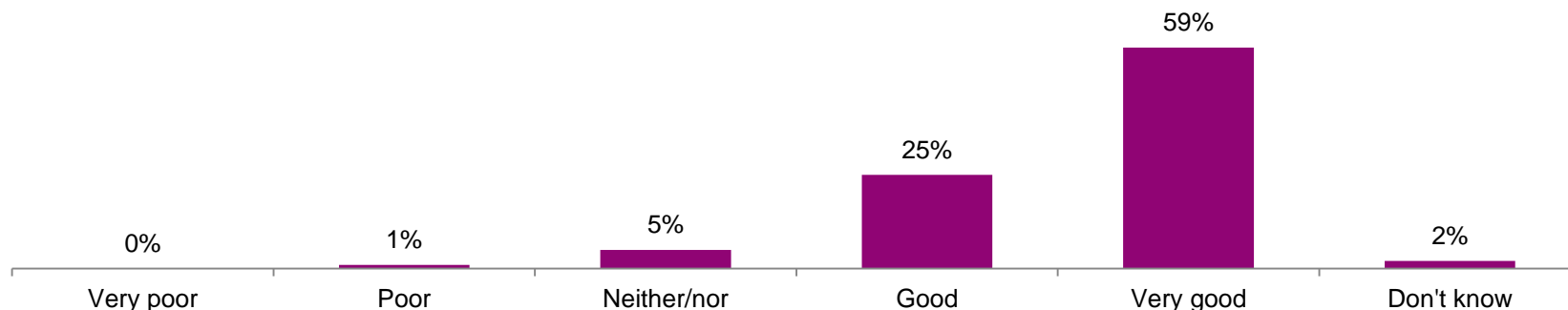
# Satisfaction: Knowledge of Staff and Volunteers



Base: All those who have engaged with VOCAL (629)

- 55% of respondents said that this aspect of their experience was “very good” and 27% that it was “good” – 82% in total had a positive experience.
- This compares with a figure of 85% in 2017.

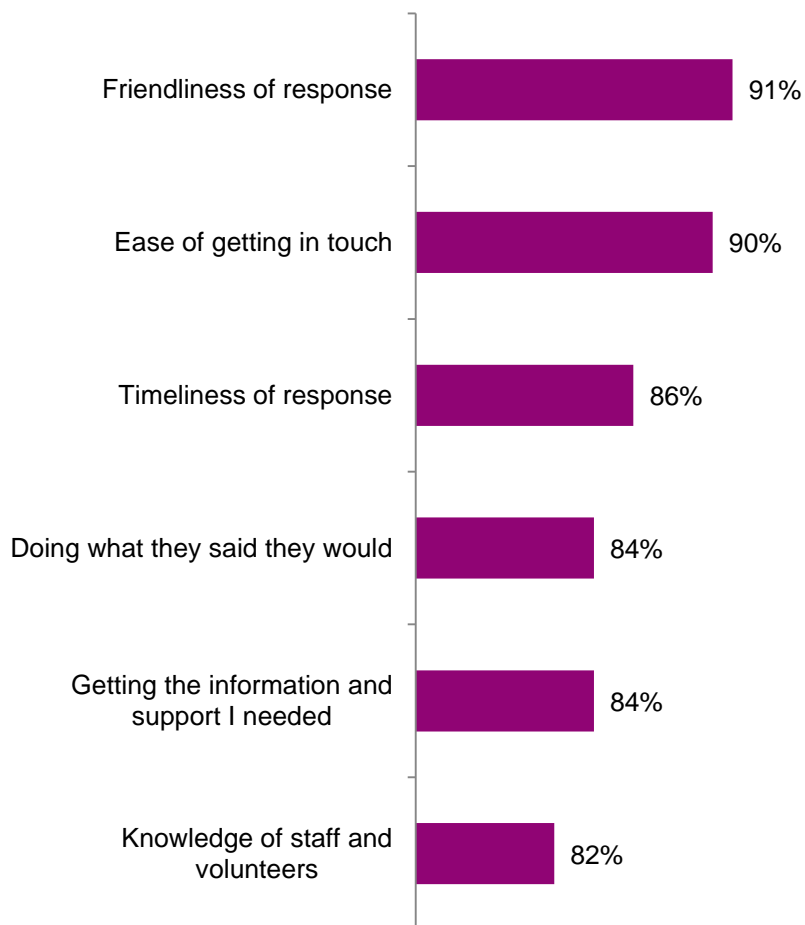
# Satisfaction: Doing What They Said They Would



Base: All those who have engaged with VOCAL (629)

- 59% of respondents said that this aspect of their experience was “very good” and 25% that it was “good” – 84% in total had a positive experience.
- This is in line with the 2017 figure of 84%.

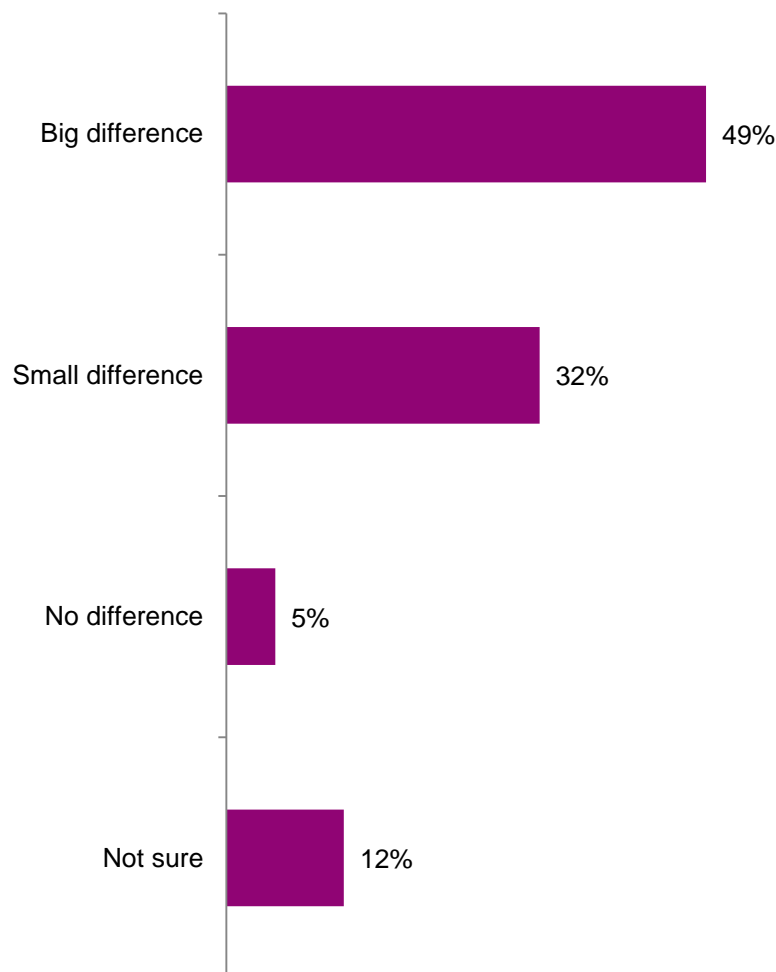
## Satisfaction Ratings: “Good” or “Very Good”



- 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 broadly in line with the figures in 2017.
- As in 2017, the friendliness of the response is a particular strength, with 72% rating this as ‘very good’.

Base: All those who have engaged with VOCAL (629)

# Impact of VOCAL



Base: All those who have engaged with VOCAL (629)

- Overall, 81% of respondents who have engaged with VOCAL say that this has made a difference to their experience as a carer.
- 49% say that VOCAL has made a big difference and 32% that it has made a small difference.
- In 2017, 88% of respondents reported that VOCAL had made a difference (65% a big difference and 23% 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.

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# The Impact of VOCAL

496 respondents described the impact of VOCAL, Edinburgh.

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

- 188 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.
  - 138 respondents cited that the impact arose through VOCAL's information or advice.
  - 64 respondents identified positive financial impacts, including securing Power of Attorney and help with applying for support.
  - 47 said that they had developed new skills that helped them in their caring role.
  - 27 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).
-

# Health Impacts

"I feel I am not alone. I know that in my day to day caring and when big decisions have to be made I can access support"

"I was at the lowest. I was sooo lost. VOCAL helped me see clearer."

"I am not so isolated. You have an understanding of my thoughts and feelings."

"VOCAL was central to keeping me sane, Without VOCAL I'm not sure how I could have managed."

"VOCAL in the background are playing an invaluable role which gives myself and my wife hope and optimism when times are difficult."

"The set of massages gave me some me time."

"The counselling was a HUGE breakthrough for me!"

"An absolute lifeline who saved my sanity and saved me from being forced to sell my home"

"They helped me find a stability in life and strike a balance between my duties as a carer and my life as a spouse and son."

"A little like a security blanket!"

## Information and Advice

"I found them very helpful when I had a query about my dad's hospital care last year."

"The VOCAL pack was excellent. I used the information to determine what I needed to do and just got on with it!"

"Getting the desired information/service quickly from one main contact point has reduced stress and uncertainties of finding and getting appropriate support."

"I was very overwhelmed and received lots of support from VOCAL."

"I still refer to some of the 'handouts' from the group training courses I attended years ago. That information at the right time for me was a good base."

"I learned more about the subject and it took away some of my concerns."

"I was called for jury service, VOCAL got me a one year exemption."

"They have signposted me over the many years I have been a carer to get advice and help."



# Financial Impacts

“Helped my Mum access attendance allowance payments, which has made a big difference to her finances.”

“The support to get benefits was a huge help”

“Helped and advised my son on PIP application which has resulted in him being more independent.”

“VOCAL helped me to fill in the PIP form, which made a difference.”

“They explained very patiently what we were entitled to and helped with filling the necessary form as well as advising which extra papers needed to be supplied.”

“They helped me show the electricity supplier that I did not owe them money.”

“I had no knowledge that a financial allowance would be paid until notified by VOCAL.”

“The help with the Power of Attorney was invaluable.”

# Time Away From Caring

“Access to short breaks gave me respite”

“My son was taken out with a carer for a while, which he enjoyed.”

“I used short break funding to start a hobby, which I am enjoying immensely.”

“It helped us to have an outing as a family.”

“Wee Break fund but due to Covid I didn't have to use it on a break, so it was used for driving lessons and it is going amazing and will make a huge difference to us.”

“The support from Wee Breaks was invaluable to us after Covid.”

“It gave me time without guilt that I wasn't being a great mother.”

“They have given me a very welcomed break for one hour a week when I can be myself and not feel guilty about it.”

# New Skills

“I have gained a mass of knowledge which has benefited me enormously in my capacity as a carer.”

“Prior to contacting VOCAL I had no knowledge of lifting and handling my partner safely.”

“The First Aid course was excellent.”

“I use what I have learned from them almost daily.”

“The half day course on dementia. Wow, what a marvellous insight.”

“Funding for art classes helped me hold on to my own identity and life away from caring.”

“The practical help supported me to support the people I care for,”

“The addiction cycle was explained to me and it helped me to change my behaviour.”

# No Impact


Respondents who said that VOCAL had made ‘no impact’ were also asked to explain their answer. 47 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:

 *“There is not much more that they are able to do.”*

 *“It was too bad an illness, what could they do?”*

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 could only join others if I didn’t have doctor, hospital, dentist appointments with my brother so I gave up trying.”*

 *“I cannot manage to attend training or well-being sessions at the moment as I am unable to leave the person I care for .I am not confident or skilled in online technology to participate in zoom sessions or online training or other services.”*



 *“I don’t want the label ‘carer’ so this is a reflection on me, not the organisation.”*

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# 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. 310 respondents answered this question.

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

-  *"I felt very validated and accepted by VOCAL's attitude that I definitely count as a carer; I hadn't really perceived myself as such until spending time at VOCAL."*
-  *"VOCAL think out of the box."*

52 respondents praised VOCAL staff and volunteers, with a further 12 highlighting the role of a specific staff member:

-  *"I find the VOCAL staff very supportive, very kind and compassionate and very friendly as well as professional!"*
-  *"I always feel listened to when speaking to staff and volunteers."*

Other positive feedback focused on: the quality of the training courses (25 respondents), the ability to meet other carers (10), staff proactively checking in on carers (6), support in emergency situations (5), attending events (5) and providing help and assistance during lockdown (2).

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## Further Feedback on VOCAL Services (2)

A comparatively small number of negative comments (47 in total) were made about carers' experiences of VOCAL:

- 17 reported communication issues (eg a phone call not being returned).
  - 7 said that they were unable to attend any of the sessions due to work or caring commitments.
  - 7 reported specific issues with the specialists/advisors they had experienced – in most cases this related to respondents not feeling comfortable with a counsellor.
  - 4 said that they felt the pandemic had impacted on VOCAL's ability to engage with them.
  - 5 had made a specific request for help or advice and were not satisfied with the outcome.
  - 4 respondents felt that they needed more help and support than VOCAL (and perhaps any agency) was able to provide.
  - 2 respondents said that they felt overwhelmed with the amount of information and resources on offer and were not sure how to navigate it all.
  - 1 respondent had attended group events but found it difficult to interact with the other participants.
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# Satisfaction with VOCAL – Key Findings

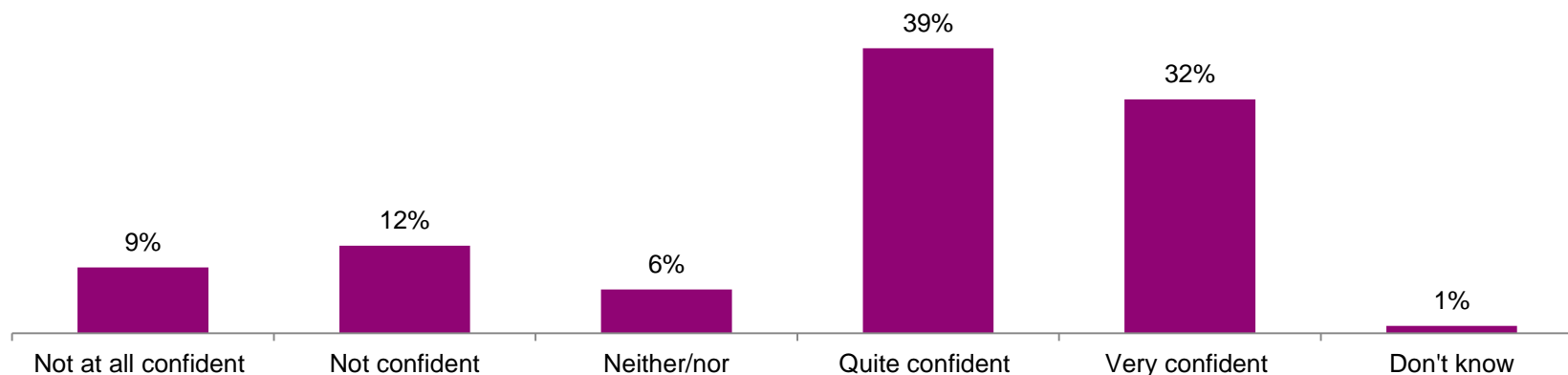
- Satisfaction with VOCAL services and support is broadly in line with the 2017 response, with no measure rating lower than 80% ‘good’ or ‘very good’.
  - To have maintained these ratings through lockdown is incredible!
  - The friendliness of the VOCAL staff is a particular strength; 72% of respondents who used VOCAL services rated this as ‘very good’.
  - 49% of respondents who have engaged with VOCAL say that the organisation has made a ‘Big Difference’ to them, and 32% that it has made a ‘Small Difference’.
  - These figures are lower than the figures in 2017 (65% and 23% 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 carers trust its advice.
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# SHAPING FURTHER SERVICES

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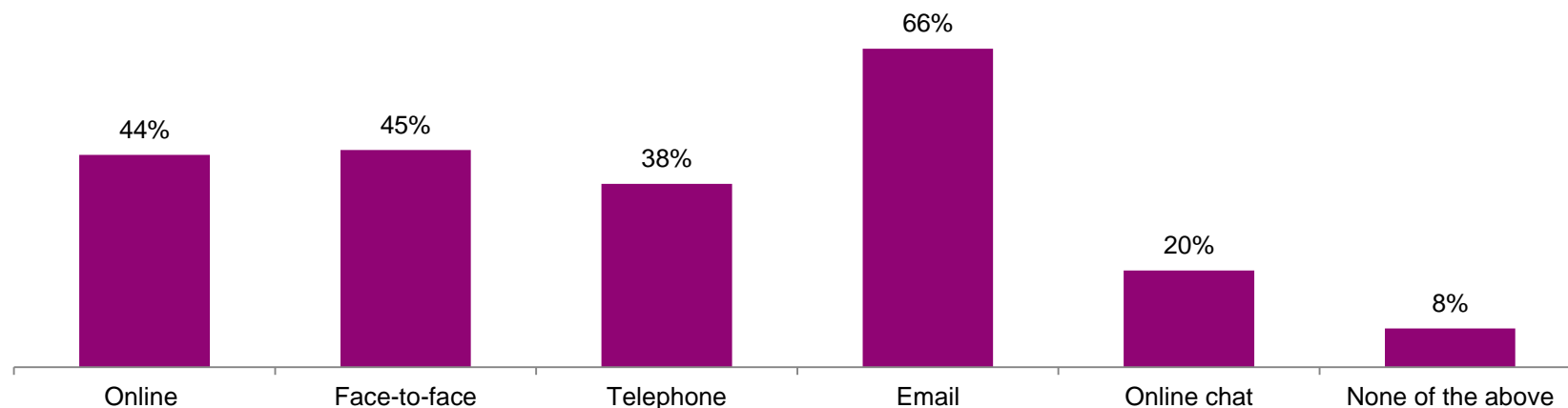


# Shaping Future Services: Using Technology



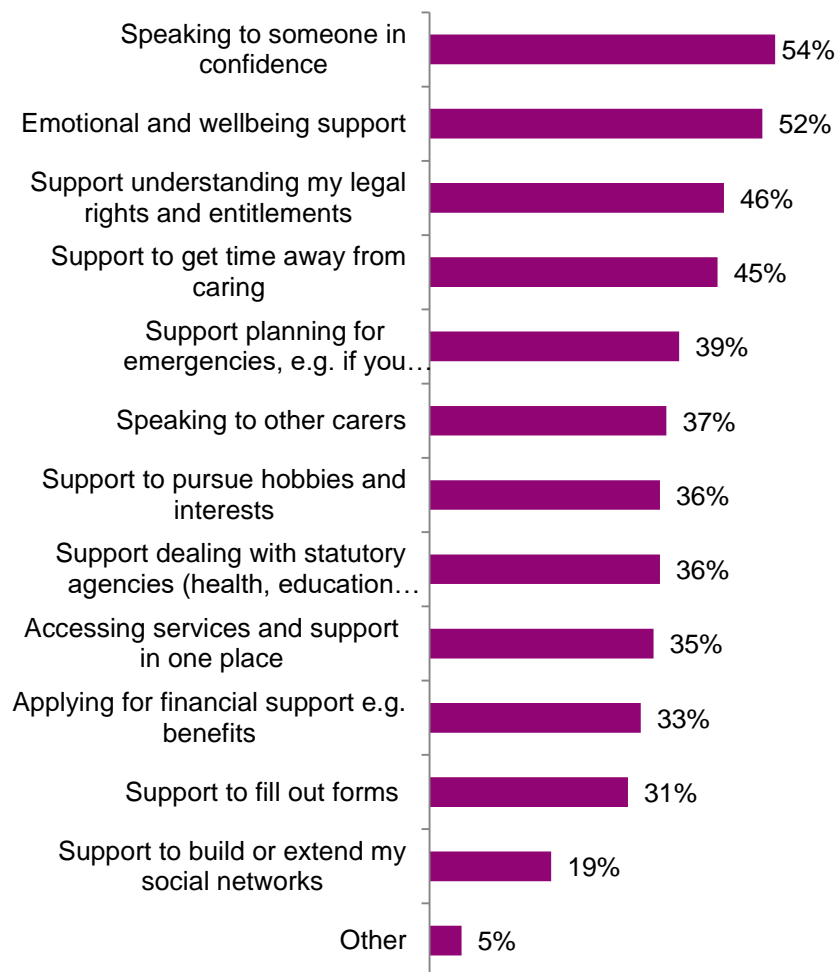
- 71% of respondents said that they were 'very' or 'quite' confident in using digital technology like the apps, internet and video calling. The corresponding figure for 2017 was 62%.
- This leaves nearly a fifth of the sample saying that they are not confident in using this type of technology. As in 2017 this figure increased with age; 0% of 16-25 year olds say fall into this category, increasing to 30% of 66-74 year olds, 36% of 75-84 year olds and 65% of those aged over 85.
- Respondents who are in paid employment or education are generally more confident than those who are retired or not in any of these categories.

# Future Support: Communication Preferences



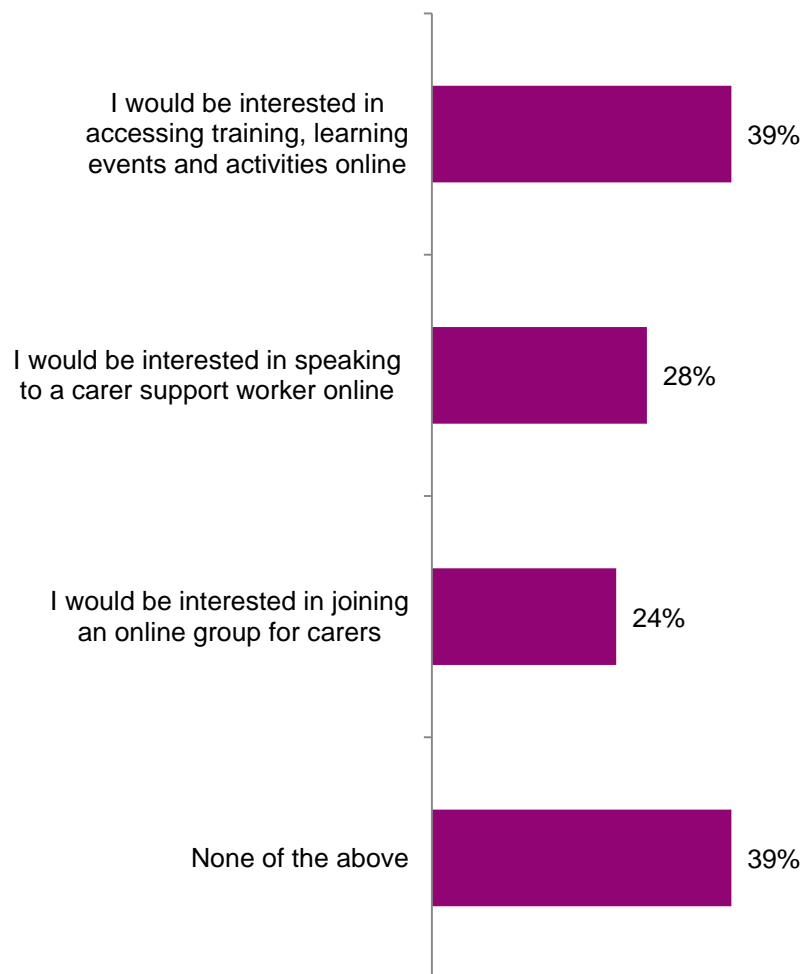
- Email is the most popular communication channel across the sample, with 66% of carers selecting this as the way in which they would like to receive support and information from VOCAL and other agencies.
- However, face to face and telephone support remains popular, underlining the importance of interpersonal 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



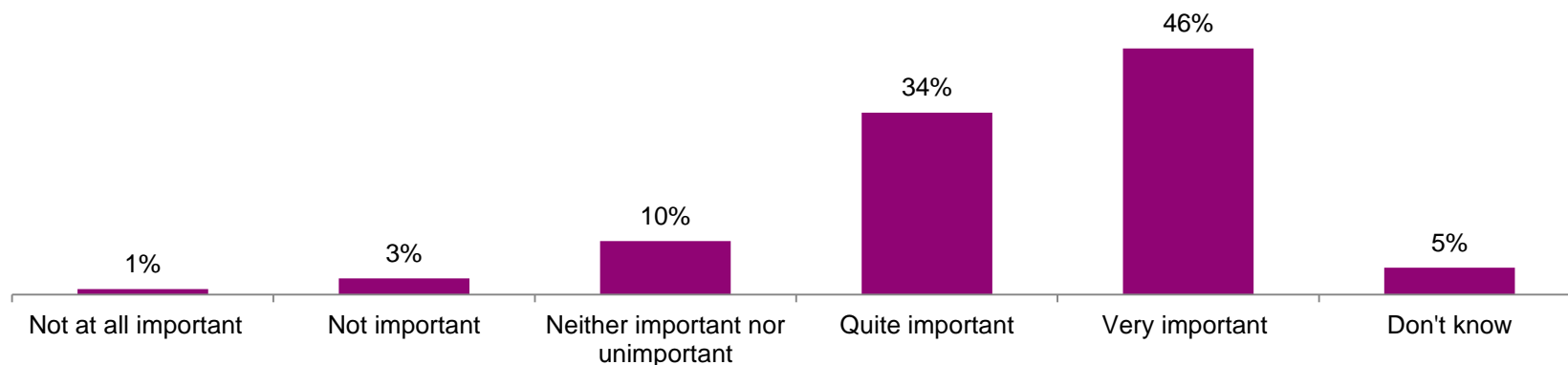
- Respondent preferences largely reflect the findings of the 2017 survey.
- The top three services: speaking to someone in confidence; emotional and wellbeing support; and support to get time away from caring, are very closely aligned to the things that VOCAL does well.
- Respondents who are not currently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

# Future Support: Interest in Online Services



- 61% of respondents would be interested in accessing services online.
- Interest in this type of provision declined with age; 83% of carers aged 26-35 were interested in online services, compared with 50% of those aged 85+.
- However, interest across all age ranges is approximately double the level reported in 2017.

# Future Support: Importance of Local Services



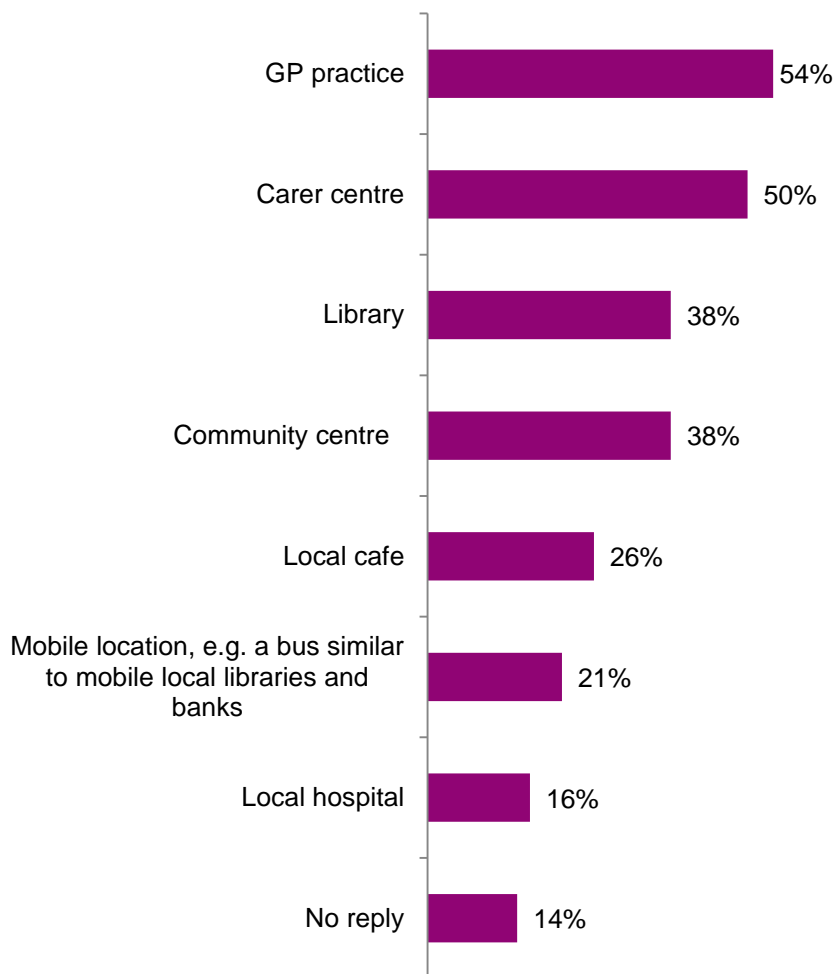
- 80% of respondents said that it was important that they had access to VOCAL services locally.
- Nearly half said that it was “very important”.
- This is slightly lower than in 2017, when 88% said that local access was important. This could perhaps be a consequence of adaptations due to lockdown, when even local services were inaccessible in the traditional way?
- As in 2017, carers of children were more likely to say that access to local services was very important (59%).

## Future Support: Location Preferences

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

Balerno (29)
Westerhailes (17)
Portobello (16)
Corstorphine (14)
Colinton (13)
South Queensferry (12)
Currie (11)
Mayfield (10)

# Future Support: Potential Service Location



- Just over 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.

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# Ideas for Better Support in the Future (1)

Respondents were asked how they could be better supported by VOCAL and other agencies. 407 respondents answered this question.

- 117 respondents said that there was nothing more that could be done and that they were happy with the support received.
  - 52 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.
  - 47 said that they would like to be able to access services closer to their own homes.
  - 41 said that they would appreciate it if agencies could proactively check in on them on a regular basis.
  - 25 would like help with respite care.
  - 21 would like agencies to visit them in their own home.
  - 17 would like a more individualised approach to support; tailored to their individual circumstances, perhaps with a named contact person.
  - 14 would like activities for the person being cared for.
  - 15 would like access to support, services and activities outside of working hours.
  - 13 would like face to face meetings to start up again, either in the community or at existing carers' centres.
  - 9 would like VOCAL to continue to lobby for better support for carers.
  - 6 would like them to better co-ordinate support across agencies, to save the carer having to navigate this process themselves
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# Future Support

“Local drop in clinics for advice/support sessions”

“We need appropriate residential care to cover holidays.”

“I would love some support at home.”

“Provide a point of contact that will stay with you and want to help you.”

“Coordinate information and activities so that when someone starts out as a carer they get all the info they will need, rather than finding out bits and pieces over time”

“Help to do things with my child and to mix with other children.”

“Online is OK but I think it would be much better to meet up in person.”

“Keeping in touch and asking how things are going.”

## 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.
  - 80% 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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