

SCOTINFORM



VOCAL Midlothian Carer Survey 2017

28 February 2018

Purpose of the Survey

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

Questionnaire design informed by:

- Previous surveys
- Briefing meeting
- Workshops in Edinburgh and Midlothian with a range of stakeholders to test out content and terminology

Different questionnaire for Edinburgh and Midlothian to reflect separate service delivery and funding mechanisms

Questionnaire mailed out to VOCAL distribution list (post and email)

Paper returns were inputted by Scotinform

Link was also shared on social media

The opportunity to enter a prize draw was offered as an incentive

Thank you to VOCAL staff and volunteers for supporting the process

Response Rate

2,391 surveys were distributed in Midlothian, with 313 returns received.

This represents a response rate of 13%

The response rate is slightly lower than in 2015 (14%), but the number of responses achieved is higher – 313 returns, compared with 180 in 2015.


57% of respondents replied to the paper format of the survey. 22% responded to the email.

Increasing the use of electronic communications would improve the environmental and resource efficiency of the process, but must be carefully balanced against the characteristics of carers.

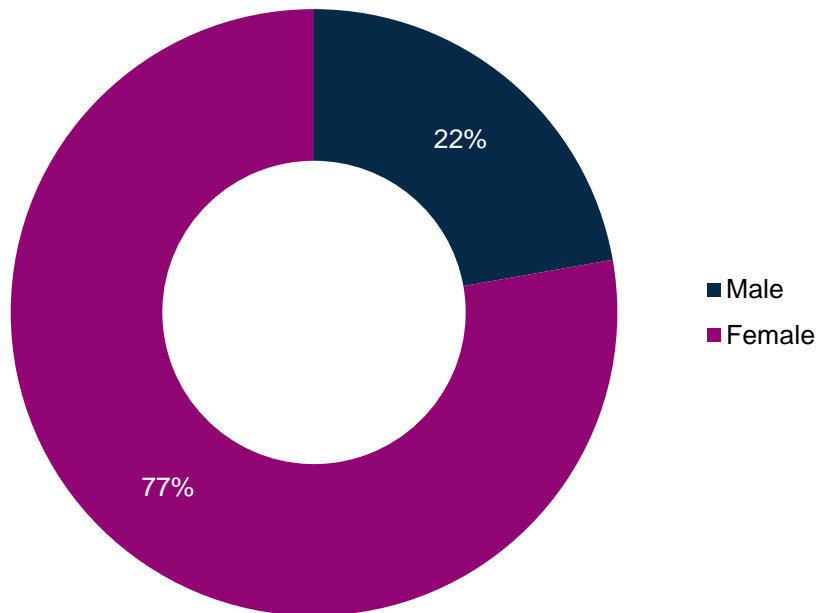
Reporting

In this report, a “Midlothian respondent” refers to someone who completed the survey and is caring for somebody living in Midlothian.

Please note:

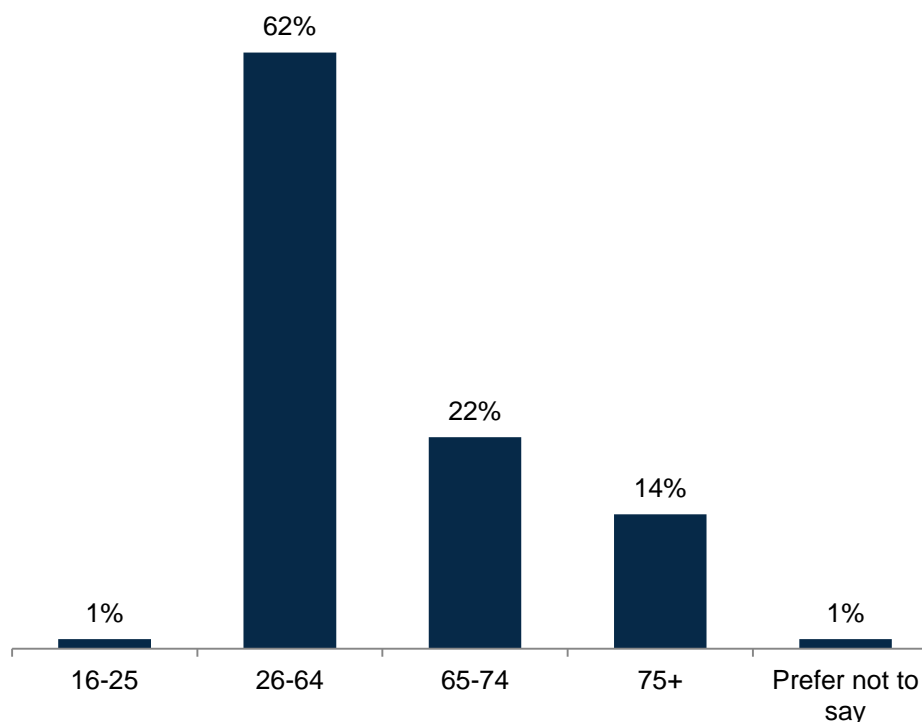
- Where percentages do not total 100% this may be due to non-responses and/or rounding
 - Where percentages exceed 100% this is due to multiple responses
 - Unless otherwise stated, the reporting base is all Midlothian respondents (313). Care should be taken when discussing the differences between sub-groups due to small sample sizes for some groups.
 - Open-ended feedback is identified with 
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Carer Characteristics – Gender



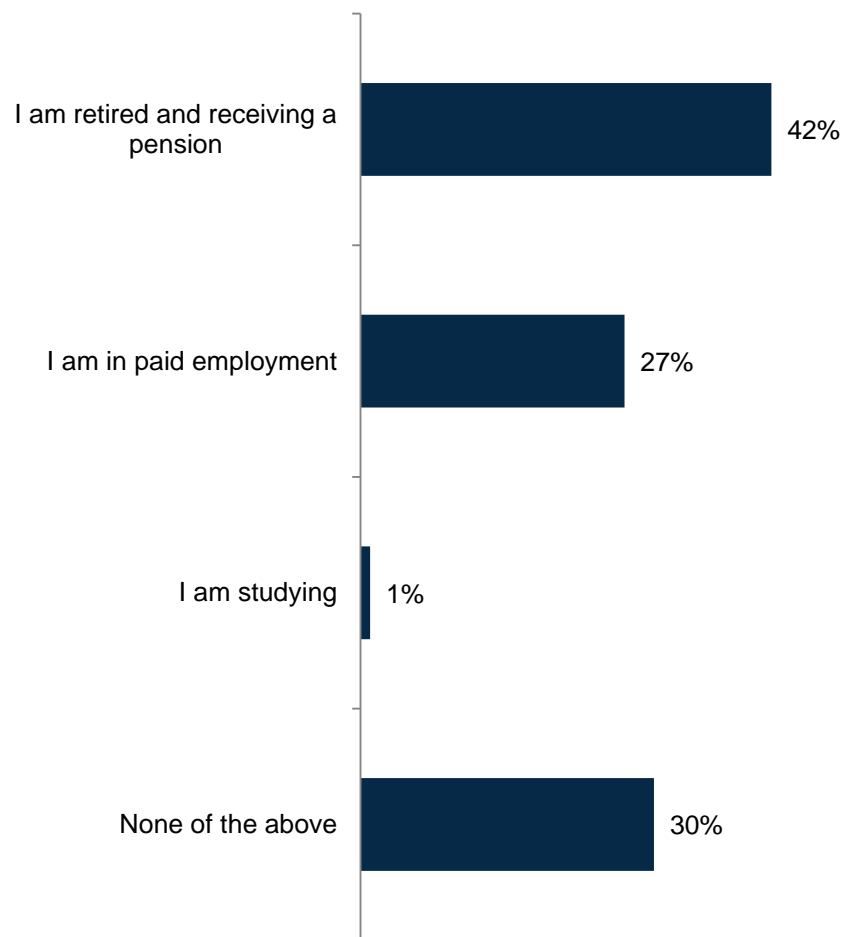
- Approximately three quarters of Midlothian respondents were female
- This is consistent with the 2015 survey (76%)
- There were no significant differences in the gender profile of different respondent types

Carer Characteristics – Age



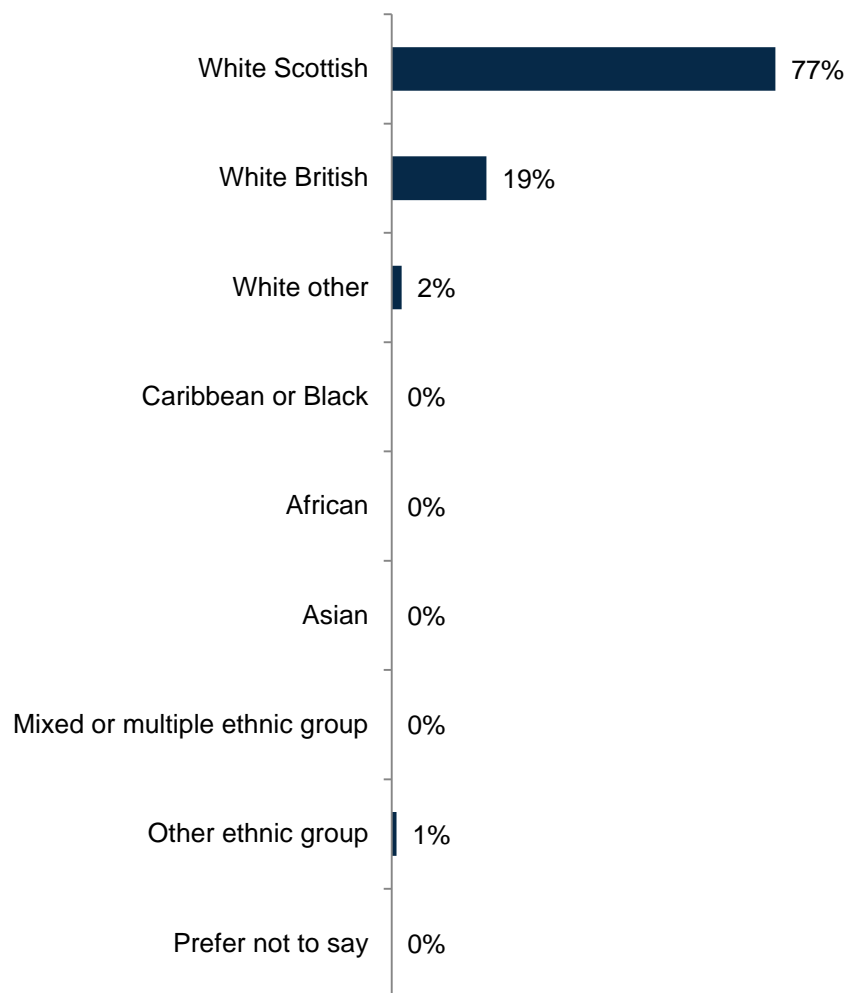
- Nearly two-thirds of Midlothian respondents were aged 26-64, with most of the balance aged over 65.
- The 2015 survey used different age bands, which makes comparison difficult.
- In 2015, 45% of Midlothian respondents were aged over 60, suggesting an increase in the proportion of working age carers.

Carer Characteristics – Economic Activity



- Just over a quarter of the sample is in paid employment, despite two-thirds being of working age. The 2015 figure was also 27%
- 30% are not in paid employment, studying, or receiving a pension.
- This figure increases for carers of children under 16 (57%) and of young adults aged 16-25 (57%).

Carer Characteristics – Ethnicity



- 98% of Midlothian respondents are white.
- This is consistent with the 2015 figure (96%).
- The proportion of BME respondents increased for carers aged 26-64 (4%)

Carer Characteristics - Location

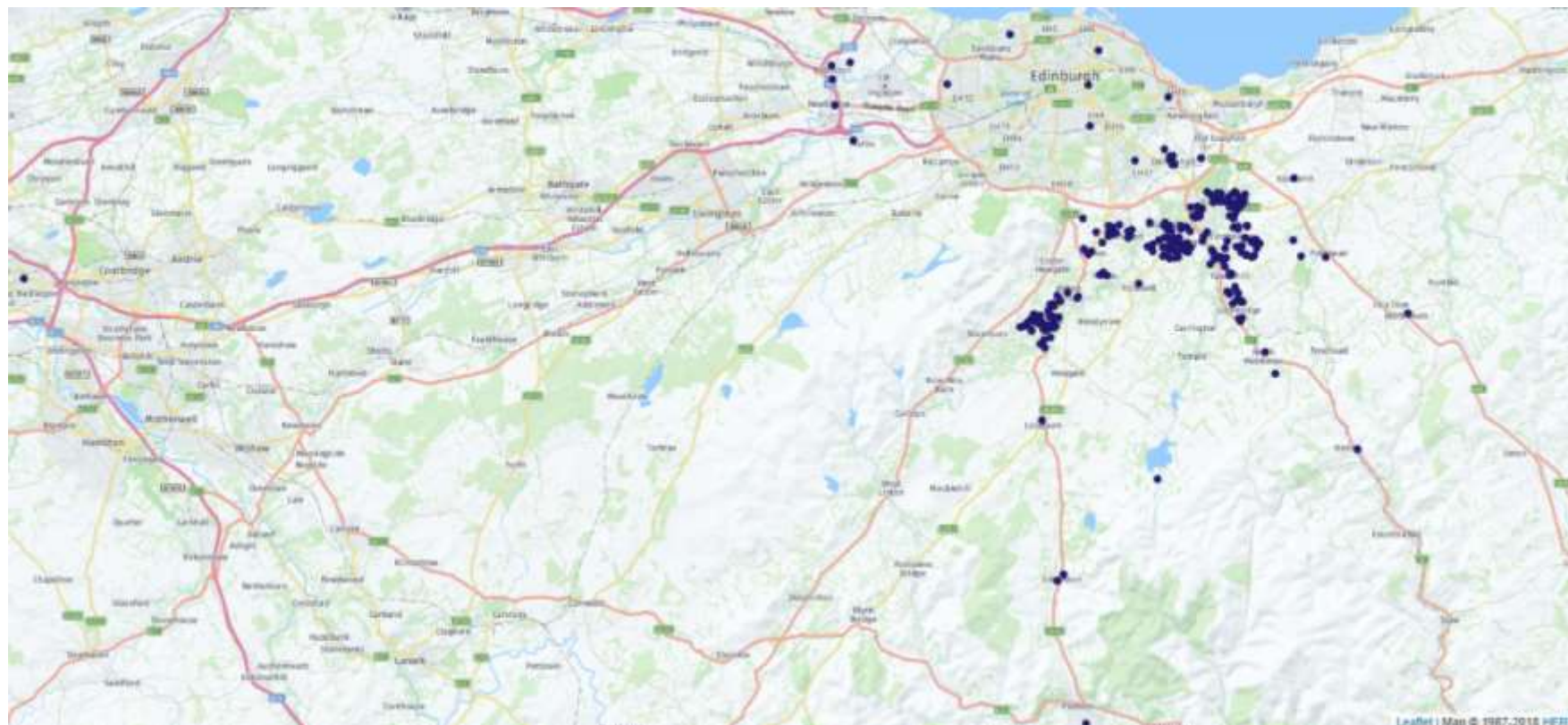
The map on the following page shows the postcodes of respondents caring for people living in Midlothian, whether or not they have accessed VOCAL services.

Scotinform was able to use verified postcode data from 300 respondents.

Most respondents also lived in Midlothian, but there was some representation from the City of Edinburgh, the Scottish Borders, West Lothian, and as far as Glasgow.

The fact that some carers live outside the Local Authority boundaries may have implications (for VOCAL and other stakeholders) in terms of funding, access and service provision.

Carer Characteristics – Location



Carer Characteristics – Mosaic Scotland

Scotinform profiled the 301 full Scottish postcodes provided by Midlothian respondents using Mosaic UK, a geodemographic profiling system that classifies postcodes into consumer groups and types.

Mosaic UK is built by Experian and contains consumer demographic data for 25m UK households. The database is built from a range of public and Experian-held data sources, as well as the 2011 Census.

All of the information used to build Mosaic is continuously updated. It is used to segment each household in the UK into 14 Groups, and then further into 57 Types.

Carer Characteristics – Mosaic Profile

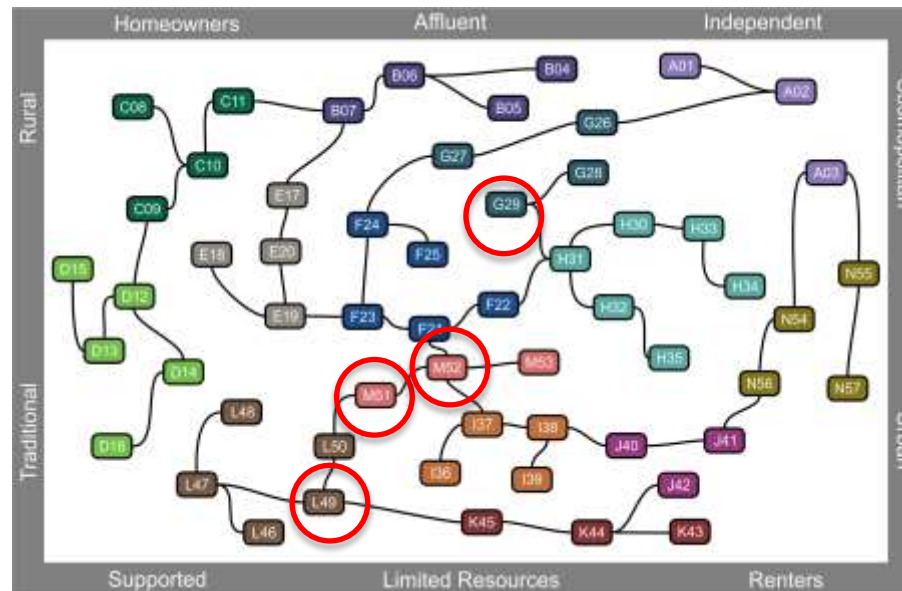
The Mosaic profile is relatively diverse, reflecting the indiscriminate nature of assuming caring responsibilities.

The four largest Mosaic Scotland groups, accounting for 50% of the postcodes, were Vintage Value (19%), Modest Traditions (12%), Prestige Positions (10%) and Suburban Stability (9%).

The four largest Mosaic Scotland types were L49 Estate Veterans (14% of records), M52 Offspring Overspill (6%), G29 Mid-Career Convention (6%) and M51 Down-to-Earth Owners (5%)

Compared with the profile of the Midlothian population overall, there are proportionally fewer Domestic Success and Aspiring Homemakers. This may reflect the geographic location of VOCAL services and support, as well as the propensity of these Groups to be caring.

Carer Characteristics – Mosaic Family Tree



- The top four types sit midway between urban and rural neighbourhoods, which seems appropriate for Midlothian.
- Three of the four are clustered together and have limited resources.
- An overview of the top four groups is presented on the following pages, along with some data about their technological and marketing preferences. Caution should be used against applying these and generalisations to all carers due to the diversity of the carer profile.

L49 Estate Veterans



- “Longstanding elderly renters of social homes who have seen neighbours change to a mix of owners and renters.”
- Half of Estate Veterans residents own or have access to a smartphone, and 75% own or have access to a laptop.
- Approximately a third of Estate Veterans will use the internet every day, but nearly a quarter do not use it at all.
- 16% of Diamond Days residents will opt out of receiving all marketing information, slightly higher than average for Scotland.
- Those who do opt in prefer to receive communications by email (55% - lower than average for Scotland) or post (20%). Preferences for mobile calls (4%) and landline calls (5%) are also much higher than average.

M52 Offspring Overspill



Mosaic Scotland



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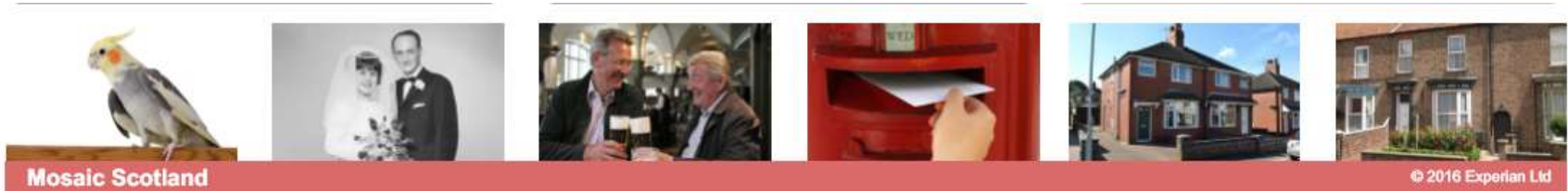
- “Lower-income owners whose adult children are still striving to gain independence, meaning space is limited.”
- Offspring Overspill residents are still working but individual incomes are not high.
- 75% of Offspring Overspill own a smartphone, and 88% have a laptop.
- 65% will use the internet several times a day and 73% check email every day.
- 14% of Offspring Overspill residents will opt out of receiving all marketing information.
- Those who do opt in prefer to receive communications by email (67%) or post (15% - slightly higher than average for Scotland).

G29 Mid-Career Convention



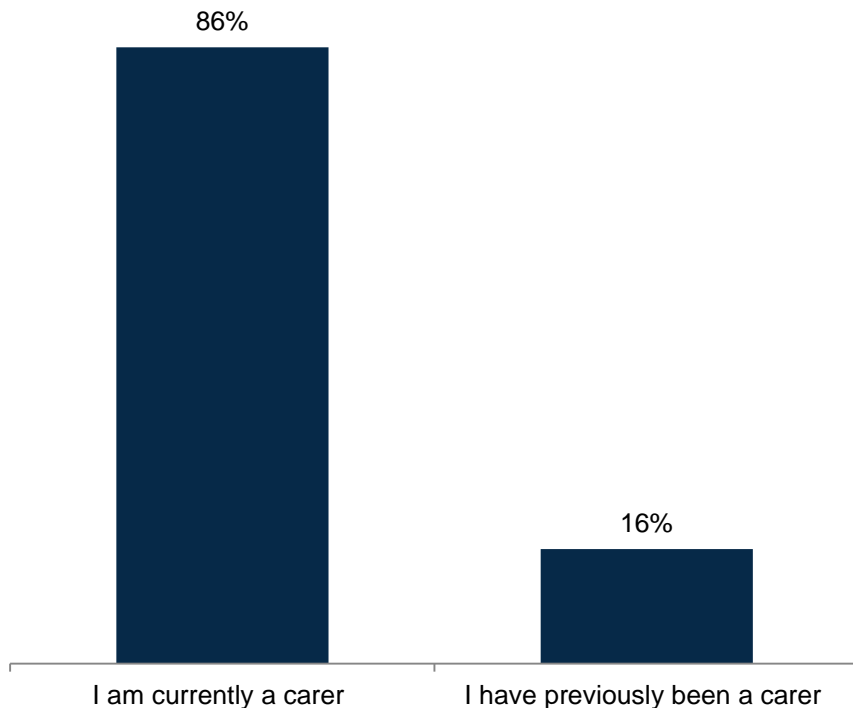
- “Professional families with children in traditional mid-range suburbs where neighbours are often older.”
- 88% of Legacy Elders own a smartphone, and 88% have a laptop.
- 71% will use the internet several times day and 75% check email every day.
- 13% of Mid-Career Convention residents will opt out of receiving all marketing information, below the average for Scotland.
- Those who do opt in prefer to receive communications by email (73%) or post (11% - lower than average for Scotland).

M51 Down-to-Earth Owners



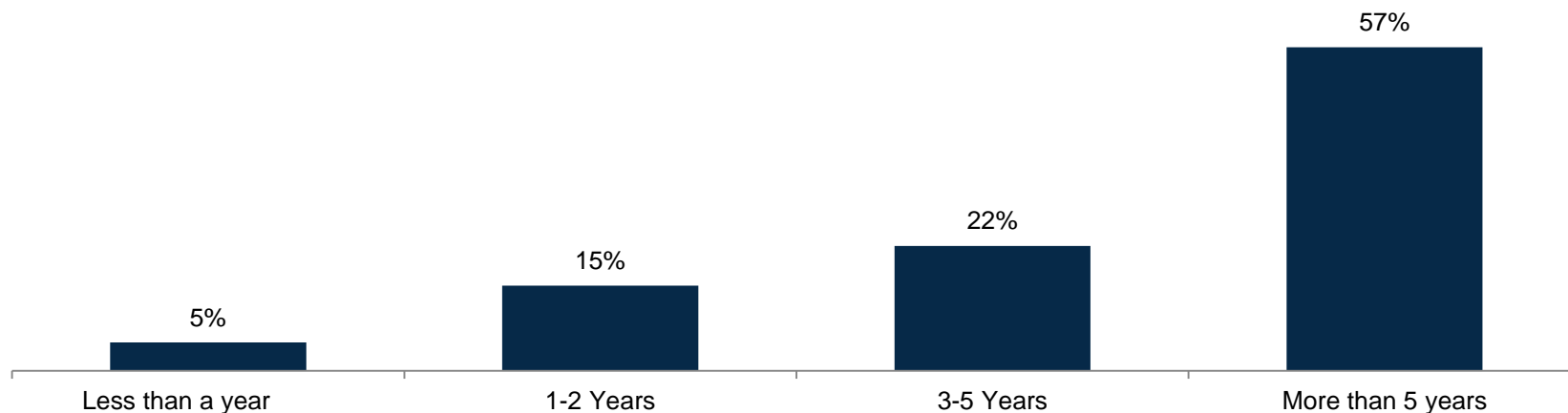
- “Ageing couples who have owned their inexpensive home for many years while working in routine jobs.”
- 61% of Central Pulse residents own a smartphone, and 80% have a laptop.
- 61% will use the internet several times day and 75% check email every day.
- 22% of Central Pulse residents will opt out of receiving all marketing information, higher than the average for Scotland.
- Those who do opt in prefer to receive communications by email (63% - lower than average for Scotland) or post (17% - higher than average).

Carer Characteristics – Caring



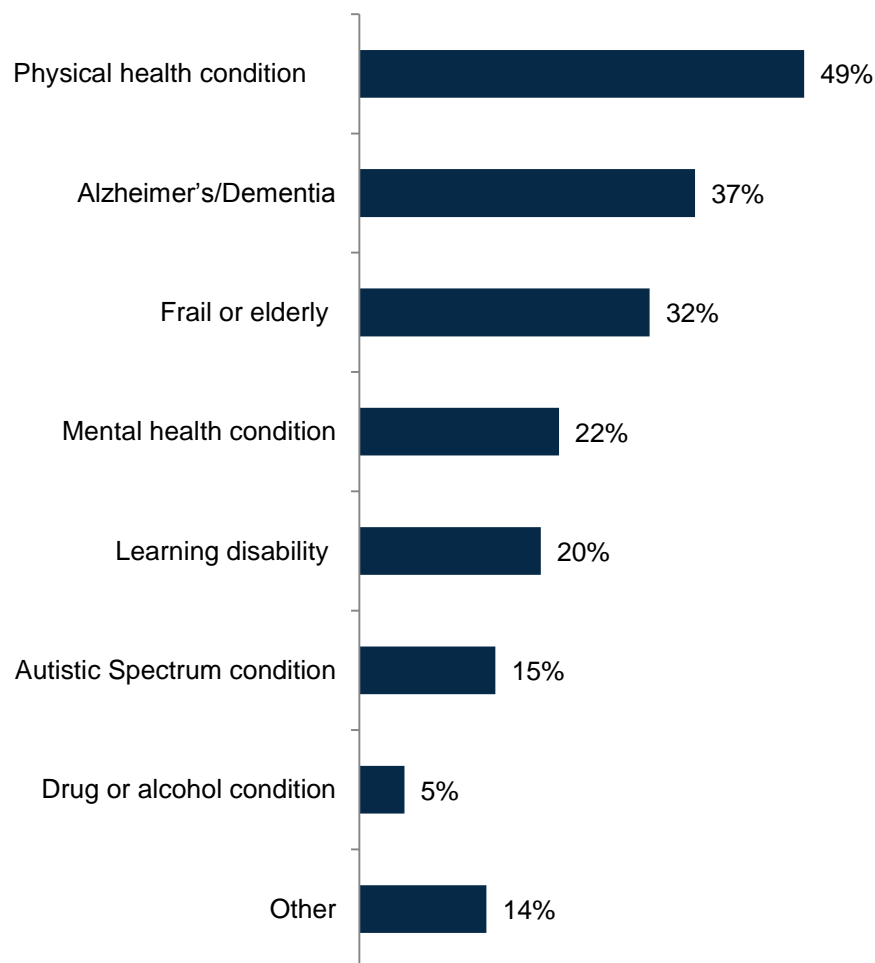
- 86% of respondents saw themselves as having an active caring role right now.
- This is consistent with the 2015 result (83% defined themselves as current carers)
- Some respondents selected both responses, suggesting that they have cared for two different people at different stages.

Sample Characteristics – Duration of Care



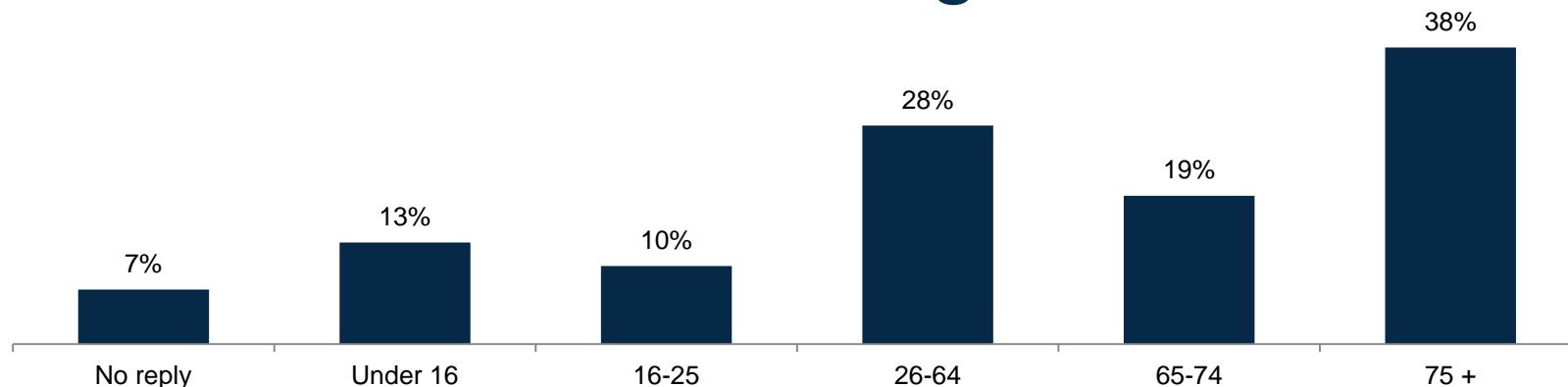
- Over half of respondents have been caring for more than 5 years.
- Long-term carers are often looking after younger people. 69% of carers of children and 97% of carers of adults aged 16-25 had been caring for more than 5 years (caution: small sample sizes).
- New carers (less than a year) were more likely than average to be aged over 75 themselves (9%).

Sample Characteristics – Conditions cared for



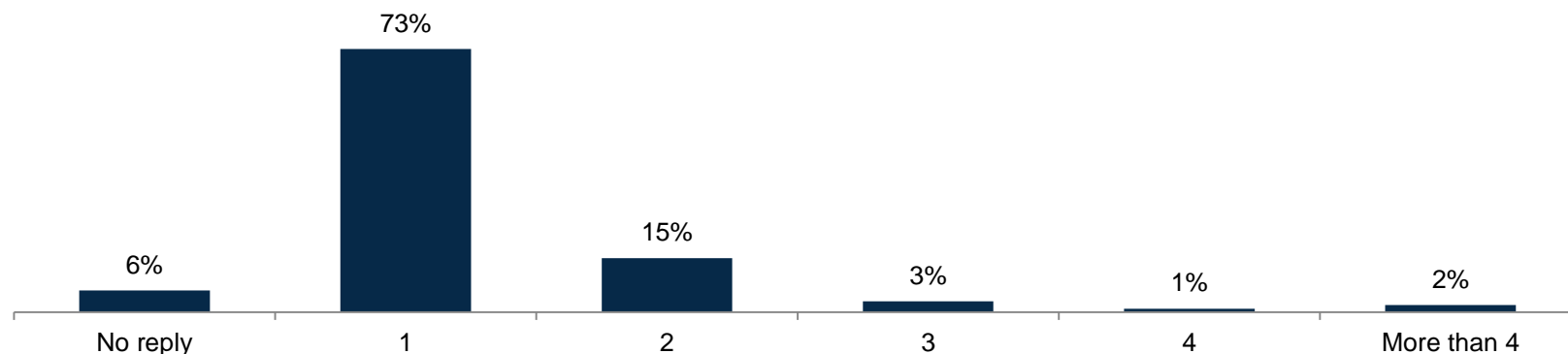
- Midlothian respondents were most likely to be caring for somebody with a physical health condition, who has Alzheimer's/dementia, or who is frail or elderly.
- The profile of conditions cared for is broadly the same as in 2015.
- “Autistic Spectrum Condition” was a new category for 2017. These carers were more likely to be long term carers (20%), and caring for somebody aged under 16 (60%) or 16-25 (50%)

Carer Characteristics – Age of Person



- Just over a third of carers are looking after someone over the age of 75, increasing to 78% for carers aged over 75.
- There is considerable variation in the sample
- Although the age categories were not the same in 2015, the figures suggest that the proportion of young people being cared for has increased.
- 37% of long-term carers are looking after someone aged 26-64

Carer Characteristics – Number of People



- Most carers are caring for one individual, but 21% are multi-carers (caring for more than one person).
- The proportion of respondents caring for 1 person is slightly lower than in 2015 (75%).
- Multi-caring is higher for long term carers (26%), those caring for children (57%) or adults aged 16-25 (46%) and for respondents aged 26-64 (25%).
- The figures provide evidence of increased pressure on carers, who are often caring for multiple generations.

Carer Characteristics – Attitude to the internet

- 58% of respondents say they are confident about using the internet to find information and support.
 - When asked to identify specific resources, respondents generally cited a browsing device (e.g. iPad) and general internet searches for information.
 - In 2015, 62% said that they were confident about using the internet – slight change in question makes comparison difficult.
 - Confidence is higher for carers looking after children (71%), carers aged under 26-64 (67%), and carers in paid employment (73%).
 - It is lower for men (51%), those aged over 75 (24%) and retirees (46%).
 - The Mosaic profiles show that the dominant Types have good access to the internet but older respondents in particular prefer to communicate by other means. Younger respondents, in contrast, are more likely to engage online.
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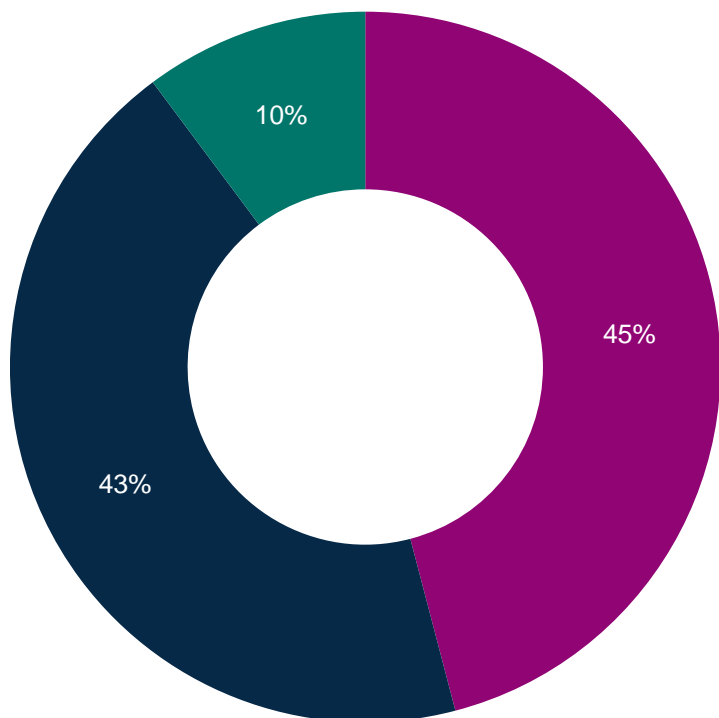
Carer Characteristics – Key Findings

- Three-quarters of carers are female.
 - Two-thirds of carers are of working age, with the balance mostly being aged over 65.
 - Just over a quarter of carers are in paid employment, despite two-thirds of the sample being of working age.
 - Caring often transcends Local Authority boundaries.
 - The Mosaic profile is diverse and suggests that VOCAL is effectively engaging with carers from a range of income levels and with varying characteristics.
 - 57% of Midlothian carers have been caring for more than 5 years.
 - Long-term carers have a slightly different profile. They are more likely to be caring for a younger person and to be caring for more than one person.
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Carer Characteristics – Key Findings (2)

- 38% of carers are looking after someone aged 75+. This figure increases to 78% for carers aged over 75.
 - There are a range of responses to using the internet to support caring
 - The diversity of the MOSAIC profile means that there are variable attitudes to communications and technology. VOCAL should continue with a dual approach of post and email for communications.
 - The profile is broadly similar to the sample in 2015, although the figures suggest that the number of young people being cared for may have increased.
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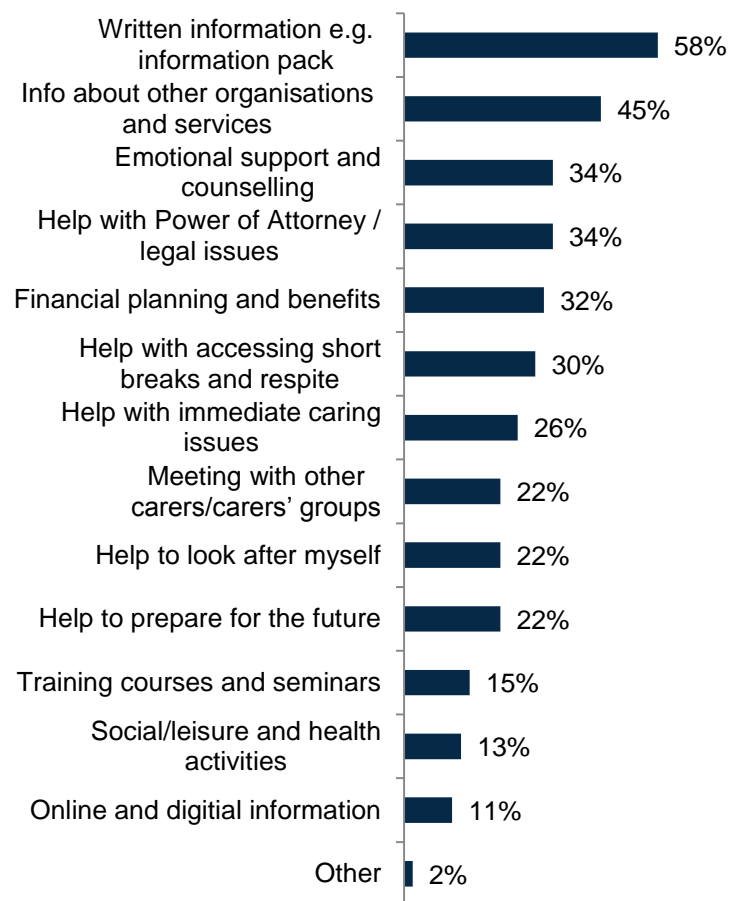
Engagement with VOCAL Services



- Within the last six months
- More than six months ago

- 45% of Midlothian respondents have used VOCAL services within the past six months, and 88% within the past year.
- The proportion of respondents who had engaged within the past six months was consistent with the 2015 figure (46%).
- Respondents were most likely to have used VOCAL services in the past six months if they had been caring for less than a year (87%) or were caring for somebody aged under 16 (58%).
- Respondents were less likely to have used VOCAL if they were aged over 75 (27)%.

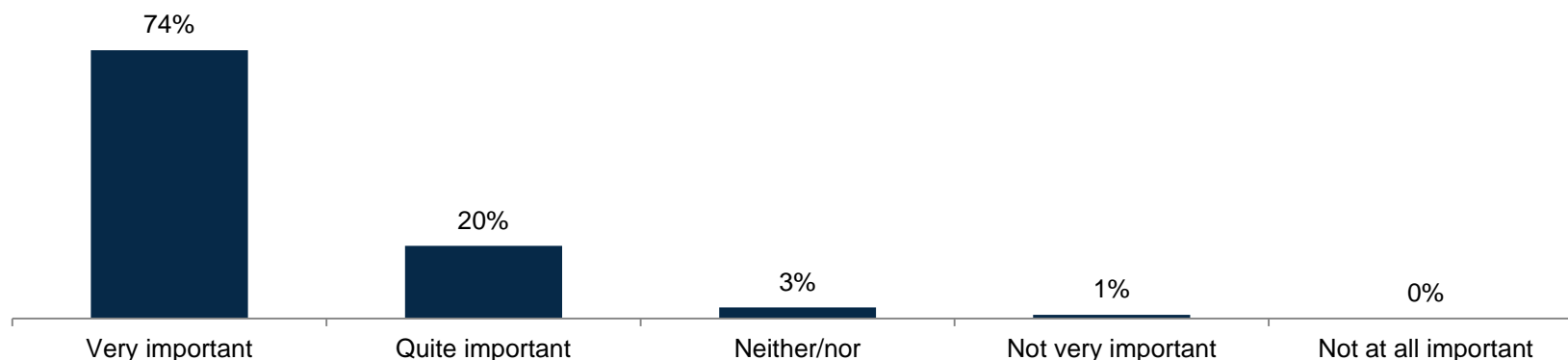
Services Found Useful



- As in 2015, respondents value a combination of practical and emotional support.
- Information, signposting and emotional support and counselling appear to be the most useful services.
- Carers of children particularly value emotional support and counselling (58%), help to look after themselves (36%) and social/leisure and health activities (25%).

Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

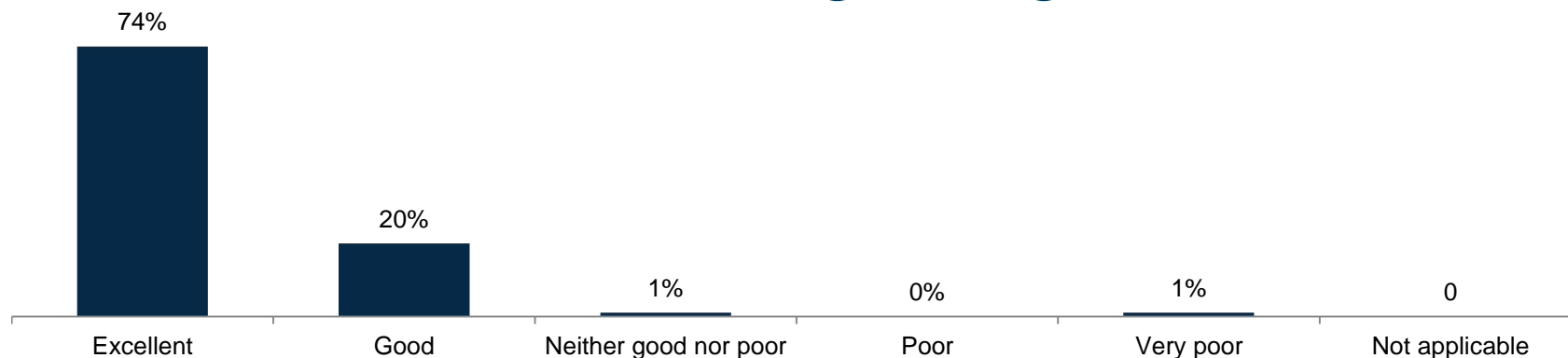
Importance of Local Services



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

- Nearly all respondents said that it was important that they had access to VOCAL services locally.
- Three quarters said that it was “very important”
- The proportion of respondents who said local access was “very important” was higher for carers of children (86%).

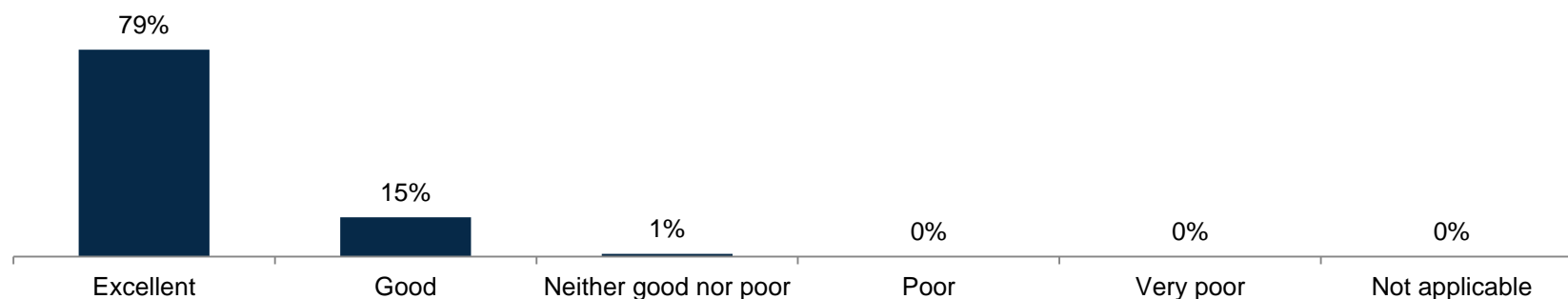
Satisfaction: Ease of getting in touch



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

- 94% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 96% (but there was no measure of non-response in 2015).
- Older carers and men were slightly less likely to give this aspect a positive score.

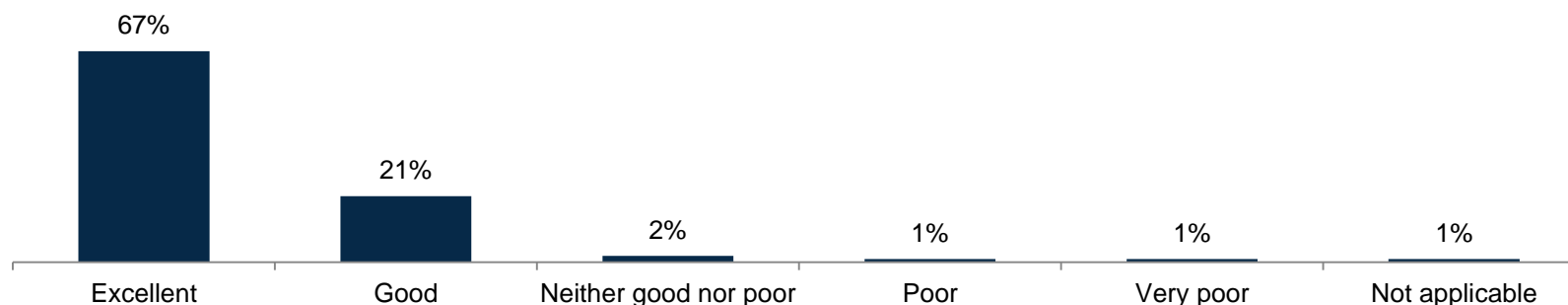
Satisfaction: Friendliness of Response



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

- 94% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 97% (but there was no measure of non-response in 2015).
- Men and carers of people aged 16-25 were slightly less likely to give this aspect a positive score.

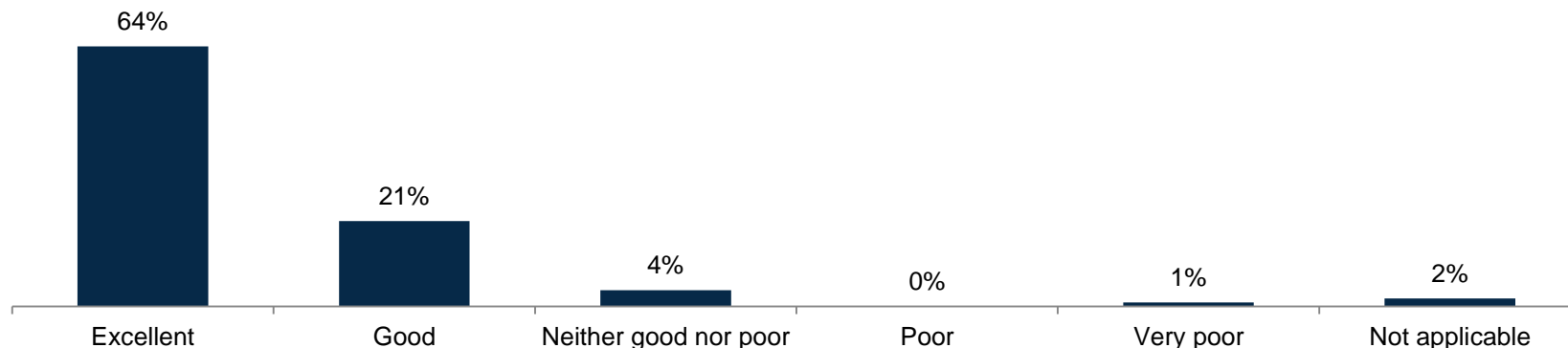
Satisfaction: Getting as much information as you needed



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

- 88% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 94% (but there was no measure of non-response in 2015).
- New carers (of less than a year), and carers of people aged between 16-25 were slightly less likely to give positive responses.

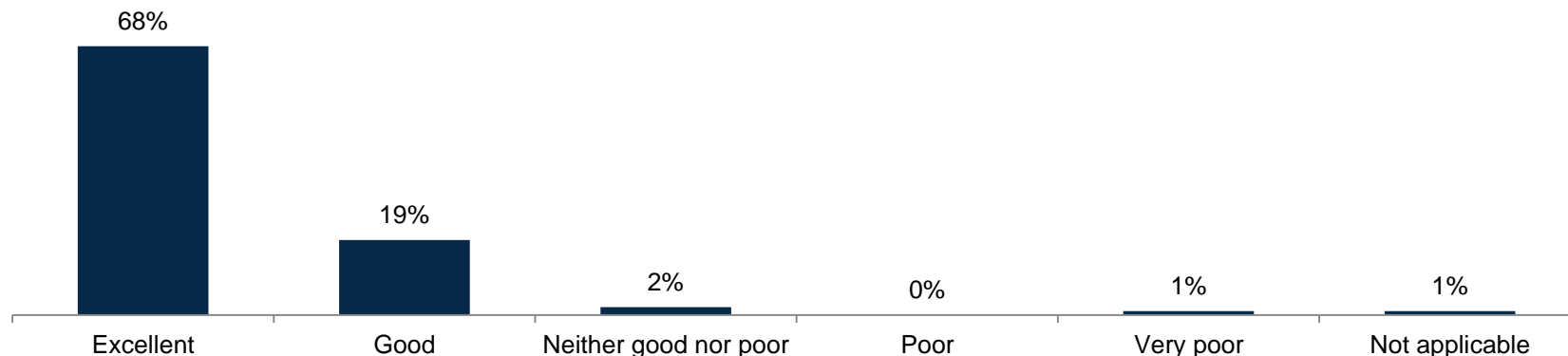
Satisfaction: Knowledge of staff and volunteers



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

- 85% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 94% (but there was no measure of non-response in 2015).
- New carers (of less than a year), carers of people aged 16-25 and carers aged 26-64 were slightly less likely to give this aspect a positive score.

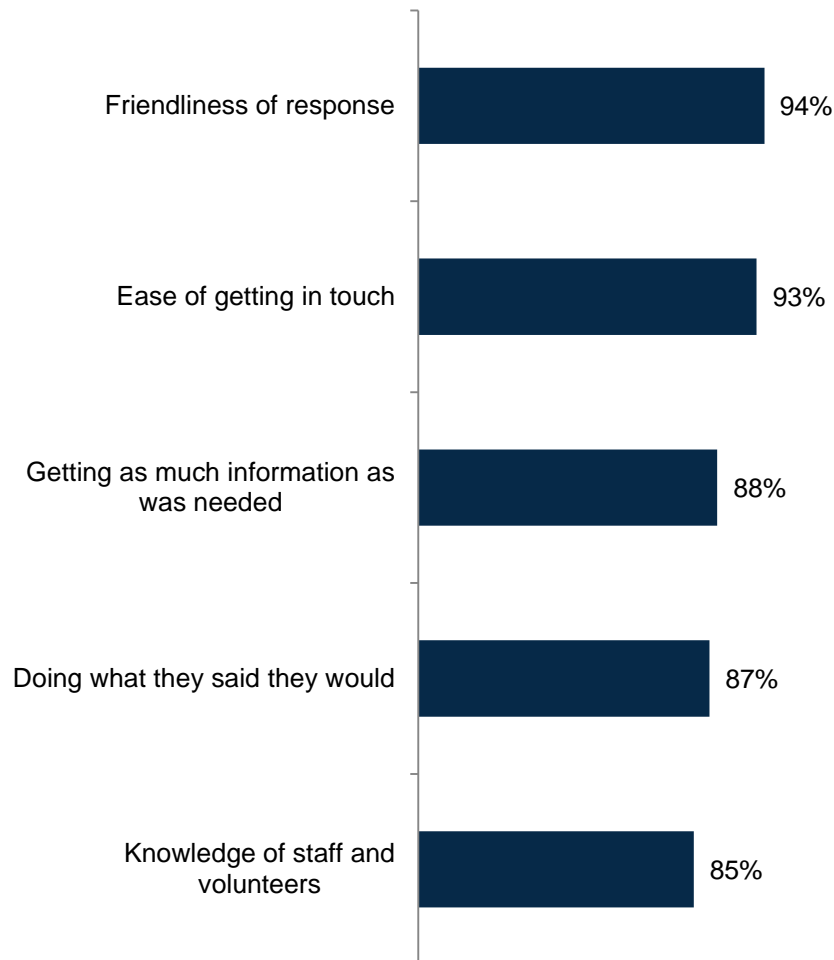
Satisfaction: Doing what they said they would



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

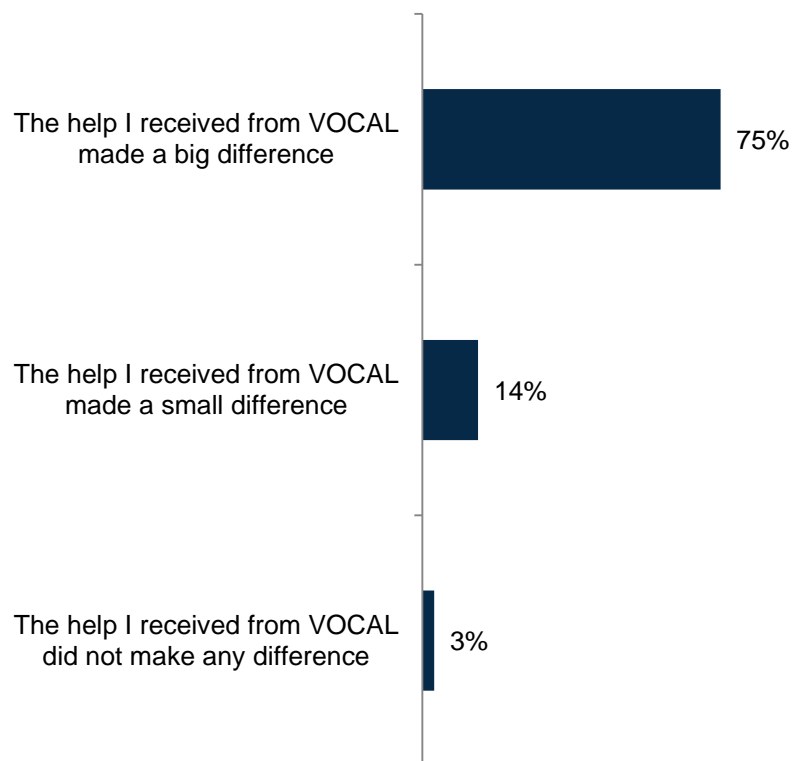
- 87% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 92% (but there was no measure of non-response in 2015).
- Carers aged 65-74, retired carers and new carers were slightly less likely to give a positive response.

Satisfaction Ratings: “Good” or “Excellent”



- Excellent performance!
- Nearly two-thirds of respondents rated VOCAL as “excellent” on every measure.
- Friendliness of staff performed particularly well – 79% excellent
- Accessibility and friendliness are key strengths
- Consistent with previous high performance

Impact of VOCAL



Base: all Midlothian Respondents who have experienced VOCAL Midlothian services (266)

- VOCAL makes a significant difference to the lives of carers in Midlothian.
- This is higher than the 2015 figure (71%).
- Carers were most likely to report a “big difference” if they were caring for somebody aged 26-64 (80%) or had been caring for 1-2 years (85%).
- Men and carers over the age of 75 were more likely to say that VOCAL did not make a difference.

The Impact of VOCAL

176 respondents described the impact of VOCAL, Midlothian.

Responses fell into four main areas:

- 82 respondents identified positive health impacts (including feeling more confident and reducing feelings of isolation).
 - 60 respondents cited that the impact arose through VOCAL's information or advice.
 - 34 respondents identified positive financial impacts, including securing Power of Attorney and help with applying for support.
 - 29 respondents identified benefits accrued through time away from caring.
-

Health Impacts

“Empowered me and has taught me to believe in myself and what I do for my children”

“Being a brand new carer, having such a comprehensive and easily accessed service calmed a lot of my fears.”

“Emotional support counselling has lifted the darkness I felt. It’s clearing the fog and allowing me to go forward more confident”

“It enabled me to address my anger and frustration effectively”

“I’m working on not being walked all over. With your help.”

“I was able to relax and be reminded I am not alone.”

“Being listened to without being judged. I feel like a weight has been lifted.”

“It has put my mind at ease and I get on a lot better than I did before.”

Information and Advice

“I did not know what I was talking about.”

“It felt like an arm of support getting the information pack..”

“VOCAL staff were amazing for providing so much useful information about local services (which I did not know, I don't live there).”

“Speaking to someone who knows.”

“Clarified several points which other agencies had said were a grey area..”

“Put me in touch with a lawyer with special awareness of disability.”

“The First Aid training was excellent.”

“The help and advice helped me to calm my emotions when I felt overwhelmed. They walked me through the practical points as well as the emotional ones.”

Financial Impacts

“Came with me to the PIP appointment.”

“Financial help towards my hobbies.”

“Filling in forms has always been difficult for me in the past and I have not received the financial help I should have.”

“Got the attendance allowance for my husband.”

“I’ve never had to worry financially before as the person I care for had his own business. When we became ill the business closed. VOCAL helped with all the benefits we were entitled to.”

“One lady I looked after was a not a relative and I didn’t want to deal with her finances alone. VOCAL supported me.”

“Being able to obtain a POA that did not cost the earth was great for Mum and it puts both her and my mind at rest.”

“Helped me receive the help and support I needed regarding my son.”

Time Away From Caring

“I’ve received short breaks, which allows me necessary time for myself.”

“It helped my husband have our last holiday together.”

“It gave myself and my wife a chance to recharge our batteries.”

“Getting away helped me to recharge and come back with more energy.”

“Got a Better Break grant, which allowed me to have therapy.”

“I received a grant to get a laptop and it helps me get a break and still be able to look after my mum.”

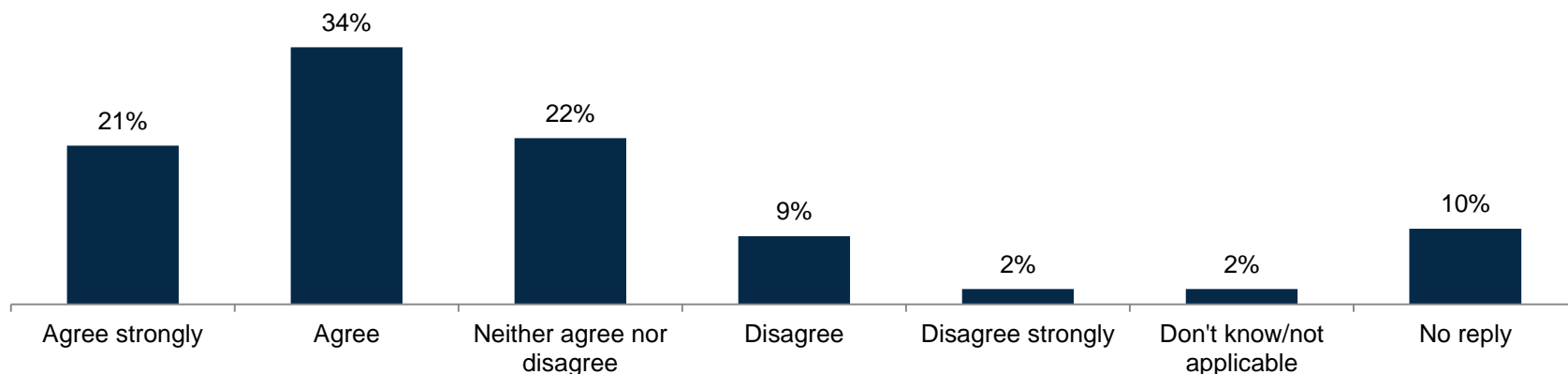
“Gave me somewhere to go out of the home but not that far away (garden shed).”

“I was helped to access funding to allow me to take short breaks from care. I’ve used it to go on confidence building courses, go to a spa and to start a women’s weightlifting class.”

Satisfaction with VOCAL – Key Findings

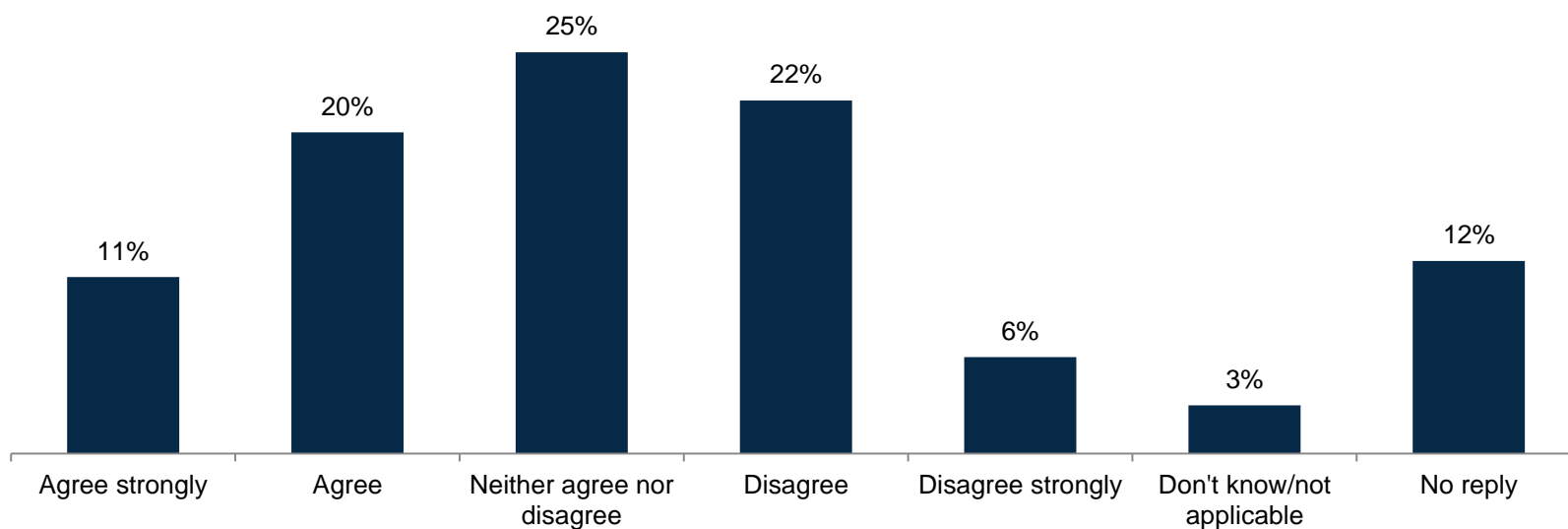
- VOCAL Midlothian has a highly satisfied cohort of carers.
 - Nearly half of respondents have engaged with VOCAL in the past six months, and nearly 90% have engaged within the past year.
 - Carers value the provision of services at a local level.
 - In Midlothian, carers particularly value the provision of information, signposting and emotional support/counselling.
 - Satisfaction ratings are excellent across all measures, and particularly in terms of friendliness of staff.
 - Three quarters of carers say that VOCAL makes a big difference.
 - Respondents identify a range of positive impacts, focusing on health, the provision of information, financial assistance, and time away from caring.
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Health and Wellbeing: “Being a carer has made my health worse.”



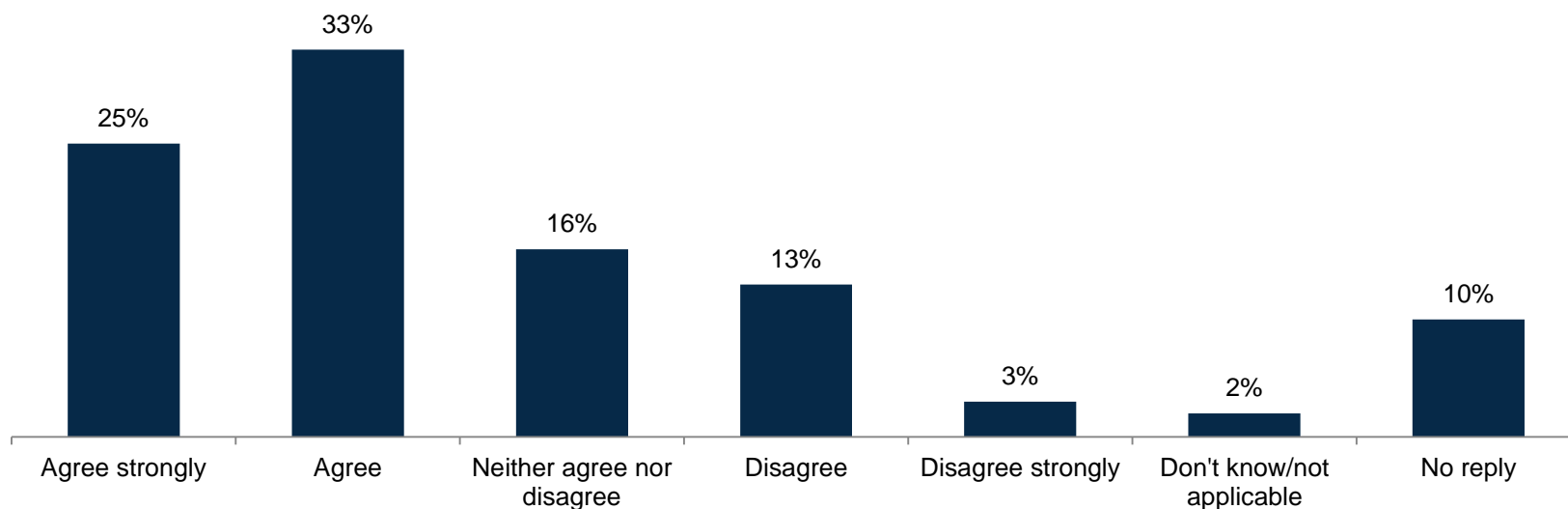
- 55% agreed that “being a carer has made my health worse”
- Carers of young people (who also tend to be long-term carers) were more likely to say their health has been impacted. 67% of carers of children agree with this statement.
- Carers aged 25-64 (63%) and carers in paid employment (60%) were also more likely to agree with this statement.

Health and Wellbeing: “Since becoming a carer I visit the GP more often.”



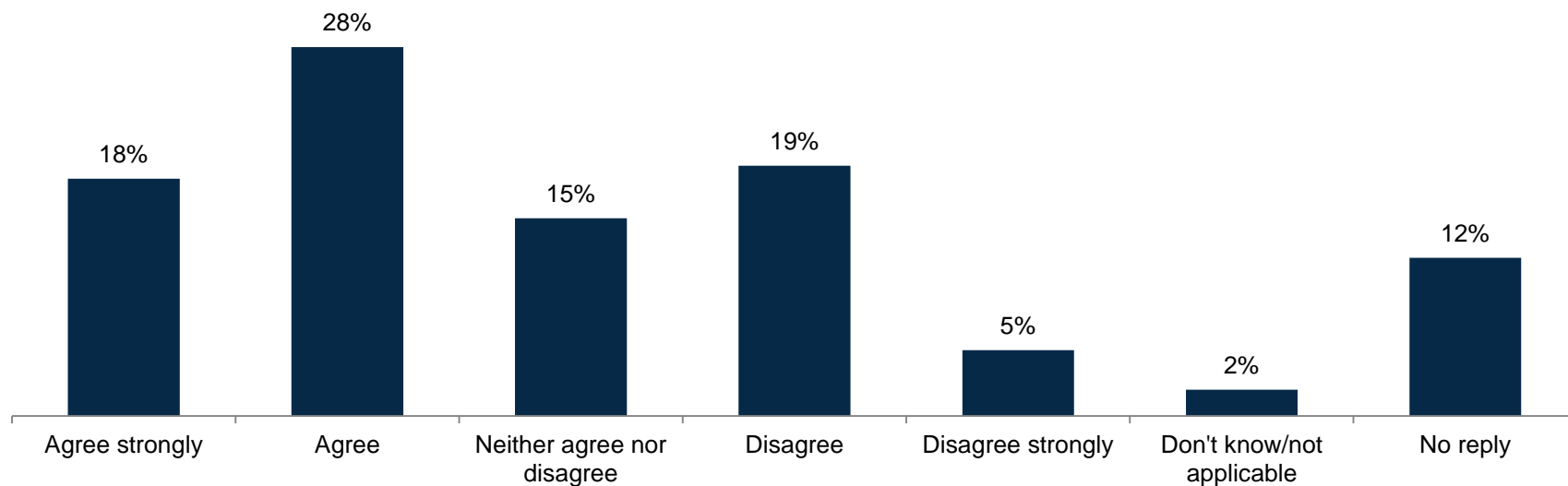
- 31% of respondents reported an increased number of GP visits.
- People who have been caring for more than 5 years (35%), men (39%) and respondents not working or receiving a pension (40%) were most likely to agree with this statement.

Health and Wellbeing: “Being a carer means that I don’t get enough sleep”



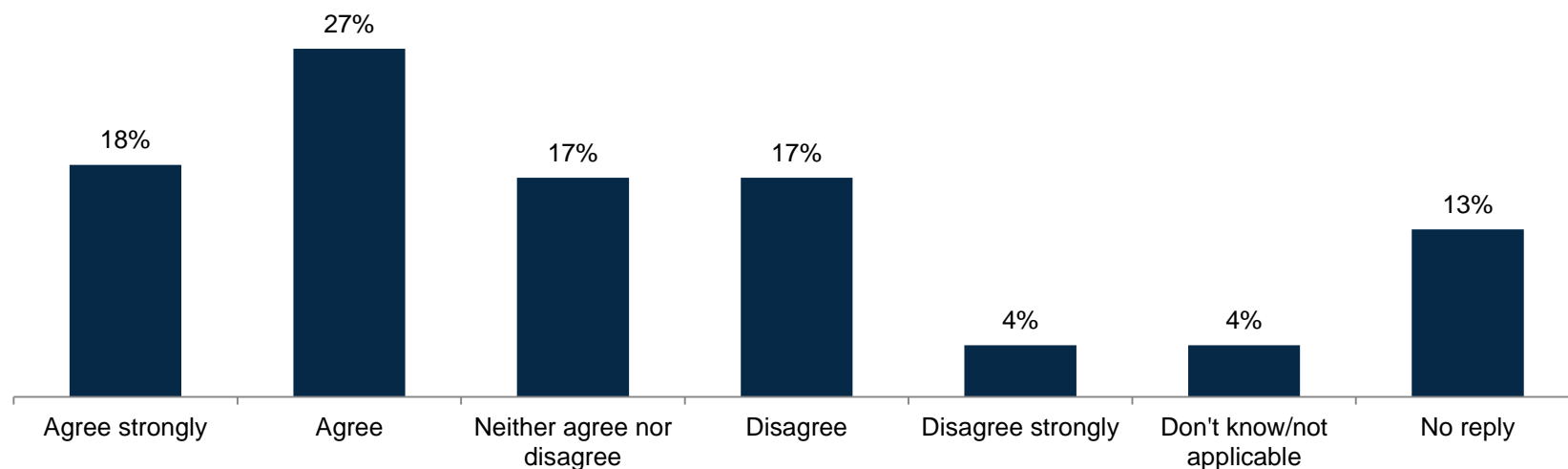
- 58% of respondents agreed that being a carer means they don't get enough sleep.
- The proportion of respondents agreeing with this statement is highest for carers of children (74%), respondents not in employment or receiving a pension (72%) and respondents aged 26-64 (66%).

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



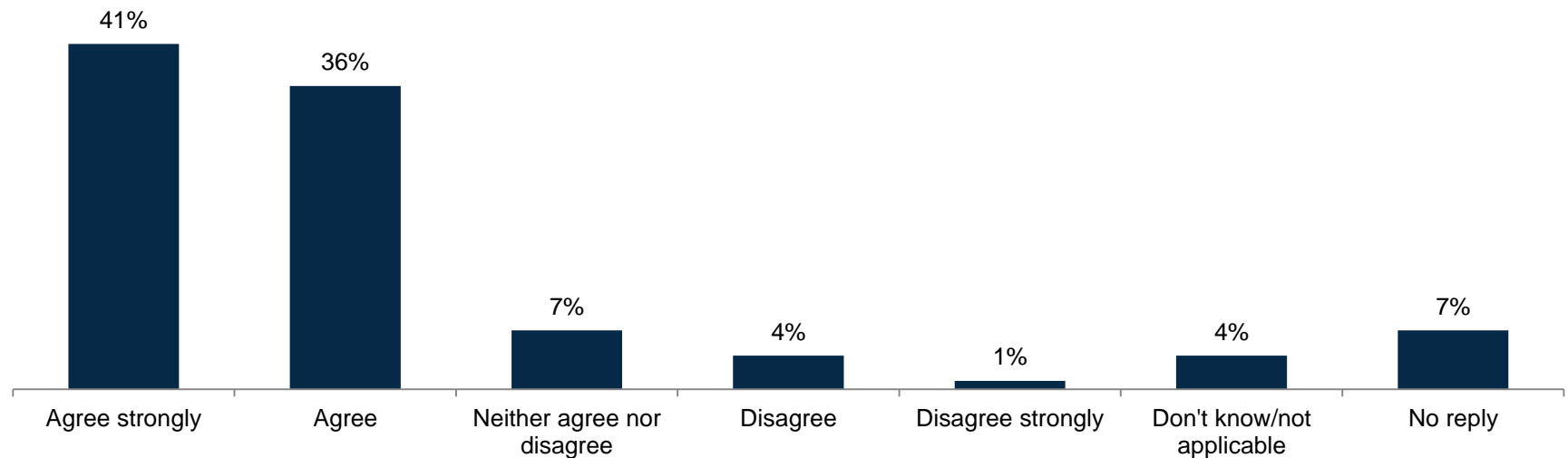
- 42% of carers agree that they feel isolated from family and friends.
- The proportion of respondents agreeing with this statement is highest for carers of children (67%), respondents aged 26-64 (55%), and respondents not working or receiving a pension (57%).

Health and Wellbeing: “I have experienced depression since becoming a carer.”



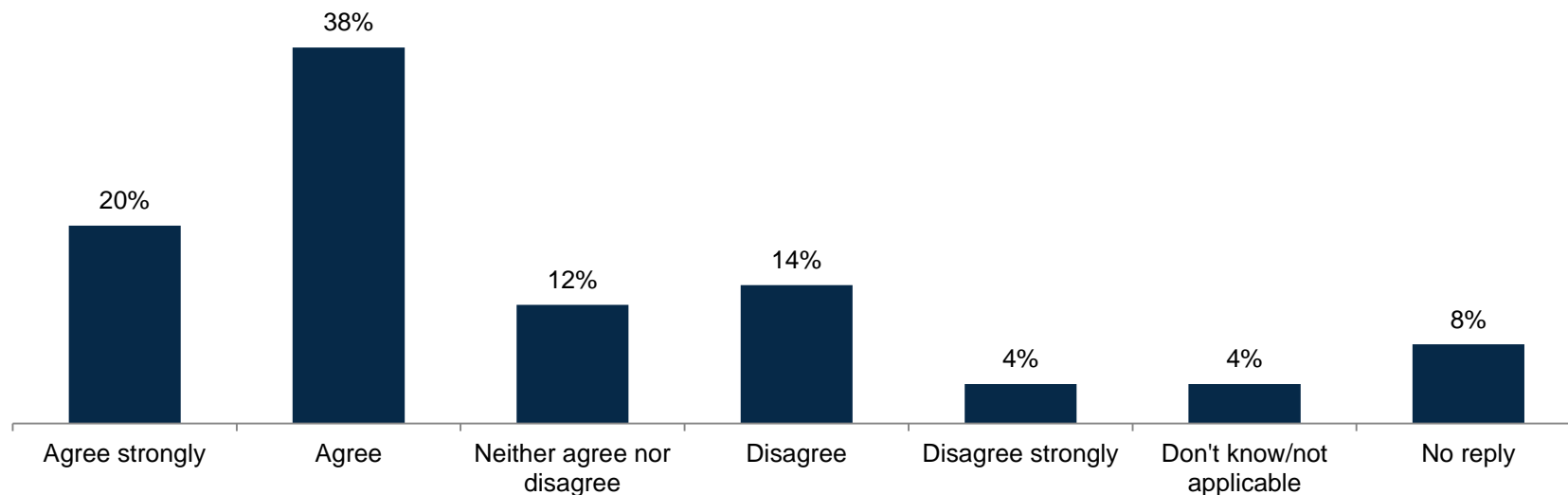
- 45% of carers reported that they had experienced depression.
- The proportion of respondents agreeing with this statement is highest for carers of children (69%) and carers of adults aged 16-25 (63%).

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



- 77% of respondents expressed concern about contingency planning.
- There were consistent levels of agreement with this statement across the sample, with a notable peak for cares of children (93%).

Health and Wellbeing: “I have someone that I rely on for support if I need it.”




- Just over half (58%) of respondents felt that they had someone to rely on for support.
- This response was similar across all sub-groups. Respondents caring for children were slightly less likely to feel that they have support (54%).

Health Impacts – Additional Comments

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

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


 *“Being a carer for someone else means that you stop caring about your own wellbeing as you focus solely on them...you forget that you are only human and not a machine and slowly over time it takes its toll. I’ve gained weight and lost hair through stress, have a bad back from lifting someone and exhaustion from working full time and caring for someone the rest of the time. I cannot remember the last time I had a full night’s sleep.”*

 *“I have nerve damage to my shoulder from lifting my dad.”*

 *“Massive impact on my mental health.”*

Health Impacts – Additional Comments

13 respondents reported that the stress of dealing with other agencies contributed to their poor health:

 *“I've had a hellish amount of battles to win just to get my son diagnosed and to get the correct support required for him. Every battle which can last for a few days to several months can have a marked effect on my health...They just don't have a clue as to what damage it causes carers to always have to fight so hard for every scrap.”*

Other subjects, each mentioned by fewer than 10 respondents, were: feelings of guilt, anger or resentment (8), concerns about relationships with other family members (5), suggestions or requests for specific support (3); concerns about the future (3) the contribution made to ill health by difficult financial circumstances (2); and a loss of a sense of self (2).

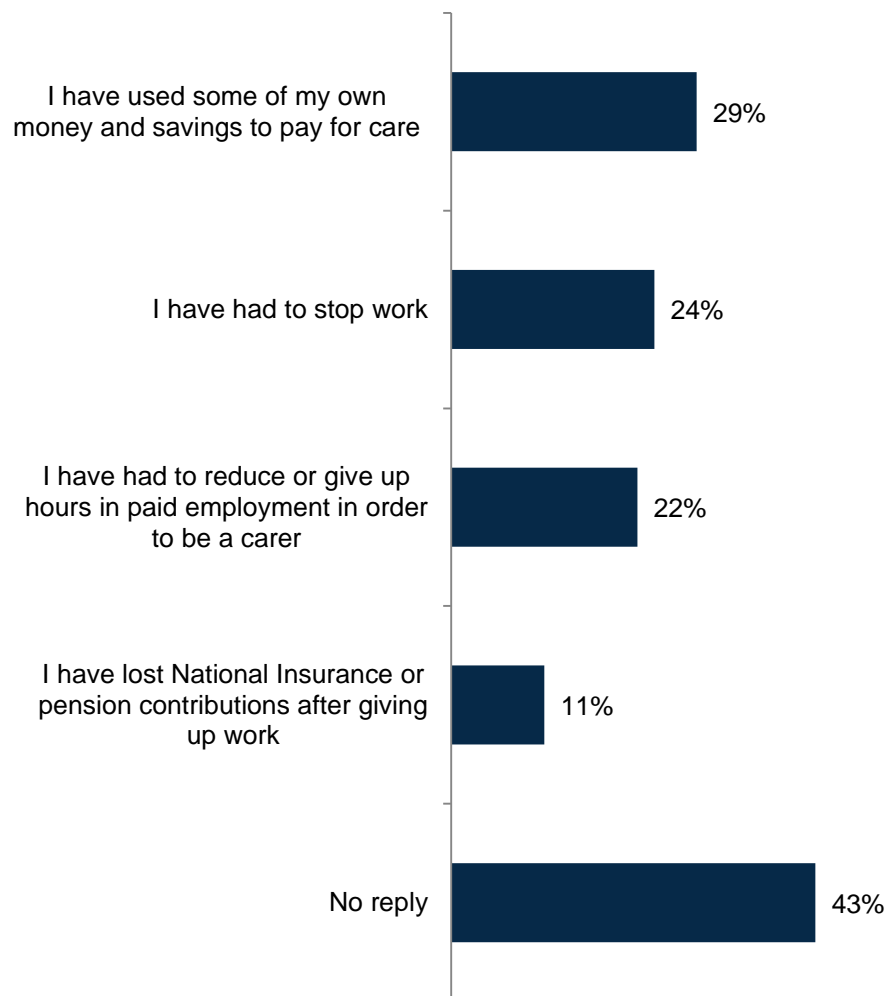
Health Impacts – Key Findings (1)

- 55% of carers in Midlothian reported that caring has had a negative impact on their health.
 - Carers of young people or of working age were more likely to report high levels of health impact.
 - Nearly a third of carers reported negative health impacts for each of the areas identified. The most frequent issues were concerns about contingency planning if respondents are unable to care, insufficient sleep, and a lack of adequate support.
 - This manifests itself in increased visits to the GP (31% of respondents) and experience of depression (45% of respondents).
 - There are also social impacts as a result of caring: nearly half of carers feel isolated from family and friends.
 - The sense of isolation and concern about contingency planning is underlined by the fact that only 58% of respondents felt that they had somebody to rely on for support.
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Health Impacts – Key Findings (2)

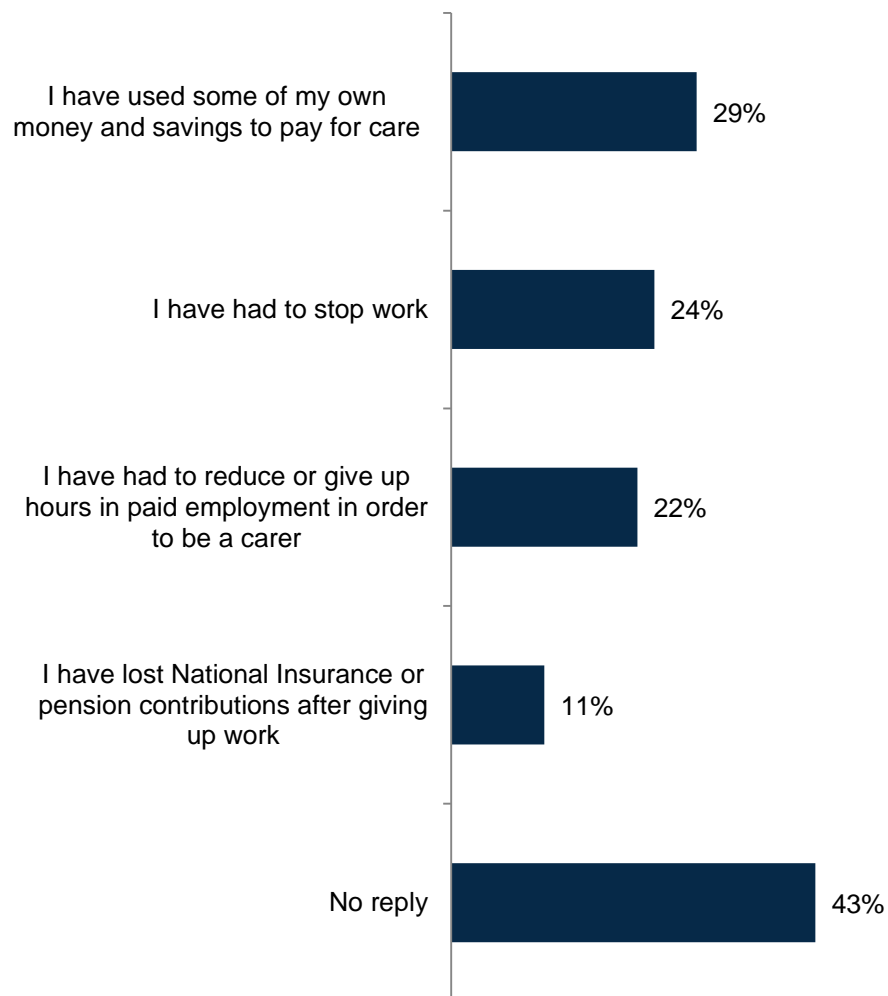
- Carers of children and respondents who were not in employment or receiving a pension were particularly likely to identify a negative health impact as a result of caring.
 - The open-ended comments made by carers underline the significant impact on carers' health, often exacerbated by the stress of dealing with various support agencies.
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Financial Impacts of Caring (1)



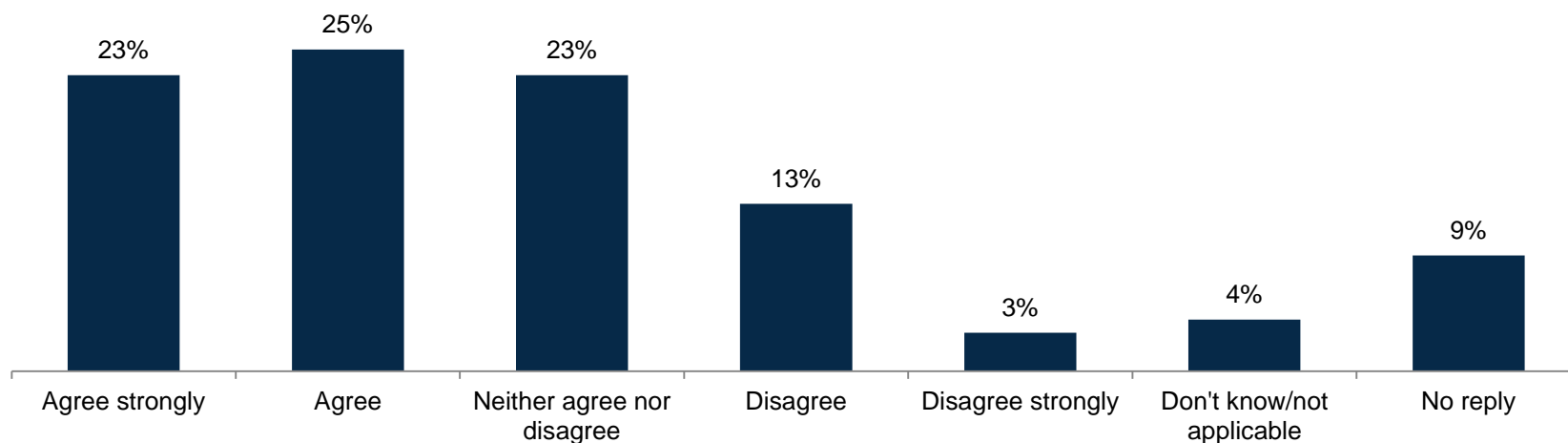
- Nearly a third of carers are financing care themselves.
- The proportion dipping into savings is higher for long term carers (34%), men (40%) and carers of children (33%).
- A quarter have had to stop working: the figure is higher for long-term carers (30%), carers of children (40%) and carers of people aged 16-25 (43%).
- Men are more likely to have had to stop work (34%) than women (20%).

Financial Impacts of Caring (2)



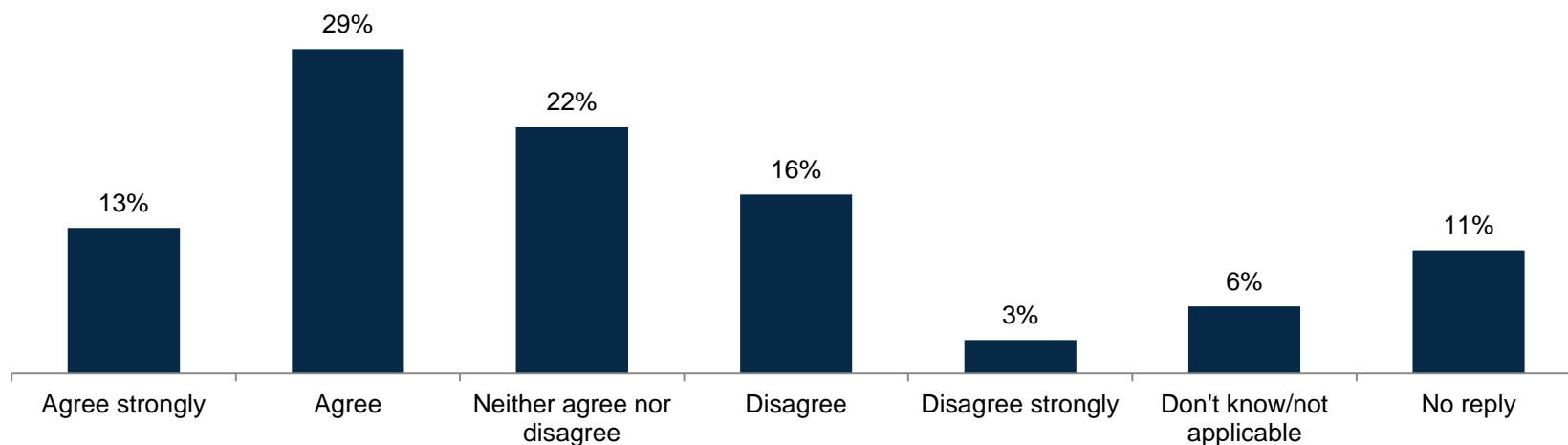
- 31% of those who do not receive a salary or a pension have had to stop work because of caring.
- 22% of respondents have had to reduce their working hours: this is higher for respondents caring for children (37%) and caring for adults aged 16-25 (34%). It is slightly more likely to affect women (23%) than men (19%).
- 11% of people have lost NI or pension contributions, illustrating the long term financial impact of caring.

Money and Work: “Being a carer has made money and finances more difficult.”



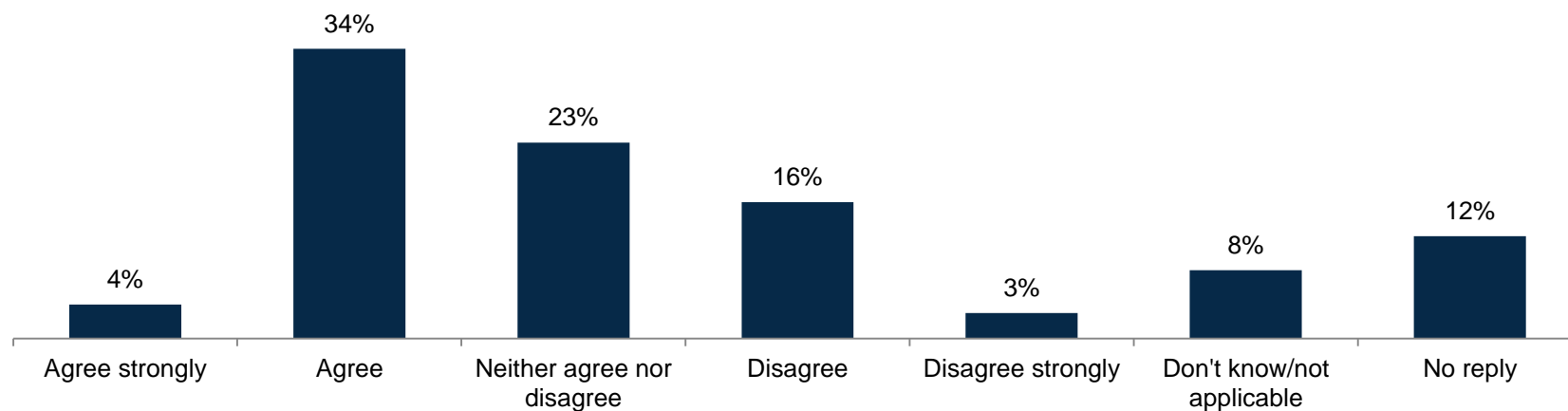
- 48% of respondents agreed with this statement.
- Cares of children (74%) and of adults aged 16-25 (87%) were most likely to agree with this statement, as were people who were not in receipt of a salary or a pension (73%).
- People who had not engaged with VOCAL were more likely to agree with this statement (57%) than those who had (note: tiny sample).

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



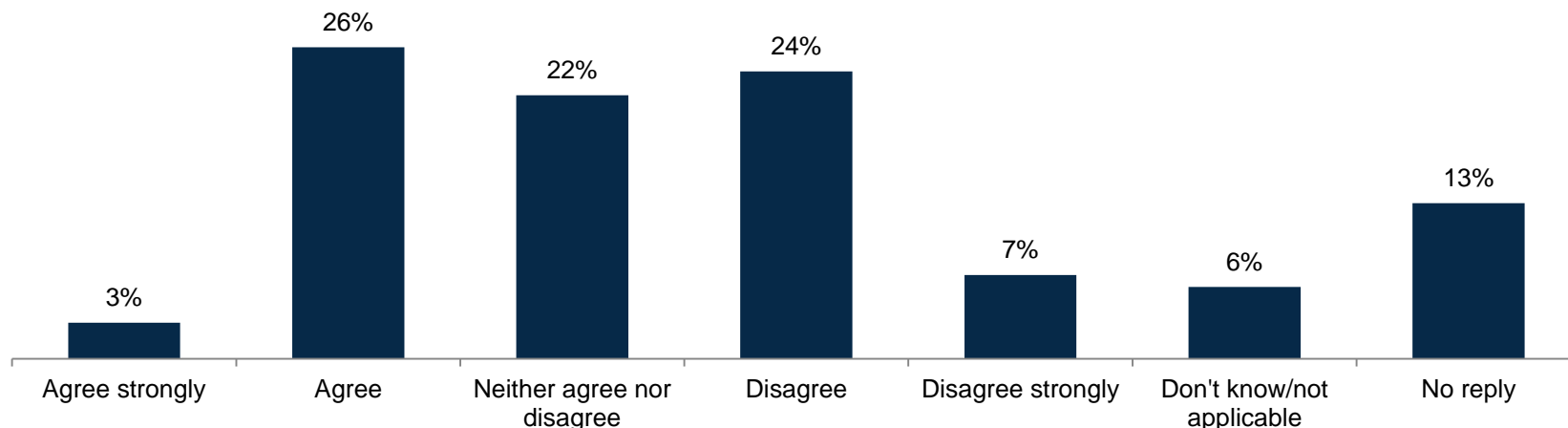
- 42% of respondents agreed with this statement.
- Respondents were more likely to agree with this statement if they were caring for children (71%), caring for adults aged 16-25 (60%) and were not in receipt of a salary or a pension (66%).
- There is clear evidence of stigma and emotional challenge associated with talking about the financial impact of caring.

Money and Work: “I know what financial support is available to me.”



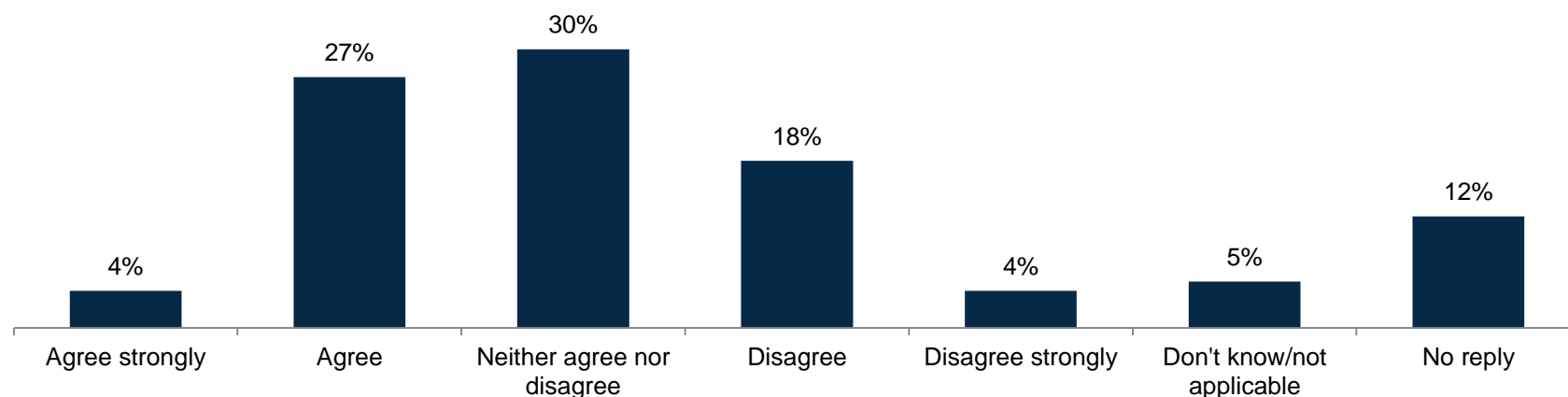
- 38% of respondents agreed with this statement, with only 4% agreeing strongly.
- Responses to this question were fairly consistent. Interestingly, respondents who had not engaged with VOCAL showed the lowest level of agreement with this statement (14%) (caution: very small sample).

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



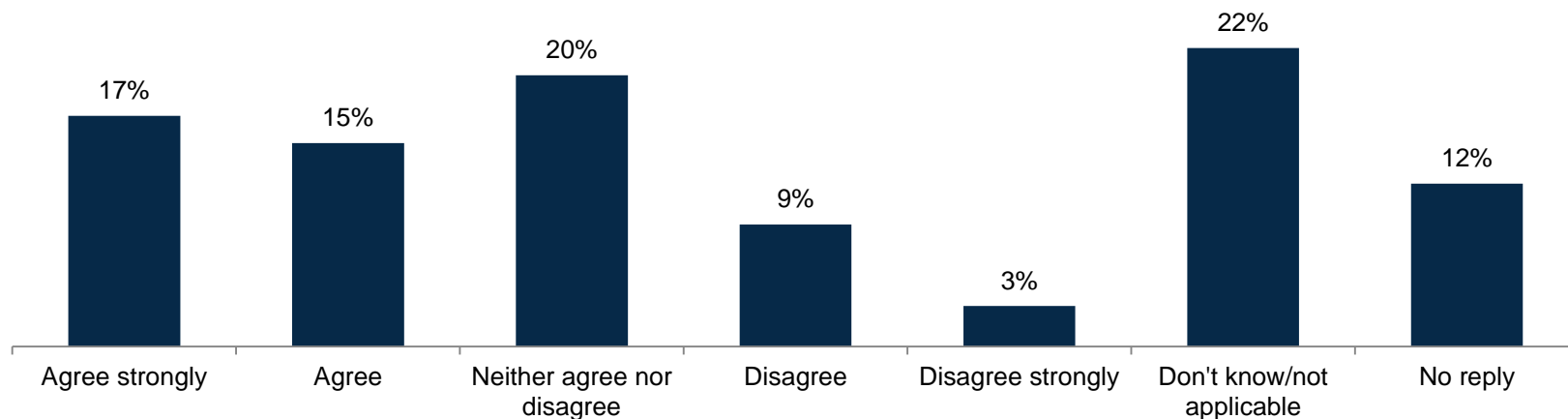
- Just 29% of respondents agreed with this statement, with only 3% agreeing strongly.
- Respondents aged over 75 (15%) and carers of people aged 65-74 (22%) showed the lowest levels of confidence when applying for financial support.

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



- Just 31% of respondents agreed with this statement, with 4% agreeing strongly.
- Respondents caring for adults aged 16-24 (10%) and respondents not in receipt of a salary or a pension (19%) were less likely to agree with this statement.
- Respondents who have not engaged with VOCAL were also less likely to agree with this statement (14%) (caution: very small sample).

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



- Nearly 32% of respondents agreed with this statement, with 17% agreeing strongly.
- Unsurprisingly perhaps, concern over paying for care homes increases with age. 44% of respondents caring for somebody over the age of 75 agreed with this statement, compared with just 7% of carers looking after children.

Money and Work– Additional Comments (1)


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

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

 *“Caring full time made working difficult so easier not to. Impacts on savings, pension and husband’s pension as all earnings needed to live supported by benefits.”*

 *“You can’t earn due to the time it takes to make endless phone calls, emails, meetings, etc.”*



18 provided further details of the financial difficulties involved with caring:

 *“It’s not the big expenses that are causing difficulty. It’s the small silly things that get ruined or need to be replaced more often that use up all the cash.”*

 *“There are a lot more bills with going to hospital appointments, regular visits in hospital and also heating and electric is rising.”*

Money and Work– Additional Comments (2)

16 respondents made comments (mostly criticisms) of the benefits system and the entitlements for carers themselves:

-  *“I can’t work due to caring roles. Carer’s Allowance is a disgrace.”*
-  *“I find it unfair that you don’t qualify for Carer’s Allowance when you turn 65. You still need help.”*

13 respondents talked about their concerns for the future:

-  *“At present we help to support my son. I’m not sure what will happen after our days.”*

Other subjects (each mentioned by fewer than 10 respondents) were: the impact of VOCAL on alleviating financial difficulties (2 respondents), requests for support or information (2), and concern about the financial impact on other family members.

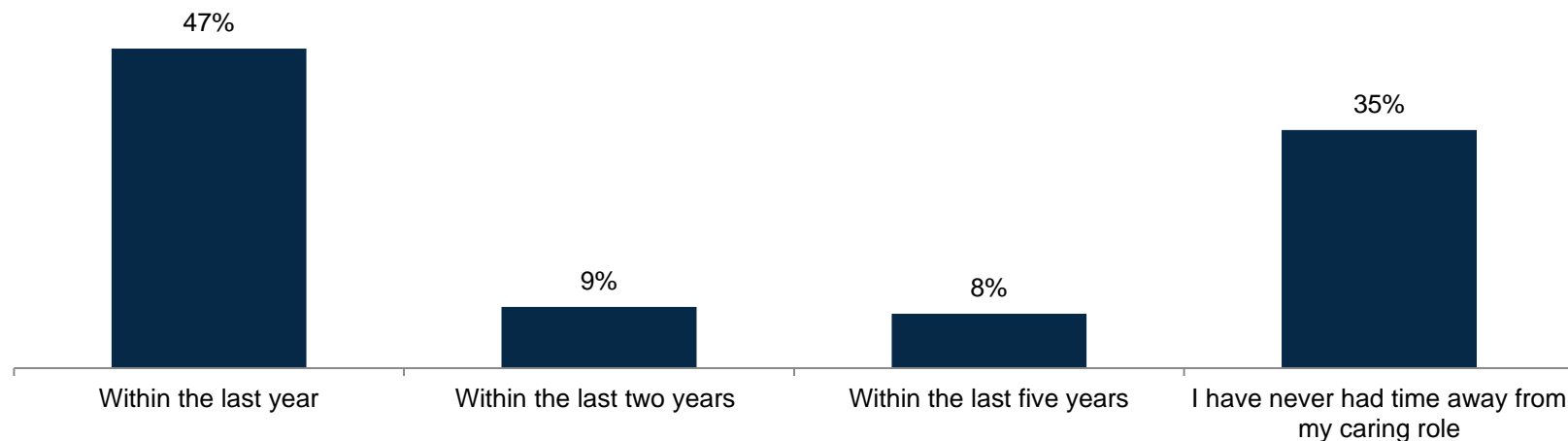
Impact on Money and Work– Key Findings (1)

- 48% of respondents agreed that being a carer had made money and finances more difficult.
- There is tangible evidence of the financial and economic impact of caring: a third of carers are paying for care out of their own savings; a quarter have had to reduce their working hours and a fifth have had to give up work altogether. 11% have lost out on NI or pension contributions as a result.
- Respondents highlighted the long-term impact of giving up work, both on future career prospects and on pension entitlements.
- Carers of children and young adults (who have often been caring for a long time and who have had to reduce or give up work), and those not in employment or receiving a pension, were more likely to report negative financial impacts.
- They were also more likely to say that they find it hard talking about these impacts. Funders and organisations working with carers must acknowledge the emotional impact of applying for financial support.

Impact on Money and Work– Key Findings (2)

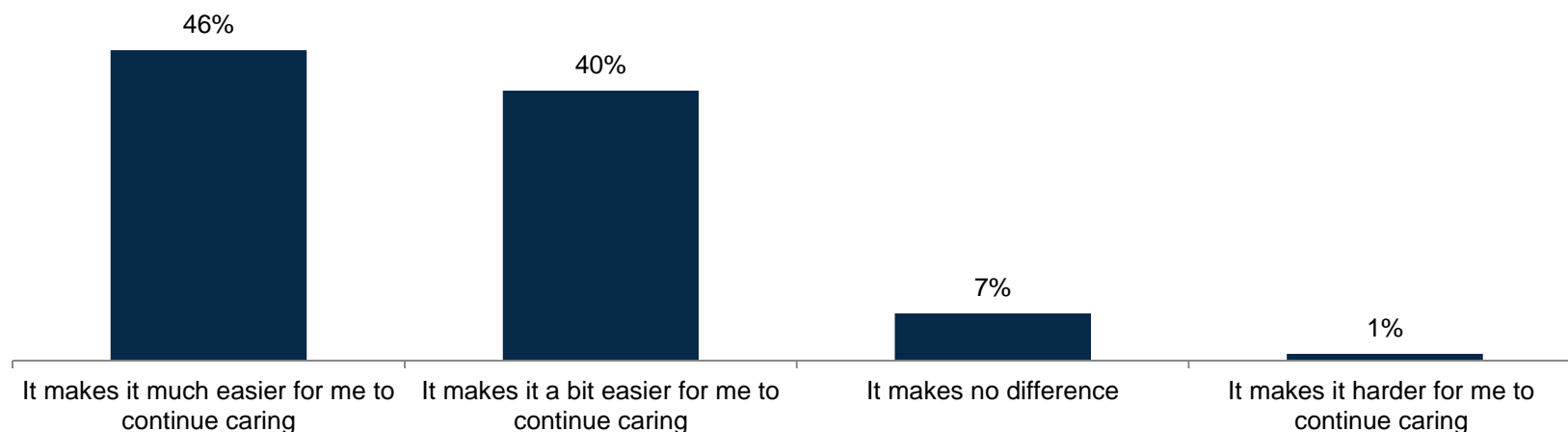
- 38% of respondents felt that they knew what financial support was available, with a third saying that they felt confident in applying for it and a similar proportion agreeing that it was sufficient. VOCAL should therefore continue to provide information to raise awareness, support carers in making applications, and lobby to ensure that the funding levels are fair.
 - Paying for care homes is a key concern for carers of adults over the age of 75, who comprise approximately one-third of this sample.
 - There is some evidence (with the caveat of a very small sample size) that respondents who engage with VOCAL report smaller negative financial impacts than those who do not.
-

Time Away From Caring



- Time away from caring was defined as “doing things you can’t do while you are caring – it can be as short as a day off or as long as a holiday away from home.”
- Just under half of carers felt that they had time away from caring in the past year.
- Over a third of carers had never had time away. This rises to 38% for carers aged 75+.
- 37% of long term carers, who have been caring for more than five years, said that they had never had time away from caring.

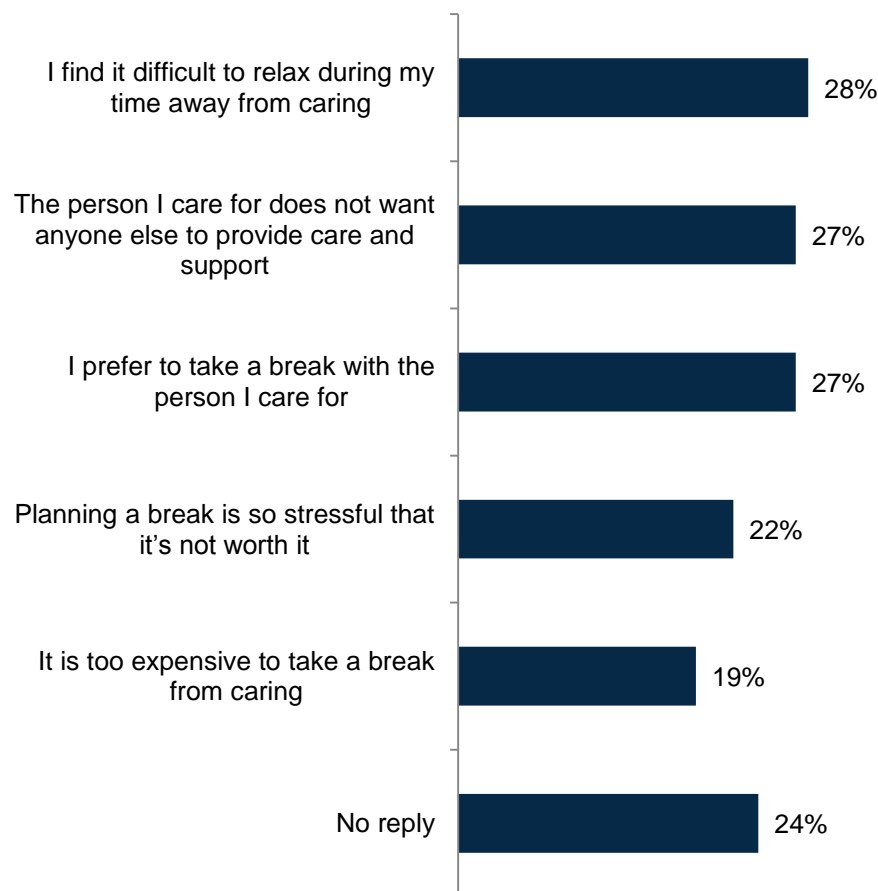
Time away: Impact on Caring



Base: all those who have ever had time away from caring (202)

- 86% of respondents who have taken time away from caring said that it helps them to continue in their caring role. 46% said that time away made things “much easier”.
- These figures underline the importance of securing regular time away from caring. Time away appears to facilitate the continuation of the provision of care.

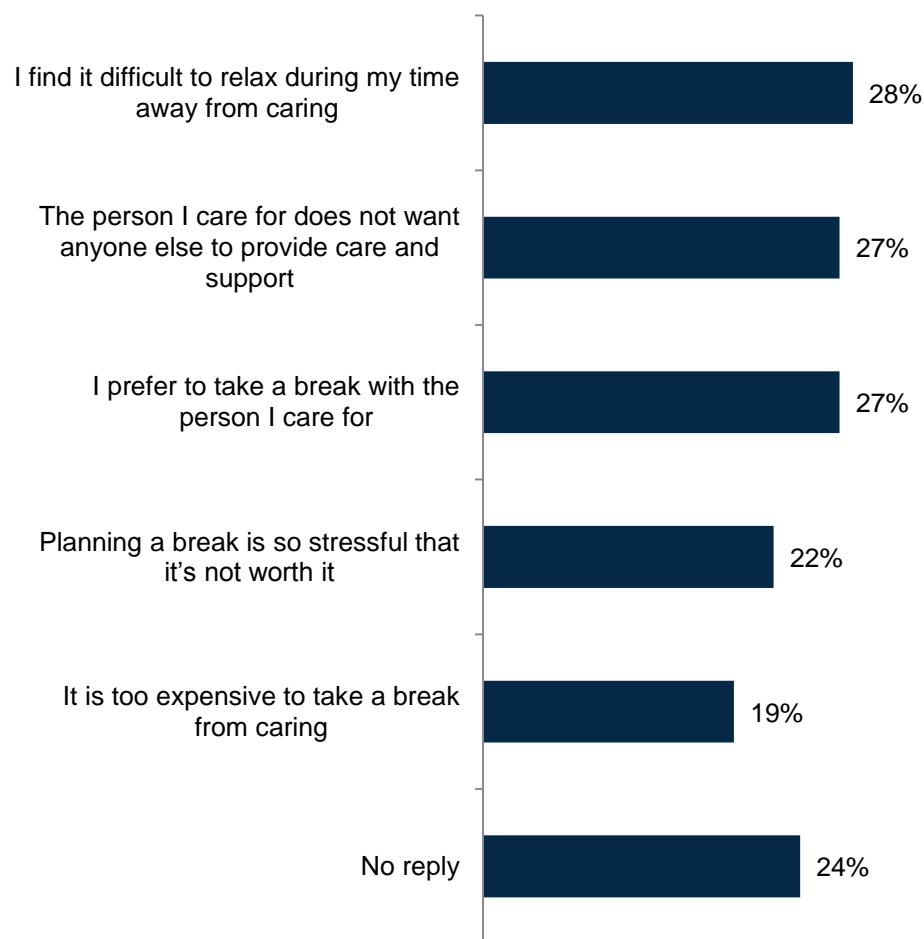
Time away: Carer Experiences and Opinions (1)



- 28% of carers reported that they find it hard to relax during their time away from caring. This increases to 33% for carers of children.
- A similar proportion felt that the person they cared for did not want anyone else to step in. This figure was higher for carers of people aged over 65.
- Over a quarter of respondents wanted to take a break with the person that they care for.

Time away: Carer Experiences and Opinions

(2)





- 22% of respondents find the stress associated with planning a break negates any benefits. This figure increased for carers of children (31%) and carers of adults aged 16-25 (33%).
- The cost of a break was significant for 19% of respondents, rising for carers of children (38%), and carers of young adults aged 16-25 (33%).



Time Away: Additional Comments (1)

90 carers made additional comments about having time away from their caring role.

20 respondents expanded on the positive impacts of taking a break:


-  *“It is essential for own self-esteem. Have a bit of time for husband and own children and recharge batteries.”*
-  *“In the summer I visit my sister in Wales where I can unload all my worries and this really helps me and gives me something to look forward to.”*

The remaining comments generally reflected barriers to effective time away. 17 respondents talked about the mental strain of being away:

-  *“I feel good for a while but I always hit rock bottom on my return as I face the blackness and despair of this never-ending caring role.”*
-  *“I feel guilty spending time away.”*

Time Away: Additional Comments (2)

15 respondents talked about the practical difficulties associated with taking time away from caring:

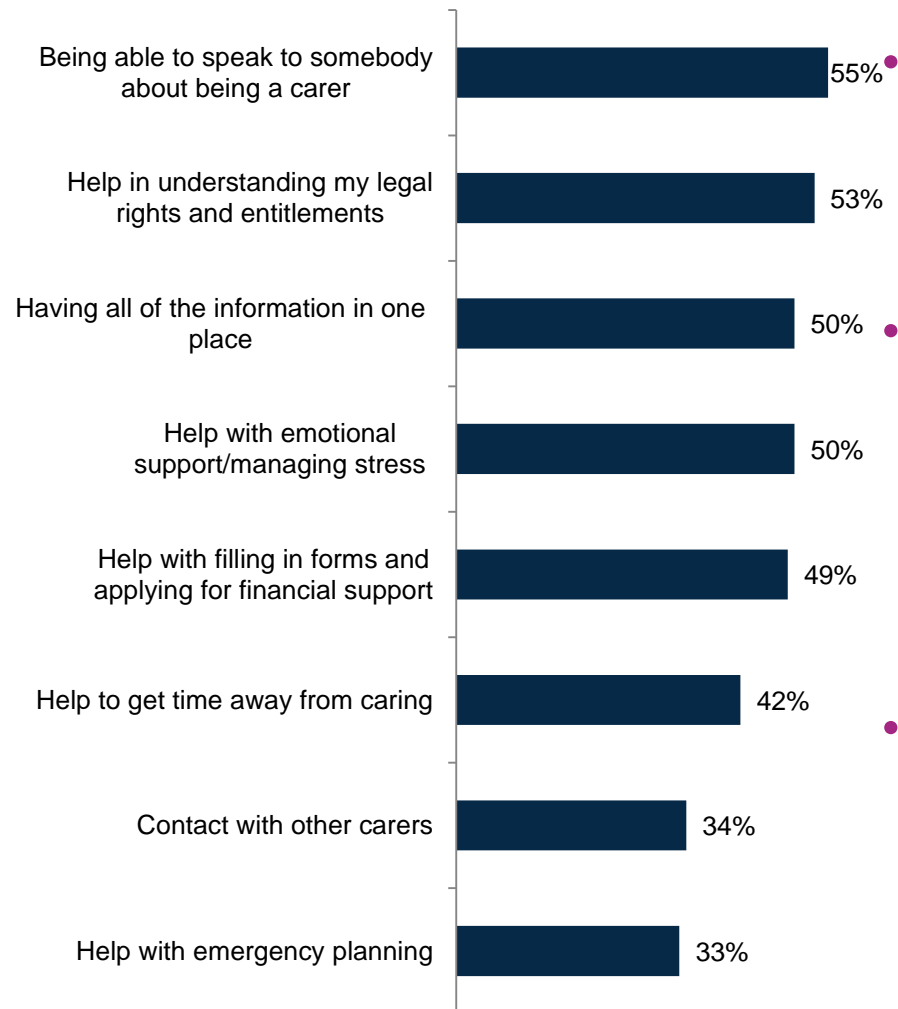
 *“It is difficult to leave my son as he needs a routine and is unaware of safety. Leaving him with family can be difficult if he has a meltdown. It is difficult for him to get his point across.”*

Other responses (each made by fewer than ten respondents) focussed on the cost of respite care being a barrier (8 respondents), the fact that the person being cared for does not want the carer to go away (8), the fact that the respondent wants to be able to take a break with the person they care for (5) and that the carer does not want to take a break (4).

Time Away: Key Findings

- Less than half of carers in Midlothian say that they have had time away from caring in the past year. More than a third say that they have never had time away at all.
 - Time away from caring can have a positive impact on carers. 86% of those who have taken time away from caring say that it has made it easier for them to continue in their caring role.
 - Barriers to effective time away include: the carer being able to relax; the preferences of the person being cared for; and the stress associated with planning and paying for a break.
 - Carers of children and young adults aged 16-25 appear to experience the above barriers more frequently than carers of older people.
 - The findings suggest that effective support for the carer and the person they care for is essential for beneficial time away.
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Interest in Potential Services from VOCAL

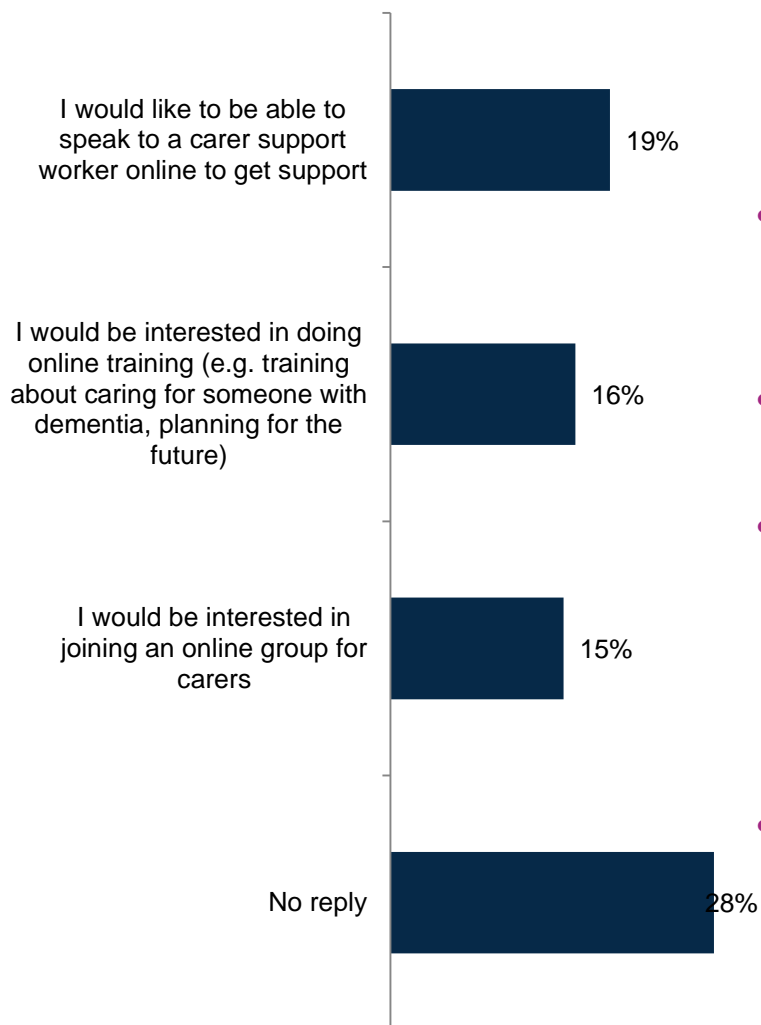


Suggested areas of support largely reflect the list of useful services already being experienced by VOCAL carers.

Helping with emotional support/managing stress was particularly interesting for people who had been caring for 1-2 years (65%) and carers of children (67%).

- Male carers were more likely than average to be interested in help with filling in forms and applying for financial support (53%).

Future Support: Online



- There are relatively low levels of interest in online provision, perhaps reflecting the lower levels of confidence about using the internet.
- There is a slightly higher level of interest in online services from carers who are of working age and in employment.
- 26% of carers looking after children would be interested in an online group for carers.
- There is generally higher interest in these services from respondents who have not currently engaged with VOCAL (caution: tiny sample size). Again, this might be an opportunity to engage new users.
- Several respondents said that they were not interested in accessing services online, due to concerns over using the technology, confidentiality, or a preference for face to face support.

Future Support: Key Findings

- Existing users like what VOCAL is doing now, and want to see it continued.
 - Interest in online services is not overwhelming. It primarily appeals to carers of working age and would need to be an enhancement of existing services, not a replacement.
 - Some Midlothian respondents are reluctant to engage online and prefer face-to-face support.
 - There is some evidence that non-users would respond well to online support. This, with a focus on the provision of information, could be a means of engaging with new users.
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Recommendations

- Communicate the excellent satisfaction ratings and feedback to staff, volunteers, funders and other stakeholders. VOCAL is an effective, authoritative voice.
 - Recognise that long-term carers show slightly different characteristics and may require additional or different support.
 - Consider the development of online services for some audiences, but as an additional service rather than to replace the current support mechanisms.
 - Use the Mosaic profile (with caution, given the diversity of the profile) to inform marketing and communications strategies and to identify possible engagement targets.
 - Communicate the enduring preference for personal and localised tailored support.
-

Recommendations (2)

- Recognise the value of time away from caring whilst understanding that it is a complex and emotive issue and the carer and the person being cared for will require support to implement it effectively.
 - Consider developing additional support or guidance for carers of children, who appear to face increased barriers to securing effective time away from caring.
 - Use the findings of the survey to demonstrate the financial and health impacts of caring, and to campaign for more support for carers.
 - Communicate (with caution) the finding that carers who have not engaged with VOCAL appear to experience more negative benefits than carers who have done so. Consider further research with both groups to validate this initial finding.
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