

# SCOTINFORM



## VOCAL Edinburgh 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

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## Response Rate

7,984 surveys were distributed in Edinburgh, with 915 returns received.

This represents a response rate of 12%

The response rate is slightly lower than in 2015 (14%), but the number of responses achieved is higher – 915 returns, compared with 728 in 2015.

61% of respondents replied to the paper format of the survey. 21% 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.

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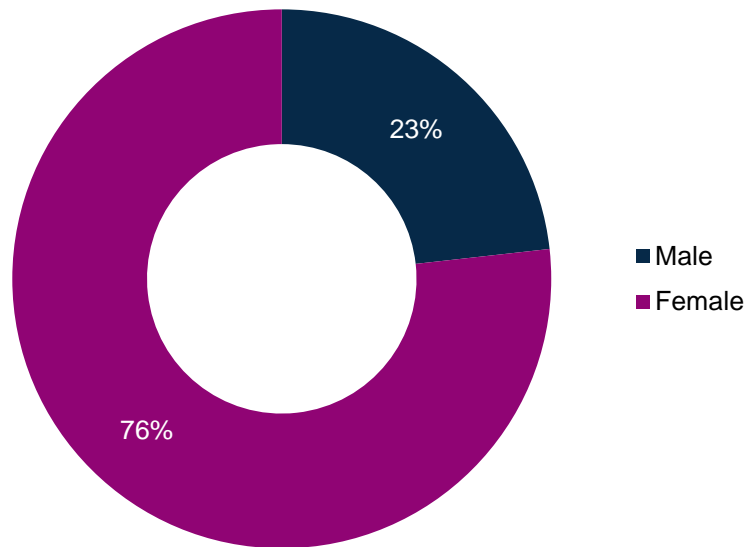
# Reporting

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

Please note:

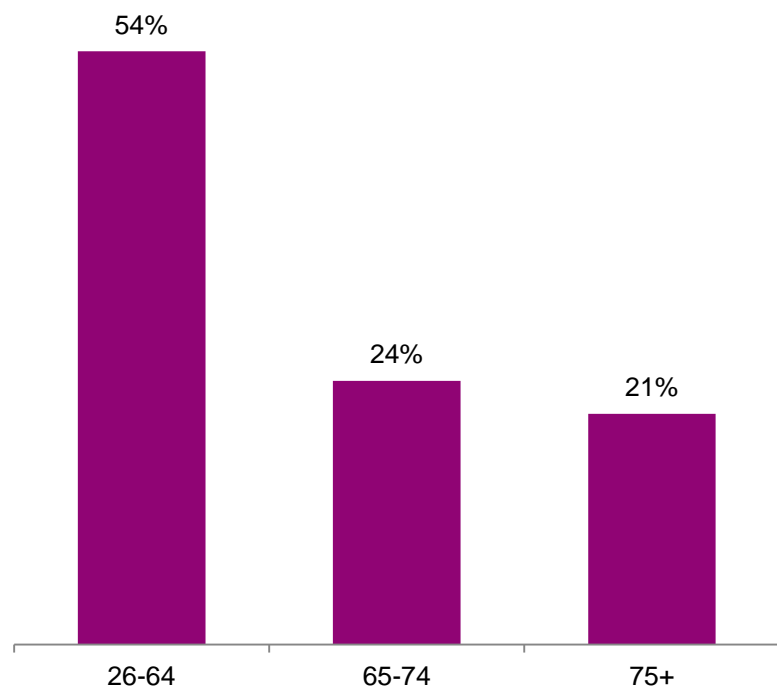
- Where percentages do not total 100% this may be due to non-responses and/or rounding
  - Where percentages exceed 100% this is due to multiple responses
  - Unless otherwise stated, the reporting base is all Edinburgh respondents (915)
  - Open-ended feedback is identified with 
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## Carer Characteristics – Gender



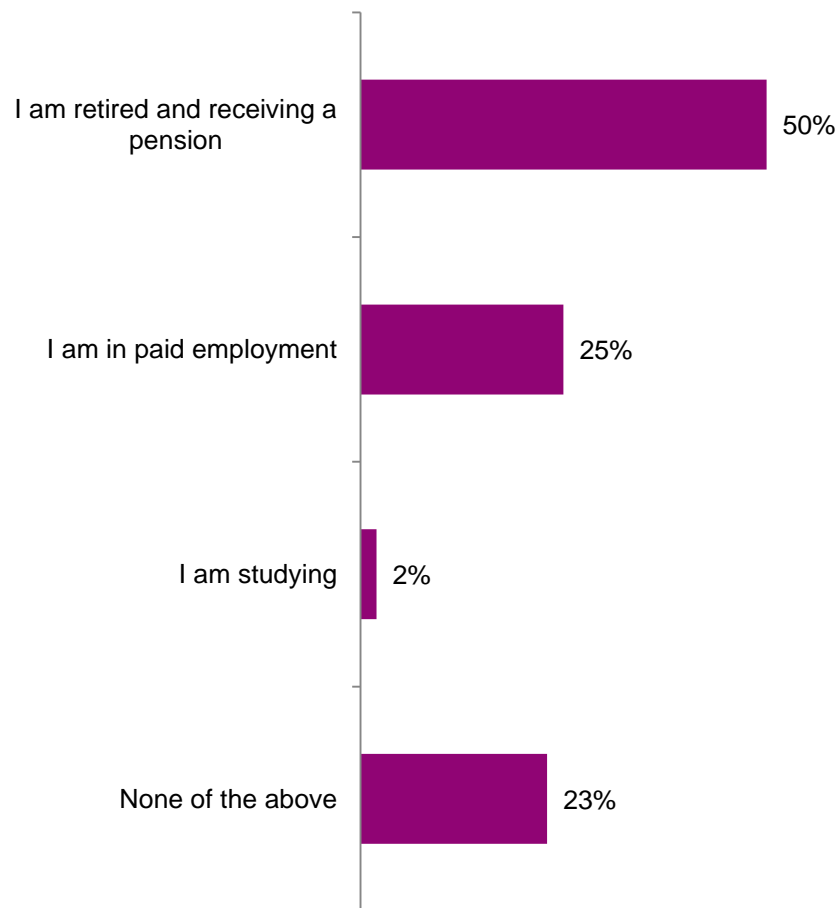
- Approximately three quarters of Edinburgh respondents were female
- This is consistent with the 2015 survey (77%)
- There were no significant differences in the gender profile of different respondent types

## Carer Characteristics – Age



- Sample is divided equally between those of working age and those of retirement age.
- The 2015 survey used different age bands, which makes comparison difficult.
- In 2015, 46% of Edinburgh respondents were aged over 60, suggesting little change in the age profile.

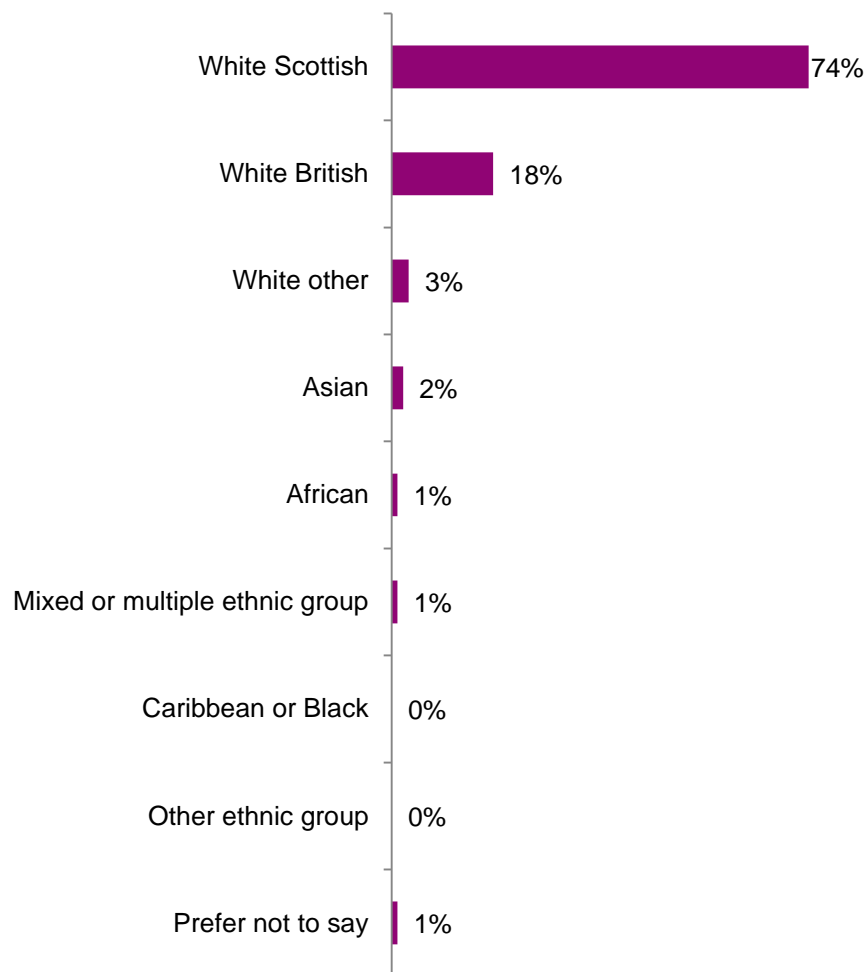
## Carer Characteristics – Economic Activity



- Almost a quarter of the sample is in paid employment, despite over half being of working age. The 2015 figure was also 25%
- 23% are not in paid employment, studying, or receiving a pension.
- This figure increases for carers of children under 16 (49%) and of young adults aged 16-25 (43%).



## Carer Characteristics – Ethnicity



- 95% of Edinburgh respondents are white.
- This is consistent with the 2015 figure (also 95%).
- The proportion of BME respondents increased for carers not in employment, education or receiving a pension (7%) and for carers looking after children (17%) or looking after adults aged 16-25 (9%).

## Carer Characteristics - Location

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

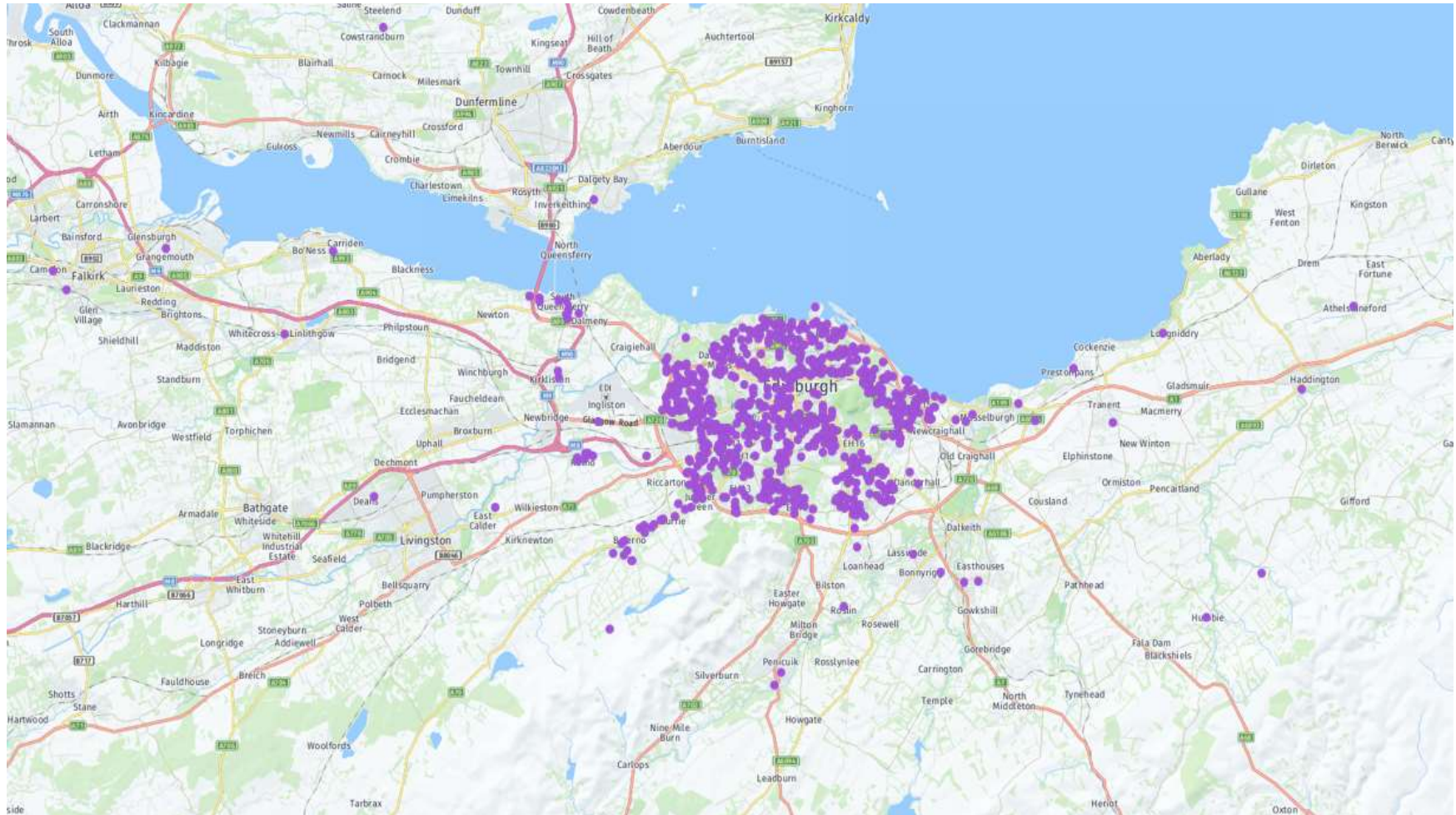
Scotinform was able to use verified postcode data from 869 respondents.

Most respondents also lived in Edinburgh, but there was some representation from East Lothian, West Lothian, Midlothian and Fife.

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.

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# Carer Characteristics – Location



# Carer Characteristics – Mosaic Scotland

Scotinform profiled the 869 full Scottish postcodes provided by Edinburgh 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.

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# Carer Characteristics – Mosaic Profile

The Mosaic profile is relatively diverse.

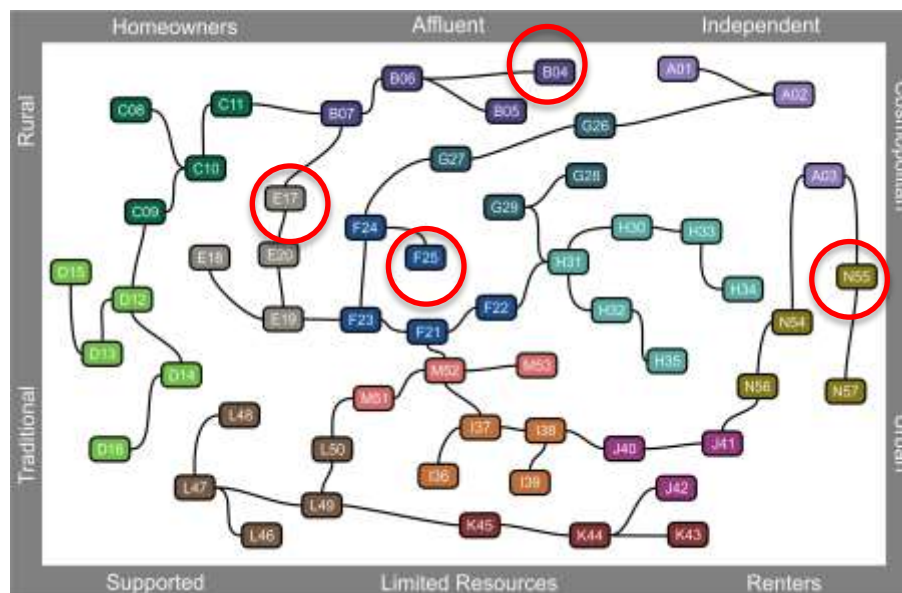
The four largest Mosaic Scotland groups, accounting for 53% of the postcodes, were Prestige Positions (15%), City Prosperity (14%), Rental Hubs (13%) and Senior Security (11%).

The three largest Mosaic Scotland types were B04 Diamond Days (9% of records), E17 Legacy Elders (7%), F25 Ageing Access (6%) and N55 Central Pulse (6%).

In comparison to the Edinburgh population as a whole, there were proportionally fewer respondents from Municipal Challenge and Transient Renters, which are characterised by low income and limited resources.

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# Carer Characteristics – Mosaic Family Tree



- The top four types are not “clustered” on the Mosaic family tree, underlining the indiscriminate nature of assuming caring responsibilities.
- They tend to have average to high income levels.
- 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.

# B04 Diamond Days



- “Retired residents in sizeable homes whose finances are secured by significant assets and generous pensions.”
- Just over half of Diamond Days residents own a smartphone, and 80% own a laptop.
- 74% will use the internet several times day and 76% will check email every day.
- 19% of Diamond Days residents will opt out of receiving all marketing information, higher than average for Scotland.
- Those who do opt in prefer to receive communications by email (65%) or post (18% - much higher than average for Scotland).

# E17 Legacy Elders



- “Time-honoured elders now mostly living alone in comfortable suburban homes on final salary pensions.”
- This is the oldest Mosaic type overall, with an average age of 78.
- 45% of Legacy Elders own a smartphone, and 70% have a laptop.
- 64% will use the internet several times day and 78% check email every day.
- 17% of Legacy Elders residents will opt out of receiving all marketing information, higher than average for Scotland.
- Those who do opt in prefer to receive communications by email (60%) or post (21% - significantly higher than average for Scotland).



# F25 Ageing Access



Mosaic Scotland



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- “Older residents now owning smaller inner suburban properties with good access to amenities.”
- 58% of Legacy Elders own a smartphone, and 81% have a laptop.
- 71% will use the internet several times day and 80% check email every day.
- 14% of Ageing Access residents will opt out of receiving all marketing information, in line with the average for Scotland.
- Those who do opt in prefer to receive communications by email (65%) or post (17% - higher than average for Scotland).

# N55 Central Pulse

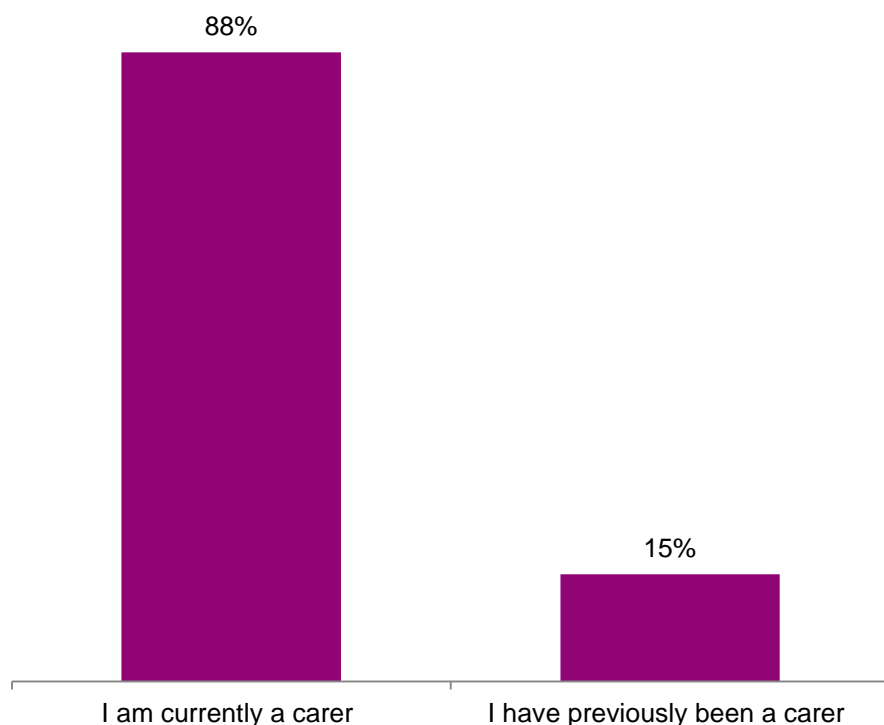


Mosaic Scotland

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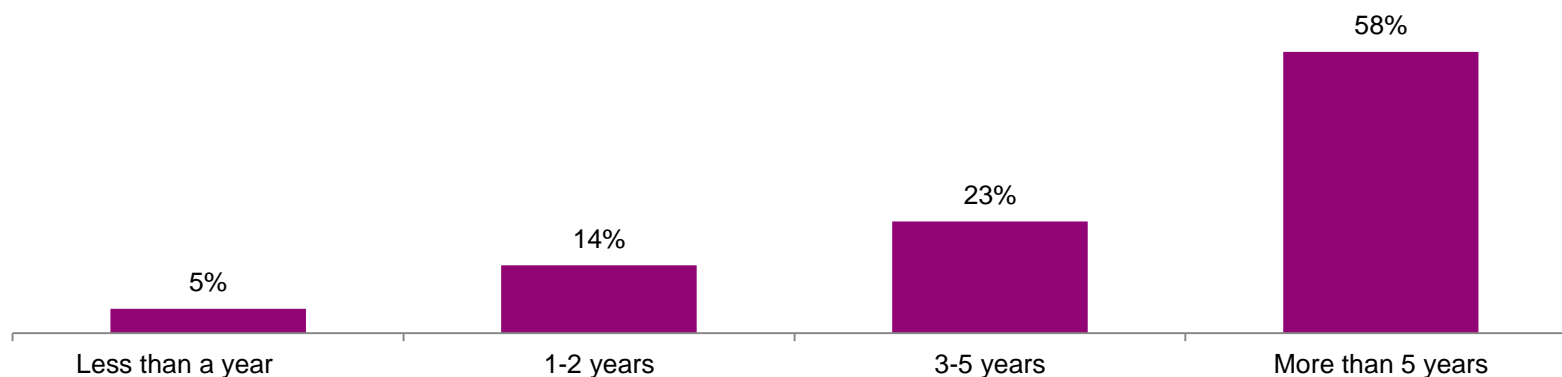
- “Entertainment-seeking youngsters renting city centre flats in vibrant locations close to jobs and nightlife.”
- This is a very different profile, with an average age of 35.
- 90% of Central Pulse residents own a smartphone, and 95% have a laptop.
- 85% will use the internet several times day and 82% check email every day.
- 15% of Central Pulse residents will opt out of receiving all marketing information, slightly higher than the average for Scotland.
- Those who do opt in prefer to receive communications by email (72%) or post (9% - much lower than average for Scotland).

## Carer Characteristics – Caring



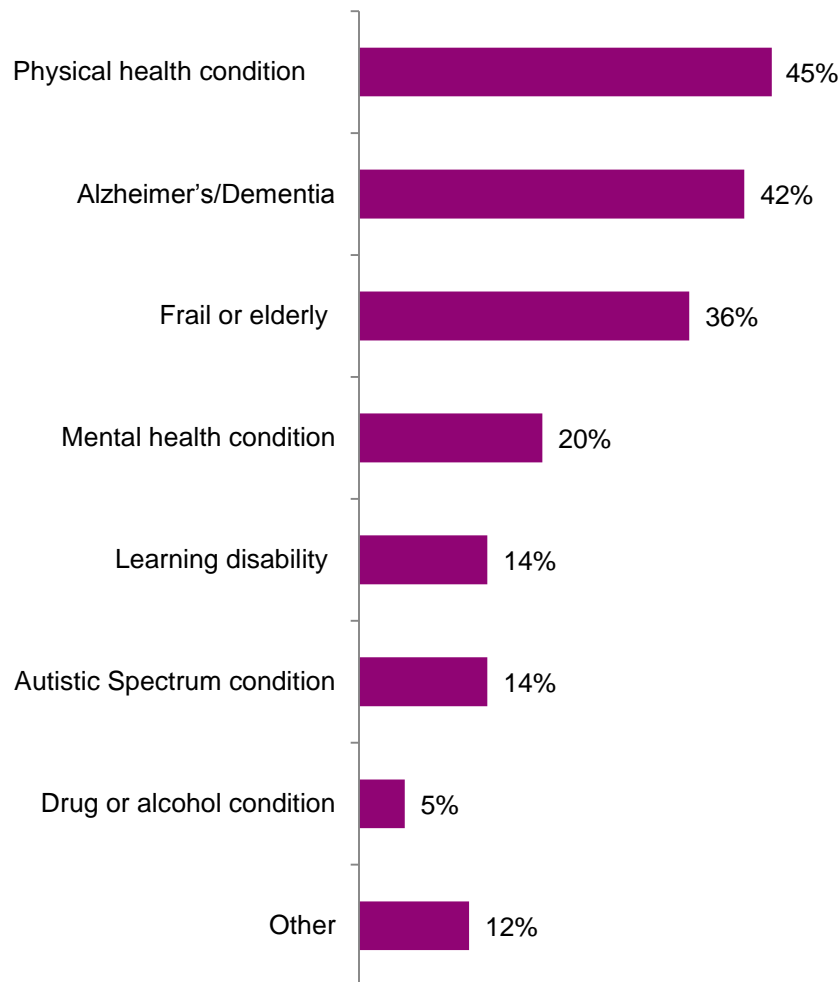
- Nearly 90% of respondents saw themselves as having an active caring role right now.
- This is consistent with the 2015 result (84% defined themselves as current carers)
- Some respondents selected both responses, suggesting that they have cared for two different people at different stages.

## Sample Characteristics – Duration of Care



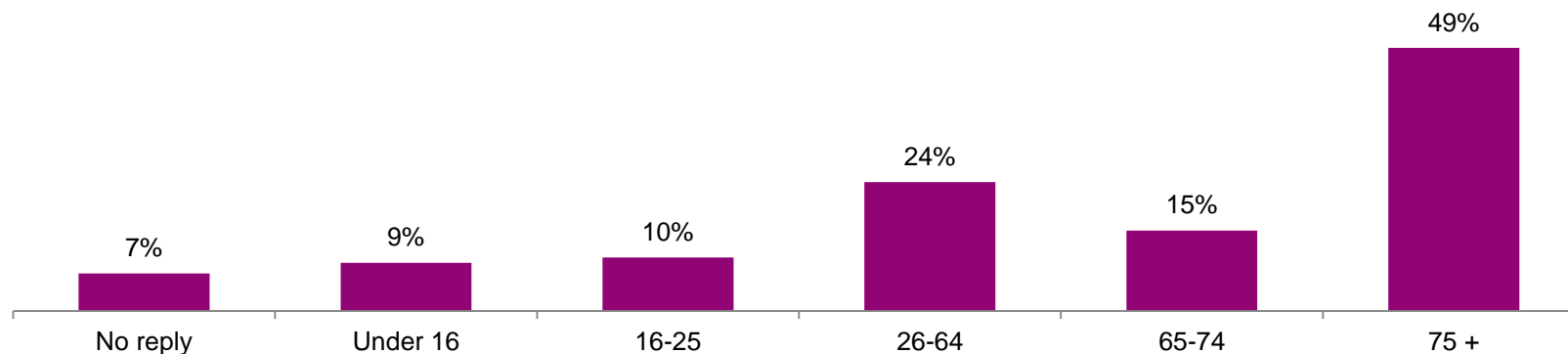
- Nearly two-thirds of respondents have been caring for more than 5 years.
- Long-term carers are often looking after younger people. 79% of carers of children and 85% of carers of adults aged 16-25 had been caring for more than 5 years.
- New carers (less than a year) were more likely than average to be aged over 75 themselves (7%).

## Sample Characteristics – Conditions cared for



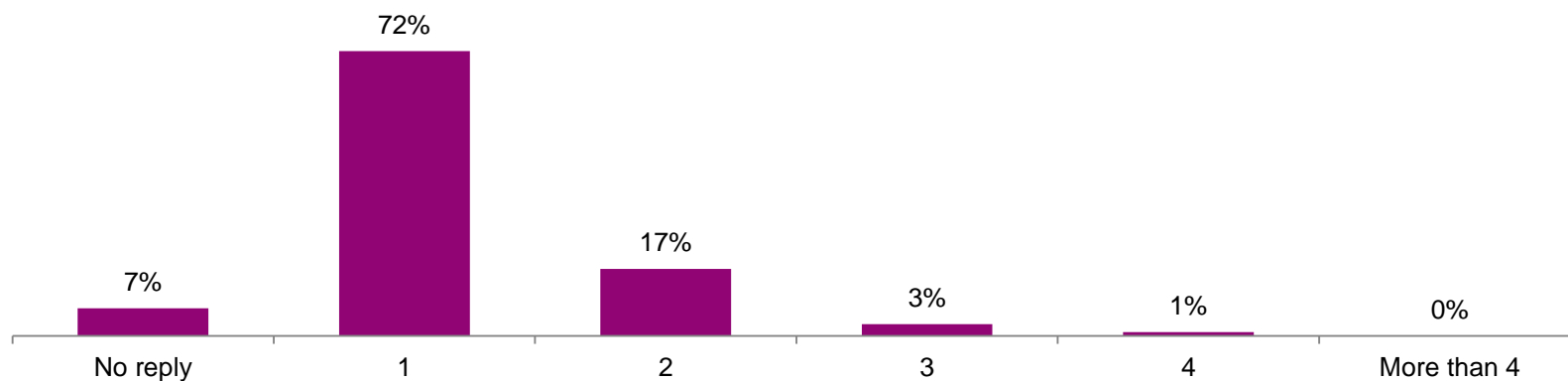
- Edinburgh respondents were most likely to be caring for somebody with a physical health condition, who has Alzheimer's/dementia, or who is frail or elderly.
- The profile of conditions cared for is broadly the same as in 2015.
- “Autistic Spectrum Condition” was a new category for 2017. These carers were more likely to be long term carers (20%), and caring for somebody aged under 16 (65%) or 16-25 (52%)

# Carer Characteristics – Age of Person



- Nearly half of carers are looking after someone over the age of 75, increasing to 76% 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.
- A third 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 (27%), those caring for children (31%) or adults aged 16-25 (45%) and for respondents aged 26-64.
- Evidence of increased pressure on carers, who are often caring for multiple generations.

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## Carer Characteristics – Attitude to the internet

- 62% 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, 69% 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 (75%), and carers in paid employment (75%).
  - It is lower for men (58%), those aged over 75 (37%) and retirees (52%).
  - 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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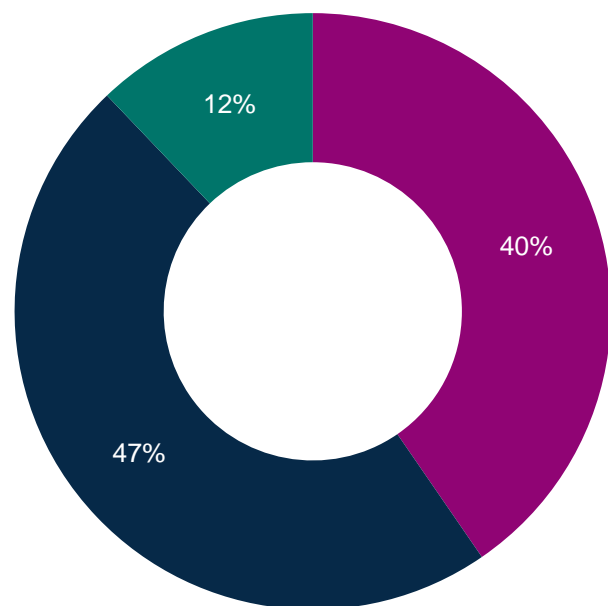
# Carer Characteristics – Key Findings

- Three-quarters of carers are female.
  - There is an even split between carers of working age and older carers.
  - A quarter of carers are in paid employment, despite half of the sample being of working age.
  - Caring often transcends Local Authority boundaries.
  - The Mosaic profile is diverse but suggests that VOCAL is effectively engaging with more affluent carers.
  - 60% of Edinburgh 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)

- 49% of carers are looking after someone aged 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 consider 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
- I have not used any VOCAL services

- 40% of Edinburgh respondents have used VOCAL services within the past six months, and 87% within the past year.
- The proportion of respondents who had engaged within the past six months was slightly lower than in 2015 (45%).
- Respondents were most likely to have used VOCAL services in the past six months if they were looking after children (58%) or were aged 26-64 (46%).
- Respondents were less likely to have used VOCAL if they had been caring for less than 2 years (15%) or if they were aged over 75 (21%).

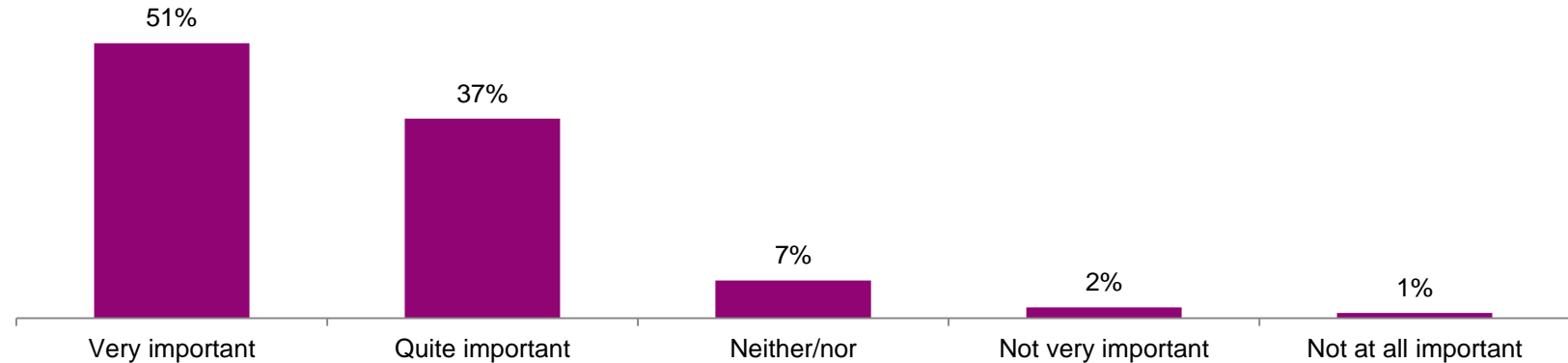
# Services Found Useful



- As in 2015, respondents value a combination of practical and emotional support.
- Information, signposting and training appear to be the most useful services.
- Carers of children particularly value social and health activities (31%) and help with accessing short breaks and respite (42%).

Base: all Edinburgh Respondents who have experienced VOCAL Edinburgh services (775)

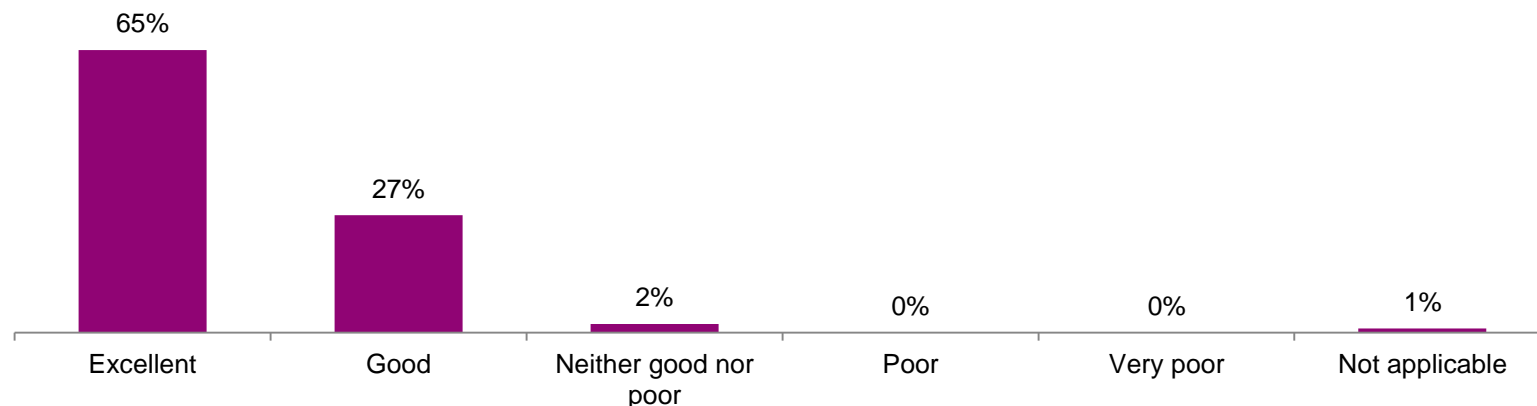
# Importance of Local Services



Base: all Edinburgh Respondents who have experienced VOCAL Edinburgh services (775)

- Nearly all respondents said that it was important that they had access to VOCAL services locally.
- Over half said that it was “very important”
- The proportion of respondents who said local access was “very important” was higher for carers of children (62%), and carers in paid employment (61%)

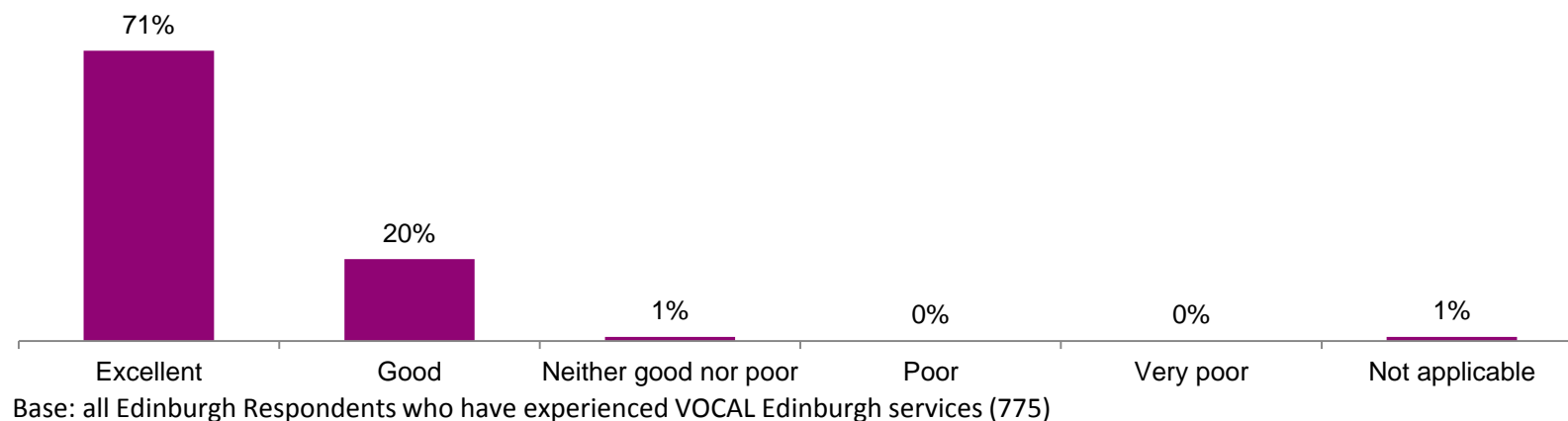
# Satisfaction: Ease of getting in touch



Base: all Edinburgh Respondents who have experienced VOCAL Edinburgh services (775)

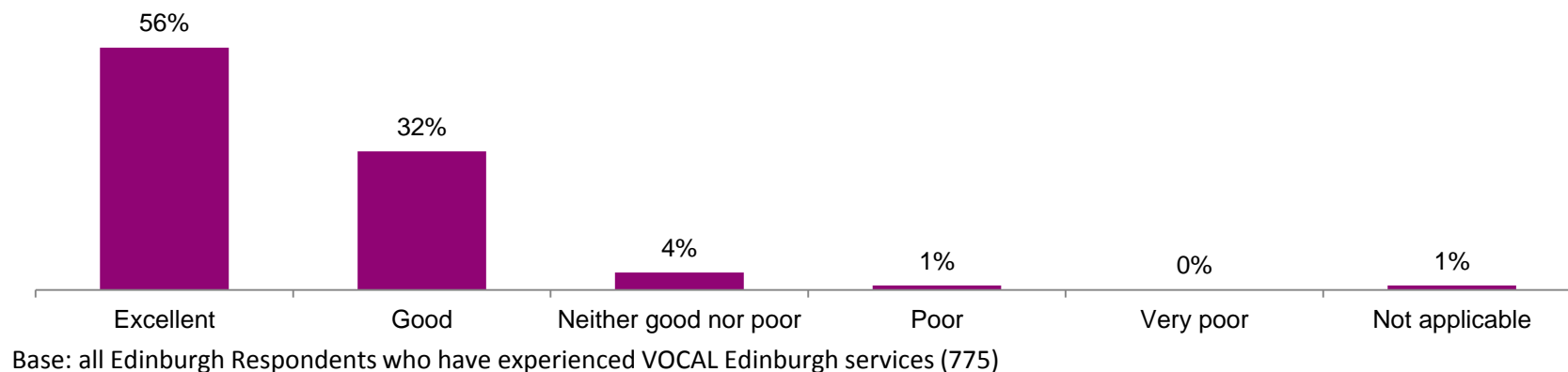
- 92% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 95% (but there was no measure of non-response in 2015).
- Older carers and carers in paid employment were slightly less likely to give this aspect a positive score.

# Satisfaction: Friendliness of Response



- 91% 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).
- New carers (of less than a year), men, and carers in paid employment were slightly less likely to give this aspect a positive score.

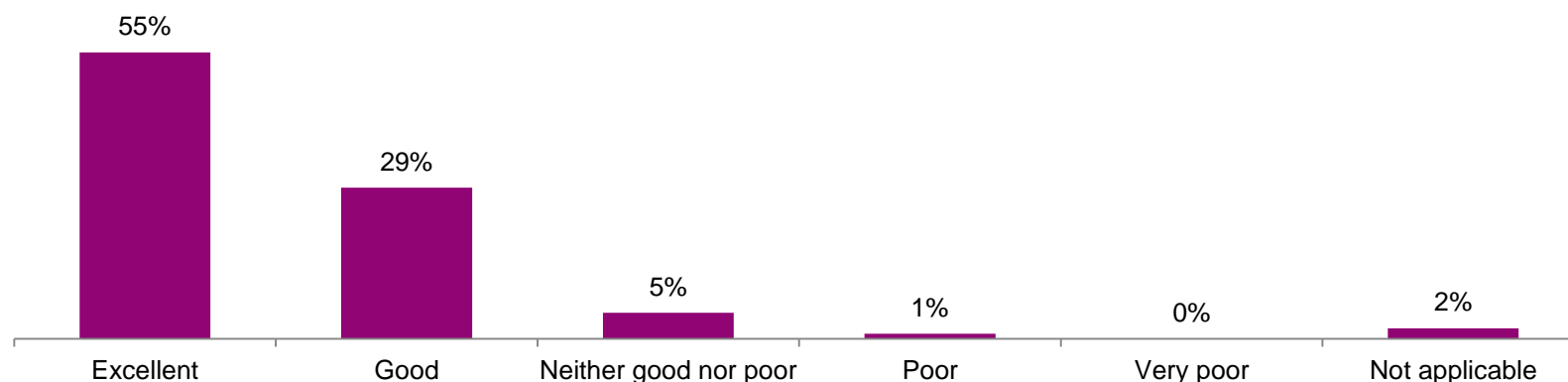
# Satisfaction: Getting as much information as you needed



- 88% 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).
- New carers (of less than a year), and carers over the age of 75 were slightly less likely to give this aspect a positive score.



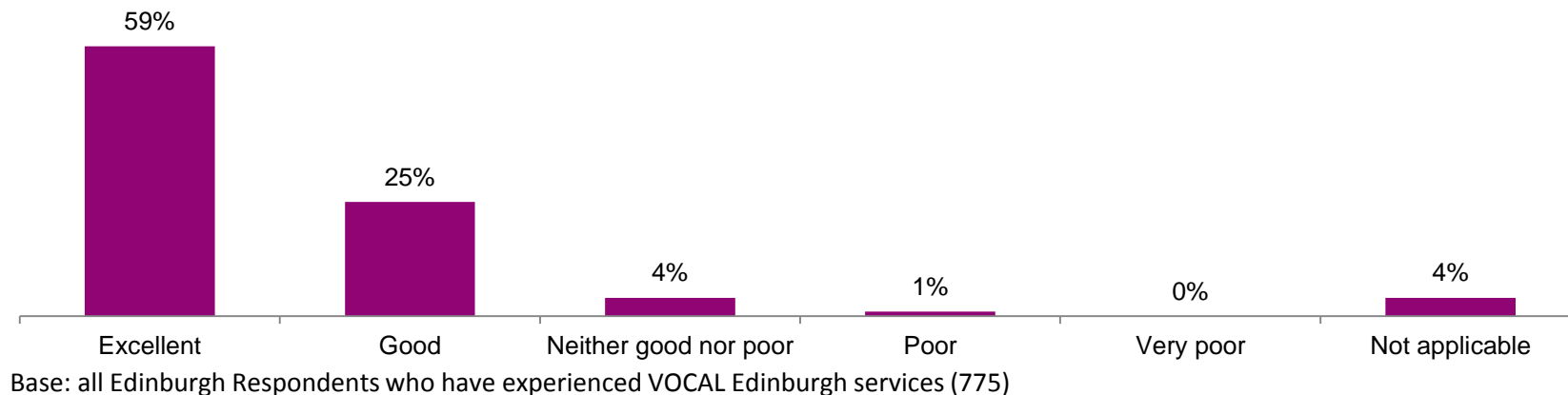
## Satisfaction: Knowledge of staff and volunteers



Base: all Edinburgh Respondents who have experienced VOCAL Edinburgh services (775)

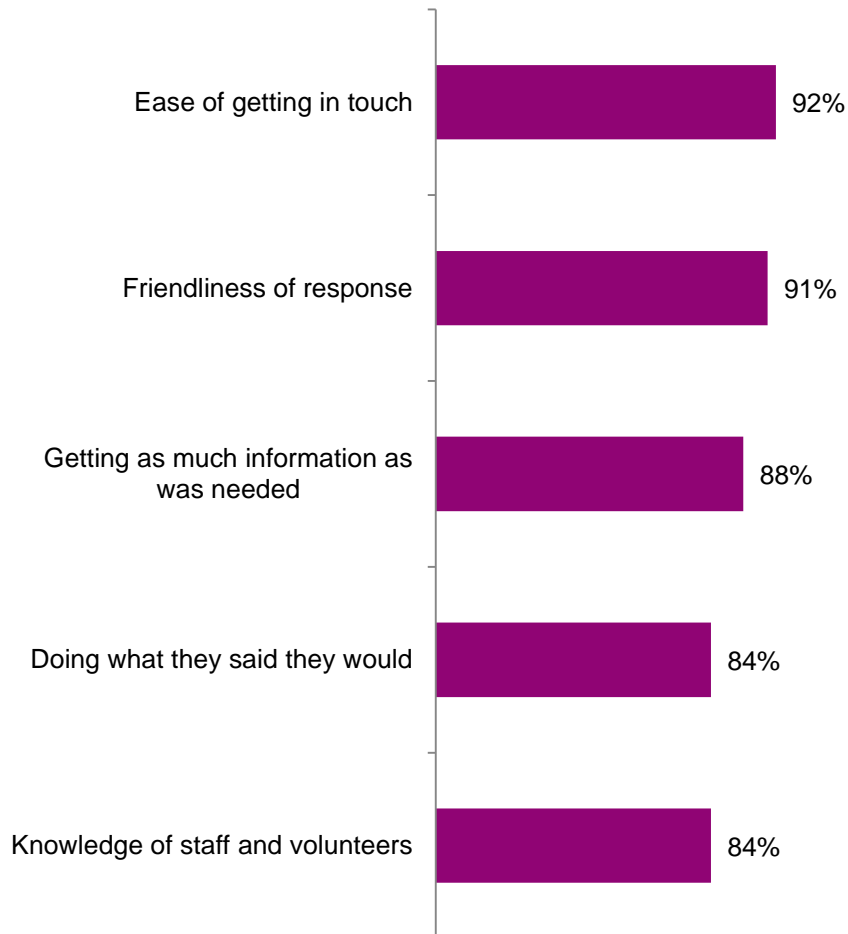
- 84% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 85% (but there was no measure of non-response in 2015).
- New carers (of less than a year), carers of people aged 25-64 and older carers aged over 75 were slightly less likely to give this aspect a positive score.

# Satisfaction: Doing what they said they would



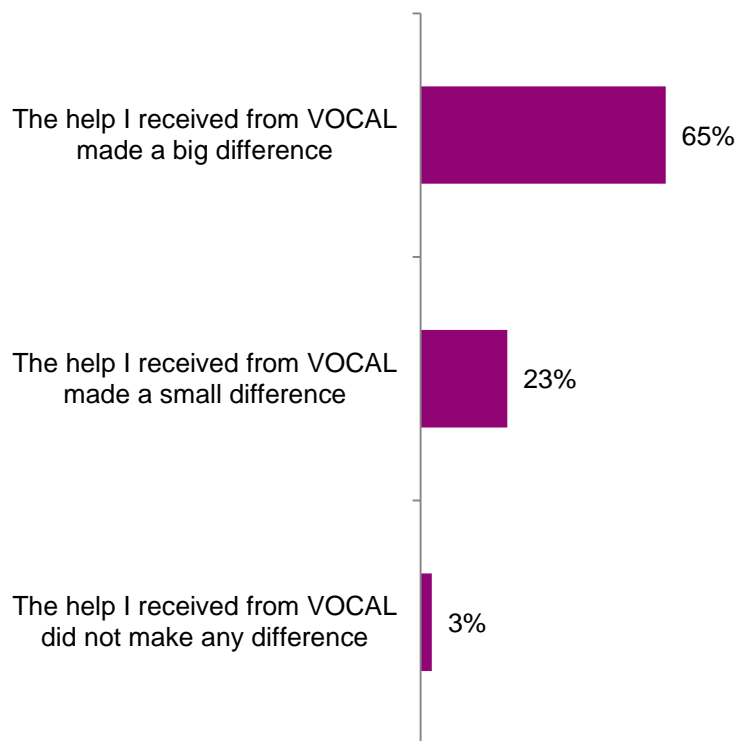
- 84% said that this aspect of their experience was “excellent” or “good”.
- In 2015 this figure was 89% (but there was no measure of non-response in 2015).
- Carers of people aged 25-64 were slightly less likely to give this aspect a positive score.

# Satisfaction Ratings: “Good” or “Excellent”



- Excellent performance!
- More than half of respondents rated VOCAL as “excellent” on every measure.
- Friendliness of staff performed particularly well – 71% excellent
- Accessibility and friendliness are key strengths
- Consistent with previous high performance

# Impact of VOCAL



Base: all Edinburgh Respondents who have experienced VOCAL Edinburgh services (775)

- VOCAL makes a significant difference to the lives of carers in Edinburgh.
- This is consistent with the 2015 figure (66%).
- Carers were most likely to report a “big difference” if they were caring for somebody aged 26-64 (715) or were in paid employment (73%).
- New carers and carers over the age of 75 were more likely to say that VOCAL did not make a difference.

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# The Impact of VOCAL

558 respondents described the impact of VOCAL, Edinburgh.

Responses fell into five main areas:

- 290 respondents identified positive health impacts (including feeling more confident and reducing feelings of isolation)
  - 207 respondents cited that the impact arose through VOCAL's information or advice
  - 130 respondents identified positive financial impacts, including securing Power of Attorney and help with applying for support.
  - 45 respondents identified benefits accrued through time away from caring
  - 34 said that they had developed new skills that helped them in their caring role.
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# Health Impacts

“VOCAL has provided love and advice, someone to talk to when the silence at home becomes impossible”

“Confidence for the future”

“It is vital to have an organisation like VOCAL that can support me so I can carry on with my caring duties – otherwise I just wouldn’t cope.”

“I was at breaking point. I now have better coping strategies in place”

“Helping me to realise I was under a lot of stress and suffering depression, For which I got help from the doctors.”

“Counselling saved my sanity”

“Felt less isolated”

“Helped me manage my caring role and caring for myself”

“Being able to focus on looking after myself...enhancing my resilience”

“Made new friends in the same position”

# Information and Advice

“We had no real help from NHS or Social Work. After diagnosis, I felt very lost. VOCAL helped with information and knowledge.”

“It helped me get access to information that government agencies are reluctant to help with.”

“It was a great learning curve, Without the VOCAL services how else do you learn about feeding, handling and care?”

“I received a lot of advice on legal matters relating to my son’s future.”

“Finding out about my rights as a carer and having some information about being able to defend the fact that I work compressed hours..”

“I had no knowledge of anything and needed all the help I could get.”

“Social Services were threatening a Guardianship Order. The advice we received managed to knock this on the head.”

“I was at my wits’ end trying to find honest, reliable tradesmen, your list of recommended firms helped me greatly!”

# Financial Impacts

“Did not have to take the person I care for before a panel to prove she was not able to work”

“Got a care package in place”

“Having Attendance Allowance to help pay for physiotherapy and domestic cleaning without reducing the household budget.”

“I saved £140 on gas bills”

“I was looking after my son for many years without financial assistance. I was not aware that we were entitled to benefits. Speaking to VOCAL made a huge difference to us.”

“We managed to secure higher level attendance allowance for my Dad.”

“I am more able to cope with the complexities of online energy suppliers”

“VOCAL encouraged me to apply for DLA and helped me complete the application, Would never have done that on my own ”



# Time Away From Caring

“Arranged visits gave me some ‘ME’ time and made a great difference to my mother’s quality of life.”

“Currently the hours I get from Better Breaks are invaluable.”

“Having time to myself to relax with the short break fund helped immensely.”

“Allowed me to go on a short holiday with my brother and sister.”

“Helped me see that it is OK to have time to myself and not feel guilty, though it’s not been easy.”

“I can go to an evening language course now as I have somebody to stay with my daughter.”

“My child received little breaks, which gave me a few hours rest”

“The Support Worker would come and spend time with my disabled son, take them out so that I could spend some time with my younger boy.”

# New Skills

“The Mindfulness course that I attended prevented a relapse of a depressive illness.”

“To do things the right way – like looking after Mum’s feet.”

“I’ve done a first aid course and it’s reassuring to know what to do in an emergency.”

“Workshops about caring and computer access.”

“Yoga for carers is extremely helpful; makes all the difference to my own physical ability to cope.”

“Gave me lots of tips on ways to care (e.g. oral care).”

“Training about dementia was invaluable (six week evening course)”

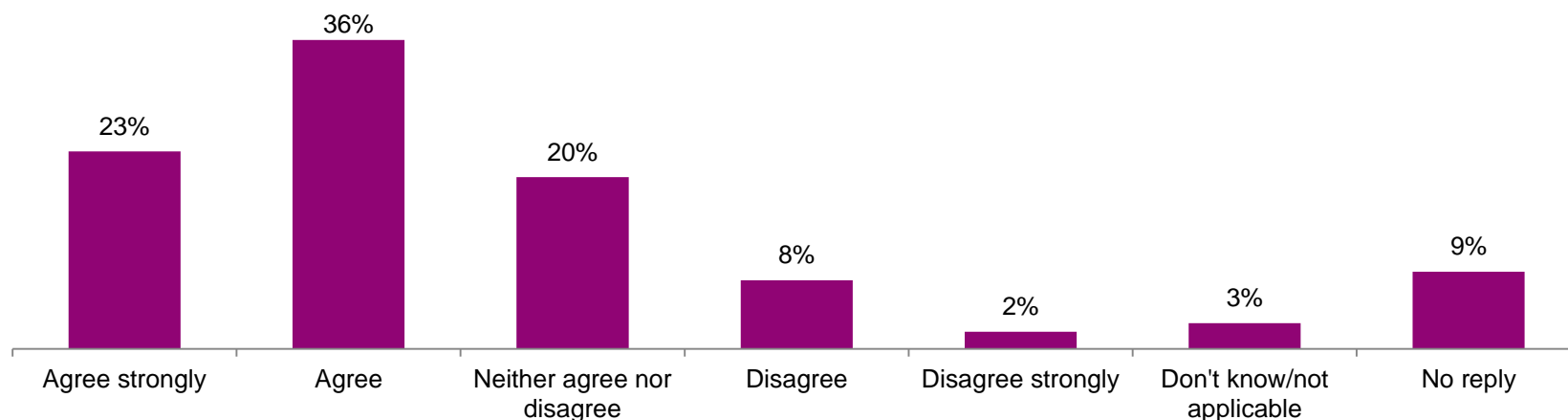
“I could understand and help my partner with her mental health problems.”

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# Satisfaction with VOCAL – Key Findings

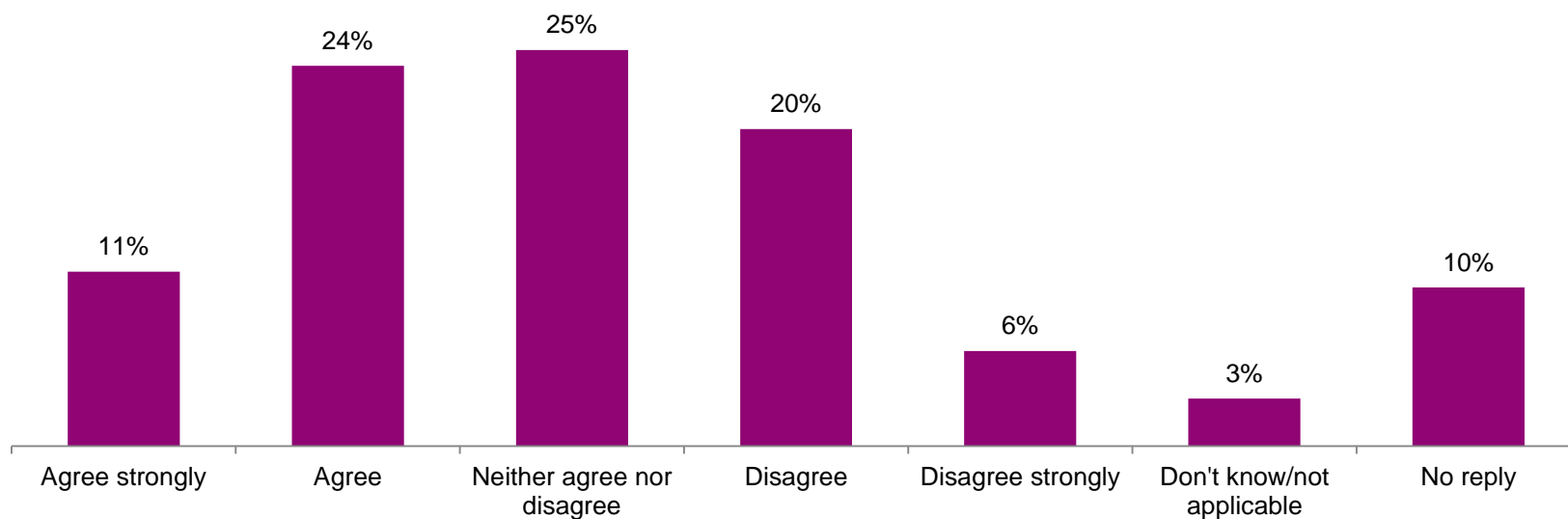
- VOCAL Edinburgh has a highly satisfied cohort of carers.
  - Nearly half of respondents have engaged with VOCAL in the past six months, and nearly 90% have engaged within the past year.
  - Carers value the provision of services at a local level.
  - In Edinburgh, carers particularly value the provision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



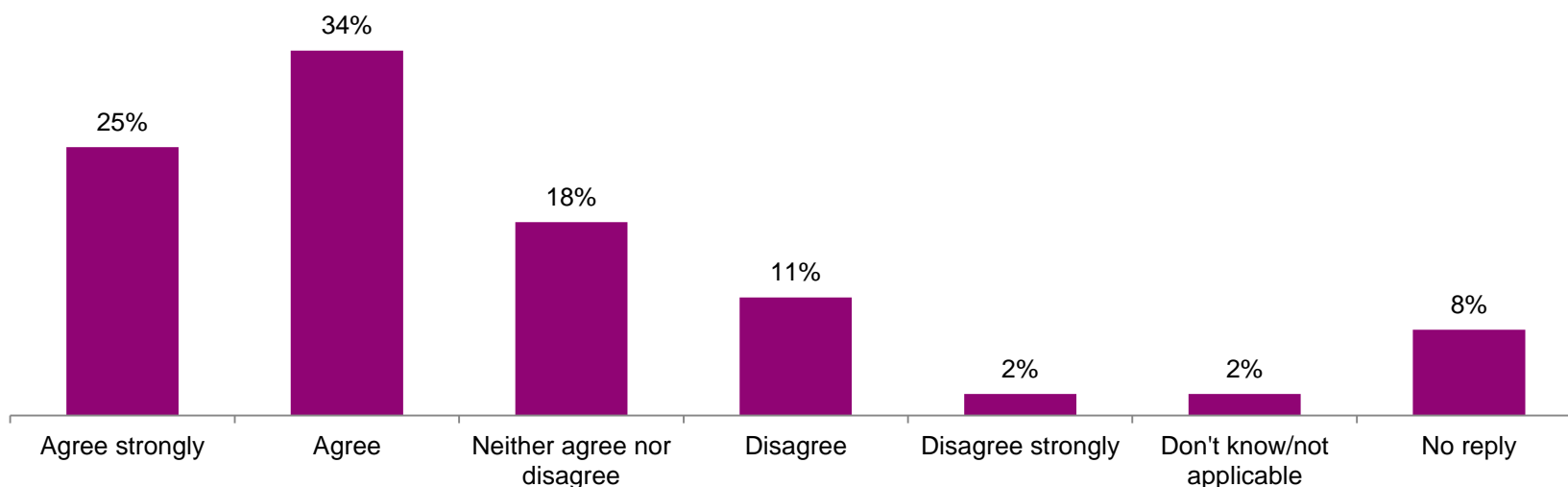
- 59% agreed that “being a carer has made my health worse”
- The figure increases to 69% for those who have not accessed VOCAL services (caution: small sample size)
- Impact on health increases with duration of care: health has got worse for 40% of new carers, compared with 57% of long-term carers.
- Carers of young people (who also tend to be long-term carers) were more likely to say their health has been impacted.

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



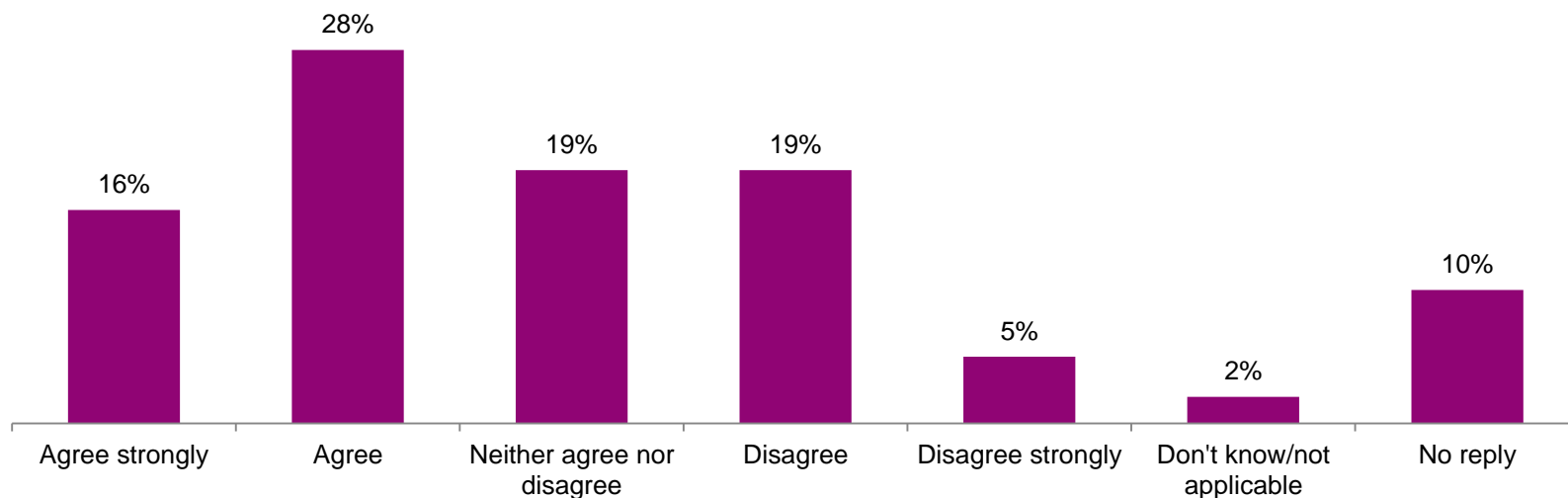
- 35% of respondents reported an increased number of GP visits.
- Carers of people aged 26-64 (40%) were more likely to agree with this statement.

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



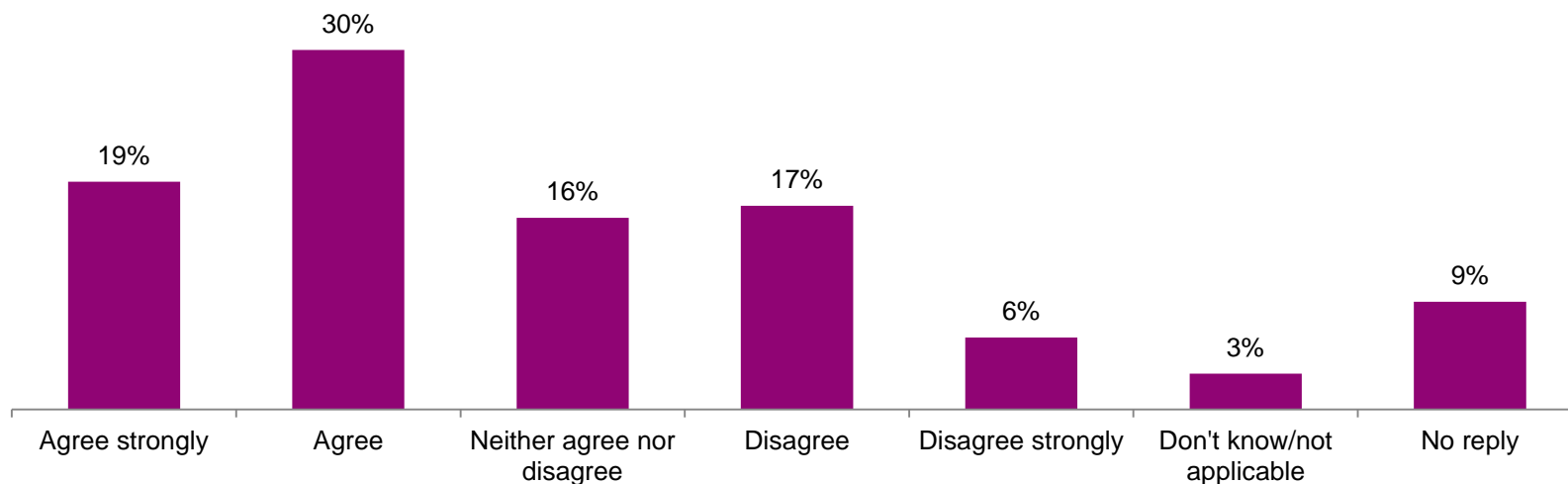
- 59% of respondents agreed that being a carer means they don't get enough sleep.
- The proportion of respondents agreeing with this statement is highest for carers of children (79%), carers of adults aged 16-25 (74%), and carers who have not engaged with VOCAL (72%).

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



- 44% 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 (70%), carers who have not engaged with VOCAL (60%), carers of adults aged 16-25 (59%) and carers who are not in paid employment, studying or receiving a pension (56%).

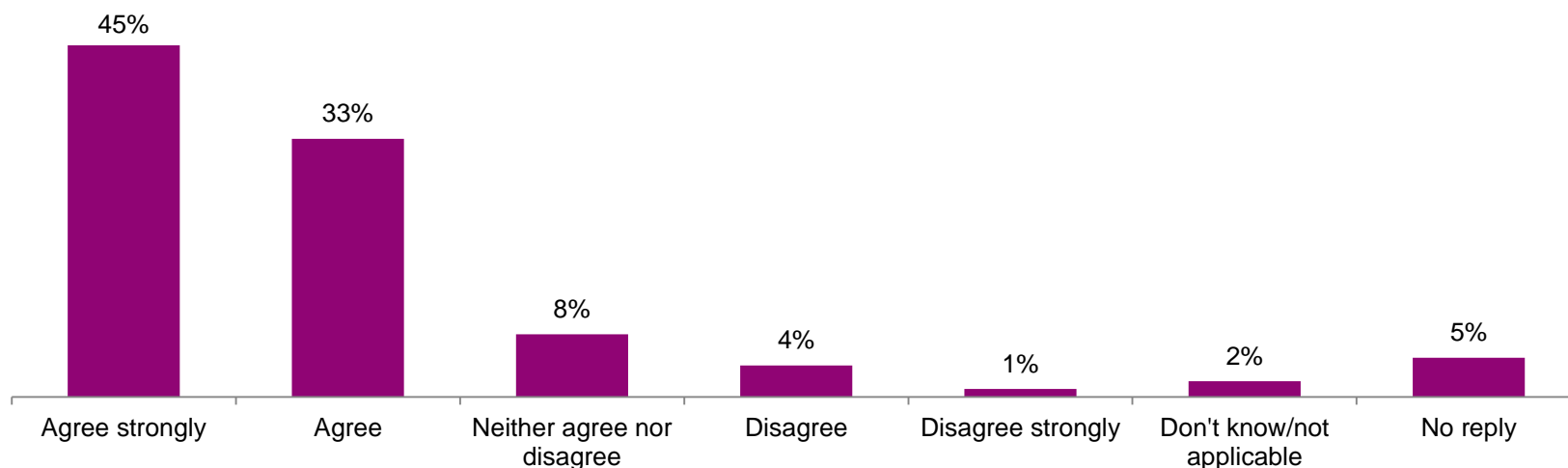
## Health and Wellbeing: “I have experienced depression since becoming a carer.”



- 49% of carers reported that they had experienced depression.
- The proportion of respondents agreeing with this statement is highest for carers of children (66%) and carers of adults aged 16-25 (62%).

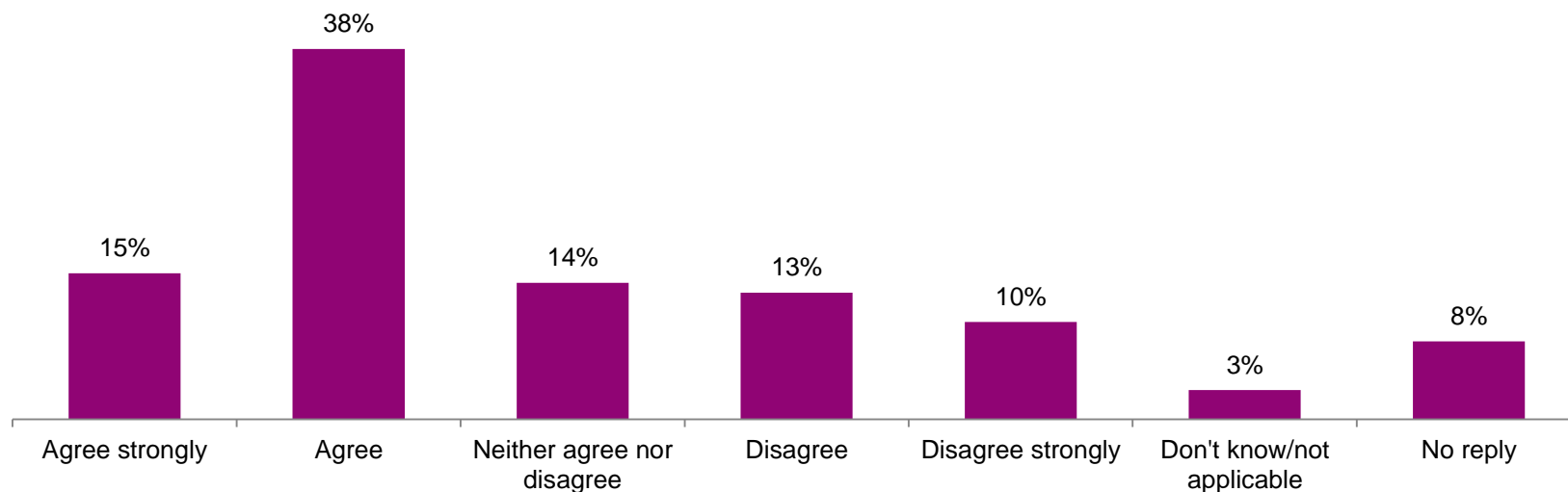


## Health and Wellbeing: “I worry about what will happen to the person I care for if I become ill.”



- 78% of respondents expressed concern about contingency planning.
- There were consistent levels of agreement with this statement across the sample, with notable peaks for carers of children (94%) and carers of adults aged 16-25 (90%)

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





- Just over half (53%) of respondents felt that they had someone to rely on for support.
- Respondents were less likely to agree with this statement if they were caring for someone aged 25-64 (45%) or had been caring for more than 5 years (48%).

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## Health Impacts – Additional Comments

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

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

-  *“I have had a nervous breakdown due to the stress along with with anxiety and depression and on top of this I have medical problems of my own. I do not get as much support as I need and feel like I am drowning.”*
  -  *“Sometimes the demands of caring mean that attending to my own health issues are compromised by the increasing demands of my caring role. This is also true of my husband, who delays attending to probable need for a knee replacement because he has concerns about how I would be able to support him in recovery whilst I am so extended in the care of my mother.”*
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## Health Impacts – Additional Comments

44 respondents reported that concerns over financial impacts were also affecting their health:

 *“I have not worked for the past fifteen years, and am concerned how this will impact on my financial security in later years.”*

25 respondents reported a loss of a sense of self:

 *“Where has my life gone? I have no time for my life too. I need to address this on so many levels.”*

23 highlighted concerns for the future:

 *“As my wife’s condition deteriorates, I often wonder if I will be able to cope with all the changes that will occur.”*

Other subjects, each mentioned by fewer than 20 respondents, were: feelings of guilt, anger or resentment (18), concerns about relationships with other family members (15), suggestions or requests for specific support (12); and the contribution to ill health made by having to deal with multiple agencies (10).

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## Health Impacts – Key Findings (1)

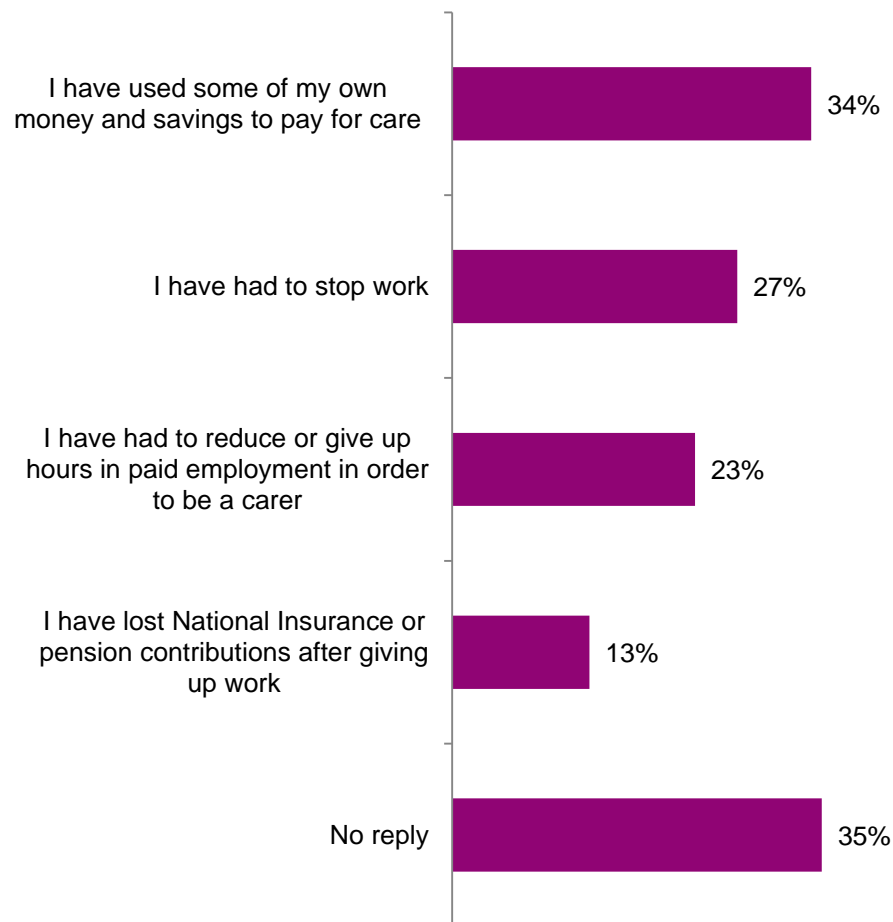
- 59% of carers in Edinburgh reported that caring has had a negative impact on their health.
  - The negative health impacts increased with the duration of care.
  - Over a third of carers reported negative health impacts for each of the areas identified. The most frequent issues were concerns about contingency planning if respondents are unable to care, and insufficient sleep.
  - This manifests itself in increased visits to the GP (35% of respondents) and experience of depression (49% 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 half of respondents felt that they had somebody to rely on for support.
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## Health Impacts – Key Findings (2)

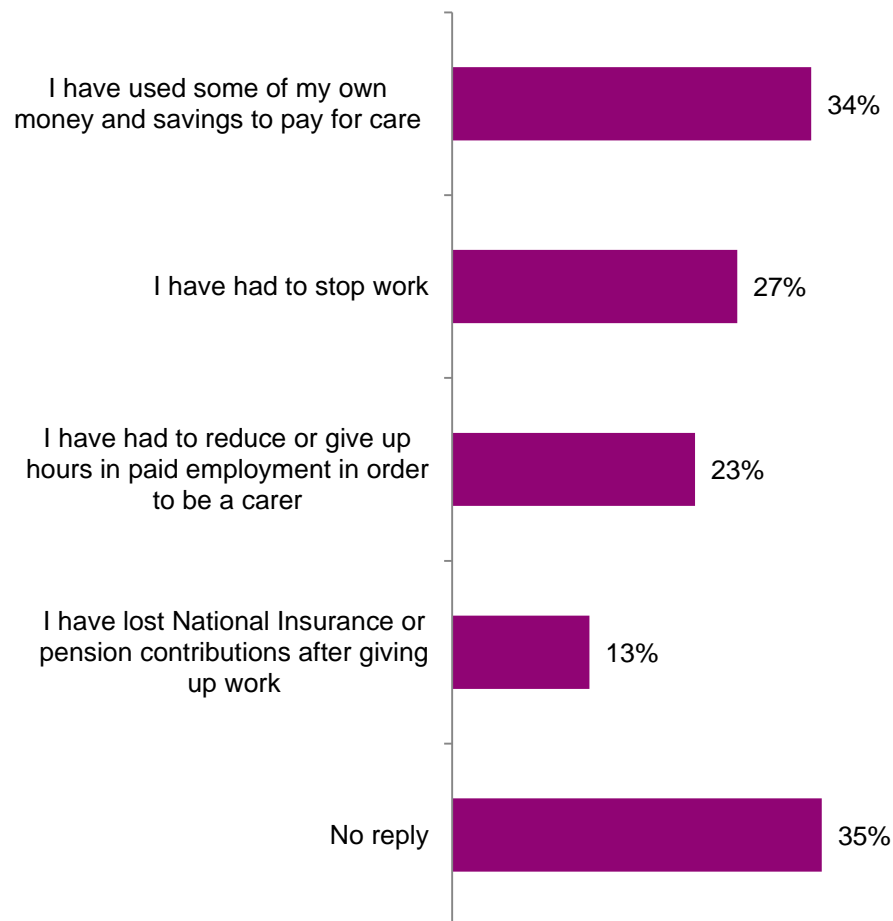
- Carers of children and of younger adults were particularly likely to identify a negative health impact as a result of caring.
  - There is some evidence (albeit with a small sample) that VOCAL can help to mitigate against some of these negative health impacts. Respondents who had not engaged with VOCAL services were more likely than the sample overall to agree that being a carer had made their health worse.
  - The open-ended comments made by carers underline the significant impact on carers' health, often exacerbated by money worries, a lack of time for self-care, and concerns about what will happen in the future.
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# Financial Impacts of Caring (1)



- A third of carers are financing care themselves.
- The proportion dipping into savings is higher for long term carers (38%), men (44%) and carers of children (44%).
- A quarter have had to stop working: the figure is higher for long-term carers (31%), carers of children (56%) and carers of people aged 16-25 (41%).
- Women are more likely to have had to stop work (28%) than men (22%).

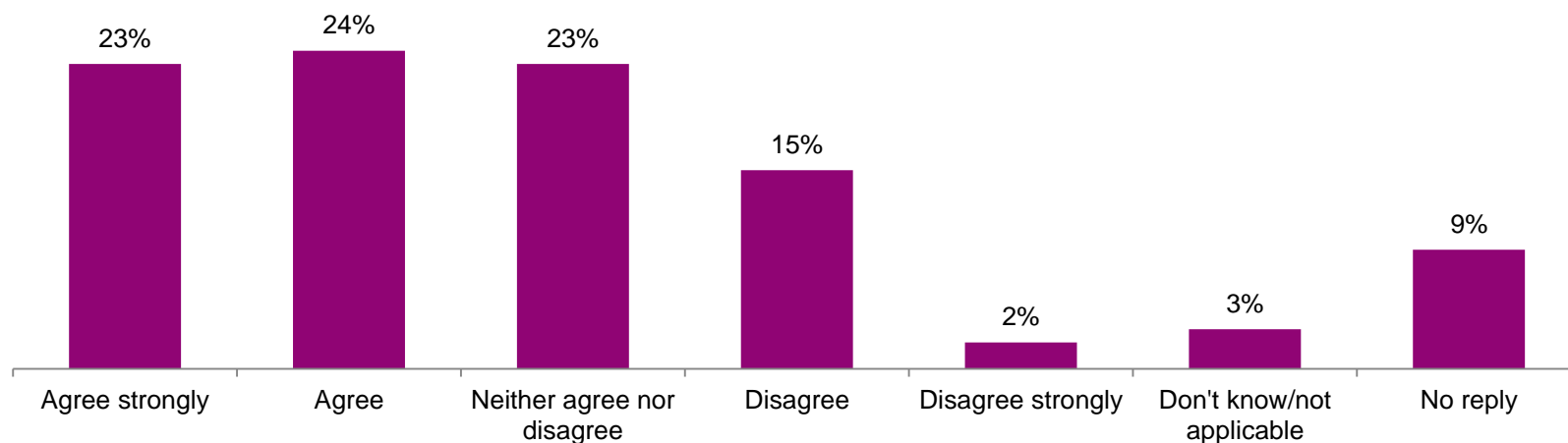
## Financial Impacts of Caring (2)



- 64% of those who do not receive a salary or a pension have had to stop work because of caring.
- A quarter of respondents have had to reduce their working hours: this is higher for respondents caring for children (39%) and caring for adults aged 16-25 (38%). It is more likely to affect women (25%) than men (18%).
- 13% of people have lost NI or pension contributions, illustrating the long term financial impact of caring.

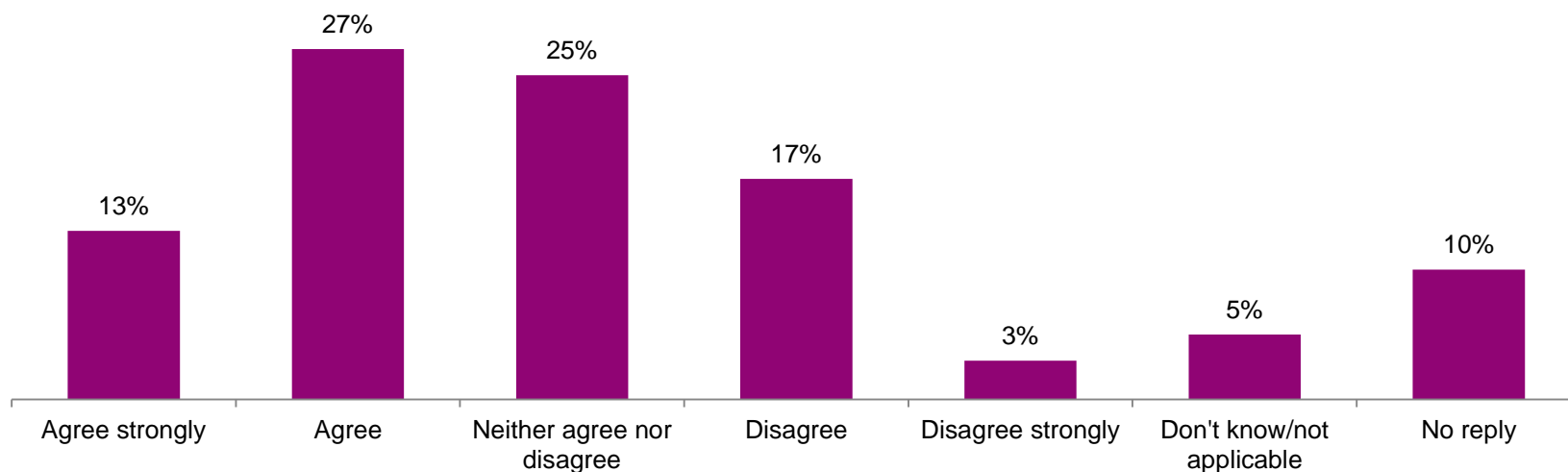


## Money and Work: “Being a carer has made money and finances more difficult.”



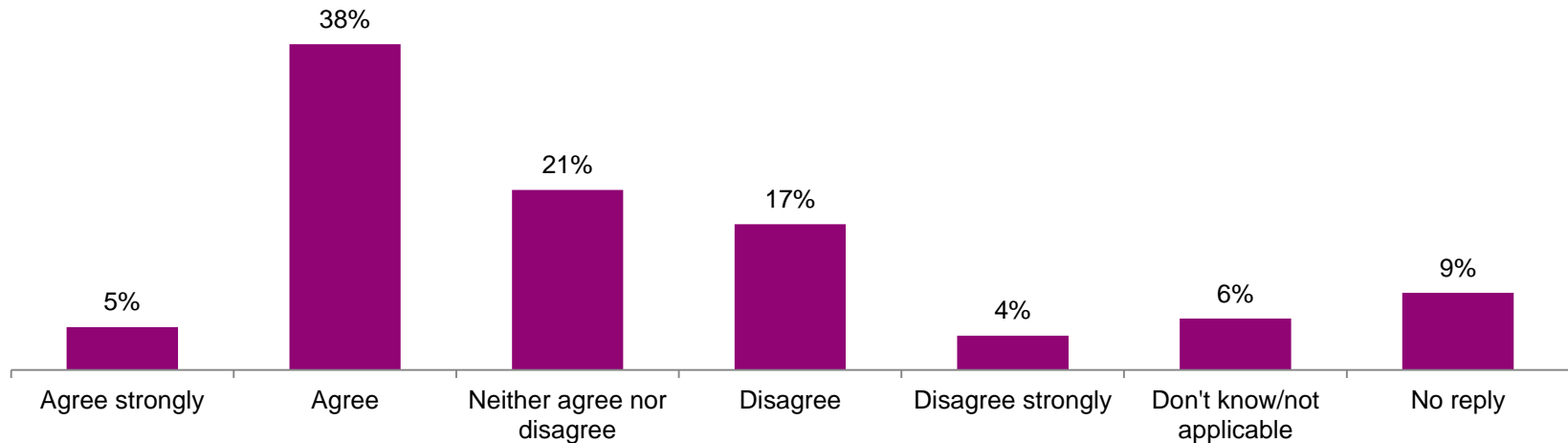
- 47% of respondents agreed with this statement.
- Cares of children (78%) and of adults aged 16-25 (77%) were most likely to agree with this statement, as were people who were not in receipt of a salary or a pension (72%).
- People who had not engaged with VOCAL were more likely to agree with this statement (57%) than those who had (note: small sample).

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



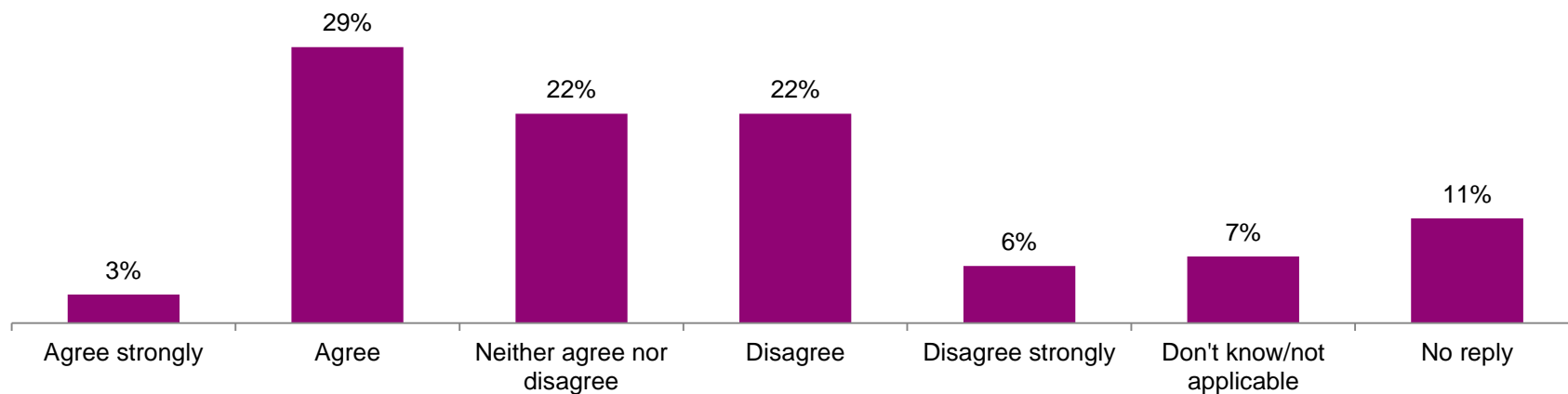
- 40% of respondents agreed with this statement.
- Respondents were more likely to agree with this statement if they were caring for children (65%), caring for adults aged 16-25 (58%) and were not in receipt of a salary or a pension (58%).
- There is clear evidence of stigma and emotional challenge associated with talking about the financial impact of caring.

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



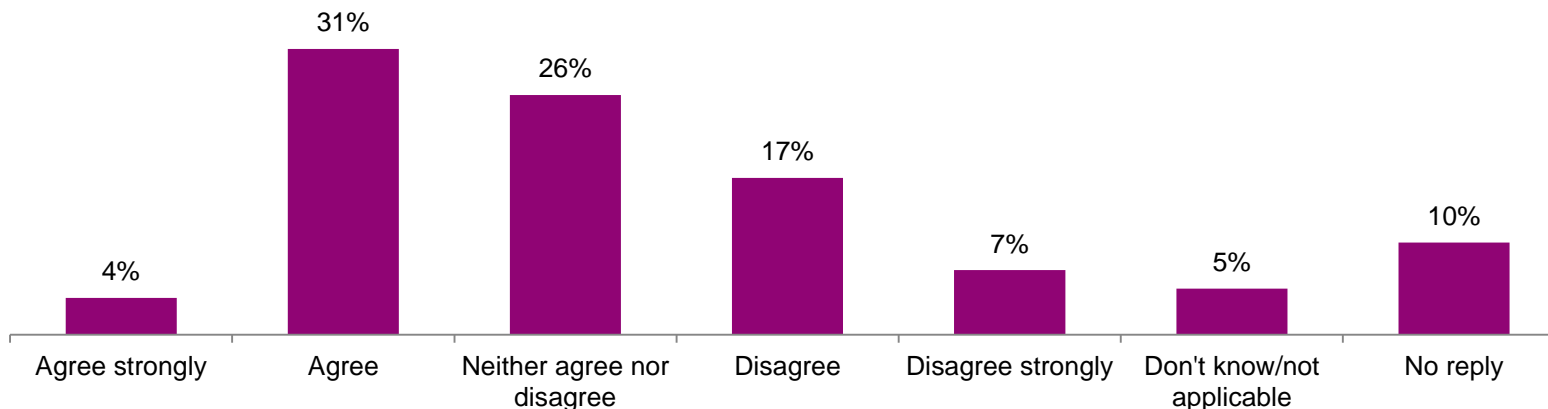
- 43% of respondents agreed with this statement, with only 5% agreeing strongly.
- Responses to this question were fairly consistent. Interestingly, respondents who had not engaged with VOCAL showed the lowest level of agreement with this statement (36%) (caution: small sample).

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



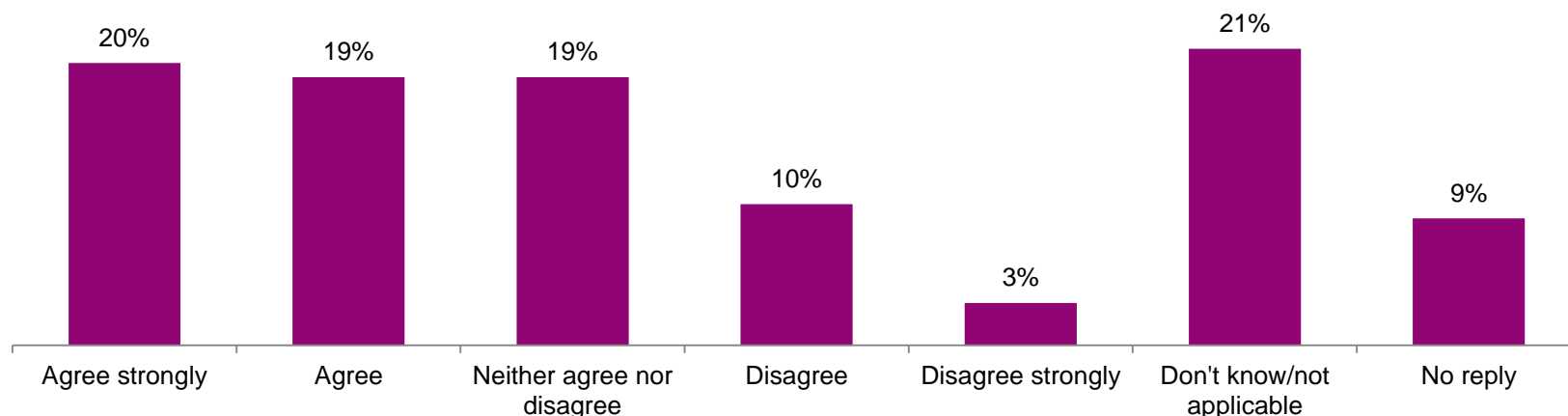
- Just 32% of respondents agreed with this statement, with only 3% agreeing strongly.
- Only a quarter of carers of adults aged 26-64 agreed with this statement, suggesting that there may be particular challenges associated with applying for support for this age group.

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



- Just 35% of respondents agreed with this statement, with 4% agreeing strongly.
- Respondents caring for adults aged 25-64 (27%) and respondents not in receipt of a salary or a pension (25%) were less likely to agree with this statement.
- Respondents who have not engaged with VOCAL were also less likely to agree with this statement (24%) (caution: small sample).

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



- Nearly 40% of respondents agreed with this statement, with a fifth agreeing strongly.
- Unsurprisingly perhaps, concern over paying for care homes increases with age. 49% of respondents caring for somebody over the age of 75 agreed with this statement, compared with just 11% of carers looking after children.


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## Money and Work– Additional Comments (1)


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


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

 *“You have to watch every penny. It’s harder in the winter with the extra heating.”*

 *“I no longer have the freedom and peace of mind to know that all my bills are paid and up to date. I have had to use food banks on many occasions.”*

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

 *“Being a carer killed my career, severely reduced my earnings and therefore my pension.”*



 *“Having to stop work because of my responsibilities has been humiliating and debilitating.”*

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## Money and Work– Additional Comments (2)

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

-  *“Don’t see why Carers’ Allowance should stop when I get state pension – I don’t stop caring and it does become harder as you get older.”*
-  *“I care for my 19 year old stepson four or five nights a week and receive none of his PIP nor have access to his disability car or parking pass or anything.”*

Other subjects (each mentioned by fewer than 20 respondents) were: the impact of caring on future financial planning (12), concerns over care home fees (10), a feeling that the benefits system should recognise the value of carers (9) the impact on pensions of giving up work (7), and difficulties in dealing with the dynamics of family finances (5).

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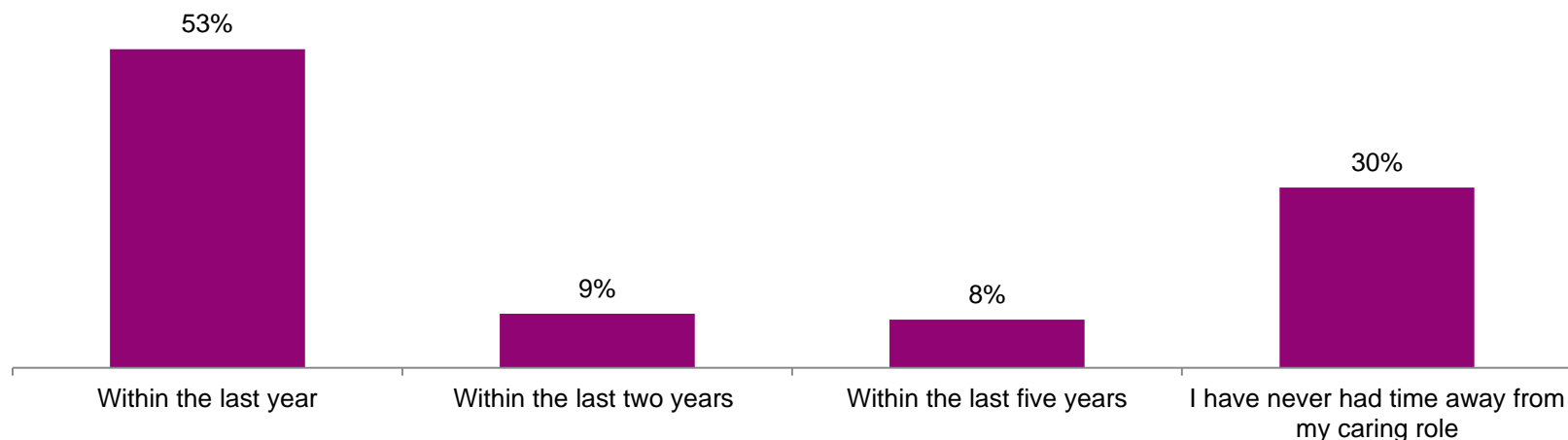
## Impact on Money and Work– Key Findings (1)

- 47% 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 further quarter have had to give up work altogether. 12% 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) 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.
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## Impact on Money and Work– Key Findings (2)

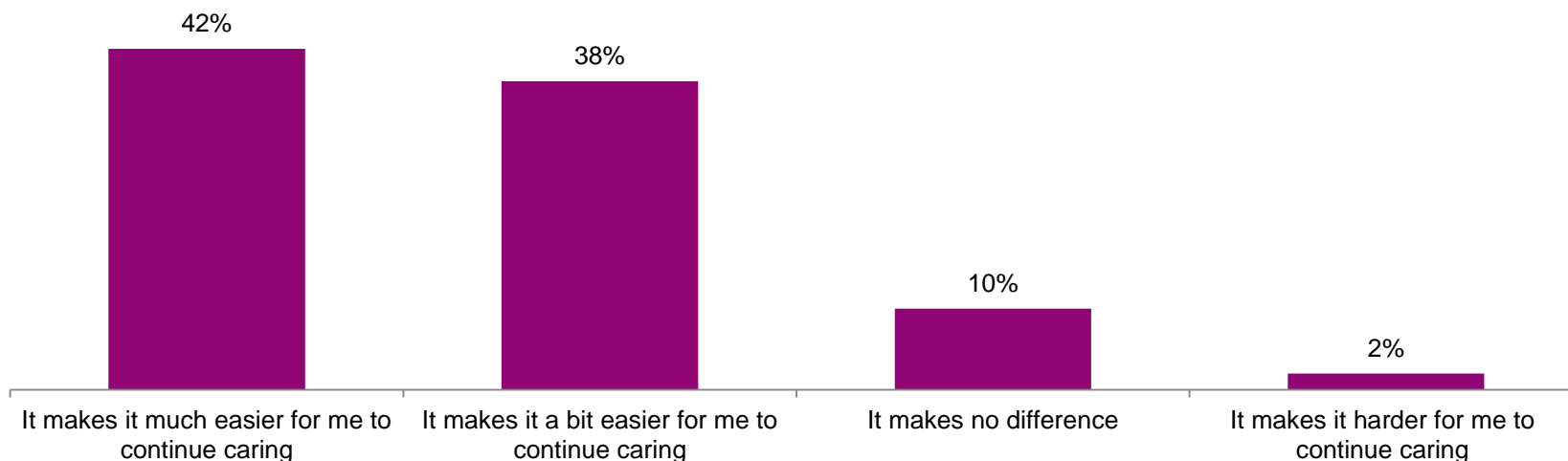
- 43% of respondents felt that they knew what financial support was available, with a third saying that they felt confident in applying for it and a similar proportion agreeing that it was sufficient. VOCAL should therefore continue to provide information to raise awareness, support carers in making applications, and lobby to ensure that the funding levels are fair. Carers of adults aged 25-64 might be a particular target here.
  - Paying for care homes is a key concern for carers of adults over the age of 75, who comprise approximately half of this sample.
  - There is some evidence (with the caveat of a 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 over half of carers felt that they had time away from caring in the past year.
- Nearly a third of carers had never had time away. This rises to 42% for carers aged 75+.
- 29% of long term carers, who have been caring for more than five years, said that they had never had time away from caring.

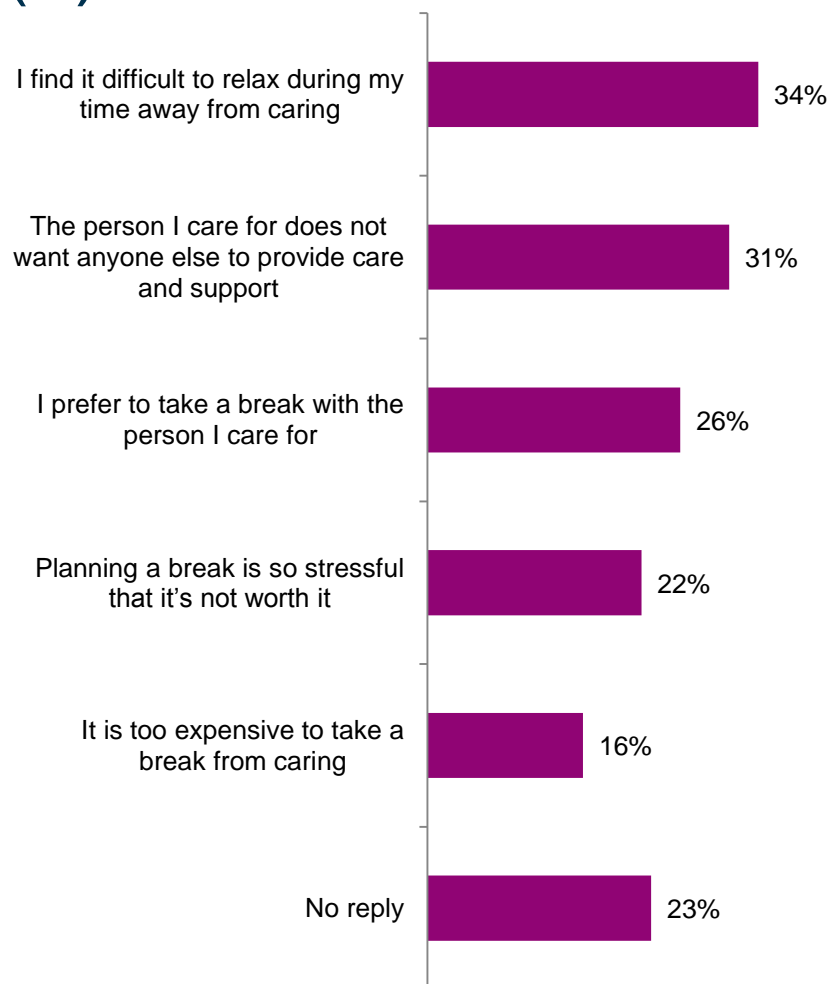
## Time away: Impact on Caring



Base: all those who have ever had time away from caring (641)

- 80% of respondents who have taken time away from caring said that it helps them to continue in their caring role. 42% 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.

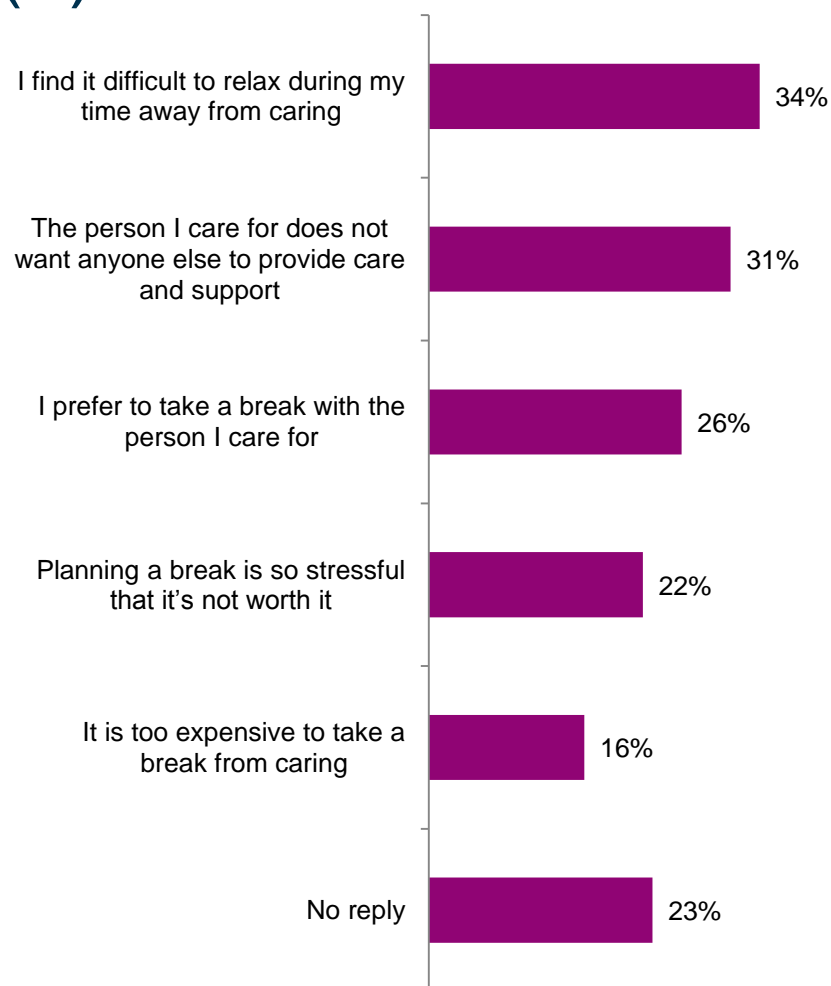
# Time away: Carer Experiences and Opinions (1)



- A third of carers reported that they find it hard to relax during their time away from caring. This increases to 42% for carers of children.
- A similar proportion felt that the person they cared for did not want anyone else to step in.
- Carers of children (40%) and male carers (34%) were most likely to want to take a break with the person 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 16% of respondents, rising for carers of children (32%), carers of young adults aged 16-25 (35%), and respondents not in receipt of a salary or pension (29%).



## Time Away: Additional Comments (1)

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

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

-  *“Crucial, without this I could not keep going. Only discover how burnt out I am when I get away.”*
-  *“It is good for everyone to get a break. The carer and the cared for.”*

The remaining comments generally reflected barriers to effective time away. 68 respondents talked about the mental strain of being away:

-  *“When you’re not caring you’re reacting, worrying or planning. It’s like being deployed to a war zone and someone suggesting you take time out for a spa.”*
-  *“I feel guilty that I can at least go out and have short breaks but my daughter’s ill health stops her from taking part in life.”*

## Time Away: Additional Comments (2)


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

 *“There is no one else who could care for him.”*

27 respondents said that the person they care for does not want them to have time away.

 *“I am constantly trying to get a decent break but am being stymied by my partner’s refusal to go into care even for a very short period.”*

25 respondents commented on the financial cost of getting time away.

 *“I think it’s more about finances. If I can pay someone to look after my daughter I could do a day or two away to relax.”*

21 respondents said that they wanted to go away with the person they care for:

 *“A break is essential but my partner and I can’t go away together.”*

13 respondents said that they did not want to leave the person they cared for.

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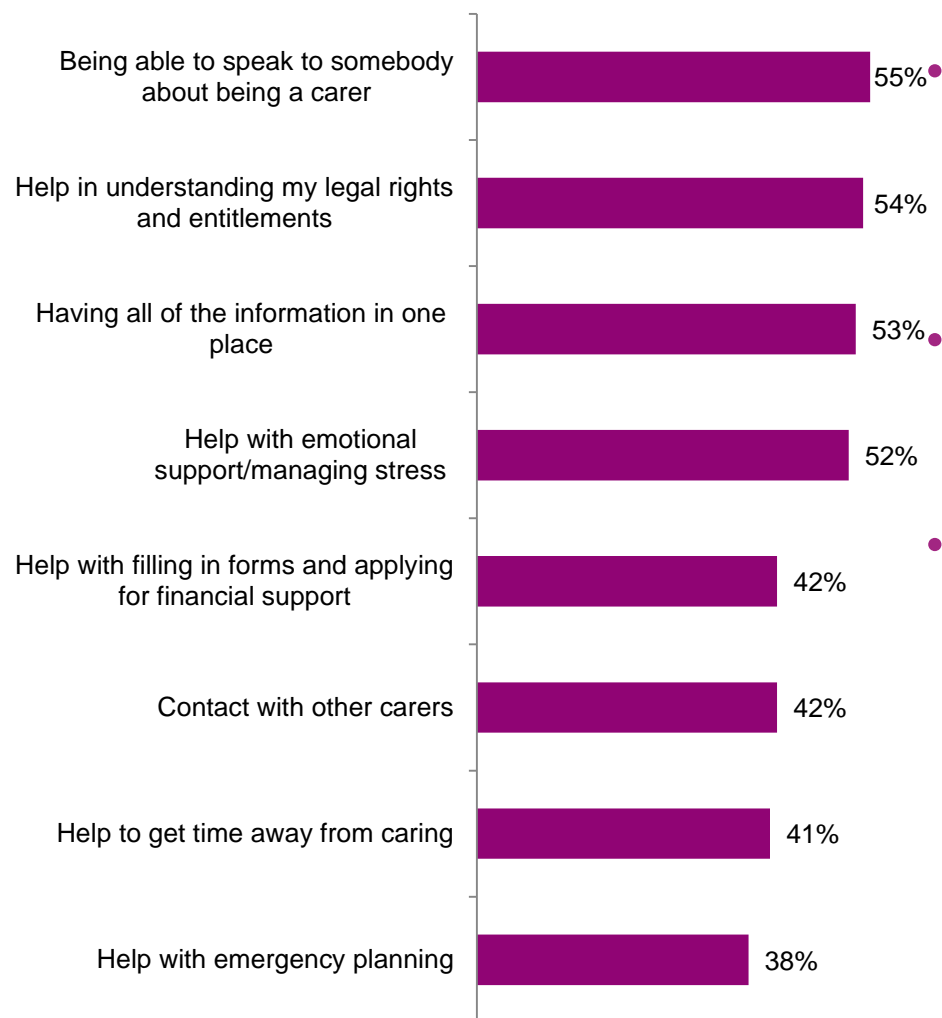


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## Time Away: Key Findings

- Only half of carers in Edinburgh say that they have had time away from caring in the past year. A third say that they have never had time away at all.
  - Time away from caring can have a positive impact on carers. 80% 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. Carers of children are more likely to want to take a break with the person they care for.
  - The findings suggest that effective support for the carer and the person they care for is essential for beneficial time away.
-

# Interest in Potential Services from VOCAL



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

The order of preference is broadly the same across all user groups.

- Respondents not engaged with VOCAL are more interested in legal rights (76%), having all the information in one place (67%) and help with emergency planning (52%) – these could be useful “hooks” to engage new users.

# 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 generally a higher level of interest in online services from carers who are of working age and in employment.
- 29% 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. Again, this might be an opportunity to engage new users.
- “Other” suggestions were specific to the caring situation but there was some demand for training in how to access online resources.

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# Future Support: Leith

Respondents were asked for their opinions on VOCAL's new facility in Leith

214 responses were received, containing 32 suggestions! Of note:

- 48 people said to keep it the same as the current offer
    -  *“Continued support and advice. Keep up the great work!”*
  - 23 asked for dedicated parking.
  - 20 suggested a café.
  - 17 suggested drop-in sessions and 8 suggested providing support outside office hours.
  - 15 asked for more general purpose and flexible space – with an emphasis on it being bright and welcoming.
  - Note that 13 respondents said they didn't like the new location: a migration communications strategy is likely to be required.
-

## 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.
  - 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.
  - Edinburgh carers would like to see “more of the same” at Leith, but with improved access and greater flexibility.
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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 (e.g. households on low incomes).
  - Develop Leith as a flexible space with good access and opportunities for social interaction.
-

## 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.
-

# SCOTINFORM

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