

The impact of providing unpaid care at home

November 2022

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Introduction

Healthwatch in Devon, Plymouth, and Torbay is the independent consumer champion for health and social care services, ensuring the voice of the community is used to influence and improve services for local people.

Nearly 85,000 people in Devon provide unpaid care, with one third (33.4%) providing more than 20 hours of unpaid care per week. To learn more about the experiences of unpaid carers and the impact of providing care at home, Healthwatch developed a survey in conjunction with Devon Carers, Improving Lives Plymouth, and the Torbay Carers Service. These organisations provide a range of support services to unpaid carers.

Methodology

A survey of 11 multiple-choice and four open-ended questions was used to ask unpaid carers about adaptations to their home, the impact of caring on their physical and mental health, and their use of support services. Additionally, four optional questions were used to collect demographic information.

121 people answered the survey. 115 left postcode data and these break down as:

Devon – 49 respondents

Plymouth – 39 respondents

Torbay – 27 respondents

The survey was circulated via Healthwatch social media pages (Facebook, Twitter, and Instagram) and email newsletters, Devon Carers, Improving Lives Plymouth, and the Torbay Carers Service. Reach and engagement figures for the Healthwatch social media are available in the Appendix.

Key findings

The following key findings have been identified from the overall responses.

- 60% of respondents answered “yes” to the question “do you feel you work from home?” 26% answered “somewhat,” and 14% answered “no.”
- 55% of respondents said they felt their health and safety was at risk due to their caring duties, 25% felt it was “somewhat” at risk, and 20% felt it was not at risk.
- 69% of respondents said their caring responsibilities “frequently” or “always” affect their ability to relax at home, and 52% of respondents said their caring duties “frequently” or “always” limited their ability to leave the house.
- 72% of respondents said their physical health had been worse since becoming a carer and 30% said it had been “about the same.” 84% of respondents said their mental health had been worse and 16% said it had been “about the same.” No respondents said their physical or mental health had improved.
- 50% of respondents said they had not accessed any physical or mental health support services. 33% said they had accessed mental health support and 16% said they had accessed physical health support.
- When asked how they would like to find out information about support services, the top three answers were Devon Carers (52%), nhs.uk (41%), and social media (31%).

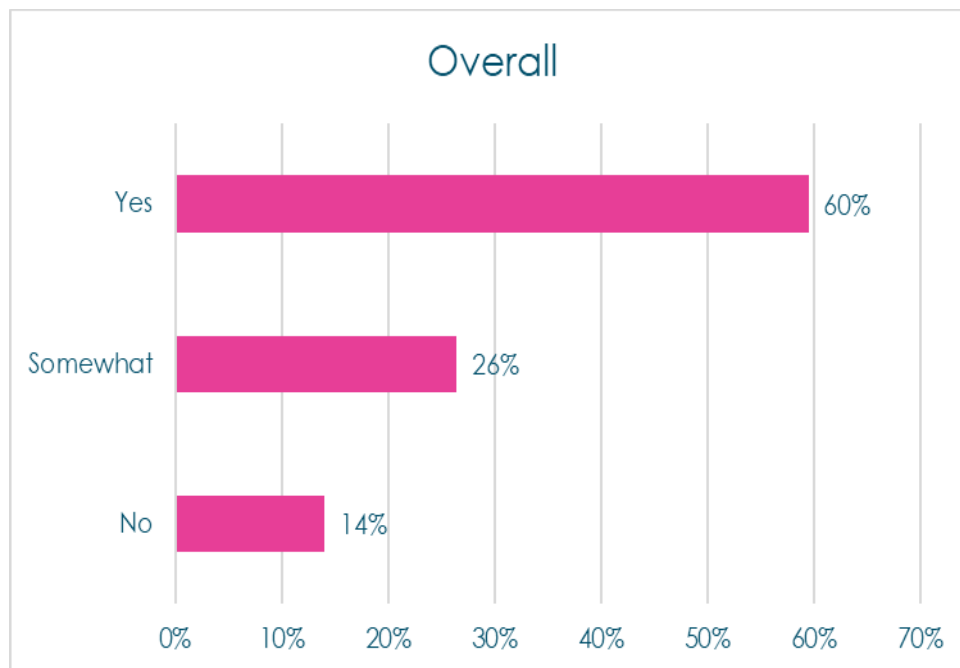
Detailed findings

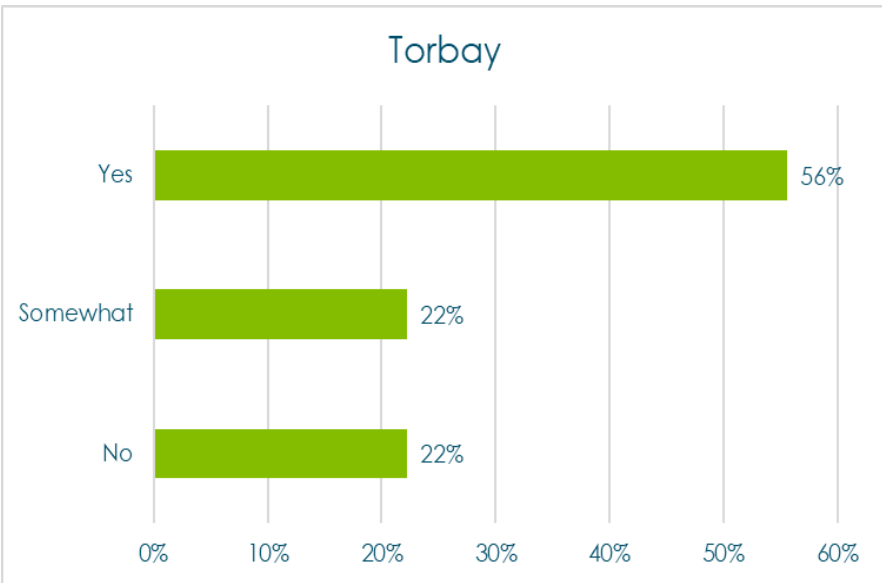
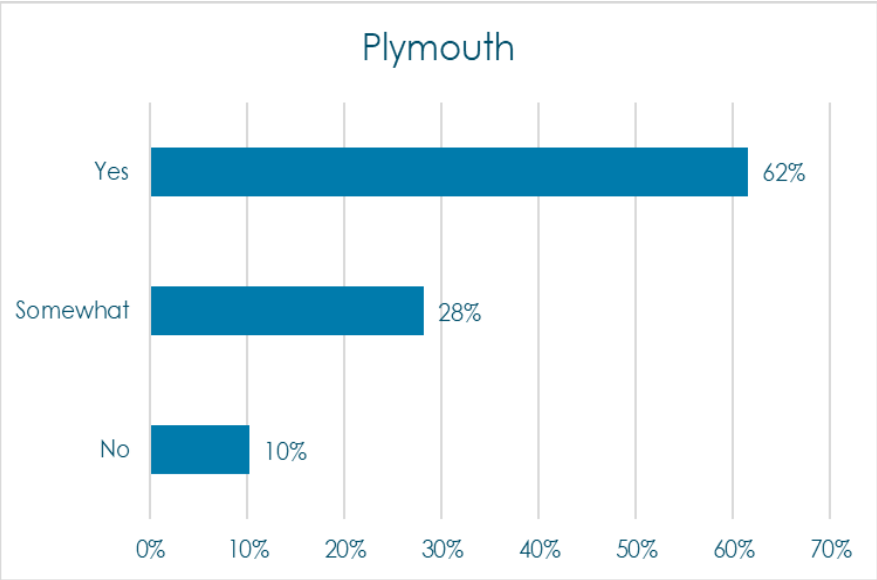
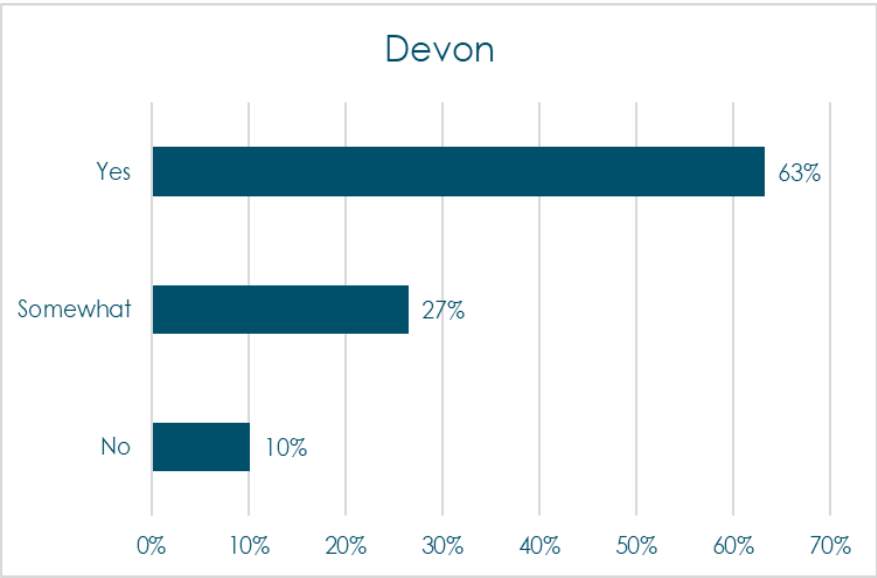
Note: Overall charts in this section contain all survey responses. Local Authority area charts contain responses from those who left postcode information.

Question 1. As a home carer, do you feel you “work” from home?

All 121 respondents answered this question. 60% of respondents (72 people) said yes, 26% (32 people) said “somewhat”, and 14% (17 people) said no.

The areas for Devon & Plymouth followed the overall trend while respondents in Torbay didn’t consider that they worked from home as much as those in Devon and Plymouth.

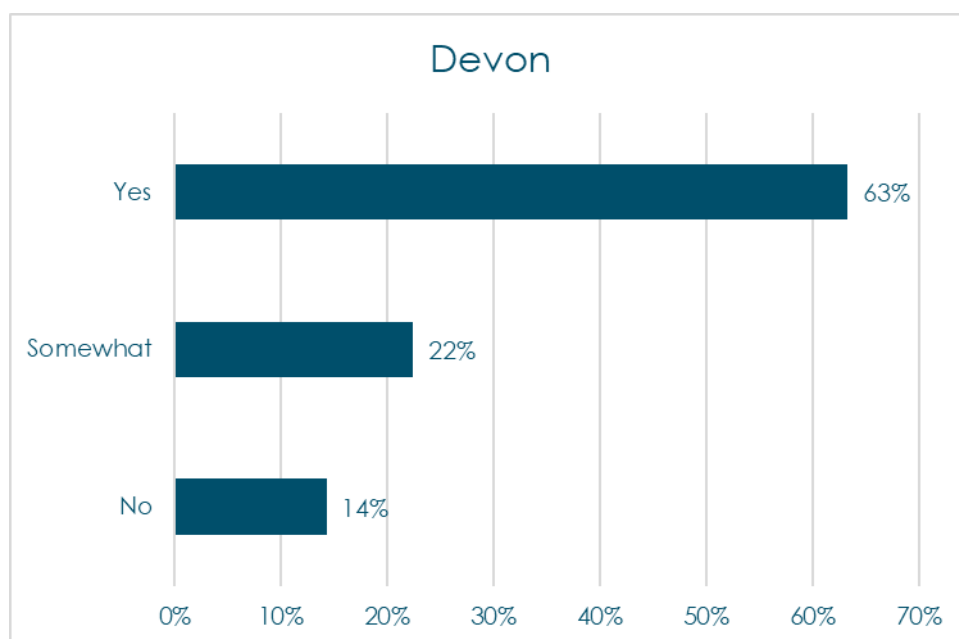
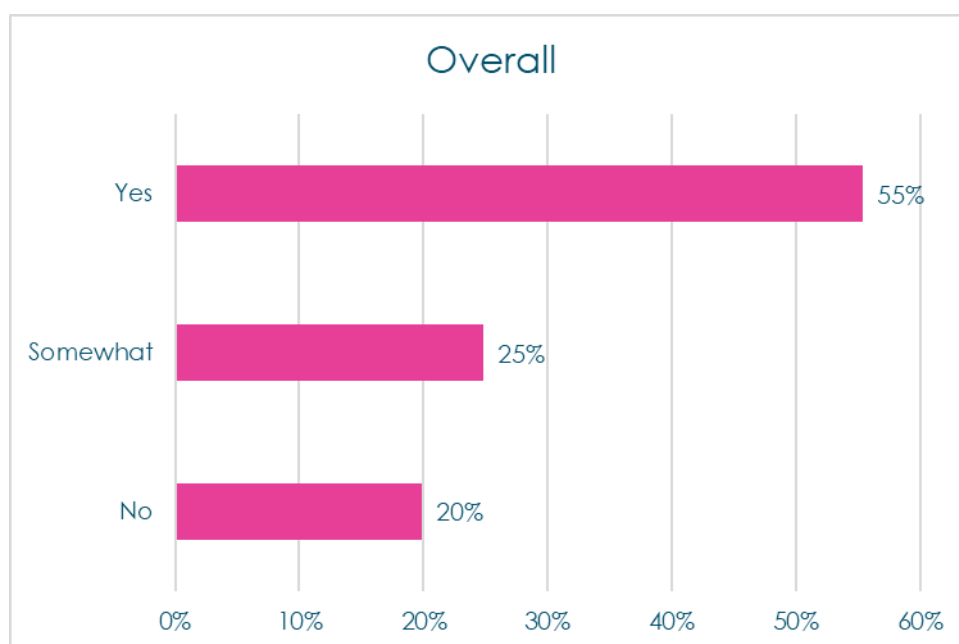


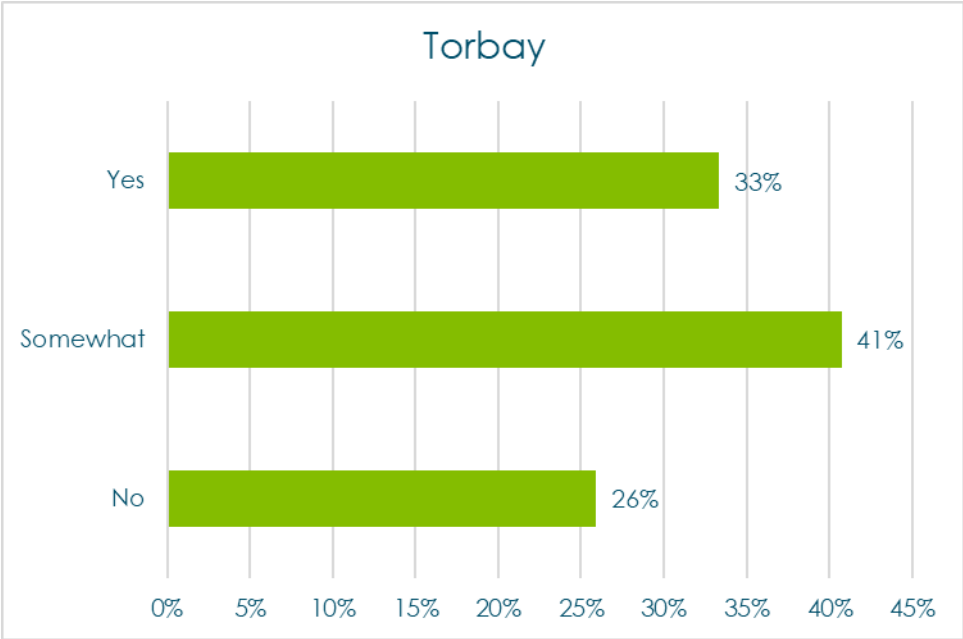
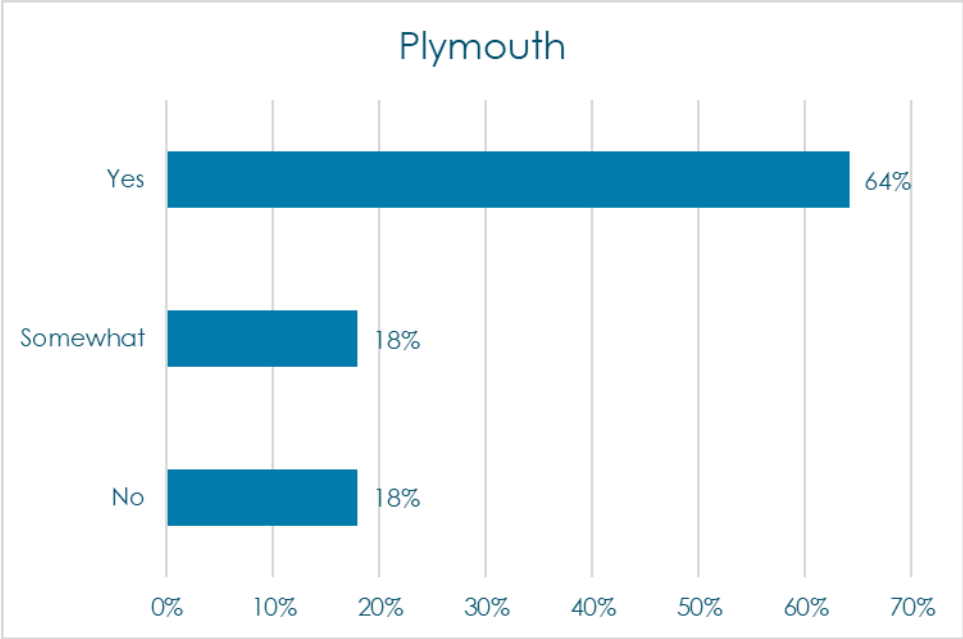


Question 2. Do you feel your health and safety is at risk due to your caring duties? (e.g. manual handling, stress, the behaviour of your cared-for person)

All 121 respondents answered this question. 55% of respondents (68 people) said yes, 24% of respondents (30 people) said somewhat, and 20% (24 people) said no.

Carers from Torbay considered it a smaller risk to their health and safety when compared to those in Devon and Plymouth.





Question 3. If you answered yes to the previous question, please explain.

76 respondents answered this question and 45 did not, though some respondents gave answers that were unclear or not applicable, respondents were able to provide more than a single answer. 37 respondents mentioned the mental impact of caring, particularly stress. 21 respondents mentioned the physical impact of caring, including tiredness and injuries caused by lifting the cared-for person. 18 respondents said they struggled to balance their caring responsibilities with other aspects of their personal life, with some saying they had no time for themselves. 13 respondents mentioned the behaviour of their cared-for person, including aggression and abusive behaviour. 18 respondents complained of difficulties accessing support services.

Stress and mental health impact (37)

- “The stress is causing me severe anxiety and depression.” (Devon)
- “My stress levels have caused me to come under the crisis mental health team.” (Plymouth)

Exhaustion and physical health impact (21)

- “[I have] back issues and I worry I will injure myself caring for my father.” (Devon)
- “It is constant physical work which leads to stress on the body and leads to a constant feeling of tiredness and pain.” (Torbay)

Balance (18)

- “[I am] often unable to leave my home for exercise or [to] meet friends. [...] No rest, no break, only holidays which include the person I care for.” Area unknown
- “It’s very stressful to have this permanent tie when other parts of my life are also trying to get dealt with.” (Torbay)

Behaviour of cared-for person (13)

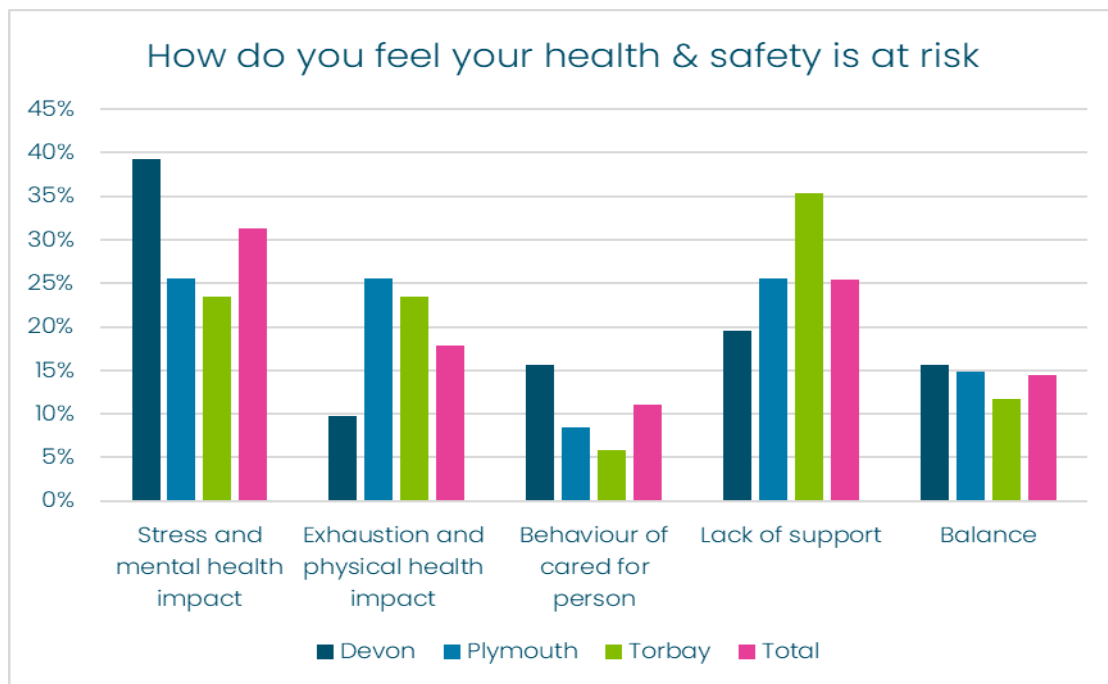
- “My [cared-for person] is developing mental health issues [...] his behaviour is verbally abusive and verges on unacceptable behaviour on occasions, which are becoming more frequent.” (Devon)

- “My [cared-for person’s] mood swings are beyond bearable and have affected our children. I’ve been diagnosed with PTSD.” (Plymouth)

Lack of support (18)

- “Carers are expected to do the job of professionals without the training or skills.” (Torbay)
- “We are left to cope with every arising situation with little or no practical support unless we fight for it.” (Devon)

The chart below illustrates both overall responses and a breakdown by Local Authority area to the main themes derived from the commentary in response to Q3. Overall, ‘Stress and mental health impact’ and ‘lack of support’ were the 2 main themes.

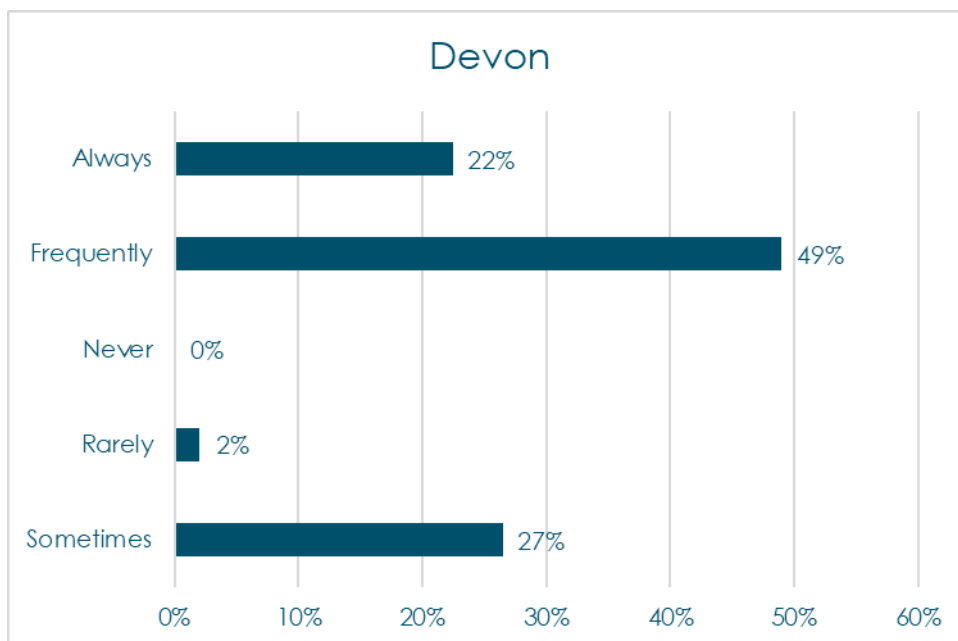
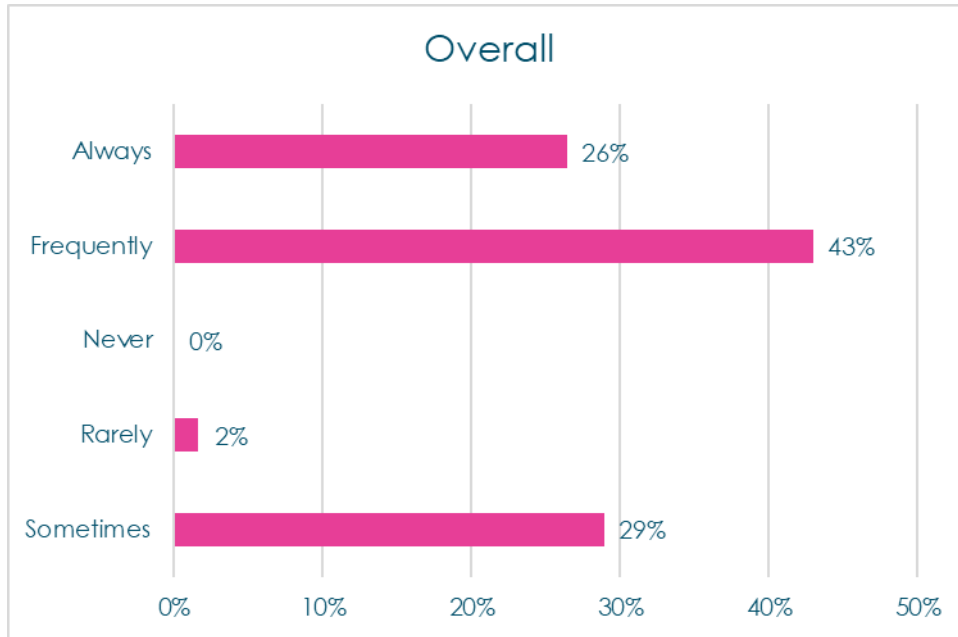


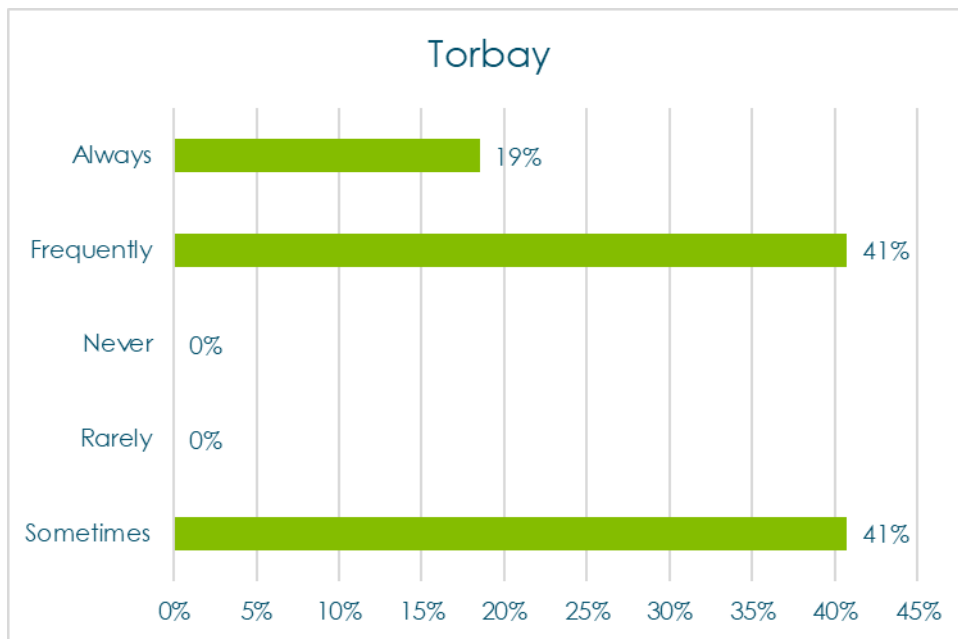
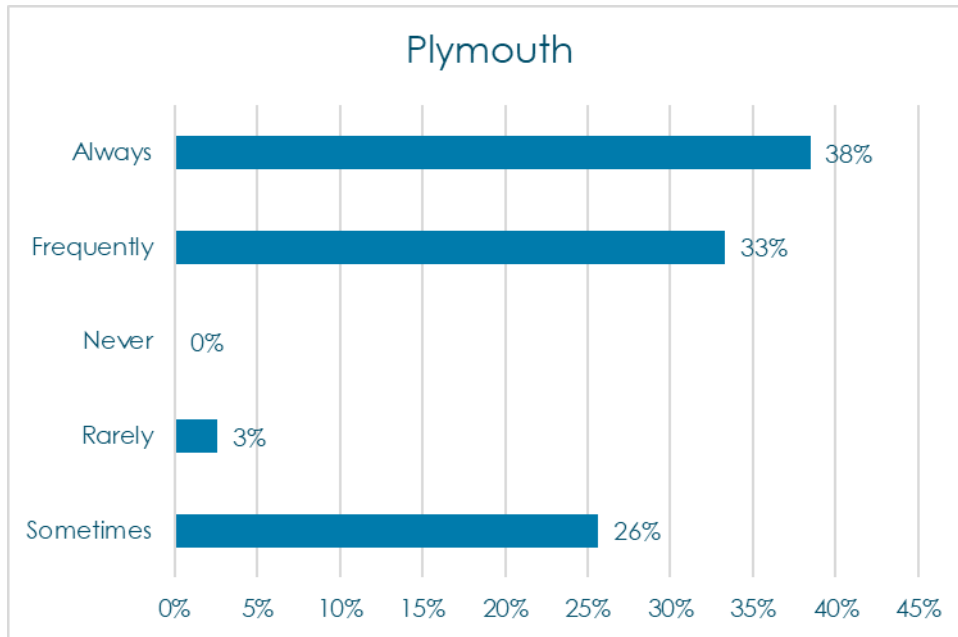
When analysing the data by Local Authority area, unpaid carers in Devon felt that ‘**stress and mental health impact**’ had the biggest risk to their health and safety, whereas those in Torbay considered that it was the ‘**lack of support**’ whilst those from the Plymouth area said that they considered ‘**stress and mental health**’, ‘**exhaustion and physical health impact**’ and ‘**lack of support**’ in equal measures had the biggest impact to their health and safety.

Question 4. Do your caring responsibilities affect your ability to relax at home?

All 121 respondents answered this question. 26% of respondents (32 people) said “always,” 43% (52 people) said “frequently,” 29% (35 people) said “sometimes,” 1.65% (two people) said “rarely,” and none of the respondents said “never.”

The respondents from Devon and Plymouth felt that there was a greater impact on their ability to relax at home than those from Torbay.





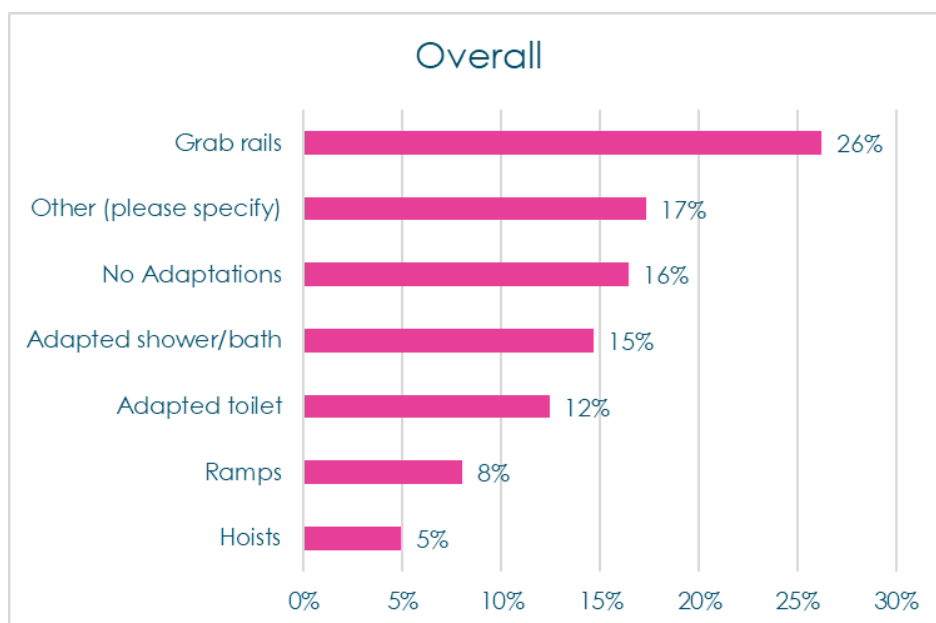
Question 5. Does your home have any of the following adaptations or equipment? Select all that apply.

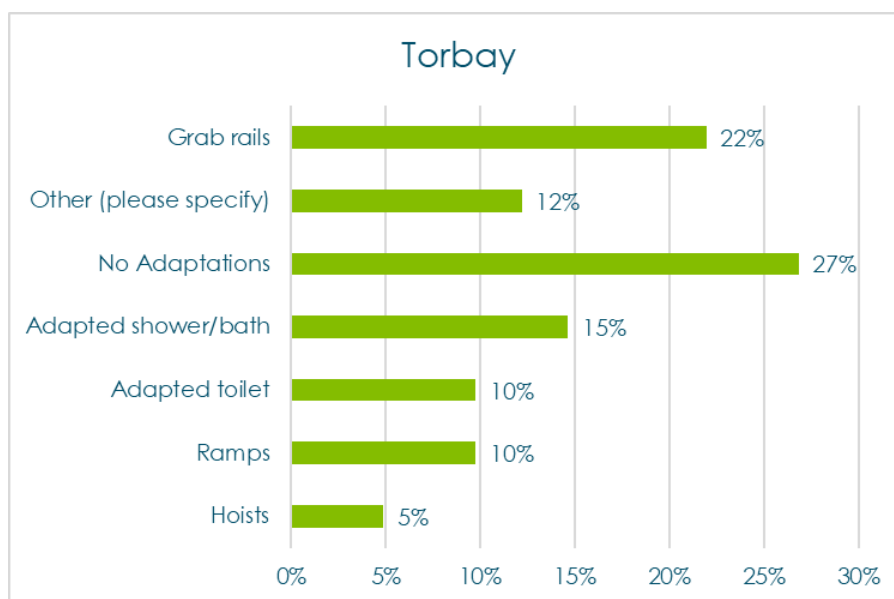
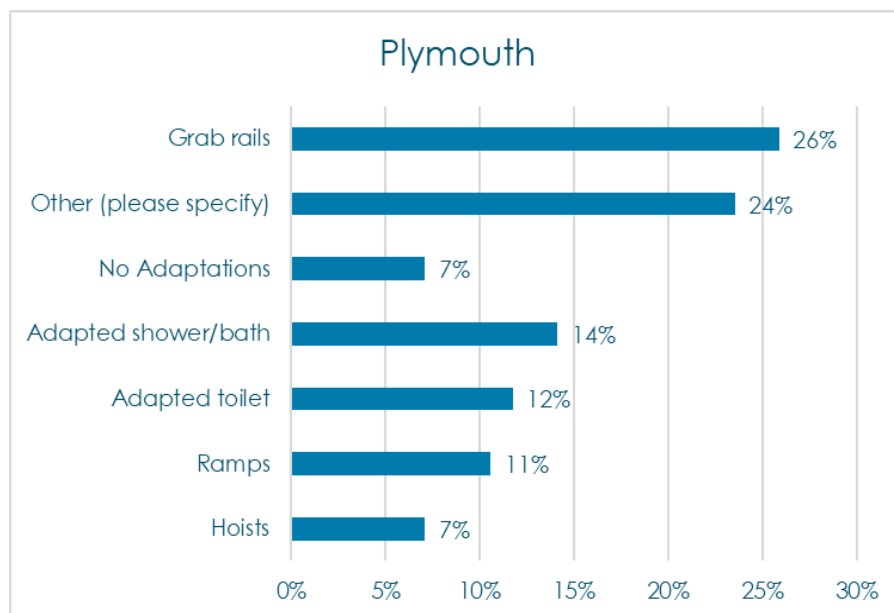
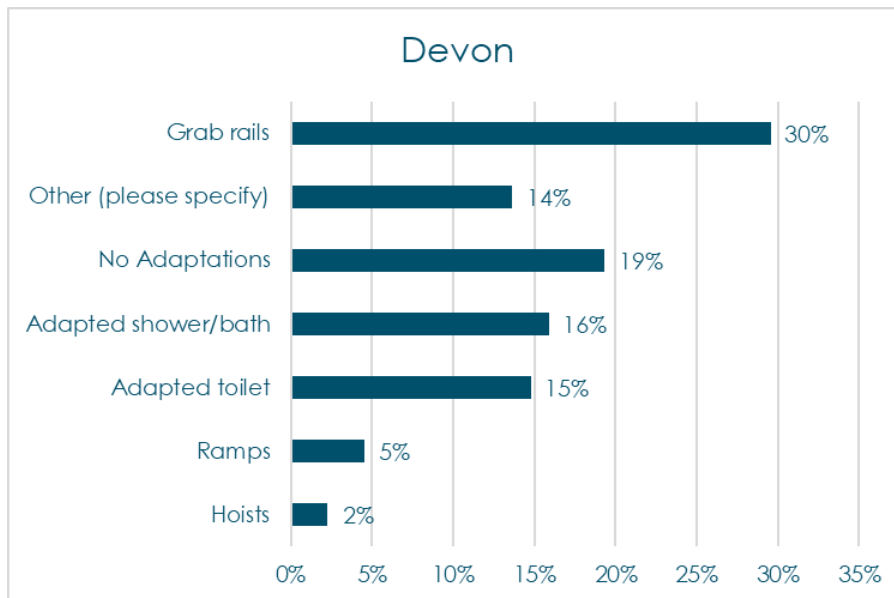
117 respondents answered this question, and four did not. As respondents could select more than one answer, percentages may total more than 100. 32% of respondents (37 people) had no adaptations or equipment at home. 50% of respondents (59 people) had grab rails, 28% (33 people) had an adapted shower or bath, 24% (28 people) had an adapted toilet, 15% (18 people) had ramps, and 9% (11 people) had hoists.

33% (39 people) selected "other." These responses included:

- Lifts and stairlifts (16)
- Not applicable/unclear (13)
- Adapted beds or seating (11)
- Steps (2)

When looking across the three Local Authority areas, the installation of grab rails is the most common adaptation followed by those adaptations not listed in the survey such as lifts and stairlifts. It's interesting to note the differences across the three regions, especially that 27% of the respondents from Torbay didn't have any adaptations to their homes.

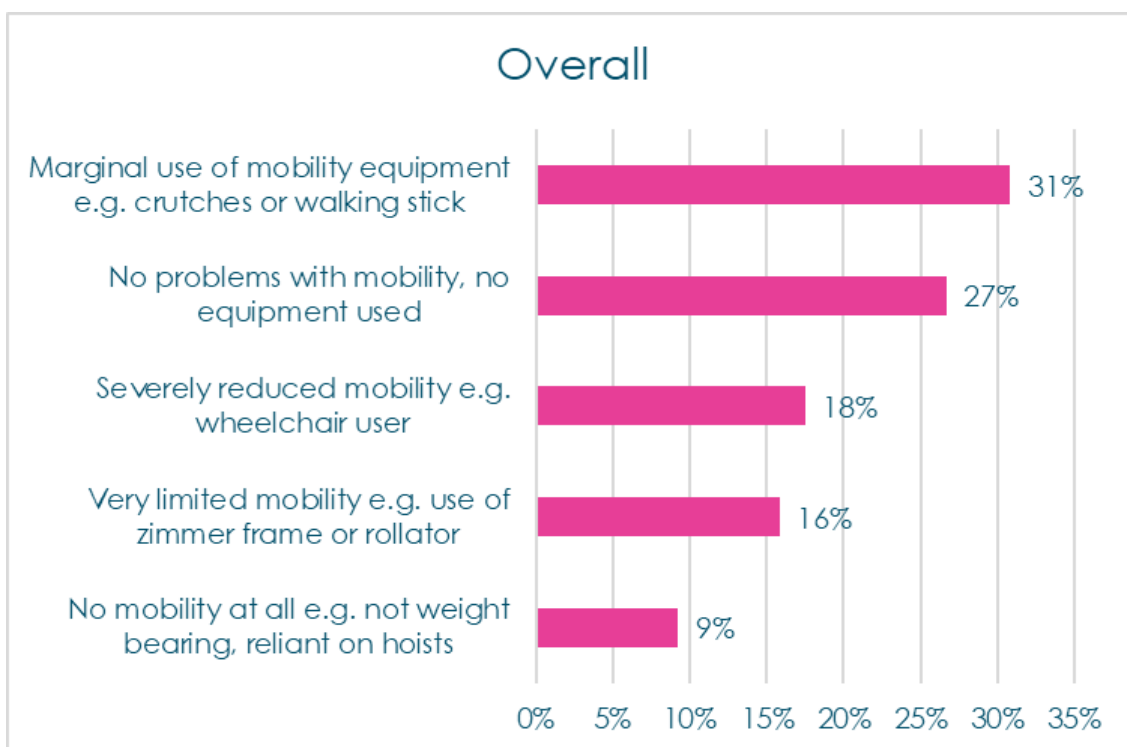


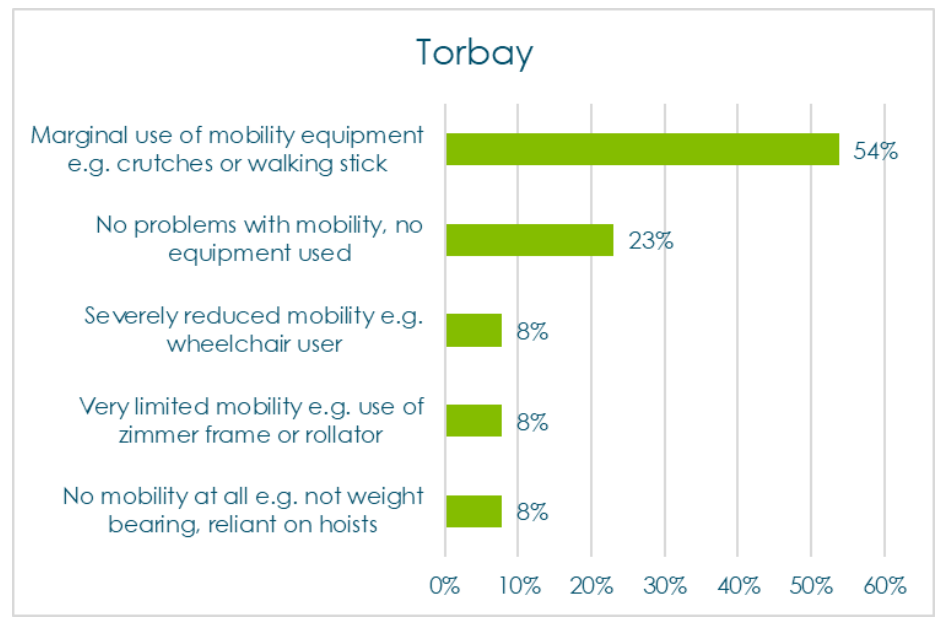
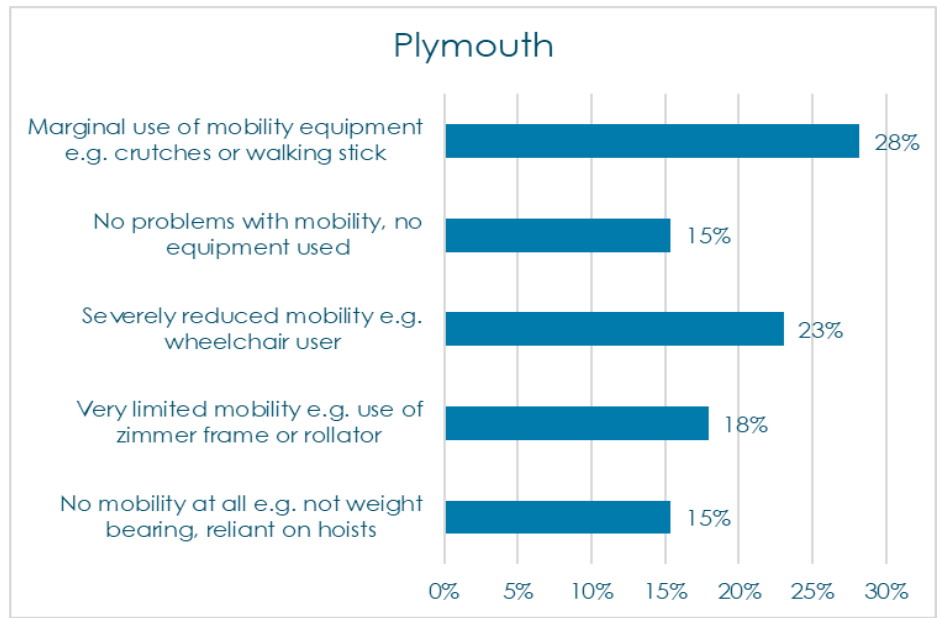
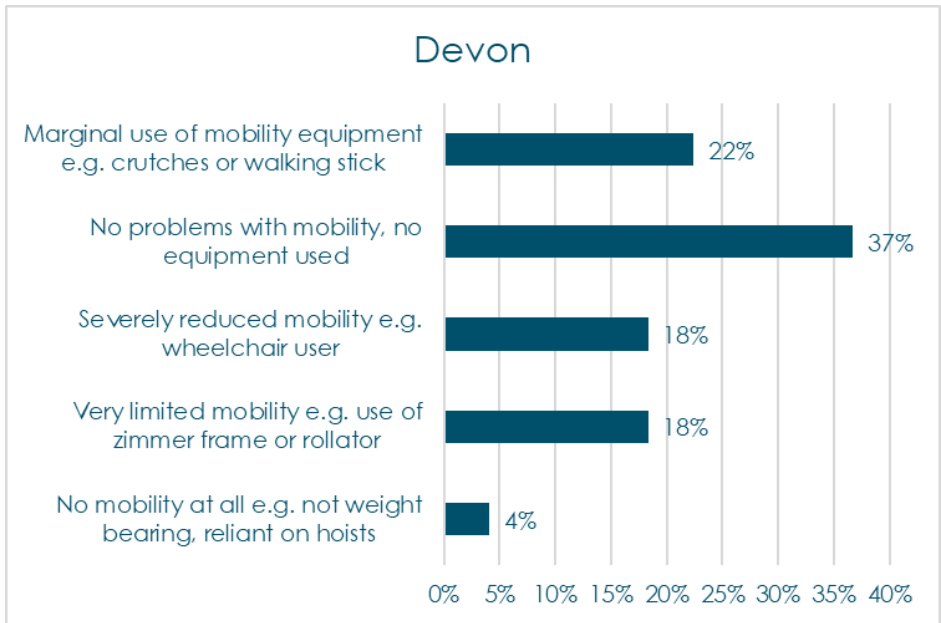


Question 6. Which of the following best describes the mobility of the person you care for?

120 respondents answered this question, and one did not. 27% of respondents (32 people) said their cared-for person had no mobility problems and did not use equipment, 31% (37 people) said their cared-for person required marginal use of mobility equipment, 15.83% (19 people) said their cared-for person had very limited mobility, 18% (21 people) said their cared-for person had severely reduced mobility, and 9% (11 people) said their cared-for person had no mobility at all.

When comparing the three Local Authority areas, Devon had the greater proportion of respondents reporting good mobility while Torbay had the most reporting a marginal use of mobility aids and Plymouth reported that 28% of the respondents required 'marginal use of mobility equipment e.g., crutches or walking stick'.

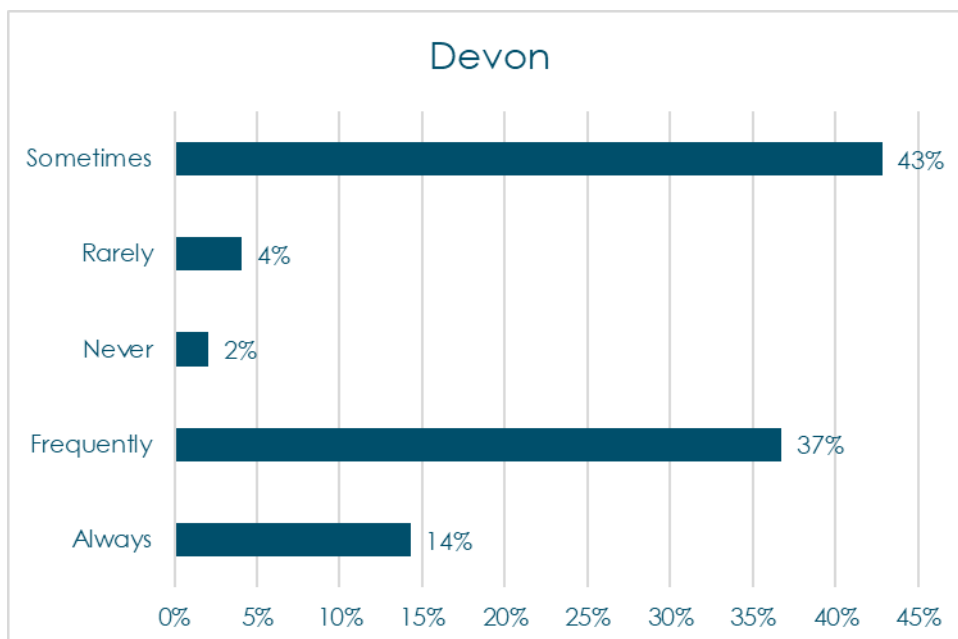
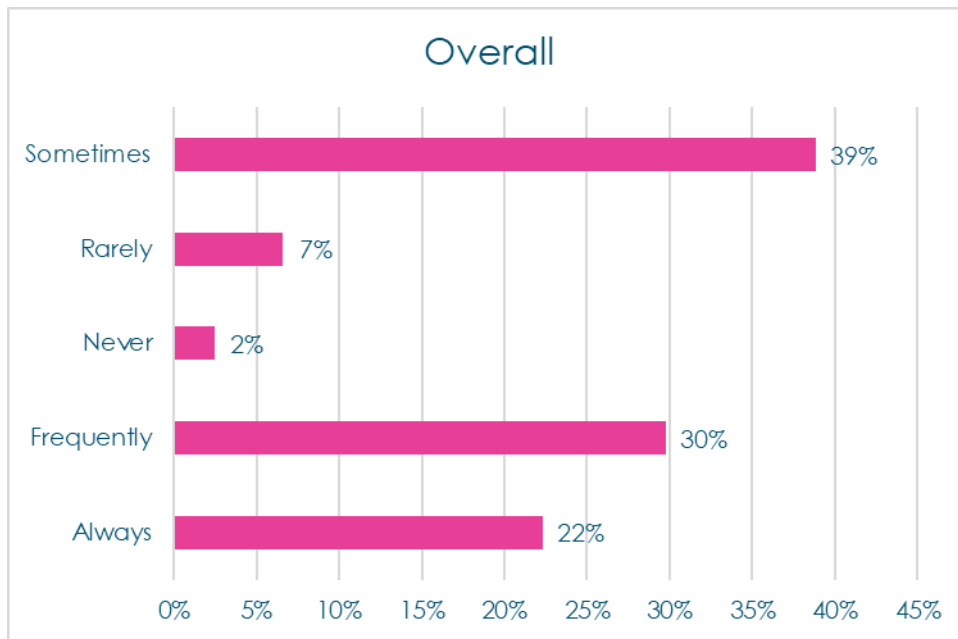


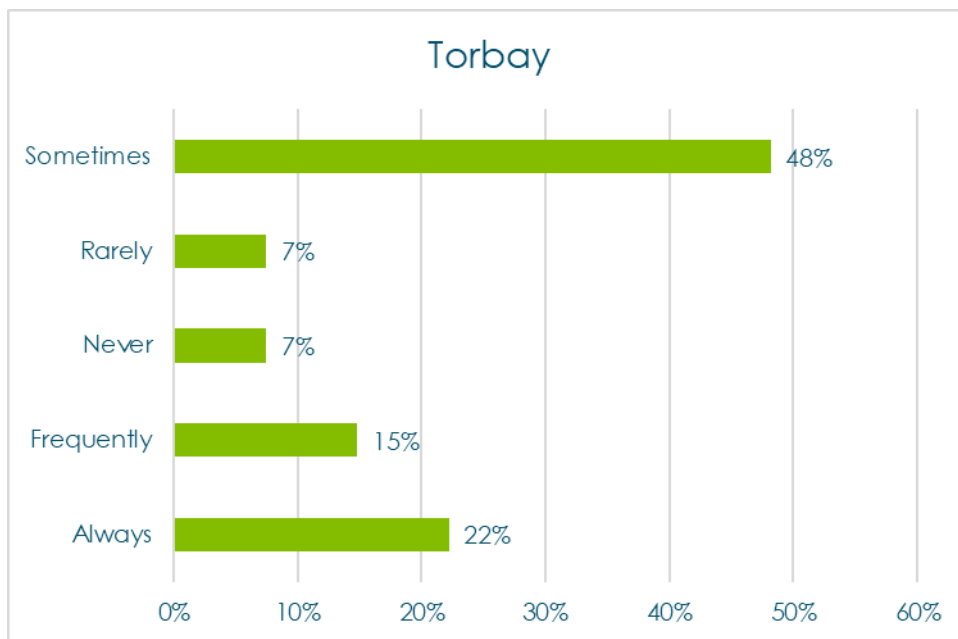
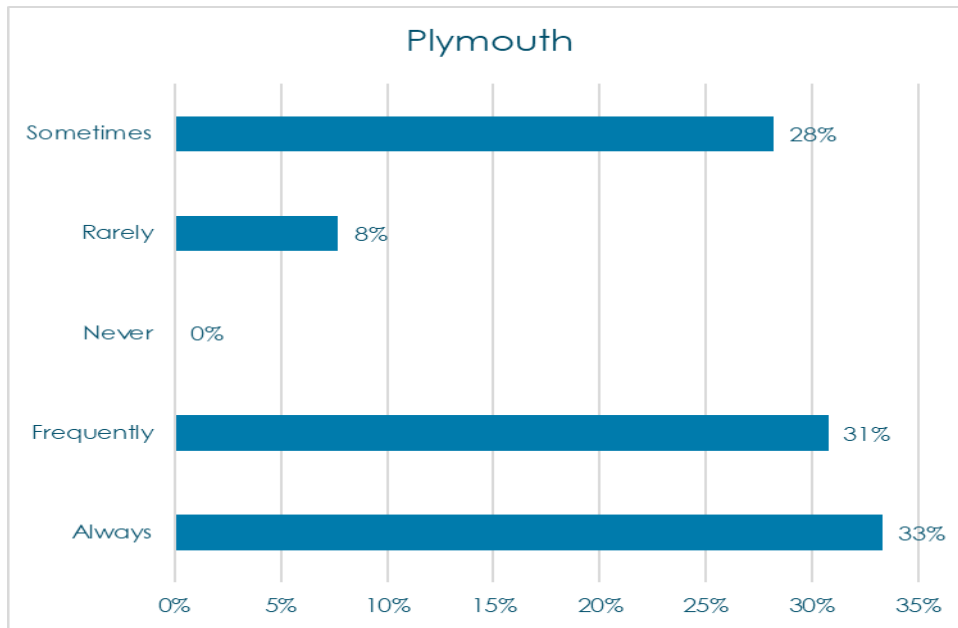


Question 7. Are you limited in your ability to leave the house due to your caring duties?

All 121 respondents answered this question. 22% of respondents (27 people) said “always,” 30% (36 people) said “frequently,” 39% (47 people) said “sometimes,” 6% (eight people) said “rarely,” and 2% (three people) said “never.”

When considering the responses by Local Authority area those in Torbay felt less restricted due to their caring responsibilities, whereas those in the Plymouth area felt the most restricted.

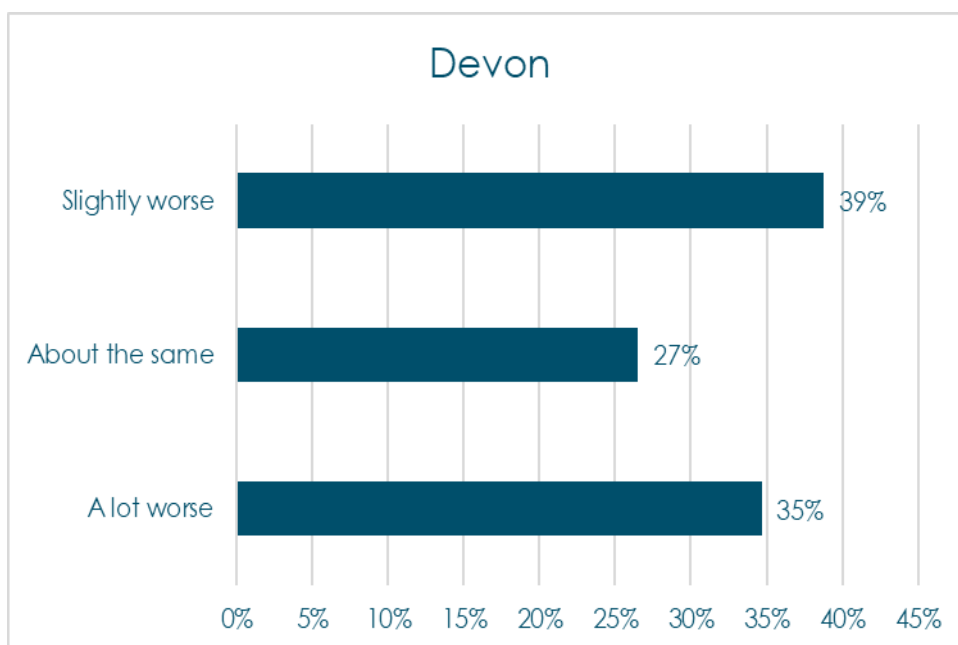
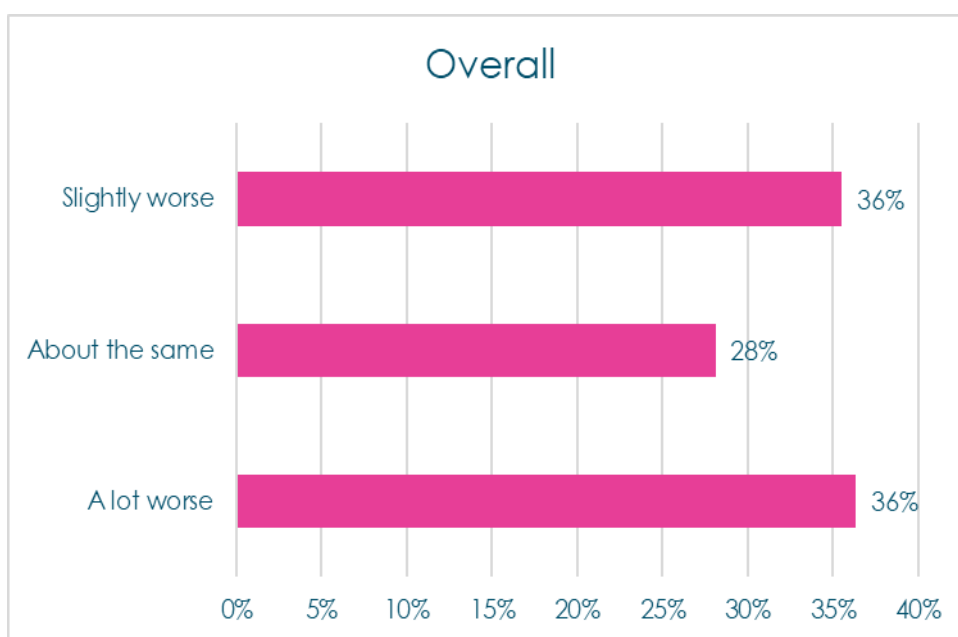


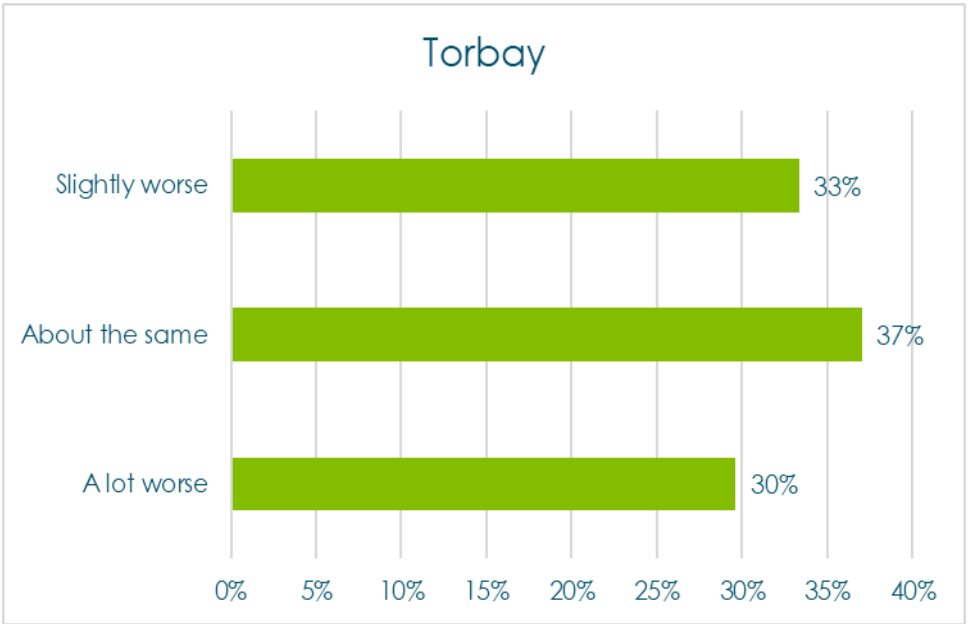
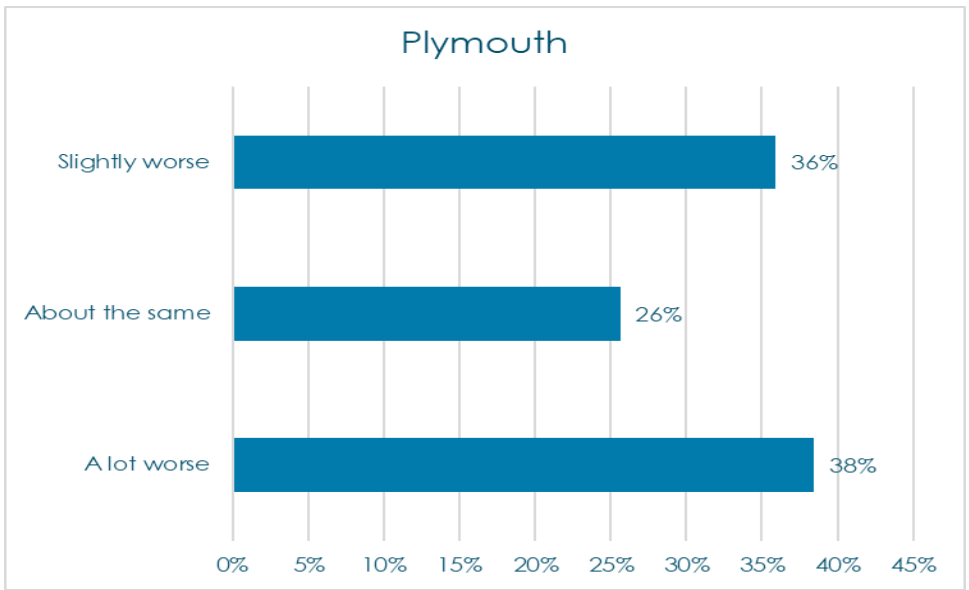


Question 8. Since becoming a carer, my physical health has been...

All 121 respondents answered this question. None of the respondents said their physical health had gotten better. 28% of respondents (34 people) said their physical health was about the same, 35% (43 people) said it was slightly worse, and 36% (44 people) said it was “a lot worse.”

Looking across the three Local Authority areas, Devon and Plymouth compared similarly to the overall picture, however, more respondents in Torbay reported that their physical health was about the same.

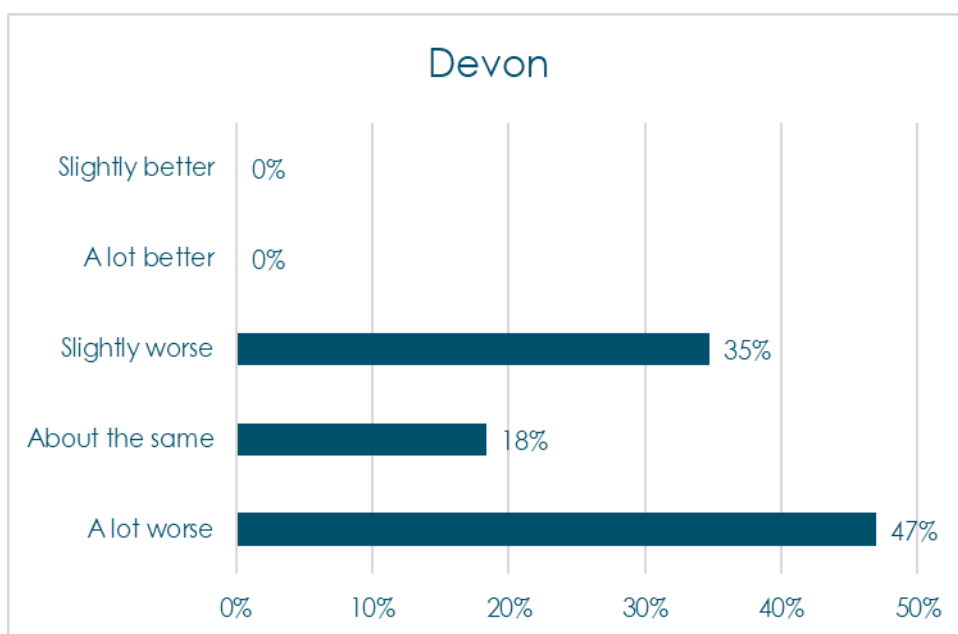
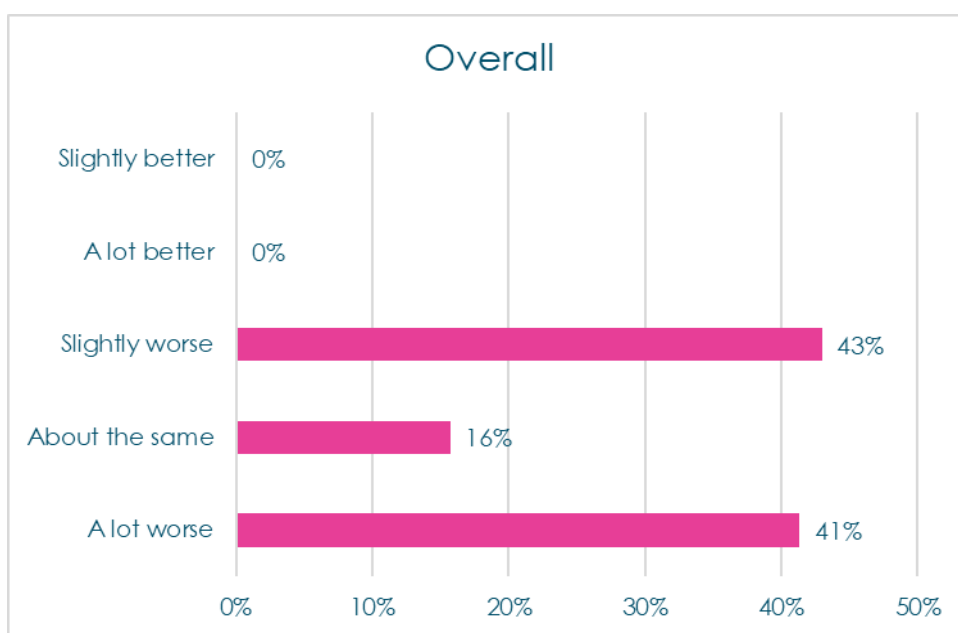


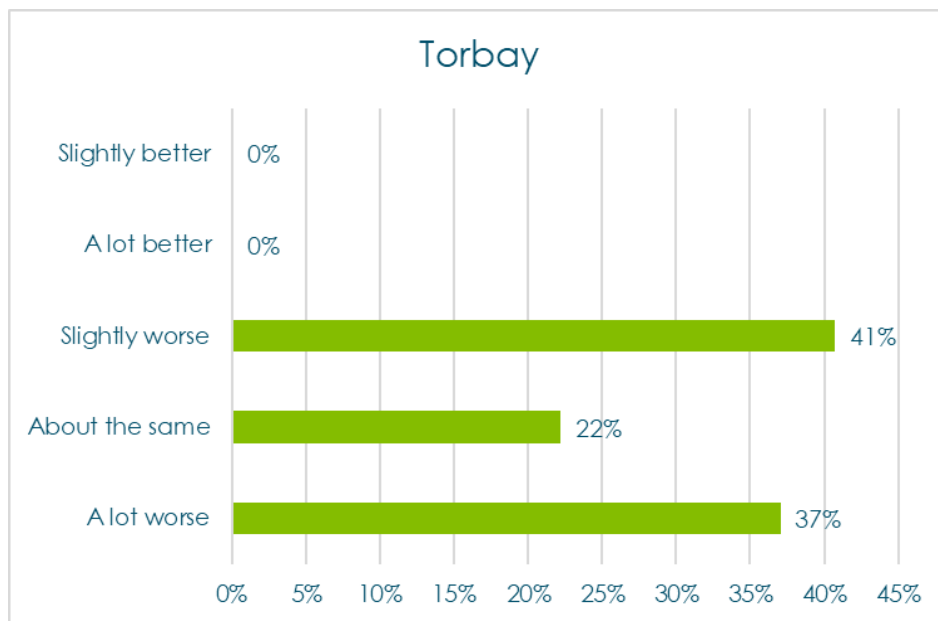
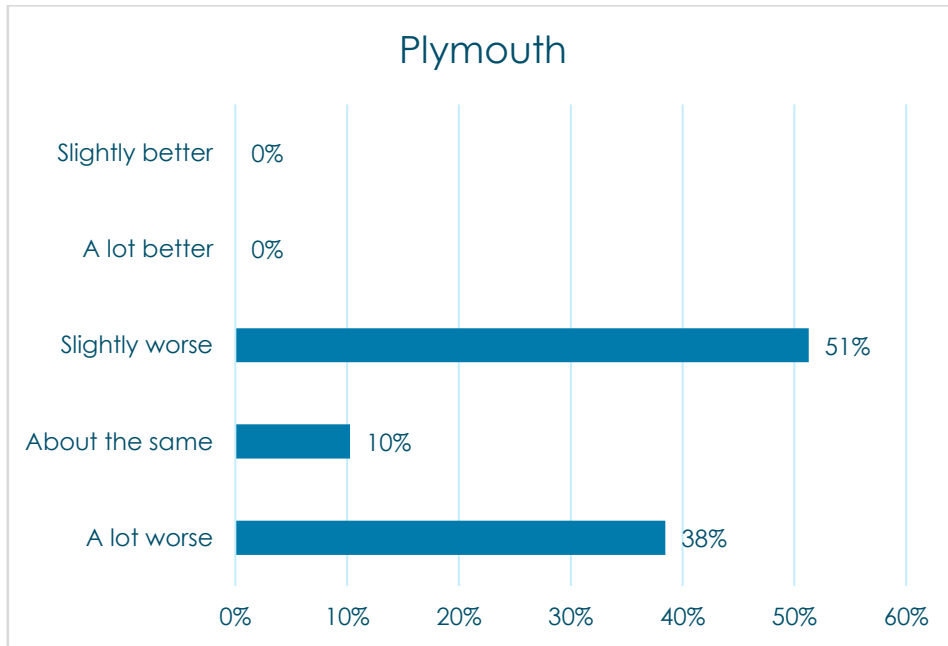


Question 9. Since becoming a carer, my mental health has been...

All 121 respondents answered this question. None of the respondents said their mental health had gotten better. 16% (19 respondents) said their mental health was about the same, 43% (52 people) said it was “slightly worse,” and 41% (50 people) said it was “a lot worse.”

This pattern was consistent across all three Local Authority areas with Devon reporting less respondents stating that their mental health was slightly worse and interestingly the Devon area also reported the greater proportion stating that their mental health was a lot worse.

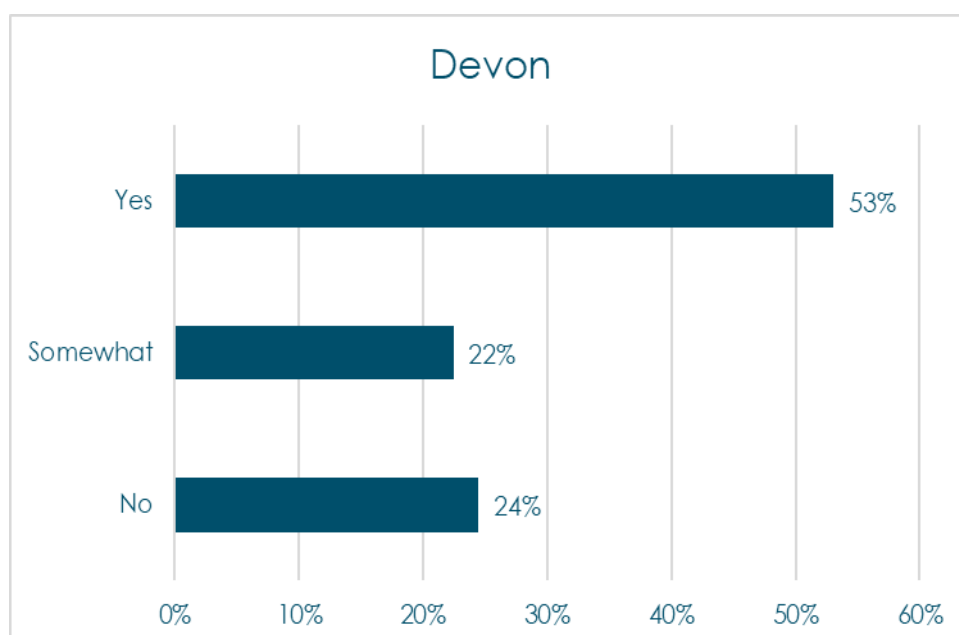
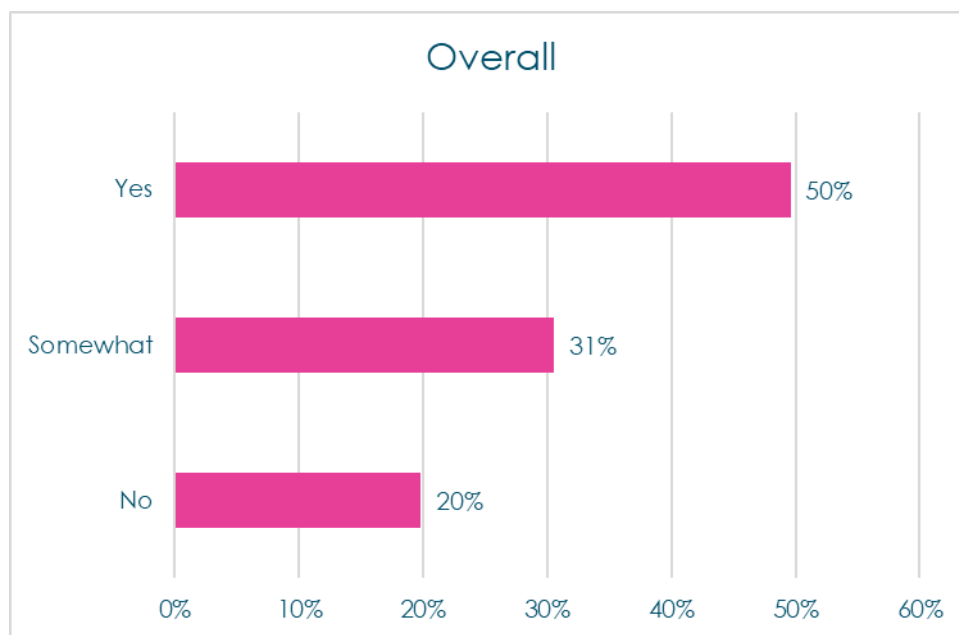


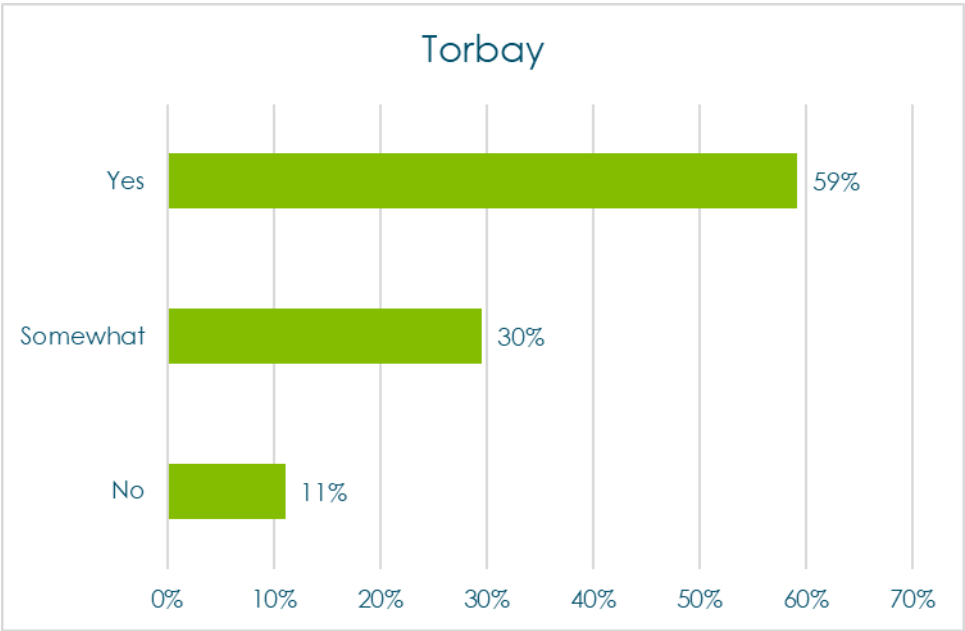
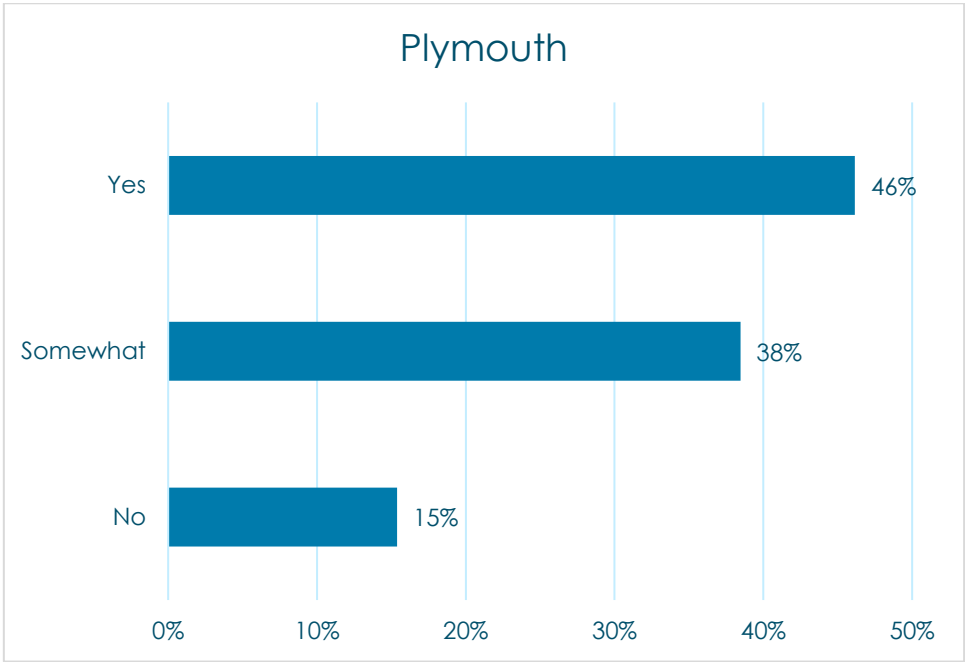


Question 10. Are you aware that physical and mental health support is available? (e.g. GP, mental health services, community support, employer-provided wellbeing packages)

All 121 respondents answered this question. Just under half of respondents (60 people) said yes, 30% (37 people) said somewhat, and 20% (24 people) said no.

These responses were in general the same for all three Local Authority areas.

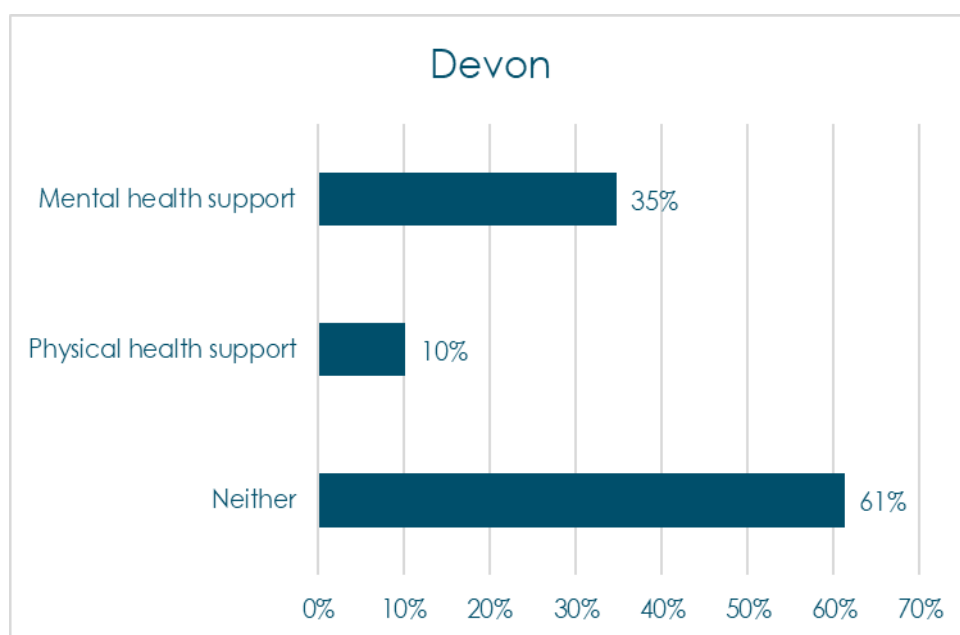
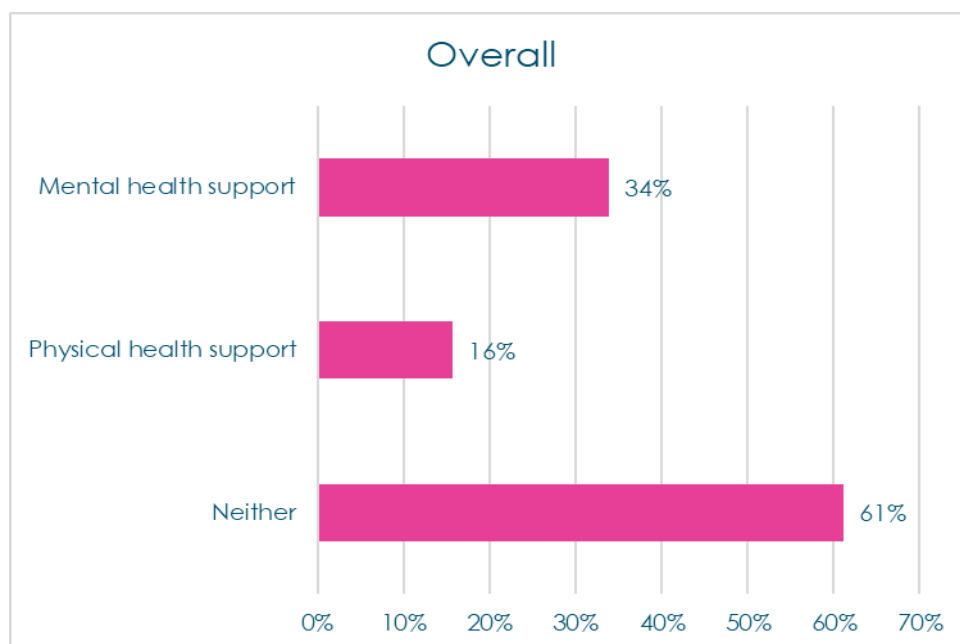


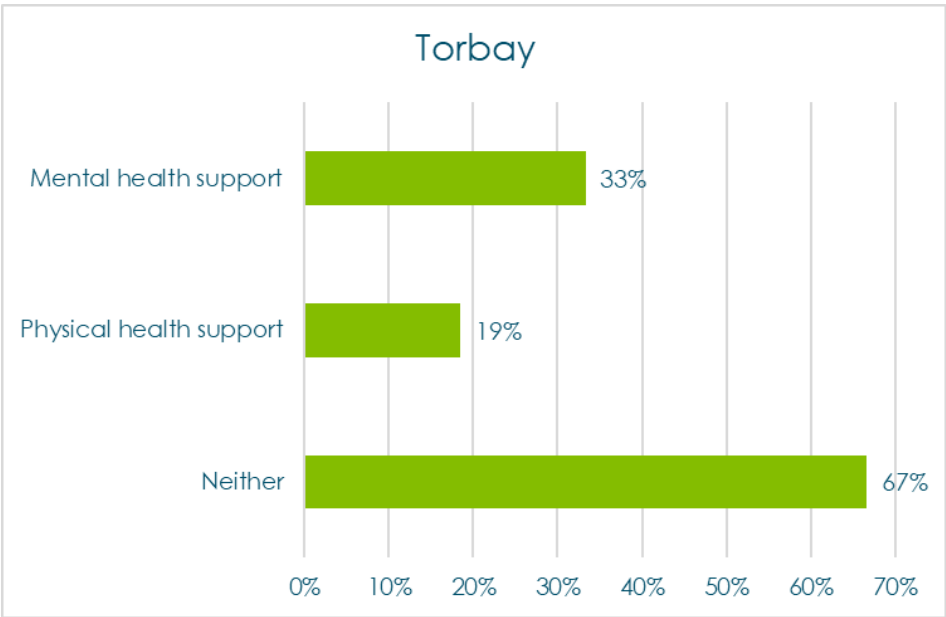
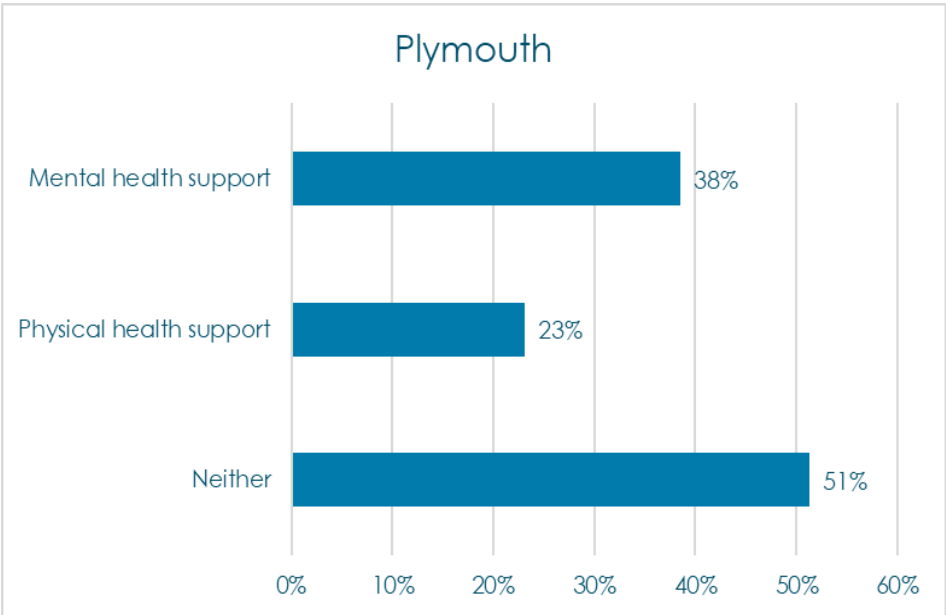


Question 11. Have you accessed any physical or mental health support?

All 121 respondents answered this question. As respondents could select more than one answer, percentages may total greater than 100. 61% of respondents (74 people) had accessed neither, 34% (41 people) had accessed mental health support, and 16% (19 people) had accessed physical health support.

When considering the replies from the three Local Authority areas, Devon and Plymouth responses were similar with the overall picture, the respondents from Torbay had the higher number saying that they had not accessed either mental health or physical support.





Question 12. If you used support services, which ones?

64 respondents answered this question and 57 did not, though some respondents gave answers that were unclear or not applicable. Where respondents named specific services, those services are listed below. The number of respondents naming each service is listed in brackets. This has then been split by each Local Authority area.

Mental health services (26)

- Counselling (9)
- TalkWorks (6)
- Livewell (4)
- HOPE (2)
- Rehab team (1)
- Community mental health team (2)
- Wonford House (1)
- Crisis mental health team (1)

Devon (9)

- Counselling (1)
- TalkWorks (4)
- HOPE (2)
- Rehab team (1)
- Wonford House (1)

Plymouth (9)

- Counselling (3)
- Livewell (4)
- Community mental health team (1)
- Crisis mental health team (1)

Torbay (8)

- Counselling (5)
- TalkWorks (2)
- Community mental health team (1)

GP services (20)

- Devon - 5
- Plymouth - 9
- Torbay - 6

Physical health services (17)

Physical health support (6)

- Physiotherapy (5)
- Diet, exercise, and lifestyle (3)
- Back clinic (1)
- Pain management (1)
- Dentist (1)

Devon (4)

- Diet, exercise, and lifestyle (2)
- Physiotherapy (2)

Plymouth (7)

- Physical health support (4)
- Physiotherapy (1)
- Back clinic (1)
- Dentist (1)

Torbay (5)

- Physical health support (2)
- Physiotherapy (2)
- Pain management (1)

Community and voluntary sector organisations (15)

- Devon Carers (6)
- Caring for Carers (2)
- Mind (2)
- The Elder Tree (1)
- Carer services (2)
- Memory Café (1)
- Carers aid Torbay (1)

Devon (6)

- Devon Carers (5)
- Memory Café (1)

Plymouth (4)

- Caring for Carers (2)
- Mind (2)
- Devon Carers (1)
- The Elder Tree (1)

Torbay (3)

- Carer services (2)
- Carer aid Torbay (1)

Carers support services (7)

- Carers support group (2)
- Carer support worker (2)
- Carer voucher scheme (1)
- Respite (1)
- Social Worker (1)

Devon (0)

- Nothing recorded

Plymouth (1)

- Social Worker (1)

Torbay (6)

- Carers support group (2)
- Carer support worker (2)
- Carer voucher scheme (1)
- Respite (1)

Nursing and domiciliary care (5)

- Bay care (1)
- Community nurse (1)
- Community nursing team (1)
- Home support (1)
- Nursing team (1)

Devon (2)

- Community nursing team (1)
- Home support (1)

Plymouth (1)

- Community nurse (1)

Torbay (2)

- Bay care (1)
- Nursing team (1)

Question 13. Are there any support services you would have liked to access, but couldn't?

66 respondents answered this question and 55 did not, though some respondents gave answers that were unclear or not applicable. The number of respondents naming each service is listed in brackets. The number services accessed for each Local Authority area is also provided.

Mental and emotional support (11)

- Devon (4)
- Plymouth (6)
- Torbay (1)

Respite care (10)

- Devon (4)
- Plymouth (1)
- Torbay (5)

Advice, training, and signposting (13)

- Devon (8)
- Plymouth (3)
- Torbay (2)

Physical healthcare and support (5)

- Devon (5)
- Plymouth (2)
- Torbay (0)

Question 14. Is there anything else you would like to tell us about your experience of being a carer?

139 respondents answered this question and 40 did not, though some respondents gave answers that were unclear or not applicable. 33 respondents talked about struggling to balance caring responsibilities with other parts of their life and the mental impact of caring. 31 respondents mentioned inadequate support, seven respondents mentioned financial concerns, and six respondents talked about needing extra help or respite care.

Balance, stress, and mental health (45)

- “I am a dual carer, so I struggle to get balance in my life, though I am working toward that by reducing hours in employment.” (Plymouth)
- “I effectively run two homes, work, and provide childcare for my grandchildren. I am exhausted, tearful, and feel constantly under pressure.” (Devon)
- It’s rewarding but exhausting mentally because you can never switch off. (Torbay)

Inadequate support (39)

- “If the support was in one place and easy to access for all care needs including the cared-for person it would relieve stress and worry.” (Plymouth)
- “It has happened quite quickly for us both and we are struggling to find out what is available.” (Area unknown)
- “It is so difficult to access appropriate statutory services that I give up.” (Devon)

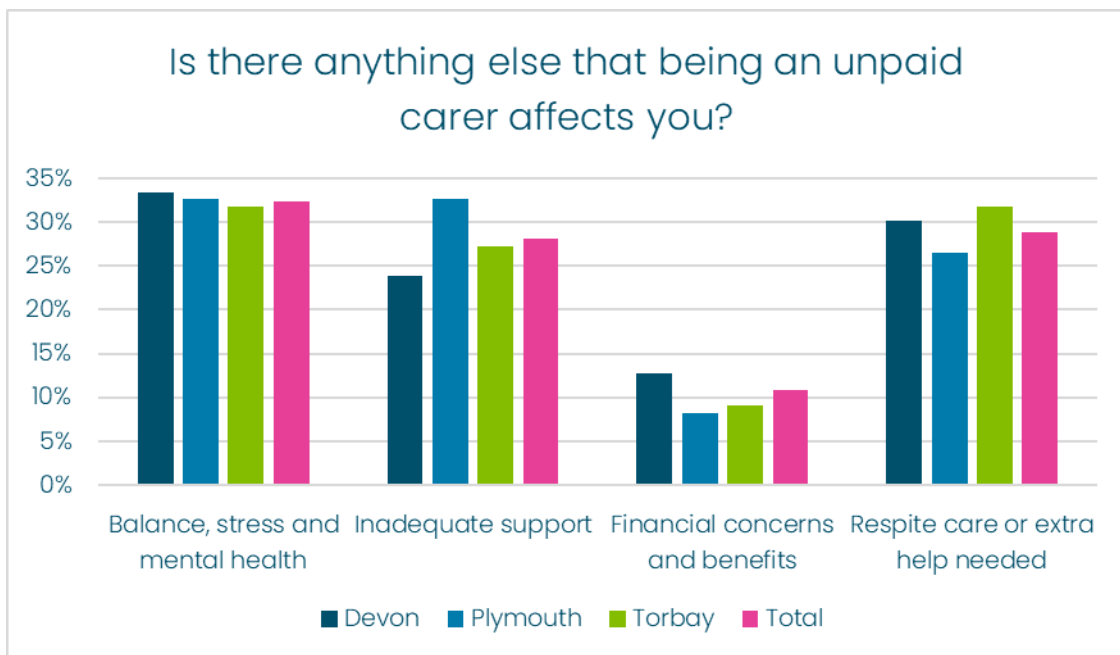
Financial concerns and benefits (15)

- “Carers allowance is abysmal.” (Devon)
- “I have had to reduce my working hours and the grants are not sufficient.” (Devon)
- “I need to get a job now but can’t because I am having to care. I only get attendance allowance and [I am] not entitled to any other help. I’m fed up [of] having to spend money on caring.” (Plymouth)

Respite care or extra help needed (40)

- “No respite help to take a holiday. Care costs make any break prohibitive.” (Devon)
- “We have had to do it all on our own.” (Plymouth)
- “Without adequate respite, my health and energy rapidly go downhill.” (Devon)

The chart below illustrates both overall responses and a breakdown by Local Authority area to the main themes derived from the commentary in response to Q14. Each of the Local Authority areas were similar were similar to the overall picture, with those in the Plymouth area saying they felt **more support** was required.



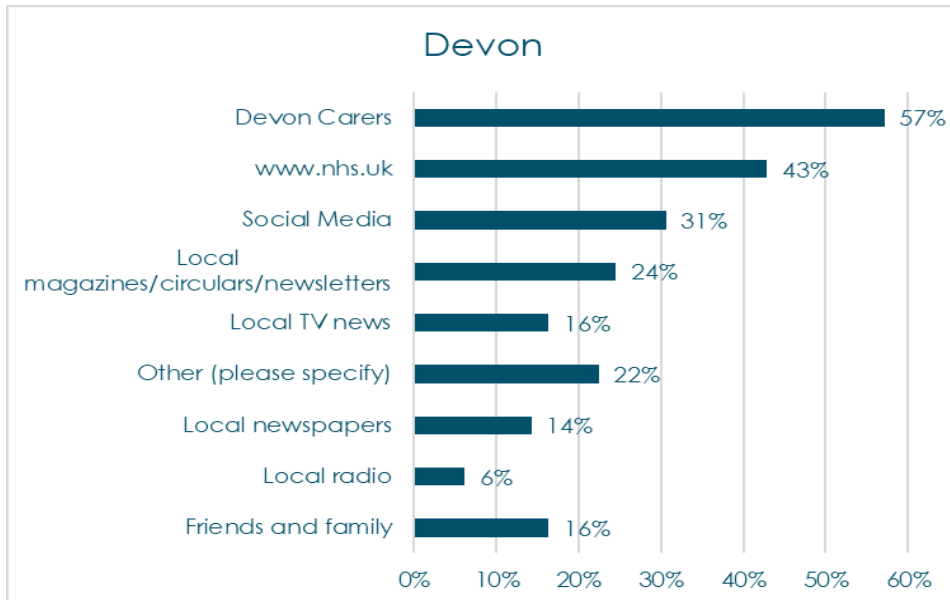
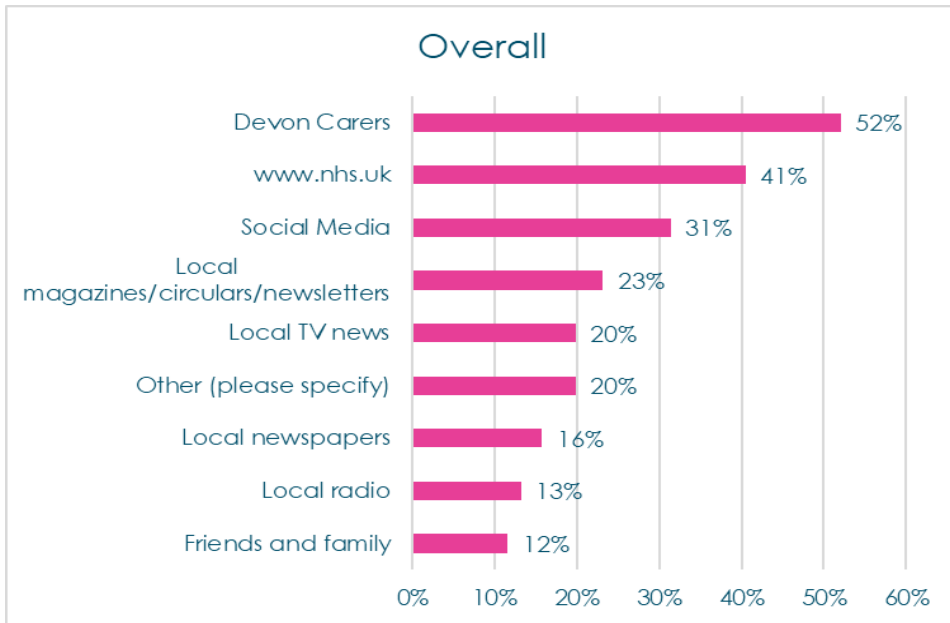
Question 15. Where would you like to find out information about support services that are available?

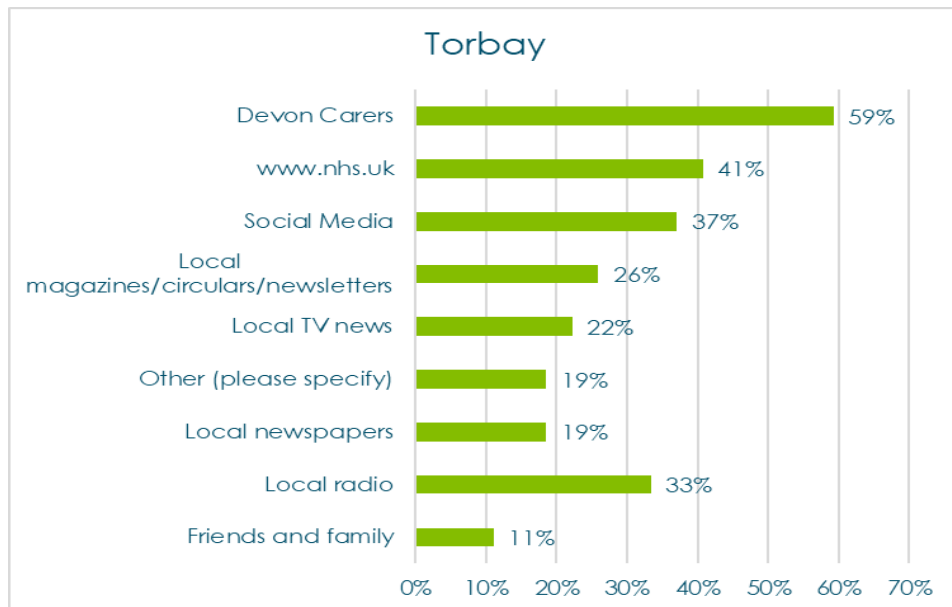
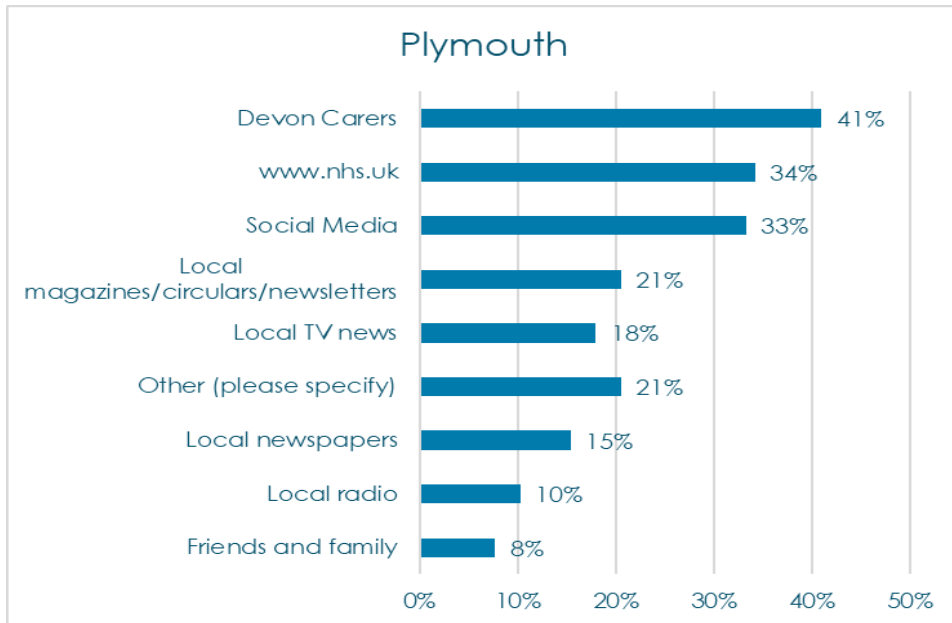
106 respondents answered this question and 15 did not. As respondents could select more than one answer, percentages may total greater than 100. 59% of respondents (63 people) said they would like information from Devon Carers, 46% (49 people) said they would like information from nhs.uk, 36% (38 people) said they would like information from social media, 26% (28 people) said they would like information from local magazines and newsletters, 23% (24 people) said they would like information from local TV news, 18% (19 people) said they would like information from local newspapers, 15% (16 people) said they would like information from local radio, and 13% (14 people) said they would like information from friends and family.

When reviewing the data by the three Local Authority areas, Torbay favoured local radio more than those from Devon and Plymouth and in Devon unpaid carers relied on friends and family more than the unpaid carers from Plymouth and Torbay.

23% (24 people) selected "other"; these responses mentioned:

- Health and social care services (7)
- Unclear/not applicable (7)
- Community and support groups (5)
- Internet and search engines (4)
- Libraries (2)
- Noticeboards (2)
- Post (1)





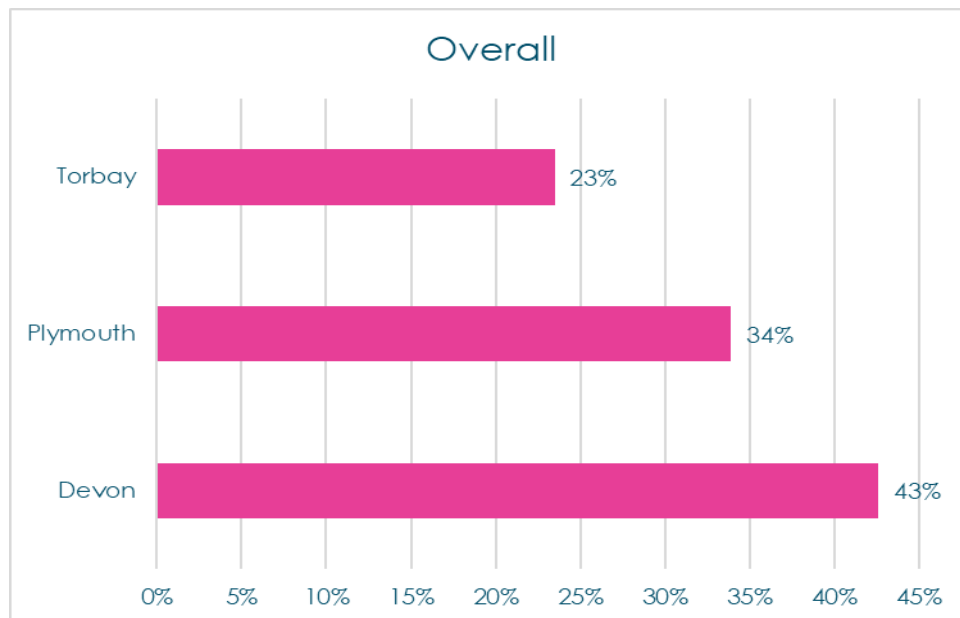
Demographics

Where fewer than five respondents belonged to a particular category, those categories have been collated and labelled as "other."

Please enter the first part of your postcode.

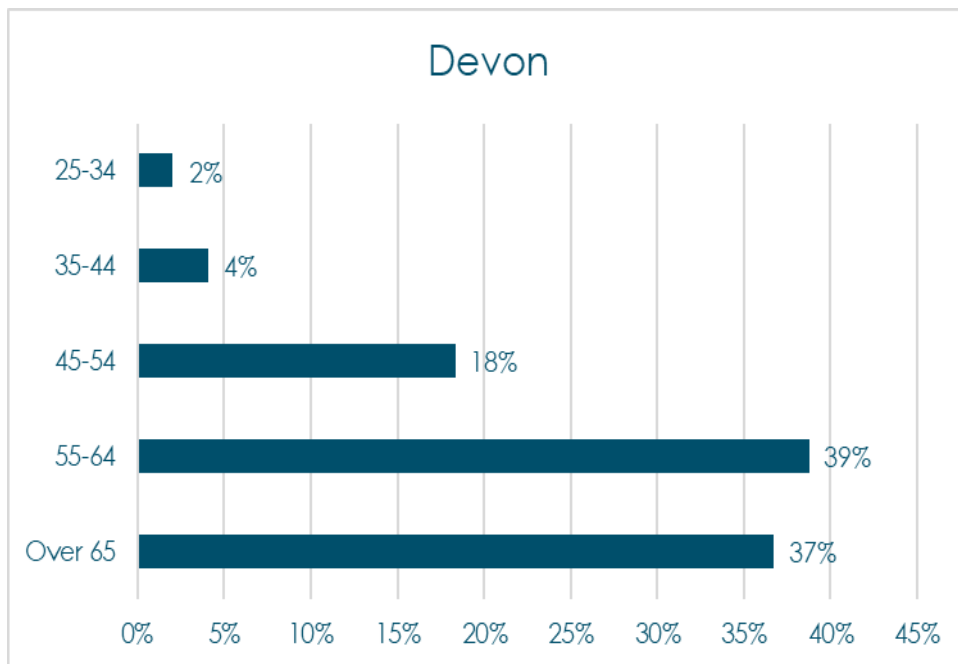
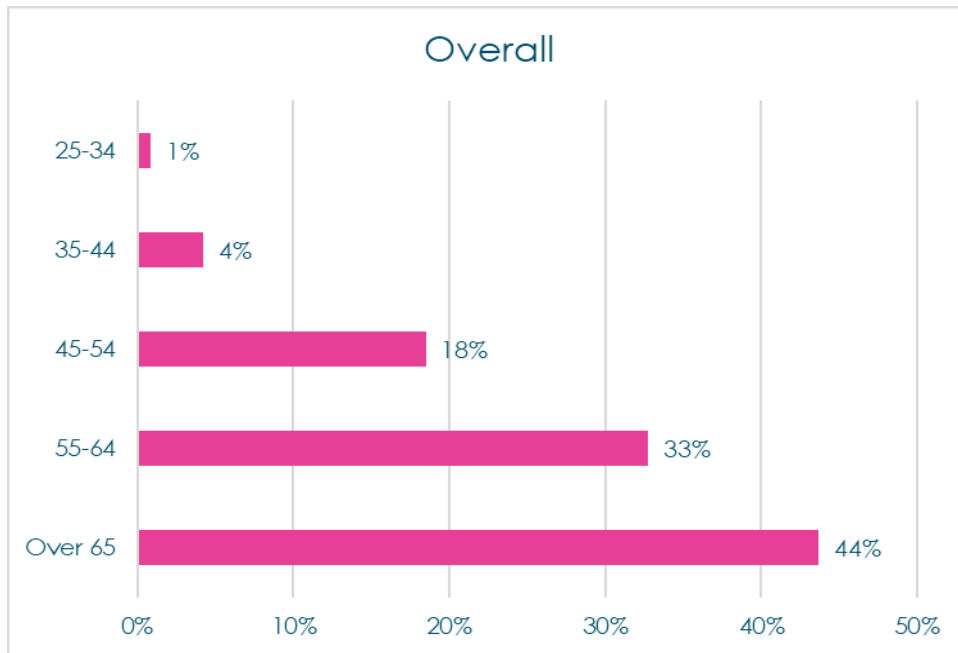
115 respondents answered this question and six did not. 49 respondents (42%) were had a Devon postcode, 39 respondents (34%) had a Plymouth area postcode (this included a Cornwall postcode), and 27 respondents (23.5%) had a Torbay postcode.

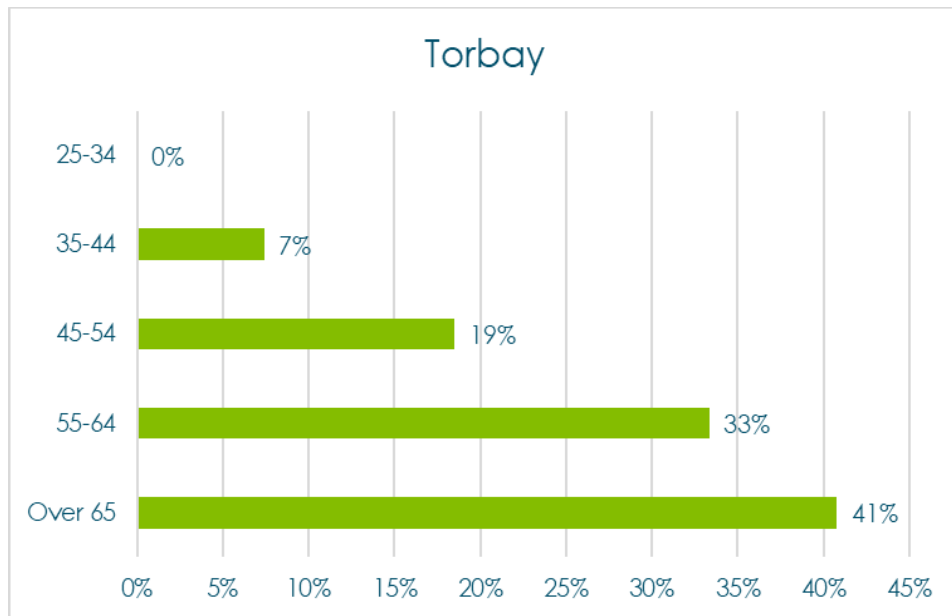
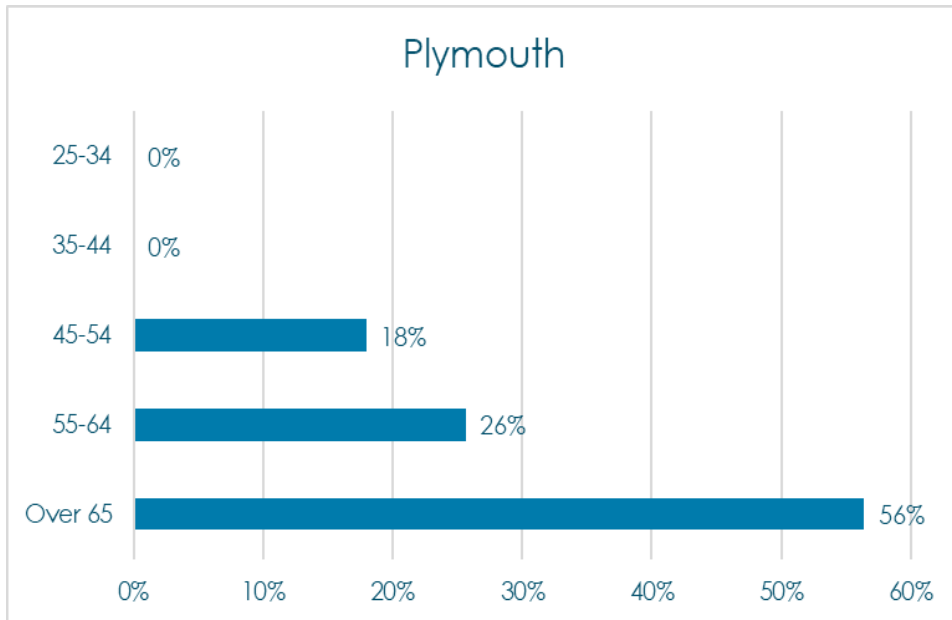
Of the Devon postcodes, 6 were in Exeter and the remainder in the 'rural' region of Devon although with the data we were unable to determine differences between people living in market towns or small villages/rural locations/



What is your age?

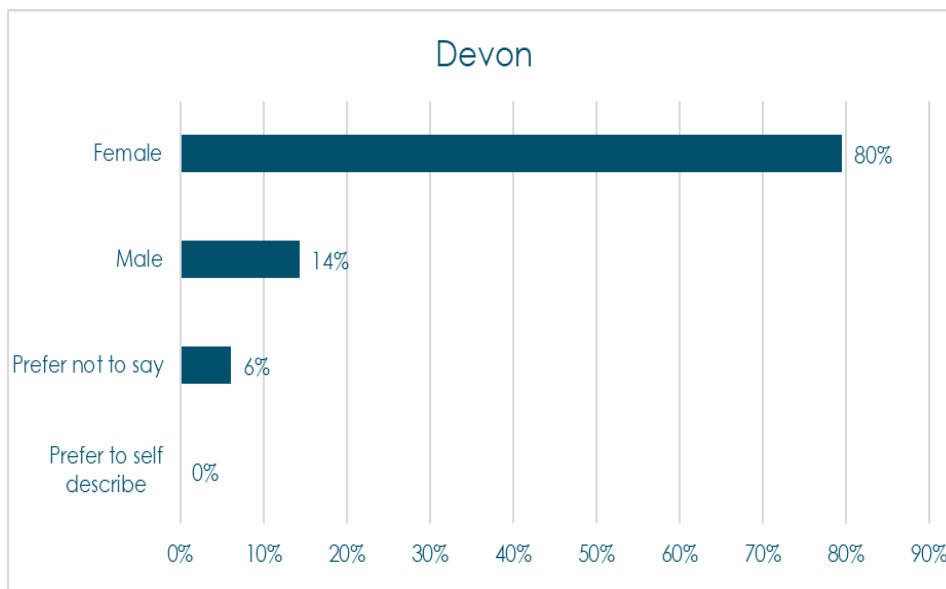
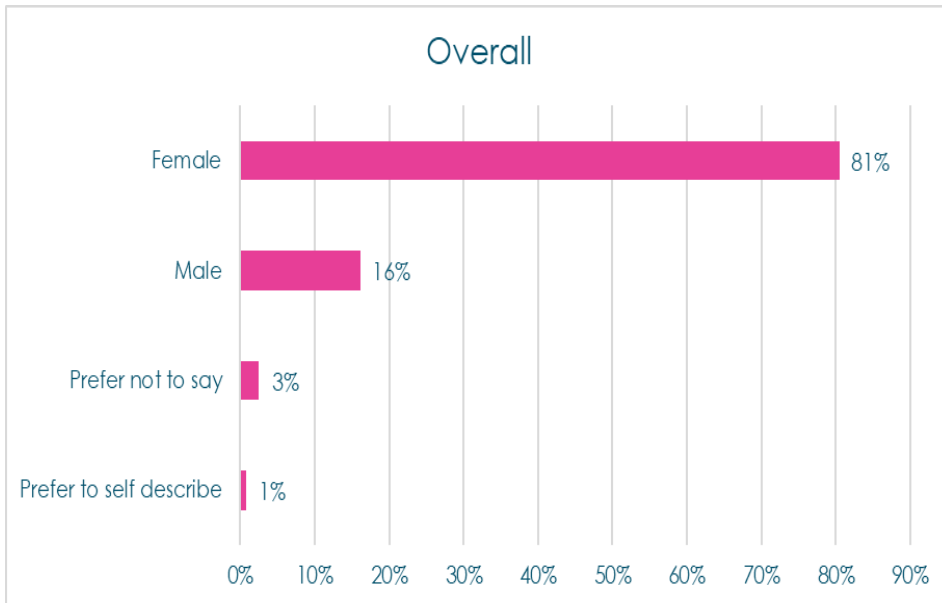
119 respondents answered this question and two did not. One respondent (0.84%) was 25 to 34. 4% of respondents (five people) were 35 to 44, 18% (22 people) were 45 to 54, 32% (39 people) were 55 to 64, and 44% (52 people) were over 65. None of the respondents were under 25. When considering the three areas there were more respondents in the over 65 and less in the 55-64 age bands from the Plymouth area than for Devon and Torbay.

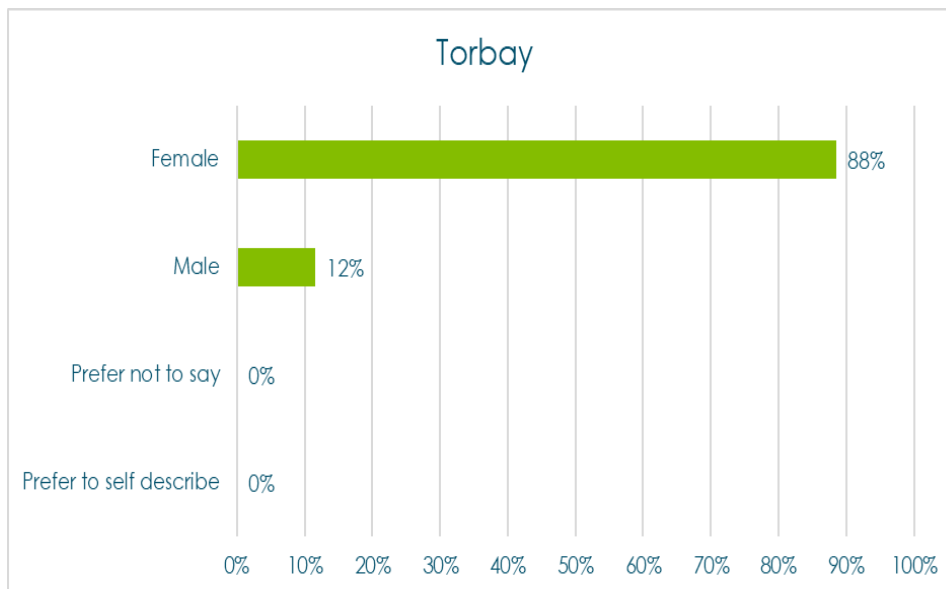
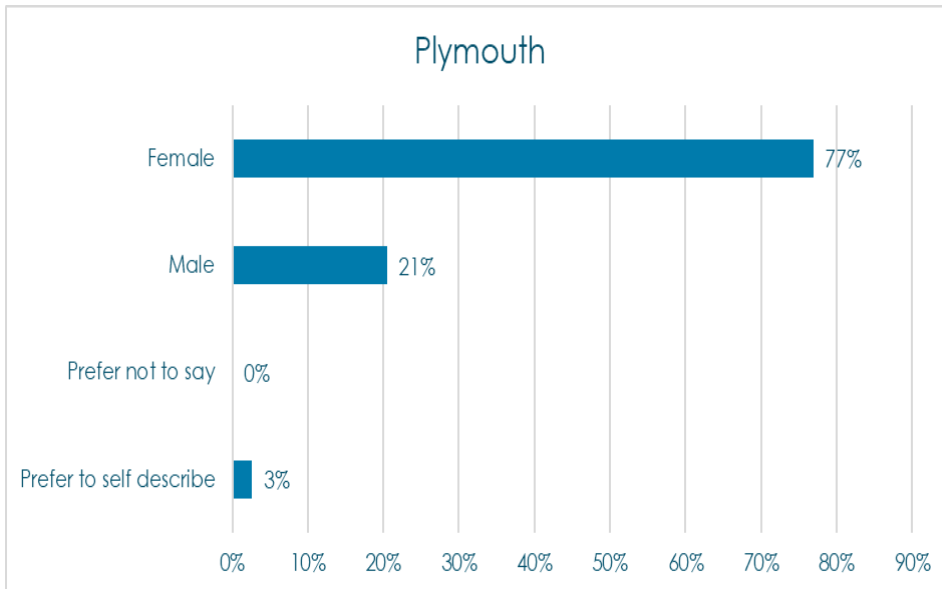




What is your gender?

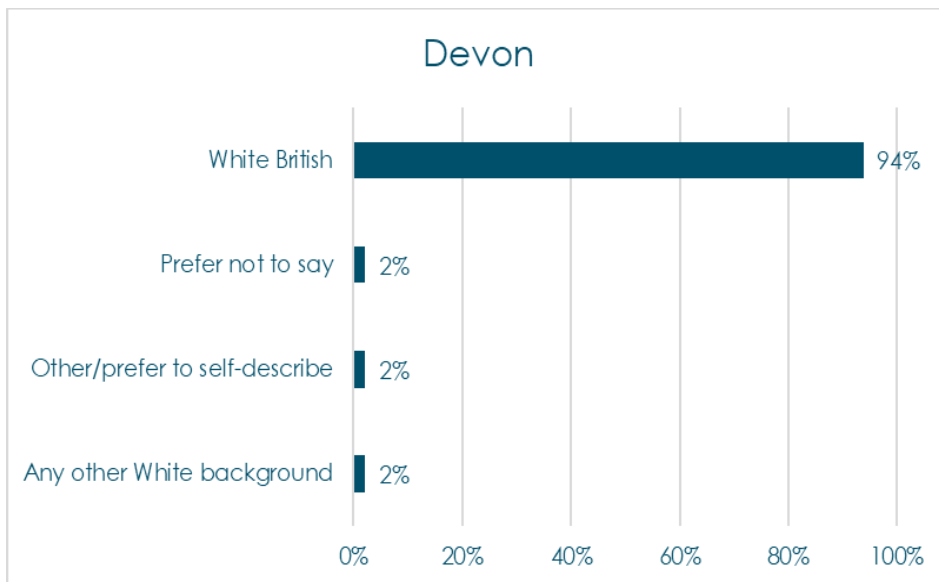
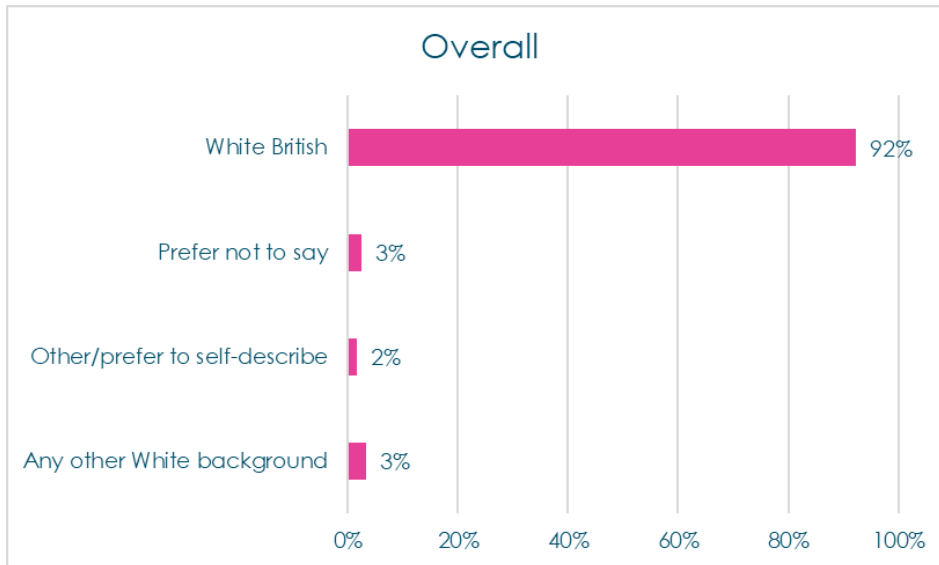
118 respondents answered this question and three skipped it. 81% of respondents (95 people) were female and 16% (19 people) were male. 2.5% (three people) selected “prefer not to say” and one respondent (0.85%) selected “prefer to self-describe.” This trend of predominately female unpaid carers was the same across all three regions.

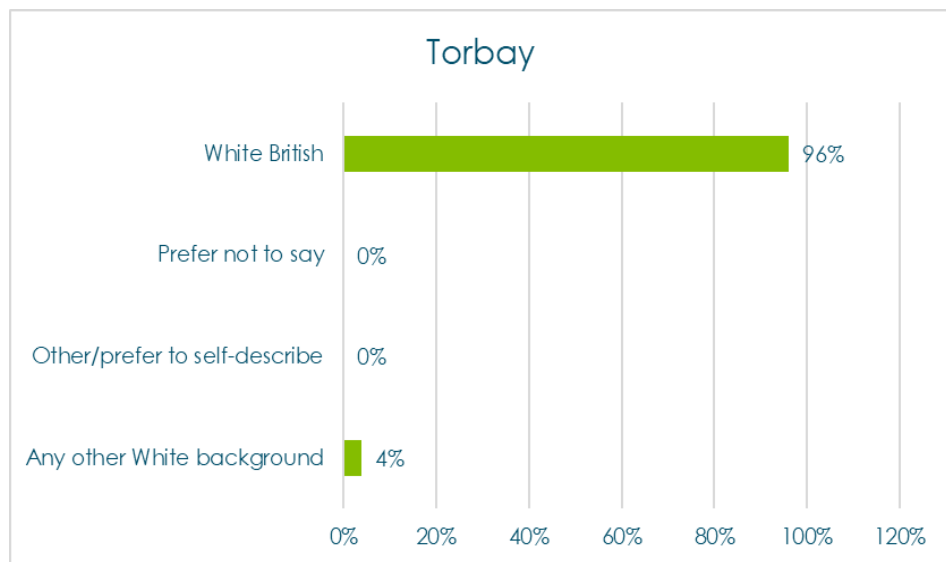
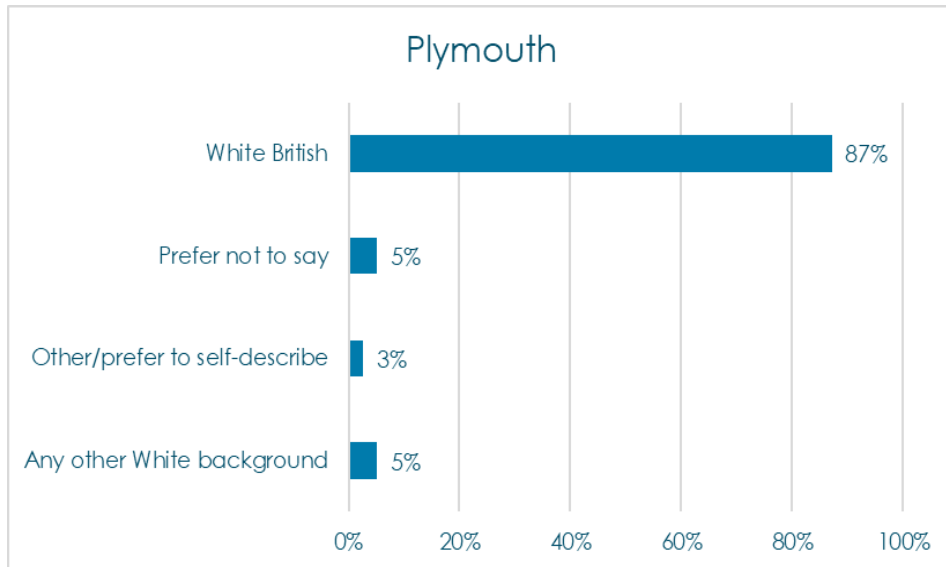




What is your ethnicity?

118 respondents answered this question and three skipped it. 92% of respondents (109 people) were White British and 5% (six people) belonged to another ethnicity. 2.5% of respondents (three people) selected “prefer not to say”. The respondents from the Plymouth area showed a slight ethnic diversity by having less respondents reporting as ‘White British’.





Healthwatch Observations

Whilst the number of responses to this survey is small compared to the number providing unpaid care across Devon, the results align very much with other surveys conducted during the Covid pandemic by other organisations and agencies and reported through national and regional media organisations.

Unpaid carers are often not recognised as such, the role is not always recorded on patients records and if new to the role, they are unaware of support available to them including financial support.

The role they undertake is often all consuming and affects their personal lives and those of their immediate family and friends. It can lead to deterioration in both physical and mental health leaving the carer unsure of where to turn to gain support.

Information on what support is available is sometimes difficult to find, particularly if not able to access or use equipment to access websites and sometimes it becomes a case of who you know and not what you know to access information.

Despite the limited response, the number of respondents who report that their caring responsibilities have had a negative impact on their health is high and yet the number of people who have sought support is low in comparison. This may be for a variety of reasons such as acceptance of their situation, insufficient time, unawareness, or lack of information of support available, or a feeling they do not need to access support. Commissioners may want to consider a follow up investigation into this area to find the specific reasons for this.

Additionally future surveys could include a question on loneliness and access to transport.

Next Steps

Healthwatch in Devon, Plymouth and Torbay will continue to monitor patient and public feedback about services and report that feedback to the Integrated Care System in Devon to inform service delivery and change. Healthwatch will also share the findings of this report directly with those responsible for commissioning Carers services for them to consider and respond to.

Recognition

Healthwatch in Devon, Plymouth, and Torbay would like to thank everyone who took the time to complete the survey and give their feedback. Healthwatch would also like to thank Devon Carers, Improving Lives Plymouth, and the Torbay Carers Service for helping to design and distribute the survey.

Appendix

Appendix 1. Healthwatch social media engagement data

Social media platform	Reach	Engagement
HW Devon Facebook	4,875	40
HW Devon Instagram	62	0
HW Devon Twitter	218	12
HW Plymouth Facebook	469	11
HW Plymouth Instagram	21	1
HW Plymouth Twitter	306	6
HW Torbay Facebook	629	11
HW Torbay Instagram	20	4
HW Torbay Twitter	198	0
Total	6,798	85

Appendix 2. Selected other commentary

Location	Commentary
Devon	It is relentless, stressful, and lonely. I am unable to bring friends round to my home now, and it is also impossible to take my 'cared for' to friends' homes - as they do not have disabled toilets - so we are stuck here - isolated! Most of my contact with friends now is via WhatsApp or zoom calls.
Devon	Twenty-five years ago, my husband suffered a subarachnoid haemorrhage which left him hemiplegic, partially sighted, brain damaged and epileptic. It had been very difficult to cope with bringing up our two daughters in these circumstances and it's only because I have been able to pay for the various services, we have needed that it's been possible to continue as a family unit.
Devon	I am feeling very depressed my life is at an end and I can see no future. All the organisations I have been in touch with offer little help as we are too isolated apparently 3 miles from town
Devon	Reviews by adult social services do not happen. Everything takes so long, and time is what the cared for doesn't have! If everything possible is being put in place for the patient, then the Carers wellbeing is going to be much better.
Devon	It is so hard to know where to find help and support for the cared-for person. There are waiting lists for assessments and treatment. You feel as if you are passed from pillar to post, everyone passing the buck, and you don't know where to get the help you need because you don't know what help is needed.
Devon	It erodes your home life - with constantly being at the beck and call of a 'controlling' cared for person who refuses to seek any outside help or support - I feel I have become solely a carer rather than a wife.
Devon	I feel if my wife gets worse, I won't be able to cope mentally.
Devon	Without adequate respite my health and energy rapidly go downhill.

Location	Commentary
Devon	Social services need to have a more open attitude, be more accessible and better equipped to offer practical help and support.
Devon	It's lonely and 24/7. Without the support of my daughters, I would be in a much worse space.
Devon	It isn't the caring itself that causes the most stress, it's the incompetent services who fail carers and disabled people time and time again.
Devon	You feel less lonely with organisations such as Devon Carers about and the services it offers. I think isolation is the biggest factor - managing alone. When I was more alone, because of my cared-for person's condition, I was living in a state of physical and emotional danger. The biggest thing about being a carer is being able to reach out to society - or society reaching out to you.
Devon	The expectation we are all IT literate, the lack of Face-to-Face professional support to truly assess the caring role. When making telephone calls, held on the line music blaring in the background all adds to the stress of caring and long speeches. Hearing a big issue.
Devon	it is relentless, the buck stops here. Hate that my home smells like a care home - mix of pee and disinfectant. Even if i get care support in I have nowhere to go - no home to relax in. Feel I have lost my home - everything revolves around my husband's care.
Devon	Lack of advice for families supporting extremely clinically vulnerable people, lack of financial support and info for employers.
Devon	We are on our own! it is so difficult to access appropriate statutory services that I give up.
Devon	I have had to reduce my working hours and the grants are not sufficient.
Devon	My wife has dementia and doesn't understand me most of the time. Gets lonely quite often, but as I do all the cooking, cleaning washing and maintenance, I don't have a lot of time anyway.

Location	Commentary
Devon	Little opportunity to do regular art/ craft or other hobbies. Often workshops are at the weekend when I am without carers. No respite help to take a holiday. Care costs makes any break prohibitive.
Devon	I care for my mum and dad. I do not live with them. I effectively run 2 homes, work, and provide childcare for my grandchildren. I am exhausted, tearful and feel constantly under pressure. Mum has dementia plus other health problems. She has carers 4 times a day. Dad has become worn out looking after mum and now needs assistance. I manage all mums' finances, order her meals, as she needs a purée diet, sort out medication, liaise with carers, day care, order her Tena products, buy her clothes, sort out transport, hospital appointments. I don't resent looking after my parents but I no longer have a life. As I will not get my state pension for another 8yrs, when I'm 67yrs I will have to work for longer. This will impact on my ability to care for my parents.
Plymouth	I am a dual carer, so I struggle to get balance in my life though I am working toward that by reducing hours in employment.
Plymouth	Caring for my adult daughter with my husband as we age has got harder but if the support was in one place and easy to access for all care needs including the cared for person it would relieve stress and worry. we love our daughter and will keep her at home for as long as we can but the present system of support needs addressing as it can be frustrating as a carer. Doctors Surgery need to be more helpful.
Plymouth	At the age of 83 I feel that I am doing the job that would require two nursing staff to complete in a proper nursing environment. Our home is not really big enough or suitably convenient for purpose of effective home nursing.
Plymouth	It's lonely. I've been caring for almost 19 years without any outside help.
Plymouth	I have been a carer for over 24 years. I feel carers are often hidden and not valued. Often treated in a patronising way

Location	Commentary
Plymouth	Nightmare. Like someone shot me and left me to die in an open grave. Seriously. You are treated like dirt. You are not allowed to complain. You are not taken seriously. You are considered a 'problem', and the only time anyone notices is when you have a mental breakdown at the GP surgery and threaten to kill yourself in a public place. Even then, no help is available. Absolutely appalling. My life ended 20 years ago.
Plymouth	Am fairly new to the intensity of it in the last twelve months with hubby. Am full time with him and also dual caring with Mum too. The scattered nature of help and time spent on admin is colossal and demands such patience. Good Mobilise page on FB for Carers. Excellent support from Caring for Carers here in Plymouth. Had Carer Assessment within a week of contacting them; a benefits assessment and help to claim Attendance Allowance which was paid in just three weeks. Amazing and so helpful. Has enabled me to address a lingering work issue and give my employer long notice; do casual hours instead, which will enable me to claim Carer Allowance and be full time carer, which is so necessary to keep my hubby mobile; keep eye on Mum and keep my sanity!!
Plymouth	Lots of support groups and workshops are offered through the Carers newsletters I receive but I am unable to take advantage because of my commitments at home! I feel an additional pressure to help my husband with his medical needs acting as a point of contact for the GP/District Nurse/ hospital admissions - I had to attend this week and spent 20 hours in A&E with my husband sat on his rollator for most of that time before being admitted. there is no NHS help for the disabled in the A&E dept and I had to insist that I stay to support him.
Plymouth	I feel I need more support to check that I am coping.
Plymouth	Promised support does not exist or rarely appears.
Plymouth	I would like to be consulted more re her care.
Plymouth	Always having to chase up professional s lack of communication.

Location	Commentary
Plymouth	It's seems impossible for me to arrange a short respite break. I emailed and called Adult Social Care and I'm still waiting for their response - 3 weeks later.
Plymouth	I have been an unpaid carer for my husband for nearly 9 years and it is getting harder as I am getting older. I get no help whatsoever and the pandemic has exacerbated this. I wish I could just get up some days and do whatever I want without having to think about getting my husband up, showered, dressed etc. I don't think other people realise how difficult it is being a carer.
Plymouth	Frustrated with the assumption by all, including medical professionals that as soon as I say I am a carer they assume the person I care for, who is right beside me, is incapable of answering basic questions, and they are ignored, and everything is addressed to me.
Plymouth	We are the forgotten ones, Left to get on with it no matter how we are feeling. The responsibility we have when caring for our loved ones is over whelming at times knowing their whole life is in our hands. Every day asking ourselves what if we fail, what if I'm ill (we still need to get on with it).
Plymouth	It is unrelenting hard work which is very emotionally draining. Easier access to a doctor would help sometimes. I don't have a life as such anymore since I can't go out or do anything much due to caring. It is hard knowing that I have nothing to look forward to, and that my daughters' condition can only worsen until she dies. I am unbearably unhappy most of the time and I do have strategies to use, and I am a normally optimistic person.
Plymouth	I love my mum to bits and will always care for her, but there needs to be better support for us unpaid carers. We should be checked in with frequently. Also, most carer 'support' is during the day when I work. I can't afford not to work.
Plymouth	I contacted Adult Social Care last summer and also last month as I would like a short respite break, still waiting for their support at present.

Location	Commentary
Torbay	My health is severely affected by my caring role over 35 + years. If I had been listened too earlier, and support services put in sooner, I am sure that I would not now be in the sorry position of being a user of services too now. I would have been able to carry on my caring role for longer. Services do not put the support in soon enough and they take too long to respond to crisis.
Torbay	It's rewarding but exhausting mentally, because you can never switch off. I am grateful for the support that I have received.
Torbay	It is properly recognised as being a carer if you are unpaid. We are taken for granted by paid health professionals to get on with it, and I feel more supported by health charities.
Torbay	I have now become a user of services due to my physical and mental decline due to my caring role and responsibility. Support Services are too wrapped up in budgets and red tape and take too long to respond to crisis need. I.e., 5, 7, 9 months for support. The complaints procedure is too difficult and time consuming for anyone to actively complain and care at the same time and not enough advocacy availability to support carers who are in need of help through the system. Need more joined up working with Devon Partnership Trust (mental health) input in decision and provision of budgets.
Torbay	It's difficult getting the balance right between working full time - my caring responsibilities and living my own life. I'm trying to create more independence for us both, but the system doesn't always present us sensible options.
Torbay	No support or check ins from social care. Nothing through covid. Just contact us when they want more contribution. Roller coaster of emotions. Have to source everything ourselves. Always a battle with social care.
Torbay	It can be very lonely and pressurized. Sometimes you can resent the person and love them at the same time.

Location	Commentary
Torbay	Be polite to the carers who do a wonderful job.
Torbay	Being an unpaid carer in Torbay is a life sentence. Adult social care has a blanket policy of signing you off once they have completed an 'episode of care'. No one checks up to see if you are doing ok. There are no care staff available in Torbay but hey, they've done their 'episode of care' by giving us a direct payment that they then take back because we can't spend it because there is no staff.
Torbay	I have found professionals in social care unhelpful, rude, not skilled in learning difficulties, and poor at dealing with long term carers.
Torbay	<p>I'm lucky to have a supportive husband but no family support beyond that. I was a professional social worker prior to having a disabled child. My skills and knowledge have enabled me to deal with everything thrown at me to keep myself well (and deal with my own health problems) so that I can care for and enable my daughter. In meeting her needs I had to give up my own life - and deal with the personal consequences. What I'd like is better understanding that caring is exhausting and if I ask it is only because I, or my daughter, need that help.</p> <p>I would also like training available for paid carers, particularly in person centred support - everyone talks about it, few people know what it means or how to engage effectively.</p>
Torbay	Due to severe cuts in care, life has become very restricted. Caring for parents on top has made life impossible.

healthwatch

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