

# I Care

Hearing the voices of unpaid carers in South Cumbria



# About Healthwatch Cumbria

Healthwatch Cumbria (HWC) was established in April 2013 as part of the implementation of the Health and Care Act 2012.

Healthwatch England (HWE) acts as the national consumer champion for all local Healthwatch organisations, enabling and supporting HWC to bring important issues to the attention of decisions makers nationally.

A key role of HWC is to champion the views of people who use health and care services in Cumbria, seeking to ensure that their experiences inform the improvement of services. HWC are constantly listening, recording, and reporting on the views of local people on a wide range of health and care issues, ensuring that people in the county are able to express their views and have a voice in improving their local health and care services.

By law, there must be a Healthwatch in every local authority, thus, Healthwatch are funded by and accountable to local authorities. Therefore, legislation states that every local Healthwatch must carry out the following statutory functions:

- Obtain the views of people about their needs and experiences of local health and social care services. Local Healthwatch make these views known to those involved in the commissioning and scrutiny of care services.
- Make reports and make recommendations about how those services could or should be improved.
- Promote and support the involvement of people in the monitoring, commissioning and provision of local health and social care services.
- Provide information and advice to the public about accessing health and social care services and the options available to them.
- Make the views and experiences of people known to Healthwatch England, helping us to carry out our role as national champion.
- Make recommendations to Healthwatch England to advise the CQC to carry out special reviews or investigations into areas of concern.

Cumbria has undertaken a Local Government Reorganisation, which took effect on the 1<sup>st</sup> April 2023. This means that there are two new local authorities (one in Cumberland, and one in Westmorland and Furness), which will be responsible for all council related services in the area including public health and social services.

Therefore, consequently, from the 1<sup>st</sup> April 2023, Healthwatch Cumbria became Healthwatch Cumberland and Healthwatch Westmorland and Furness, commissioned by the two new local authorities. The goal remains the same, to obtain the views of local people, to promote and support the involvement of people in the monitoring, commissioning and provision of local health and social care services.

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# Foreword

By Jane Scattergood,

Director, Health and Care Integration for

South Cumbria

“This is a challenging time for health and care services in Lancashire and South Cumbria; almost a third of our residents live in very disadvantaged areas with the effects of poor health and inequalities getting worse over time. We want people in Lancashire and South Cumbria to live longer, healthier, happier lives than they currently do. Our Integrated Care System is committed to improving the health and wellbeing of people, and we recognise that without the support of people caring for their loved ones the NHS and social care alone would not be able to provide the level of care people should receive.

Informal carers are those amazing individuals who, unpaid, care for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. They make up a large part of the support those in poor health might receive and yet those informal carers will have their own health needs which can so often go unmet because of time and family pressures.

For many carers, caring can have positive and rewarding aspects; however, caring for others may also leave informal carers needing support for themselves in different aspects of their lives including health and wellbeing, money and benefits, and time for themselves or respite care for their loved one.

We want to make sure that anyone who cares for someone else has access to the health, care and support services they need to keep well, in a safe, timely and accessible way.

Recognising the links between the things that affect health and people’s overall wellbeing is a big part of how we will support people to remain healthy and well. Making sure that those who care for others – especially informal carers who might not see themselves as carers – have enough help and support to stay well is vital. We have heard from a number of informal carers through the work of Healthwatch and the voluntary and community groups who support all kinds of carers in South Cumbria and this insight will help us put residents at the centre of what we do, listening to their experiences and perspectives, and acting on what we have heard. I would like to thank those individual carer for taking the time to contribute to this valuable insight report.”

# Quote from Lisa Forster

## Senior Engagement Officer

"Firstly, I would like to express my deepest thanks to all the unpaid carers who took their time to share their experiences for this project. It was a privilege to be trusted with your stories.

Secondly, these stories, at times, could be emotional for people to share and I was asked several times whether these would be used to help support carers in the future. I think it is important to use the feedback received, the knowledge gained and the recommendations from this project to revisit at a future date to discover the impact this has had upon the lives of unpaid carers within South Cumbria and Millom.

During the engagement, themes emerged which I felt needed highlighting. These were:

- Some unpaid carers didn't originally identify themselves as unpaid carers primarily, they cared for their loved ones because they loved them.
- Some unpaid carers didn't classify themselves as this either as they received Carers Allowance from the government, therefore they felt this was being paid to care.
- Although a privilege, caring for a loved one can encompass all parts of a carer's life and once the cared for has sadly passed, their carer can feel that they are left with a void in their life. They had spent so long with their cared for, caring for them, that they could be at a loss once their caring role has ended."

# Executive Summary

Lancashire and South Cumbria ICB commissioned Healthwatch to undertake a programme of engagement with unpaid carers in South Cumbria to understand their experience, the challenges they face and what system partners could do to support carers meet their needs. The purpose of the carer engagement work is to understand experiences of what it is like to be an unpaid carer in South Cumbria; to identify what is working well, as well as what areas could be improved to make their lives easier; and where there are gaps in support.

This included understanding the emotional, mental, and physical impact being an unpaid carer has had on these individuals. This report outlines the feedback received from engagement, which has been used to form a list of recommendations and next steps for the NHS Lancashire and South Cumbria ICP to consider.

## **Engagement Overview**

Healthwatch Cumbria (HWC) engaged with 76 members of the public, via 57 survey responses (of which 47 were completed as face to face case studies) and five focus groups (with a combined total of 19 participants).

The main themes highlighted by this engagement were:

- Some unpaid carers didn't originally identify themselves as unpaid carers.
- Unpaid carers care for their loved ones because they love them.
- Being an unpaid carer can be very time consuming.
- Being an unpaid carer can be emotionally and mentally draining.
- being an unpaid carer can feel very isolating, as their social life can decline.
- Being an unpaid carer can mean a loss of self-identity.
- Unpaid carers know about the services in the area but do not always access them.

As a result of gathering and analysing rich feedback from members of the public, particularly those who are seldom heard, HWC has formulated a list of 11 recommendations.

# Section 1: Introduction

Healthwatch Together was tasked with supporting the NHS Lancashire and South Cumbria ICB to undertake bespoke engagement with local residents on health and care topics which are prevalent to them. Jane Scattergood, the Director of Health and Care Integration – South Cumbria Place Based Partnership (PBP), requested that HWC’s first engagement focussed on hearing the voice of unpaid carers in South Cumbria.

The purpose of this project was to gather the feelings, hopes and experiences of unpaid carers in South Cumbria (including Millom). To learn what it is like to be an unpaid carer in the area, to identify barriers and gaps in service provision, highlight good practice and emphasise what more can be done to support unpaid carers in the area. The engagement work needed to gain an understanding of the emotional, mental, and physical impact being an unpaid carer has had on these individuals.

NHS England defines an unpaid carer as “*anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.*”<sup>1</sup> But not everyone that fits within this definition considers themselves to be an unpaid carer.

Carers UK and the Centre for Care at the University of Sheffield have published a new report sharing the value of the support unpaid carers provide. Their research concluded that “the economic value of the contributions made by unpaid carers in England and Wales is roughly equivalent to the budget for NHS health service spending”<sup>2</sup>.

Furthermore, the Office of National Statistics realised the following figures, which provide background on the number of people providing unpaid care on a local level, in South Cumbria and the number of hours they do<sup>3</sup>:

The number of people providing unpaid care in March 2021:	
In Barrow Borough	6,331 (9.8%)
In South Lakeland	8,990 (8.2%)

The number of people providing over 20 hours unpaid care per week in 2021:	
In Barrow Borough	3,419 (with 2,029 of these providing over 50 hours)
In South Lakeland	3,868 (with 2,430 of these providing over 50 hours)

<sup>1</sup> NHS England: Who is considered a carer? < <https://www.england.nhs.uk/commissioning/comm-carers/carers/#:~:text=A%20carer%20is%20anyone%2C%20including,care%20they%20give%20is%20unpaid> > (accessed 07/04/2023)

<sup>2</sup> Petrillo, M. and Bennett, M.R. (2023), *Valuing Carers 2021: England and Wales*, (London: Carers UK). p.5

<sup>3</sup> Figures in both tables from can be obtained from Office of National Statistics: Census 2021, Provision of unpaid care < <https://www.ons.gov.uk/datasets/TS039/editions/2021/versions/3> > (accessed 02/05/2023)

HWC wanted to hear both adults and young carers, who provide care to children, young people and/or adults. Capturing the views of those who self-identify as carers as well as those who may not be aware they are providing care.

This final report provides an insight to the thoughts and feelings of unpaid carers from a snapshot in time. In the future the plan is to speak with unpaid carers at regular intervals to better capture the journey these individuals are on.

# Section 2: Methodology

Following the initial project meeting, HWC focused on engaging with unpaid carers. A range of methods were used to optimise the opportunities for people to participate. There was engagement with a total of 76 people across South Cumbria, to understand their experiences of being an unpaid carer. This work consisted of 47 case studies (responses were inputted into the survey), 10 independent survey responses, and 5 focus groups (with a combined total of 19 participants).

A project/steering group supported and monitored the delivery of this project, consisting of:

- HWC representatives,
- Key health colleagues from the ICB,
- Furness Carers,
- Carers Support South Lakes,
- Cumbria County Council.

Engagement ran from 18<sup>th</sup> January 2023 until the 12<sup>th</sup> March 2023.

An online survey was developed and received a total of 57 responses. The survey link to the online survey was widely circulated and promoted throughout the engagement period, to both new and existing contacts who had links to the unpaid carers' community. The survey link was also widely promoted in Healthwatch newsletters, websites, and social media platforms, with a social media campaign/graphics produced to promote the project.

Engagement was carried out across South Cumbria, at 7 different locations, consisting of attending public events, and running 'pop-up' sessions in public spaces:

- St Mary's Living Well Centre (Barrow-in-Furness)
  - Learning disabilities coffee afternoon
- Walney Community Centre
  - Stitchability group
- HARRI (Health, Advice, Recovery, Resilience, and Information) bus
  - Asda, Walney Road
- Millom Health and Wellbeing Expo
- Furness General Hospital
- Barrow Market
- Ulverston Market

At these events, unpaid carers were given the opportunity to partake in a case study with a Healthwatch engagement officer. However, if they were unable to do this at the time, members of public had the option to either leave their contact details to participate in a case study at an arranged time or were given details on how to complete the online survey themselves. The 47 case studies contribute to the 57 survey responses, as they were conducted as structured

interviews, using the survey questions. Thus, the responses were added to the online survey to be analysed together.

To capture the experiences of unpaid carers, engagement officers also carried out targeted engagement, by attending community groups/sessions and gathered data through facilitating focus groups. There were 5 focus groups facilitated at 4 different locations:

- Furness Carers
  - Furness Carers Friday Carers Café
  - Young Carers holiday activity session
- St Mary's Living Well Centre (Barrow-in-Furness)
  - Barrow dementia hub drop in
- North Scale Community Centre
  - Warm Hub

A question proforma was produced which allowed engagement officers to capture qualitative information covering key topics of interest during the discussions.

A table outlining the Project timeline and details of the activities undertaken by HWC is provided in Appendix 1.

Beyond the pursuit of the project's main objectives, wherever necessary and possible HWC provided signposting information to support participants.

## Section 3: Findings from survey

The survey captured a range of experiences from unpaid carers across South Cumbria, with a total of 57 respondents partially or fully completed it (either independently or via a case study conversation).

All the respondents either considered themselves to be an unpaid carer (80.70%) or fit the NHS description even if they do not consider themselves to be an unpaid carer (19.30%). However, further data relating to the background (questions 1 to 9) and demographics (questions 27 – 31) of the respondents can be found in appendix 2.

### Physical, mental and emotional wellbeing

Respondents were asked to rate their physical, mental and emotional wellbeing on a scale from very good to very poor.

	Very good	Good	Fair	Poor	Very poor
Physical wellbeing	10.53%	38.60%	29.82%	19.30%	1.75%
Mental wellbeing	12.28%	24.56%	28.07%	24.56%	10.53%
Emotional wellbeing	10.71%	25.00%	32.14%	23.21%	8.93%

In all three areas of wellbeing the more participants rated their wellbeing to be either 'very good' or 'good' than 'poor' or 'very poor'. However, more participants rated their mental and emotional wellbeing as 'poor' or 'very poor' than their physical wellbeing. Indicating, that being an unpaid carer has a larger impact on an individual's mental or emotional wellbeing than their physical wellbeing.

### Impact on lifestyle

Respondents openly shared that being an unpaid carer had significantly impacted on their daily life. With the majority of respondents spending more than 50 hours a week on caring responsibilities.

Number of Hours spent on caring responsibilities a week	% of respondents
1 – 19 hours	24.56%
20 – 49 hours	28.07%
More than 50 hours	47.37%

While it was evident that these individuals took on the unpaid carer role because they deeply care for those they are looking after and want them to be cared for and supported. It was also clear that the amount of time the unpaid carers spend on caring responsibilities leaves little time for themselves, with several people sharing that they have "no social life":

- "Tied to the house mostly. Number of visitors dwindles over time."
- "No social life or time for hobbies when too tired."

- *“There is no spontaneity. I cannot meet friends for longer than an hour...The hardest thing is that I have no one to rely on.”*
- *“I became more isolated as looking after mum, don’t see friends or go out as much.”*

Some respondents went further, and shared that being an unpaid carer has impacted their life so much that they feel that they don’t really have a life of their ‘own’:

- *“Previous lifestyle barely remembered; spur of the moment choices not possible.”*
- *“Always on call, care for both parents... Often have to sleep over and therefore missing family life with husband and children.”*
- *“You give up on your life.”*
- *“Don’t have a life of my own to do the things that drive or inspire me anymore.”*
- *“My life had to revolve around them”*

From this feedback, it appears that those who are giving up so much time to care for others are unable to spend time investing in their other relationships and friendships, which sometimes means that they can feel isolated with a limited support structure of their own. That whilst they are helping someone live a life, they themselves are not living or able to create the life they want to live.

Respondents also shared that they regularly worry about the person they care for and in general the role of unpaid carer can be emotionally draining:

- *“I am run off my feet. I have very little relaxation. Poor sleep due to worry.”*
- *“Did have lots of sleepless nights worrying about my daughter... though you never stop worrying over your child and with my daughter’s condition it has increased this.”*
- *“I think of her before I do anything. I have to scan rooms/places we go to in case she falls over something, I need to make sure she’s ok and has everything even if I go to have a bath or go out to the garden.”*
- *“Just feel drained and get frustrated as my parent has dementia.”*
- *“I worry about what she’ll do if I don’t get to her when she expects us...So I’m always worrying about her even when I am not there.”*

But despite worrying about the person, they care for, many of the unpaid carers mentioned that they do not give themselves the same care and attention:

- *“It is frustrating and very tiring to constantly arguing and pushing to get their needs met. You don’t have the time or the energy to get your own needs met.”*
- *“I spent a lot of time worrying about my nan and her care. I work full time and was studying a full-time course which I have not passed partly due to the need to look after my nan.”*
- *“Don’t sleep well, overeat when stressed, neglect the house, neglect myself.”*
- *“I am always playing catch up with basic household chores, I feel like there are not enough hours in the day and I am constantly tired.”*

But the impact of being an unpaid carer has not all been negative, some individuals shared that it has also had a positive influence on them and their lives. Some unpaid carers liked that

they are able to spend so much time with their loved/cared ones and highly value the moments of joy and fun they get to share with them:

- *“Positive – having meals at mums, I also see my mum and spend time with her daily.”*
- *“Both my parents had a great sense of humour, there were moments of joy, I remember dad dancing and listening to music, when he did that he remembered who I was, he loved Barry Manilow and if that was on he recognised me again.”*
- *“My daughter has a good sense of humour we can have a laugh when she is behaving well.”*
- *“Spend more time as a couple.”*

For some it was also important to them, and they saw it as a positive that they were the person who looked after the person they cared for. It fulfils them and they are glad that they are able to help someone who needs it:

- *“When she got Cancer, I was so pleased that I could help her when she needed support the most.”*
- *“I like that my mum’s alright and that I am looking after her. I am glad that I’m the only person she trusts to care for her, it’s an honour.”*
- *“Positive – interaction with loved ones and making a difference to their lives and enabling them to be independent.”*
- *“Positive – being able to be at home to support her, providing for her when she needed support.”*

While it was evident from the respondents that the demand of being an unpaid carer has a larger variety of negative impacts than positives, there were still aspects that people like.

### **What is working well**

Respondents were asked to share as an unpaid carer what has been working well for them. The following are aspects which people mentioned:

- Getting to spend time with their loved ones whilst caring for them.
- The support from official organisations (such as Furness Carers, and support groups).
- Being able to work effectively together as a family unit (in some cases this has brought some families closer together).
- The friendships that have been formed with other unpaid carers.
- Any respite that individuals have received, either when they go to work or having those they care for go somewhere (for example school).
- Of those who managed to get financial support it was very positively received and beneficial.

### **Challenges**

Respondents were also asked to share as an unpaid carer what are the challenges that they have faced. The following are aspects which people highlighted:

- Lack of support available or having to fight to get the support required.
- Not being able to get necessary respite and take the holidays they need.

- Financial difficulties.
- The attitudes of those they care for can be difficult to deal with sometimes (those being cared for can be aggressive or abrasive on occasions).
- The level of responsibility that gets put on unpaid carers to look after someone else and themselves, is tough and exhausting and often results in them neglecting to look after themselves. The unpaid carers hold themselves to high expectations, but several also indicated there are high expectations put on them by those they care for as well as by the system.
- The decline/lack of social life resulting in feelings of isolation.
- Emotionally draining and being constantly tired.
- Not having enough time to do everything that needs done, including the many elements of their caring responsibilities (for example, shopping, cleaning, etc).

Respondents were asked what support they would benefit from the most, some were unable to choose just one declaring that they would benefit most from a combination of support. On the other hand, 3.64% of respondents shared that they did not want any more support. But this small number indicates that in general unpaid carers would appreciate and benefit from more support.

From the responses it is evident that respondents would like to receive more support by receiving respite, closely followed by practical and financial support:

What support would you benefit from the most to help with your health and wellbeing?	% of respondents
Respite	23.64%
Financial	18.18%
Practical	18.18%
Emotional	10.91%
Support group	10.91%
Advocacy support	3.64%
Other	10.91%
None	3.64%

### Accessing services

Nearly 73.22% of respondents have been able to access the services they need to look after their own health and wellbeing. However, on the other hand, this means that 26.79% have not been able to access these services:

Have you been able to access the services you need to look after your own health and wellbeing?	% of respondents
Yes, always	39.29%
Yes, but only sometimes	21.43%

Yes, but only when an emergency	12.50%
No	26.79%

However, those that expressed that they found it hard or have been unable to access these services but for many unpaid carers this was not always related to having caring responsibilities. Sharing that they feel it is just generally hard to access GPs and dentists in the current climate.

- *“No dentists around here and hard to get to see doctors anyway.”*
- *“Not due to my caring roles but I find it hard to access doctors and dentists as no appointments available.”*
- *“Hard to get through to surgery by phone. Hard to get timely appointments. Last week had a telephone appointment arranged out of hours but no-one rang.”*
- *“NHS service is now going private in the area I live and not many dentists are taking these patients on.”*

But for others not being able to access services is due to time constraints of being an unpaid carer, not having anyone else able to take over the caring responsibilities for them to be able to attend an appointment, or prioritising the person they are caring for over themselves:

- *“No time to get appointments.”*
- *“Hard to fit things in.”*
- *“No time it takes all my time to look after mum.”*
- *“Nobody to take over caring responsibilities.”*
- *“Cannot predict when needed. Cannot keep appointments without help and transport.”*
- *“Hard to leave the catering to someone else.”*
- *“I’m constantly prioritising my children’s appointments.”*
- *“Only started looking after myself now we have some carers coming in.”*
- *“You are too busy chasing appointments and professionals for the person you are caring for and trying to do everything else needed.”*

Respondents were asked about a variety of services based in South Cumbria that could be accessed and beneficial to unpaid carers. The following table shows the percentage of those respondents that the services are applicable to that are aware or not aware of the services:

Service	Number of respondents spoken to the service is applicable to	% of respondents that were aware of the service	% of the respondents were not aware of the service
Adult Social Care	45	93.34%	6.67%
Carer Support South Lakes	34	50.00%	50.00%
Furness Carers	42	80.95%	19.05%

Carer Support West Cumbria	28	35.71%	64.29%
Family Action	19	36.84%	63.16%
Action for Children	13	46.15%	53.85%
Alzheimer's Society	27	92.59%	7.41%
Mencap	28	71.43%	28.57%
Mind	35	88.57%	11.43%
Barnardo's	11	81.82%	18.18%
Cancer Care/Support	14	92.86%	7.14%

However, of those respondents that the services were applicable to and were aware off them, not everyone accessed this support:

Service	% who were aware of the service and accessed the support
Adult Social Care	66.67%
Carer Support South Lakes	23.53%
Furness Carers	44.12%
Carer Support West Cumbria	10.00%
Family Action	42.86%
Action for Children	0.00%
Alzheimer's Society	28.00%
Mencap	10.00%
Mind	9.68%
Barnardo's	0.00%
Cancer Care/Support	23.08%

This feedback shows that Adult Social Care is used most by those that it applies to and who are aware of it. Furness Carers and Family Action also appear to be accessed a fair amount by unpaid carers in the South Cumbria area. Therefore, this shows that many unpaid carers know about some of the key support services in the area, however, it appears that this does not always translate into them being able to access the support. The main reasons that respondents did not access the support available was because it was not fit for purpose for their situation.

## Employment

Respondents were asked, as well as their caring responsibilities what their current employment status was at the time of answering the questions:

Employment status	% of respondents
Full time employment	35.09%
Part time employment	12.28%
Self-employed	3.51%

Unemployed	7.02%
In full time education	0.00%
Retired	17.54%
Disabled and unable to work	12.28%
Other	12.28%

Of those unpaid carers that were in either full time or part time employment 65.38% have told their place of employment about their caring responsibilities.

Some respondents shared that their employers had been supportive:

- *“Very flexible, let me work from home.”*
- *“Let me leave work if an emergency arises.”*
- *“My employer fully supports me with my caring role and are flexible to my needs.”*

Other respondents mentioned that their employers had not been supportive of their role of an unpaid carer:

- *“Not at all supportive.”*
- *“No, they haven’t – gave me two days carers leave but then I’ve had to take everything else as holidays if I needed to attend an appointment with dad.”*

While some respondents have found their employers reaction mixed:

- *“Very hit and miss. Emergency days off, for medical emergencies I have been able to take annual leave. However, total lack of sympathy for my situation. I Was even told my partner must be ‘raking it in’ on PIP.”*
- *“My night-time manager is understanding, my daytime manager is not flexible.”*

Respondents shared ways that being an unpaid carer has impacted on their employment:

- 6 people had to leave their job
- 5 had to reduce the number of hours they were working
- 1 had to increase the number of hours they were working
- 5 adopted flexible working arrangements
- 3 have had their employment options limited

Respondents were asked if they had ever considered being a carer for a career, however, only 17.54% had. But it was mentioned if they were to become a carer as a career they would need the following:

- Flexible hours
- Additional training
- Wages (that are enough to live on)

Several unpaid carers expressed that they already care for someone and thus do not want their job to be also caring for someone in a similar manner.

## End of life care

62.96% of respondents have discussed with the person they care for end of life planning, including power of attorney, wills, funeral planning and financial decisions. However, only 20.00% of respondents are supporting someone who has an end of life plan in place.

Several respondents shared that they believe that those that they care for would need more support if they died, that if it was the other way round:

- *"I don't like to think about it, but they would need more support if I die than I would need if they die."*
- *"They would need support, to replace me if I die first. None needed for me."*
- *"If I die first my partner would probably have to go into a home, as they need 24 hour care."*

Some suggested if they died that the person they care for would need to be looked after by someone else preferably another family member, as there would already be an element of trust and a prior relationship. In many cases, the support that would be required would be 24 hour care or something similar. The unpaid carers mentioned that the person they support would most likely need both emotional and practical support if this sort of situation occurred:

- *"If mum died my stepdad would have to go in a home as can't look after himself, if I died mum would need more support from the family."*
- *"Support from another member of the family if I die."*
- *"My son will need 24/7 support with nearly every aspect of his daily life. He would need someone trusted to help him manage financially. He would need to be able to feel confident and comfortable with person, preferably a family member as he feels very let down and that he isn't understood by many professionals we have encountered and would need as consistent team as possible."*
- *"Someone else will have to step into the role for my parents and my son. Hopefully, his father although he had a severe stroke last year and I am the emergency contact for him. My siblings would have to organise and care for my parents, and the sibling who needs care themselves would have to rely on others."*
- *"Wife would need practical support with things like shopping."*

Some unpaid carers also mentioned that they would need grief and bereavement counselling, if the person they cared for passed away:

- *"If I died mum would need 24-hour care, for me grief counselling – definitely."*
- *"Grief counselling, as still haven't grieved for my dad who died two years ago, because I have to look after mum, think may end up grieving for both when she goes."*
- *"Possible bereavement support for short period."*
- *"Think there needs to be more grief support available widely... lots of people don't know what's out there."*

From the responses it was evident that this line of thinking was uncomfortable for many unpaid carers. But it also indicated that unpaid carers have to recognise that their role is not sustainable, so that developing contingency plans for several potential outcomes is necessary.

## Anything else?

Respondents were asked if they would like to share anything else with Healthwatch about their experience and thoughts of being an unpaid carer:

- There is a feeling that the Carers Allowance needs to be increased, especially in the current national economic situation ('cost-of-living' crisis).
- Several individuals did not initially consider themselves to be unpaid carers, but did fit the description.
- There is a feeling of 'lost identity' as some no longer know they are as individuals outside of being an unpaid carer.
- Some resent having to be an unpaid carer but do it because they love the person they look after and feel to some extent that it is their duty to do so.
- The amount of community centres offering social activities have gone down since the Covid-19 pandemic, and some unpaid carers feel that day centres need reopening.

# Section 4: Findings from focus groups

Further data relating to the demographics of the focus group participants of both adult and young unpaid carers can be found in appendix 3.

## Adult unpaid carers

There was a total of 15 participants, from 4 focus groups, that shared their personal experiences of being an adult unpaid carer.

	Number of participants	Where/Location?
Focus Group 1	2	Walney Warm Hub, North Scale, Teasdale Road
Focus Group 2	2	Barrow and District Dementia Hub, St Marys Living Well Centre, Duke Street, Barrow
Focus Group 3	5	Furness Carers, Friday
Focus Group 4	6	Carers' Café, Hindpool Road, Barrow

73.33% of the focus group participants consider themselves to be/have been (until recently) an unpaid carer. The other 26.67% of participants do not consider themselves to be an unpaid carer but do fit the NHS description. Those that did not initially identify as an unpaid carer, did not label themselves as such because they are looking after people they love.

Participants explained that they are willing to look after family members and be their unpaid carer because they love them and feel like giving back. Others did reveal that sometimes there can be feelings of resentment, as they feel forced into becoming an unpaid carer. Viewing it as something that they *“just have to do”* because of who it is that needs care, and they feel that they should and are expected to look after them.

All 15 participants were asked to rate their physical, mental and emotional wellbeing on a scale from very good to very poor.

	Very good	Good	Fair	Poor	Very poor
Physical wellbeing	0.00%	46.67%	46.67%	6.67%	0.00%
Mental wellbeing	0.00%	13.33%	53.33%	33.33%	0.00%

Emotional wellbeing	0.00%	6.67%	40.00%	53.33%	0.00%
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The participants all rated their physical, mental and emotional wellbeing as being either 'good', 'fair' or 'poor'. Participants rated their physical wellbeing to be overall better than their mental and emotional wellbeing. Furthermore, as a group these unpaid carers their emotional wellbeing seems to be slightly worse than their mental health.

Participants shared that it is physically, emotionally and mentally tiring to care for someone for a variety of reasons. Several mentioned that the amount of time that they dedicate to caring for someone, means that they do not have a lot of time left to spend looking after themselves, which has an impact on their own wellbeing. Some shared that they felt that their life/world has shrunk, with one individual sharing that they had to move into their mother's house to look after her.

A couple of participants mentioned that as a result of their condition/diagnosis the person they care for don't recognise them which has been difficult to deal with. While, others mentioned that they are constantly worried because sometimes those that they care for can 'turn' and their attitudes can become 'prickly', which is challenging.

Participants highlighted the importance of having support networks as an unpaid carer. Several had met friends and developed close bounds with people by attending support groups. They shared that with the time restrictions that being an unpaid carer imposes it can be difficult to maintain and develop new friendships, therefore meeting people through these groups who are going through the same experience is a good way to create connections and build a support network. Therefore, participants expressed that more social activities and support would be beneficial to them.

It was mentioned that a positive of being an unpaid carer was the quality time that they get to spend with their loved ones. Several unpaid carers mentioned that they were still able to have a 'laugh' with those that they care for. One participant shared that their husband (who she cared for) had recently passed away and as a result she was diagnosed with depression. She had dedicated so much of her time and energy into caring for him, when he died, she felt really 'lost'. But the bereavement counselling she has been receiving has helped immensely.

Several participants shared that they had discussed plans with the people they care for concerning end of life, including wills, funeral plans, and power of attorney. However, for the unpaid carers themselves, they shared that if anything was to happen to them, other family members would have to support the person they care for.

One unpaid carer did express that getting the mental health diagnosis for the person they care for has been a real challenge for them. Other participants had issues with accessing services, mainly being unable to get GP appointments, however they shared this was not because of their caring responsibilities.

## Young unpaid carers

There was a total of 4 participants ages ranging from 8 to 11, from a single focus group, that shared their personal experiences of being a young unpaid carer.

	Number of participants	Where/Location?
Focus Group 1	4	Tuesday Young Carers half-term multi sports session, Furness Carers, Hindpool Road, Barrow

Only 1 out of the 4 young people consider themselves to be an unpaid carer. The other 3 do not but do fit the NHS description. All four had been assessed as having caring responsibilities and two of these also had siblings caring for them – co-dependency caring.

From the conversation, it was evident that all participants had emotional issues around their caring responsibilities or their family circumstances.

Participants shared the ways that they care for other people:

- *“I care for my younger brother who has epilepsy, autism and is nonverbal. Her brother is younger than her. I help him when he has a meltdown, I play with him and put him to bed. I’ll sit with him when we go out to keep him company.”*
- *“I care for mum and also dad, I look after them and care for them, I remind them about their tablets and make sure they’re happy.”*
- *“I care for my brother who has an autism diagnosis, I play with him. I also look after my mum, she’s had heart attack and now has a new Fitbit type watch. It checks her heart, so she knows if she’s having a heart attack. I clean up like the kitchen.”*
- One of the participants had been assessed as caring for their mum but didn’t seem to realise this.

The participants were asked about how they feel lately concerning their daily lives (including being an unpaid carer), they responded:

- Two said that they were happy,
- One said they were a little bit sad,
- And the other said they felt shy.

Participants were asked if they had any worries or found anything hard when looking after someone else. One participant mentioned that they get worried when *“my brother gets into trouble with his autism and kicks off. I worry I will get blamed for it too. I worry about mum as she’s had heart attack.”* But she also mentioned that her dad worries about her.

Another participant shared that she finds it difficult *“when my brother attacks me I find that difficult. He’s only playing but he’s too strong and doesn’t know he is. I say “Excuse me” to him to let him know.”*

Three participants expressed that they would like to have more social activities. With one individual sharing that meeting new people worries them and can be difficult for them.

Three participants expressed that they would like to have more social activities. With one individual sharing that meeting new people worries them and can be difficult for them.

# Section 5: Conclusion and Recommendations

The aim of this project was to listen to and share the experiences of unpaid carers in South Cumbria (including Millom), with the purpose of highlighting what it is like to be an unpaid carer in the area.

HWC engaged with a total of 76 unpaid carers, via 47 case studies, 10 independent survey responses, and 5 focus groups (with a combined total of 19 participants). The unpaid carers were a mix of adults and young carers, who provide care to children, young people and/or adults.

It was evident from the experiences shared that being an unpaid carer is challenging and often tough for people. It can be emotionally and mentally draining, with many spending so much of their time and energy looking after someone else, they don't have the capacity to take care of themselves to the same degree. Because of the amount of time they spend with the person they care for, they can lose their own identity outside of being an unpaid carer. Meaning in some cases they do not feel that they are living the life they want, and for some this can lead to feelings of resentment towards the situation.

It was highlighted that being an unpaid carer can feel very isolating, as their social life can decline and therefore so does their support network. There are support services in the area, and many know about them however this does not always translate into unpaid carers being able to access the support. But the support cannot stop once the person who is being cared for has passed away, as for the unpaid carer this creates a big hole in their life and can leave them feeling very lost. Therefore, grief counselling is also very important.

## Recommendations

The following is a list of recommendations based on the feedback given by unpaid carers, to suggest what can be done to help improve their lives:

1. Increase public knowledge on the definition of an unpaid carer and their rights, so that individuals realise that they fit this description and thus be more inclined to access the support available to them.
2. On an individual's medical record flag if they are an unpaid carer, so that health services are aware and are able to accommodate reasonable adjustments (such as times of appointments).
3. Raise awareness of unpaid carers in organisations, especially in large employers and anchor institutions (such as the NHS and Local Authority Organisations), so that employers can accommodate reasonable adjustments.

4. Increase the social activity offers for both the people being cared for (allowing respite time for unpaid carers) and for unpaid carers themselves (to support them to increase their social lives).
5. Promote and signpost the support services in the area, what they offer and how to access them (i.e. if there is eligibility criteria).
  - make sure the process to access services is as simple, quick and easy as possible so it is not a time consuming process.
6. Free professional carer training to be offered to unpaid carers so that they can further develop their skills and get tips on handling different situations (such as dealing with difficult behaviours, conditions, etc.).
7. Promote emotional wellbeing techniques to unpaid carers, to help with improving their emotional wellbeing.
8. Increase amount of time unpaid carers have for themselves, by increasing the respite and practical unpaid carer offer in South Cumbria.
9. Advertise the financial support that unpaid carers can access and support them in obtaining this support.
10. Support unpaid carers and those they care for to create and develop an end of life plan. Help to facilitate conversations about advanced planning, and crisis contingency.
11. Signpost and offer unpaid carers bereavement counselling when the person they care for passes away.

### Next steps

This report has been and will continue to be shared. It has or will be presented to:

- The project group
- Lancashire and South Cumbria ICB through the Patient Involvement Engagement Advisory Committee (PIEAC)
- Westmorland and Furness Council
- The public via Healthwatch circulation (including newsletter and website)

The report will be continually updated with any system response and republished on the Healthwatch website with the latest version, and shared with Healthwatch England.

Lancashire and South Cumbria ICB and Westmorland and Furness Council, will review the report and consider the recommendations, agreeing a plan of action on how to deliver on the changes highlighted.

Healthwatch will revisit this project at the start of 2024 to determine what the impact has been and access the improvements to the lives of unpaid carers in South Cumbria.

### A provider response from a Carer Organisation Support Service

Furness Carers, Carers Support South Lakes and Carer Support West Cumbria work together to provide support to unpaid carers across South Cumbria. Furness Carers have been part of the project group and have contributed to the facilitation of this project. They have provided the following response to the findings:

*“Across the South Cumbria area, the three dedicated Carer Support Organisations work together with other specialist condition/illness related organisations, to provide support to unpaid carers in the area. This includes, providing a variety of social and respite services, raising awareness of unpaid carers, promoting emotional wellbeing techniques through their website and facilitated sessions, and providing training for carers. On average, in a year only 10% of known Unpaid Carers are referred or access Carer support services. Thus, more work is required in ensuring Carer support services are promoted, signposted or referred to. An established systematic approach towards referrals would help to improve this. Furthermore, as highlighted in the report, there is a need for more support to be made available to unpaid carers across South Cumbria, particularly within rural settings. This includes more coproduction work to be done and ensuring that during the Carers Assessment process when staff look at each case individually, they are effectively signposting and supporting unpaid carers to access the support they require.”*

# Section 6: Acknowledgements

Healthwatch Cumbria (HWC) would like to thank the NHS Lancashire and South Cumbria Integrated Care Board (ICB) for commissioning this project, and the project steering group for their support and guidance.

We also thank all the organisations that helped to make this project possible by circulating the survey, sharing details on their social media channels and allowing us to host pop up events in their premises or focus groups in with their group members.

- Furness Carers
  - Furness Carers Friday Carers Café
  - Young Carers holiday activity session
- St Mary's Living Well Centre (Barrow-in-Furness)
  - Learning disabilities coffee afternoon
  - Barrow dementia hub drop in
- North Scale Community Centre
  - Warm Hub
- Walney Community Centre
  - Stitchability group
- HARRI bus
  - Asda, Walney Road
- Millom Health and Wellbeing Expo
- Furness General Hospital
- Barrow Market
- Ulverston Market
- Carers Support South Lakes
- Admiral Nurses, UHMB Foundation Trust
- Barrow ICC and Community Development Team
- Community Enterprise Catalysts

Finally, we thank all the people who contributed to this study by sharing their personal experiences, including those who took part in the survey, case studies and focus groups.

## References

NHS England: Who is considered a carer?

<https://www.england.nhs.uk/commissioning/comm-carers/carers/#:~:text=A%20carer%20is%20anyone%2C%20including,care%20they%20give%20is%20unpaid>

Office of National Statistics: Census 2021, Provision of unpaid care

<https://www.ons.gov.uk/datasets/TS039/editions/2021/versions/3>

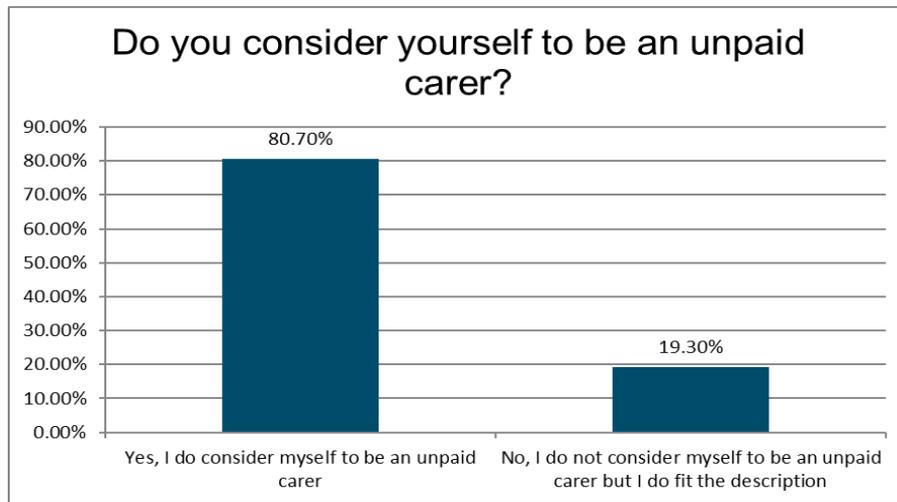
# Section 7: Appendices

Appendix 1: Table showing the project timeline and details of activities undertaken

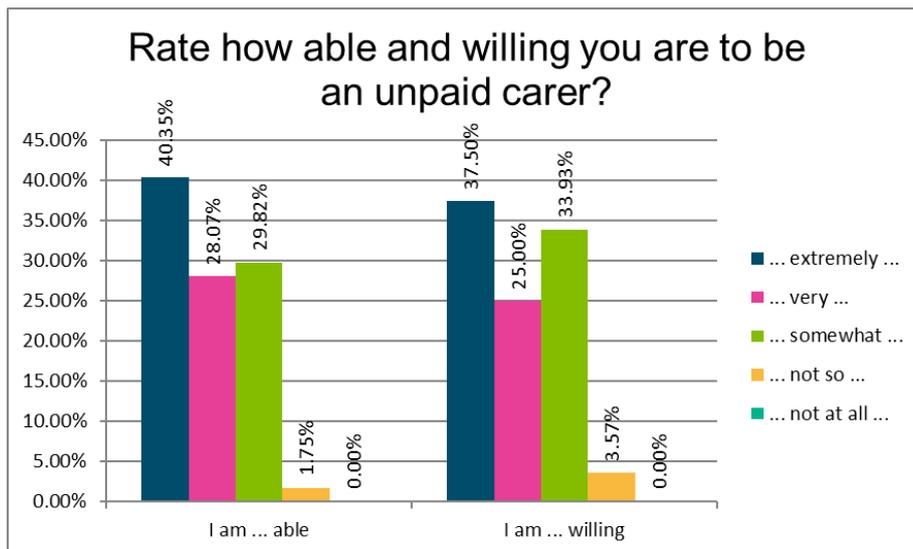
Phase	Timescales	Activity
<b>Mobilisation</b>	December 2022	Finalise Project Brief
		Coordinate Steering Group
<b>Engagement</b>	January – March 2023	Facilitate focus groups/Case studies
		Pop up engagement
		Online survey goes live
<b>Analysis and Draft Report Sign off</b>	March – April 2023	Analysis and Draft report compilation
		Draft report circulated to ICB/Place Based Partnership and project steering group for comments and feedback
		Draft Report update
		Report sign off by South Cumbria Place based Director of Health & Care integration
		Final report ready for presentation
<b>Showcasing</b>	April – May 2023	Final report to be presented to the Patient Involvement & Engagement Committee (PIEC)
		L&SC Carer Partnership Group

Appendix 2: Graphs illustrating the background and demographics of online survey respondents  
 Survey respondents background questions are 1 to 9 and their demographics are questions 27 – 31.

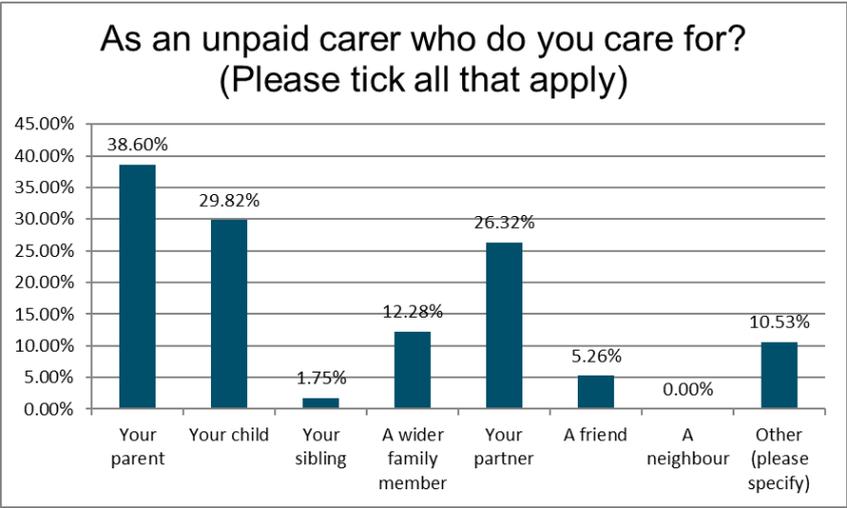
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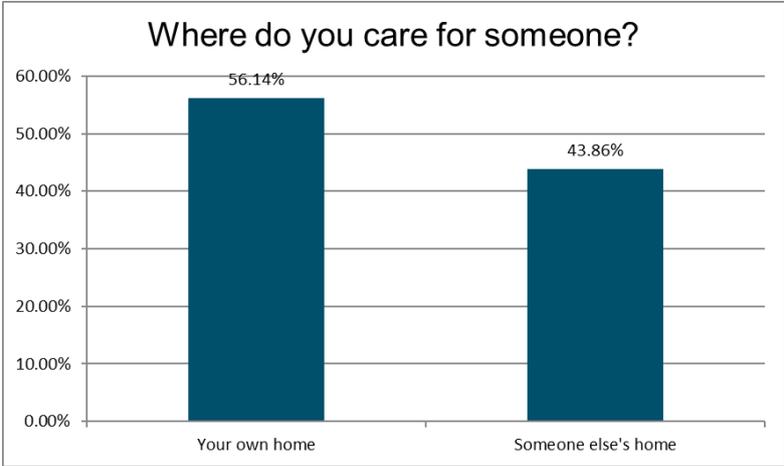
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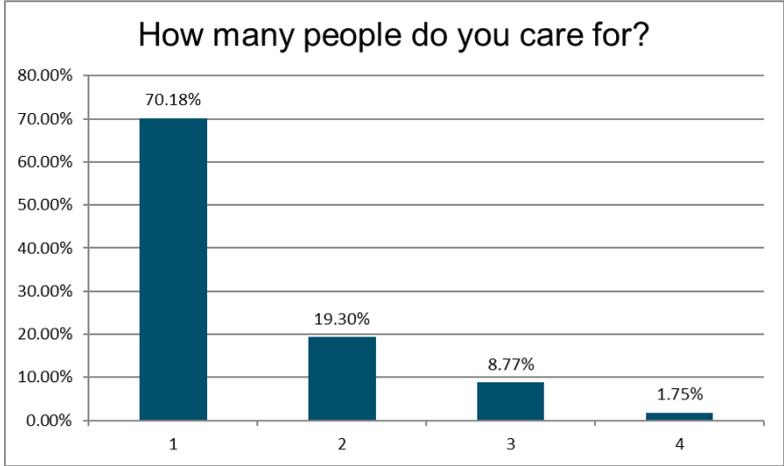
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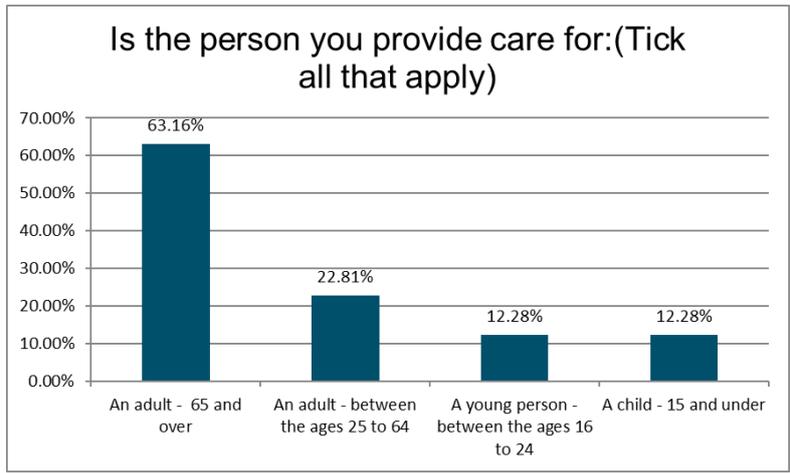
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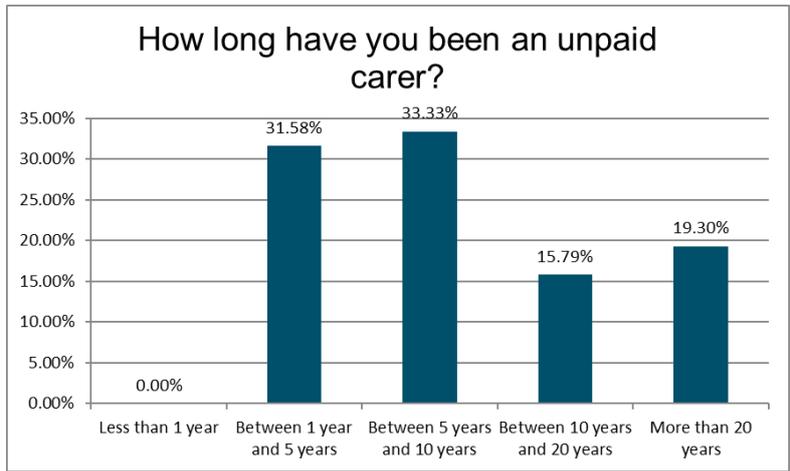
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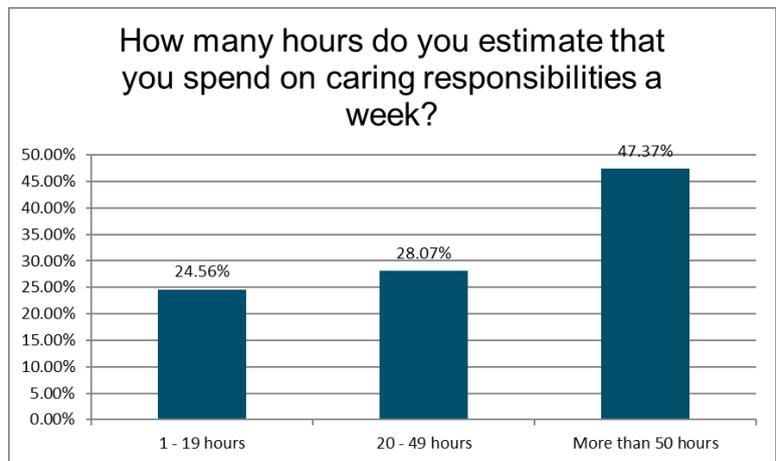
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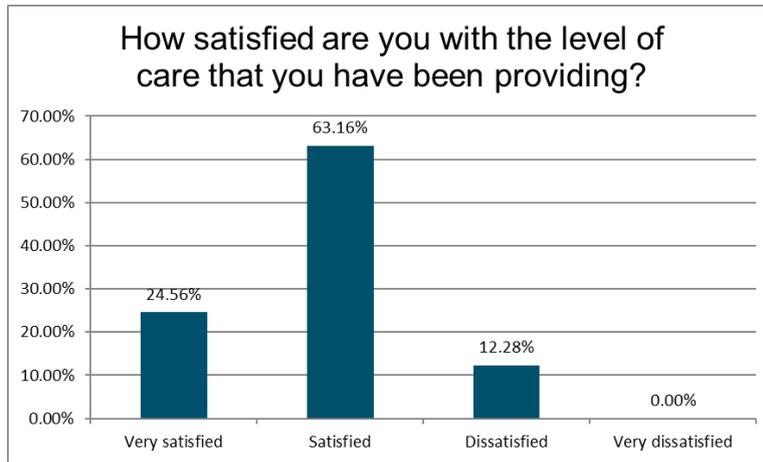
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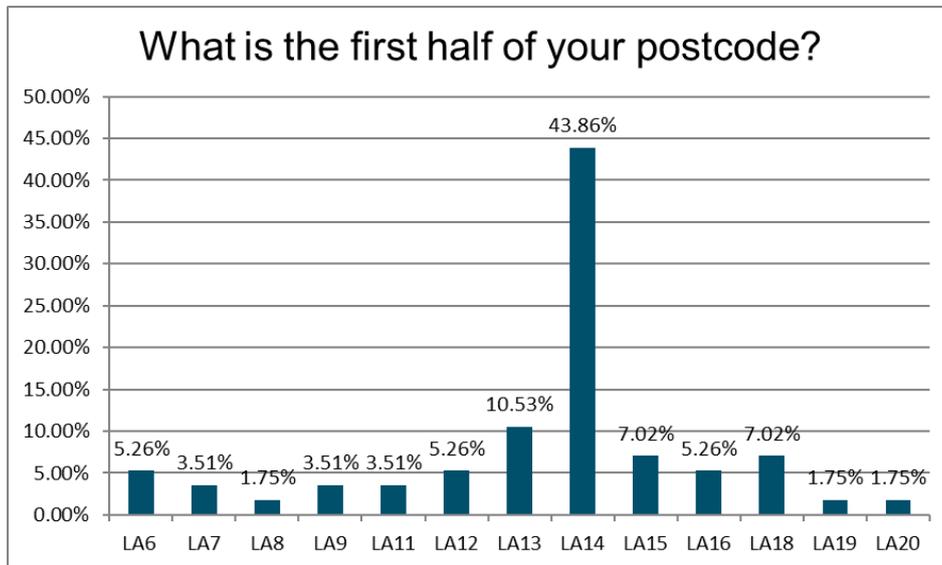
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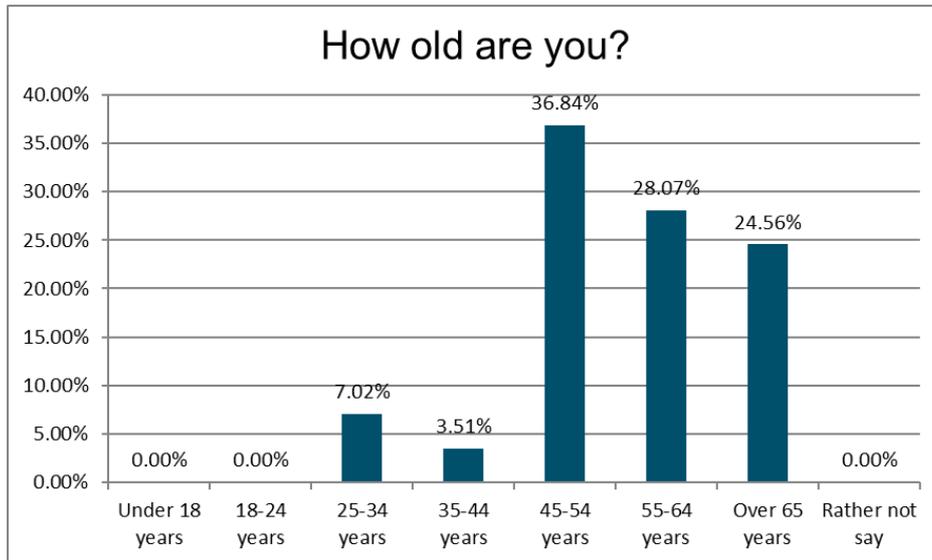
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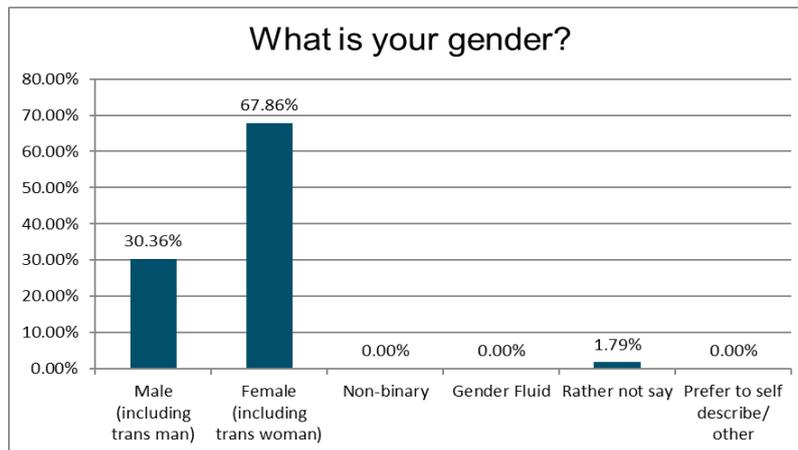
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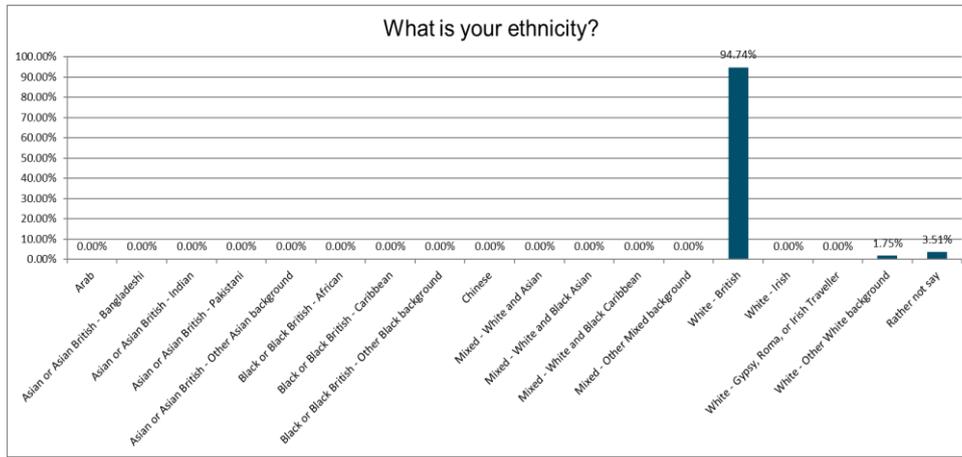
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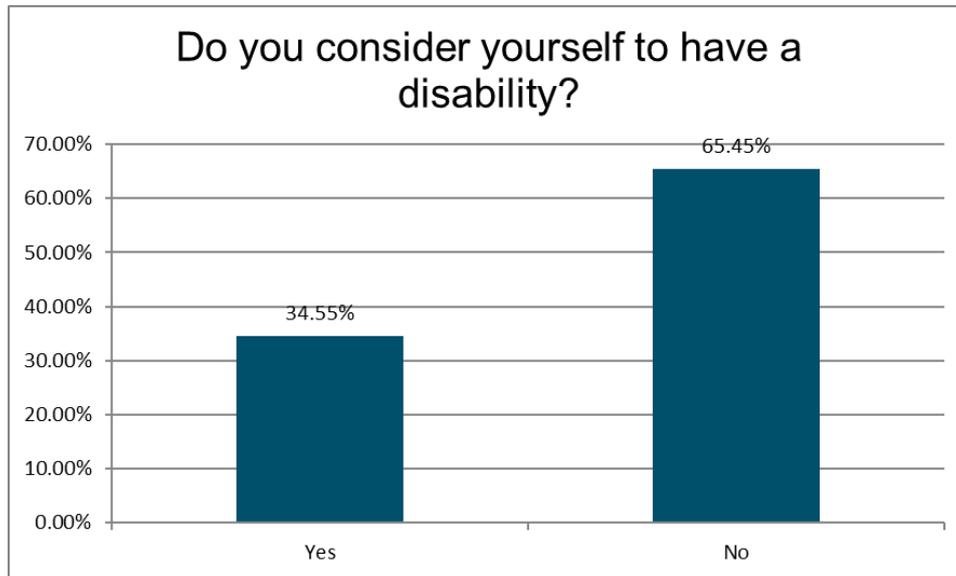
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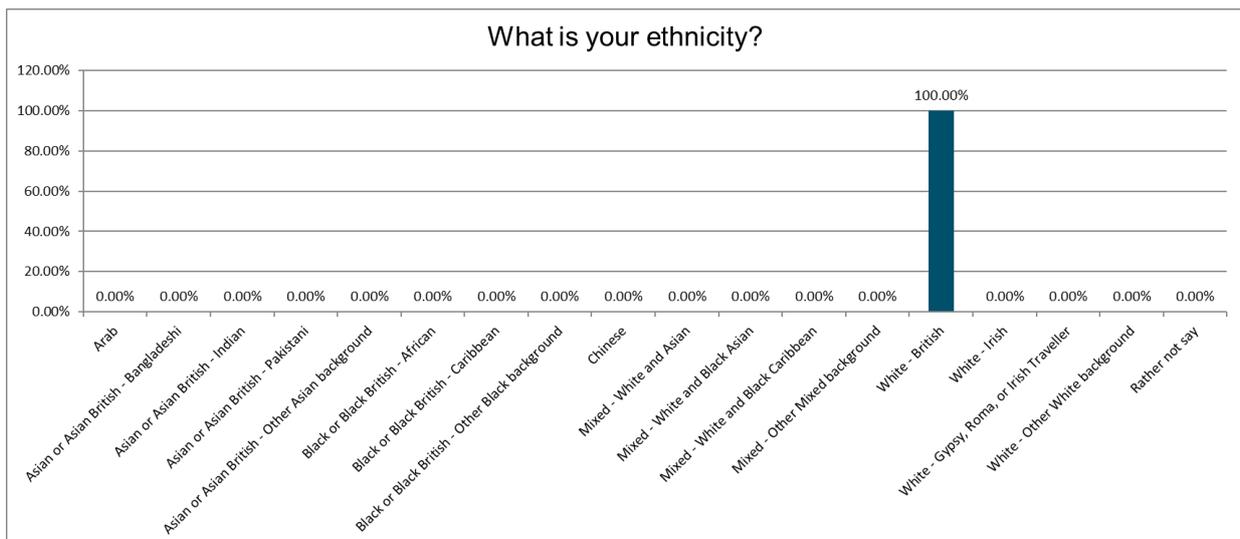
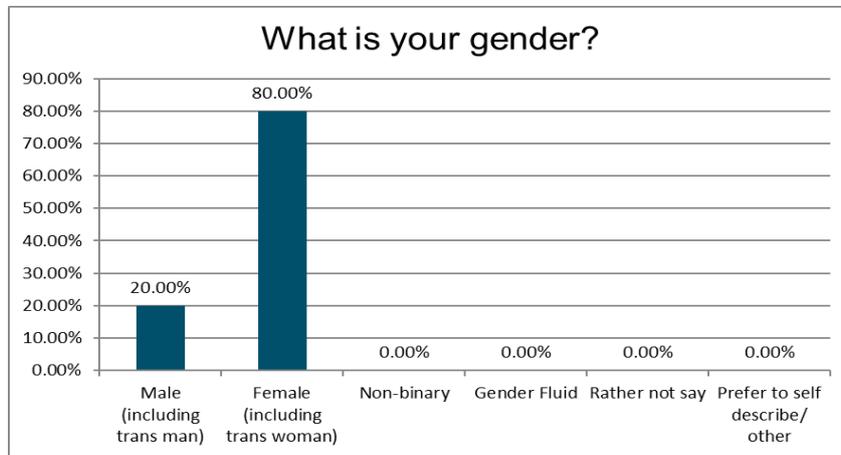
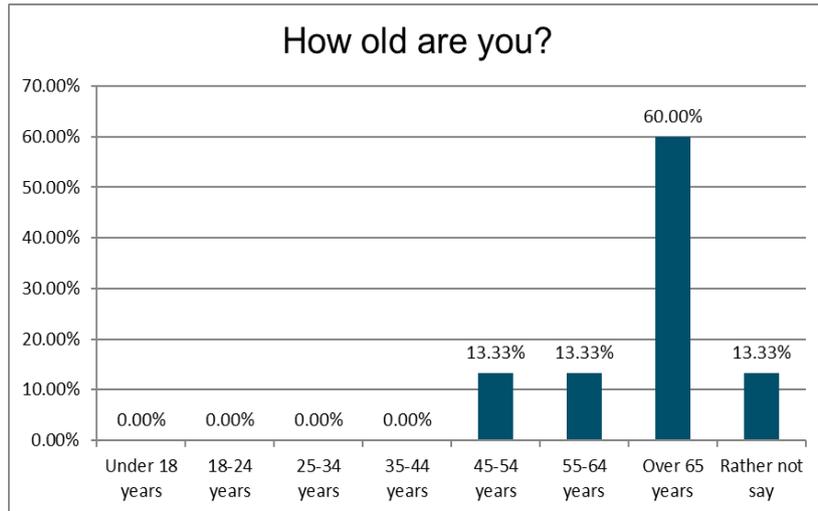


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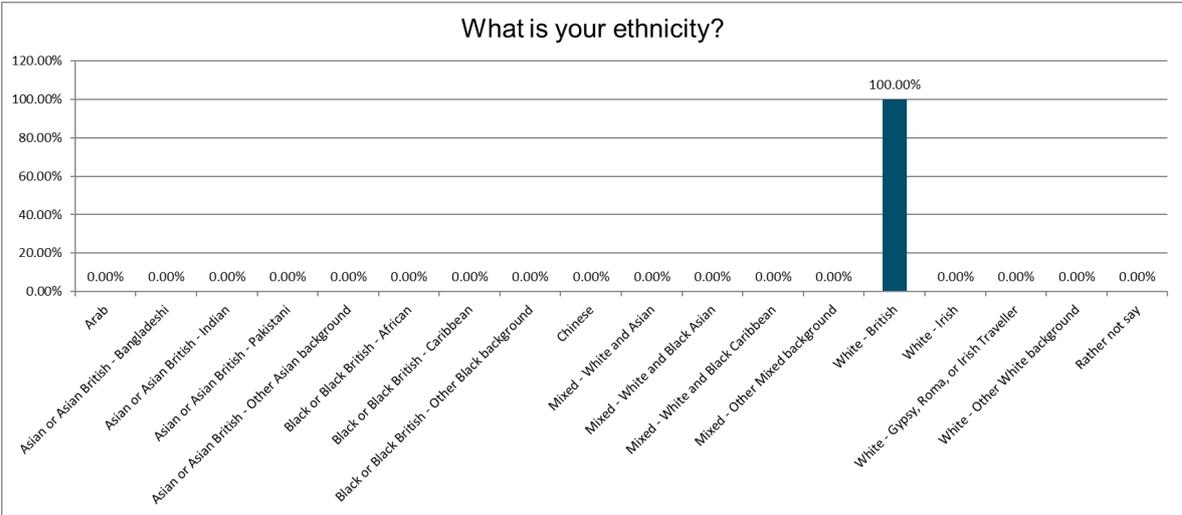
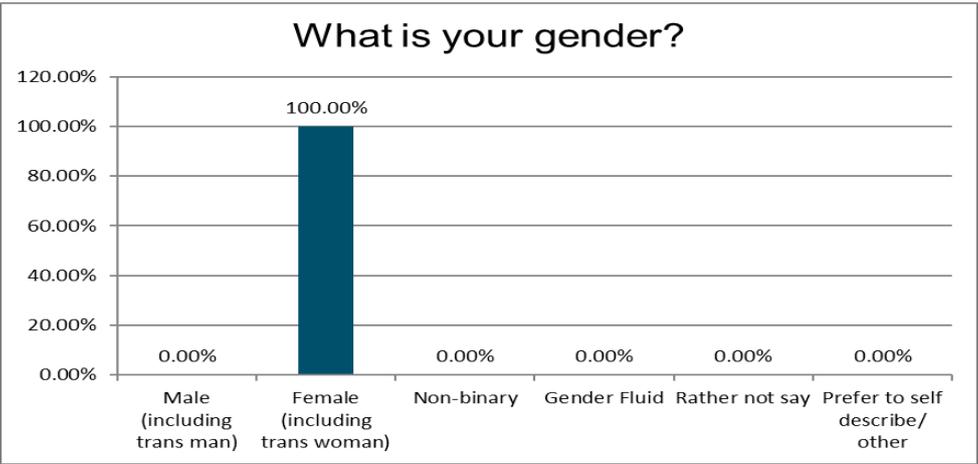
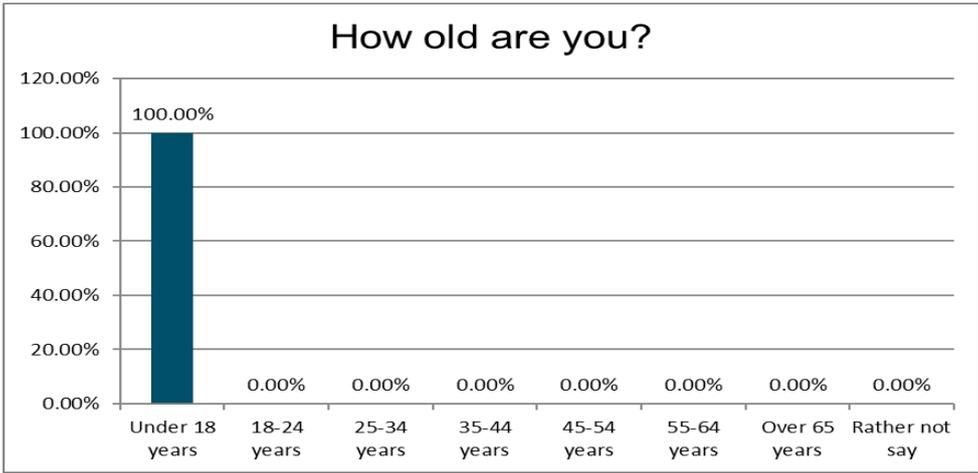


### Appendix 3: Graphs illustrating the demographics of focus group participants

Adult unpaid carer demographics:



Young unpaid carer demographics:





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