Research

Community Participatory Action Research 2: 2023-2024

How has the cost of living crisis affected people with a dementia diagnosis and their families?

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Contents

Executive Summary

The research was based in the dementia community in Hampshire and the research question was ‘How has the Cost of Living Crisis affected people living with dementia and their families?

Method

We started with a focus group and then developed a survey and a questionnaire for face to face interviews. We had 100 responses to the survey and carried out 6 face to face interviews to gain deeper insight. The vast majority of participants lived in Hampshire.

Findings

The cost of living crisis has affected the dementia community in many ways. It has altered the way people shop, now purchasing in less expensive supermarkets, reduced items and ‘own’ brands. Only half of the participants have had a holiday in the last 2 years. Routine health checks (dentists, opticians, hearing, chiropody etc) have reduced and this will have the knock on effect of poorer health in the future. Although 79% of people surveyed still travel by car 45.9% are concerned about travel costs. The financial concerns have also shown a potential increase in social isolation as participants have reduced the number of visits to social spaces. Those diagnosed with Young Onset Dementia have been dramatically affected financially. Concerns about paying for basics such as food, mortgage and days out, have also had a huge impact on the quality of life for the whole family. The fear of losing their home due to the loss of salaries impacts on all financial decisions.

Key Findings

There were 3 main findings from the research.

Cost of Care now and in the Future

Firstly the cost of care now and in the future. This is affecting how people live now as every spending decision is from a background of concern about finances today and their way of life for the future.

Quality of Life

The quality of life of those with a diagnosis and their families is affected by the cost of living as this prohibits their ability to spend on anything that is not essential. The inability to fund hobbies, have an independent life, socialising and getting out and about has an immense impact on their quality of life. This may lead to poor physical and mental health and wellbeing that will have a knock on impact on themselves as well as the NHS and Social Care.

Young Onset Dementia

Young Onset Dementia has a disproportionate impact on families affected. Those with this diagnosis often have young families, are still working and may have a mortgage. The concern about the diagnosis itself, and the fact that it is life limiting, is only part of the devastating impact. At a time when families should be making memories, everything they do and the decisions they make are underpinned by fear and the future financial situation.

Actions

- Government policy changes to address the care funding crisis
- Improved access to financial planning and information
- Timely Financial, Carers and Care assessments
- Informed funding for existing projects as well as new projects in the VCSE sector
- Care Funders to be more flexible and imaginative to look at alternative solutions for care

1. Introduction

Recapture Life CIC was set up as a response to the perceived low level of support for people with dementia and their families. We have developed Cognitive Stimulation Therapy (CST) groups for the person with a diagnosis. CST is a researched and evidenced intervention that helps to slow the progression of dementia. Katie and Lesley carry out these groups in the community and this also provides weekly 3 hour respite for the unpaid carers (wives/husbands/family).

“We were very keen to be involved in Community Participatory Action Research for the Dementia Community. We decided on a research question early on and that is “How has the Cost of Living Crisis affected people with a Dementia diagnosis and their families.”

The Founder of Recapture Life, who was the Lead and also a researcher, Lesley Barton, has lived experience having lived with her mother with Alzheimers, and has also worked in the dementia community for many years.

Katie Dodds, Director Recapture Life, has been working in this area for a few years and also has a relative with dementia.

Jane Ward, Dementia Friendly Hampshire, who was one of our researchers, also cared for her mother with Vascular Dementia and has vast experience in dementia and has been involved in dementia research for over 15 years.

This research investigates the effect that the cost of living crisis has had on people with dementia, their informal carers and family. The second iteration of the Community Participatory Action Research (CPAR2) programme provides community groups in the South East of England with training and mentoring support in order to plan, carry out and use research for the benefit of their community. CPAR 2 is funded by the Workforce Training & Education Directorate, NHS England South East and facilitated by Reading University and the Scottish Community Development Centre (SCDC). Reading University arranged the training of the researchers and the SCDC provided support and mentoring of the researchers.

2. The Research Proposal

The focus for the research was the dementia community in Hampshire, meaning any person who had been directly impacted by a dementia diagnosis. We included people with a dementia diagnosis, their unpaid carers which may be a partner, sibling,or adult children and wider family. We did not include any family members under the age of 18 or any parents of a family with a diagnosis. The research was undertaken between August 2023 and April 2024. It is estimated that two thirds of people with a dementia diagnosis are living in the community.

The current number of people with dementia in the UK is 982,000 and is anticipated to be 1.4 million by 2040. In Hampshire the number is 16,766 according to the Alzheimers Society. The Alzheimer's Society also reports that 1 in 3 people with dementia don’t have a diagnosis. This means that there could be over 25,000 people with dementia living in Hampshire.

The Alzheimer's Society 2024 report includes the following:

- A high percentage of the costs of dementia, estimated at 63%, are borne by patients and their families.
- By 2040, 43% more people are expected to receive unpaid care. A third of dementia carers report spending more than 100 hours a week in unpaid care.
- By 2040, 76,000 more people with dementia are projected to live in a residential home and 30,000 more in a nursing home. Already more than half of social care providers report challenges recruiting new staff.
- Nearly 50% of people fully fund their own residential and nursing care.

It is well documented that people and families with a dementia diagnosis are very concerned about the cost of care and what the financial implications are for the future.

3. Research process and methods

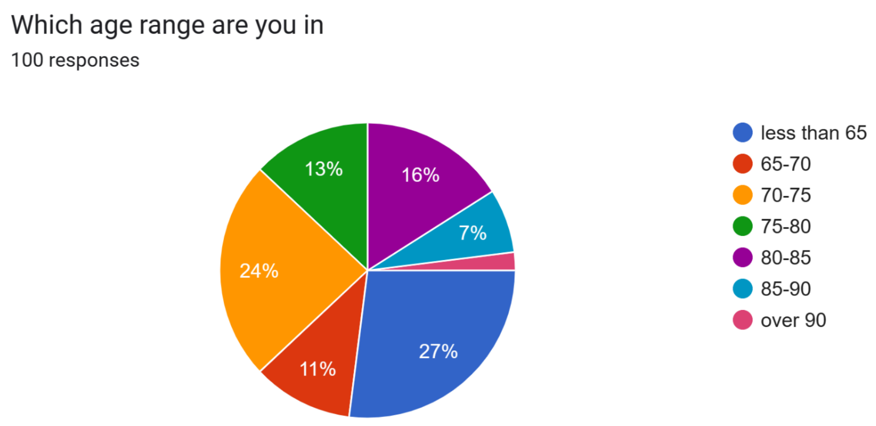
There were 3 Researchers, 2 from Recapture Life CIC and 1 from Dementia Friendly Hampshire.

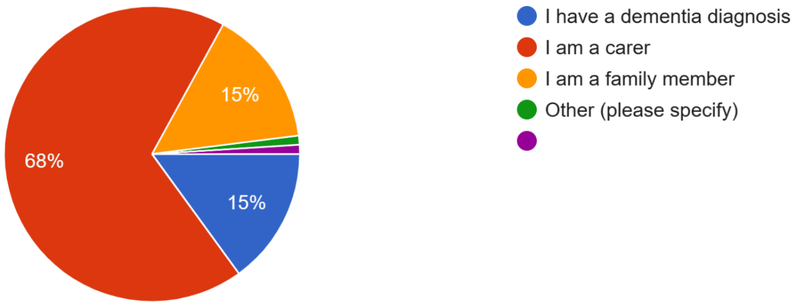
Initially we set up 2 focus groups to identify the main focus for our research. Following consultation with Dawn from SCDC we decided upon using surveys and individual face to face interviews as we felt there was a need to provide both qualitative and quantitative data.

The surveys were produced in both paper form and online in order to reach as many participants as possible. The paper copies were available for those who did not have internet access and were taken to groups dedicated to people with a dementia diagnosis and their carers. We supported people with the completion of the forms and gathered more information from the conversations around the surveys. The online forms were sent out to current contacts and posted on social media. 100 responses were received which combined both paper and online surveys. The surveys were completed anonymously. The demographics of the areas we covered are shown in appendix 6

The survey asked 20 questions appendix 1. With the interviews we had 5 open questions which allowed us to to delve into more detail with the participants and gain more information.

68% of participants were unpaid carers and 27% were under the age of 65.





Please select one of the following options.

100 responses

The 6 individual interviews were undertaken face to face or via zoom. They included both people with a diagnosis and their carers, including couples where possible.

As part of the research we also spoke to some Domiciliary Care providers one of which responded.

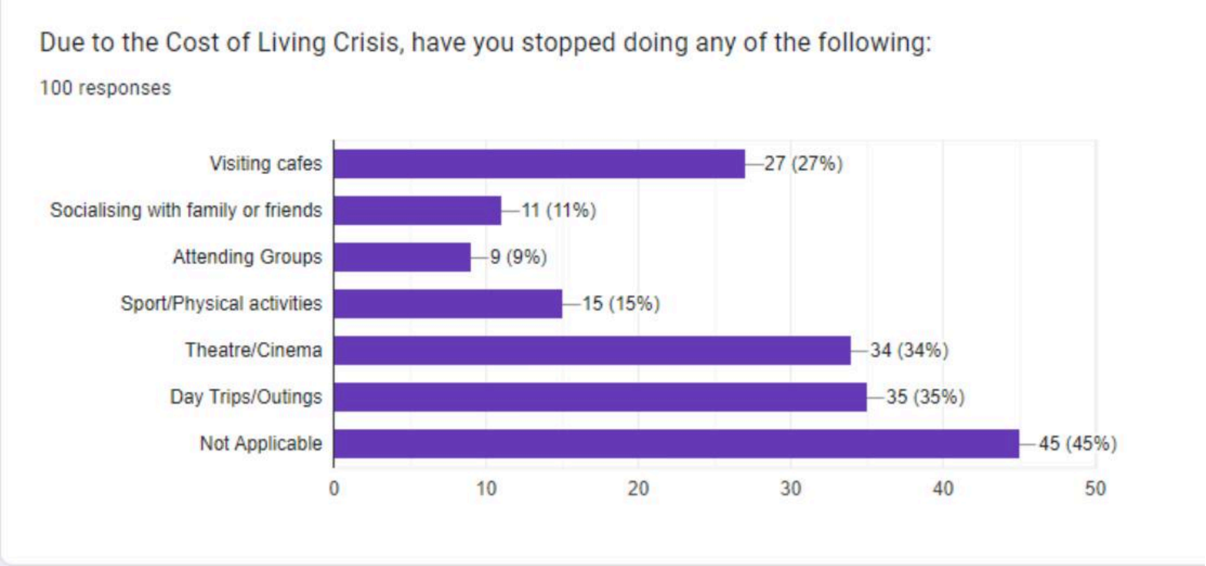
4. Research findings

The research findings are shown below. We produced a survey using Google Forms to enable us to show our data in the form of graphs or charts. Some questions were open for the participants to select more than one answer.

Socialising

For many people affected by dementia their social life has declined hugely since the diagnosis. Our participants were wary of how other people would react to the dementia diagnosis and the carer often worried if they would be able to cope with the person with dementia. Incontinence and fear that their partner may get lost in unfamiliar surroundings were other issues which impacted on their confidence to go out socially.

In addition you can see from the figures below, the majority of people are not going out as much as they did due to financial constraints, although 45% said that the cost of living crisis did not stop them from going out.


Due to the Cost of Living Crisis, have you stopped doing any of the following:

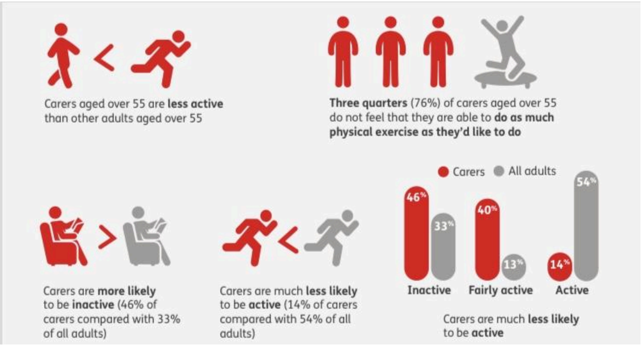
100 responses

A recent study has found that people who are socially isolated had lower brain volume in regions associated with learning and thinking. These brain regions are typically among the first to be affected by Alzheimer's, the most common cause of dementia. The data shows that people who were socially isolated were 26% more likely to develop dementia compared to those who are not. For those who already have a diagnosis of dementia, social isolation will cause their cognition to deteriorate more rapidly. Similarly UCL researchers have found that people who are socially engaged when middle aged and beyond are 30-50% less likely to develop dementia later on.

15% have reduced their sport/physical activities due to the cost of living crisis - this is in addition to an existing issue for carers. A study by CarersUK of the barriers, motivations and experiences of unpaid carers aged 55 and over in England found that carers over 55 are already likely to be less active than non-carers over 55.

(Carers and physical activity: A study of the barriers, motivations and experiences of unpaid carers aged 55 and over in England. Research by CarersUK, funded by The National Lottery and Sport England.

ISBN Number ISBN - 978-1-9161712-5-1 Publication code UK4091_0421)


Carers aged over 55 are **less active** than other adults aged over 55

Three quarters (76%) of carers aged over 55 do not feel that they are able to **do as much physical exercise as they'd like to do**

Carers are **more likely** to be **inactive** (46% of carers compared with 33% of all adults)

Carers are much **less likely** to be **active** (14% of carers compared with 54% of all adults)

Carers are much **less likely** to be **active**


Top reasons carers would take part in physical activity:

- Better physical health
- To relax/ unwind
- Better mental health

Biggest barriers to physical activity:

- **Not having the time** to take part in physical activity (88%)
- **Not being motivated** (71%)
- **Not being able to afford the costs** (67%)
- **Not having anyone to go with** (59%)

For active carers, a pattern of being active...

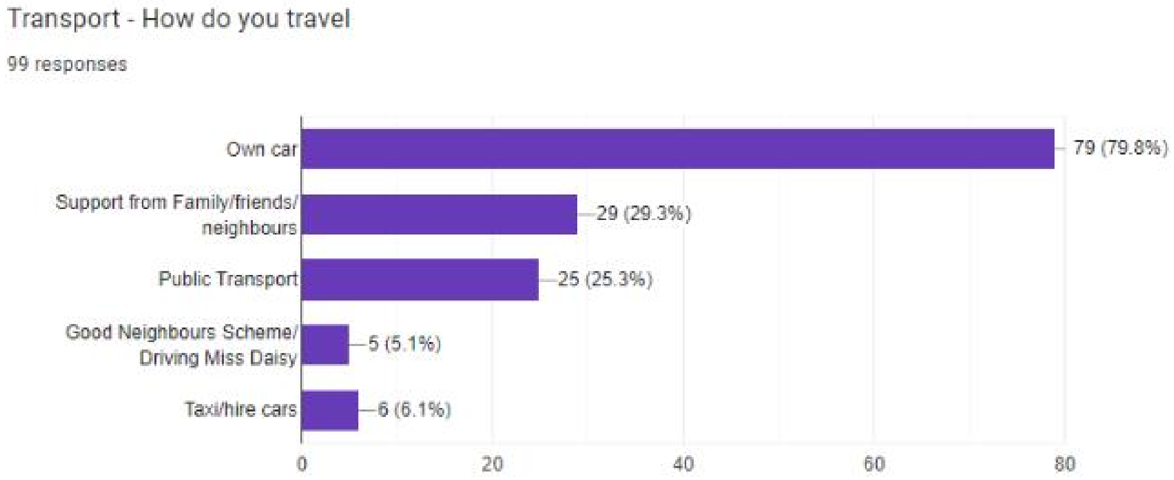
Leads to an increase in:
• Life satisfaction • Happiness
• Feelings of worthwhile

Leads to a decrease in:
• Anxiety

A common thread between their research participants was lack of, insufficient or poor quality replacement care, meaning that they do not feel able to take a break from their caring role.

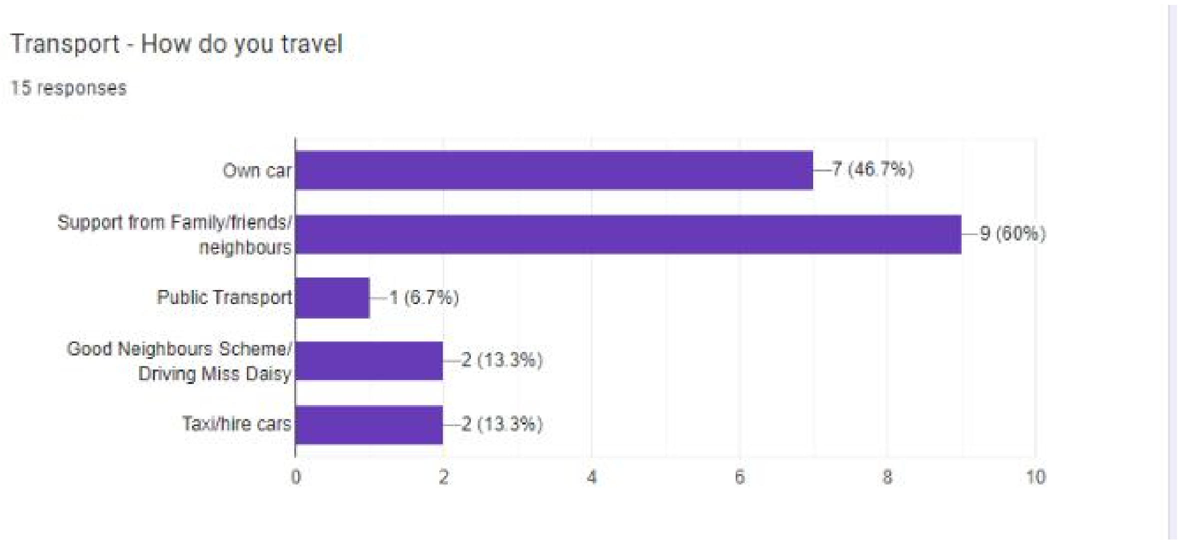
One of our participants is going to the gym three times per week but needs to pay an additional £80 per week simply to pay a carer to be with her husband. She feels guilty for wanting her own time. She is also stressed as this funding comes out of future care costs.

Transport



Although 79% of participants have their own car, only 35.7% did not state concern about the cost of transport. 39.8% were concerned about being able to continue to run the car in the future. 4.5% have already considered giving their car due to cost. In this study and a previous one predominantly people attending support groups use their own car. 16.3% have stopped going out because of cost of transport
Almost a third of participants rely on support from family, friends and neighbours while only a quarter use public transport.

When we looked at the results for the people who had a diagnosis of dementia (subgroup), the proportion who had their own car reduced to 46% while 60% relied on family, friends and neighbours.Only one participant with dementia used public transport.



Shopping

We asked if their shopping habits had changed due to the cost of living. 75% said that their habits had changed.

Holidays

- 49% have had a holiday or break in the last 2 years
- 56.7% are concerned about costs of holidays
- 51.5% are concerned about the journey
- 49.5% are concerned about coping in an unfamiliar place

Paying for Help in the House or for care

Over half of the participants do not pay for any help in the home whether this be a cleaner, home help or gardener. Only 14.3% have a carer coming in to help the person with dementia.

- 57.6% do not pay for any help at home or for care
- 31.9% have a cleaner or home help
- 27.5% pay a gardener
- 14.3% will have a carer and this may include personal care
- 14.3% go to a Day Centre
- Of those people who do not pay for any support at home
    - 29.7% did not think they needed any help
    - 15.4% cannot afford any help
    - 15.4% are putting off paying for help *
    - 3.3% can't find the right person
    - 1% the person with dementia refuses to have help

* In response to this information we sought a different perspective from a local Domiciliary Care Provider who stated

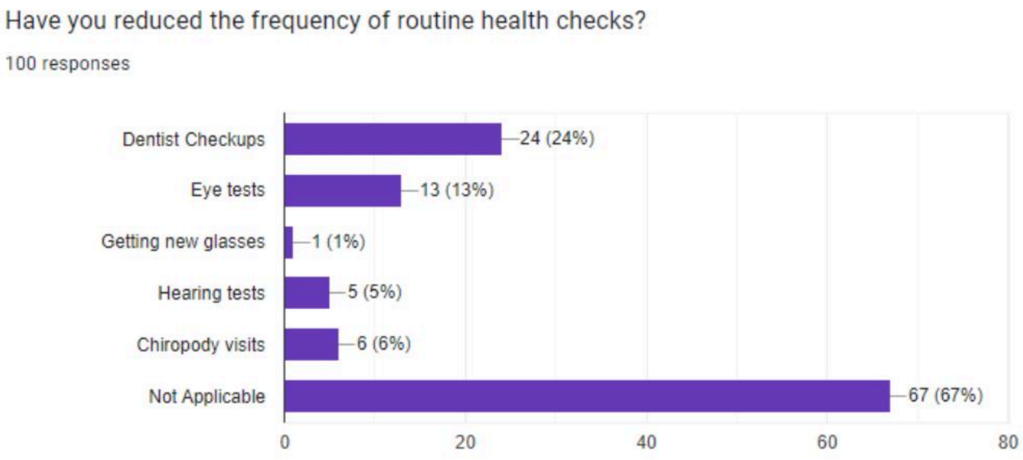
- Average tenure of client has reduced from 42 months to 11 months 2014 v 2024
- Significant shift in the type of care being commissioned; 2014 65% of our delivered care hours were companionship v 20% in 2024
- Clients are more significantly complex in their needs when we start care; average hours per client is x 4 2024 v 2014

Anecdotally they found

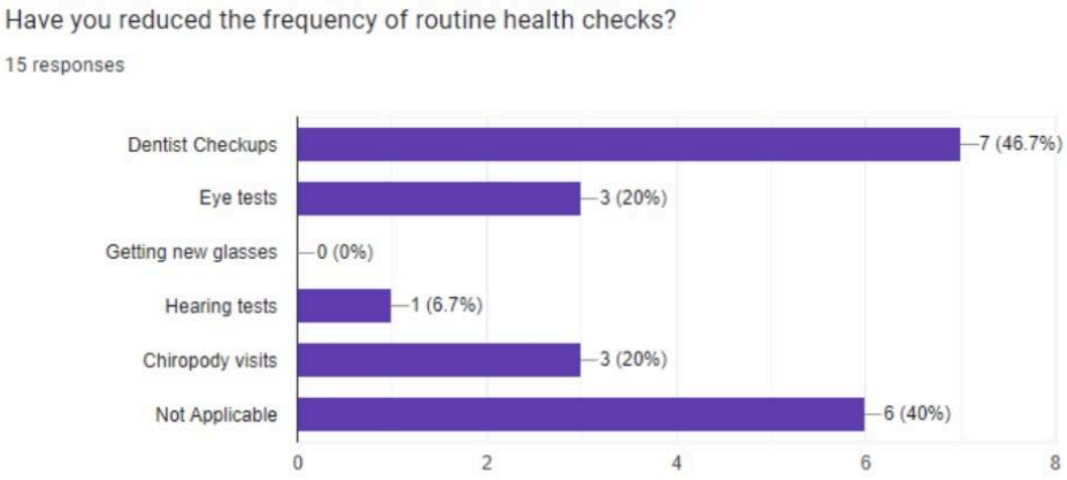
- Affordability is a key issue and this has become especially acute in the past 12 months
- Enquiries are very obviously more price sensitive in the past 12 months
- Affordability is different from price sensitivity; enquirers are often choosing private care options from unregulated carers v any regulated provider
- Increasingly people have been relying on informal shared family support before commissioning professional support
- Live in care has seen very significant growth in the past 18 months; families commissioning care are more evidently reluctant to choose a residential setting citing COVID visiting restrictions as a primary issue
- Securing a face-to-face needs assessment from the Local Authority, which the Care Act requires them to provide, is the exception post COVID rather than the norm pre COVID

- Needs assessments are increasingly being completed by telephone and the outcomes are variable at best

Routine Health Checks



Although it is reassuring that 67% of participants overall have not reduced their regular health checkups, it is a little concerning that within the subgroup of people with a dementia diagnosis, this reduces to 40%.



Almost half have reduced the frequency of the dental checkups. Poor oral health leads not only to dental decay and gum disease, but is increasingly being linked with a number of general health conditions such as diabetes, heart disease, dementia and, most often, pneumonia. Severe toothache, other mouth pain or an infection can also put you at higher risk of delirium.

Everyone should have regular sight tests to check their vision and eye health. Sight tests are especially important for people with dementia because the symptoms of dementia might mask the symptoms of sight loss. People affected by dementia can often experience difficulties in understanding their environments and this can lead to increased risk of falls and with it a loss of confidence in going out.

Evidence suggests that managing hearing loss could reduce or delay the impact of dementia. It's therefore important to check your hearing regularly. Over 40% of people over 50 have hearing loss, so checking your hearing in mid-life is especially important. Hearing aids can significantly increase people's ability to take part in everyday life and communicate with friends and family, improving people's wellbeing. This potentially reduces the risk of depression and social isolation and slows cognitive decline.

Research by UCL found hearing loss to be one of the major modifiable risk factors for dementia.

(Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, Prof Gill Livingston et al, The Lancet, July 30, 2020
DOI:https://doi.org/10.1016/S0140-6736(20)30367-6)

Good foot care is essential for mobility and may be a barrier for people going out to socialise. Also good foot care is a key preventative measure.

Future Concerns

- 80.6% of participants are concerned about the cost of future care needs
- 60% worried about the cost of heating
- 40% worried about the costs of routine healthcare (dentist etc)
- 37% worried about the cost of food
- 17% worried about the cost of pet care
- 16% worried about the cost of socialising with family and friends
- 50% are concerned about being isolated
- 49% are concerned about not having enough for heating
- 39.8% are concerned about not affording to run a car
- 23.5% are concerned about not having enough money for food
- 15.3% are concerned about not being able to afford to socialise

5. Key findings

Both the quantitative and qualitative data showed similar findings.

The main concerns are as follows:

Through the research we asked many questions, however most of the responses fell into 3 significant findings. Although the cost of living crisis has a demonstrable effect now, as shown in the figures above, it is not just the current financial situation, but concern about costs in the future. The financial strain also has a significant effect on the health and wellbeing of families affected by dementia, however the consequences are far greater. Young Onset Dementia (those diagnosed with dementia under the age of 65) has a huge impact on families finances and their quality of life.

5.1 Cost of Care (Now and in the Future)

It is evident that people have cut back on spending in a variety of ways. The participants were very vocal on the impact dementia has on their lives. This has been exacerbated by the cost of living crisis. 80.6 percent said that they are concerned about the future cost of care.

The cost of domiciliary care in the South East of England (care at home) has risen hugely. The lowest cost per hour is approximately £20 (private carers) and can cost over £40 per hour. The cost of care in a residential setting is now in excess of £1,200 per week (£5,200 per month). An unacceptable amount of the financial burden of dementia is falling on individuals and families – 63% of the total cost of dementia is borne by patients and their families.
*www.dementiaresearcher.nihr.ac.uk/uk-dementia-care-costs-reach-42billion-alzheimers-society/

There is support from Adult Services, dependent on individuals financial circumstances. However, the current wait for financial assessment required to trigger funding is currently at least 6 months in Hampshire.

Through the research it has become apparent that the cost of care now and in the future affects most of the decisions that are made about finances and spending now. This includes decisions about how they shop, transport, holidays, socialising and healthcare and paying for support either at home or in a care home. This is having an effect that carers are putting off paying for care support now which is having a detrimental effect on their lives and health. There also appears to be a mentality that says that they should cope and not ask for help.

The responses show that their concerns are not only whether they will be able to pay for the standard of care they want their loved one to have,but also how it will impact on their own future. Questions such as what will happen to them; will they have the standard of life in retirement that they had hoped and planned for?

One of the participants stated “I wouldn't have used some of my pension pot to pay the mortgage off had I known that I would now be paying for his care!”

A participant said “the cost of care is becoming too much to carry on working, so I will have to give up very soon.”

There is little or no support from financial experts on how to plan now and in the future, unless they are able to pay for this. This in turn adds to the stress.

One of the participants stated that their partner with dementia, who had previously been very generous, had now become extremely fearful about money and spending and this had led to many arguments.

The long term consequences of carers stress and carers breakdown will have a further impact on the NHS and Adult Services. Who will look after the person with dementia if the carer is no longer able? One of the participants who is a carer had a heart attack due to the stress of caring. Another put off having an operation as the cost of respite was too great, but the cost to his mobility is having an additional effect.

5.2 Quality of Life

‘It has been recognised that a third of unpaid dementia carers are caring for more than 100 hours per week on average.’ Carers UK. valuing-carers-report.pdf (carersuk.org)

What does this mean to the carers?

Carer

The following were some of the quotes from participants

“I have no time for myself. He just follows me around the house all day and I can’t even go shopping on my own.”

“I am not able to continue with my own life. I no longer have the same relationship with my wife and I feel that I have lost her. It is not the future that we were planning and looking forward to.”

“All I do is exist”

“I was so stressed mentally and physically that I got to the stage of considering suicide”

This highlights the stress that unpaid carers are under. In addition to this they felt socially isolated as they were not able to go out on their own to meet up with friends. Some also felt that their previous friends now avoided them as they ‘couldn’t cope with the dementia and didn't know how to respond. They felt that they could no longer live their lives as all their time is spent on caring responsibilities.

As stated in the cost of care above, the guilt associated with expressing their own needs was felt acutely by carers.

The culmination of the stress, lack of independence, loss of the relationship, not having a break, social isolation, resentment at the situation, not being able to carry out hobbies, the 24/7 responsibility of caring (often on their own) leads to carers breakdown and stress and will have long term health effects.

"I am so resentful as this is no longer the man I married. I don't have a life anymore."

"I really don't know how much longer I can keep going. Thinking of the future is not a very nice equation."

Stress of finances and future, not wanting to pay for support now so the quality of life is poor and people are feeling trapped.

Person with Dementia

It was noted that once given a dementia diagnosis, it was often felt that they were no longer able to work or pay a contribution to society, community and the family. The fear of not wanting others to know about the diagnosis, for example the reasons for not working and stopping socialising, left them and their spouses socially isolated.

In addition, at diagnosis, very few people were given information and advice about the diagnosis and what this may mean, and were left to find out for themselves. This could lead to depression and further isolation.

"When we talk to the GP they know very little about what can help us, how to get help or signposting. It feels just like you are abandoned."

Added to this was the uncertainty of what the future would hold and the effect the diagnosis would have on their lives.

5.3 Young Onset Dementia

Over 70,800 people in the UK have Young Onset Dementia (people who are diagnosed with dementia before the age of 65). Alzheimer's Research UK states that over 19,000 people in England are estimated to be living with Young Onset Dementia without a diagnosis.

Five in every hundred people with an Alzheimer's diagnosis are under the age of 65 according to Alzheimer's research. However, this is not the only dementia that affects younger people. These ‘younger’ dementias tend to be less well understood, have more complex and difficult symptoms and a faster progression. People with Young Onset Dementia are far more difficult to diagnose and it often takes twice as long to get the diagnosis from the first visit to the GP as it is for the older generation.

The Young Person with Dementia Charity says ‘Studies have shown the the indirect cost of illness in the younger person with dementia (informal care costs, treatment and mortality costs) are up to 16 times those of older people’

The research shows that those with Young Onset Dementia are disproportionately disadvantaged financially. This is the conclusion we made. This is for the following reasons:

- The person is much more likely to be working so will stop working at an earlier age
- The carer of someone with a Young Onset Dementia could also be working, but may have to give up to take on the caring role
- This will have an effect on their pension pots
- They may still have a mortgage
- They may have young children and the costs associated with a family
- They may not have had time to accrue savings
- Concerns about future costs, trying to save money now to ensure support later if needed

Older people with dementia probably don’t pay for prescriptions or public transport.

There is also the emotional cost this has on the whole family. The carers of people with a Young Onset Dementia feel especially stressed as they grieve for the loss of the life they expected in their 50/60’s, and also of the life of the whole family. Just at a time when they would be making memories with their families, they are restricting spending for the fear of future financial restrictions. Please see Case Study 1 attached.

“We have stopped some of the clubs for our daughters – I’m constantly juggling expenses”
“It feels as though it would be easier if I wasn’t here anymore – my life insurance would make a real difference.”

Young onset dementia and the link to 65 years of age probably originally related to retirement age. There has been consideration of raising to 70 or lowering the symptom development age but until this happens, there is a gap in support.

6. Actions

- **Recommendations**
    - Change in Government Policy to support People with Dementia and their carers
    - Support the health and mental wellbeing of all carers by providing a service to support them
    - Improve the speed of access to the legally required Financial Assessment, Care Assessment and Carers Assessment
    - All carers to receive the Take a Break Service if requested regardless of the progress of the dementia
    - Support the development of an increased number of support services at no or low cost for people with dementia and their unpaid carers
    - Increase the age under which the young onset dementia diagnosis is labelled
    - Offer more financial information (tailored to individuals not just generic leaflets), and understand how to get it to people
    - Bridge the gap between Young Onset Dementia diagnosis age and retirement age
    - More funding streams available to continue projects which have proven their worth
    - Connectivity between NHS, Adult Services and the VCSE sector and appreciation of what the VCSE sector can and do offer

- **Our actions and next steps**
    - To gain funding for more Memory Cafe's particularly in areas of the County that are currently underserved
    - To gain funding for more respite opportunities
    - To set up a group for people with Young Onset Dementia
    - Feedback to individuals,groups and organisations that fed into the research
    - Develop the Deep group to bring dementia voices to the many stakeholders that have an influence in the dementia arena
    - Research into the following areas:
        - The mental health of unpaid carers
        - Look at available information on financial planning - work with the dementia community to compile some helpful information and how to deliver this
        - Explore the specific issues of Young Onset Dementia - understand better the options for people who need to give up work early or ways to help them to continue working
        - Explore why people have not mentioned food banks
        - Research community transport options

- **Actions for other organisations**
    - Support us to gain funding for the development of services and research
    - Contract with VCSE sector to reduce the cost of respite and Take a Break Service

7. Actions already taken

- Introducing Meeting Centres in Hampshire Meeting Centres - University Of Worcester
- Introducing more respite facilities
- Keeping costs to a bare minimum
- New Young Onset Dementia Groups launching in Havant and Alton

8. Acknowledgements

- NHS England South East - Joanne McEwan
- SCDC - Dawn Brown and Andrew Paterson
- Reading University - Esther Oenga
- Dementia Friendly Hampshire
- Dementia Friendly Alton
- Kim’s Cafe
- Waterlooville Dementia Group
- Andover Mind groups
- Eastleigh
- New Forest Dementia Groups
- Sunflower Group, Bordon
- Creative MoJo Groups
- Kym Devine Reminiscence Groups
- Kit Bags Live on Group
- Recapture Life Groups
- Other CPAR2 Groups
- IVAR

Appendices

- Survey
- Interview Form
- Case Study 1
- Case Study 2
- Case Study 3
- Demographic
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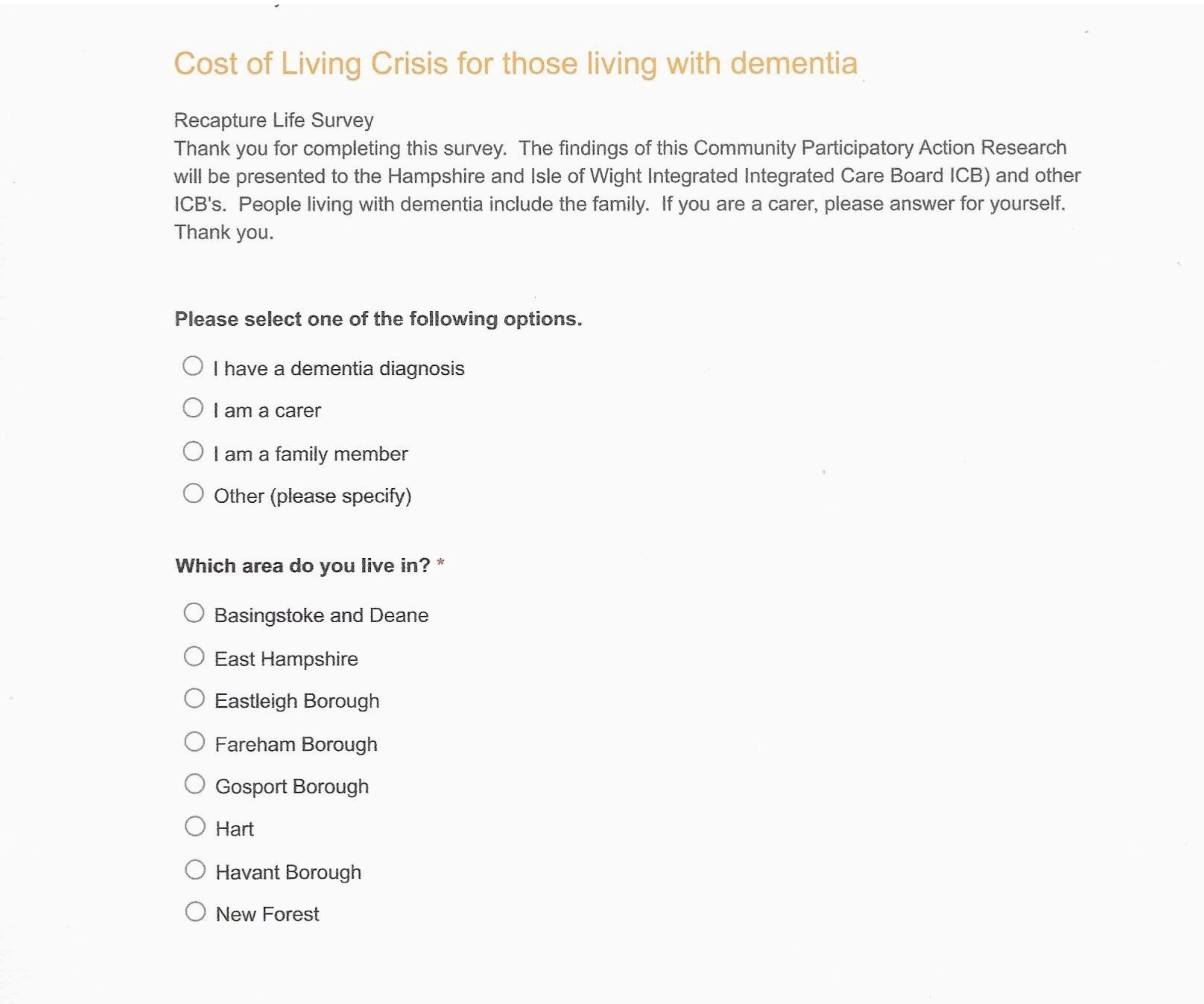


Cost of Living Crisis for those living with dementia

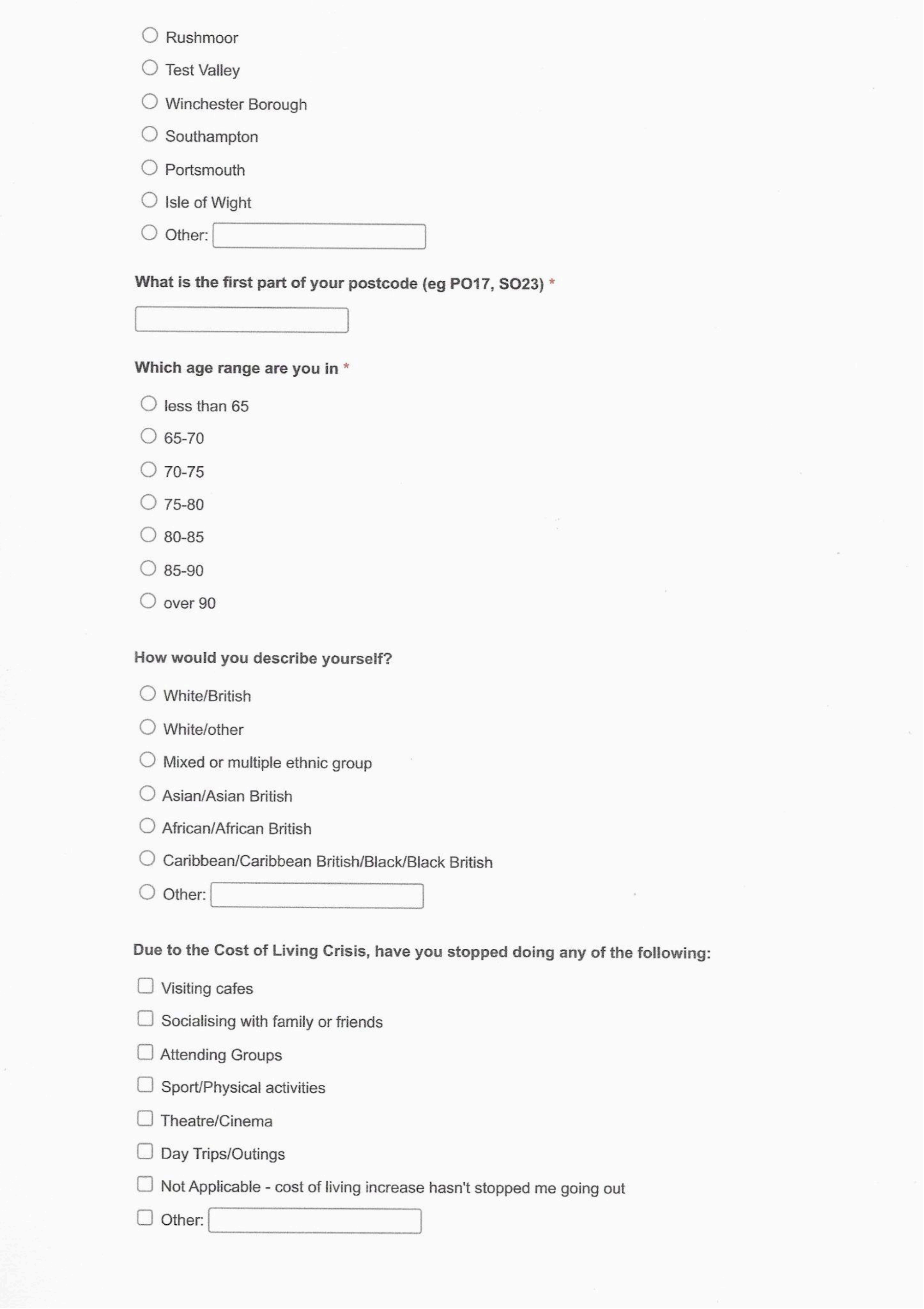
Recapture Life Survey
Thank you for completing this survey. The findings of this Community Participatory Action Research will be presented to the Hampshire and Isle of Wight Integrated Integrated Care Board ICB) and other ICB's. People living with dementia include the family. If you are a carer, please answer for yourself. Thank you.

Please select one of the following options.

- ○ I have a dementia diagnosis
- ○ I am a carer
- ○ I am a family member
- ○ Other (please specify)

Which area do you live in? *

- ○ Basingstoke and Deane
- ○ East Hampshire
- ○ Eastleigh Borough
- ○ Fareham Borough
- ○ Gosport Borough
- ○ Hart
- ○ Havant Borough
- ○ New Forest



○ Rushmoor

○ Test Valley

○ Winchester Borough

○ Southampton

○ Portsmouth

○ Isle of Wight

○ Other:

What is the first part of your postcode (eg PO17, SO23) *

Which age range are you in *

○ less than 65

○ 65-70

○ 70-75

○ 75-80

○ 80-85

○ 85-90

○ over 90

How would you describe yourself?

○ White/British

○ White/other

○ Mixed or multiple ethnic group

○ Asian/Asian British

○ African/African British

○ Caribbean/Caribbean British/Black/Black British

○ Other:

Due to the Cost of Living Crisis, have you stopped doing any of the following:

☐ Visiting cafes

☐ Socialising with family or friends

☐ Attending Groups

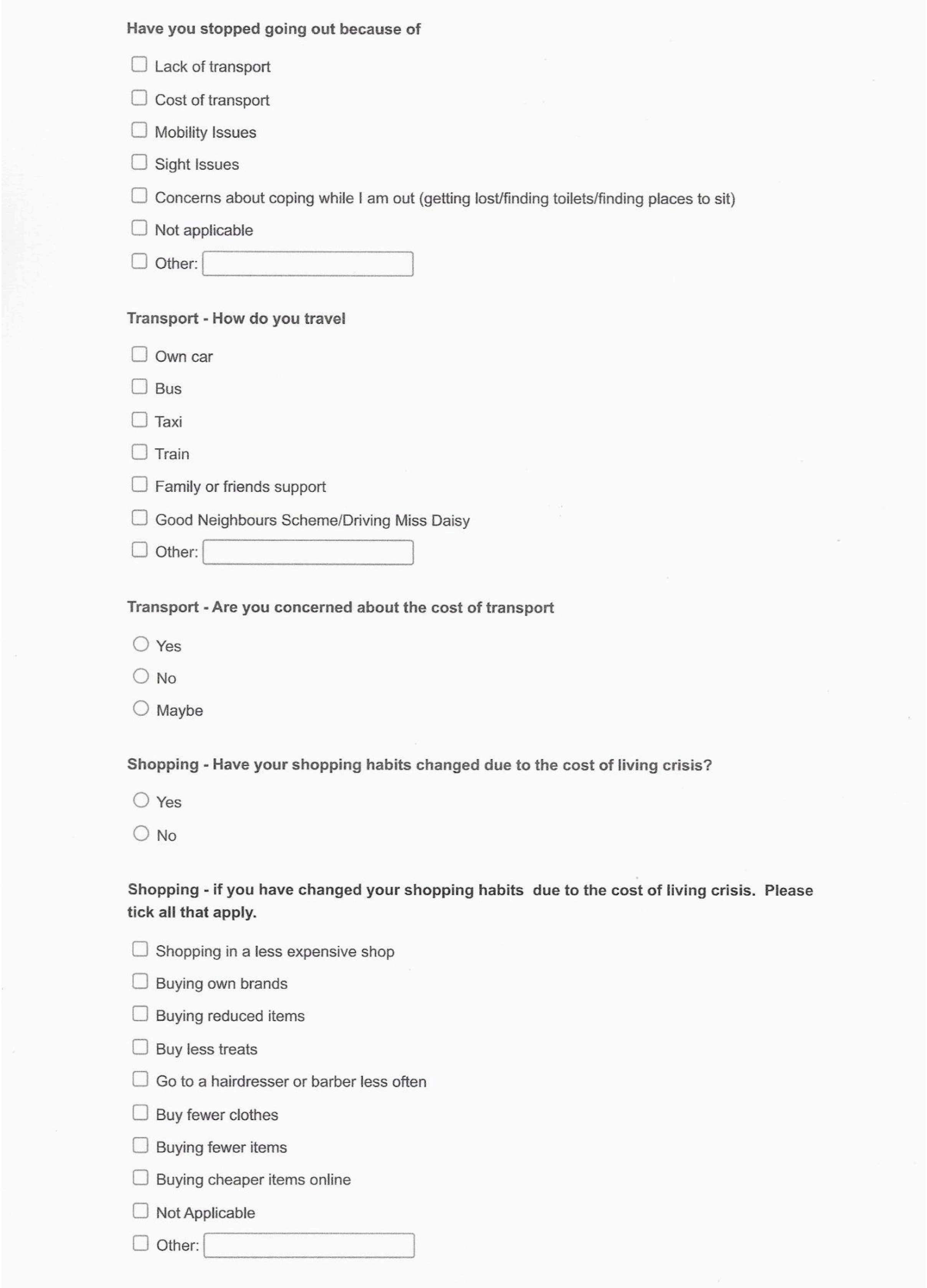
☐ Sport/Physical activities

☐ Theatre/Cinema

☐ Day Trips/Outings

☐ Not Applicable - cost of living increase hasn't stopped me going out

☐ Other:



Have you stopped going out because of

☐ Lack of transport
☐ Cost of transport
☐ Mobility Issues
☐ Sight Issues
☐ Concerns about coping while I am out (getting lost/finding toilets/finding places to sit)
☐ Not applicable
☐ Other:

Transport - How do you travel

☐ Own car
☐ Bus
☐ Taxi
☐ Train
☐ Family or friends support
☐ Good Neighbours Scheme/Driving Miss Daisy
☐ Other:

Transport - Are you concerned about the cost of transport

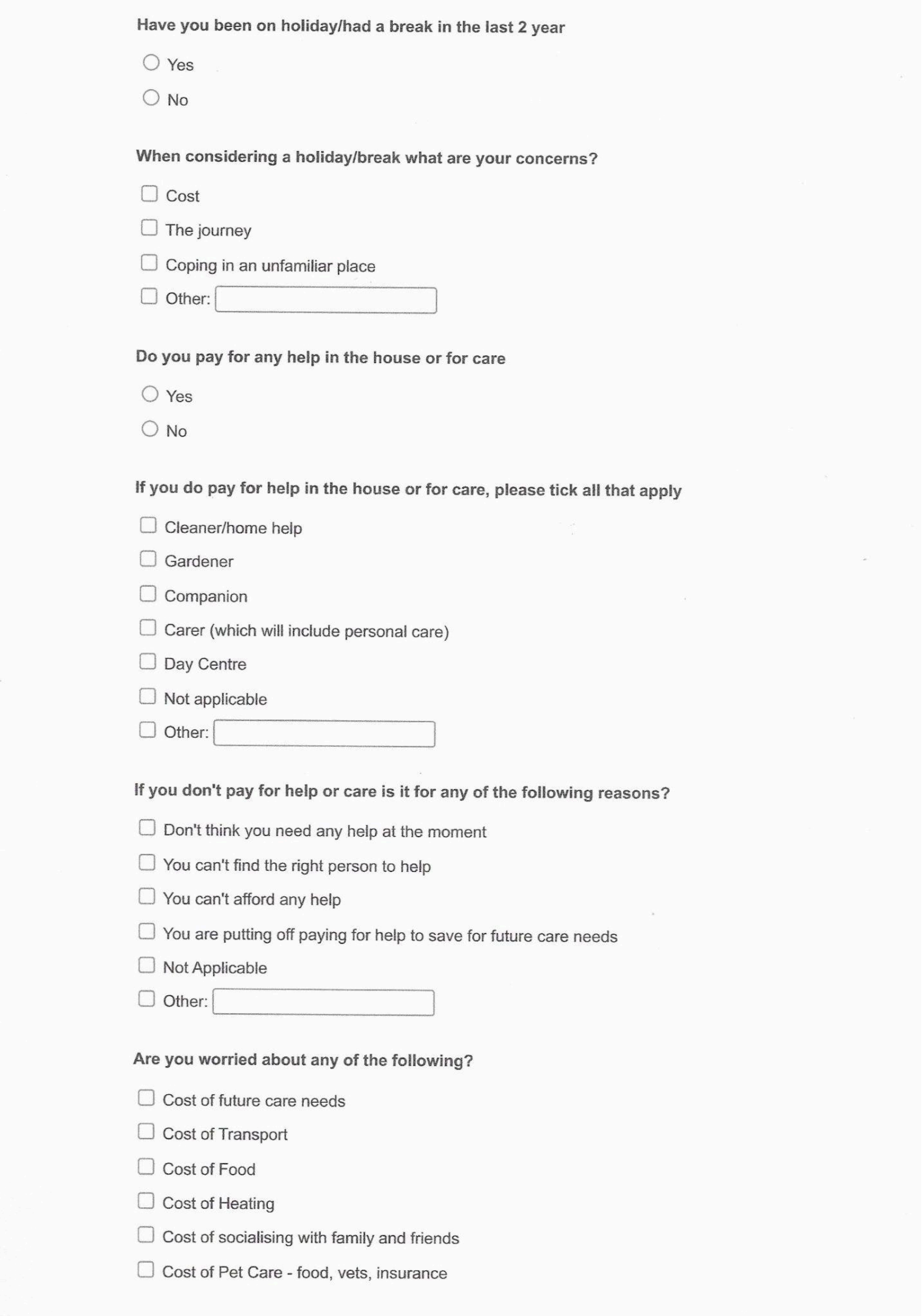
○ Yes
○ No
○ Maybe

Shopping - Have your shopping habits changed due to the cost of living crisis?

○ Yes
○ No

Shopping - if you have changed your shopping habits due to the cost of living crisis. Please tick all that apply.

☐ Shopping in a less expensive shop
☐ Buying own brands
☐ Buying reduced items
☐ Buy less treats
☐ Go to a hairdresser or barber less often
☐ Buy fewer clothes
☐ Buying fewer items
☐ Buying cheaper items online
☐ Not Applicable
☐ Other:



Have you been on holiday/had a break in the last 2 year

○ Yes

○ No

When considering a holiday/break what are your concerns?

☐ Cost

☐ The journey

☐ Coping in an unfamiliar place

☐ Other:

Do you pay for any help in the house or for care

○ Yes

○ No

If you do pay for help in the house or for care, please tick all that apply

☐ Cleaner/home help

☐ Gardener

☐ Companion

☐ Carer (which will include personal care)

☐ Day Centre

☐ Not applicable

☐ Other:

If you don't pay for help or care is it for any of the following reasons?

☐ Don't think you need any help at the moment

☐ You can't find the right person to help

☐ You can't afford any help

☐ You are putting off paying for help to save for future care needs

☐ Not Applicable

☐ Other:

Are you worried about any of the following?

☐ Cost of future care needs

☐ Cost of Transport

☐ Cost of Food

☐ Cost of Heating

☐ Cost of socialising with family and friends

☐ Cost of Pet Care - food, vets, insurance

☐ Costs of Healthcare - Dentists, eye tests, hearing tests etc

☐ Not Applicable

☐ Other: ____

Have you reduced the frequency of routine health checks?

☐ Dentist Checkups

☐ Eye tests

☐ Hearing tests

☐ Chiropody visits

☐ Not Applicable - I continue to have routine check ups with the same regularity

☐ Other: ____

If you have ticked yes to any of the above options

☐ Does this stop you paying for support

☐ Does this stop you going out

☐ Do you buy less

☐ Do you turn your heating on less

☐ Does it stop you from meeting up to socialise

☐ Have you considered giving up your car to save money

☐ Have you considered giving up your pet

☐ Not applicable

☐ Other: ____

What are your biggest concerns for the future. Please tick 3 items

☐ Cost of care

☐ Being isolated

☐ Not having enough money for food

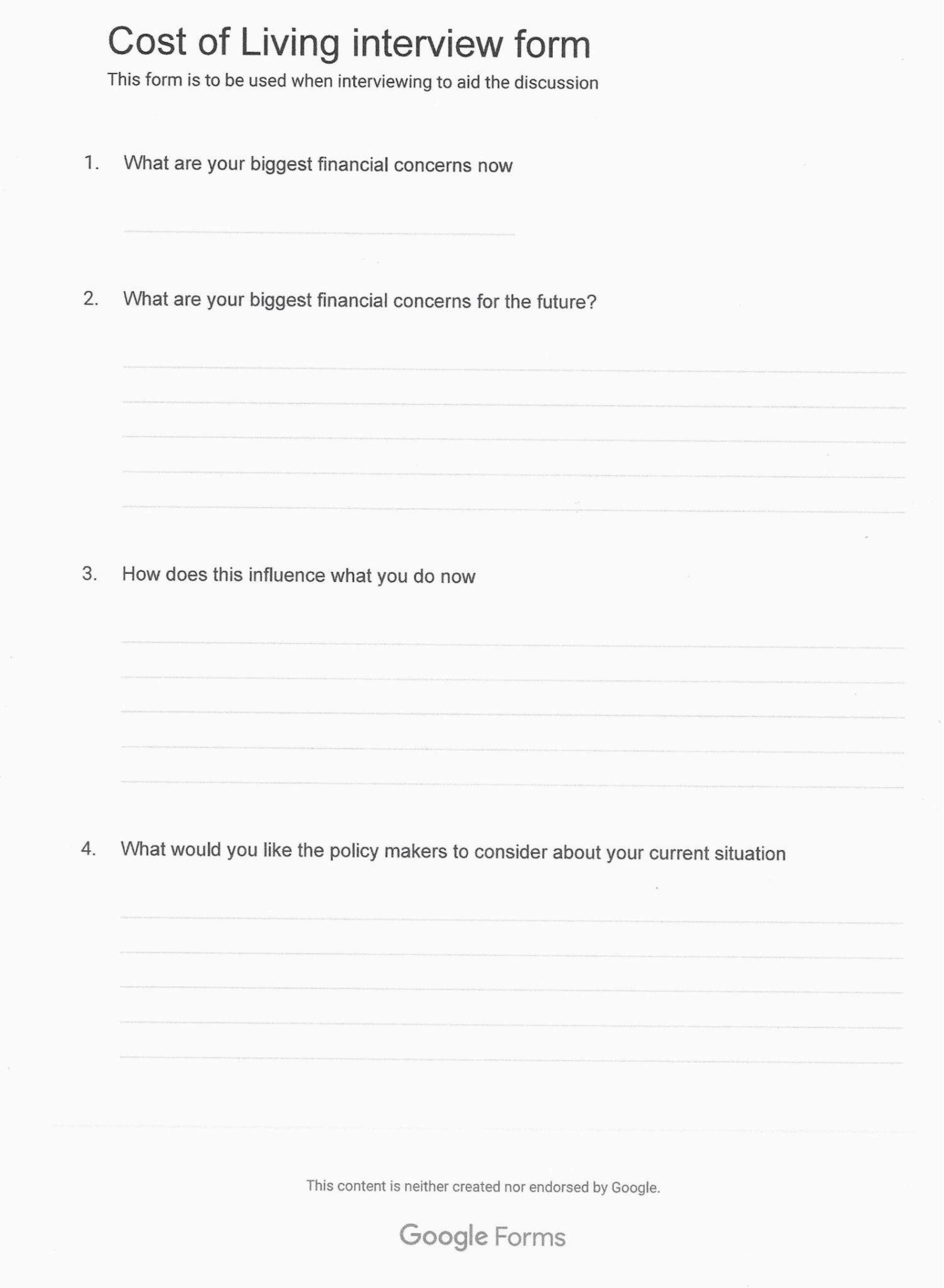
☐ Not having enough money for going out

☐ Not having enough money for heating

☐ Not being able to run a car

☐ Costs of having a pet

☐ Other: ____



Cost of Living interview form

This form is to be used when interviewing to aid the discussion

1. What are your biggest financial concerns now

2. What are your biggest financial concerns for the future?

3. How does this influence what you do now

4. What would you like the policy makers to consider about your current situation

Case Study 1

M is in his mid 40's and was diagnosed with Young Onset Dementia over 3 years ago. M still works part time at an office where he used to be manager. S, his wife, is in her early 40's and is still working full time. They have 2 daughters who are 8 and 5.

M and S were interviewed together for this project and also completed the survey individually. When asked about their main concerns for the future they both said that the future of their home was their main fear. Their fixed rate mortgage ends next year and they almost certainly won't be able to get a new mortgage on their current income. This is something they both worry about constantly.

They are extremely careful in their shopping and are the only people we talked to who mentioned using a food bank. They have reduced their spending on their daughters and feel guilt that the girls don't go to all of the clubs and outings their friends attend. They are also concerned that the younger daughter will never have a birthday party like her sister had at her age.

It was particularly sad to hear that they avoid buying the girls ice creams when they are out. "When we go out we always take packed lunches, we can't afford cafes now. If we go out on sunny days, we have to think twice about buying ice creams – we won't have one even if we buy them for the girls."

The girls will probably lose their father while young, but while in a perfect scenario, the family would be spending as much time as possible making memories, they are counting their pennies! They should be sharing sunny days eating ice creams on the beach together!

Case Study 2

A was diagnosed with Parkinson's and subsequently dementia. C and A are in their late 60's. They married later in life as a second marriage. C took early retirement and with her pension lump sum she paid off their mortgage.

A had always been very generous financially but once he had the dementia diagnosis he became very concerned about money and spending. C had to register the Power of Attorney which became an issue between them.

C has children and grandchildren from a previous marriage and they have enjoyed a very family orientated life. Having family times also became a problem due to A's hallucinations and the noise of the family. C became resentful of the illness, losing both her partner and the life they would have enjoyed.

C stated that she wouldn't have paid off the mortgage if she had known that they would have to pay for support so early on. C had less time with the family as she used to look after and teach her grandchildren. This added another financial strain for her children as they now had to pay for childcare which they found difficult to fund and C missed seeing the grandchildren so much. This was not in their plans for the future. C was diagnosed with depression and felt so low on many occasions that she felt like she could not go on. C is very concerned about their future finances and how this will affect their lives.

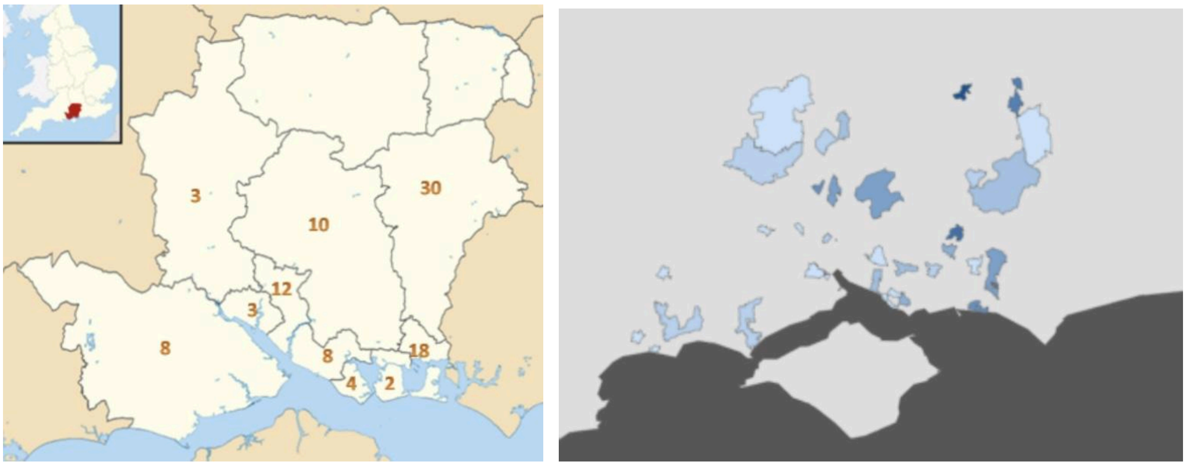
Case Study 3

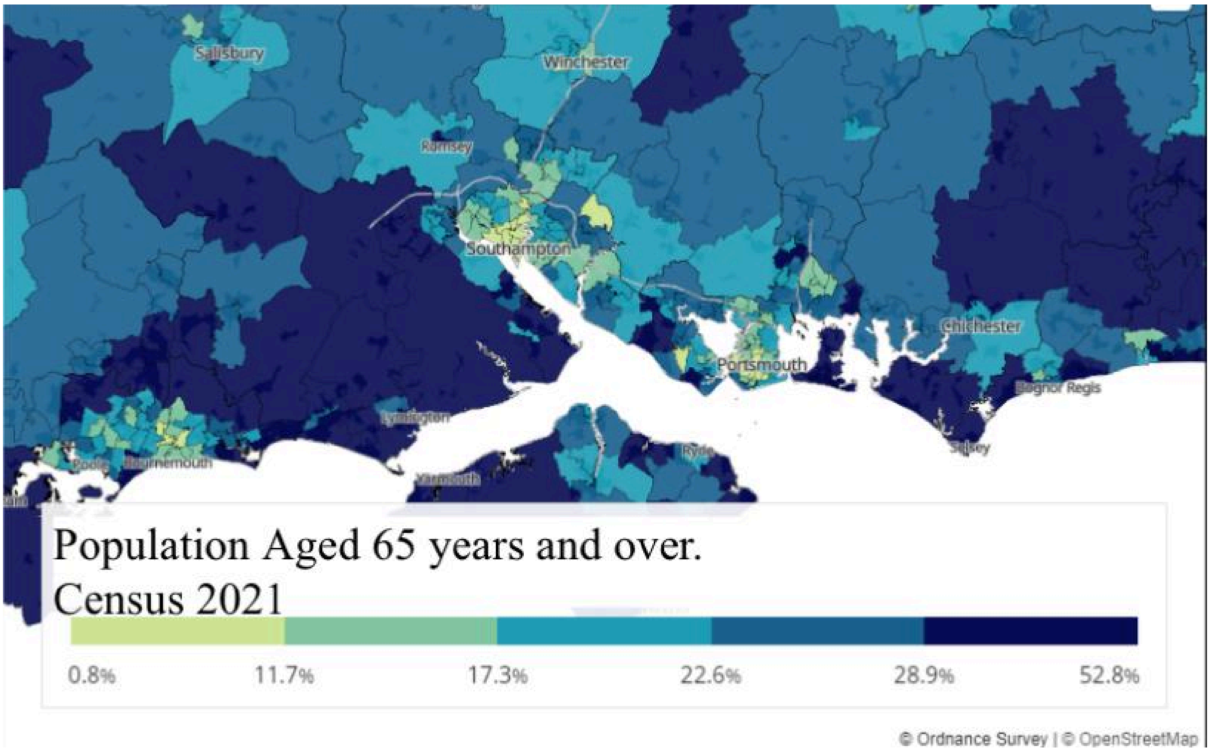
C was diagnosed with Young Onset Dementia in her late 50’s, about 8 years ago. She is still very active and continues to horse ride and play tennis.

T is still working, mainly from home but to ensure that they are financially stable they feel this is important to them both. He works part time, but the hours he works have reduced over the last year. He would love to carry on working, but he is finding it increasingly difficult. He says that C’s needs are becoming greater and to continue working is not financially viable as the care costs exceed the earnings. He is concerned that this also has an impact on their pensions. He says “The Government is missing a trick as they would be gaining funds from taxes and NIC”.

T ensures that C has plenty of hobbies and activities, but at the expense of his own opportunity to take part in what he enjoys. He said that the cost of his activities in addition to paying for care for C becomes impossible to fund. T says that he will need to give up work this year, which he doesn't want to do because it takes at least 2 hours to get C ready for the day and she now requires much more reassurance and wonders where he is whilst he is working.

Location of our participants (number in each district) & density across postcodes





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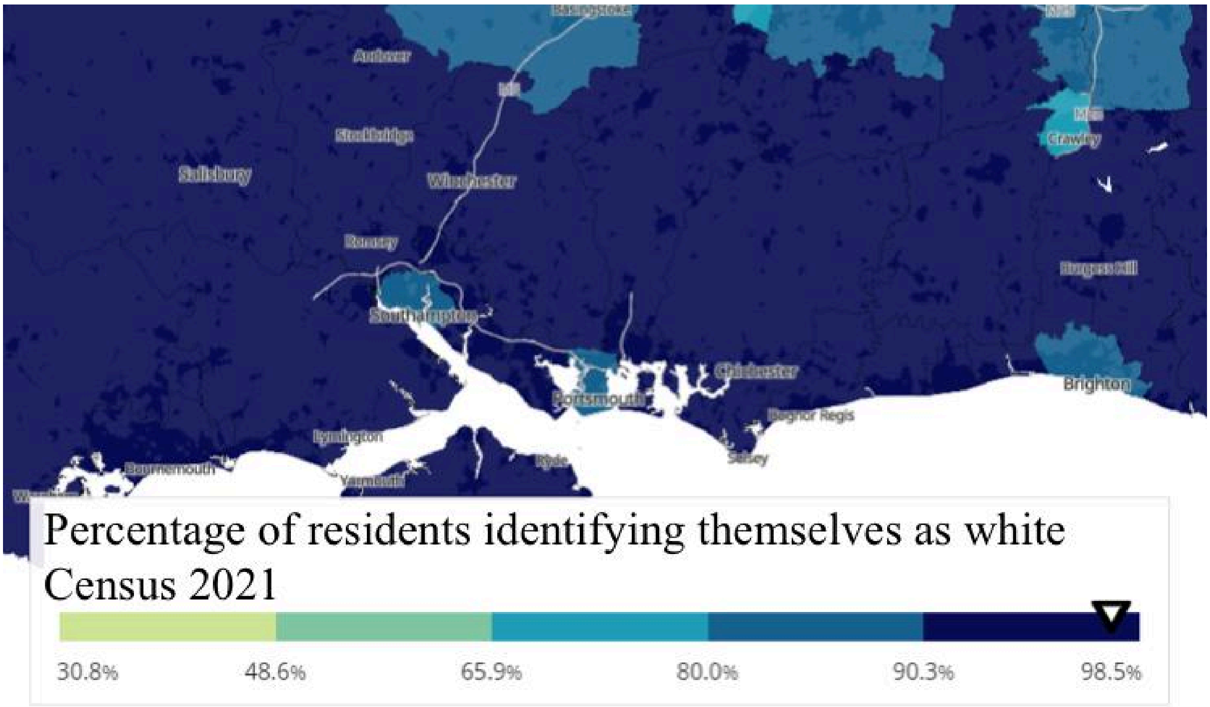
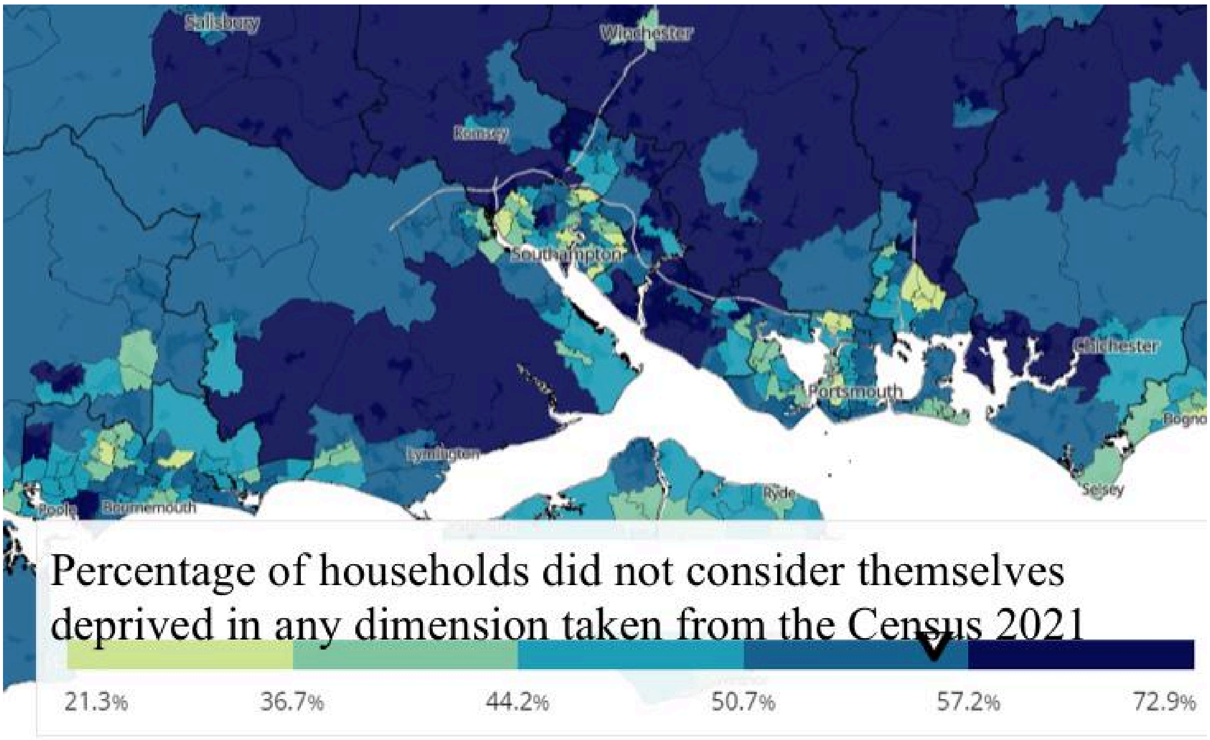


Percentage of residents identifying themselves as white Census 2021



Percentage of households did not consider themselves deprived in any dimension taken from the Census 2021

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