Survey of Carers Funded by NIHR | National Institute for Health and Care Research
Centre for Care
University of Sheffield
UNIVERSITY OF BIRMINGHAM

Item 3 of 3
Survey of Carers Pilot Study
Self-Completion Paper Questionnaire

How to fill in this questionnaire

Please answer the questions by:

Ticking in a box like this: ☑

Or writing a number in the box like this: 3

Or writing in block capitals like this: ANSWER

Sometimes you will find instructions telling you which questions to answer next like this:

☐ Yes → Go to **5**

☐ No → Go to **6**

Sometimes you will find a question asking how often you have done something over a period of time.

Please start the questionnaire at question 1 on the next page.

Thank you again for your help.

Section 1: About you

This group of questions helps us to get a better picture of the types of carers who take part in this survey.

1 **In the last 12 months, have you provided support to a family member, friend, neighbour or someone else, for reasons related to long-term illness, disability, physical or mental health conditions or illnesses, substance misuse, or older age?**

By providing support we mean things like organising or doing the shopping, helping with medical care, providing emotional support, helping with personal care such as dressing, bathing, cutting nails, feeding, or helping them use the toilet, etc. Please do not include anything you do as part of your paid job or volunteer work.

Please tick [✓] one box

☐ Yes → Go to **2**

☐ No

If you have selected No, then you are not eligible for this survey. Thank you for your time and interest.

If you have selected Yes, please move to the next question.

2 **What is your age?**

Please tick [✓] one box

- ☐ 18 to 24 years
- ☐ 25 to 29 years
- ☐ 30 to 34 years
- ☐ 35 to 39 years
- ☐ 40 to 44 years
- ☐ 45 to 49 years
- ☐ 50 to 54 years
- ☐ 55 to 59 years
- ☐ 60 to 64 years
- ☐ 65 to 69 years
- ☐ 70 to 74 years
- ☐ 75 to 79 years
- ☐ 80 to 84 years
- ☐ 85 plus
- ☐ Prefer not to say

3 **What is your sex?**

Please tick [✓] one box

- ☐ Male
- ☐ Female
- ☐ Prefer not to say

4 **Is the gender you identify with the same as your sex registered at birth?**

Please tick [✓] one box

- ☐ Yes
- ☐ No, enter gender identity

☐

- ☐ Prefer not to say

5 **What is your ethnic group?**

Please tick [✓] one box that best describes your ethnic group or background

White

- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background, please describe

Black / African / Caribbean / Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / African / Caribbean background, please describe

Asian / Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background, please describe

Mixed / multiple ethnic groups

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed / Multiple background, please describe

Other ethnic group

- [ ] Arab
- [ ] Any other ethnic group, please describe

[ ]

- [ ] **Prefer not to say**

6 **What is your religion?**

Please tick [✓] one box

- [ ] No religion
- [ ] Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- [ ] Buddhist
- [ ] Hindu
- [ ] Jewish
- [ ] Muslim
- [ ] Sikh
- [ ] Any other religion, please describe

[ ]

- [ ] Prefer not to say

7 **What is your legal marital status?**

Please tick [✓] one box

- ☐ Married
- ☐ In a registered civil partnership
- ☐ Separated (after being married or in a civil partnership)
- ☐ Divorced/dissolved civil partnership
- ☐ Widowed/surviving partner from a civil partnership
- ☐ Single (never married/never in a civil partnership)
- ☐ Don't know
- ☐ Prefer not to say

8 **How many children aged 18 or under do you have parental responsibility for?**

Please tick [✓] one box

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4 or more
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

9 **Which of the following options best describes how you think of yourself?**

Please tick [✓] one box

- ☐ Heterosexual or Straight
- ☐ Gay or Lesbian
- ☐ Bisexual
- ☐ Other
- ☐ Prefer not to say

10 **Do you have any health conditions or illnesses which affect you in any of the following areas?**

Please tick [✓] all that apply

- ☐ Vision (for example blindness or partial sight)
- ☐ Hearing (for example deafness or partial hearing)
- ☐ Mobility (for example walking short distances or climbing stairs)
- ☐ Dexterity (for example lifting and carrying objects, using a keyboard)
- ☐ Learning or understanding or concentrating
- ☐ Memory
- ☐ Mental health
- ☐ Stamina or breathing or fatigue
- ☐ Socially or behaviourally (for example associated with autism spectrum disorder (ASD) which includes Asperger's, or attention deficit hyperactivity disorder (ADHD))
- ☐ Other (please specify):

☐

- ☐ None of the above
- ☐ Prefer not to say

11 **Which local authority (council) do you live in?**

If you do not know, prefer not to say, or this question does not apply to you, please leave this question blank.

We need to know this so that we can compare people who live in different areas and to understand the level of need and support. We will not be able to identify you through your authority.

Please write the name of your local authority (council) on the line below.

Section 2: Your experiences of support and services

The questions in this section ask about the support and services that you use as a carer and how useful you find them. They may be provided by different sources, such as voluntary organisations and charities as well as Social Care and carer organisations in your local area.

12 **In the last 12 months, have you had a carer's assessment about your needs or a review of your carer's assessment?**

A carer's assessment is a detailed conversation about your needs for supporting your own health and wellbeing and to have a life of your own alongside your caring responsibilities.

This might be carried out by your council or Social Care, carer organisations in your area, or voluntary organisations and charities by telephone, in-person, or online.

Please tick [✓] all that apply

- ☐ Yes, a full assessment
- ☐ Yes, a review of your carer's assessment
- ☐ No
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

13 **In the last 12 months, how useful have the support or services you have received as a carer been?**

They may be arranged or signposted by Social Care at your council, or provided by carer organisations in your area or voluntary organisations and charities.

Please tick [✓] one box per row

	Very useful	Quite useful	Neither useful nor not useful	Not very useful	Not at all useful	Tried to get but did not receive it	I was not aware of it	Not applicable
a. Carer's assessment or review of your carer's assessment								
b. Information and advice about support, services or benefits (e.g. support to remain or return to work, support groups, leisure places, education and training for carer role, and direct payments)								

	Very useful	Quite useful	Neither useful nor not useful	Not very useful	Not at all useful	Tried to get but did not receive it	I was not aware of it	Not applicable
c. Support plan for you as the carer								
d. Personal budget (money allocated to meet your assessed support needs)								
e. Received a direct payment (payment to help you arrange and pay for your own care and support needs)								
f. Replacement care (sometimes known as respite, day care and day service)								
g. Support from carer groups or someone to talk to in confidence								

	Very useful	Quite useful	Neither useful nor not useful	Not very useful	Not at all useful	Tried to get but did not receive it	I was not aware of it	Not applicable
h. Training to help you provide care and support								
i. Support to keep you or get you in employment (e.g. employment advice, help with CVs)								
j. Professional support to help you know your rights and express your views								
k. Emergency or contingency plan (showing the support needed if you are unable to look after the person that you care for at short notice, e.g. key contact numbers, medication schedule)								

	Very useful	Quite useful	Neither useful nor not useful	Not very useful	Not at all useful	Tried to get but did not receive it	I was not aware of it	Not applicable
l. Financial benefits or advice for you (e.g. Carers' Allowance, Carers' credit)								
m. Advice or support about abuse, neglect, exploitation, or keeping someone safe								

14 **In the last 12 months, do you feel you have been involved as much as you wanted to be, in discussions about the support or services provided to the person you care for?**

This may be provided by Social Care at your council, carer organisations in your area, voluntary organisations and charities.

Please tick [✓] one box

- [ ] There have been no discussions that I am aware of, in the last 12 months
- [ ] I always felt involved
- [ ] I usually felt involved
- [ ] I sometimes felt involved
- [ ] I never felt involved
- [ ] Don't know
- [ ] Prefer not to say
- [ ] Not applicable

15 **Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Care and carer organisations in your local area in the last 12 months?**

This could include information and advice you found in leaflets, over the telephone, during visits to centres, or online, for example through websites or Google.

Please tick [✓] one box

- ☐ We haven't received any support or services from Social Care and carer organisations in the last 12 months
- ☐ I am extremely satisfied
- ☐ I am very satisfied
- ☐ I am quite satisfied
- ☐ I am neither satisfied nor dissatisfied
- ☐ I am quite dissatisfied
- ☐ I am very dissatisfied
- ☐ I am extremely dissatisfied
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

16 **In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits to support your caring role?**

Please include information and advice from different sources, such as voluntary organisations and charities, as well as Social Care and carer organisations in your local area.

Please tick [✓] one box

- ☐ I have not tried to find information or advice in the last 12 months
- ☐ Very easy to find
- ☐ Fairly easy to find
- ☐ Fairly difficult to find
- ☐ Very difficult to find
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

Section 3: The impact of caring and your quality of life

Some of the questions in this section look at the impact of caring on particular aspects of your life, while others ask about the quality of different parts of your life more generally.

17 **Which of the following statements best describes how you spend your time?**

When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others.

Please tick [✓] one box

- ☐ I'm able to spend my time as I want, doing things I value or enjoy
- ☐ I'm able to do enough of the things I value or enjoy with my time
- ☐ I do some of the things I value or enjoy with my time, but not enough
- ☐ I don't do anything I value or enjoy with my time
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

18 **Which of the following statements best describes how much control you have over your daily life?**

Please tick [✓] one box

- [ ] I have as much control over my daily life as I want
- [ ] I have adequate control over my daily life
- [ ] I have some control over my daily life, but not enough
- [ ] I have no control over my daily life
- [ ] Don't know
- [ ] Prefer not to say
- [ ] Not applicable

19 **Which of the following statements best describes how safe you feel?**

By 'feeling safe' we mean feeling safe from fear of abuse, being attacked or other physical harm, such as accidents, which are a result of your caring role.

Please tick [✓] one box

- ☐ I feel as safe as I want
- ☐ Generally I feel adequately safe, but not as safe as I would like
- ☐ I feel less than adequately safe
- ☐ I don't feel at all safe
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

If you have any concerns about your personal safety, please contact your local authority social care, or safeguarding services, or carers services in your local area.

Information and contact details are available on your local authority website or via the Carers Trust: https://carers.org/help-for-carers/carer-services-near-you

Please note: This is not the end of the survey.

This page signposts you to support that could help you. The survey continues on the next page.

Support if you think you or someone is at risk

If you are concerned that an adult with care and support needs is at risk of or experiencing abuse or neglect, you should contact the safeguarding adults' team at the relevant local authority.

If you or someone else is in immediate danger or you think a crime has been committed, you should contact the police: **call 999**.

Support if you have concerns about your safety or wellbeing

If you are concerned or worried about your safety or wellbeing in relation to your caring role, or if you need advice or guidance, help and support are available.

1. You can contact your local authority's social care or safeguarding service on your local authority's website.
   - They can listen to your concerns.
   - They can give you advice and guidance.
   - They can help you get the support you need.
   - You can ask for a carer's assessment where you can talk about your needs for supporting your own health and wellbeing.

2. You can contact a carers service in your local area.

Carers Trust:

- Visit: https://carers.org/help-for-carers/carer-services-near-you

Carers UK Helpline

- Phone: **0808 808 777**
- Opening hours: Monday to Friday, 9am–6pm (including Bank Holidays)

3. If you would like someone to talk to, you can contact:

Samaritans for free at any time

- Phone: **116 123**
- Opening hours: 24 hours a day, every day of the year.

Mind Support Line

- Phone: **0300 102 1234**
- Opening hours: Monday to Friday, 9am to 6pm

More Support

To find other support services, visit: https://surveyofcarers.bham.ac.uk/support/

20 **Thinking about how well you look after yourself – such as, getting enough sleep or eating well – which statement best describes your present situation?**

Please tick [✓] one box

- ☐ I look after myself as well as I want
- ☐ I look after myself well enough
- ☐ Sometimes I can't look after myself well enough
- ☐ I feel I am neglecting myself
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

21 **Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?**

Please tick [✓] one box

- ☐ I have all the space and time I need to be myself
- ☐ I have adequate space and time to be myself
- ☐ I have some of the space and time I need to be myself, but not enough
- ☐ I don't have any space or time to be myself
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

22 **Thinking about how much contact you have with people you like, which of the following statements best describes your social situation?**

Please tick [✓] one box

- ☐ I have as much social contact as I want with people I like
- ☐ I have adequate social contact with people
- ☐ I have some social contact with people, but not enough
- ☐ I have little social contact with people and feel socially isolated
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

23 **Thinking about feeling supported and encouraged in your caring role, which of the following statements best describes your present situation?**

*This question is asking about **feeling** supported and encouraged, rather than how you are supported and encouraged by particular people or organisations.*

Please tick [✓] one box

- ☐ I feel I have the encouragement and support I want
- ☐ I feel I have adequate encouragement and support
- ☐ I feel I have some encouragement and support, but not enough
- ☐ I feel I have no encouragement and support
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

Section 4: Your caring role and the person you care for

The questions in this section ask about one person you care for, by which we mean someone you look after or help, and your experience of support and services in relation to that person.

If you care for more than one person, please answer only in relation to:

- the person you spend the most time helping;
- if you spend an equal amount of time caring for two or more people, please answer in relation to the person who lives with you or, if none of them lives with you, the person who lives closest to you;
- if you live with two or more people or are closest to two or more people that you spend an equal amount of time caring for, please choose one person to answer about.

If you care for more than one person and told us that you would like to answer some questions about another person you care for, the research team have included additional sets of questions in your survey pack. You can answer these questions for up to three other people you care for.

24 **How old is the person you care for?**

If you don't know the exact age, please give an approximate one.

_____ **years**

☐ Don't know ☐ Prefer not to say ☐ Not applicable

25 **Does the person you care for have....?**

Please tick [✓] all that apply

- ☐ Dementia
- ☐ A physical disability or long-term physical health condition
- ☐ Sight loss
- ☐ Hearing loss
- ☐ A mental health condition
- ☐ Problems connected to ageing
- ☐ Mobility impairment (e.g. walking short distances or climbing stairs)
- ☐ Dexterity impairment (e.g. lifting and carrying objects, using a keyboard)
- ☐ A learning disability (e.g. Down syndrome)
- ☐ A learning difficulty (e.g. dyslexia)
- ☐ Memory problems
- ☐ Stamina or breathing or fatigue
- ☐ Long-standing illness
- ☐ Autism or another neurodivergent condition
- ☐ Terminal illness
- ☐ Alcohol or drug dependency
- ☐ Other condition (please specify):

☐

- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

26 **In the last 12 months, has the person you care for received any formal care, help or support that is provided, arranged or funded by the council or Social Care?**

This may also be provided by carer organisations in your area, or voluntary organisations and charities.

Please tick [✓] one box

- ☐ Yes, all arranged or paid for by the council or other care organisations
- ☐ Yes, some arranged or funded by the council or other care organisations
- ☐ No, all support is privately arranged or paid for by the person you care for and/or family
- ☐ No, they do not receive any formal care or support
- ☐ Other (e.g. NHS Continuing Healthcare)
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

27 **Over the last 12 months, what kinds of things did you usually do for the person you care for?**

Please tick [✓] all that apply

- ☐ Personal care (e.g. dressing, bathing, washing, shaving, cutting nails, feeding, or helping them use the toilet)
- ☐ Physical help (e.g. helping with walking, getting up and down stairs, or getting into and out of bed)
- ☐ Helping with dealing with care services and benefits (e.g. making appointments and phone calls, filling in forms)
- ☐ Helping with paperwork or financial matters (e.g. writing letters, sending cards, filling in forms, dealing with bills or banking)
- ☐ Other practical help (e.g. preparing meals, doing shopping, laundry, housework, gardening, decorating, household repairs, or taking the person you care for to medical appointments)
- ☐ Keeping the person you care for company (e.g. visiting, sitting with them, reading to them, talking to them, or calling them, or playing cards or games)
- ☐ Taking the person you care for out (e.g. for a walk or drive, or to see friends or relatives)
- ☐ Giving medicines (e.g. making sure they take medication, giving injections, or changing dressings)
- ☐ Keeping an eye on the person you care for to make sure they are safe and well
- ☐ Giving emotional support
- ☐ Other (please specify):

☐ Don't know

☐ Prefer not to say

☐ Not applicable

28 **About how long have you been looking after or helping the person you care for?**

Please tick [✓] one box

- ☐ Less than 6 months
- ☐ 6 months to less than a year
- ☐ 1 year to less than 3 years
- ☐ 3 years to less than 5 years
- ☐ 5 years to less than 10 years
- ☐ 10 years to less than 15 years
- ☐ 15 years to less than 20 years
- ☐ 20 years or more
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

29 **About how long do you spend each week looking after or helping the person you care for?**

Please tick [✓] one box

- ☐ 0-9 hours per week
- ☐ 10-19 hours per week
- ☐ 20-34 hours per week
- ☐ 35-49 hours per week
- ☐ 50-74 hours per week
- ☐ 75-99 hours per week
- ☐ 100 or more hours per week
- ☐ Varies – Under 20 hours per week
- ☐ Varies – 20 hours or more per week
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

30 **How long does it usually take you to travel from your home to where the person you care for lives?**

Please tick [✓] one box

- ☐ The person I care for lives with me
- ☐ Less than 10 minutes
- ☐ 10 to 20 minutes
- ☐ 21 to 40 minutes
- ☐ 41 to 59 minutes
- ☐ 1 to 2 hours
- ☐ More than 2 hours
- ☐ Don't know
- ☐ Prefer not to say

31 **In the last 12 months, how many people have you provided care or support to?**

Please write the number in each category, and leave it blank if none apply

- ☐ Spouse/partner/husband/wife
- ☐ Child/son/daughter under the age of 18 (including biological, adopted, foster or stepchildren)
- ☐ Adult child/son/daughter aged 18 or over (including biological, adopted, foster or stepchildren)
- ☐ Sibling/brother/sister (including biological, adopted, foster or step-siblings)
- ☐ Parent/mother/father (including biological, adopted, foster or step-parents)
- ☐ Parent-in-law /mother-in-law/father-in-law
- ☐ Grandparent/grandmother/grandfather
- ☐ Friend or neighbour
- ☐ Other relative/family member
- ☐ Other (please specify):

Section 5: Paid work and your caring responsibilities

The following questions are about your paid work situation and how this relates to your caring responsibilities. This includes whether you are currently in paid work or looking for work, as well as your experience of combining paid work and caring.

32 **Thinking about combining your paid work and caring responsibilities, which of the following statements best describe your current situation?**

Please tick [✓] one box

Not in paid work and not looking for paid work

- ☐ I am not in paid work because of my caring responsibilities, and I am not looking for paid work
- ☐ I am not in paid work because I'm retired, and I am not looking for paid work
- ☐ I am not in paid work for other reasons (e.g. health, own decision), and I am not looking for paid work

Not in paid work and looking for paid work

- ☐ I am not in paid work because of my caring responsibilities, and I am looking for paid work
- ☐ I am not in paid work because I'm retired, and I am looking for paid work
- ☐ I am not in paid work for other reasons (e.g. health, own decision), and I am looking for paid work

In paid work (full-time and part-time)

- [ ] I am in paid work, and I feel supported by my employer
- [ ] I am in paid work, but I don't feel supported by my employer
- [ ] I am in paid work, and I do not need any support from my employer to combine my work and caring responsibilities

Self-employed (full-time and part-time)

- [ ] I am self-employed and I am able to combine my work and caring responsibilities
- [ ] I am self-employed but I am unable to combine my work and caring responsibilities
- [ ] **Don't know**
- [ ] **Prefer not to say**
- [ ] **Not applicable**

33 **Currently, how easy or difficult is it for you to combine your caregiving responsibilities with your working commitments? Would you say it is....**

Please tick [✓] one box

- ☐ Not in paid work
- ☐ Very easy
- ☐ Fairly easy
- ☐ Neither easy nor difficult
- ☐ Fairly difficult
- ☐ Very difficult
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

Section 6: Your experiences with NHS services

The following question asks you about your interactions with a range of NHS services while supporting the people you care for.

34a **In the last 12 months, which NHS services have you interacted with while supporting the people you care for?**

For example, this could include attending appointments with them, speaking to NHS staff about their care, or helping them access NHS services.

Please tick [✓] all that apply

- ☐ GP services
- ☐ Hospital services, urgent and emergency care services
- ☐ Community and mental health services
- ☐ Other NHS services, including pharmacy and dental services
- ☐ None of these
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Not applicable

34b **Thinking only about each NHS service you mentioned above, to what extent do you agree or disagree with the following statements?**

If something doesn't feel relevant to you, please tick 'Not applicable'.

Please tick [✓] one box per row

GP services

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was recognised and supported in my role as an unpaid carer.						
I was included in discussions and decisions about the care, treatment and support of the person I care for.						
I received clear information about the condition, medication, treatment or care needs of the person I care for, and/or who to contact if I had questions.						

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was given information or referred to support available to me as an unpaid carer.						
I was involved in planning the discharge of the person I care for from the service.						

Hospital services, urgent and emergency care services

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was recognised and supported in my role as an unpaid carer.						
I was included in discussions and decisions about the care, treatment and support of the person I care for.						

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I received clear information about the condition, medication, treatment or care needs of the person I care for, and/or who to contact if I had questions.						
I was given information or referred to support available to me as an unpaid carer.						
I was involved in planning the discharge of the person I care for from the service.						

Community and mental health services

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was recognised and supported in my role as an unpaid carer.						
I was included in discussions and decisions about the care, treatment and support of the person I care for.						
I received clear information about the condition, medication, treatment or care needs of the person I care for, and/or who to contact if I had questions.						
I was given information or referred to support available to me as an unpaid carer.						

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was involved in planning the discharge of the person I care for from the service.						

Other NHS services, including pharmacy and dental services

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was recognised and supported in my role as an unpaid carer.						
I was included in discussions and decisions about the care, treatment and support of the person I care for.						
I received clear information about the condition, medication, treatment or care needs of the person I care for, and/or who to contact if I had questions.						

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
I was given information or referred to support available to me as an unpaid carer.						

Section 7: Future research

The following question asks you about whether you would be interested in receiving updates about this study or taking part in follow-up research.

35 **We may contact some participants in the future with updates about this study or to invite them to take part in follow-up research related to this study. Would you be happy to be contacted about this?**

Note that even if you say "yes" there will be no obligation to take part in the future.

Please tick [✓] one box

☐ Yes

☐ No

If yes, please provide your contact details below:

Please enter a valid UK telephone or mobile number
(for example: 0121 234 5678 or 07123 456789).

Please enter your full address, including your postcode
(for example: 101 High Street, Birmingham B1 1AA).

Name:

Telephone/mobile number:

Email address:

Home address:

Section 8: Additional Module - Your experiences and views

The following questions give you an opportunity to tell us more about your caring role, including its impact on different aspects of your life, your experiences as a carer, and anything that may not have been covered elsewhere in the survey. You do not have to answer them, but your responses would be useful to us.

These are now four additional questions. You do not have to answer them, but your responses would be useful to us.

36 **In the last 12 months, have your caring responsibilities affected any of the following aspects of your life?**

Please tick [✓] one box per row

A. Impact on your work and employment due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Working hours or work patterns (e.g. part-time, flexible and shift work)					
Ability to remain in a job					
Ability to get a job					
Ability to progress in your career					

B. Impact on your financial situation due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Ability to meet basic everyday living costs (e.g food)					
Household bills (e.g. heating, electricity, water)					
Income or savings					
Personal or household debt (e.g. loans, credit cards)					
Your future financial planning					

C. Impact on your education and training due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Participation or opportunities in education and training					
Future plans or goals					

D. Impact on your health and well-being due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Mental health and emotional wellbeing (e.g. stress, anxiety, depression, feeling short-tempered or irritable)					
Physical health (e.g. fatigue, headaches, disturbed sleep, physical strain)					
Physical wellbeing (e.g. self-care, exercise, or healthy routines)					
Confidence or how you see yourself					
How others see you					

There are now an additional four questions. You do not have to answer them, but your responses would be useful to us.

E. Impact on your costs of caring

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Buying equipment or home adaptations					
Travel or transport costs					

F. Impact on your location due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Moving home because of caring					
The person you care for moving into your home					

G. Impact on your personal life due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Leisure or social activities					
Ability to take breaks or go on holiday					
Time for yourself or self-care					
Relationships with family and friends					

H. Impact on your religion and spirituality due to your caring responsibilities

	Positive impact	Negative impact	Both positive and negative impact	No impact	Not applicable
Participation in religious and spiritual activities					
Faith or beliefs or spiritual well-being (e.g. relationship with God)					
Time or space for religious or spiritual practices (e.g. prayer, reflection, meditation)					

There are now two additional questions. You do not have to answer them, but your responses would be useful to us.

37 **What is the one thing that would make the biggest positive difference to your life as a carer right now?**

Please write your answer below

38 **Please use the space provided below to describe any other experiences you would like to tell us about, or to write any other comments you would like to make?**

Please write your answer below