Item 1 of 3
Survey of Carers
Participant Information

Your Voice Matters

You are being invited to take part in a research study about unpaid carers in England. This survey is an opportunity to hear from adults aged 18 or over providing unpaid care so we can help create meaningful change.

At the heart of this survey is a commitment to understanding the needs and experiences of carers.

This is not just about collecting data. It is about ensuring that carers' voices are heard and used to improve support and services. Before you decide whether to participate, it is important for you to understand why this research is being done and what it will involve.

Please take time to read the following information carefully.

What is included in this Participant Information Sheet?

1. How to take part
2. About the study
3. Why should I take part?
4. What will I be asked?
5. What will you do with my answers?
6. What happens after I take part?
7. Who is carrying out the study?
8. Why have I been asked to take part?
9. Who is conducting the study?
10. Questions about taking part
11. Confidentiality and data protection
12. Further help
13. Privacy Notice

1. How to take part

To confirm that you would like to take part in the Survey of Carers Pilot Study, please complete the Consent Form provided in the envelope (item 2 of 3). The consent form will ask if you are happy to be involved and if you are aged 18 or over. Once you complete the consent form, please complete the attached survey questionnaire (item 3 of 3).

How to fill in the questionnaire

The questionnaire (item 3 of 3) asks whether you have 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. It also includes questions about your caring role and experiences.

- Please answer the questions based on your experiences by ticking a box or writing your answers in the space provided.
- Sometimes you will find instructions telling you which questions to answer next.
- Please answer as many questions as you feel comfortable answering.
- If a question does not apply to you, follow the instructions provided or leave it blank where appropriate.

When you finish answering the questions, please return the completed questionnaire (item 3 of 3) and consent form (item 2 of 3) only, using the enclosed return envelope to the following address:

Survey of Carers Pilot Study
School of Social Policy and Society,
Muirhead Tower,
The University of Birmingham,
Edgbaston,
Birmingham, B15 2TT

Thank you for your support. The deadline for completing and returning the questionnaire and consent form is on **Monday 14 December 2026.** The information you provide will be treated as confidential in accordance with the Code of Practice for Statistics available at https://uksa.statisticsauthority.gov.uk.

2. About the study

What is this study about?

You are consenting to take part in the Survey of Carers Pilot Study. The Survey of Carers Pilot Study is a new survey designed to better understand the experiences and lives of adults aged 18 or over who provide support to a family member, friend, neighbour or someone else because of a long-term illness, disability, physical or mental health conditions or illnesses, substance misuse, or older age. All responses collected in the survey will remain confidential and anonymous.

Supporting someone can involve many things, including (but not limited to):

- Washing, dressing, or cooking for them
- Helping them move around or get in and out of bed
- Making phone calls or appointments on their behalf
- Helping them fill in forms or manage their money
- Shopping, housework, or going with them to the doctor
- Giving company or emotional support

The survey asks you about your experiences in your role supporting the person you care for. We will ask you about your caring role and responsibilities, what matters to you, your health and wellbeing, services and support, work and your background (e.g. age, gender, ethnicity). If you care for more than one person, you also have the opportunity to answer up to seven questions for up to three other people you care for.

3. Why should I take part?

We will use what you tell us in the survey to build a more inclusive picture of England. This means you will help your local council, government departments, charities and public bodies make better informed decisions that reflect the country's changing needs.

Your responses will provide valuable information not available from any other sources. This is your chance to have your say.

Current information about people who provide care and support is limited . This pilot study will help us:

- Understand what matters to you.
- Improve how we collect information about millions of people who provide care and support.
- Ensure future surveys like this are more inclusive and representative.
- Better understand the experiences, needs, and support of people who provide care and support.
- Help inform government and local authorities how to better support you.

4. What will I be asked?

The Survey of Carers Pilot Study covers a range of topics, including information about:

- You and the person you support
- Your health
- Services and support
- Work

The questions we ask can be based on both facts and opinions.

You do not need any specialist knowledge to take part. Some questions ask about your experiences and circumstances and there are no right or wrong answers. Your honest responses are vital for us to produce reliable statistics about our society.

We respect your right to a private life – your responses will not be used to identify you in any way. We will ask you whether you would like to provide us with any of your contact details for potential follow-up. Providing any of your contact details is completely voluntary. If you provide us with your contact details, these will be stored separately from your survey responses so that they cannot be linked. If you do not wish to answer a question, you can always leave it unanswered.

Do I have to answer all the questions?

Answering the questions is voluntary. If you do not want to answer some or any of the questions, you do not have to. Please answer as many questions as you can, to ensure that your experiences and circumstances are counted.

If taking part raises difficult feelings

Some people who take part in this study may find it upsetting to think about their caring experiences, particularly if their caring role has recently ended or if the person they cared for has died. If you feel distressed at any point, you can take a break, skip any questions you do not wish to answer, or stop the survey altogether. Taking part is entirely voluntary.

If you would like additional support, the following organisations may be helpful:

Cruse Bereavement Support

Provides free bereavement information and support across England, Wales and Northern Ireland.
Telephone: 0808 808 1677
Website: https://www.cruse.org.uk/

Carers UK

Offers information, advice and support for current and former carers.
Telephone: 0808 808 7777
Website: https://www.carersuk.org/

Samaritans

If you are experiencing emotional distress and would like someone to talk to, Samaritans provides confidential support 24 hours a day.
Telephone: 116 123 (free from any phone in the UK)
Website: https://www.samaritans.org/

5. What will you do with my answers?

Your personal information will remain confidential. We will combine the details you provide with those of everyone else taking part so we can produce statistics. We will never publish data that identifies you or your household.

We do not sell on your data, and you will not receive junk mail or marketing calls as a result of taking part in our study. Your data will be securely stored by the University of Birmingham using protected systems and handled in line with UK data protection laws (UK GDPR). The University of Birmingham will store the data in its archiving facilities for ten years. It will be deleted after this time. If you want to know more, please visit https://www.birmingham.ac.uk/privacy and see the section about our commitment to protecting your data.

6. What happens after I take part?

Once you have completed the survey, we will combine your responses with those of other people taking part. We will analyse this information to better understand the experiences of unpaid carers and produce statistics and research findings.
If you agree to be contacted, we may also contact you with updates about this research or invite you to take part in future research opportunities.

7. Who is carrying out the study?

This study is being carried out by the Centre for Care at the University of Birmingham.

We are:

- Independent, unbiased and impartial: we are separate from other organisations and do not allow anything to influence the statistics we publish.
- Not interested in the information we collect beyond its intended purpose.
- Only interested in society as a whole, and not you as an individual: statistics represent groups of people; we remove your personal details as we are not interested in singling you out.

We are not:

- A commercial or market research organisation: we do not work for profit and will not try to sell you anything.
- Associated with any political parties: we produce statistics, no matter who the Prime Minister is or which political party is in government.
- Going to sell on your data under any circumstances: we value your involvement in our study and do not profit from your data; you will not receive any "junk mail" as a result of taking part.
- Monitoring you, as the data you provide will only be used for producing statistics: we will not use your information to contact you about other matters such as your tax, income or benefits, and we will not provide your information to anyone else for them to do so either.

Read more about what we do at the Centre for Care by visiting: https://www.centreforcare.ac.uk.

8. Why have I been asked to take part?

To build a better, more inclusive picture of our society, we need to talk to a variety of people.

It is not possible to ask everyone to take part in our ongoing studies; instead, we invite a sample of individuals to ensure that everyone is represented.

Whoever you are, whatever you do, we want to hear from you.

We are inviting you to take part in the Survey of Carers Pilot Study, which is being led by the Centre for Care at the University of Birmingham. You may have heard about this study because you consented to taking part earlier in the year, saw an advertisement or social media post, received information from a carer organisation or local council, or received the survey link or QR code from someone you know.

9. Who is conducting the study?

The Centre for Care at the University of Birmingham has been commissioned by the Department for Health and Social Care (DHSC) to carry out the data collection and analysis aspects of this study. However, the Centre for Care at the University of Birmingham will receive all data collected and remain in control of all responses given by all study participants. The University of Birmingham is not party-political and is conducting this research independently of DHSC. We will not share your data with the DHSC or the Department for Work and Pensions (DWP).

This project is funded by the NIHR Policy Research Programme [award number NIHR512760]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Who designed the study?

The survey has been co-produced by the Centre for Care at the University of Birmingham, alongside hundreds of people who provide this support, local authorities, government, and charities, ensuring it reflects real-life experiences.

10. Questions about taking part

Do I have to take part?

We hope we have explained just how important your response is to us and the value of your information in producing reliable statistics for decision-making. If you missed this, or need a reminder, see our section 3 – "Why should I take part?".

You do not have to take part if you do not want to. However, taking part is your chance to have your voice heard. To help us paint an accurate picture of our society, it is vital that we hear from as many people as possible, from all walks of life.

I have completed the survey, but I want to change my answers; what do I do?

If you have submitted your response but would like to change your answers, please call us on 07483 450 340 or email us at surveyofcarers@contacts.bham.ac.uk, to let us know. Operating hours are between 9:00 am and 5:00 pm Monday to Friday. You can also leave a voicemail in case your call is missed or you call out of hours.

Can I withdraw?

You are free to withdraw from the study up until 31st December 2026, without giving a reason. To withdraw, please call us on 07483 450 340 or email us at surveyofcarers@contacts.bham.ac.uk to let us know. After this time, we will have started analysing responses and published anonymous findings, so we will not be able to withdraw your data after 31st December 2026.

Please note that we can only withdraw your data if you provided us with your contact information within the survey. If you did not provide us with your contact information, there is no way for us to identify your data and you will be completely anonymous.

Operating hours are between 9:00 am and 5:00 pm Monday to Friday. You can also leave a voicemail in case your call is missed or you call out of hours.

11. Confidentiality and data protection

How we have selected you

You may have heard about this study because you consented to taking part earlier in the year, saw an advertisement or social media post, received information from a carer organisation or local council, or received the survey link or QR code from someone you know.

Full details of the source of your contact details can be obtained by calling 07483 450 340 or emailing us at surveyofcarers@contacts.bham.ac.uk. [operating hours between 9:00 am and 5:00 pm Monday to Friday]. You can also leave a voicemail in case your call is missed or you call out of hours.

Will I be identifiable in the results?

No, the information you submit will be treated as confidential as directed by the Code of Practice for Statistics available at: https://uksa.statisticsauthority.gov.uk/
Any statistics or results produced will not identify you or anyone in your household.

Will anyone else see my answers?

Your data will be processed by a small and authorised research team at the Centre for Care at the University of Birmingham. No one else will see the answers you provide. We will not share your data with the Department for Health and Social Care (DHSC) or the Department for Work and Pensions (DWP).

How will we use the information you provide?

Your personal information will remain confidential.

The details you provide will be combined with those of everyone else taking part so we can produce statistics. Any data we publish will never identify you or your household. We do not sell on your data, and you will not receive junk mail or marketing calls as a result of taking part in one of our studies.

How long will you keep the information I provide?

The information you provide will not identify you or your household. We will store this data for ten years in line with GDPR requirements. Your data will be deleted after this time.

What precautions for data protection and confidentiality have been taken?

The University of Birmingham adheres to the Code of Practice for Statistics available at https://uksa.statisticsauthority.gov.uk and the Data Protection Act 2018 also available at https://www.legislation.gov.uk/ukpga/2018/12 and processes all personal information with respect, keeping it secure and confidential. Any personal data collected are processed in systems that have been accredited by the University of Birmingham Data Security team, designed to uphold the security of the data and that are subject to regular assessment. Once the study is completed, the University of Birmingham will destroy all personal data securely.

How do we ensure your personal information is held securely?

We take our responsibilities to keep your personal information secure very seriously. As such, we take every reasonable precaution to ensure your information is protected from loss, theft or misuse. These precautions include appropriate physical security of our offices, controlled access to computer systems, and use of secure, encrypted internet connections when collecting personal information.

12. Further help

If you have any questions or need help, please contact our research team:
Email: **surveyofcarers@contacts.bham.ac.uk**
Mobile Helpline: **07483 450 340** (Operating hours between 9:00 am and 5:00 pm Monday to Friday. You can also leave a voicemail in case your call is missed or you call out of hours.)

13. Privacy notice

Your personal data

The University of Birmingham will be what is known as the "Data Controller" of your personal data processed in relation to the Survey of Carers Pilot Study. This privacy notice will explain how the University of Birmingham will process your personal data.

Why we need it

As part of the survey, we will ask whether you would like to provide any of your contact details for potential follow-up. Providing any of your contact details is completely voluntary. If you choose to provide any of them, this may involve collecting your name, telephone or mobile number, email address and home address. We may use these contact details to contact you with updates about this research or to invite you to take part in future research opportunities.

Other data that we collect in this survey will not be linked to your contact details in any way, and as such, it will not be possible for anyone to know what responses were provided from this particular form of contact detail. Your name, telephone or mobile number, email address and home address are "personal data" for legal purposes.

Legal basis for processing your data

We must have a legal basis for processing your name, telephone or mobile number, email address and home address. In this instance, the legal basis is your consent to participate, as evidenced by you stating that you want to take part in the Survey of Carers Pilot Study.

What we do with it and who we share it with

Your name, telephone or mobile number, email address and home address (if you provided them) are processed by the Centre for Care research staff at the University of Birmingham. This data will not be shared with any other individual, organisation or third parties. We will not share your data with the Department for Health and Social Care (DHSC) or the Department for Work and Pensions (DWP).

How long do we keep it for?

Following GDPR guidelines at the University of Birmingham, data should be kept for a minimum of ten years. After this time, it will be securely deleted.

What are your rights?

You can request access to the information we process about you (that is, your name, telephone or mobile number, email address and home address) at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may, in some instances, request to have it restricted, corrected, or erased. You may also have the right to object to the processing of data and the right to data portability.

You also have the right to withdraw your data if you have provided your name, telephone or mobile number, email address or home address. Please note that we can only withdraw your data if you provided contact information within the survey. If you did not provide contact information, we will not be able to identify your survey response and therefore will not be able to withdraw it. You are free to withdraw from the study up until 31st December 2026, without giving a reason. After this time, we will have started analyses and published anonymous findings.

To withdraw, please call us on 07483 450 340, or email us at surveyofcarers@contacts.bham.ac.uk, to let us know. Operating hours are between 9:00 am and 5:00 pm Monday to Friday.

If you wish to exercise any of these rights, you can also download and complete our Subject Access Request form available at https://www.birmingham.ac.uk/about/leadership/governance/policies-and-regulations/data-protection-access-to-personal-information. The form has been designed to assist you with your request. Requests and/or completed forms with relevant attachments (including evidence of your identity) should be emailed to: dataprotection@contacts.bham.ac.uk, or posted to:

The Information Compliance Manager
Legal Services
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University of Birmingham Ethics Committee who will investigate the matter.

The University of Birmingham Ethics Committee can be contacted at: ethics-queries@contacts.bham.ac.uk.

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) (https://ico.org.uk/).

Thank You

For any questions, please contact the team via surveyofcarers@contacts.bham.ac.uk

