

## INFORMATION SHEET FOR PARTICIPANTS



*Ethical Clearance Reference Number: HR/DP-20/21-21362*

### YOU WILL BE OFFERED A COPY OF THIS INFORMATION SHEET

#### **Title of project**

Understanding resilience in carers: An online study.

#### **Invitation Paragraph**

I would like to invite you to participate in this research project which forms part of my doctoral research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the project?**

More and more people are providing unpaid care for family, friends and neighbours with physical and mental health conditions. We know that carers can show resilience as they live with long-term stress challenging circumstances. Resilience can be described as the ability to adapt to or 'bounce back' from difficulty. We also know that providing this care can negatively affect carers' own physical and mental wellbeing.

We would like to find out whether certain ways of thinking are associated with being more resilient. Understanding this can help us to identify new ways to help increase resilience. By supporting carers to increase resilience, we could reduce the impact of caregiving on wellbeing.

#### **Why have I been invited to take part?**

You are being invited to participate in this project because we are seeking participants who identify as a carer of an individual with a physical and/or mental health condition. For the purpose of this study a carer is defined as a person aged 18 or over, currently providing unpaid care, and who has been in this caregiving role for at least six months.

Inclusion criteria: All participants must be UK residents, over 18, be fluent in English and with normal (or corrected to normal) vision. Participants must be currently providing unpaid care to another person over the age of 18, and have been doing so for at least six months.

Exclusion criteria: Individuals cannot take part if they are resident outside of the UK, are under the age of 18, or do not provide unpaid care to another adult (over 18). Individuals cannot take part if they are not fluent in English, or are unable to see words and coloured objects on-screen (and have no correction aids available, e.g. glasses or contact lenses).

#### **What will happen if I take part?**

If you choose to take part in the project you will be invited to complete a series of questionnaires and a simple card-sorting task online. Four months later, you will be invited to complete two of these questionnaires again.

As part of participation, you will be asked to provide information about you and the person you provide care for (such as age, gender, ethnicity, and employment status). You will be also be asked to provide information about your caring responsibilities (such as the time spent caring, and how long you have been in the caring role). The questionnaires include questions about ways of thinking (such as being able to think about different solutions to problems), resilience (ways of responding to stress and adversity) and mental wellbeing (low mood, anxiety and stress).

Participation will take place online, using your own computer or tablet. This means you can take part at home, at a time that suits you best. The first set of questionnaires and card-sorting task should take no longer than 35-45 minutes to complete, and the second set of questionnaires should take no longer than 10-15 minutes. The researchers will not be able to give you individual feedback on your performance, but they will be able to give you an overview of the study.

### **Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about taking part. If you decide to take part, you will be asked to indicate your consent on a consent form and you can request a copy of this to keep.

### **Incentives**

To contribute towards your time, you will be invited to enter a prize draw to win one of several gift vouchers worth £10, £25 or £50, by entering your email address when you have completed each of the two surveys.

### **What are the possible risks of taking part?**

The study will involve completing questionnaires that ask questions about mood, anxiety and stress. Thinking about this may lead to temporary increases in distress, but this is expected to go away quickly. You will be free to stop at any point if you wish to do so. Signposting to appropriate support services will be made available at the end of the survey.

Please note the questions that you answer in this study are not diagnostic tools. If you have any concerns about your mental wellbeing, please contact your GP, or other community health worker. You may also find it useful to see services listed by MIND: <https://www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/useful-contacts/>

If you are in need of urgent mental health support, please call one of the numbers below immediately:

- The Samaritans: 08457 90 90 90 (open 24 hours)

- Mind Infoline: 0300 123 3393 (open 9am-6pm)
- Rethink advice and information service: 0300 5000 927 (open 10am-1pm)
- If you are based in Croydon, Lambeth, Lewisham or Southwark, the South London and Maudsley NHS Foundation Trust (SLaM) has a helpline: 0800 731 2864 (open 24 hours)
- CALM Helpline for men at risk of suicide, or wishing to talk to someone: 0800 5858585 or 0808 8025858 if you are within London (5pm - midnight, everyday). CALM London text service (start your first message CALM 1) and Merseyside text service (start your first message CALM 2) on 07537 404 717 (5pm - midnight, everyday).
- HOPELineUK: For young people up to the age of 35, 0800 068 41 41 (10am - 5pm & 7pm - 10pm, Weekends 2pm - 5pm). Or text: 07786 209697 or email: pat@papyrus-uk.org

### **What are the possible benefits of taking part?**

We hope that you will find it interesting to take part in this research, and you will be offered a summary of the results at the end of the study. The information we will collect from this study will help us understand more about the resilience and wellbeing of long-term carers, and about the mental processes that predict resilience. We hope this will inform the development of new accessible treatments tailored to support those caring for someone with a long-term physical or mental health condition.

### **Data handling and confidentiality**

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR). All information collected about you, including your answers to questionnaires and computer-based tasks, will be kept strictly confidential. Information will be pseudonymised during the data collection period. This means you will be allocated a participant number and the only way to identify your data will be by your participant ID number. You are not required to provide any personal identifiable data as part of the study, other than your email address to be contacted for the second part of the study, and if you wish to be entered into the prize draw, receive results of the study or be contacted about future research. At the end of the study, your personal data (email) and the link between your personal data and participant ID will be deleted, to ensure full anonymity. No participants will be identifiable in the final report. If any information is disclosed which could seriously affect the welfare of yourself or others, a third party may need to be contacted for legal reasons. Data will be stored in a secure online storage repository provided by King's College London for up to 10 years. This information will only be seen by members of the research team, and will not be shared with any third parties.

### **Data Protection Statement**

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). If you would like more information about how your data will be processed in accordance with GDPR please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

**What if I change my mind about taking part?**

You are free to withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way. You are able to withdraw your data from the project up to two weeks after you have completed the study, after which withdrawal of your data will no longer be possible due to data being committed to analysis and writing of the final report. If you choose to withdraw from the project we will not retain the information you have given thus far. Please note once you complete a page of the survey, you will not be able to change your answers.

**How is the project being funded?**

This project is being funded by King's College London.

**Who has reviewed the study?**

The study has been reviewed by an informal carer representative from the FAST-R Service, Maudsley Biomedical Research Centre.

**What will happen to the results of the project?**

All data will be reported at a group level; individual data will not be reported and you will not be identified in any report or publication. The results of the project will be summarised in a thesis for a doctorate in Clinical Psychology (DClinPsy). The findings may be published in a peer-reviewed journal, presented at conferences and/or discussed at other public events. Findings may be published or disseminated via online platforms of charities, academic and/or healthcare organisations. If you would like a copy of the research findings, please let the researcher know and we will arrange for this to be sent to you as soon as it is available.

**Who should I contact for further information?**

If you have any questions or require more information about this project, please contact me using the following contact details:

Bethany Nicholson

Department of Psychology  
Henry Wellcome Building  
De Crespigny Park  
London  
SE5 8AF

[bethany.nicholson@kcl.ac.uk](mailto:bethany.nicholson@kcl.ac.uk)

**What if I have further questions, or if something goes wrong?**

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you can contact King's College London using the details below for further advice and information:

Dr Colette Hirsch

Department of Psychology  
Henry Wellcome Building  
De Crespigny Park  
London  
SE5 8AF

[Colette.Hirsch@kcl.ac.uk](mailto:Colette.Hirsch@kcl.ac.uk)

020 7838 0697

**Thank you for reading this information sheet and for considering taking part in this research.**