



## **Participant Information Leaflet (Questionnaire Study)**

<b>Study Title:</b>	Investigating Caregiver Satisfaction with Online and In-Person Support Groups for Caregivers of People with Dementia
<b>Investigator(s):</b>	Bethany McLoughlin (Warwick Medical School, University of Warwick)

### **Introduction**

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **Who is organising and funding the study?**

This research is part of a PhD project being conducted at Warwick Medical School. The PhD is funded by a scholarship from the ESRC (Economic and Social Research Council).

### **What is the study about?**

The purpose of this study is to find out what caregivers of people with dementia think about online support groups compared to face-to-face support groups. As many support groups have moved online due to lockdown, we are interested to hear about your experience of your support group moving online.

### **What would taking part involve?**

Taking part involves filling in a questionnaire online (alternatively, a postal version of the same questionnaire can be provided upon request). This questionnaire should take between 15 and 30 minutes to complete and questions will concern:

- Your demographic data (age, gender, ethnicity etc.)
- General information about your support group (how often your group meets, roughly how many people attend, what happens during an average session)
- Experience with your support group moving online
- Preferences about support groups

In the last section of the questionnaire you will be asked if you are interested in attending a 45 to 60-minute interview about your experience with support groups at a later date but this is completely optional.

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

No. Participation in this study is completely voluntary and choosing not to take part will not affect you in any way. You can also choose to withdraw your participation at any time, without giving a reason by contacting one of the research team. Further details about withdrawing from the study are provided later on in this document.

## **What are the possible benefits of taking part in this study?**

The findings of this study can be used to help organisations to improve their services and help other caregivers in a similar situation to yours in the future.

## **What are the possible disadvantages, side effects or risks, of taking part in this study?**

Taking part in the study will involve you giving up 15-30 minutes of your time. It is possible that the questions on the questionnaire may cause distress when recounting your experiences with support groups. If you do become distressed, you do not have to complete the questionnaire. Please note that there is a list of services that can support you on the study webpage:

<https://warwick.ac.uk/fac/sci/med/research/hscience/apc/digitalhealthcare/caregiversatisfaction/recruitment/>

If you received a postal version of the questionnaire, this list will be included in your envelope.

## **Expenses and payments**

There will be no payment for taking part in this study. If you request a postal version of the questionnaire, it will be sent along with a stamped addressed envelope to return the questionnaire in, so you do not have to pay for postage yourself.

## **Will my taking part be kept confidential?**

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. No questionnaire data will be transferred outside of the University.

If completed online, your questionnaire data will be collected from the survey host (Qualtrics) and held in a database. Information from the paper versions of the questionnaire will be entered into a database and then stored in a locked filing cabinet at Warwick University. All data will be anonymised and will be stored securely in a password-protected folder at Warwick University (in reporting, any identifying information removed to ensure confidentiality).

All contact details will be safely stored. Only the named researcher will have access to the data.

## **What will happen to the data collected about me?**

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from your questionnaire in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of

individuals in line with data protection legislation. The University of Warwick will store the research data from this study for up to 10 years.

No identifiable data will be collected from you as part of this study. This means that once your responses have been submitted to the research team, it will not be possible to withdraw this data as your individual responses cannot be identified.

However, if you wish to participate in the interview element of the study you will be asked to provide an email address which will make your data identifiable. Email addresses will only be collected for the purposes of arranging interviews and will be deleted after the interview has taken place to ensure your data is anonymised.

### **Data Sharing**

Your data will not be shared outside of the university. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here:

<https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice> or by contacting the Legal and Compliance Team at [GDPR@warwick.ac.uk](mailto:GDPR@warwick.ac.uk).

### **What will happen if I don't want to carry on being part of the study?**

Participation in this study is entirely voluntary, you can decide to withdraw from the study at any time without having to give a reason and this will not affect you in any way.

If you withdraw from the study, it will not be possible to withdraw your data which has already been collected, after it has already been anonymised. To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University's Information and Data Compliance policies.

### **What will happen to the results of the study?**

The results will be submitted for publication in a peer-reviewed academic journal. The results may also appear in the PhD thesis associated with this study.

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Warwick's Biomedical & Scientific Research Ethics Committee (BSREC): BSREC 35/20-21.

### **Who should I contact if I want further information?**

If you have any further questions please contact [bethany.mcloughlin@warwick.ac.uk](mailto:bethany.mcloughlin@warwick.ac.uk) (researcher) or [jeremy.dale@warwick.ac.uk](mailto:jeremy.dale@warwick.ac.uk) (supervisor).

### **Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

**Head of Research Governance**

Jane Prewett  
Research & Impact Services  
University House  
University of Warwick  
Coventry  
CV4 8UW  
Email: [researchgovernance@warwick.ac.uk](mailto:researchgovernance@warwick.ac.uk)  
Tel: 024 76 522746

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter: [DPO@warwick.ac.uk](mailto:DPO@warwick.ac.uk).

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

**Thank you for taking the time to read this Participant Information Leaflet**