



Participant Information Leaflet

Study Title: Increasing Access to Health and Social Care Services for People with Dementia and their Carers

Investigator(s): Dr Rene Wiedner (Principal Investigator, Warwick Business School), Tamsin Jewell (Research Assistant, Warwick Business School); Dr Stephanie Tierney (Oxford University); Dr Alexander Komashie (Cambridge University); Dr Anne-Marie Boylan (Oxford University).

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 study is led by Dr Rene Wiedner, together with a Patient and Public Involvement and Engagement (PPI-E) panel and a reference group representing clinicians, social care workers and commissioners across Oxfordshire and Warwickshire. It is funded by the University of Warwick Institutional Research Support Fund.

What is the study about?

This study hopes to find ways of improving access to relevant care services for people living with dementia and their informal carers. From this small-scale project that focuses on experiences in Oxfordshire and Warwickshire, we aim to develop a funding bid for more extensive research which would include trying out solutions.

What would taking part involve?

Taking part in this study will involve being interviewed in an informal way. In the interview you will be asked to share your own experiences of identifying and accessing dementia care-related services. We expect interviews to last no longer than 90 minutes and will fit in around your commitments. We can arrange a shorter interview and a separate follow-up interview if you prefer. Each interview will be with two members of the research team, one of whom has personal experience of caring for someone with dementia and experience working in health or social care.

If possible, the interview will be conducted as an online video call (via Zoom, Microsoft

Teams or any other application that you are comfortable with). You do not need to use the video setting. Alternatively, we can arrange a telephone call. Before we begin, we will ask you for your permission to record it. We will also send you a copy of the questions we will be asking you so that you know which topics we will be covering. You do not need to prepare for the interview.

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 at any time, without giving a reason, by contacting a member 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?

This study deals with a practical problem that affects people with dementia and their informal carers. Your participation will support finding ways to improve access to dementia care services.

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

We are not aware of any disadvantages, side effects or risks of taking part in this study. However, we acknowledge that talking about experiences of living with dementia may cause some sadness or anxiety. If you become upset during an interview, we will stop asking questions and check that you are OK. You can decide if you want to continue or not. One of the interviewers is a qualified social worker with extensive experience of work with adults with complex physical and mental health needs, and an adult safeguarding expert. They will be able to signpost to appropriate agencies for support.

Expenses and payments

We understand that it may be difficult to find time for an interview, especially if you are currently providing care for a person with dementia. You will receive a single payment of £20 as compensation for your time.

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. The only time we will disclose information to others is if we have reason to believe that you or others are at serious risk of harm. Records of what you say in the interview will not have your name attached. Your contact details, including your name, will be kept in a separate, password-protected file. All data will be stored on a secure server via the University of Warwick. Only members of the research team will be able to look at the records.

What will happen to the data collected about me?

As a publicly-funded organisation, the University of Warwick has 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 carry out the research study.

We will be using information from you 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 keep information about you for a minimum of 10 years, in line with university policy.

As soon after the interview as possible, the interviewers will remove your personal details from the results that have been gained and replace them with a number. This number will connect with your personal details, but will be stored separately in a password protected file to keep your identity private. Additionally, any names, place names, health and social care staff names, and organization names that you mention will be removed when the recording of your interview is typed up.

Data Sharing

We will need to convert interview recordings to text to help us analyse what you have said. If we employ someone from outside our team to help us with this, we will continue to protect your identity. We will only use Warwick University approved suppliers with whom we have an agreement concerning data use and storage.

You will not be able to read or change what you have said in the interview because we need to manage your information carefully 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 concerning access to dementia care services, 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.

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

If you have indicated that you would like to participate in this study but no longer wish to do so, please contact any member of the research team or directly notify the principal investigator (Dr Rene Wiedner, rene.wiedner@wbs.ac.uk, telephone: 07387 238 359). You do not need to provide any reason for your withdrawal and it will not affect you in any way. All contact information that we have collected about you will be deleted.

You may request the withdrawal of your data after you have been interviewed. However, it will not be possible to withdraw data once it has been included in a publication. If you would like to have any data about you withdrawn, please notify the principal investigator (Dr Rene Wiedner, rene.wiedner@wbs.ac.uk, telephone: 07387 238 359). Please remember that we will make sure that anything you say cannot be traced back to you because we will remove your name and any other sensitive information from the interview records.

What will happen to the results of the study?

The results of this study will be shared with all study participants, members of the Patient and Public Involvement and Engagement (PPI-E) panel and members of the reference group representing clinicians, social care workers and commissioners across Oxfordshire and

Warwickshire. The results will be presented in newsletters and online calls (using Zoom or Microsoft Teams).

Additionally, findings may be submitted to academic conferences and journals in the areas of healthcare management; organization studies; dementia care; and/or related fields.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): Ref 100/20-21.

Who should I contact if I want further information?

Please contact Dr Rene Wiedner (rene.wiedner@wbs.ac.uk; tel: 07387 238 359) if you would like further information.

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 looked at. 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

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

Email: researchgovernance@warwick.ac.uk

Tel: 02476 575733

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.

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.