

## Information sheet for carers

### **Exploring perceptions of Quality of Life in people with learning Disabilities and dementia.**

#### **Introduction**

My name is Winnie Tsang, I am a PhD student at the Tizard Centre, University of Kent. I am currently conducting research in developing a quality of life measure for people with a learning disability and dementia. My supervisors are Dr. Paraskevi Triantafyllou and Professor David Oliver. Some background information has been provided below to help you decide if you want to take part.

#### **Background of this project**

People with a learning disability are at a higher risk and more likely to develop dementia at an earlier age compared to the general population.

I would like to invite you to participate in a focus group looking at quality of life for people with learning disabilities and dementia. You will be asked to participate in discussions with other carers regarding quality of life for people with learning disabilities and dementia. 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. Your participation is voluntary and there are no adverse consequences in refusing to participate

#### **What will happen during the focus group?**

Each focus group will consist of 7 carers who have experience in caring for those with dementia and a learning disability. This will take approximately two hours with a 10 minute break. The researcher (Winnie) will lead the discussion and will guide you through the various issues. There are no right or wrong answers in a discussion of this kind – we are simply interested in your opinions. The focus groups will take place online using Microsoft teams. Upon completion, a £10 voucher will be provided for your time in the study.

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

We will video-record each focus group and these will be independently transcribed by the researcher. The analysed material will be used for the purpose of publication and in my PhD thesis. A copy of the transcript of your interview can be provided upon request.

#### **What about confidentiality?**

The focus groups will be recorded and transcribed. However, everything will be anonymised during transcription. We would like to remind participants to respect the privacy of their fellow participants and not repeat what is said in the focus group to others. We will not tell anyone that you have taken part in the focus group. We will also not name you in any of the reports or publications. In our publications, we will use quotes from the focus groups to help illustrate the points that are being made. Some of these quotes may come from you. We will not use any quotes that might reveal who you are, however. If cases of abuses have been revealed, we are required to breach confidentiality and report this to the local authorities

## Privacy Notice

Please use this link to read a related privacy notice related to how we will handle your data, <https://cdn-researchkent.pressidium.com/ris-operations/wp-content/uploads/sites/2308/2020/06/GDPR-Privacy-Notice-Research.pdf>. 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. The University of Kent's Data Protection Officer can be contacted at: <https://www.kent.ac.uk/infocompliance/dp/staff-info/staff-info.html> This study has received ethical approval from the Tizard Centre Ethics Committee. If you wish to make a complain please contact [issjethics@kent.ac.uk](mailto:issjethics@kent.ac.uk)

## How will my data be used?

The University of Kent will be using information from you in order to undertake this project and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Kent will keep information collected from you as part of the project for 5 years after the study has finished. To safeguard your rights, we will anonymise your information. The information collected from you will only be used for the purposes of this project and cannot be used to contact you for other purposes.

## What if I want to withdraw from the study?

If you decide to withdraw from the focus group, please contact Winnie Tsang (email: [wt66@kent.ac.uk](mailto:wt66@kent.ac.uk)) before the focus group date. After the focus group takes place, it will not be possible for you to withdraw your data as these will be part of an ongoing discussion that will then be analysed.

## How do I participate?

If you are interested in taking part in the focus group or if you have any questions, please contact Winnie Tsang (email [wt66@kent.ac.uk](mailto:wt66@kent.ac.uk)) for further information. This information sheet is for you to keep, and you will be asked to sign a consent form to take part in the study.

If you have any concerns or complaints about your participation, you can contact Winnie's supervisors

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