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IRAS Project ID: 291425

Title of Study: **Online peer support for people with Young Onset Dementia**

Chief Investigator: Prof Martin Orrell

Local Researcher(s): Miss Esther Gerritzen

What is this project about?

People with Young Onset Dementia (YOD) are diagnosed with dementia before the age of 65. It is widely acknowledged that younger people often find it difficult to locate age-appropriate support services, or meet other people with YOD. Supporting each other (peer support) can be an opportunity to stay socially connected and share knowledge and experiences. Peer support can happen in-person, for example through a support group, but it can also be online. Examples of online peer support can be: Facebook groups, Twitter, discussion forums, or Zoom meetings.

My PhD project has three aims: (1) learn more about the experiences of people with YOD with online peer support (2) learn how online peer support can be meaningful in daily life, and (3) learn about the barriers to online peer support, and how these could be overcome.

What participants are we looking for?

People with a YOD diagnosis. They do not have to be 65 or younger at the time they participate in the study, as long as they received their diagnosis before the age of 65. People do not need to have any experience with online peer support in order to take part.

What is expected from participants?

We ask participants to fill out an online survey. This survey includes questions related to demographic information, and about any experiences they may have with online peer support, and why or why not they engage in online peer support. Participants can fill in the survey anonymously. At the end we will give participants the option to share their name and contact details if they want to receive updates on the study, or if they want to participate in further parts of the study. People can also request a paper copy of the survey if they want.

How can you help us?

We would be very grateful for your help in recruiting people with a YOD diagnosis. We will send you a recruitment message that also includes the link to the survey and our contact details. All we would like to ask from you is to share this with people with YOD.

What is the timeline?

The survey will be open from 1 August 2021 and close on 12 September 2021.

Contact: If you have any questions, please don't hesitate to get in touch. You can email the PhD student, Esther Gerritzen on Esther.Gerritzen@nottingham.ac.uk.