PPI NEWSLETTER

ISSUE 2
FEB 2023

Thank you for your interest in the TIMES research project, which is exploring approaches to sleep disturbances for people living with dementia or mild cognitive impairment and ways to improve its assessment, treatment, and management in the community. This newsletter contains the latest project updates.

Please contact Jess on **jessica.a.blake@uea.ac.uk** for any feedback, comments or questions.

TIMES NEWS

REALIST REVIEW UPDATE (WORK PACKAGE 1A)

The first part of the project is almost complete. We have reviewed 60 papers looking at how sleep disturbance is currently assessed and managed in primary care, and what the experiences of service users and informal caregivers are.

The preliminary results indicate there is low awareness of sleep disturbance and ways to address it among healthcare professionals, people living with dementia and mild cognitive impairment, and their caregivers. Sleep management strategies, particularly in care homes, do not always cater to individual needs or wishes. Caregivers expressed interest in learning more about ways to manage sleep disturbance but expressed feeling unsupported by healthcare professionals to do this.

We are now writing up the research and will send out a draft write up for you and other members of TIMES to read and review.

The findings of the review will be presented at the British Journal of General Practitioners conference in March, with submissions to more conferences to follow.

FIELD RESEARCH UPDATE (WORK PACKAGE 1B)

Five GP practices have been identified as sites for our primary research, and work has begun on data collection. These sites comprise two GP surgeries in Yorkshire and Humber, two in the East of England and one in North-West London. We are looking to include people from under-served communities and people from minority ethnic backgrounds when recruiting patients and caregivers at these sites.

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MILD COGNITIVE IMPAIRMENT REPRESENTATIVES

The TIMES PPI management group meeting was held in November 2022. It was identified that there is low representation from people with mild cognitive impairment among the TIMES PPI representatives. TIMES have now recruited two men with mild cognitive impairment and are now looking to involve more women with this condition. If you are aware of anyone who may be interested, please email **times@exeter.ac.uk** or Rachael **rachael@myid.org.uk**

LIVERPOOL CHINESE WELLBEING

Chinese Wellbeing met with TIMES in November 2022. It was agreed that a Mandarin and Cantonese interpreter will be present for future meetings. The meetings will be held on Zoom, but Chinese Wellbeing will meet as a group and share a computer screen for those who prefer face-to-face. The next meeting is scheduled 14 February.

LIVED EXPERIENCE ADVISORY FORUM SLEEP (LEAFS)

The LEAFS group met in November 2022. The TIMES study was introduced to people living with dementia and their carers in two separate groups. Current issues relating to sleep and experiences of healthcare were shared. The groups have agreed to meet informally on a monthly basis with a larger meeting every 3 months.

**********GET INVOLVED: CO-DESIGN WORKSHOPS**********

We are holding a series of **online workshops** to discuss how findings from the review of scientific literature and observations at GP practices inform the **development** and **implementation** of the **TIMES intervention**.

Workshops will be based on:

(1) Developing the content and delivery of the intervention; and
(2) Revising outputs from the first workshop.

Health Care Professionals and Carers are invited to participate in four meetings: 03 May; 10 May; 06 June; 20 June: 14:00-17:00

People Living With Dementia or Mild Cognitive Impairment are invited to participate in two additional meetings: 27 June; 28 June: 13:00-16:00

We are looking for: 3-4 GPs; 3-4 pharmacists; 3-4 primary care nurses; 3-4 social care professionals; 3-4 sleep physicians; 3-4 Informal Carers; 3-4 People Living With Dementia or Mild Cognitive Impairment; 3-4 Social Prescribing experts; and 2 practice systems experts (IT manager, practice manager).

Attendance will be compensated at £30/hour

Places are limited so please contact **TIMES@exeter.ac.uk** if you would like to be involved.

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USEFUL RESOURCES

FREE CONFERENCE – HEALTH AND TECHNOLOGY

Prof. Chris Fox will be delivering a free in-person conference on the use of technology and smartphone apps within healthcare, with particular emphasis on rehabilitation, sleep, and caring.

The conference is on Monday 13th February and is part of the Norwich Science Festival. The event is free, but booking is required.
Click here for more information.

NEW PPI MEMBERS

A warm welcome to our two new members who have joined the PPI group (LEAFS), Daniel and Philip.

Anne has kindly agreed to take on a deputy role for George, and has joined our Programme Management Group to provide regular oversight of the programme. Thank you Anne!

MEET THE TEAM

Rachael Litherland

Rachael co-founded Innovations in Dementia in 2007 - a UK community interest company that supports people with dementia to be in control of their lives. She has a background in advocacy in care homes and psychology and works on a number of projects supporting people with dementia to shape and deliver research. Rachael was instrumental in setting up the Dementia Engagement and Empowerment Project (DEEP) network - a UK wide network of grassroots groups of people with dementia who aim to influence the world around them.

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Ruth Eley

Ruth is a social worker by training and held various senior management roles in local government, the NHS and the Department of Health in England, where she was the National Programme Lead for Older People, Dignity and Dementia. She has been working independently since 2011. She chairs the Board of trustees for Together in Dementia Everyday (TIDE) and is also vice-chair of the Liverpool Dementia Action Alliance. She believes passionately in involving family carers of people with dementia as equal partners in policy, practice, training, and research and works alongside carer members of the LEAFS group.

Di Burbidge

Di has worked at a senior level in banking, business support and as Commercialisation (IP) Manager for a local University. For several years, she worked on a voluntary basis for a Chinese Business Association. Di is now Service Development Manager for Chinese Wellbeing, a charity which provides social care and a range of wellbeing support services. Since 2012, Di has led on the development of culturally appropriate dementia support services for the Chinese community in Liverpool and has presented at the annual National Dementia Congress. Di is Chair of the Liverpool DAA Diversity Sub Group, Director of Liverpool Home Care Providers CIC and of Chinese Wellbeing Trading Services Ltd.