



VALID Research Trial

What has happened since we were last in touch?

As reported last time (Issue 6, Summer 2017), we closed recruitment to the research trial at the end of June with a grand total of 468 pairs of participants (a pair being a person living with dementia plus a family supporter).

All the community occupational therapy visits (COTiD-UK) have now finished, so many thanks to all the occupational therapists who provided these, often alongside their already very busy work schedules; and to the pairs who gave their time to take part.

The plan has always been to review 10% of all assessments collected at each of the time points for accuracy. This has kept the core team very busy and the Baseline and 78 week audits are now complete. The audit is also well underway for all other data collection points. We are pleased to report an overall low error rate so far and anticipate the complete audit to be finished by the end of January 2018.

How was it?

Last time we described the interviews being conducted to explore and better understand the experience and impact of taking part in the community occupational therapy visits (COTiD-UK). Currently we are analysing the data collected from interviewing seven occupational therapists who delivered the sessions. We are due to review our initial findings with the VALID Occupational Therapy Reference Group in December.

We have now finished interviewing 22 people with dementia and their family supporters who took part in the sessions. We will start analysing this data once the recordings have been transcribed. We will then review our initial findings with the VALID Patient & Public Involvement (PPI) Reference Group.

Thank you to all those who have been involved in setting up, and taking part in, these interviews; which have been conducted across ten NHS Trusts, ranging from the West Country to Yorkshire so as to reflect the diversity of research sites.

The next steps – into 2018

The researcher follow-up visits will continue until January 2018 to collect information from participants. With the bumper recruitment at the end of June 2017 it promises to be a busy December for everyone.

It is important to retain as many participants as possible across the sites in order to have as full a dataset as we can to analyse. The data will be checked for accuracy and then the statistical and health economics analyses can begin. We expect to have initial results in May 2018.

Our final Report has to be submitted to the National Institute for Health Research (NIHR) who funded the research early in July 2018. Following this, we will publicise the results via publications and events in order to disseminate the findings and to discuss the implications with relevant interested parties.

For more information, see: www.ucl.ac.uk/valid
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Data Monitoring & Ethics Committee

Our independent Data Monitoring and Ethics Committee (DMEC) met in October to review the safety and efficacy of the research trial. The committee consists of an independent statistician, an expert occupational therapist (OT) and Patient and Public Involvement representatives (PPI). The committee was pleased with the management of the trial and made no recommendation for changes, following the presentation by Jacki Mundy and Rumana Omar.

Top row left to right: Dr Rekha Elaswarapu, (PPI representative), Professor Rumana Omar (Trial Statistician), Dr Stephanie Daley, (Occupational Therapy specialist), Jane Hopkins (PPI representative), Jacki Mundy (VALID Trial Manager).

Bottom row left to right: Shamime Lakda (PPI representative), Professor Jill Manthorpe (Chair), Sandra Nolle (VALID Administrator).



'Celebration of Excellence in Occupational Therapy' award ceremony

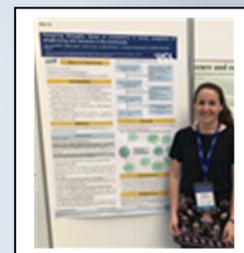


We reported last time that Jennifer Wenborn was awarded a Fellowship by the Royal College of Occupational Therapists (RCOT) in recognition of her contribution to occupational therapy practice and research. Also, that Becky Field, occupational therapist researcher and PhD student (University of Sheffield) was awarded the UK Occupational Therapy Research Foundation (UKOTRF) 2017 Early Researcher Award for her presentation at the RCOT Conference in the summer, reporting the first phase of her PhD study. Jennifer and Becky received their Awards at the RCOT's Celebration of Excellence in Occupational Therapy' ceremony at Fishmongers' Hall in the City of London in September.

Thank you to Becky for her contribution to the VALID research programme as she leaves to work with the 'Perfect Patient Pathway Test Bed, Evaluation Team' at Sheffield University.

Alzheimer Europe Conference, Berlin

Jacki Stansfeld attended the Alzheimer Europe conference, 'Care Today, Cure Tomorrow', in Berlin to present aspects of her PhD. She presented a paper: 'Investigating the impact of positive aspects of caregiving on sense of competence: A national survey'. Jacki also displayed a poster outlining a systematic review: 'Caregiving strengths: sense of competence in family caregivers of people living with dementia in the community'. Both presentations raised much discussion about the need to present a more balanced view on caregiving and to investigate the positive aspects of supporting someone living with dementia. It was a particular highlight to have supporters themselves engaging in the presentations and raising their own questions and comments.



The Valuing Active Life in Dementia (VALID) research study is funded by the National Institute for Health Research's Programme Grants for Applied Research Programme (RP-PG-0610-10108); and is a partnership between North East London NHS Foundation Trust and University College London, University of Sheffield, University of Hull, Radboud University Nijmegen Medical Centre, University of East Anglia, University of Manchester, Swansea University, Kings College London, Institute of Mental Health Nottingham and Dementia UK. The VALID research team acknowledges the support of the National Institute of Health Research Clinical Research Network. The views expressed in this newsletter are those of the author(s) and not necessarily those of the NHS, NIHR or the Department of Health.

