

DREAMS : START

Dementia RElAted Manual for Sleep : STrAtegies for RelaTives

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WELCOME TO OUR TRIAL E-NEWSLETTER

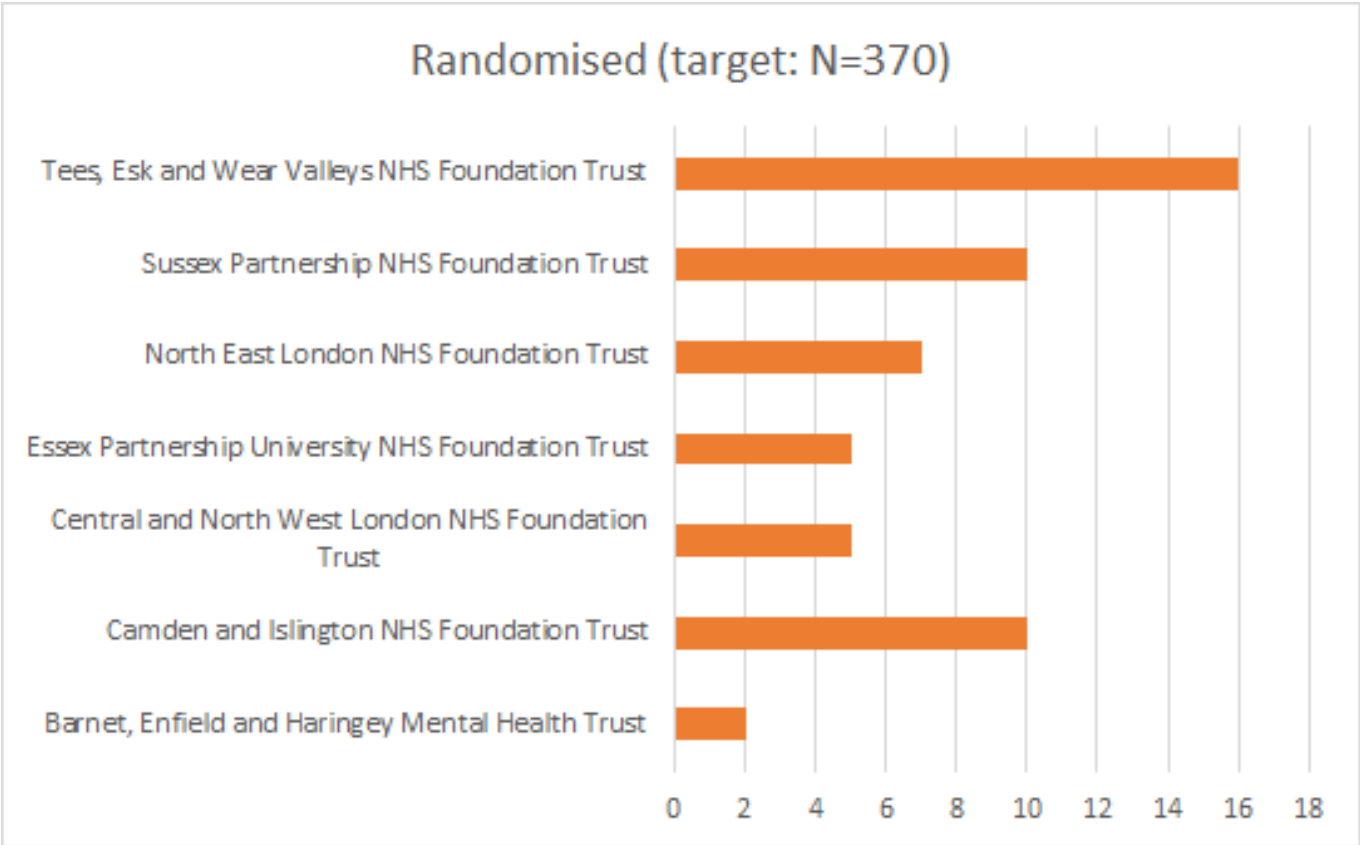
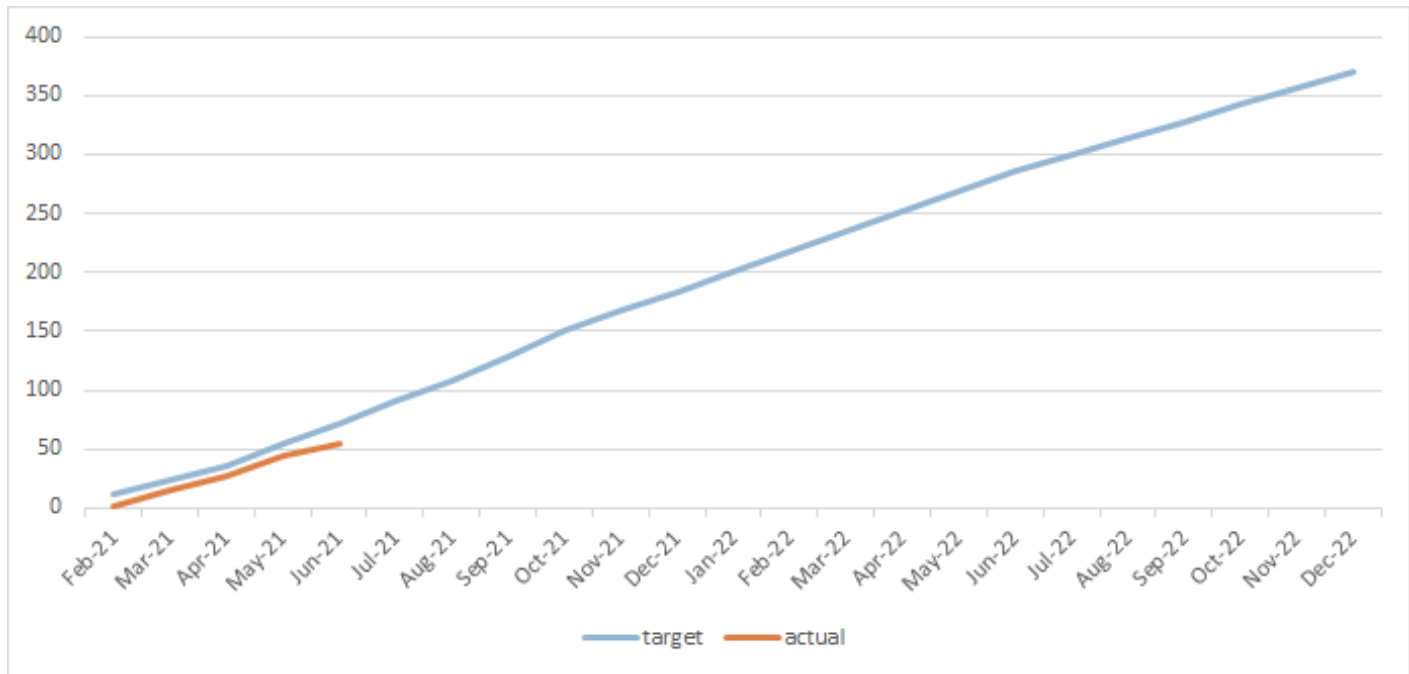
WHAT'S HAPPENING, WHAT'S COMING UP

We are four months into our 23-month recruitment period (February 2021-December 2022), and off to flying start with 55 participant dyads recruited to date (see page 2). Congratulations everyone, and especially Tees, Esk and Wear Valleys NHS Foundation Trust who are leading with 16 recruits!

Our first dyad was randomised end of February 2021, so our first round of monitoring visits will be coming up very soon (see page 3 for further details).

We will soon also be welcoming two more recruitment sites to the trial: East London NHS Foundation Trust (local PI: Michelle Hamill) and West London NHS Foundation Trust (local PI: Oliver Hill). Please join us in welcoming ELFT and West London to the team.

RECRUITMENT UPDATE



MEET THE TEAM

SARAH MORRIS (TEES, ESK AND WEAR VALLEYS NHS FOUNDATION TRUST)

Role at the Trust: As a Join Dementia Research (JDR) lead with TEWV, I play a key role in promoting JDR to our newly diagnosed patients. I also coordinate the referrals that come in from clinicians and help our patients sign up to research. My aim is also to embed research within the clinical pathways of our patients and make research accessible to all.

Role on DREAMS: As a research assistant on DREAMS I support in identifying and recruiting patients from within TEWV or on JDR.

Biggest challenge so far: Not being able to offer the intervention to everyone due to it being a randomised controlled trial (which allocates participants randomly to either the intervention or control group). There is definitely a huge need for the intervention to support our carers and patients living with dementia.

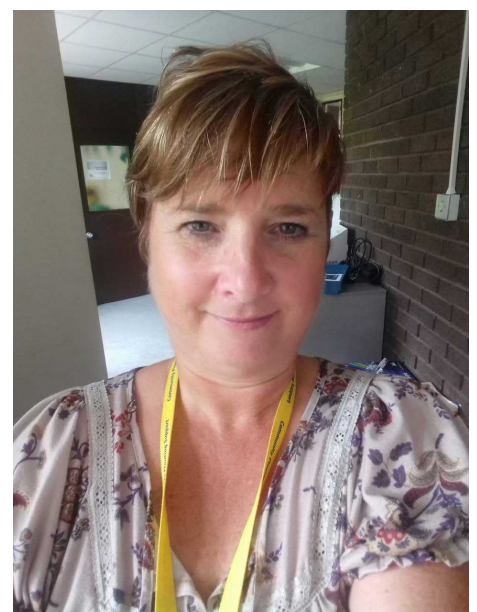
How are participants responding so far? I have found participants to be so thankful that they have been thought of and approached for this study.

How has COVID impacted your work on DREAMS? We have tried not to let COVID impact the study. In TEWV we have been able to offer face to face visits with our patients, ideally in their gardens but if not in their living rooms.

What do you most enjoy about your role? I love the study as a whole and in TEWV there is definitely a great need for the intervention. I have enjoyed bringing a tiny bit of normality into our participants lives after such a difficult year. Knowing I have listened to the participant and provided them with support allows me to leave my visit with a big smile on my face.



"KNOWING I HAVE LISTENED TO THE PARTICIPANT AND PROVIDED THEM WITH SUPPORT ALLOWS ME TO LEAVE MY VISIT WITH A BIG SMILE ON MY FACE"



COMING UP:

VIRTUAL MONITORING VISITS

Why do we monitor? To oversee the progress of the trial, and ensure that it is conducted and documented in accordance with the protocol and any amendments, and Good Clinical Practice.

Who is monitoring? The Trial is jointly monitored by the UCL central study team and PRIMENT who are the Clinical Trials Unit (CTU) through which the trial is managed.

How will DREAMS START be monitored? Due to current COVID-19 restrictions, monitoring visits will be conducted virtually using a compatible video conference platform (e.g. MS TEAMS or Zoom) until we are able to conduct on-site visits.

What should I do to prepare? The Trial Manager will be in touch with local PIs to facilitate the virtual visit led by PRIMENT. The trial manager will be in touch with guidance on what to prepare ahead of the visit, and will also provide PIs with a copy of the template used by the monitor to file their report.

KEY DATES

06-MAY-2021

Data Monitoring and
Ethics Committee
meeting

17-MAY-2021

Community of
Practice Inaugural
Meeting

25-MAY-2021

Programme
Management Group
Meeting

09-JUN-2021

Trial Steering
Committee Meeting

**11, 20, 27 MAY
& 7 JUNE 2021**

DREAMS START
training for new
facilitators



FREQUENTLY ASKED QUESTIONS

RECRUITMENT

Q. Who are we looking to recruit? People with dementia living at home who have sleep difficulties and their family/friend carer

Q. Can we recruit people with any type of dementia to the trial (e.g. Dementia with Lewy Bodies)? Yes, People with any type of dementia can be recruited to the trial (except alcohol-related dementia).

Q. Can we include people living with dementia who have experienced sleep problems prior to their dementia diagnosis? Yes. Only people with a known primary sleep disorder preceding the dementing illness (e.g. sleep apnoea) are excluded



RECURRING MEETINGS

Weekly team meeting for researchers supporting recruitment and data collection

Every Monday at 9AM we meet on MS Teams to update on recruitment, celebrate successes and share learning across sites - please contact the trial manager if you would like to join us

Fortnightly clinical Supervision for facilitators

Facilitators currently delivering DREAMS START attend clinical supervision once a fortnight - group sessions run twice weekly on MS TEAMS for London/Sussex sites, and by arrangement in TEWV - please contact Dr Penny Rapaport or Dr Chris Clarke for further information

KEY CONTACTS

DREAMS : START

FOR FURTHER INFORMATION OR IF THERE IS ANYTHING YOU WOULD LIKE TO SEE IN THE NEXT NEWSLETTER PLEASE CONTACT THE TRIAL MANAGER

Co-Chief investigators

Penny Rapaport p.rapaport@ucl.ac.uk

Gill Livingston g.livingston@ucl.ac.uk

Sponsor Representative

Priscilla Essuman sponsor.noclor@nhs.net

CTU representative (PRIMENT)

Sabrina Kassim s.kassim@ucl.ac.uk

Trial manager

Sarah Amador s.amador@ucl.ac.uk or +44 (0) 20 3549 5867

Clinical supervisor (London/Sussex)

Penny Rapaport p.rapaport@ucl.ac.uk

Clinical supervisor (TEWV)

Chris Clarke christopher.clarke@nhs.net