

LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL PROGRAMME



Inside the Spring Issue...

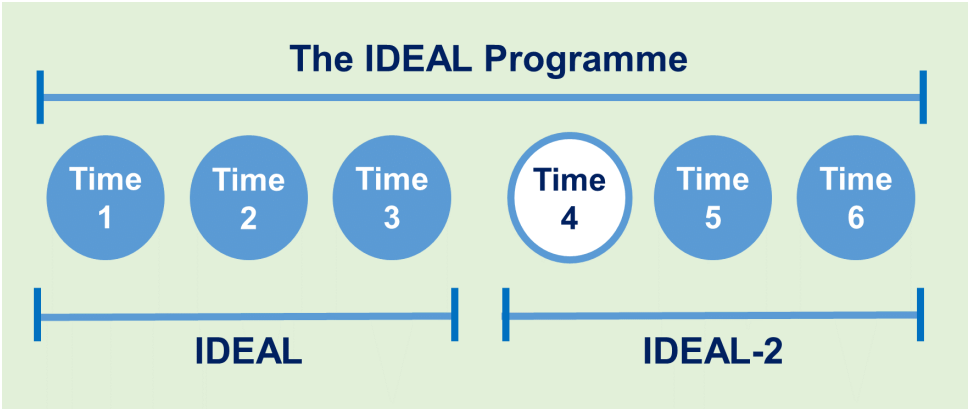
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IDEAL Programme Progress

Many of you will have been involved in IDEAL (time 1 to 3). However, we also welcome new participants joining us for IDEAL-2 (at Time 4). We are recruiting new people at Time 4 to ensure people of different ages and diagnoses are properly represented in the study.



28 NHS sites across the UK are currently visiting participants for Time 4.



46% of target number of people with dementia joining at T4



Visits from September 2019 onwards (one year after time 4 visit)



Visits from September 2020 onwards (one year after time 5 visit)



Additional IDEAL Programme Projects

Project 2 Co-production	Project 3 Advanced dementia	Project 4a Black and Asian and Minority Ethnic communities	Project 4b Undiagnosed dementia	Project 5 Service use & costs	Project 6 Policy & Practice
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DEAR group (Dementia Experts into Action Research)

We are a group of 11 people with dementia working with the University of Exeter to create a way of measuring what it means to 'live well with dementia'.

Personalised questionnaire

Our questionnaire lets you pick your own statements about what living well *means to you*. We will be testing this over the next few months to see how well it works.



Developing a standardized questionnaire

In Autumn 2019, we will be working on a standardized questionnaire - where everyone is asked the same questions in the same way.

Joy's experience

*"DEAR has given me a focus, a reason to get out of bed. I'm excited about being part of research. I **can** contribute, the dementia will not dictate"*

Recent Publications

All IDEAL publications and plain English summaries are available at www.idealproject.org.uk/activities/papers/

The IDEAL programme team have published two overarching papers in the journal *Alzheimer Disease and Associated Disorders*, led by IDEAL Chief Investigator Professor Linda Clare. One paper looks at what contributes to people with dementia being able to live well. A second explores which factors are important for those caring for them (friends/family) to live well. Psychological and physical health were highlighted as important for both groups, as well as feeling valued within the community and managing everyday tasks for people with dementia, and more positive experiences of caregiving.

Researcher Ruth Lamont and colleagues published findings from IDEAL in the journal *Aging & Mental Health*. The paper highlights the importance of feeling valued, useful and optimistic for being able to live better with dementia.

Researcher Catherine Quinn led on an article about caregivers' beliefs about dementia published in the journal *Psychology & Health*. The research team found that the way in which carers thought and spoke about dementia was related to their level of well-being.

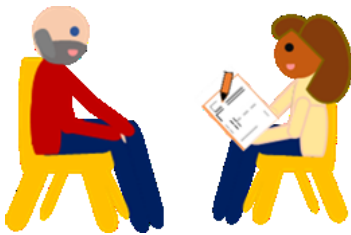
Working on IDEAL—Reflections from the Kent Team

Following the Kent & Medway NHS & Social Care Partnership Trust research team's success in being **top recruiting site** for the IDEAL study, we were very excited to be invited back as a recruiting site for the IDEAL-2 study and to be able to offer this additional opportunity for people living with dementia in Kent.



It's wonderful to see the study continue on to collect data over a longer time period, as this will be even more useful in providing information on **what people living with dementia and those close to them need to live well**.

We have found that **visits have been enjoyable and simple** for both researchers and participants due to the new streamlined layout of the questionnaires, and this has allowed for a relaxed experience for our participants.



For returning participants, the questions may be familiar as they follow a similar layout to the questions asked in IDEAL. However, the verbal feedback to date from both individuals living with dementia and their study partners has been that it is useful for them to be asked these questions again, as it encourages them to **evaluate how their situation may have changed** since we saw them two years ago and what support might benefit them currently.

For new participants joining IDEAL-2 without having participated in IDEAL, **the programme has been very well received** and the process of joining the programme without having taken part previously is simple.

We look forward to continuing to see both returning and new participants for IDEAL-2, and to working with the team at the University of Exeter to deliver this important programme to our service users living across Kent.

Jamie Harper— Assistant Clinical Research Coordinator

IDEAL Programme Events

Celebrating the completion of IDEAL

In November 2018 we met in London to celebrate the end of the first half of the IDEAL programme (Time 1-3) and to introduce the second half (Time 4-6). The event included talks from the project advisory group and the ALWAYSs (Action on Living Well: Asking You) group, and MP Debbie Abrahams. Findings to date were presented to those involved in care and policy for people with dementia.



International Network on 'living well' with dementia



In February 2019, researchers and representatives of national Alzheimer's Associations from countries including Brazil, Canada, Germany, Ireland, Japan, Lebanon, New Zealand, Taiwan and the USA attended a 2-day workshop. The IDEAL team shared what we have learned so far, and the group explored how we can learn more about living well with dementia from our international counterparts.

Unfurling of the 'Budding Friends' banner

In April 2019, the IDEAL programme and AgeUK Exeter unveiled the latest banner as part of our ongoing work to show people's experiences of living with dementia through art. The banner was co-created with people with dementia and shows the positive impact of gardening together.



We are sending you this newsletter because you have taken part in the IDEAL programme and have given us your permission to contact you.

For more information go to: www.idealproject.org.uk
You can also follow us on twitter  @IDEALStudyTweet

To update your contact details, please contact:

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