



LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL STUDY



Dear IDEAL participant,

Back in 2014, the National Institute for Health Research and the Economic and Social Research Council awarded a team of researchers from over 13 organisations funding to start the IDEAL study. The study set out to explore the experiences of people affected by dementia and to find out what helps them to 'live well'.

More than 200 IDEAL researchers across Great Britain have visited 1500+ volunteers (like you) for IDEAL, along with their family and/or friends. The researchers asked people about many different aspects of their day-to-day lives and how they are coping. This is more comprehensive than previous research.

IDEAL is also the first major study to re-visit people over the course of 3 years to see how things change for them over time. **This newsletter marks an important milestone, the completion of the IDEAL visits.**

You can be proud of the fact that the study has already been represented at over 45

academic conferences and public events and featured on TV and radio. Your responses so far have led to 18 publications.

Visit: www.idealproject.org.uk/activities/papers/

Most important, IDEAL has been recognised by Alzheimer's Society who have chosen to fund its continuation. This extension of IDEAL, known as 'IDEAL-2' will allow us to see how your experiences change over a longer period of time. In IDEAL-2 we will also invite new people to join the IDEAL programme of research, especially from groups that are underrepresented.

We are very grateful to everyone who has given their time and insights to this project. We hope that we will see you again for IDEAL-2.

With my very best wishes,

Linda Clare

Professor Linda Clare
(Principal Investigator)

What helps people living with mild-to-moderate dementia to 'live well'? Findings from the IDEAL programme



In IDEAL we asked 1547 people living with mild-to-moderate dementia to rate their quality of life, satisfaction with life, and well-being. We combined these ratings into one 'living well' score



We found a number of factors to be related to the capability of people with dementia to live well...



Psychological characteristics and psychological health: such as personality, optimism, self-esteem, loneliness, and depression



Physical fitness and health: such as lifestyle and health conditions



Resources and assets: such as size of social networks, and taking part in social and cultural activities



Managing everyday life with dementia: such as the ability to do routine activities



Social situation: such as social class and perceived social standing in the community

Ways to improve the capability of people with dementia to live well...

- 1) Sustain good mental health, such as by reducing levels of depression
- 2) Maintain good physical health and enable people to manage their activities more effectively
- 3) Reduce isolation, increase social and cultural engagement and help people with dementia to feel more secure and more engaged with their local communities

Paper reference: Clare, L., Wu, Y-T., Jones, I.R., Victor, C.R., Nelis, S.M., Martyr, A., Quinn, C., Litherland, R., Pickett, J.A., Hindle, J.V., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Rusted, J.M., Thom, J.M., Lamont, R.A., Henderson, C., Rippon, I., Hillman, A., & Matthews, F.E., on behalf of the IDEAL study team. A comprehensive model of factors associated with subjective perceptions of living well with dementia: findings from the IDEAL study. *Alzheimer's Disease and Associated Disorders*. [Accepted October 2018]

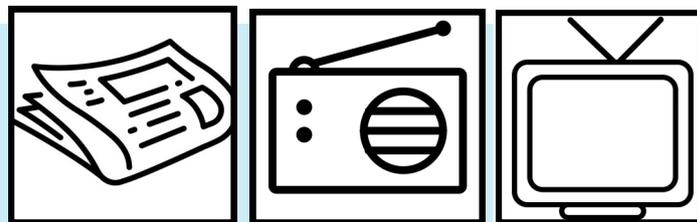
FURTHER IDEAL PUBLICATIONS

'A comprehensive model of factors associated with capability to 'live well' for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study': In this paper, Professor Linda Clare examined responses of friends/family involved in IDEAL to look at what can be done to improve their well-being also.

'Reflections on PPI from the 'Action on Living Well: Asking You' (ALWAYS) advisory network of people with dementia and carers as part of the IDEAL study': Members of the public living with dementia, called the 'ALWAYS' group, have been advisors for IDEAL. Led by Rachael Litherland from the charity 'Innovations in Dementia', the group have written a paper on their experiences of supporting the IDEAL project and the role they played. This paper will provide recommendations for future research projects looking to involve the public in shaping their research.

'Beliefs about dementia: Development and validation of the Representations and Adjustment to Dementia Index (RADIX)' : This paper led by Dr Catherine Quinn comments on the development of a measure (set of questions) for use in future research. The measure explores the beliefs people in IDEAL have about their condition and what is happening to them. For more information on IDEAL publications, visit:

www.idealproject.org.uk/activities/papers/



Sharing your experiences with others: Could you help?

IDEAL is producing many findings and will continue to do so as we look more at the data. This means that sometimes it will attract media attention. We are looking for volunteers who:

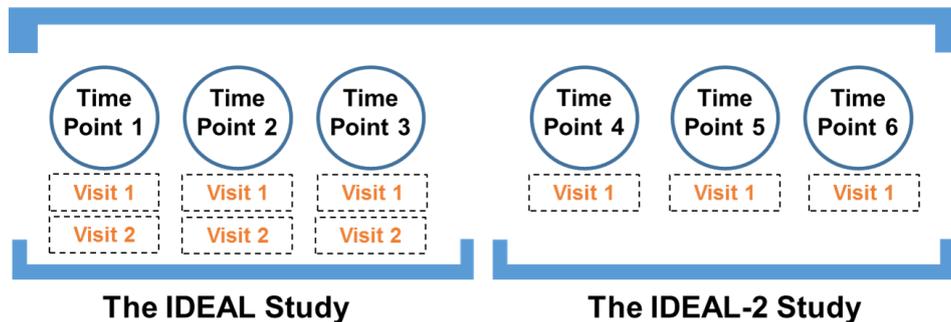
1. Have taken part in IDEAL as either someone living with dementia or supporting someone with dementia
2. Would be willing to speak with journalists about their experiences (e.g., newspapers, TV and radio) in light of IDEAL findings

Any volunteers would be helped to prepare for media engagements and accompanied on the day by our research team and/or press office. If this is something you would like to explore, please get in touch with Louise Vennells (L.Vennells@exeter.ac.uk).

What's next for the IDEAL programme?

The IDEAL study is now complete and included 3 visits, each a year apart. These were known as **timepoint 1, 2 and 3**. Through funding from Alzheimer's Society for an **IDEAL-2 study**, we are now able to continue to visit IDEAL participants three more times (again 1 year apart), for **timepoint 4, 5 and 6**. Together, IDEAL and IDEAL-2 make up our now extensive and exciting **IDEAL Programme**. Researchers from your local area will contact you over the next few months to see if you would like to take part in IDEAL-2.

The IDEAL Programme



What is different about IDEAL-2?

- Unlike previous years, there is a **2 year gap** between the last IDEAL visit (known as time point 3) and when you will be invited to start time point 4
- There are **less questions** to answer, so you will only need one visit to complete the questionnaires
- We have used the **feedback from participants** to make the questionnaire booklets easier to use

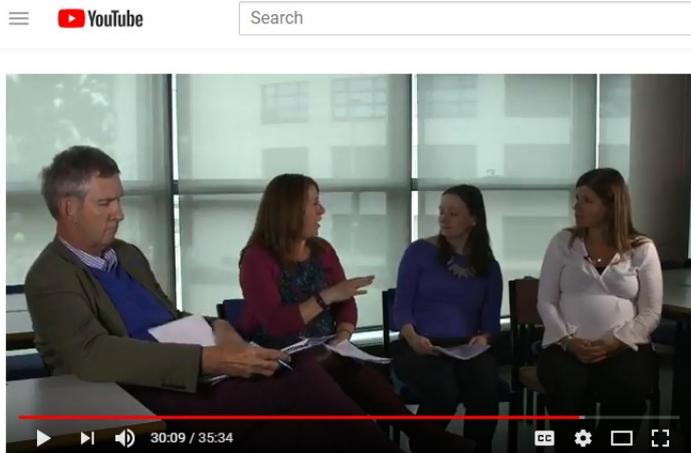
Coming up...

- Several sites across the UK are now completing timepoint 4 study visits, with more sites opening each week
- In November, the IDEAL programme team are holding a conference in London for professionals who shape support for those with dementia. The conference will discuss what we have learned to date and how we can continue to support people to live better with dementia
- We will keep you updated with the study's progress with IDEAL programme newsletters



● = IDEAL-2 site

RECENT IDEAL ACTIVITIES



IDEAL Study Masterclass on Involving People with Dementia and Carers in Research

[left] August 2018– IDEAL released two **online masterclasses** to upskill those doing research in the area of dementia. The masterclasses focus on interviewing skills and public involvement in research design:

www.idealproject.org.uk/takingpart/mclass/

[right] July 2018- Professor Linda Clare (lead on IDEAL) and Keith Oliver (IDEAL project advisor and advocate living with dementia) presented at the **Alzheimer's Disease International 33rd Conference** in Chicago.

At this prestigious conference they highlighted the work and findings of IDEAL.



[left] June 2018– The IDEAL team meet with **Alzheimer's Society** to discuss findings coming out of IDEAL and how they can best be used.

The expertise of Alzheimer's Society will be utilised to make sure IDEAL findings are understandable and useful for others.



[top left] May 2018– IDEAL researchers, Ruth Lamont and Anthony Martyr display IDEAL artwork for Dementia Action Week (DAW18) in the Exeter Guildhall shopping centre.

[bottom left] The right to get out and about when living with dementia was the focus of our most recent IDEAL booklet. This is the work of three artists and three groups: 'DEEP Vibes Scarborough', 'York Minds and Voices' and 'Face It Together' in Bradford. Their grand launch during DAW18 involved unfurling banners, a band and meeting people and local journalists in York train station. www.idealproject.org.uk/projects/almo/chapbooks/

A note on the protection of your data...

The University of Exeter is committed to protecting your personal data and working in accordance with all relevant data protection legislation. The IDEAL research team adhere to the University of Exeter guidance on the use of research participant data and data protection principles under the General Data Protection Regulation (GDPR).

If you would like any further information on this, please see our full statement online at www.idealproject.org.uk/datapolicy/ or contact us to send you a copy.

We are sending you this newsletter because you have taken part in the IDEAL study 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, contact:

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