

# LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL STUDY



## Welcome to the 'IDEAL Study' newsletter.

We are sending you this newsletter because you have taken part in the IDEAL study and have given us your permission to contact you. In this newsletter we would like to update you on how the study is progressing and tell you about upcoming opportunities.

For more information go to: [www.idealproject.org.uk](http://www.idealproject.org.uk)

## Featured in the Media

The IDEAL study and its participants have been recognised in the media since the study commenced.

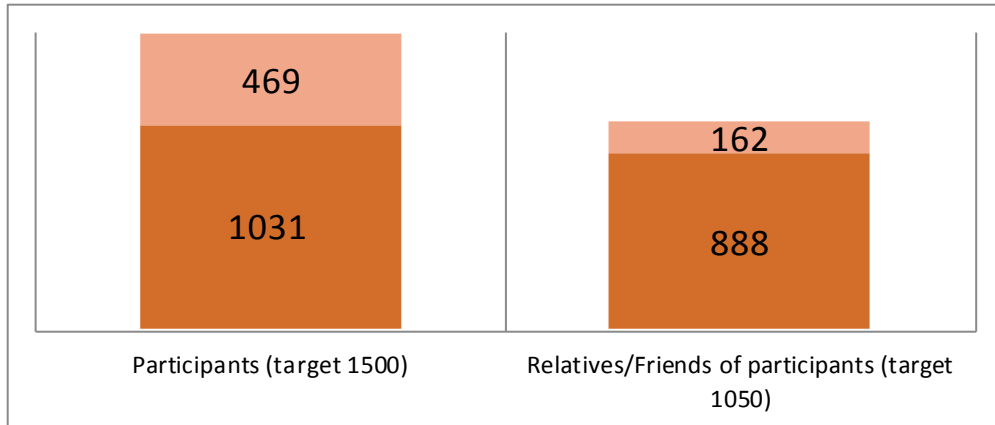
- \* The IDEAL study was named in media reports as an example of the work supported by the Join Dementia Research (JDR) initiative, and also as part of Dementia Awareness Week in May 2015. Participants appeared in the Newark Advertiser, the Yorkshire Evening Post, and on the National Institute for Health Research NHS webpage. Encouragingly, JDR has recently reported a 60% rise in the number of volunteers taking part in research studies.
- \* In August an IDEAL study participant, from North Wales, appeared on BBC breakfast to discuss his participation in dementia research, mentioning the IDEAL study as part of this.
- \* The IDEAL study was also featured in the June 2015 Alzheimer's society magazine.
- \* The study has been discussed at a number of National and International conferences, and in November 2015 we presented the study at the Gerontological Society of America meeting in Florida.
- \* We have also published the study protocol: Improving the experience of dementia and enhancing active life - living well with dementia: study protocol for the IDEAL study. This was published in the journal *Health and Quality of Life Outcomes*.

## IDEAL Study Timeline 2014-2016

TIME 1 (Aug '14 - June '16)

**August 2014** - As an IDEAL study participant you will already have been visited in your home by a researcher to answer questions relating to your experiences of living with dementia, or having a loved one living with dementia. This is called 'TIME 1' in the study process.

### Recruitment Update



We are very pleased to report that up to the 26th November 2015, we have recruited 75% of participants (totalling 1919 people).

Thank you to everyone who has taken part.

TIME 2 (Aug '15 - June '17)

**August 2015** - TIME 2 visits have now begun. We would like to visit everyone who took part at TIME 1, 12 months after their initial involvement to see how things are now. This will be shorter than the first set of visits.

You will be contacted by researchers in your local area in advance of these visits. We hope you will take the time to support the study again and to share your experiences with us.

**January 2016** - A number of people taking part in IDEAL will also have the opportunity to take part in **Interviews** (see page 3).

We have recently received additional funding to develop an arts-based program within IDEAL called '**A Life More Ordinary**'. This work will commence with a series of workshops in Exeter, Stockport/Manchester and Kent. People taking part in IDEAL will be invited to take part (for more details see the flyer enclosed).

## Introduction to the IDEAL Interviews

We are grateful for your contributions to the study so far. We will be asking a small selection of people to take part in some additional in-depth interviews.

Dr Alexandra Hillman (profile below) is conducting these interviews as a way of further understanding peoples' experiences of living with dementia.

The interviews will involve meeting with Alexandra for an initial interview and then again for a follow-up interview 10-14 months later.

Both interviews will involve talking about those aspects of your life that help or hinder you in living well with dementia.

The interviews will be open and will give you the opportunity to talk freely about your experiences and what you believe is important.

We hope this will be of interest to you and will be contacting people in the Spring of 2016 to ask if they are interested in helping with this part of the study.

### Researcher profile

My name is Dr Alexandra Hillman, I am part of the research team working on the IDEAL study. I am based at Cardiff University and work within the Wales Institute for Social and Economic Research, Data & Methods (WISERD).



I have conducted research in a number of important areas:

- \* Exploring the social and ethical issues surrounding the diagnosis of dementia, and concerns of newly diagnosed people with dementia and their families.
- \* Seeking to improve dignity and dignified care of older people on NHS hospital wards, as well as highlighting the challenges facing older people being assessed and treated in A&E services.
- \* More recently I have been working with people with dementia, looking into whether social and ethical concerns are addressed alongside the treatment of the condition.

*I look forward to meeting with you.*

## The ALWAYS Group: Involving People

The ALWAYS group (Action on Living Well: Asking You) is an advisory network of participants and their relatives/friends that provide invaluable support to the IDEAL study. We continue to ask their advice, and during 2015 members of the group have:

- \* Consulted on the questions we ask during the visits and provided suggestions for removing questions and adding open-ended questions;
- \* Advised us on the introduction of data linkage. Their feedback helped in the training of researchers who conduct the visits;
- \* Met with the photographer Ian Beesley to discuss the 'A Life More Ordinary' project;
- \* ALWAYS group members will also be involved in piloting of the IDEAL interviews.

## The IDEAL study moves to Exeter

Prof. Linda Clare, chief investigator of the IDEAL study moved to the University of Exeter in March 2015. We are pleased to say the rest of the team working on the IDEAL study have now moved to Exeter and have been joined by some new team members. The IDEAL study is now co-ordinated from the University of Exeter.

The University of Exeter has recently been ranked within the top 100 global



institutions. It is therefore an exciting move for the IDEAL team.

The IDEAL study is now supported by 29 local research networks throughout England, Scotland, and Wales.

Please be assured that any correspondence relating to IDEAL will be forwarded from Bangor to Exeter.

## With Thanks & Happy New Year 2016

### Please keep us updated

**If we do not have your most up-to-date address or if you are moving in the near future please do let us know so that we can keep you updated on IDEAL study progress and opportunities for involvement.**

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