



LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL STUDY

Leading the fight
against dementia
**Alzheimer's
Society**

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id Innovations
in Dementia

**KING'S
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POLITICAL SCIENCE

**NEWCASTLE
UPON TYNE
CENTRE
FOR
HEALTH
RESEARCH**

RICE

US
University of Sussex

Welcome to the first 'Living Well and Enhancing Active Life: The IDEAL Study' newsletter. We are sending you this newsletter because you have taken part in the IDEAL study in one of the areas shown on the map below, and you gave us permission to contact you about this study. This is the first of a series of newsletters to keep you up to date with the IDEAL study progress. More information on the study can be found at our project website www.idealproject.org.uk

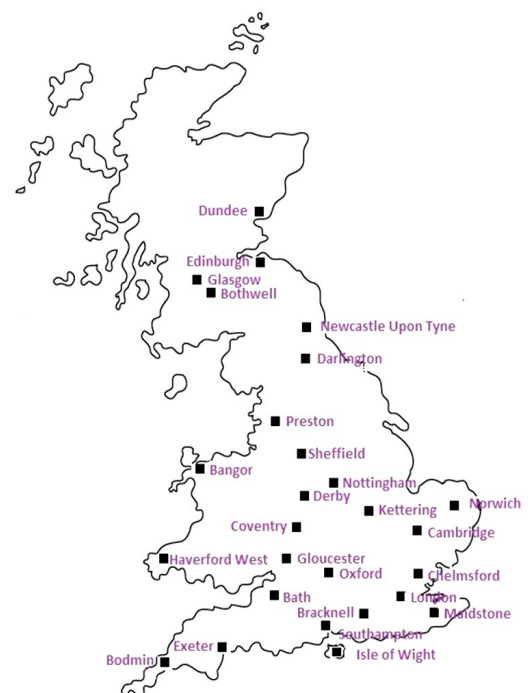
Thank you to all our participants On behalf of all of us in the IDEAL team, we would like to extend our warmest thanks to all participants who have taken part in the IDEAL Study. We appreciate your personal involvement and are looking forward to working with you again as the study continues.

How have we involved people in the study?

People from throughout Great Britain are involved in the study and have been contacted by researchers from the NIHR Clinical Research Network in England, the SDCRN in Scotland, and NISCHR CRC in Wales. These researchers have conducted interviews and collected information from people across all the regions as shown in the map. We have 28 sites involved in the study, with 26 sites up and running.

The IDEAL Study is listed on the Join Dementia Research register. This is an on-line self-registration service that enables volunteers to register their interest in taking part in research and a number of people have joined IDEAL from this register. For more information please visit www.joindementiaresearch.nihr.ac.uk

This map shows the regions that are participating in the IDEAL study

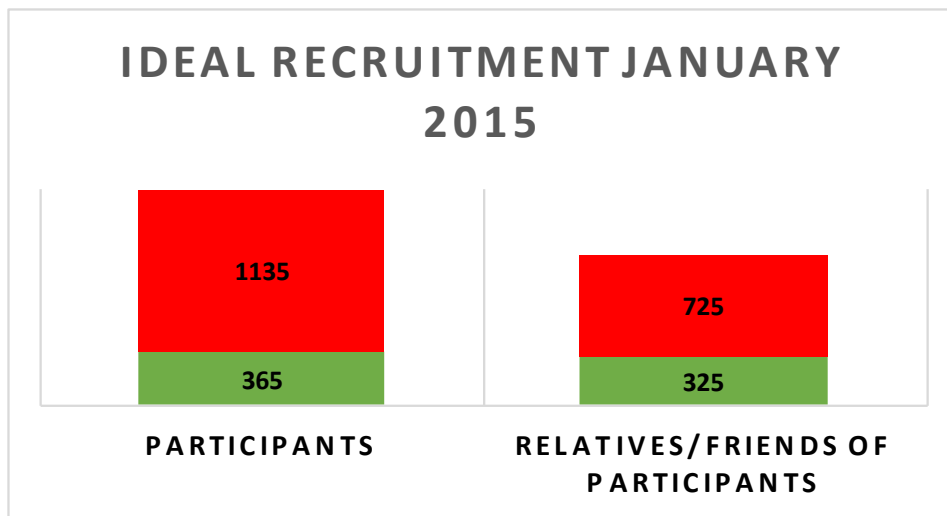


Recruitment update

The IDEAL Study started to invite people to take part in August 2014.

We aim to recruit 1500 participants and at least 1000 relatives/friends.

We are very pleased to report that we have recruited 365 participants and 325 relatives/friends up to January 2015.



How have people felt about taking part?

Some people who have taken part have provided some nice feedback on the study:

"Very enjoyable - provided me with a greater insight into the future and what it may hold"

"The project is thought provoking and enjoyable. Hope this will help others. Very interesting, made daughter and mother talk about things they had not done before 'opened our eyes' "

"Found the experience very interesting. Good research project that may help people in the future"

"I am happy to be taking part. It has heightened my awareness of our circumstances. I hope there will be positive outcomes from this research for future provision"

"Happy to contribute and help other people"



RESEARCH SITE HIGHLIGHT we would like to share the experience of one of the research teams involved in the study: **RICE - Research Institute For The Care Of Older People based in BATH.** Dr Krist Noonan – Local Principal Investigator for Bath and North East Somerset writes:

The IDEAL study opened at the RICE centre in Bath in August 2014 and since this time we have recruited 18 couples into the project. The scope of the project has allowed us to involve people who have not been eligible to take part in other studies. At Bath the study is led by the psychology team at the RICE centre, but the Clinical Research Network of the West of England have been instrumental in supporting recruitment and ensuring that we are able to offer this study to as many people as possible. Our colleagues in local NHS trusts – The Royal United Hospital, Avon and Wiltshire Mental Health Partnership and North Bristol NHS Trust – have also been very supportive of this project and have allowed us to reach out to participants in the broader southwest area.

Many of our participants have commented that the opportunity to be able to voice their opinions on a diverse range of topics related to the dementia journey has been very rewarding and we are sure that the knowledge obtained from this process will be directly relevant to informing future healthcare policy.



Advisory Group and Network

We have formed an **advisory network** of participants and their relatives/friends called the Action on Living Well: Asking You (ALWAYS) group. Members of the group have advised us on the visits to participants, reviewed the questions we ask and also provided information to help train the researchers. We will continue to work with the group to help shape the project during 2015.

We have also formed an **Project Advisory** of independent members, including health professionals and service providers and members of the ALWAYS group. The group will meet twice year and will provide advice to the research team .

In the news Since the launch of the study we have:

Spread the word about the project at both National and International events: British Psychological Society Faculty for the Psychology of Older People Conference, Shrewsbury; National Eisteddfod of Wales; Older People & Ageing Research & Development Network, Swansea; Edinburgh University; University College Dublin and The Alzheimer's Association International Conference, Copenhagen, Denmark.

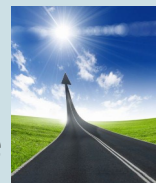
Informed Policy makers and voluntary agencies of the study aims and plans.

Worked on **academic papers** on quality of life, social isolation, and published the study protocol.

Change to the study: From March 2015 the Chief Investigator of the study Prof. Linda Clare will leave Bangor University and move to the University of Exeter. Other staff will move later in 2015. This change will not affect your continued involvement in the study. Please be assured that any correspondence relating to IDEAL will be forwarded from Bangor to Exeter.

Next steps for participants

- We will continue to invite people into the study until June 2016.
- It will be 2016 before we will have all the data to be able to provide some results but we will let you know when results are available.
- For people who took part in 2014 we will be following you up one year on from your first involvement to see how you are doing. A researcher will contact you again about taking part.
- A small number of people who have taken part, may be approached about being interviewed in further depth.



Please keep in touch: If this newsletter has been forwarded to you at an address that is different from the one we have on record or if you are moving in the near future we would appreciate if you could give us your new contact details.

Please contact: Rachel Clarke

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