

# LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL PROGRAMME



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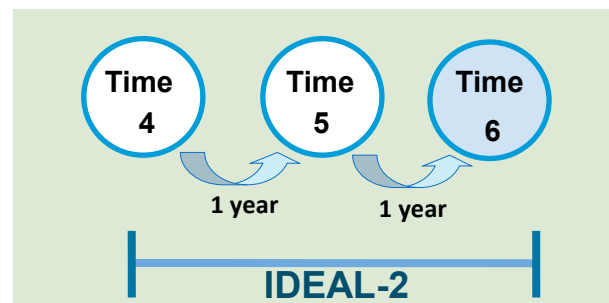
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## IDEAL Programme Progress

**Thank you** to those who have been involved in IDEAL. We are currently seeing people for their T4 and T5 visits. We still need your help to meet our recruitment targets. We greatly appreciate your continued involvement and acknowledge this is not always easy.



### Time 4

Over the past 18 months 207 people with dementia and 208 carers have agreed to take part in IDEAL-2 and have completed their Time 4 visits.

February 2020

**Recruitment to the IDEAL-2 study closes in just 6 months.**

July 2020

**We want to gain the perspectives of as many people as possible so please continue your support if you can.**

### Time 5

Time 5 visits (which take place 1 year after Time 4 visits) have been taking place over the past 6 months.

February 2020

Time 5 visits will continue to take place over the next 17 months.

June 2021

## Additional IDEAL Programme Projects

Project 2 Co- production	<b>Project 3</b> The perspectives of people with more severe dementia in research	Project 4a Black, Asian and Minority Ethnic communities	Project 4b Undiagnosed dementia	Project 5 Service use & costs	Project 6 Policy & Practice
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### Why is this project needed?

People whose dementia has progressed to the point that they are not able to fill in questionnaires still have something to say, and their perspective is important. Many people with more severe dementia are able to say what is important to them, while others communicate their feelings and preferences non-verbally. We are researching different ways of obtaining the perspectives of people with more severe dementia in research.

### What we aim to achieve:

a) To review what is already known from research and published guidelines about how to obtain the perspective of people with more severe dementia.

b) To develop and test a range of communication techniques that researchers can use to obtain the perspective of people with more severe dementia in research.

### Progress:

a) Dr Anthony Martyr is reviewing published research and recommendations and has started to identify instances where the views of people with more severe dementia have been included.

b) We have conducted interviews and groups discussions with carers, and with experts in communication. Dr Rachel Collins is analysing these as part of the first step in developing the toolkit.

## Recent Publications

The following researchers have answered important questions using your IDEAL questionnaire responses. All IDEAL publications and plain English summaries are available at [www.idealproject.org.uk/activities/papers/](http://www.idealproject.org.uk/activities/papers/)

Dr. Cate Henderson (London School of Economics) examined the use of different types of care (health care, social care and unpaid care) by people with mild-to-moderate dementia, and the associated costs. The study shows that the majority of care costs are largely shouldered by unpaid carers who typically provide about 36 hours of care per week. This highlights the need for policy makers to consider the support needs of unpaid carers.

Dr Anthony Martyr (University of Exeter) examined the relationship between 'living well' among people with mild-to-moderate dementia and their ability to perform everyday tasks, such as being able to make a cup of tea, or use the telephone. He found that those who reported having difficulties in performing everyday tasks believed that their ability to live well was low and those who had fewer difficulties with these tasks believed that their ability to live well was higher. This supports the need to enable people with dementia to remain independent for longer.

Dr Catherine Quinn (University of Bradford) was interested in whether what the family carer experiences has an influence on the ability of the person with dementia to 'live well'. Dr Quinn found that where carers were highly stressed, lacked a feeling of being competent in their caring role, and experienced a reduction in social activities, the people they cared for rated their quality of life, well-being, and satisfaction with life less positively. This highlights that both practical and emotional support could be helpful for family carers, and the people they support.

## Working on IDEAL-2: Reflections from the Lancashire & South Cumbria Team

**Visiting participants** has offered an invaluable insight into how diverse the progression of dementia can be. This is not only due to different sub-types of dementia but also the different individual experiences faced over the years. The different challenges carers face and how they cope varies greatly too. They are very much an underappreciated part of society, and so the collection of IDEAL information from participants over time is very important.



This is how we collect IDEAL information from participants:

For new participants we arrange a call to discuss the project and arrange a home visit. Two weeks before the visit we contact the participant again and if they agree to continue we send the relevant participant information sheets. A week later, we call them again just to confirm they are still happy to continue. Prior to the visit we create pre-prepared packs, which contain everything we will need for the visit.



For each returning participant from IDEAL we have created a tool that helps us identify a target visit date and timeframe. As with new participants, we contact the participant two weeks before the visit is due to determine if they wish to continue. We send relevant participant information sheets and do a follow-up call. It is often the relative who responds and they may feel visits are no longer appropriate. In such scenarios, we explain the

questionnaires have been adapted accordingly to make it easier and that the participants views at any stage are still important to us. We remind them that the participant can stop at any point if s/he wishes.

Sometimes visits need **additional time** for people who may have more severe dementia, e.g. those in residential or nursing care. In such cases, we sometimes need to visit people twice in order to complete questionnaires. Participants & their relatives are always thanked for their time. They are also given a voucher as thanks for their participation, and are also asked to confirm whether they are happy to be contacted again in the future.

**Daniel Pulford (Site Co-ordinator)**

## IDEAL Programme Events



Throughout the IDEAL project a team of artists has been working with groups of people with dementia from different parts of the country. Together they have created a series of banners to raise public awareness of some of the issues faced by people with dementia. Each of the 14 banners is accompanied by a description of the banner, a poem, and some artwork created during its development.

These fantastic 'dementia banners' are now touring the country and are available for you to go and see at the following venues:

**Exeter Library:** 16th October 2019 to 31st March 2020

**The Lighthouse, Poole, Dorset:** 18th January to 16 March 2020

**The Harris Museum, Art Gallery & Library, Preston:** 15th February to 23rd May 2020

**Gallery Oldham:** 20th February to 25th April 2020

**Surrey Quays, Southwark, London:** 11th to 17th May 2020

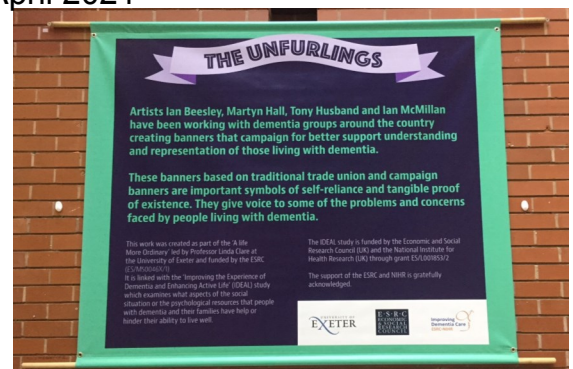
**Sheffield Cathedral:** 12th to 20th July 2020

**Salts Mill, Saltaire:** 11th to 21st September (open everyday) and 22nd September to 31st October 2020 (open weekends only)

**Bradford Industrial Museum:** 22nd November 2020 to April 2021

**Thackray Medical Museum, Leeds:** December 2020 to May 2021

These pictures are from the exhibition opening day at the People's History Museum in Manchester (open from 16th December 2019 - 19th January 2020). More pictures and information about the posters can be found on our twitter page: [@IDEALStudyTweet](https://twitter.com/IDEALStudyTweet)



**Gerontological Society of America (GSA) Conference:** Researchers and clinicians from a number of countries attended the IDEAL symposium at the GSA conference in Texas on the topic of loneliness and isolation. The presentations sparked interesting debate and further highlighted the potential for IDEAL evidence to be used internationally.

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](http://www.idealproject.org.uk)**

**You can also follow us on twitter  [@IDEALStudyTweet](https://twitter.com/IDEALStudyTweet)**

**To update your contact details, please contact:**

IDEAL Team, Centre for Research in Ageing and Cognitive Health (REACH), South Cloisters, University of Exeter, St. Luke's Campus, Heavitree Road, Exeter, EX1 2LU  
**Tel:** 01392 722990 **Email:** [IDEAL@exeter.ac.uk](mailto:IDEAL@exeter.ac.uk)