

LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL PROGRAMME



IDEAL Programme Progress

We hope you are well during these very challenging times.

Since the COVID -19 outbreak, researchers have been unable to visit participants at home. Instead, we are starting to contact participants by telephone to find out about their experiences. You can read more about this in the next section. We will do this until we are able to start visiting people again. In the meantime, our NHS researchers have been doing an amazing job working in hospitals and on COVID -19 related studies across England, Scotland and Wales.

New IDEAL Programme Project: INCLUDE

We are very pleased to let you know that the IDEAL team has now been awarded funding to carry out more in-depth research to understand the impact of the COVID-19 epidemic and the resulting restrictions on people living with memory problems and dementia, and their families. This study is called '**INCLUDE**'.

In the INCLUDE study, we will be contacting everyone who takes part in the IDEAL-2 study to ask if they are willing to tell us about their experiences since the COVID-19 outbreak started. All communication will be via phone or online, which will remove any potential risk of COVID-19 transmission.

We want to know how the restrictions around going out and seeing other people have affected our participants. This is so that we can recommend better ways of supporting people in the future. We will use what we learn to produce a set of resources called 'Living Well Alongside COVID' (LILAC). This will include resources for people living with memory problems and dementia, and their families, alongside guidance for health, social care and voluntary sector staff.

What is involved in taking part in the INCLUDE Study?

Between September 2020 and March 2021, researchers from the IDEAL team will be contacting IDEAL-2 participants to see if they would like to be part of this additional study. If participants agree, they will discuss their experiences with a researcher over the phone at a time that suits them. These interviews will be shorter than before and will give participants the opportunity to talk about their experiences in their own words.

If you would like more information about the INCLUDE study, or to express your interest in taking part, please email: IDEAL@exeter.ac.uk or call 01392 724653 and leave a message with your name and number.

Additional IDEAL Programme Projects

The IDEAL team produced two leaflets which outline five key ways that people with dementia, and those who support them, can stay well during the COVID-19 outbreak.



Insights were based on what we have learned from IDEAL participants and new information from our networks. A PDF copy of the leaflets can be found on the COVID-19 section of our website: www.idealproject.org.uk/covid/

Thank you for your contribution to the IDEAL programme, which has helped to make this work possible! We are grateful for support from the Department of Health and Social Care and the National Institute of Health Research, which enabled us to produce these leaflets rapidly.

During lockdown we also received a small amount of funding from the Department of Health and Social Care (DHSC), which allowed us to contact some IDEAL-2 participants and talk to them over the telephone about their experiences and what helped them to cope with the situation. We have given briefings to the DHSC and Public Health England based on what we found. Our initial findings can be found online here:

<https://includeproject.org.uk/qualitative-research/>

One of Our Recent Publications:

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

Professor Christina Victor (Brunel University, London) wanted to explore how common loneliness is among people with dementia and carers, and to identify what aspects of a person's situation makes that person more likely to feel lonely. She found that one-third of people with dementia in IDEAL feel lonely. People with dementia who live alone, feel depressed or have little support from others are more likely to feel lonely. Rates of loneliness were higher among carers; two-thirds of people caring for a relative with dementia felt lonely. Carers who felt lonely tended to feel more stressed and less well supported. They were also more likely to say that the relationship with the person they cared for was strained. This highlights the need to recognise the effect of loneliness on both people living with dementia and carers, and to find out what would help them to feel better and more supported.

Working on IDEAL - Reflections from a Researcher

Living well with memory problems for people from Black and South Asian communities in the UK.

We do not yet know much about the perspectives of people from Black and Asian communities in the UK who are living with memory problems or dementia, and their families, about what helps them to 'live well'. The IDEAL team at Brunel University aims to find out more about this. Two questions the team hopes to answer are:

1. What makes it easier or harder for people with dementia and carers from Black and South Asian communities to 'live well'?
2. How can we help to make sure that people with dementia and carers from Black and South Asian communities are included in research and that their views are considered when developing support services?



Eleanor van den Heuvel, an IDEAL researcher at Brunel University, explains a little more about this part of study:

“We started by engaging community and faith leaders, asking them for their insights into the challenges their communities faced with ageing and memory problems. We ran information and awareness sessions for community groups to explain some of the basics of dementia in a way that allowed people to talk about the topic.

Based on what people told us, we developed a questionnaire survey. We featured our project on the Join Dementia Research recruitment site to encourage people to take part. We were able to visit people at home to complete the questionnaires for some people but after COVID-19 restrictions came in we had to change our approach and send out questionnaires by post and ask for them to be completed and returned. We have extended this study nationwide on the Join Dementia Research website.”

What has this part of the study found so far?

“Many of the issues around memory problems for people in these communities are similar to the population as a whole, but we did identify some particular concerns. People tended to view memory difficulties as just a part of ageing, until a crisis point was reached. People often felt that services did not take into account their cultural expectations and preferences, and a lack of trust sometimes stopped people from getting the help they needed. The word ‘dementia’ is not really used as it seems to carry a huge stigma. These issues may partly explain why many people do not get a diagnosis. Many reported that faith communities and good family support were essential for living well. People were happy when their personal preferences, for example about eating and drinking, or personal care, were taken into account. These insights will help us to recommend ways to engage people from Black and Ethnic Minority groups in research and to tailor services in the future.”



IDEAL Related Activity

Working with Creatives — Banners for Hope and Change:

We have released a book featuring the 'Banners for Hope and Change' created in collaboration with groups of people who have been affected by dementia across the country.

These groups have been working with professional photographer and artist Ian Beesley; poet, journalist, playwright, and broadcaster Ian McMillan and award winning cartoonist Tony Husband to create and unfurl a series of banners to highlight and give voice to some of the problems and concerns faced by people living with dementia and demonstrate some positive solutions.

For more information you can visit the dedicated Unfurlings website: <http://theunfurlings.org.uk/>

You can see the book by going to: <https://issuu.com/universityofexeter/docs/>



Dementia Diaries

In this newsletter, we are shedding a light on a fantastic project that IDEAL collaborates with.



Dementia Diaries is a UK-wide project that brings together people's diverse experiences of living with dementia as a series of audio diaries. It serves as a public record and a personal archive that documents the views, reflections and day-to-day lives of people living with dementia, with the aim of prompting dialogue and changing attitudes.

Visit the Dementia Diaries website here <https://dementiadiaries.org/about-the-project>

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 or let us know of any changes to your circumstances, please contact:

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