

### Welcome



Welcome to the Spring 2018 edition (issue 7) of the newsletter for the:

**ESRC / NIHR  
Neighbourhoods and  
Dementia Study**

### Spotlight on Work Programme 4 Greater Manchester



*Andrew and Sarah collect a European Foundations' Initiative on Dementia Award in Sofia, Bulgaria.*

In January Andrew and Sarah travelled to Bulgaria under the auspices of the Bulgarian Presidency of the Council of the European Union to collect a European Foundations' Initiative on Dementia Award in Sofia. They joined 11 other awardees recognised for work that values the voice of people living with dementia. The awards evening took place following a series of workshops with people and organisations seeking to improve the lives of people living with dementia across Europe.

We have also been successful in gaining additional funding from the ESRC to support our programme of dissemination work, including the development of creative outputs under the guidance of a team of people living with dementia and their carers who participated in the earlier stages of the research.

## Work Programme 1– Member Involvement

**Open Doors:** On 22 February, **Open Doors** launched 'The Changing Face of Our Neighbourhoods', which is a suite of three short cultural heritage films. These will be available to view on YouTube over the coming weeks. With over 60 attendees, Lesley gave a fabulous presentation on her own experiences of growing up in Salford. We have recently been awarded further funding from the Economic and Social Research Council to transform the footage into animations, also working alongside Manchester Camerata to co-produce a biographical soundtrack. We are also just about to submit another project for ethical approval.



**Salford Inspire:** On 24 March, Salford INSPIRE held a 'Together We Can' event at Salford Museum and Art Gallery. With over 80 signed up to the event, there were opportunities to take part in calligraphy, sing along with a local choir, watch a film (complete with popcorn!) and for the children, hunt for Mr Alzheimer's! Well done to Emma and Joy for organising a truly brilliant day! The Mr Alzheimer's primary school campaign is going really well and we are looking to extend it to other schools. Our latest newsletter can be found [here](#). Visit us on [Twitter \(@Inspire Salford\)](#) and [Facebook \(https://www.facebook.com/SalfordInspire/\)](https://www.facebook.com/SalfordInspire/).



## Work Programme 2 - English Longitudinal Study of Ageing

The work package using the English Longitudinal Study of Ageing to understand area effects on cognition and dementia has been focusing on reporting the findings from their research to peer reviewed journals. The report presenting the local authority level prevalence of dementia level cognitive function in England and its determinants was submitted to the International Journal of Geriatric Psychiatry late last year. This is titled 'Dementia across local districts in England 2014-2015'. This showed marked variation in area level prevalence across England posing challenges to the local authorities delivering services and care for adults with dementia. This can be visualized in the figures we produced with the manuscript. We were able to examine individuals' risk factors (such as education, comorbidities and lifestyles) and area level features within the same analytical models we used. The results are interesting and we will explore these in future newsletters. We have recently had useful feedback from reviewers on this submission and have been invited to modify our manuscript according to these. We also look forward to ways in which our area work can be further developed in future research.

## Work Programme 3 - Developing a core outcome set for people with dementia living at home in their neighbourhoods

The Work Programme 3 research team are keen to find out which outcomes are important to people living with dementia. The team completed its Delphi survey in February 2018. This was a two round process involving people living with dementia, carers, health & social care professionals, policy makers and researchers (n=288 R1, with an 84% response rate for R2). Following the Delphi survey, a successful Consensus Meeting was held at Lancaster University to which participants in the Delphi survey were invited to attend. The team were delighted to have such a high proportion of people living with dementia and their carers attend the day and the meeting was chaired by experienced and skilled facilitator [Katherine Cowan](#). The results of the Consensus Meeting were fed back to the participants in the meeting and will be written up and published over the coming months. The team will also conduct systematic reviews and use existing reviews to assign any existing robust outcome measures to corresponding outcomes found to be core through the Delphi & Consensus Meeting.



The Work Programme 3 research team is delighted that they will shortly have their [Protocol published in the BMC Trials](#) journal. The team are also currently awaiting the outcome of a submission to Aging & Mental Health outlining the co-research approach. This outlines how we are meeting our underpinning objective (of the Neighbourhoods and Dementia Programme) of involving people living with dementia and their carers in our research. The team at Lancaster would also like to congratulate Dr Andrew Harding on achieving his PhD following a successful viva.



Dr Andrew Harding & Dr Faraz Ahmed, WP3 Consensus Meeting : 22nd March 2018.

WP3 Contact : [jdclancaster@lancaster.ac.uk](mailto:jdclancaster@lancaster.ac.uk) or telephone Andy Harding (01524 592847) or Marie Crane (01524 592976).

## Work Programme 4 - Our People, Our Places

**Stirling:** A lot has happened here at Stirling since our last update. The project team collaborated with the other fieldsites on writing our first academic paper reporting initial findings for a special edition on 'Social Health' published by International Psychogeriatrics. The paper is Open Access and you can find a link [here](#).

Another achievement for the team has been the award of funding to carry out a community development project informed by our research in collaboration with local organisations and people living with dementia. The 'Our Connected Neighbourhood' project is funded by the Life Changes Trust and will run for 3

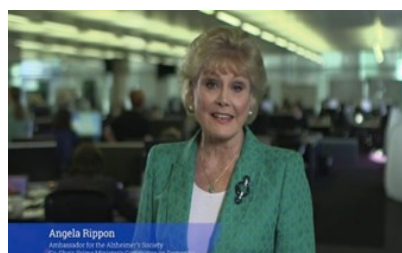
years. Having designed the project using our research findings we will pilot an approach to dementia friendly community development in the Stirling North area before rolling it out on a larger scale across the Forth Valley region.

We are now about to enter our final year of WP4 and cannot believe how quickly the time has passed. There is still much to be done. Currently we are busy analysing our data and have a series of publications planned to come out of this. The WP4 team have also been commissioned by Policy Press to produce a book on the theme of neighbourhoods and dementia. Watch this space!

**Linköping (Sweden):** Our team based at Linköping University has also made great strides in securing funding to set in motion the first dementia friendly community for Sweden. The team are collaborating with local service providers and people with dementia to plan and set up this initiative over the course of the next 3 years. They've also delivered a series of conference papers including a paper to the 32nd International Conference of Alzheimer's Disease International, 26-29 April 2017, Kyoto, Japan.

## Work Programme 5 - Developing the evidence base for evaluating dementia training in NHS hospitals (DEMTRAIN)

Work Programme 5 has commenced its staff survey on training, recruiting staff from across 24 hospitals. This survey will look at dementia knowledge and attitudes, as well as staff strain and organisational culture of a diverse group of staff in a hospital setting. In addition, the Critical Interpretive Synthesis protocol has been registered on PROSPERO (International prospective register of systematic reviews): A critical interpretive synthesis (CIS) review of the current evidence base for dementia training in hospitals: [Prospero](#).



**DEMTRAIN** is also fortunate to have the support of Angela Rippon CBE, *co-chair The Prime Minister's Champion Group on Dementia Friendly Communities and Alzheimer's Society Ambassador*, who has recorded a short film about the DEMTRAIN study

as a member of the DEMTRAIN advisory group. The video will be available on the website soon and we urge you to take a look:

<http://www.neighbourhoodsanddementia.org/work-programme-5-description/>

## Work Programme 6 - Couplehood

The app DemPower is near final version. We are collaborating with WP4, who will facilitate the pre-feasibility testing of the app and review evaluation questionnaires in the beginning of April. The pre-testing will to explore the contents of the guide and if the questions raised during the analysis will be addressed by this couple-management guide app. Both the sites have started recruitment and have obtained



Karl Gustafsson (geriatrician), Kerstin Fredriksson (occupational therapist) and Susanne Rahm (social worker) at the Memory Clinic in Norrköping are contacting possible participants.

positive responses so far. The Manchester site has recruited the majority of the participants and we hope to start the trial there in the middle of April. The Swedish site has started to include participants via the Memory Clinic in Norrköping. The staff at clinic will identify couples, contact potential participants to discuss the study and obtain expression of interest.

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## Work Programme 7 – Digital Life Story

We are delighted to report that our paper “How might the cultural significance of storytelling in Deaf communities influence the development of a life story work intervention for Deaf people with dementia?” has been accepted for publication in *Ageing and Society*. Once this has been published, we will share the URL with the team.

Data collection has commenced - We held one discussion group with Deaf carers of Deaf people living with dementia in the South-West of England. There is one more discussion group scheduled for the North-West in April 2018. There are also some individual interviews exploring the development of life stories with Deaf people living with dementia booked in for mid-April 2018.

We have submitted an abstract to the Gerontological Society of America's annual conference in Boston with the Neighbourhoods team. We will find out if this has been successful in late July 2018.

## Work Programme 8 – Wellbeing Service

The Staff Well-being Service is continuing to provide 1:1 sessions for staff on the Neighbourhoods and Dementia Study.

Ruth is looking forward to her final year of work on the programme, and if anyone would like to make a new self-referral to the service, please contact Ruth at [ruth.elvish@manchester.ac.uk](mailto:ruth.elvish@manchester.ac.uk).

Recruitment for the research element of the Staff Well-being Service is underway, and data is currently being collected through the use of interviews. Thank you to all who have agreed to participate in the research.

## Meet the Scientific Advisory Committee



**Thomas Scharf** is Chair of the committee. He is Professor of Social Gerontology in the Institute of Health & Society and Institute for Ageing, Newcastle University



**Myrra Vernooij-Dassen** is Professor in Psychosocial Care for Frail Elderly People. She is affiliated to the Scientific Institute of Quality of Healthcare & is Chair of Interdem



**Agnes Houston** was diagnosed with Early Onset Alzheimer's Dementia in 2006 at the age of 57. She is an active member of the Scottish Dementia Working Group and is vice chair of the European Working Group of People with Dementia



**Christine Milligan** is a Professor, Social Geographer and Director of the Centre for Ageing Research at Lancaster University



**Jean Georges** is the Executive Director of Alzheimer Europe

**Donna Houston** is a nurse by background and supports her mother, Agnes on her national and international engagements, raising awareness of dementia

