

## Welcome



Welcome to the Autumn 2017 edition (issue 5) of the newsletter for the:

**ESRC / NIHR  
Neighbourhoods and  
Dementia Study**

### Spotlight on Work Programme 4

You may have heard recently of plans to create 'dementia-friendly communities' (DFC) across many parts of the UK. The idea behind this is to bring local communities together to ensure that their local environment is accessible, so that anyone diagnosed with dementia can remain an active part of their community. But what makes a community 'dementia-friendly'? And how can we ensure that people with dementia have a voice within their local community? This is what we hope to discover.

The Stirling and Forth Valley Participatory Neighbourhoods project, which has been informed by the data collected from the Neighbourhoods: Our People, Our Places (WP4) project, has been awarded an initial 3-year funding by the Life Changes Trust. It will be led by people with dementia and carers, and supported by a number of different local organisations in partnership with the University of Stirling. Our aim is to empower people living with dementia to work with their fellow residents at a neighbourhood level to bring about positive changes within their communities. Our plan is to run a pilot project in Stirling North before we expand to other areas of the Forth Valley. The project has three phases over three years and will be evaluated by local residents facilitated by a team from the University of Stirling.

We wish ensure the sustainability of our work and will seek to identify and apply for funding to further develop our work. You can follow our progress via our website (which will be advertised shortly) or via Twitter @InclusiveSFV



## Work Programme 1 - Member Involvement

**Salford INSPIRE:** Joy & Emma have been busy meeting with pupils and school councils in local Primary Schools and are excited to now work alongside two primary schools as pilot sites. Fire certification has been obtained and Joy & Emma are busy recruiting sewers for the campaign (<https://www.youtube.com/watch?v=T1j8clKxOMA>). The daily activities of

Salford INSPIRE can be found on Facebook (registration is not required) <https://www.facebook.com/SalfordInspire/>. Joy and Emma are giving a Dementia Friends Session in Morrisons Supermarket in Eccles on Thursday 19<sup>th</sup> October (5.30-6.30pm). To book a place, please contact Emma at: [esmith@ageuksalford.org.uk](mailto:esmith@ageuksalford.org.uk) or telephone 07791 022429.

**Open Doors:** Having finished filming for our project 'The Changing Face of Our

Neighbourhoods' earlier this year, we are now in the final stages of editing the three films for a public launch early in the New Year. We are delighted to report that we are presenting this project at the UK Dementia Congress in Doncaster in November. Lesley, Cathy and Caroline are giving a joint presentation and we are currently writing a paper for the project. We are also busy planning for our next project!

Open Doors, Salford INSPIRE and Caroline are meeting with the 'Friendly Face' initiative team in Flintshire in October. We are really looking forward to meeting everyone!

**EDUCATE:** We are currently applying for ethical approval for our project about Dementia-Friendly Marple (Stockport), working in collaboration with the Marple Steering Group.

## Work Programme 2 - English Longitudinal Study of Ageing

Our aim is to determine neighbourhood characteristics associated with good/poor cognitive ageing. At first we used longitudinal measures of episodic memory to define good and poor trajectories decline over 12 year period of study. This was completed in the 1st phase of the work stream

& we have submitted two research papers from this to academic journals. As part of a separate funded stream the field work included a cognitive test called the Telephone Interview of Cognitive Status (TICS). Following work in the sister programme in USA, the Health & Retirement Survey (HRS) we were able to classify

individuals as: normal cognition; cognitive impairment not dementia (CIND); dementia. Integrating this with Office of National Statistics produced data we could then take our work further than we had originally been able and closer to the overarching aims of the programme. From this work we have been able

to produce a map of dementia prevalence for England showing clear variation. From our initial analyses, the individual level risk factors seem to explain the area differences in dementia prevalence rather than local environmental features.

## Work Programme 3 - Core Outcome Set

WP3 has been busy sharing its work at other meetings & conferences over the summer. In July, Andrew Harding gave a presentation at the British Society of Gerontology meeting in Swansea, on how WP3 has privileged the views of people living with dementia in the study design, which was well-received. A week or so

later the Division of Health Research at Lancaster University funded Andrew to travel to San Francisco to take part in the 2017 meeting of the International Association of Gerontology and Geriatrics, the theme of which was Global Aging and Health: Bridging science, policy and practice. His presentation focused on the differences noted between

trial outcomes vs what is important to people living with dementia.

Having gained a successful NHS REC ethics amendment, recruitment is due to start soon for a Delphi survey involving people living with dementia, care partners, health & social care professionals, researchers and policymakers/commissioners.

Anyone interested in taking part is invited to contact Andrew Harding ([a.harding5@lancaster.ac.uk](mailto:a.harding5@lancaster.ac.uk)) for further information.



## Work Programme 4 - Our People, Our Places

There are 3 fieldsites for WP4: Stirling / Forth Valley (Scotland), Greater Manchester & Ostergotland (Sweden). The research phase for the project is now complete and we're underway with data analysis pulling together the learning from approximately 350 in-

depth interviews conducted with people living with dementia and carers. Our next phase involves translating our research findings into community development projects. We have been lucky enough to secure funding for a three-year planning and foundation-laying programme in

the Swedish fieldsite, which we understand will lead to the establishment of the very first dementia-enabling community for Sweden. In Stirling we have funding to carry out a three-year community-development project with a focus on "place making" which will position

people with dementia to decide upon and lead changes within their local areas. In Manchester the focus will be on evaluating some short term projects that build upon insights & learning from the research.

## Work Programme 5 - Hospital Training

WP5 was invited to attend the 2017 Town and Gown event on 7 September in Lancaster Town Hall. This was well attended by members of the public, including people living with dementia and their care partners, as well as those involved in research and delivery. It was an excellent opportunity to share research to date and to

hear about their work and experiences. Our survey of acute hospitals in England commenced in January 2017. So far we have been successful in recruiting 75 hospitals to this part of the study. All participating hospitals were entered into a prize draw – we have had four lucky winners (worth up to £500 for either equipment that enhances the hospital experience for patients living with de-

mementia or a dementia-related charitable donation). The next stage involves surveying staff members and recruitment will start in autumn 2017; please contact [f.ahmed5@lancaster.ac.uk](mailto:f.ahmed5@lancaster.ac.uk) for more information. Dr Siobhan Reilly and Dr Faraz Ahmed both attended the recent HSRUK Symposium 2017 (6 - 7 July 2017) in Nottingham where they

presented a poster highlighting the work of Work Programme 5. In addition, an abstract has been accepted for an oral presentation at the forthcoming Alzheimer's Europe Congress in Berlin from 2 – 4 October 2017.

## Work Programme 6 - Couplehood

Filming of video clips with couples for the app in Manchester and Linköping, Sweden, has been completed. The video clips and the animations are for the moment under revision. The prototype for the app DemPower is near final version, will be ready by November, and pre-tested within WP4. The ethical review boards, in Sweden and the UK,

have approved the feasibility study (Phase two of WP6). Recruitment of participants will start shortly.



Screenshot of a Swedish video where the couple talks about the "meaning of home".

## Work Programme 7 – Digital Life Story

We have undertaken a literature review entitled: “**How might the cultural significance of storytelling in Deaf communities influence the development of a life story work intervention for Deaf people with dementia?**” This will be submitted shortly.

We are currently applying for a substantial amendment to our original ethical approval to accommodate some changes to the focus of the work programme. The original overarching objective of this aspect of research remains the same: “*To develop a linguistically appropriate and culturally sensitive personalised digitised life story tool for use by and with Deaf sign language users with dementia.*”.

Changes to the scale and manner of data collection are required but we remain on course to deliver the intended outputs of the work programme on schedule.

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## Work Programme 8 – Wellbeing Service

The Staff Well-being Service has received 12 referrals to date. This is 25% of the Neighbourhoods and Dementia Study staff group. If you would like to make a self-referral, please contact Ruth Elvish [ruth.elvish@manchester.ac.uk](mailto:ruth.elvish@manchester.ac.uk).

After three attempts, I have been unsuccessful in obtaining a favourable ethics opinion for the use of a researcher-practitioner model to explore the staff well-being service. I therefore intend to submit a proposal which will involve the use of an external person undertaking interviews with staff who choose to take part in the study. Whilst this is a solution which will enable the research project to hopefully move forward, I am disappointed that a researcher-practitioner model cannot be implemented. This, for me, would have been best practice in this context. However, looking ahead, I am now looking forward to the research element of work programme 8 progressing in the coming months.

## 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

