

## Welcome

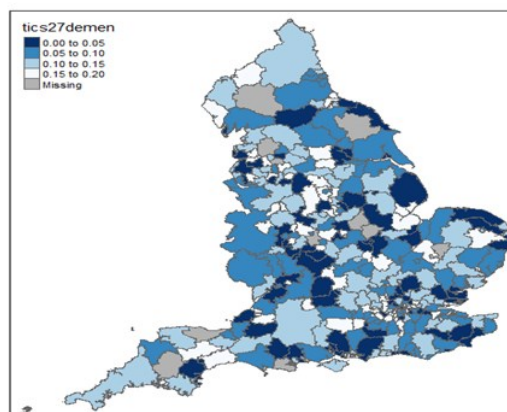


Welcome to the Summer 2017 edition (issue 4) of the newsletter for the:

**ESRC / NIHR  
Neighbourhoods and  
Dementia Study**

### Spotlight on WP2 – Generating Neighbourhood Profiles Of Cognitive Ageing & Service Use Using Nationally Representative Population Data

This is a timely point to review the previous three years work from our work programme 2. The team responsible for the activity and progress is Dr Gindo Tambupolon, Professor James Nazroo and I (Neil Pendleton). We are an interdisciplinary group of medical, social gerontologists, geriatrician and social statistician. The aim of our work programme, using representative longitudinal cohort study in England, is to determine neighbourhood characteristics associated with good/poor cognitive ageing. We also show individual and area level associations with these different paths in ageing cognition. For this we have used the population representative sample of adults, the English Longitudinal Study of Ageing (ELSA). Using data from the Office of National Statistics and linked dementia prevalence data we have combined output areas into 310 local authorities or districts across England producing geographical maps. These show geographical variation in dementia prevalence across England. We followed this with a multilevel model to determine individual risk factors or area features associated with dementia prevalence. The results suggest that area differences in dementia prevalence are determined by individual risk factors such as gender, education, and physical activity but not area features such as index of deprivation or land use mixes. Of course this is the first analysis and cannot examine all area features effects regarding dementia prevalence. Although the work in our team is close to completion we look forward to developing our findings further and contributing to the Neighbourhoods and Dementia programme in the years to come.



## Work Programme 1 - Member Involvement

Work Programme 1 has had a very busy couple of months. **Open Doors:** Alongside Chronicle Films, we spent two days in early April filming for 'The Changing Face of Our Neighbourhoods' project. Forty-five members of Open Doors took part in the project and over 20 members were involved in the filming. We are currently in the editing process with a launch planned for October/November 2017. We are also in the midst of planning our second project. **EDUCATE:** We are currently planning a project around 'Dementia-Friendly Marple'. At a recent meeting, we received support from Marple Steering Committee to take this project forward. Caroline and Reena will spend the summer preparing all of the paper work for ethical approval for discussion at our next group meeting in September. **Salford INSPIRE:** Joy and Emma headed the Good Life Festival at Helly Hanson Watersports Centre, Salford for Dementia Awareness Week. Over 200 people joined in the festivities. Salford INSPIRE are also driving forward their Mr Alzheimer's primary school awareness-raising campaign.



## 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

The key aim of work programme 3 is to create a 'core set of outcomes' that are a minimum set of measures when used to evaluate community health and social support for people with dementia living at home. this study is particularly interested in finding out which outcomes should be measured from a number of different perspectives people living with dementia, their care partners, health and social care professionals, researchers and policy makers. The study has 4 phases. Work programme 3 will shortly enter phase 2 – a Delphi survey. Considerable work, from the research team and member involvement participants, has gone into designing an accessible Delphi survey. This will allow people living with dementia to participate with other stakeholders (care partners, health and social care professionals, policy makers and researchers) and rate the importance of outcomes in relation to community based programmes. The data from the Delphi survey will then inform a consensus workshop, where there will be facilitated discussion and deliberation among stakeholder groups as to what should go into the final core outcome set. For more information contact:

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## Work Programme 4 - Our People, Our Places

**Greater Manchester update**—we are now in the 2<sup>nd</sup> phase of our data collection & have recruited 55 participants. We have been privileged to have completed 34 walks, 44 social network maps & 28 home tours with our participants. This has given us a unique insight into how people live day to day with dementia in their

communities. We are continuing to undertake data collection and analysis and are developing ideas for the next stage of the project in which we begin to develop practical applications.

**Stirling update**—We've completed recruiting participants for the 1<sup>st</sup> phase of the project. We've spoken to 15 couples, 7 people living with

dementia who are living alone and 8 carers of people living with dementia who are in residential care. Over the coming months we will dig deeper into our data and start to pull out key findings that will help to inform our locally based interventions. We are delighted with the response we've had from people

we've approached to work in partnership with us and we are excited about the difference this could make helping people living with dementia to stay connected to their neighbourhoods for as long as possible.

## Work Programme 5 - Hospital Training

The DEMTRAIN study aims to develop the evidence base for dementia training in NHS hospitals. Viewing the acute hospital as a neighbourhood space increasingly occupied by people living with dementia, the research will examine the impact of dementia training on staff skills, knowledge, confidence and satisfaction, and improved outcomes for patients living with

dementia in these settings. Over four study phases, which includes analysis of hospital episode data and economic cost modelling, this mixed method study is examining quality and effectiveness of training programmes in acute hospital settings and their impact on length of hospital stay and readmissions for people living with dementia. The hospital survey question-

naire has been developed with support and guidance from our member involvement groups, including, invaluable discussions with the Scottish Dementia Working Group: Neighbourhoods and Dementia Programme Research Group. WP5's organisational survey of dementia training in all acute hospital across England is live till the end of July.

A hospital staff survey is also being designed to be distributed in 24 acute NHS hospitals soon (autumn term). If you are interested in taking part in these surveys or would like to know more about our study and get involved, please contact: [jdclancaster@lancaster.ac.uk](mailto:jdclancaster@lancaster.ac.uk)

## Work Programme 6 - Couplehood

We have 2 broad phases, 1) to develop and 2) to investigate the feasibility and acceptability of the couple-management guide via an interactive and user-friendly app called DemPower. Currently, the two phases are overlapping. Firstly, the prototype is the near final version and will be ready by November.

Filming of video clips with couples for the app are in process in Manchester and Linköping, Sweden, and will be completed in July. The DemPower app will soon be introduced to couples in ongoing advisory/consultation meetings. This will partly be conducted in collaboration with WP4 who will facilitate the pre-feasibility testing of the app & review evaluation questionnaires. Secondly, phase 2 of WP6 is ongoing. Ethical applications for the feasibility study both in Sweden and in the UK are submitted and under review. The recruitment of couples for the second phase of the study will begin in the autumn after approval from the ethical review boards.



*The WP6 team discussing progress and planning next stages at a meeting on 15 June in Manchester*

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## Work Programme 7 – Digital Life Story

Within Work Programme 7, there are ongoing preparations to co-design a Deaf-friendly app that will be presented in BSL, using archived materials from the British Deaf Association Deaf Heritage Project which can be seen at <https://www.bda.org.uk/share-deaf-visual-archive>. The co-design has taken place directly with a Deaf person who cared for their Deaf father living with dementia; their personal experiences of missing out on culturally appropriate service provision has strongly influenced their wishes as to how the app should be laid out. For example, there will be guide questions within the app that will prompt conversations between Deaf people living with dementia and their hearing carers. The questions will not just be translated from English into BSL; they will be culturally modified to match the linguistic register for Deaf BSL users who may find it difficult to understand new concepts.

## 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)

A submission to ethics was made at the beginning of the year, which proposed the use of a researcher-practitioner model to explore the use of 1:1 sessions within the service. Obtaining a favourable ethics opinion for this has been challenging. Ways to research the service are currently being explored, and it is hoped that a solution will be found to enable us to share the unique work that is being undertaken by the service as part of the Neighbourhoods and Dementia Study.

## 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