

Margaret Dangoor on her involvement in PSSRU's MODEM project

Margaret Dangoor joined the Personal Social Services Research Unit at LSE earlier in the year as Research Involvement Manager for a major new study on the costs and outcomes of dementia (MODEM). Here she talks about the MODEM project, how she came to be involved and her role, as well as her experiences as a carer.

Last December, the G8 countries held a **Dementia Summit** in London. Following the summit, on 13 May 2014 MODEM, a major dementia research project, was launched at an event held in the House of Lords and chaired by Baroness Greengross OBE on behalf of the International Longevity Centre UK. MODEM is one of six dementia projects being funded under a major new **Economic and Social Research Council (ESCR) and National Institute for Health Research (NIHR) programme**.

The MODEM project

MODEM will take a comprehensive approach to modelling outcome and cost impacts of interventions for dementia to 2040; it is a ground-breaking, unique 4-year study. The team of researchers is led by **Professor Martin Knapp** and team members from the PSSRU at the LSE will work in partnership with Newcastle University, the Universities of Southampton and Sussex and the International Longevity Centre UK.

The project will generate new evidence to inform policy and practice so as to better meet the needs of people with dementia, promote health and wellbeing, while at the same time achieving effectiveness in the use of society's resources. A comprehensive set of quantitative models will be developed to forecast how many people will develop dementia in England over the next 30 years and predict the needs, the unpaid and formal care requirements and the associated expenditure. The typical life-time costs of dementia will be estimated, under varying assumptions about risk factors, patterns of care and support and preferences. The outcomes will guide the planning of good, affordable dementia care up to 2040.

New evidence will be gathered on the lives of people with dementia and their carers, and on interventions that could delay onset, slow deterioration in cognition, functioning or behaviour, or reduce their adverse impacts on wellbeing and on costs. This evidence will be gathered through literature reviews, data from previous/ongoing trials, and observational studies; also primary data from a new cohort of people with dementia, qualitative interviews and focus groups.

Towards the end of the project a publicly available web-tool (a 'legacy model' and associated media) will be developed to enable service commissioners, providers, advocacy groups, individuals and families to access the findings and outputs of the project. Using the information they will be able to make their own projections of the expected needs for care and support, the outcomes and costs.

It is apparent from the foregoing that the outcomes of this project will make a major contribution to the knowledge base available to both the policy decision makers and practitioners. The final report will outline findings and possible steps for government and other responsible agencies and a major event at the end of the project will present findings to central and local governments, voluntary organisations, people with dementia, carers and academics.

Involvement in the project

With high expectations for this project as a significant influencer in relation to the future planning and delivery of dementia care it was considered vital that the design of the project and formation

of the research team provided for the facilitation of effective involvement of people with dementia, their carers, front line professionals and the wider public. This led to my joining the academic team as a co-investigator on the MODEM project with the responsibility of ensuring that such involvement takes place.

Bringing my experience as a carer to the study

As a carer for my husband who has advanced dementia my role within the project has a particular synergy for me. My husband's Alzheimer's disease has progressed from early signs of memory impairment around 2004. My mother, who died in early 2013 at the age of 102 years, also suffered from long-standing dementia and first demonstrated symptoms of memory loss as far back as 1994; her dementia journey being one of slow decline.

I have been actively involved with the carer community and people with dementia for many years. My professional background was as a registered nurse and later a general manager. My involvement with the charitable, voluntary and community sector goes back at least 25 years, when I was first working in the NHS with responsibility for the management of a regional rehabilitation service. I became a trustee of a charity supporting people with various disabilities and over the years I have sat on the boards of, or chaired, a number of locally based charities and patient and public involvement organisations, and have represented carers' and users' views on many occasions at national or local level committees, working parties and task groups etc.

I am currently an Ambassador for Carers UK, working at local level to support carers and also promoting carer interests within general practice. I volunteer for the Alzheimer's Society and am a Dementia Friend and a Dementia Champion helping to raise awareness of dementia and the needs of people with dementia within the community. I also run an 'Experts by Experience' group for carers of people with dementia.

Having achieved a masters in health law as a mature student I left the NHS to lead a not-for-profit medico-legal, risk management, patient safety organisation based, as an independent organisation, at the Royal Society of Medicine (RSM). I became a Fellow of the RSM, a member of Council and served a term as Vice-President. It was during that period that I met **Professor Jill Manthorpe**, also a fellow at the RSM. Jill was a member of the original executive team charged with establishing the **NIHR School of Social Care Research**. It was through my contact with Jill that I was invited to become a member of SSCR's User, Carer, Practitioner Group (UCPRG) which was just being set up at the time. The UCPRG has thrived since and has made a valuable contribution to the success of the School, whether providing input into the choice of research priorities or the annual business plan or reviewing research applications to ensure user/carer involvement is robustly designed into each proposal submitted to the School for funding. UCPRG members also contribute to the school in other ways depending on their particular interests, availability and expertise.

SSCR is now at the beginning of a new 5-year programme and I will continue my involvement with the School. Apart from my involvement now as a member of the PSSRU team at the LSE, I am also a research advisor for the PSSRU and the **DH-funded Quality and Outcomes of Person-centred Care Research Unit** at the University of Kent.

From time-to-time in my professional life I have participated in research projects and more recently, related to my patient and public involvement activities I was an active participant as a patient/user representative on two NIHR-funded projects. All these experiences have provided a view of research from different perspectives; the active researcher, the patient/user participant or the research reviewer; useful experience for leading on user/carer involvement in research.

My involvement in MODEM

As I outlined earlier, my role within the MODEM project is to ensure that people with dementia, their carers, professionals working at the 'front line' and the wider public are involved throughout

the various stages of the project. Following the launch of the project, MODEM was featured on the BBC Radio 4 programme 'You and Yours'. After the programme, a few listeners who are carers made contact with us and we will ensure they are kept in touch with the project's progress and able to participate actively if they want more direct involvement.

As the first stage of developing 'involvement' we are developing a 'central' reference group of primarily people with dementia and their carers. To further facilitate involvement, a reference group and wider network is being established at a more local level in the general area of south west London. We already have a core membership 'signed up' to our central reference group and a growing network at local level. There will be continual development of a wider network of interested parties across the country as the project progresses. At appropriate stages of the project we will be sharing our findings, holding workshops, using web-based tools and also through academic and lay-readership outputs. An important part of my role will be to ensure that as interim findings come out of the research that the findings are 'translated' into accessible formats for a non-academic audience. Engagement will be continual, in order to maintain the interest of our reference groups and wider network but from time-to-time as preliminary findings are reported there will be periods of increased activity to enable knowledge exchange and consultation and feedback from our user, carer, practitioner 'membership'.

As a non-academic team member, my role may be 'a first' as a co-investigator on a major research project. The establishment of the role demonstrates a clear commitment to the involvement in research of 'users' and carers and professionals at the front line of service delivery. I certainly feel a responsibility to deliver.

September 14th, 2014 | [Dementia Care](#) | [1 Comment](#)

☺