

EVIDEM: Evidence-based interventions in dementia

Newsletter 8 Summer 2011

www.evidem.org.uk

Summer 2011 arrived early and from the 1st of August, the EVIDEM programme will have reached its fifth and final year. The Health and Social Care landscape seems to be dramatically shifting, and our work must suit the systems as we find them. Our aim of 'Changing practice in dementia care in the community' has not altered and so a great amount of work remains to be completed. We will be working hard over the final year, finishing our data collection and finding ways to help practitioners to put our results to use.

The team has produced several products that have already been put into practice. For example, the tool developed to help General Practice improve the care they deliver, is being rolled out by Oxfordshire Primary Care Trust. The research is ongoing and it remains to be seen whether the results will show that the tool is beneficial, but the health care community seems to be convinced that it will be. The eagerness to get started before the results are out probably reflects a desire on the part of primary care for tools that help them improve their practice. We also hope that this is recognition of the quality of the tool developed by Steve Iliffe's team.

EVIDEM has also made contributions that will encourage more high quality research to take place after the programme has finished (2012). We have helped build systems to give people with dementia who want to be involved in research more choice and opportunity to get involved—and this is described in more detail below. We have also provided and encouraged the training of individuals to move toward careers in dementia healthcare research. Three of the EVIDEM team are serving their 'apprenticeships' as researchers by completing their reading for their Doctorates of Philosophy (PhD). Kritika Samsi has successfully completed her thesis, while Laura Cole and Arlinda Cerga-Pashoja have both successfully finished their crucial first year evaluation. We all applaud their efforts.

Connecting people with dementia to research

DemReg: A Registry of people with dementia interested in research participation

Opportunities to participate in dementia related research can be a bit of a lottery. You have to be in the right clinic at the right time.

A number of factors affect whether a person will be invited into a research study. Firstly, they usually need to have a diagnosis. We know around 2 out of 3 people with dementia will not have one, and so a great many people are likely to miss out on research projects that could be of interest and/or benefit to them.

Individuals will usually only be invited if they see a health or social service practitioner who is inviting people into research at that time. This may or may not be the case; depending on things like location

the service, the relationship between health & social care practitioners running that service and if the practitioner feels confident supporting research.

We believe the current ways of inviting people with dementia into research studies are not ideal. For a person who wants to take part, opportunities are few and far between. When they do arrive, the research might involve things that they are not interested in. For researchers, it makes it difficult to be sure that their findings are true of all people with dementia and not just specific to the people included in the study.

The EVIDEM team have worked with DeNDRoN (see below) and several NHS Trusts on new ways to 'connect' those interested in research with those who are conducting research. Together, we have built a list of people with dementia who have said that they'd be interested to hear about opportunities to take part in research ('DemReg').

Registries are a way of working that have been used successfully to support research for other groups of people (e.g., people with cancer), but this is new to dementia related research. There are lots of reasons why we have to be careful when developing 'DemReg' and so we are making sure that we are thorough in our planning, monitoring and evaluation of this.

Having said that, I'm pleased to report that the list now contains around 600 people, and has played an extremely important part in helping some of the EVIDEM team to recruit people onto their projects. For example, the trial of exercise has recruited almost 47% of the people taking part from DemReg. In addition, the Government is paying particular attention to this through the Ministerial Advisory Group on Dementia Research. We hope it they will give its support for more widespread use of this system in the near future.

What is DeNDRoN?

- DeNDRoN stands for Dementia and Neurodegenerative Diseases Research Network
- It is an organisation funded by the Government
- It is designed to carry out the administration and management tasks necessary to support research in the NHS
- This allows researchers to get on with the task of conducting their studies

Workshops in Dementia Care:

Putting evidence from the EVIDEM programme into practice

Date: 7th October 2011

Venue: CNWL NHS Trust HQ, Stephenson House, Hampstead Road

Event Objective: This half day event is aimed at team leaders within the older adult directorate (CNWL NHS Trust).

Delegates will by the end of the event be able to improve their practice in aspects of care aligned to 3 of the 5 EVIDEM themes. They will also be able demonstrate and encourage this good practice amongst their colleagues.

Modules:

- Training techniques: developing skills in demonstrating good practice – Sharmini Rajenthiran – Teaching Fellow (CNWL)
- Neglect and ill treatment: updates on criminal case law and the implications for your practice Manthorpe (King's College London)
- Recognising signs and symptoms of dementia - Steve Iliffe (University College London)
- Managing Behavioural & Psychological Symptoms of Dementia - James Warner (CNWL)
- Continence Promotion & Incontinence Management - Vari Drennan (St George's, University of London)
- Establishing a dialogue on advanced decisions - Claire Goodman (University of Hertfordshire)

Format: practical demonstration and interactive exercises delivered to small groups

Contact: If you're a team leader, you should have already heard about this event. If you haven't and you should attend this event, then please contact d.lowery@ucl.ac.uk (020) 3214 5889

Call For steering group members

Steering groups play a pivotal role in the success of research projects—particularly on the type of subjects that EVIDEM covers. Each EVIDEM project has its own steering group. The majority of members are not part of the EVIDEM team and include representatives from a wide range of health and social care disciplines, voluntary organisations, carers and people with dementia.

Wide and inclusive memberships of steering groups are helpful because it's the quickest way for researchers to get an idea on how their work will be received. This is important throughout the life of projects. For example, the EVIDEM-E steering group helped shape the design of the exercise program to be tested. They identified easy and useful ways for people with dementia and their carers to monitor their own performance. They also helped to develop a risk assessment that would meet appropriate standards of good practice. Given that the trial involves people who may be vulnerable to falls, it was important that experts were consulted. The chartered physiotherapist and personal trainers in the group were able to provide this.

As we enter the final year of the EVIDEM programme, project steering groups will turn their focus to interpreting findings and supporting ways of putting these into practice. For example, the Mental Capacity Act project is looking at how professionals can help stop the crimes of neglect and ill-treatment. There are a number of limited places open on the steering groups, and we are eager to hear from people who would like to contribute in this way. Meetings are usually held 2-4 times a year, and last around 1-2 hours. Meetings are held at venues in and around London. Travel expenses are always reimbursed, and refreshments are also provided.

For more information or to register your interest, contact: David Lowery (d.lowery@ucl.ac.uk/ 020 3214 5889)

EVIDEM Outputs

Publications

Culture, consent, costs and care homes: Enabling older people with dementia to participate in research (2011) *Goodman C, et al. Aging & Mental Health* **15 (4)** 475-481

Clinicians as recruiters to dementia trials: lessons from the EVIDEM-E Project (2011) *Lowery D, et al. International Journal of Geriatric Psychiatry* **26** 765-769

Developing a Dementia Research Registry: a descriptive case study from North Thames DeNDRO to the EVIDEM programme (2011) *Iliffe S, et al. BMC Medical Research Methodology* **11**:9

'Early days': Knowledge and use of the Mental Capacity Act 2005 by care home managers and staff (published online on May 10, 2011) *Manthorpe J et al., Dementia* doi: [10.1177/1471301211403970](https://doi.org/10.1177/1471301211403970). *Dementia* **May 10, 2011** [1471301211403970](https://doi.org/10.1177/1471301211403970).

Project Specific Newsletters

For more up to date information on individual EVIDEM projects, you can download project specific newsletters. The latest editions include an **algorithm for managing behavioural and psychological symptoms** of dementia in primary care (<http://www.evidem.org.uk/Documents/evidem-ed-news/EVIDEM-ED-newsletter3.pdf>); an opportunity to **meet the Steering Committee** and read about **feedback from CNWL clinical staff** on the trial of exercise (www.evidem.org.uk/Documents/evidem-e-news/newsletter-ev2-final.pdf); an invite to take part in the latest phase of the continence study—exploring the uses of **absorbent pads** (<http://www.evidem.org.uk/Documents/evidem-c-news/evidem-c-newsletter-2-final.pdf>); and find out how the End of Life project team are **testing appreciative inquiry** as a way to **enhance professional relationships** around the care home (<http://www.evidem.org.uk/Documents/evidem-eol-news/news-spring-2011.pdf>).

For a full list of all EVIDEM Outputs visit www.evidem.org.uk/reports

EVIDEM Contacts

We are happy to receive feedback, field questions and listen to requests to get involved—so please do get in touch.

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