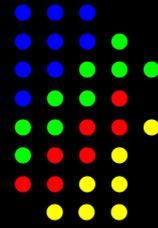


EVIDEM: Evidence-based interventions in dementia

Newsletter 1 Spring 2008

www.evidem.org.uk



Welcome to the first quarterly newsletter of the EVIDEM research programme

EVIDEM is the short title for a new programme of research funded by the National Institute for Health Research~ "Evidence -based Interventions in Dementia: Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life" .This NIHR programme of research is hosted by the Central and North West London NHS Trust. The programme of research has 5 'nested projects' see BOX 1.

Advocacy organisations, researchers and practitioners have long complained about the limited funding for dementia research in the UK. Funding seemed to fail to address significant gaps in knowledge by favouring biomedical studies rather than health services or social care research.

This situation is changing because dementia is rising up the research agenda, and funding streams are appearing not only for basic sciences research but also for social and organisational studies.

We now have an increasingly integrated research and development process, with a dementia research agenda emerging from the National Institute of Health and Clinical Excellence (NICE), a government-funded UK wide research infrastructure developing for Dementias and Neurodegenerative Diseases (DeNDRoN) and substantial funding for programmes of dementia research being awarded by the National Institute for Health Research (NIHR).

Central and North West London



NHS Foundation Trust

BOX 1 The EVIDEM programme

The Host: Central and North West London NHS Foundation Trust, which provides services for people with dementia across a wide area. Professor Steve Iliffe (University College London) is responsible for the overall management of the programme. The research activities include:

1. finding a **cohort of people with memory problems and dementia**, and their close carers willing to participate in research, led by Dr Greta Rait
2. a project on **early diagnosis in general practice** led by Prof. Steve Iliffe Projects
3. a project testing **exercise as a therapy for psychological symptoms** led by Dr James Warner.
4. a project on **promotion of continence and management of incontinence for people with memory problems living at home** led by Professor Vari Drennan
5. **a project on the quality of care at the end of life led by** Professor Claire Goodman (University of Hertfordshire)
6. a project measuring the **impact of the Mental Capacity Act (2005)** led by Professor Jill Manthorpe (King's College London).

In addition there are built in opportunities for sharing and learning across professional groups as part of the programme (See Box on Summer school)

The first wave of NIHR programmes had an explicit remit to improve services, and therefore favoured non-pharmacological therapies and studies that could demonstrate relevance for practice. One of these, Evidence-based interventions in dementia (EVIDEM), is a five year,

programme which contains five projects run by a multi-disciplinary group of researchers (See box 1).

The inclusiveness of the EVIDEM proposal was a winning characteristic for the EVIDEM team, injecting a 'real life' dimension to

research and development by joining together projects along the trajectory of the disease process, from diagnosis to end-of-life care.

So was its base in north London, with its diverse population and often

fragmented services; if practice can be changed in London, it can be changed anywhere. The programme's host, Central & North West London NHS Foundation Trust, exemplified the promise of grounded research & development.



Introducing the Research Team

EVIDEM-ED Early Diagnosis in General Practice

Steve Iliffe, Principal Investigator, is Professor of Primary Care for Older People at UCL, and co-director of the Centre for Ageing Population Studies in the Research Department of Primary Care. He has a background in general practice, having worked at Lonsdale Medical Centre and its predecessor practice in Kilburn for 30 years. His research interests are in ageing and health, particularly in relation to mental health. He has published extensively on the recognition of, and response to dementia in primary care. He is an associate Director of the Dementia and Neurodegenerative diseases Research Network's co-ordinating centre, was a member of the NICE/SCIE dementia guidelines development group, and of the Alzheimer's Society external reference group on the UK Dementia Strategy. (s.iliffe@pcps.ucl.ac.uk)



Jane Wilcock is Senior Research Fellow at UCL. Jane has worked for several years in the field of dementia research. Notably she has been involved on projects surrounding palliative care for people with dementia and the development of education material for dementia diagnosis in primary care. Jane has experience with a range of research methods and programme management. Currently on maternity leave, Jane will on her return support the management of the overarching EVIDEM programme.

Assembling the Cohort



Greta Rait is a GP and Senior Clinical Lecturer in the Research Department of Primary Care at UCL, and has held several research posts,

most notably a MRC awarded training fellowship. She joined UCL in 1998 as a clinical lecturer and maintains a part-time GP role at Clerkenwell Medical Practice, London. Her research interests include mental health, infections and complex interventions in primary care. (g.rait@pcps.ucl.ac.uk)



EVIDEM-E: Exercise as a therapy for psychological symptoms



James Warner is a Consultant and Honorary Senior Lecturer in Old Age Psychiatry. His clinical base is at St. Charles Hospital, London, and his interests are in teaching and putting psychiatry research into practice. He has recently completed a trial of Gingko Biloba as a therapy for cognitive impairment, and he is researching dementia and sexuality in old age. He has co-written a

book for carers, *Alzheimer's at your fingertips*. (j.warner@imperial.ac.uk)

Imperial College
London

EVIDEM-MCA: Mental Capacity Act

Jill Manthorpe is Professor of Social Work and Director of the Department of Health funded Social Care Workforce Research Unit at King's College London. She has been interested in and researching the ways in which the law affects 'vulnerable older people' for over 20 years. She has worked in the voluntary sector and in higher education, specializing in older people's services and policies. (jill.manthorpe@kcl.ac.uk)



KING'S
College
LONDON

University of London

Jess Harris is a research assistant for the EVIDEM-MCA study. She has worked within older people's organisations and community engagement in health services. She has undertaken studies of citizen rights and adult protection, of disability discrimination, of increasing access to professional education and dignity in older people's care.

Spotlight on the Mental Capacity Act 2005 Project

The exciting bit about the Mental Capacity Act (MCA) 2005 part of the EVIDEM programme is that it is taking place at the very start of the Act and will continue for five years. This is a rare opportunity to see if a piece of legislation really makes a difference to the lives of people with dementia and their carers.

We want to find out how the Act affects the services and practices of staff working with people with dementia and their carers. Part of this will involve thinking about how training is used to inform staff, carers and people with dementia about the Act.

Recent concerns about training in dementia care make this a good subject to explore because the training on the Act covers everyone. We will also work with staff and carers to see how the Act links to adult protection and safeguarding – subjects that are often very worrying for many people.

We have five main research questions:

1. What challenges face staff when they come across issues of mental capacity when working with people with dementia?
2. What do professionals think about the MCA when working with people with dementia?
3. What are the expectation of older people and carers about the MCA?
4. What do professionals write down about giving information about the MCA to people with dementia and their carers, and how does this change over the period of five years?
5. What links between the MCA and adult protection services arise in practice, and is the MCA helping to safeguard people with dementia?

We think these are important questions because they often arise in conversations with people with dementia, carers and practitioners, as well as being reflected in research literature. There is a general lack of certainty about what to do when making decisions on behalf of somebody else and whether people are doing the right thing. These decisions can cover very small acts of care, such as making decisions about what to wear, to major ones such as going into a care home.

We think it important, but we also think that it is highly productive to build on earlier studies and experiences. Some of these have specifically covered dementia care but our previous work on advocacy, cash for care schemes, elder abuse and professional education is very relevant to making decisions.

We hope that our enthusiasm for the questions is infectious as we will need the help of many people to make this study work and to come up with findings that are helpful. If you are interested in this area and would like to participate in the study please contact us. (jill.manthorpe@kcl.ac.uk).

EVIDEM-C: Promoting continence and managing incontinence at home

Vari Drennan is Professor of Health Policy and Service Delivery in the Faculty of Health and Social Care Sciences at St George's University London. She has an active and wide ranging research



portfolio that includes health and social care for older people with dementia and their carers outside of hospitals, medicine management issues for older people with complex health and social care problems

living at home, and inter professional working across primary health and social care. (vdrennan@hscs.sgul.ac.uk)



EVIDEM-EOL: Quality of Care at the End of Life



Claire Goodman is Professor in Health Care Research at the University of Hertfordshire, and has a clinical background in district nursing. She has an international reputation in primary care nursing and end of life care for older people. Her current research focuses on the contribution of primary care nursing to promoting the health and well being of community dwelling older people, evaluations of new roles in primary care nursing and the health needs of excluded groups in primary care. (c.goodman@herts.ac.uk)



Research Management, Support & Researchers

Kalpa Kharicha is a Senior Research Fellow in the Centre for Ageing Population Studies in the Research Department of Primary Care at University College London. Her research interests in older people range from health promotion and disability prevention, the health and social care interface and quality of life in long-term care. She is the EVIDEM programme manager, during Jane Wilcock's maternity leave. (k.kharicha@pcps.ucl.ac.uk)



David Lowery Currently supports EVIDEM as the Research Programme Manager based in Central & North West London NHS Foundation Trust. He has held research posts within both the NHS and universities. His research interests include the impact of interventions on cognitive functioning and patients' perceptions of the services they receive. (d.lowery@nhs.net)



Martin Knapp is Professor of Social Policy at the London School of Economics and Political Science and Director of the Personal Social Services Research Unit. He also holds several visiting and honorary 'Professorships' in the UK and beyond. Martin's research activities are primarily in the mental health, long-term care and social care fields, focusing particularly on policy analysis and economic aspects of practice. His expertise has been sought by many government departments and other official bodies both in the UK and elsewhere.

Mark Griffin is a Lecturer in Medical Statistics at UCL. His research interests include primary care research with a particular focus on mental health, design, conduct and analysis of Randomised Controlled Trials and the analysis of primary care routinely collected data. Mark is providing statistical advice to the EVIDEM programme

Patricia Labro is Personal Assistant to Professor Steve Iliffe and Research Administrator to the EVIDEM programme. She has held a variety of administrative posts within the Royal Free Hospital and the Medical School, and prior to that worked as a P.A. in the International Department at the Institute for Child Health. (p.labro@pcps.ucl.ac.uk)



If you would like some more information on EVIDEM or one of the projects or want to get involved please contact:

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Alternatively you can visit us at our website:

www.evidem.org.uk

July 1st 2008 – The State of the Art in Dementia Care: Summer School and Stakeholders Event

A joint event organised by the EVIDEM team and the London Centre for Dementia Care to showcase good practice and research in London



Cruciform Building, University College London, Gower St, London,

The day will feature workshops including:

- The proposed National Dementia Strategy
- Management of behavioural and psychological symptoms of dementia
- End of Life care
- The Mental Capacity Act
- Management of incontinence
- Early diagnosis and intervention
- Telecare
- Ethnically sensitive support for black and minority older people

For more information please go to www.evidem.org.uk,
email Priya Jain on: p.jain@pcps.ucl.ac.uk or call 020
7830 2239 (ex. 38527)

