

The EVIDEM programme: a test for primary care research in London?

*Professor Steve Iliffe
Professor Jill Manthorpe
Professor Vari Drennan
Professor Claire Goodman
Dr James Warner*

The recent decision by the National Institute for Health Research to fund a large programme of research and development work on dementia syndromes may be a watershed for London's primary care. Evidence-based interventions in dementia (EVIDEM) is a five year, £2 million, research programme led by primary care which reaches into specialist areas, and which contains five projects run by a multi-disciplinary group of researchers (See box 1). It is highly unusual in that it is a translational programme of applied research, designed to change clinical and organisational practice, rather than the traditional 'blue skies' research that academia often prefers. Primary care researchers were able to win this programme against formidable competition from specialist consortia because of our background in such unfashionable applied research, and in doing so demonstrated that often rivalrous Universities could collaborate around a coherent R&D programme.

The dementia syndromes are becoming more prevalent as the population ages, and will inflate health and social care costs very significantly in the next decades¹. Their insidious onset, variable presentation and progressive course make diagnosis and management problematic^{2,3} particularly for primary care professionals who throughout the industrialised world struggle with both the recognition of dementia syndromes and with tailoring appropriate responses^{4,5,6,7,8,9} when psychosocial support is in short supply. It is hardly surprising that dementia care is rising up the policy agenda, with a growing emphasis on changing clinical practice likely to find expression in the autumn in the Department of Health's Dementia Strategy.

The inclusiveness of the EVIDEM programme was a winning characteristic for the research 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 anywhere. Links with networks of people with dementia and their carers were also crucial in demonstrating public and patient involvement. The programme's host, Central & North West London NHS Foundation Trust, reinforced the promise of grounded research and development.

The headiness of success wears off quickly, and the problems of primary care research rapidly re-assert themselves. There are many reasons why this programme might fail, which is why we think of it as a watershed. Such an ambitious programme requires collaboration beyond the inner group of researchers and institutions, for it will test the usefulness of research networks; the interest of provider Trusts in research,

Correspondence to

Professor Steve Iliffe
Professor of Primary Care for
Older People,
Associate Director, DeNDRoN
national co-ordinating centre
Dept. of Primary Care & Population
Sciences,
University College London,
Hampstead Campus,
Rowland Hill St., London NW3
2PF

Box 1 The EVIDEM team and projects

Recognition of & response to dementia in primary care: an RCT of educational Interventions ~led by Professor Steve Iliffe (Primary Care at UCL)
s.iliffe@pcps.ucl.ac.uk

Exercise for Behavioural & Psychological Symptoms in Dementia: a randomized controlled trial of exercise as therapy ~ led by Dr James Warner (Old Age Psychiatry in Central & NW London NHS Foundation Trust)
j.warner@imperial.ac.uk

Management of urinary incontinence in the community: developing and testing Practitioner toolkits ~ led by Professor Vari Drennan (Health Services Research, St. George's & Kingston University) vdrennan@hscs.sgul.ac.uk

End of life care in dementia: developing and testing 'best practice' guidelines ~ led by Professor Claire Goodman (Health Services Research, University of Hertfordshire) c.goodman@herts.ac.uk

Evaluating the implementation of the Mental Capacity Act 2005: ~ led by Professor Jill Manthorpe (Social Work, King's College London)
jill.manthorpe@kcl.ac.uk

Cohort development ~ led by Dr. Greta Rait (Primary Care at UCL)

Statistics & trial design ~ led by Mark Griffin (Primary care at UCL)

Health Economics ~ led by Professor Martin Knapp, (LSE)

the collegiality of specialists; the ability of the research bureaucracy to facilitate wide-scale R&D in the community; and the engagement of general practitioners (amongst others e.g. district nurses, care home staff) in activities without instant yield.

RESEARCH NETWORKS

EVIDEM seeks to recruit a cohort of 2,000 people with dementia and their carers, over a five year period. Most people with dementia are living at home, and their main source of medical care is their general practitioner. In theory we should be able to identify people with dementia through their general practices, a task made easier by the QOF requirement to keep a register. In practice there are multiple obstacles to recruiting through general practice, and two recent dementia trials that attempted to do so struggled to reach their recruitment targets^{10,11}. The QOF requirement may

have changed this and made it easier to identify people with dementia, and so we will work with the Primary Care Research Network for Greater London (PCRN-GL) to test this. Nevertheless to accrue people with dementia at the speed we need (400 consenting to join a cohort each year) we will have to rely, at least initially, on recruitment through memory clinics and outpatient clinics. This means having a working relationship with the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) in North Thames.

The Dementia & Neurodegenerative Diseases Research Network (DeNDRoN) has developed local networks to recruit large numbers of people for community-based trials, and it has been clear from the outset that primary care researchers will have an important role in developing these networks, and carrying out the trials¹². The

argument that primary care research on new diagnostic tools and therapeutic interventions, and on the use of clinical signs and symptoms to estimate prognosis and select the appropriate interventions, is crucial to understanding and improving care for this group has been well made, but putting it into practice may be more difficult.

COLLEGIALITY

Researchers from specialist backgrounds all too often see primary care as a source of 'research material' rather than a source of research partnership. A programme led from primary care that encroaches on specialist domains and recruits through specialist sites reverses the usual order, and may need some negotiation. This test of specialist collegiality will be felt strongly in the host Trust, which now has a legal obligation to deliver the research programme without interfering with its much greater commitment to service provision. Practitioners with busy jobs, or who are disgruntled by re-engineering of services and re-writing of job descriptions, will need to be persuaded of the merits of recruiting patients to a cohort. It is not just general practitioners who feel so busy that clinical tasks squeeze out all other interests. Since the projects within the EVIDEM programme are translational, with as much evidence on development as on research, implementing their findings will be a test of the roles of organisational culture, leadership, and evaluation in research utilization¹⁴. Here too there is a watershed, for as long as efficacy and effectiveness trials are considered complete without considering implementation in non-research settings, the public health potential of the original investments will not be realized. The EVIDEM programme will utilise and also test, models for translating research into practice derived from theories about the diffusion of innovations¹⁵, models of change in service delivery^{16,17,18} and measures of the population-based effectiveness of translation¹⁹.

WORKLOAD PRESSURES

Dementia is not core business for many general practitioners, regardless of QOF incentives, and there is some evidence that as a discipline they feel unskilled in working with people who are cognitively impaired. This evidence, based on reports from the Audit Commission²⁰ and the

National Audit Office²¹, is probably overstated. The core skills required for working with patients with dementia are already present in the discipline²², and the construction of meanings, dialogue about explanatory models of illness and the search for shared understanding that are necessary in dementia care are also part of the expertise of general practice²³. General practitioners are highly regarded by families of people with dementia²⁴ because they provide continuity of care across the whole trajectory of the disease, have established relationships of trust, act as advocates and problem-solvers when other agencies fail to do so, and open the gate to other sources of help. We will rely on these characteristics to recruit to the EVIDEM cohort through general practice, albeit at a slower rate than we can through DeNDRoN.

RESEARCH BUREAUCRACY

Researchers now have to work their way through a multitude of organisations before a single person can be recruited. Trusts weighed down with the administration of clinical services have to find space and time to manage unfamiliar research contracts, full of issues about ownership of knowledge and responsibility for governance and probity. Ethics committees have to reach judgements about approaching people who might be deemed vulnerable to seek their engagement with research, and take the job seriously but also differently in different places. Research governance offices in PCTs require their own forms completed and their own criteria to be satisfied before approval can be given for research to proceed. Practitioners can add their understandings and misunderstandings to discussions about rights of access to clinical information, ownership of data, and the ethics of inviting cognitively impaired people to participate in research. A mood of risk aversion permeates the research bureaucracy, and at times this can paralyse research activity. Against this we will argue that involvement in research improves outcomes for patients that protecting people with dementia from the opportunity to join research projects is a denial of their human rights, and that research and development are essential for clinical services if they are to flourish rather than merely survive. In five years time we will know if we have won the arguments.

DEMENTIA: STIGMA & TABOO

Perhaps the biggest obstacle to the programme is the condition being researched. Loss of cognition can be so devastating, and so wrapped around with stigma and taboo, that we may not be able to engage people on the scale that we hope. The progressive nature of cognitive losses may make consent difficult to achieve and renew over time, making us reliant on assent from others, and therefore more cautious in how we study people and their experiences. However, experience-based design, in which the traditional view of the user as a passive recipient of a product or service has begun to give way to the new view of users as integral to the improvement and innovation process²⁵, is at the centre of the EVIDEM programme. There are signs that the concerns about engaging people with dementia in research are also exaggerated, and that they and their carers will understand the benefits of being involved in research, take the opportunity to advance knowledge for others' benefits rather than their own, and demonstrate that they are engaged citizens, just like us.

In five years time we will know which way this research is flowing, and a lot more about the potential for large-scale applied research in primary care in London. We look forward to reporting the lessons, positive and negative, in this journal. Primary care professionals who are interested in contributing to the EVIDEM programme are welcome to contact us. We would particularly like to hear from: general practitioners, and practice and community nurses who are interested in diagnosis of dementia; from community nurses and social workers about incontinence management; from care home practitioners interested in BPSD management and end-of-life care; and from all staff trying to understand the implications of the Mental Capacity Act 2005.

To get in touch with the EVIDEM programme contact David Lowery (CNWL NHS Foundation Trust) d.lowery@nhs.net 020-3214-5889 or Kalpa Kharicha (Primary Care at UCL) k.kharicha@pcps.ucl.ac.uk, 0207-830-2392

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