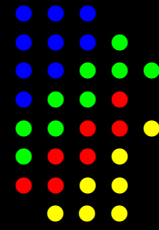


# ***EVIDEM: Evidence-Based Interventions in Dementia***

***Newsletter 2 Summer 2008***

**[www.evidem.org.uk](http://www.evidem.org.uk)**



## **Welcome to the second quarterly newsletter of the EVIDEM research programme**

**Welcome again to the EVIDEM quarterly newsletter. EVIDEM is now well underway and we bring you news of our progress in this newsletter. In this issue you will also find our regular 'spotlight' feature focussing on the End of Life**

**(EVIDEM-EoL) and Contenance (EVIDEM-C) projects. Our events section will give you a chance to see some of the feedback from events we've organised and break out the diary for forthcoming events that might interest you.**

### **EVIDEM engaging with services**

Since our spring edition the EVIDEM team has invited key stakeholders from local authorities and the voluntary sector to meet the team. This was an excellent way of both raising awareness of the EVIDEM programme and sharing valuable information about research and local practice. By actively engaging with the people and organisations that on a day to day basis support people with dementia and their caregivers, we hope to keep EVIDEM grounded in the reality of the important issues for the people that matter.

If you are part of a local government or voluntary organisation that comes into contact with people with dementia and would still like to be involved, we would be delighted to talk to you. A member of the EVIDEM team can arrange to

come to your local branch or office to give a brief presentation on the programme, and perhaps you may have some valuable insight to offer us.

If you would like to invite us to come and talk to you please complete and return the slip below.

**Your Name:**.....  
**Organisation:**.....  
**Address:**.....  
 .....  
**Telephone No.**.....  
**Email:**.....  
**Suggested Times & Dates:**.....

You can return this form by email [d.lowery@nhs.net](mailto:d.lowery@nhs.net) or by post:  
**David Lowery, CNWL NHS Trust,  
 Greater London House,  
 Hampstead Rd, NW1 7QY**

## Upcoming Events

### **EVIDEM Steering Group Meeting**

Tuesday, September 16<sup>th</sup> 2008, 14:00-16:00

### **EVIDEM Advisory Group Meeting**

Friday, October 10<sup>th</sup> 2008, 10:00-12:00

### **Dementia Care Congress**

28-29 October 2008, Bournemouth

**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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**020 7830 2392**

**k.kharicha@pcps.ucl.ac.uk**

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**020-3214-5889**

**d.lowery@nhs.net**

Alternatively you can visit us at our website:

**[www.evidem.org.uk](http://www.evidem.org.uk)**

## NIHR: Programme Grant for Applied Research



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### ***Spotlight on the 'Continence' Study (EVIDEM-C)***

#### What is EVIDEM-C about?

Urinary or faecal incontinence (involuntary leakage) are distressing for any adult and they can impact on many aspects of health and quality of life. Up to a third of people with memory problems living at home have difficulties in remaining continent and this cannot always be resolved with medical treatment. There is lack of detailed knowledge of these issues and particularly around management; this is reflected in the lack of guidance for health and social care professionals on how to help. This study aims to describe the range and impact of incontinence as well as test out some management strategies that might help.

#### Why is it important to study EVIDEM-C?

Incontinence lowers quality of life, has a negative effect on mental health and creates significant practical and financial problems. It can also be a significant factor in the decision to take up residence in a care home.

#### How will you carry out EVIDEM-C?

EVIDEM-C involves a number of activities which include undertaking a review of what's already known about managing incontinence, asking the views of people with memory problems, their carers and health and social care professionals about the problems they face and what strategies they use to manage incontinence. The project will then attempt to use this learning to develop and test guidance on strategies to help manage incontinence better. The perspectives of the person with memory problems, their carers and professionals are essential for this project and will be monitored throughout.

#### When will EVIDEM-C happen?

We have begun and are looking for people to volunteer and join us.

#### What difference do you think EVIDEM-C will make?

We hope to produce practical information that will help people with memory loss living with continence problems. We also hope that our findings will inform those who plan NHS and social care and help them to develop services to support people to remain continent and manage incontinence. Lastly, we hope to provide information for future studies on particular types of medical interventions to help people with incontinence.

#### How can I get involved in EVIDEM-C?

There are a number of ways people with memory loss, their family and carers and health and social care staff could be involved. To talk to someone about how you can become involved please contact Laura Cole on 020 8725 3867 or ([lcole@hscs.sgul.ac.uk](mailto:lcole@hscs.sgul.ac.uk)) or Vari Drennan, on 020 8725 2339 ([vdrennan@hscs.sgul.ac.uk](mailto:vdrennan@hscs.sgul.ac.uk))

## State of Art in Dementia Care: Summer School & Stakeholders Event

On July 1<sup>st</sup> 2008, EVIDEM and London Centre for Dementia Care (LCDC) teamed up to organize a one day Summer School on the 'State of Art in Dementia Care'.



The conference included presentations from leading professionals in the field of dementia care on the draft National Dementia Strategy and 'Management of behavioural and psychological symptoms in people with dementia'. Overviews of two National Institute of Health Research funded dementia research and development programmes, currently underway – SHIELD and EVIDEM - were given, as well as an update of activities at LCDC. In addition, delegates engaged and contributed to the conference through the sessions on End of Life Care, the Mental Capacity Act, Assistive Technology, Management of Incontinence and Support for Older People in BME Groups. The event was a huge success with 144 people in attendance. Delegates arrived from around the UK representing a range of professional backgrounds including health care professionals, researchers, social workers, social and voluntary organization managers, carers, care home managers and independent trainers. Importantly this range of stakeholders gave the event an invaluable perspective into the current state of dementia care in England.

We invited feedback via evaluation forms on the experience of the conference. On the whole the feedback received was very positive. The delegates found the event to be *'...highly educative and thought provoking'* and they *'enjoyed the day, the workshops and the presentations'*. They found the dissemination of information, with contact information and support for practice, very helpful. The event *'changed (their) interpretations of behaviour in dementia'*.

Some delegates mentioned that they would like to incorporate the learning from the seminar into their *'...teaching/training programmes'* and will be *'sharing information & raising awareness to the colleagues'*. They were keen to use the information to *'feed into development of strategy, policy and procedures'* of their organization. Delegates also showed interest in sharing the research information and becoming involved with them. *"I will ....possibly take part in the undergoing studies/research work."*

You can find all the presentations from the summer school along with the full programme on our EVIDEM website at [www.evidem.org.uk](http://www.evidem.org.uk) . We will be happy to hear more from you on Summer school at [evidem.programme@googlemail.com](mailto:evidem.programme@googlemail.com) .



The Summer School will be an annual event for the duration of the EVIDEM programme.

### ***Spotlight on the 'End of Life' Study (EVIDEM-EoL)***

The majority of research on palliative care for people with a diagnosis of dementia has been undertaken in specialist units and hospices. Less is known about providing palliative care for this population when they are being supported at home or in care homes. The EVIDEM 'End of Life' (EoL) project focuses on older people with dementia who live in a care home with personal care (a residential care home), and their support needs and care towards the end of life. We know little about these individuals' experiences at the end of life, how NHS services work with care staff to provide care or, if recognising when an individual with dementia is nearing the end of life, how they can improve the services they receive, particularly how and where people with dementia die.

We have six main research objectives

1. To describe the different characteristics of older people with dementia and their experiences of living and dying in a care home.
2. To describe the care and support needs of older people with dementia living in a care home and their carers.
3. To establish how staff and NHS primary care practitioners define, assess and provide end of life care for older people with dementia in a care home.
4. To describe how different models of care in a care home influence an older person with dementia's experience of end of life care.
5. To identify the treatments and interventions received, and services and resources used, leading up to an older person's death.
6. To establish if dementia specific educational support and assessment tools can improve experiences and outcomes for older people with dementia dying in a care home.

This longitudinal study will run for four years and work with up to 10 care homes across North London and the south of England. We will track the care older people with dementia receive, and work with care homes, and NHS staff, to develop and refine a resource pack for practitioners and organisations that focuses on the needs of older people with dementia as they approach the end of their life. This will inform and complement existing palliative care initiatives being introduced across the NHS and within care homes (e.g. Gold Standard Framework for Care homes).

The study is important because little research has considered the older person's experience of living and dying with dementia in a care home, or considered how a care home's approach to care affects the care provided or the outcome of care, such as, wellbeing. Many tools have been developed to support practitioners in caring for people with dementia, such as tools for assessing pain, and advance care planning but we do not know what supports their implementation by different practitioners and care workers. To develop practice in dementia care we think it is important to understand older people's experiences, current practice and to develop and test the best way of supporting care staff and NHS practitioners to care for older people with dementia towards the end of their lives. If you are interested in this study and would like more information, or to find out ways to support the study please contact either Catherine Evans ([c.j.evans@herts.ac.uk](mailto:c.j.evans@herts.ac.uk)) or Claire Goodman ([c.goodman@herts.ac.uk](mailto:c.goodman@herts.ac.uk)).