

## **Introduction**

The National Care Homes Research and Development Forum was established in 2003 to provide a platform for researchers and practitioners to network, share information and ideas arising from their work. Members believe that the Forum has the potential to bring together a wealth of knowledge and talent and could exert a considerable influence on future research agendas for long-term care for older people.

## **Why the Forum was established?**

***The majority of long term care for older people in the UK is now provided in care homes, and approximately half a million frail older people live in these environments with the greater proportion of this population aged 85 and over (Laing & Buisson, 2010). This is arguably one of the most vulnerable populations and until relatively recently what occurred in care homes – the experience of those living in these settings and the care practices - received little attention from policy makers and researchers. This needed to change and is changing with the raft of policy and legislative initiatives that have been introduced since 2000. Research that is devoted to understanding the complexities of this environment has also increased.***

Those who conduct their research in care homes all too readily recognise the challenges that they face in their day-to-day practice. The nature of the setting, itself, is ambiguous. It is both a domestic setting and an institutional one where a duty of care exists between those who provide and those who receive care. A factor that compounds this further is the differing status of residents that can exist within a care home. For example, some residents may purchase their entire tenancy and package of care through a personal contract with the home, whereas the contract is established between the statutory services and the care home under the eligibility criteria for other residents. With respect to carrying out research in a care home the rights of the residents to participate in research will be the same, regardless of their contractual arrangements. However, the processes for gaining permissions to carry out research will differ. To approach those who are self-funding to take part in research there may be procedures developed by the care home to approve the research or there may be no obvious procedures to follow at all. In contrast, the researcher may have to negotiate research governance processes in the health and social care sectors to invite those who are funded by statutory services to take part in the research (Reed, Cook and Cook, 2004). This is a complex and confusing situation for researchers, service providers, residents and their families, as the research governance processes in the UK statutory sector is evolving and the procedures for gaining permissions is constantly changing.

Another central challenge of conducting research in care homes is developing practices that are appropriate across the resident population. The difficulties in doing this are illustrated in the way that the principles and practices of gaining consent from residents to participate in research are applied in everyday practice. Older people become care home residents when they require assistance and care or they anticipate that they will need care in the near future. This does not automatically mean that their ability to make decisions is impaired. They are adults and it should be assumed that they are competent to make decisions, unless it can be demonstrated

otherwise. This principle is enshrined in precedential law in Britain. Researchers have responsibilities in this situation to provide the conditions where the older person is provided with information to enable them to make an informed decision about their involvement in research and to support them to execute their decisions.

The reality for care home residents is that they can be marginalized from such decisions because they are regarded as 'vulnerable' and others, such as the care home staff or their family, make decisions about their participation in research on their behalf. Although these practices are carried out in the best interests of the older person, this situation serves to undermine their rights and increase their vulnerability. Researchers can debate these issues with care home staff, resident's families and research ethics committees with the aim of gaining a consensus across these different communities to support practices that uphold the right of the older person to make their own decision about participating in research. What is more challenging is the situation where the capacity of the older person fluctuates or their capacity is diminished. Although guidance (such as BMA and Law Society, 1995) and notions of process consent have developed in recent years (see for example Dewing, 2002) gaining consent and permissions to carry out research in these situations continues to be fraught with difficulty.

These examples are illustrative of the challenges that researchers encounter in their work in care homes. It must be remembered that researchers are only one of the groups that encounter challenges in their work in this sector. Care home managers also face many challenges. They have competing demands for their time, yet they continue to struggle to support research and endeavour to ensure that the research that is carried out in the home is appropriate and is of the highest scientific quality. Some attempt to do this in circumstances where there is minimal understanding of research processes, pointing to the need for researchers and service providers to work together to enhance the evidence base for their practice.

Some of these issues have received attention in the wider literature and researchers extrapolate from the experiences of others to shape their own work. This is a lonely exercise in the pursuit of the best practice for research in care homes and a process that will only effect change slowly. With this in mind researchers have come together as members of the National Care Homes Research and Development forum with the aim of building on existing good practice and to effect change that will come about quickly.

The aims of the Forum are to:

- share personal experiences of conducting research in care homes to examine the issues and challenges that were encountered and how these were addressed
- debate the (in)appropriateness of methodologies for researching in care homes and explore possibilities for methodological development
- influence the national agenda on research and development in care homes identify and share information about sources of funding for research in this field
- agree an ethical code of practice
- provide support for post-graduate students

***What has been achieved by the forum?***

There are now 177 members who meet 2-4 times annually.

Completed activities include:

2005

- ESRC research seminar series 2005/6 Transitions in Care Homes: meeting the demands of the 21st century (<http://www.esrc.ac.uk/my-esrc/grants/RES-451-25-4155/read/reports>)

2006

- Dissemination conference 'Research into Practice' Using research to improve the care in care homes, 18 October 2006, Somerset.

2007

- A literature review on quality of life in care homes (*My Home Life*) commissioned by Help the Aged (NCHR&D, 2007)

2008

- Series of workshops on themes of *My Home Life* at National Care Homes Congress 2008 (6<sup>th</sup> March, Birmingham)
- Series of papers in practice development section of International Journal of Older People Nursing (Volume 3, Issue 4).

2009

- International symposium on quality of life in care homes and inaugural meeting of International Care Homes Research and Development Forum
- Publication of an edited book including contributions by members of the Forum Froggatt K, Davies S and Meyer J (eds) (2009) *Understanding Care Homes; A Research and Development Perspective*. Jessica Kingsley Press. London.

2011

- NIHR SSCRU Methods Review
  - Luff, R; Ferreira, Z; Meyer, J (2011) Reviews in Methodology: Research in Care Homes, submitted to NHIR SCRU.
  - Goodman, C; Froggatt, K; Mathie, E (2011) Reviews in Methodology: End of Life Care, submitted to NHIR SCRU.

### **Convened by**

Professor Julienne Meyer (City University), Dr Katherine Froggatt (Lancaster University) and Dr Sue Davies (University of Sheffield),

Meetings are held in different venues around the UK, dependent upon who is able to hosts a meeting. A small charge covers refreshments. They take two forms:

1. They can be a vehicle for a host institution to present information about their programme of research in care homes, or
2. They may take a themed approach with a focus that uses presentations by researchers from across the UK and overseas.

### **References**

British Medical Association and Law Society (1995) *Assessment of mental capacity*.  
British Medical Association and Law Society

Dewing J (2002) From ritual to relationship: a person centred approach to consent in qualitative research with older people who have a dementia. *Dementia: The International Journal of Social Research and Practice*. vol1 (2),156-171

Laing and Buisson (2010) *Care of older people: market survey 2010*, 13<sup>th</sup> London, Laing and Buisson

NCHR&D (2007) *My Home Life: Quality of life in care homes – Literature review*, Help the Aged, London ([www.myhomelife.org.uk](http://www.myhomelife.org.uk))

Reed, J; Cook, G. and Cook, M (2004) Research Governance Issues in the Care Home sector. *Nursing Times Research* vol 9(6), 430- 439