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Methods Review 8

Care homes

Rebekah Luff, Zara Ferreira and
Julienne Meyer

Improving the evidence base for
adult social care practice

The School for Social Care Research

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ABSTRACT

This review is an evidence-based guide, written with the primary aim of helping those new to the field of researching in care homes to learn from the experience of others in undertaking studies in these complex settings. The paper draws on illustrative examples from a range of studies and is broadly structured to reflect the various stages of a research project through planning, fieldwork and dissemination. The review aims to promote researchers' understanding of specific issues relating to research in a care home at each stage of the process.

Whilst the focus of this review is on care homes for older people, observations may be relevant to researchers in similar care settings such as those working in the field of intellectual disabilities. Pragmatically, this review cannot be a systematic trawl across all research methods. It focuses on three broad methodologies as applied in care home research: Qualitative, (e.g. interviews and observations); Quantitative (e.g. structured instruments and control trials) and Participative (e.g. action research).

RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

- Research in care homes must be understood to be a complex undertaking, one which should take into account the needs of residents, relatives and staff.
- Researchers should consider the value of working with residents, relatives and staff as research partners in order to enhance the experience, reach and dissemination of work.
- Researchers should consider the impact that cognitive and physical frailty, staffing pressures and the unique environments of care homes. These may impact upon the process and progress of research projects.
- The well-being of participants and associated stakeholders must be considered paramount to research design.

KEYWORDS

Care home, research methods

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INTRODUCTION

This review will focus on three broad research methodologies: qualitative, quantitative and participatory research. Qualitative research in this context refers to a researcher undertaking interviews with staff, residents or family members, or researchers observing daily life, specific activities or interactions in a care home. Qualitative research is recognised as an approach which seeks to understand the experiences of those people working in, living in or visiting care homes and how they make sense of these experiences, their relationships or roles.

Quantitative research is usually hypothesis-driven and may involve surveys, questionnaires, psychometric scales, and other forms of 'structured instruments'. There can also be overlap with qualitative methods, including observations and interviews, used to generate quantitative data. Within a care home setting there are many levels at which these data could be collected, from the organisational level (whole systems) to the individual level (including perspectives from residents, families and visitors). Research can be a snapshot of a particular time period or may assess change over time, for example in control trials or longitudinal studies. While the epistemological arguments for quantitative research are the same in care homes studies as for other research areas and will not be discussed here (see Moriarty 2011) there are issues around sampling, data collecting, generalisability and dissemination that are more specific to the care home environment.

Quantitative and qualitative research methods are both subject to critique for failing to take adequate account of how findings subsequently influence policy and practice in order to improve the lives and experiences of residents, staff and visitors (see Froggatt *et al*. 2009). Participatory research methods, including action research, offer scope to understand practice within a care home, use this knowledge to introduce interventions or influence change, and assess the outcome. These participatory and action-orientated methods have more commonly cast care homes as research partners, as opposed to the research 'object', and the approach can be summarised in four principles:

Equity – the assumption that all staff, residents and families have equal worth and should be valued;

Engagement – ensuring that everyone has the opportunity to participate as they would like;

Mutual learning – recognising that all participants have the opportunity to learn from each other;

Honesty – the importance of being explicit about processes, including when things do not work out as planned (Froggatt *et al*. 2009).

UNDERSTANDING CARE HOMES

The focus of this review is research within care homes in the UK (in particular, England) although the findings are likely to be of wider interest.

The context and culture of care homes

In this review, the term *care home* refers to all residential long-term care settings which provide group living and personal and/or nursing care for older people and other adults. In the past, homes were separated into two distinct types: nursing homes, which provided personal care and on-site nursing care; and residential homes, which provided personal care only, with nursing care being provided by local NHS primary care services. Currently, the terms care home, or care-only home, and care home with nursing are applied. Within both categories, homes can be further registered as specialising in dementia care (often referred to as Elderly Mentally Infirm, or EMI homes), where staff care for a greater number of residents with moderate or severe dementia. However, a recent census of 18,700 older people living in care homes found 63 per cent of residents across all types of care homes have some form of dementia (BUPA 2009) highlighting that nearly all care homes care for a high proportion of residents with dementia, not only EMI homes. Some care homes specialise in other areas of mental health, for example, addictions or schizophrenia, while others support people with learning or intellectual disabilities.

In the UK, 80 per cent of residential care is provided by the independent sector, predominantly in private sector (for-profit) homes (Laing and Buisson 2009) with a decreasing number being run by local government (local authority homes). In 2009, 73 per cent of care-only homes were private sector, 19 per cent in the voluntary sector and most of the rest were run by local authorities. Of the care homes providing nursing care, 89 per cent were run by the private sector (Eborall *et al*. 2010). About 55 per cent of residents in private sector care homes are funded by local authorities, 6 per cent by the NHS and 39 per cent privately (self-funders) (Laing and Buisson 2009). More in-depth discussion of the mixed economies of UK care homes can be found in Froggatt *et al*. (2009) and NCHR&D (2007).

Inspecting bodies for care homes across the UK have changed several times in recent years. Currently care homes in England must adhere to 28 quality and safety regulations, set out in the *Health and Social Care Act 2008 (Regulated Activities) Regulations (2009)* (Department of Health 2009b) and the *Care Quality Commission (Registration) Regulations* (Care Quality Commission 2009). The Care Quality Commission (CQC) regulates health and adult social care services in England, whether they are provided by the NHS, local authorities, private companies or voluntary organisations. Most recent inspection reports for all care homes, including the registration of each care home for its regulated activity (i.e. accommodation for people who require nursing or personal care) are accessible on the CQC website.

About UK care homes – different cultures

There are many examples of care homes research (Reed and Payton 1997, Nolan *et al*. 2006, Manley *et al*. 2004, NCHR&D 2007), particularly intervention-based research, which cite the importance of care home culture, also described as 'the atmosphere', 'philosophy' or 'care priorities' in a home. Titman (2003) defined key areas of information that people felt they would like to have when making choices about care homes, which included atmosphere, staff, resident interaction and philosophy. The literature review by NCHR&D (2007) includes a chapter entitled 'Promoting positive culture in care homes'. This is a useful starting point for new care home researchers to understand the complexity of resident, relatives, and staff needs and relationships, and highlights the features of a 'positive' care home culture.

Given the evolution and shifting remits of relevant regulatory bodies, researchers entering the care home field should be aware of what constitutes current 'best practice' by familiarizing themselves with up-to-date literature and guidelines (e.g. *My Home Life*, CQC website).

About the workforce

Care work is poorly paid, with many staff earning little over the minimum wage (Low Pay Commission 2009, Hussein 2009, Eborall *et al*. 2010). Pay and responsibility structures creating a clearly defined career ladder for care staff are often absent, with little opportunity for individuals to progress either into training or managerial roles, or to specialise in specific aspects of care where both training and better remuneration are provided (Hussein and Manthorpe 2011). There is arguably little opportunity or motivation for many care staff to progress in their careers. However, the type of ownership and management style varies, and some care homes do invest carefully in staff training and creating career progression structures.

Gender, age and education of the workforce

Staff in care homes are predominantly female (Eborall *et al*. 2010). The median age of care staff is 40–44 years, with ages fairly evenly distributed, and a high proportion work part-time.

The *National Minimum Care Standards for Care Homes for Older People* (Department of Health 2002) prescribe that a minimum of 50 per cent of care assistants in any given care home, including staff employed through agencies, should have National Vocational Qualification (NVQ) level 2. As of March 2009, 10–15 per cent of care homes had not met the qualification criteria, in part due to a shortage of NVQ trainers and examiners (Eborall *et al*. 2010).

Ethnic and national diversity within the workforce

Many UK care homes employ 'overseas' staff, including both those who have lived in the

UK for many years and people who have recently migrated. Recent estimates suggest that approximately 20 per cent of the care workforce in England were born outside the UK (Hussein *et al*. 2010), although the proportion varies greatly across the country, with migrant care workers constituting an estimated 68 per cent of the workforce in London (Hussein 2010).

Care staff originate from a number of countries, commonly Zimbabwe, Nigeria, the Philippines, Ghana and Poland (Hussein 2010). Recent free labour movements within an enlarged EU have seen an increase in the number of Eastern European care staff. Thus there is a rich nationality and ethnic mix among care home staff, with a high proportion speaking English as an acquired language, and having diverse cultural backgrounds and experiences.

PREPARING TO DO RESEARCH AND DEVELOPMENT IN CARE HOMES

The introduction to this review highlighted the heterogeneity of care homes and therefore, the experiences of researchers within these different types of care homes and within different cultures of care can vary significantly.

Experience, skills and readiness of researchers

The experience, skills and readiness of a researcher to engage in care home settings should be explored at the outset of a given project by researchers, project leaders or supervisors. Consideration should be given to the researcher's experience of working in a care setting, working with vulnerable groups, and of working with people who may have serious physical and/or mental health problems, or disabilities. For example, recent interest in health technologies has led to researchers going into care homes to explore how their knowledge and expertise might best be used in this context. However, such researchers would also require the communication skills needed to talk with frail older people or other people with high support needs, particularly those with dementia. That is not to say that those without experience should not undertake research in these environments, but that lack of researcher experience should be acknowledged and adequate time allocated for preparation and support. Even those with a social care or healthcare background can find research in care homes challenging. The Medical Crises in Older People (MCOP) research programme at the University of Nottingham (http://nottingham.ac.uk/mcop/index.aspx) included a care homes work stream, and whilst the researchers had backgrounds in nursing and medicine they were struck by the swift decline of some residents and the poignancy of collecting data from residents who died during the study.

The importance of the skills which researchers must bring to their work in care homes should not be underestimated. These include an ability to relate to others, communicate effectively, empathise, make ethical judgements, remain flexible, be patient and, importantly, to ensure the wellbeing of the residents, relatives and staff are central at all times. Skills that enable excellent research in other fields do not guarantee high quality, balanced and compassionate research within a care home, where inter-personal and emotional skills may be as important as an understanding of research methods. Such complex settings may be ideally suited to practitioner research, where the researcher has a working background in social or health care and some experience of talking with people in this setting. However, it should not be assumed that practitioner researchers automatically have appropriate skills. In a recent study exploring the needs of renal patients, Noble (2010) found that, as a practitioner researcher, the communication skills she used were too medically oriented and failed to adequately address quality of life and emotions related to dying.

Resources

Dewing (2009) argues that the culture of a care home has numerous consequences for staff and residents, impacting on the sense of purpose within the home, the organisational systems and processes, and how adaptable and flexible the home is in order to meet residents' needs. These cultures also influence any research undertaken within a care home and impact on the researchers' experience. Simply explained, two care homes may have exactly the same layout, residents may be similar in need, and the care staff may be equally capable and caring. However, if in one home the leadership is strong, easily accessible and ensures communication throughout the home, while the other home lacks strong leadership and has haphazard communication, this will be felt throughout the home and will greatly influence the research experience (see the SomnIA project below, page 16).

Preparing to be reflexive

How then can researchers prepare for fieldwork within care homes? Dewing (2009) maintains that researchers should be reflexive at all stages of the research process. Prior to starting, they should take time to think over their views of care homes, residents, relatives and staff and where these views come from. Are the researcher's positions from their own work experience (with or without a thorough understanding of the social care context), the media, or experience of a relative moving into a care home? Awareness of these views and any hopes or concerns regarding the research process should be acknowledged. This approach must also require researchers to be reflexive about how those living, visiting and working in the care homes may view the research and the researcher. On the MCOP study (http://nottingham.ac.uk/mcop/index.aspx) the research team came from two different perspectives: medical and sociological. In preparation for their interviews with care home staff, researchers piloted the interview schedule on each other to increase awareness of their own and colleagues' perspectives, as well as preparing them for interviews with staff, carers and GPs. This preparation enabled an understanding of the apprehension and concerns felt by residents, relatives and staff, alongside those of the researcher. This reflexive approach, while resource-intensive, encouraged researchers to address assumptions they may have made regarding care home culture and the individuals involved.

Ashburner (2005) found a reflexive approach invaluable to gaining a better understanding of the challenging context (an NHS continuing care unit) which she engaged for a PhD study concerned with developing person-centred care through action research. Initial mistrust of the researcher on the part of staff meant that it took two years before changes occurred and Ashburner concluded that there should have been greater clarification of roles, negotiation and airing of misgivings during the first phase of the project. She felt she had underestimated the fears and perceived sense of threat her presence would evoke. However, applying reflexivity and psychodynamic theory, Ashburner framed this situation around an enactment of the projections within the unit. In so doing, she was able to tolerate hostility from participants in the study, keep them engaged, and bring them through to a place of success, where care was thought to be delivered in a more person-centred way and where staff learned to enjoy their work more.

Time and flexibility

Time and flexibility are two of the most valuable resources for care homes researchers. Preparation by researchers and project leaders must not underestimate the time which is needed for care homes and researchers to familiarise themselves with each other. Evans (2008) found preliminary fieldwork undertaken as a visitor to the care homes in her study a necessary and extremely useful phase. It increased her understanding of the home environment and culture, and helped to establish institutional support for the study. Simply allowing for the usual amounts of time in ‘data collection’ is to risk underestimating the complexity of care homes research, and also detracts from the many positive aspects of this type of work, including spending time with, and learning about, the residents, relatives and staff in order to gain mutual trust, respect and engagement.

Research in care homes is a potentially sensitive area according to the definition of sensitive research as that which

> potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding, and/or dissemination of research data (Lee and Renzetti 1993, p.5).

Care homes are places in which frail older people not only live, but also, die. The researcher may be seen as an intruder in the person’s own home or as an unnecessary presence at a key moment such as death, which can be a sensitive time not only for the dying person, but also for those close to them. Care homes research then can pose a challenge to both participants and researchers. Both academic and reflexive supervision may be needed to support the researcher. At City University, several PhD researchers (Ashburner 2005, Holman 2007, Nicholson 2009) received additional supervision from psychodynamically informed counsellors to support them in their studies. Both Ashburner and Holman were engaged in educational projects within NHS continuing care units (with some similarities to care homes) and it was thought wise to build in clinical supervision to support the change component to their work. Nicholson (2009) used Biographic-Narrative Interpretive Methodology to explore frailty over time in the community and found benefit from receiving additional clinical supervision to support her when managing some of the sensitive issues that arose. This has led to it becoming normal practice in the wider team, and those working on the *My Home Life* programme – which is delivering action learning sets to care home managers across the UK – has its own group discussion meeting, led by a psychodynamically informed facilitator, to help 'hold' some of the anxiety projected by the care home managers when discussing their everyday challenges.

Researchers' contemplation of their own ageing and disability

Dewing (2009) explicitly highlights the effect of planning and undertaking research in care homes in relation to researchers' reflections on their own ageing as well as other people's. Researchers should expect to witness both cognitive and physical frailty. This research setting is emotionally demanding, thus it should be anticipated by those leading the research that distressing current or past personal circumstances, such as experiences of ill health or loss of family, could surface for researchers while undertaking research. Assuming that researchers leave their private lives at the door is not realistic or helpful in this emotionally complex and challenging context. Researchers could be encouraged to keep reflective diaries during the course of their research to capture their own emotional response to the issues raised. This can help them reflect on the impact of their emotion on the research itself and on themselves. Some PhD students have purposefully used their reflective field notes as an additional source of data collection, using 'self' as a research instrument (Ashburner 2005, Holman 2007, Nicholson 2009). For instance, Holman (2007) used herself as a research instrument to detect the emotions being projected onto her by the participants. By using a participant observation method and comparing it with issues raised by staff in the Reflective Working Group, she was able to compare her emotional experience and the care staff's. She was then able to make suggestions about the aspects of work that were omitted or glossed over in the care staff's accounts of their experience. Tapping into her own emotions, while exploring those of staff, placed increased demands on her. So to support her in this work, she was part of a work-based discussion group (mentioned above) run by a psychodynamic counsellor for two years of the study. In so doing, she was able to reflect on and process the emotional burden of care and use it as data, rather than feeling overwhelmed.

Therefore, as noted, researchers and their managers should ensure that emotional support is available for research staff should they wish it (for example, access to counselling services). This support, its relevance and importance should be made explicit during planning stages. For example, it could be included in funding applications as an essential requirement to support researchers.

Doing research 'with' and 'for' care homes or 'on' care homes

Froggatt *et al*. (2009) noted that research and development work may challenge care homes, as it adds yet another pressure on an already heavily-burdened sector. The relevance of research to the participating home may be lost in the day-to-day struggle to provide quality care. Thus, many care home staff and managers may, understandably, not give research and development high priority. The onus is therefore on the researcher to

Box 1: Useful strategies and methods in care homes research and development

- participant observation – spending time getting to know participants and the context in which they live and work, and providing opportunities for them to get to know you
- action research/action cycles – especially where participants are involved in identifying the areas for development
- action learning sets – providing opportunities for staff to meet with peers with a constructive focus
- engaging with biography (residents, families and staff) and using this to create a sense of significance for participants
- using theoretical, conceptual and practice frameworks to provide a structure for a development or intervention and its evaluation
- supervision/reflection, particularly for staff
- looking for evidence of achievement
- staff nomination/allocating specific roles within an initiative or development
- developing partnerships with outside agencies (e.g. a lecturer in a school of nursing, a community practitioner)
- independent advocacy to empower residents, particularly those without any external support
- witnessing (attentive valuing, seeing, understanding and telling what goes on for another)
- rapid feedback of findings to avoid disillusionment with the process.

Source: Davies *et al*. 2009, p.256

minimise disruption or added work within the care home, make clear the potential benefits to that particular care home and/or the care home sector, and work with the care home, either as a research partner, or at the very least try to fit in with the rhythm and norms of the home.

The *My Home Life* (MHL) movement (www.myhomelifemovement.org/) began as a project, developed into a programme and is now seen as a social movement for change. The Directors (Julienne Meyer and Tom Owen) believe this is due to the value-driven way that the MHL team has worked with the care home sector, drawing on Appreciative Inquiry (AI) (Reed 2007). AI is a participative method that takes a whole systems approach to change and focuses on the positive. In so doing, it does not focus on what care homes are doing wrong or blame practitioners for poor practice. Instead it draws out what is working (the best of what is) and shares that.

As discussed, care homes are heterogeneous and it is wrong to assume that they will always want to be involved in research. They are mostly run as businesses and need to know what is in it for them. This is why research at the 'development' end of a 'research and development' spectrum may offer the possibility of improvement, whilst learning the lessons from researching the process and outcomes of change. Froggatt *et al*. (2009) described research that was designed to be participative and engaging with the sector. They demonstrated how it may be possible to minimise disruption or added work within the home, clarify the potential benefits to that particular home and/or the sector and work with the care home, either as a research partner, or at the very least not to be disruptive. In particular, Davies *et al*. (2009) proposed the need for:

- understanding the context and culture
- being explicit about values and principles
- having a clear theoretical perspective or framework
- having shared goals that include something for everyone
- using methods and strategies that are inclusive and authentic
- anticipating and dealing with barriers to change
- celebrating success.

The authors suggested that good relationships are crucial and that the time invested in getting to know individuals at a personal level may ensure that people feel comfortable to participate and are willing to share their time and energy, contributing to a successful outcome. They outlined a number of methods and strategies (see Box 1) that are inclusive and authentic, and argued that participation in research within care homes can be a creative and empowering experience for all concerned.

RESEARCH FUNDING

Funding for care home research may come from many sources due to the way in which care homes straddle the interface between health and social care. Funding may be awarded by either health or social care mainstream research and development programmes (for example, European Commission, Economic and Social Research Council and other research councils, National Institute of Health Research (NIHR) strands, including the NIHR School for Social Care Research (SSCR) or NIHR Research for Patient Benefit programme (RfPB)), specific charities interested in the needs of disabled or older people (such as Age UK, Joseph Rowntree Foundation, Alzheimer's Society, Macmillan), the care home sector itself (for example, BUPA) or local authorities and primary care trusts. Sometimes researchers may need to be creative about sources of funding. For those doing participative research, especially those focused on improving practice as part of the research process (such as action research), funding can come from other sources. For instance, money normally used for practice development or education of staff could be used for research purposes too if the boundaries between research, education and practice are blurred. For example, both Ashburner's and Holman's PhDs were based on educational projects funded by continuing professional development monies. By using action research they were able to make improvements in practice by working alongside participants in the field and teaching them to use research to interrogate their everyday practice (Ashburner 2005, Holman 2007). In addition, staff might be encouraged to become co-researchers and register their own work for accreditation (such as professional doctorates, Masters of research). For instance, one care home manager has been inspired by the MHL programme and other research undertaken in her own home (the SomnIA project) and is now registered for PhD studies.

If researchers think creatively about problems in need of solution within the care home sector and are willing to work in partnership with care home providers to co-design the work, smaller scale work may be pump-primed by care home owners, with a view to accessing more traditional sources of funding for larger studies of wider relevance to others. For example, the MHL programme began as a small-scale project funded by Help the Aged to synthesise the literature on quality of life in care homes for older people. It was undertaken collaboratively by 57 academics from several universities through the National Care Homes Research and Development Forum (NCHR&DF) and led to BUPA funding the dissemination of its findings to 18,000 care homes.

Funders have specific requirements for research proposals. Doing research in care homes is complex – hence the need for this review. It is therefore important to build flexibility and contingency plans into costings in case things go wrong and explain carefully the reasons for this. Applicants may also need to carefully justify different research approaches. For instance, action research is not always seen as part of mainstream research, so helping funders to accept its legitimacy by providing recognised criteria by which it might be judged may be helpful (see, for example, Waterman *et al*. 2001).

The world of research can be very different from the everyday world of care homes and researchers should recognise the importance of 'giving something back'. For researchers to be accepted into care homes, they need to consider 'what is in it' for care homes. Care homes need to benefit from the research, either directly through taking part (such as action research) or indirectly through learning about the findings, once analysed. Members of staff are unlikely to be interested in, or find the time to read research findings if they are presented in a way that is inaccessible. Researchers may therefore need to ensure more creative approaches to disseminating findings. For instance, the MHL programme website contains resources that have been developed with the sector to share its research messages (www.myhomelifemovement.org/).

Another example of creative and accessible dissemination was research undertaken on the very sensitive topic of 'Managing Risk and Minimising Restraint in Care Homes' (Owen and Meyer 2009). Findings have been developed into E-learning resources (see http://www.scie.org.uk/publications/elearning/restraint/index.asp).

Researchers in care homes can often feel as isolated as those working in them. It is important to network early in the research process with others who have experience of doing research in care homes. The National Care Homes Research and Development Forum (NCHR&D) was established in 2003 to provide a platform for practitioners and researchers to network, share information and ideas. It provided the evidence base that underpins the MHL programme and remains an academic resource to the work. It also links with others doing research and development in care homes internationally. (To join this forum and meet others researching in this field, contact mhl@city.ac.uk.) The Emerging Researchers in Ageing network (ERA), part of the British Society of Gerontology (BSG), also welcomes students and early-stage researchers.

ETHICS IN CARE HOME RESEARCH

It is rightly held that social researchers working with human subjects should aim to conduct work which is ethically sound (Blaxter *et al*. 2001, Economic and Social Research Council 2010, Marshall and Rossman 2010), ensuring that the dignity, rights, safety and well-being of participants are protected (Department of Health 2005b). Another SSCR methods review cover this subject (see Woolham 2011). This section focuses on practical considerations when planning and implementing various stages of a study.

Ethics Committees

In accordance with the Department of Health's Research Governance Framework for Health and Social Care (Department of Health 2005b), any work that is conducted within either NHS or social care settings in England must be presented to a Research Ethics Committee (REC) operating under the umbrella of the National Research Ethics Service

(NRES) (http://www.nres.npsa.nhs.uk).* RECs provide an independent review of all research applications for work that involves human participants and/or their components (such as tissues and/or organs), considering all aspects of proposed participant involvement. If the study is not a clinical trial and nor does it include the collection of human tissue or involve access via the NHS, proposals can be presented to the Social Care Research Ethics Committee (SCREC) (http://www.screc.org.uk/index.asp). The SCREC is authorised to approve proposals involving people deemed to lack capacity under the terms of the Mental Capacity Act (Department of Health 2005a) and this may be relevant to much research in care homes.**

Additional considerations

A Criminal Records Bureau (CRB) check may be required for researchers. While not currently mandated by the National Research Ethics Service (NRES), an enhanced CRB check is required for anyone working in regulated activity with children and vulnerable adults, and increasingly ethics committees and the organisations where studies are being conducted may ask individual researchers to complete a check. An enhanced CRB check includes information on 'spent' convictions such as those gained as a minor, non-conviction information held on police record that is considered relevant to a given post, and a check against the Independent Safeguarding Authority's Children's and/or Vulnerable Adults list.

CRB checks will generally only provide the dates and names of convictions and any associated sentences. Excluding those offences which explicitly prohibit an individual from working with children or vulnerable adults, it is generally the responsibility of a requesting body to decide whether any disclosed conviction will affect the individual's ability to fulfil a given role (CIPD 2010).

As with submissions to a REC, making an application to the CRB incurs time and costs which should be factored into the planning of any project. The CRB currently states that it aims to return 90 per cent of enhanced checks in 28 days and standard checks within 10 days – although mistakes on the application can delay the process. Additionally, when recruiting researchers to work in care homes, the need for an advanced CRB check will need to be explicit in advertising.

Informed and ongoing consent

In both principle and practice, one of the most important aspects of an 'ethical' research undertaking is securing informed consent from all participants (Kenkmann *et al*. 2010).

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* The NRES was established in 2007 and fulfils the role previously undertaken by COREC. There are similar offices in Ireland (ORECNI), Scotland (SRES) and Wales, and the four work together closely in order to ensure that a UK-wide framework of standards is upheld.

All SSCR-funded studies are required to obtain ethics approval from SCREC as appropriate.

Informed consent may be defined as:

> the provision of information to participants, about purposes of research, its procedures, potential risks and alternatives, so that the individual understands the information and can make a voluntary decision whether to enrol and continue to participate (Emanuel *et al.* 2000, p.2703).

Cohen-Mansfield *et al*. (1988) suggested that the concept must encompass three important components: voluntariness, information and competency. Consider for a moment these features for people living and working in care homes. There is high probability that securing informed consent in such settings will demand that the researcher addresses factors associated with communication problems, physical and cognitive frailty, socioeconomic and/or emotional vulnerability and health impairments (Hall *et al*. 2009).

Gaining informed consent within care homes is a continuous process of information provision and renegotiation (see Dewing 2002, Evans 2008, Iliffe *et al*. 2008, Usher and Arthur 1998). It might need to take account of verbal or non-verbal cues and behavioural indicators as opposed to the traditional signature on a consent form. The need to re-engage with issues of consent over the course of a study demands a dynamic approach on the part of the researcher, such as the five-stage process consent model (see Box 2) described by Dewing (2002, 2007).

In the case of work that includes people who, at the time of involvement, have dementia or other conditions which may impair decision-making ability, researchers must also follow closely the regulations set out in the Mental Capacity Act 2005 (Department of Health 2005a).

Box 2: The Process Consent Model

Stage 1:	Background and preparation
Stage 2:	Establishing the basis for capacity
Stage 3:	Initial consent
Stage 4:	Ongoing consent monitoring
Stage 5:	Feedback and support

Consent forms

Consent forms and participant information sheets are traditional mechanisms by which a researcher provides information to potential participants and keeps an accurate record of who has agreed to involvement, with any qualifications that may apply. However, some of the literature explored for this review suggests that written consent is often not singly appropriate when conducting research with those who live or work in care homes. Hall *et al*. (2009) obtained written consent from residents of a care home for older people in the manner of ‘expression of interest’ forms which were filled in by potential participants only after a member of the research team had outlined the project’s aims and answered any resulting questions. However, when interviews began, ten people who had completed consent forms could not remember doing so. The interviewer needed to spend time with each person, reiterating the details of the study and ensuring participants had a reasonable understanding before continuing. Six further people were deemed, for unspecified reasons, unable to participate – despite completing consent slips - and were excluded from further involvement in the study.

It is not only residents for whom traditional examples of written consent might be inadequate. In an action research project that used mixed methods including staff observations and focus groups, Hockley *et al*. (2005) reported sometimes having to supplement the use of written consent forms with verbal agreement to take account of the dynamic, shifting composition of groups. Similarly, when accompanying and observing staff performing care work, having to explain the study protocol and obtain a signed consent form would be problematic and inhibit data collection.

For written consent forms it is worth paying attention to the formatting and presentation of these documents – especially in relation to a sample of participants composed of care home residents. Larger fonts and appropriate pictures may present information clearly and concisely (Ferreira 2009, Hall *et al*. 2009).

Who is consenting?

Care homes are communal environments where people will generally live, work and visit in close proximity. This can have an interesting effect on the issue of consent. Depending on the nature of data collection, researchers may be presented with potential data from people who have not directly agreed to take part in a study. Brown-Wilson (2007) described how some people (invariably relatives and staff) were happy to have the researcher present in public spaces but did not want to be observed themselves, or to have formal records made of their conversations. One might also consider who is the ‘target’ of research. If the topic is focussed on staff yet the researcher spends time observing the performance of care work are they then obliged to seek consent from residents even if residents will not in and of themselves be providing data?

Consent and participants with dementia or cognitive frailty

Researchers must increasingly make concerted efforts to ensure that the voices, attitudes and experiences of people with dementia are given due attention (Department of Health 2009a). This presents many challenges, not least surrounding the fundamental issue of ensuring informed consent (Warner *et al*. 2009). Dewing (2009) suggested that on one level, researchers may find it easier to restrict themselves to working with people in the earlier stages of dementia, not only because of consent issues, but also to ensure that participants themselves find their involvement meaningful.

Revisiting consent

As mentioned previously, consent should not be regarded as a static or singular state. People’s willingness to participate may vary over time and in accordance with personal circumstances (Dewing 2002, Evans 2008). Researchers may need to readdress consent every time they engage with participants, and will probably need to tell people that they are in the care home in the role of researcher, not just as an ordinary visitor or member of staff. The process consent approach mentioned earlier in this section makes allowance for the researcher to use physical props and cues to set themselves apart from care staff. This technique can prove particularly useful when trying to maintain meaningful consent from people with dementia. Dewing (2004) ascertained consent on an occasion-by-occasion basis by using repeated conversations with participants to secure they were happy to participate in specific research and data collection. This technique helped her to decide, for example, whether or not it was appropriate to video-record participants on a given day despite their previous consent. Additionally, Brown-Wilson (2007) set out a multi-stage process of seeking informed consent in care homes, one that encompassed verbal and written sources and was repeated at different stages in the project. She described adopting a form of 'researcher's uniform' by wearing the same sort of clothing on each visit and carrying a red folder to stand out from other visitors, and to help both residents and staff to recognise her over time. Significantly, she provided written information and supplemented this with face-to-face discussions with prospective participants. People were also able to offer different levels of consent, for example to be observed within public areas, but to opt out of a formal involvement in interviews or focus groups. While this is a conscientious and effective approach, it asks a lot of a researcher, especially one working on their own.

WORKING WITH GATEKEEPERS, GAINING ACCESS AND RETENTION

Each research project will have its own sampling design and 'sampling frame' ranging from just one to many care homes.

Understanding the hierarchy of management and ownership

When approaching a care home to participate in research, it is important to understand the hierarchies within that particular care home, who owns the home, who manages it, who makes decisions regarding access and whether that same person will actually be participating in the research. While managers of individual, independent care homes may relatively easily be able to decide whether to participate in research, this may not be the case for homes operating within larger care providers. It is often necessary to approach the company (i.e. BUPA, Methodist Homes for the Aged, Anchor, etc) in order to gain permission from the head office (head of research, head of ethics, etc), before approaching a care home manager. This approach can be time-consuming, involving several months and a number of meetings. However, it can be extremely positive, especially if good relations are formed at an early stage. Access to several care homes may be gained, and introductions to the care homes involved will be made by those within the company which can help to build trust. However, as found by Luff (2008, 2010), care chains may understandably prefer researchers visit their ‘best’ or flagship care homes, thus giving rise to a possible sampling bias. Alternatively, a care home manager may contact the necessary person within head office on the researcher’s behalf.

Communicating at all levels

Once a researcher has gained access to a care home, communication with all those potentially participating or in any way affected by the research should be a priority. The approach taken will be strongly influenced by the communication structure within the care home. For example, in the ‘SomnIA: Sleep in Ageing’ (www.somnia.surrey.ac.uk) project, a 12 week light-trial accompanied by intensive data collection, was undertaken in seven care homes. Initial introductions to the care staff, residents and families involved the use of posters and information packs/letters, as well as arranged meeting times where all those who wished to could meet the researchers. However, within each home, the level of communication that existed between management and staff, residents and families greatly impacted on staff preparedness for the researcher’s initial visits. In some homes, researchers visited residents over a period of two weeks, to familiarise themselves with the home and residents, and so the residents and staff could get to know the research staff and find out about the research. The process of communication in some homes was straightforward, with the manager highlighting the importance of the research and being enthusiastic about the involvement of staff. In other homes, there was very little communication between care staff and management and researchers spoke to members of staff individually. In homes with a high number of care staff, including bank and temporary agency staff, this was time-consuming and not always effective. Similarly, initial introductions with residents were most positive when facilitated by a known and trusted member of staff, particularly when entering a resident’s bedroom to meet them for the first time. Activities co-ordinators were often particularly supportive in this role. However, in any care home, time spent in a home prior to starting to recruit participants or any data collection helps establish good communication. This also includes communication with those who may not be able or willing to participate, but will be seeing the researchers around the home.

Respecting residents’ privacy and recognising place as home

Research in care homes differs to that undertaken in hospitals (for example) as it is undertaken within the residents’ own home. Within a communal living environment, there are, of course, some more public areas, and observing or meeting residents in these areas is generally socially acceptable to residents, staff and family. However, research may also involve spending time in the resident’s private spaces, usually their bedroom. It is therefore essential for research staff to recognise and respect this and ensure they have permission to be in them. Ellmers (2009, also see Luff *et al*. 2011) undertook observations and interviews with residents in four care homes as part of the SomnIA project. Observations were conducted in the communal areas unless she was invited by a resident into their room. Even in the communal areas observations could feel intrusive, for example if a toilet door had been left ajar, or a bedroom door was open when a resident was half-dressed. For those residents who do not use the public areas of the care home and for whom initial introductions may be within their rooms (possibly with the resident in bed), the vulnerability of the resident may be reduced by asking a family member or care staff to first ask for permission from the resident and then to make the first introduction.

Working with 'gatekeepers' as resource and research partner

Care homes research can appear challenging from the perspective of the number of 'gatekeepers' involved in gaining access to staff and residents. Residents, understandably, are the most protected group within a care home and researchers may need the permission and/or support of managers, care staff and family members in order to approach residents. However, while working with 'gatekeepers' requires time and a great deal of communication, it is also highly valuable to researchers, and, by reframing the role of 'gatekeepers' as research partners, the research can be enhanced.

Due to staff turnover, including managers, researchers undertaking research over a number of months may need to renegotiate access with changing 'gatekeepers'. For example, in the MCOP study some participants were recruited from a care home in which the manager changed three times over the course of one year. Researchers who had recruited residents and were being followed up six months later, as part of the method design, were occasionally refused access. This necessitated new agreements between new managers and the research team. This care home was experiencing severe difficulties, and for the managers involved, their day-to-day work took precedence over research.

Hall *et al*. (2009) described the process by which care home managers identified residents whom they deemed eligible for the study. This is not uncommon, with managers and care staff directing researchers as to whom they can and cannot approach. It is not only residents who are 'protected' or selected by staff, Fleming *et al*. (2008) found that gatekeepers in different homes varied significantly in their willingness to support negotiations between the research team and relatives. Some were very helpful and offered to arrange meetings or pass on contact details, while others refused to do this. There is a risk that the sample will therefore be biased, with the most able and possibly most 'positive' or 'compliant' residents being suggested. However, to ignore such directions from the managers and care staff undermines their role in safeguarding vulnerable adults in their care and also their wealth of knowledge about residents. Therefore, ensuring that managers and care staff fully understand what the research involves and therefore who would be able to, or interested in, taking part is essential.

Trust between researchers and participants is important in care homes research. This may extend to 'gatekeepers' being involved in approaching potential participants. For example, the Nurse Manager/Matron approached residents, staff and families in Brown-Wilson's (2007) study, thus indicating to potential participants that the researcher was trusted by the Nurse Manager. Staff may also provide a wealth of information as to how best to approach some residents, what time of day they are most alert, cues that suggest the resident is anxious or distressed, and topics a resident likes to talk about.

Gatekeepers can also provide an extra ethical layer. That is, they encourage the researchers to view the study from a different standpoint. For example, researchers may begin to think whether they would be happy for their own relatives to participate in such a study and what would make them feel more comfortable with doing so.

Recruiting residents with dementia can be particularly challenging (see Dewing 2009), because professionals, family and care staff can have different, and often strong, feelings about the participation of residents with dementia. Dewing (2007) argued that this should be expected because practitioners have a responsibility towards those in their care (as of course do others). Effective leadership within a care home, from a manager who is enthusiastic about the research, is therefore particularly valuable in terms of access for these vulnerable groups. Researchers should emphasise to gatekeepers that while the research is important and relevant, the immediate welfare of the resident is the priority and will remain so throughout the project.

Retention issues

Once participants have been recruited, retention can also be challenging in care homes, depending on the research. For example, Fleming *et al*. (2008) undertook a longitudinal study looking at falls in people aged over 90, including those who had moved into a care home. This involved recruiting residents that had previously taken part in a longitudinal survey, interviewing them and then also following up using, falls calendars, and telephone calls across 12 months. It was not possible to interview some residents as they could not be located, or access was denied by a relative or GP, or the resident was too ill, or the resident did not wish to participate. In some cases, proxy informants were used to gain data if the resident wished to participate, but was unable to provide accurate information. In some cases, ‘proxy’ information from key workers, matrons and family members was quite straightforward, with care homes aiding the requests for information directly or by supporting contact with relatives. However, in one instance the only ‘proxy’ was a new care assistant, and in others the care home staff did not pass on information to family members either because they refused to or they did not do so despite having agreed they would. By using these two different methods, both direct interviews and ‘proxy’ information, a good sample was retained; however, there was also some unavoidable data loss.

Other reasons for data loss, which should be anticipated, are resident death, resident illness, resident moving (for example, from a care home to a care home with nursing), staff illness and staff turnover. Less common, but needing to be anticipated, are management or care home ownership changes. In preparing for care homes research, these occurrences cannot be prevented or avoided. However, building in time and flexibility, as well as being realistic about sample sizes, is useful.

SPECIAL CONSIDERATION FOR DIFFERENT METHODS – PREPARING TO START RESEARCH

This section outlines a number of the special considerations that both novice and experienced social care and health researchers may need to bear in mind in a care home context. The fundamental questions about methodological applicability or the philosophical underpinnings of a method are not best answered here. These important questions are best addressed in the preliminary design stages of a project, by a researcher immersed in the reality of imminent data collection. Rather, this review can best serve as an introduction to key approaches and an appraisal of other people's experiences in their implementation.

Qualitative methods

Observations in care homes

Observations are an ethnographic method which may be used to study distinct social groups, and embedded cultural clues (Fielding 2001). Within the context of care homes, the method can offer unprecedented access to the daily machinations and minutiae of a residential environment (Bowling 2009). The proximity of a researcher (Britten 2006) undertaking observation to the experiences and routines of a given research population can provide levels of detail about 'physical and social dynamics' (Brown-Wilson *et al*. 2009), which may not be as effectively gleaned from other methods, such as surveys or interviews. The intensity of this research method can be problematic, and the researcher should be aware that people, especially those who live, work or visit complex environments such as care homes, may fear exposure. Kerrison (2007) encountered significant problems trying to recruit a sample of care home inspectors and when trying to follow up with potential participants about their disinclination to be involved, the researcher was met with comments such as 'over my dead body'. People intending to carry out observations in care homes may wish to make the aims and limits of their proposed project clear in any communication with potential participants, and ensure that any claims to confidentiality and anonymity are explicit.

By their very nature, observations take place in naturalistic settings, with the researcher playing as discrete a role as possible. In a care home context this means the researcher will need to be aware of the public and private spaces within a given establishment and the presence of people who may not be aware of/wish to be involved in the project. As noted above, issues of privacy and space are of importance in care homes. Brown-Wilson (2007) described witnessing incidences of personal care during participant observations which were carefully integrated into her study by using them to form the basis of discussions about relationships between care worker and resident. The novice researcher - or even an experienced one who may yet be new to the field of care home research - must consider how they will record, make use of and justify the inclusion of reports about such private moments.

It is likely that observations will need to take place over time in order to establish a clear and honest picture of experience and practices. This need for sustained access (Cooper *et al*. 2004, Hockley *et al*. 2005) has obvious connotations when conducting research within care homes, not least because of the mortality of residents. Additionally, the nature of staffing and employment within such environments may affect the researcher's ability to access a consistent sample, given the relatively high levels of staff turnover in some homes (Simonazzi 2009).

Observations as practitioner-researcher

Observations within a care home context are sometimes used by practitioner-researchers collecting data while working in such varied positions as care worker, nurse, or manager. The method can be described as the submission of a researcher into 'the daily round of petty contingencies' (Goffman 1961) to which they and their participants are subject. Accordingly, the approach, which sees the individual adopting a dynamic research role within a familiar work environment and conducting their observations from the vantage point of someone involved in day-to-day activities, makes distinct demands upon the practitioner-researcher.

Whilst participants' observations may be credited as allowing one to 'view people with their hair down' (Foner 1994), they also expose the researcher to a raft of potential emotional and practical issues. The principal researcher in Hockley *et al*.'s (2005) study of palliative care in care homes was a nurse practitioner and admitted concerns about entering a familiar field as a researcher. She describes deliberately dressing in her own clothes rather than a nurse's uniform, and wearing a badge that explicitly identified her as a researcher. Additionally, she reports making detailed field notes to reflect upon after data collection to prevent he professional assumptions from colouring subsequent analysis. Kydd (2008) highlighted her feeling of a 'clash' between her two roles of nurse and researcher. Again, she used critical reflection as a means of coping with and framing issues as and when they arose.

Interviewing in care homes

The qualitative research interview is a technique that dominates the fields of human enquiry. The interview, whether structured or unstructured, locates a participant and their divulged experience at centre stage (Bowling 2009) . An unquestionable strength of the interview as a research method is the mechanism it provides to hear the direct testimony of participants (Gubrium and Holstein 2002).

Timing and location of interviews

One problematic aspect that a researcher can encounter while interviewing in care homes is to do with location. A delicate balance must be struck between ease of access to resources (participants, staff support and space) and matters such as privacy or participant comfort. Hall *et al*. (2009) provided a useful account of their interviews with residents around issues of dignity and their reflection that 'seizing opportunities' was not always easy. As a visitor to the care home the researcher had to negotiate around the daily routine of residents in order to secure their participation. Appointments with GPs, visits from family members and meal times all impacted upon the interviews. Additionally, when interviews did take place, the researcher struggled to maintain the privacy of residents in an environment where bedroom doors were left open, or interviews were conducted in more public spaces, such as lounges.

Considering physical and cognitive frailty

Evans (2008) described her experiences of interviewing care home residents as 'encouraging and reflective' (p.5). However, these encounters were mediated by the physical frailty of participants. She had to be flexible enough to enable participants to take frequent refreshment breaks or to be completed on a different day. Similarly, Ellmers (2009) identified six common issues when interviewing frail residents about their sleep and night-times as part of the SomnIA project: resident fatigue; discomfort from sitting in the same position; pain due to existing health problems; hearing problems; dry mouth from talking; and poor-fitting dentures making speech difficult.

The importance of involving people with dementia in research and some of the challenges have been discussed above. However, once these matters are satisfied, how are data collected from such participants? This is not easy and in some instances researchers may find themselves unwilling or unable to make the trade-offs necessary to facilitate the involvement of people with dementia. Hockley *et al*. (2005) had originally intended to interview care home residents at end-of-life about their experiences. However, they found that many people in the potential sample had dementia, and despite securing consent from residents, relatives and staff, they decided not to continue interviews with residents, opting to talk to relatives instead.

Goodman *et al*. (2011) actively pursued the involvement of residents with dementia in their study and described a resource-intensive process (for both researchers and care homes) where staff supported participants with dementia during interviews. In addition to these occasions, staff also met with the research team to discuss the nature of the project and how to identify appropriate participants. In some instances they also contributed to negotiating consent with consultees. The research team highlighted that the time spent on these endeavours would otherwise have been spent on caring for residents. Researchers must therefore be constantly aware of the demands that a particular methodology or research population may make on the care home.

Quantitative methods

This section will focus mainly on forms of quantitative research within care homes which involve residents, relatives and care staff (including managers) to respond to written questionnaires or to questions asked by the researcher. These may be one-off questions or repeated over weeks or months in longitudinal or within-subject control trials. Even relatively short, simple and validated scales or questions may be complex to undertake in this setting and strategies for optimising data may be needed.

In all forms of quantitative research sample size is often a problem. The desired sample size in order to give statistical power or acceptability can be difficult to achieve. In care homes research, a common error is to greatly overestimate the response rate. This can occur at all levels of data collection, from sampling care homes as a whole, to residents, staff and family members.

Quantitative data

As already discussed, care home staff and managers often have a high workload, and participating in research may not be prioritised. Therefore, gaining a random or 'representative' sample of care homes, for a survey or to precede more in-depth research, can be challenging. A good example is the Personal Social Services Research Unit (PSSRU) report looking at measuring outcomes in care homes (Netten, *et al*., 2010). In this study, researchers gained a 35 per cent response rate from care homes for older adults. While a low response rate was expected, this was lower than the researchers would have liked. Repeated postal surveys can be better than web-based surveys as there is generally limited internet availability for anyone other than the manager and administrative staff, but they can have a varied response depending on what the survey is and who sent it. Surveys conducted 'in-house' by care chains or those supported by care chains may have a much better response if they are endorsed by management (see for example BUPA 2009). Researchers should avoid asking questions to which the answers are already available online (such as on the CQC website) as this is understandably seen as time-wasting.

There are no clear rules as to how to gain the best survey response from care homes, given that researchers seek varied responses on topics that may or may not appear relevant to the care homes themselves. However, as with many aspects of care homes research, the process will likely take time with numerous contacts, usually by different means (phone, email, post). For example, Sidell *et al*. (1997) conducted a postal survey of 1,000 homes in England on the subject of death and dying in care homes. A follow-up call was made to non-respondents two weeks later, followed by a reminder with a covering letter by post. In all, 412 homes completed the questionnaire and the researchers acknowledged the possibility of a skewed sample as those who did respond commented on how important they thought the topic was. Given the variation in response rates, researchers should prepare for a range of sample sizes in determining the power calculations and statistical analysis plan for care homes surveys. Acknowledging possible biases is also important; for example, Netten *et al*. (2010) provided a detailed outline of the response rates and characteristics of those homes that did and did not participate in their study.

In studies involving a smaller number of homes, sampling is still important. For example, researchers may wish care homes to be of a certain size, be owned privately, care for residents with particular needs, or follow a certain ethos. Again, it can be difficult to recruit care homes that meet the selection criteria, or indeed to gain something approaching a random sample. Therefore, the approach adopted is often to use a convenience sample set within a particular sampling frame (for example Kydd 2008, Luff 2008). Researchers should be aware that sampling bias is common in care homes research, with those homes with the more stable staffing, strong management and most focused on change more likely to participate than those with staffing shortages, weaker management or high management turnover, and lack or trust or ambivalence towards research and change. This is important in terms of the generalisability of findings.

Quantitative data and care staff

As discussed above, care home staff are predominantly female, often part-time, have varying levels of education, may have few or no qualifications, and may not speak English as a first language (see Hussein *et al*. 2009). Therefore researchers should prepare suitable materials for these groups. Long, complex questionnaires which are very culturally specific are unlikely to be completed. Questionnaires or structured interviews should be as short as possible, using clear language with a 'friendly' layout. Luff (2008) piloted research materials with a few care staff, to gain feedback and to get a realistic understanding of how long completion took. From this process, the wording of some items in her survey was changed and some items were removed. She was then able to provide an accurate idea of completion times on the information sheet given to staff.

Non-participation can be a problem as care staff are often extremely busy. In the experience of the authors, increased 'paperwork' within care homes also means that some care staff may prefer not to participate. Some staff are understandably cautious about taking part in research due to fear of criticism, personally and for the home. Researchers distributing questionnaires, especially on sensitive issues, should expect to spend time to gain the trust of staff and be easily contactable within the home and externally by email or by telephone. Distribution of questionnaires can also take some time. Unless there is a system within the home by which questionnaires can be distributed (such as during handover), researchers should expect to visit the home several times, including in the evenings and at weekends, if they wish to speak to every member of staff.

Validated questionnaires are most likely to have been tested for reliability with people who speak English as a first language, and often on those with a relatively high level of education. Researchers should therefore expect to re-assess any scales used for reliability and validity and make adjustments. For instance, Luff (2008) used the Emotional Labour Scale (Brotheridge and Lee 2003), an instrument that had been previously used and validated with a number of different occupational groups. After piloting the scale it was clear that the wording of some items was difficult for those whose level of English was not high. For example, when referring to emotions, the word 'display' was changed to 'show'. During analysis she found that some items were unreliable with this population, and some items were particularly problematic for those who did not speak English as a first language, including a question referring to how often staff 'hide your true feelings about a situation'. Missing data analysis is particularly helpful in seeking to understand which items were most commonly missed and by whom. 'Cleaning' data is time-consuming, but should be expected.

Alongside understanding missing data, sample bias among care staff should also be anticipated. Usually, participating care staff form a self-selecting group. Those who may choose not to participate could include night staff, those who work few shifts a week, those who do not feel confident with paperwork in general and those who find written English difficult. During data collection in one home, Luff (2008) distributed questionnaires to all day-time staff. The senior staff predicted very accurately who would and would not return a questionnaire, arguing some staff were just more dedicated and participated within the care home much more than others. Those who completed the questionnaire were most likely to go to staff meetings, attend training and help with fund-raising and trips. It was clear then that the sample was positively biased. Depending on the topic of the research, there is, as in all research, a tendency for those who have strong opinions on that topic to be most likely to participate, with those occupying the 'middle ground' or having no strong opinions, refusing.

The capacity of staff to complete questionnaires in terms of how much time they have is also reflected in return rates. Being aware of the quieter times within the home is helpful. When conducting longer term or longitudinal studies, turnover, holidays and ill health among staff should be anticipated.

Quantitative data collection and residents

Some quantitative data relating to individual residents can be collected using care home records, care plans, with help from care staff or by observations that are not intrusive to the resident. Relying on care home or medical records can still be complex as Fleming *et al*. (2008) found when looking at falls in care homes. Their approach was to fill in missing data by gathering information from as many sources as possible rather than relying on just one. Hooper (see Kenkmann *et al*. 2010) also aimed to use routinely collected data on nutrition and wellbeing, but found that these types of data were not actually so routinely collected as first assumed, making it difficult to compare across resident notes. It was also difficult to track down the notes of residents who had died or had moved over the study period.

Quantitative data involving residents answering questions or completing a test or task, such as the Mini-Metal State Examination (MMSE; Folstein *et al*. 1975), requires special consideration both in terms of undertaking this in a care home and the needs and abilities of the individual residents. Researchers should also think about the rationale and appropriateness of the questions or tests. For example during the MCOP study, the DEMQoL measure (Measurement of Health-related Quality of Life for People with Dementia), which asks people questions around whether they are happy, was used (Smith *et al*. 2007). Some other questions were concerned with quality of life measures. These included difficult questions to ask, such as 'do you feel worthless?' Therefore, the researcher must have the skills to assess the situation on an individual basis and make an ethical decision as to the usefulness versus potentially damaging effect of the question. This example demonstrates that quantitative methods ought not to be underestimated either emotionally or ethically.

While self-report scales and questionnaires are traditionally ‘quick and easy’ forms of data collection, this may not be the case when working with people living in care homes. Very few residents will be able to complete written questions themselves and a high proportion are cognitively and/or physically frail, and levels of sensory deprivation are high. For example, part of the SomnIA project, examined the sleep and activities of residents living in ten care homes (work package 3 www.somnia.surrey.ac.uk, see Meadows *et al*. 2010). Researchers completed daily sleep and activity diaries with residents who were able, by going into the home every day and ‘chatting’ to each participating resident. While in theory, this might take 10 minutes per resident, it usually took much longer, sometimes up to an hour as it was not possible, ethical or desirable, only to ask the listed questions and then leave, without spending time with each resident if they wished. This also had to fit around a resident’s routines and activities; and the timing of visits to each resident was planned the previous day where possible. Thus a short questionnaire could take two researchers most of the day to complete with 20 residents, and the residents and researchers built up relationships over the 14 days of data collection, which had to be considered when withdrawing from the study site.

Researchers should think about what they want to achieve from undertaking quantitative data collection, as there will be a risk of a biased sample of the less disabled or less ill residents as well as relatively small sample sizes (as in the diary data for the SomnIA project). They will need to assess if quantitative materials can be undertaken with the majority of residents, and if this may reduce or change the reliability or validity of the measures used. One possibility is to have varying levels of participation, so that nearly all residents can participate to a minimal extent (for example, by responding to questions based on how they feel right at that moment), to greater participation that only the more able residents may be able to complete. In the SomnIA project (Meadows *et al*. 2010) researching residents’ sleep, those wishing to participate but unable to complete daily diaries with researcher support were asked to wear a small motion-sensor on their wrist, like a watch. Even this minimal level of participation required researchers to visit participating residents daily to see if there were any problems and to ensure continued consent.

As with staff research, analysis of resident data is likely to involve missing data analysis and re-evaluating measures for reliability and validity. Longitudinal research projects should anticipate resident ill health, cognitive decline and death, and prepare for realistic sample sizes.

Any measures undertaken with residents in care homes should be piloted. Ideally, flexibility in adapting written materials should be built into the ethical approval in order to allow for changes to be made.

In conclusion, traditionally quick and low-effort quantitative data collection methods can require far greater levels of both time and staffing, often involving one-to-one time with residents and so can be more emotionally demanding, but also rewarding for both the researcher and the resident. Measures and scales that are already validated for other populations may well need adapting for use with care home residents; therefore, research staff should expect to be flexible and to make changes.

Quantitative data and family members

The most common methods of quantitative data involving family members are questionnaires, either written or verbally administered (these can be conducted by telephone). For example, Kenkmann *et al*. (2010) gave/posted surveys about food and drink to family members, providing them with a stamped addressed envelope. In terms of response rates, the same issues that affect any postal survey should be considered. However, thought should be given to the sensitivity of the topic and any possible distress it could cause. Again, sampling needs to be considered, both in terms of the sample size and who participates. Depending on the research, data from a family member may be important, or it may be the individual family member who is relevant (therefore there can be more than one per resident). If types of family or visitors are relevant (i.e. spouse, siblings, children, grandchildren all grouped separately) then sample size should be carefully considered. However, if grouping all family/visitors together, it is useful to acknowledge the heterogeneity of the group.

Reflections on participatory research

Participatory research is an approach to research, rather than a method. As the name suggests, it is a participatory process that involves those being researched in the research itself to varying degrees, from having a say in the design of the study to being a co-researcher and involved in all or many stages of the research process. Some forms of participatory research, for instance action research (Meyer 2000), are also concerned with engaging those being researched in attempts to improve practice (action) and making the focus of their research the lessons learnt from the process and outcomes of change (Meyer 2001). This form of research requires change-management skills, as well as research skills. Typically, although not always, participatory research is small scale and written up as a mixed-method case study. As such, it potentially makes those being researched more easily identifiable and therefore potentially more vulnerable. A trusting relationship needs to be established between those being researched and the researcher, and this requires those being researched to have more control over what does or does not get shared with others. This generally involves feeding back findings and inviting participants to comment on whether their ‘voices’ have been adequately represented and whether there are any changes that they would like to the way the research is being presented. Participatory research linked to action (action research) is an iterative process and at the outset of the study, it cannot be predicted what will happen as those being researched will inform its development. This means that researchers working in this paradigm cannot rely on traditional methods of informed consent. Instead the research needs to be done within an ethical code of practice with ground rules set at the beginning as to how participants are going to work with each other to protect each other from harm through the research process (Meyer 1993, 2003). The researcher also needs to write themselves into the account and to be aware of any emergent sensitive issues and their impact on the research. Reflexivity is an important feature of participatory research.

SPECIAL CONSIDERATION FOR PARTICIPANTS

As already discussed, research within care homes may add extra work to already burdened groups. It is therefore important, both for the care home and for building and maintaining good relationships with participants, for researchers to be as flexible as possible and to be sensitive to any disruption they may cause to residents and staff.

Good practice for residents, staff and family

Rigid data collection designs based on the researchers' needs, and not accounting for the culture and routines within each individual care home, are likely to increase stress within the home. More flexible approaches are important. For example, Brown-Wilson (2007) arranged data collection incrementally, allowing for an 'emergent design' based on the requirements within each care home and in consultation with care staff.

Some projects may require taking staff 'off the floor', spending time with the researcher that they may otherwise have spent working and this should be negotiated with the manager, senior staff and care workers. For example, Luff (2008) negotiated that staff interviews would be undertaken during the care home's time (i.e. while staff were on duty) and not during break-times or before/after work. This was understood and supported at all levels from the manager, senior staff/team-leaders and the care assistants.

For family members, flexibility in terms of location may be required. For example Brown-Wilson (2007) gave families a choice as to where they wished to be interviewed. Given that family members may also be aware of the resident and staff routines and busy periods, and so may choose to visit during 'quieter times', researchers should be aware that they may interrupt family members whether or not they are participating. In the SomnIA project, family members were informed of the research, although they did not participate and they were able to contact the researchers directly if they had any questions. Researchers avoided interrupting family visits and would time data collection around them if their visits were known in advance. Some family members encouraged the researchers to visit when they were there, possibly to also reassure them as to what was involved, and also residents wished to introduce research staff to their visitors. The relationship with family members was important even though they were not directly involved in data collection.

Flexibility of time – care home routine and staff busy periods

In care homes research, it is the researcher who needs to be as flexible with their time as possible, rather than the home. For example, in a current research project looking at end-of-life care for older people with dementia (led by Professor Gill Livingston, University College London, jointly funded by the King's Fund and Jewish Care), researchers have found that between 2pm and 5pm are the best times for staff to take time away from their shifts for interviews. Sometimes the researchers also undertook data collection at weekends, thus adding to the time taken for data collection. Night staff proved hard to recruit, and the researchers spent some late nights, up until 11pm, undertaking interviews so they could fit in round their busy periods. In general, researchers should expect to work outside of usual 9 to 5 hours in order to fit in with the 24-hour care provided within a home.

In more extreme circumstances, staff and/or resident illness may result in the research being delayed or having to take a break as the staff are under too much pressure, or even have to close the home to outside visitors, until an infection has been cleared (see Luff 2008). While these delays can be time-consuming and frustrating, working with staff during these difficult times and showing understanding for their situation are likely to be appreciated and help build positive relationships.

Researcher conduct and attitude

Researchers' conduct and attitude are essential aspects of building good relationships within a care home. While researchers may be experts in their particular field, staff, residents and family members are also experts when it comes to the care home, the needs and likes of the residents, and what is or is not acceptable within the home. Researchers may spend a substantial amount of time with staff, residents and family members in the course of the research. In order to build a positive relationship and to build rapport with these research partners, researchers need to allow plenty of time.

Researchers should maintain an awareness of their conduct and attitude and how they, and their research, may be perceived by those in the care home. For example, during early interviews with care staff on the MCOP Care Home study the researchers found that care staff could be anxious or even fearful, particularly as they are highly scrutinised and judged by regulators and the media. Some staff were concerned that they might not give the 'right' answers, as if they were being examined. By thinking about the experiences of care staff in terms of inspections and how care homes are often portrayed, research staff worked hard to reassure staff that they were aiming to gain an understanding of their work. Researchers were mindful of the potential interpretation of questions as being judgemental and adjusted questions and language to avoid distressing the participants. Building trust within a care home therefore takes time, and the ability to empathise with the perspective of those participating, in order to ensure their wellbeing.

Withdrawing from the field

As described on page 21, during the SomnIA project examining residents' sleep, research staff visited residents every day for 14 days in order to complete a sleep and activities diary. Although completing the diary only took 10 minutes, more time was taken with residents if they wished to chat, and researchers built some strong relationships with some of the residents. This made the research experience more positive for both the researcher and the resident. However, it could also involve high levels of emotion work from the researcher and made withdrawing from the care home occasionally difficult. Each resident was given a thank-you card at the end of data collection. Similarly, in another, more intensive research work package, as part of the SomnIA project, residents were each given a card and a gift at the end of the project, and, where it was possible, a small party was held, both at the half-way point and at the end of data collection in order to thank residents. In this way the individual contribution of each resident was acknowledged, and the researchers were able to show their appreciation for the time and effort residents had put into the project.

In a large-scale project such as SomnIA it was possible to organise a free workshop for care home staff and managers, so that participating homes could be informed about the findings from the research, as well as having the opportunity to provide feedback and meet staff from other participating homes to discuss policy and practice implications. On smaller projects, holding such an event may not be realistic. However, researchers should provide participating homes with some kind of feedback that is relevant and useful to that home. For example, Luff (2008) discussed with each of the five participating homes when analysis would realistically be undertaken and wrote an individual report for each home, feeding back some of the general themes relating to the emotion work of staff. This included reporting aspects that staff were already adept in, and where the homes provided good support, as well as the challenges staff struggled with, or areas where care homes could better support staff. For one small home, it was felt that individualised feedback could compromise staff confidentiality, so a more general report was provided. One care chain asked to be acknowledged in conference papers and journal articles and this has been done. In these ways, the care home staff and managers received continued thanks for their participation and felt included in the project, thus withdrawing from the field was not the end of the relationship.

Good practice for research staff

One aspect of care homes research which is vital to the wellbeing of the researchers is understanding and anticipating the emotional aspects of working in this environment. Good communication with staff and working closely with residents require excellent interpersonal skills, and both the rewards as well as the potential emotional cost to the researcher should be acknowledged, prepared for and supported throughout.

Awareness of own attitudes

Dewing (2009), in her review of research and development in care homes, found a paucity of literature relating to researchers' awareness of their own attitudes while undertaking research. While some described their experience within care homes, health-care settings or with vulnerable adults, they did not reflect on how this influenced their attitudes towards the care homes they were researching. Furthermore, Dewing stressed that researchers generally did not reflect on how others saw them and that there were no other accounts of the research experience, for example, by care staff. Researchers' attitudes influence how they frame their research, how they communicate and respond to residents, staff, managers and family members, and also their emotional reactions to the process of data collecting within care homes. Therefore, it is relevant for researchers to reflect on their attitudes and expectations prior to conducting research and also throughout data collection.

Allowing research staff enough time

In larger research projects, the lead investigators may well not spend much time within the care homes being studied as other staff undertake the data collection. This is common in research. However, there is a danger that senior investigators who are experienced in research but not in care homes research might underestimate the time needed to access homes, recruit participants and collect data. Allowing researchers enough time to undertake considerate, ethical research, without high levels of emotional stress or exhaustion is essential within the study parameters.

Challenging environments

Care home research presents a challenging environment for researchers. This review has highlighted the need for researchers to be flexible and accommodate their time and research around the care home as far as possible. However, the delays, 'dead time' spent waiting, wasted journeys, altered methods and adjusted timetables may be frustrating for researchers. Researchers must cope with the pressure of balancing the needs and realities of the care home with the requirements and time pressures of the research project (see Dewing 2009).

Distressing events

Probably one of the most difficult aspects of research within a care home is witnessing poor practice by staff, residents in pain or distress, or being told about distressing events by residents or staff. These situations can be both ethically challenging and emotionally upsetting.

In order to simplify this complex aspect of care homes research, two different 'types' of researcher can be determined. First, there are those with no care home experience, and without a social or healthcare background. Second, there are those with experience of working in care homes or similar settings (such as day centres). The former group of researchers may find observing aspects of frailty and dementia new and possibly intimidating or shocking. Their expectations may reflect the negative media surrounding care homes, or experiences of hospitals or time spent with older relatives. The second group may be more used to physical or cognitive frailty, but may also have experience and strong opinions on good caregiving and the care home environment, and find their role as a researcher in conflict with their role (past or present) as a practitioner.

Brown-Wilson (2007), when undertaking participatory research that included her being a ‘helping hand’ within the care home, ‘supportively intervened’ when she witnessed poor care. One example concerned a resident becoming distressed while having her nails cut. She suggested the resident might prefer to have it done later, but the care worker said there would not be time then. She offered to cut the resident’s nails later instead, and this offer was accepted by the care staff. However, in non-participatory research, and where researchers do not have experience as a care professional, this type of intervention may not be possible.

Dewing (2009) argued that the experience of ‘bearing witness’ may be particularly difficult for researchers. She noted her own complex feelings in relation to residents’ distress and how they were living. Even in ‘excellent’ care homes, residents can be distressed, disorientated, or have an accident, such as a fall. Researchers are likely to witness some situations which could be emotionally distressing. There is no particular way of preventing this, but rather, researchers and their supervisors should be prepared and have explicitly discussed a system of support for the researcher.

For any researcher, but particularly those without experience of working with frail older people, it may be difficult to distinguish abuse, or poor practice, from some of the most complex aspects of care, especially when working with residents with dementia. For example, in the MCOP study, the researcher had 25 years of nursing experience, but still found it difficult and even shocking when residents with complex cognitive needs ‘put themselves on the floor’. This was not falling, but an expression of the agitation felt by the residents. The staff were familiar with this regular occurrence and responded in a safe and humane way; they were working with exceptionally dependent residents, in difficult circumstances, and the care home was introducing a dementia care team, while also hiring extra staff. Therefore, what may have appeared to be a neglectful and chaotic situation to those who were unfamiliar with such complex needs within a care home setting required more balanced consideration. All researchers and their managers need to be aware of their responsibilities in respect of adult safeguarding and should clarify what their reporting systems are in cases where they suspect ill-treatment, neglect or abuse. The local adult safeguarding service can be contacted though the local authority.

Support and supervision

Students and junior researchers generally receive regular supervision but this may be academic and task-centred. However, in this context, more personally and emotionally supportive support should be available. Researchers working in a care home, especially those new to the caring environment, should have the opportunity to discuss their experiences and voice any concerns. It is important for researchers and managers to think about this ahead of the research. Similarly, if the researchers are working varied hours, including weekends and evenings, a point of contact should be available.

REFLECTIONS ON ANALYSIS

Analysis marks a unique opportunity to draw breath and begin the process of cleaning, reflecting upon, pulling apart and exploring in depth original data in order to answer the research questions. The specific techniques used in analysis will be shaped in part by the sorts of questions being asked, as well as the style of collecting and recording data – most obviously whether a methodology was qualitative or quantitative. Information about the practical aspects of analysis - for example, the use of software such as SPSS or NVivo, the treatment of raw data, any weighting which might be applied, and the impact of the researcher's epistemological frameworks – can be found in many of the available research methods guides. This section draws researchers' attention briefly to the sorts of issues relevant to care home contexts which might shape and affect their analysis, and which are arguably beyond the realm of an individual study design.

Whether it is a distinct phase occurring after a period of data collection, or an ongoing reflection in the ethnographic or constructivist traditions, data analysis undertaken by the researcher in care homes is invariably affected by their position, and points of view. It is important for the researcher to reflect upon their own experiences during fieldwork and the impact that these may have on the handling, viewing and interpretation of data. There is a real need for the researcher to acknowledge the unique context they will have been working in, their exposure to vulnerable populations (whether residents, relatives or staff), and the complex social environments that care homes undoubtedly constitute. In the previous sections we discussed some special considerations that researchers should take into account when working in care homes, and arguably these same topics apply to the ways in which data are handled during analysis.

The use of ongoing, concurrent analysis of field notes, interview transcripts and research diaries seems to be a common mechanism for guiding analysis among researchers in care homes. Brown-Wilson *et al*. (2009), Hockley *et al*. (2005) and Kydd (2008) have described how information from such sources informed their interpretations of data, and in some cases formed the basis of further work with care home staff and managers.

It is important for researchers in care homes to consider who they spoke to and who was omitted from research. For example, were people with dementia effectively involved if appropriate (Dewing 2007)? Given the mixed economy of care and the complex provision and funding of care places, are all types of provider accounted for? Siddell *et al*. (1997) selected large and small homes, in urban and rural areas, as well as for-profit and not-for profit homes in their study of palliative care, but this may not always be possible. Also some care homes can be oppressive and dis-empowering (Peace *et al*. 1997), so the researcher must consider whether data collection techniques allowed people to speak freely or feel empowered as research participants.

DISSEMINATING FINDINGS

This section will examine some of the issues particular to the dissemination of care homes research. The potential vulnerability of participants, the importance of non-academic dissemination that reaches those it could benefit, and being sensitive to the tone of dissemination to care homes will be addressed.

Dissemination of qualitative data usually involves quotes and/or field notes. The knowledge that quotes from their interviews could be made public can leave participants feeling vulnerable, for example, if a resident has criticised staff or if those working in the care home are concerned about a negative image being projected. Brown-Wilson (2007) had some concerns that residents may have been speaking to her as a visitor rather than a researcher. To ensure that all participants understood and were happy for their views and words to be used in dissemination, they were given a summary of what they had said, so that they had the opportunity to say if they felt they had been misrepresented or interpreted. Any quotes the researcher wished to use in publications were also included, so participants had the option for their own words not to be used.

Care homes research should be disseminated so that findings reach care homes, care providers, policy makers and the interested public. Ideally, time and resources for this non-academic dissemination should be built into a research project. While it is often not possible for researchers to organise workshops or conferences specifically aimed at older people, families, carers and practitioners, other forms of dissemination should be considered. Practice-based journals and publications outside of the researcher's usual academic disciplines (such as the *Journal of Dementia Care*, *Community Care*, *Caring Times*) can be used to target some practitioner groups. The MHL movement (as described in section 3.4) is an example of communication and practice-sharing with care homes. It may be possible for projects to link with MHL in order to disseminate directly to care homes. Groups and forums for care providers and care home managers such as the National Care Forum (representing not-for-profit care homes) and the English Community Care Association (ECCA) may also be interested in disseminating findings. Groups and charities representing older people, carers and relatives, such as Alzheimer's Society and Age UK, offer opportunities for communication with researchers.

Researchers should be aware of the tone of their dissemination, and how it may be received by different groups. They may need to balance an awareness of the negative images surrounding care homes with an understanding of the need for change. Criticism should be constructive and acknowledge any limitations of the research. Luff (2008) used a methodology that focused on the perspective of the care staff only. This was made explicit in the dissemination, and therefore any findings, while important and relevant to care staff and managers, did not represent the views of the residents or family members. A difference should also be made between research that establishes that a particular model or system is not working well and that which intervenes and tests a new model, as in action research.

CONCLUSION

This review has taken a broad overview of each of the steps of the research process, for qualitative, quantitative and participatory research within care homes, building on previous work (such as NCHR&D 2007, Froggatt *et al*. 2009). The review has highlighted some of the issues common to undertaking research in this area, providing examples of how researchers have responded to the problems that arose or were anticipated. Across the review there are three key points.

First, whatever the methodology that is being used, much can be gained by being familiar with and incorporating some of the philosophy of participatory or action-based research. By valuing the care home residents, staff and family members as research partners, developing relationships and being prepared to provide rapid and relevant feedback to care homes, not only can the research experience be enhanced for both researchers and participants, but the research could make a real impact, by being both useful to care homes and sensitively disseminated.

A second message is that it is not possible to prepare for every eventuality in care homes, although some can be anticipated. The cognitive and physical frailty of residents, heavy workloads of staff, high staff turnover, different managerial styles and varying opinions regarding research, all make care home research unpredictable. Flexibility is therefore necessary in care homes research, as is time. To be able to adapt and alter research methods or even questions is vital, as is giving researchers the time to work with participants, build relationships and make changes.

The final message is that the wellbeing of everyone concerned, including the research staff, should be central to research designs. Research in care homes is emotionally as well as ethically demanding. Researchers should therefore be supported in order for them to undertake research sensitively, to a high standard and without risk of burnout or emotional fatigue. Non-academic support and supervision are highly desirable for some studies, and could be built into a project from the start.

This review is unable to cover in detail all aspects of care homes research, or fully capture the many varied experiences of researchers. However, it encourages planning and careful consideration of methods in this essential area of social care research. By learning from the experiences of other researchers, the experience of care homes research can be improved for both the researchers and participants, enabling research that is not only of a high quality, but that continues to build on and develop relationships between the research community and care providers.

References

Ashburner C (2005) *Person-centred Care: Change through Action Research*, Unpublished PhD thesis, City University, London.

Blaxter L, Hughes C, Tight M (2001) *How to Research*, 2nd edition, Open University Press, Buckingham.

Bowling A (2009) *Research Methods in Health: Investigating Health and Health Services*, 3rd edition, Open University Press, Maidenhead.

Britten N (2006) Qualitative interviews, in Pope C, May N (eds) *Qualitative Research in Health Care*, 3rd edition, Blackwell Publishing Inc, Oxford, pp. 12–20.

Brotheridge CM, Lee RT (2003) Development and validation of the emotional labour scale, *Journal of Occupational and Organizational Psychology*, 76, 3, 365–379.

Brown-Wilson CR (2007) *Exploring Relationships in Care Homes. A Constructivist Inquiry*, Unpublished PhD thesis, University of Sheffield, Sheffield.

Brown-Wilson C, Davies S, Nolan M (2009) Developing personal relationships in care homes: realising the contributions of staff, residents and family members, *Aging and Society*, 29, 7, 1041–1063.

BUPA (2009) *First international Census of Care Home Residents*, BUPA, London. http://www.bupa.com/healthcare/ageing/care-homes-census

Care Quality Commission (2009) *Care Quality Commission (Registration) Regulations*, Care Quality Commission, London. http://www.cqc.org.uk/_db/_documents/CQCRegistration Regulations2009.pdf

CIPD (2010), *Pre-employment checks*, factsheet [online] http://www.cipd.co.uk/subjects/recruitmen/general/pre-employment-checks.htm

Cohen-Mansfield J, Kerin P, Pawlson G, Lipson S, Holdridge K (1988) Informed consent for research in a nursing home: processes and issues, *The Gerontologist*, 28, 3, 355–360.

Cooper J, Lewis R, Urquhart C (2004) Using participant or non-participant observation to explain information behaviour, *Information Research*, 9, 4, paper 184. http://informationr.net/ir/9-4/paper184.html

Davies S, Froggatt K, Meyer J (2009) Reflections on the way forward, in Froggatt K, Davies S, Meyer J (eds) *Understanding Care Homes: A Research and Development Perspective*, Jessica Kingsley Publishers, London, pp. 242–264.

Department of Health (2002) *Care Homes for Older People: National Minimum Standards*, Department of Health, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4054007.pdf

Department of Health (2005a) *Mental Capacity Act 2005*, Department of Health, London.

Department of Health (2005b) *Research Governance Framework for Health and Social Care*, 2nd edition, Department of Health, London. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

Department of Health (2009a) *Living Well with Dementia: A National Dementia Strategy*, Department of Health, London. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

Department of Health (2009b) *The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010*, Department of Health, London. http://www.opsi.gov.uk/si/si2009/draft/ukdsi_9780111487006_en_1

Dewing J (2002) From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have dementia, *Dementia*, 1, 2, 157–171.

Dewing J (2004) Concerns relating to the application of frameworks to promote person-centredness in nursing with older people, *Journal of Clinical Nursing*, 13, S1, 39–44. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2004.00925.x/full

Dewing J (2007) Participatory research: A method for process consent with persons who have dementia, *Dementia*, 6, 1, 11–25.

Dewing J (2009) Making it work: a model for research and development in care homes, in Froggatt K, Davies S, Meyer J (eds) *Understanding Care Homes: A Research and Development Perspective*, Jessica Kingsley Publishers, London, pp. 222–241.

EborallC, Fenton W, Woodrow S (2010) *The State of the Adult Social Care Workforce in England*, Executive Summary, Skills for Care, Leeds. http://www.skillsforcare.org.uk/research/research_reports/annual_reports_SCW.aspx

Economic and Social Research Council (2010) *Framework for Research Ethics*, Economic and Social Research Council. http://www.esrc.ac.uk/_images/Framework_for_Research_Ethics_tcm8-4586.pdf.

Ellmers T (2009) Methodological and ethical dilemmas of sleep research in care homes, in Ageing Body & Society Conference, July 19 th 2009, British Library, London.

Emanuel EJ, Wendler D, Grady C (2000) What makes clinical research ethical?, *Journal of the American Medical Association*, 283, 20, 2701–2711.

Evans CJ (2008) *The Analysis of Experiences and Representations of Older People's Health in Care Homes to Develop Primary Care Nursing Practice*, Unpublished PhD Thesis, King's College London, London.

Ferreira Z (2009) *Sex, Socialization, Status and a Sense of Self: Using the Identity Capital Model to Explore the Narratives of People with Intellectual Disabilities and Accounts of Sexual Relationships or Intimate Experiences*, Unpublished PhD Thesis, University of Nottingham, Nottingham.

Fielding N (2001) Ethnography, in Gilbert N (ed) *Researching Social Life*, 2nd edition, Sage Publications, London, pp.154–171.

Fleming J, Matthews FE, Brayne C (2008) Falls in advanced old age: recalled falls and prospective follow-up of over-90-year-olds in the Cambridge City over-75s Cohort (CC75C) study collaboration, *BMC Geriatrics*, 8, 6. http://www.biomedcentral.com/1471-2318/8/6

Folstein MF, Folstein SE, McHugh PR (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician, *Journal of Psychiatric Research*, 12, 3, 189–198.

Foner N (1994) Nursing home aides: saints or monsters, *The Gerontologist*, 34, 2, 245–250.

Froggatt K, Davies S, Meyer J (2009) Research and development in care homes: setting the scene, in Froggatt K, Davies S, Meyer J (eds) *Understanding Care Homes: A Research and Development Perspective*, Jessica Kingsley Publishers, London, pp. 9–24.

Goffman E (1961) *Asylums*, Doubleday, New York.

Goodman C, Baron NL, Machen I, Stevenson E, Evans C, Davies SL, Iliffe S (2011) Culture, consent, costs and care homes: enabling older people with dementia to participate in research, *Aging & Mental Health*, 15, 4, 475–481.

Gubrium JF, Holstein JA (2002) *Handbook of Interview Research: Context and Method*, Sage Publications, Thousand Oaks CA.

Hall S, Longhurst S, Higginson IJ (2009) Challenges to conducting research with older people living in nursing homes, *BMC Geriatrics*, 9, 38. http://www.biomedcentral.com/1471-2318/9/38

Hockley J, Dewer B, Watson J (2005) Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life, *Journal of Research in Nursing*, 10, 2, 135–152.

Holman C (2007) *Living Bereavement: An Exploration of Health Care Workers' Responses to Loss and Grief in an NHS Continuing Care Ward for Older People*, Unpublished PhD thesis, City University, London.

Hussein S (2009) Social care workforce profile: Age, gender and ethnicity, *Social Care Workforce Periodical*, Issue 2, Social Care Workforce Research Unit, King's College London, London. http://www.kcl.ac.uk/content/1/c6/06/89/16/SCWPissue2FINAL.pdf

Hussein S (2010) Pay in adult social care in England, *Social Care Workforce Periodical*, Issue 6, Social Care Workforce Research Unit, King's College London, London. http://www.kcl.ac.uk/content/1/c6/07/28/76/Hussein2010SCWP6.pdf

Hussein S, Stevens M, Manthorpe J, Rapaport J, Martineau S, Harris J (2009) Banned from working in social care: a secondary analysis of staff characteristics and reasons for their referrals to the POVA list in England and Wales, *Health and Social Care in the Community*, 17, 5, 423–433.

Hussein S, Manthorpe J, Stevens M (2010) People in places: a qualitative exploration of recruitment agencies' perspectives on the employment of international social workers in the UK, *British Journal of Social Work*, 40, 3, 1000–1016.

Hussein S, Manthorpe J (2011) The dementia social care workforce in England: Secondary analysis of a national workforce dataset, *Aging & Mental Health*, DOI: 10.1080/13607863.2011.596808, available online 21 July 2011.

Iliffe S, Manthorpe J, Drennan V, Goodman C, Warner J (2008) The EVIDEM programme: a test for primary care research in London? *London Journal of Primary Care*. http://www.londonjournalofprimarycare.org.uk/articles/934646.pdf

Kenkmann A, Price GM, Bolton J, Hooper L (2010) Health, wellbeing and nutritional status of older people living in UK care homes: an exploratory evaluation of changes in food and drink provision, *BMC Geriatrics*, 10, 28. http://www.biomedcentral.com/1471-2318/10/28

Kerrison S (2007) *Images of Protection in Nursing Home Regulation*, Unpublished PhD Thesis, London School of Economics and Political Science, London.

Kydd A (2008) The patient experience of being a delayed discharge, *Journal of Nursing Management*, 16, 2, 121–126.

Laing & Buisson (2009) *Care of Elderly People UK: Market Survey 2009*, Laing & Buisson, London.

Lee RM, Renzetti CM (1993) The problems of researching sensitive topics: An overview and introduction, in Renzetti CM, Lee RM (eds) *Researching Sensitive Topics*, Sage Publications, Thousand Oaks CA, pp.3–13.

Low Pay Commission (2009) *National Minimum Wage: Low Pay Commission Report*, The Stationary Office, London.

Luff R (2008) *The Emotion Work of Care Assistants Working with Older People Living in a Care Home*, Unpublished Doctoral Dissertation, University of Surrey, Guildford.

Luff R (2010) Forms of empathy of care home staff working with older people, *International Journal of Work Organisation and Emotion*, 2, 3, 302–316.

Luff R, Ellmers T, Eyers I, Cope E, Arber S (2011) Time spent in bed at night by care home residents: choice or compromise?, *Ageing and Society*, 31, published online: 28 January 2011.

Manley K, Hardy SE, Garbett R, Titchen A, McCormack B (2004) *Changing Patients' Worlds through Nursing Practice Expertise*, Research Report, Royal College of Nursing Institute, London.

Marshall C, Rossman GB (2010) *Designing Qualitative Research*, 5th edition, Sage Publications, Thousand Oaks CA.

Meadows R, Luff R, Eyers I, Venn S, Cope E, Arber S (2010) An actigraphic study comparing community dwelling poor sleepers with non-demented care home residents, *Chronobiology International*, 27, 4, 842–854.

Meyer JE (1993) Lay participation in care: a challenge for multi-disciplinary teamwork, *Journal of Interprofessional Care*, 7, 1, 57–66.

Meyer J (2000) Using qualitative methods in health related action research, *British Medical Journal,* 320, 178.

Meyer J (2001) Action research, in Fulop N, Allen P, Clarke A, Black N (eds) *Studying the Organisation and Delivery of Health Services: Research Methods*, Routledge, London.

Meyer J (2003) Stages in the process: a personal account, *Action Research*, 24–37.

Moriarty J (2011) *Qualitative Methods Overview*, SSCR Methods Review 1, NIHR School for Social Care Research, London. http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/2011/moriarty2011 qualitativemethods.pdf

NCHR&D (2007) *My Home Life – Quality of Life in Care Homes: A Review of the Literature*, Help the Aged, London.

Netten A, Beadle-Brown J, Trukeschitz B, Towers A, Welch E, Forder J, Smith J, Alden E (2010) *Measuring the Outcomes of Care Homes: Final Report*, Personal Social Services Research Unit, Canterbury. http://www.pssru.ac.uk/pdf/dp2696_2.pdf

Nicolson C (2009) *Living on Thin Ice: Facing the Future in Late Old Age*, Unpublished PhD thesis, City University, London.

Noble H (2010) *Opting Not to Dialyse: A Practitioner Research Study of Patient Experience*, Unpublished PhD thesis, City University, London.

Nolan MR, Brown J, Davies S, Nolan J, Keady J (2006) *The Senses Framework: Improving Care for Older People Through a Relationship-centred Approach*, GRIP report no. 2, University of Sheffield, Sheffield.

Owens T, Meyer J (2009) *Minimising the Use of 'Restraint' in Care Homes: Challenges, Dilemmas and Positive Approaches*, Adult services report 25, Social Care Institute for Excellence, London.

Peace SM, Kellaher LA, Willcocks DM (1997) *Re-evaluating Residential Care*, Open University Press, Buckingham.

Reed J (2007) *Appreciative Inquiry: Research for Change*, Sage Publications, London.

Reed J, Payton V (1997) Understanding the dynamics of life in care homes for older people; implications for de-institutionalising practice, *Health and Social Care in the Community*, 5, 4, 261–268.

Sidell M, Katz JT, Komaromy C (1997) *Death and Dying in Residential and Nursing Homes for Older People: Examining the Case for Palliative Care*, Report for the Department of Health, Open University, Milton Keynes.

Simonazzi A (2009) Care regimes and national employment models, *Cambridge Journal of Economics*, 33, 2, 211–232.

Smith S, Lamping D, Banerjee S, Harwood R, Foley B, Smith P, Cook J, Murray J, Prince M, Levin E, Mann A, Knapp M (2007) Development of a new measure of health-related quality of life for people with dementia: DEMQOL, *Psychological Medicine*, 37, 737–746.

Titman A (2003) The homeliness in care homes, *Working with Older People*, 7, 2, 30–34.

Usher KJ, Arthur D (1998) Process consent: a model for enhancing informed consent in mental health nursing, *Journal of Advanced Nursing*, 27, 4, 692–697.

Warner J, McCarthy R, Griffin M, Hill K, Fisher P (2009) Participation in dementia research: rates and correlates of capacity to give informed consent, *Journal of Medical Ethics*, 34, 3, 167–170.

Waterman H, Tillen D, Dickson R, de Konig K (2001) Action research: a systematic review and guidance for assessment, *Health Technology Assessment*, 5, 23, iii–157.

Woolham J (2011) Research governance and ethics for adult social care research: procedures, practices and challenges, SSCR Methods Review 4, NIHR School for Social Care Research, London.