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# A guide to research with care homes

Rebekah Luff, Anne Laybourne, Zara Ferreira and Julienne Meyer

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Dr Anne Laybourne, Dr Zara Ferreira and Professor Julienne Meyer, all based at City University London, London, UK.

## Abstract

**Purpose** – *A growing older population with complex care needs, including dementia, are living in care homes. It is important to support researchers in conducting ethical and appropriate work in this complex research environment. The purpose of this paper is to discuss key issues in care homes research including examples of best practice. The intention is to inform researchers across disciplines, leading to more sensitive and meaningful care home research practice.*

**Design/methodology/approach** – *Experienced care homes researchers were invited to provide methodological insights and details not already reported in their publications. These have been analysed, creating key themes and linked to project publications.*

**Findings** – *The need for reflexivity was a key finding. In particular, researchers need to: appreciate that the work is complex; see participants as potential research partners; and consider how cognitive and physical frailty of residents, staffing pressures and the unique environments of care homes might impact upon their research. Other challenges include recruitment and consenting people who lack mental capacity.*

**Research limitations/implications** – *As the care homes research landscape continues to develop and grow, there still remains limited reflection and discussion of methodological issues with a need for a “safe space” for researchers to discuss challenges.*

**Originality/value** – *This review is an updated methodological guide for care homes researchers, also highlighting current gaps in the mechanisms for continuing to share best research practice.*

**Keywords** *Older people, Frailty, Research, Skills, Workforce, Care homes*

**Paper type** *General review*

## Introduction

Older people living in care homes, including those with dementia, have historically been excluded from research (Davies *et al.*, 2014) and, compared to the wider gerontological research field, care homes are also relatively under-researched (Katz, 2011). In response to the paucity of research and the projected increase in numbers of people with dementia in need of residential care, together with the broader focus on integrated care; national mainstream funding bodies have now widened their scope to include social care research. As a result, in the last five years, there has been an increase in the number of research studies taking place within the care home setting, where the workforce is mainly social care (Gordon *et al.*, 2012). The NHS *Five Year Forward View* (NHS England, 2014), with its emphasis on new models of care and enhanced health in care homes, is likely to lead to even more research. The increased academic interest is clearly welcome and essential, as care homes are places where some of the most vulnerable citizens in society are being cared for. There are four times as many people over 65 in care homes in England, as in hospital beds, at any given time (Oliver *et al.*, 2014). Through research being conducted in care homes, we can learn more about the experiences of those who are frail (including those living with dementia) and come to better understand how to manage complexity at the end stage of life in a setting that little is known about. The research process itself also creates an opportunity for people living, dying, visiting and working in homes to be exposed to a wider range of perspectives and practices and may help them to feel more connected to and valued by their local community.

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Care homes are a unique, complex and heterogeneous environment to research. ~~Broadly~~, care homes differ substantially in terms of funding and workforce in addition to the diverse population living in them and are run as independent businesses. Approximately 90 per cent of care home provision for older people is supplied by voluntary and for-profit organisations (Allan and Forder, 2012). The workforce is also an important defining factor of care homes, as care work is poorly paid with many staff earning little over the minimum wage (Carr, 2014). Pay and responsibility structures creating a clearly defined career ladder are often absent with little opportunity for individuals to progress within either training or managerial roles or to specialise (Hussein and Manthorpe, 2012). Overwhelmingly, staff in care homes are female and around a fifth originate from outside the UK with large regional variations (Skills for Care, 2015), providing a rich and diverse workforce.

Given the complexity of the setting, it is important that researchers value and respect the work within care homes and appreciate the demands being placed upon them when considering a research project. NIHR felt this unique new frontier of ageing research might present challenges to the inexperienced researcher or to those more experienced researchers new to the setting and commissioned a methods review to share lessons learnt in the field of care home research. Key aspects of the NIHR review are reported in this review and, where available, literature from the research projects involved has been updated. Additionally this paper discusses the future of methodological innovations and developments in care homes and current gaps in the mechanisms for continuing to share best research practice. This paper is timely, as there is a risk that momentum following the original NIHR report will be lost and at this time of fast paced change emphasising the integration of health, social care and housing; it is vital that the research community build on and continue to develop research skills and relationships within care homes.

## Method

The original NIHR Care Home Methods Review (Luff *et al.*, 2011) had built on previous work (National Care Home Research & Development Forum, 2007; Davies *et al.*, 2009) and was undertaken in collaboration with the National Care Home Research and Development Forum (NCHRD) and My Home Life (MHL) programme ([www.myhomelife.org.uk](http://www.myhomelife.org.uk)). The NCHRD Forum provides a platform for researchers and practitioners to network, share information and ideas arising from their work. MHL is a collaborative initiative aimed at promoting quality of life for those who are living, dying, visiting and working in care homes for older people through relationship-centred, evidence-based practice. The NCHRD literature review identified items from the fields of nursing, health, medicine, allied health, social gerontology, social work and psychology. Synthesis of the literature focused upon the experiences of residents, family care-givers and staff in order to identify strategies which practitioners could use to enhance the quality of life in care homes (see Appendix 2 for further details on the methods used in the NCHRD review). The review involved contributions from 57 members of the NCHRD and is a key resource for understanding best practice within care homes. The NIHR Care Homes Methods Review began by looking at these NCHRD papers, together with more recent papers which had involved primary data collection in care homes, to see what the researchers had shared in terms of methodological lessons learnt in this setting. If the methods section was lacking in sufficient detail, items were excluded. Relevant articles were then read in full. While many studies alluded to methodological weaknesses in the study, these were not often detailed and failed to provide future researchers with enough information to avoid repeating mistakes or identify more successful approaches where multiple approaches were used. In general, there was little discussion by authors reflecting on the process of undertaking research in a care home setting. Most journal articles and reports were therefore inadequate for advancing the methodological knowledge-base. In the absence of much being written, the NIHR review took a unique approach and invited researchers and authors to provide methodological details, not present in their publications, about their experience of conducting the research which might be of help to others.

The team went on to take additional evidence from experienced researchers in the NCHRD Forum and MHL network, including contributors to the original NCHRD literature review and also the NCHRD authors of an edited book on research and development in care homes

(Froggart *et al.*, 2009), about some of the pitfalls they had encountered in engaging with research in this sector. Contributors were asked to provide more detailed methodological information and reflections about their projects, including challenges, obstacles and successes. These were provided in writing; usually via e-mail with permission from authors to use examples or an indication where they would rather issues were highlighted without reference to their specific project. These insights were linked to published research papers where permitted and possible, providing additional information to that in the public sphere. Further calls for contributions were made via MHL, the NCHRD and relevant online mailing lists (including British Society of Gerontology and British Gerontological Association).

The current paper both summarises the original review, providing a useful resource across a range of disciplines, as well as, updating some of the literature. Research projects which were recent or still on-going at the time of the original report have been revisited and peer reviewed articles published from these projects added.

## Findings and discussion

### *The researcher: experience and ability to be reflexive*

Research skills appropriate for care home work include an ability to relate to others, communicate effectively, empathise, make ethical judgments, remain flexible, be patient and importantly, to ensure that the well-being of the residents, relatives and staff are kept 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. 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 or supervisors. Consideration should be given to the researcher's experience of working in a care setting and with vulnerable groups, including people who may have serious physical and/or mental health problems, or disabilities.

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 (Gladman and Chikura, 2011; Robbins *et al.*, 2013), 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. Such complex settings may seem ideally suited to practitioner research, where the researcher has some experience of talking with people in this setting. However, it should not be assumed that practitioner researchers automatically have appropriate skills as these skills could be embedded within a profession or discipline, for example, being particularly medically orientated in communication styles.

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. These views could be informed by their own work experience, the media or more personal experiences of a relative moving into a care home. Awareness of these views and any hopes or concerns regarding the research process should be acknowledged. Reflexivity also includes researchers carefully considering how those living, dying, visiting and working in the care homes may view the research and the researcher. An example of good research practice is highlighted by the MCOP study. 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 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 in her action research within an NHS continuing care unit (similar to a care home setting). 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. However, by applying reflexivity and psychodynamic theory, Ashburner was able to tolerate hostility from participants in the study, keep them engaged and support positive change, resulting in care being delivered in a more person-centred way and staff enjoying their work more.

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. 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. Furthermore, 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. Since then, little has changed, with one key paper relating to reflexivity (Wilson, 2011), but little consideration is evident within standard publications. It has not been possible to determine if this reflexivity is absent in research projects, or under-reported and not published. Unless reflexivity is the topic of a paper, it is unrealistic that this level of detail be included in most journal articles, although project reports do provide more opportunity.

Related to the reflexivity of a researcher is their contemplation of their own, and others', ageing and disability. Some researchers have kept 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; Nicolson, 2009). 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 findings with issues raised by staff, she was able to compare her emotional experience and the care staff's. To support her in this demanding work, she was part of a work-based discussion group run by a psychodynamic counsellor and so was able to reflect on and process the emotional burden of care and use it as data, rather than feeling overwhelmed by it. 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.

### *Time and flexibility*

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 (2007) found preliminary fieldwork undertaken as a visitor to the care homes in her study necessary and extremely useful. 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.

Regarding the timing of conducting research in care homes, it is the researcher who needs to be as flexible with their time as possible, rather than the home. For example, in a research project looking at end-of-life care for older people with dementia (Livingston *et al.*, 2012; Jewish Care, 2012), researchers found that between 2 p.m. and 5 p.m. are the best times for staff to take time away from their shifts for interviews. Sometimes the researchers also undertook data collection at weekends, or late at night. In general, researchers should expect to work outside of usual nine to five 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 as the staff are under too much pressure, or may even have to close the home to outside visitors (Luff, 2008). While these delays can be frustrating, working with staff during these difficult times and showing understanding for their situation is likely to be appreciated and help build positive relationships.

### *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 is 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](http://www.somnia.surrey.ac.uk)) project, a 12-week light-trial accompanied by intensive data collection, was undertaken in seven care homes (Skene, 2009). Initial introductions to the care staff, residents and families involved the use of posters and information packs/letters, as well as arranged meeting times. 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. 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. In the Jewish Care (2012) project into end of life, the researchers found that even with management support, some staff were reticent to participate at the start but that; “Once people started having the 1:1 meetings, word of mouth was that it wasn’t scary, arduous or frightening, so more people agreed to participate”. Similarly, initial introductions with residents are usually 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. Time spent in a home prior to starting to recruit participants or any data collection helps establish good communication including with those who may not be participating, but will be seeing the researchers around the home.

### *“Gatekeepers” as resource and research partner*

Access to care homes can be challenging and involves gaining ethical approval, sometimes from more than one committee. There have been developments in building a network between care homes and researchers to prepare and support those involved in research (Enabling Research in Care Homes (ENRICH), [www.enrich.nihr.ac.uk](http://www.enrich.nihr.ac.uk)). Even once access to a home is established, there are likely to be a 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 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, 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, who were then followed up six months later, 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. Similarly, Fleming *et al.* (2008) found that gatekeepers in different homes varied in their willingness to support negotiations between the research team and relatives, even when the project was part of a well-established longitudinal study (the Cambridge City over-1975s Cohort). There is therefore a risk of selection bias within a sample, 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. Ensuring that managers and care staff fully understand what the research involves and so who would be able to, or interested in, taking part is essential. Gatekeepers may also be 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 helpful 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 preferred conversation topics.

Gatekeepers can also provide an extra ethical layer as 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, again relating to reflexivity. Recruiting residents with dementia can be particularly challenging (Dewing, 2009), because professionals, family and care staff can have different, and often strong, feelings about the participation of residents with dementia and this should be expected. 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 will be the priority 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 following up across 12 months. It was not possible to interview some residents as they could not be located, access was denied by a relative or GP, 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 gaining “proxy” information 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. By using both direct interviews and “proxy” information, a good sample was retained; however, there was also some unavoidable data loss despite these considerable efforts.

Other reasons for data loss, which should be anticipated, are resident death, resident illness, residents moving, staff illness and staff turnover. Less common, but needing to be anticipated, are management or care home ownership changes such as occurred in the MCOP study. 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.

### *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 and supported by the manager, senior staff and care workers. For family members, flexibility in terms of location may be required. For example, Brown-Wilson 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.

The issue of consent is particularly important in care home research. Residents especially may lack the capacity to consent to taking part in a research study. In such situations, researchers must work according to The Mental Capacity Act (2005) under which capacity should be assumed, unless established otherwise. Demonstrable steps must be taken to ensure the respondent can fully comprehend or retain information about the study. If it is assessed that



the person does not have the capacity to consent to the research, a Consultee (usually a relative) must be identified and if they cannot be identified, researchers must nominate someone else who can act in this capacity – a “nominated Consultee”. Consultees should be asked to consider whether or not the person who lacks capacity would want to take part in the study if they were able to consent to do so. Safeguards should be put in place to monitor the participant’s on-going consent and a resident should be withdrawn if they actively express discomfort or distress, or appears to not consent to research processes, regardless of any Consultee’s advice. For a good, brief guide to the Mental Capacity Act and research, please see [Social Care Institute for Excellence’s Fact Sheet for Social Scientists](#).

### *Withdrawing from the field*

During one work package of the SomnIA project examining residents’ sleep (Luff *et al.*, 2011; Evers *et al.*, 2012), research staff visited residents in ten care homes every day for 14 days in order to complete a sleep and activities diary. Although completing the diary only took ten minutes, significantly more time was taken with residents if they wished to chat, and researchers built some strong relationships with participants. This made the research experience more positive for both the researcher and the resident. However, it also 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, 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. For 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, 2010) wrote an individual report for each home involved in the study, feeding back some of the general themes relating to the emotion work of staff. One care chain asked to be acknowledged in conference papers and journal articles. 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.

### **Concluding remarks**

A strong message from this expert review 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, 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 original review was aimed at social care researchers and although it did include some more medical projects, there is a gap in the literature regarding how those conducting trials or interventions, which would typically use a far more rigid methodology, manage to balance data quality with the inherent needs of those living and working in care homes.

The well-being 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 be supported in order for them to undertake research sensitively, to a high standard and without risk of burnout or emotional fatigue. Support and supervision which is not just academic, but more pastoral in nature are highly desirable for some studies, and could be built into a project from the start. This review identified reflexivity as a key aspect of care homes research, highlighting some different examples where this was in place. More research in this area is needed as it is not clear to what extent this is undertaken. Currently, the term

“reflexivity” can appear rather vague, and may have different professional or discipline-specific definitions. A simple framework to guide researchers in being reflexive would be of value as a cross-discipline tool.

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 gerontological research. There have been advances in supporting care homes research, particularly the ENRICH website which includes helpful case studies of research undertaken in care homes demonstrating approaches researchers used. Looking to the future, it is hoped and anticipated that the methodological landscape of care homes research will continue to grow and develop. It is vital that expertise and developments are shared for the benefit of all. Currently there is not a widely-used mechanism by which this occurs and it is unrealistic to expect that journal articles can contain this level of detail. There are some examples of good practice in project report writing (see, e.g. Jewish Care (2012) report, Chapter 5), and methodological discussions are a requirement of some funding bodies. The level of detail and frankness varies greatly though and researchers may be more forthcoming with discussing challenges and problems they encountered in their research if it is not directly attributed to them. There is a potential need then for a safe space in which researchers can share ethical and methodological concerns without the usual dissemination channels. Given the range of stakeholders involved in care homes and the range of professions involved in the care of vulnerable older adults, research should reflect this variety as should the sharing of methodological developments and best practice. By learning from the experiences of other researchers, across disciplines, 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.

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