



**'Acting ethically is down to you' applying ethical protocols
in qualitative fieldwork in care homes**

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Table 1: Characteristics of the studies

Study	Study 1	Study 2
Researcher	XX	XX
Methodology	Case Study design	Appreciative Inquiry
Number of care homes	4	2
Care home types	Residential (2) With nursing (2)	With nursing (2)
Care home ownership	Not for profit (2) Private (2)	Not for profit (1) Private (1)
Care home location	Rural (2) Urban (2)	Urban (2)
Care home size:		
Number of residents	Range 24-38	90 beds (2)
Consent approach	Informed consent via information sheet, discussions and signing a consent form	Informed consent via information sheet, discussions and signing a consent form
Consent approach for those without mental capacity	Consultee declaration (family or close friend signing to say whether the person would have been likely to take part had they have had capacity to make the decision)	Opt-out consent, process consent and consultee declaration
Focus of observations	Management of dementia-related behaviours	Everyday decisions in care homes – residents with dementia
Observation participants	People living with dementia and care-home staff	People living with dementia, care home staff and care partners
Observer role	Participant	Non-participant
Total observation hours	384	72
Place of observations	Shared spaces	Shared spaces
Note taking	Covert - after observations	Overt - during observations

Interview participants	Care-home staff	People living with dementia, care home staff and family care partners
Number of interviews	37 (40 participants)	26 (30 participants)
Focus Groups	0	13 (between 3 and 8 participants per group)
Number of total participants	72	Up to 102
Reflection on observations	After each observation period	After each observation period

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Abstract

Purpose: Research ethics committees and ethical standards govern research. To conduct research involving participants, researchers must first gain a favourable opinion on their protocol from a research ethics committee. This article aims to promote researcher reflexivity and openness about applying agreed ethical protocols in practice.

Approach: Using examples from qualitative fieldwork in two care home studies, we critically reflect on the issues encountered when applying ethics committee agreed protocols in real-world situations.

Findings: Three areas of research practice are reflected on: 1) recruitment and consent, 2) approach to observations, and 3) research processes, shared spaces, and access to data. The interface between researcher and participant did not always mirror textbook scenarios. Ultimately, this left researchers accountable for taking ethically acceptable actions while conducting research.

Originality: Drawing on research experiences in care homes, we consider the reliance on the researcher to be authentic and morally driven over and above formal ethical approvals. We conclude that the researcher is the bridging agent between ethical protocols and ethical practice in the field. As such, researchers need to be open and reflexive about their practices in fieldwork.

Key words: ethics, ethical practice, care home, qualitative, interviews, observations, dementia

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‘Acting ethically is down to you’ applying ethical protocols in qualitative fieldwork in care homes

The ethical principles for medical research involving human subjects are guided by the World Medical Association Declaration of Helsinki (WMA, 2013). Whilst the Declaration is focused on medical doctors, it encourages researchers from associated professions to adopt the same principles, safeguarding and promoting the health of participants in health research. The declaration is supplemented with country-specific, government authorised guidelines and ethics committees (for example, in Australia the National Health and Medical Research Council (NHMRC, 2018) and in the United States (US) the National Institutes of Health (NIH, 2019)).

The United Kingdom (UK) Policy Framework for Health and Social Care Research outlines principles of good practice for health and social care research. Research can only commence once a suitable research ethics committee (REC) and other relevant approval bodies have favourably reviewed the full application (Health Research Authority, 2021^a). Processes for devolved nations may differ, however in England, the Health Research Authority (HRA) appraises and facilitates ethical health research and protects the rights of participants via REC review (Health Research Authority, 2021^b). Care home research proposals have the potential to involve participants who may lack mental capacity. These proposals must be presented to RECs flagged as able to review research involving adults unable to consent for themselves (Health Research Authority, 2021^a) and researchers are required to detail how their study will protect and maximise involvement of participants. The challenge for researchers is that it is not made clear whether care home studies should be presented to health or social care RECs. Researchers are encouraged to attend the ethics

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3 committee meeting to answer questions about their application. Participant recruitment
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5 can only commence once the protocol and study documents are agreed by the committee.
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8 Any amendments to processes, protocols and/or documents are re-reviewed and agreed by
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10 the committee. However, this process can never fully anticipate all the intricacies that may
11
12 emerge during the fieldwork process, particularly with qualitative research (Atkinson, 2009;
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14 Fahie, 2014; Israel, 2015). The researcher must continuously interpret ethical principles and
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16 make 'in-the-moment' decisions when confronted by unexpected circumstances in the field
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19 (Iphofen, 2013).
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24 Care homes are distinctive settings that create unique fieldwork situations (Luff *et*
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26 *al.*, 2015). The term 'care home' in England refers to residential services that provide 24-
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28 hour onsite care, with or without qualified nursing, that are registered with the Care Quality
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30 Commission (Care Quality Commission, 2021). Approximately 80 per cent of UK care-home
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32 residents are living with dementia or significant memory problems (Prince *et al.*, 2014;
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34 Thraves, 2016). Research conducted in care homes needs to adhere to the highest ethical
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36 standards due to the presence of such a potentially vulnerable population (Dickson-Swift *et*
37
38 *al.*, 2009). When recruiting to research in England, mental capacity (mental competence in
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40 the US context) is presumed for informed consent, unless there is evidence to suggest the
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42 contrary (Mental Capacity Act (MCA) (2005)). Where residents lack capacity, personal
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44 consultees: "Someone who knows the person who lacks capacity in a personal capacity who
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46 is able to advise the researcher about the person who lacks capacity's wishes and feelings in
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48 relation to the project and whether they should join the research" (Department of Health,
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50 2008; p 3) can be approached. Other countries have similar processes, for example, in the
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52 US regulations permit consent by a legally authorised representative, although federal
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3 regulations devolve authority to individual States regarding the definition of who can fulfil
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5 that role (Beattie, 2009).
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12 To date, research in care homes has enhanced understanding in multiple areas
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14 including end of life care (Amador *et al.*, 2014; Goodman *et al.*, 2015; Collingridge Moore *et*
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16 *al.*, 2019), care home cultures (DeForge *et al.*, 2011; Killett *et al.*, 2016; McCormack *et al.*,
17
18 2012), use of monitoring technologies (Hall *et al.*, 2017), and residents' experiences of
19
20 mealtimes (Watkins *et al.*, 2017). However, a review of care home research concluded that
21
22 the research base for improvements in the lives of care-home residents remains
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24 underdeveloped (NIHR, 2017). With clear scope for further research in care homes, it is
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26 imperative that we learn from past experiences, so that other researchers can prepare more
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28 comprehensively for research in these settings.
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35 Overall, there is a need for reflexivity in care home research (Luff *et al.*, 2015;
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37 Collingridge Moore *et al.*, 2019). For example, Hall *et al.*, (2009) advocate patience and extra
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39 time to overcome challenges in gaining consent from residents and ensuring privacy during
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41 interviews within care-home settings. Here, we aim to provide reflection on some
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43 unanticipated ethical aspects of health and care research in dementia care homes, these
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45 scenarios are seldom talked about, or reported but can add to discussions concerning the
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47 role of the researcher in the conduct of ethical qualitative research within care-home
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49 settings.
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54 **The studies**

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This article draws on the experiences of two researchers conducting qualitative research in care-home settings using observations, interviews and focus groups. Both researchers (XX and XX) were undertaking their doctoral work, and both had approximately 20-years' experience working in, and with, nursing and residential care homes. XX worked in care homes as a care worker and XX worked in and with care homes as a Registered Nurse(RN). Table 1 shows the characteristics of the two studies. We provide a brief description of each study before reflecting on the fieldwork experiences in relation to three aspects: 1) recruitment and consent, 2) approach to observations, and 3) research processes, spaces, and access to data.

< Insert Table 1 about here >

Study 1

This research aimed to explore the management of dementia-related behaviours in four care homes (Author *et al.*, 2014; Author *et al.*, 2016; Author *et al.*, 2018). The focus included pharmacological (psychotropic medications), non-pharmacological (for example, music therapy or distraction) and organisational (for example, monitoring) approaches. Social Care Research Ethics Committee (SCREC) reference number: anonymised.

Study 2

The aim of this study was to 1) understand the everyday decisions that people living with dementia and communication difficulties make and share in care homes, and 2) enhance how they make and share those everyday decisions with their staff and family care partners (Author *et al.*, 2018). Integrated Research Application System (IRAS) reference number: anonymised).

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Reflections on care home fieldwork

Recruitment and consent

Initial consent to access the care homes was gained from the manager, owner and/or organisation via a letter and discussion processes. In study 2, the care home's readiness to participate in research was assessed (Goodman *et al.*, 2017). Both studies used purposive sampling to recruit individual residents and care-home staff for observations, interviews and/or focus groups.

All staff participants in both studies provided informed consent. The staff consent process followed an introduction by the care-home manager. Staff were provided with study information, verbal and written, and offered time to consider their consent. Common to both studies was care-home staffs' lack of confidence. Several care staff appeared surprised that they would be asked to take part, particularly in interviews or focus groups where they thought they had little to offer. XX reflected on the balance between providing the reassurance that they had valuable knowledge and the possibility of coercion, particularly because there were few clear refusals to participating in Study 1. Instead, many staff members would evade the issue of consent. To manage this dilemma, staff members were only followed-up twice, since any further negotiations could have felt like coercion.

In Study 1, a resident with the mental capacity to consent said he was happy to take part but was not prepared to sign any paperwork. This aspect was absent in the ethical application and due to this the resident was not included in the research. On reflection, the ethical application could have included an additional option of verbal consent. For Study 2, different consent processes were used at different points in the study. Observations were used as a precursor to process consent, which enabled participants with fluctuating capacity

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3 to be included in interviews and focus groups. Process consent is a non-linear, five stage
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5 model where consent is continually sought and renegotiated (Dewing, 2007, 2008).
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8 Observations were undertaken on an 'opt-out' consent basis (Lawton, 2001; Martin, 2000).
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10 Whilst this is a recognised approach, and was approved by the ethics committee, there were
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12 situations where it was uncertain whether some residents with advanced dementia and
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14 severe communication difficulties could have opted-out if they were not happy to
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16 participate. This was not anticipated or made provision for in the ethics application. In these
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18 instances, observations were ceased in that area and no field notes were taken. On
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20 reflection, opt-out consent may not be appropriate for undertaking observations of people
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22 with advanced dementia. Exploring the appropriateness of research processes at protocol
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24 development stage and adapting processes to the target participants are lessons learned.
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30 *Approach to observations* Each study used a different approach to observations but
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32 both researchers ensured that all residents, staff, and visitors (participants and non-
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34 participants) were aware and accepting of their presence in the room before commencing
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36 observations and only wrote field notes about the topic under investigation.
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41 In Study 1, the role of 'observer as participant' (Gold, 1958; Junker, 1960) was
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43 adopted for the observations. This involved taking on small tasks in the shared spaces of the
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45 home for example, table setting, serving meals, and helping with activities such as the drinks
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47 trolley or crafts. This approach was chosen to facilitate researcher/participant relationships
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49 and provide some reciprocity to counter any inconvenience of the research, while also
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51 enabling researcher enough freedom to focus on and follow the most relevant actions
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53 within care homes as they unfolded (Bailey, 2007).
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Care-home staff were not familiar with having a researcher within the home. Due to researcher participation in some tasks, staff had different expectations of the researcher role and often asked help with tasks outside of the researcher remit. For example, staff members would ask for help transferring a resident (manual handling) and one offered access to observe a bath. This made necessary the frequent reiteration of the boundaries of the researcher role.

One difficult decision was about 'stepping in' or not: the conflict of potentially changing the data or allowing circumstances to unfold naturally. For example, one day a resident with dementia took another resident's mobility aid while they were walking across the room. Intervening to help the resident who was now unsupported was automatic, while staff members rushed to prevent any injuries; the resident who had taken the frame was swinging it near other residents. The priority was the wellbeing of participants and other people in the care home communities (Luff *et al.*, 2011). Residents' safety had to come first, regardless of the consequences for the data.

In Study 2, the research role was a non-participant observer (Fitzpatrick and Boulton, 1994). The role of non-participant observer was challenging, highlighting the difference between being an experienced RN and a novice researcher. Although professional status promoted credibility within the care homes, balancing professional accountability with adhering to ethical research protocols proved challenging at times. On one occasion, a male resident was excited to be going out on a trip but fell asleep in his wheelchair. The staff agreed to leave him sleeping and not take him out. The non-participant role became untenable, and I interjected [XX]. There were other occasions where not intervening felt uncomfortable as a practitioner. I did 'step-in' (for example, a resident calling for assistance with a drink) when

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3 the staff were busy; I remain bound by the Nursing and Midwifery Council (NMC) Code
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5 (2018). To promote transparency as a practitioner researcher, I made it clear that I was not
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7 assuming a clinical role, maintained detailed reflective diaries, and accessed regular clinical
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9 and academic supervision.
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16 *Research processes, shared spaces, and access to data*

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19 Although the care homes and their staff were accommodating in terms of offering
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21 quiet spaces to complete the interviews (and focus groups in Study 2), both researchers
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23 experienced frequent interruptions. For example, residents or staff would enter the room,
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25 call alarms and telephones would ring, or other staff would come in to consult the
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27 interviewee. This emphasised that the time care-home staff were participating in the studies
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29 was time away from residents. Other challenges encountered included: distractions,
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31 interruptions, background noise (such as radio, vacuum cleaner), abrupt endings to
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33 interviews (for example, due to arising needs of residents), and time limited interviews.
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35 Issues were predominantly overcome by being flexible, prioritising salient issues in
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37 interviews, and adapting to the time, place, and person in the moment.
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44 Participants were offered information about the studies several days prior to
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46 interviews and asked if they would like to participate. In Study 2, some of the residents
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48 living with dementia had fluctuating capacity and once they agreed to the study, they
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50 wanted to do the interview immediately. In these instances, the resident was given a paper
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52 copy of the accessible information leaflet (based on guidance from Pearl and Cruice, 2017),
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54 capacity and consent revisited throughout and open opportunities to ask questions and
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56 discuss the study. One such interview was cut short because of uncertainty that the resident
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3 fully understood a question. After ending the interview, a social chat continued to ensure
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5 that the resident knew they were valued as part of the research process (McKillop and
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8 Wilkinson 2004).
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11 A care partner in Study 2 agreed to all aspects of the study except voice recording
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13 the interview. As this had not been anticipated the interview only went ahead agreeing that
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15 detailed notes of responses would be an acceptable compromise. Although this worked well
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17 it did mean that the interview could not be revisited for clarification. This person was keen
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21 to be interviewed.
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24 Shared spaces in a care home are much like a shared space in your own home, not a
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26 'public' space, a term used by some researchers (for example, Martin, 2000). In order to not
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28 be intrusive and respect residents' privacy, observations were only conducted in the shared
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30 spaces within the care homes (lounges, dining areas, entrance halls and corridors) with the
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32 assent of the residents and staff. Both researchers were clear from the outset that they
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34 would only enter private spaces (for example, bedrooms, staff rooms) by direct invitation of
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38 the occupants.
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42 Study 1: Being in the care home environments meant that information about
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44 residents and staff members was encountered unexpectedly. For example, a nurse station
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46 had a whiteboard with information on, staff would verbally plan their next care task,
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48 conversations of a personal nature took place between staff and residents, and handovers
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50 would discuss each resident in detail. Sometimes private actions occurred in shared spaces.
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52 For example, one day a resident took off their incontinence pad in the lounge. Via these
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56 avenues, awareness of sometimes intimate details about residents personal or health
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3 statuses became apparent. Care was taken not to document information about non-
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5 participants, or which were not relevant to the study topic.
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9 For Study 2, the ethics application did not include access to residents' files to obtain
10 demographic information. When asking a member of staff for information about a resident
11 in one of the homes, she offered the resident's file. There was no ethical clearance in place
12 to access residents' records so looking up this information independently was not
13 acceptable. As a result, staff took time to answer demographic questions about residents
14 who had given consent. On reflection, requesting ethical approval to access residents'
15 records and including it in consent processes would have reduced the time impact on staff.
16 Taking staff away from resident contact to complete additional paperwork seemed unfair.
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29 **Public and Patient Involvement (PPI)**

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32 Reporting PPI is important (Staniszewska *et al.*, 2011), Study 1 used PPI to examine
33 and test fill-in a survey in a separate phase of the research. The research questions and
34 study design of Study 2 were reviewed by PPI with specific suggestions incorporated into the
35 study design and outcomes fed back (Mathie, 2018).
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42 **Discussion**

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45 Conducting qualitative research in care-home settings requires researchers to be
46 ethically driven individuals. Drawing on first-hand examples from fieldwork conducted in
47 care homes, we have examined dilemmas of applying ethical protocols in real-world settings
48 (Hammersley, 2009). In doing so, we have captured seldom reported experiences, which
49 demonstrate that situations do not always reflect prior expectations and ethical conduct
50 relies on the researcher's inner moral compass as well as formal ethical approvals.
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3 Atkinson (2009) highlighted the risk that strict regulatory ethical guidelines could
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5 lead to researcher deviance and reports of 'half-truths' about their ethical conduct.

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8 However, there is a scarcity of literature discussing the everyday experiences of researchers,
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10 particularly in care-home settings, possibly due to researchers perceiving 1) that there may
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12 be risk in exposing their actions, which could be viewed as ethically ambiguous in some way,
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14 or 2) they may jeopardise future ethics applications, despite demonstrating a proactive
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16 approach and awareness for ethical research. Consequently, ethical challenges in relation to
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18 enacting regulatory approvals, remain largely unexpressed.
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24 Since, navigating unanticipated scenarios proved commonplace, we argue that
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26 preparation for fieldwork is key, particularly in complex systems such as care homes.
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28 Articulating that preparation in the study protocol is essential in order for a REC to make a
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30 judgement about the proposal. However, it is unlikely that any researcher, however
31
32 experienced, can anticipate all possible challenges (Hammersley, 2009; Israel, 2015).
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34 Additionally, applying for ethical amendments to study protocols and documents can be
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36 challenging within short study timelines, leaving researchers with limited options for
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38 flexibility in the moment and limited feedback processes for ethics committees. With these
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40 factors in mind, we propose that researchers take additional time to prepare
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42 comprehensive ethical applications with elements of inbuilt flexibility (for example, options
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44 for participants to provide written or verbal consent). We recommend working closely with
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46 relevant patient and public involvement groups in designing ethically driven study
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48 applications. Consulting such representatives in developing study processes could mitigate
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50 future ethical dilemmas.
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Authentic ethical research requires more than unthinking conformity to an ethics committee approved protocol (Dickson and Holland, 2016; Iphofen, 2017). Ethical protocols and procedures are imperative; however, researchers need the skills to uphold moral and social values as well (Resnik, 2020). Responsible researchers need to attend to subtleties that would not be specified in a research protocol. The lived ethical experience of research practice can be different to that of regulatory board discussions. Despite committee reviews of both studies being thorough, rigorous, and well informed, and the process contributing to the preparedness for fieldwork, past experiences and individual inner moral compasses were relied on at times, to decide how to proceed in the field. Ongoing training in autonomous ethical practice, responsible decision-making and critical skills could better prepare researchers for virtuous practice (Iphofen, 2016; Iphofen, 2017).

In assessing applications for ethical approval, health and/or social RECs are evaluating not only the rigour of the study protocol, but also the ethical prowess of the principal investigator, the wider research team and organisation (Iphofen, 2016). It helps to view the ethical approval process positively as a safeguard to protect people participating in research and researchers. Ethics committees have much expert experience to draw on and can be incredibly useful during the ethical approval process. However, Hammersley (2009) argues that it is impossible for REC members to have a comprehensive understanding of how all selected methodologies may be applied in specific environmental contexts, or how the research design might need to develop as part of an iterative process. It is therefore essential for researchers to have a sound understanding of those underlying contexts to be prepared to react to events effectively.

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3 Sharing examples and experiences is important to contribute to discussions about
4 ethical practice in care home research (Luff *et al.*, 2015). Every care home is unique, but
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6 these examples from six care homes across two studies serve to illustrate trends that other
7
8 researchers may find useful when designing or conducting their own care home fieldwork.
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10 We advocate extending the recommendation that researchers should be open and reflexive
11
12 about their fieldwork decision-making (Luff *et al.*, 2015), to include unforeseen ethical
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14 challenges encountered in the field. We recommend including regular clinical and academic
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16 supervision time (as appropriate) to reflect on exposure to, and management of, ethically
17
18 challenging situations.
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26 Care-home residents and staff have previously been labelled 'difficult to research
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28 groups' (Hall *et al.*, 2009; Zermansky *et al.*, 2007). But including the voices and experiences
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30 of care-home residents and staff is key for improving services (Backhouse *et al.*, 2016;
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32 Hellstrom *et al.*, 2007). Our experiences reinforce that there is no single right way to
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34 conduct research in care homes. Some proponents argue that research ethics procedures
35
36 and protocols have become too formal (Haggerty, 2004). Research governance frameworks
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38 and infrastructure are largely underdeveloped in social care. Ethical protocols, therefore,
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40 play a pivotal role in social care research accountability. A balance is needed between
41
42 conducting care home research that is ethically sound, and not creating additional barriers
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44 to involving this unique group of people in research by further constraining complex
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46 qualitative research with ethical criteria (Hammersley, 2009).
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53 Our experiences suggest that the researcher is the bridging agent between the ethically
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55 approved study protocol and the wellbeing of participants. This interface invariably depends
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57 on the researcher making decisions in how to proceed and conduct themselves throughout
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3 the research process. All social research is inherently biased by the positioning of the
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5 researcher (Bushe, 2011). Researcher 1 has extensive experience in care homes as a care
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7 worker and Researcher 2 is an RN, professionally accountable to the NMC. Professional
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9 history impacted on ethical decision-making, with professional and/or experiential norms
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11 framing perspectives, actions, and interpretations of fieldwork events. However, similarities
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13 were noted across studies that appear unrelated to professional socialisation or culture.
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22 Our experiences are consistent with other reflections on care home research, in that
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24 that there is an emotional impact on researchers contending with the weight of ethical
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26 judgements on their shoulders (Lee-Treweek, 2000). Ethical practice in research is a
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28 relational process which requires continuous rethinking and adjustment (Ward and
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30 Campbell, 2013). Developing relationships with senior staff members (or gatekeepers) at
31
32 each care home was a key facilitator in assisting access to staff and residents. Gatekeepers
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34 of research sites need to be approached with care (Holloway *et al.*, 2010). They can help or
35
36 hinder access to research participants, which in turn has a positive or negative effect on
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38 data collection and emotional resilience (Spacey *et al.*, 2020). Expectations and perceptions
39
40 of the researcher role can vary between participants and the researcher themselves, making
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42 skills in developing personal relationships key. We believe that interpersonal skills
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44 developed over years as practitioners combined with previous experience in similar settings,
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46 facilitated relationship building and increased transparency, credibility, and trust.
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54 **Conclusions**

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57 Comprehensive planning in gaining ethical approval for research is paramount in
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59 preparing fieldwork processes. However, inevitably, unforeseen circumstances will be
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3 encountered in the field and these have to be tackled by researchers as they happen.

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5 Health and social care researchers must be vigilant, trustworthy, and ethically astute over
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7 and above formal ethical approvals, since during fieldwork they must rely on their own
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9 moral code to make ethical decisions. Reflexivity about fieldwork experiences can allow
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11 researchers to share knowledge to promote learning and further develop ethical
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13 proficiency. Ethical research requires continuously discussing and reflecting on fieldwork
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15 experiences and decisions in order to analyse and reassess ethical decision-making and
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17 enhance practice. Ultimately, as a researcher, acting ethically is down to you!
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