

Addendum to Project Proposal Dementia Friendly Communities in Care Homes (Kinectons)

Addendum relates to Phase 2 of Project- Inclusion of Adults with Incapacity

Ethical approval for Project ID 4257 – Kinectons Strengthening Community in Care Homes- was granted by UWS School of Health, Nursing and Midwifery Ethics Committee in February 2018. An amendment to this submission was approved in June 2018 in order to gain approval for Phase 2 of the research study.

(Original and Amended Versions attached).

The Project Team would like to request approval from the Scotland A Research Ethics Committee to include adults with incapacity in Phase 2 of the study, with a proposed start date of August/ September 2020 if possible to access care homes at this time.

Inclusion of Residents in Care Homes who do not have capacity to give consent

Approximately 36.5% of people living with dementia in Scotland reside in care homes (Goodman et al., 2011). This study is exploring the topic of dementia-friendly communities in care homes, and thus it is the position of the project team that it is imperative to include residents, both those living with dementia and those without a diagnosis of dementia or other cognitive impairment in order to fully explore how to enhance a dementia-friendly community experience for all who live in care homes.

Areas of the Experiences of Persons with Dementia (adults with incapacity) of Interest in this Study include:

- Other people getting to know me and learning my language, for example my expressions of personal preferences (for those who no longer have access to verbal communication)
- Opportunities for connection with others in my day-to-day life
- Ways in which I contribute to the community around me
- Ways in I am supported by and support other residents in my community

The ways in which data will be collected using a social- participant as observer approach (Cowdell, 2008) which will involve the researcher observing residents with incapacity during the residents' relational interactions or activities; the researcher will at times also involve

themselves in these interactions or activities, for example by joining in a conversation or participating in an art activity.

Further description of both these methods will be outlined in subsequent section 'Approach to Data Generation'.

Why the Research Team wish to include adults with incapacity?

The intention of including people with dementia who lack capacity in this study is to ensure that their day-to-day experiences in a communal context are explored to discover how they experience their community in a care home. Inherent in the inclusion of people with incapacity is a desire to enact a basic shift in power inequalities, to challenge the assumption that people with incapacity are unable to share their views and experiences and to ensure that the most marginalised of voices of experience are heard and represented in their communities.

There is now a recognition that research into the experiences of people with dementia should move away from the biomedical model and that ethically sound research with people with dementia is possible, including into the later stages of the illness (Norman, 2006; Cowdell, 2008; Scottish Dementia Working Group Research Sub-group, 2014). This study is seeking to develop a deeper understanding of the concept of dementia-friendly communities in care homes as it is experienced during the various stages of people's dementia journey.

Building on the Findings thus Far

Data generation for Phase 1 of this research study began in February 2018 and so we have had the possibility of gathering perspectives of residents who do have capacity. Owing to the significant percentage of residents living with dementia who do not capacity the research team feel it is imperative to include this group in order to gather the fullest possible picture of enhancing the care home community experience for people at all stages of their dementia journey.

Approach to Data Generation

As has been outlined observation will be the data generation method which will be used with people who do not have capacity to give consent. The social- participant observation approach, whereby the researcher is involved in social, rather than clinical activity (Cowdell, 2008) will be used. The observation will also include adults with capacity, who are in the social space of the person without capacity who is being observed. Adults with capacity will have given their prior consent to being involved in the observation. Adults with capacity participants in this social observation may include: care home staff, visiting relatives and friends, creative practitioners, health and social care professionals, inspectors or local authority staff visiting the home, They will be observed for the purposes of gathering information on the variety of ways people engage and interact with people with dementia.

The choice of these methods have been informed by the work of Watson (2015) in her study of relationship-centred care for people with advanced dementia until the end of life in care homes. Whilst this study is not positioning itself as an ethnographic study as is the case in Watson's research, the research team will draw on the learning generated by Watson (2015).

The use of a social- participant as observer approach in this study draws on the literature which suggests that participant observation is a method which allows researchers to gather rich data of the in-the-moment experiences, and capture the variability of these experiences (Patterson and Morin, 2012 and Nygard, 2006). The richness of the data is also demonstrated through the capacity of participant observation to generate learning on human experiences such as friendship, humour and empathy (Wu et al., 2015).

Selection and Recruitment of People Living with Dementia

The care home manager will be approached in the first instance to identify potential residents for recruitment to the study. The care home manager may also involve key members of staff who have close relationships with residents and an understanding of how they convey emotions such as enjoyment or upset.

Recruitment of Adults with Incapacity

It is proposed that up to five residents with a diagnosis of dementia, who do not have the capacity to give consent, will be recruited from each of the care homes (n=15 care homes).

Those residents recruited will have had established lack of capacity with the relevant Adults with Incapacity (Scotland) Act paperwork in place.

1. Researcher engages with care home manager and staff to identify possible participants
2. Letter sent by care home manager/nominated person to welfare guardian/relative/friend informing them of the study and requesting they get in touch if they would like to hear more/consent for the resident to become involved. Please see 'Invitation Letter'.
3. If/when welfare guardian/relative/friend responds they are invited to have a conversation with researcher for further description and discussion about the study, and their perceptions of whether the resident would like to be involved. They are also offered a copy of Information Sheet and Consent Form.
4. Following written consent being obtained in line with the Adults with Incapacity (Scotland) Act, further principles as outlined by Alzheimer's Scotland (2000) will also be followed. These are:
 - (i) Whatever the degree of dementia, the person with dementia should be made aware, as far as possible, of what will be involved.
 - (ii) if the person with dementia is not willing to participate then he or she should not be recruited to the research project (even if it is a relative's wish that they participate).

Selection and Recruitment of Adults with Capacity

The researcher will liaise with the Care Home Manager to identify the people with capacity most likely to be in the care setting during the period of observation.

This will involve looking at staff schedules, planned social events, and booked visits from health and social care professionals, inspectors and local authority staff.

Recruitment of Adults with Capacity

Prior to commencing data generation the researcher will have spent time in the care home

Following consultation with the care home manager the researcher will recruit up to a maximum of:

20 members of care home staff

10 visiting family and friends

10 creative practitioners, health and social care professionals, inspectors, local authority staff

Data Generation

Up to 15 people living with dementia who do not have capacity to give consent will be recruited to the study.

As has been outlined, observation will be used as the data generation method in this study. Prior to the first period of observation with each of the residents recruited, the researcher will liaise with the care home staff, and other relevant people where appropriate, to discuss ways (verbal and non-verbal) in which the resident expresses positive emotions as well as feelings of disinterest, discomfort or distress.

The researcher will carry out a maximum of 5 observations per person over the course of 3 months, with the average observation expected to last between 5-15 minutes.

Approach to Observation Activity

The researcher will be guided in their observation activity by the Quality of Interaction Schedule (Healthcare Improvement Scotland, 2012) and Caring Conversations Framework (Dewar, 2011).

Quality of Interaction Schedule

Developed for use in the acute hospital setting, this tool offers guidance for inspecting (observing) acute care of older people. This tool was chosen as it focuses on interactions between people.

This Schedule outlines a range of different areas which can be used to inform assessment of care being offered is person-centred- these areas include dignity and respect, communication and decision-making.

The following is an example of some prompts from the Schedule to enable the person carrying out the observation to think about the essence of what person-centred care might look like

“Do staff promote older people’s autonomy and independence?”

- Supporting or encouraging older people to do things for themselves, but providing assistance where needed
- Supporting older people’s preferences and choices
- Recognising and acknowledging older people’s achievements”

(Health Improvement Scotland 2012,p. 6)

Whilst the Quality of Interaction Schedule can be used for the observer (inspector) on to rate the quality of the interaction (Positive/Social, Neutral or Negative), the purpose of its use in this study is solely to guide the researchers attention during the observation and the field notes that are recorded following the observation.

Caring Conversations Framework

The second framework which will inform the observations, the Caring Conversations Framework, was developed following extensive research on an older adult ward. The elements included in this framework have been found to be central to facilitating and enhancing relationships centred care between patients/residents, staff and relatives. (Dewar and MacBride, 2017;

Caring Conversations are comprised of 7 C’s:

- Becoming courageous
- Celebrating
- Connecting emotionally
- Becoming curious
- Considering other perspectives
- Collaborating
- Compromising.

During the observation episodes the researcher will be attentive for examples of where elements of the 7 C's have been demonstrated in the interactions.

The two ways in which data will be generated with adults with incapacity will be:

Field Notes on Observation- what has been observed

- Observation by researcher of interactions between resident and staff or resident and visiting family or friend, creative practitioner, health and social care professional, inspector or local authority staff member, where this person has given consent to be observed. These observations would be in the context of the researcher being in the resident's social environment and/or being alongside care home staff (or other adults with capacity as listed above) as they engage in activities or interactions with the resident without capacity. Field notes will be made in a timely manner, but not during the period of engagement with the resident. These field notes will be typed up by the researcher. The researcher will also engage with the care home staff, sharing with the care home staff what they observed and having conversations about any new learning or ideas that emerge in terms of helping the resident achieve positive outcomes.

Reflective Notes on the Researchers Thoughts and Feelings during Interactions with Residents

- Documentation of researcher's reflections, thoughts and feelings of their own engagement with the resident in social activities, which may include sitting in silence together, walking together or doing an activity, for example the telling of a sensory story which are part of normal activities which care home staff would engage in. Again, these reflection notes will not be typed during the time of engagement with the resident.

They will be typed up immediately after the observation event, stored on an encrypted laptop and written notes destroyed.

Feeding Back of Field-Notes prior to them being included as Data

The procedure for participants with capacity involved in the study is that once data has been generated, for example transcripts or field-notes, these are then returned to the participant for them to review and amend if needed, prior to them being included as data.

In the case of field-notes collected in relation to people who do not have capacity the following options will be offered to the resident's relative/ friend/ person who is giving consent.

Option 1: Field-notes are typed up and returned to them after each period of observation prior to these notes being included as data

Option 2: Arrangement is made for the relative/ friend/person giving consent to speak with the researcher after the first period of observation, review the notes taken, and decide from there how often they would like to receive information.

Option 3: The relative/friend/person giving consent may also decide that they do not feel the need to be contacted regarding the data generated in the observation notes.

In the case of adults with capacity:

A copy of data collected during the observation episode will be shared with them. They will be invited to comment on the notes, offering any further clarification or perspectives on what had been observed.

If for any reason the person giving consent requests that the data not be included in the study this will be respected without them having to provide any reason.

The following paragraphs will further address the ways in which this study will adhere to ethical and moral research practice, pertinent to involving people without capacity. Ethical and moral issues in research practice related to people with capacity are addressed in the original research proposal for Phase 1 of this project. Ethical permission for this research proposal

Benefit to the people with dementia

A sense of reciprocal achievement has been reported by people with dementia participating in research; this includes feelings that they themselves and their experiences have been acknowledged as valued and valuable (Van Baalen et al.,2010). For people with dementia in this study the benefit results from being able to contribute to a community which has valued their in-the-moment experiences and through the study will take action to emphasise wellbeing, inclusion, joy and enjoyment. This study is looking to identify ways in which residents, including those with advanced dementia, support others and are supported to be part of their community.

Observation and minimum necessary intrusion

In the first instance the researcher will liaise with care home manager/senior staff member on each occasion prior to engaging with residents who lack capacity. This will afford an opportunity for the researcher to be informed of any circumstances or considerations that will be pertinent to bear in mind prior to being with the residents. The researcher will at all times be sensitive to the fact that they are in the living space of residents and so will be mindful to be respectful and attuned to what is happening in the care home environment.

Takes account of the wishes of the adult and encourages the adult to exercise residual capacity

Process consent, whereby there is an ongoing iterative approach to confirming consent is being used for all persons involved in this study. For residents who lack capacity process consent (Dewing, 2007) will be enacted through the researcher seeking permission from the person at the time of each interaction. This may be permission to join them in an activity, or to sit with them. The researcher will introduce themselves by name and role, and will use their professional experience of engaging with adults with incapacity to tailor their descriptions of the nature of the research.

- The researchers engagement with the resident will be led by them, and will predominantly focus on being with them in their everyday context- for example

being with them in the care home lounge, it will not involve removing the resident to a separate area in order to for observation to take place

- During periods of observation the researcher will show ongoing attentiveness to any signs of disinterest, discomfort or distress from the resident. If signs of these develop, such as suggestion that the resident is becoming agitated, then the researcher will stop the observation. Conversely, if the researcher notices that the resident appears to be engaged and enjoying the activity this information will be highlighted with care home staff.

Consultation with others

When speaking with the person giving consent the researcher will ask if the resident has in the past expressed a view regarding participation in research. If no particular view has been expressed the researcher will ask the person giving consent to consider if they think it likely that being involved in a study exploring community might be something that the resident would be agreeable to.

Consent as a Process

The use of ongoing, process consent has been developed and described in terms of its use with people with dementia (Dewing, 2007). This process underpins the research experience for all research participants, including those who do or do not have capacity to give written consent. Ongoing consent monitoring, feedback and support will be established through a working partnership between the resident, care home staff, welfare guardian/ relative/ friend and researcher.

Assent and Dissent

Assent has been defined as “an affirmative agreement to participate as expressed verbally (i.e., orally) or a non-verbal indication of willingness to cooperate with study procedures, both at the time of enrolment and over the course of the study” and dissent as “a verbal or non-verbal indication of unwillingness to participate in study procedures” (Black et al., 2010, p. 77). Verbal cues and utterances, non-verbal gestures and any other behaviour or emotional signals will be the means by which information will be gathered as to the residents assent or

dissent. Examples of indications of assent could include a verbal 'yes', nods, positive facial expressions. If the resident shows signs of stress or distress during the period of observation, the observation will be discontinued. In order to harvest potential learning from these instances the researcher will ask any other research participants present at the time e.g. care home staff, to share what they learned about the resident or themselves from the experience. This conversation with the care home staff member will take place after the resident has been supported and is no longer experiencing stress/distress.

Mitigation of Risks

The methodology and methods used in this study are grounded in an assets-based approach and so engagement with the person with dementia will be undertaken from the perspective that they have valuable insights and expertise to offer. The primary focus of the research will be the exploration of what appears to be working well, and what is important to the person with dementia; alongside observing how small but significant everyday experiences that enhance people's lives, for example playing a cd of rainfall with a resident who staff noticed enjoyed looking outside when it's raining.

The researcher will liaise closely with care home manager and care staff who have rich knowledge, and experience of being in relationship with the person with dementia, throughout the duration of the research activity in the care home. Working in collaboration the researcher and care home staff will support the person to be involved in the study for as long as the person wishes, and respond immediately if they show any signs of no longer wanting to be involved.

Process consent will underpin engagements with all those, including people with dementia, involved in the study. Therefore, there will be an ongoing process for the duration of the study of checking-in with the person regarding their desire to stay involved as has been described in the assent/dissent paragraphs above.

Should the researcher observe care or practices that causes concern this will be immediately raised with the care home manager.

Should the researcher observe a situation where the resident being observed, or another resident is at risk of harm due to falling or an act of physical contact, the researcher will work

within their scope of capability; seek the assistance of staff and use verbal means to try to prevent any harm coming to any resident.

Anonymity

The data generated will be pseudo-anonymised with the resident being attributed a pseudonym.

If there are characteristics of the resident which may render them identifiable these will be removed or altered in order to preserve anonymity.

The person undertaking the observations

The professional background of the researcher, Dr Edel Roddy undertaking this research has experience of working as a registered nurse in the care home sector and in a care of the older person unit in an acute care hospital.

Alongside professional experience of working in care home settings the researcher also has experience of being a researcher in care homes during her PhD which explored the experience of inspection in care homes. Since February 2018 she has also been spending 6-8 days each month in care homes as part of the first phase of this Kinnections- community in care homes project.

Dr Edel Roddy is the Project Lead, and is supported and supervised in this role by the Principal Investigator, Dr Anna Jack-Waugh. Dr Anna Jack-Waugh is a Later Life and Dementia Lecturer in the Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland and has expertise in working with people with dementia and their families, with a particular interest in person-centred care and challenging stigma.

Alongside adherence to standard principles as outlined in the Adults with Incapacity Act the researcher feels it imperative to also bear cognisance to the ethical question posed by (Richardson and McMullan, 2007) 'what sort of person should I be?'. To this end the researcher is committed to being a sensitive, reflexive practitioner who places the welfare of people above all else and is continually mindful that the research is taking place in people's 'home'.

Reading

Adults with Incapacity (Scotland) Act 2000. www.legislation.gov.uk/asp/2000/4/contents

Alzheimer Scotland, 2000. *Volunteering for Research in Dementia*

<http://www.alzscot.org/pages/info/researchvol.htm>

Black, B, Rabins, P, Sugarman, J. and Karlawish, J., 2010. Seeking Assent and Respecting Dissent in Dementia Research, *American Journal of Geriatric Psychiatry*, 18(1) pp 77–85.

Cowdell, F., 2010. The care of older people with dementia in acute hospitals. *International Journal of Older People Nursing* [online], 5(2), pp. 83–92 [viewed 25 August 2018].

Available: <http://dx.doi.org/10.1111/j.1748-3743.2010.00208.x>.

Cowdell, F., 2008. Engaging older people with dementia in research: myth or possibility. *International Journal of Older People Nursing* [online], 3(1), pp. 29–34 [viewed 20 June 2018]. Available: <http://dx.doi.org/10.1111/j.1748-3743.2007.00096.x>.

Dewar, B. 2011. Caring about Caring: An Appreciative Inquiry about Compassionate Relationship-Centred Care. Unpublished Thesis. Edinburgh Napier University.

Dewar, B. and MacBride, T. 2017. Developing Caring Conversations in Care Homes: an Appreciative Inquiry. *Health and Social Care in the Community* 25(4), 1375-1386.

Dewing, J., 2007. Participatory research: A method for process consent with persons with dementia *Dementia*, 6(11), pp. 11-24

Digby, R., Moss, C. & Bloomer, M., 2012. Transferring from an acute hospital and settling into a subacute facility: the experience of patients with dementia. *International Journal of Older People Nursing* [online], 7(1), pp. 57–64 [viewed 20 June 2018]. Available:

<http://dx.doi.org/10.1111/j.1748-3743.2011.00282.x>.

Norman, R., 2006. Observations of the experiences of people with dementia on general hospital wards. *Journal of Research in Nursing* [online], 11(5), pp. 453–465 [viewed 24 June 2018]. Available: <http://dx.doi.org/10.1177/1744987106065684>.

Nygård, L., 2006, 'How can we get access to the experiences of people with dementia? Suggestions and reflections', *Scandinavian Journal of Occupational Therapy*, [online], 13, 2, pp. 101-112.

Patterson B, Morin K (2012) Methodological considerations for studying social processes. *Nurse Researcher*, 20 (1), pp. 33-38.

Richardson, S & McMullan, M. (2007) Research ethics in the UK: What can Sociology learn from Health *Sociology*, 4(6), pp. 1115-1132.

Scottish Dementia Working Group Research Sub-Group, 2014. Core principles for involving people with dementia in research: innovative practice. *Dementia (London, England)* [online], 13(5), pp. 680–685 [viewed 14 May 2018.] Available: https://www.dementiaallianceinternational.org/wp-content/uploads/2014/08/Core-Principles_SGWG.pdf.

Thistledown Project, 2016. *A Short Guide to Ethical Practice and Governance for Ethnographic Research with People who have Dementia* [online] Accessed 17 Oct 2017

Watson, J., 2015. Caring with integrity: Developing the conceptual underpinning of relationship-centred palliative dementia care in care homes. Unpublished PhD Thesis, University of Edinburgh, UK.

Wu, E, Barnes, D, Ackerman, S, Lee, J, Chesney, M, & Mehling, W. (2015)

'Preventing Loss of Independence through Exercise (PLIÉ): qualitative analysis of a clinical trial in older adults with dementia', *Aging & Mental Health*, 19 (4), 353-362.