



## **The experiences of participants in care home research**

### **FINAL REPORT**

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**Timescale:** 19.06.2017 - 15.09.2017

**Date completed:** 15.09.2017

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## Executive Summary

**Background:** There are approximately 421,000 older adults aged 65+ living in care homes to date<sup>1</sup>. Many of these residents have complex needs, requiring varied degrees of specialised health care. Out of 14,900 rated care homes, 4% were rated as inadequate and 47% needed improvement, largely due to issues with understaffing, lack of skills, and inadequate management of medicines<sup>2</sup>. For the necessary improvements to take place, research is required to test new technologies, services, and methods of health care delivery. However, the vulnerability of this population<sup>3</sup> and limited resources of care homes<sup>2</sup> make this a challenging task. Care home research networks such as ENRICH (Enabling Research in Care Home) have been established to tackle this issue, and to help improve the lives and care of older people in the UK<sup>1</sup>. Identifying barriers to effective research is essential to improving the quality of care, and this information will help research networks to assist researchers to work with care homes and help tackle their biggest challenges. To do that, the valuable and under-researched experiences of participants in care home research must be explored, so that their unique perspective can inform research practice.

**Aim:** To summarise the findings for an eight-week project exploring the experiences of care home participants, putting forward possible benefits, challenges, and recommendations for future practice.

**Method:** A short systematic narrative review was undertaken to explore the current literature on the experiences of participants of care home research. This was followed by undertaking five qualitative interviews with participants who had previously taken part in case study research looking at the use of telemedicine for remote health care provision, interviewees included; manager, deputy manager, nurse, care assistance, family member. Key findings from the data were identified to help inform researchers and care home staff on what some of the challenges to undertaking research in this setting, with recommendations for future practice.

**Results:** The key themes that emerged from analysis of the qualitative interviews were perceptions of research, the research community engagement process, and advice that they would give to a researcher. Recommendations for future researchers from the participants' perspectives have been made, and future research questions have been proposed.

### **Recommendations:**

- Allowing staff time to participate in research may help reduce professional isolation, enable staff to inform future practice and enable staff members to develop their professional confidence. These findings may be useful when promoting research to care homes, and researchers may wish to consider including in their engagement strategy.
- Staff below management recognise the value and importance of taking part in research, both in practice and personal development. Whilst the manager may be the most qualified person to decide if a proposed project is of good fit, involving staff in this decision may provide a fresh perspective on how a project may be integrated into practice.
- Researchers may benefit from approaching care home associations as part of their recruitment process.
- Researchers should be aware of the limited resources available to care homes, and be mindful of restrictions on staff time during project design.
- Ensure that best times to contact are established early in the engagement process to ensure communication is effective.
- Include time in research design to developing a relationship with the care home as early as possible to establish connections, and familiarise with the residents, staff, and their schedule and culture.
- Reduce the amount of administrative effort of the care home where possible.
- A friendly and approachable communication style without appearing too formal will help residents feel more comfortable.
- Dementia awareness training should be undertaken before entering the care home
- Keeping care homes up to date about the progress of the research and showing how their contribution has helped.
- Managers who identify employees who struggle with confidence could consider them as good candidates for participation.
- Employees or volunteers with a keen interest for research should be considered for research championship roles.
- Research networks or care home associations should collect data on the reasons why care homes accept or decline research projects, and provide researchers with this information.

- Providing the decision maker with a logic model explaining the potential impact of their project on health care challenges that they consider a priority may be a way for researchers to increase the uptake of their projects.
- Consult with participants at all levels on how formal feedback can be formatted for wider uses to increase its value to them.
- Research networks should collect data on the prevalence of agency staff in care homes, and identify ways for them to be included in research.
- Some projects that require less staff time may be suitable for participation of night shift staff, and their inclusion should be considered by researchers where possible.
- Flexibility for unplanned events is essential for all researchers and must be considered when developing project timeframes.
- Researchers must endeavour to include care homes in rural or distant locations to ensure representativeness. No care home should be left behind.
- Care home managers should increase the presence of the researcher and project in the care home so that all residents and staff are aware, not just the participants.

**Conclusion:** Interviewing participants on their experiences of care home research projects has revealed unique and useful perspectives on the challenges of integrating projects into the busy care home environment. Twenty recommendations have been made to inform care home associations, research networks and researchers based on the participants' perspectives.

## Report

### Background:

There are approximately 421,000 older adults aged 65+ living in care homes to date<sup>1</sup>. Many of these residents have complex needs, requiring varied degrees of specialised health care. Out of 14,900 rated care homes, 4% were rated as inadequate and 47% needed improvement, largely due to issues with understaffing, lack of skills, and inadequate management of medicines<sup>2</sup>. For the necessary improvements to take place, research is required to test new technologies, services, and methods of health care delivery. However, the vulnerability of this population<sup>3</sup> and limited resources of care homes<sup>2</sup> make this a challenging task. Care home research networks such as ENRICH (Enabling Research in Care Home) have been established to tackle this issue, and to help improve the lives and care of older people in the UK<sup>1</sup>. Identifying barriers to effective research is essential to improving the quality of care, and this information will help research networks to assist researchers to work with care homes and help tackle their biggest challenges. To do that, the valuable and under-researched experiences of participants in care home research must be explored, so that their unique perspective can inform research practice.

**Aim:** To summarise the findings for an eight-week project exploring the experiences of care home participants, putting forward possible benefits, challenges, and recommendations for future practice.

### Method:

#### Literature Review

A short systematic narrative review was conducted to identify current research on the experience of research participants in care homes. The research included was used to help identify current work in the area, identify possible themes and to inform data collection for the project. Papers that included the experiences of participants on the any aspect of the research process, from the perspective of researchers, staff, or the participants themselves were included in the review. Papers were excluded if the participant experience was only discussed in terms of the respective interventions and not the research processes.

## **Qualitative study**

A small qualitative study was designed. Here, six individuals from different roles from within care homes, including manager, deputy manager, nurse, care assistance, family member and resident. Due to a deterioration in health, no residents were included, and Interviews were carried out with the remaining five participants. The contents were coded and thematically analysed using NVivo 11.

## **Results:**

### **Literature Review**

Four themes emerged from the thirty articles that were selected for inclusion; practical matters and recruitment; participatory action research; capacity, ethics, and informed consent; and family involvement in care and research. The following themes were used to inform the semi structured interview guide.

### **Practical matters and recruitment**

Understanding organizational routine and patterns of communication is considered important to ensure the research project can be successfully conducted and cause minimum disruption<sup>4,5</sup>. Barriers to recruitment can include scepticism and mistrust of the researchers and their objectives<sup>6</sup>. It has been suggested that the recruitment process can be improved by having an existing relationship with care home staff, providing clarity on the steps of the project, and increasing buy-in by helping staff develop sense of ownership, and establishing trust with visits prior to the project<sup>6</sup>. Clear communication within and between researchers and the host care home is a tenet to the success of a project. It has been suggested that the presence of the project should be increased by ensuring that all staff and residents are aware that the research is taking place, not just those participating<sup>5</sup>. The process of disseminating findings and feedback should be clearly thought out, as it has been found that one-directional dissemination by using a poster resulted in many lower paid staff being unaware of the results<sup>4</sup>. Autonomy and a sense of purpose are deeply important quality of life factors for care home residents,<sup>7</sup> and there is an opportunity for these experiences to be

provided through research participation. The importance of research is recognised by care home staff, and recently a study proposed what they consider should be research priorities, which included person-centred care, dignity, appropriate staffing levels, and staff training<sup>8</sup>. Participation can also provide health care assistants with an opportunity to share their perspective, and provide hope to those who feel undervalued in their work<sup>4</sup>. If measures are taken by both parties to overcome these practical and communicative barriers, the benefits for all participants can be maximised, and proposed projects that ultimately focus on improving the lives of residents (for example see <sup>9</sup>) can be conducted efficiently and effectively.

### **Participatory Action Research**

When searching for the experiences of participants in care home research, nine of the results returned were Participatory Action Research based studies. Benefits of research participation of this design has been found to provide the opportunity for participants to express their views; have their experiences and expertise validated, experience being part of something beyond than their own care environments, enjoy seeing meaningful changes take place based on their own ideas and reflections, develop a sense of ownership of a project, which increases adherence to new developments, and helps to overcome scepticism and 'research fatigue'<sup>10-16</sup>. Empowerment of participants is a key aim of participatory action research, and the experiences of participants are often a primary objective<sup>17</sup>. In other research designs, the experiences of participants are more frequently discussed in terms an observation rather than an objective (for example see <sup>18</sup>). The potential of missed opportunities for the valuable insight of participants on various aspects of research design and implementation to be explored adds weight to the rationale of this study.

Whilst some recommendations made based on participatory action experiences may not be translatable to all research designs, there are practical challenges that all researchers working with care homes are likely to encounter irrespective of design or epistemology<sup>1</sup>. For instance, barriers such as unsupportive, fragmented leadership and constrained resources, and facilitators such as efficient teamwork and well-established relationships found in participatory action research and patient public involvement studies<sup>19,20</sup> reflect the challenges experienced by researchers conducting clinical trials<sup>18</sup> or randomized controlled trials<sup>21</sup>. Developing a research protocol that fails to fit in with the day-to-day running of the care home, such as those requiring a large time commitment from care home staff, will act

as a barrier to uptake of any project<sup>22,23</sup>. The development of positive relationships, encouraging the sharing of ideas and consulting with staff and residents on implementation tactics, and concise, regular communication using appropriate language will help to facilitate research in care homes by increasing a sense of ownership amongst participants<sup>24,25</sup>.

### **Capacity, ethics, and informed consent**

Five papers focussed on issues around ethical challenges of responsible recruitment of older adults in care homes. Residents may be considered at high-risk of exploitation, be it due to cognitive difficulties, or a potential fear that unwillingness to participate may have an impact on the quality of their care<sup>26</sup>. Whilst some research projects may be less ethically challenging than others<sup>27</sup>, the importance of truly informed consent in all cases cannot be overstated<sup>28</sup>. Older age and less formal education has been found to be associated with impaired understanding; an issue which is made more complex when considering those with declining or fluctuating capacity<sup>29</sup>, as if a person is unable to understand and retain the meaning of informed consent, the same applies to their understanding of the right to withdraw at any time<sup>30,31</sup>. The task of recruiting residents with dementia is resource-heavy, and researchers will need to allocate extra time to recruit them following ethical procedures<sup>32</sup>, which is highly challenging given the difficulties of selecting participants who frequently have multiple health issues and may be at end of life<sup>18</sup>. Further, the varying degrees between participants of what is considered an acceptable amount of information and overwhelming them with paperwork means that there is no one strategy that can cater to the needs and preferences of all residents<sup>31,33</sup>. Having a 'trial run' of participation to enhance understanding has been found to increase consent to participation, however, this is a resource-heavy task and is not suitable for all research projects such as those involving medicine<sup>34</sup>. These findings demonstrate the amount of resources required by researchers, staff, and family members for research to be conducted safely, from supplies which are all often extremely limited.

### **Family involvement**

Families may be more likely to participate in a retrospective assessment of care for a family member with dementia who had passed away when palliative and end of life care has been of significantly higher standard in factors such as nursing care, odour, and mouth care, and

when physicians reported treatment consensus between families and care home staff<sup>35</sup>. These findings suggest that family may be less likely to participate when care has not always been perceived as optimum, or when incidents that challenge families' perceptions of staff competency have arisen, such as their resident being treated in an undignified manner<sup>36</sup>, or in instances of unease when the perceptions of what is best for the family member may not have been congruent between family members and staff<sup>37</sup>. The residents who have been subject to such experiences can be considered as the most vulnerable, and research is required to help improve their quality of care. Yet, the circumstances surrounding residents' personal care, such as suspected or potential negligence, or contrasting attitudes within and between staff, family and residents acts as a barrier to potential participants ability and / or willingness to take part in research<sup>10,37</sup>. This yields a significant issue in care home research, as it limits accessibility to the most at-risk persons within a vulnerable population, who arguably need the help of researchers the most.

### **Qualitative study**

The duration of the participant's roles within their respective care homes ranged from 2 years (nurse, care assistant and relative) and 22 years (manager and deputy manager). The research process was considered by each participant who had their own unique roles and contexts within the care home, and discussed in terms of the challenges they faced in their own professional and personal capacities. All participants understood why research was important, and they each took different benefits from it, and considered participation as an opportunity for their voices to be heard.

#### **1. Perceptions of research**

The nurse perceived research participation as a benefit as it combatted isolation of the care home from the wider care and research communities, the cause of which was identified as the care home's small size and rural location. Their nursing team was described as highly motivated to keep up-to-date, but the nurse felt that there was not enough engagement from the wider research community.

*"C2N01: I think that it is beneficial, because as I say we get a bit isolated, and if you've got, like, a group that you meet regularly, you lose touch with what's*

*going on don't you, if you don't go to outside of the training days and things; I think you miss a lot of what's going on. It's not like working in a hospital setting where you've got more access to information. I think it's totally different in care homes ... when you're sat in a little care home like we are, with just one nurse, and that's it, it's totally different, you know"*

The deputy manager, who was still highly involved in the care of the residents identified that the role of a carer is often misunderstood to be an easy job research participation as an opportunity to express that their role is not as easy as it is interpreted. They took their role of a care provider very seriously, and saw the act of research participation as an opportunity for this misunderstanding to be corrected, and for people who normally wouldn't get to see the day-to-day practice of high quality care to be recognised.

*"A lot of people think you work in a residential home, it's just sitting down with cups of tea, and it isn't. So from that side, it's good for them to come in and think, 'well actually, there's a lot goes on in places like this' ... You know, it's their lives in our ands really, and it's the last stages of their lives, so... you know, we've got to try and make it as perfect as we can for them. And a lot of work goes in that."*

The care assistant similarly viewed the role of a carer to be misunderstood by people outside of the care home, and saw research participation as an opportunity for their point of view to be expressed, and used to inform people both in and outside of the care environment. Additionally, the care assistant considered the process of being interviewed to be beneficial to their confidence, which is something that they struggle with on a personal level, as it provided an opportunity for her expertise and knowledge to be professionally validated by someone taking a specific interest provided an opportunity for her to express her point of view. Perceptions of potential negative effects of participation were not expressed by any participant when asked.

**Recommendation: Allowing staff time to participate in research may help reduce professional isolation, enable staff to inform future practice and enable staff members to develop their professional confidence. These findings may be useful when promoting research to care homes, and researchers may wish to consider including in their engagement strategy.**

## 2. The research engagement process

The theme of research engagement is concerned with the process of involvement with the wider research community. This includes the level of awareness of research networks, method, and approach to engagement from these networks, and level of satisfaction with the current level of engagement. The nurse and the manager were the only two who could explore this at length, as their professional roles were the most affected by these processes. The other participants state that all research opportunities come from the manager downwards. Both the manager and nurse were keen to engage with the wider research community, and both described information-seeking behaviour of new research developments as part of their day-to-day practice. However, they each had contrasting experiences and views of the engagement process.

The manager viewed the care homes current level and approach to engagement with research networks with satisfaction. Their home is reportedly a member of two care home associations that provide information about research opportunities, and the manager regularly attends reference group meetings with the local health authority, which have various projects. The current method for the wider research community to engage with the manager's care home is to contact the care home associations, who then get in touch with the manager via email to state that a research opportunity has arisen. The manager then makes the decision alone whether to take part in the proposed project or not. The critical factor they considered most important was the time that any project would take to take part was the allocation of staff and time it may take away from residents:

*“CM3M01: Yeah. I mean, I think if a research problem – a research project – is going to be time consuming for the staff, it's not always the best thing for this home, because the staff here are very geared towards the residents, and they have to spend time with the residents ... And we have a lot of staff on duty of course. So if it were to impact, I think anything, if it was to impact on client care, then you would think twice about, doing it.”*

The nurse remained academically engaged with the progress of nursing research, and was passionate about keeping up-to-date with relevant projects and academic developments. Their nursing team were stated to take opportunities to engage with other teams with

different specialist teams coming to the care home, and viewed these as opportunities to learn and grow. However, as all research opportunities are fed to their team through the area manager level, they were unhappy with the current level of engagement with the research community. Further, they viewed research participation as such a valuable opportunity to learn, they predicted that the standards of care could drop if the current level of engagement with the research community was not increased. They also expressed an interest in having more involvement in the project selection process, and saw this as an opportunity for the varied backgrounds of the nurses within her team to be utilized, by offering ideas and perspectives to the project selection process that an area manager may not if judging the fit of a project on their own criteria. If this level of engagement was to ensue, they pointed out that information of opportunities may need to be communicated by a variety of means, as not all nurses and other care home staff have consistent access to the same methods of communication as part of their role.

*“I think care homes need to be contacted to say what’s out there. I know they do have regular forums, but that tends to be at the management level, it’s not at the nurse level, and so they can go out to the regular forums ... But we don’t get that opportunity to go out and do that, and meet with other colleagues really, apart from the ones you work with ... and I’m sure there’s a lot of nurses that’d take advantage of these, if there was more going on locally.”*

Further, the nurse recognised that there was an opportunity for the experience of participation to contribute towards the nursing revalidation process, and could contribute to their reflective practice with critical thinking and awareness of their own practice in a wider context. This indicates that a potential advancement to be made in research recruitment and participation could be to include something to demonstrate this link and show how this can contribute to nursing development.

*“I think we’d just like more I think. Because at the minute, we don’t get much at all. And it would – anything that people that people can come along and bring is very useful to us all. As I say, because you do tend to get isolated in little care home groups, or you know, you work with your small team, you know, and there’s some people that might only work with a couple more nurses, so they don’t see anything outside of that, and their immediate group, you know. Then again, you’ll*

*get some nurses that are quite happy with that, but I think as individuals we've all got to keep upskilling, and learning new things."*

**Recommendation:**

- **Staff below management recognise the value and importance of taking part in research, both in practice and personal development. Whilst the manager may be the most qualified person to decide if a proposed project is of good fit, involving staff in this decision may provide a fresh perspective on how a project may be integrated into practice.**
- **Researchers may benefit from approaching care home associations as part of their recruitment process.**

**3. "What advice would you give to a researcher?"**

Towards the end of the interviews, each of the participants were asked what advice would they give to a researcher. This provided a platform for them to reflect on their previous experiences, things that went well, or not so well, to discuss observations that they had made, comment on things that were well received, share their ideas, and talk about what they would like to see happen in the future, and do so with confidence knowing that they are regarded as an expert of their experience.

Most of the advice offered was regarding the practical fit of research in the care home. This included allocation of time, flexibility and having adequate resources. Avoiding busy times in the routines was a consistent theme across all interviews, including mornings, dinner times, and regularly scheduled professional visitors. Mondays and Fridays have also been identified as particularly busy days in two of the three care homes. Exercising patience and flexibility for unplanned events, such as falls, illnesses, attacks, deaths, staff absence are essential for any researcher or visitor entering the care environment, and it is something that the previous researcher was praised for, particularly at the third care home where they were aware that things hadn't always gone to plan. The issues of time management, however, were not one sided, as the more senior participants (manager, deputy manager and nurse) all took ownership of the organisation and time management, with the manager being particularly aware that it was an area for improvement. Participants with more senior

positions had a sense of ownership for being responsible for finding the time to welcome a researcher into their practice.

In the manager's case, the fit of research extended beyond practicality into their wider approach to care, and with their wider approach to care; that is, the congruence of the priorities and objectives of the research congruent with the priorities and objectives of the manager's care home. For instance, they reflected positively upon a previous research project on mobility in older age, where residents were asked to wear belts that monitored their levels of physical activity. The manager views mobility as a very important issue in elderly care, as in their experience, cessation of mobility for any resident is associated with other complications such a decreased social interaction and circulatory health problems, and so monitoring activity levels is an integral component of the care they offer. Both the research method and aim of this project was congruent with the manager's approach to care, and therefore described by the manager as 'one that was close to [their] heart'. In addition to this, they also expressed that they would like to receive more information about the impact of the research they take part in.

Professional attributes of the researcher were also discussed, such as demonstrating awareness and respect for the working environment that they are visiting. Dementia awareness and training was also seen as an advantage by all participants, to ensure that interactions with residents were informed and safe for everyone involved. Additionally, personal attributes and social skills of a researcher were deemed as important, i.e., being friendly and approachable, and good with the residents. Again, this was discussed in context of things that went well in the previous project they took part in, and is regarded particularly by the manager and deputy manager and relatives a prerequisite to successful integration and engagement between a care home and a researcher. As both the manager and relative stated, ensuring that any worries, concerns and wishes of the residents and family members are addressed is key to best practice. Therefore, social competence and being able to communicate effectively could be considered essential to patient and person-centred care in research.

*"You know, it's not just about flexibility, it's about personality as well. They were very good".*

A recurring topic in the interview with the relative was worry in the elderly residents, and that so much free time can enable them to worry about the smallest things. He stressed that not appearing too formal, and ensuring that any worries or concerns were counteracted with reassurance and making sure that they understand that they know that the presence of a researcher is a positive thing for the care home to take part in, and that risks are minimal. He also mentioned that overhearing and worrying about unfamiliar people could spark unwarranted worry, and that this could be avoided by using a suitable space to conduct research. This was also evident in the interview as we were interrupted several times as the most suitable space for us to use was a connecting room between the care and staff areas. Ensuring that all residents are aware and not afraid of the research project is considered essential. In addition, they noticed that the staff spend a great deal of time on paperwork, and so anything a researcher can do to reduce or condense the amount of documentation involved in the project would benefit the staff and residents by allowing for more time to care.

**Recommendations:**

- **Researchers should be aware of the limited resources available to care homes, and be mindful of restrictions on staff time during project design.**
- **Ensure that best times to contact are established early in the engagement process to ensure communication is effective.**
- **Include time in research design to developing a relationship with the care home as early as possible to establish connections, and familiarise with the residents, staff, and their schedule and culture.**
- **Reduce the amount of administrative effort of the care home where possible.**
- **A friendly and approachable communication style without appearing too formal will help residents feel more comfortable.**
- **Dementia awareness training should be undertaken before entering the care home**
- **Keeping care homes up to date about the progress of the research and showing how their contribution has helped .**

**Discussion:**

A literature review was conducted prior to conducting qualitative interviews with a nurse, manager, deputy manager, care assistant and relative were conducted on their experiences

of participants of care home research. The qualitative research found that perceptions of research were largely positive. All participants recognised the value of research, and benefits from participation ranged from personal to professional, and benefits for the practice within the care home itself. On a personal level, the care assistant that took part reported experiencing a boost in personal and social confidence by taking part.

**Recommendation: Managers who identify employees who struggle with confidence could consider them as good candidates for participation.**

Congruency between aims and objectives of the research with the ethos and approach to care of the host care home may increase the success of integration and uptake of the project amongst staff. As previously identified<sup>24</sup>, topics that are considered personally relevant to participants and relevant to the home are more likely to be participated in. This is reflected in the manager's interest and fondness of a previous mobility project, which they described as being 'close to [their] heart', and described the personal benefits for the residents who participated, as it fulfilled the needs of a sense of purpose and autonomy<sup>7</sup>. As fifteen research priorities of managers, matrons, registered nurses and care assistants have recently been identified<sup>8</sup>, providing the decision maker with a logic model explaining the relatedness and impact of the proposed project on these priorities may be a way to increase uptake of research within care homes. The nurse identified that their nursing team would like to get involved in the manager's decision process, which could provide benefits such as a new perspective to an integration problem, and an increase of ownership from participants. Health care employees with passion for research should be considered for research championship roles that can assist researchers with the planning, recruitment and integration of research projects in the care home<sup>38</sup>. Additionally, if research networks collected data on the reasons why a care home choose to accept or decline a research project, this could be used to help future researchers identify suitable care homes more efficiently, or practical aspects of their projects that they could alter to increase the number of suitable homes.

**Recommendations:**

- **Managers should consider consulting with staff members on project suitability before deciding to accept or decline participation.**
- **Employees or volunteers with a keen interest for research should be considered for research championship roles.**

- **Research networks or care home associations should collect data on the reasons why care homes accept or decline research projects, and provide researchers with this information.**
- **Providing the decision maker with a logic model explaining the potential impact of their project on health care challenges that they consider a priority may be a way for researchers to increase the uptake of their projects.**

The interviews have revealed the importance of focussing on benefits of research participation, and reflect those previously reported<sup>22</sup>. The manager suggested they would like more information on the impact of projects they took part in, i.e. where the results have been used and where they have influenced change. The nurse saw a great advantage in professional development from participation, referring to how participation encourages reflective practice, and how the experience is relevant to the Nursing & Midwifery Council revalidation process. Formal recognition of efforts has been previously recommended<sup>6</sup>, yet feedback given in any one format may not be useful for all staff members<sup>4</sup>. Providing reward in a format for wider use such as nursing revalidation processes, funding applications or Care Quality Commission reports may increase the value of participation.

**Recommendation: Consult with participants at all levels on how formal feedback can be formatted for wider uses to increase its value to them.**

The practical recommendations made by participants largely reflect those documented elsewhere<sup>22</sup>, in that projects that require a lot of staff hours are less likely to be accepted. Mornings and meal times should be avoided. The researcher should be familiar with the schedule of the care home, and must remain flexible for unplanned events. Two of the interviews revealed potential difficulties of including permanent night staff and agency staff in research. Projects that do not include these staff members may not be representative of the care home workforce, and where possible researchers should take measures to include them. Similarly, the nurse repeatedly described their care home as being isolated from the wider health and research community. Yet as recommended by previous researchers<sup>18</sup>, an effective strategy to reduce cost and time is to recruit care homes from within the local area, leaving those in more rural locations at risk. Inclusion and representativeness of research is at risk if rural care homes are left behind. Whilst the manager, deputy manager all recognised that they needed to make time for research projects, the wider research

community should endeavour to include 'hard to reach' participants, as although recruiting from a pool of easily accessible participants may conserve resources, it may be at the expense of representativeness.

**Recommendations:**

- **Research networks should collect data on the prevalence of agency staff in care homes, and identify ways for them to be included in research.**
- **Some projects that require less staff time may be suitable for participation of night shift staff, and their inclusion should be considered by researchers where possible.**
- **Flexibility for unplanned events is essential for all researchers and must be considered when developing project timeframes.**
- **Researchers must endeavour to include care homes in rural or distant locations to ensure representativeness. No care home should be left behind.**

The involvement of family members of care home residents could also be considered an untapped resource for researchers. The relative has an extensive knowledge of the care home residents which could be highly valuable to a researcher, and potential for those that visit frequently to act as a gatekeeper when a researcher is getting to know the residents. They discussed the topic of irrational worry amongst some residents, and suggests that making sure they understand why the researcher is present is essential to ensure they can rest well. It has been suggested that posters and leaflets can help to accomplish this<sup>5</sup>.

**Recommendation: Care home managers should increase the presence of the researcher and project in the care home so that all residents and staff are aware, not just the participants.**

**Conclusion:**

Interviewing participants on their experiences of care home research projects has revealed unique and useful perspectives on the challenges of integrating projects into the busy care home environment. Managers, nursing staff, care assistants and family members understand the importance and benefits of research, and are willing to participate. Staff members below management level are keen to engage, as this provide personal and professional development opportunities. Appropriate fit of research in terms of practicality and approach to care are key determinants on the likelihood of participation in research



projects. Ensuring that the decision makers are given clear information on the immediate and wider benefits of participation could encourage an increase in uptake of research projects. Twenty recommendations have been made to inform care home associations, research networks and researchers based on the participants' perspectives.

## References

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