Public Involvement in Care Home Research Workshop Report

Research Design Service Yorkshire and the Humber

February 2013

Acknowledgements

David Alldred, Senior Lecturer in Pharmacy Practice, University of Bradford

Francis Brown, lay representative

Mike Clark, Research Programme Manager, NIHR School for Social Care Research, London School of Economics

Cath Davies, Wellsprings Nursing Home, Bradford

Anne Heaven, Research Fellow, Bradford Teaching Hospitals Foundation Trust

Terry McGrath, PPI member, Dementias and neurological diseases research network (DenDRoN)

Kirste Mellish, Research Manager, Care Home Research Network, Bradford Institute for Health Research

Arvin Prashar, Research Fellow, Bradford Institute for Health Research

Alicia Ridout, Enterprise and Innovation Development Manage (Healthcare), University of Leeds

Adam Smith, Programme Manager, Dementias and neurological diseases research network (DenDRoN)

Maryrose Tarpey,Assistant Director, INVOLVE Co-ordinating Centre

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Public Involvement in Care Home Research, Workshop Report, February 2013

Introduction

This is a report of a workshop held in Leeds in February 2013. The aim is to provide a resource for researchers who are new to public involvement in care homes for older people (see page 8 for definition of a care home) and want to involve **residents, their relatives and friends** in developing or guiding their research.   This report has been complied by a group comprising researchers, care home staff and members of the public who have experience of working with older people, working in care homes or public involvement more generally. Sadly, no care home residents could attend the workshop but we met separately with them and their ideas are also incorporated into this report. Where we can we include links to existing material provided by researchers involved in the workshop, and those who provided written feedback on the evolving report (e. g. ENRICH, Social Care Institute for Excellence and National Institute for Health Research (NIHR) School of Social Care Research).

In this report we will:

1. Provide a brief introduction to involving people in research
2. Describe different sorts of care homes
3. Provide some specific guidance on involving people in care homes in research, using examples from our own work and that of others

Policy and research documents often to talk about '**Public Involvement'** in research. NIHR INVOLVE defines public involvement in research as "*research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*" (INVOLVE, 2012). INVOLVE use the term **public** to mean all the people who use or are affected by health and social care services. Some research traditions do not use the term public and refer to people as service users, so tend to talk about 'user involvement' in research. When undertaking involvement activities in care homes, the general principles of public involvement still apply and you may want to read this document alongside more general guidance, such as that provided by INVOLVE. However, there are issues which are particular to care homes.

At times care home residents may become involved in research because they have a particular illness or condition (e. g. Diabetes); however this is not always the case. Researchers may wish to engage with residents because of their experience living within a care home environment. Therefore in this document we will refer to **residents, relatives and friends**, rather than 'public', 'patients' or 'service users'. Although we recognise that identifying ways to involve care home staff in research is important, and is an underdeveloped area, it is not the focus of attention for this guidance. We will nevertheless talk about staff because of the role they play in facilitating the involvement of residents.

What is involvement?

When we talk about '*involvement in research'* we are talking about research being carried out '*with*' or '*by*' care home residents, relatives or friends. This may include activities such as:

- Involvement in identifying research priorities
- Devising or driving research questions
- Planning a research project
- Being a co-applicant on a research proposal for funding
- Being an active researcher in the project e. g. collecting primary data and/or assisting in analysis and reporting
- Being a member of a steering committee/advisory group
- Commenting on participant information, questionnaires, and other aspects of the research, such as design, recruitment, inclusion criteria and ways of assessing outcomes in this population.

Involvement in research is not:

- Involving people as 'subjects' or participants (i. e. people from whom you collect data to answer your research question)
- Raising awareness of research / science / health issues (this is generally known as public engagement)
- Disseminating your results to those who provided data for your research (i.e. to participants)

INVOLVE: *Briefing notes for researchers*, (INVOLVE, 2012) provide more general information on ways of involving people in research (http://www. invo. org. uk/resource-centre/resource-for-researchers/).

The NIHR School for Social Care Research has also produced a scoping review of user-controlled research (i. e. where people who use services control the whole research process) which gives examples of user control over research in this setting and others (Beresford and Croft, 2012).

Our workshop was about *Involvement in research*, if you want to know about **undertaking research** in care homes, the NIHR School of Health and Social Care have produced two excellent reviews, the first on care home research Luff et al. (2011), and the second on end of life research Goodman et al. (2012).

Care Homes

Definition of a Care Home

In these guidance notes we use the definition of a **care home** provided by Luff et al (2011) as "*all residential long-term care settings which provide group living and personal and/or nursing care for older people and other adults.*" (p2).

This report focusses on care homes for older people. Different rules apply to research in children's homes, and although some of the ideas presented may be useful, care should be taken in extrapolating this advice to other settings. Similarly, when considering other residential care settings, such as those for adults with learning disabilities some of what is discussed here may not apply.

The care home environment

It's important to recognise that every care home is different in terms of size, staffing levels, management structure, culture and philosophy. Get to know the specific environment you will be working within before you start. Time for this should be factored in when planning your project. The following section contains some general information to help you understand the different care home settings. Information on this topic is also provided by Luff et al (2011) and on the ENRICH website (www.enrich.dendron.nihr.ac.uk).

Care homes can be separated into three groups:

- Residential home/care home only: Providing accommodation and personal care.
- Nursing home/care home with nursing: Providing qualified nursing care in addition to accommodation and personal care.
- Homes which are dual registered, providing a mixture of both nursing and residential care.

Care homes can also be registered for a specific care need, for example dementia or mental health conditions.

Ownership of care homes falls into one of four categories:

- Private - Commercially run and owned by individuals, partnerships, limited companies or commercial care home groups
- Voluntary - Run not-for-profit and owned by charities, associations, societies or trusts
- Local authority
- NHS (uncommon)

Private and voluntary sector ownership together account for over 90% of all care homes, and this is on the increase. This ranges from individuals who own, and may also manage, a single care home to large organisations that own several hundred care homes with an associated infrastructure. As care homes can have very different corporate structures, the people you will you need to contact for access will vary, and the likely constraints imposed on involvement will likewise differ. The dominance of commercially run care homes has implications for researchers. Collaboration can be more difficult to achieve as homes are private businesses, and so the economic imperative will impact on their decision making.

How to identify care homes

The first step is to identify possible care homes to work with. Think about what sort of care homes will be able to *help residents* work with you to develop your research ideas. You may need to engage with a range of care homes at the research planning stage, to ensure you get a broad range of views. From our own experience we know that just because a recruitment plan or data collection approach works in

one care home, this does not mean it will work in another! Engaging with a range of homes at the design stage will allow you to work through these issues before starting your study.   It may be that you carry on working with all these homes throughout your research, or you may continue to work with a few who have expressed an interest in continuing to work with you throughout the project. Obviously a longer term relationship with a home or homes is preferable, but a lot will depend on what you are planning to research, and what you have been given permission to do.

There are a number of organisations that can help you identify potential sites for you to undertake your involvement work. Sources of support include:

- Care Home Networks
  At the time of writing this report there are several care home research networks across England. The largest is the NIHR ENRICH - Research Ready Care Home Network (http://www. dendron.nihr.ac.uk/5413/research-ready-care-homes/) which has over 500 care homes participating to support research, local networks supported by the NIHR CRN provide around 85% coverage and the rest of the country is supported through corporate partnerships with large providers such as BUPA. Locally, the West Yorkshire Care Home Research Network (contact: a.forster@leeds.ac.uk) works closely with care home owners and managers to develop a sustainable research culture, and other care home networks exist across England. These networks support a variety of research involvement activities and they will be able to tell you which care homes in your area are research active, or interested in getting involved, and which ones are not in a position to help. They will also have a list of care homes already involved in other studies. However, some care homes will be involved in studies of which the network is not aware.

- The Care Quality Commission (CQC http://www.cqc.org.uk/) website enables you to search for care homes in your area. You can also see information about their specialisms and last inspection (Care Quality Commission, 2014)

- Local Authority Care Home Forums

- The commercial website Care Home UK lets you search for homes by keyword and location.   You can also search by other categories such as care homes with awards or recommendations, type of owner, type of care and facilities (Carehome.co.uk, 2014)

- National/local care home groups e. g. BUPA or Anchor membership
- Membership organisations such as the Registered Nursing Home Association (RNHA), National Care Forum, National Care Association and the English Community Care Association may be helpful in terms of identifying their member's homes in your area. They may also be interested in the research in their own right.

How to approach a care home

Although you want to engage residents, your initial approach is likely to be to the care home, rather than to individual residents. The following suggestions represent tried and tested methods of making contact with a care home:

- Approach via the Research Ready Care Home Network or local care home research network. It may be worth making an informal presentation or distributing flyers to get a sense of initial interest.
- Approach via the care home organisation e. g. head office or regional manager. You will need their permission to enter the care home, so if you contact them first they can then filter your request down to the local home.
- Approach by letter. Researchers have found that writing to the care home manager or owner and putting the letter on brightly coloured paper often works. Follow up by telephone one week later – they are likely to remember the 'pink' or 'green' letter. Remember to make it clear that you are not asking about participation in the study **but about involvement** at whatever stage.
- Presentation at a local care home forum (most likely to be run by the local authority).
- Engage with the local Primary Care providers who will be able to provide advice and sometimes support introductions to suitable care homes / residents.

Timeliness of the approach is important - it is counterproductive to get expressions of interest too far in advance as care home staffing can change quite quickly (over weeks). However, it can take time and perseverance to access care home managers, even before you get to meet with residents. Leave substantial time prior to any submission deadlines to facilitate meaningful engagement. If more information

is requested, always offer to visit in person. Explain what you may be able to offer the home in return for their help (see engaging staff, P12).

It's important to be clear early on about what the project can achieve, and the funding process. The management of expectations of everyone involved at an early stage is vital to successful involvement. For example, if you are involving people at the grant application stage, make it clear that the project may not get funded and that the review process may take some time.

Engaging care home owners, managers and other staff

The focus of this document is *working with residents, their families and friends*. However we have chosen to talk about staff here in recognition of the important role they play in facilitating access to care homes and residents.

Think about how you 'sell' involvement in research to owners and staff. It may take a significant amount of time and effort on the part of care home staff to facilitate you working with residents. What will they get out of working with you? Is there an opportunity for them to learn something new? Could you badge this as an opportunity for staff to learn more about the experiences of their residents and to improve the reputation of the home?

Our workshop participants suggested these tips for engaging with staff:

- Care homes are more likely to engage if you approach them in a non-judgemental way. Make it clear that research is not about 'checking up' on them but about learning together.
- A partnership approach (i.e. working with them, throughout the life of a project) may be more successful than a consultation approach (i.e. a one off event where you get feedback on your ideas then take the project forward).
- Be respectful of all members of staff, their knowledge and their work commitments and priorities, your research project may not be at the top.
- When working with larger care home groups, make sure that local and regional/national management are kept fully informed.
- Consider asking if you could speak at a staff meeting to outline your research ideas. Staff may have concerns about research. They may worry that research will paint their work in a poor light, involve additional demands being made upon

them or put vulnerable residents at risk. Be mindful of these potential concerns when presenting ideas to staff.

- Do not rely on internal structures to cascade information to care staff as they may not have time to do so. If possible try to attend staff meetings in person.

- Staff may act as gatekeepers to residents; they will want to protect both the residents and the routine of the home. There are both costs and benefits to 'gate keeping'. Staff can help you identify people to talk to, but they may choose not to introduce you to some residents who would perhaps show the home in a poorer light. Taking time to build up a trusting relationship with staff may help reduce this bias.

- Some members of care home staff may have research ideas of their own. If you can, try to explore these ideas with them. It may not be possible to incorporate their ideas into your present project, but consider if their ideas could form the basis of a new collaboration.

- Staff will have a good understanding of what it is feasible to do within care homes, so be open to their views.

Identifying Individuals to Involve

Before you start, ask yourself:

- Do you have the relevant skills to work with this group of people? (e.g. able to communicate effectively with residents with dementia).
- Do you need training or support before you engage with residents? (e.g. from care home managers, researchers, or clinicians who have worked in care homes)
- Are you fully aware of relevant local policies and national requirements, e.g. safeguarding procedures and the Mental Capacity Act? (see page 16 for information on MCA)

You are likely to have to use a range of approaches, depending on the care home and the needs of individual residents. The first stage is to generate interest in your research ideas and identify people who are willing to talk to you. The sorts of people you involve will depend on your research idea but may include residents with specific experiences and needs (e.g. people with dementia (mild/moderate), or people with specific health problems). Be aware that different approaches will be needed in order

to involve people with different communication needs (see links at end of this document).

Approaches that have been used include:

- Speaking at or attending resident/family meetings
- Holding an informal event at the care home to advertise your study e.g. a tea party
- Providing information for people to take away and read
- Spending time in communal areas of the care home to chat to people and answer questions
- If you want to engage with a particular resident, you may find it useful to identify who they engage with most closely and approach the resident through this intermediary
- Create a poster with your picture and contact details. This will also act as a useful reminder to residents about who you are
- Residents are more likely to engage with you if they understand why you are there. Involving them in setting the agenda for the project will help with this process.

This report focusses on involving residents in research as they are a discrete group of people who will have their own perspective on your research question, and we would encourage you to find ways of involving them in your research. However, there may be occasions when you want to involve parallel populations in addition to, or instead of residents. For example, you could involve people of a similar age but living in the community or the relatives of care home residents in your research. Both will bring expertise to your study, and may be particularly useful when residents have significant levels of dementia, or the topic is particularly sensitive (see box 1 for two examples).

Box 1: 'Talking about living and dying with the oldest old: public involvement in a study on end of life care in care homes'

PI: C Goodman, University of Hertfordshire

The PIRg (Public Involvement in Research group) based in CRIPACC (Centre for Research in Primary and Community Care), University of Hertfordshire was set up in 2005 and has 12 lay members, 4 academic staff and one co-ordinator. Members meet on a regular basis, have access to research training and hold an honorary contract with the University. The EPOCH research study team included four members of PIRg (who were of similar age to those of the care home residents and had experience of care homes through family members or friends), who contributed to preliminary discussions about the research proposal. All four PIRg members sat on the steering committee and three were involved with other stages of the research process; including review of study documentation, recruitment (explanation of information leaflets, consenting process), data analysis (reading interview transcripts, identification of key themes, discuss findings), running discussion groups in the care homes to discuss the emergent themes and dissemination (commenting on final report, co-presenting/sole presenters).

Goodman et al (2011) identifies three main areas where public involvement directly affected the outcomes of the study which were recruitment, governance and safeguarding and the discussion and interpretation of emergent findings with the care home residents. The research paper also acknowledges the power relations between researchers and PIRg members.

Mathie, E., Goodman, C., Crang, C., Iliffe, S. Manthorpe, J. Barclay, S. (2012) An Uncertain Future: The Unchanging Views of Care Home Residents about Living and Dying, *Palliative Medicine,* June 22, doi: 10.1177/0269216311412233.

Goodman, C., Mathie, E.J, Cowe, M., Mendoza, A., Westwood, D., Munday, D.M., Wilson, P.M., Crang, C., Froggatt, K., Iliffe, S., Manthorpe, J., Gage H. and Barclay

S. (2011) Talking about living and dying with the oldest old: public involvement in a study on end of life care in care homes. *BMC Palliative Care*: 10:20 doi:10.1186/1472-684X-10-20 (23 November 2011).

'A study of suspected scabies outbreaks in residential care facilities'

PI - J Cassell, Brighton and Sussex Medical School.

Outbreaks of scabies in residential care can be difficult to control, and are often difficult to diagnose in the elderly. It is associated with stigma for both the patient and care home, and so if often under-reported. We obtained funding for a small pilot study from the British Skin Foundation to study suspected outbreaks in care facilities. At the very start of the project we wondered who we could get on board for PPI. There are no scabies patient groups, so we moved our thoughts into the area of nursing home experience and where could we find lay people who had something to offer in this particular area? We contacted the Alzheimer's Society to ask if they had any lay members with experience of scabies in any way.

Two ladies came on board; one was a retired nursing home manager who had experience of a scabies outbreak in her home; the other had her elderly mother in residential care where there was a scabies outbreak. We identified an ethical issue with our study in that many residents lack capacity to consent, and it was our PPI members who knew about another study that had developed a novel approach to gaining consent, which we adapted. As a result of plenty of work from everyone but including the significant help from our lay members our study is now funded. (Michael Head, University College London)

How to Involve Residents, Relatives and Friends in your Research

INVOLVE provides useful generic guidance about how you might involve people throughout a research study (INVOLVE, 2012). Readers who are new to involvement are advised to visit their website for the latest guidance.

As with any involvement activity it's useful to think about the research question/topic before you start, as this will influence **who you involve**, **how**, and **when**. It is also

important to consider *why* you want to involve people (purpose of involvement). Taking time to work through these questions will help with planning your involvement activities.

Designing your research

- Identify what is important to residents, staff and relatives and use this to formulate possible research questions
- Use your preliminary research question as a starting point for discussions. Be prepared to adapt/change your question as you learn more about the care home setting
- Staff and residents are unlikely to know much about research so you could start with an information sharing stage
- Residents and relatives can provide insight into the feasibility of your design. It is worth talking to a few different care homes. What will work in one, may not work in another
- Managing expectations is vital. Be clear about which aspects of the design can and cannot be changed and why; especially if there are limits imposed by funders on what is and is not possible
- Feed back to residents the details of any changes to your study as a result of talking to them

Maintaining communication

Once your project has started, maintaining communication with the care homes you have involved at the design stage is good practice, especially if you want them to be involved at later stages of the research. You can keep people informed by:

- Producing a short newsletter
- Identifying someone in the care home to act as link person and disseminating information via them
- Attending staff/resident/family meetings and updating the meeting regularly on progress.

Study management

Do you want a resident/relative to be a co-applicant on your grant?   Things to think about are:

- Being a co-applicant is a significant responsibility and so you, and they, will need to be aware of the potential strain involved. Be honest and discuss this in advance. If inviting a family member to be a co-applicant, will they have the time to devote to this?

- You should discuss the issue of payment for their time (see page 28 for a discussion).

- Most research meetings are 2-3 hours long and take place at university or NHS sites. Consider the accessibility of the venue, timing and duration of meetings. Can potential lay co-applicants attend these meetings? Are the rest of the team willing to run meetings in an accessible way? What can you do to facilitate their involvement?

- You may also want to invite a staff member to be a co-applicant but this isn't a substitute for involving residents/their family members.

Is an advisory group appropriate?

Another way of involving residents in the management of your research is to set up an advisory group. Research advisory groups benefit greatly from the involvement of people who live in care homes. Generally, it is a good idea to have a few residents and/or relatives involved in the group so that they can support each other. If you hold some meetings at the care home even relatively frail residents can have the opportunity to get involved. If you schedule shorter meetings at times to suit residents this also increases their opportunities to get involved (see box 2). Alternatively, you might try developing a 'virtual' advisory group with care home staff facilitating feedback from residents to the research team on an ad hoc basis.

Box 2: Pilot Trial of Stop Delirium!

PI: Najma Siddiqi, Leeds University

We produced a patient information DVD in collaboration with the two lay members of our steering group. They both edited the script and delivered the message. Both of these members had an existing interest in delirium and friends or relatives resident in care homes. We then sent the DVD for review by residents in a care home not involved in the study. As a result of the review some of the graphics were changed and the background music removed.

Parallel groups

A number of universities and research organisations have set up parallel groups, with people who are of a similar age to the residents and have experience of care homes via friends and family members (see box 1). Another example of this form of involvement is the NIHR School for Social Care Research which has a standing User/Carer/ Practitioner reference group (http://sscr.nihr.ac.uk/ucprg.php) that includes people who work in care homes and carers of people living in care homes. The group ensures that people who have insight into life in a care home are fully involved in grant award decisions; in reviewing applications for funding, scrutinising research reports from funded projects, and attending presentations by researchers, sometimes chairing such events.

Participatory research

There are no rights and wrongs in terms of the involvement methods researchers choose to adopt. Different methods are appropriate for answering different kinds of research questions. The NIHR INVOLVE definition separates 'research participation' from 'research involvement', but 'participatory research' blurs these boundaries. This is because the research methods themselves are built on principles of community engagement and hearing the service user voice. These approaches include Participatory Action Research (PAR), Co-production, and Appreciative Inquiry. In this type of research, the research process itself is change-orientated, and the changes in question are intended to be brought about through collaborative social action. The participants are regarded as co-researchers, and there is a conscious intention to remove, or at least reduce, traditional power inequalities and role differentiation between participants and researchers. There is no attempt to carry out research under the controlled conditions necessary in other areas e.g. drug trials. Instead the purpose is to effect change through collaborative processes (see box 3 for an example). Researchers learn what they need to know from participants, who are regarded as the experts on their own experience. Such approaches are therefore particularly appropriate for research which is aimed at practice improvement and culture change.

Box 3: 'Can participatory video enhance social participation and well-being for people with dementia in long-term social care?'

PI: Andrea Capstick, University of Bradford

A research study which took place in a voluntary sector care environment piloted the use of a film-making approach called Participatory Video (PV). The aim was to find out whether taking part in this activity enhanced social participation and well-being for people with dementia. PV had been used previously with other socially marginalised groups, but not with people with dementia living in long-term care. The aim was for each of the 10 participants to make a short film whose content was decided entirely by that participant. The researchers were directed by the participants regarding their own choice of images, sound effects and narrative. The content of the films proved to be a valuable way of communicating to others what was important to each participant. By communicating his or her values, interests and beliefs, the films also provided indications of improvements that could be made to each person's quality of life. Participants' responses to, and evaluations of, the film-making approach was integral to the study outcomes. Their feedback on various aspects of the process therefore had a major influence on whether the aims of the study were deemed to have been met or not. Whilst there were also people with dementia on the advisory group for the study, their role was to receive updates about what the participants had been doing and advise on any ethical issues. They did not have the same active role in directing the research process that the co-researcher participants had.

Carrying out your research

As well as general oversight of your study, you may also want to invite advisory group members to be involved in specific research tasks, for example helping to design interview schedules, choosing outcome measures, helping with recruitment, interviewing, co-facilitating focus groups or interpreting data. This will depend upon the people you are working with, your methodology and the time you are able to put into supporting their involvement. Don't forget to cost in their time and their travel and maybe care costs.

Dissemination

- Residents and family members may be willing to give quotes/interviews regarding the research and why it is important to them. This could help you to reach a wider audience who may not normally be interested in research.
- It's good practice to feed back the findings of your research to participants. Involving care home partners in this process (e.g. deciding on methods of dissemination; commenting on the wording /format of dissemination materials) will help ensure that the findings are presented in a way that is relevant and accessible.
- If you involve relatives in your research they can help with dissemination and discussion of emergent findings with participants (Goodman et al., 2011).
- Publish the findings.

Facilitating Involvement

Ideally, this should start with setting the research question together. However, we are aware that this is not always possible (e. g. in the case of commissioned research where the question is set by the funder). **It's never too late to involve people**. If you already have a research idea, you could start by checking that the question is relevant and interesting to residents. You are not likely to be able to involve everyone, so take the time to explain to residents why some people are not being approached to avoid any feeling of bias.

Many older people living in care homes will have some form of cognitive impairment (e.g. Dementia). You may need to take extra steps to facilitate the involvement of these people. In the next sections we provide some suggestions to help you think through these issues.

Once you have identified people to talk to, a range of approaches may be useful. Care home staff can be helpful in identifying techniques which will facilitate conversations with individual residents, or with groups of residents. Some of these techniques are also data collection approaches but they are just as useful for the involvement activities described in this document.

Getting people together

- You could you arrange to talk to people at a time they come together anyway (e.g. an exercise or reminiscence group), or arrange for some entertainment to be put on at the home after your session by way of a thank you

- Embed your objective in an activity that is pleasurable for residents. Organise an involvement activity that allows you time to talk to residents about your research topic – e.g. a cookery demonstration or activity could elicit information about diet and eating patterns within the home to help you focus your research question

- Arrange a series of meetings with a group of interested residents

- Arrange meetings with a specific family group when they come to visit. This will allow you to include residents who may be unable / unwilling to take part in discussions with other residents. It will also allow you to gain the perspective of family members

- One-to-one chats with residents may be just as useful as formal meetings (see box 4). Sitting down and having a general conversation which is not focussed on the specifics of your research question can be helpful, especially if the resident has cognitive impairments such as dementia. These ad hoc conversations are vital for building up a rapport with residents and hence encouraging people to give you their views about your research question/design. They may also provide insight into what is (and is not) important to residents. Remember that every conversation counts!

Box 4: 'You win some, you lose some!'

During the development of this report, we sought input from two care homes. In the first home we were invited to sit down with residents individually and chat to them about what we were doing. We did not give the draft report to residents to read but spent time asking them what it was like when people they did not know came into their home, and how they would like visitors (e.g. CQC) to behave. These conversations lead to the inclusion of some of the tips contained in this report.

At another home we asked if we could go and talk at a residents and relatives

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meeting. We were told only 2-4 relatives tend to come to the meetings, so we planned an interactive session with 3-6 people. By chance, over 40 people came that night and we were asked to give a 40 minute talk. We were unprepared for so many people and opportunities were missed because the audience was too large for our planned activities. For us, smaller sessions worked better than giving a larger presentation. It was hard to engage with residents in such a big group. We learnt that the care home environment can be unpredictable and that is it useful to have a variety of techniques and approaches ready to use as needed.

'Involving staff, residents and relatives in the development of a physical activity intervention'

PI: Anne Forster, Academic Unit of Elderly Care, University of Leeds

As part of the REACH (physical activity in care homes) Programme of Research we've involved care home staff, residents and relatives in an external reference group to discuss the components of an intervention to enhance movement of residents in care homes. This proved very useful. One of the issues that the process raised was who participated and how that shaped the views and experiences expressed. This isn't about representativeness in the way it is typically discussed by those who are lukewarm/anxious about public involvement; rather it is about being aware that those residents and staff who can engage in a forum outside of the care home will have different experiences to those that cannot. For example, the two residents both came from one home where some residents are physically and cognitively active and alert and go out of the home on their own. Ensuring that the voices of more typical care home residents are heard requires creative strategies. We've found it extremely useful to spend time with residents within care homes and through observation and conversations gain an understanding of people's varied views and experiences.

Communication techniques

- Offer opportunities for residents to give written feedback or comments. Some residents may not be willing to speak up in a group setting but may be willing to

put things in writing. Don't assume that all care home residents will be unable to provide written comments.

- Some residents may benefit from having someone with them when they talk to you. Be aware that this could be a member of staff, another resident or family member. Give residents the option. Ensure that the other person understands that this is not participation in research but involvement in research. Outline the stage you are at, e.g. at the preliminary stages of design or preparing material for dissemination.

- Communication can be a significant challenge for some residents. At times, non-verbal communication methods might be useful. Picture Exchange Communication systems (PECS) are widely used with people who have communication difficulties, and can be helpful. If in doubt, talk to your local Stroke Services or Speech and Language therapists as they may be able to help you address the communication needs of individual residents.

- Remind residents as to why you are there and what you are doing, as some residents may forget or become confused.

General advice when working within a care home

- **Be clear about why you are involving people in your research**. Questions to ask yourself are: What do you hope to get out of it? What are you asking of residents, and why?

- **Respect** - the fact that you are going into someone's home. This creates a different dynamic to involvement activities which are held in public places such as hospitals or universities. Residents may view areas such as the care home lounge as 'public space', and view their room as 'home'. You will need to find out where they feel most comfortable speaking to you. Remember that most residents cannot leave when they have had enough. Try to pick up on cues and regularly give people the option to take a break or stop. If you arrange to meet a resident at a specific time, it may also be useful to ring ahead to remind them you are coming and check they are still happy (and well enough) to speak to you.

- **Schedules** - Find out about the care home schedule and think carefully about when to plan involvement activities. Consider the times of meals, social activities, personal care, medication etc. Ensure that your research processes fit in with them, rather than assuming that care home staff will fit around your research.

Also remember that residents may want to rest after certain activities. You may have quite a small window to work with residents. Relatives are also likely to have other important commitments.

- **An ad hoc approach** may work best at first e.g. waiting in a shared area to talk to people as they pass. You may also want to consider evenings and weekends.
- **Spend time in the care home -** familiarise yourself with the residents so that they feel comfortable with you being around. General conversations with residents focused upon them demonstrate an interest in and respect for them. Some residents can feel socially isolated, and moving into a care home can be a difficult if not traumatic process, so developing social interaction with residents is vital for instilling confidence.
- **Privacy and confidentiality** - maintaining confidentiality in shared living areas may be challenging. Find out if there are any quiet areas available to talk to residents. You will need to find ways to ensure privacy and confidentiality. Depending on your research there may be issues of confidentiality due to patents, or licences. Some residents may not remember this, and this possibility needs to be negotiated with the research team/funder.
- **Diversity of involvement activities** - think about the individual needs of the people you are working with and give them choices about how to be involved in the project. The type of care home you are working in may influence this. For example, the dynamic in a home which specialises in dementia care may be quite different to a care home which does not.
- **Adapting your involvement activities to your population -** think about the particular needs of the residents you want to involve and adapt accordingly e. g. pace of discussions, support if deaf or hard of hearing and language support.
- **Personal safety** - some residents may become confused easily or have a history of aggression. Ask staff and relatives (where appropriate) to advise you on the best way to involve those residents. Ask someone to stay with you if you feel unsafe. Some residents may also require help to move between different areas within the care home. Don't help residents to move if you are not trained to do so-seek assistance from staff.
- **Health and safety -** understand the health and safety issues.

- o Get to know the specific health and safety procedures at each home e.g. are certain doors kept locked? What is the fire procedure?
- o Find out what the procedures are if someone falls ill and requires immediate medical attention. Are there alarm systems in each of the rooms? How are they operated? Where are they located?
- o Illness - don't go in if you're feeling unwell. Bugs spread quickly within care homes and you may be putting vulnerable residents at risk.

- **Raising concerns** – be aware of the local adult safeguarding contact, in case you observe anything which you feel needs to be reported to someone (if in doubt contact the CQC). There should be a key person within the research team that research staff can talk to if they have concerns. Also let residents, relatives and staff know who to speak to if they are unhappy with your conduct. It is good practice to provide them with an information sheet (as you would if you were collecting data) as this acts as a reminder for them.

- **Allow extra time** – working with a frail older population is likely to take a great deal longer than a researcher anticipates. Allow extra time for residents to pace themselves, digress into areas of interest to them (not necessarily you). And be prepared to repeat work, especially with those who have memory problems.

Ethical Considerations

A statement has been developed by the National Research Ethics Service (NRES) and INVOLVE, which provides guidance on patient and public involvement in research. The statement has been approved by the NRES Advisory Group on NHS Service Users and Ethical Review, and means that the majority of (PPI) activities do not require formal ethical approval or formal consent procedures (INVOLVE, 2009). However there are still ethical considerations and researchers should still maintain a high level of ethical and professional practice. Similarly, the Mental Capacity Act 2005 (http://www. legislation. gov. uk/ukpga/2005/9/contents) is not written with involvement activities in mind; however the main principles are relevant. The Mental Capacity Act (MCA) states that capacity should be assumed in the first instance, i.e. it is wrong to assume that all residents with dementia lack capacity. The MCA also states that every effort should be made to help people to express their views before deciding they lack capacity. In this instance this is the capacity to make a decision about taking part in your discussions. A useful resource is the Adults Lacking

Capacity to consent in research toolkit, developed for NRES by the Universities of Leicester and Bristol (https://connect. le. ac.uk/alctoolkit). The toolkit reviews capacity in the light of UK law and how this applies to research (2010), not involvement, but it does provide useful guidance about the importance of ensuring ongoing capacity, and this will be time-specific, and decision-specific. Saying you will only involve those with capacity is not straightforward. You may have to assess whether they have consent to take part today, and whilst acknowledging this may not be the case tomorrow.

The principle of inclusivity which underpins the MCA should be applied to involvement, and, where appropriate, advice should be sought from someone who knows the resident. Traditional meetings or focus groups are likely to be challenging for people with cognitive impairments or other communication difficulties. Offering a variety of involvement activities and adapting your processes to meet the needs of individual residents may help make your project accessible and inclusive. The MCA should not be used to inappropriately exclude residents from involvement activities. Although some residents may only be able to make a small contribution to your project, it may still be very valuable.

Support and training Needs

It is important that residents and family members feel well supported when taking part in involvement activities. People may also require training for specific research roles, although providing training to members of the public involved in research has been widely debated (Staley, 2009, Ives et al., 2012). Residents, relatives and friends are likely to have different support, training and information needs, and these should be tailored to them. Their needs will depend on their past experience of research and the nature of their involvement. Training and support can be addressed in different ways and using different mediums, for example, formal training workshops, one to one meetings or online training. More information about involvement training and support is available on the INVOLVE website http://www.invo.org.uk/resource-centre/training-resource/.

Reward and Recognition

One of the principles of involvement is that there should be a reciprocal relationship between members of the public and researchers. This means acknowledging and rewarding their contributions appropriately. Consider the different forms of recognition and reward which you can offer to individual residents in and the care homes themselves. This might include:

- Homes may have an activities fund or something similar which you can contribute to (see below for more information).
- Offering to present the results of your study (even if you do not go on to collect data from that home) or other projects to residents, family members and staff.
- Contributing to the reputation of the home, for example by writing something about research for their website.
- Providing certificates to show how residents and/or staff have been involved in research at a particular stage.
- Providing some materials/training about research (although in our experience these are unlikely to be enticing to residents, they may be attractive to staff).
- Acknowledging people in publications/reports (this may include co-authorship).

Offering payments for people's time

It is considered good practice to offer a reasonable reimbursement for people's time when they are involved in research. The Mental Health Research Network and INVOLVE have produced an online cost calculator and guidance to help researchers budget for involvement (Mental Health Research Network and INVOLVE, 2013). However, when considering how and what to pay care home residents, things can become more complicated. It may be appropriate to offer individuals payment for their time. For example, you may invite a resident to become part of a steering committee where other members are being paid a fee /salary to attend. In this example it is equitable to also offer a fee to them.

As discussed in other parts of this document, less formal involvement activities are likely to be used in this setting. When this is the case, it may be harder to decide what level of research is reasonable. You may decide that a donation to the care

home (for example to the resident's fund) is more appropriate in these circumstances.

Some residents may not manage their own finances (e.g. people with severe cognitive impairments or people at the end of their life). It's important to seek advice from staff and family members about the appropriateness of, and mechanisms for, making payments to these residents.

 Following these basic principles may also be helpful:

- Whatever approach you take must be made clear and agreed by everyone involved (residents, family members and staff).
- Nobody should be out of pocket due to involvement activities.
- If payments are offered, rates should reflect preparation time, the level of skill being used and the rate which other members of the research team are being paid for similar activities.

It's possible that people may turn down payments when offered. The vast majority of residents and relatives we spoke to during the development of this report felt that it would be more appropriate to give a payment or gift to the care home than to an individual.

Paying expenses

As a minimum, individuals and care homes should be offered expenses. Again, the INVOLVE guidance will help when budgeting for this. It's important to stress that that the actual cost of involvement activities undertaken outside a care home (e g. if residents and/or staff are asked to attend external meetings or workshops) is likely to be quite high when expenses such as travel costs, and the cost of care worker time etc. are factored in. In addition to offering expenses to residents, it is also important to ensure that care homes are not out of pocket from supporting your project. For example, you may need to consider payment to backfill staff time, if they are busy supporting your work.

It's important to recognise that care homes have different structures and different needs regarding equipment, activities funds, staffing etc. There is no "one size fits

all" solution. Researchers need to work with care home staff and residents to work out how best to proceed. It's important that any reimbursements are compliant with financial policies within your organisation and HMRC requirements.

Evaluating Involvement Activities in Care Homes

During our workshop there was much discussion about if and how involvement activities should be evaluated. One advantage of evaluating your involvement activities is that it can enable you to appraise your own practice and share positive experiences with others. A formal evaluation framework can be used, for example the Public Involvement Impact Assessment framework (http://piiaf. org. uk/) ([(Popay et al., 2014)](http://piiaf. org. uk/))). Alternatively a more informal, iterative approach can be adopted, for example, keeping a log of key learning throughout the project and adapting your approach to PPI as needed.

It is worth asking what you hope to get from involvement activities at the start of your project. This could be used as the basis on which to evaluate the success or otherwise of the involvement activities.

Areas that can be assessed/evaluated include:
- The extent to which researchers involved residents
- Any 'adverse events' – things that didn't go well
- Any changes that were made to the research design/conduct as a direct result of resident's involvement
- Extent to which 'harder to involve' residents took part (e.g. those with cognitive impairments, co-morbidities, learning disabilities)
- Impact on residents and family members e.g. changes to their levels of knowledge and/or self- confidence
- Impact on researchers e.g. what did you learn from working with residents and family members?
- The format of involvement activities e.g. were some more effective than others?

Evaluations should involve seeking the perspective of residents, family members, and care home staff as well as that of the researchers. Different approaches would be needed for each of these stakeholder groups. Any survey or questionnaire for

residents should be as short and simple to understand as possible, and tailored to different people's needs. Tick-sheets or 'happy-sad' sheets have also been used effectively.

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USEFUL WEBSITES

Association for Real Change: http://arcuk.org.uk/care-providers-alliance/

Care Quality Commission: http://www.cqc.org.uk/

DeNDRoN ENRICH toolkit: http://www.enrich.dendron.nihr.ac.uk

Mental Capacity Act Code of Practice can be found at:
http://www.dca.gov.uk/menincap/legis.htm#codeofpractice

National Care Association: http://www.nationalcareassociation.org.uk/aboutus.asp

National Care Forum: http://www.nationalcareforum.org.uk

NIHR School for Social Care Research: http://sscr.nihr.ac.uk/

Registered Nursing home Association Ltd: http://www.rnha.co.uk

Royal College of Nursing (information on communicating with people with dementia):
(http://www.rcn.org.uk/development/practice/dementia/supporting_people_with_dementia/communication).

SCIE (Social Care Institute for Excellence) has a MRC resource section with useful materials to support researchers communication needs:
http://www.screc.org.uk/mca.asp)

The Research Ethics Service (NRES) has produced a number of guidance documents and an online toolkit about research and the MCA. These are available from the website http://www.hra.nhs.uk/