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PPI report for proposed study, ‘Listen and Learn’

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Context

Patient and Public Involvement (PPI) work was undertaken to engage relevant stakeholders (residents, family members, volunteers and staff) in order to incorporate their experiences and insights into our NIHR grant proposal, *"Listen and learn"*. The proposed research study aims to explore the use of resident feedback in care homes to embolden person-centred care.

NIHR RDS formally funded PPI activity in the NW throughout the summer of 2016. Using similar methods, researchers from project teams across the UK also informally engaged with residents, care managers, volunteers and family members in their networks to provide perspectives from across the UK. This report focuses on the NW engagement but is reflective of the wider, informal engagements.

Aims

The PPI activity was undertaken in order to learn from older people, their formal carers and families/relatives:

- The relevance to them of the proposed research question
- How best to attract, recruit and retain people as research participants
- Identification of ethical issues and concerns
- How best to support staff and volunteers during research
- How best to communicate the difference (impact) our project makes

Design

Fieldwork was conducted in July 2016. Loosely structured conversation schedule organised around key project landmarks or areas of risk (project aims and objectives, project methods, identification of impact, keeping people safe). Conversational evidence captured by hand-written field notes during afternoon-length visits to the care environments. Fieldwork conducted and transcribed by a researcher with experience working with older people (Dr Beth Luxmoore, Alzheimer's Society).

Recruitment

An MMU colleague who currently provides oversight to NHS-funded care home care in GM provided the names of potential venues and care home managers in the NW region. Dr Nigel Cox (MMU team and co-chair North West People in Research forum) then identified gatekeepers for the purposes of PPI work. Two care homes were contacted and provided with written information about the proposed project, contacts, and the PPI activities planned. Both agreed to grant access-in-principle.

Venues

Venue 1: a 'village style' community for older people in Cheshire (visit date 4 July 2016). CQC profile, rated 'good'. Venue described as "[A] purpose-built complex that provides modern accommodation for people who require nursing or personal care. The village is located in a residential area of Crewe. There are six separate households, each able to accommodate 10 or 12 people who require differing levels of care, support and treatment. For the purpose of this report we will refer to the accommodation as households."

Venue 2: a traditional care home for older people in Lancashire (visit date 21 July 2016). CQC profile, rated 'requires improvement'. Venue described as "provid[ing] accommodation and personal care for up to 20 people in a large converted and extended residential building. The service is located approximately one mile from […] town centre. Accommodation is provided over two floors with a passenger lift and stairs between the floors."

Participants

Participants were approached by the care home manager, and information provided to them in order to ascertain their interest in the involvement/PPI activity. Refreshments were also supplied, although one care home provider preferred to supply their own refreshments. The researcher was permitted supervised access, and interviews/conversations were conducted in a range of locations, e.g. in resident's rooms, with their permission; a meeting room and a conservatory for conversations with staff and volunteers, and one of the homes provided use of their 'relaxation room'.

The participants comprised:

- Care home staff (n=3), coded A1-3 in evidence below
- Care home residents (n=4), coded B1-4
- Relatives of care home residents (n=2), coded C1-2
- Volunteer, coded D1

Method

The fieldwork researcher devised a set of themed prompt questions (Appendix 2). Evidence from these responses was anonymised at source, transcribed and stored securely, with only the PPI team (BL, NC, JT) able to access the material. Evidence was then pragmatically and thematically précised and implications for project planning, design and implementation identified.

Findings

Theme: time

Evidence synopsis

Barriers to communication develop over time: whilst communication might be of a high standard when a resident first moves into a care setting, this can deteriorate over time (A1). Communication standards over a long period are important, e.g. "We've had a very good experience over the last 4-5 years. The organisation is amazing and has high standards" (C1). Importance of regular involvement with incisive observation, e.g. "Changes can be very subtle, situations, opinions and outlooks can change. You can only see these changes if you know the person well" (D1).

Implications for project planning, design and implementation

- Immersion and contact with the field over a protracted period
- Researcher time to develop rapport and fieldwork relationships
- Range of data collection methods that capture nuance and subtle change over time
- Researcher role specification & post-recruitment support commensurate with above

Theme: voicing concerns

Evidence synopsis

Some residents who took part expressed that they would feel able to raise a concern with care home staff (e.g. B1, B3), although they were sometimes unclear about how to accomplish this, or with whom (B1). However, residents and their relatives/guests[1] often feel like they are “nit-picking” (A1), sometimes find that it is difficult to communicate with a large team of staff and “often give up” communicating if they feel that initial approaches have been overlooked or ignored. Feeling unheard can be a cause of upset, “unbearable, causing people to blow up” (A1). Some residents had formed a clear view of the best way to achieve communication in the care home, but recognised the potential for conflict, e.g. “It is important to say what you think, as long as it is polite …I don’t like arguments, I just like to talk. Some people like to pick a fight.” (B2)

Implications for project planning, design and implementation

- Clear and consistent use of terminology, e.g. ‘carers’ defined differently
- Methodology to determine difference between policy intentions and practice
- Analysis of institutional texts (e.g. policies) alongside narrative to identify deviations
- Researcher role specification & post-recruitment support commensurate with above

Theme: fostering communication

Evidence synopsis

The importance of a named family member being the “central contact” (C2) to enable communication was highlighted. Family members and significant others have different communication preferences, e.g. text message, e-mail or phone calls. One carer described how they still “stayed in touch” with the families of former residents (A2). Another setting used a private Facebook group (A3) to enact sharing of care home activities, e.g. “photos and stories” from the care home. Communication strategies (e.g. manager’s “open door” policy) were perceived by leaders to be effective (A3), e.g. “relatives are not afraid to speak up”, but might not be recognised or utilised by residents or guests, e.g. “residents seem fine, but will say things to relatives that they wouldn’t say to us” (A2). One manager described the use of “My Diary”, where residents could record their “preferences and life story” (A3).

Implications for project planning, design and implementation

- Clear ethical parameters (e.g. problematic, “staying in touch”, social media, etc.)
- Consider visual/storyboarding/diary methods, within ethical parameters
- Methodology to determine experience of policy vs. practice (e.g. “open door policy”)
- Methodology to determine relationship between staff hierarchies and communication

Theme: privacy, isolation and fieldwork geography

Evidence synopsis

Residents’ perceived importance of privacy (B4), reconciled with they and their family’s recognition (C2) of isolation, e.g. “I keep myself to myself, but this isn’t always a good idea”, and having “no idea who I would speak to [if concerned]” (B1), contrasting with manager’s perspective, e.g. “We need to be personally involved with residents. Detachment doesn’t work” (A3). The physical environment was seen to influence communication (D1), and homes that were smaller and “less intimate” (C2) were seen to impact negatively on communication; this might be compounded in care settings that

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[1] Relatives/guests, i.e. visiting family or friends. Use of the term ‘Carer’ may be problematic, as this evidence shows that the term can be used to describe a partner/family member who cared for the person *prior* to their move into the care home, but it is also used within care settings to describe people who are employed in paid care-delivery/support roles, e.g. care assistants, support workers.

are distributed across a number of buildings, e.g. the ‘care village’ format (A1). The physical environment was seen to influence communication (D1), and homes that were smaller and “less intimate” (C2) were seen to impact negatively on communication.

Implications for project planning, design and implementation

- Methodological endeavour to ethically ‘reach’ those who prefer privacy/isolation
- Difference in communication strategies and success in large/small/diffuse contexts
- Exploration of language in use (e.g. ‘holistic’) vs. actuality in practice

Theme: volunteers as ‘go-betweens’

Q: We are suggesting that volunteers could be used to facilitate feedback about care experiences between people who live in care homes and their family carers with the employed staff who provide care and support in the care home environment. What do you think about this idea?

Evidence synopsis:

Overall, cautious positive remarks made about volunteering roles, and their role as a fresh pair of eyes (A2), but with some caveats. Queries and concerns about recruitment, “local competition for volunteers” and managing relationships between all involved (A1) and “muddying the waters” of staff-resident relations (C2); reminder that relationships take time to evolve (A1,A2,C2,D1); training is important/may be required (A1,A2,C1) especially with people with dementia (C1). Knowing more about the background/suitability, supervision and trustworthiness of volunteers is important to some (B1,B2,C1,D1), gender and ethnicity might be important for some residents (A2).

Implications for project planning, design and implementation

- Fieldwork time sufficient to develop rapport and fieldwork relationships
- Need to scope volunteer resource pool/interest in fieldwork location
- Clear recruitment parameters and process for volunteers
- Consideration of complex needs/skills requirements, e.g. dementia
- Attention to ethical conduct, supervision and safeguarding processes

Theme: understanding the difference the project could make

Q: Do you think the proposed way of working using volunteers, could make a difference to the care of people who live in care homes? Are there other ways we can understand how improved communication between residents and family carers and the care home staff could make a difference to people's experiences of living in a care home?

Evidence synopsis

Overall insight into the need for multiple evaluation approaches, e.g. using resident’s monthly reviews as a data point; confidential survey (A1), but recognition that observations alone might not reveal impact (A1); Staff and relatives indicated that body language might be useful indicator (A2,C2); social media, e.g. “Our ‘my blog’ tool could be used for this” (A3). Caution about reliance upon audit processes which “shift power back into the hands of the staff” (A3); make sure that benefits noted are those for the person, not the home (B1); evidence of a “nice environment” [did not qualify what this entails] (B2); improvements might not be immediately obvious (C1); resident’s own knowledge essential in the measurement of impact (C1); anecdotal evidence from families (C1), but concern about representing those who don’t have families (C1).

Implications for project planning, design and implementation

- Research or evaluation methods that are mixed and consider non-verbal communication
- Methods that consider the environment of care
- Critical stance when using audit data
- Potential for use of social media/blogs to evidence impact
- Benefits/impacts focused on people, not institutions
- Sufficient time to ascertain impact
- Inclusion and participation of those without family or other networks of support

Theme: keeping people safe: ideas to improve communication

Q: What else (beyond what is planned) might we do to make it easy for people to speak up about their experiences of living in a care home?

Evidence synopsis:

Remarks about adjustments for people with specific LTC/disability (Parkinson disease example); culture of the care home environment is important, this “trickles down” from managers (A1); can be difficult to “keep tabs” on staff in a large home (A1); residents’ meetings, group discussions, cookery classes, music shows, suggested as facilitators/methods to support communication and identifying needs (A2,C1); dementia good practice (A2,C2); a “companion system” [not detailed] (A2); Social media (A3); “Challenging the processes e.g. excessive health and safety bureaucracy” (A3); changing attitudes across the workforce (A3); guidance about speaking up (B2,C1); recognition of different family sizes/structures and communication needs/guidance (B2,D1); time to do things, “I like not having to rush”, relaxed, quiet (B2,C1, D1); “We need to learn from different countries” (about communication) (B3); independence important, “doing my own things” (B4); children can have a (positive) impact in the home (C1); informal chats better than forums (C2).

Implications for project planning, design and implementation

- Equality impact assessment/reasonable adjustments/supports for people with specific LTC/disability or dementia
- Methods that capture cultural environment and evidence management/leadership contexts, e.g. barriers introduced due to health and safety requirements
- Alternative contexts for research, e.g. cookery classes, music shows, ‘informal’ conversations vs formal interview approaches
- Guidance/protocol about speaking up about standards of care

Theme: how has this experience been for you?

Evidence synopsis

Very few remarks, all of which were positive, some suggestions about alternate approaches, e.g. “it is easier to talk about ideas than to write about them, this can disrupt the thought process”, “it’s good to share anecdotes and experiences” (C2); suggested recording discussions rather than writing them down (C2); some people might prefer to write their own notes (rather than an interview) (D1).

Implications for project planning, design and implementation

- Anecdotal/experiential ways to ask questions, i.e. ethnographic interviewing approaches
- Possibility of participants writing/recording their own data in their own time

Appendix 1: Learning from involvement mapped against NIHR application PPI areas

Design considerations following PPI activity (mapped against NIHR 'planned patient/public active involvement in proposed research' checklist)	
Design aspect	**Summary of issues raised during PPI and points for consideration**
Design of the research	1. Recruitment of volunteers may be challenging in some contexts/geographical areas due to limited pools of people and/or location, so there is a need to scope volunteer resource pool/interest in fieldwork location 2. Clear recruitment parameters and process for volunteers; clear communication of ethical conduct, supervision and safeguarding processes in order to reassure participants 3. Methodology to determine difference between policy intentions and practice, audit data vs real-world experience, staff hierarchies and communication, barriers related to health and safety, management etc. 4. Methodology to consider alternative and bespoke approaches, e.g. visual/storyboarding/diary methods, ethnographic interviewing approaches, participants writing/recording their own data in their own time 5. Methodology that affords sufficient time and depth of immersion in the context(s) to develop rapport and fieldwork relationships with participants; methods that capture nuance and subtle change over time 6. Methodology that is mixed and considers non-verbal communication, the wider care environment, and addresses a diverse resident population, e.g. dementia, disability, LTCs., other equality strands. 7. Methodology that is flexible enough to allow alternative contexts for research activity, e.g. cookery classes, music shows, 'informal' conversations vs formal interview approaches were thought beneficial 8. Sampling/selection that promotes Inclusion and participation of those without family or other networks of support, including methodological endeavour to ethically 'reach' those who prefer privacy/isolation 9. Recognition that different kinds of care setting/layouts will require different kinds of engagement and communication strategy, e.g. large residential care settings, small/diffuse contexts, e.g. care villages.
Management of the research (eg steering/advisory group)	1. Ensuring representation from people with specific disability/LTC that may inhibit invitation and/or participation and/or contribution in some form to the steering/advisory group 2. Ensuring representation from diverse or seldom-heard people, e.g. those without the social networks or social capital that are necessary to facilitate access and influence steering group
Developing participant information resources	1. Clear and consistent use of terminology, e.g. 'carers' defined and understood differently by different audiences at different times and will be need to made clear throughout documentation 2. Unforeseen disclosure or observation of care concerns during the conduct of fieldwork, i.e. guidance for participants/protocol for researchers about speaking up about standards of care

Undertaking/analysing the research (e.g. member of research team)	1. Researcher role specification & post-recruitment support commensurate with above; important to PPI consultees that researchers were skilled with regard to complex needs, e.g. dementia, communication, etc.
Contributing to the reporting of the research	1. Clear ethical parameters/standards of reporting when reporting detailed qualitative data; consideration of risks of deductive/retrospective disclosure especially in context of volunteer activity/social media, etc.
Dissemination of research findings	1. Potential for use of social media/blogs to evidence impact with ethical caveats and safeguards 2. Benefits/impacts focused on people, not just institutions 3. Sufficient time to ascertain impact 4. Dissemination/reporting to consider equality impact/reasonable adjustments/supports for people with specific LTC/disability or dementia
Other	1. Researcher role specification & post-recruitment support commensurate with above

Appendix 2: fieldwork questions

1. Project aims and objectives – is there a need to improve communication?

A key aim of the proposed project is that improved communication between people who live in care homes, their relatives and paid carers can improve residents' experience of care. Do you agree with this? Why is this project important / not important in your eyes?

2. Project methods – volunteers as go-betweens

We are suggesting that volunteers could be used to facilitate feedback about care experiences between people who live in care homes and their family carers with the employed staff who provide care and support in the care home environment. What do you think about this idea?

3. Understanding the difference the project makes

Do you think the proposed way of working using volunteers, could make a difference to the care of people who live in care homes? Are there other ways we can understand how improved communication between residents and family carers and the care home staff could make a difference to people's experiences of living in a care home?

4. Keeping people safe – any other ideas to improve communication?

What else (beyond what is planned) might we do to make it easy for people to speak up about their experiences of living in a care home?

5. How has this experience been for you?