RESEARCH PRIORITY SETTING IN CARE HOMES

Research Proposals Briefing

Victoria Shepherd

Dr Fiona Wood

Professor Kerry Hood

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Research Priority Setting in Care Homes – Research Proposals Briefing

Aim of this report

The purpose of this confidential briefing report is to aid the development of research topics identified during the Research Priority Setting in Care Homes project to be taken further as the basis for specific research projects.

The briefing is in four parts for each research question identified as a 'top 15' priority:

- General context
- The question in a structured format
- What the research evidence says
- Alignment with any relevant research priority criteria

We hope the study findings, and additional contextual information, are helpful to those interested in developing research proposals around the questions and themes identified.

Victoria Shepherd, South East Wales Trials Unit*

Dr Fiona Wood, Division of Population Medicine

Professor Kerry Hood, Centre for Trials Research

*ShepherdVL1@cardiff.ac.uk

Research Priority Setting in Care Homes

Background

Currently, there is little evidence base for much of the care provided in care homes for residents. Research involving care homes is more complex and resource intensive than in other healthcare settings. Given the wide range of topics that require further investigation, and limited resources, one solution is to identify the priorities for future research. Setting research priorities assists researchers and policymakers to effectively target research that has the greatest potential public health benefit. A number of research priority setting partnerships have recently been established to determine research priorities which involved older people. However, these relate to specific conditions that affect older people, such as Alzheimer's disease and Parkinson's disease. We conducted the first research priority setting exercise to examine health and care related issues specific to this population, as identified by stakeholders within the care home sector.

Methods

The Delphi technique was used to identify research topics and develop consensus among care home staff participants. Care home staff from nursing and residential care homes throughout the UK were invited to take part, either by direct invitation, a link posted on websites or through local research networks. The process was informed by a review of existing evidence and the identification of emerging themes. The survey was conducted across three rounds by email or postal questionnaires. Firstly to elicit topics or areas of uncertainty that were considered by participants to require further research, secondly to prioritise the long list of research questions, followed by a third round to reach a consensus on the short list of questions.

Results

The study was conducted between March and October 2015. 83 participants responded to the initial survey, providing 144 uncertainties or questions. Following analysis and review against existing evidence, 76 research questions remained for prioritisation in the next round. 40/83 participants responded to the interim prioritisation round, and 43/83 participants responded to the final round which ranked the top 15 research questions by importance. After ranking, the top 15 research priorities included questions on person-centred care, dignity, appropriate staffing levels, and training and support requirements for care home staff. Two other groups (60 other care home staff, and 33 professionals including occupational therapists, doctors and social workers) also participated in the final ranking. The results from these groups had a similar ordering to those from the original cohort of participants.

Conclusion

This is the first study to establish the research priorities for older people in UK care homes. Research priorities identified by a key stakeholder group have been endorsed by other health and social care professionals involved in the care of older people.

Research to address the research questions identified as priorities during this study is required. Sharing these results with researchers, clinicians, and funding bodies will help to inform the care of older people by ensuring the future research agenda can be focused on the areas of greatest need.

Further research to identify the research priorities of care home residents and their friends and families, and to explore the evidence-practice gap for topics with existing evidence, may be useful.

Summary of Results

This study has established a set of research priorities for older people requiring long term care in the UK (Table 1). The themes most highly rated are person-centred care, staffing levels, end of life care, and the care home environment. The lowest ranked priorities were those that related to mobility, service delivery, and nutrition and hydration. The long list of research questions identified, and the interim order of the top 30 questions are found at the end of the report (Appendix 1 and Appendix 2).

Table 1 Final Top 15 Ranked Priorities

Rank	RQ ID	Research Question (RQ)
1	Person2	How can **person-centred care** be provided in care homes appropriate to the person's individualised needs?
2	Person1	How can **dignity** be enhanced for residents in care home settings?
=3	Staff5	What are appropriate **staffing levels** in relation to the number of residents in care homes and their relative care needs?
=3	Staff4	What are the **attitudes** of inexperienced care home staff towards providing person-centred care, and can training and support improve awareness of the need for person-centred care?
5	Staff1	What are the essential elements required when **training** carers working with older people in care homes?
6	End2	How can early and appropriate discussion with older people in care home about **end of life care** be supported?
7	Staff2	How can recruitment of carers with essential qualities such as **compassion and empathy** be improved by care homes?
8	Person3	How can **best interest decisions** made for care home residents with dementia be properly documented in care plans?
9	Env1	How can care homes be made to feel more **like a home**?
10	Comm3	What is the **public and media perception** of care homes compared with other care settings, and what is the impact on care home staff attitudes?
11	Oral2	What is the impact of levels of **oral hygiene** on the **nutritional status** of older people living in care homes?
12	End1	How can families and healthcare professionals contribute to improving **end of life care** for older people in care homes?
13	Activity1	What activities can improve the **quality of life** for care home residents with **impaired vision** or **hearing**?
14	Activity3	How can the provision of **visual aids** enhance the quality of life of people with end stage dementia?
15	Staff8	Can education strategies improve care home **staff attitudes** towards use of power and authority in their relationship with older people with cognitive impairments?

PERSON-CENTRED CARE

#1 RESEARCH QUESTION Person2: How can person-centred care be provided in care homes appropriate to the person's individualised needs?

#=3 RESEARCH QUESTION Staff4: What are the attitudes of inexperienced care home staff towards providing person-centred care, and can training and support improve awareness of the need for person-centred care?

These research questions stem from questions around ways of improving how individual residents' (both with and without dementia) needs, such as diet and hobbies, are specifically addressed. Other questions arose around how to develop a needs assessment procedure for care staff to carry out to develop person centred care to meet their individual needs, and around training of staff to improve delivery of person-centred care in care homes. There was a strong perception that junior staff, particularly those inexperienced in care work, did not appear to understand, respect or value the needs of residents, or were unable to balance competing preferences. Examples given included tuning TVs and radios into staff preferences rather than the residents'.

General context and definitions:

The principles and values of person-centred care (PCC) are enshrined in nursing and healthcare policy and strategy. Person-centred care considers the whole person, taking into account each individual's unique qualities, abilities, interests, preferences and needs. There is a regulatory requirement for person centred care 'Providers must do everything reasonably practicable to make sure that people who use the service receive person-centred care and treatment that is appropriate, meets their needs and reflects their personal preferences, whatever they might be' (Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 9) which is regulated by the CQC. The Department of Health's 2014 fundamental standards for health and social care providers emphasise the importance of person- centred care, including the provision of 'meaningful' activities that promote mental stimulation and can improve general health. Such activities can also help avoid challenging behaviours. As the North West Dementia Centre 2005 paper on activities in care homes for people with dementia states: 'Everyone has an inbuilt need to participate in activity and what we do makes us who we are.' In addition, providing meaningful activities can help ensure local authorities meet their safeguarding responsibilities, as a lack of meaningful activity can often be part of a wider pattern of neglect.

A number of initiatives to improve person centred care have been developed (My Home Life, JRF) including those with dementia (Dementia Care Mapping (DCM), VIPS framework (Brooker et al 2007). However, there is a need to develop multiple and creative strategies for evaluating the outcomes arising from the implementation of person-centred care in practice. The evaluation of person-centred outcomes is complex. Descriptive accounts of person-centred care demonstrate the impact on patients' experience of care and nurses' and the healthcare teams' experiences of caring (Parley, 2001; Webster and Dewing, 2007; Edvardsson et al., 2008).

NICE advice on Older People in Care Homes (2015) recommends that care homes work with residents to deliver person-centred care, which includes: take into account the person's needs and preferences, involve family members and carers, promote choice and control, not discriminate (that is, not exclude people with dementia from services to which others might have access), involve the person in care planning, take account of the person's lifestyle, and take account of the effect of dementia on relationships.

NICE also states that care homes should ensure staff training emphasises the importance of person-centred care and use the quality statement on participation in meaningful activity from NICE's mental wellbeing in care homes quality standard to ensure older people in care homes can choose the activities they take part in.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people living in care homes
Intervention:	Person-centred needs assessment followed by individualised needs-based intervention (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator:	Non-intervention/control
Outcomes of Interest:	Participant satisfaction/QoL, staff satisfaction, changes in person-centred care using specific measures: Individualised Care Scale, the Measure of Processes of Care and the Person-centred Care Assessment Tool and others

What the research evidence says:

Large amount of evidence relating to the importance and need for person centred care (PCC) (Coren 2010), however may need further evidence for implementing it in practice (barriers etc). In terms of nursing outcomes, effective teamwork, workload management, time management and staff relationships are important in order to create a culture where there is a more democratic and inclusive approach to practice and space for the formation of person-centred relationships (McCormack et al 2010). Further exploration of person-centred care (PCC) and the various features of this model have been recommended (Barbosa et al 2015), together with more RCTs examining the efficacy of PCC evidence-based training programmes (Li et al 2014).

Ongoing studies/ Trials in progress:

WHELD RCT An Optimized Person Centred Intervention to Improve Quality of Life for People with Dementia Living in Care Homes. A cluster Randomised Controlled Trial. (NIHR, Prof Clive Ballard, London) - a factorial study and qualitative evaluation, to combine: training on person-centred care, promoting person-centred activities and interactions, and providing care home staff and general practitioners with updated knowledge regarding the optimal use of psychotropic medications for persons with dementia in care homes

PEPPeRS - Multidisciplinary Person Centred Caring: Its conceptualisation and measurement through three instruments (PErsonalisation, ParticiPation and ResponSiveness) (Ms Heather Strachan, Fife)

How does this fit with any relevant research priority criteria?

Size of the health problem:

Of the 400,000+ older people living in care homes in UK, 75% have neurological or mental disorder. PCC is thought to be effective in improving the quality of life and mental health compared to the usual care provided to people (with dementia) living in care homes. PCC is of central importance of the Unified Assessment and Care Management system in identifying and meeting individuals' holistic needs. This also relies on the appropriate personal and professional behaviour of staff, and on a whole systems infrastructure in which integrated health and social care services are planned and delivered. Consultation with older people, however, has highlighted that the care they receive is often not person centred (NSF Older People in Wales).

The potential for health improvement:

Person-centred care ensures that patients/residents and their families are treated as individuals and their views, values and beliefs are respected and listened to. PCC is a measure of the quality of health care, research has shown that patient-centred interactions promote adherence and lead to improved health outcomes.

Person-centred care (including meaningful activities) promotes mental stimulation, can improve general health, and help avoid challenging behaviours. In addition, providing meaningful activities can help ensure local authorities meet their safeguarding responsibilities, as a lack of meaningful activity can often be part of a wider pattern of neglect.

The practicality of the research question:
Very broad questions. Complex issue which would need to be focussed on specific aspects – if so should be practicable to address. High levels of interest in person-centred care.

Alignment with local health priorities:
1000 Lives Campaign: Improving Healthcare White Paper – Person driven care 2012
Welsh Assembly: National Service Framework for Older People in Wales (PCC one of 6 cross-cutting themes)

Guidelines & Government Strategies relating to this area:

Department of Health: National Dementia Strategy (NDS), 2009

NICE advice [LGB25] Older people in care homes. Published: February 2015

NICE guidelines [CG42] Dementia: supporting people with dementia and their carers in health and social care. Published: November 2006

Department of Health: Fundamental standards for health and social care providers 2014

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Rowett R, (2010) Practice Guidance – Supporting the Social Care Workforce to Deliver Person Centred Care for People with Dementia, Care Council for Wales, Cardiff

Older People's Commissioner Wales: A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales 2014

Health Foundation: Person-centred care made simple 2014

Welsh Assembly: National Service Framework for Older People in Wales http://www.wales.nhs.uk/documents/NSF%20for%20Older%20People.pdf

Relevant references:

McCormack, Brendan, et al. "Developing person- centred practice: nursing outcomes arising from changes to the care environment in residential settings for older people." International Journal of Older People Nursing 5.2 (2010): 93-107.

Barbosa A, Sousa L, Nolan M, Figueiredo D. Effects of Person-Centred Care Approaches to Dementia Care on Staff: A Systematic Review. American Journal of Alzheimer's Disease and Other Dementias. 2015 December 1, 2015; 30(8): 713-22.

Li J, Porock D. Resident outcomes of person-centred care in long-term care: A narrative review of interventional research. International Journal of Nursing Studies. 2014 10//; 51(10): 1395-415.

DIGNITY

#2 RESEARCH QUESTION Person1: How can dignity be enhanced for residents in care home settings?

This topic stems from questions around how to improve the dignity and independence of older people (both with and without dementia) living in care homes. Maintaining the independence of the person was seen as an intrinsic part of enhancing their dignity.

General context and definitions:

Despite the importance attached to the enhancement of dignity and quality of life, it has been recognised that less attention has been paid to the dignity-related concerns of older, frail individuals who are in long term care settings. Interventions to enhance dignity has included a range of training interventions for staff, and Dignity Therapy (Chochinov et al 2012, Hall et al 2012 and 2014).

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people (with or without dementia) living in care homes
Intervention:	Individualised needs-based intervention(s) to enhance the dignity and/or independence (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator:	Non-intervention/control
Outcomes of Interest:	Participant satisfaction/QoL, staff satisfaction, changes in perception of dignity using specific measures: The Herth Hope Index (HHI), The Patient Dignity Inventory (PDI), Perceived Quality of Life, and Satisfaction with Quality Life Ratings and others. Changes in ADL index.

What the research evidence says:

Staff attitudes and awareness of dignity and autonomy of older adults in healthcare settings is low (Lothian and Philip 2001) and there is an identified need for staff education. The CQC published a report on nutrition and dignity findings in care homes

(CQC 2012). The Mid Staffs events led to the Commission on Improving Dignity in Care for older people in hospitals and care homes (NHS Confederation 2012). Recommendations were then made in 'Delivering Dignity' 2014 (Commission on Dignity in Care, a collaboration established by the NHS Confederation, the Local Government Association and Age UK) and are now the subject of a project to implement the recommendations with the Burdett Trust for Nursing. Dignity Therapy intervention may be effective but time consuming (Hall et al 2012, Hall et al 2014).

Delivering Dignity states that all staff are responsible for promoting and ensuring the dignity and wellbeing of those in their care, and must be given the training and support to help them to do so. Their recommendations include that care homes need to invest in facilitators, who can lead active learning to give staff the confidence to do the right thing for the people in their care and challenge undignified care when they see it. Commissioning and delivering dignified care across health and social care is not something that can be achieved by a series of disconnected projects. Hospitals and care homes need to put in place integrated programmes to improve care, sustained by a long-term investment in energy, time and money to embed cultural and behavioural changes

My Home Life (www.myhomelife.org.uk) is a UK-wide initiative promoting quality of life for those who are living in, dying in, visiting or working in care homes for older people through relationship-centred, evidence-based practice. The initiative is led by Age UK, in collaboration with the Joseph Rowntree Foundation and City University London, and has the support of all the national representative bodies for providers of care homes. There is also a focus on maintaining identity in a care home http://myhomelife.org.uk/wp-content/uploads/2014/11/MHL-CYMRU-MAINTAINING-IDENTITY.pdf

Schemes to promote independence have been developed (SCIE Personalisation: promoting independence in care homes), but most interventions are aimed at promoting independence to maintain older people in own homes. No empirical evidence found of the benefit of maintaining independence of older people in care homes, but it is expected to be associated with quality of life aspects of maintaining autonomy, and enhancing dignity.

NICE advice on Older People in Care Homes (2015) recommends that care homes should ensure older people in care homes retain their independence and identity through: consistent and stable staffing, retaining a familiar environment, minimising relocations, flexibility to accommodate fluctuating abilities, assessment and care‑planning advice about independent toileting skills, and support to allow people to go at their own pace and participate in activities they enjoy.

A Help the Aged study aimed to identify indicators of dignity in care for older people in all settings. The aim was to make recommendations on the best way to measure each of the Help the Aged domains of dignified care: personal hygiene; eating and nutrition; privacy; communication; pain; autonomy; personal care; end-of-life care and social inclusion. Their recommendations for future research are:

- the development of shared definitions which could inform the development of new indicators and measures reflecting both older people's and care professionals' perspectives
- further research exploring older people's and care professionals' perceptions of dignity in care across a range of settings, with particular focus on where similarities and differences exist
- further research to identify which aspects of care may be relevant to particular care settings, and the development of indicators and measures for these aspects of care

Ongoing studies/ Trials in progress:

Some evidence in development of practices to improve dignity for older people in care homes. No definite studies/trials identified.

How does this fit with any relevant research priority criteria?

Size of the health problem:

The Commission on Dignity in Care for Older People was established following the publication in February 2011 of Care and Compassion, the report by the Parliamentary and Health Service Ombudsman which exposed shocking failures in the care of older people.

The potential for health improvement:

The measurement of users' experience of health and social care services is increasingly seen as central to the maintenance of high-quality care. The extent to which care services treat people with respect and dignity is a major focus programmes of assessment and inspection.

The practicality of the research question:

Broad question, and large body of work already conducted. Practicable to build on research recommendations from research report from Help the Aged.

Alignment with local health priorities:

Wales' National Service Framework for Older People is underpinned with fundamental principles for the promotion of dignity and independence.

Delivering Dignity recommendations are directed at the system in England, but expected that the key messages will also be of value in Wales (who were involved in the consultation by the Commission on Dignity in Care).

Guidelines & Government Strategies relating to this area:

Welsh Assembly: National Service Framework for Older People in Wales. 2006 http://www.wales.nhs.uk/documents/NSF%20for%20Older%20People.pdf

Commission on Dignity in Care: Delivering Dignity. 2014 http://www.ageuk.org.uk/Global/Delivering%20Dignity%20Report.pdf?dtrk=true

NICE advice [LGB25] Older people in care homes. Published: February 2015

Help the Aged: Measuring Dignity in Care for Older People - A research report for Help the Aged. 2008 http://www.ageuk.org.uk/documents/en-gb/for-professionals/research/measuring%20dignity%20in%20care%20(2008)_pro.pdf?dtrk=true

Department of Health: Care Homes for Older People National Minimum Standards and Care Homes Regulations 2001

http://www.dignityincare.org.uk/_library/resources/dignity/csipcomment/csci_national_minimum_standards.pdf

Relevant References:

Bayer, Tony, Win Tadd, and Stefan Krajcik. Dignity: the voice of older people. Quality in Ageing and Older Adults 6.1 (2005): 22-29. http://www.emeraldinsight.com/doi/abs/10.1108/14717794200500005

Johnston B et al Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy 2014 http://www.qnis.org.uk/wp-content/uploads/2015/02/Living-Well-with-Dementia-Report.pdf

Hall, Sue, et al. Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: a phase II randomized controlled trial of a brief palliative care psychotherapy. Palliative medicine 26.5 (2012): 703-712. http://web.a.ebscohost.com/ehost/detail/detail?sid=7eff8ab7-e8f0-468e-baea-ac4abac115ab%40sessionmgr4001&vid=0&hid=4107&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#AN=21859743&db=mdc

Chochinov, Harvey Max, et al. Dignity therapy: a feasibility study of elders in long-term care. Palliative and Supportive Care 10.01 (2012): 3-15. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8487868&fulltextType=RA&fileId=S1478951511000538

Hall, Sue, Rachael H. Dodd, and Irene J. Higginson. Maintaining dignity for residents of care homes: A qualitative study of the views of care home staff, community nurses, residents and their families. Geriatric Nursing 35.1 (2014): 55-60. https://www.researchgate.net/profile/Rachael_Dodd/publication/258700262_Maintaining_dignity_for_residents_of_care_homes_A_qualitative_study_of_the_views_of_care_home_staff_community_nurses_residents_and_their_families/links/53e4db5a0cf2fb748710f426.pdf

#=3 RESEARCH QUESTION Staff5: What are appropriate staffing levels in relation to the number of residents in care homes and their relative care needs?

This arose from a number of questions about staffing levels in care homes and the need for levels to be appropriate to the amount of residents being looked after and the level of care required. Similar questions arose about the right ratio of staff to residents, particularly in dementia care, to improve outcomes for residents and job satisfaction for staff. Participants also asked if there a significant difference in care outcomes associated to staffing levels i.e. ‘lower staff numbers equals poor care’. This was described as ‘the elephant in the room’.

The same questions were identified as priorities areas for future research and development during a multi-method scoping project commissioned by the RCN Foundation (led by Professor Karen Spilsbury, University of York, February 2015). These questions were ‘What is the association between staffing levels and quality of care?’ and ‘How adequate is the staff to resident ratio?’

General context and definitions:

Safe staffing levels and appropriate skill mix of staff, both within and outside the NHS, has been the subject of much attention. Public expectation and the quality agenda demand that the disastrous effects of short staffing witnessed at NHS hospitals such as Mid Staffordshire should not be allowed to happen again. Inadequate staffing has been identified by coroners’ reports and inquiries as a key factor in deaths of patients and care home residents. The Health Select Committee 2009 report states: ‘inadequate staffing levels have been major factors in undermining patient safety in a number of notorious cases’. In one year the National Patient Safety Agency (NPSA) recorded more than 30,000 patient safety incidents related to staffing problems.

In the care home sector there has been a recent reduction in the skill-mix (RNs make up 25 per cent of staff in care homes according to RCN employment survey in 2009, compared with 34 per cent in 2007). This corresponds to an increase in the number of patients per RN on duty (from 15.5 on average to 18.3). At night the average number of patients per RN has increased to from 22 to 26. A recent survey undertaken by the RCN (RCN 2010) covering care homes in England, reported a similar ratio – 17 residents per RN during the day – and that 29 per cent of respondents considered that there were not enough permanent RNs employed to meet the needs of residents.

The following are offered as guideline staff: patient ratios (Nursing Homes Regulation and Quality Improvement Authority (2009)). Proposed nursing homes staffed so that over 24-hour period there is an average of 35 per cent registered nurses and 65 per cent care assistants:

- Early shifts 1:5
- Late shifts 1:6
- Night 1:10.

What the research evidence says:

Evidence of impact of staffing levels in acute hospital settings, little evidence in UK care homes. A systematic review examined the relationships between nurse staffing levels in nursing homes and quality of care provided to residents, but predominantly focused on US nursing facilities. The studies used disparate methods for defining and measuring quality (42 measures of quality identified) and nurse staffing (52 ways of measuring staffing identified). Highest staffing levels was associated with providing higher quality care in US care homes (Schnelle et al 2004), both directly and indirectly (Weech-Maldonado et al 2004). They concluded that a focus on numbers of nurses fails to address the influence of other staffing factors (e.g. turnover, agency staff use), training and experience of staff, and care organisation and management. 'Quality' is a difficult concept to capture directly and the measures used focused mainly on 'clinical' outcomes for residents.

These findings were supported by study in Norway which concluded that the relationship between staffing levels, ratio of registered nurses and quality of care is complex. Increasing staffing levels or the ratio of registered nurses alone is not likely to be sufficient for increasing the quality of care.

Lower RN staffing numbers were associated with pressure ulcer development and other adverse outcomes in a US study (Horn et al 2005) and also quality indicators (Castle and Anderson 2011). They also impact on job satisfaction by care home staff: adequate levels of supervisory support linked to job satisfaction (McGilton et al 2007) and lower workload associated with improved job satisfaction and lower levels of staff turnover (Castle et al 2006).

A range of tools to assist with staff planning are available (summary in RCN Guidance on Staff Planning 2010 Appendix 2), few in care home setting. Care Homes Staffing Model (CHSM, http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Care-Homes/Staffing-Model/) informs care hours provided by social/nursing care staff. 'Proof of concept' electronic tool allows care homes to calculate their current dependency level (it is an augmented version of the Indicator of Relative Need (IoRN) which can be applied to all residents). But does not consider quality of the care home, nor the current mix of staff. The original study was limited to care homes with less than 70 beds – so the application to larger sites must be made with caution.

Ongoing studies/ Trials in progress:

CLOSED: RN4CAST the association between registered nurse staffing, hospital characteristics and patient outcomes (RN4CAST): observational study

CLOSED: The MEMOS-DSPD study Multi-method evaluation of the management, organisation and staffing (MEMOS) in high security treatment services for people with dangerous and severe personality disorder (DSPD)

How does this fit with any relevant research priority criteria?

Size of the health problem:

There is a huge focus on staffing levels in all areas of health and social care. Staffing has been linked to quality of care in a number of studies and, in addition, staffing is emphasized in both the media and by the public as one of the most crucial elements for quality in nursing homes.

The potential for health improvement:

There may be potential for improvement in the quality of care provided in care homes, leading to improved health outcomes

The practicality of the research question:

The relationship between quality of care and staffing levels and the ratio of registered nurses may be more complex, other factors such as leadership and staff turnover are likely to impact.

Alignment with local health priorities:

Recent drive to legislate for minimum safe staffing levels in Welsh NHS.

The recent PANICOA report (2013) calls on UK governments to ensure regulators set and monitor standards for minimum staffing levels that care homes would be required to meet. It also said councils must work with providers to agree practicable staff to resident ratios “sufficient to ensure the safe and respectful care of older people at all times”, and to use this as the basis for a “fair and accurate fee structure”.

Minimum standards in Wales require that staffing numbers and the skill mix of qualified/unqualified staff are appropriate to the assessed needs of the service users, as well as the size, layout and purpose of the home, at all times (WAG 2004) and with reference to qualifications, Minimum Standards call for at least 50% of care staff to hold NVQ level 2 in care or a similar qualification recognised by the Care Council for Wales, or a higher level qualification in care.

Guidelines & Government Strategies relating to this area:

Guidance on safe nurse staffing levels in adult inpatient wards in acute hospitals produced by NICE 2014 (NICE safe staffing programme suspended 2015). No staffing level recommendations for care homes - although calls for guidelines/recommendations widespread.

The Safe Nurse Staffing Levels (Wales) Bill – applies to Welsh NHS only

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 18 (Staffing). CQC guidance states 'Providers must deploy sufficient numbers of suitably qualified, competent, skilled and experienced staff to make sure that they can meet people's care and treatment needs'

RCN Guidance on safe nurse staffing levels in the UK 2010. https://www2.rcn.org.uk/__data/assets/pdf_file/0005/353237/003860.pdf

Relevant References:

RCN Foundation Supporting nursing in care homes: Patient Care and Professional Development for Nursing Staff in Care and Nursing Homes: A Research and Consultation Project 2015 http://www.rcnfoundation.org.uk/?a=620718&now=1429088648

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Lupton C & Croft-White C (2013). Respect and Protect: The experience of older people and staff in care homes and hospitals. PANICOA/Comic Relief

Welsh Assembly Government (2004). National Minimum Standards for Care homes for Older People. Retrieved from: http://www.csiw.wales.gov.uk/docs/nmscarehomes_oldpeople_revised_e.pdf

#5 RESEARCH QUESTION Staff1: What are the essential elements required when training carers working with older people in care homes?

This arose from a question around what training is essential for a care assistant (as opposed to a qualified/registered nurse). Other questions were received about the most effective format of training. There were uncertainties as to why there is an emphasis on 'eLearning' when care work is often of a practical nature but also incorporates other aspects such as dignity and compassion which are harder to address in this format. Criticisms included that there is too much over reliance on life experiences which a great number of young people who are employed as care assistants do not have.

General context and definitions:

Care assistants receive variable levels and quality of training. Some may be new to the care sector, whist some will be very experienced and may be in more senior roles with additional responsibilities. Online training is widely used as it is cost-effective, but was criticised as being insufficient to appropriately train carers.

Following the Francis Report (Mid-Staffs), the Cavendish Review called for a rigorous quality assurance mechanism for training courses and vocational qualifications (Recommendation 5). It also recommended that the main trade associations and social care employers lead a process to agree on core national competences that go beyond the minimum (Recommendation 2). Government accepted the recommendation to develop a 'Certificate of Fundamental Care' for healthcare assistants and care support workers, to be developed by Health Education England (HEE).

Since then, Health Education England (HEE), Skills for Care (SfC) and Skills for Health (SfH), have developed the Care Certificate which was launched April 2015. The Care Certificate is a set of standards for social care and health workers, it is the minimum standards that should be covered as part of induction training of new care workers through a number of modules/workbooks http://www.skillsforcare.org.uk/Learning-development/Care-Certificate/Care-Certificate.aspx

The Gold Standard Framework Care Homes Training programme is the most widely used training programme for all care homes in the UK through flexible programmes http://www.goldstandardsframework.org.uk/care-homes-training-programme

A suite of knowledge-only qualifications is available for those interested in working in adult social care in England across a range of levels (NVQ, QCF, NQF) http://www.skillsforcare.org.uk/Documents/Learning-and-development/Qualifications/Guide-to-qualifications-in-adult-social-care.pdf

According to the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 18 Staffing – staff should receive such appropriate support, training, professional development, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform. Providers must ensure that they have an induction programme that prepares staff for their role and should follow the Care Certificate standards to make sure new staff are supported, skilled and assessed as competent to carry out their roles.

What the research evidence says:

There is evidence of a training gap from analysis of 300 inspection reports published by the Care Quality Commission (CQC) between 1 October 2014 and 31 August 2015 (Community Care October 2015 http://www.communitycare.co.uk/2015/10/28/training-deficit-among-care-home-staff-leaving-residents-risk-investigation-finds/) where training had been identified as an issue by inspectors:

•Training gaps were identified in 71% of care homes told to improve by the CQC.

•Dementia care, safeguarding and the Mental Capacity Act were the topic areas that fared worst – especially in homes that were 'specialist dementia homes'.

•Almost half (49%) of the homes told to improve by the CQC were breaching regulations that require them to ensure a suitably trained and supported workforce.

In a survey in 2001 (PSSRU), two-thirds of homes had staff with NVQs or BTEC awards, and a higher proportion reported that staff were working towards these. The majority of homes — 97% — had used in-house training; staff from 83% of homes had attended external courses; and 69% had brought an outside expert into the home. Local authority residential homes, dual registered homes and nursing homes were more likely to employ such experts or to send staff on outside courses, although 75%of private and voluntary residential homes also sent staff for external training. About one-third of dual registered and nursing homes reported that their staff had followed distance learning programmes.

A small number of studies have focussed on staff training requirements, such as Promoting Excellence in All Care Homes (PEACH) study (Win Tadd et al, Cardiff University, 2012). This study focussed on the needs, knowledge and practices of the care home workforce in relation to abuse, neglect and loss of dignity, and a preliminary evaluation of an evidence-based training package http://www.cardiff.ac.uk/socsi/dignity/peach/PEACHReport.pdf.

The questions identified in the priority setting study reflected the findings in PEACH: that the majority of staff disliked e-learning or being sat in front of a computer ticking boxes, and many found that existing training, even mandatory skills such as lifting and handling did not really prepare them for using equipment and such like in practice where they had to work with very frail, physically impaired or uncooperative residents. Added to this, the low level of language and literacy skills of many staff meant that approaches which only relied on text based approaches were less effective. Instead staff wanted the opportunity to discuss the practical issues and concerns they faced in their day to day experience with colleagues and experienced and knowledgeable personnel.

PEACH study recommendations included that mandatory training should include specific themes beyond those that are task focused and which promote a more holistic approach to understanding residents' needs. In particular the following aspects should be included: Respectful communication; dignity and dignified care; dealing with challenging behaviour; understanding risk management. Further research on what are the essential elements and the effectiveness of standardised training for care staff that centres on these elements in quality of care outcomes or staff satisfaction outcomes.

Ongoing studies/ Trials in progress:

None identified – studies on individual aspects of training included communication (Moriarty et al 2010) and aspects of dementia-specific care such as challenging behaviour etc (Bhaduri et al 2007).

How does this fit with any relevant research priority criteria?

Size of the health problem:

There are 1.5 million care assistants in social care alone, who deliver almost 60% of hands-on care in hospitals, care homes etc (Raising the Bar - Shape of Caring Review)

The practicality of the research question:

Practicable to address. Would require large scale scoping of evidence and consensus building on essential elements of training and format.

Alignment with local health priorities:

HEE work and National Minimum Standards focuses on England

Guidelines & Government Strategies relating to this area:

Health Education England. Raising the Bar - Shape of Caring: A Review of the Future Education and Training of Registered Nurses and Care Assistants. November 2015 https://www.hee.nhs.uk/sites/default/files/documents/2348-Shape-of-caring-review-FINAL_0.pdf

Relevant References:

Bhaduri, Reba, and Caroline Sutcliffe. Implementing evidence-based training in dementia care for frontline workers in the social care workforce: Reaching the horizon? Journal of Care Services Management 1.3 (2007): 294-302.

Moriarty, Jo, et al. Communication training for care home workers: outcomes for older people, staff, families and friends. Vol. 34. Social Care Institute for Excellence (SCIE), 2010.

END OF LIFE CARE

#6 RESEARCH QUESTION End2: How can early and appropriate discussion with older people in care home about end of life care be supported?

 # 12 RESEARCH QUESTION End1: How can families and healthcare professionals contribute to improving end of life care for older people in care homes?

RESEARCH QUESTION End3: What is the level of staff knowledge and awareness of the legal implications of Advance Care Planning?

This was a clearly defined question on how care home staff can get more people discussing what they need at the end of life, earlier to ensure wishes are met. There was a widely held perception that most discussions about end of life care (EoLC) were held too late for the person's views to be sought or clearly elucidated, or to be acted on.

Other questions related to how the resident's family and health care professionals can provide quality end of life, and what is the level of staff knowledge and awareness of the legal implications of Advance Care Planning?

General context and definitions:

Each year an average of 41,969 people die in a nursing home and 32,138 in a residential care home (National End of Life Care Intelligence Network, 2010). Most residents living in care homes will die there. Residents in care homes are in the last years of life and often present with multiple health needs, cognitive impairment, and particular palliative care needs due to their advanced age

Care homes have adopted a range of practices to meet the challenges of caring for residents at the end of life, however some rely on GPs to hospitalise all but the most straightforward of cases, resulting in unwanted and potentially distressing inappropriate admissions. The main goal in delivering good end of life care is to be able to clarify peoples' wishes, needs and preferences and deliver care to meet these needs.

In England, the End of Life Care Strategy (DH, 2008a) established the NHS National End of Life Care Programme. Three initiatives that subsequently emerged are the Liverpool Care Pathway (LCP), the Gold Standards Framework (GSF) and Preferred Priorities for

Care (PPC). The NEoLCP has also instigated a care home workstream, with resources including quality assessment and guidance on organisational change and staff development.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people (with or without a terminal diagnosis or non-cancer diagnosis) living in care homes
Intervention:	Individualised needs-based intervention to enhance EoLC discussion, support, and development of ACP (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator:	Non-intervention/control
Outcomes of Interest:	Participant satisfaction/QoL, staff satisfaction, changes in quality of EoLC using specific measures: NICE quality standard, Quality of End-of-Life Care (QEOLC) questionnaire

What the research evidence says:

Little is known about how well homes meet individual needs (Seymour et al, 2005), how relatives' views may be elicited (Hennings, et al, 2010), or the importance of care home cultures to end-of-life practice (NEoLCP, 2012a; Froggatt, 2000).

There has been a focus on implementing training and education on EoLC, including large UK Gold Standard Framework project (Kings Fund - training and accreditation) – which places emphasis on early and frequent discussions about EoLC – and ABC End of Life Education Programme. An evaluation found that staff preferred the ABC training as they valued the supportive visits from the palliative care nurse and it was more cost-effective (Pyper et al 2013). The training could also be delivered through a Train the Trainer method, where there was a supportive and stable workforce (Mynhofer et al 2016).

Although most evidence relates to advance care planning for those considered at the end of life - not prior to the end of life. A study which found the lack of any discussion about EoLC with families of residents with dementia on entry to care home found barriers included lack of staff time and confidence (Moore et al 2015). A study on staff and residents views on EoLC (Percival et al 2013) identified a number of themes such as personalised care, dignity and respect, making time, talking about death, relatives' roles, and staff support. The authors emphasised the relevance of a holistic approach that recognises the significance of personally meaningful end-of-life care interventions and interactions. The factors around the timing of such discussions were not included in the study.

There is no empirical evidence that early discussion is beneficial, although it presents the greatest opportunity to include the wishes of resident who may lose capacity. There is evidence of the importance of training in EoLC to staff caring for residents, but no evidence when these would be most appropriate for those prior to end of life.

Advance Care (ACP) is a structured discussion with patients and their families or carers about their wishes and thoughts for the future. It is a key means of improving care for people nearing the end of life and of enabling better planning and provision of care, to help them live and die in the place and the manner of their choosing.

It is not clear how many residents are transferred from the care home to hospital or other care setting for EoLC, or how many are in accordance with residents' wishes or are avoidable. Further research on views of older people in care homes and care home staff about their views of EoLC may be warranted. This could also include views on ACP.

Ongoing studies/ Trials in progress:

OPTCare Elderly: Optimising palliative care for older people in community settings development and evaluation of a new short term integrated service (NIHR, Dr Catherine Evans and Prof Irene Higginson, KCL)

CLOSED: MORECare programme - Methods for evaluating service delivery models for end of life care (EoLC): including development of best practice guidance and MORECare Capacity – Methods for Researching End of Life care; processes of consent for adults lacking capacity (MRC and NIHR, Cicely Saunders Institute KCL)

CLOSED: EVIDEM programme consisting of five projects to develop and test interventions that improve patient, carer and service outcomes at three major stages of dementia – including end of life care in care homes (Prof Barbara Hanratty, Newcastle University).

How does this fit with any relevant research priority criteria?

Size of the health problem:

More than half a million people die in England and Wales every year; five deaths in every six are of people aged 65 or older; and one in five of all deaths take place in a care home.

The potential for health improvement:

Given the number of residents who die whilst a care home resident, and their specific EoLC needs, there is great potential to equip and sustain the workforce to provide generalist palliative care in settings where the staff have limited access to specialist services, many do not have a formal qualification, and turnover of staff is high. Both to ensure that it is in accordance with residents and their families wishes, and avoids inappropriate admission to hospital. Part of this, is to address early and appropriate discussion, involvement of the wider MDT team and families, and ensure ACP is in place and adhered to.

The practicality of the research question:
There are a range of questions that could be addressed separately, or part of a larger programme.

Alignment with local health priorities:
Welsh Government: Together for Health – Delivering End of Life Care (A Delivery Plan up to 2016 for NHS Wales and its Partners, 2013) states that access to appropriate support and symptom control must be the same wherever they die - at home, in hospital, in a care home or a hospice. Those who wish their care and dying to occur at home should be supported in this choice. Inappropriate unplanned admissions arising through inadequate service provision or inappropriate referral should be avoided.

Guidelines & Government Strategies relating to this area:

NICE quality standard End of life care for adults [QS13]. Published: November 2011

PHE: National End of Life Intelligence Framework. NEoLCIN aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life http://www.endoflifecare-intelligence.org.uk/home

Relevant References:

Percival J et al (2013) End-of-life care in nursing and care homes. Nursing Times; 109: 1/2, 20-22. http://www.nursingtimes.net/clinical-subjects/end-of-life-and-palliative-care/end-of-life-care-in-nursing-and-care-homes/5053468.fullarticle

Mayrhofer, A., Goodman, C., Smeeton, N. C., Handley, M., Amador, S., & Davies, S. (2016). The feasibility of a train-the-trainer approach to end of life care training in care homes: an evaluation. BMC Palliative Care, 15, [11]. http://researchprofiles.herts.ac.uk/portal/files/9784693/907271.pdf

Gold Standards Framework: Advanced Care Planning http://www.goldstandardsframework.org.uk/advance-care-planning

Marie Curie Living and dying well with dementia in Wales: barriers to care (2015) https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf

 # 7 RESEARCH QUESTION Staff2: How can recruitment of carers with essential qualities such as compassion and empathy be improved by care homes?

These stem from questions around qualities of care assistants, and how caring, compassionate staff that are motivated to work in the care sector. Other questions were received about how to identify candidates for care assistant posts who have sufficient levels of empathy – potentially through administration of a formal test. See also Staff Training section (RQ Staff1: What are the essential elements required when training carers working with older people in care homes?).

General context and definitions:

Working with emotionally vulnerable, cognitively impaired and frail older people is emotionally, mentally and physically challenging and demanding. There is a recognised link between the values, skills and attitudes of staff and positive outcomes for staff and those they care for. There has been an increasing focus on values in recent years thanks in part to the Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis, 2013), which highlighted the vital role of the workforce in providing high quality, safe and compassionate healthcare, particularly the values and behaviours of staff caring for patients/residents. The NHS and other organisations have recognised the need to develop evidence based approaches to recruitment and selection for training programmes based on values and behaviours as well as technical and academic skills. Employers should also ensure that the continuing personal development of staff reinforces these values.

The recruitment and retention of high quality care staff is vital to older people's quality of life. Many of the best care homes are those with high morale among care staff and low staff turnover. In the Dignity and Older Europeans study, Calnan and Tadd (2005) suggested the barriers to appropriate and dignified care included the values and motivations of the carer.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Care staff (qualified nurses and care support workers) working in care homes for older people
Intervention:	Values-based recruitment and retention intervention
Comparator:	Non-intervention/control

Outcomes of Interest:	Staff satisfaction, staff retention, changes in quality of care outcomes

What the research evidence says:

An active learning model has been shown to increase knowledge, skills and empathy of care staff (Biegel 2005). There is evidence around instruments to measure empathy, such as Jefferson Scale of Physician Empathy, which showed in a study of US medical students that empathy is likely to be a stable trait not easily changed by training programs (Mangione et al 2002). Empathy Quotient (EQ) is a valid, reliable, self-reported scale designed to measure empathy (Lawrence et al 2004). There is evidence that there are different forms of empathy when care staff are looking after older people - such as direct and indirect empathy (Luff 2010) - which are used to form caring rules and also relate to care staff's own 'philosophy of care'. Additionally, higher empathy scores have been found to be related to more positive attitudes to the role and workload (Astrom et al 1991).

The National Skills Academy for Adult Social Care, Skills for Care, MacIntyre Charity, and the Department of Health have developed a value-based recruitment toolkit (VBRT) for adult social care. It was designed to help employers recruit people with the right social care values, the primary purpose of the assessment tool was to provide information for discussion at interview. It measured emotional intelligence and attitudes, but not explicitly compassion or empathy. Evaluation of a 12 month pilot found that use of the VBRT tools and resources added value to the recruitment of social care workers http://www.skillsforcare.org.uk/Document-library/Finding-and-keeping-workers/Practical-toolkits/Values-based-recruitment/Final-report.pdf.

In a US study, a greater job commitment by care assistants was associated with better quality of relationships and life for residents (Bishop et al 2008).

The National Skills Academy for Social Care lists the following as examples of the kinds of values that should underpin the training, skills and competencies of all staff, ensuring that services are delivered by 'the right people who do the right thing in the right way': Compassion, Courage, Respect, Responsibility, Empathy, Imagination, Treating people with dignity, Adaptability, Integrity

North East Dementia Alliance commissioned a toolkit 'Working with people with dementia and their carers: Values Based Recruitment' (North of England Mental Health Development Unit 2013) http://www.ncl.ac.uk/media/wwwnclacuk/instituteforageing/files/values-based-recruitment.pdf

Ongoing studies/ Trials in progress:

A study into the Impact of the Value-Based Recruitment Tool (Skills for Care) aims to understand the impact of values-based recruitment by capturing changes in key business performance indicators such as staff retention, sickness, absence, performance and quality measures. The focus of the study will be on employer-level measures rather than changes to service user experience http://www.hra.nhs.uk/news/research-summaries/study-into-the-impact-of-the-value-based-recruitment-tool/#sthash.C3VTq3tu.dpuf

How does this fit with any relevant research priority criteria?

Size of the health problem:

Recruiting, and retaining, staff with the qualities and attitudes needed for working in the care sector is a widespread challenge.

The potential for health improvement:

A values-based approach to recruitment and retention may reduce time and resources spent on inappropriate staff recruitment, improve care outcomes, as well as fulfil legal requirements for employing care workers. There is a need for further research especially in non-traditional methods of selection and assessment (Posthuma et al 2002 cited in NEDA toolkit).

The practicality of the research question:

Work already done in this area by HEE and Skills for Care but further work on identifying essential qualities and understanding the barriers to recruiting and retaining staff with these qualities required.

Alignment with local health priorities:

Finding and keeping workers also supports the implementation of the adult social care recruitment and retention strategy 2014-2017. Severe lack of available care home staff, especially qualified nurses, in Wales – 'at crisis point' according to Care Forum Wales.

Guidelines & Government Strategies relating to this area:

NHS Employers: Values based recruitment http://www.nhsemployers.org/your-workforce/recruit/employer-led-recruitment/values-based-recruitment

Relevant references:

Lawrence, E. J., et al. "Measuring empathy: reliability and validity of the Empathy Quotient." Psychological medicine 34.05 (2004): 911-920. https://www.researchgate.net/profile/Simon_Baron-Cohen/publication/8217454_Measuring_empathy_Reliability_and_validity_of_the_Empathy_Quotient/links/0c9605173acd41b991000000.pdf

Beyond Employment Interview Validity: A Comprehensive Narrative Review of Recent Research and Trends over Time, Posthuma R et al, Personnel Psychology Volume 55, Issue 1, March 2002 (cited in NEDA toolkit)

Luff, Rebekah. "Forms of empathy of care home staff working with older people." International Journal of Work Organisation and Emotion 3.3 (2010): 302-316. http://www.inderscienceonline.com/doi/abs/10.1504/IJWOE.2010.032928

BEST INTERESTS

#8 RESEARCH QUESTION Person3: How can best interest decisions made for care home residents with dementia be properly documented in care plans?

These stem from questions around how care home staff can ensure that best interest decisions made for people with dementia are recorded properly in care plans in order to provide a legal record that will subsequently be adhered to.

General context and definitions:

The Mental Capacity Act (MCA) states that if a person lacks mental capacity to make a particular decision then whoever is making that decision or taking any action on that person's behalf must do this in the person's best interests. The person who has to make the decision is known as the 'decision-maker' and normally will be the carer responsible for the day to day care (including both care staff, relatives or friends), or a professional such as a doctor, nurse or social worker where decisions about treatment, care arrangements or accommodation have to be made.

Decisions about a person's property or their financial matters must be in the person's best interests but can only be made by an attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney (LPA or EPA), a court-appointed deputy, or the Court of Protection. Certain decisions must never be made on behalf of a person who lacks capacity, called 'excluded decisions' (marriage, voting, assisted suicide etc).

If a person has a valid and applicable advance decision to refuse treatment then that decision must be respected even if it may not appear to be in the person's best interests. If a person who lacks capacity needs to be kept in a care home or hospital because it is in their best interests then additional safeguards may apply. These are called the Deprivation of Liberty Safeguards (DoLS) and there is additional guidance about them in a separate Code of Practice (Deprivation of liberty safeguards - Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice – 2008).

There is formal guidance in the MCA and Code of Practice and local authority documents, but little evidence of how and when decisions are made on a day to day basis in care homes, and how these are documented and acted upon.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people with dementia living in care homes
Intervention:	Best interests assessment followed by individualised assessment-based decision (which may or may not involve health and social care professional/s training, skills or attitudes) as an intervention, in a care home setting,
Comparator:	Non-intervention as control
Outcomes of Interest:	Adherence to legal standards/best practice/principles, documented decisions, involvement views/wishes/advanced decisions, staff satisfaction, other specific measures as appropriate: Individualised Care Scale, the Measure of Processes of Care and the Person-centred Care Assessment Tool

What the research evidence says:

A study into best interest decisions in a range of health care settings (BIDS, commissioned and funded by the Policy Research Programme (PRP) in Department of Health, led by Valerie Williams, University of Bristol) found that decisions were not always made via meetings; sometimes they were made through informal processes in everyday decisions in care homes. However, it was then even more important to find a way to record matters well, and person-centred plans were said to be useful in determining in general how best interests decisions may be made.

It also found that outcomes for people with dementia were often limited by resources, the availability of home care services, and the need to consider relatives' views. Temporary admissions to care homes were sometimes made permanent, without the agreement of all parties concerned, and DoLS applications were only made in a minority of cases. On the whole, it appeared that people with dementia were somewhat disadvantaged in relation to capacity assessment and best interests processes, in comparison with other groups. Recommendations included that:

- further research is carried out to understand better the different perspectives of those involved in best interests decisions, including people lacking capacity themselves and their family carers.
- research about the practices involved in assessing capacity. For instance, it would be useful to examine everyday decision making
- the Department of Health should, in consultation with health and social care providers, develop mental capacity assessment and best interests pro-formas that provide a flexible framework and guidance, and include a section for action planning.

There was a preference for formal record keeping with a structured format, BIDS Study found decisions were most likely to be formally documented if there was a diagnosis of dementia and significant decision to be made, although standard documents were not always linked to good practice. Examples of formal documents for recording using a structured format (see Cardiff and Vale Mental Capacity Partnership Best Interest Decision Form, Manchester Best Interests Decision Form http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=7&ved=0ahUKEwinoL_qtK7LAhVJlxoKHWqCC5IQFghFMAY&url=http%3A%2F%2Fwww.manchester.gov.uk%2Fdownload%2Fdownloads%2Fid%2F19115%2Fbest_interest_decisions_form&usg=AFQjCNEF7r1V-Ikt2DRRKLMtiUVE4YI8fQ).

Ongoing studies/ Trials in progress:

CLOSED: ACBID Assessment of capacity and best interests in dementia: on going home from hospital, Prof Julian Hughes, Newcastle University - observing how such decisions are made in day to day practice. The aim is finding out what patients, their family carers and clinicians feel about the decisions that are being made. To attempt to gain some insight into their consequences, by seeing people after the decisions have been put into effect. In consultation with lay people, voluntary bodies and relevant professionals, they will develop a protocol to make the decision-making process clearer. The content of the protocol (or care pathway) will emerge from the research. This research may affect understanding of the relevant concepts from an ethical and legal point of view, and has the potential to improve clinical decision-making and outcomes both for families and in terms of respect for the liberty and dignity of patients.

How does this fit with any relevant research priority criteria?

Size of the health problem:

One-third of people with dementia live in care homes and at least two-thirds of all people living in care homes have a form of dementia. DH, Living well with Dementia, National Strategy (2009)www.dh.gov.uk

The potential for health improvement:

Ensuring that best interest decisions are appropriately made, documented, and acted upon is essential to ensure that older people in care homes are protected (including their human rights) when unable to make decisions for themselves due to conditions such as dementia

The practicality of the research question:

Practicable to address – scoping of practice (major decisions such as DOL and covert medication and less significant), comparison to legal standards/frameworks, development of evidence-based tool for documentation/review of best interest decisions.

Alignment with local health priorities:
Public Policy Institute for Wales commissioned research into 'Increasing understanding and uptake of Advance Decisions in Wales (Kitzinger and Kitzinger, Cardiff University 2016) research report http://ppiw.org.uk/files/2016/02/PPIW-Report-Increasing-the-awareness-and-uptake-of-Advance-Decisions.pdf

Guidelines & Government Strategies relating to this area:

Older People's Commissioner for Wales' report into older people in care homes (2014) highlighted the importance of ensuring the human rights of older people are upheld in care homes across the Local Authority, including peoples' views and experiences in decisions that affect them, and access to independent advocate where appropriate
http://www.olderpeoplewales.com/Libraries/Uploads/A_Place_to_Call_Home_-_A_Review_into_the_Quality_of_Life_and_Care_of_Older_People_living_in_Care_Homes_in_Wales.sflb.ashx

Relevant References:

Williams et al Making best interest decisions: people and processes 2012 https://www.mentalhealth.org.uk/sites/default/files/BIDS_report_24-02-12_FINAL1.pdf

Carpenter J, Langan J, Patsios D, Jepson M (2013). Deprivation of Liberty Safeguards: what determines the judgements of Best Interests Assessors? A factorial survey. Journal of Social Work, 1–18.

Jepson M et al School for Policy Studies, University of Bristol The Deprivation of Liberty Safeguards: their impact on care practice. Research findings:
http://www.sscr.nihr.ac.uk/PDF/Findings/RF4.pdf

Emmett, Charlotte, Poole, Marie, Bond, John and Hughes, Julian (2013) Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards. International Journal of Law and Psychiatry, 36 (1). pp. 73-82
http://nrl.northumbria.ac.uk/10291/2/IJLP%20Final%20version%20July%202012%20sent%20for%20publication.pdf

Marie Curie Living and dying well with dementia in Wales: barriers to care (2015)
https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf

CARE HOME ENVIRONMENT

#9 RESEARCH QUESTION Env1: How can care homes be made to feel more like a home?

This arose from questions around how a care home can be made to feel more like a 'home' (a family environment) rather than a hospital/medical environment.

General context and definitions:

There is an emphasis in care home literature about the importance of creating a 'homely' or 'home from home' environment in care homes. A number of dementia studies focus on some ‘dementia-friendly’ features of the care home environment such as safety and ability to navigate the environment, and the importance of dining experiences.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people (with or without dementia) living in care homes
Intervention:	Care home ‘homelike’ intervention (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator:	Non-intervention as control
Outcomes of Interest:	Resident satisfaction/QoL, staff satisfaction, number of adverse outcomes (agitation etc),

What the research evidence says:

A systematic review of qualitative studies on living well in care homes (Bradshaw et al 2012) found that a number of studies reported factors within the care home environment that facilitated acceptance. A homely physical environment ensured continuation of their QoL, allowing a smoother transition from home to care home. Having one's own room and bathroom, enough storage and a quiet place facilitated residents' abilities to exercise control. When a homelike environment is absent, a sense of ‘institutionalised living’ occurs and the home is described as regimented and restricted, where daily life is routine and boring. Homely features included privacy, homelike mealtimes and food, aesthetic and spacious environment. A meaningful daily life and homelike environment both emphasise the importance of the care home as a home, recognised in conjunction with the care home as a place that also provides care. However the study defined a 'homelike environment' as one where carers treat residents with respect, taking into account their individuality and identity – more like person-centred care than 'homely' which has been described elsewhere as linked with small numbers in groups, involvement in daily household activities like cooking and cleaning (Peace and Holland 2001) – difficult to provide in anything other than the small homes with less than four residential places, run by the proprietor and her family, described in the pilot study.

This has some similarities with the hospice environment where there has been a focus on a home-like environment as a 'therapeutic landscape'. A study focussing on the lived experience of hospice care (Moore et al 2013) described how a physical sense of a "home from home" at the hospice incorporated items and symbols which were familiar to patients, such as flowers on the balcony, comfortable furniture and a place to relax and regenerate. Other symbolic items included odd mismatched furniture - elements in the symbolic environment of home extended a sense of the domestic, creating a less institutional, more informal homely space, valued by the patients. This may contrast with the 'corporate' or hotel-like environment in some large care homes, particularly those that are part of national care home groups.

A Help the Aged and My Home Life report (2014 http://myhomelife.org.uk/wp-content/uploads/2014/11/mhl_report.pdf) points out that the characteristics associated with 'home', such as family, shared memories, comfortable familiarities, autonomy and a sense of security, are difficult to replicate even within the smallest of care homes (Stafford, 2003; Peace and Holland, 2001; Savishinsky, 1991). Rather than trying to make care homes more home-like, the alternative objective of creating care homes as 'communities' may offer a useful way forward, although it is worth noting that community life is not always easy or straightforward, and is likely to mirror the complicated relations existing in any environment where people live or work with each other (Reed and Payton, 1996).

Despite a focus on creating a home from home in care home advertisement materials etc, there appears to be no evidence about the benefits of a 'homely' environment, what constitutes a 'home' or family environment, or how care homes can really be made to feel more like a home. Those living with dementia may have particular needs from the care home environment.

Ongoing studies/ Trials in progress:

None identified

How does this fit with any relevant research priority criteria?

Size of the health problem:

400,000+ older people living in care homes in UK

The potential for health improvement:

The Alzheimer's Society advises that the 'environment of the care home should be as comfortable and homely as possible. A smart hotel-style environment might impress you as a visitor initially, but remember that it is going to be a place to live. People with dementia often need to have things to stimulate their interest and so an overly tidy environment is not always helpful. A home with pictures and objects on tables, and with opportunities for residents to do household tasks such as dusting or folding towels, will give you an indication that residents are welcome to get involved in the community of the home'.

The practicality of the research question:

Practicable – review of literature and scoping, consensus on features of 'home' environment, pilot of 'home from home' care home level intervention

Alignment with local health priorities:

Older People's Commissioner in Wales' report was critical that 'many care homes have a functional, institutional and clinical feel, with a design and layout that is often unsuitable, rather than being homely, comfortable and welcoming'.

In Scotland, the Convention on the Rights of Residents in Care Homes for Adults and Older People (2015) includes Article 16: Residents have the right to a safe, secure and homelike environment http://www.scottishcare.org/docs/037_280__scottishcareconventionontherightsofresidentsincarehomesforadultsandolderpeople3_1447953353.pdf

NICE's resource for carers and care providers on supporting people to live well with dementia advises about the value of creating homely settings that enable people to participate in day to day living activities; of having simple layouts that are easy to follow; of the impact that contrasting colours, good signage and effective lighting can have; and of the benefits that a secure garden can offer (Statement 7).

Guidelines & Government Strategies relating to this area:

Older People's Commissioner for Wales' report into older people in care homes (2014) http://www.olderpeoplewales.com/Libraries/Uploads/A_Place_to_Call_Home_-_A_Review_into_the_Quality_of_Life_and_Care_of_Older_People_living_in_Care_Homes_in_Wales.sflb.ashx

NICE Tailored resource for carers and care providers on supporting people to live well with dementia https://www.nice.org.uk/About/NICE-Communities/Social-care/Tailored-resources/Dementia/Statement-7?type=careproviders

Relevant References:

Bradshaw, Siobhan Aine, E. Diane Playford, and Afsane Riazi. "Living well in care homes: a systematic review of qualitative studies." Age and ageing (2012): afs069. https://ageing.oxfordjournals.org/content/early/2012/06/07/ageing.afs069.full

Peace, Sheila and Holland, Caroline (2001). Homely residential care: a contradiction in terms? Journal of Social Policy, 30(3) pp. 393–410. http://oro.open.ac.uk/1127/1/download.pdf

Moore A et al ‘I am closer to this place’—Space, place and notions of home in lived experiences of hospice day care Health & place:2013 vol:19 pg:151 -158 http://www.sciencedirect.com/science/article/pii/S1353829212001931

#10 RESEARCH QUESTION Comm3: What is the public and media perception of care homes compared with other care settings, and what is the impact on care home staff attitudes?

This stems from a range of questions around whether the public/media perception of care homes match what actually happens in practice: What is public/media perception? How does that compare with other care settings, such as an elderly care ward which might receive significantly greater level of funding? What/how do care home staff feel about this issue? How can care home staff overcome the negative public/media perception to carry on and provide care day in/day out? How does this impact on perceptions of older people who are facing decisions about relocation and long term care?

General context and definitions:

Examples of neglect and abuse in a variety of care settings, but particularly the care home sector, are frequently seen in the media. This is through the reporting of care regulator's reports, court proceedings, documentaries, and individuals and families' personal stories. These are occasionally accompanied by video clips from covert filming within care homes.

Media coverage, public perceptions and academic debates on abuse, neglect and lack of dignity suggests that it has a broad prevalence within institutional care settings (Hussein et al., 2007), however until recently very little research had been carried out in the field. The impact on current and potential care home residents, their families, and particularly care home staff, has not been evaluated.

What the research evidence says:

The perceived likelihood of having to enter a residential care home has been found to represent one of the most pervasive sources of fear and stress affecting older people (Lee 1997). Considering the sustained criticism of residential care by academics (Nolan 1999) and reports of neglect or abuse, under-trained staff and profit-making homes in the media (Lee 1997), it is not difficult to understand why such placement is often regarded by elders as the final sign of failure' (Victor 1992). These perceptions and fears have a negative influence on older residents' adjustment when they are faced with this challenge (Nolan 1999). Of UK adults responding to an Alzheimer's Society YouGov poll in 2013, 70% said they would feel scared about moving into a care home in the future.

Following the release of CQC report in 2012 which painted a fairly positive picture of the sector, the Chief Executive of Care England highlighted that all the headlines were negative. 'This raises some serious questions about how the CQC presents the report and what messages they feed into the media'.

Alzheimer's Society report 2013 'Low Expectations' (https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1628) highlighted negative perception of sector by UK families. The issue of abuse in care homes is one which has received significant attention in light of high-profile incidences reported in the media, the Society's poll found that when asked what their biggest concern would be about a relative going into a care home, over a half of UK adults (53%) said it would be of their relative being abused.

The Promoting Excellence in All Care Homes (PEACH) study (Win Tadd, cardiff University 2012) were unable to recruit homes with low 'star ratings' as even the two star homes commented on the negative media reporting with which they were constantly bombarded and how this impacted on staff and increased the anxiety of relatives.

Data from Demos poll (2013) found negative perceptions of care home, which had an impact on views about moving into a care home in the future. However, the polling consistently showed that people with first-hand experience of residential care generally held more positive views, and are more likely to consider care homes for themselves http://www.wired-gov.net/wg/wg-news-1.nsf/0/FB22818072A28DEF80257C24004AC9CC?OpenDocument .

A survey was commissioned by Radio 2 (BBC) in 2007 to provide background information for the Respect Your Elders campaign run by the BBC Social Action Unit (http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2384444). It found low expectations of the quality of care in both hospitals and care homes, responders believed that neglect and mistreatment occur frequently within them. These views were most prevalent among middle-aged women and in certain regions. These findings may provide valuable guidance for the services that seek to target their assistance and advice. Those working in care home and hospital services may not be fully aware of the anxiety that surrounds the quality of care and treatment of vulnerable older people in these settings.

Negative stereotypes of care homes have an impact on the confidence of staff and managers. A recommendation from My Home Life (2012) was that they and partner organisations should consider how they can encourage more fair and balanced press coverage http://myhomelife.org.uk/wp-content/uploads/2015/02/JRF-report-on-care-home-quality-of-life-summary.pdf.

Ongoing studies/ Trials in progress:

No studies/trials identified.

Demos 2014 launched a ‘Commission on Residential Care’ which in part aims to tackle problems over negative perceptions of care homes and champion best practice in order to identify the direction in which residential care could and should develop in the future (Professor Julienne Meyer, City University London)

How does this fit with any relevant research priority criteria?

Size of the health problem:

A poll in 2013 showed negative perceptions damaging the image of Britain’s care homes, with as few as 1 in 4 people considering moving there in their old age (Demos). Only 1 in 10 (9%) of responders associated care homes with ‘respect’.

The potential for health improvement:

The aim is to improve public perception by identifying good practice that can be shared with the sector and with the public, so that people can see that a good care home can make all the difference to older and disabled people who might otherwise lead very lonely, difficult lives in their own homes. This could have an impact on attitudes towards moving into a care home when appropriate.

The practicality of the research question:

Practicable to address.

Alignment with local health priorities:

Highlighted in the Older People’s Commission in Wales’ report: older people and their families can have low expectations about quality of life in care homes, driven by a range of factors such as the fact that moving into a care home is often not seen as a positive choice, but rather as a last resort, and a media portrayal of care homes that concentrates on failures and poor care.

Guidelines & Government Strategies relating to this area:

Older People’s Commissioner for Wales’ report into older people in care homes (2014)
http://www.olderpeoplewales.com/Libraries/Uploads/A_Place_to_Call_Home_-_A_Review_into_the_Quality_of_Life_and_Care_of_Older_People_living_in_Care_Homes_in_Wales.sflb.ashx

Relevant References:

Alzheimer's Society report 2013 ‘Low Expectations’
(https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1628

Tadd W et al Promoting Excellence in All Care Homes (PEACH) study 2012.
http://www.cardiff.ac.uk/socsi/dignity/peach/PEACHReport.pdf.

Hussein S, Manthorpe J and Penhale B, (2007). ‘Public perceptions of the neglect and mistreatment of older people: findings from a UK survey’. Ageing and Society. 27: 6: pp.

#11 RESEARCH QUESTION Oral2: What is the impact of levels of oral hygiene on the nutritional status of older people living in care homes?

This topic arose from questions on how oral hygiene impacts on the nutritional status of older people in care homes, and questions around what are the most effective methods of providing oral care for older people in care homes with particular oral care needs, such as dementia or requiring end of life care.

General context and definitions:

Oral care is a fundamental part of health care and is particularly important for those older people with co-morbidities which can increase their risk of oral diseases. This is especially the case for those with dementia, and where medication side effects include oral side-effects such as dry mouth. Behavioural problems in people with dementia can be caused or exacerbated by dental pain and problems. Effective oral hygiene helps to maintain an individual's wellbeing and dignity, and contributes to their quality of life. Long-term conditions can limit older people's ability to carry out their usual daily activities, which may impact on their oral hygiene routine and diet. Many residents have poor or inadequate oral health when they move to their care home, often as a result of deteriorating health and mobility during the preceding years (Welsh Health Circular 2015). UK and Wales surveys confirm mouth care for residents in care homes is seldom optimal (PHE 2015, Wales Care Home Dental Survey 2010-11, Morgan et al).

In Wales, the CSSIW National Minimum Standards (NMS) for care homes for older people includes a number of requirements for delivery of appropriate dental and oral health care. In addition, the Fundamentals of Care includes "Oral Health and Hygiene" as a key standard and recognises this aspect as essential to residents health and wellbeing. Reviews of the effectiveness, best practice, and barriers and facilitators for oral health of all adults in care homes have been undertaken (NICE Evidence Review 1, 2&3).

Ensuring that people can participate in social life free from embarrassment or pain and continue to enjoy a balanced and nutritious diet, contributes hugely to quality of life and general health. Malnutrition is a particular problem among the elderly, with 1.3 million of the 3 million people affected in the UK over the age of 65 (AgeUK, 2015). Any restrictions placed on the variety of foods that an individual is able to eat, such as painful or loose teeth or dentures may contribute to deteriorating nutritional status (PHE 2015).

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people (with or without dementia) living in care homes
Intervention:	Oral hygiene/care intervention (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator:	Non-intervention as control
Outcomes of Interest:	Oral Health related Quality of Life (OHrQOL), nutritional assessment (dietary intake, MUST etc), staff satisfaction, oral hygiene measures, number of adverse outcomes (agitation etc)

What the research evidence says:

A review of the literature found that oral care for older people living in care homes is generally poor, particularly in people with dementia, and there is a need for an assessment tool and evidence for effective methods of oral care, and trials of preventative strategies and staff education interventions (Chalmers and Pearson 2005). They proposed that further research with this population is needed to develop and validate oral assessment tools and staff education programmes, trial preventive oral hygiene care strategies/products and trial dementia-focused behaviour management and communication strategies.

There are a number of studies evaluating assessment tools and educational interventions for caregivers on improving oral health knowledge and attitudes (e.g Frenkel et al 2001). Aside from some evidence that oral care can reduce infections, such as aspiration pneumonia (a systematic review by Sjogren et al 2008), oral hygiene is undervalued in terms of its effects on health and nutrition.

There is limited evidence supporting a possible association between poor oral health and dementia. Additional studies of the relationships between oral health and cognition are required (PHW 2011 Oral health and systemic disease: a rapid review of the evidence).

Ongoing studies/ Trials in progress:

Developing evidence-based oral healthcare for older Irish adults, comparing two different tooth replacement strategies for partially dentate older patients in NI (Dr Gerald McKenna, Cork University Dental School and Hospital). Primary outcome is Oral Health related Quality of Life (OHrQOL), one of the secondary outcomes is nutritional status using MUST tool. All partially dentate patients aged 65+ in community (not care home based), excludes those unable to attend hospital appointments or unable to give consent.

How does this fit with any relevant research priority criteria?

In 'A Place to Call Home?' the Older People's Commissioner for Wales recognises the importance of oral hygiene and supports the need for timely and appropriate dental care for older people in care homes throughout Wales. Welsh Government and local health boards have developed an "Improving Oral Health for Older People Living in Care Homes" oral health programme (WHC February 2015). Similar strategies are in place in Scotland and England

Guidelines & Government Strategies relating to this area:

Oral health for adults in care homes NICE guidance in development [GID-PHG62]. Anticipated publication date: July 2016
https://www.nice.org.uk/guidance/indevelopment/gid-phg62/documents

WAG 2015. Improving Oral Health for Older People Living in Care Homes in Wales
http://www.wales.nhs.uk/improvingoralhealthforolderpeoplelivingincarehomesinwales

Relevant References:

Karki AJ, Monaghan N, Morgan M. Oral health status of older people living in care homes in Wales. British Dental Journal 219, 331 - 334 (2015)
http://www.nature.com/bdj/journal/v219/n7/full/sj.bdj.2015.756.html

Public Health England 2015. What is Known About the Oral Health of Older People in England and Wales: A review of oral health surveys of older people
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/489756/What_is_known_about_the_oral_health_of_older_people.pdf]

Welsh Oral Health Information Unit (WOHIU) works with the Wales Dental Epidemiology Co-ordinator to plan and deliver the NHS Dental Survey Programme for Wales http://www.cardiff.ac.uk/research/explore/research-units/welsh-oral-health-information-unit

Public Health Wales 1000 Lives Programme 2011. Oral health and systemic disease: a rapid review of the evidence http://www.1000livesplus.wales.nhs.uk/mouthcare

#13 RESEARCH QUESTION Activity1: What activities can improve the quality of life for care home residents with impaired vision or hearing?

A large number of questions were raised on activities for care home residents generally, as well activities for those with dementia, impaired hearing, impaired vision, or those who had limited functional ability or were 'bed-bound'. The stated aim was often for the older person to 'keep interest', perceiving a loss of interest as having a negative impact of the person's quality of life.

General context and definitions:

Mild but progressive sight and hearing losses are a common feature of ageing and may go unnoticed for some time, but can have a serious effect on a person's communication, confidence and independence. Though there is little scientific evidence on the extent of sensory impairment in the care home population, there is evidence that visual impairment and hearing loss are major health problems in older people (Keller et al., 2001; Yueh et al., 2003. Estimates of vision impairment at ages 75–84 range 7–16%, and at ages 85+, 24–38% (Tate et al., 2006), and 71% of the over 70 age group experience hearing loss (Royal National Institute for Deaf and Hard of Hearing People: RNID, 2006).

Sensory problems vary from minimal impairments to major sight loss and hearing impairment. Even mild hearing impairment has been shown to have a major impact on the social functioning of older people with increased reports of isolation, and loneliness (Wallhagen et al., 2001). In frail older people, hearing impairment is associated with a decrease in functioning in instrumental activities of daily living, and reduced social engagement, which may contribute to a reduced quality of life (Keller et al., 1999; Dalton et al.,2003).

It is important that older people in care homes have the opportunity to take part in activity that helps to maintain or improve their health and mental wellbeing. They should be encouraged to take an active role in choosing and defining activities that are meaningful to them.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Older people with impaired vision and/or hearing living in care homes
Intervention:	Activity-based intervention (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator:	Non-intervention as control
Outcomes of Interest:	Quality of Life measures (QOL), depression measure/HADS,

What the research evidence says:

Resnick et al (1997) examined the relationships between three sensory and communication abilities and two areas of nursing home resident behaviour in US. They found and increasing level of visual impairment is associated with low levels of social engagement and low time in activities, and both moderate and severe hearing impairment are associated with low time in activities. The combined effects of visual and communications impairments are associated with low social engagement and depression. Increasing attention to sensory and communication losses may lead to improve quality of life in this population.

Jung and Cimaroll's 2012 study examined personal and health-related factors associated with long-stay nursing home residents' preferences for various recreational activities. They found that vision impairment was associated with placing less importance on vision-specific activities (reading), and hearing impairment was related to placing less importance on hearing-specific activities (listening to music).

There is evidence on interventions to improve sensory impairment (e.g Elliott et al 2009) and assessment of impairment (Pavey et al March 2012). No evidence of activity interventions for care home residents with hearing/visual impairment to improve QoL.

Ongoing studies/ Trials in progress:

Small number of activity interventions for care home residents generally, e.g:

Feasibility study of a personalised activity programme with accompanying environmental and organisational changes - Active Residents in Care Homes Programme (ARCH) will improve the activity levels, health and quality of life of residents (Kingston University and St George's University of London, funded by The Chartered Society of Physiotherapy's Charitable Trust).

How does this fit with any relevant research priority criteria?

Size of the health problem:
Sensory impairments become increasingly common as people age: around 80% of people over 60 have a visual impairment, 75% of people over 60 have a hearing impairment, and 22% have both a visual and hearing impairment. This may be significantly higher in care home populations as they are generally the oldest old, and visual impairment and blindness is a known contributing factor to an older person requiring a placement in a care home.

The potential for health improvement:
Person centred care is a measure of the quality of health care, research has shown that patient-centred interactions lead to improved health outcomes.

Person-centred care (including meaningful activities) promotes mental stimulation, can improve general health and quality of life, and reduce social isolation and depression.

The practicality of the research question:
Should be practicable to address. High levels of interest in person-centred care generally. There is a need for evidence around the activity preferences of care home residents with visual and/or gearing impairments, prior to evaluation of preferred activities on QoL and other outcomes.

Alignment with local health priorities:
National Service Framework for Older People in Wales (PCC one of 6 cross-cutting themes).

Guidelines & Government Strategies relating to this area:

Mental wellbeing of older people in care homes NICE quality standard [QS50], Quality statement 4: Recognition of sensory impairment and Quality statement 1: Participation in meaningful activity https://www.nice.org.uk/guidance/qs50

DoH. Care Homes for Older People National Minimum Standards 2003. Standard 12: ‘Service users’ interests are recorded and they are given opportunities for stimulation through leisure and recreational activities in and outside the home which suit their needs, preferences and capacities; particular consideration is given to people with dementia and other cognitive impairments, those with visual, hearing or dual sensory impairments, those with physical disabilities or learning disabilities’.
http://www.dignityincare.org.uk/_library/resources/dignity/csipcomment/csci_national_minimum_standards.pdf

Centre for Policy on Ageing. Sensory loss in older age. April 2016
http://www.cpa.org.uk/information/readings/sensory_loss.pdf

Relevant References:

Jung, S., and V. R. Cimarolli. 2012. PERSONAL AND HEALTH-RELATED FACTORS ASSOCIATED WITH RECREATIONAL ACTIVITY PREFERENCES AMONG NURSING HOME RESIDENTS. http://www.jnursinghomeresearch.com/509-personal-and-health-related-factors-associated-with-recreational-activity-preferences-among-nursing-home-residents.html

Cook et al 2006. The impact of sensory impairment on social interaction between residents in care homes. International Journal of Older People Nursing http://onlinelibrary.wiley.com/doi/10.1111/j.1748-3743.2006.00034.x/abstract

Action on Hearing Loss https://www.actiononhearingloss.org.uk/supporting-you/care-and-support/proposed-standards-for-care-homes/communication.aspx

RNIB http://www.rnib.org.uk/services-we-offer-advice-professionals-social-care-professionals/working-older-people

Sense (deaf blind) https://www.sense.org.uk/content/information-professionals-working-older-people

VISUAL AIDS IN DEMENTIA

#14 RESEARCH QUESTION Activity3: How can the provision of visual aids enhance the quality of life of people with end stage dementia?

There were a number of questions raised about activities and person-centred care for care home residents with dementia, however this question specifically related to the use of visual aids for care home residents with severe dementia. Visual aids may range from communication aids, environmental aids such as signage, memory aids, multi-sensory environments, and aids to improve vision.

General context and definitions:

Visual impairment is a common symptom of Alzheimer's disease (AD). Deficits in vision have been found in both 'lower' levels of visual processing, such as contrast sensitivity, visual acuity, colour and motion perception as well as 'higher' visual processing such as reading, object recognition, and spatial localisation (Kirby et al 2010). The majority of studies have found the visual impairment in AD to be related to the severity of the disease and deficits in vision in AD patients have also been shown to significantly correlate with performance of instrumental activities of daily living, even after disease severity was controlled for in analysis (Glosser et al 2002). The enhancement of computerized images through increasing signal strength has been shown to improve performance on cognitive assessments, which demonstrates the importance of vision in improving AD interventions (Kirby et al 2010).

A range of visual aids, such as signage and communication aids, can be used to improve AD patients' visual memory, so as to allow them to complete the task at hand. This could be finding the correct medication or in more severe cases finding the bathroom for example. Visual aids can also be used to stimulate the memory of patients which may help to reduce stress and frustration, and may give a greater sense of control. External memory aids can be used as a cueing strategy to improve communication and activities of daily living, such as taking medication. A range of visual aids are available to correct visual deficits, which may require modification to address the needs of those with dementia.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population: Older people with end stage dementia living in care homes
Intervention: Visual aid-based intervention (which may or may not involve health and social care professional/s training, skills or attitudes), in a care home setting,
Comparator: Non-intervention as control
Outcomes of Interest: Quality of Life measures (QOL) or dementia-related quality of life (DEMQoL etc), vision-related aspects of function and behaviour, number of adverse outcomes (agitation etc)

What the research evidence says:

Early findings from PrOVIDe Study (NIHR HS&DR) with people with dementia, are that prevalence of presenting VI was 32.5% (95% CI 28.7 to 36.5) and 16.3% (13.5 to 19.6) for visual acuity (VA) worse than 6/12 and 6/18 respectively in people aged 60-89 years, generally higher than in comparable data from prevalence studies on the general population after adjustment for age and sex. The unadjusted rate ratios of all types of VI were two to two-and-a-half times greater for care home residents compared with participants living in their own homes; these higher rates persisted even after age and gender adjustments. Exploratory analysis found evidence for deficits in some vision-related aspects of function and behaviour in participants with VI vs. those without VI.
http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0003/160734/FLS-11-2000-13.pdf

A range of visual aids have been developed for use by people with dementia, with some evaluation. There is evidence for the effectiveness of low-tech interventions to assist communication such as Talking Mats (JRF, Murphy et al 2010), prompting devices - assistive technology (Tsui and Yanco 2010) and associated cost-effectiveness (Bowes et al 2013), computer based aids (reminisence etc) (Alm et al 2013). There is also evidence on effective environments for people with dementia and visual impoiarment (Fleming et al 2008).

Training approaches, such as Spaced Retrieval (SR) and a modified Cueing Hierarchy (CH), were found to be effective for teaching persons with dementia a strategy goal involving an external memory aid (Bourgeios et al 2003). Optical aids may reduce visual hallucinations (Plankow et al 1996).

A systematic review has been conducted on the effectiveness of interventions designed to modify and maintain perceptual abilities on the occupational performance of people with Alzheimer's disease (Letts et al 2001). No evidence of a systematic review of the effect of visual aids by those specifically in care homes, or on other outcomes such as quality of life.

The All Wales Visual Impairment Database could be developed into a research resource, providing useful information for policy makers, service providers and researchers concerned with improving the lives of people with sight loss. In particular, it could be used to provide samples for research projects and to investigate how a person's service use and vision change over time (Thomas

Pocklington Trust 2010 http://pocklington-trust.org.uk/wp-content/uploads/2016/02/All-Wales-VI-Database.pdf).

Ongoing studies/ Trials in progress:

CLOSED: The PrOVIDe study (Prevalence of Visual Impairment in Dementia) (NIHR HS&DR, Mr Michael Bowen, the College of Optometrists) aims to measure the prevalence of a range of vision problems in people with dementia, and to propose a UK Dementia Eye Care Pathway
http://www.nets.nihr.ac.uk/projects/hsdr/11200013

How does this fit with any relevant research priority criteria?

Size of the health problem:
Sensory impairments become increasingly common as people age. Evidence suggests that the prevalence of people with dementia presenting VI (VA 6/12) was 32.5% (PrOVIDe study).

The potential for health improvement:
The disproportionately high prevalence of VI in care home residents suggest that eye care for people with dementia could be enhanced. Suggestions include a specialised care pathway, early cataract intervention, changes to spectacles provision (increased incidence of spectacles being broken or lost) or alternative materials to prevent breakage, developing the role of a specialist optometric practitioner for people with dementia, and other interventions to reduce the impact of VI. Measures to reduce the impact of VI may improve quality of life and some vision-related aspects of function and behaviour.

The practicality of the research question:
Practical to conduct a systematic review of the use of visual aids for people with dementia, with a range of outcomes including QoL, prior to potentially developing a visual aid intervention or further evaluation of existing aids where evidence gaps are identified.

Alignment with local health priorities:
The Visual Impairment and Dementia Summit (VIDem, 2015) identified the need to focus on practical outcomes which will make a difference to people's quality of life, but also to provide professionals with better guidelines, information and tools.

Guidelines & Government Strategies relating to this area:

Mental wellbeing of older people in care homes NICE quality standard [QS50], Quality statement 4: Recognition of sensory impairment
https://www.nice.org.uk/guidance/qs50

DoH. Care Homes for Older People National Minimum Standards 2003. Standard 12: 'Service users' interests are recorded and they are given opportunities for stimulation through leisure and recreational activities in and outside the home which suit their needs, preferences and capacities; particular consideration is given to people with dementia and other cognitive impairments, those with visual, hearing or dual sensory impairments, those with physical disabilities or learning disabilities'. http://www.dignityincare.org.uk/_library/resources/dignity/csipcomment/csci_national_minimum_standards.pdf

Centre for Policy on Ageing. Sensory loss in older age. April 2016 http://www.cpa.org.uk/information/readings/sensory_loss.pdf

Relevant References:

Kirby et al 2010 Visual Impairment in Alzheimer's disease: A Critical Review. Journal of Alzheimer's Disease 21 (2010) 15–34 http://content.iospress.com/download/journal-of-alzheimers-disease/jad080785?id=journal-of-alzheimers-disease%2Fjad080785

Visual Impairment and Dementia (VIDem) summit report (College of Optometrists March 2016) includes priorities such as "What are the most effective components of care that keep a person with visual impairment and dementia as independent as they can be at all stages of the disease in all care settings?" and other questions such as "How can aids and equipment be designed for people with visual impairment and dementia e.g. provision of safe glasses?"

Bourgeois, M. S., Camp, C., Rose, M., White, B., Malone, M., Carr, J., & Rovine, M. (2003). A comparison of training strategies to enhance use of external aids by persons with dementia. Journal of communication disorders, 36(5), 361-378.

Letts, L., Minezes, J., Edwards, M., Berenyi, J., Moros, K., O'Neill, C., & O'Toole, C. (2011). Effectiveness of interventions designed to modify and maintain perceptual abilities in people with Alzheimer's disease and related dementias. American Journal of Occupational Therapy, 65(5), 505-513. http://ajot.aota.org/Article.aspx?articleid=1851500

Thomas Pocklington Trust for people with sight loss have published a number of papers on dementia and visual impairment, including hallucinations, and fund social and public health research and development projects on sight loss issues (£300,000 per annum). http://www.pocklington-trust.org.uk/health-and-well-being/

Ryan, B. and Margrain, T. H. 2010. Research findings no 28: All Wales visual impairment database. Project Report. London, UK: Thomas Pocklington Trust.

#15 RESEARCH QUESTION Staff8: Can education strategies improve care home staff attitudes towards use of power and authority in their relationship with older people with cognitive impairments?

A number of questions were raised about staff training (see # 7 and # 5 RESEARCH QUESTIONS), however this specific question related to how staff can be trained to ensure they do not abuse the authority/power they have over residents who have cognitive impairments. Although there are difficulties around the concepts of 'abuse' and 'neglect', and an inconsistency in definitions, abuse of power and authority can be seen as ignoring, overriding or not seeking personal preferences of care home residents, to coercion, to overt psychological, physical or financial abuse.

General context and definitions:

A Health Select Committee report (2004) noted that abuse and neglect in institutional settings may be a cause for particular concern, stating that '… a number of submissions drew particular attention to the potential for abuse to occur behind closed doors'. Not only may residents have less immediate access to the outside world, but they may be subject to an inappropriate institutional culture, manifested in attitudes and styles of communication as well as care practices.

Interpersonal relationships and interactions between care home staff and residents should be centred on dignity and respect principles. One important element of good practice is to guard against any kind of exploitation, neglect or abuse of care home residents. An environment which is constantly seeking to improve the life and care of residents automatically tends to guard against bad practice.

In spite of registration, inspection, internal monitoring, quality assurance systems and codes of practice, regrettably abuse occurs. Sometimes this may be unwitting or unintentional perhaps through ignorance or neglect. At other times, however, it may be deliberate, whether subtle or overtly cruel. There is now greater recognition of the fact that abuse does occur and a fuller understanding of how it arises.

The Care Act 2014, together with a range of regulations and statutory guidance, is the base upon which social care will develop over the next few decades. It enshrines the new statutory principle of individual wellbeing, the driving force behind the Act, and makes it the responsibility of local authorities to promote wellbeing when carrying out any of their care and support functions. Most of the Act's changes took effect from April 2015. One of the elements of 'wellbeing' is protection from abuse and neglect, and new statutory safeguarding duties are guided by six key safeguarding principles - empowerment, prevention, proportionality, protection, partnership and accountability - organisations must promote the adult's wellbeing in their safeguarding arrangements.

The question in a structured format:

In considering this as a research question, we could frame it as following:

Population:	Care home staff caring for older people with dementia living in care homes
Intervention:	Education intervention to improve health and social care professional/s attitudes towards the use of power and authority in relationships, in a care home setting,
Comparator:	Non-intervention as control
Outcomes of Interest:	Staff satisfaction, changes in care home residents' perception of dignity using specific measures: The Herth Hope Index (HHI), The Patient Dignity Inventory (PDI), Perceived Quality of Life, and Satisfaction with Quality Life Ratings and others. Quality of Life measures (QOL) or dementia-related quality of life (DEMQoL etc).

What the research evidence says:

For maltreatment to be recognized, staff, residents, and the general public need to be aware of what precisely constitutes abuse. One of the prominent ways of raising awareness is through staff education and training. A few studies have identified raised staff awareness of maltreatment via educational initiatives, however, these studies tend to be single-point evaluations, many undertaken at the end of the training program, where sensitivity to maltreatment is heightened (Fealy et al 2014). Some studies identified the limitations of current educational programs with Smith et al 2010 emphasizing that a focus on more interactive and personally relevant programs has the ability to imbue a deeper understanding of the issue. Education should be guided by a continuous practice development focus on safeguarding residents (Phelan 2015).

Equality and human rights and basic values training should be provided to all residential care staff. This should include dignity and respect principles, attitudes and values, empathy, equality and human rights awareness and challenging negative stereotypes (Older Person's Commissioner for Wales 2014).

Care homes can create a culture of practice where older people, their families and staff are supported to develop positive relationships with one another (relationship-centred care), to interact and explore ideas together in an informal way. Through this culture, staff are more able to connect with older people, to engage with them as individuals, to understand and respond to their interests, opinions, aspirations and needs. Relationship-centred care is different to person-centred care, which focuses on individual service users, promoting their independence and consumer choice. It has been argued that, in long-term care settings, positive relationships between older people, relatives and staff and interdependence matter more (My Home Life/JRF 2015).

A relationship-centred approach to care is highly desired by residents (Brown-Wilson and Davies 2009). However, this requires the involvement of both staff and residents, and an examination of the philosophy and values of the culture and management of the care home as these will undoubtedly affect the well-being of all who live and work there (McKinley and Adler 2006).

Ongoing studies/ Trials in progress:

CLOSED: ResPECT Study of Organisational Dynamics of Elder Care commissioned by Comic Relief and Department of Health through the Prevention of Abuse and Neglect In the Care of Older Adults programme (PANICOA).
http://www.panicoa.org.uk/

How does this fit with any relevant research priority criteria?

Size of the health problem:

Discovering the prevalence of abuse, perpetrated against vulnerable people by those they rely on, is inherently difficult, further complicated by the lack of consensus around definitions. In a systematic review (Cooper et al 2007) the prevalence of overall abuse ranged between 3.2 and 27.5% in general population studies, a quarter of the dependent older people reported significant levels of psychological abuse and 1% reported physical abuse, and About 10% of staff admitted physical abuse and 40% any psychologically abusive act in the last year. Other studies reported on abuse by family members, and abuse in their own home.

The potential for health improvement:

Experiences can range from a lack of empowerment and choice, loss of dignity, to the extremes of physical and psychological harm. Ensuring that care home residents do not experience a misuse of power and authority by care home staff caring for them may have a positive impact on care home residents' perception of dignity and esteem, and quality of life. Staff satisfaction and the care culture within a care home may also improve.

The practicality of the research question:

Research involving such a sensitive and emotive issue is inherently difficult, further complicated by the lack of consensus around definitions. However, the success of the PANICOA research programme has demonstrated that it is practicable to conduct research in this area, with engagement with a range of stakeholders.

Alignment with local health priorities:
There are no accurate statistics that would identify the prevalence of abuse in care homes in Wales, however, the Care and Social Services Inspectorate for Wales Annual Report 2012-13 reports that 888 concerns were raised with them about care in 405 care settings. The most common concerns raised were about the neglect of service users, protection and physical abuse of service users and concerns about the behaviour and attitude of management. The Older People's Commissioner for Wales has identified the priority areas for identification and action on abuse of, and crimes against, older people (Older People's Commissioner for Wales, 2014).

Guidelines & Government Strategies relating to this area:

Older Person's Commissioner for Wales (2014). A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales http://www.olderpeoplewales.com/Libraries/Uploads/A_Place_to_Call_Home_-_A_Review_into_the_Quality_of_Life_and_Care_of_Older_People_living_in_Care_Homes_in_Wales.sflb.ashx

Older People's Commissioner for Wales, 2014. Abuse of, and crimes against, older people http://www.olderpeoplewales.com/Libraries/Uploads/Policy_Statement_-_Adult_Protection.sflb.ashx

Relevant References:

My Home Life/Joseph Rowntree Foundation: Promoting Quality of Life in Care Homes (2015) http://myhomelife.org.uk/wp-content/uploads/2015/02/JRF-report-on-care-home-quality-of-life-summary.pdf

Brown-Wilson C, Davies S. Developing relationships in long term care environments: the contribution of staff. J Clin Nurs 2009;18:1746-55.

McKinley K, Adler G. Quality of life in nursing homes. Soc Pol J 2006;4:37-51

Manthorpe, J., Stevens, M., Hussein, S., Heath, H., & Lievesley, N. (2011). The abuse, neglect and mistreatment of older people in care homes and hospitals in England: observations on the potential for secondary data analysis. Social Care Workforce Research Unit. http://www.kcl.ac.uk/sspp/policy-institute/scwru/pubs/2011/manthorpeetal2011abuse.pdf

Fealy G, O'Donnell D, Patton D, Downes C, O'Connor T. An Evaluation of the HSE National Training Programme in Preventing Elder Abuse. Dublin: NCPOP; 2014

Smith MK, Davis BH, Blowers A, Shenk D, Jackson K, Kaslaw K. Twelve important minutes: introducing enhanced on line materials about elder abuse to nursing assistants. J Contin Ed Nurs. 2010;46(1):281–288.

Phelan, A. (2015). Protecting care home residents from mistreatment and abuse: on the need for policy. Risk management and healthcare policy, 8, 215. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4657805/

Cooper, C., Selwood, A., & Livingston, G. (2008). The prevalence of elder abuse and neglect: a systematic review. Age and ageing, 37(2), 151-160. https://ageing.oxfordjournals.org/content/37/2/151.full

Appendix 1: Longlist of identified research topics

Medication
1. Can medication for agitation and aggression be effectively and cost effectively given in patch form?
2. Is giving medicines covertly to residents in care homes acceptable?
3. Are there more time-efficient methods of conducting nurse medication rounds in care homes without compromising patient safety?
4. What are the cost benefits of prescribing liquids or other formulations of medicines for older people living in care homes in terms of medication adherence and outcomes?
5. What is the impact on the individual and other care home residents of a reduction of psychotropic medication for psychosis/challenging behaviour?
6. Is there equity in drugs prescribing for Parkinson's disease within care homes?
Staffing and dependency
1. What are the essential elements required when training carers working with older people in care homes?
2. How can recruitment of carers with essential qualities such as compassion and empathy be improved by care homes?
3. Can retention of care home staff be improved by greater decision-making involvement in the management of care homes?
4. What are the attitudes of inexperienced care home staff towards providing person-centred care, and can training and support improve awareness of the need for person-centred care?
5. What are appropriate staffing levels in relation to the number of residents in care homes and their relative care needs?
6. How can care home staff be trained and supported in 'whistle-blowing policies' to report inappropriate practices in care homes?
7. What strategies can be used to reduce overt and covert racism in interactions between residents and care home staff and between other healthcare professionals and staff?
8. Can education strategies improve care home staff attitudes towards use of power and authority in their relationship with older people with cognitive impairments?
Person centred care
1. How can dignity be enhanced for residents in care home settings?
2. How can person-centred care be provided in care homes appropriate to the person's individualised needs?
3. How can best interest decisions made for care home residents with dementia be properly documented in care plans?
Urinary

1. In care home residents, does the reduction of caffeine intake reduce levels of incontinence and use of incontinence aids?
2. Can provision of quality person-centred care improve incontinence in care home residents?
3. In care home residents, does the reduction of caffeine intake with or without an increase in fluid intake reduce incidence of urinary tract infections?
Activities
1. What activities can improve the quality of life for care home residents with impaired vision or hearing?
2. What aids/activities can improve the quality of life for care home residents with restricted physical abilities?
3. How can the provision of visual aids enhance the quality of life of people with end stage dementia?
End of life care
1. How can families and healthcare professionals contribute to improving end of life care for older people in care homes?
2. How can early and appropriate discussion with older people in care home about end of life care be supported?
3. What is the level of staff knowledge and awareness of the legal implications of Advance Care Planning?
Mobility
1. How can mobility levels of older people moving into care homes be increased?
2. Is post-fracture community physiotherapy effective in improving outcomes for care home residents with dementia?
Pressure area care
1. Are Waterlow scores accurate in assessing the risk of pressure ulcer development in older people living in care homes?
2. What is the effectiveness and cost-effectiveness of strategies to reduce pressure ulcers in care home residents?
3. Can provision of quality person-centred care prevent or reduce the incidence of pressure ulcers in care home residents?
4. What is nurse assessors' knowledge of device use for the prevention and management of pressure ulcers in care homes?
5. Does an education intervention for care home staff reduce the incidence of pressure ulcer development?
Service delivery
1. How can Incident Reporting in Care Homes be improved?

2. Can standardised care planning tools be developed for care home residents throughout UK?
3. Does the expectation and experience of care by residents in care homes correlate with CQC requirements and what is the impact on outcomes of care?
4. Can electronic health records and point of care recording in care homes improve early warning of health issues?
5. How can communication and information sharing be improved between service providers to improve care and efficiency?

6. What can be learned from the US sub acute model (transition/intermediate care)? Can it enable UK care homes to improve participation in 'care closer to home' initiatives?
Relationships
1. How can family members of residents living in a care home with dementia be supported in the community?
2. How can the emotional needs be met of older people living in the community and in care homes?
3. What are the most effective strategies to involve primary carers of older people moving into care homes to maintain caring relationship?
4. What models of family involvement can improve resident outcomes in care homes?
Oral care
1. What are the most effective methods of providing oral care for older people in care homes with particular oral care needs, such as dementia or requiring end of life care?
2. What is the impact of levels of oral hygiene on the nutritional status of older people living in care homes?
Community
1. How can there be greater integration between older people living in the community and care homes?
2. How can we best encourage care home residents to participate and engage in community resources?
3. What is the public and media perception of care homes compared with other care settings, and what is the impact on care home staff attitudes?
Environment
1. How can care homes be made to feel more like a home?
Nutrition and hydration
1. In older people living in care homes, does the use of MUST accurately assess nutritional status in comparison with other nutritional screening tools?

2. What is the effect of altering main meal timings on preventing weight loss in residents in care homes?
3. How can long term PEG feeding be best managed and nutritional needs met for care home residents?
4. What are the advantages and disadvantages of closing care homes to visitors (including medical staff) during meal times?
5. How can the nutritional needs of older people in care homes with dysphagia be best supported?
6. What is the impact of environmental factors on dietary intake/nutritional status of care home residents with dementia?
7. How can care home staff be supported to respect residents and their families' wishes which conflict with specialist advice regarding best care, such as refusing a soft diet?
Behaviour
1. What interventions are effective to reduce anxiety in care home residents?
2. Can a pain management assessment tool be effective amongst dementia patients in care home settings?
3. How can de-escalation techniques be used to minimise agitation in care home residents?
4. What are the most effective strategies to improve depression in care home residents with dementia?
5. What strategies reduce levels of violence by residents towards staff in care homes?
6. In care home residents with dementia, does a reduction of caffeine intake reduce levels of agitation?
7. Can the use of herbal drinks, such as valerian root tea, reduce 'sundown syndrome' in older people in care homes?
8. Comparison of effectiveness of non-drug related therapies by demographic characteristics of care home residents with dementia
9. What are the most effective strategies to improve integration and socialisation of older people following admission in care homes?
10. What are the most effective strategies to enhance communication with people in care homes with advanced dementia and other communication problems?
11. How can families of people with dementia be better informed about dementia and the experience of living with dementia?
12. How can older people with end stage dementia be supported to retain their individuality?
13. How can families be helped to cope with aggressive behaviour in care home residents?
14. What environmental factors influence levels of agitation in care home residents?

15. What strategies can families and healthcare professionals use to best manage challenging behaviour in care home residents in addition to drug therapy?
Access to services
1. What is the effect of the level of access to mental health services on the use of anti-psychotic medication in care homes?
2. What is the best model of provision of dental services for care home residents?
3. What is the effectiveness and cost effectiveness of nursing services such as wound care being provided by nurses in care homes as opposed to district nurses?
4. What is the best model of access to mental health services in an appropriate timescale for care home residents?
5. What are the advantages and disadvantages of joint care home provision for both frail elderly and adults with learning disabilities?

Appendix 2: Shortlist - Interim rank order of top 30 research questions

Rank	**RQ ID**	**Research Question (RQ)**
1	staff1	What are the essential elements required when training carers working with older people in care homes?
2	staff2	How can recruitment of carers with essential qualities such as compassion and empathy be improved by care homes?
3	person1	How can dignity be enhanced for residents in care home settings?
4	staff5	What are appropriate staffing levels in relation to the number of residents in care homes and their relative care needs?
5	person2	How can person-centred care be provided in care homes appropriate to the person's individualised needs?
6	person3	How can best interest decisions made for care home residents with dementia be properly documented in care plans?
7	end1	How can families and healthcare professionals contribute to improving end of life care for older people in care homes?
8	end2	How can early and appropriate discussion with older people in care home about end of life care be supported?
9	activity3	How can the provision of visual aids enhance the quality of life of people with end stage dementia?
10	comm3	What is the public and media perception of care homes compared with other care settings, and what is the impact on care home staff attitudes?
11	env1	How can care homes be made to feel more like a home?
12	staff4	What are the attitudes of inexperienced care home staff towards providing person-centred care, and can training and support improve awareness of the need for person-centred care?
13	activity1	What activities can improve the quality of life for care home residents with impaired vision or hearing?
14	oral2	What is the impact of levels of oral hygiene on the nutritional status of older people living in care homes?
15	staff8	Can education strategies improve care home staff attitudes towards use of power and authority in their relationship with older people with cognitive impairments?
16	beh1	What interventions are effective to reduce anxiety in care home residents?
17	beh4	What are the most effective strategies to improve depression in care home residents with dementia?
18	staff3	Can retention of care home staff be improved by greater decision-making involvement in the management of care homes?
19	oral1	What are the most effective methods of providing oral care for older people in care homes with particular oral care needs, such as dementia or requiring end of life care?

20	beh12	How can older people with end stage dementia be supported to retain their individuality?
21	beh11	How can families of people with dementia be better informed about dementia and the experience of living with dementia?
22	beh15	What strategies can families and healthcare professionals use to best manage challenging behaviour in care home residents in addition to drug therapy?
23	beh3	How can de-escalation techniques be used to minimise agitation in care home residents?
24	beh5	What strategies reduce levels of violence by residents towards staff in care homes?
25	mobile1	How can mobility levels of older people moving into care homes be increased?
26	staff6	How can care home staff be trained and supported in 'whistle-blowing policies' to report inappropriate practices in care homes?
27	pressure5	Does an education intervention for care home staff reduce the incidence of pressure ulcer development?
28	nutr6	What is the impact of environmental factors on dietary intake/nutritional status of care home residents with dementia?
29	pressure3	Can provision of quality person-centred care prevent or reduce the incidence of pressure ulcers in care home residents?
30	nutri7	How can care home staff be supported to respect residents and their families' wishes which conflict with specialist advice regarding best care, such as refusing a soft diet?