Prioritising Research through Engagement with older Adult Care Homes

Background

Care home research has grown in recent decades, and information collected by these studies can be repurposed, offering a valuable, low-risk and cost-effective opportunity for 'secondary analysis' – looking at information already available in a new way to see if we gain further learning from it. The Virtual International Care Homes Trials Archive (VICHTA) combines information from multiple studies about different care models and health conditions, including data from over 6000 residents(1).

Despite this wealth of information, topics researchers want to study may not reflect the priorities of people living in care homes, their families, or staff caring for them. Funders highlight the importance of talking to these people, to make sure we're using data from studies wisely and focusing research funding on the right things. We now seek to discover what key stakeholders think is most important to learn from research, by asking residents, their families, care home staff, owners, clinicians, commissioners and research funders. Priority setting presents an opportunity to actively engage with care home networks and generate research ideas grounded in the lived experiences of residents.

Rationale:

Historically, health and social care research agenda has been largely investigator-driven with limited input from other stakeholders. This leads to an evidence mismatch between research interests of residents, staff and researchers, and investment may be misdirected to areas of low priority or fail to address important needs of relevant stakeholders. Priority setting is an opportunity to become actively involved in care home networks, and test how to identify and generate new research ideas that are grounded in the lives and experiences of those who live and work in care homes.

The Virtual International Care Home Trials Archive (VICHTA) is a repository of data pooled from randomised controlled trials (RCTs) conducted exclusively in older adult care homes. There are currently 6 trials, comprising individual participant data on 5700 residents in 340 UK care homes, collected 2011-2019. We propose to extend this work, by identifying key research priorities reported by care home staff, residents, their representatives, local authority commissioners and regulators, that secondary data analysis of VICHTA trial data can answer.

Aims:

1. Identify and build relationships with key care home stakeholders who can publicise the project among their networks and disseminate results

2. Identify key research priorities, particularly for care home residents and their carers, through a mixture of online, postal and in-person engagement

3. Map stated priorities with data available through VICHTA trials archive and other secondary data sources

Stakeholders

Stakeholders in older adult care home research are individuals, groups, or organizations who have a vested interest in or are affected by the outcomes of the research. Identifying and engaging various stakeholders is crucial for ensuring that research priorities, methodologies, and findings align with the diverse needs and perspectives of those involved in or impacted by care home services. We will be seeking to engage predominantly with stakeholders based in the UK (as we will be mapping research priorities to data from trials completed in the UK), but international respondents will also be able to participate in our online survey.

Key stakeholders in older adult care home research include:

Residents
Older adults residing in care homes are primary stakeholders. Their experiences, preferences, and needs are essential for shaping research priorities.

Family carers:
Family members are important stakeholders as they can advocate for their loved ones, particularly if the resident is unable to communicate their own needs.

Care Home Staff:
Staff members, including healthcare professionals, nurses, administrators, and support staff, have a direct impact on the quality of care provided. Their insights are vital for understanding the challenges and opportunities within care homes.

Care Home Owners and Managers:
Administrators and managers play a key role in decision-making, resource allocation, and overall management of care homes. Research involving their perspectives can inform policy and practice.

Healthcare Providers:
External healthcare providers, such as physicians, therapists, and specialists, who collaborate with care homes or provide services to residents, are stakeholders with valuable insights into the integration of healthcare services.

Policy Makers and Government Agencies:
Government officials, policymakers, and regulatory bodies influence the legal and regulatory framework of care homes. Research findings can inform policy decisions and regulations.

Community Organisations:

Local community organisations, advocacy groups, and NGOs may have a stake in the well-being of older adults in care homes. Collaborating with these entities can enhance community support and resources.

Researchers:
Academics and researchers studying aging, healthcare, and long-term care are stakeholders contributing to the body of knowledge in the field. Their research can influence best practices and policies.

Research Funding Bodies:
Organisations providing funding for research projects related to older adult care homes are stakeholders. Their priorities and interests can shape the focus of research initiatives.

Technology Providers:
Companies developing and supplying technology solutions for care homes, such as health monitoring systems or communication tools, have a stake in research that explores the impact of technology on care outcomes.

Local authority commissioners who fund care:
Insurers providing coverage for long-term care services may be interested in research that informs risk assessments, quality of care, and the overall well-being of residents.

Engaging a diverse range of stakeholders ensures that research in older adult care homes is comprehensive, relevant, and has a meaningful impact on the quality of care and the lives of residents.

Residents	Family carers	Care home staff	Care home managers and owners	Healthcare providers
Community Organisations	Researchers	Research Funding Bodies	Technology Providers	Local authority commissioners who fund care:

Context and Scope

The scope will include:

- Any research pertaining to residential and/or nursing homes catering predominantly for older adults
- Any health area, any intervention, any healthcare delivery – provided it takes place in older adult care homes
- Any research area including but not limited to: day-to-day life, quality of life, diagnosis, prevention, treatments, health services, psychosocial, behavioural science, economics or finance
- Timeframe may be short or long-term

- Target audience may be policy makers, funders, researchers, commercial providers and others who have the potential to implement the priorities identified

Out of scope:

- Priorities addressing older people living in the community or hospital settings without any reference to transitioning to residential care
- Residential care focused on children or rehabilitation for learning difficulties or physical disabilities in younger adults

Methodology

Step 1: Set up

Establishing advisory group

We will establish an advisory group representing key stakeholder groups and social care researchers, with the aim to foster networks and working partnerships, to promote priority setting

An advisory group will facilitate broad reach, recruitment and participation across stakeholder groups, with public members reimbursed at NIHR recommended rates. Terms of Reference will be established including agreeing on the projects scope, enabling access to key stakeholder groups, and contributing intellectually towards study methods and interpretation. We will identify partner organisations to support the project through promoting the online survey and encouraging their represented groups to participate. (See also Appendix X Long list of stakeholder organisations)

Website

We will develop a project website (https://www.carehomepriorities.com/) with the principal purpose of providing additional information for people interested in taking part in the online survey. In addition to linking to the online survey, it will offer details on the study background, purpose, and trial data available through VICHTA. The site will also include information about stakeholders and partner organisations, and links to how and when the priorities will be disseminated.   There will also be a section dedicated to the resident engagement aspect of the project, including downloadable resource packs for care homes and information on taking part.

Step 2: Gathering priorities

Data collection will be in the form of an online survey available to all stakeholders, and for residents, open discussions and suggestion cards to be completed by residents, staff, visitors at the care homes where activity packs will be distributed.

Online Survey

We anticipate the majority of priorities will be gathered through the online survey, which will largely follow methods employed by James Lind Alliance priority setting partnerships (2). This will be designed on JISC Online Survey software and piloted by our advisory group members prior to

launch. It will collect opinions and preferences from all stakeholders, through open-ended questions. While most responses will be gathered online at https://app.onlinesurveys.jisc.ac.uk/s/herts/care-home-priorities , a postal version will be available on request.

We will not ask any personal information but will record what stakeholder group the respondent aligns most closely to. This will allow us to monitor responses on different stakeholder groups to help refine and target the promotion of the survey towards the under-represented groups if necessary.

To raise awareness and encourage participation of the survey we will ask the Advisory group to promote it among their networks. Resources including printable posters with QR codes, social media flyers and short explainer videos will be circulated in researcher, professional and industry newsletters, and available to download from the study website.

The survey will remain open for several months (July 2024 – Spring 2025) and will be disseminated through various channels, including social media, personal emails, family support group websites, and care home research seminars.

Residents' activity groups

The prioritisation exercises with residents will be facilitated by activity coordinators already known to the care home residents. This will provide multiple benefits. The activity coordinators have pre-existing relationships with residents - this may help residents feel comfortable with sharing their thoughts or declining participation if this is their wish. Activity coordinators are also likely to have a good understanding of the individual needs of residents and how to maximize their ability to participate/respond. Participation is entirely voluntary, and we request that only residents with capacity to consent (i.e., understand the nature of the exercise and can make informed decisions) take part. As this project is focused on public involvement, rather than treating residents as research participants in a traditional sense, we will not seek individual consent to take part, however we will seek care home level manager consent for the activity to be undertaken in the premises.

Co-designing resource packs: Through an ongoing study we have established working relationships with residents and activity coordinators in two Norfolk care homes(3). Materials for discussions will be piloted and co-designed with these two homes, promoting meaningful and creative engagement. The project emphasises the importance of residents influencing ongoing research and acknowledges their unique insights into life within care homes.

The resource packs to aid prioritisation activities will be distributed to each care home, with the option to have this sent by post or to download all resources from the project website. We will ensure there are accessible activity options for individuals with communication, visual, or cognitive difficulties. Materials may include easy-read text options, pictorial prompts, and video clips. The sessions, based in care homes and facilitated by activity coordinators, offer residents the option to engage in groups or one-to-one activities, respecting individual preferences.   Activity coordinators will extend participation invitations to residents, emphasizing its optional nature.

The resource packs will include Freepost return envelopes to allow suggestion cards, and interactive materials with ideas added to be sent back to the research team to be processed. Staff can alternatively enter ideas in the online survey, which will run concurrently. To minimise burden for care home staff and ensure anonymity, we will not record any additional information about the residents.

Recruiting activity coordinators: PREACH is part of the NIHR Research Delivery Network (RDN) portfolio, enabling access to a wide network of care homes. We will work with RDN in the

recruitment process, to assist in identifying, contacting, and onboarding care homes for the study. Other recruitment methods will include engaging the largest care home chains (as registered with CQC) to endorse the project and distribute information through company newsletters and internal updates. Additionally, we will request support from sector policy organisations such as National Care Forum and Care England, to reach out to non-profit and independent care homes. To connect with potential activity staff, we will engage with online forums and groups, including three "Care Home Activity Organisers" Facebook pages with a combined membership of 21,000. We will also seek support from the National Activity Providers Association to further broaden our reach. We aim to recruit APs throughout England and Wales with a broad inclusion criterion, with a provisional budget for 100 resource packs. As an incentive, all activity coordinators who return completed suggestion cards will be entered into a prize draw for £50 shopping vouchers, and every participating care home will receive a certificate of engagement.

Preparation

PREACH team prepare resource pack with Fairfield residents

Preparatory meeting with activity providers (and NAPA?)

Consultation with residents

Activity providers introduce theme

Discuss activity using tools tailored to individual residents

Feedback to research team

Suggestion forms and completed activity forms returned via SAE

Review of priorities identified by other research groups

We are aware of existing research to identify research priorities in care homes and similar demographic groups. This includes several James Lind Alliance Priority-Setting-Partnerships (4-10), priorities with specific stakeholder groups (4, 11, 12) and a recent systematic review of community-dwelling older people (13), for which many priorities will be comparable. Priorities identified in this previous research will be combined with research ideas collected prospectively.

Step 3: Processing priorities

As stakeholders submit their suggestions, raw statements will be organised and defined into clear, understandable summary questions. Duplicate responses will be combined, while retaining information on which stakeholder group (or previous research) the original idea came from. Questions unrelated to older adult care homes will be compiled separately and available upon request. We will use NVivo software to identify emerging themes through thematic analysis(14). This approach allows us to count the frequency of raised topics and identifying the stakeholder groups behind each question, eliminating the need for a second-stage prioritisation survey. Instead of ranking questions, the analysis focuses on understanding the prevalence and origin of topic within the stakeholder engagement data.

Step 4: Checking against existing evidence

We will conduct a rapid evidence synthesis to determine if proposed research ideas have been addressed in previous studies. Adopting a tiered search methodology, we will focus on questions with a more quantitative nature, which are more likely to benefit from secondary analysis than

qualitative research. We will seek advice from experts in our Advisory group to identify key literature and potentially help to interpret findings.

Guided by EEPRU information specialists, we will utilise the [TRIP database](#) (Turning Research into Practice), an online searchable database of high-quality research content, including national guidelines, key primary research, and ongoing trials and systematic reviews. Searches will be restricted to publications from the last 5 years within the UK care home setting.

For each question, we will construct a comprehensive table of evidence, highlighting key findings, the quality and relevance of that evidence, and identifying evidence gaps. This approach ensures a transparency and pragmatism in our review process.

Step 5: Mapping to available data

Mapping to Virtual International Care Homes Trials Archive (VICHTA)

VICHTA(1) is a comprehensive repository that gathers and provides access to individual participant data from randomized controlled trials conducted in care home settings since 2010, spanning various health conditions impacting older individuals, enabling secondary analyses and informing the design of future studies. By mapping the identified research priorities to the VICHTA dataset, researchers aim to leverage the wealth of information already available within VICHTA to address or supplement the prioritized research questions. This mapping ensures future research aligns with existing datasets, optimizing resources and potentially uncovering insights from the wealth of information contained in the VICHTA database.

Mapping to other data sources

Apart from VICHTA, we will explore and identify additional external data sources that could contribute valuable information to address the prioritized research questions. One such dataset is the VIVALDI project(15), but we will search for other relevant care home datasets, databases, or sources of information that provide complementary insights or enhance the overall robustness of the research. The goal is to create a comprehensive approach to data collection by integrating multiple sources, ensuring a well-rounded and thorough exploration of the research topics.

Primary data collection needed

While making use of existing datasets like VICHTA and other external sources is valuable, there may be instances where certain research questions cannot be adequately addressed through pre-existing data. In such cases, primary data collection becomes essential. Primary data collection ensures researchers obtain targeted and up-to-date information to address aspects of the research that may not be covered by existing datasets.

Step 6: Dissemination

Communicate to all PRUs and wider research community:

    a. 'Oven-ready' research ideas (mapped to VICHTA data)
    b. Ideas which were considered important and could be answered with other data sources
    c. Ideas which were considered important but require primary data collection

The top research priorities will be shared with potential funders, researchers and long-term care related organisations identified by the Advisory group. Dissemination routes will include the network of partners who distributed the surveys, older peoples' charities and support groups and social care academic and clinical networks. Findings will be presented at academic healthcare conferences related to older people and long-term care and published in peer-reviewed open-access academic

journals. Additionally, we will create accessible online content such as animated videos and infographics for wider dissemination. Establishing priorities will allow researchers and research funders to focus resources on the most crucial topics important to residents, carers, and healthcare professionals, thus decreasing research waste and ensuring funding will be spent wisely

Limitations

We are not aligning our methods to a single framework (such as James Lind Alliance), and rather combining aspects of different methods. We will adhere to recommended reporting guidelines for priority setting exercises (16) will critique existing methods and provide justification for our approach (17) (18). Our emphasis is on generating 'oven-ready' research questions, which could be adopted by PRU members or any other research team.

Policy Relevance

By working with people who really know about care homes, we're making sure our research questions are relevant and useful. We will end up with a solid list of research priorities based on what these people think is most important. We will share these priorities through social media, circulation among NIHR Policy Research Units, academic journals, sector magazines, newsletters and webinars to build collaborations. This approach aims to advance priority-setting methodology by mapping not only against existing *evidence*, but also against existing *data* that can be repurposed to address the suggested research questions, ensuring the optimal use of publicly funded research data.

Research prioritisation is an important means for minimising research waste and ensuring research resources are targeted towards questions of the most potential benefit. Repurposing existing data represents value for money for funders and ultimately the wider public. VICHTA provides substantial data for secondary uses, and this work will enhance its usefulness, by informing how best to exploit that data. This is a pivotal moment to collect this information, to inform future direction of research. COVID-19 has exposed significant gaps in understanding about how long-term care works and what is needed to support staff and residents. By undertaking priority setting, it will ensure the new questions asked are of benefit and a priority to key stakeholders in social care, including care home residents, relatives, staff, owners, local authorities and national policy makers. The list of priorities will be promoted among other PRUs, with the anticipation this can foster new collaborations.

There is a strong emphasis on patient and public involvement in this project. As well as online and postal survey for a wide range of stakeholders, we are engaging directly with care home residents, facilitated through activity co-ordinators already working in the home.

Ethical considerations

As priority setting is classified as service evaluation and development, it does not come under the remit of Health Research Authority (HRA) approvals. The University of Hertfordshire is the sponsor for the study, and their Ethics Review Board has approved this methodology (HSK/SF/UH/05642 approved 29/05/24)

Participation in the online survey and the residents' activity is entirely voluntary. We will not collect any personal information. All anonymous responses will be held securely on University of Hertfordshire One Drive storage.

For the care home activities, we request that only residents with capacity to understand the nature of the exercise and can make informed decisions to take part.

Dissemination Plan

A project-specific website will be developed to host the online survey, explainer videos, protocol and any further information. A social media strategy will be developed to ensure engagement in the survey. Top priorities will be circulated among NIHR PRU members and published on the study website and social media. The project all also report on how priorities vary between stakeholders, and extract insights for the future. The research protocol and main results will be submitted to academic journals. Wide outreach will include sector magazines, webinars (e.g. National Care Forum, NAPA, Margaret Butterworth), supported by our stakeholders' advisory group.

Timeline / GANTT

We plan to run the Priority Setting Exercise for approximately six months from Summer 2024 and report proposed research ideas by Autumn 2025. We do not anticipate further revisions or updates of reported priorities following the project's conclusion.

Appendix

Additional documents needed for ethics

Consultation rather than treating respondents as research participants – does not require Health Research Authority ethical approval. Ethics approved by University of Hertfordshire HSK/SF/UH/05642

- Information for activity staff for collaboration with PREACH
- Plain English Summary for PREACH study
- Care home activity packs (draft/outline)

- Poster for care homes – advertising online survey including QR code
- Promotion of survey for social media including QR code

Types of data available in VICHTA

Type of data	Examples of data available
Trial level	Study design; Duration of follow-up; Timing of assessment points Intervention details Region / geographical area covered
Care home level	Staff-resident ratios; staff mix; staff retention Number of residential / nursing / dementia beds; bed occupancy rates Funding mix; ownership; CQC ratings
Participant level	Inclusion & exclusion criteria for residents Age at randomisation; Age at entry; length of stay in care home Sex; Ethnicity; BMI Medical conditions, presence of dementia, other comorbidities Status at end of follow-up (alive/dead/lost to follow-up), Cause of death Health & social care resource use during follow-up Hospitalisations during follow-up; Medication use; Advanced care planning
Outcome measures	Health/functional ability participant level outcome measures Individual domain levels and Summary scores Resident-reported, carer-reported, or researcher-reported responses Baseline measures and Follow-up measures

Long list of stakeholders

Stakeholder groups	Examples of stakeholders to be invited
Care home residents	Engagement through in-house activity co-ordinators, recruited across UK via national chain head offices; NIHR Research Delivery Network (RDN) & ENRICH; Outstanding Society, and pre-existing network Residents at two Norfolk care homes – In-person PPIE groups
Relatives and carers	Family carers, family carers of people living with dementia, family carers of people living with long term conditions NICHE PPIE group / UH PIRG, Care Rights UK, Rights for Residents
Care home staff	Nursing homes, residential homes and dementia specialist homes. Focus on older people as opposed to learning difficulties Mailing list @ Skills for Care; CQC monthly newsletter CHAIN network: Ask largest chains to circulate internally Researchers in Residence
Care home owners and senior management	• Chains & independent • Research-ready & not research active • Digital & paper-based records
Health professionals	Geriatricians; GPs; Pharmacists Specialist community nurses and therapists: Physio, OT, SLT, mental health teams
Local Authorities & regulators	Commissioners of Adult Social Care, Social workers Care Quality Commission & devolved government equivalents
Policymakers	Care England; Care Providers Alliance; National care forum; MyHomeLife Directors of Adult Social Services (ADASS); National Registered Nursing Home Association; Alzheimer's Society, AgeUK; DHSC; NIHR
Policy Research Units	Cross-reference with various NIHR PRUs including: • Healthy Ageing (Newcastle) • Dementia (*2: QMUL & Exeter) • Palliative & End of Life (KCL) • Health & Social Care Workforce (KCL) • Adult Social Care (ASCRU, LSE) • Quality, Safety and Outcomes (QSO, Kent)

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