

Stop and Go: Barriers and facilitators to care home research

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Abstract

Barriers to care home research have always existed, but have been thrown into sharp relief by the COVID-19 pandemic. Existing infrastructure failed to deliver the research, or outcomes, which care home residents deserved and we need to look, again, at how these barriers can be taken down. Barriers can be categorised as procedural (encountered before research starts), system (encountered during research) or resident-specific. To tackle these, research regulatory bodies need to adopt a standardised approach to how care home research is developed and designed, reviewed and regulated, and how such approaches can enable recruitment of as wide a range of residents and their representatives as possible, including those without the mental capacity to consent for research. Establishment of local, inter-disciplinary collaborations between universities, general practices, health and social care providers and care homes is another priority. This should be based on pre-existing models such as the 'Living lab' model developed in The Netherlands and now being implemented in the UK and Austria. These changes are critical to develop a sustainable research model. If well designed this will deliver better outcomes for residents and align with the individual and organisational priorities of those who care for them.

Keywords: care homes, older people, research infrastructure, barriers, facilitators

Commentary

The COVID-19 pandemic put care home research under the spotlight. The extant research infrastructure, although well set-up to support large scale hospital and primary care studies, failed to support the rapid set-up and delivery of clinical care home research when it was needed the most [1, 2]. There is opportunity for re-evaluation to better understand barriers to care home research and ways to break them down post-COVID-19 [1, 2]. In this article, 'care homes' describe long-term care facilities that accommodate people who require 24 hour assistance including help with daily activities, and can also include nursing care. These facilities are compatible with the international consensus definition of a nursing home [3].

Re-evaluation of care and research delivery takes place in the context of an intense focus within social care services for older people, in the UK and internationally, on achieving better outcomes with less resources [4]. This challenge reflects systematic resource constraints including staff attrition during the pandemic and funding shortfalls attributable in part to the post-pandemic global economic slowdown. These constraints both challenge and make the case for increased research activity in care homes. On one hand, research becomes harder to do when there is intense focus on efficiencies in day-to-day care. On the other hand, research is a means to accurately define the needs of care home residents and has the potential to influence policy decisions related to their care. Historically, care home residents have been excluded from research based on age or complexity, and data from other groups has been applied to them. Conversely it is the complexity of care home residents that means that data from other cohorts cannot be reliably extrapolated to them, hence the importance of their inclusion in research to develop tailored, evidence-based treatments that can improve health and wellbeing.

To date, efforts to advance care home research have mainly focused on sharing of research experiences to improve researchers' knowledge of the different barriers, and ways to overcome these. A National Institute for Health and Care Research School for Social Care Research methods review draws on illustrative examples of previously conducted studies, and summarises three key messages for research success: (1) make the well-being of research staff, carers and residents central to research designs; (2) develop relationships with carers, residents and their family members and view them as 'research partners', and (3) prepare to adapt research to account for high staff turnover, different managerial styles and cognitive and physical abilities of residents [5]. Another methodological review recommended a 'safe space' for researchers to discuss barriers they have encountered while conducting research to facilitate the sharing of ideas on how to overcome them [6]. This idea has been

incorporated into the Enabling Research In Care Homes (ENRICH) networks in England, Scotland and Wales [7].

A more proactive and involved approach is needed, though, to break down (not just overcome) barriers to care home research (**Table 1**). These barriers can be broadly categorised as procedural (encountered before research starts), system (encountered during research) or resident-specific (**Table 1**). Procedural and system barriers accentuate the gaps in care home research infrastructure and governance that need to be addressed by research Sponsors, Ethics Committees and the organisations responsible for research infrastructure. Barriers pertaining to residents, such as impaired cognitive or physical functioning, highlight the need for researchers to develop or adapt tools that can facilitate meaningful data collection in this cohort (**Table 1**).

Major procedural barriers to care home research are the inclusion of residents without the mental capacity to consent to care home research, and the documentation required to register care homes as research sites. Up to 70% of care home residents live with cognitive impairment, and therefore for care home research outputs to be valuable, representative, and generalisable, adults without capacity must be included [8]. In most jurisdictions, regulations are in place to safeguard these individuals, but the steps required in adhering to these can delay progress with research. In the US, a Stakeholder Advisory Panel was convened in response to research challenges in nursing homes during COVID-19 [2]. The panel recommended nursing home specific clinical trial regulations designed to facilitate resident access to participation in research, in recognition of the fact that many people admitted to care homes with impaired decision-making capacity have no named representative [2]. This is an example of a practical way to ensure regulatory research bodies adopt a pragmatic approach when reviewing care home research proposals, whilst continuing to protect the individual rights of residents. Recruiting those with care home expertise to work with Sponsors and Ethics Committees could also help facilitate this (**Table 1**). An additional procedural barrier comes from the fact that, in many countries, the organisations running care homes are different to those running hospitals and community healthcare organisations, and are often subject to different contractual, governance and insurance specifications [1]. Funders, Sponsors and regulators need to recognise these differences, ensure that care home specific contractual arrangements are in place, and that provider organisations are supported to engage with governance and research contracts. Examples might include having a research administrator as part of research support networks, as is the case for Enabling Research In Care Homes (ENRICH) in Wales, or a solicitor who works closely with care homes to scrutinise research contracts and governance arrangements (**Table 1**).

Recruitment of residents poses another procedural challenge. Data privacy regulations, such as the General Data Protection Regulations that cover all European Union member countries and the UK, mean that researchers cannot approach residents or their representatives without prior consent. General Practitioners (GPs) and/or care home staff must therefore play a 'gatekeeper' role, approaching potential participants or their representatives if they lack mental capacity to provide consent in order to enable a subsequent approach by the research team – adding both a barrier and a delay to recruitment. Such barriers could be removed by establishing resident and representatives' preparedness to be approached at the point of care home admission (**Table 1**). In countries, such as the UK, where primary care is provided by doctors outside of the care home, then this can lead to multiple doctors supporting a single care home, representing a further procedural barrier to research activity because approvals must be sought from individual GPs to access residents' medical records. In England, the COVID-19 pandemic has already prompted acceleration of plans to align GPs and care homes 1:1 where possible, and for NHS employed clinical leads to be appointed for each care home [9]. Recognising formally in research contracts the role that GPs play in facilitating research in care homes would be the next logical step.

Alignment between universities and care homes in their locality can be important in building familiarity, trust and effective working relationships. This is the foundation of the successful "Living Lab in Ageing and Long-Term Care" [10] that was established over 20 years ago in Maastricht, The Netherlands and, more recently, living labs in Liverpool, UK, Austria, and as part of the "Nurturing Innovation in Care Home Excellence project" [11] in Leeds, UK. Living labs are not a physical space, but describe a network of researchers, health professionals, policy makers and older people living in care homes and their family. Through continuous discussions, research projects are co-created to find targeted solutions to the challenges they face [10]. Wider implementation of this approach would breakdown communication-related system barriers, and make high care home staff turnover less detrimental to research activities through the use of practice and research "linking pins", who are professionals working in the care home and university respectively (**Table 1**). Care homes who are already part of the ENRICH community might be ideal to approach first about opportunities for these new collaborations, although more flexible approaches are needed to engage care homes that haven't historically been oriented towards the healthcare or research. Such homes might be better approached through community organisations, including the third sector [12].

We need to better understand what incentivises care home residents, staff and organisations to engage with research. There is no doubt that appropriate financial remuneration has a role to play – research should be a professional endeavour in social care as in healthcare. Investing in the development of the care home workforce will make staff feel more valued and give them the recognition they deserve to match the importance of their work [13]. There is, though, also a need to consider how research activities align with the existing ethos and priorities of those whose help we need to enlist. Research should not distract, detract or generate opportunity costs in routine care. Instead, it should be recognised in job plans and career progression for care home staff [14]. It will also help care home organisations achieve their objectives, and be seen to be doing so, by recognition of research participation and excellence by regulators (**Table 1**).

These barriers to care home research share substantial commonality between countries, despite differences in care home and research infrastructures depending on economic, political, social and cultural aspects [15]. International consortia around care home research were evident before the pandemic [16], and have been accelerated through the COVID-19 pandemic [17]. Advancements in care home research will improve care and support implementation of targeted solutions to specific challenges faced by care home residents and staff. Change has to start from the top with research regulatory bodies, followed by the establishment of networks between universities, GPs, health and social care providers and care homes. With a sustainable research model based on trust between researchers, healthcare professionals, care managers, staff, residents and their family, there will be a domino effect with the breakdown of other procedural, system and resident-specific research barriers. This will facilitate an expansive range of both interventional and observational care home research.

Funding

None.

Conflicts of interest

A.L.G is a member of the Social Care Working Group of the Scientific Advisory Group for Emergencies (SAGE). P.E.P owns four shares in AstraZeneca PLC and has received honoraria and/or travel reimbursement for events sponsored by AKCEA, Amgen, AMRYT, Link Medical, Napp, Sanofi. D.A.L has received investigator-initiated educational grants from Bristol-Myers Squibb (BMS), has been a speaker for Bayer, Boehringer Ingelheim, and BMS/Pfizer and has consulted for BMS, and Boehringer Ingelheim. A.A has received a National Institute for Health Research Applied Research Collaboration

grant, a Liverpool Clinical Commissioning Group grant, honoraria for lectures on behalf of Astellas and Profile Pharma, meeting and travel reimbursement on behalf of the British Geriatrics Society, has consulted for the British Medical Journal, is on the external advisory group for the cognitive frailty interdisciplinary network, the study steering committee for VOICE2 and is the Deputy chair for the British Geriatrics Society, England Council. L.A.R has no conflicts of interest to declare.

Table 1. Stop and Go: Barriers and facilitators to care home research.

Barriers	Facilitators
Procedural	
Obtaining Sponsorship/REC approval to include residents without the mental capacity to consent for research	<ul style="list-style-type: none"> • Approach a Sponsor/REC orientated to care home research for review and approval. • Encourage care home research naïve Sponsor/REC to familiarise themselves with care home settings and how care is delivered, e.g. arrange care home visits. • Universities/regulatory bodies to impress the need for Sponsor/REC requirements to be standardised irrespective of prior experience supporting care home research. • Establishment of a care home specific Sponsor/REC. • Representation of individual(s) experienced in care of older people or care home research to be on Sponsor/REC review panels. • Emphasise importance of inclusivity in care home research so research outputs are representative, provide examples of published work including residents without capacity in Sponsorship/REC applications. • Create a repository of researchers' experiences with Sponsor/REC applications for care home research.
Recruitment of residents to comply with General Data Protection Regulations	<ul style="list-style-type: none"> • At point of care home entry, residents and/or representatives give consent, or 'opt-out' to being contacted by research teams. • Conduct research in 'Living lab' teaching care homes, e.g. Living Lab in Ageing and Long-Term Care in Maastricht, Netherlands, Nurturing Innovation in Care Home Excellence project in Leeds, UK. Facilitates recruitment from all registered teaching care homes.
Obtaining agreement for residents without mental capacity to participate in research	<ul style="list-style-type: none"> • Sponsor/REC improved understanding of regulations for inclusion of people without capacity in non-CTIMP and CTIMP studies (UK specific terminology): Non-CTIMPs: inclusion permitted provided agreement obtained from consultee (in order of preference): <ol style="list-style-type: none"> 1. Personal consultee (i.e. friend or family member) **Does not need to hold Power of Attorney** 2. Nominated consultee (e.g. healthcare professional external to research team) 3. Care home manager/carer consultee (approval of this approach is variable depending on Sponsor/REC)

CTIMPs: inclusion permitted provided there is a legal representative (in order of preference):

1. Personal legal representative (i.e. next of kin ****Does not need to hold Power of Attorney**** or Power of Attorney)
2. Professional legal representative (e.g. healthcare professional external to research team)

Documentation to sign care home up to research (research contract)

- Establish if a research contract is needed. If care home staff are not required to carry out research activities, a 1-2 page research agreement may suffice (approval of this approach is variable depending on Sponsor/REC).
- If a formal contract is needed, establish who is required to sign (care home manager or care home owner who holds legal responsibility).
- Establish support for care home to review contract:
 - ENRICH Wales has a research administrator who will do this
 - Option to ask solicitor who works closely with care homes

System

High care home staff turnover – need to re-introduce study/researchers and re-gain approval

- Research training to be included in care home staff induction.
- Establish a network of care home carer champions and incentivise this to promote research.
- Arrange informal catch up to re-introduce research team.

Difficulties establishing if residents have capacity from care home/medical records

- Different options depending on care home/research team:
 - Option 1: initial capacity screening undertaken by care home staff, second screening by researchers using a Three Question Test (e.g. resident given a sentence with three key components and asked to recall, if unable to then deemed to lack capacity)
 - Option 2: capacity assessment at discretion of researchers if familiar with capacity assessments (e.g. clinicians)

Difficulty communicating with care home staff/manager outside of care home setting (e.g. via telephone/email)

- Provide additional support mechanisms for care home managers/staff (e.g. set up of WhatsApp group, Microsoft Teams Group Chat, videoconferencing).

Difficulty recruiting care homes

- Establish more interdisciplinary collaborations between universities, general practices, health and social care organisations, and care homes (e.g. Living Lab in Ageing and Long-Term Care in Maastricht, The Netherlands, Nurturing Innovation in Care Home Excellence project in Leeds, UK).

- Establish incentives for care homes to take part in research:
 - Recognition for involvement in research – certificates, awards, regulator reports and ratings
 - Funding for better technology in care homes taking part in research to support communication/researcher-resident interactions
 - Reimbursement for time
 - Share research findings to show benefits for staff and residents
 - Set up interactive non-research focused workshop events (could be part of ENRICH) to reach out to care homes, ask care home managers for email addresses if interested in taking part
 - Incentivised network of care home carer champions

Difficulty accessing medical records for residents (approval required from each general practice which provides care to different residents in the same care home)

- Re-structuring of care delivery to residents by primary care. All residents within the same home to be registered to one general practice or group of practices.

Resident

Data collection in residents with cognitive impairment, substantial diversity across care home populations

- Avoid use of complex questionnaires not applicable to care home setting (e.g. including questions about self-administration of medication and different types of physical activity, such as sports).
- In residents without capacity, consider use of proxy questionnaires.
- Development of toolkits with validated questionnaires suitable for residents with/without capacity, cognitive impairment, learning disabilities, or for completion by friends/family/carers (e.g. Adult Social Care Outcomes Toolkit).

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