



Involving care homes, residents and relatives in research

Developing resources And minimum data set for Care Homes' Adoption (DACHA) Study

Changes, Benefits and Learning from Public Contributors: Public Involvement Impact Case Study

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Introduction

The UK National Standards of Public Involvement are used as a framework for the ARC EoE Public, Community, Involvement, Engagement and Participation (PCIEP) Strategy and includes 'impact'. We define 'impact' as "**the changes, benefits and learning**, gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiative's" (*NIHR Patient and Public Involvement Impact Working Group, 2019*). Through this, we seek improvement by identifying and sharing the difference that public involvement makes to research.

The ARC EoE PCIEP Impact Case Studies are used to evaluate the impact of PCIEP on ARC EoE research and to highlight the changes, benefits and learning gained from partnership working and public involvement in ARC EoE.

Public contributors have been invited to co-produce the case studies and the perspectives of public contributors are included in the case study.



Public Involvement Impact Case Study: Involving care home providers, residents, and relatives in research

Project Title:

Developing resources And minimum data set for Care Homes' Adoption (DACHA) Study

What problem is this research addressing?

All care homes collect data about their residents as part of routine care. This might include data about resident care needs, like the types of medications they need to take, as well as other important information, such as their likes and dislikes, their quality of life, the number of falls they have had or whether they have had to attend hospital. These data are gathered and used for many purposes, both internally (e.g., informing resident care plans and to monitor and improve care) and externally (e.g., meeting the information requests from local commissioners, Care Quality Commission or Skills for Care).

However, there is no consistent approach to what data care homes should collect. There is also variation in how data are collected, stored, and subsequently used. This impacts upon care at multiple levels. Nationally, it is difficult for policy makers to understand the needs of residents and plan for the future as data cannot be easily collated if different care homes hold different types and amounts of data. At the care home level, the burden on staff to collect and input data can be high and detract from resident care. Furthermore, information is often not shared in an effective way between care providers (e.g., NHS and independent care homes) which can affect the care that person receives, for example, on admission or discharge from hospital. Without being able to share data, care homes are not able to compare and contrast their own performance with that of other care homes for the purpose of quality improvement. Furthermore, care home researchers are not able to use routinely gathered care home data in their studies for comparative purposes. One way to

address these issues is to establish an agreed Minimum Data Set (MDS) – information that all care homes collect and share, in a secure way, across organisations.

The aim of DACHA Study is to explore and enhance how resident quality of life and care data are shared between the different health and social care organisations working with care homes. We want to know:

- What data are already gathered about residents, by whom and how these are stored and shared?
- How to optimize existing and future collection and secure sharing of resident data?
- What the contents of a potential care home MDS should be?

Once developed, we plan to trial the prototype MDS within care homes in three different counties to see if it works as intended.

This research will be of benefit to a range of key stakeholders including: care home residents, relatives and staff; commissioners, regulators, inspectors and providers of health and social care; researchers and policy makers.

Ultimately, the purpose of this research is to enhance the care residents are receiving by ensuring that organisations hold accurate, up-to-date information about them that can be shared in an appropriate and secure way between care settings. DACHA Study commenced in November 2019 and is aiming to complete in Spring 2024.

How were the public involved in this research?

The importance of listening to the voices of residents, relatives and care home providers was recognised from the study's inception. Patient and Public Involvement and Engagement (PPIE) has been a core thread woven throughout the DACHA Study, with the PPIE team consisting of co-investigators in both researcher and non-academic roles.

Early on, a PPIE team handbook which includes information about the project, a glossary of terms and agreed ways of working was developed to help guide our work. The PPIE team meets monthly via Zoom and also on a regular basis either in person or via Zoom with the Chief Investigator, Core Research Team and Research Management Team. Interim communication is via email, with access to an online drive shared with the rest of the DACHA research team. The PPIE team uses the [UK Standards for Public Involvement](#) to help evaluate our approach and impact.

The aims of the DACHA Study's PPIE are:

- To keep the aspirations and concerns of residents, relatives, and care home providers (managers and staff) about data recording and information sharing at the centre of DACHA study.
- To ensure that DACHA study is well-informed about the day-to-day realities of care home work and systems so that study findings are relevant, practical, and useful.
- To achieve co-design in each of the DACHA work packages, as well as any study dissemination and implementation work.
- To help publicise DACHA Study so that findings can be put into practice.
- To provide a good example of the involvement of care home residents, their relatives and staff in research projects and to learn more about supporting effective involvement.

To achieve the above, we took several different approaches.

Listening to the voices of residents

Initially, the PPIE team planned to hold regular group sessions with residents in two care homes throughout the duration of the project to enable residents to inform the DACHA Study. However, with the onset of the Covid-19 pandemic in 2020, access to care homes was heavily restricted and a new approach was required. The team decided to collaborate with the National Activity Providers' Association (NAPA) (<https://napa-activities.co.uk/>) as a Public Involvement partner to recruit activity providers (APs) working in care homes; APs could then help facilitate Public Involvement activities and discussions with residents on behalf of the DACHA Public Involvement team. The APs now work collaboratively with the Public Involvement team to develop user-friendly materials for use in Public Involvement sessions, which stimulate discussion and debate about the research in a meaningful way for residents. The DACHA Public Involvement team have submitted a research paper about the lessons learnt from this approach.

Listening to the voices of relatives and care providers

Public Involvement Panel meetings are held via Zoom on a tri-monthly basis. The Panel has twelve members, all of whom hold experience either as a relative of someone living or dying in a care home or as a care provider (for instance, a care home manager or care worker). Members of the DACHA Study research team attend the panel sessions, which are facilitated by the Public Involvement team, to explain the work that they are doing and any questions or uncertainties that they would like to explore with the Panel. The Panel has fed into many different aspects of the study, including: helping to select care-related outcome measures to be used in the prototype MDS, informing the study's plans for recruiting and consenting residents, implementing the MDS (how it will be put into practice), and analysing the emergent data.

National and regional stakeholder consultation

DACHA Study has held national online consultation events to inform various aspects of the study. Those invited to contribute their thoughts include representatives of residents and relatives and care home providers; commissioners, regulators and inspectors of health and social care; together with researchers and family carers. In 2021, there were five consultation events held between February-June that explored data collection, access, and sharing in different care settings. In 2022, two online surveys were held with care homes via the Thiscovery platform to help inform the study as to what useful data were already routinely gathered in care homes and what care-related quality of life outcome measures might be helpful in the proposed prototype MDS.

Other

The DACHA Study has a Study Steering Committee which meets every six months, consisting of members with expertise in health and care home sectors, information technology, data analysis and data governance.

DACHA Study also runs associated social media accounts on Twitter (https://twitter.com/DACHA_Study) and Facebook (<https://www.facebook.com/DACHA-Study-102225059220346>).

A website for DACHA is available at: <http://dachastudy.com/>

What were the outcomes of public involvement in this project?

Public Involvement influenced DACHA Study in many ways and an exhaustive list would not be possible within the remit of a case study. Some key outcomes of Public Involvement include:

Inclusion of care-related quality of life data in the prototype MDS

Throughout the study, the Public Involvement team received strong and consistent feedback from a range of stakeholders (including residents, relatives and care home providers) that data relating to resident quality of life is important, valuable for the purpose of informing resident care and that it must be included in the proposed MDS. Care home minimum data sets already in use in other countries do not routinely include quality of life data, so examples of how this might be captured were not readily available. To address this, the DACHA Study team completed a substantial amount of work (including national consultation activities) to identify appropriate quality of life outcome measures for inclusion in the MDS to ensure that these data will be captured. Alongside helping to establish the need for these data, the Public Involvement Panel in particular were crucial in the process of selecting which specific care-related quality of life outcome measures were chosen to be included in the prototype MDS. Members reviewed potential options at a panel session and also took part in the national consultation.

Prioritisation of types of data to be included in the MDS

Public Involvement was used to help prioritise the importance of potential categories/types of data to be captured as part of the MDS. Their feedback led to several types of data being included that would not have otherwise been captured, including data about the input of community nurses and allied health professionals into residents' day-to-day care.

Consent process

Public Involvement was used to enhance the process of consenting residents to the study. The PPIE Panel reviewed and helped to amend DACHA Study consent and resident information forms. PPIE contributors also advised DACHA researchers on how best to approach residents (e.g., wording that might help explain the study and where and when it might be best to discuss consent to participate).

Empowering residents and meaningful changes to care home practice due to Public Involvement participation

An unexpected outcome was that involving residents created a forum in which residents could express their thoughts around their own care to the activity providers (APs) facilitating the sessions. Discussions initially sparked by topics exploring aspects of DACHA Study led to APs asking residents questions that would not usually be explored in routine practice. APs reported that the sessions allowed them to get to know their residents better and that residents felt the process was empowering. APs were keen to respond to resident feedback and action meaningful changes in practice – for example, some residents expressed a wish to be involved in reviewing their care plans with staff, which was later implemented at that particular care home.

Exploring use of technology in care homes

Activity Providers have been leading consultation activities with care home residents. A topic about technology use in care homes led to several impacts at both the level of participating care homes and individual residents. One care home learned through these activities that residents and visiting

family members do not know that staff are using small devices (e.g. electronic tablets) to input into care plans, mistaking this as staff using them for leisure during work time. As such, the care home plans to improve communication surrounding staff use of electronic care plans and digital technology within the care home. At an individual level, following participation in a DACHA Public Involvement session an elderly care home resident previously unfamiliar with electronic tablets subsequently became interested in learning how to use them, now being able to make online calls to friends and family independently.

Approaches to analysis

The DACHA Public Involvement panel and residents were approached regarding plans for colleagues from The Health Foundation (THF) to analyse pseudonymised resident data gathered as part of their work on DACHA. Representatives were told about potential approaches to analysis and asked what they would want to learn from this. Residents expressed a wish to learn if the data could tell us more about the impacts of hospital admissions on residents' physical and mental wellbeing, while Public Involvement panel members expressed an interest in how the data could be used for constructive benchmarking between care homes. THF have incorporated this feedback into their analysis plan and will explore if the pseudonymised data can address these topics.

How did public involvement influence the project overall?

Much has been learnt from Public Involvement contributions over the course of the study. Examples of key points of learning include:

- **Creating a meaningful and feasible Minimum Data Set (MDS):** Learning from our Public Involvement contributors has shaped our development and piloting of the prototype MDS, including its content, implementation and evaluation. Their input has helped us to learn about the expectations of various stakeholders, including what resident data they would find useful. It has informed us about how the MDS might be used in routine practice, potential facilitators and barriers to use and the importance of avoiding a top-down approach if the MDS is to be implemented successfully. PPIE contributors have fed into how we might evaluate the prototype MDS (for example, the sort of questions we might want to ask when we interview care home providers who participated in trialling the MDS) and have also helped advise us on what data we need to collect (and from whom) to explore implementation of the MDS in our pilot care homes.
- **Residents want to be actively involved in maintaining their health:** Care home residents who participated in Public Involvement in this research expressed that they wish to have greater understanding of, and control over, their health and wellbeing. Residents wished to have a say in their care, to know what is in their care plan and about any upcoming medical appointments. Residents wish to be more than a passive recipient of care.
- **Experiences of managers and care staff in relation to data:** Care home providers told us about the demands placed upon them to collect data, how this can lead to duplication of effort (if the same data must be recorded in many different ways) and the many external organisations that expect data from care homes with little return or benefit to the care home providers themselves. They expressed frustration due to poor communication between care settings and how this can impact upon the care that they are able to provide, often to the

detriment of residents. One output from this learning was a plain English infographic depicting all the different ways staff must record information when a resident has had a fall and all the organisations this information must be sent to.

- **Learning from the data:** Care home providers expressed an appetite for data to support trusted benchmarking that could help drive quality improvement. At present, it is not clear where much of the data care homes gather on behalf of other organisations goes and how it is used – which is particularly frustrating given the time and effort taken to collect it. Care home providers feel it would be helpful – and incentivizing – if data could be shared back in a safe and sensitive way to support comparison and learning.
- **Relatives wish to have active engagement with resident data:** Relatives/family carers were keen for real-time access to resident data (where this was appropriate). Aside from being able to learn more about their family member’s health status and care, relatives felt that being able to access this data would reduce demands on care staff as they would not have to respond to repeated requests from relatives for updates.

What was the feedback from public contributors involved in this project?

Feedback from co-investigators

Liz Jones: ‘It’s been a real privilege to be part of this group, learning together as we have worked through the different asks of the study, reflecting on the different perspectives from the panel and feeling that all views have been respectfully heard and responded to. As a policy nerd, it’s also been good to be able to bring some understanding of the wider policy perspective to help the panel understand the context and importance of the study.’

Resident feedback

Feedback from our PPIE with care home residents indicated that this was a positive process that residents were happy to engage with:

‘...once again, they felt empowered by doing this...’ – Activity provider

‘I didn’t have to force anything. People were happy to speak up.’ – Activity provider

Participation in DACHA Study PPIE also created a space where residents could discuss elements of their care that perhaps would not be otherwise explored:

‘...I thought, “Right...” Because before they [the residents] wouldn’t have mentioned it, but by asking a few simple questions...’ – Activity provider.

Further information about this approach is available online in the published article called [‘Activity Provider-Facilitated Patient and Public Involvement with Care Home Residents’](https://doi.org/10.1186/s40900-023-00537-z).
<https://doi.org/10.1186/s40900-023-00537-z>

PPIE Panel feedback

As part of a recent PPIE Panel session held in February 2023, panel members were asked to reflect on their hopes and fears about being involved in the panel, whether either of these have been realised, things that have worked well and things that could be done differently. The panel members reflected on challenges – for example, they discussed how difficult it can be to fully understand and keep abreast of developments in such a large and technical research project. They reflected that panel agendas can feel packed, so time for in-depth discussion can be limited which means that panel members cannot always fully develop and convey their thoughts before the session moves on. However, feedback was generally very positive about participation in the panel:

'What I've been amazed at is how much you can learn from taking part in these panels, so I feel I've learned a lot... it's been fantastic, I've enjoyed every meeting.' – Relative

'One of the things that's really useful for me from this is being in the room with family carers that aren't my own customers...

'My fear coming in was about what I've experienced working in social care compared to the wider world, which is that there's this disconnect and lack of understanding about what we do in care homes. I was worried that the panel and the proposed ideas would be so wildly different from what I thought would work, and that the PPIE panel would be something of a box ticking exercise on your part, but it hasn't felt tokenistic at any point. Our views have been valued...having the chance to connect with a group of people that come at it from such different perspectives that care very deeply about the subject matter has been a real boost in morale. It's been very interesting as well, the discussions and things that I wouldn't have thought about coming at it from my blinkered perspective as somebody working in a care home, coming at it from outside, their experiences of care for their loved one, it's been really valuable and definitely informed my work as a carer and made my care better, so thank you.' – Care home practitioner

What are the reflections and learning from public involvement in this research?

Blogs have been written over the course of the DACHA study (<http://dachastudy.com/dacha-blogs/>), with several focused on the lessons learnt from the public involvement approach. One was written by the late Sue Fortescue (former Public Involvement Team member) who talked about the potential for volunteers to improve the quality of lives of people with dementia living in care homes working alongside researchers (Sue's story: Supporting research in care homes). Another blog (Watching out for 'elephant traps' and keeping ahead of the game), highlighted the importance of listening also to the voice of providers and the value of having a member of a national body representing care home providers as a Co-Investigator. In the DACHA Study, we have tried to create a space within our Research Management Meetings for an update on PPIE and to discuss with each other what is currently happening in practice, in relation to the topic. This means that the questions taken to residents, relatives and staff for exploration are more focused, relevant and up-to-date. For instance, the Public Involvement Panel suggested that a particular tool identified by researchers was no longer in use and seen as out of date. Given the size of the PPIE Panel this may (or may not) have been the case. The national care home provider representative (National Care Forum) was able to do two things. First, they consulted their members about its use quickly at their next routine meeting and, secondly, they asked a software company to extract data on the use of this tool from their digital care planning platform to helpfully confirm it was still being used. Without a national representative to check the issues raised by the PPIE Panel at a more collective level, the research team may have been mis-guided.

In another blog (Conflict as Lesson: Learning from PPIE in DACHA Study), other lessons learnt included:

- Consider changing PPIE to PPPIE (Personal, Public and Provider Involvement and Engagement)
- Ensure PPIE/PPPIE team, including those with lived experience, are Co-Investigators in the study
- Put systems in place to share PPIE/PPPIE activities and learning across the whole team
- Co-create agreed ways of working that are relational and inclusive
- Be open to challenge and find time to listen
- Be prepared to educate about the slow nature and limitations of research
- Evaluate PPIE/PPPIE Activities in relation to UK Standards for Better Public Involvement
- Give feedback to those involved on the basis of “You said, We did”
- Engage in more creative ways to access the voice of residents
- Allow sufficient time to listen to what people want to share
- Share research findings quickly for maximum impact
- Consider employing a media expert to help with dissemination
- Be open to different perspectives and possible conflicts of interest

Further Resources

A co-produced academic article was published:

The authors included two senior care home professionals, Marlene Kelly and Emily Allison, from the DACHA PPIE Panel, who co-produced an academic article with Kerry Micklewright (DACHA PPIE team member) about their 'expert-by-experience' perspective on what it is like to be involved in research. This was published at Nursing and Residential Care in December 2023:

www.magonlinelibrary.com/doi/full/10.12968/nrec.2023.0048

Further information about this approach is available online in the published article called '[Activity Provider-Facilitated Patient and Public Involvement with Care Home Residents](https://doi.org/10.1186/s40900-023-00537-z)'.

<https://doi.org/10.1186/s40900-023-00537-z>

DACHA Study Website dachastudy.com

The case study template is informed by GRIPP 2-SF (Staniszewska et al., 2017)

For more information, visit the [project webpage](#)

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