



The practicalities of engaging care homes, residents and relatives in the pilot study of a Minimum Dataset for older adult's care homes: the DACHA study

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Overview of the DACHA Minimum Dataset (MDS) Pilot study

A pilot study to develop and test a Minimum Dataset for care homes for older adults in England.

- A minimum data set is a *standardised way of collecting data which can be brought together to improve care and outcomes for residents.*
- Led by Prof Ann-Marie Towers (University of Kent) and Prof Adam Gordon (University of Nottingham).
- Aim was to recruit 60 care homes (20 each in 3 Integrated Care Systems in England - Surrey Heartlands, Nottingham & Nottinghamshire, and North East & North Cumbria) and 900+ residents.
- All care homes had to already be using digital care record software from one of two providers (*Person Centred Software (PCS) or Nourish*).



Overview of the MDS Pilot study

- Data already collected in the digital care record software is being extracted at baseline (currently happening) and 6 months later and matched to the routinely collected health and social care data (*led by The Health Foundation*).
- Some additional data collection in software (mainly residents' quality of life).
- Once a care home was onboard, we invited all permanent 65+ residents to take part. Consent process for each resident.
- Recruited 46 care homes across the three sites and 975 residents (recruitment from September 2022-March 2023).

Data already collected in the software
(PCS/ Nourish)

Additional measures in the software
(PCS/ Nourish)

Routinely collected health and social care data

(GP/ 111/ 999/ A&E/ secondary services/ CQC datasets)

How did we engage with care homes to get them on board?



Before recruitment began, we asked DACHA's Public and Patient Involvement and Engagement (PPIE) Group for advice:

1. Helpful for care homes to see other homes taking part (e.g. webinars)
2. Make use of connections & care home forums



Began with contacting the homes via the software provider, then emailing and following up with phone calls.

Also began with any existing connections with any of the eligible care homes.

However, for most eligible homes we had no prior connections.



Many care homes had previously not taken part in any research.

So, we needed other ways to engage them beyond us just contacting them and in line with PPIE suggestions.

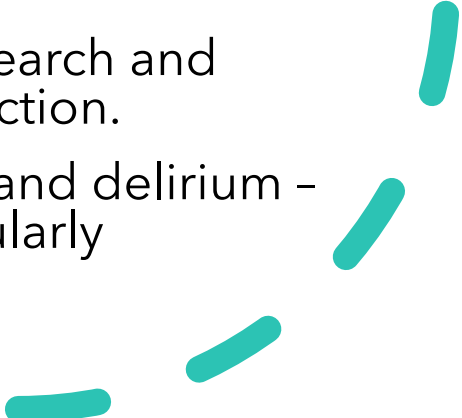
The wider DACHA team used their contacts to engage with stakeholders.

How did we engage with care homes to get them on board?

Used networks from range of stakeholders working in or with the care home sector:

- For example, Care Quality Commission (CQC), Local Authorities (including forums), Care Associations, Integrated Care Systems, Academic Health Science Networks, National Care Forum, Skills for Care, Care home managers networks.
- Clinical Research Networks – supported with recruitment.

Emphasised potential benefits:

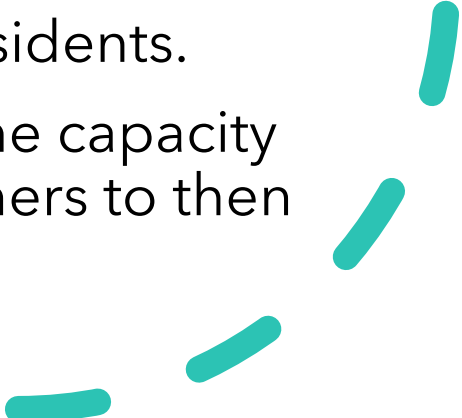
- They will help shape what goes into the finalised minimum dataset.
 - DACHA is feeding into work being undertaken by the Department of Health and Social Care, and by being involved homes can help shape this.
 - CQC encourage homes to participate in research and look favourably on it if is evidenced at inspection.
 - Additional measures include Quality of Life and delirium – important to homes as they may not be regularly collected.
- 

How did we engage with residents in the consent process?

Advice from DACHA PPIE group:

- Staff member introducing the research and researcher to the resident (during researchers visit, but also sometimes in advance).
- Group discussion with a few residents (but may need private conversation afterwards).
- Involve activities coordinator or staff member they trust.

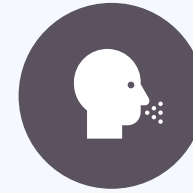
Advice & information from care home staff:

- Staff member to sit in with you.
 - Any relevant information for certain residents.
 - Advice on which residents may have the capacity to consent for themselves (for researchers to then assess the residents' capacity).
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How did we engage with residents in the consent process?



Face-to-face consent meetings with resident, often in their own room.



Mindful of language - saying 'information' rather than 'data'.



Assessed residents' capacity to consent to the study.
Explain study to them then ask them questions about it.



Practised how to explain digital aspects of the study simply.



Often long conversations - 30+ minutes.




Sometimes residents asked us to speak with their relative instead.

How did we engage their relatives (to act as consultees)?

- Important as 70% of residents have cognitive impairment or dementia (Alzheimer's Society) so need to be included in care home research.
- Relatives can act as personal consultees - give their opinion on if the resident would have wanted to take part if they could decide.

Advice from DACHA PPIE group:

- Attend relative's groups, feed into newsletters, meet them when they're visiting the home.
 - Emphasising that residents' quality of life is being measured in the study and added into the software so homes can routinely collect this.
- 

How did we engage their relatives (to act as consultees)?

DACHA Study - Exploring how health and social care data can be brought together to improve care and outcomes for people living in care homes

Please click if you agree

- | | |
|---|--------------------------|
| 1. I confirm that I have read the information sheet (Version 1.1 dated 06/06/2022) for the above study. | <input type="checkbox"/> |
| 2. I have been able to ask questions about the study, and my questions have been answered in a way that I understand and am satisfied with. | <input type="checkbox"/> |
| 3. I understand that participation of the person (about whom I am giving advice) is voluntary. | <input type="checkbox"/> |
| 4. I understand that I can advise that the person should be withdrawn at any time, without giving any reason, and my request will be respected. | <input type="checkbox"/> |
| 5. I understand that the person's personal data will be stored securely and only accessed by members of the research team. | <input type="checkbox"/> |
| 6. I give permission for the care home to share the person's data with the research team. | <input type="checkbox"/> |

- Digital version of the consultee declaration form – as paper version sometimes was a barrier.
- Clinical Research Network researchers (in Surrey) had '*letter of assurance*' signed by each care home manager which allowed them to access relatives contacts details.
- However, not all residents will have a relative (or next-of-kin) who knows them well, or who engages with contact from the care home or researchers. Therefore, we also used professional/nominated consultees.

Having care
home staff
act as
professional/
nominated
consultees

- Approval from the Research Ethics Committee to use care home staff as nominated consultees.
- Only after 2 weeks of a relative being first contacted, and if no response (either a yes or a no) has been received from them.
- Needs to be a staff member who knows the resident very well and is happy to act as a consultee.
- Similar to with relatives - we're asking the staff member to give their opinion on if the resident would have wanted to take part if they could decide.

How did we engage with care home staff to act as professional / nominated consultees?



Discussed with care home manager at set up meetings to see if they were happy with this process, and if so, who would be the most appropriate staff member for certain residents.



Ensured each staff member who acted as a professional consultee understood what this role meant.

Most commonly, the manager acted as a consultee.

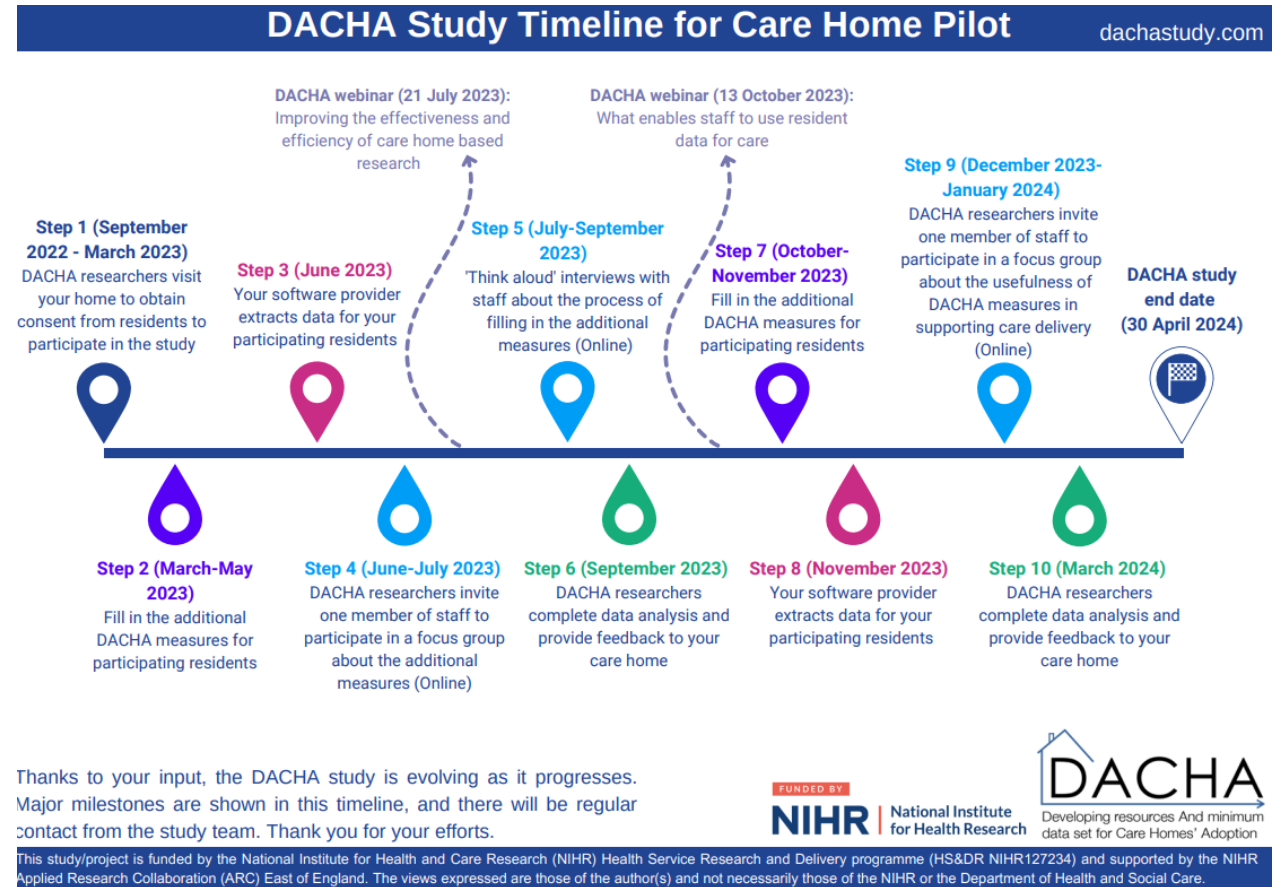


In some care homes, the manager said no to any staff member acting as a professional consultee.

In other homes, staff were unsure about certain residents, and therefore we did not include them in the study.

How do we plan to keep our care homes engaged?

- Keep them up to date with the study progress.
- Making sure they know what to expect next e.g., roadmap.
- Meeting with new managers.
- Feedback reports summarising data from the first extraction.



Thanks to Dr Gizdem Akdur for the roadmap



Thank you for listening!

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