



Developing a minimum data set for older adult care homes in the UK: key principles

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Introduction

The DACHA study seeks to develop agreement between care homes and those that work with care homes (e.g., commissioners, inspectors, regulators, external health providers) about the most useful information (data) that needs to be collected, held, and shared about older people living in care homes (a minimum data set). This document explains why a minimum data set is needed and identifies some key principles for its success.

Why is a minimum data set needed?

In recent years, people have been moving into care homes later, sicker, and frailer and have much more complex health and social care needs. The pandemic highlighted a range of issues with how information is collected from care homes and used by external organisations to ensure that older people's needs are being met, that residents have a great quality of life and that they are getting a high-quality service. For instance, care homes often collect useful data on their residents to ensure they provide really good quality, responsive, and tailored care but the nature of these data vary between care homes and are not always shared with external organisations (e.g., the National Health Service and local authorities). Care homes are also often expected to respond to multiple data requests from various external organisations. The requests may overlap and ask for the same information in different formats, adding to administrative burden due to duplication of effort. Information collected from care homes can easily be misinterpreted, especially when viewed out of context. Further, care homes rarely get to see how their data compares to others, what they can learn from this and how they can improve quality of life and quality of care for their residents.

A streamlined, shared data collection that is mutually beneficial to both care homes and external organisations offers the chance to provide a better all-round service, across health

& social care. It would enable staff to have more time to dedicate to direct care, rather than responding to multiple and overlapping data requests; and better analysis, management and use of the data can bring important insights to improve services for older people in care homes.

Methods being used

To make the most of what is already known, a series of reviews of the evidence have identified what information is important when measuring residents' health and wellbeing and how that information can be shared and used by different practitioners and organisations. This work included a review of existing research databases and completed care homes research to learn what works and the evidence about resident groups available from these studies. These findings are being compared with what care home residents, family members and care home staff involved in providing day-to-day care identify as information that is important.

Next, we will test how to combine information which is already routinely collected for health and social care with new information to achieve consistent ways of organising data for the benefit of residents and also researchers. We are consulting with stakeholders to develop a schedule of questions and linked outcome measures that could be the basis of a national database. Working with IT specialists, we will test these questions and the feasibility of asking them in practice. Throughout the study, we are working with all interested parties (commissioners, care home owners, residents and their representatives, NHS staff and the regulator, researchers and data management and privacy experts) to develop a consensus on the minimum content of shared records, guidance on how to standardise the way it is recorded and outcomes measured and linked to existing routinely collected data.

Finally, we will test the feasibility of using the shared care record in geographically dissimilar areas that are already working to integrate health and social care data. Throughout the study, we aim to create new ways of working and doing research in and with care homes, so that the outputs benefit not only researchers, but also residents.

What have we learnt so far from DACHA study?

There are some key principles that are essential to creating a minimum data set for care homes.

- 1. The MDS must focus on measuring what matters most to support those living in care homes.** Lots of different people (e.g., clinicians, researchers, and policy makers) want different information from care homes about the people living there, but the most important voices in the debate are those with lived experience of living, dying, visiting, and working in care homes. Data gathered needs to inform not only monitoring systems, but also, quality improvement. The DACHA team are ensuring that everyone's voices are being heard.

2. **The MDS must be informed by evidence and experience.** The MDS must be useful not only to care homes, but also, those working with care homes to ensure quality of life and quality of care for residents. We want to understand more about the needs of people living in care homes, how to make sure that care homes are well run, and how to plan better for the future. The study team are addressing these challenges by capturing the lessons learnt from previous research and from those with lived experience in practice.
3. **The MDS must reduce administrative burden due to duplication of effort.** Data comes at a cost. It takes time and effort to gather and keep information up to date. It can also be very time consuming and complicated to share. Data should not be required at the expense of time to care. DACHA is focused on what is the minimum level of information needed for shared benefit between care homes and external organisations.
4. **Digital care records are vital.** Many care homes use digital care planning systems to create residents' records and individual care plans. These systems hold lots of detailed, sensitive personal information so that care can be tailored to their personal needs and wishes. The MDS would not hold this sort of data at the individual level, but it would bring this information together to create a better picture of the population of the care home to understand more about their characteristics, spot trends and see what is changing over time, as well as what is working well and what is not. To ease administrative burden, much of this data needs to come from the digital care planning records.
5. **The MDS should record the care home staffing model.** The people working in care homes are essential to providing frontline care and support. The MDS needs to include the numbers of staff in different roles and shift cover patterns to ensure safe staffing levels.
6. **The MDS must bring together different sources of information.** The MDS should join up data from care homes with data from elsewhere (e.g., hospital and General Practice) about residents and care services. There is a lot of data about people in care homes in other systems, especially the NHS. This data is very important and needs to be seen in the round.
7. **Data sharing with external users of the MDS must have an agreed purpose.** Care home residents' privacy rights must be protected, and data sharing must be defined and formalised in data sharing agreements, using secure environments for access where appropriate.
8. **Care homes must be supported to access and use MDS data.** Care homes should be supported to access and use the data they collect and share with others so they can see trends over time, compare their services where relevant and helpful, and assess how well their services are being run and how they might improve. It is vital that residents, relatives, and staff see some benefit from sharing their data with others.
9. **The MDS requires investment and integration with existing systems.** The MDS will need investment both in supporting and training care home staff to gather and use the data, as

well as in systems and technology to capture and interpret the data. Given that many care homes already have care planning software systems, the MDS needs to integrate with existing digital care planning systems to ensure flow of data, with all the necessary consents and safeguards. The MDS will also need data interrogation and analysis tools to make sure the data is used effectively for resident benefit.

What does it mean?

COVID-19 has highlighted the urgent need for better data and information about social care, especially in care homes. Indeed, the government in England has mandated this to happen by 2024.

Policy makers and those who commission care, as well as those who provide care and use care, all agree that it is essential to work together to agree what information should be gathered about people in care homes and how it should, or should not, be used and shared. This must be done together.

A minimum data set must be relevant, useful, of good quality, easy to collect and easy to use. It must include clear consent and have agreement and rules about how and when it is used and shared and for what purposes. It must bring benefit to all including those whose data it is, those who collect it, as well as those who are able to see it and use it and analyse it.

The DACHA team includes academics, practitioners, and analysts with a long-established interest in care homes, who want to share their learning and experience to inform the wider debate. This paper highlights some important emergent key principles that the study team believe are key to the success of an MDS. Findings are likely to be of international relevance, especially in those countries seeking to introduce an MDS in care homes too.