Developing a minimum data set for older adult care homes in the UK: exploring the concept and defining early core principles

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Reforms to social care in response to the COVID-19 pandemic, in the UK and internationally, place data at the heart of proposed innovations and solutions. The principles are not well established of what constitutes core, or minimum, data to support care home residents. Often, what is included privileges data on resident health over day-to-day care priorities and quality of life. This Personal View argues for evidence-based principles on which to base the development of a UK minimum data set (MDS) for care homes. Co-produced work involving care home staff and older people working with stakeholders is required to define and agree the format, content, structure, and operationalisation of the MDS. Implementation decisions will determine the success of the MDS, affecting aspects including data quality, completeness, and usability. Care home staff who collect the data need to benefit from the MDS and see value in their contribution, and residents must derive benefit from data collection and synthesis.

Introduction

UK care homes are intelligence and information-rich environments. They operate with substantial data requirements from both internal and external stakeholders and regulators, while providing care for a complex and vulnerable population. Unlike several developed countries, the UK has no system for standardised data capture for residents in long-term care settings.

The Developing research resources And minimum data set for Care Homes' Adoption and use (DACHA) study is funded from 2019 to 2023 and aims to synthesise existing evidence and data sources with care home-generated resident data to deliver a minimum data set (MDS) that is usable and authoritative for different stakeholders. Our focus is older adults living in care homes, who account for the greatest proportion of services and beds across the UK. The key aspects of DACHA are summarised in panel 1. We will develop and test a prototype MDS, making recommendations for implementation and adoption.

In a context of rapidly increasing technological capacity to collect data and information overload, this paper considers how an MDS for older adult care homes should be constructed to be relevant for adoption in the UK. The principles of what constitutes core, or minimum, data required to support care home residents are not well established. Often, what is included prioritises data on resident health over social care priorities and what matters to people in care homes to ensure quality of life. This paper therefore sets out nine early core principles derived from our work to date (panel 2) to ensure that resident data are relevant and usable for those receiving, providing, and monitoring care.

Recognising heterogeneity in terminology,[1] the term "care home" in this paper denotes 24-hour residential care settings providing care and support for older adults (aged ≥65 years) both with and without on-site registered nursing staff. This inclusive approach to residential

long-term care is important for two reasons. Firstly, it recognises the considerable numbers of people resident in care homes without on-site nursing staff whose care is often not documented by existing international MDS. Secondly, it ensures from the outset that residents, staff, and family members' care priorities are given equal importance to biomedical information and documented clinical needs. Residential facilities for children, adults with learning disabilities or mental health problems (other than dementia), and specialist addiction services are also considered care homes in the UK,[2] but these services have distinct data requirements from an MDS, and are not considered here.

This Personal View has arisen from a collaboration of academics, clinicians, care providers, and analysts working to deliver an MDS that is usable and authoritative

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Panel 1: Key aspects of DACHA study design

DACHA is underpinned by public involvement and stakeholder engagement and is designed to:

- Learn from and build on the existing evidence and best practice by undertaking reviews of outcome measures and international minimum data sets
- Identify care home-generated variables that capture the needs of those living in care homes, and best describe outcomes that matter to residents and their families and friends
- Combine care home-generated data with administrative and NHS data and compare specific shared characteristics
- Explore the use of administrative and NHS data to reduce the data demands on care homes
- Demonstrate how a minimum data set can meet the information needs of a range of stakeholders and users interested in older adults living in care homes

DACHA=Developing research resources And minimum data set for Care Homes' Adoption and use.

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For the **DACHA study** see https://dachastudy.com

Panel 2: Early core principles for a UK minimum data set (MDS) for older adult care home residents

1 The MDS must primarily focus on measuring what matters most to support those living in care homes through systematic data collection and sharing.

2 The MDS must be evidence-based in design and contents, requiring co-production with key stakeholders.

3 The MDS must reduce data burden and duplication of effort for the care home. This will be achieved through piloting, collaboration, and ongoing engagement with homes.

4 The MDS will be most effective when underpinned by digital care planning and care records systems, within the care home, serving the day-to-day needs of residents, staff, families, and friends. This requires digital infrastructure and investment to deliver at scale.

5 The MDS will include information on the care home service, individual-level data on residents, and information on the model of staffing that supports them, but will not include individual-level data identifying the workforce in each home.

6 The MDS should bring together data from within the care home, coupled with data held externally about residents and care services.

7 Data sharing with external users of the MDS must have an agreed purpose. Data sharing pathways must be defined and formalised in data sharing agreements, using secure environments for access where appropriate. Care home residents' privacy rights must be protected.

8 Care homes should be supported to access and use the data they collect and share using electronic dashboards.

9 The MDS requires national infrastructure and integration with existing data systems.

for different user groups. References cited here provide context on the origins of the work, UK care home and policy context, and relevant international research. It also draws on completed reviews as part of the DACHA study of international MDS measures and use in research, what has supported international MDS implementation, and a national survey of English care homes' use of resident data.[3]

UK care home context

Key to understanding UK care homes for older adults is appreciating that their model of care is delivered by care staff and registered nurses (providing fundamental social and health care), with external support provided by practitioners employed by the National Health Service (NHS). While some homes employ registered nursing staff, many residents live in care homes without on-site nurses, receiving input from community nursing teams when indicated. Medical care is primarily provided by primary care physicians (general practitioners), with access to specialist services and clinicians coordinated through them. Care can be commissioned for individual

residents by local authority adult social services and is coordinated by local authorities and social care providers,[4] but a substantial proportion of older people fund their own care and many more pay top-up payments to have more choice.[5] This differs from countries where long-term care is more medicalised, centralised, or both.[6] The UK social care model is increasingly focused on rights-based care, recognising care homes as people's own homes. Maintaining a home-like environment has to accommodate the increasing dependency and complexity of residents' needs being met in a collective setting.[7]

Current data collection and sharing

The NHS and local authorities can hold a range of data about people living in care homes, often inaccessible to care home staff. Similarly, care homes collect vast amounts of data on their residents, which is often unseen by external staff supporting residents. Care homes are required to respond to multiple data requests from various external agencies. The requests might overlap and ask for the same information in different formats. The unintended consequences of this lack of coordination include administrative burden, duplication of effort, and data being misinterpreted when viewed out of context. Once submitted to an outside authority, care homes rarely see their data compared with others and are typically given limited feedback on the data's secondary use. All of these represent opportunity costs where, if data collection was streamlined and information was more readily shared, care home staff would have more time to dedicate to direct care, and time spent requesting and managing data could instead be used analysing and deriving important insights to improve care.

Pandemic context

The COVID-19 pandemic has increased the demands on care homes to generate and share data, and exposed the absence of established data sharing mechanisms.[8] It has also accelerated existing moves to adopt digital technologies, particularly the use of electronic care planning, remote monitoring, and digital consultation software.[9,10] However, there is inequitable access to resources across care homes and providers, with differential adoption across organisations and inequalities in access to devices, broadband, and wireless capabilities.[11] There is also ongoing use of paper-based record systems alongside digital systems or as the sole method of recording information. One of many implementation challenges to address nationally is staff familiarity with information technology and the development of formal infrastructure for digital skills development.

The pandemic has provided opportunities for rapid change, and through emergency legislation has accelerated development and implementation of data tools to track infection rates and inform resource allocation (including the Capacity Tracker in England

and Turas Care Management Safety Huddle in Scotland). Building more sustainable interoperable data systems, tailored to the needs of those living in care homes and those supporting them, requires genuine co-production between health and social care coupled with financial investment.[12]

Origins of the MDS concept

It is important to understand the international context and meaning around the term "minimum data set". There is no systematic data collection and synthesis in UK care homes, which is unusual for a country with a mature long-term care sector. Internationally, data systems such as the international Resident Assessment Instrument (interRAI)[13] and the Minimum Data Set[14] are used widely in the USA, Canada, New Zealand, and mainland Europe.[15,16] Critically, these are multidomain health-oriented datasets. They capture detailed individual-level information about residents, on a regular basis, often for insurance purposes. This information is used to understand needs and changes over time, including the impact of new interventions or ways of supporting care.[17] Using data to achieve these purposes requires concerted effort to help staff see the relevance of data to their practice and use data as a tool to support them to enact change.[18] Data capture needs to be intuitive and incorporated into the home's work flows, making a positive contribution to care and not creating additional administrative burden. Previous attempts to introduce interRAI in the UK were unsuccessful,[19] even within the intensive approaches possible during a funded research study.[20]

Nine early core principles

1. The MDS purpose must focus on measuring what matters to support those living in care homes

Historically, clinicians, researchers, and policy makers have had more influence on the content and focus of an MDS than those providing and receiving care. How content is defined and agreed reflects whose interests are being prioritised. An MDS usable for different stakeholders needs to serve a range of complementary but distinctive purposes. At present, UK data are inaccessible and fragmented, without standardisation in collection. Achieving consensus around the purpose of an MDS and who is responsible for completion are essential starting points. MDS data should characterise the population and their needs, including systematically capturing what matters to support those living in care homes and those who support them. MDS data should be the basis for exploration of variations in care moving beyond raw comparisons or counts to generate evidence from practice, supporting practice development and evaluation of innovation. Used this way, data from an MDS can provide information for evidence-based policy making, service planning, commissioning, and regulation, and form the basis of epidemiological studies looking at population changes over time. There are diverse stakeholders with an interest in improved care home data.[21] A summary of the purposes of the MDS is provided in the table.

Common data standards—by which we mean shared understanding of meaning, what is measured, how measures are recorded, and outcomes of interest—are

	Relationship to MDS data	MDS purposes
Care home residents	Access to data about residents used to populate the MDS and anonymised summary of data about the home as a whole	Accurate and contemporaneous data which make visible health, care, and support needs and changes over time; use of MDS data to improve quality of life and the experience of care, both within the care home and by secondary data users
Care home staff	Primary data users	Collection of variables which matter to those delivering care; support to access and use data and to view data in context; insights informed by data within the home to inform practice development, including improving quality of care; reduced data burden and duplication, releasing time for direct care
Families and friends	Access to anonymised summary of data about the home as a whole; access to outputs and insights from users	Access to care and support for loved ones living in care homes informed by insights from practice and structured national data collection
Wider health and care team	Primary and secondary data users	Standardised data to evaluate needs and monitor progress; in-depth insights about population requiring support; data to inform evaluation of models of care to support residents and staff
Integrated care providers including local government	Primary data users	Commissioning of effective, responsive services for care home population; evaluation of service changes at local level; monitoring of diversity and quality of the care sector in a locality using agreed standardised metrics
Regulatory bodies	Primary and secondary data users	Routine and systematic collection of data, monitoring the quality, safety, and effectiveness of care
Care representative bodies	Secondary data users	Accurate, national data to inform policy development, lobbying, and sectoral support to articulate and evidence needs of the sector without requiring bespoke surveys of members
Statistics providers	Secondary data users	Breadth of relevant data for whole of the sector to look at trends and inform social care policy making
National government	Secondary data users	Reliable, standardised, contextually meaningful information to inform policy and planning
Academic researchers	Secondary data users	Access to deidentified routinely collected national care home data in secure environments for approved defined research purposes; MDS will ensure researchers can access meaningful variables to inform insights
Wider society	No direct access to MDS data but to outputs and insights from users	Improved accurate, contemporary information about a pivotal sector to UK society for prospective users of services

MDS=minimum data set.

Table: Summary of the purposes of an MDS to different stakeholders

beneficial for clarity and supporting a common purpose.[22] The challenge is how this can still support individualisation of care and support. It requires effort to define the contents collaboratively around what really matters to those receiving care. For example, core outcome sets tailored to older adults and those living with dementia include a range of measures such as mood, quality of life, relationships, and participation, in addition to traditional health-oriented measures.[23,24] In the UK, the Adult Social Care Outcomes Toolkit (ASCOT) for care homes has been developed. It is a person-centred care-related quality of life measure which is designed to capture what matters most to residents.[25,26] Independent evaluation found ASCOT to be one of the most valued indicators of care home quality to older people, family members, and professionals, in England and the Netherlands.[27] Internationally, the WE-THRIVE consortium are working to identify common data elements focusing on person-centred long-term care in order to facilitate research.[28] What is collected and assessed becomes the focus of effort and resources. Although there is a role for data to inform regulation and safeguarding, the DACHA study team believes that the purpose of data capture must extend beyond safety and take account of the social care context to express and value measurement of the quality of care delivered.

Only when there is a move away from data systems that are influenced and designed by those not directly involved in data capture will an MDS become a resource for care. Ultimately, the two stakeholder groups pivotal to MDS success in the UK care context are residents and their representatives (in terms of acceptability of sharing information) and frontline staff, home managers, and care providers (collecting individual data necessary for useful insights). All other stakeholder groups can act to enable and facilitate MDS co-production and development but must recognise their part is distinctive due to their specific interest in data reuse.

2. The MDS must be evidence-based in design and content

The pace of change and innovation in the digital social care ambition has accelerated.[29] Using mixed methods approaches, our aim is to contribute to the evidence base to inform innovation and practice development, with structured evaluation and engagement. The lack of comprehensive individual-level information about those living in care homes impaired the pandemic response, but beyond the pandemic context results in missed opportunities to identify unmet needs and respond effectively to support residents and staff.[21] There is a (not widely recognised) wealth of information, but a lack of infrastructure to combine these data effectively. Therefore a systematic approach is needed to MDS development and testing that can both optimise the accessibility, usability, and usefulness of existing data and provide a context-attuned analytical resource to make sense of and derive meaning from existing information.

The DACHA study design includes engagement with care staff, residents, and their families and friends, whose contributions are important for policy making and decision making on content. A key motivation of our work is to amplify their perspectives so the focus is retained on recommendations that will have positive impact and redress the power imbalances currently at play. The goal is an MDS that is useful to external stakeholders to monitor services, and to care homes to enhance residents' quality of life and effectiveness of care.

Defining content requires a collaborative approach to select variables that address resident and service needs and minimise redundant information requested. Stakeholders have different priorities and data needs. These might relate to individual sensitivities about specific variables, commercial dimensions of information, regulatory or assurance roles, and oversight or responsibility.

The study team are addressing these challenges by collecting and synthesising evidence of how data are captured and used for different purposes. These include evidence reviews of care home intervention studies and international MDS research, a national survey of data currently captured by UK care homes, engagement with data stakeholders around their requests of care homes, and a review of care planning software to create a possible MDS content for piloting. Core to this review, synthesis, and consensus-building work is a decision-making trail that makes explicit how and why variables are included or not.

3. The MDS must reduce the data sharing burden for the care home

Care home staff spend considerable time providing data about their service and their residents to external agencies and organisations. An intended benefit of developing an MDS for UK care homes is working collaboratively to reduce this data sharing burden on homes and time wasted reformatting data. This can be achieved by piloting and refinement of content, frequency, and structure of the data collected. Working with homes who hold and submit data ensures that data requests are proportionate and aligned to the data held. Collaborative working requires a shared understanding by those requesting data of why it is important to align format, timings, and structure of items requested. There is a collective responsibility not to increase the data collection burden. Piloting and ongoing engagement with the sector will refine the MDS and support care homes in managing requests for information and in agreeing where changes are justified and necessary, to keep pace with evolving best practice.

4. Digital care records are critical underpinnings of the proposed MDS

Critically, the proposed MDS is not a replacement of an individual's care plan, nor of the day-to-day care record and evidence of care delivery collated daily, for each

resident, in every care home across the UK. These records contain highly personal information, necessary to deliver care, for which wider sharing would be disproportionate and unjustified. However, an MDS needs to be designed to be compatible with structured care plans. By extension, the MDS is not a tool that is intended to provide real-time data to friends and family about the wellbeing of their loved ones and daily activities; this need can be met using the existing functionality of modern care-planning software. Instead, an MDS draws together agreed individual-level information that can be used to identify residents' needs, changes over time, and health and wellbeing measures in the context of the home in which they are living. Longitudinal data capture and analysis can assist in identifying changing needs, particularly as an individual is approaching the end of their life. For care homes, it can help to set a benchmark against other care homes to inform quality improvement and enable frontline staff to identify trends in residents' condition and monitor strategies developed within the home to address needs. At a systems level, MDS data can be used to inform regulation processes, together with commissioning and monitoring of health and care services; to tailor and evaluate interventions such as enhanced service models; to support research to improve the quality of life of residents; and to generate evidence from practice. For policy makers, knowing about the population living in care homes enables effective planning for future care and support provision. To ensure equitable access and participation in the MDS, substantial national improvements in digital infrastructure for care homes supported by government investment are required.

5. The MDS should record the care home staffing model

The workforce is crucial to the delivery of frontline care and support. Thus, the question of whether workforce data would form part of an MDS in the UK naturally arises. Both Skills for Care (in England) and the Scottish Social Services Council collect detailed individual-level information on the social care workforce, with broader scope than just people working in care homes.[30,31] Neither are inclusive of all staff working in the care home sector. However, care homes see much benefit from providing workforce data as it enables themselves to benchmark against each other. Other organisations that register professionals, such as the Royal College of Nursing, also hold data on their members who work in care homes.[32] Collecting mandated individual-level, linkable data on those working in care homes within our MDS would represent a considerable shift from current practice. NHS datasets do not collect individual-level staffing data at scale and there are ethical issues to consider around identification of staff from their own health and care data. More proportionate would be to operationalise and standardise recording of care home staffing models (eg, numbers of staff by professional group and shift cover), to accord with development of safe staffing

recommendations and help identify where services might benefit from additional support or resources.[33]

6. The MDS must bring together different data sources

The proposed MDS will bring together information generated within the care home about individual residents, staffing model, and the service, with external data about residents and services supporting the home and regulatory and notifiable data. The data flows are summarised in the figure. There are complex issues to consider and consult upon around use of individual-level data and bringing together data from a range of sources. These issues are primarily around how to maximise the value of the data without putting individuals at risk, working within existing legal frameworks.

It is often not appreciated just how much secondary use of deidentified data occurs through existing arrangements. For example, every GP appointment, every prescription dispensed, every operation undertaken, and every hospital admission all generate routine data that can be made available for analysis with appropriate safeguards in place. Address-matching approaches can identify individuals who live at care home addresses and extract their NHS data to explore health-care resource use or evaluate interventions.[34,35] None of these data uses require individual consent. However, there are calls to build-in consent models to the use of routine health and social care data sources.[36] In contrast, research undertaken in care homes that involves interacting with residents and using their care home-held data, collecting blood tests, or carrying out other interventions always requires consent. For individuals who lack capacity to consent to participate in research, considerable resource is required to contact their representatives in order to legally facilitate participation if wished.[37]

A core underpinning of responsible data (re-)use is effective communication with the public and prospective data subjects about how data are used and around deidentification and other safeguards, such as that seen
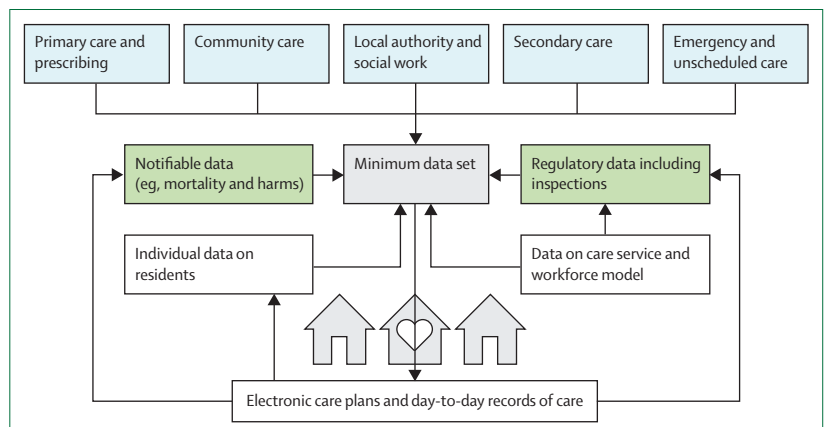

Figure: Graphical summary of proposed structure of the minimum data set combining care home and external data

in the Understanding Patient Data initiative.[38] Little is known about how this applies to social care data, in particular the very personal information that is known and held within a care home to look after a resident. Much of this data is not relevant to external stakeholders and should not be shared. Other aspects, fundamental to understanding the needs of those living in care homes, need to be explained, with an emphasis on the privacy protections and safeguards in place.

It is important to be explicit about the biases within the existing data landscape, particularly around use of routinely collected health data sources. Health care is incontrovertibly important to older adults living in care homes, but health-care service utilisation data alone are not a meaningful outcome measure of the quality of care. Such data are complex to interpret without adequate contextualisation (eg, comparing care homes on the basis of hospital attendance rates lacks meaning without knowing the characteristics and history of the population living in that home and the model of care in place to support them). In planning content for an MDS, active consideration must be given in the design to measuring what matters most, rather than what is easiest to measure, particularly when using data at scale. How it is agreed what is important is a negotiated act with those who use and need the data most, to ensure the MDS is a shared and meaningful enterprise.

7. Data sharing purposes and pathways must be defined and formalised

Ownership of an MDS is complicated. Care homes are data controllers of the records they collect and hold, but would also be users of collated MDS data. Care homes collect data about residents to evidence care delivery, which must be shared with appropriate organisations, such as their regulators. There is an ambition for all citizens to have an electronic care record, which can be shared with all those who have a relevant purpose.[29,39] An MDS will draw from these sources but is not intended to replace these tools for frontline care delivery. Other stakeholders might provide data to inform the MDS, such as the Care Quality Commission (care regulator), and would consequently also be users of collated MDS data. Members of the health and care team, supporting residents, are potential users of the data, and the care records they collate and hold about residents might be data sources used to populate MDS content. Wider secondary uses of the data (eg, for research or evaluation) requires agreed terms of engagement and defined data sharing agreements.

Care homes are individuals' homes. There is a need to respect the privacy of residents and avoid identification of individuals in secondary data uses. This can be achieved through careful pseudonymisation and curation of data, with strict access controls in place. Key in collating the MDS will be deidentification of information for external users and aggregation of information derived

from individual-level insights. In addition, in line with current best practice on secure data access,[40] trusted data environments should disseminate access to the data, rather than disseminating the data themselves, allowing data to be held in one or more centralised and controlled environments.

One potential model to overcome the challenges of bringing together data that are held by private companies (eg, care homes, software providers) and public institutions (eg, local authorities, NHS) is that an independent third party should collect, hold, aggregate, and disseminate the MDS using a collaborative governance structure in which all parties agree on how their data are used.[41]

Temporary solutions to address a public health emergency can operate under different terms of engagement than sustainable long-term systems. Instead, to instil confidence in the system and safeguard resident confidentiality, a long-term robust mechanism to share data is required.

8. Care homes must be supported to access and use MDS data

Throughout the pandemic, care homes have expressed a wish to know how information that they have submitted elsewhere is being used by different organisations, and to be supported in making use of the data they collect—for example, using dashboard functionality to display trends over time and using systematic data collection to evaluate effectiveness of quality improvement work. In the pilot phase of the DACHA study, it is likely that summaries will be generated by the research team and shared with the care home. However, a principle for future implementation is to make sure care homes can easily derive insights from the MDS by allowing them to view their data in the context of other routinely collected information and compare their home against other similar deidentified care home services across the country. Exemplars of how to do this include primary care prescribing data and secondary care utilisation data, which are provided at general practice level and can help inform quality monitoring and identify where additional resources are needed. Adult Social Care Outcomes Framework data for England have also been made available at local authority, regional, and national level to facilitate comparisons.[42] This is important to support ownership of the data within homes and care provider organisations and to ensure that the data are reviewed and used, retaining their utility and meaning in care. Such engagement is critical, so that MDS data collection is not seen as a task of collating information for external secondary users.

9. The MDS requires infrastructure and integration with existing systems

The creation of an MDS requires national infrastructure and investment. This includes investment in practice

development and staff support to ensure that data within the MDS are seen as a valuable tool to inform care within the home and that staff have the skills and resources to use the data effectively.

Close integration of the MDS and care home software will minimise the data collection burden on care home staff. In turn, the software could provide the platform to access the MDS, integrating with existing data analysis and insight tools already available in many software platforms. Interoperability of systems is critical to facilitate data flows, in view of the range of software providers in the care market. Similarly, integration and interoperability with other software, particularly that within primary care and community nursing, is critical in facilitating effective data sharing for resident benefit.

Conclusions

There is a new consensus between UK governments around the need for improved data collection in care homes,[29,39] and a mandate to achieve it by 2024 in England. Co-produced work is required to define and agree the format, content, structure, and operationalisation of such change. Without this, it is likely that stakeholders and their organisations, who are external to the care home, will influence most what data are collected. Implementation decisions on data collection, use, and onwards dissemination will determine the success of an MDS, affecting aspects such as data quality, completeness, and usability. Our pilot work will allow for evaluation of implementation issues and enable informed recommendations for widespread adoption. To realise the potential benefits of an MDS, data collected need to be of consistent quality and the data need to be easy for staff to collect. Care home staff who collect data and residents who provide data need to benefit from the MDS and see value in their contribution. As a team of academics, practitioners, and analysts with established care home interests, we have proposed some early underpinning principles around the development of an MDS for older adult care homes in the UK. We intend to share the experiences and learning from the DACHA study to inform the wider debate and concept development. The knowledge gained from the DACHA study has potential to advance how we capture and share data from all types of long-term care settings by giving parity between biomedical data and data reflecting the priorities and interests of care. This has the potential to influence the narrative on data in long-term care settings and inform a global understanding of what matters to residents, their families, and the staff who support them.

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