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Health and Social Care Delivery Research

Synopsis

Developing research resources and minimum data set for care homes' adoption and use (DACHA)

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Abstract

Background: In England, care homes are the primary providers of long-term care for older adults. The increasing recognition of the importance of social care underscores the importance of collaboration between the National Health Service and care homes. The lack of data sharing among stakeholders limits opportunities for co-ordinated care, service development and research.

Objectives:

1. Identify how to support research, service development and innovation in care homes.
2. Combine existing evidence with care home-generated resident data to create a minimum data set that is relevant and usable for stakeholders, including residents, relatives, practitioners, researchers, regulators and commissioners.

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Design and methods: The study used a mixed-methods approach, structured into five work packages, supported by patient and public involvement and engagement with residents, carers and staff:

- **Work package 1:** Conducted two evidence reviews on outcome measures and factors enhancing research productivity in care homes.
- **Work package 2:** Created a trial archive for secondary data analysis.
- **Work package 3:** Conducted a scoping review, a realist review and a national survey to define minimum data set content and assess implementation challenges in English care homes.
- **Work package 4:** Linked residents' data from National Health Service and social care data sets with data from study care homes, deriving useful minimum data set variables and assessing data quality.
- **Work package 5:** Piloted the minimum data set at two points in care homes within three integrated care systems, conducted focus groups and interviews with care home and integrated care system staff.

Three national consultations explored how stakeholders use resident information, measure quality of life and minimum data set usefulness. Additionally, subprojects examined data availability in domiciliary settings, staff reasoning when assessing resident well-being and completing research during rapid policy changes.

Findings:

- The reviews revealed significant heterogeneity in outcome measurement and questioned the appropriateness of some methods and measures used for care home research.
- The Virtual International Care Home Trials Archive merged data from 6 United Kingdom randomised controlled trials with 5674 residents across 308 care homes.
- International minimum data set studies are a valuable resource for international comparative research. The wide range of measures used are mostly clinical with under-representation of measures important to care homes (e.g. quality of life).
- A national survey of care homes demonstrated the range of information, including clinical measures being routinely collected.
- The realist review identified motivation, front-line staff monitoring and embedded recording systems as important for minimum data set implementation.
- The pilot study recruited 996 residents from 45 care homes, with 727 residents' data included in the minimum data set. Residents' digital care records were linked to statutory health and social care data sets, creating a viable minimum data set prototype with metadata as resource.

Conclusions: The study provided an evidence-based critique of care home research and a resource for secondary data analysis for future research. It developed a prototype minimum data set linking National Health Service, social care and care home data, demonstrating its importance as a basis for discussions between health and care staff.
Limitations: The COVID-19 pandemic disrupted relationships and recruitment. Governance challenges prevented linking residents' data to general practitioner records.
Future work: Future research should assess whether the care home minimum data set improves resident outcomes, service delivery, staff experience, cross-sector collaboration, resource use and digital technology implementation.
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Introduction

Background

In England, there are over 1.5 million people aged over 85 years[1] and over 370,000 care home residents as reported by the Office for National Statistics (ONS).[2] Almost three-quarters of the care home population are aged over 80 years, with half aged over 85 years.[3] It is estimated that 70% of people in care homes are living with dementia or severe memory problems.[4]

Long-term care for older people is a heterogeneous market, with care homes varying in size and the types of provision offered. Almost all are in the independent sector. Care homes provide 24/7 care with on-site care workers, including registered nurses.[5] Care homes rely on primary care and community services for access to medical and specialist health care. Research consistently demonstrates that the strength of working relationships, the value placed on care home staff expertise and the support provided by care systems for access and referral to health care all significantly affect residents' outcomes and their use of secondary care.[6–8] For example, the evidence-informed Enhanced Health Care in Care Homes framework was purposefully designed to operationalise relational working by specifying how general practitioners (GPs) and community staff should work with care home staff to plan and deliver personalised care.[9]

The 2019 NHS Long Term Plan[10] introduced regional integrated care systems (ICSs) that facilitate closer working between the NHS, local authorities and the voluntary sector.[11,12] Systems that support data integration and standardisation of recording residents' information have the potential to underpin and improve working relationships with care homes as well as the commissioning, delivery and review of services. There is no agreed framework for collecting, sharing and interpreting data collected by the organisations that are involved in supporting care homes. Multiple health and social care databases contain information about the characteristics and the needs of care home residents and the services they receive. Outside of research, little is known about the care home population in England, as anonymised resident information is not routinely shared across the wider system.[13] Compared to many developed health and care systems, the UK is an outlier in how it captures data on long-term care. The Developing resources And minimum data set for Care Homes' Adoption (DACHA) study, involving nine universities, six National Institute for Health and Care Research (NIHR) Applied Research Collaborations (ARCs), The Health Foundation (THF) and the National Care Forum, aimed to determine what promotes research and innovation in care homes. It also sought to identify the core data that are useful and usable for those who work in and with care homes and for care homes in England.

Published subsequent to the start of the DACHA study and post pandemic, the Department of Health and Social Care's (DHSC) roadmap[14] for transforming social care data aims to achieve better joined-up care. This includes the development of a minimum operating data set to streamline existing data flows into a single collection designed to meet all user needs. In April 2024, to support interoperability across a wide range of health and adult social care systems, the DHSC Digitising Social Care programme released an operational data specification for the Adult Social Care Minimum Operational Data Standard (MODS).[15] This sets out essential information for care providers to record. The DHSC vision covers all services under the adult social care (for ≥ 18 years old) umbrella, including care through homecare (domiciliary care), day centres, residential homes and nursing homes, reablement services, adaptations for people's homes and support for family carers.[16] It has been introduced to ensure a consistent baseline recording of direct care using digital care records (DCRs) by Care Quality Commission (CQC)-registered adult social care providers.

The DACHA study

The DACHA study ran from November 2019 to April 2024. Commissioned before the COVID-19 pandemic, it had two aims: to provide resources that support research and uptake of innovation in care homes, and to address the fragmentation of residents' data across many systems and databases. The initial work packages (WPs) focused on how to support research in care homes. This work informed the subsequent development of the minimum data set (MDS) content, the linkage of care home data with health and care administrative data sets and implementation of a prototype MDS.

The need for efficient and effective use of resident data for purposes of care, planning and evaluation was increasingly highlighted during and after the COVID-19 pandemic.[13,17,18] The public health response for the care home population was compromised by the lack of standardised and accessible information about the people living in care homes, their needs and health and social care use.[19]

Minimum data sets are stand-alone systems that support comprehensive assessment of care home residents, care planning, service commissioning, multidisciplinary teams working together and quality assessment.[20–26] These data sets have historically relied on health metrics with fewer social care measures included. Several OECD developed countries have been using resident MDSs. These MDSs include MDS 3.0,[27] used in the USA, and the International Resident Assessment Instrument (interRAI), which originated in Canada, interRAI has been adapted and mandated for different care systems in Belgium, Finland, Ireland, Hong Kong, New Zealand, Singapore, Switzerland and some US states.[28] Research shows that a MDS can provide a comprehensive account of characteristics of residents, use of resources and quality of care outcomes in areas such as functional ability, pain and infections.[29–32] MDSs can also inform planning and evaluation of both care of residents and research in care homes from the point of first assessment on admission to end of life.[33,34]

In the DACHA study, we define a MDS as a standardised account of essential demographic, social and health and care characteristics and needs of older people living in care homes.[35] There is no standardised approach to collecting residents' health and social care data in England

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that can be used by all service providers (care homes, GPs, community nurses, NHS acute and urgent services, local authorities, etc.) to access information about residents and inform their service provision.

Electronic care management products have been commercially developed for use in social care settings in the UK. This terminology includes care planning/recording, medication management, workforce planning and digital learning tools. Potential exists to facilitate access between DCRs and primary care records.[36] These products have been developed collaboratively, reflecting the diverse needs of the social care sector in terms of the individuals they support, the services provided and their digital needs. This includes the ability to personalise and tailor content around client needs. Work has been done around ensuring data security and alignment with CQC requirements.[37,38]

Although guidance exists for providers in switching to digital systems, less is known about how these are integrated and used as part of care home activities. The GEARED UP project from Scotland highlights that there are large volumes of individual-level data collected in care homes, with potential to use these sets of data to improve services and support research that can benefit care home residents and providers.[39] Previous research in the UK has looked at the internationally standardised approaches to care home resident assessments, including interRAI[32,40] and Comprehensive Geriatric Assessment.[41] This research, however, is limited to the requirements for effective implementation of a standardised MDS developed by clinicians in North America, which does not reflect the English funding or organisation of care. For example, among all adults receiving long-term care from local authorities in England, older people (aged ≥ 65 years) make up 65% of the recipients.[16] Most money paid by local authorities for older people's adult social care services is spent on care homes (nursing homes and residential homes), although nearly 50% of residents are self-funding or paying top-up fees.[42]

The DACHA study primarily focuses on the data related to older people living in care homes, which is collected across multiple health and care systems. DACHA also focuses on providing resources and guidance to older people's care homes and the researchers who work with care homes. See *Report Supplementary Material 1* for the study protocols. A smaller study within a project (SWAP) was funded to study the information collected about older people's domiciliary care [DACHA Domiciliary Care (DACHA-DOM)].

Throughout the DACHA study, we linked with the DHSC and National Health Service England (NHSE) teams to ensure our work was complementary and to ensure early study findings are fed into recommendations for the MODS (see *Report Supplementary Material 2* shows how the DACHA study and DHSC informed each other's work). We also consulted with software provider organisations via their representative body, Care Software Providers Association (CASPA),[43] partnering with two approved suppliers for our pilot MDS.

DACHA aims and objectives

There is a growing interest in improving the evidence and care of care home residents. The rationale for the DACHA study is that achieving this goal requires resources to support the research process and implement findings, informed by data about residents from national data sets linked with care home-generated data. The DACHA study has two main aims:

- to establish what needs to be in place to support research, service development and uptake of innovation in care homes
- to synthesise existing data from national sources with resident data from care homes to deliver a prototype MDS that is relevant and usable for different groups (care home residents, relatives of residents, practitioners, researchers, service providers, analysts, regulators and commissioners).

Between November 2019 and April 2024, the DACHA researchers worked on five WPs, four SWAPs, one of which added a third site for the testing of the prototype MDS, and work streams supporting patient and public involvement and engagement (PPIE) and national consultations on MDS content to accomplish the following outputs:

- guidance for researchers and commissioners on doing research in care homes, resources on assessment measures and core outcomes in care home research
- an archive of care home randomised controlled trials (RCTs) conducted in the UK, designed to support secondary data analysis in future research without burdening care home staff and residents
- evidence on what needs to be in place for a MDS to support its uptake
- a prototype MDS, linking NHS and social care data with care home-generated data, which inform commissioning, needs assessment, care delivery and research

- a set of resources, including MDS metadata and information on data quality and derivations, for others looking to link data on care home residents.

Research design and overview of DACHA work packages

Patient and public involvement and engagement and iterative national consultations were threaded through each stage of the study. WP 1 and 2 addressed the aim of the DACHA study to make better use of existing research and routine data. WP 3, 4 and 5 and the consultation work built on these findings to develop a useful and usable MDS.

In early stages of DACHA, the study team developed nine early core principles[44] to oversee the development and implementation of a care home MDS.

The core tenets of the MDS specified in *Table 1*, underpinned the development of the MDS and how the study engaged with external partners, for example, briefings with DHSC and NHSE and NHS Improvement (NHSEI), and informed discussion at research management team meetings. All these were overseen by the Study Steering Committee (SSC).

The following summarises each WP and linked work:

1. **WP 1:** Two systematic evidence reviews:[45,46] about key outcome measures used in contemporary international care home research (scoping review), and on the evidence of what needs to be in place to trial care home interventions to reduce the risk of implementation failure (systematic review of process evaluations). The WP includes guidance for care homes and researchers, outlining key factors that management should consider before supporting a research study.
2. **WP 2:** This WP designed and created a care home trials archive, initially including trial data on 5674 residents from 6 trials (as of April 2024), with a further trial joining, and the capacity to add new trials beyond the project. UK RCTs conducted since 2010

TABLE 1 Core principles of a MDS

1. The MDS must primarily focus on measuring what matters most to support those living in care homes through systematic data collection and sharing	**6.** The MDS should bring together data from within the care home, coupled with data held externally about residents and care services
2. The MDS must be evidence-based in design and contents, requiring coproduction with key stakeholders	**7.** Data sharing with external users of the MDS must have an agreed purpose. Data-sharing pathways must be defined and formalised in DSAs, using secure environments for access where appropriate. Care home residents' privacy rights must be protected
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	**8.** Care homes should be supported to access and use the data they collect and share using electronic dashboards
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	**9.** The MDS requires national infrastructure and integration with existing data systems
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	

DSA, data-sharing agreement.

Source

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were identified through scoping of relevant literature. Principal investigators of these RCTs contributed to the archive. Virtual International Care Home Trials Archive (VICHTA), sits under Virtual Trials Archives (VTA), which is a not-for-profit collaboration hosted at the University of Glasgow.[47]

3. **WP 3:** Made of up three components, it established what is known about the implementation and content of MDSs that could be relevant in the UK context. The realist review[35] developed a theory-driven account of what needs to be in place for care home staff to implement a MDS to inform care and improve residents' outcomes. The mapping review[48] addressed the content of MDSs relevant for UK systems of care, and the national survey[49] identified resident data routinely collected in care homes across England.
4. **WP 4:** Focused on accessing and linking pseudonymised data for the prototype MDS. This mapped the information in the prototype MDS to existing administrative data sources. This included managing information governance (IG) and pseudonymisation of residents' data. Data-sharing agreements (DSAs) and data flows were established with study care homes, NHSE, three ICSs and two care home software providers. The quality of the data from administrative data sets was reviewed and reported and, where applicable, informative variables from the source data were derived. Metadata, including a data specification of all MDS variables and descriptive analyses, were produced[50] (see *Report Supplementary Material 3*).
5. **WP 5:** Focused on data collected through DCRs at the care home level. Working with two software providers who supply DCRs to care homes, routinely collected data were mapped to the prototype MDS. Key measures identified for inclusion in the prototype MDS, not routinely collected in DCRs, were added to the study care homes' DCRs by software providers. These were completed at baseline and at 6 months to demonstrate longitudinal feasibility. These data were extracted by the software providers, along with other routinely collected data from DCRs, for data cleaning, exploration of consistency between sources and quality ahead of linkage with residents' data held in NHS and Social Care routine data sets (WP 4). MDS data from DCRs were assessed for feasibility by completeness. Data quality was evaluated by reporting descriptive statistics. We assessed the internal consistency and construct validity of four resident-level quality-of-life (QoL) measures and demonstrated the value of these data.[51,52] Focus groups and individual interviews were conducted with care home staff and participants from the linked ICSs to develop an understanding of implementation issues and the utility of the MDS.[53]
6. **Consultation with stakeholders:** Consultations about the proposed content and usefulness of the prototype MDS were conducted via online groups and national surveys. These occurred three times during the study. We recruited representatives who work for, in or with care homes, or have direct experience of care provision. The experience of the COVID-19 pandemic directly informed stakeholders' accounts in the first consultation in 2021: specifically, what affected the access, use and sharing of care home data and information that was unavailable. In 2022, a two-stage survey was held on the Thiscovery platform[54] to ask: (1) what aspects and principles should be captured in QoL measurement in care homes, and (2) which shortlisted QoL measures could be included in the DACHA MDS. The final consultation discussed with online expertise-based stakeholder groups about the relevance and usefulness of the prototype MDS. To further test consensus, findings from these groups and the prototype MDS were shared in an online public survey. Descriptive statistics were used to analyse the survey results.
7. **SWAPs:** Four post-award studies were funded:
   A. *An additional ICS study site* (North East and North Cumbria) to include underserved and socioeconomically deprived communities.
   B. *Staff assessment of mental health and multiple long-term conditions ('Think-aloud' SWAP)* explored how care home staff understand, complete, interpret and use the assessment tools and scales within DCRs to evaluate and support the QoL and well-being of residents.
      - Part 1 used cognitive interviewing techniques to understand how staff interpret questions and choose responses as they complete MDS items on the mental health, QoL and well-being of residents with multiple long-term conditions.
      - Part 2 explored how making and recording an assessment of a resident's mental health and well-being triggers staff actions.

   C. *Domiciliary care (SWAP)* explored how the learning from DACHA about MDS in residential settings can be applied to implementing a MDS in domiciliary care in England. It involved:
      - a scoping review of international literature on routine data collected in homecare

  - a survey of homecare providers to determine the content, mode and uses of current routine data collection
  - workshops, focus groups and interviews with care recipients and families, providers, commissioners and researchers to understand the range of views on the content of a homecare MDS and the barriers to implementation.

D. *Research in a time of rapid policy change (implementation SWAP)* explored how, in the context of rapid changes in policy and practice – including a shift towards digitalisation, data linkage and the creation of ICSs, the research team and other stakeholders adapted and responded. It focused on the experiences and learning of the core DACHA study team and key stakeholders, including software providers, policy-makers and relevant others. The study aimed to inform the work of those involved in innovation and improvement efforts in adult social care who are facing comparable challenges. Data analysis is informed by the Consolidated Framework for Implementation Research (CFIR).[55]

Interpretation/discussion

Principal findings

This section is divided into subsections reporting findings from the WPs, the SWAPs and the consultations.

Work package 1 findings and take-home messages

This WP demonstrated the importance of researchers understanding and engaging with care home staff to better understand the needs of older residents and the context of care homes. Older people in care home settings value both QoL and the quality of care. We must not assume that clinical interventions, ways of working and outcome measures are always appropriate in this setting.

Scoping review of resident outcome measures

The scoping review of resident outcome measures used in contemporary international care home research addressed an evidence gap relevant to both DACHA aims.[45] Firstly, to inform the research community on common measures and to inform the proposed MDS content. By focusing on the outcomes chosen in 436 papers, the review highlights several issues likely to affect the quality and relevance of care home research. Namely, the lack of consensus on the best methods to capture residents' functional status, behaviour and medication use and the critical absence of measures tailored to social care, including the lack of any social care-related QoL measures. This is further exacerbated by the relative scarcity of research measuring outcomes for conditions often present in the care home population, such as incontinence, visual impairment and ability to communicate. The lack of information on who recorded the data, including how long they took to complete, directly affects how findings can be interpreted and implemented.

Care home intervention research is increasing, as evidenced by the growing number of studies. However, the diversity in assessment methods and inconsistent use of measures hinder the development of knowledge specific to the care home population. This inconsistency also results in research waste when measures are not sensitive to changes in this population. There is an urgent need to use measures that are appropriate and sensitive to the care home context. Collaboration is essential to ensure that research studies focus on what matters most and to do so in the most efficient and least burdensome way.

Systematic review of process evaluations

Process evaluations of research trials explore the similarities and differences between what was planned and delivered. Our systematic review aimed to identify contextual factors that function as facilitators or barriers to successful complex intervention trial implementation in care homes.[46] We synthesised the data from 33 process evaluations using a complex adaptive systems lens. We highlighted two priorities for research teams implementing trials in care homes: (1) preventing 'procedural drift' (where studies gradually lose momentum and drift from the aims of the original intervention), and (2) prioritising participatory action learning. To reduce the prevalence of costly implementation failures of care home research trials, effective implementation of care home research trials requires: the collaborative design of the intervention, alignment with a shared objective, integration into existing daily work routines and adequate resourcing.

Guidance for care homes and researchers

A professional journal article targeted at care homes managers[56] and a guidance leaflet for researchers[57] highlighted from review findings what should be considered when supporting care home research. Both outputs reiterated the importance of identifying research topics with care home staff involvement, staff being able to comment on and contribute to research design, assisting in the implementation of research, and applying for funding to lead studies. They addressed the significant resources (time, money and energy) that trial studies require. Key considerations were the capacity and resources of the care home, the readiness and commitment of the care home team and the support offered. This work provides evidence of the value in creating and maintaining opportunities for staff to be equal partners and leaders in the research process, ensuring that the research remains relevant and sustainable.

Work package 2 findings and take-home messages

Work package 2 established an archive of individual participant data (IPD) from RCTs conducted in UK care homes. Outcome data collected in the trials also helped to inform decisions about content for the MDS.

We developed our protocol[58] using an established methodology developed by the University of Glasgow VTA[47] to construct the 'VICHTA'. Trialists from care home trials, undertaken in UK since 2010, were invited to contribute anonymised IPD and care home-level data. DSAs and contracts were required, alongside preparation and pooling of relevant variables. VICHTA is a legacy output from DACHA, providing a research resource for secondary data analysis, with scope to involve additional RCTs and broaden inclusion beyond UK trials. Secondary use of pooled data is overseen by a Steering Committee with representatives from each participating trial. Researcher access is enabled remotely using a secure online analysis platform.

A scoping review identified potential care home trials for inclusion. When possible, we leveraged personal connections within the study team to introduce the project. By the end of 2023, VICHTA included data from six UK RCTs with IPD on 5674 residents across 308 care homes, collected between 2011 and 2019.[59] A further trial was added in mid-2024.[60] The six initial trials tested interventions, including polypharmacy, falls prevention, incontinence and dementia care delivery and symptom management. The median age of residents at baseline was 86 years [interquartile range (IQR) 45.3–104.0], who were mostly female (4077; 72%), with 74% having a known dementia diagnosis. The median follow-up duration was 228 days (IQR 149–394), and 1370 (24%) residents died before trial completion. IPD include basic demographics, outcome measures, health resource use and care home characteristics such as case mix, funding and occupancy.

Virtual international care home trials archive demonstrates the breadth of data collected about UK care homes and their residents through trials research. By connecting data based on setting of care instead of a single topic area, a broad range of research areas from a social care setting emerge. Identification of resident subgroups and better understanding of care home markets and long-term trends in care homes are potential future uses of the pooled data. VICHTA also demonstrates the feasibility of consolidating and providing access to a wealth of repurposed trial data, to investigate new topics in care home research, thereby reducing research waste. Interested collaborators can submit trial data or submit research proposals at www.virtualtrialsarchives.org/vichta/. This work is being taken forward with research identifying social care research questions that could be answered by secondary data analysis[58] and the continued growth of the archive [see *Report Supplementary Material 6* for the Prioritising Research through Engagement with older Adult Care Homes (PREACH) study protocol].

Work package 3 findings and take-home messages

This WP focused on the conditions that make using and implementing a MDS viable, information about residents that is already available in care homes and the content of existing MDS used in other countries.

Realist review

We conducted a realist review to develop a theory-driven account of what supports the adoption and use of MDSs by care home staff to improve residents' care.[35,61] It was a starting point of the review that MDSs are valued by commissioners and service providers. Previous work on MDS development is dominated by their content and what can be achieved with the information they generate, often at the aggregate level of assessment.

The study's findings, based on 51 papers and stakeholder interviews, demonstrated that staff motivation, integration of the MDS into care home routines and staff capacity to use digital technology affected MDS uptake and quality of data capture. Mandating the initial use of a MDS is necessary, but it must be supported by ongoing training, tailored resources and engagement from visiting clinicians. Under these conditions, MDS use can significantly enhance day-to-day resident care and outcomes as well as improve the regional and national understanding of the care home population.

Implementing digital tools in care homes requires more than just equipping staff to enter data. The study's findings parallel those from WP 1 on research readiness, emphasising that sustained engagement and support from visiting healthcare professionals, who collaborate with care home staff to use and review resident information, are crucial. This approach ensures that data entry is seen as more than just an administrative task, fostering long-term commitment and cross-disciplinary utilisation.

Mapping review

The review aimed to identify the topics that have used MDS data in research studies and key measures used in long-term care facilities (LTCF) for older adults.[48] Along with the survey findings, it provided an important resource for subsequent WPs on MDS content and focus. Studies were grouped by topic, and brief descriptive data were charted without quality assessment. Six hundred and sixty-one articles were included, a majority from the USA and Canada. The studies encompassed individual resident functioning (e.g. mobility), health conditions and symptoms (e.g. dementia and pain), health care in the home (e.g. prescribing and end-of-life care), hospital contacts, transitions to and from care homes, quality of care and system-wide issues. Medications were the most common focus of research, and there was a paucity of studies on topics linked to care rather than treatment. Information from MDS is also commonly used to supplement data collection in empirical studies, enhancing the efficiency of research. Linkage to other data sets was a common approach, which enables research with MDS to provide a comprehensive picture of care and outcomes. Measurement tools used reflected the content of the major established MDS, with little consensus on QoL measurement. MDSs are a unique resource to support the study of care home residents and the impact of interventions over time.

National survey

This online survey explored data collection practices in residential and nursing care homes in England.[49] We explored the variety of data categories and data collection methods used by care homes based on 273 responses, representing over 5000 organisations.

Care homes collect extensive data on residents, particularly on health (including clinical observations, data on falls, pain, common conditions and skin integrity); care and support needs of residents (including mobility, balance, continence and sleep quality); and residents' personal preferences and activities (including bathing preferences and nutritional needs). Although clinical measures are commonly used in care homes, QoL was collected by fewer than a third of respondents. The biggest concerns raised were about privacy and data protection when sharing information outside the care homes.

The extensive range of data already collected by care homes indicates a strong motivation to gather information on residents for internal use challenging assumptions about there being a lack of data collected in care homes and the knowledge and insights staff have about residents. Documentation practices were less clear in terms of whether all data categories were consistently completed or how frequently they were updated. Data collection in care homes is influenced by the demands of the external organisations such as the regulator, Health and Safety Executive, NHS and local authorities. The move towards standardising measures presents an opportunity to collaborate with sector representatives to review, adapt and enhance existing data capture methods, reducing duplication of effort. Policy-makers should work with care home providers to ensure new reporting requirements build on existing data practices.

Development of prototype minimum data set

The trail of evidence towards building the MDS can be found in *Appendix 1*. The early core principles[44] (see *Table 1*) were used alongside other production activities to create the MDS. Team members from WP 5 were involved in the early mapping of the variables that drew on WPs 1–3 findings. It was revised twice during the study in response to new findings and the changing availability of data in care homes and national data sets (see *Report Supplementary Material 3*). *Figure 1* shows the categories of MDS variables and in which data sets they are located.

Work package 4 findings and take-home messages

To develop a prototype MDS, based on the aspirational list, we worked with organisations controlling or processing the data to understand available data items, agree about data flows and set up DSAs to access these data. By extracting information directly from these data sets whenever feasible, we minimised the burden on care home staff.

Nine key routinely collected, health and social care data sets were accessed and linked with residents' care home data to create the prototype MDS[50,62] (see *Report Supplementary Material 3*). As data controller for the prototype MDS, WP 4 involved liaising with data processors to manage pseudonymisation of each data set at source prior to linkage. WP 4 showed that it was possible to work with several data controllers and processors [NHSE, Commissioning Support Units (CSUs), care homes and care home software providers] to access, pseudonymise and link resident-level data.

Establishing data flows was slower and more resource-intensive than anticipated due to IG challenges (see *Challenges and limitations*). These delays and scarce IG resources within ICSs meant that it was not possible to proceed to extraction of GP data before the end of the study. We agreed a list of variables with one ICS[50]

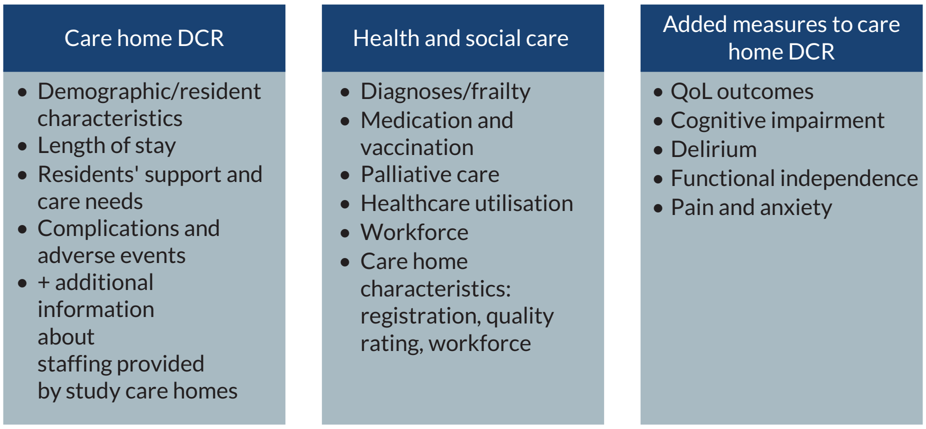

FIGURE 1 Overview of categories of MDS variables and location of resident data. Data sets used: care home-generated DCRs, Secondary Uses Service (SUS) Admitted Patient Care data, SUS Outpatient data, SUS Emergency Care Data Set, Personal Demographics Service (PDS), Community Services Data Set (CSDS), National ambulance data set, Adult Social Care Client-Level Data Set (ASC-CLD), Care home residency table [Arden and GEM Commissioning Support Unit (CSU) estimated care home residency dates], CQC care home data, ONS Index of Multiple Deprivation, Survey data on study care homes.

and set up a process, working with a CSU, by which we could have accessed and linked GP data from another ICS, demonstrating that it is possible (see Appendix IV in Gordon *et al.*[62]).

A planned additional MDS version based only on administrative data, but encompassing all care home residents in three ICSs, was not possible. The MDS included only the smaller sample of consented residents, limiting the insights that could be derived. However, descriptive analyses based on feedback from stakeholders (varied groups within ICSs, NHSE teams and PPIE panel) demonstrated its potential value, with a larger sample.[50]

We reviewed data quality and derived informative variables using established definitions or in consultation with clinicians. For data items available from more than one data source, we constructed a hierarchy to determine which data source would populate the prototype MDS. There is rich information available in routinely collected data, and combining information across data sets, improved data completeness, reducing missingness. However, not all fields were of sufficient quality to be useful, particularly in newer data sets.

As a resource for others looking to link the same data sources, we provide metadata, including a data specification of the final MDS with derivation methods, details of source data, data quality and a summary of main data issues[50,62] (see *Report Supplementary Material 3*). Comparisons between data sources are also available.

Significant time and resource are needed for setting up IG processes, accessing and linking data sources. Competing priorities, particularly for IG staff, meant that some ICSs could not engage in the research. Continued buy-in from senior stakeholders is needed to access data for similar research work.

Work package 5 and the 'think-aloud' study within a project findings and take-home messages

The SWAP that addressed how staff assessed the mental health and well-being of residents using 'think-aloud methods'[63] was incorporated into the qualitative analyses within WP 5.

For data that could not be populated from existing data sets, we worked with the software providers to establish which variables could be extracted from their systems. Several variables were either not collected or were collected in free-text or non-standardised formats. To address this, validated measures were added to each software system. These included measures of delirium (Informant Assessment of Geriatric Delirium Scale[64]); cognitive performance [the MDS Cognitive Performance Scale;[65] functioning (Barthel Index[66]) and QoL; selection of QoL measures was informed by national consultations with stakeholders].[67] Four multi-item staff proxy-report measures were chosen: health-related [EuroQol-5 Dimensions, five-level version (EQ-5D-5L)-Proxy2[68]]; social care-related [Adult Social Care Outcomes Toolkit (ASCOT)-Proxy[69]]; older people's capability well-being [ICEpop (Investigating Choice Experiments for the preferences of older people) CAPability measure for Older people (ICECAP-O[70])] and dementia-specific [Quality of Life for People with Dementia (QUALIDEM[71])]. To give residents an opportunity to rate their own QoL, a single-item QoL measure was also included.[72]

All DCR variables were collected twice, 6 months apart, in 2023.[50] We also conducted a short online survey of care homes at baseline to better understand the context of their care service.[50,72] We recruited 996 residents from 45 care homes in three ICS areas[50] (see *Appendix 3*). The final prototype MDS had linked health and DCR data for 727 residents, of which 696 residents could also be linked to data about their care home.[50] The psychometric properties of the four QoL measures were assessed to explore the feasibility of assessing resident QoL by staff proxy.[72] Less than 15% of residents were able to self-report, but collecting QoL data through staff proxy was feasible, with low levels of missing data. Psychometric evidence supported the construct validity and internal consistency of the ASCOT-Proxy-Resident, ICECAP-O and EQ-5D-5L-Proxy2.[52,72] Using the baseline data from the prototype MDS, multilevel regression models were developed to understand the influence of personal characteristics and resident use of health services (potentially avoidable emergency hospital admissions) on QoL.[51] All three measures were negatively associated with levels of cognitive impairment, while ICECAP-O and EQ-5D-5L-Proxy2 were negatively associated with low levels of functional ability. ASCOT-Proxy-Resident had an association with aspects of quality and care effectiveness at both resident and care home levels.

Nine cognitive interviews were conducted with staff to understand how they completed the ASCOT-Proxy, ICECAP-O and QUALIDEM. These explored their comprehension, retrieval of relevant information, judgement and response. Few issues were identified. Some staff were unsure about the extent to which residents should be involved in completing the measures. Taken together, findings indicate that more guidance around completing the QoL measures, what to consider and whom to include would be beneficial.

Focus groups and interviews with care staff, managers and ICS stakeholders explored the use and implementation of the MDS.[53] Staff recognised the value of QoL data, function and cognition with promising accounts and examples of how a MDS might be used to enhance care. However, implementation requires strategies that sustain trust and confidence among those collecting and interpreting data over time.[53]

The WP developed and demonstrated the value of a MDS based on DCR data linkage (WP 5) to other data sources (WP 4) for English care homes. We demonstrated the value in combining data sources, including data collected in DCRs and, especially, QoL, function and cognition. Future work should focus on enabling data-informed approaches that support day-to-day care well, as service design, commissioning and policy for the care home sector are a priority.

Domiciliary care (DACHA Domiciliary Care) study within a project findings and take-home messages

Home or domiciliary care supports almost 1 million people in the UK. Critical to the independence of the individuals who receive support, it accounts for a major component on public spending on welfare. The introduction of DCRs in England offers an opportunity to ask if a MDS for homecare would be acceptable, feasible and useful.

Contemporary literature was reviewed to explore current concepts and develop a working definition of homecare. A survey of homecare providers asked about information collection and storage, experiences of digitalisation and views on contributing data to a MDS in homecare.

Four focus groups and 12 individual interviews were conducted in 2023. The first focus groups explored the views of 21 homecare providers from four types of organisations (single/multiple operating bases and paper/digital/mixed records). Further focus groups were held with 14 commissioners from 12 local authorities and ICSs and 9 academic experts/potential end-users of aggregate data from a homecare MDS. Twelve homecare clients and eight family members were interviewed. This work was supported by PPIE partners.

Our work defined homecare as a service that enables people with physical, mental and/or cognitive impairments to live in their own homes.[73] It takes the form of direct support (intermittent or 24 hours). This will normally include personal care (e.g. help with washing) and/or other activities essential to living at home. Homecare is generally a paid-for service, subject to some form of regulation and/or inspection.

The survey from all regions of England found that providers collected data on client characteristics and care delivery, but little information was available to monitor client well-being, and few used standard measurement tools (e.g. for functional status or mood).[74] Care packages were reviewed at least every 6 months and updating was more regular for self-funding clients.

Care providers supported the digital agenda and the potential impacts on care quality and efficiency.[75] However, digital transformation in the sector has been overlooked. Commissioners saw many possible uses of a MDS, including tracking care journeys across services (especially with the NHS), enhanced understanding of care needs and outcomes, resource allocation, market intelligence and value for money. Concerns were expressed about staff skills, the significant expansion of data collection activities and resource requirements needed to support the adoption and use of a MDS. The changes required to introduce a MDS into homecare are more extensive than in care homes. It requires an understanding of the homecare context that includes care recipients' and families' priorities.

Implementation in DACHA and take-home messages

Implementation science was integrated into all parts of the project. To structure this, we used the Double Diamond Approach,[76] an iterative method with four stages, that we mapped to the DACHA WPs as follows:

1 *Discover*: explore and identify stakeholders' needs (WPs 1–3).
2 *Define*: define challenges to be met and problems to be solved (WPs 1–3).
3 *Develop*: collectively design and test ways of addressing these challenges and problems (national stakeholder consultations and WPs 4 and 5).
4 *Deliver*: deliver solutions that work and that align with stakeholders' needs and expectations (WPs 4 and 5, including SWAP on policy relevant research in a time of rapid policy change).

Details of these elements within the original project plan are shown in *Figure 2*.

Project meetings and workshops enabled us to capture potential barriers and facilitators across system levels to the implementation of a MDS. This was complemented by the review findings.[35,46] DACHA consultation activities were important in exploring and developing our shared understanding of the needs and priorities of stakeholders and receiving feedback on potential approaches that we might take. The WP 5 piloted the implementation of the MDS, enabling learning and refinement about the approach taken as well as the fit with stakeholders' needs.

Undertaking research in a time of rapid policy change SWAP study

The SWAP captured how the DACHA study team and key stakeholders responded to rapid policy changes at the national and regional levels to integrate health and social care data and deliver standardised measures for adult social care. We aimed to summarise: (1) the experience of completing a study during a time of rapid system changes, and (2) transferable learning for researchers in how to adapt studies to retain integrity and relevance in a rapidly changing practice environment.

We completed online interviews with 19 people who were directly or indirectly involved in implementing a prototype MDS in three ICS regions in England. Analysis of the data was informed by the Updated CFIR[77] to develop understanding of the main determinants/factors influencing the implementation of a MDS to improve resident care. While the DACHA MDS was supported, implementation was affected by fluctuating value/engagement, information technology (IT) infrastructure/skills and IG challenges.

Key influences included:

1. How the benefits of the MDS fitted with care home staffs' aspirations and work when compared to other innovations/current practice.
2. The value of established multidisciplinary partnerships/connections in implementing strategies and solutions, particularly during large-scale critical incidents like the COVID-19 pandemic. These partnerships become even more significant in complex practice and policy contexts, where the need for and interest in a MDS fluctuated.
3. Knowing how the different care home/group settings, including the IT mindset/infrastructure, skills of staff, the quality of relationships and communications within a care home affected MDS engagement and use.
4. Working relationships with input from individuals who are high-level leaders who could support implementation at all levels (national, regional and local care home).
5. An implementation process that planned active engagement with a tailored approach for each setting and team members who were available and responsive.

Stakeholder consultation findings and take-home messages

National consultation 1: February–June 2021

The first consultation considered the information that different stakeholders identified as important in a MDS. Forty stakeholder representatives from England and Wales participated online in seven expertise-based meeting groups (local authority officials; researchers, old age psychiatrists and geriatricians; government officials; data analysts and data researchers; primary healthcare professionals; care home staff; and senior operations

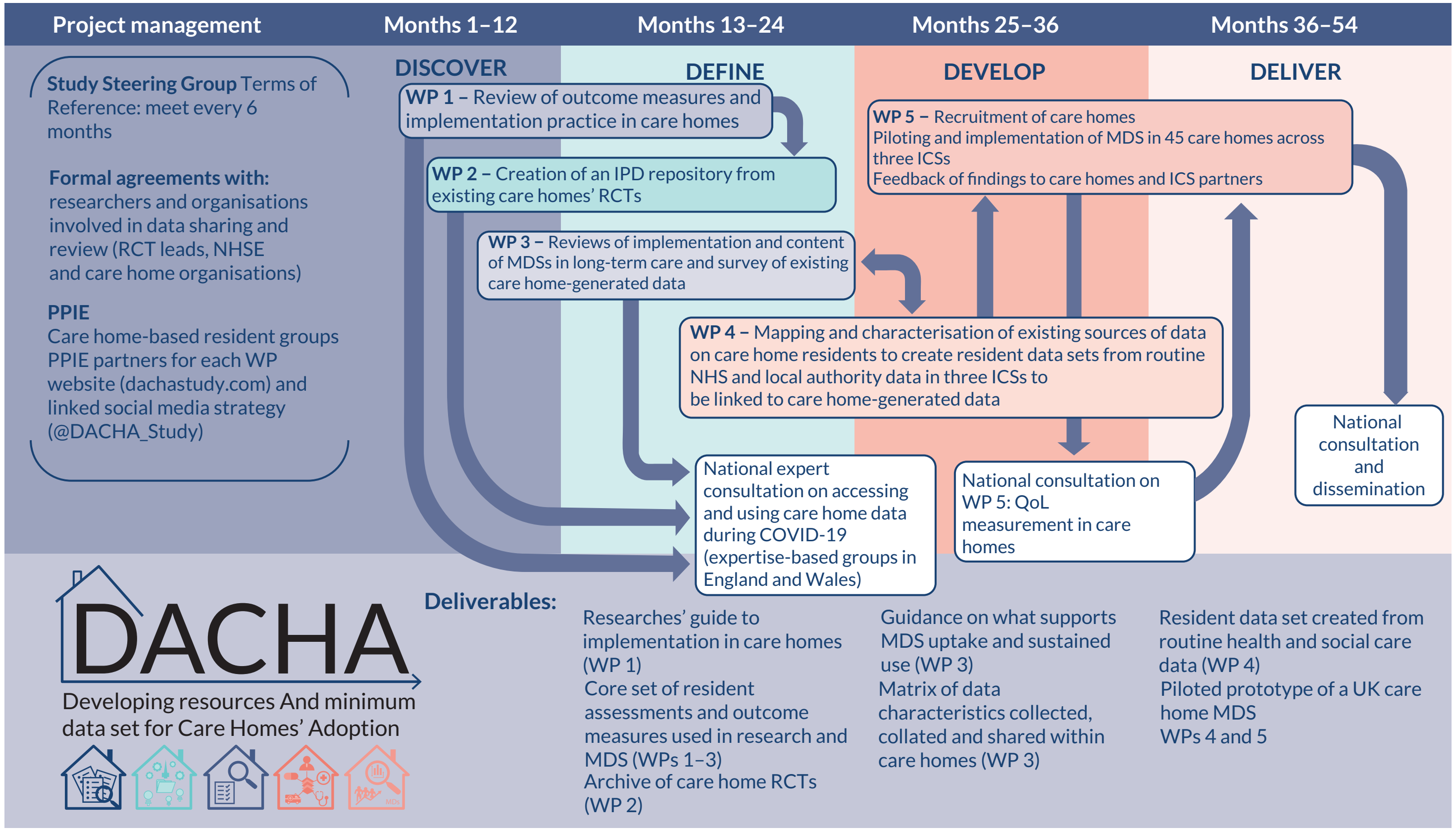

FIGURE 2 The original implementation plan in the DACHA study.

managers/care home managers). Influenced by the COVID-19 pandemic, data about infections, mortality and changes in residents' health were prioritised. A gap identified in resident data was meaningful information about residents' QoL. All stakeholders recognised the growing demand for information from care homes that was standardised. Findings were shared with the stakeholders and with public in a feedback report.[78]

National consultation 2: June–September 2022

The second consultation was a two-stage online survey.[67,79] The aim was to identify which aspects and principles should be considered when measuring QoL outcomes in care homes (Round 1) and use the information to select and consult on QoL outcome measures that could be added to the MDS (Round 2). DACHA collaborated with Thiscovery (an online platform for remote engagement and research)[54] to launch and analyse the surveys. They ranked 12 principles and 9 aspects of QoL. Resident inclusion was rated as the top principle for any measure used, and assessment of mental health was rated as the highest aspect of QoL to include in a care home measure. Based on Round 1 findings and evidence relating to their UK use, we shortlisted five QoL outcome measures that satisfied the highest rated criteria from Round 1. These were: ASCOT-Proxy, ICECAP-O, EQ-5D-5L-Proxy, QUALIDEM and Dementia Quality of Life – Care Home (DEMQOL-CH).

The Round 2 online survey widened the consultation to participants who were interested in how to capture the residence experience of living in a care home. This round received 72 responses with two-thirds of the respondents, indicating that they would use information from these measures in their role if it was available. We asked respondents which dementia QoL measure (QUALIDEM or DEMQOL-CH) they would prefer, and QUALIDEM was selected by 70% more people than DEMQOL-CH. The ASCOT-Proxy, ICECAP-O, EQ-5D-5L-Proxy and QUALIDEM were included in the QoL section of the MDS.

National consultation 3: December 2023–March 2024

This took place in two stages: expertise-based consultation group meetings, including a care home residents' group, and an online public survey. The aim was to find out how useful and relevant the DACHA MDS is for people who (1) work in and with care homes; (2) have direct experience of care in a care home and (3) are a family member/relative of a care home resident.[80] We asked how relevant the MDS was in their role, what parts of the MDS were of the most value for them and what feedback and suggestions they had for a future MDS. Thirty-three stakeholders joined the consultation groups. The importance of staff training, feedback loop mechanisms between care homes and other organisations, digital connectedness and the focus on QoL were emphasised.

The online survey received 62 responses from around the UK. Eighty-eight per cent indicated that either the whole or certain sections of the MDS would be relevant for their role. There was interest in QoL recorded in care homes, and more than 25% indicated that they would use the QoL data monthly if it were available, while 15% said they would use it quarterly. The survey respondents concurred with the views from the consultation meetings, emphasising that clarity around how MDS can help different user groups would be helpful when releasing a future MDS (see *Report Supplementary Material 5* for the summary report).

Key publications from DACHA work packages and studies within a project

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11. Healey J, Davey V, Liddle J, O'Rourke G, Hanratty B, Beresford B. UK homecare providers' views about, and experiences of, digitalisation: a national survey. *Digital Health* 2024;**10**:255477. https://doi.org/10.1177/20552076241255477
12. Rand S, Towers AM, Allan S, Webster L, Palmer S, Carroll R, *et al*. Exploratory factor analysis and Rasch analysis to assess the structural validity of the Adult Social Care Outcomes Toolkit Proxy version (ASCOT-Proxy) completed by care home staff. *Qual Life Res* 2024;**33**:1555–67. https://doi.org/10.1007/s11136-024-03631-1
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Strengths and weaknesses

Strengths

DACHA as a whole

By working closely with residents and their families, staff working in care homes and representatives from health and social care, DACHA addressed policy objectives of integrated care for care home residents. The delivery of online and published research-linked resources and a RCT repository have increased research capacity and reoriented research in this field to the interests and priorities of social care. The delivery of a prototype MDS linking resident data in routine data sets with care home-generated data using a process and approach to content development that align with the principles of the Professional Record Standards Body (PRSB) (see *Report Supplementary Material 4*) demonstrates the potential for data-driven commissioning, planning, delivery and evaluation of resident care.

The multidisciplinary research team, including PPIE representatives, healthcare and social care professionals and third-sector representatives, working with six NIHR ARCs and two organisations (National Care Forum and THF) contributed to the study's robustness and relevance for different groups. The findings offer transferable learning on MDS content, implementation, its relevance for UK settings, the level of engagement required to initiate and sustain systematic approaches to data capture and what supports ongoing cross-sector discussions.

The study also provides a case study of what enables a research study to respond to a rapidly changing policy landscape. It does so by linking with those leading the digitalisation agenda and by identifying what is needed to maintain active communication (see *Report Supplementary Material 2*) with national teams responsible for implementation. This approach helps reduce the risk of duplication or redundancy of its findings.

The relationships built throughout the study between the collaborators have enabled researchers to leverage these connections for related DACHA SWAPs and future projects.

Work package 1: scoping review

The review's scope, structured search of four databases and inclusion of international studies enabled us to collate outcome measurement instruments across a wide range of different interventions and study designs reflecting the breadth of recent research in care homes. We have mapped outcomes to an adapted version of an international framework for long-term care, enabling both

This synopsis should be referenced as follows:
Goodman C, Akdur G, Irvine L, Burton JK, Hanratty B, Killett A, *et al*. Developing research resources and minimum data set for care homes' adoption and use (DACHA). *Health Soc Care Deliv Res* 2026;**14**(3):1–44. https://doi.org/10.3310/PKFR6453

the tool/measure analysis and domain analysis of this body of literature.[45]

Work package 1: systematic review

The theory-based framework synthesis method allowed descriptive content to be indexed in a structured format and also combined inductive thematic analysis to support enhanced interpretation. The Systems Engineering Initiative for Patient Safety model does not aim to attribute causality, only plausible contributions to desirable and undesirable outcomes that may occur over short or longer time frames.[46]

Work package 2: virtual international care home trials' archive

We created an archive of setting-specific trial data for a typically undercharacterised research population. VICHTA capitalises on existing research infrastructure for reuse of fully anonymised data for novel research purposes and reduces data waste. Data were collated at the level of the individual participant; data at this level are often missing from the research landscape. Contributing trialists can participate in future research proposals that make use of their data sets and can inform the interpretation and applicability of findings in relation to their original data sets. The large sample size and diverse conditions covered in each trial enhances the robustness of VICHTA. It provides a resource for questions specific to social care that are amenable to secondary data analysis.[58,59]

Work package 3: realist review, national survey and mapping review of minimum data set indicators

Work package 3 provided a review of the content of MDSs,[48] how they have been used in long-term care[49] and what supports meaningful implementation.[35] WP 3's theory-driven approach went beyond identifying barriers to implementation to signal what is likely to sustain uptake and use. Unlike previous research, it is a strength that the findings enabled us to develop a prototype MDS that was not externally imposed and provided balance to the clinician-led MDS versions. It addressed the different priorities of those who work in and with care homes to understand how different stakeholder groups could use a MDS at meso-, macro- and micro-levels of care, ensuring the information care homes already collect about their residents, or would like added, was included.

Work package 4: data linkage for prototype minimum data set

The study linked many data sources, including community services, social care and healthcare data sets, proving the 'proof-of-concept' MDS. By combining these data sources, we improved the quality of the data and provided useful information without burdening care homes. Most of the data came from national sources under a single data owner, which is helpful for a future 'real' national MDS. For instance, the new Adult Social Care Client-Level Data Set (ASC-CLD) contained social care data from across all local authorities. We navigated complex IG processes with multiple organisations, overcoming risk aversion around data sharing.

Work package 5: optimising the value of care home digital care records

We demonstrated that DCRs used by care home staff can be adapted to include additional measures and linked to populate a MDS, with minimum disruption to staff work and routines. We found that three measures of QoL (ASCOT-Proxy-Resident, ICECAP-O and EQ-5D-5L-Proxy) have acceptable construct validity for use in care homes. We demonstrated the value of the data in the prototype MDS for stakeholders interested in individual residents' care, service provision and commissioning.

Weaknesses

The impact of the pandemic and the organisational changes affected the timelines and our ability to maintain relationships with key organisational partners, especially data controllers. The project took longer than expected to recruit care homes and secure responses to data requests. All the evidence reviews were limited to the English language, focusing on studies from high-income countries to maximise learning for the English setting.

Work package 1: scoping review

We did not undertake formal quality assessment. We only focused on resident outcome measures. Staff and relative experiences were not captured, although the views of residents were included.

Work package 1: systematic review

Broadening the eligibility criteria to include studies discussing contextual factors influencing research implementation processes would have reflected the heterogeneity of study methods.

Work package 2: care home trials' archive

The representativeness of the population to the wider care home residents cannot be easily ascertained. Currently, in the absence of a national MDS, IPD of care home residents do not exist; summary-level data are more common at the level of the care home rather than at the level of the residents. There is under-representation of smaller care homes in our database due to a bias in recruitment from smaller care homes within each trial. There is a dearth of data over the COVID-19 period, as the pandemic impacted upon peoples' abilities to recruit from care homes during this period.

Work package 3: minimum data set indicators' review, national survey of care homes and realist review

Both the realist review and the review of MDS indicators drew on a disproportionate number of North American studies. This gave prominence to studies where completion is influenced by mandates and financial remuneration. The wider narratives and discourses around nationally deployed social care information systems and/or MDSs were not included. We were limited by how much evidence was available that focused on the experience of data completion and use. To capture real-world data, we excluded studies that relied on researcher-facilitated MDS completion.

It was beyond the scope of the survey to demonstrate if all the resident information listed was collected, how frequently, what was prioritised, the perceived usefulness of the different measures or the accuracy of completion.

Work package 4: data linkage for prototype minimum data set

There were no GP data available within the time frames, although it was demonstrated to be possible in one ICS. The MDS was based on a smaller sample of only consented residents, which was not necessarily representative of all care home residents in three ICSs across all administrative data sets. Some data were of too low quality to be useful; for example, in the ambulance data set, the field on reason for callout was empty (see *Report Supplementary Material 3*).

Work package 5: minimum data set care home pilot

Data quality issues for QoL measures in Wave 2 (due to the operationalisation of data re-entry by one of the software providers) meant that longitudinal analysis was not possible.

Challenges and limitations

The rapid digitalisation agenda led to DACHA working with CASPA to future proof the MDS for digital records. This restricted recruitment to care homes using one of two software products, who were based in three ICS regions.

The pandemic and post pandemic policies on data use, changing approaches to data integration/governance and establishment of ICSs affected the timeline of the study. Working within a system with scarce business intelligence and IG resources presented significant challenges in identifying, locally and at the NHSE level, the individuals or entities who could provide authorisation to access data and satisfying internal processes.

Changes to a national data flow resulted in the algorithm used to identify care home residents in national NHS data[81] requiring redevelopment and validation by NHSE. This update was not available in time for the DACHA study, impeding the team's ability to create a separate MDS based only on administrative sources for all care home residents in the participating ICSs. Besides not being able to compare recruited residents to the wider care home population, this meant that planned analyses to demonstrate wider utility of the MDS, around deprivation and frailty measures, could not be undertaken.

Progressing data flows and IG required an agreed data specification, which needed input from local teams to determine available variables. However, these teams struggled to allocate resources without this agreement in place, creating a circular issue.

As a data processor on behalf of NHSE, THF's Improvement Analytics Unit can access data for agreed projects through their data processing agreement (DPA) with NHSE, updated yearly. Although DACHA was explicitly listed in this DPA in 2022–3 and 2023–4, in February 2023, NHSE raised concerns about access to NHSE data for DACHA under the DPA. It took several months to receive clarification from a senior IG lead. In July 2023, it was established that data controlled by NHSE could not be linked with DCRs under the DPA. Consequently, it was agreed that THF would be the data controller, and a new DSA with NHSE was required. The NHSE Data Protection Impact Assessment (DPIA) for this agreement had to be reviewed by the Caldicott Guardian, and following feedback, clarification notes were sent to participating care homes, restating how linked health data would be shared by NHSE. Each of these steps took considerable time. The NHSE DPIA was finalised in October 2023. Only then, the data flows could be updated and shared with other organisations such as ICSs, and discussions could begin with the data processor, Arden & GEM CSU, to prepare for data extracts. The DSA was signed in January 2024, allowing data held by NHSE to be shared with THF. The length of time required to set up the data flow after the July 2023 meeting reflected internal upheavals and competing priorities in NHSE, and the fact this was research based on consent, which NHSE does not usually support. These delays and scarce IG resources within ICS meant that it was not possible to proceed to the extraction of GP data before the end of the study.

From the outset, we had established that GP data were accessible to ICSs, and the disappointing responses and delays demonstrated the lack of clarity around access for research in the study sites. This lack of certainty triggered risk-averse organisational responses and a situation where authorising access became an extended bureaucratic exercise of additional checks and approvals.

What could have been done differently?

Inclusion of care homes in discussions with software providers

We worked with two software providers to include the additional variables to the MDS and work with study care homes to upload consented residents' data for data linkage (see also *Impact and learning*). Involving care home staff in this process would have addressed, at the development stage, how questions were displayed and completed on screens, thereby optimising data completion.

Data linkage

Despite senior stakeholder buy-in in the three ICS areas, there was a lengthy period between initial contact and approaching the sites for data requests (20 months). During that time, senior stakeholders had moved on, and there was no institutional memory of the DACHA study and the previous commitment. If the original bid had included a senior stakeholder as a co-applicant and ring-fenced funding for someone in the ICS to work with the study, this could have mitigated some of the difficulties encountered. However, at the time of the application, the ICSs were only coming into being. At a minimum, we recommend a letter of agreement with the organisation, outlining anticipated roles and responsibilities.

Patient and public involvement and engagement

Patient and public involvement and engagement enhanced the study process and usefulness of findings. Stakeholders included care home staff, care home managers, residents and the family and friends of residents. All study outputs were written in collaboration with PPIE members to produce accessible/lay summaries.

A dedicated five-member PPIE team (consisting of both academic and non-academic members) implemented PPIE activities and supported the engagement between stakeholders and DACHA study WPs. PPIE was embedded throughout the study in the form of:

- co-applicants (including a care provider representative and individuals with experience of providing both paid and informal/unpaid care for older people)
- a 12-member, quarterly, online PPIE panel of care home managers, care home staff and relatives of care home residents, with members feeding into the project on a range of topics and key research processes[82]
- national and regional stakeholder consultation events
- ongoing consultation with care home residents via collaboration with the National Activity Providers Association (NAPA)
- use of a website, which includes plain language summaries of all DACHA study publications,[82] and social media
- a SSC, including two PPIE members who met every 6 months.

The collaboration with NAPA was a change to planned PPIE activities; initially, the team planned to sustain care home resident groups (two groups, each in a different care home). This was impossible because of COVID-19 visiting restrictions. Instead, activity providers were recruited via NAPA to facilitate activity and discussion sessions with residents (see the associated publication[83] whose messages were subsequently fed back to the research team[84]). This proved to be an innovative model that was appreciated by all involved, which is being evaluated in an ongoing funded study, Care Home Activity Providers facilitating Public Involvement in research as meaningful activity for care home residents (CHAPPI).[85]

Clear guidance on how to embed PPIE in care home research was grounded in the PPIE process and related evidence reviews on what supports research engagement.

Equality, diversity and inclusion

Care home research historically is biased to health-dominated narratives, framing questions in terms of health need and use of NHS resources. The starting point and design of this study was to enable participation and active inclusion of those who lived, visited and worked in and with care homes. This inclusive approach is reflected in the study design, team expertise, PPIE engagement, study advisory committee membership, partnership with representative bodies and iterative consultation with stakeholder groups and policy leads. Early in the study and subsequently at a national event, we established the principles and recommendations for a MDS.[44,86] These articulated the importance of focusing on what matters to those living in care homes to ensure that study outputs and resources were accessible and addressed the priorities of people living in care homes

The study enabled residents' inclusion (see also *Patient and public involvement and engagement*) by facilitating participation from their home and by engaging with front-line care home staff. Both groups, historically, have few opportunities to inform research.

The study methods (evidence reviews, surveys, consultation primary data collection and secondary data analysis) sought to capture and reflect the diversity of care home residents, and where possible, including those living in smaller care homes and those who lack capacity. For example, the diversity of the participants from multiple trials in terms of medical history, comorbidities and baseline frailty increases the likelihood that the pooled results can be applied to a broader range of residents in non-research-active homes. Also, the DACHA study's incorporation of QoL measures and review of proxy methods of assessment have enabled reliable capture of data, which are inclusive of those people cognitively unable to respond for themselves.

The realist review identified questions from the international MDS literature about under-reporting of key symptoms in Black and Hispanic older people – something that is yet to be considered in UK research on how different ethnic backgrounds can affect what is documented.[35]

The study has addressed the digital divide that can exclude those with limited expertise or access to IT infrastructure by working with care home representatives' organisations to share findings that can help address these known inequities. The findings also address ongoing questions about ownership and access to data and inherent power imbalances in health and social care. Representation from social care relied on the active involvement of the National Care Forum and liaising with the Care Provider Alliance, and future work could extend involvement to strengthen the sector's voice and influence in the research and its dissemination.

Data collection for WPs 4 and 5 purposively took place in three regions that were geographically disparate, serving populations living with different types and levels of social deprivation, ethnic mix and social exclusion. Recruitment materials were, however, in English, and the tools staff were using to evaluate residents were not translated. Although we know the area-based deprivation of the care home and ethnicity of residents, we were unable to comment about the involvement or priorities of different minority groups living and working in care homes, and we do not have any data about the residents in participating homes who did not take part (i.e. to explore systematic bias within the recruited sample). Many older people who identify as lesbian, gay, bisexual, transgender, queer/questioning and more (LGBTQ+) face significant barriers and inequalities when engaging with social care services,[87] but, because data about gender identity and sexuality are not recorded (and those conversations not supported), we were unable to explore the differences in needs and outcomes in this population.

The research team were multidisciplinary from multiple organisations. The development of the team via the NIHR ARC network maximised opportunities to influence and join the study. Early career researchers were supported to lead on the analysis and reporting of key areas of the study.[88]

Impact and learning

What difference has been made already?

From the outset, the objective was to generate research that is mutually beneficial – facilitating evidence-informed decision-making while also supporting the collective identity transformation required to advance care home research and to develop and implement a MDS that is part of routine practice. Within one study, it was possible to complete stand-alone outputs (four evidence reviews, trials archive, survey of care homes' use of data, consultations on the data different stakeholders prioritise and use, new methods to involve care home residents in research, a prototype MDS that linked care home data with additional measures with residents' data held in routine data sets, an overview of how data are organised for people receiving care at home and what enables research in a time of rapid policy change) that, together, have increased learning about research and working with and for care homes.

The DACHA study developed a model of cross-sector working that enabled it to be responsive at each stage of the study to external policy changes and attentive to different stakeholder views. This has led to sector-wide engagement with resources to support research in care homes [e.g. Enabling Research in Care Homes (ENRICH)] and adoption of methods of working in subsequent studies, briefings to national bodies (e.g. NHSE and ONS) and proposed inclusion of the MDS variables in the upcoming NHSE social care data directory. The option to use the additional standardised measures on QoL has been requested by some study care homes and was retained in the adapted software by the partner providers. Findings from the DACHA study have been used in NIHR plenary presentations (School for Social Care Research), vignette and case studies as an example of innovation and building capacity in social care research.

Longer-term impact

The recognition that research in and with care homes had to address the heterogeneity of the sector, and the burden it placed on an overstretched workforce, informed its design, delivery and outputs for different audiences. *Appendix 4* summarises the key points of learning from each WP output.

The impact of the DACHA study has been its influence on how social care priorities are discussed and how research with the sector is negotiated and engagement is achieved with care home residents and front-line staff. It has helped to change the conversation about social care research by demonstrating what supports effective research in and with care homes, what fosters effective use of residents' data for care, commissioning and evaluation and what is needed for the implementation of a MDS to be useful and usable by different stakeholder groups. Conducted during a period of rapid change, the DACHA study capitalised on an interest in how health and social care questions converge to address the needs and experiences of older adults, both in care homes and increasingly in their own homes. The study held in tension the need to select and standardise variables for a prototype MDS, with creating a person-centred database recognisable to multiple stakeholders invested in the care of older people. It systematically brought social care values and priorities to the debate about whose data, and how information, are organised, presented and interpreted. This included demonstrating the range of data already available in care homes and, as staff absorb more healthcare work, the need for health data to reflect the context of care.

Work package 1 provides a care home-centric evaluation of what supports effective research and its implementation. It highlights the need for bespoke study designs that can learn from, but not replicate healthcare studies, and what needs to be in place for the active engagement of care home staff. This is not to downplay the importance of studies addressing health-related questions. Rather, it emphasises the need for designs and measures that capture changes over extended periods, highlighting key outcomes that are often overlooked in acute settings. The outputs from these evidence reviews are a resource for researchers and care home staff and are a marker as to how studies are designed and executed in these settings. Similarly, the WP 2 trials archive demonstrates the value and potential of a setting-specific focus, providing an important resource for secondary data analysis addressing questions important to the sector. The size and detail of the archive enable studies to address the heterogeneity of the population and consider within-group differences as well as comparative work.

The impact of the MDS development work in WPs 3–5 was threefold. It provided a critique of MDS use that favoured a care home perspective about content, how data are used, accessed and crucially used by external organisations. This provided a focal point and live resource for sector representatives in gauging how the digitalisation agenda could and should be implemented. Additional resources for service planning, evaluation and future research are the anonymised version of the DCRs part of the MDS and learning from the data linkage work. The data linkage work demonstrated what was possible and also signalled how the absence of a national approach to IG that cuts across ICSs can unintentionally, at best, delay and, at worse, sabotage research. Thirdly, the work on measuring QoL and how staff interpret its significance begins to address how to support data literacy for the benefit of residents' care.

Establishing a baseline of MDS content from international evidence, a theory of how a MDS could be implemented in England and the information routinely available from care homes help to reduce the risk of creating parallel systems of data capture in health and social care. Their inclusion was tested against the principles of the DACHA MDS,[44] debated with social care representative bodies and tested in the iterative national consultations about content and purpose. The process shared with the NHSE and DHSC teams responsible for improving social care data resulting in the DACHA study being referenced in the draft version of the roadmap for better data for adult social care.[14] It was also reviewed by the PRSB for its rigour, transparency and adherence to recognised steps in record development (see *Report Supplementary Material 4*).

The process of collaborating with CASPA and selecting two software providers to upload residents' data for linkage with routine data sets was innovative and has been adopted by subsequent NIHR-funded studies. It provided valuable insights for the team and software engineers regarding the presentation of categories, the identification and organisation of variables and how these factors affect data quality and consistency of data entry. This key learning addresses the engineering aspects of a MDS. Care homes found completing the additional measures acceptable, and software providers were able to process that data and extract it on their behalf for the purposes of populating a MDS. As care homes rapidly digitalise their systems, understanding how staff engage with data capture needs to guide both presentation of categories and decisions about the frequency of completion. Qualitative data on the experience of collecting and uploading residents' data using the care home MDS demonstrated that, once familiar with the processes, staff could incorporate these tasks into the routine of the care home.

The study provided a range of metadata, including details of all variables included in the MDS, how they were derived and from which source data (see *Report Supplementary Material 3*). The linkage of many data sources, including community care, social care and health care, provided proof of concept, generating rich individual-level data, without placing all the burden for data collection on care homes. We did not access all anticipated data sources but demonstrated that it was possible to include GP data, with a list of the variables that could be accessed as part of a future MDS.[50]

There was a gap between the recognised value and purpose of the data linkage work and organisations having the resources and governance infrastructure to facilitate this. This finding, though not novel, resonates with other studies that consistently describe the disproportionate and unanticipated length of time required to access and link data and the absence of nationally agreed-upon processes and governance requirements.[89,90] Together, these issues have significant, but not insurmountable, implications for data quality and the understanding of health inequalities.[89,91–93] Within ICSs, there is evidence of combined administrative data sets, for example, Greater Manchester and Salford,[94] and Barking and Dagenham.[95] However, so far, these do not include care home data.

The introduction of validated QoL outcome measures represented a major contribution to how resident QoL data can be systematically collected and used to review care. There were promising examples of how this data collection informed care, particularly in discussions around residents' priorities and interests. However, persistent narratives and concerns remain about quantifying residents' experiences of care, ownership of care home data and how these data are interpreted and utilised to inform decisions about care quality. The interviews with ICS representatives reiterated the need to structure and facilitate opportunities for discussions to build trust and favour shared problem-solving.[96] It would be naive to assume that this will happen spontaneously or solely because of data availability. This process requires investment in training to foster understanding the value and importance of capturing these data and incentivising data-driven discussions at the resident, service, regional and national levels.

Related work, collaborations, further funding and future work

The research methods developed for PPIE and creating a care home trial archive have informed separately funded studies and one fellowship award:

- The NIHR Research for Social Care-funded CHAPPI study has extended the partnership with activity providers to evaluate how care home residents can be active partners in research.
- The NIHR Economic Methods of Evaluation in Health and Care Interventions Unit has funded the PREACH study to identify social care research questions suitable for secondary data analysis using VICHTA. Further analytic work is planned for the archive to compare the use of EuroQol-5 Dimensions in different care settings. See *Report Supplementary Material 6* for the PREACH protocol.
- The NIHR Vivaldi pilot study, as part of its extensive engagement work partnered with researchers from the DACHA study, to develop Vivaldi Social Care 'activity packs', which are delivered by activity providers in participating care homes.
- The care home manager involved in the PPIE panel received NIHR ARC funding to be supported to develop her own research questions around the support care home managers need in their work.
- The care home-focused work of DACHA directly informed the DACHA-DOM SWAP on homecare provision. The findings from this exploratory work underscore the imperative for further efforts to ensure that the organisation and content of adult social care data for older people are aligned consistently across all settings. There is a stark contrast between the minimal information that can be captured from domiciliary care compared to care homes, highlighting the absence of standardised outcome measures. This research is being taken forward in collaboration with the NIHR Older People and Frailty Policy Research Unit and NHSE.

At a national level, the DACHA study continues to meet regularly with representatives from DHSC and NHSE to share the variables from the MDS for proposed future inclusion as part of the forthcoming Adult Social Care terminology data catalogue. We have also briefed policy think tanks (Nuffield Trust) on implications of DACHA findings for long-term care priority setting and worked with the NIHR Health Technology Assessment Social Care Prioritisation Committee.

Internationally, the British Geriatrics Society *Smarter Data, Better Care* event[86] convened senior stakeholders from health and social care across the devolved nations.

This synopsis should be referenced as follows:
Goodman C, Akdur G, Irvine L, Burton JK, Hanratty B, Killett A, *et al*. Developing research resources and minimum data set for care homes' adoption and use (DACHA). *Health Soc Care Deliv Res* 2026;**14**(3):1–44. https://doi.org/10.3310/PKFR6453

The event shared insights from the DACHA study, along with contributions from Canadian team working with the international MDS, interRAI and findings from other studies utilising social care data. It created the opportunity to review the accumulated experience of research and data teams and to reflect on the 'state of the art' in MDSs. The subsequent policy report offered 12 recommendations for effective implementation and delivery of a MDS.[86] Besides symposia at international conferences, DACHA findings will feed into work of the Long-Term Care Policy Interest Group of the Global Observatory of Long-Term Care on generating and using comparative data on long-term care.

Implications for decision-makers

The DACHA study provides valuable learning for decision-makers involved in commissioning and designing research with and for care homes, allocating resources for data integration and using social care data with healthcare data for commissioning, planning, providing and reviewing residents' care. It has articulated the tensions which exist around using different research paradigms in care home research, what needs to be in place for data sharing for routine data, including consent and IG, and ongoing challenges about enabling access from all data controllers.

Commissioning and designing research in care homes

The DACHA study investigated ways to enhance the adoption and application of research in care homes, aiming to reduce redundancy and inefficiency. The findings suggest that decision-makers responsible for funding and designing care home research should expect and ideally require care home staff in research development in formulating research questions and the design of the research. This will require funding for the time care home staff spend on the research development and their ongoing involvement in its implementation.

The scoping review clearly demonstrated the importance of selecting relevant outcome measures.[45] To inform decision-making, funders could include in their commissioning calls a requirement that proposals should demonstrate how their chosen outcome measures are meaningful for the care home population and the care setting.

Commissioners of research could capitalise on the findings from the trial archive in two ways: firstly, to consider if research questions and linked commissioning calls could be addressed by secondary data analysis, and secondly, make it a requirement that trial data are included in the VICHTA.

Management and organisation of integrated data at national and regional levels and addressing bias

The DACHA study findings along with other studies have highlighted the opaque data access processes to achieve data linkage between health and social care and, particularly, with primary care.[50] As digitalisation of systems and data integration become established, this is an optimal time for those responsible for the organisation and management of data to engage and invest in infrastructure development that cocreates how data are organised, shared and fed back to the different groups. This is needed to address the bias to health data and NHS control.

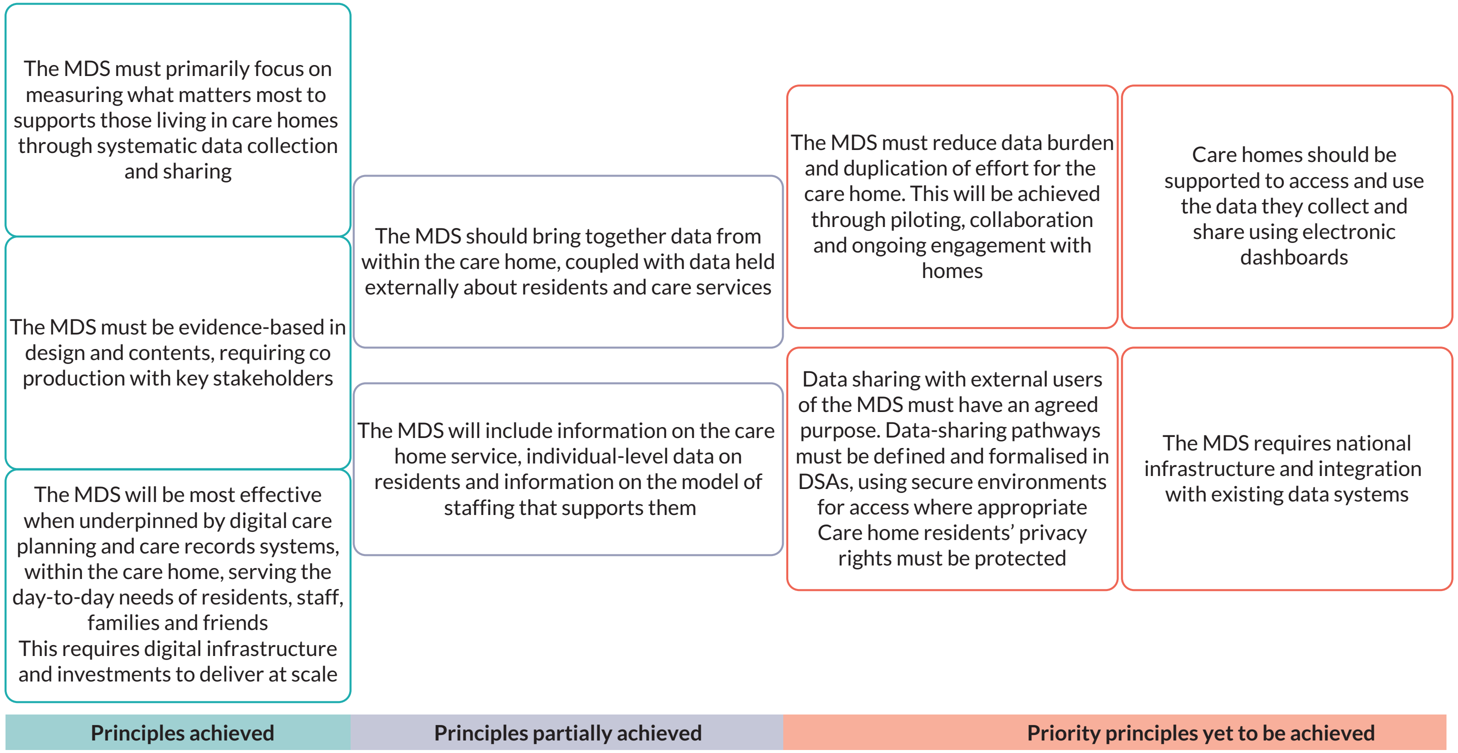
Using social care data with healthcare data for commissioning, planning, providing and reviewing residents' care

The study demonstrated the range of data that already exists about social care and how that can be harnessed via existing methods of data capture. As DCRs are introduced, decision-makers working with software providers can exploit this resource as the basis for delivering a standardised and meaningful picture of the care home population. Decision-makers should resist demanding additional data without evidence that the information is not already in the system.

It was a finding from the national consultation that palliative care measures should be included, although we were unable to demonstrate whether GP data could address that need. The additional care-related QoL outcome measures that DACHA included in the prototype MDS tackle the widespread recognition that there is a need for standardised measures for QoL. To implement this, decision-makers should invest in a process of collaborative working across the different contexts of health and social care.

The review and the implementation of the prototype MDS demonstrate the value of assessing staff readiness, enhancing data literacy and implementing a standardised MDS to improve care within and across care homes.

During the DACHA study period, there has been recognition by decision-makers across the UK of the necessity for improved national data about people living in care homes and the services which support them. This changed context is welcomed. However, we would advocate that the principles outlined in our early work should inform data innovation and MDS development going forwards. *Figure 3* shows which core MDS priority principles[44] are achieved, partially achieved and are yet to be achieved, in the social care context. Our prototype was able to focus on measuring what matters to support people



Principles achieved

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

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

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 investments to deliver at scale

Principles partially achieved

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

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

Priority principles yet to be achieved

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

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

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

The MDS requires national infrastructure and integration with existing data systems

FIGURE 3 Minimum data set of principles achieved, partially achieved and yet to be achieved. Reproduced with permission from Burton *et al.*[44] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The figure includes minor additions and formatting changes to the original text.

living in care homes. It was developed using an evidence-based approach, coproduced with key stakeholders.

The sector, accelerated by large-scale DHSC investment, is switching to digital solutions, making the routine capture of data achievable, with 70% of social care providers now using digital care planning software (as of July 2024). Further work is needed to link care home data with data held externally, and we would advocate a more inclusive culture of data sharing across organisations to serve the day-to-day needs of people living in care homes and the professionals who support them (e.g. hospital discharge/outpatient correspondence and GP summary records). Understanding the staffing model is critical, but this remains an area of development as the national workforce data collection is not comprehensive.

Beyond the scope of our pilot, but a priority, is to reduce data burden and duplication. This requires alignment of local and national bodies and a commitment to request only data which are necessary, drawing from shared sources. Care homes require support to access and use the data they are sharing, including the development of dashboards adjusted to the variation within the population and service provision.

Furthermore, the governance around national data collection needs to be made explicit, with care homes and resident rights respected. Care home organisations must be equal partners in determining who has access to what data under what circumstances and with what levels of identification. This contrasts with experiences during the pandemic where identifiable data were published lacking sensitivity and context. Finally, for a MDS to achieve potential, there is a need for national integration and infrastructure. This must be inclusive of care homes themselves to ensure that resident needs and support remain the focus.[97]

Research recommendations

The DACHA study demonstrated the feasibility of developing a prototype MDS that would be usable and useful to different stakeholder groups. Future research on MDS content should explore the added value of incorporating primary care data and client-level data on commissioning, service provision and care planning. Research is also needed on how feedback to staff on residents' needs affects care within the care home and discussions with visiting clinicians on resident outcomes, including QoL.

A recent review of the factors influencing effective data-sharing between health care and social care for older people identified the misleading view that motivation alone is sufficient.[98] Future research should address what supports social care staffs' digital literacy, how to build relationships that foster trust and confidence when using MDS and standardised measures as routine data.

Our review of outcome measures from international older adult care home intervention research[45] showed heterogeneity and inconsistency in outcome assessment approaches. DACHA demonstrated the validity of using standardised QoL outcome measures by reviewing evidence on psychometrics and gaining consensus among stakeholders. Future research should build a consensus with the sector on validated measures (beyond QoL) in care homes, such as core outcome sets developed by the Core Outcome Measures in Effectiveness Trials Initiative,[99] to reduce research waste and build consensus across health and social care.

We propose that investigators and trialists of future UK care home trials should be encouraged by funders to make their trial data available through VICHTA. Additionally, the data available in the VICHTA archive could inform future research by enabling adjustments in methodologies, as some care home research questions could be addressed using the existing data in the archive.

The dearth of research on how information about the characteristics, needs and care received by people living at home is documented, used and linked to other data sets needs to be addressed.

More detail of WP-specific research recommendations from the published outputs are provided elsewhere (see *Appendix 2*).

Conclusions

The DACHA study highlighted the role of data as an asset and a tool for building relationships across healthcare and social care sectors. The study uncovered, and the development of the prototype MDS addressed, the well-known issues about the different perspectives and languages of health and social care and the difficulties of introducing new ways of using data when there are constant organisational turbulence and changes.[100] To be able to address important questions, there is enough descriptive research on the challenges of keeping data simultaneously safe, robust and accessible. Our study, unfortunately, added to that body of knowledge, but it has provided suggestions for much needed change.

The study findings demonstrate what is possible while acknowledging the need for investment in capacity building to enable staff from different organisations and within care homes to learn together. Without this, there is a risk of data capture becoming yet another administrative task or historical account of work completed. For data to inform care requires it being part of a shared language that fosters understanding across all involved stakeholders.

In returning to the nine principles[44] that guided how the study used evidence and developed the MDS, we reiterate the importance of research methods, application of evidence and use of data that reflects what matters most to older people and the staff who support them. The study has demonstrated that it is possible to work with care homes to use a MDS in ways that fit with their goals and the potential for digital care planning and data linkage. Further work is needed to formalise data-sharing pathways and ensure that care homes have equal access to data and shared dashboards that could be the basis for cross-sector working. Finally, DACHA-DOM exposed the need to apply the principles enacted for care homes to homecare services and the challenge (and the opportunity) to apply the DACHA findings to build a MDS that reflects the experiences of care in different settings.

Additional information

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Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

Work package 2 care home trial archive received ethical approval from Health, Science, Engineering and Technology ECDA – University of Hertfordshire (HSK/SF/UH/04185) on 18 June 2020.

Work package 3 realist review received ethical approval from Health, Science, Engineering and Technology ECDA – University of Hertfordshire (HSK/SF/UH/04169) on 22 May 2020.

Work package 3 national care home survey received ethical approval from Health, Science, Engineering and Technology ECDA – University of Hertfordshire (HSK/SF/UH/04301) on 23 June 2021.

Work packages 4 and 5 pilot study in care homes has received ethical approval from the London Queen's Square Research Ethics Committee (22/LO/0250) on 7 June 2022.

National consultation 2022 received ethical approval from Health, Science, Engineering and Technology ECDA – University of Hertfordshire (HSK/SF/UH/05009) on 30 May 2022.

National consultation 2023–4 received ethical approval from Health, Science, Engineering and Technology ECDA – University of Hertfordshire (HSK/SF/UH/05487) on 8 November 2023.

Patient and public involvement and engagement in care homes via activity providers was approved by the Faculty of Medicine and Health Sciences Research Ethics Subcommittee, University of East Anglia (ETH2122-1602) on 15 June 2022.

Implementation SWAP received ethical approval from the University of Exeter Medical School (4878694) on 4 January 2024.

DACHA-DOM SWAP received ethical approval from Research Policy Intelligence and Ethics Team (23491/2022) on 9 June 2022.

Think-aloud SWAP received ethical approval from the University of Kent (0883) on 30 May 2023.

Information governance statement

The University of Hertfordshire as sponsor of the DACHA study is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, University of Hertfordshire is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here: www.herts.ac.uk/about-us/legal/freedom-of-information-data-protection/data-protection.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/PKFR6453.

Primary conflicts of interest: Claire Goodman received funding from National Institute of Health and Care Research as a Senior Investigator between 2017 and 2024. She is a member of the NIHR Funding Committee for the NIHR Senior Investigator's award and a member of Alzheimer's Society Research Strategy Committee. NIHR Social Care Research Advisory Group Panel member NIHR HS&DR.

Claire Goodman (East of England), Barbara Hanratty (Northeast and Cumbria), Ann-Marie Towers and Stacey Rand (Kent, Surrey and Sussex), Adam L Gordon (East Midlands), Karen Spilsbury (York and Humber), Jo Day and Iain Lang (PenARC) received support from NIHR ARC who also supported the DACHA study.

Jennifer Kirsty Burton is a member of the NIHR Health and Social Care Delivery Research Funding Committee (Trainee January 2022–May 2023; Panel member January 2022–current). Her clinical academic training is funded by an NHS Education for Scotland/Chief Scientists Office Postdoctoral Clinical Lectureship (PCL/21/01).

Anne Killett is a Social Care Committee member of the NIHR Research for Social Care and Research Programme.

Ann-Marie Towers is associated with the NIHR Research Programme for Social Care as funding panel member; with NIHR School for Social Care as funding panel member; and as panel member for NIHR Three School's Dementia Awards. She was lead for the ASCOT programme (till July 2024) and remains a member of the ASCOT team.

Stacey Rand is associated with the NIHR Research Programme for Social Care as funding panel member; with NIHR School for Social Care as funding panel member; and as panel member for NIHR Three School's Dementia Award. She is currently lead of the ASCOT programme (from July 2024) and has been a member of the ASCOT team since 2014.

Karen Spilsbury and Adam Gordon are both NIHR Senior Investigators in receipt of funding.

Department of Health and Social Care disclaimer

This publication presents independent research commissioned by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, MRC, NIHR Coordinating Centre, the Health and Social Care Delivery Research programme or the Department of Health and Social Care.

This synopsis was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

Publications

These publications have been completed during the study period and are given in addition to the key publications given in *Key publications from DACHA work packages and studies within a project*.

Burton JK, Goodman C, Guthrie B, Gordon AL, Hanratty B, Quinn TJ. Closing the UK care home data gap – methodological challenges and solutions. *Int J Popul Data Sci* 2020;**5**:3. https://doi.org/10.23889/ijpds.v5i4.1391

Hanratty B, Burton JK, Goodman C, Gordon AL, Spilsbury K. COVID-19 and lack of linked data sets for care homes. *BMJ* 2020;**369**:m2463. https://doi.org/10.1136/bmj.m2463

Musa MK, Akdur G, Hanratty B, Kelly S, Gordon AL, Peryer G, *et al.* The uptake and use of a minimum data set (MDS) for older people living and dying in care homes in England – a realist review protocol. *BMJ Open* 2020;**10**:e040397. https://doi.org/10.1136/bmjopen-2020-040397

Irvine L, Burton JK, Ali M, Quinn TJ, Goodman C. Protocol for the development of a repository of individual participant data from randomised controlled trials conducted in adult care homes [the Virtual International Care Homes Trials Archive (VICHTA)]. *Trials* 2021;**22**:157. https://doi.org/10.1186/s13063-021-05103-0

Towers AM, Gordon A, Wolters A, Allen S, Rand S, Webster L, *et al.* Piloting of a minimum data set for older people living in care homes in England: protocol for a longitudinal, mixed-methods study. *BMJ Open* 2023;**13**:e071686. https://doi.org/10.1136/bmjopen-2023-071686

Allan S, Rand S, Towers AM, De Corte K, Tracey F, Crellin E, *et al.* Construct validity of measures of care home resident quality of life: cross-sectional analysis using data from a pilot minimum data set in England. *Health Qual Life Outcomes* 2025;**23**:33. https://doi.org/10.1186/s12955-025-02356-0

Musa M, Akdur G, Goodman C, Fortescue S, Jones L, Lang I, *et al*. Work Package 3 PROSPERO registration. The uptake and use of the minimum data set (MDS) for older people living and dying in care homes in care home settings: a realist review. PROSPERO 2024. www.crd.york.ac.uk/PROSPERO/view/CRD42020171323

Work Package 1 PROSPERO registration. A systematic review of process and contextual factors that influence research implementation in care homes and identification of key measures and outcomes in care home research. 10 January 2020.

Conferences and events joined

The presentations can be accessed via the links provided.

International Long Term Care Policy Network Conference. Bilbao 2024. Seminar and Panel discussion comparing use of long term care data in different countries. www.ilpnetwork.org/2024-conference/

HSR UK Conference 2024. Hosted by University of Oxford. 8–10 July 2024. Value of DACHA MDS and Health social care data linkage. https://dachastudy.com/wp-content/uploads/2024/08/A-proof-of-concept-minimum-data-set-for-older-care-home-residents-what-value-does-this-add-HSR-2024.pdf and https://dachastudy.com/wp-content/uploads/2024/08/A-game-of-snakes-and-ladders-the-world-of-complex-health-and-social-care-data-linkage-HSR-2024.pdf

British Society of Gerontology Annual Conference 2024. Hosted by Newcastle University. 3–5 July 2024. DACHA quality of life and Ownership of care records. https://dachastudy.com/wp-content/uploads/2024/08/DACHA-Quality-of-Life.pdf and https://dachastudy.com/wp-content/uploads/2024/08/Expectations-and-sense-of-ownership-of-care-records.pdf

Five Nations Care Forum Communiqué. 29 April 2024. DACHA overview and DACHA-DOM overview. https://dachastudy.com/wp-content/uploads/2024/05/DACHA-Five-nations-.pdf and https://dachastudy.com/wp-content/uploads/2024/05/DACHA-DOM-5-nations-.pdf

Nineteenth European Geriatric Medicine Society Congress, Helsinki – Finland. 20–22 September 2023. DACHA overview. https://dachastudy.com/wp-content/uploads/2023/10/EuGMS-DACHA-16.09.23-RC.pdf

British Geriatrics Society (BGS) – Care Home Data Sets event. 12 September 2023. bgs.org.uk/events/care-homes-data-sets

Global Ageing Conference 2023. 7 September 2023. DACHA PPIE work was presented: DACHA PPIE. https://dachastudy.com/wp-content/uploads/2023/09/GAN-Conference-07092023.pdf

British Society of Gerontology Conference 2023. DACHA symposium (chaired by Claire Goodman): Developing a minimum data set for older adult care homes in the UK: keeping important perspectives at the heart of work. 6 July 2023. The DACHA presentations can be accessed here: pilot study of minimum data set; PPIE work with Activity Providers; Consultation on Quality of Life; CHAPPI overview. https://dachastudy.com/wp-content/uploads/2023/07/DACHA-Work-Package-5-BSG-Slides.pdf; https://dachastudy.com/wp-content/uploads/2023/07/DACHA-NAPA-Symposium-June-2023-KM.pdf; https://dachastudy.com/wp-content/uploads/2023/07/BSG-Conference-2023_stage-4960_question-Presentation-Upload_id-295.pdf; https://dachastudy.com/wp-content/uploads/2023/07/CHAPPI-presentation-BSG-2023.pdf

Margaret Butterworth Care Home Forum June 2023. 14 June 2023. DACHA Work Package 2 work was presented: DACHA VICHTA June 2023. https://dachastudy.com/wp-content/uploads/2023/06/VICHTA_MargaretButterworth_June2023.pdf

Rapid evaluation in health care conference 2023. 16 May 2023. Bringing care homes into a broader data landscape. https://dachastudy.com/wp-content/uploads/2023/05/Rapid-Evaluation-conference-16.5.23-Bringing-care-homes-into-a-broader-data-landscape.pdf

Care Home Research Forum 2022, Hammerson House – London, 16 November 2022. An overview of DACHA work was presented.

Norfolk and Waveney Integrated Care System Inaugural Conference, 12 October 2022. DACHA PPI N&W ICS Conference. https://dachastudy.com/wp-content/uploads/2022/10/DACHA-PPI-NW-ICS-Conference-121022.pdf

EuGMS International Congress, London, 28–30 September 2022. EuGMS22 DACHA presentation. https://dachastudy.com/wp-content/uploads/2022/10/EuGMS22-002.pdf

International Long-term Care Policy Network ILPN: The sixth International Conference on Evidence-based Policy in Long-term Care. 7–10 September 2022. DACHA presentations can be accessed here: Overview; Work Package 2 – Trials Archive; Work Packages 4 and 5 – MDS pilot; PPIE; Study within a Project: Domiciliary Care. https://dachastudy.com/wp-content/uploads/2022/09/DACHA-session-ILPN-CG.pdf; https://dachastudy.com/wp-content/uploads/2022/09/ILPN-2022-DACHA-session-VICHTA-presentation-LI.pdf; https://dachastudy.com/wp-content/uploads/2022/09/DACHA-ILPN-2022-WP5_Towers-et-al_.pdf; https://dachastudy.com/wp-content/uploads/2022/09/DACHA-ILPN-2022-PPI-presentation-AK.pdf; https://dachastudy.com/wp-content/uploads/2022/09/DACHA-DOM_ILPN-10.09.22_vd.pdf

ARC East of England and ARC South London Webinar. 4 May 2022. Policy priorities for high-quality care in care homes: what does the evidence suggest? DACHA EoE South London webinar. https://arc-sl.nihr.ac.uk/events-training/events-training/policy-priorities-high-quality-care-care-homes

Working with ENRICH. 8 February 2022. The presentations can be accessed here: DACHA Overview; Implementation in Care Homes; Public Involvement. https://arc-sl.nihr.ac.uk/events-training/events-training/policy-priorities-high-quality-care-care-homes

THIS Space 2021. Improving the evidence for improving cross-sector working. 24 November 2021. DACHA THIS Space. https://info.thisinstitute.cam.ac.uk/this-space-2021

PEDS-Knowledge Exchange Seminar Series. DACHA: an overview of the project and the care home trials archive. 23 November 2021. DACHA PEDS. youtube.com/watch?v=YY6-JYBWDcw

LTCcovid Expert Panel – Claire Goodman, Jenni Burton, Liz Jones. 18 October 2021. https://ukpandemicethics.org/ DACHA LTCcovid

Presentation at The Care Show. Social care data matters! Lessons learnt from DACHA study. 14 October 2021. DACHA Care Show. www.careshow.co.uk/conference-programme-2021/dacha-study

East Midlands Research into Ageing Network (EMRAN) webinar. June 2021.

Presentation at Open Data Saves Lives. 6 May 2021. DACHA Open Data Saves Lives. https://opendatasaveslives.org/events/session-27/

Presentation at the Applied Social Care Research Using Routine Data workshop by ARC West/HDRUK. Developing resources and minimum data set for care homes adoption (DACHA). 10 December 2020. DACHA presentation. youtube.com/watch?v=6HzePDf3tG8

Presentation at HSR UK Conference 2020. Repurposing of clinical trial data: developing a Repository of Care Home Trials. 17 June 2020. DACHA HSR UK. www.youtube.com/watch?v=7GtpwuQTjDY

Presentation at Dementia Care Research Summit 2020. Sharing dementia care research data. 12 February 2020. DACHA Dementia Care. www.youtube.com/watch?v=uwb5wdScsU4

DACHA online seminar series

Webinar 1: 21 July 2023. 12.00–3.30. Theme: *Improving the effectiveness and efficiency of care home-based research: Shifting the balance – enabling care home staff and residents to be partners and leaders in research*.

Webinar 2: 13 October 2023, 12.00–13.30. Theme: *What enables staff to use resident data for care: Implementing change in care homes: what works to support the uptake and use of information about people living in care homes.*

Webinar 3: 8 December 2023, 12.00–13.30. Theme: *Quality of measurement: tackling competing agendas for data capture and use.*

Webinar 4: 15 May 2024, 12.00–13.30. Theme: *Data integration and maximising learning from routine data: Building a minimum data set: data linkage, understanding data hierarchy and showing value to the local system.*

The recording for webinars is available at: https://arc-eoe.nihr.ac.uk/dacha-webinar-series-lunchtime-webinars

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This synopsis provided an overview of the research award *Developing research resources And minimum data set for Care Homes' Adoption and use (the DACHA study)*. For other articles from this thread and for more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR127234).

About this synopsis

The contractual start date for this research was in November 2019. This article began editorial review in October 2024 and was accepted for publication in July 2025. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Health and Social Care Delivery Research editors and publisher have tried to ensure the accuracy of the authors' article and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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List of supplementary material

Report Supplementary Material 1
DACHA Study protocols

Report Supplementary Material 2
DACHA and DHSC summary of work

Report Supplementary Material 3
Minimum data set data specification and data dictionary

Report Supplementary Material 4
Report on DACHA minimum data set from the Professional Records Standards Body

Report Supplementary Material 5
2023–4 National DACHA Consultation Summary report

Report Supplementary Material 6
Prioritising Research through Engagement with older Adult Care Homes (PREACH) protocol

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/PKFR6453).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

List of abbreviations

ARC	Applied Research Collaboration
ASC-CLD	Adult Social Care Client-Level Data Set
ASCOT	Adult Social Care Outcomes Toolkit
CASPA	Care Software Providers Association
CFIR	Consolidated Framework for Implementation Research
CHAPPI	Care Home Activity Providers facilitating Public Involvement in research as meaningful activity for care home residents

CQC	Care Quality Commission
CSU	Commissioning Support Unit
DACHA	Developing research resources And minimum data set for Care Homes' Adoption and use
DACHA-DOM	DACHA Domiciliary Care
DCR	digital care record
DEMQOL-CH	Dementia Quality of Life – Care Home
DHSC	Department of Health and Social Care
DPA	data processing agreement
DPIA	Data Protection Impact Assessment
DSA	data-sharing agreement
EQ-5D-5L	EuroQol-5 Dimensions, five-level version
GP	general practitioner
ICECAP-O	ICEpop (Investigating Choice Experiments for the preferences of older people) CAPability measure for Older people
ICS	integrated care system
IG	information governance
interRAI	International Resident Assessment Instrument
IPD	individual participant data
IT	information technology
LTCF	long-term care facilities
MDS	minimum data set
MODS	Minimum Operational Data Standard
NAPA	National Activity Providers Association
NHSE	National Health Service England
NIHR	National Institute for Health and Care Research
ONS	Office for National Statistics
PPIE	patient and public involvement and engagement
PREACH	Prioritising Research through Engagement with older Adult Care Homes
PRSB	Professional Record Standards Body
QoL	quality of life
QUALIDEM	Quality of Life for People with Dementia
RCT	randomised controlled trial
SSC	Study Steering Committee
SUS	Secondary Uses Service
SWAP	study within a project
THF	The Health Foundation
VICHTA	Virtual International Care Homes Trials Archive
VTA	Virtual Trials Archives
WP	work package

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Appendix 1 Activities to populate the Developing research resources And minimum data set for Care Homes’ Adoption and use project’s minimum data set

TABLE 2 Report on activities towards building a MDS

Activity	When	Type of activity	Stakeholders involved	Contributed how?
Scoping review of outcome measures and a systematic review of process evaluations from international older adult care home intervention research (WP 1)	2020–2	Evidence gathering	Theoretical/published literature	The scoping review showed that people were not using standardised measures in long-term care settings for older people. It identified areas that are important to capture in care homes The systematic review demonstrated that collaborative efforts/shared priorities are needed for research
National care home survey (WP 3)	2021	Evidence gathering	Care home staff	The survey attracted 273 responses from care homes in England and showed what care homes already collect and which systematic measures the care homes are using. It also showed that only one-third of care homes collect QoL data on residents
Realist review (WP 3)	2020–1	Evidence gathering	Theoretical/published literature. Interview with three stakeholders who handle care home data	It shows the usefulness of international MDSs in providing commissioners, service providers and researchers with standardised information useful for commissioning, planning, and analysis
Stakeholder consultation event 1	Summer 2020	Evidence gathering	Key stakeholders[a]	Online focus groups Focus on COVID-19 and new ways to collect data from care homes, including the capacity tracker
Evaluation of interRAI (The interRAI) variables	2020–1	Evidence gathering	Theoretical/published literature	Investigating the applicability of interRAI LTCF and interRAI palliative care forms to understand what is measured in this assessment type, which is mandated by some American, European and Australasian countries
Within-team/internal review of international MDSs and the scope of their items/questions	2021	Evidence gathering	Theoretical/published literature	The team conducted an internal review of various core data sets used in long-term care settings and looked for evidence on outcome measures used in these instruments
Within-team/internal review of nine QoL instruments	2021	Evidence gathering	Theoretical/published literature	The team specifically looked for evidence on the applicability and usability of QoL measures for within the UK. Process measures were excluded, while outcome measures were included

TABLE 2 Report on activities towards building a MDS (*continued*)

Activity	When	Type of activity	Stakeholders involved	Contributed how?
Two DACHA WP 4 'THF workshops' with internal stakeholders	May 2021	Evidence gathering/ production	DACHA team members	Investigating what the internal stakeholders (the DACHA research management team) would like to see in a MDS for use in older people care homes
WP 4 tabulation of variables	2021	Production	DACHA team members	The top variables from workshops that are outcome measures (not process measures) were made into an early draft of the MDS
MDS principles paper[44]	2021–2	Production	DACHA team members	Clearly defined the objective and purpose of the MDS by setting nine standards that should be adhered to. These principles reiterated the focus of the MDS to be on outcome measures and not on day-to-day activities
WP 5 team away day	November 2021	Production	DACHA team members	The variables for the MDS were brought together from WP 4 workshop findings and were informed by the DACHA MDS principles paper, two internal reviews of QoL and international MDSs outlined above (2021), WP 3 survey findings and relevant interRAI sections
WPs 4 and 5 evaluation of the sources for MDS variables within England	2022	Evidence gathering, supplementary	DACHA team members	The teams identified where the variables of the DACHA MDS would come from, besides care homes, to populate the MDS with administrative data held on care home residents
Prioritisation of MDS variables: 'York residential'	2022	Sense checking, supplementary	DACHA team members	The DACHA team came together to decide which variables of the MDS are of essential, desirable and optional priority ratings (P1–P3, respectively). This activity focused on around half of the MDS variables
WP 5 investigation of variables on the software platforms of two care home software providers	2022	Evidence gathering, supplementary	Software companies	WP 5 team collaborated with two care home software providers. The team started their longitudinal pilot in care homes, with resident recruitment activities starting in late 2022. The team investigated what measures and variables from the MDS are already present on the care home electronic records as supplied by these two vendors. The team made decisions on what extra variables to add onto these systems for the pilot study based on this investigation This was to avoid duplication of efforts and to promote data consistency
WP 4 investigation of routine administrative data sources	2020–1	Evidence gathering, production	NHSE, ICS data governance teams	Approached relevant stakeholders, data owners, controllers and processors. Established data flows and pseudonymisation process. Ensured compliance with data security and regulatory requirements. Linked data derived insights
Working together with PRSB	2022–4	Sense checking	PSRB colleagues, DACHA team	PRSB looked at the evidence towards building a MDS and provided feedback on the MDS variables about their applicability

continued

TABLE 2 Report on activities towards building a MDS (*continued*)

Activity	When	Type of activity	Stakeholders involved	Contributed how?
National stakeholder online consultation on one section of the MDS – QoL	June–September 2022	Sense checking, Evidence gathering	Key stakeholders[a]	This national external stakeholder consultation that was held online on the Thiscovery platform focused on Section 5 of the MDS and helped the DACHA team decide on the most usable QoL measures to be included in the MDS
Briefings with DHSC and NHSE and NHS Improvement (NHSEI)	2021–4	Sense checking, evidence gathering	DHSC and NHSEI	The DACHA team had regular briefing meetings with the DHSC and NHSEI teams to discuss the MDSs that DHSC, NHSEI and DACHA are producing separately. The meetings looked at how these data sets do come together and shared consultation findings with each other
DACHA SSC input	2020–4	Sense checking	DACHA Steering Committee	The DACHA team met the Steering Committee twice yearly and shared the progress of the study and the MDS in these meetings. The committee had an overall view of the MDS and approved the sections and variables
DACHA PPIE panel input	2020–4	Sense checking, evidence gathering	DACHA PPIE panel – family carers and care home staff	Addressed ethical considerations related to data privacy, consent and confidentiality
Resident involvement	2021–4	Sense checking, evidence gathering	Residents	Through collaboration with NAPA – activities and discussions completed with care home residents exploring factors perceived to contribute to QoL and who would be best placed to judge QoL if residents could not self-report
Psychometric evaluation of QoL measures (WP 5)	2023–4	Sense checking, evidence gathering	Theoretical/data analysis	The WP 5 team conducted and reported psychometric evaluation of the included QoL measures to assess their performance. These findings were used alongside evidence from focus groups and interviews (below) to inform our recommendation of which QoL measure(s) ought to be included/taken forward to the national consultation
Focus groups and interviews (WP 5)	2023–4	Sense checking, evidence gathering	Care home staff[a]	The WP 5 team held focus groups and interviews with key staff members at the participating pilot study care homes to learn what the challenges and benefits were to staff with data collection for MDS The focus groups looked at user acceptability/insights on practical usefulness
Final national consultation	December 2023–February 2024	Sense checking, evidence gathering	Key stakeholders[a]	The final consultation invited the participants from previous consultations who are members of the stakeholder groups (i.e. who live, visit, work in and with care homes) to comment on DACHA findings and the study's implications for practice, commissioning and future research

[a] Key stakeholders in 2021 consultations: 1 – local authority and Clinical Commissioning Group (CCG) officials; 2 – researchers, old age psychiatrists, geriatricians; 3 – government officials; 4 – data analysts and data researchers; 5 – primary healthcare professionals; 6 – care home staff; 7 – senior operational and care home managers. For 2022 consultations, we also asked family members and friends of care home residents to participate in the survey. For 2024 consultations, we also asked residents directly in their own home.

Appendix 2 Work package 4 synopsis

Aims

The WP 4 aimed to create a proof-of-concept prototype MDS by linking NHS and social care data with care home-generated data, known as DCRs. WP 4 aimed for the MDS to reflect the aspirational data set,[101] using routine data where possible to minimise the burden of care homes and creating a data set that was relevant and usable for different groups, including care home residents, relatives of residents, practitioners, researchers, service providers, analysts, regulators and commissioners. This WP aimed to produce metadata to provide useful resources for others looking to link these data in the future and to demonstrate the value that a MDS would have to a range of stakeholders.

Methods

Data access

Work packages 4 and 5 mapped the information in the aspirational MDS to DCRs and existing administrative data sources. WP 4 approached the relevant data controllers/processors to understand what specific data items they held, agree data flows and set up DSAs. There was significant engagement with stakeholders within the three ICSs (then Clinical Commissioning Groups) to re-establish buy-in, as a significant period had elapsed since the start of the study and buy-in had dissipated due to organisational change, the pandemic and competing priorities.

Data management and linkage

As data controller for the prototype MDS, WP 4 liaised with data processors to manage pseudonymisation of each data set at source prior to extraction and linkage of resident-level and care home-level data sets. All pseudonymised data were held on THF's secure data environment. The detailed steps for data hosting, pseudonymisation and linkage are described in Gordon *et al.*[62]

Data quality and derivations

We reviewed data quality and derived informative variables using established definitions or in consultation with clinicians. From the longitudinal data sources, we derived a cross-sectional data set with one row per resident. For example, we derived the number of out-of-hours emergency department attendances (per resident) and derived comorbidities based on the Elixhauser list, using *International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision codes recorded in hospital admissions data from the previous 3 years.[102] All derivation methods are detailed or referenced in *Report Supplementary Material 3A*.

For data items available from more than one data source, we compared the level of completeness and agreement between sources and, where applicable, constructed a hierarchy to determine which data source(s) would be prioritised to populate the prototype MDS. Detailed methods and results are described in Gordon *et al.*[62]

Analysis

We reported descriptive statistics for all variables in the prototype MDS, including levels of missingness (see *Report Supplementary Material 3*). We sought input from a wide range of stakeholders (varied groups within ICSs, NHSE teams and the PPIE panel) on potential insights that could be derived from a MDS and demonstrated the value by producing some examples.

Key findings

This WP demonstrated that it is possible to build a MDS linking care home-generated data with health and social care data. However, it did not achieve all original aims: importantly, we were not able to proceed to extraction of GP data within the time frames of the study. Nonetheless, we agreed a list of variables with one ICS and set up a process, working with a CSU by which we could have accessed and linked GP data from another ICS, demonstrating that it is feasible (Appendices IV and VII in Gordon *et al.*[62]).

Work package 4 showed that it was possible to work with several different data controllers and processors – NHSE, CSUs, care homes and care home software providers – to access, pseudonymise and link resident-level data. However, establishing data flows and data access was slower and more resource intensive than anticipated due to IG challenges (see *Challenges and limitations*).

Significant time and resource are needed for setting up IG processes and accessing data sources. For example, as individual GP practices are data controllers for their patients' data, individual DSAs had to be signed with each GP practice. Competing priorities, particularly for IG staff, meant that some ICSs could not engage in the research.

Data accessed

Nine routinely collected, key health and social care data sets were accessed and linked with residents' care home data to create the prototype MDS. The MDS was constructed from the following data sources:

- care home-generated DCRs
- Secondary Uses Service (SUS) Admitted Patient Care data
- SUS Outpatient data
- SUS Emergency Care Data Set
- Personal Demographics Service
- Community Services Data Set
- the new National ambulance data set
- the new ASC-CLD
- Care home residency table (Arden & GEM CSU estimated care home residency dates)
- CQC care home data
- ONS Index of Multiple Deprivation data
- Survey data on participating care homes.

Most of the data sources above are held by a single data owner, NHSE. This is helpful for a future 'real' national MDS, as data can be requested and accessed through one process.

As a resource for others, the following are made available:

- a data specification for the final prototype MDS, detailing the derivation of each variable (see *Report Supplementary Material 3*)
- a full list of variables required from the source data sets to recreate our prototype MDS (*see Report Supplementary Material 3*)
- details of the data items in the aspirational list that could not be included in the MDS or that were derived from different data sources than planned (see *Report Supplementary Material 3*)
- a table with descriptive statistics for the prototype MDS, including proportions of missing values (see *Report Supplementary Material 3*).

Hierarchy

Where similar data were collected across more than one data source, we compared the level of completeness and agreement between sources. Where variables had the same definition, information was pooled using the agreed hierarchy. This led to substantial improvements in completeness: 96% for ethnicity to > 99% for sex and date of birth. For dementia, there was some disagreement between records, with 75% agreement between dementia identification in hospital admission records and the DCR. We took an additive approach, as definitions used to code dementia in hospital admissions' data varied from that used in DCRs.[62]

There is rich information available in routinely collected data, and combining information across data sets improves data completeness, reducing missingness. However, not all fields were of sufficient quality to be useful, particularly in newer data sets.

Analysis

Descriptive analyses are presented in Gordon *et al.*[62] To demonstrate some of the potential values of a MDS, some descriptive analyses of emergency care use by resident and care home characteristics were presented as an example. Our stakeholder engagement also highlighted other areas where a more complete MDS could provide insights. These included: understanding reasons for hospital admissions to inform local service provision or training; looking nationally at most common medication incidents; understanding pathways and access to services for residents with particular conditions or needs, for example, with diabetes or mental ill health; and reviewing safeguarding events.

Limitations

At the initiation of the DACHA project, there was an aspiration to create a MDS that could be shared with care homes and that residents and their families could access. That was not within scope of this study, as there was no legal basis to share identifiable data, and pseudonymised data would not be feasible for direct patient care.

A planned additional MDS version based only on administrative data but encompassing all care home residents in three ICSs was not possible. The MDS included only the smaller sample of consented residents, limiting the insights that could be derived. Some data were of too low quality to be useful; for example, in the ambulance data set, the field on reason for callout was empty, so it was not possible to derive ambulance callouts due to falls (see *Report Supplementary Material 3*).

There were no GP data available within the time frames, although it was demonstrated to be possible in one ICS. These limitations were due to significant challenges, resulting in major delays (see *Challenges and limitations*). It was not possible to compare details on comorbidities between GP and secondary care data, as originally planned, due to the lack of GP data.

Appendix 3 Work package 5 minimum data set pilot care home recruitment summary

TABLE 3 Work package 5 MDS pilot care home recruitment summary

ICS area	Target recruitment	Actual recruitment
1	20 care homes	19 care homes
	320 residents	537 residents
2	20 care homes	15 care homes
	358 residents	286 residents
3	20 care homes	11 care homes
	292 residents	173 residents
Total	60 care homes	45 care homes
	970 residents	996 residents

Source
Reproduced with permission from Gordon *et al.*[50] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The table includes minor additions and formatting changes to the original text.

Appendix 4 Lessons learnt for future research

TABLE 4 Lessons learnt for future research

DACHA publication	Future research recommendations
Outcome measures from older adult care home intervention research: a scoping review – Kelly *et al.* (2023)[45]	- More use of measures in research tailored to social care and concepts, such as social-care-related QoL, was suggested - There is a need for more formal evaluation of the psychometric and measurement properties of tools used for research in care homes - There is a need to apply outcome measures that are appropriate and sensitive to the care home context, working with residents, family and friends and staff
Contextual factors influencing research implementation processes in care homes: a systematic review and framework synthesis – Peryer *et al.* (2022)[46]	- The review identified studies that used the term 'process evaluation' specifically. Further reviews can broaden the eligibility criteria to include additional studies discussing contextual factors influencing research implementation processes - Further trials can reduce the risk of expensive research implementation failures when research teams: • do not underestimate the effects of restructuring habitual ways of working • help staff identify meaning behind implementation activities, for sustained engagement • identify ways to detect procedural drift and potentially take corrective action • do not consider staff and healthcare clinicians involved in implementing the intervention as passive delivery conduits
What care home teams should consider before partnering with a trial research group – Spilsbury *et al.* (2023)[56]	- Prior to agreeing to support a trial, there are questions a care home manager, staff, residents and their families and friends should consider - Is the trial topic a priority? Does it matter for people living and working in care homes? - Could the trial offer benefits for people living or working in care homes?
Data Resource Profile: the Virtual International Care Homes Trials Archive (VICHTA) – Irvine *et al.* (2024)[59]	- Planned expansion to international care home RCTs will facilitate a wider range of research questions. - For research efficiency and reducing research waste, existing care home trials can be used for secondary data analysis

continued

TABLE 4 Lessons learnt for future research (*continued*)

DACHA publication	Future research recommendations
The uptake and use of a minimum data set (MDS) for older people living and dying in care homes: a realist review – Musa *et al.* (2022)[35]	- For future MDS implementation, the review highlights how to tailor and implement a MDS that is likely to inform residents' everyday care - Creating effective interstakeholder dialogue and building learning communities needed in future research for introduction of electronic forms of MDSs in the care sector
Developing a minimum data set for older adult care homes in the UK: exploring the concept and defining early core principles – Burton *et al.* (2022)[44]	- Coproduced work is required to define and agree the format, content, structure and operationalisation of MDSs. Without this, it is likely that stakeholders and their organisations, who are external to the care home, will influence most what data are collected
Data collection in care homes for older adults: a national survey in England – Hanratty *et al.* (2023)[49]	- Care homes already collect an extensive range of resident-level information for their own uses, without a mandate or incentives
Application and Content of Minimum Data Sets for Care Homes: A Mapping Review – Hanratty *et al.* (2024)[48]	- Generating baseline data from a MDS or providing a comparison group for an intervention study helps to keep research costs down by reducing the work of data collection - QoL can be prioritised as it has been relatively neglected. There has been absence of any consensus on how this should be measured in care homes
Assessing the feasibility of measuring residents' quality of life in English care homes and the construct validity and internal consistency of measures completed by staff proxy: a cross-sectional study – Towers *et al.* (2025)[72]	- More research is needed to establish the psychometric properties of the QUALIDEM in an English care home setting - EQ-5D-5L, ASCOT-Proxy-Resident and ICECAP-O can be used effectively in care homes for older people
Piloting a minimum data set for older people living in care homes in England: a developmental longitudinal validation cohort study – Gordon *et al.* (2025)[50]	- Researchers should keep in mind that: • IG for linking data across multiple data owners and data processors is complex and time consuming • Standardisation across DCR systems would enable data to be used more effectively across the care home sector • Establishing shared priorities across key stakeholders interested in care home data is essential for effective MDS implementation
Piloting a Minimum Data Set (MDS) in English Care Homes: A Qualitative Study of Professional Perspectives on Implementation and Data Use – Carroll *et al.* (2024)[53]	- Recommendations to support MDS implementation • Planned data collection periods that reflect care home priorities and routines • Resource to support additional data gathering • Training to support staff familiarisation, confidence and adoption of new measures • Adequate IT facilities and fit between the hardware and software • Ability for data to influence residents' care planning • Care home leadership engaged with data capture • Care home staff, commissioners and visiting professionals develop ways of working that reference MDS findings • Resources and policy briefings that promote a shared understanding of QoL outcome measures. Specifically, how they can inform practice, commissioning and evaluation
Exploratory factor analysis and Rasch analysis to assess the structural validity of the ASCOT-Proxy completed by care home staff – Rand *et al.* (2024)[52]	- Further qualitative study of how care home staff complete and perceive the ASCOT-Proxy is encouraged for future studies - The ASCOT-Proxy-Resident can be used as a valid instrument of SCRQoL for older adults resident in care homes
Construct validity of measures of care home resident quality of life: cross-sectional analysis using data from a pilot minimum data set in England – Allan *et al.* (2025)[51]	- ASCOT-Proxy-Resident, ICECAP-O and EQ-5D-5L-Proxy2 QoL measures can be included in any future MDS

TABLE 4 Lessons learnt for future research (*continued*)

DACHA publication	Future research recommendations
National stakeholder consultation on how to measure care home residents' quality of life – Akdur *et al.* (2024)[67]	- Future research should focus on actively involving care home residents in stakeholder consultations. Insights into the actual experiences of residents can ensure that the delivery of a prototype or services is directly reflective of resident perspectives
Activity provider-facilitated patient and public involvement with care home residents – Micklewright *et al.* (2024)[84]	- Activity provider-facilitated patient and public involvement is possible for research studies - The PPIE resources created could be developed and refined in future studies both for use with individuals living in care homes and other groups
Public involvement to enhance care home research; collaboration on a minimum data set for care homes – Killett *et al.* (2025)[82]	- Next steps of development and implementation of a MDS for care homes should build on such relations, incorporating relevant knowledge and experience, in order to minimise negative unforeseen consequences
Routine data collection in home care: a national survey of home care providers in England – Davey *et al.* (2025)[74]	- Future research should be aware that homecare organisations reliant on public funding are among the least prepared to implement a domiciliary care MDS - Future work is needed to understand how best to promote, support and possibly incentivise the implementation and maintenance of digital records in homecare
Defining Home care: An exploration of Its Roles, Challenges, and Data Needs – Davey *et al.* (preprint)[73]	- It is necessary to explore why providing care may be more complex in certain environments beyond the sum of its individual client base - Finding out what makes a consensus possible on the purpose and scope of services for standardised data collection on people receiving homecare

SCRQoL, Social Care Related Quality of Life.