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Developing research resources And minimum data set for Care Homes' Adoption and use (DACHA) study

Version	Date	Description
1.0	28.06.2019	Original.
2.0	01.05.2020	Updates and minor changes about the project noted, such as the change in the number of consultation group meetings. General copy-edit. New images added to illustrate important information on consultation groups, and the timeline of Work Package 2.
2.1	11.05.2020	Minor improvements; version control table added, the file name changed, sponsor branding added, SSC names removed. General copy-edit.
3.0	21.04.2021	Information on national consultation events updated. General copy-edit.
4.0	18.01.2022	Information on SWAPS (studies within a project) integrated into the text and relevant parts of work packages relating to the SWAPs changed accordingly. General copy edit.
5.0	28.10 – 17.11.2022	Information in the sections relating to the consultation events, WP4-5 timelines and numbers, DACHA-DOM (SWAP) details, and project timetable revised.
6.0	07.02.2023	Work Package 5 timelines and recruitment information revised. Overall timelines updated. General copy-edit.

SUMMARY OF RESEARCH (ABSTRACT)

BACKGROUND
In England, long-term continuing care for older people is principally provided by care homes. Residents and staff rely on the NHS for medical care and access to specialist nursing and therapy services. The creation of Integrated Care Systems https://www.england.nhs.uk/integratedcare/integrated-care-systems/ in England and recognition of the role of social care as an essential part of care provision for this population underline the need to develop reciprocal systems of working between the NHS and care homes that optimise current provision and research on its effectiveness. Within ten years future demand for long term care will outstrip current capacity (1, 2). There is currently no agreed framework for collating, sharing and interpreting data collected by the stakeholder organisations involved in supporting care homes – this is a missed opportunity for co-ordination of care, service development and commissioning, as well as the conduct of research. Other countries have highly evolved minimum datasets which have shown utility in all of these areas.

AIMS
To establish what data need to be in place to support research, service development and uptake of innovation in care homes

To synthesise existing evidence and data sources with care home generated resident data to deliver a minimum data set (MDS) that is usable and authoritative for different user groups (residents, relatives, business, practitioners, academics, regulators and commissioners).

DESIGN
A mixed method study drawing on design and implementation theories.

- **Work package (WP) 1** Evidence reviews on what improves the productivity of care homes research and key measures and outcomes that have been incorporated in UK care home research that could inform an MDS.
- **WP 2** Creation of a care home trial repository, initially including trial data on 6000 residents, with the ability to add new trials beyond the project duration. This will allow secondary data analysis and test key resident characteristics and outcomes relevant to the development of an MDS
- **WP 3** To establish what is known about the implementation and content of MDS relevant to UK systems of care. A realist review building on WP1 to understand how MDS work in different care home settings and the attributes and situations in which their use supports improved outcomes for residents, family, staff and organisations. A scoping review of the content of Minimum data sets relevant for English systems of care MDS and survey of existing care home generated data to inform the development of an MDS.
- **WP 4** Mapping and characterisation of existing sources of data on care home residents to create resident datasets from routine NHS and Local Authority data in two (three from 2022 onwards) integrated care sites (ICS) to link with data collected in study care homes. Combined with WP1-3 findings and national consultation this will enable critical appraisal of feasibility of inclusion of assessment and outcome measures in a care home generated MDS for testing

- **WP 5** Pilot and test the MDS by collecting data at two time points on 300 residents of care homes across three integrated care systems (ICS). We will pilot collecting the care home components of the MDS directly from cloud-based digital care records and matching this to other resident and care home level data from NHS and social care databases to form the full dataset. Data from the MDS will be collected at baseline and 6 months to understand the impact of seasonality. Focus groups conducted in care homes at each time point will develop an understanding of implementation issues including the perceived utility of the MDS data to key stakeholders. The MDS data will be assessed for feasibility by completeness (percentage missing data) and timeliness of completion. Data quality will be evaluated by reporting descriptive statistics, including percentage floor and ceiling. For validated measures (e.g. the Adult Social Care Outcomes Toolkit), exploratory factor analysis will be used to identify the underlying factor structure of the data in the MDS. We will also examine the internal consistency of participants' responses (i.e. whether items tap into a single underlying construct) using Cronbach's alpha statistic **Consultation with stakeholders:** This is embedded throughout study: A national expert group of resident and relative representatives, care home owners and staff representatives, commissioners of health and social care to care homes, researchers, and NHS providers and staff will review the DACHA work at three points in the study. This will inform the planning of WPs 1-4, develop a consensus on proposed MDS for testing, and develop recommendations for implementation. Ensuring this element of co-production is part of the project throughout will ensure outputs are fit for use and "shovel ready".
- **Studies Within a Project (SWAPs):** These additional parts of the DACHA project were granted approval in late 2021 and became part of the study from early 2022 onwards. The SWAPs of DACHA are as follows:
    - The Multiple Long-Term Conditions SWAP: will explore how care home staff understand, complete, interpret and use the assessment tools and scales within their digital care software to evaluate and support the quality of life and wellbeing of residents.
    - The Social Care SWAP 1: has funded the inclusion of a third ICS (in Northeast England) in WP4 and WP5 to account for representation in the DACHA study of underserved, socio-economically deprived communities.
    - The Social Care SWAP 2: will explore how the learning from DACHA about MDS in residential settings can be applied to implementing an MDS in domiciliary care (DACHA-DOM).

PROPOSED OUTPUTS

i) Guidance for researchers and commissioners on health care implementation in care homes, resource on assessment tools and core outcomes in care home research,
ii) A repository of care home RCTs to support secondary data analysis and inform MDS development that can support more research and useful findings for priority questions, without the expense and burden of involving care homes and residents in research.
iii) Evidence on what needs to be in place for an MDS to support staff uptake, resident assessment, care and improved outcomes.
iv) An implementation strategy for MDS that links NHS, social care and care home generated data.
v) A prototype MDS to inform commissioning, needs assessment, and care delivery.

BENEFITS

There is widespread interest in how to improve the uptake of best evidence and care for care home residents. Combining existing data with care home generated data in the development of the MDS could improve the quality of life of care home residents and their experience of care and reduce NHS and related costs. By working closely with resident representatives, the care home industry, NHS England, Local Authorities, commissioners and the regulator, this study addresses policy objectives of integrated care for this group with a paradigm shift towards individual and care home level information being routinely shared and used to underpin research, innovation and intervention.

BACKGROUND AND RATIONALE

There are approximately 420,000 older people living in long term care settings (3, 4). They are among the most frail and vulnerable in society and rely on the NHS for access to medical care, specialist nursing, and therapy (5, 6). Care homes are a sector under pressure both financially and because of rising numbers of the oldest old (1, 2, 7) and this directly affects how the whole health and social care system performs. Care home providers and NHS partners need to understand who their residents are and what kind of services enable them to live and die well. Capacity to assess quality, monitor resource use and care costs, and to evaluate and spread innovations is radically undermined by a lack of strategy and standardisation of how resident needs and service use are documented.

There is a growing abundance of data about the care home sector and the residents it serves from both service delivery and research data. These data are not, though, currently harnessed in an effective way to the benefit of the sector and the residents it serves.

Care homes compile data to plan and document care, to inform business plans, and as evidence for regulators, Local Authorities, and NHS commissioners. Data on residents are also generated by NHS practitioners (e.g. GPs, community nurses, therapists, and paramedics) when they visit care homes and when residents are admitted to hospital. Increasingly they are also generating resident specific data via the use of sensor technologies that monitor movement and vital signs (8). In England some work has been done to systematise resident data (9) and Scotland aim to have an integrated dataset (10) by autumn 2020. There are, however, no mechanised systems to aggregate this data at a care home level that captures the resident experience of care even in these pioneering areas.

From a research perspective, equivocal findings and underused data from robust RCTs conducted in care home environments are a further concern (11). Researchers require care home specific evidence on how intervention processes and organisational context affect uptake, and how best to collect and measure data (12, 13). Optimising existing data to maximise learning about residents from previous research (14) would help to target future expenditure, minimise risks of repeating identifiable failings in trial implementation, and maximise a return on investment that has already been made in research.

Consumers (residents and relatives) also want information about care homes (15) with value placed on indicators of residents' quality of life as well as satisfaction with services (15-17). More efficient use of existing data and the creation of Minimum Data Sets (MDS) could answer key service delivery and research questions about the way NHS services are delivered to care homes, the impact of different models of care, or which services are needed by which subgroups of residents and how resident data are shared (5, 18). There is a need to map current information provision and how it can be organised and standardised to inform and

translate securely to IT systems that all parties want to use, and will be able to use, to support the planning and provision of care to care home residents.

Minimum data sets provide a comprehensive account of resident characteristics, resource use, and quality of care outcomes in key areas (e.g., functional ability, pain, and infections (19-24). MDS can also help to inform planning and evaluation of care and research from assessment on admission to end of life (25, 26). One of the most widely used MDS, the international Resident Assessment Instrument (interRAI), was developed in the late 1980s and implemented in North American nursing homes in 1996 (20, 27). and is now used in many countries internationally. Countries often use MDS because they are mandated and/or linked to reimbursement systems and quality monitoring (28, 29). What is less clear is how the priorities of social care providers, residents and families are addressed, how the resources required to sustain the system are established, and how use of MDS supports change in care practices and personalised care within individual care homes (30).

This submission responds to all parts of the commissioning brief.

Why the research is needed now

The recent NIHR themed review of care home research (11) concluded that research in care homes is relatively undeveloped. It recommended that future work is grounded in the reality of care home life, supporting partnership working between health professionals, staff, residents, and relatives in designing and delivering new approaches to care, and this proposal arises from such collaboration. The importance of building capacity in care home research and the need for a minimum data set to improve understanding of how care for residents is planned, delivered, and reviewed were identified as priorities. Discussions about the proposal with representatives from care home chains, NHS England, Care Quality Commission (CQC), the Cabinet Office working group on social care measurement confirm that this work is both timely and urgently needed. This research is also timely in response to the impact of the COVID-19 pandemic in care homes and need for accurate data about residents.

In England, the absence of a national mandate, lack of links with NHS data, and implementation challenges (31) have meant that MDS and data-driven approaches to resident assessment have been limited to single projects (32, 33). Routinely collected data on resident and care home characteristics (e.g. by GPs), RCT data from care home research, and studies of health and social care outcomes specific to social care (16) have the potential to inform a MDS that is specific to England. The challenge is to establish systems of assessment and documentation that are evidence-based and usable by all those involved in receiving, providing, commissioning, and regulating care.

Test-bed initiatives supported by NHS England (Care home Vanguards), The Health Foundation, Nuffield Trust (34, 35) and NIHR-funded research (36, 37) have demonstrated the benefits for residents and staff of close working relationships between care homes and the NHS. The New Care Models Programme (36), by beginning to integrate NHS data sources, demonstrates that health and care professionals can access the necessary information to provide treatment and support. Research is needed to exploit these developments to improve the care of residents.

In July 2018, at a meeting of the National Care Home Research and Development Forum, 67 participants representing commissioners, family carers, regulators, care homes, and the NHS described local initiatives where health and social care services are sharing data e.g. to support safeguarding and risk reduction. There were also a few examples of shared access to cloud-based systems. This work with key stakeholders confirmed that a MDS is recognised

as a needed resource when the care of frail older people requires the ability of different services and practitioners to work across health and social care organisations (38, 39).

AIMS

Demonstrate the utility of the matched MDS data to different stakeholders involved in commissioning, providing, receiving, and regulating care (WP 3-5)

RESEARCH PLAN AND METHODS

Design and Theoretical Framework

As an overarching approach to think through implementation issues (and theory) and how different stakeholders will inform the co-design of a MDS, we have used the Double-Diamond design process (www.bsbd.org.uk/double-diamond-design-process) to structure the work packages (WPs) of this mixed methods study. There are four stages involved in this process:

1. **Discover** - open up and explore the focus of the project and needs of knowledge users (WP1-3)
2. **Define** - focus in on the important issues to tackle and define problems to be addressed (WP1-3)
3. **Develop** - collectively design and test potential solutions to the problem (corresponding to the national stakeholder consultation and WPs 4-5)
4. **Deliver** - narrow in on a practical, working solution and implement it (WP 4-5).

This approach to implementation is guided by the principles of integrated knowledge translation (IKT), that emphasizes collaboration between researchers and decision-makers (40) and by design-based approaches to co-production (41-44). Each of these is based in the idea that collaboration between those who produce research and those who use it will improve its quality, relevance, and usefulness. From IKT we take the broad framing of knowledge co-production based in an ongoing relationship between researchers and decision-makers or knowledge users (such as clinicians, managers, or policymakers). This ensures the production of mutually beneficial research that both supports decision-making and the kind of group-level identity transformation needed to support the development and delivery of a MDS for health and social care (40, 45, 46).

National Consultation with expert reference group on Minimum Data Set development

In addition to Patient and Public Involvement and Engagement (PPIE), and to support the co-design approach throughout the study, we will organise six national expert consultation group meetings in England organised in collaboration with the Applied Research Collaborations and the Academic Health Science Networks (ARC/AHSN) national care home collaboration. The consultation groups have been extended via the Department of Health and Social Care to Wales. Four expert groups will be formed in Wales. All groups in England and Wales groups will involve up to ten representatives per group.

The expertise-based consultation groups in England and Wales include the following stakeholders:

1- Care Quality Commission experts and commissioners, Local Authority and health and social care commissioners.
2- Care home managers, and directors of quality.
3- Primary care professionals (GPs, community psychiatric nurses, geriatricians, community nurses, social workers, physiotherapists, etc.).

4- Care home staff at senior and junior carer grade who work with paper-based resident records.
5- Care home staff at senior and junior carer grade who work with electronic resident records.
6- Geriatricians and old age psychiatrists with explicit interest in MDS and researchers with prior knowledge of care home research and/or MDS implementation.
7- Family relatives of care home residents and carers

Consultation 1 (2021) with each of the aforementioned groups will review the use of care home data during the Covid-19 pandemic; what data are the most/least useful for each of the stakeholder groups. The meetings with the stakeholders will take place online in the form of 1 hr workshops. This is a change from the original plan due to the unprecedented changes and changing priorities in care homes impacted by the Covid-19 pandemic. Consultation 2 (2022) will review the Quality of Life (QoL)section of the Minimum Data Set (MDS), to highlight which principles are deemed to be the most important and which outcome measures can be incorporated into the MDS. The consensus activity will take place online on the THIS Institute's Thiscovery platform in the form of two surveys. The first survey will consult stakeholders on the criteria for selection and inclusion of QoL outcome measures. The second survey will include measures that meet the agreed criteria for inclusion and will widen the consultation target group to include more representatives from the above stakeholder groups. The second survey will focus on preferred measures for possible inclusion and if there is within and cross group consensus. National Consultation 3 (2023-24) will present the WP4&5 findings for discussion about the usefulness and usability of the pilot MDS implementation in care homes, This will take place online. This approach recognises the importance of emphasizing process and of ensuring we bring together all participants – residents, families, staff, managers, clinicians, commissioners and regulators – in a way that enables us to collectively elicit and share experiences and perspectives and to engage in "collective making" as a form of knowledge mobilisation (42). We will work with the conceptualisation of stakeholder engagement proposed by Boaz and colleagues (41) and with their proposed 15 design principles for stakeholder engagement.

Work package 1 (WP) Research in and with care homes

This work responds to the research brief's identification of the need for evidence that can both improve the productivity of care home research and capture the key measures and outcomes used in UK care home research that could inform an MDS.

Review One will provide an overview of resident reported outcomes and care quality relating to interventions or programme implementation in care homes, and any evidence of sensitivity to change. Attention will be paid to the use of functional and quality of life measures. Based on our prior work we anticipate considerable heterogeneity and knowledge gaps (e.g. in resident/family reported outcome measures). By identifying those outcomes measured in care home studies that are sensitive to change, clinically meaningful, and address the lived experience of the older people resident in care homes this review will both be a resource for researchers planning future work and inform the work of developing a MDS.

The review will include RCTs, pragmatic trials, natural experiments and implementation studies. It will focus on the range of interventions conducted in care homes in OECD countries since 2015 to reflect contemporary research practice. Included studies will be categorised by focus and outcome categories (e.g. cognitive ability, function, quality of life and care) and

analysis will consider frequency of use across studies and data on the feasibility and utility of the outcome measures used.

Review Two will provide a synthesis of the evidence from process evaluations of complex interventions conducted in care homes. The process of delivering an intervention in a care home setting can mediate the validity of the outcome measures directly. A process evaluation describes how delivery is achieved, what is actually delivered, how the delivered intervention was reported as producing change, and what affected implementation and outcomes (47, 48). This evidence synthesis will identify common factors from previously published studies and programmes that have reported a process evaluation that may affect outcomes, fidelity, and quality of implementation. Taking a human-factors approach to data organisation and analysis, it will examine the relationship between the organisational context of care homes involving a subset of embedded work systems: i) physical environment, ii) tools and technologies, iii) care tasks, and iv) the carer/resident. This fits with the design principles of stakeholder engagement (41) with care home staff that places the resident at the centre of the work system model.

Search strategy: Both reviews will use high quality evidence synthesis methods. The conduct and reporting of reviews will follow the guidelines of the PRISMA statement where appropriate. The protocol for both reviews was registered on PROSPERO with the reference ID: CRD42020155923. Searches for relevant evidence will include databases of peer-reviewed literature (MEDLINE, EMBASE, CINAHL, Social Sciences Citation Index) and sources that include grey literature (SIGLE, Open Grey, Google Scholar. Studies for inclusion will be limited to English language and of relevance to the UK care home context. To assess quality of conduct and reporting of studies, studies will be assessed against the MRC recommended criteria for process evaluation (https://mrc.ukri.org/documents/pdf/mrc-phsrn-process-evaluation-guidance-final/). GRADE-CERQual will be used to assess the overall strength of the available evidence to guide recommendations (www.cerqual.org/).

A preliminary scoping of the literature for Review One identified 75-100 studies offering UK relevant evidence. A preliminary scoping exercise for Review Two identified 12 studies with a published process evaluation, and 14 ongoing process evaluations in a care home setting.WP1 will identify a list of salient contextual factors that influence implementation of care interventions in a care home setting. This will also inform implementation of the MDS. The output will be guidance and resources for researchers and commissioners aiming to test and implement health and care interventions in care homes.

Work Package 2 Creation of an individual patient data (IPD) repository of UK care home trials

WP2 complements WP1 and responds to the research brief's identification of "*the potential for secondary data analysis of existing research data to track residents' outcomes before and after significant events or new approaches to providing health and social care*". This WP will develop a repository of individual resident data from existing care home trials. Secondary analysis of existing trial data is low-risk, low-cost, and a priority for NIHR (49). Large RCTs conducted solely in care homes are a growing resource. While these RCTs focus on a variety of health/care topics (e.g. falls risk, medication management, nutrition, or infection) there is much overlap in outcome measures used, and information collected on both residents and the care home structure. Trials in care homes monitor participants regularly, for up to one year. Outcome measures, health resource use, and clinical events as well as care home characteristics can therefore be tracked over this period, allowing for longitudinal analysis. If individual patient data (IPD) from existing trials could be pooled, they would collectively

provide a much larger and more useful dataset. Individual patient data (IPD) can be used for exploratory analysis to better understand this population, reduce duplication of effort, and refine future research questions (50-52).

To enable development of the repository, we will first complete a scoping review to identify potential care home trials for inclusion. Initial work has identified large trials conducted in UK care homes (see table below). We have secured the agreement of five lead investigators, who will work with us. Work-package coordinator (LI) has a working knowledge of one of these datasets (54), as trial health economist. Additional trials will be identified systematically through the reviews in WP1, and by contacting all trialists listed in the NIHR "Advancing Care" Themed Review (11) (44 studies featured), the CLAHRC/ ARC National Work stream Report (55) (32 studies featured), and snowballing techniques. We have set up a database of potential studies for inclusion that monitors how IPD is requested and managed and that logs all contacts with trialists and respective ENRICH units.

A collaboration of trialists will make up the repository Steering Committee, to oversee sharing, combining and repurposing of their existing trial data. Together they will agree ground rules for the collaboration, including approval process for data requests. Based on conversations and confirmation of intention to participate, the repository will combine trial data for over 4200 residents from 254 care homes across the UK, with the potential to add seven more trials (representing 4166 residents from 384 care homes) as the repository develops.

Trial	**OPERA (56)**	**ChallengeDemCare**	**DCM-EPIC (57)**	**CHIPPS (54)**	**ELECTRIC (58)**
Data available	Now	Now	2019	2021	2021
PI	Underwood	Moniz-Cook	Surr	Wright	Booth
Location	England	England	England	England, Scotland & NI	England & Scotland
N participants	1054	832	1020	880	500
N care homes	77	63	50	44	20
Follow-up (months)	12	12	16	6	4
Treatment focus	Exercise for depression	People with Dementia	People with Dementia	Medication management	People with urinary Incontinence

Initial trials to include in Repository

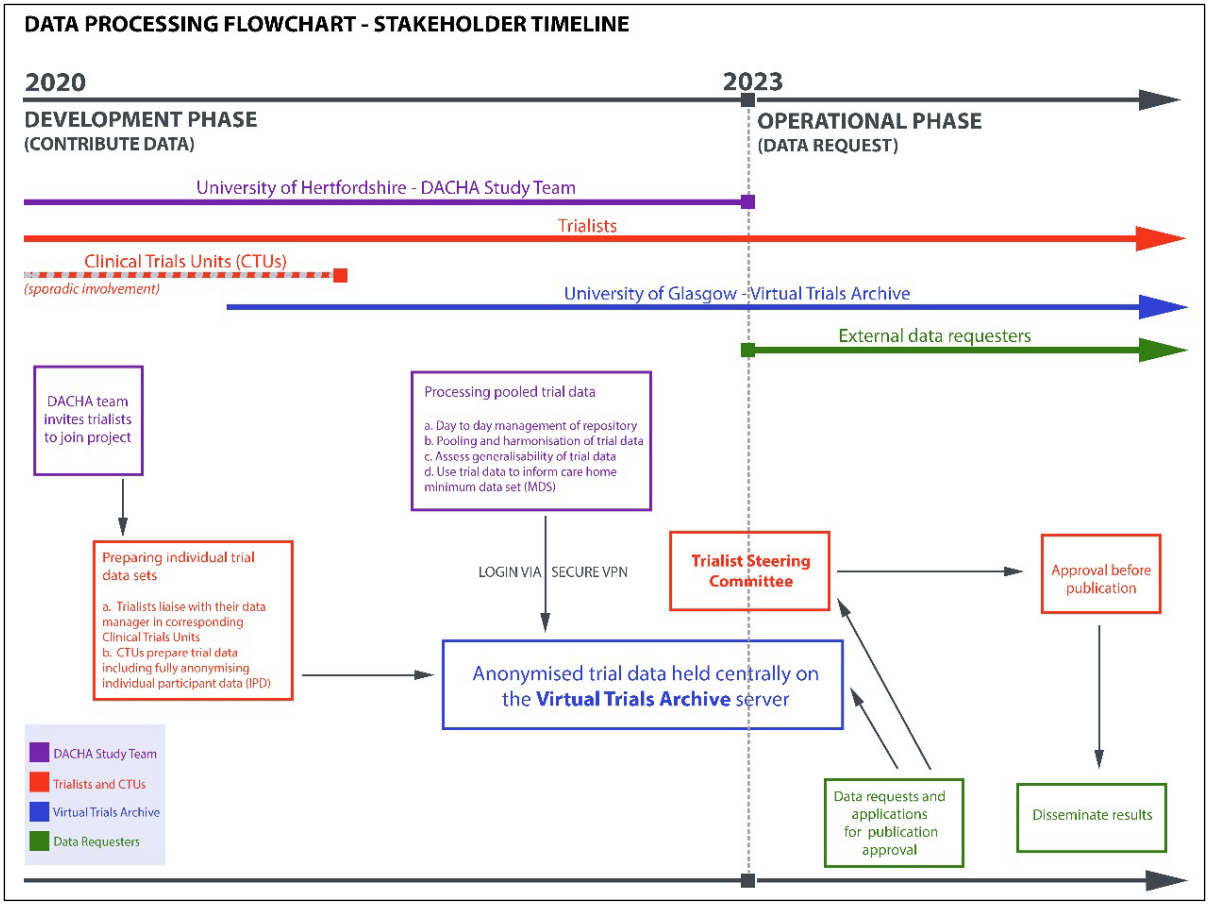
The repository will be set up as a parallel to (59, 60) similar collaborations (notably the VISTA stroke repository) and have infrastructure to host data securely and expertise to manage future trial inclusion and data access requests beyond the duration of DACHA.

Informed by WP1 and national consultation, key variables will be prioritised. Study characteristics (inclusion/exclusion, trial methodology, and intervention details), care home

specific details (staff ratios, staff retention, bed size, case mix, ownership) and individual participant level data (demographics, outcome measures, resource use, and medications) will be included. Variable names will be standardized, and data reorganized so that *pooled* individual patient data can be presented to future users in user-friendly datasets. We will report baseline characteristics about care homes and residents as derived from all pooled trial data, focusing on what data from trials may be appropriate to include in a MDS framework. Possible proxy measures for the outcomes listed in WP4 will also be explored, such as using prescribing data to identify long term conditions. We will also evaluate how generalizable the repository data is, compared to alternative data sources. Specifically, we will compare point estimates from data derived in WP4 (data collected from administrative sources e.g. CQC) and WP5 (data prospectively collected within the MDS framework). This will test if there is a difference in care home resident's participation in RCTs and observational studies and what can be derived from GPs, hospitals and social care.

Finally, drawing on the findings from WPs 1&3, feedback from the expert consultation groups, and with PPIE input (see text box below) we will prioritise questions for future use of the repository data. For example, can we use trial IPD to identify sub-populations of residents who are most likely to benefit from particular types of interventions?

The input of the consultation group will also be important at this stage in ensuring that the thinking around these issues remains oriented to the ultimate goal of successful implementation.



National Expert Consultation Exercise 1 (2021): *We will purposively recruit care home managers, care home staff, local authority commissioners, geriatricians and researchers, and primary care professionals to form separate expertise-based groups. They will meet online in separate expertise-based groups, with a max number of 10 participants per group, to review the early findings of DACHA, and talk about their use of care home data during the Covid-19 pandemic (what data from care homes were the most useful and of limited value for their work, and what types of data they used or shared the most during the pandemic). Researchers will facilitate and record the discussions to ensure all views are captured and where necessary follow up with telephone interviews for points of clarification or where there were polarised views within the group. Findings from the groups will be grouped and synthesised and fed back to participants for final comment. The final feedback report will be shared on the DACHA website.*

Work package 3 (WP) Development and implementation of an MDS
This WP has 3 elements: **(i) a realist review**; **(ii) mapping of care home generated data**, and **(iii) a consultation and priority setting exercise**. The aims are to:

- Develop an understanding of how a MDS could work in the UK context,
- Identify care home generated data that could contribute to an MDS
- Generate a matrix of potential variables and their characteristics, and identify stakeholder priorities for inclusion in an MDS.

(i) Realist review: We will draw on realist methods (61) to develop a theory driven understanding of how internationally deployed MDS systems offer transferable learning and/or utility for the UK. The realist approach assumes that causal mechanisms are embedded within particular contexts and social processes, and that it is crucial to understand the relationship between these mechanisms and the effect that context has on their operationalization and outcome (62).

Established MDS aim to support comprehensive assessment of the resident, their needs and linked care planning (63). The Inter RAI (International Resident Assessment Instrument) is the most commonly used MDS. It consists of a data collection form, a set of assessment items with identical definitions, time frames for observation specific to the long term care setting, built in protocols for clinical and quality assessment, triggers that identify residents at risk, status and outcome measures and user manual. Research has demonstrated the value of a MDS to commissioners and service providers in enabling identification of care needs and residents at risk of ill health (20, 64-68). In North America, where its use is mandated, it is used in large scale research and cross-national comparisons, for example in measuring the quality of care in different facilities. Our NIHR OPTIMAL study on NHS working with care homes employed an adapted interRAI. Whilst it was possible to identify resident characteristics associated with unplanned hospital admission, some measures were not appropriate for UK residents; staff found reported that it added to the burden of record keeping, and plus, its use did not influence care decisions. Other studies identify the need to integrate the use of MDS into the routines of the care home to achieve a sustained impact on resident outcomes (69). There is also evidence that residents with worse health status are more likely

to have missing data, it adds to work stress (affecting staff retention) and does not always capture what is important to residents and carers (27, 70-72).

To develop a theoretical understanding of how effective implementation of a MDS improves resident and organisational outcomes within the current care system the review will have three iterative stages: (1) Synthesis of review findings from WP1, linked work on integration of NHS, social care and CQC data, the use of Comprehensive Geriatric Assessment (73) in care homes and scoping of how MDS is represented as changing staff behaviours, practice and quality of care to achieve improved resident and service outcomes; (2) Development of likely 'Context-Mechanism-Outcome' (C-M-O) configurations to build an explanatory theory(or theories) of how a MDS might work in the UK that are tested in the evidence on MDS implementation; (3) analysis and synthesis of the programme theory (61, 74, 75).

Searches will be conducted from 2009 (to reflect the growing interest in MDS related research) purposive and iteratively, and will include MEDLINE, EMBASE, CINAHL, Social Sciences Citation Index, sources of grey literature and Google Scholar and lateral searches. The realist review protocol was registered on PROSPERO with the reference ID: CRD42020171323.

The outcomes of interest will be informed by WP1 as well as resident identified priorities for care from the PPIE work (if different to the research evidence) but will include, resident outcomes, staff adherence to MDS processes and resources used. The review will consider recurring patterns of association between contexts and mechanisms (demi-regularities) detectable across studies. It is likely analysis will be informed by systems thinking and organisational theories of change that focus on the way that values and beliefs defined at a strategic level are embedded across the workforce (76, 77).

Findings from the review will be tested further in with a mix of semi-structured and group interviews with frontline staff working with staff who use predominately paper-based records supplemented with resident specific digital data from monitoring technology) staff who have used e-records for two years or more. The realist review findings will directly inform how the development and introduction of a MDS in WP5 is conceptualised and implemented.

(ii) Scoping of international MDS content and mapping of care home generated data for inclusion in MDS: To identify the full range of data variables, scales and outcome measures used in MDS across the world, we will conduct a rapid scoping review of international MDS research on resident assessment and care. Using the libraries generated by searches for WP1 and the realist review, this review will chart the variables/outcome measures used and care processes or experiences evaluated. Our focus will be on outcomes relevant to resident quality of life and the provision/monitoring of care, but not available from existing health and social care data (e.g. on pain, social engagement).

We will use established methods (78, 79) and apply strict inclusion criteria (English language publications since 2009 identified by searches in WP1 and 2, observational or experimental study designs, data generated by MDS in long term care facilities for older adults). Data will be extracted and charted without quality assessment. This work will produce an accessible guide to the current content of international MDS and relate each data item to the component of resident care or experience being measured. Of direct relevance to WPs 4 and 5, the content review will also be a freely available resource for researchers, supporting the development of international comparative studies and MDS development.

(iii) Mapping of care home generated data for potential inclusion in MDS: Our previous work with care homes has identified multiple data sources specific to the care home that are not synthesised, shared or electronically stored. Care home providers collect information to

support care delivery and for reporting to commissioners and regulatory authorities. This includes technology generated data on resident vital signs and mobility, medication intake, preferences and risk assessments. This component of WP3 aims to map data collected by care home providers for their own use that has potential for inclusion in an MDS. We will compile a list of the content, form and use of care home generated data, and assess the willingness of care home providers to contribute data items to an MDS that is shared with external partners such as the NHS.

Participants: Working with a purposive sample of English care providers (110 or 20% of the 5500 organisations who run the 11,300 care homes in the UK) that will include the five largest providers who are responsible for over 20% of beds. The sampling matrix will account for funding source for care homes (not/for profit) and residents (self-funder, local authority, NHS continuing care); size of organisation; bed numbers; nursing/residential status; CQC rating and geographical location.

Intervention: The findings of the realist and scoping reviews will be used to develop a semi-structured telephone and online survey for care home providers and local regulators. This will collect objective data on what and how information (on care processes and delivery, resident characteristics, health status, functional ability and quality of life) is collected, collated and shared within care homes and provider organisations. We will address the issue of commercial sensitivity, with carefully worded questions on willingness to contribute to an MDS and barriers to data sharing. The survey will be discussed, piloted and launched with the cooperation of the Care Providers Alliance (who represent 11 national associations of independent and voluntary adult social care providers) and study steering group members from LaingBuisson, Four Seasons, Quantum Care and the Registered Nursing Home Association. Follow up by email (x2) and telephone (x2) will be used to boost response rate.

Outcomes: An overview of the range of data generated and collated by care home providers in England to support care delivery and to fulfil regulatory and governance requirements.

Matrix development. The findings of the scoping review and care home survey will be synthesised into a matrix that presents potential MDS content items, alongside characteristics such as ease of access, availability, cost of collection, and perspective (resident, clinical provider, resource manager, etc.). This visual display of potential MDS content, with pros and cons of individual items and scales clearly articulated, will be a resource for use in a priority setting exercise with the expert national collaboration (see below) and in discussion with stakeholders and the research team. Used in this way, it will inform the content and direction of WP5.

Consultation and priority setting: Working with the national expert consultation groups we will run a national consultation exercise. This consultation will use the evidence and expert opinion to build on the earlier stakeholder input to rank the evidence for resource requirements, ease of access, utility and relevance of items and scales identified.

Work Package 4 Data linkage of existing administrative data sources to inform the prototype MDS.

The NHS collects a huge amount of data, including the electronic medical record in general practice, administrative hospital data, and operational data sets from the emergency services, urgent care and community health. Local authorities (LA) also collect data on packages of social care funded publicly and needs assessments. This work package will identify, document (create metadata) and link these existing data sources together to establish a basis for the

MDS. This will demonstrate what a MDS could look like without the need of additional data collection by care homes.

Led by The Health Foundation (THF) who have experience bringing data together for research and evaluation within its secure data environment (34, 80-84) this WP focuses on three (two prior to the SWAP application) Integrated Care System (ICS) sites who have agreed to participate (Surrey Heartlands, Nottingham & Nottinghamshire, and North East & North Cumbria) to:

i. Identify and document sources of data on **all** care home residents in the three ICS held by health and social care.

ii. Create three linked administrative datasets on care home residents, one for each ICS.

iii. Demonstrate the benefit of routinely linking these data together by providing descriptive analysis of the linked data sets and share the results with the ICS and care home managers involved.

(i) Identify and document sources of data on care home residents held by health and social care: To test the feasibility of using data routinely held by NHS and Social Care to populate a MDS for improving quality of care as well as for research. The team will:

- Map out the data sets available in three Integrated Care Service sites, including existing information about the contents and scope of the data (Meta data), existing information governance agreements, and privacy impact assessments.
- Explore using address information stored in GP records. Address information can be used to identify care home residents that are self-funded, and not included in LA datasets.

Informed by the national findings from the expert consultation groups, by input from the care home based PPIE groups and the PPIE panel and WPs 1-3 the data sets will be prioritised based on which are likely to produce most value to the minimum data set. It will include hospital administrative data (from the Secondary Uses Service), GP records, local authority social care data, and data from urgent and emergency care and community health.

(ii) Create a linked dataset on care home residents for each ICS. Based on the priorities identified above, relevant data sets will be transferred, linked and processed in the secure data environment at THF. This is a complex process that involves agreeing with each of the relevant stakeholders the purposes of the data collection, the way in which patients and the public will be kept informed of the data processing, and the safeguards that will be put in place. All data will be processed in the ISO 27001 accredited secure data environment at the Health Foundation. It will also be 'pseudonymised' before the data are transferred. However, three linkage keys will be created: two of these will relate to the individual (one formed by encrypting the NHS number, and another by encrypting a combination of the person's initials, gender and date of birth, to be used to validate the linkage by NHS number or when the NHS number is not present) (81). The other key will relate to the address of the person involved, formed by encrypting the unique property reference number (84). We will support the data providers to assign the unique property reference number to their data sets where they are not already present.

The data linkage process will operate in two stages, the first will identify the information required to create the linkage keys required to link the data. Once created, we will extract the relevant information on care home residents from the various administrative data sources.

Information on clinical needs will be collected from NHS data (for example GP prescriptions and hospital data), and other information such as mobility assessments from social care datasets.

(iii) Analysis of the linked datasets, and presentation of results with the ICS and care home managers. Using the administrative datasets, we will demonstrate the benefit of routinely linking these data by providing descriptive analysis of these data to stakeholder in the ICS sites and care home managers involved in WP 5. Previous engagement with stake holders (34) demonstrated that descriptive statistics (e.g. a breakdown of the reason of admission to hospital for potentially avoidable admissions at care home level) are useful for care home managers. The specification of the descriptive analysis will be agreed with local stakeholders to ensure relevance and make explicit the data from routine data that could be linked with a care home generated MDS.

Once the linked datasets are established, we will liaise with analytical teams to gauge interest in using these data for further analysis and/or evaluation to further maximise the benefit of linking these datasets (e.g. the Improvement Analytics Unit, a partnership between NHS England and the Health Foundation, works closely with ICSs to evaluate their impact and might benefit from an existing linked dataset). This additional analysis is outside the scope of the current grant application.

National Consultation Exercise 2 (2022): Priority setting

Meeting 2 with the experts from various stakeholder groups (care home staff, care home managers, old age specialists (clinical/research), primary care professionals, commissioners, regulators, providers, and family relatives of care home residents/carers) will review the proposed Quality of Life (QoL) section of the Minimum Data Set, and help the DACHA team decide which QoL outcome measures can be prioritised in MDS inclusion. This consultation will be divided in two exercises (online surveys), and will take place on the THIS institute's Thiscovery platform. The first exercise will build on evidence from literature regarding the principles and aspects that QoL measures can capture; the stakeholders will rank the most important factors to have when measuring the QoL in care homes. . Before the second round, the findings from the first exercise will inform which QoL measures to shortlist for review by stakeholders. Based on literature evidence as well, the shortlisted tools will be applicable for care home use within the UK. In the second exercise, the stakeholders will be asked about their familiarity with the shortlisted QoL measures, their confidence levels in these measures, whether they would use them as part of their role if given the opportunity, and which dementia related QoL measure would be the best in capturing the QoL for care home residents living with dementia. Findings will feed into WP5.

Work Package 5 Longitudinal pilot of the MDS

Led by the Universities of Kent and Nottingham, WP5 has four aims:

- Assess the feasibility of collecting data directly from care homes with digital care records and matching this to native data to populate a complete MDS.
- Assess the quality of the MDS data, comprising care home-collected data alongside native data, to create a MDS with the minimum number of scales/attributes required.
- Demonstrate the utility of the matched MDS data to stakeholders (ICSs, CCGs, local authorities, providers and residents and their families).

- Systematically assess potential barriers and facilitators to wider implementation of the MDS.

Design: A mixed-methods longitudinal pilot of the MDS (including a protocol for integrating these with native data from NHS and social care databases to form the full dataset) in 20 care homes in each of our three partner ICS sites (N=60 homes).

WPs 4 and 5 will work with the three ICSs to identify care homes in their areas and work with us to identify priority research and service development questions that the MDS might help them address at the local level.

Work packages 1-4 will have informed the content of the MDS, taking into account its utility to key stakeholders in our three ICS sites (WP4). The final MDS, in addition to routinely collected data and care home-generated indicators is likely to include validated measures of assessment of resident priorities, function, symptoms, treatment and measures specific to social care. We will also capture data from care homes at baseline on the proportion of self-funders, number of NHS continuing care packages and funding to support rehabilitation and respite care. Given the rapid acceleration towards digital shared care records and the imminent establishment of a data framework for adult social care, this pilot will recruit only care homes already using digital care planning software in the participating ICS sites. The final content of the MDS will not be finalised until year three (after WPs 1-4) at which point ethical and governance approvals will be sought (including approval from the Association of Directors of Adult Social Services ADASS). It will consist of routinely held health and social care data and data extracted from care records. Clinical Research Networks will support resident recruitment within participating care homes. We will be working with the Care Software Providers Association (CASPA), a consortium of software providers (*https://caspa.care*), and two software companies (Person Centred Software (*https://personcentredsoftware.com/gb/*) and Nourish (*https://nourishcare.co.uk/*)).

Sampling: The WP5 study teams are based at Kent, Nottingham and Newcastle. Each will work closely with 20 care homes for older adults (total N=60 homes) in their closest participating ICS. Data held by the Care Quality Commission indicates that Surrey Heartlands ICS has 279 care homes (11,121 beds) for older adults, Nottingham and Nottinghamshire has 222 homes (8,451 beds) and North East and North Cumbria ICS has 636 homes (26,968 beds). Of these, at least 157 homes are eligible for inclusion in the study because they are routinely using digital care record platforms from the two participating software vendors. Care homes for learning disabilities will not be included in this study.

Assuming an occupancy rate of 90% (4), for our target sample to be representative of the resident population of these homes across the three ICS in total would be 302 (263 + 15% extra for attrition of sample over time). To achieve this sample size, we will first stratify care home selection by size, maintaining an even split of nursing and residential homes in each ICS, where possible. Small care homes (fewer than ten beds) will be excluded, and larger care homes in each ICS will be over-selected – we anticipate that approximately three out of every four care homes selected will be above average size (40 beds). We will exclude homes with less than ten beds from the study for three reasons:

- Smaller homes are more likely to close during the study and represent a higher risk within a longitudinal design;
- Small homes are an inefficient way to recruit a large cohort of residents, due to the initial administrative burden associated with recruiting each home
- To ensure an adequate sample size (i.e. to avoid under-recruitment).

For recruitment, we will then utilise a census approach where all eligible care home residents (long-stay/permanent beds) in participating homes will be invited to take part. We assume that there will be a 33% response rate using this approach (86). We aim to recruit 150+ residents in each ICS, where possible, to ensure that each geographic area is well represented. We anticipate that overall recruitment will be between 450-750 residents. Median length of stay for residents in care homes has been estimated at 15-18 months in England (87, 88), but this will vary by location and provider. We will liaise with care home managers to assess any potential issue with occupancy rates and attrition, looking to identify ways to resolve this, e.g. target higher response rates for specific homes, re-sampling of residents.

All permanent/long-stay residents will be eligible for inclusion in the study. We will support recruitment of adults without mental capacity by using established consultee process and an appointed independent consultee for residents with nobody to act on their behalf. Exclusion criteria would include residents receiving respite or on temporary/short-stay care, or people identified by the care home staff as being in the last week of life at the point of study inception.

Method Working with care homes who use digital care planning software will substantially reduce the data collection burden on participating care homes, as most of the data can be extracted digitally through the software without requiring new or additional form filling by staff. However, we anticipate that some resident-level data will not be collected regularly for all residents (e.g. some scales might only be completed or updated when the resident's needs change, rather than routinely recorded every month). Other data is unlikely to be captured at all or at least not in a way that is suitable for quantitative analysis (e.g. quality of life). In such cases, staff will be asked to update or complete a limited number of additional measures for every participating resident. New measures (e.g. for quality of life) will be integrated into the digital care records by the software vendors in a way that is familiar to staff using the system. This means that participating care homes will also be able to use the new and additional data for direct care, rather than for this information only to be of use for the research team. For example, information on residents' quality of life could be used by the homes to inform care by giving them a better understanding of residents' quality of life needs and outcomes.

The frequency of data input for the prototype MDS will have been determined as part of the co-design process in WP4. To understand how this is operating, we propose a longitudinal design with two data collection points (baseline and 6 months), consisting of an audit of the data from all consenting eligible care home residents in participating homes.

A longitudinal design will enable us to assess the feasibility of the tool by looking at completion rates and implementation over time and will also provide insights into seasonal variation. This will enable seasonal factors to be controlled for in the analysis when responding to the priority questions identified by the CCGs (e.g. hospital admissions from care homes and what affects this). It will also generate data into how seasonal pressures on the care home sector affect data completion rates.

Linking the resident data collected through the digital care records with the resident data collated from other sources in WP4, we will further compare what information can be accurately captured in existing administrative data, and what data has to be collected at care home level to create a valuable MDS. Linking the two datasets together provides an opportunity to validate the identification of care home residents in the administrative data, especially where self-funders are concerned.

After each wave of data collection, we will give participating homes from each cohort aggregated summaries of their MDS data, benchmarked against other resident data from the whole sample in their ICS. This will include administrative comparisons, such as MDS completion rates, as well as benchmarking indicators of residents' health, use of services and outcomes (e.g. ASCOT, if collected). Previous work by AMT suggests homes find this information valuable and that it can increase participation in research.

	MDS data completed/updated by homes	Data extraction	Feedback to homes	Focus groups and interviews
Wave 1	February / March 2023	March 2023	May 2023	May-June 2023
Wave 2	August/ September 2023	September 2023	November2023	November-December 2023

A member of staff from each home will be invited to participate in a focus group interview with other care homes from their ICS after waves one and two. Focus group interviews (up to 2 hours long) will explore:

- Implementation issues
- Applicability and utility for the sector
- Modifications to the MDS.

Focus groups will be facilitated by two researchers and audio -recorded. We will keep focus group interviews to a manageable size (up to 10 per group) running additional groups to accommodate the views of staff from all participating homes, if required. At the end of data collection period, we will conduct telephone or face-to-face interviews with key representatives in each ICS or CCG (n=9, 3 interviews per ICS) to explore their views of the implementation process and the relevance of the data to their local priorities. To systematically assess potential barriers and facilitators to the wider implementation of the MDS, the implementation aspects of these focus groups will be structured using the Consolidated Framework for Implementation Research (CFIR) (90).

A final stakeholder event will be held in each participating ICS area to present summary data on the MDS, constituent variables and linked health and social care outcomes. Group discussions will explore the utility and feasibility of the final MDS.

Support for homes

To provide appropriate support to homes throughout, each ICS will have a dedicated, local researcher from WP5 who will be their main point of contact for the duration of the study. A guide outlining the new measures and how to complete them in the digital care records system will be provided to each home. All of the measures included in the pilot will be rigorously tested questionnaires, which have been tested in care homes already and are designed to be completed by staff. This should improve implementation and reduce burden on staff. The researcher responsible for each ICS will remind homes to complete the fields included in the MDS before each wave of data collection and will be available to respond to questions as they arise.

Data synthesis and analysis

WP5 will generate care home level data from the MDS and pilot the process of matching this to native data sources, collated by The Health Foundation. In addition, there will be focus group data and interview data. As such, there will be both quantitative and qualitative data collected by the study at different levels (resident, care home, CCG and ICS). Plans for analysis of this data are described according to the aims they address below:

Assess the feasibility of collecting data directly from care homes and matching this to native data to populate an MDS. Analysis of the implementation process will be structured to test the findings of WP4 of what enables uptake and use of MDS in care home settings and what is perceived by different stakeholders as key to successful uptake (shared aims, utility, ease of use). Data from each ICS will be analysed separately, to identify local area themes and then together to identify common themes for national learning. We propose to use NVivo 11 for Windows (QSR International Pty Ltd) to store and analyse the qualitative data.

Understanding measurement attributes of the MDS and how care home organisational factors impact these. Basic descriptive statistics will be used to describe measurement attributes of variables within the MDS, including completion rates, median/mean and measures of distribution, and floor and ceiling effects (proportion of candidates returning lowest or highest score respectively). Regression analysis will be used to consider the influence of baseline care home contextual factors on completion rates. An initial step will consider the effect of individual organisation characteristics on completion rates, using student t-test, Mann Whitney U and chi squared for parametric, non-parametric and categorical variables respectively. We will then use multiple linear regression for continuous variables such as care home size, and multiple logistic regression for categorical variables such as care home type, to build a model that explains the impact of care home organisational factors on completion rates. Variables will be entered stepwise in the model in an order determined by the strength of association in univariate analysis, with candidate variable removed from the model if they don't contribute to the effect

Considering the psychometrics of the MDS. The MDS data will be assessed for feasibility by completeness (percentage missing data) and timeliness of completion. Data quality will be evaluated by reporting descriptive statistics, including percentage floor and ceiling. Where data are collected from two sources (i.e. from care homes or residents vs. routinely-collected datasets), they will be compared to determine potential redundancy of items. For validated measures (e.g. the Adult Social Care Outcomes Toolkit), exploratory factor analysis will be used to identify the underlying factor structure of the data in the MDS. We will also examine the internal consistency of participants' responses (i.e. whether items tap into a single underlying construct) using Cronbach's alpha statistic (Cronbach, 1951).

Demonstrate the utility of the matched MDS data to the local CCGs. To demonstrate the utility of MDS data, we will work with The Health Foundation team and the four CCGs that have supported the pilot studies in care homes to assess priority areas. There are a number of potential analyses and the choice of which to use will depend on the data held in the MDS. These include substitution analysis, drivers of average total cost, and evaluating specific interventions. For example, one area that could be explored is the impact of social care related quality of life on health care use, the latter measured by number of GP visits, hospitalisations, total costs to the NHS, etc. Another would be exploring the sensitivity of outcomes measures

in the MDS to changes in residents' health and functional abilities over time, controlling for baseline characteristics. Quantitative analysis using appropriate econometric techniques will be used to analyse the data, exploiting the longitudinal nature of the data.

National Expert Final Consultation Exercise (2023-24)
The final consultation will be held online and will bring together the participants from previous consultations. To widen the discussion of the findings the final consultation will invite participants who are members of the stakeholder groups (that is: who live, visit, work in and with care homes) and the members of the Study Steering Committee to engage with the findings and their implications for practice, commissioning, and future research. Participants will receive a briefing prior to attending. The findings will be presented and followed by an online exercise with questions about the implications of the DACHA work presented. The participants will be asked about their recommendations, which will later feed into the final report. The consultation findings will prompt the DACHA team to discuss and review the views, recommendations, and priorities for implementation.

Studies within a Project (SWAPs) – 2022 onwards

1. Additional ICS inclusion

The Social Care SWAP relating to the extension of the ICS regions in WP4 and WP5 will be integrated into both work packages. This additional site (North East and North Cumbria in addition to the original ICSs; Nottingham and Nottinghamshire, and Surrey Heartlands) will help in establishing a complementary resident data set generated from routine Local Authority (LA) and NHS data (WP4) and recruiting an additional 20 care homes with which to pilot the MDS (WP5). This work will address under representation in the DACHA study of underserved, socio-economically deprived communities. The North-East region of England has the lowest healthy life expectancy of any region with men and women spending a larger proportion of their shorter lives in not good or poor health.

This SWAP will also enable researchers to work with a health and social care system with a track record of proactive working with care homes during the Covid-19 pandemic and a network of engaged practitioners.

2. DACHA MDS in Domiciliary Care (DACHA-DOM)

The Social Care SWAP will explore the potential to extend DACHA's work on a minimum data set in care homes (MDS) into domiciliary care and will be carried out for 12 months from February 2022. This SWAP will be standalone and not a part of the previous work packages. In UK there are over 10,000 registered domiciliary social care providers serving almost one million clients. Yet little information is available on older care recipients, and we lack a systematic approach to sharing data as people access different services.

Methods

1. Scoping review on information collected in home care settings

International scoping review to understand the different ways 'homecare' providers collect information about their clients in different countries, and how such information is stored and used and appraise the design, content, structure or application of systems for

collecting data in homecare. This scoping review will contribute towards developing an evidence based MDS for home care.

2. National survey on existing data collection by UK homecare organisations in England

To investigate the types of information homecare organisations collect, how it is stored and used, and who can access it. It will also ask homecare providers about their views about contributing to national data set on people who use homecare.

3. Consultations about the content, feasibility and acceptability of a minimum data set for homecare.

Building on our survey findings, we will use discussion groups and interviews with key stakeholder groups (senior and front-line staff, clients and families, commissioning organisations, national leads) to hear their views about: what information should be contained in a MDS for homecare, the extent to which the DACHA Care Home MDS applies to homecare, and how acceptable and practical would be a MDS for home care.

We will use the Consolidated Framework for Implementation Research (CFIR) to help interpret findings and structure our understanding of factors that might support or hinder the introduction of an MDS into home care, drawing on the consultation work and, other parts of the work.

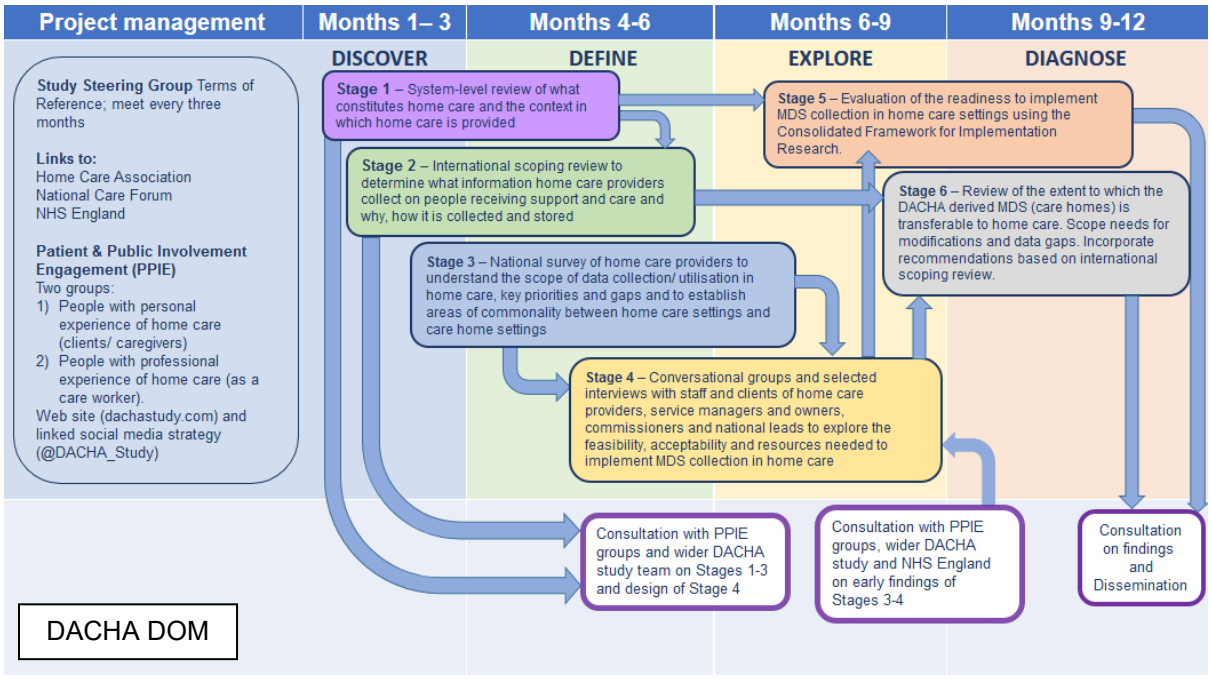
4. Adaptation of Minimum Data Set to the home care setting

The final stage of the work will provide practical recommendations to adapting the Minimum Data Set developed by the DACHA team for use in care homes, to home care settings.

Outputs

- A position paper to define and discusses the data challenges in homecare using the Consolidated Framework for Implementation Research (CFIR) as a diagnostic tool for system-level information prior to implementation. This paper considers how ambiguities related to the scope, purpose of home care and current organisational features pose challenges to the implementation of a MDS in homecare.
- An overview of international variation in homecare data collection/utilisation practices.
- A summary of the extent and range of data collection in domiciliary care.
- A summary of domiciliary care stakeholder, client and family, and commissioners', views on an MDS in this setting to inform future work.
- An initial specification for the DACHA MDS, adapted for domiciliary care services, ready to pilot/implement/evaluate (if appropriate).

Schedule



3. The Use of Assessment Tools by Care Home Staff

There has been accelerated uptake of digital care planning and recording software within UK care homes. However, it is not known how staff complete such assessments and the response an assessment may trigger. Some research instruments capturing aspects of older adults' mental health have not been validated in the care home context. Most were designed for self-report or clinician diagnosis. Self-report can be problematic for those living in care homes due to cognition and communication difficulties.

This Multiple Long-Term Conditions SWAP will explore how care home staff understand, complete, interpret and use the assessment tools and scales within their digital care software to evaluate and support the quality of life and wellbeing of residents. It will be embedded within Work Package 5 (Pilot of prototype MDS) and responds to priorities from DACHA PPIE workstream.

Methods:

Two-part semi-structured interviews with care home staff and managers (n=40, min of 12 in each ICS site) in participating homes will be undertaken face-to-face or online, depending on the preferences of those involved.

Part one will use a 'think aloud' technique commonly used in cognitive interviewing, to better understand how staff interpret questions and choose response options as they complete scales/questions included in the pilot MDS on the mental health, quality of life and wellbeing of a resident with multiple long-term conditions.

In part two, once these scales/items have been completed for the resident they have in mind, we will take a semi-structured approach to explore how making and recording an assessment of a resident's mental health and wellbeing triggers staff actions/responses. This second part in critical to understanding how an MDS might inform and benefit the direct care of care home residents.

Outputs:

The findings of the SWAP will help to address a recurring issue, that international MDS are invariably health-dominated, to the detriment of assessing quality of life for residents living with the cumulative impact of multiple conditions. Part one of the interviews will document how care staff understand, interpret and complete the tools used, at the item level, including any issues with item acceptability, comprehension or completion, and will be used to inform decisions regarding the recommended MDS content, alongside the quantitative data analysis in WP5. Part two will ensure that critical domains, which cannot be measured by administrative or NHS data, can be operationalised from within digital care software to inform direct care. This has a benefit to the development of an MDS, but more broadly to other researchers looking to use routinely collected care home data in their research. Such methods are likely to be preferred as a sustainable method, without requiring researcher to be physically present within the care home.

DISSEMINATION, OUTPUTS AND ANTICIPATED IMPACT

The goal is to produce resources for those researching, living in, and working in and with care homes and to ensure these are clinically relevant and nationally informative. The national collaborations and organisational partners are the basis of our dissemination strategy. The study has a website (https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/ageing-and-multi-morbidity/dacha-study), and maintains a social media presence (monthly blog, and Twitter). Alongside the national consultation and review process that are threaded through the project each WP will work with the ARCs (formerly CLAHRCs) in the care home collaboration, to share briefings about findings and resources relevant to their partners and to ensure that local implementation issues are identified early. Conference presentations and papers in professional and academic journals will be produced from each WP. We will organise 3 half-day dissemination events targeting different audiences and will work with the King's Fund and My Home Life, Professional Record Standards Body, Health Education England and the Care Provider Alliance.

Outputs

WP1 – Care home resource and guidance (available online and as briefings) for researchers and those supporting care home research and innovation

WP2 – Trial repository (ongoing development post-funding)

WP3 – Evidence of what is known about the implementation and content of Minimum data sets relevant for English systems of care and a prototype care home generated resident MDS

WP4 – Resident data set developed from routinely collected health and social care data

WP5 – Prototype MDS that aligns with clinical and care records standards

Anticipated Impact for stakeholders

For residents and family: US research using MDS has demonstrated how information about resource use and resident care can inform care home selection and quality assessment. A

MDS supports identification of residents' care priorities, implementation of evidence based approaches, ensures secure transfer of personal information and reduces the burden of research on the individual.

Care home staff & providers: A MDS prioritises collection of resident focused information, increases visibility of residents' needs and areas for building capacity in the workforce to support them. Through integration of data it makes explicit care homes' roles and impact in intermediate care, palliative care and service innovation. It reduces research burden on care home staff.

MDS as a resource for integrated working: Shared care records and the use of linked health and social care datasets reduce duplication of effort, identify care gaps and improve productivity. Previous research and the Vanguard care homes demonstrated the importance of recognising care homes as part of the health care economy. A MDS could support working methods that facilitate assessment, review, and continuity of care across organisations. Our work with domiciliary care will inform development of MDS for this setting.

Supporting equity of access to health and social care: A 20-year history of research describes the ad hoc nature and inequity of health care provision to care home residents. This research provides the resource to address this and ensure equity of access to health care.

Research and planning: Despite a proliferation of care evaluation measurement tools many are of questionable quality and relevance to the UK systems of care. The development of a RCT repository for secondary data analysis on key issues (e.g. medication optimisation), resources to build research capacity in care homes plus standardized, organised, accessible MDS offers the resources necessary to measure the impact of different initiatives and models of service delivery. As noted above, a MDS enables implementation of evidence-based practices and thus will offer researchers a powerful tool to support the co-production of research and implementation of research findings.

For care home providers: The study addresses the heterogeneity of the care home market and ever-increasing range of IT solutions for data capture. A MDS can inform how future systems standardise data for individual care management and service improvement

National government and wider society: Understanding the role of care homes in the continuum of care for complex adults. An improved understanding of the care home population and evidence of the positive role care homes play in UK society would contribute to improving attitudes towards long-term care provision and resource

Further development: If we are able to demonstrate the feasibility and utility of a Minimum Data Set, we anticipate that it will be added to and adapted as care in this sector and digital capability expands. Further work will be needed to standardise its use for system wide uptake across the different providers and developers of IT systems for care homes.

PROJECT/RESEARCH TIMETABLE

Plan of investigation and timetable	
Research team set up meetings. Meetings with staff in Integrated Care Systems sites to put in place permissions and governance for accessing data (Nottinghamshire and Surrey Heartlands) Recruitment national expert consultation groups. Confirmation of study steering committee	Completed prior to start of study

Set up Activity Provider (The National Activity Providers Association) meetings with care home resident groups to meet regularly throughout the project. Set up a PPIE panel to meet regularly throughout the project (AK,SF JM,IL,SB)	1-3 months then ongoing until 53m
Work package 1 and 2 Reviews and trial repository Design development and testing of care home research resources (GP,SK,LI,JB with input from CG,AK, AG)	1-48m
WP 3 Realist review, scoping review, survey and consultation with expert consultation groups Development of prototype MDS (CG,BH, KS,SB with input from ALL)	7-52m
WP 4 Integration of resident health and social care resident data sets in Nottinghamshire and Surrey Heartlands (AS, with input from JB,AMT,AG,CG)	12-50m
National expert consultation events X 3 Consultation 1: 18m Consultation 2: 32-36m Consultation 3: 48-52m (CG,KS,IL,BH,AG,JM,SB,LI)	
WP 5: Ethics submission, recruitment and MDS intervention and analysis (AMT, AG with input from ALL)	20 - 50m
Studies within a Project (SWAPs) (AMT, AG, AW, BH, AK)	29- 54m
Dissemination of preliminary findings and expert consultation Final Report Workshops and dissemination of findings (ALL)	50-54m

PROJECT MANAGEMENT

Claire Goodman will lead and oversee the project supported by an administrator. The research team will meet every 8 weeks alternating between face-to-face meetings in London and online meetings. Work Package leads and their research staff will meet monthly and circulate updates to the rest of the team.

The study steering committee will meet every six months, with the first meeting taking place in March 2020. The committee consists of members with expertise in health and care home sectors, IT, PPIE, data analysis, data governance, and implementation of interRAI.

ETHICS AND REGULATORY APPROVALS

The study will adhere to the UK Framework for Health and Social Care research and require HRA and Association of Directors of Adult Social Service (ADASS) approvals. Working with The Health Foundation team we will establish the individual permissions, information governance and approvals required to support the resident data sharing and commercial sensitivities. Where additional data has to be collected prospectively, and then linked, we will work to a consent acceptable to NHS digital.

PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT

Sue Fortescue, a former carer and retired IT specialist, joined the research management team as a co-applicant and stayed on the project until 2021**.** Building on the preparation of the bid and links with representative organisations the aim is to have an infrastructure that fosters ongoing conversations, both formal and informal, both within and across work packages. To keep the person being cared for at the centre of our thinking in ways that inform delivery of care/patient benefit we will convene two care home based resident PPI groups that meet over the life of the study.

Previous work by members of the team (91) have identified the value of developing job specifications with PPIE members to ensure that expectations around involvement are shared. To achieve this and maintain continuity of involvement for the life of the study a UH researcher will be the link person with administrative support for PPIE representatives providing feedback on study progress and the impact of their involvement (92, 93).

In addition to the PPIE involvement in the national expert consultation group and the study steering groups, involvement from staff in direct care roles and management roles, family carers and representatives of people living with dementia will be achieved by setting up a PPIE panel. The panel meets throughout the life of the research project and offers a hub-and-spoke model of PPIE where each work package is working with up to three PPIE representatives.

PROJECT RESEARCH /EXPERTISE

The research team has extensive experience of working in and with care homes and have in the last 10 years together and independently completed over 35 externally funded care home studies. Particular expertise includes social care and building capacity in care home research (JM,AMT,SB,KS,AK,AG), social care and primary care workforce (KS, BH, CG), integrated working between health and social care (CG,BH,AG), geriatric medicine, nursing and quality improvement (ALG,JB,SB,CG,JM), health economics (LI), implementation science (IL,CG), data analytics, tracking residents' care across health systems, large health and social care datasets (AS,JB,AG), PPIE (SF,AK,JM,IL), evidence review, realist review and data synthesis (CG,KS,GP,SK), method expertise in assessment tools and MDS development (AG,AMT).

SUCCESS CRITERIA AND BARRIERS TO PROPOSED WORK

The success of the study will be judged by

- The level of engagement and consensus achieved at each stage of the study from care home representatives, residents and families, health and social care commissioners, providers and the regulator
- The delivery of online and published research resources evaluated as useful by researchers and care home staff and a RCT repository that can improve the effectiveness and efficiency of care home research
- The delivery of a MDS that links routine resident data with care home generated data that supports commissioning, planning, delivery and evaluation of resident care

RISKS	Mitigation
The project is too ambitious and not achievable within the timescale of the study	The study has addressed the whole commissioning brief linking findings about the range of measures and outcomes used in care home research, implementation challenges with work on the development and use of an MDS. The allocation of senior staff to lead each WP and build a cumulative programme of work ensures that it will deliver to time and target. Success relies on the active engagement of the different stakeholders. The proposal is grounded in a national collaboration of care home researchers working with local

	NIHR research organisations, social care providers (National Care Forum, Care England, Care Providers Alliance) and relatives of residents. Complemented by links with Your Care Rating (www.yourcarerating.org) CQC, Cabinet Office, international care home networks and MDS initiatives. The need for a MDS to standardise how information is shared and improve the public understanding of care homes is a priority. The study is ambitious but there is the cross-sector commitment, expertise and a national infrastructure of support to sustain it to completion.
The research resources and RCT repository are not used	The NIHR Dissemination Centre review (11) emphasised the need to move beyond descriptive work, resources and a repository for secondary data analysis builds research capacity and the scope for analysis of resident and staff needs.
Heterogeneity of care home market &multiple systems of data collection leading to partial uptake and resistance to change	There is a cross-sector consensus that a workable MDS could support residents 'access to health care, experience of care and quality review and reduce duplication of effort. This project provides the structure for standardisation and cross sector working. Work packages 1-4 systematically address the range of resident data and related outcomes, how care homes use and collect data and the potential to link this to existing datasets to create an MDS. The involvement of the Professional Records and Standardisation Board in the consultation and dissemination events ensures that outputs from the project could be incorporated into national records.
Existing MDS and linked commercial systems are established. This duplicates prior work.	This study addresses the content, utility and feasibility of using existing MDS. We have argued they provide a partial account of the resident experience, have not gained traction in England, superimpose a layer of administration and do not link with routinely collected care data. Dr George Heckman is an interRAI Fellow at Waterloo University with experience of the Canada Health Infoway (CHI), a single point of contact for health information standards. He has agreed to be an international expert to maximise opportunities for shared learning.
Resident consent and data governance	This is addressed throughout the study and the findings will demonstrate about what needs to be in place to develop a resident MDS that merges multiple data sources.
Care home and NHS staff will not co-operate.	By using established approaches from design and implementation science potential obstacles to implementation are identified early. Ongoing engagement with stakeholders will allow us to reduce and streamline data entry demands on staff. The involvement of the Professional Record Standards Body, the experience of The Health Foundation with NHS England plus the PPIE involvement will help to 'future proof' the MDS.
Data protection and resident privacy	Standard operating procedures will ensure data is protected. All data processing will be on the Health Foundation's purpose-built secure data environment that is accredited to hold and process patient information.

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Glossary of Abbreviations and Meanings

Acronym	Meaning
ACT	Alberta Context Assessment
AHSN	Academic Health Science Networks
ARC	Applied Research Collaboration
ASCOT	Adapting the adult social care outcomes toolkit
CFIR	Consolidated Framework for Implementation Research
CCG	Clinical commissioning group
NIHR ARC	National Institute for Health Research Applied Research Collaborations (formerly known as NIHR CLAHRC)
NIHR CLAHRC	National Institute for Health Research Collaborations for Leadership in Applied Health Research and Care
CQC	Care Quality Commission
CTU	Clinical Trials Unit
ENRICH	Enabling research in care homes network
GP	General Practitioner
InterRAI	International Resident Assessment Instrument
ICS	Integrated Care Systems (https://www.england.nhs.uk/systemchange/integrated-care-systems/) Ten regionally determined pioneer integrated health and social care systems Established April 2018 and using new tools for understanding local health data
IPD	Individual patient data
LA	Local authority
LTCF	Long-term care facilities
MDS	Minimum Data Set
NIHR	National institute for Health Research
PPIE	Patient and Public Involvement

PPIE	Patient and Public Involve and Engagement
QOF	Quality and Outcomes Framework
RCT	Randomized Controlled Trial
THF	The Health Foundation