DACHA

Developing resources And minimum data set for Care Homes' Adoption

DEVELOPING A MINIMUM DATASET FOR OLDER ADULT CARE HOMES IN THE UK: THE DACHA STUDY

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On behalf of the DACHA team

FUNDED BY NIHR | National Institute for Health Research

SPONSORED BY University of Hertfordshire UH

SUPPORTED BY NIHR | Applied Research Collaboration East of England

Policy challenges of the care home sector

Divided from the NHS….. **but** key partner

Heterogenous, independent sector.
11,000 care homes >65s : 5,000 different providers.

Nearly half self-funders or paying top ups

No centralised system of control or voice

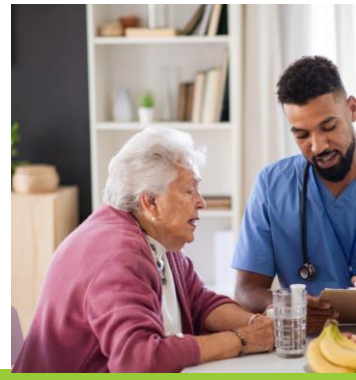
Under-valued, under resourced, misunderstood

How to incorporate care home data in Integrated Care Systems

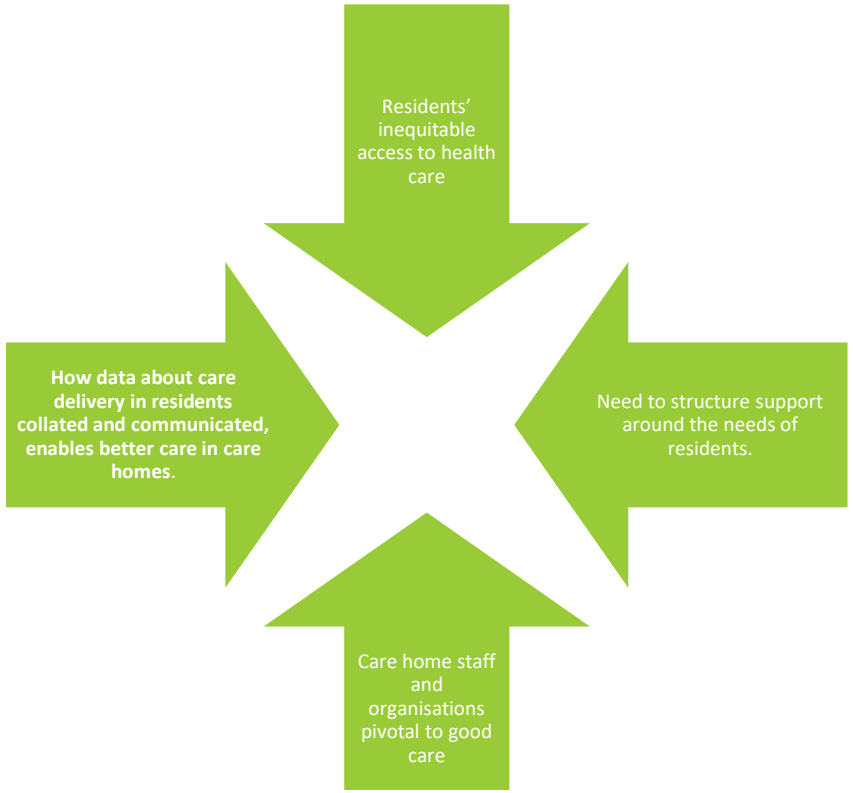
"The UK needs a new model of care for older adults. The large and diverse network of independent providers does not look like a resilient form of provision and is likely to have become even less resilient following the pandemic

…". Mary Daly

(Daly 2020 https://doi.org/10.1111/spol.12645)



Research leading up to DACHA



"In the UK.....a risk that whole services are designed without consulting the residents and care home staff .... majority of NHS England initiatives have been designed with preventing care home resident admissions to hospital as a primary focus"

From Warkworth House to the 21st century care homes: progress marked by persistent challenges

FREE

Adam L Gordon ✉, Karen Spilsbury, Wilco P Achterberg, Rich Adams, Liz Jones, Claire Goodman

Age and Ageing, Volume 51, Issue 7, July 2022, afac169, https://doi.org/10.1093/ageing/afac169

University of Hertfordshire UH · University of Cambridge · University of East Anglia · University of Exeter · University of Glasgow · University of Kent · University of Leeds · Newcastle University · The University of Nottingham · NCF The National Care Forum · The Health Foundation

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DACHA principles

- **Measure what matters** most to support those living in care homes through systematic data collection and sharing.
- **Evidence based** in design and content, based on co-production with key stakeholders.
- **Reduce** data burden and duplication of effort for the care home.
- **Underpinned** by digital care planning and records systems, serving the day-to-day needs of residents, staff, families, and friends.
- **Include** information on the care home service, individual-level resident data, and staffing model that supports them
- **Bring together** data from within the care home, **with** data held externally about residents and care services.
- **Data sharing** with external users of the MDS **has an agreed purpose**. Data sharing pathways defined and formalised. Residents' privacy protected.
- Care homes **access and use** the data they collect and share using electronic dashboards.
- **Requires national** infrastructure and integration with existing data systems.

Burton, J. K., et al. "Developing a minimum data set for older adult care homes in the UK: exploring the concept and defining early core principles." The Lancet Healthy Longevity 3.3 (2022): e186-e193. https://doi.org/10.1016/S2666-7568(22)00010-1

DACHA

DACHA 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 an agreed data set **- (Minimum Data Set) -** usable and authoritative for different user groups.

Study Deliverables for working in and with care homes

Guidance on resident assessment, outcome measurement and implementation of innovation

New methods to support staff and resident engagement in research

Trial repository for secondary data analysis

(currently 6000+ older people, 340 care homes)

Prototype MDS tested in three Integrated Care Systems (ICS)

Recommendations on implementation of MDS for social care

DACHA study design Underpinned by ongoing public involvement and care home stakeholder engagement

Build on **existing evidence** and best practice : reviews of outcome measures and international minimum data sets

Identify and consult on **care home-generated variables** that capture the needs of those living in care homes, and outcomes that matter to residents, families and friends

Combine care home-generated data with administrative and NHS data

Demonstrate how a minimum data set meets the information needs of a range of stakeholders and users

Evidence

Development and implementation of an MDS
(Hanratty et. al)

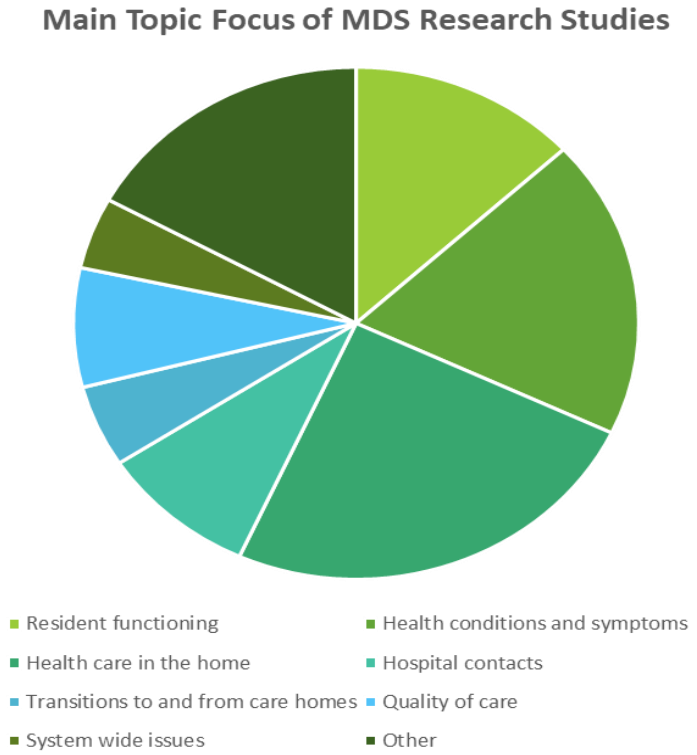
National Survey of 273 providers representing 5000 care homes

- **Care home resident data**
  - Collection (what, why, how)
  - Storage (what, how, where)
  - Sharing (who, how, barriers)
- **COVID accelerated adoption of technology**
- **Data on medications, health conditions, frailty, cognition, and NEWS (National Early Warning Score) updated monthly**
- **Limited use of quality-of-life measures**

National Consultations: representatives from 5 stakeholder groups

Professional Records Standards Body review

REVIEW OF MDS CONTENT *of existing MDS used routinely in care homes e.g., North America, NZ and regions of Belgium, Netherlands and Australia*



What does almost ***everyone*** collect?

Topic	% of respondents whose homes collect these data
Independence One to one care Sensory impairments Mobility and balance Help with eating, drinking, dressing bathing, using the toilet, transfers	>95%
Activities Social activities Getting outdoors *Physical activity 84%*	>95%
Preferences and priorities for care Advance care planning Do not resuscitate	> 90%
Continence Incontinence Continence aids Bowel movements *Urinary output 75%*	*>86%*

What does almost ***everyone*** collect?

Topics	% of respondents whose homes collect these data
Consultations with health care professionals GP, nurses, Allied Health Professionals, hospitals	>98%
Diet and nutrition	>95%
Hygiene Bathing frequency and preference Oral health Foot, hand, nail, hair care	> 90%
Communication Hearing, speech, languages *Signing 64%* *Literacy 70%*	*>90%*

Examples of clinical measures and tools in use

Stool Charts 86%

Frailty measures 55%

Pain scales 89%

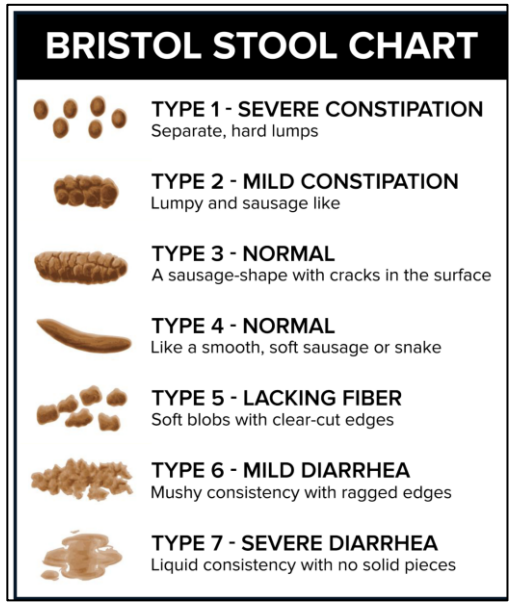
National Early Warning scores 36%/RESTORE 45%/SBAR 31%

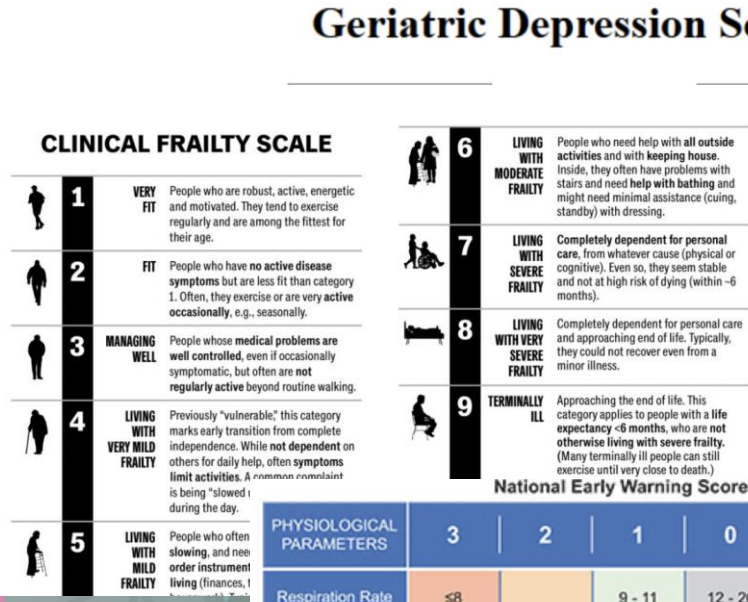
Nutrition scores 72%

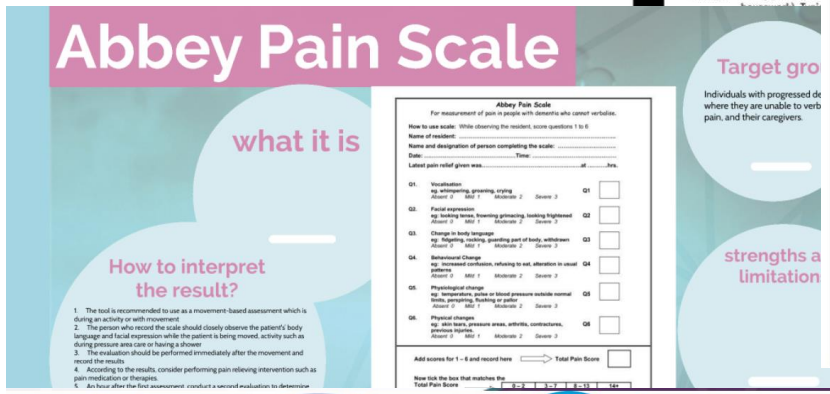
Skin status scores (Waterlow 85%)

Depression and anxiety 25%

Quality of life score 15%







National Early Warning Score (NEWS)*

PHYSIOLOGICAL PARAMETERS	3	2	1	0	1	2	3
Respiration Rate	≤8		9 - 11	12 - 20		21 - 24	≥25
Oxygen Saturations	≤91	92 - 93	94 - 95	≥96			
Any Supplemental Oxygen		Yes		No			
Temperature	≤35.0		35.1 - 36.0	36.1 - 38.0	38.1 - 39.0	≥39.1	
Systolic BP	≤90	91 - 100	101 - 110	111 - 219			≥220
Heart Rate	≤40		41 - 50	51 - 90	91 - 110	111 - 130	≥131
Level of Consciousness				A			V, P, or U

RESTORE2™

Recognise Early Soft Signs, Take Observations, Respond, Escalate

Implementation

Implementation MDS : 50 papers

What works when and in what circumstances at the resident level of care?

- **Mandate with ongoing training** across **multidisciplinary** team
- **Basis** for within and cross care home conversations
- **Asset for care** not an administrative distraction
- Addressing **what matters** to care home staff and **valuing** their contribution
- **Digital literacy and ongoing support**

*"Depending on who was confident enough to use MDS and the supporting technology, who had permission to use it and opportunity to inform the MDS **either** created a sense of shared endeavour **or** led to parallel systems of information exchange for the purposes of care. Linked to this was how resident data could be shared to inform care with **outside** organisations".*

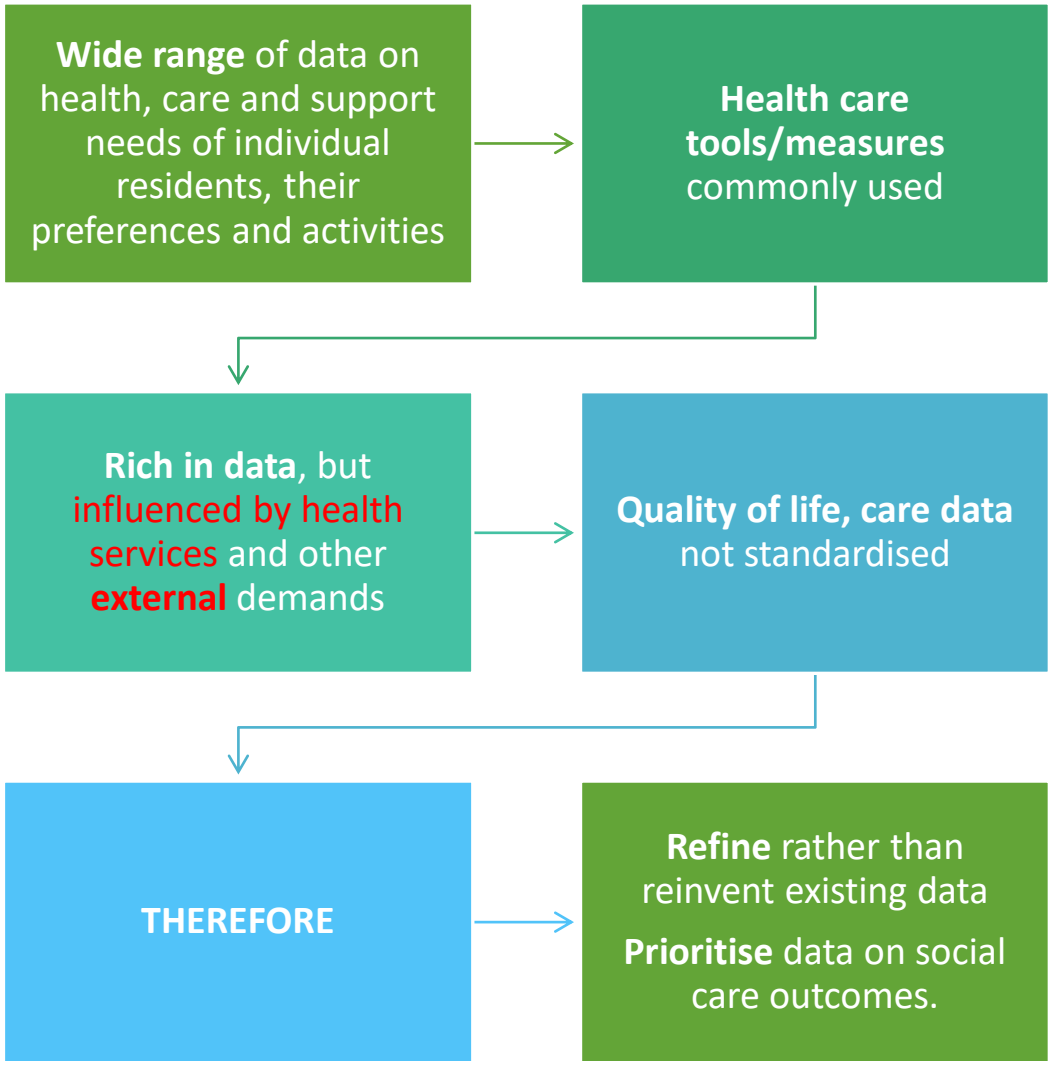

Musa et al. BMC Geriatrics (2022) 22:33
https://doi.org/10.1186/s12877-021-02705-w

BMC Geriatrics

RESEARCH Open Access

The uptake and use of a minimum data set (MDS) for older people living and dying in care homes: a realist review

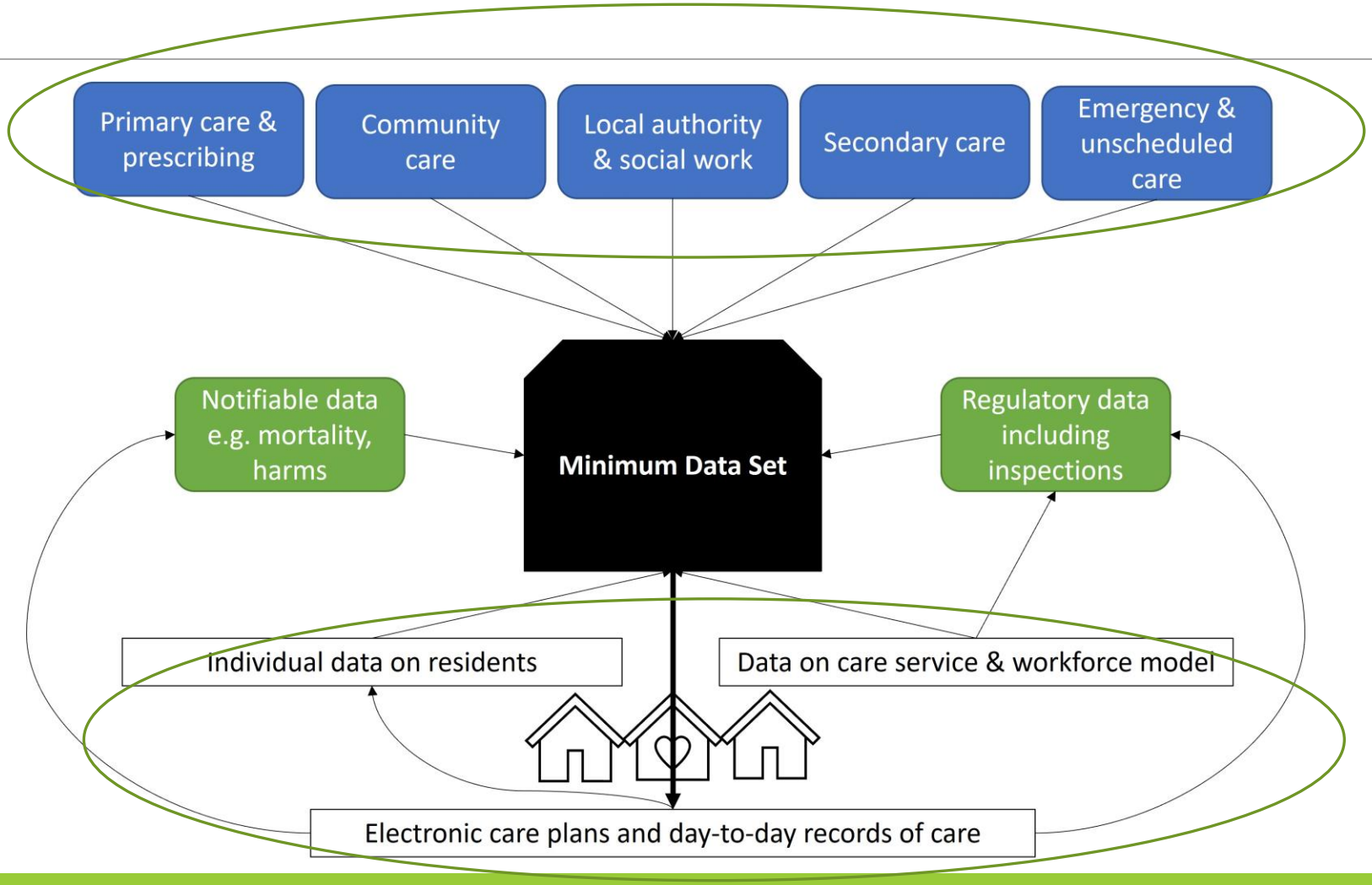
Massirfufulay Kpehe Musa[1], Gizdem Akdur[1], Sarah Brand[2], Anne Killett[3], Karen Spilsbury[4,5], Guy Peryer[6], Jennifer Kirsty Burton[6], Adam Lee Gordon[7,8], Barbara Hanratty[9,10], Ann-Marie Towers[11,12], Lisa Irvine[1], Sarah Kelly[13], Liz Jones[14], Julienne Meyer[15] and Claire Goodman[1,16*]



Implications for MDS

Structure of the DACHA care home prototype MDS

Routine Data
The Health foundation



Care home data

Burton et al (2022): https://doi.org/10.1016/S2666-7568(22)00010-1

DACHA
MDS variable categories

Demographics
Palliative care needs
Care home stay
Resident needs
Quality of Life
Complications and adverse events
Diagnoses
Medication and vaccination
Health care utilisation
Home and workforce characteristics

Testing a Minimum Data Set in Care Homes in England

A **longitudinal pilot** of the minimum data set (MDS) completed by care homes in three ICS sites

Data from care home software (NOURISH, PCS) + additional measures

- 996 care home residents from 45 care homes consented across three ICS sites.

- Assess feasibility of collecting data **directly** from care homes and **linking** this to **routinely** collected health and social care data
- Assess the quality of MDS data, to **create a MDS with the minimum number of scales/attributes required**;
- **Evaluate the utility** of the matched MDS data to stakeholders (ICSs, providers, residents and their families);

DACHA

Existing data sources

Demographics: Personal Demographics Service

Palliative care: GP data

Resident needs: GP data (cognition), Secondary User Services data (oral/nutrition status), community datasets (continence).

Complications/adverse events (GP data, secondary user services data, ambulance data, 999 data)

Diagnoses (GP data)

Medication and vaccination (GP data)

Healthcare utilisation (GP data, 111, 999, community services, ambulance, secondary user services data.

Care home characteristics (CQC)

Workforce characteristics (Skills for Care)

Data linkage in three ICS

Changes and pressures in wider health system: merger NHS England / NHS Digital, creation of ICBs, impact of pandemic

Different stages of development: some sophisticated systems, scope for pooled learning.

Information Governance (IG): difficult to access IG resource to support data applications at national and regional level different requirements and limited resource across both.

ICS level: Different landscapes to understand for data access and linkage, combined with limited available resource to support

Changes in recording systems e.g. fundamental change to how care home residents are identified in NHS England dataset

Requires **linkage of expertise** and ongoing conversations about design, access and implementation achievements and challenges.

Data from care homes

MDS data already held in DSCRs :

- Demographics – resident characteristics
- Care Home Stay
- Resident needs
- Complications / adverse events
- Diagnoses
- Medication and vaccination
- Health care utilisation

Measures we needed to add:

Cognition (Cognitive Performance Scale)

Delirium (Informant Assessment of Geriatric Delirium)

Activities of daily living (Barthel)

Quality of life….

More than health!

Social relationships and personhood, a safe and supportive environment enabled to take risks

Consultation with different groups who use and need data about residents

No consensus on what quality of life is but some areas of convergence

Difficult decision to have proxy measures to include ALL residents

Included four validated outcome measures added to the MDS

Quality of life measures

Constructs	Measures
QoL for older people	ICECAP-O*
Social care-related QoL	ASCOT-proxy*
Health-related QoL	EQ-5D-5L (proxy)*
Disease specific (dementia)	QUALIDEM

*Preference-weighted for use in economic evaluation

MDS data from DSCRs: staff views

- Staff understand and support an MDS as a basis for interdisciplinary working

"it's kind of helping us to simplify sharing data amongst different teams and professionals" (manager)

- Working with software vendors is feasible and reduces burden on staff

"we use [software] and it's just really easy actually to use this assessment…we didn't have any problem actually to do them because we'd already done just something similar." (manager)

"So, in my view, I am hoping that this will help streamline, reduce the workload." (RN)

- Additional measures perceived as an asset for care, not an administrative distraction

"[QoL assessments] It is extremely important. If we don't have this information, we won't be able to care for people in the way we need." (manager)

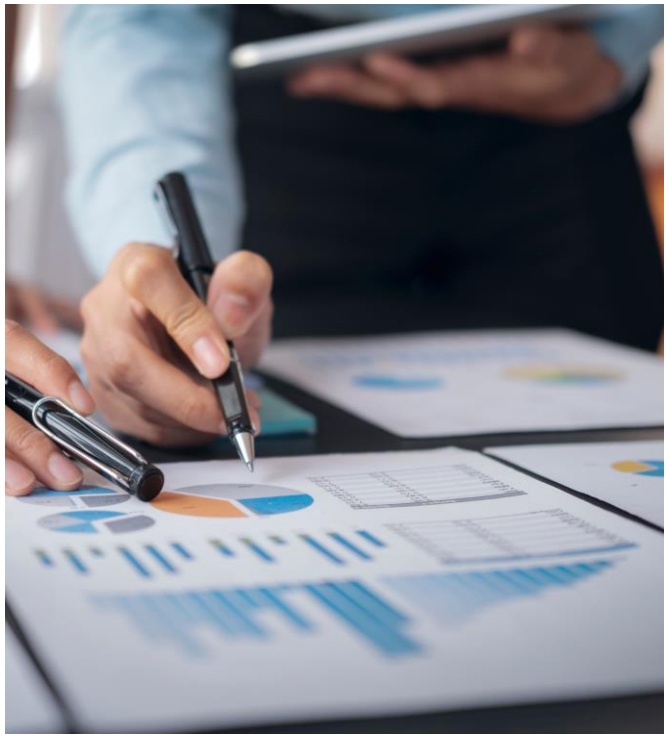
Emerging findings from prototype MDS

- **Feasible**: possible to extract MDS data from care homes using DSCRs
- **Acceptable**: staff completed additional variables; see value; potential to reduce data burden.
- **Partial uptake** if key people move or systems change, needs sustained engagement from care home to authorise/ upload data. (61% residents data uploaded so far)
- **Information governance**: care homes are data controllers and software vendors data processors
  - Different processes for managing this within the software: implications for future national rollout
- **Scalability:** Exploit opportunities to work with existing software and data capture practices to harmonise data sources and support interoperability

Next steps :

- Making explicit what the MDS can and cannot achieve for different stakeholders and what is reasonable for care homes.
- Developing strategies now to ensure MDS data is the resource for decision making, delivery and review across stakeholder groups.
- Demonstrating what is useful and usable feedback for care homes and other stakeholders

KEEPING the **MINIMUM** in the Minimum Data Set !!



The pandemic revealed invisibility of UK care home residents

Exposed data failings that have hindered service development and research for years.

Post covid Policy priority :

A Minimum Data Set as a resource for health **and** social care, not just regulation or cost containment.

Shared digital social care record

Care home residents become **part of a data system**

Conclusion

Care homes already collect, use and share vast amounts of data as part of everyday care for residents, regulation & oversight

Time spent collecting new/additional data **is time not spent delivering care and has a cost**

Address health bias & include quality of life and social care measures.

An MDS that **refines and adapts** existing methods of data capture is possible.

Investment in MDS implementation across different stakeholder groups and systems of care **key** to deliver meaningful engagement

FUNDED BY NIHR | National Institute for Health Research

SPONSORED BY University of Hertfordshire UH

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Thank you!

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Project website: www.dachastudy.com

Survey and review of MDS Barbara Hanratty Barbara.hanratty@newcastle.ac.uk

Care home resident data set from routine data Therese.Lloyd@health.org.uk

MDS prototype Ann-Marie Towers a.towers@kent.ac.uk and Adam Gordon adam.gordon@nottingham.ac.uk

Age and Ageing 2023; 52: 1–10
https://doi.org/10.1093/ageing/afad069

REVIEW

Outcome measures from international older adult care home intervention research: a scoping review

Sarah Kelly[1,2], Andy Cowan[1], Gizdem Akdur[3], Lisa Irvine[3], Guy Peryer[4,5], Silje Welsh[6], Stacey Rand[7], Iain A. Lang[8,9], Ann-Marie Towers[10,11], Karen Spilsbury[12,13], Anne Killett[4,5], Adam Lee Gordon[14,15], Barbara Hanratty[16,17], Liz Jones[18], Julienne Meyer[18,19], Claire Goodman[3,5], Jennifer Kirsty Burton[6]

Suddenly social care data matters! So let's future proof it properly

July 7th, 2021 | Categories: DACHA Blog

Age and Ageing 2022; 51: 1–2
https://doi.org/10.1093/ageing/afac070

ITORIAL

lsing linked health and social care data to nderstand service delivery and planning and nprove outcomes

Keywords: Older people, long-term care, social care, data

Key Points

- The COVID-19 pandemic has highlighted the need for reliable, routinely collected, shared care data.
- Existing linked data sets are not comprehensive enough to accurately predict demand for long-term care in England.
- The DACHA study will pilot linking health and social care data for service planning and delivery.

Adult social care provides short or long-term support with many essential activities of daily living, such as washing, social care amongst older adults (age 75 and over) and build a predictive risk model forecasting future service use.

The Northwest London Discover Database, which is used in the research [2], links data from primary, secondary and tertiary care, community and mental health care, emergency departments and social care. The linked data contain rich information of participants' sociodemographic characteristics and health conditions. However, its power to accurately predict demand and access to adult social care is limited by a lack of data on key indicators, such as availability of informal support (whether or not the person lived alone was missing for 82% of the sample), the individual's socioeconomic status and if they were funding their own social care. Unsurprisingly, the study found that individuals were more likely to receive long-term, publicly funded adult social care if they were older, lived in areas with higher socioeconomic deprivation and had a preexisting mental health or neurological condition (which are likely to be associated with loss of function and independence in old age). The lack of

Age and Ageing 2022; 51: 1–16
https://doi.org/10.1093/ageing/afac014

QUALITATIVE PAPER

Contextual factors influencing complex intervention research processes in care homes: a systematic review and framework synthesis

Guy Peryer[1,2], Sarah Kelly[3,4], Jessica Blake[5], Jennifer K. Burton[6], Lisa Irvine[5], Andy Cowan[3], Gizdem Akdur[5], Anne Killett[1,2], Sarah L. Brand[7,8], Massirfufulay Kpehe Musa[5], Julienne Meyer[9], Adam L. Gordon[10,11], Claire Goodman[5,2]

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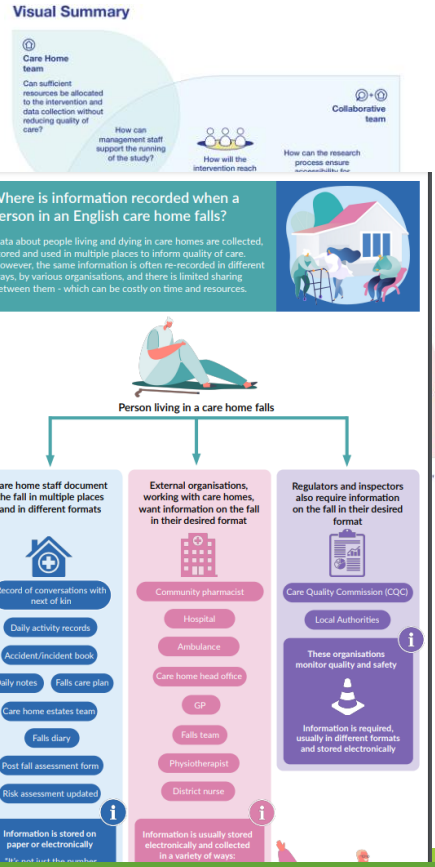
http://dachastudy.com

Visual Summary



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Ensuring trial interventions in care homes have their best chance of success

A Visual Guide

Inside: Key considerations for rese
home teams across each stage of t
process - from designing the proto
undertaking an evaluation.

Back: A visual summary of the mo
features of collaboration.

Check for updates

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3 University of Hertfordshire, Hatfield, UK
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http://dx.doi.org/10.1136/bmj.m2463
Published: 24 June 2020

Covid-19 and lack of linked datasets for care homes

The pandemic has shed harsh light on the need for a live minimum dataset

Barbara Hanratty, [1] Jennifer Kirsty Burton, [2] Claire Goodman, [3] Adam L Gordon, [4] Karen Spilsbury[5]

Residents of care homes are centre stage in the covid-19 pandemic for all the wrong reasons. Home to vulnerable people with complex needs, these settings should have been an obvious focus and priority in pandemic planning.[1] Almost half of newly admitted residents in the UK are transferred from hospitals, creating a resident population with wide ranging needs spread across 450 000 beds in almost 11 000 homes.[2 3] This is more than double the number of beds in NHS hospitals,[3] but unlike NHS facilities most homes are privately owned, with residents responsible for some or all of the costs of their care.

was introduced in England to generate data on care home bed occupancy and staffing.[11]

To date there has been no national, systematic approach in the UK to develop care home datasets or to exploit their full potential to enhance residents' care. We are collaborating on a study to design, develop, and implement a minimum dataset for UK care homes such as that developed in the US for the Centers for Medicare and Medicaid Services.[12] The learning from covid-19 will directly inform this work, and we intend that any minimum dataset built for UK care homes should be a resource to support residents' care and not just a tool for regulation or cost containment.

DACHA

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

Musa et al. BMC Geriatrics (2022) 22:33
https://doi.org/10.1186/s12877-021-02705-w

BMC Geriatrics

RESEARCH Open Access

The uptake and use of a minimum data set (MDS) for older people living and dying in care homes: a realist review

Massirfufulay Kpehe Musa[1], Gizdem Akdur[1], Sarah Brand[2], Anne Killett[3], Karen Spilsbury[4,5], Guy Peryer[2], Jennifer Kirsty Burton[6], Adam Lee Gordon[7,8], Barbara Hanratty[9,10], Ann-Marie Towers[11,12], Lisa Irvine[1], Sarah Kelly[13], Liz Jones[14], Julienne Meyer[15] and Claire Goodman[1,16*]

Abstract

Background: Care homes provide long term care for older people. Countries with standardised approaches to residents' assessment, care planning and review (known as minimum data sets (MDS)) use the aggregate data to guide resource allocation, monitor quality, and for research. Less is known about how an MDS affects how staff assess, provide and review residents' everyday care. The review aimed to develop a theory-driven understanding of how care home staff can effectively implement and use MDS to plan and deliver care for residents.

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

Jennifer Kirsty Burton, Arne Timon Wolters, Ann-Marie Towers, Liz Jones, Julienne Meyer, Adam Lee Gordon, Lisa Irvine, Barbara Hanratty, Karen Spilsbury, Guy Peryer, Stacey Rand, Anne Killett, Gizdem Akdur, Stephen Allan, Priti Biswas, Claire Goodman

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

Lancet Healthy Longev 2022; 3: e186–93

Institute of Cardiovascular a Medical Sciences, University Glasgow, Glasgow Royal Infirmary, Glasgow, UK (J K Burton PhD); Improvem Analytics Unit, The Health Foundation, London, UK (A T Wolters MSc); Centre for Health Services Studies (A-M Towers MSc) and Perso Social Services Research Uni

Irvine et al. Trials (2021) 22:157
https://doi.org/10.1186/s13063-021-05107-w

Trials

STUDY PROTOCOL Open Access

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))

Lisa Irvine[1*], Jennifer Kirsty Burton[2], Myzoon Ali[2], Terence J. Quinn[2] and Claire Goodman[1,3]

Abstract

Background: Approximately 418,000 people live in care homes in the UK, yet accessible, robust data on care home populations and organisation are lacking. This hampers our ability to plan, allocate resources or prevent risk. Large randomised controlled trials (RCTs) conducted in care homes offer a potential solution. The value of detailed data

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