EXPLORING AND ENHANCING HOW RESIDENTS’ DATA ARE SYSTEMATICALLY CAPTURED AND USED.

Claire Goodman on behalf of the DACHA team

Centre for Research in Public health and Community Care - University of Hertfordshire

Lead Ageing and Multimorbidity Theme NIHR ARC East Of England
Care homes hiding in plain sight...

Need for linked routine health and social care data with information from care homes. Collated, accessible data on residents' health and service use to support resident focused planning & care.

Making care homes part of a data system a postCOVID-19 priority.

DACHA Study reporting 2024.
What care home staff tell us about data

Would like to sit round a table and discuss what data are meaningful and how these could be shared across organisations (Care Quality Commission, Local Authorities Clinical Commissioning groups)… too often being asked for the same information in different formats by different people… could agree a core set of data.

Approach to data collection has changed over time used to be more relational about quality improvement, now more punitive and focussed on monitoring.

Money wasted to change care plan systems. Mixed messages e.g. national nutritional screening tool not recognised as valid by all organisations.

The heart of all this is the resident themselves and what they want and what means most to them.
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.
DACHA: Five interlinked work packages Nov 2019- Oct 2023

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<th>Work package</th>
<th>Description</th>
<th>Team Leaders</th>
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<td>Review of Care home intervention research assessment, outcome measurement and process</td>
<td>Sarah Kelly, Guy Peryer</td>
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<td><strong>2</strong></td>
<td>Creation of a Care home trial repository</td>
<td>Lisa Irvine, Jenni Burton</td>
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<td><strong>3</strong></td>
<td>Review of content and use of Minimum Data Sets (MDS) and Survey of data care homes collect</td>
<td>Barbara Hanratty, Claire Goodman</td>
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<td><strong>4</strong></td>
<td>Mapping and characterisation of resident data in existing NHS and Local Authority data sets in two Integrated Care Systems (ICS)</td>
<td>Arne Wolters, Adam Steventon</td>
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<td><strong>5</strong></td>
<td>Piloting and implementation of a MDS in 40 care homes in two ICS</td>
<td>Ann-Marie Towers, Adam Gordon</td>
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**Underpinned by:**

**National consultation groups (five groups) x 3:** Sarah Brand, Anne Killett, Adam Gordon, Barbara Hanratty, Karen Spilsbury, Anne Killett, Julienne Meyer, Sue Fortescue
Work Package 3: Development and implementation of an MDS

**SURVEY:**

- Care home resident data
  - Collection (what, why, how)
  - Storage (what, how, where)
  - Sharing (who, how, barriers)

- COVID-19 changes to resident and staff data collection

**Pilot work**

Aggregate data (daily/monthly) collected for external scrutiny (Care Quality Commission, Local Authority Contracting, Clinical Commissioning Groups, different NHS services, Health and Safety/environmental (duplication ++++, minimal feedback)

Individual Resident data: residents care needs e.g. medication, wound care, those at risk (e.g. nutrition, falls, infection, choking), changing care needs e.g. palliative care, key events, visiting NHS staff input

Staff and Staffing information

Unclear how as resident data changes over time data guides care home based conversations about day to day care

Hybrid systems for recording and storage (digital & paper) in different locations within care home

**REALIST REVIEW** to understand what supports use and uptake of MDS and possible utility for UK care homes.

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

- Mandate with support and training focusing on how all staff can use it to guide care

- Clinician involvement and partnership in resident data use, sharing and discussion

- Data literacy that goes beyond skills in data entry

- Limited evidence of how changes in residents’ priorities or family views are incorporated
Research studies using MDS data: *early findings*

758 included studies. Particular interest in pain, depression and oral health

DACHA Scoping Review
Annual number of empirical studies published using MDS care home data 2011-2021

Main Topic Focus of MDS Research Studies

- Resident functioning
- Health conditions and symptoms
- Health care in the home
- Hospital contacts
- Transitions to and from care homes
- Quality of care
- System wide issues
- Other
## Work Package 4: Data linkage of existing routine data sources

<table>
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<th>Building</th>
<th>Building on work and expertise with NHS England Vanguards e.g. identifying residents</th>
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<tr>
<td>Linking</td>
<td>Linking relevant administrative health and social care records centred around the care home resident</td>
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<tr>
<td>Using</td>
<td>Using routinely collected data aim to minimise burden on care homes to collect data.</td>
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<tr>
<td>Working</td>
<td>Working with 2 Integrated Care Systems (ICSs), and 40 care homes to build a prototype resident Minimum Data Set</td>
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- **Focus:** making linked data sets - used for direct care - available for secondary use (e.g. commissioning, service evaluation or research)

- **Resources permitting,** extending coverage of the prototype MDS beyond 2 Integrated Care Systems (ICS).

Led by

[The Health Foundation]
• **Service evaluation vs research**
  - Most administrative data collected for direct care purposes.
  - Secondary use of these data governed by rules and legislation.
  - Depends on the purpose of the re-use of the data:
    - Strict information governance guidelines needed for creating linked administrative datasets.
    - The minimum dataset pseudonymised, no residents can be directly identified.

• **Interoperability**
  - Administrative data sources in health care standardised (to some degree), and regularly re-used.
  - Social care data varies by provider or local council, less standardised.
  - Linked dataset in two distinct ICS areas: identify data items routinely collected across two sites.

**Ownership**

Once linked, descriptive analysis to demonstrate the value of these data, and share learning with the local ICSs.

**Data platforms**

Exploring how access to these data might be provided.
Work Package 5: Testing a Minimum Data Set in Care Homes in England

- Builds on previous work packages
- A longitudinal pilot of the minimum data set (MDS) completed by care homes in two ICS sites
- 600+ care home residents across two ICS sites.

- Assess feasibility of collecting data directly from care homes and matching this to routinely collected health and social care data to populate a complete MDS;
- Assess the quality of MDS data, to create an MDS with the minimum number of scales/attributes required;
- Evaluate the utility of the matched MDS data to external stakeholder organisations and individuals (e.g. local authorities, NHS providers, residents and their families);
Summary

- Care homes challenged by current & increasing demands for data from different organisations
- An MDS offers wide ranging opportunities to enhance care
- Data linkage enhances the potential of MDS, without burdening care homes
- Multiple measurement tools are available - but few in common use
- Ensuring measures are feasible and practical for the UK context is key.
- Need focus on implementation of approaches to data capture to ensure relevance for residents’ daily care
- DACHA study seeking to establish a core dataset based on resident-level information, linked to wider data sources.
Thank you!

c.goodman@herts.ac.uk

@HDEMCOP   @DACHA_Study

Project website: [www.dachastudy.com](http://www.dachastudy.com)

Work package 3 survey and review of MDS  Professor Barbara Hanratty  Barbara.hanratty@newcastle.ac.uk

Work package 4  Arne Wolters Arne.Wolters@health.org.uk
Acknowledgements


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