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Developing resources And minimum data set for Care Homes' Adoption

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

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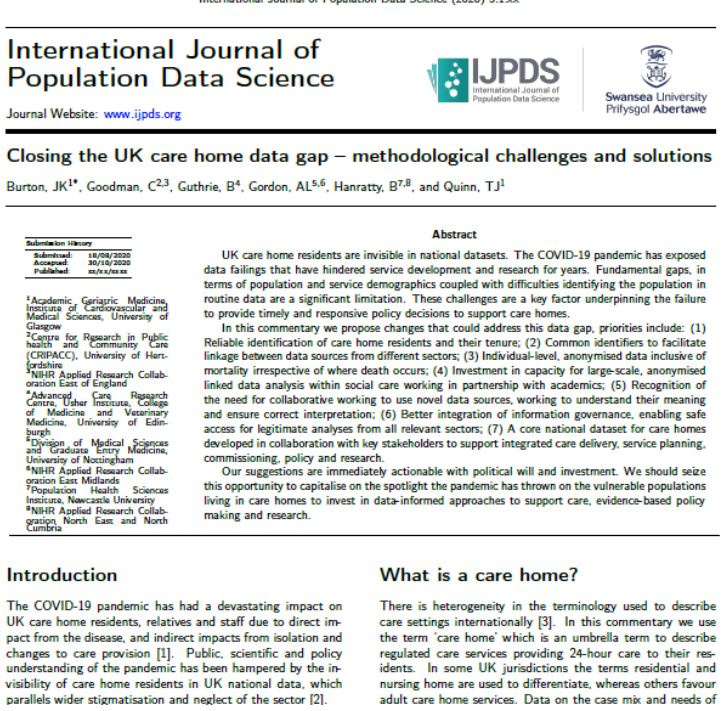
Care homes hiding in plain sight…

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.



International Journal of Population Data Science

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IJPDS International Journal of Population Data Science

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Closing the UK care home data gap – methodological challenges and solutions

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Abstract

UK care home residents are invisible in national datasets. The COVID-19 pandemic has exposed data failings that have hindered service development and research for years. Fundamental gaps, in terms of population and service demographics coupled with difficulties identifying the population in routine data are a significant limitation. These challenges are a key factor underpinning the failure to provide timely and responsive policy decisions to support care homes.

In this commentary we propose changes that could address this data gap, priorities include: (1) Reliable identification of care home residents and their tenure; (2) Common identifiers to facilitate linkage between data sources from different sectors; (3) Individual-level, anonymised data inclusive of mortality irrespective of where death occurs; (4) Investment in capacity for large-scale, anonymised linked data analysis within social care working in partnership with academics; (5) Recognition of the need for collaborative working to use novel data sources, working to understand their meaning and ensure correct interpretation; (6) Better integration of information governance, enabling safe access for legitimate analyses from all relevant sectors; (7) A core national dataset for care homes developed in collaboration with key stakeholders to support integrated care delivery, service planning, commissioning, policy and research.

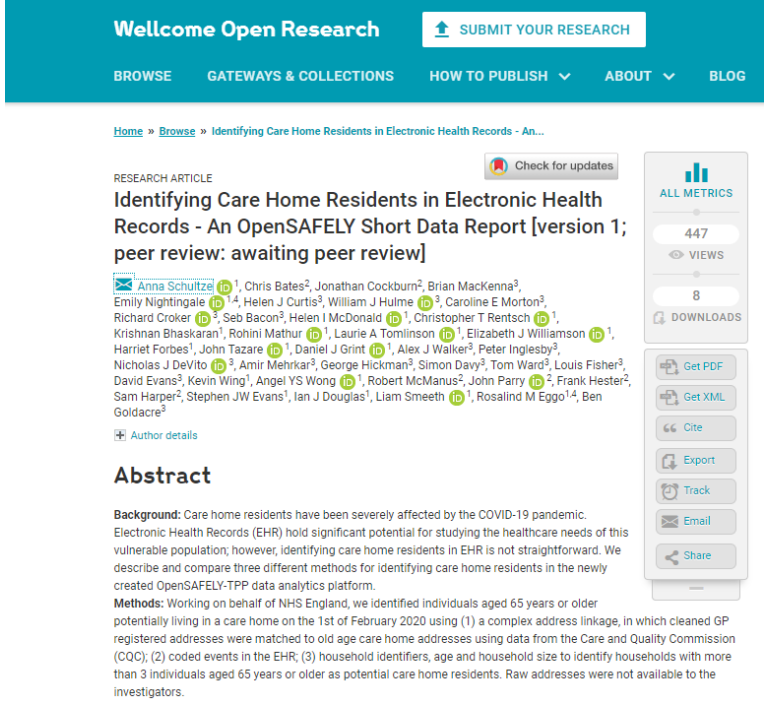
Our suggestions are immediately actionable with political will and investment. We should seize this opportunity to capitalise on the spotlight the pandemic has thrown on the vulnerable populations living in care homes to invest in data-informed approaches to support care, evidence-based policy making and research.

Introduction

The COVID-19 pandemic has had a devastating impact on UK care home residents, relatives and staff due to direct impact from the disease, and indirect impacts from isolation and changes to care provision [1]. Public, scientific and policy understanding of the pandemic has been hampered by the invisibility of care home residents in UK national data, which parallels wider stigmatisation and neglect of the sector [2].

What is a care home?

There is heterogeneity in the terminology used to describe care settings internationally [3]. In this commentary we use the term 'care home' which is an umbrella term to describe regulated care services providing 24-hour care to their residents. In some UK jurisdictions the terms residential and nursing home are used to differentiate, whereas others favour adult care home services. Data on the case mix and needs of



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RESEARCH ARTICLE

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Identifying Care Home Residents in Electronic Health Records - An OpenSAFELY Short Data Report [version 1; peer review: awaiting peer review]

Anna Schultze[1], Chris Bates[2], Jonathan Cockburn[2], Brian MacKenna[3], Emily Nightingale[1,4], Helen J Curtis[3], William J Hulme[3], Caroline E Morton[3], Richard Croker[3], Seb Bacon[3], Helen I McDonald[1], Christopher T Rentsch[1], Krishnan Bhaskaran[1], Rohini Mathur[1], Laurie A Tomlinson[1], Elizabeth J Williamson[1], Harriet Forbes[1], John Tazare[1], Daniel J Grint[1], Alex J Walker[3], Peter Inglesby[3], Nicholas J DeVito[3], Amir Mehrkar[3], George Hickman[3], Simon Davy[3], Tom Ward[3], Louis Fisher[3], David Evans[3], Kevin Wing[1], Angel YS Wong[1], Robert McManus[2], John Parry[2], Frank Hester[2], Sam Harper[2], Stephen JW Evans[1], Ian J Douglas[1], Liam Smeeth[1], Rosalind M Eggo[1,4], Ben Goldacre[3]

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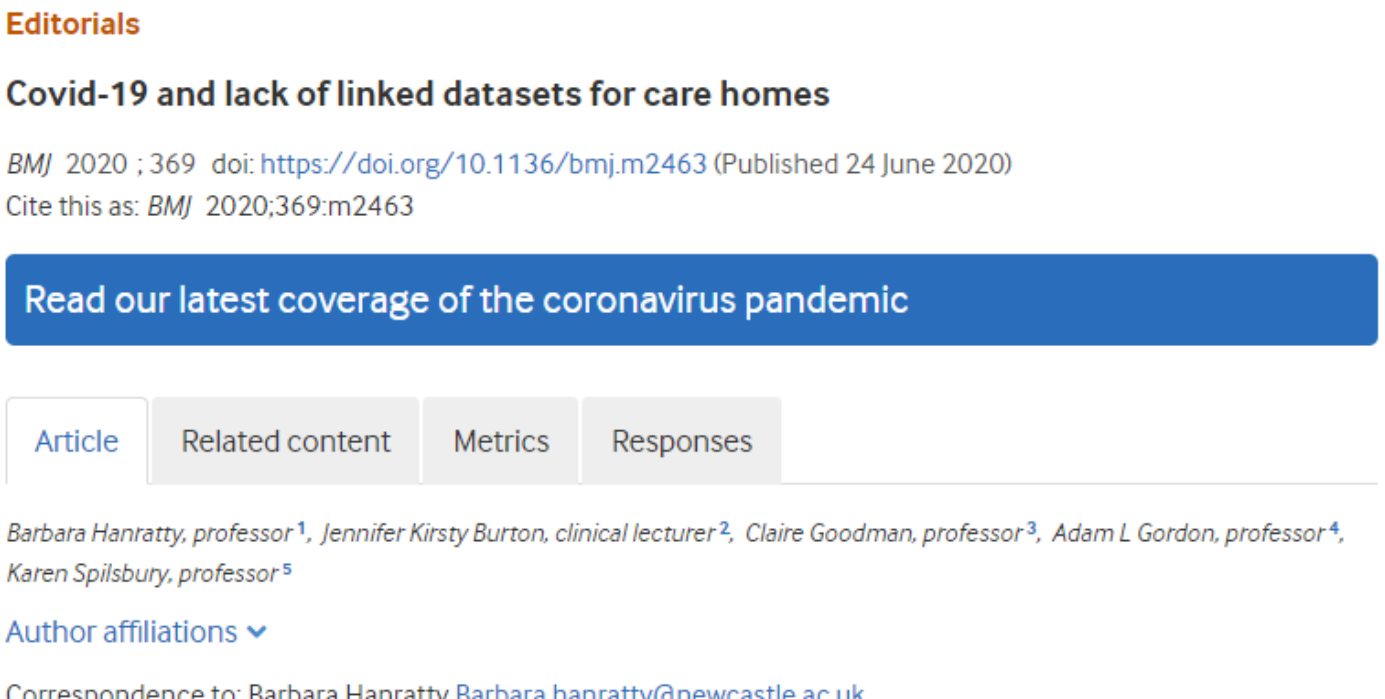
Abstract

Background: Care home residents have been severely affected by the COVID-19 pandemic. Electronic Health Records (EHR) hold significant potential for studying the healthcare needs of this vulnerable population; however, identifying care home residents in EHR is not straightforward. We describe and compare three different methods for identifying care home residents in the newly created OpenSAFELY-TPP data analytics platform.

Methods: Working on behalf of NHS England, we identified individuals aged 65 years or older potentially living in a care home on the 1st of February 2020 using (1) a complex address linkage, in which cleaned GP registered addresses were matched to old age care home addresses using data from the Care and Quality Commission (CQC); (2) coded events in the EHR; (3) household identifiers, age and household size to identify households with more than 3 individuals aged 65 years or older as potential care home residents. Raw addresses were not available to the investigators.



Editorials

Covid-19 and lack of linked datasets for care homes

BMJ 2020 ; 369 doi: https://doi.org/10.1136/bmj.m2463 (Published 24 June 2020)
Cite this as: *BMJ* 2020;369:m2463

Read our latest coverage of the coronavirus pandemic

Article Related content Metrics Responses

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

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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

Care Quality Commission
Care Home Organisation
Contract and Quality monitoring (Local Authority)
Visiting NHS health care professionals
NHS Capacity Tracker
Safeguarding
Key events/Accidents reporting
Families/visitors
Surveys
Resident details, priorities and care

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

Work package 1: Review of Care home intervention research assessment, outcome measurement and process : Sarah Kelly, Guy Peryer

Work package 2: Creation of a Care home trial repository: Lisa Irvine, Jenni Burton

Work package 3: Review of content and use of Minimum Data Sets (MDS) and Survey of data care homes collect Barbara Hanratty, Claire Goodman

Work package 4: Mapping and characterisation of resident data in existing NHS and Local Authority data sets in two Integrated Care Systems (ICS) Arne Wolters, Adam Steventon

Work package 5: Piloting and implementation of a MDS in 40 care homes in two ICS: Ann-Marie Towers, Adam Gordon

Underpinned by:

National consultation groups (five groups) x 3 : Sarah Brand, Anne Killett, Adam Gordon, Barbara Hanratty, Karen Spilsbury,

Patient and Public Involvement and engagement group panel and residents' panels 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

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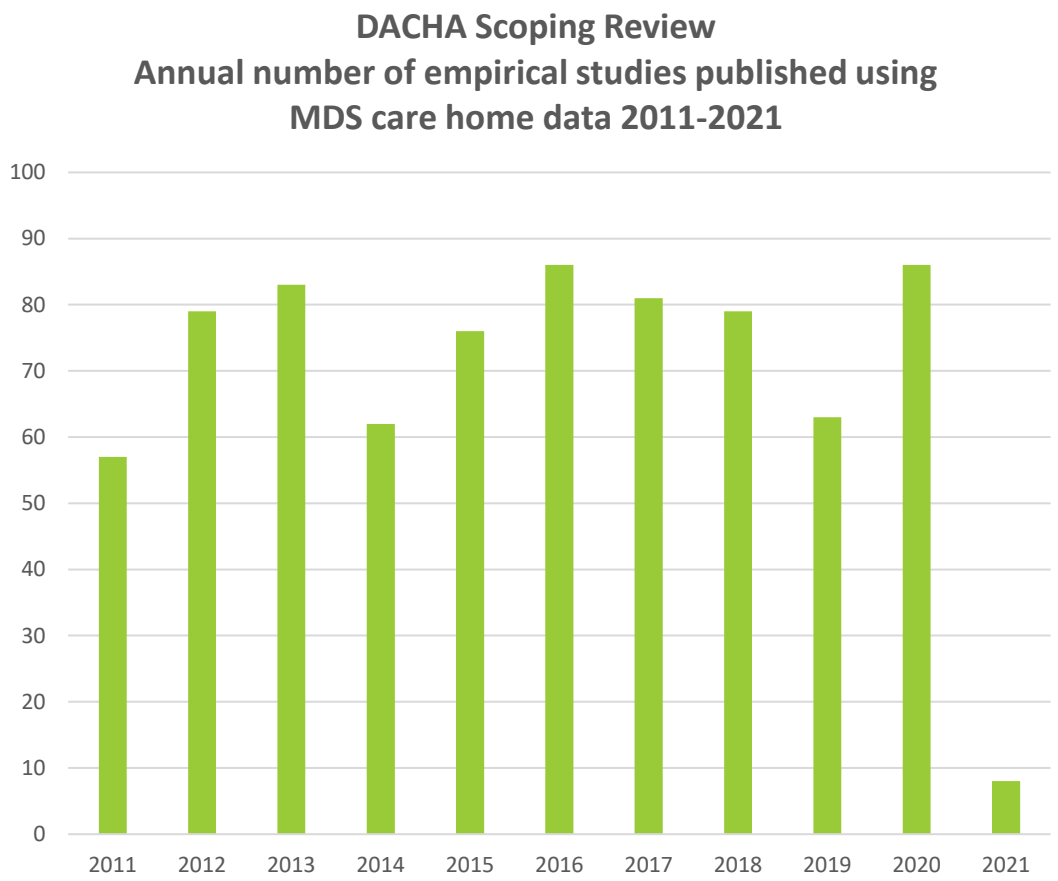
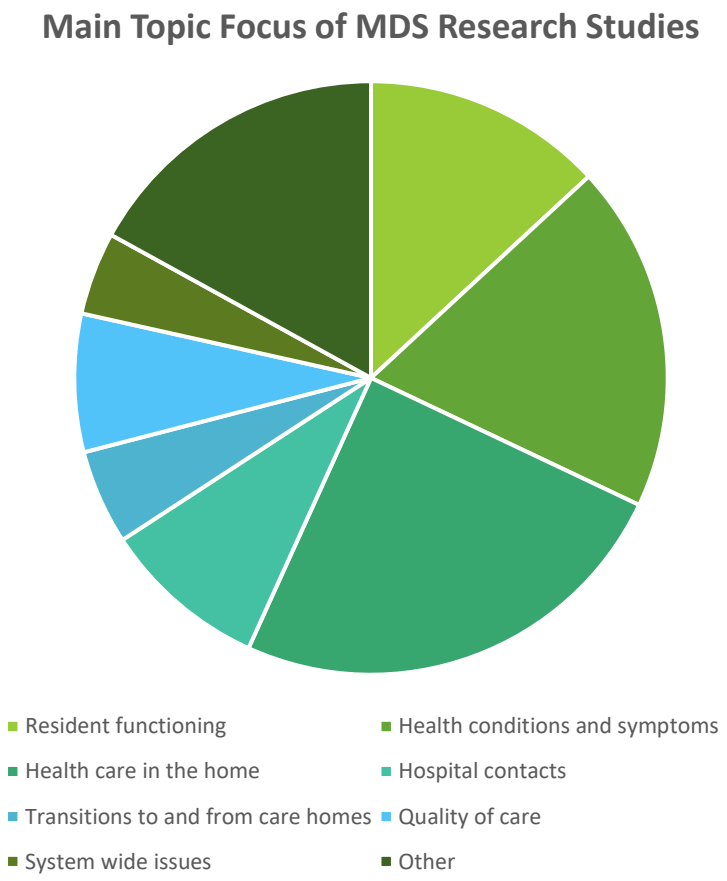
Research studies using MDS data: *early findings*

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





Work Package 4: Data linkage of existing routine data sources

Building	Building on work and expertise with NHS England Vanguards e.g. identifying residents
Linking	Linking relevant administrative health and social care records centred around the care home resident
Using	Using routinely collected data aim to minimise burden on care homes to collect data.
Working	Working with 2 Integrated Care Systems (ICSs), and 40 care homes to build a prototype resident Minimum Data Set

- 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).

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Issues to consider

- **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);

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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.

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Thank you!

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