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Developing resources And minimum data set for Care Homes' Adoption

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Lead Ageing and Multimorbidity Theme NIHR ARC East Of England

FUNDED BY NIHR | National Institute for Health Research

SPONSORED BY University of Hertfordshire UH

SUPPORTED BY NIHR | Applied Research Collaboration East of England

NIHR ARC Care home network initiated study

Care home national event: Priority setting

Fed into NIHR commissioning brief

Conversations within and across ARCs

6 ARCs, 9 universities, 2 charities (PPIE), and 1 representative organisation

Residents, care home staff, family carers

Care home sector

Outside of research little known about population

Long history of residents' inequitable and unpredictable access to health care

A solution and a problem for the NHS

Basic data collected by multiple agencies in unaligned databases

No agreed systematic approach to capturing care home activity

> 2x as many beds as secondary care

Average: 28 beds with nursing and 30 without nursing.

Self funders 45%. Paying top ups 12%, State funded 34%

NHS continuing care 8%

33% of care homes for older people = small businesses with 1-2 care homes

Source LaingBuisson 2019 Market report

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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 priority post-COVID

DACHA Study design, develop and implement a minimum dataset for UK care homes, report 2024.

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

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

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

International Journal of Population Data Science (2020) 5:1:xx

International Journal of Population Data Science

IJPDS International Journal of Population Data Science

Swansea University Prifysgol Abertawe

Journal Website: www.ijpds.org

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

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Submission History
Submitted: 18/08/2020
Accepted: 30/10/2020
Published: xx/x/xx xx

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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].

COVID-19 has highlighted data failings that have hindered

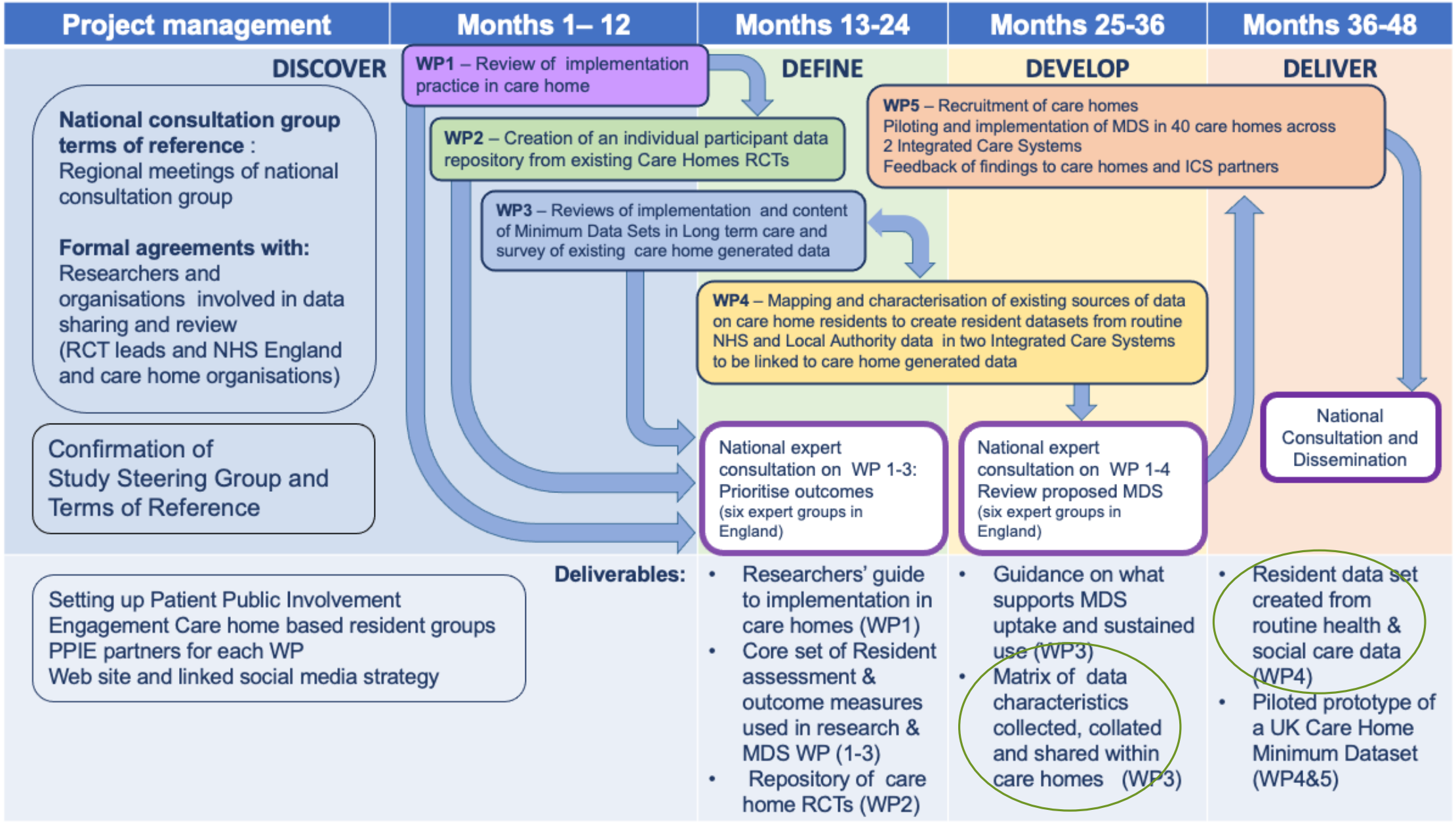
What is a care home?

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 residents within care home services are often lacking.

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.


Project management
Months 1– 12
Months 13-24
Months 25-36
Months 36-48
DISCOVER
DEFINE
DEVELOP
DELIVER
WP1 – Review of implementation practice in care home
WP2 – Creation of an individual participant data repository from existing Care Homes RCTs
WP3 – Reviews of implementation and content of Minimum Data Sets in Long term care and survey of existing care home generated data
WP4 – 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 Integrated Care Systems to be linked to care home generated data
WP5 – Recruitment of care homes
Piloting and implementation of MDS in 40 care homes across 2 Integrated Care Systems
Feedback of findings to care homes and ICS partners
National consultation group terms of reference :
Regional meetings of national consultation group
Formal agreements with:
Researchers and organisations involved in data sharing and review
(RCT leads and NHS England and care home organisations)
Confirmation of Study Steering Group and Terms of Reference
National expert consultation on WP 1-3: Prioritise outcomes
(six expert groups in England)
National expert consultation on WP 1-4 Review proposed MDS
(six expert groups in England)
National Consultation and Dissemination
Setting up Patient Public Involvement Engagement Care home based resident groups
PPIE partners for each WP
Web site and linked social media strategy
Deliverables:
Researchers' guide to implementation in care homes (WP1)
Core set of Resident assessment & outcome measures used in research & MDS WP (1-3)
Repository of care home RCTs (WP2)
Guidance on what supports MDS uptake and sustained use (WP3)
Matrix of data characteristics collected, collated and shared within care homes (WP3)
Resident data set created from routine health & social care data (WP4)
Piloted prototype of a UK Care Home Minimum Dataset (WP4&5)

Work Package 3: Development and implementation of an MDS

SURVEY of care home providers via ARCs to capture range of data on residents' health, functioning, wellbeing

- **Care home resident data**
  - Collection (what, why, how)
  - Storage (what, how, where)
  - Sharing (who, how, barriers)
- **Software and technologies**
- **COVID-related changes to collection and use of resident and staff data**
- **New approaches to data sharing**

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

REALIST REVIEW to understand use and uptake of internationally deployed MDS & transferable learning and/or utility for UK care homes.

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

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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 ICSs.

Now: 29 ICSs covering more than 35 million in England, > 60% pop

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Issues to consider

- **Service evaluation vs research**
  - Most administrative data are collected for direct care purposes.
  - Secondary use of these data strictly governed by rules and legislation
  - Depends on the purpose of the re-use of the data:
    - **Service evaluation** – retrospective evaluation or analysis to support commissioning, planning and improving of services over time
    - **Research** – use of data that will direct affect the care provided to specific individuals (e.g. trial)
- **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 these two sites
  - If resources allow include other ICS areas = understand challenges in interoperability, maximises the re-use of commonly recorded information

Issues to consider cont..

Governance and ethics

Strict information governance guidelines needed for creating linked administrative datasets.

The minimum dataset pseudonymised, **no** residents can be directly identified

Working with local authorities and health and social care providers, to link data safely and securely

If required, work with a trusted third party (e.g. NHS digital) to facilitate the linkage of data.

Ownership

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

Exploring ways of disseminating access to the linked data, to maximise value beyond DACHA

Data platforms

Too early to tell 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 a MDS with the minimum number of scales/attributes required**;
- Evaluate the utility of the matched MDS data to stakeholders (ICSs, CCGs, local authorities, providers, residents and their families);

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Summary

- The heterogeneity of care homes and residents
- Absence of high-quality routine data for care home residents
- Challenges of unaligned data sets & urgent need for data linkage, impact of COVID
- DACHA study seeking to by establish a core dataset based on resident-level information, linked to wider data sources.
- Potential of a Minimum Data Set for improving the commissioning and delivery of residents' care …….

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Thank you!

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FUNDED BY
NIHR | National Institute for Health Research

Acknowledgements

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Disclaimer

This study is funded by the National Institute for Health Research (NIHR) (HS&DR 127234/Health Service Delivery Research programme] and supported by NIHR ARC EoE. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.