

Developing resources And minimum data set for Care Homes' Adoption

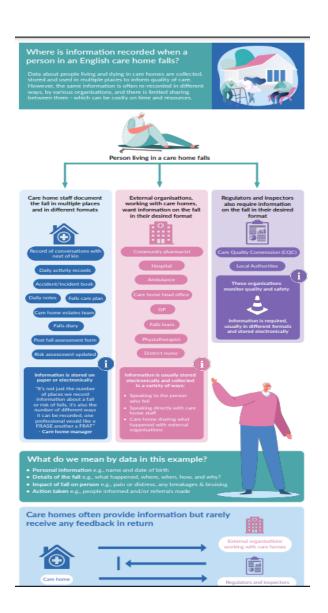
DACHA: (Developing research resources And minimum data set for Care Homes' Adoption and use)

October 2019-November 2023



### DACHA AIMS

- To develop resources to support research, and innovation in care homes.
- To synthesise evidence and data sources to deliver an agreed data set - (Minimum care home generated resident Data Set) usable for different stakeholders



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

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

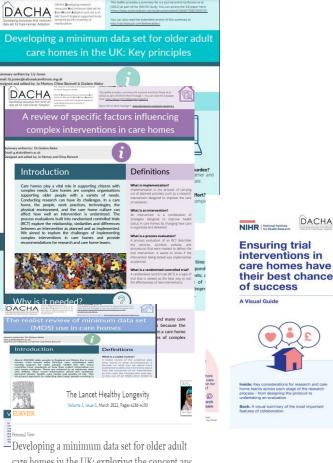
**Work package 3**: Review of content and use of Minimum Data Sets (MDS) and Survey of data care homes collect **Barbara Hanratty**, Claire Goodman Gizdem Akdur Jenny Liddle

**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 Richard brine, Liz Crellin, Kaat de Corte

**Work package 5:** Piloting and implementation of a MDS in 60 care homes in two ICS: Ann-Marie **Towers**, Adam Gordon Jenni Burton Stacey Rand, Stephen Allan, Nicholas Fox, Lucy Webster Sinead Palmer Rachel Carroll, Ian Spencer

National consultation groups Gizdem Akdur Iain Lang, Anne Killett, Adam Gordon, Barbara Hanratty, Karen Spilsbury, THIS Institute

Patient and Public Involvement and engagement group panel and residents' panels working with NAPA Anne Killett, Julienne Meyer, Pamela Blades, Kerry Micklewright



care homes in the UK: exploring the concept and defining early core principles

PhD \* 2 Arne Timon Wolters MSc <sup>b</sup> Ann-Marie Towers MSc <sup>S, e</sup> Liz Jones BA <sup>f</sup> Pro ne**bm**i News & Views - Campaigns -

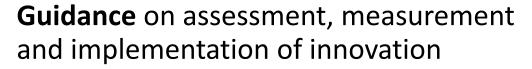
Covid-19 and lack of linked datasets for care home 3M/ 2020 : 369 doi: https://doi.org/10.1136/bmi.m2463 (Published 24 e this as: BMJ 2020;369:m2463

d our latest coverage of **BMC Geriatrics** 

Research | Open Access | Published: 07 January 2022

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, Gizdem Akdur, Sarah Brand, Anne Killett, Karen Spilsbury, Guy Perver, Jennifer Kirsty Burton, Adam Lee Gordon, Barbara Hanratty, Ann-Marie Towers, Lisa Irvine, Sarah Kelly, Liz Jones, Volume 51 Issue Julienne Mever & Claire Goodman March 2022



**New methods** for staff and resident engagement

Trial repository for secondary data analysis

**Prototype MDS** tested in three ICS with 60 care homes

Informing post Covid debate and national policy on MDS for social care

JOURNAL ARTICLE

DACHA

Contextual factors influencing complex intervention research processes in care homes: a systematic review and framework synthesis 👌 Guv Perver 🖾, Sarah Kelly, Jessica Blake, Jennifer K Burton, Lisa Irvine, Andy Cowan

Gizdem Akdur, Anne Killett, Sarah L Brand, Massirfufulay Kpehe Musa ... Show more

Age and Ageing, Volume 51, Issue 3, March 2022, afac014.





#### Data Collection in Care Homes: an English Survey

- COVID-19 highlighted the gap in accessible, aggregate data on the care home population in England
- Care homes faced multiple requests for data from external agencies who had little knowledge of what care homes were already collecting
- Recent, rapid growth in plans for digital social care records & a minimum dataset









#### **DACHA Survey of Care Homes:**

#### To find out:

- What information is being collected in care homes? How is it collected and stored?
- What do care homes feel about sharing data?
- If a Minimum Dataset was introduced, would it generate extra work for care homes?









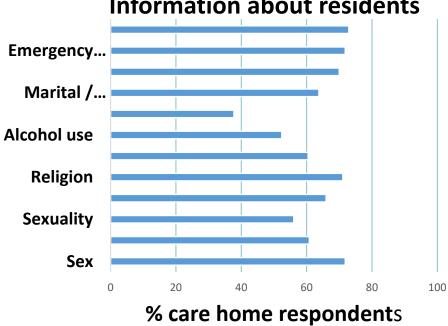
### Who responded?

- •273 respondents (England)
- •Organisations of >5000 care homes
- •Beds 71% >25 beds
- •Group size: 45% one home, 48% 1 -100 care homes
- Care home ownership: For-profit 41%, Not for-profit P 31%, Local authority 1.8%









### **Information about residents**

\*LPOA: Lasting Power of attorney





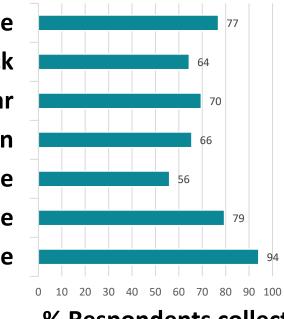
Торіс	% of respondents whose homes collect these data		
Independence	>95%		
Activities	>95%		
Preferences and priorities for care	> 90%		
Continence	>86%		
Hygiene	>90%		
Diet and nutrition	>95%		
Communication	>90%		
Consultations with health professionals	>98%		





#### **Clinical measurements**

Clinical measurements common, despite only 45% of respondents from homes with nursing beds Fluid balance Urine dipstick Blood sugar Oxygen saturation Respiratory rate Blood pressure Temperature



#### % Respondents collecti measurement



# Examples of clinical measures and tools in use

Stool Charts 86% Frailty measures 55% Pain scales 89%

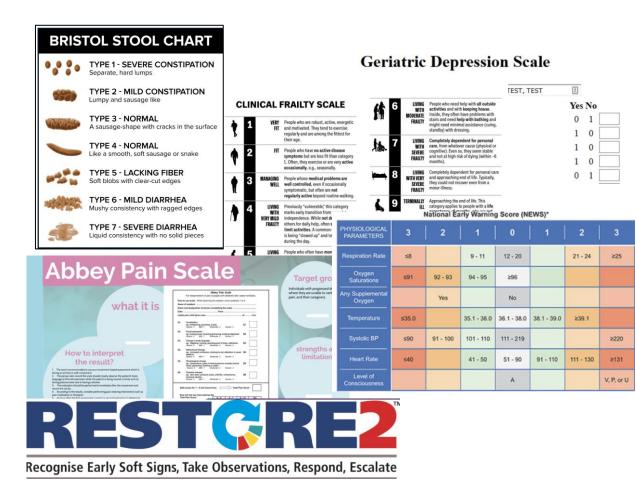
National Early Warning scores 36%

Nutrition scores 72%

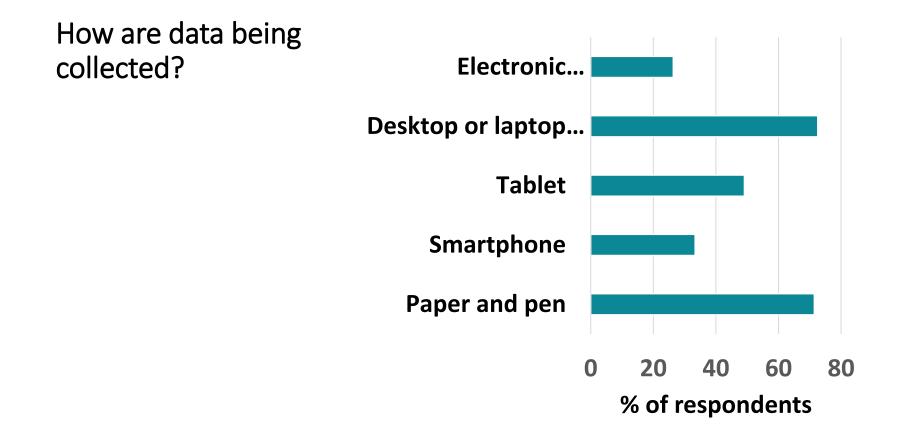
Skin status scores 85%

Depression & anxiety 25%

Quality of life 15%









## How are data being stored?

Paper records 80%

Computer records 82%

Using dedicated software 62%

• Most data updated at least monthly







## Care homes and data collection



- Care homes have unique data on the person, dependency and disability
- Clinical measurements tools are common
- Health, rather than social care outcomes are emphasized
- Digital technology is in widespread use
- Are the tools in use validated / appropriate for this setting?



#### Conclusions



- Data collection in care homes is extensive, without incentives or mandate.
- Care home organisations are collecting an extensive range of resident level information for their own uses.
- Countries that are considering introducing social care records or an MDS should start by working with care home organisations to review existing data collection and evaluate the implications of collecting and sharing data.
- A critical approach to the appropriateness of health-related tools in this setting is overdue.



#### **Funding Acknowledgement**

This study/project is funded by the National Institute for Health Research (NIHR) Health Service Research and Delivery programme (HS&DR NIHR127234) and supported by the NIHR Applied Research Collaboration (ARC) East of England. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

#### **DACHA Study Research Management Team**

University of Hertfordshire: Prof Claire Goodman, Dr Gizdem Akdur, Lisa Irvine University of Cambridge: Dr Sarah Kelly University of East Anglia: Dr Guy Peryer, Dr Anne Killett University if Exeter: Dr Iain Lang University of Glasgow: Dr Jenni Burton University of Kent: Ann-Marie Towers University of Leeds: Professor Karen Spilsbury Newcastle University: Professor Barbara Hanratty University of Nottingham: Professor Adam Gordon National Care Home Forum: Professor Julienne Meyer, Liz Jones The Health Foundation: Arne Wolters PPI Representative: Pamela Blades



Developing resources And minimum data set for Care Homes' Adoption









### Developing the Care Homes Trials Archive

Lisa Irvine University of Hertfordshire

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#### Lack of reliable data on care home populations

OPPORTU	NITY	quality data	Randomised controlled trials (RCTs) collect detailed, high quality data on all care homes and residents recruited Regular observations for up to one year		
BENEFI	TS	Pooling	individual participant More data, more pov		
Low risk, low cost		Anonymised data sharing	Inform clinical trial design	Exploratory analysis	



lomes

Type of data	Examples of data available from care home RCTs			
Trial level	Duration of follow-up, Timing of assessment points, Intervention details			
iiiai ievei	Region / geographical area covered			
Care home level	Number of beds; bed occupancy rates (at baseline and follow-up)			
Care nome level	Case mix; funding mix; ownership; CQC rating; staff ratios; staff retention			
	Inclusion & exclusion criteria for residents			
	Age at randomisation / Time living in care home / Sex / Ethnicity / BMI			
	Medical conditions e.g. dementia, diabetes, COPD, previous stroke			
Participant level	Status at end of follow-up (alive/dead/lost to follow-up) / Cause of death			
	Health resource use including hospitalisations and medications			
	Events during follow-up e.g. falls, infections, advanced care planning, change in			
	funding			
0	Individual domain levels & summary scores			
Outcome	Resident-reported, carer-reported, or researcher-reported responses			
measures	Baseline measures & follow-up measures			



International Care Homes

**Trial Archive** 

### **Developing the trials archive**

#### Inclusion criteria:

- RCTs conducted in UK older adult care homes, published since 2010
- Any intervention, any clinical area
- Documented protocol, evidence of consent, data validation

#### Role of Trialist Steering Committee (TSC)

Original trialists act as gatekeeper for their respective datasets

- Oversight of how trial data will be used
- Opportunity to contribute to novel research
- Recognition in any future publications using their data
- As new trials are added, new trialists join the Committee



### Process for sharing pooled trial data

Pooling IPD from multiple sources – considerable effort Need to establish as a longer term resource

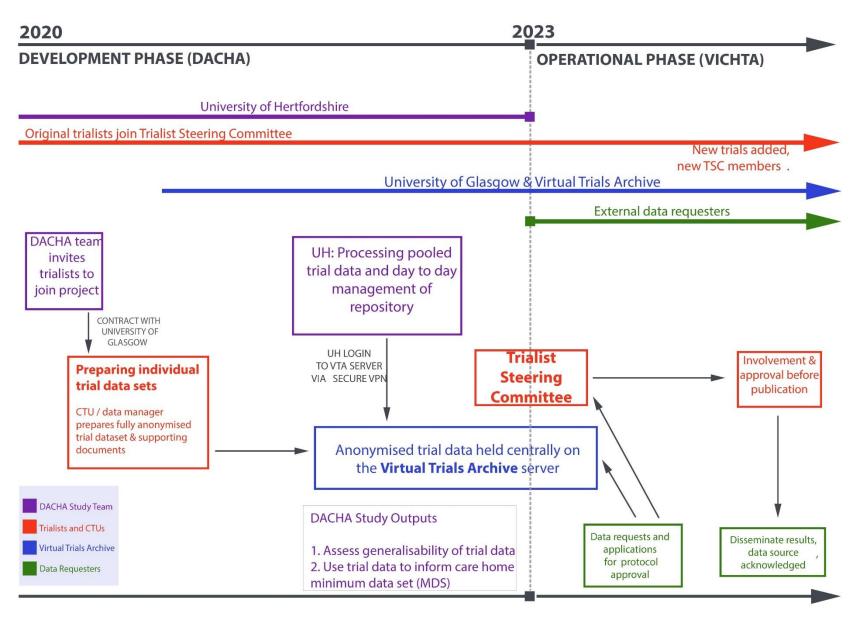
Working with Virtual Trials Archive (VTA) at University of Glasgow



- VTA established 2002 Stroke trials
- All trial data stored securely on the University of Glasgow (UG) server
- Management transferred from Herts to VTA at end of DACHA funding
- External researchers send proposals/data access request via VTA website
- VTA manage data requests with oversight from Trialist Steering Committee
- Analysis completed on VTA data platform



#### DATA PROCESSING FLOWCHART



## Preparing and Pooling IPD

- Data access via Glasgow server 2 part log-in, similar to future users
- Checking data received all we need? Nothing identifiable? Linkage possible? Long or wide format? Labels defined? How are missing values coded? Compare IPD received to published consort diagram, baseline characteristics, sense-check dates, number ranges, categorical values within range?
- **Resolving discrepancies** original trialists in Steering Committee, contact CTUs
- Standardisation rename variables, recode categorical/binary variables, all measures on the same scale? Seek advice from TSC and record all decisions
- Creating Master IPD & codebook



### Trials included so far...

	Challenge DemCare	CAREMED	FINCH	CHIPPS	DCM-EPIC	ELECTRIC
Recruitment	2011-12	2011-12	2016-18	2017-19	2014-16	2018-19
Location	England	England	England	Eng, Scot & NI	England	Engl & Scot
Budget (£ 2020)	£2.9M	£350k	£2.3M	£2.2M	£2.7M	£1.3M
N participants	832	826	1698	WP6: 880 WP5 Pilot: 40	Cohort 1: 726 Cohort 2: 261	406
N care homes	63	30	84	44	50	37
Follow up (months)	4	12	12	6	16	4
Intervention type	Dementia	Medication management	Falls prevention	Pharmacist review	Dementia	Incontinence
Outcome measures	Challenging behaviour; CMAI; Clinical dementia; EQ5D3L; Neuropsych inventory	<b>Falls</b> , STOPP/START	<b>Falls</b> ; Barthel; DEMQoL; EQ5D5L; Fear of Falling	<b>Falls</b> , Barthel; EQ5D5L; STOPP/START; MMSE	<b>CMAI</b> ;EQ5D5L DEMQoL; QUALIDEM QOLAD-CH NPI; Clinical dementia	Barthel; Clinical frailty; DEMQoL; MMSE; Minnesota Toilet, Bladder





### Total data availability – "VICHTA Key Dem"

- Variables with complete data (n=5669)
  - Age : range 23 106 Mean 85
  - Sex 72% female
  - Duration follow-up
  - Death status at study end (DeathYN)
  - · Capacity / Ability to consent
  - Year of follow-up
  - Country, Region
  - Timepoints
- Other factors collected in some trials
  - Education level, Previous residence
  - Care home mix, funding
  - Staffing, occupancy

#### Outcome measures

- Proxy(staff)
  - QoL: EQ5D, DEMQoL,
  - Cognitive: MMSE, QUALID, QUALIDEM, DEMQoL
  - Physical: Barthel, Clinical Frailty Score, PAM-RC
  - Disease specific: Minnesota toilet, Waterlow
- Co-morbidities varying denominator
  - Dementia diagnosis
  - Stroke, Diabetes, CHD, Parkinsons
  - Charlson index
  - Later try to map to medications?



### Potential future uses for VICHTA

- Identifying subgroups of residents
- Data harmonization and/or multiple imputation simulation studies
- Mapping / crosswalk for outcome measures (esp. Quality of life)
- Focus on health resource use / medications data
- Social care workforce issues (linked with resident outcomes)
- Macroeconomic studies based on care home characteristics
- "A year in the life of a care home resident"
- Role of PPIE in DACHA -next steps: priority setting
- Promoting to research centres





More information in our protocol paper:

More information on the DACHA study is also available at: <u>www.dachastudy.com</u>

> Contact me at: <u>I.Irvine@herts.ac.uk</u> @lisirv

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

#### STUDY PROTOCOL

Open Access

Trials

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<sup>1\*</sup><sup>(6)</sup>, Jennifer Kirsty Burton<sup>2</sup>, Myzoon Ali<sup>2</sup>, Terence J. Quinn<sup>2</sup> and Claire Goodman<sup>1,3</sup>

#### 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 on residents' demographics outcomes and contextual information cantured in RCTs has use to be fully realised.

This study is funded by the National Institute for Health and Care Research (NIHR) Health Service Research and Delivery programme (HS&DR NIHR127234) and supported by the NIHR Applied Research Collaboration (ARC) East of England. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.



**Bringing together** administrative data and data from digital care records to create a minimum dataset for care home residents

Prof Ann-Marie Towers on behalf of the WP4/WP5 team:

Prof Adam Gordon, Arne Wolters, Dr Stacey Rand, Dr Stephen Allan, Dr Lucy Webster, Sinead Palmer, Richard Brine, Liz Crellin, Prof Barbara Hanratty, Dr Jenny Burton, Dr Rachael Carroll, Kaat de Corte, Nick Smith





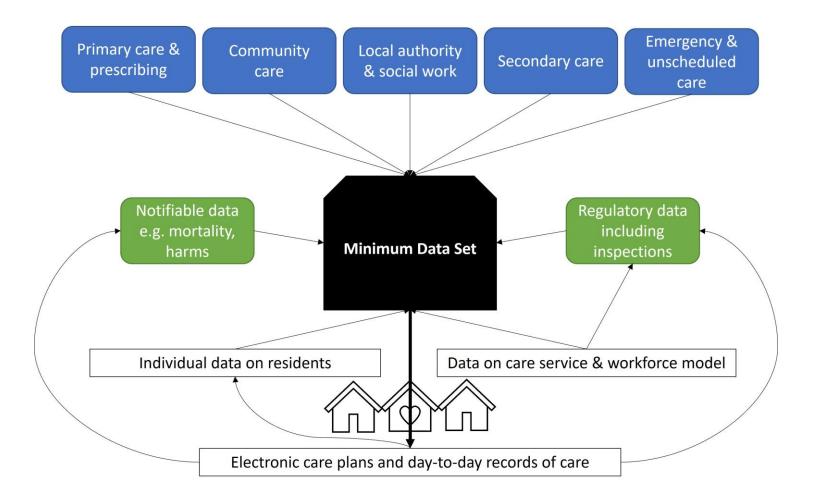




## **Research Questions**

- Can we collect resident data directly from care homes and match this to routinely collected health and social care data?
- What is the quality of the data we collect?
- How can the data be used to provide better, joined up health and social care for residents?
- What do we need to consider to enable wider roll out of a minimum data set for care homes in England?

### **Proposed structure of the DACHA care home MDS**



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

## Study design

- Mixed-methods longitudinal pilot of a prototype MDS
- 3 Integrated Care Systems Sites (ICSs)
  - Regional partnerships between NHS, local councils and others to coordinate and provide health and social care.
  - Nottingham and Nottinghamshire, Surrey Heartlands, and North East and North Cumbria
- 20 care homes per ICS
- Working with Care Software Providers Association (CASPA), and two software companies: Person Centred Software (PCS) and Nourish.

### Content of the MDS

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

Data from digital care records

- Demographics (DOB, NHS ID, ethnicity, marital status)
- Care home stay (date of entry, date of death)
- Resident needs (communication, cognitive impairment\*, functioning\*)
- Quality of life\*
- Complications and adverse events (e.g. falls, infections)
- \*Being added to the software

## New measures

- Lots of relevant information in the software but not in a format suitable for quantitative analysis (e.g. care notes, 'about me' information).
- Adding some additional measures:
- Quality of life (out for consultation now)
- Cognition
- Delirium
- Activities of daily living

Other 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)

## How will it work?



PCS: The home will create a 'DACHA extraction community' within the software and add consented residents to this.



Nourish: The home will be able to 'tag' consented residents to highlight they are participating in DACHA.



Participating care homes will be the data controllers.



The software providers will be the data processors (they will pseudonymise the data and transfer securely to THF)



The pseudonymised data will be stored securely on THF servers.

Final year of the study



#### Two extractions 6 months apart

Pilot the process

d.

Examine data quality and make recommendations about future data sources

Use the data to answer priority research questions for stakeholders in our ICSs



Focus group interviews with managers and staff (implementation focus)



Staff interviews (how do they complete the new measures; how do they use the information?)

## Public involvement in DACHA: approaches and implications with tailored involvement for different groups

Dr Anne Killett on behalf of the PPIE team:

Julienne Meyer, Liz Jones, Pamela Blades, Kerry Micklewright and Chloe Bennet





- Key partners
- Range of needs and interest
- Risks if insufficient collaboration







# Approaches to public involvement in DACHA

- Co-applicants
- PPIE Panel
- Collaboration with National Activity Providers' Association
- Consultations with varied experts
- Advisory group membership



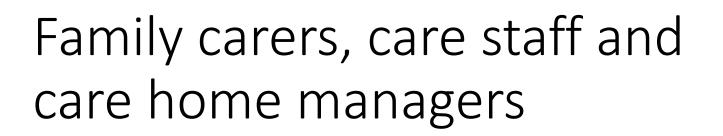
### Co-applicants



- Input at key developmental stage
- Developing shared expectations
- Maintaining relationships







- PPIE Panel
- Mixed membership
- Facilitating to draw out contributions from all
- Supporting participation



DACHA





# Older people living in care homes

- Aim to build relationships and trust
- Working with National Activity Providers Association
- Involvement materials coproduced between researchers and activity providers
- Range of activities carried out by activity providers with interested residents
- Fed back to research team



## Care home industry, regulators, commissioners and policy expertise

- Tailored consultation activities at 3 points in the programme
- Brought together specific expertise
- On-line consultation for detailed engagement



DACHA





## What is valued: wellbeing and quality of life

- Measuring what is valued may be challenging
- Implications for the MDS in this project
- Potential to advance MDS beyond other examples



DACHA

# Desire for real time information Description Sharing in MDS

- To bring major return for care home staff for their contribution to data
- For deepening family engagement without adding to burden on staff
- For residents wanting better information on their health care
- But beyond scope of DACHA







# Responsibility for recommendations

- Tendency for organisations, systems and ways of working to shift in response to data collection requirements
- What will be valued in routine care influenced by data that is expected
- Informative data may underpin planning, inform policy
- Varied sector with varied capacity for responding to expectations to provide data

Emphasising the importance of collaboration with the relevant groups throughout the programme

### Thank you for your interest

https://dachastudy.com



data set for Care Homes' Adoption

### **Funding Acknowledgement**

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