



Hanratty, B. et al. (2023) Data collection in care homes for older adults: A national survey in England. *Journal of Long-Term Care*, pp. 288-296. (doi: [10.31389/jltc.199](https://doi.org/10.31389/jltc.199))

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Deposited on 18 September 2023

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## **Title : Data collection in care homes for older adults: A national survey in England**

### **Abstract**

**Context:** In many countries, there is a specification for information that should be collected by care homes. So-called 'minimum data-sets' (MDS) are often lengthy, and report on resident health and wellbeing, staff and facilities. In the UK, the absence of any easily accessible data on the care home population was highlighted at the start of the COVID-19 pandemic. Care homes faced multiple requests for data from external agencies who had little knowledge of what care homes were already collecting.

**Objective:** This study aimed to identify the range (and method) of data collected by care home organisations, in a country without a mandated MDS.

**Methods:** Online survey of care homes (with/without nursing) in England. Care homes recruited via research and care home networks, social media. Questions covered data content, storage and views on data sharing, analysed with descriptive statistics.

**Findings:** 273 responses were received, representing over 5000 care homes. Care homes reported extensive data on the health, care and support needs of individual residents, their preferences and activities. Clinical measures and tools adopted from health were commonly used, but few collected information on quality-of-life. Care homes reported uses of these data that included monitoring care quality, medication use, staff training needs, budgeting and marketing. Concerns over privacy and data protection regulations are potential barriers to data sharing.

### **Implications**

These findings challenge the notion that incentives or mandates are required to stimulate data collection in care homes. Care home organisations are collecting an extensive range of resident level information for their own uses. Countries considering introducing social care records or an MDS could 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.

**Key words** – aged; nursing homes; data collection; minimum datasets

## Background

Care home residents are some of the most complex recipients of health and social care (Anon, 2021c, Anon, 2021b). Residents need support with daily activities and many live with dementia, multiple long-term conditions and frailty. Optimising the care of this population is critical, and data have a key role (Anon, 2021a, DHSC, 2020). Information on individuals can enhance care within the home, and be invaluable when communicating with external services. Aggregate data may be used for planning, evaluating quality of care and monitoring health trends at a population level (Gordon et al., 2020, Peryer et al., 2022). Despite all of these potential benefits, in many countries there is no standardised data collection in care homes. This means that it is difficult to access information on care home residents outside of a research setting, or to identify residents in routine health service data. Where systematic data collection is in place, specifications have been established for information that should be collected by and from care homes. So-called 'minimum data-sets' (MDS) are often lengthy, and generally report on individual resident health and wellbeing, staff and facilities. For example, in the USA, collection of a core set of information from care homes is federally mandated and linked to financial reimbursement in homes that accept residents subject to Medicaid/Medicare reimbursement. In other countries, coverage is often less comprehensive but minimum datasets can play a significant role in quality improvement (Anon, 2021c, Anon, 2021b, Anon, 2021a). For example, our recent realist review described how an MDS may be useful to promote staff understanding of what is important for resident care (Musa et al., 2022).

In England, government plans to develop digital social care records have increased interest in the concept of a minimum dataset for care homes (DHSC, 2020). Local and national authorities' demands for information from care homes grew during the COVID-19 pandemic, when care homes experienced some of the highest infection and mortality rates (Gordon et al., 2020, Comas-Herrera A et al., 2021). In the absence of a core set of information from all care homes, care home resources were diverted to collect, collate and communicate data to a range of different organisations. Few of the external agencies had any knowledge of what was already being collected by care homes, and requests for information were often duplicated or difficult to fulfil (Spilsbury et al., 2021). Linked to this, different stakeholders all have their own understanding of the purpose of an MDS in the care home sector, and how it should look.(Burton et al., 2022) For example, national and local government authorities will require population level data to inform commissioning, regulation and planning to meet the demands on health services, including from future pandemics. Families and residents may be more likely to value information on day-to-day experiences, to guide their initial choice of home, and monitor ongoing care. This study is part of a larger programme of work, to

develop and test the feasibility of a minimum dataset for care homes in England. It addresses the question of what data are already being collected by care homes, so that any future work can build on this foundation. The aim of the survey was to describe the range of data collected by care homes in a country without an MDS, identify any common content and investigate the methods used to collect and store data.

## **Methods**

We surveyed care home staff (managers or senior carers) in England, via the National Institute for Health Research ENRICH network (<https://enrich.nihr.ac.uk>), care home umbrella organisations and networks, (e.g. <https://www.nationalcareforum.org.uk>, <https://myhomelife.org.uk>), and social media between July and September 2021. We aimed for the broadest possible reach across the country and did not target any specific localities or regions.

The survey consisted of 72 fixed-response questions exploring care home and resident characteristics, data collection, recording, storage, utilisation, access and sharing, COVID-19 and technology use. Additional information could be added in free text boxes. The content was informed by the authors' previous research and discussion/piloting with care home and health care professionals and members of the public. Our focus was on data collection by care homes and not on information provided by families, or drawn from other routine sources. These will be covered in our past and future work (<https://dachastudy.com>, last accessed 14/08/2023).

Potential participants were sent an email with a weblink to the survey. To encourage participation and maintain anonymity we did not collect contact details and sent no individual reminders. Responses were analysed using descriptive statistics. This study was approved by Research Ethics Committees at the University of Hertfordshire and Newcastle University (Ref: 4888/2020, Ref HSK/SF/UK/04301).

## **Results**

### *Respondent characteristics*

273 completed surveys were received from organisations responsible for over 5000 care homes. Just under half (45.5%) of respondents were from homes with nursing beds. 31.1% respondents were from not-for-profit providers and 41% from for-profit. Most (86.8%) were outstanding or good in their most recent regulator (Care Quality Commission (CQC)) inspection. Comparison with national CQC data showed that our respondents were more likely to be from larger homes and those

with nursing beds. Not-for-profit and homes with higher quality ratings were overrepresented in our sample. (Table 1)

### **Table 1 Survey respondent characteristics**

#### *Basic information about residents*

Homes were collecting an extensive range of data about residents. Preferences and priorities for care were recorded in almost all respondents' homes (268, 98.2%), including for resuscitation (94.5%) and advanced care planning (90.8%). Information on some protected characteristics, alcohol and substance use were recorded less often. (See Table 2 Appendix)

#### *Health related data collection*

Common clinical observations (temperature, blood pressure), body measurements and data on falls, pain, common conditions and skin integrity were collected by most homes. More than half of homes were recording respiratory rate, oxygen saturation and data on frailty.(Table 3) Most respondents (246, 91%) reported that their homes were collecting information on medications required by the CQC and keeping a log of any remote or in-person contacts with health services. Tools to structure communication between care home and the National Health Service (NHS) were being used by a minority (e.g. RESTORE2, NEWS) (Table 4)

### **Table 3 Health-related data collection in care homes**

### **Table 4 Data on contacts with health services and use of structured communication tools**

#### *Information to support care delivery*

Data on hearing, sight, speech, independence, needs for care and support (including mobility, balance, continence, bathing preferences/habits, care of hair, nails and teeth and sleep quality) were recorded by most homes. Around three quarters collected information on food intake, preferences, and nutritional needs, including allergies, choking risk and weight loss.(Table 5, Appendix). Information on quality of life was collected by fewer than a third of respondents (85, 31.1%).

#### *Collection, storage and use of data*

Data were collected digitally (computer 72.3%) or paper and pen (71.4%). Use of devices that transmit information automatically, e.g. via Bluetooth, was uncommon (8.8%) (Table 6, Appendix). Data storage followed a similar pattern. Storage location did not vary by data category, except for medications, where paper records were in widespread use (Table 7, Appendix). Sixty-two percent

reported use of specific computer software. From more than 17 different systems being used by our respondents, one software system (Person Centred Software (17.9%)) was the most commonly reported. Data on medications, health conditions, cognition and frailty and were updated at least monthly by most homes. (Table 8, Appendix)

Care homes put their own data to a range of uses, including monitoring care quality (96.7%), ordering medications (93%), identifying training needs (87.2%), tracking staffing requirements (83.2%), recording adverse events (81%), informing responses to COVID-19 infections (79.5%), responding to data requests (74.4%) and for marketing/promotion (31.9%) and budgeting (54.6%). Concerns about data sharing were focused on privacy (94.1%), data protection (79.5%), staff time (67.4%), existing data storage in multiple formats and locations (76.9%) and a lack of technology (69.6%). (Table 9)

#### **Table 9 Use of data collected by care homes and source of concerns about sharing data**

##### *Changes during the COVID-19 pandemic*

Most respondents were aware of their homes using an NHS or local 'capacity tracker' application to record and share data with local authorities during the COVID-19 pandemic. Almost one in four (23.1%) had initiated new use of technology during the pandemic, started collecting (15.4%) or sharing (15.2%) additional data, or participated in specific local data collection initiatives (19.4%). (Table 10 Appendix)

## **Discussion**

### **Summary of findings**

Care homes in this study collect extensive data on the health, care and support needs of individual residents, their preferences and activities. Tools and measures adopted from health services are in widespread use, but collection of information on quality of life is uncommon. Most homes have digital records, and the COVID-19 pandemic prompted adoption of technology and an increase in data collection and sharing. Care homes report that uses of these data include monitoring care quality, medication use, staff training needs, budgeting and marketing. The overall picture is of a care home sector rich in data, but with collection strongly influenced by National Health Service and other external local and central government demands.

### **Comparison with other work**

Minimum datasets (MDS) that are in use in North America stipulate a wide range of data that must be collected by care homes. (Anon, 2021c) Our scoping review of international care home MDS has found that data collection encompasses individual resident functioning (e.g. mobility, incontinence), health conditions and symptoms (e.g. depression, pain), health care in the home (e.g. prescribing, end of life care), hospital attendances and admissions, transitions to and from care homes, quality of care and systemwide issues (Hanratty et al unpublished data). The information collected by care homes in this study covers all the main domains within established MDS, but is less extensive in scope. Our study noted widespread use of clinical measures such as blood pressure and fluid balance, and tools such as the Bristol stool chart. This was unexpected, as fewer than half of respondents were from homes with nursing. It suggests that staff without professional registration have an extended skill-set. It may also confirm previously described increases in complexity and acuity amongst residents in residential settings (Barker et al., 2021). Heterogeneity in use of measures was also noted in a survey of six Scottish care homes (Johnston et al., 2020). However, we found that within each topic area, one measure was generally being used more than the rest – the Abbey Pain Scale, for example (Abbey et al., 2004). Previous research has highlighted how care home data may be collected and stored in a number of different places within a single care home (Goodman et al., 2017). Our survey respondents raised this issue as a potential barrier to sharing data more widely, presumably because of the work generated in collating such data.

### **Strengths and limitations**

To our knowledge, this is the first attempt to establish the extent of data collection in care homes at a national level, in a country without an MDS. Our survey was designed to be comprehensive in its coverage of potential data and the paucity of free text comments suggest this was achieved. Respondents were drawn from organisations with more than 5000 care homes, just over a third of the UK total. Care home and group size and geographical location in our sample were broadly representative of the sector as a whole (Laing, 2021). A majority of responses were from homes with good or excellent CQC ratings (CQC, 2021), in keeping with what we know about research participants. It was not feasible to ask about frequency of data collection for different variables, or when information gathering started. Several of the clinical measures may have been introduced during the COVID-19 pandemic, and it is possible that their use will not be sustained.

Care homes have a unique perspective to contribute to the overall assessment of residents' health and wellbeing. Trends in weight and cognition, for example, may be critical to healthcare decisions.

Our findings suggest that care homes are collecting and updating clinical measures with sufficient regularity to produce a useful dataset for monitoring health. Data on dependency and disability are collected by most care homes but virtually absent from healthcare records. These, along with information on quality of life, would make a unique contribution from care homes to our understanding of the older population. It is even possible that insights into health service (NHS) use by residents could be addressed with information already collected by care homes. The overall scale of data collection in care homes is vast, but important questions remain about whether it best reflects the care provided, and how data quality and security varies between homes and across sectors. A greater focus on quality of life and wellbeing, viewing the resident as a social being, would demand a shift in the data collected. As these are outcomes of central importance to social care, this should surely be a priority. Some selection of the healthcare tools in use is also needed, with critical assessment of their appropriateness for care homes, and acknowledgement of existing staff skills. Unmet needs for care and support are often overlooked, and they were not part of our survey. However, the range of data collected by care homes would lend itself to an analysis of which needs are met and which are not. (The survey findings, and the paucity of standardised quality of life measures in this setting, informed a decision to consult on a range of validated quality of life outcome measures in the DACHA prototype MDS (Towers et al., 2023)).

It is important to emphasise that this study did not set out to define the ideal content of an MDS. The purpose of the survey was to generate detailed information about current data collection, so that any future MDS could build on this. One of our questions asked about recording of NHS numbers, which would allow linkage with data from health services. An essential next step in MDS development will be to test the feasibility of linking individual data from care homes to NHS information, and its ability to support longitudinal analyses. At the stage of defining and implementing an MDS, there are many different constituencies, views on, and uses for an MDS. Ensuring that the needs of residents and families are identified and considered will be critical to the success of MDS implementation. (This is part of our ongoing research study). Before an MDS is made mandatory, or financial incentives applied, it will also be important to consider the potential consequences, intended and unintended. Care homes are currently collecting a wide range of data. Imposition of an MDS should produce a standardised data set from all homes. But it may also lead to a reduction in the amount of data collected, and a focus on the process, rather than use of the data to enhance care. Our recent review of how MDS have been implemented in other countries found that having a mandate was important to achieve uptake. However, other incentives were required



to ensure the MDS was not seen as an administrative task separate to the core work of providing care (Musa et al., 2022).

### **Conclusions**

This study suggests that care homes in England may be collecting a high proportion of the information required by MDS in other countries, without incentives or mandate. Future developments in care home records and data collection, including definition of any minimum dataset, could focus on refining rather than extending existing data collection, prioritising the needs and experiences of residents and staff, and emphasising the assessment of social care outcomes.

### **Supplementary material**

Appendix Table 2 Sociodemographic/basic data collection

Appendix Table 4 Information to support care provision

Appendix Table 5 Methods of data collection and storage

Appendix Table 6 Location of storage of different items of information

Appendix Table 7 Frequency of updating information on residents

Appendix Table 10 Changes to data collection and storage as a result of the coronavirus pandemic

**Table 1. Survey respondent characteristics**

	<b>Number (%)</b>	<b>Comparison to national % from the Care Quality Commission (regulator)</b>
<b>Geographical region of England</b>		
North East	20 (7.3%)	4.82%
North West	30 (11.0%)	12.47%
Yorkshire & the Humber	27 (9.9%)	9.63%
West Midlands	26 (9.5%)	10.94%
South East	36 (13.2%)	19.22%
South West	30 (11.0%)	13.21%
East of England	10 (3.7%)	10.94%
Greater London	13 (4.8%)	8.89%
East Midlands	26 (9.5%)	9.90%
Unknown	55 (20.1%)	
<b>Care Home Characteristics</b>		
<b>Size</b>		
<26 beds	77 (28.2%)	51.59%
>26 beds	194 (71.1%)	48.41%
<b>Care provided</b>		
Nursing care beds	124 (45.4%)	28.35%
Dementia specialist beds	194 (71.1%)	49.56%
<b>Organisation size</b>		
Single home	113 (41.4%)	61.36%
2 - 10 homes	95 (34.5%)	4.18%
11 - 50 homes	9 (3.3%)	15.16%
51 - 100 homes	31 (11.4%)	8.23%
101 - 200 homes	9 (3.3%)	6.30%
>200 homes	2 (0.7%)	4.77%
Unknown	14 (5.1%)	
<b>Ownership model</b>		
For-profit	112 (41%)	84.29%
Not-for-profit	85 (31.1%)	13.30%
Local authority	5 (1.8%)	2.41%
NHS	1 (0.4%)	
Other	61 (22.3%)	
Unknown	9 (3.3%)	
<b>Care Quality Commission Rating</b>		
Outstanding	29 (10.6%)	4.44%
Good	208 (76.2%)	78.04%
Requires Improvement	31 (11.4%)	16.14%
Under appeal/no rating	2 (0.7%)	1.37%
No response	3 (1.1%)	0.01%

**Table 3. Health-related data collection in care homes**

<b>Clinical observations</b>	<b>Number (%) respondents</b>
Temperature	257 (94.1%)
Blood pressure	217 (79.5%)
Breathing	184 (67.4%)
Blood sugar	190 (69.6%)
Urine dipstick	176 (64.5%)
Fluid balance	210 (76.9%)
Other clinical observation	19 (7%)
<b>Body measurements</b>	
Weight	271 (99.3%)
Height	249 (91.2%)
Body mass index	248 (90.8%)
Other body measurement	9 (3.3%)
<b>Pain</b>	245 (89.7%)
Abbey Pain Scale	170 (62.3%)
Faces pain scale	41 (15%)
Pain map of body	67 (34.5%)
Pain Thermometer	10 (3.7%)
Brief Pain Inventory	7 (2.6%)
Pain Assessment in Advanced Dementia (PAINAD)	36 (13.2%)
Other measure of pain	19 (7%)
<b>Information on Frailty</b>	150 (54.9%)
Clinical Frailty Scale	76 (27.8%)
Frailty Index	15 (5.5%)
Edmonton Frailty Scale	21 (7.7%)
Other frailty measure	18 (6.6%)
<b>Information on Falls</b>	269 (98.5%)
Number of falls	264 (96.7%)
Falls injury/harm	261 (95.6%)
Falls risk	259 (94.9%)
Timed up and go test	38 (13.9%)
<b>Health conditions</b>	
Long-term conditions	270 (98.9%)
Common infections	265 (97.1%)
Self-limiting conditions	221 (81.0%)
End-of-life pathway	232 (85.0%)
Accidents	262 (96.0%)
Sleep quality /habits	251 (91.9%)
<b>Mental Health</b>	266 (97.4%)
Memory/Thinking	238 (87.2%)
Mood & Emotions	236 (86.4%)
Agitation	247 (90.5%)
Distress	242 (88.6%)
Use of physical restraints	81 (29.7%)
Other mental health information	7 (2.6%)
<b>Mental health tools - cognitive impairment / dementia</b>	<b>Number (%)</b>
Abbreviated Mental Test score (AMT)	252 (92.3%)

Mini Mental State Examination (MMSE)	71 (26%)
Six Item Cognitive Impairment Test (6-CIT)	13 (4.8%)
Montreal Cognitive Assessment (MoCA)	4 (1.5%)
Addenbrook's Cognitive Examination (ACE)	5 (1.8%)
General Practitioner Assessment of Cognition (GPCOG)	67 (24.5%)
Other measures	28 (10.3%)
<b>Mental health tools – anxiety/depression</b>	
The Patient Health Questionnaire (PHQ9)	2 (0.7%)
Geriatric Depression Scale	64 (2%)
Generalised Anxiety Disorder (GAD7)	3 (1.1%)
Other mental health tools	42 (15.4%)

**Table 4 Data on contacts with health services and use of structured communication tools**

<b>Contacts with Health Services</b>	<b>Number (%)</b>
Hospital admissions	268 (98.2%)
Outpatient appointments	268 (98.2%)
Emergency department attendance	258 (94.5%)
Family physician visits face-to-face	269 (98.5%)
Family physician telephone or video contacts	263 (96.3%)
Family physician telephone or video advice to staff	264 (96.7%)
Nurse visits face to face	254 (93.0%)
Nurse telephone or video contacts	240 (87.9%)
Paramedic visits	262 (96.0%)
Any other health professional/allied health professional contacts	259 (94.9%)
Other contacts not covered by the above	202 (74.0%)
<b>Structured communication tool</b>	
National Early Warning Score (NEWS/2)	98 (35.9%)
RESTORE	124 (45.4%)
Is my resident unwell?	72 (26.4%)
SBAR	84 (30.8%)
Other communication tools	25 (9.2%)

**Table 9 Use of data collected by care homes and source of concerns about sharing data**

<b>Data usage</b>	<b>Number (%)</b>
Monitoring quality	264 (96.7%)
Adverse events	221 (81%)
Ordering medications	254 (93%)
Stock control	199 (72.9%)
Budgeting	149 (54.6%)
Identifying training needs	238 (87.2%)
Monitoring staffing requirements	227 (83.2%)
Marketing and promotion	87 (31.9%)
Decisions about responses to COVID	217 (79.5%)
Responding to data requests	203 (74.4%)

  

<b>Source of concerns about sharing data</b>	
Privacy	257 (94.1%)
General Data Protection Regulation (GDPR)	217 (79.5%)
Staff time	184 (67.4%)
Lack of technology	190 (69.6%)
Current paper data collection	176 (64.5%)
Data storage in multiple formats/places	210 (76.9%)
Commercial sensitivities	19 (7%)

## **Ethical Approval**

This survey was approved by Research Ethics Committees at the University of Hertfordshire and Newcastle University (Ref: 4888/2020, Ref HSK/SF/UK/04301).

## **Funding**

This work is funded by National Institute for Health and Care Research (NIHR) Health and Social care Delivery Research (HSDR) Programme, grant number NIHR127234. Adam Gordon, Claire Goodman, Anne Killeth, Barbara Hanratty and Ann-Marie Towers are part-funded by the NIHR Applied Research Collaborations for East Midlands (ARC-EM), East of England (ARC-EoE), North-East and North Cumbria (ARC-NENC) and Kent, Surrey and Sussex (ARC-KSS), respectively. The views expressed in this publication are those of the authors and not necessarily those of the NIHR.

## **Role of the funding source**

The funder and sponsor played no part in study design, data analysis and interpretation, writing of this article or the decision to submit for publication.

## **Acknowledgements**

We are grateful to a) the participants who gave their time to complete our survey during the pandemic; b) our Patient and Public Involvement and Engagement partners for their constructive criticism and ideas and c) to Emily McKean, University of Kent for invaluable help with recruitment.

## **Authors' contributions**

BH, JL and KW designed and piloted the survey and analysed the findings, with input from all co-authors. BH wrote the first draft of the paper and had critical input from all co-authors, with approval of the final draft.

## **Conflicts of interest**

The authors have none to report

## **Data Accessibility statement**

Access to anonymised data may be available on reasonable request to the first author.

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