RESEARCH PAPER

Developing a care home data platform in Scotland: a mixed methods study of data routinely collected in care homes

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Abstract

Background: care homes collect extensive data about their residents, and their care, in multiple ways, for multiple purposes. We aimed to (i) identify what data are routinely collected and (ii) collate care home managers' views and experiences of collecting, using and sharing data.

Methods: we examined data collected in six care homes across Lothian, Scotland. We extracted the meta-data, cross-referenced definitions and assessed the degree of harmonisation between care homes and with data sets currently in use in Scotland and internationally. We interviewed care home managers about their views and experiences of collecting, using and sharing data.

Results: we identified 15 core data items used routinely, with significant heterogeneity in tools and assessments used, and very limited harmonisation. Two overarching themes were identified of importance to the development of a care home data platform: (i) the *rationale* for collecting data, including to (a) support person-centred care, (b) share information, (c) manage workforce and budget and (d) provide evidence to statutory bodies and (ii) the *reality* of collecting data, including data accuracy, and understanding data in context.

Discussion: considerable information is collected by care home staff, in varied formats, with heterogeneity of scope and definition, for range of reasons. We discuss the issues that should be considered to ensure that individual resident-level form the strong foundations for any data platform for care homes, which must also include, robust infrastructure and clear interoperability, with appropriate governance. It must be co-produced by academics, policy makers and sector representatives, with residents, their families and care staff.

Keywords: data, care home, data platform, mixed methods, older people

Key Points

- Care homes collect a large amount of data, in multiple ways, for multiple purposes.
- Fifteen core data items are used routinely to support person-centred care, but these are collected using heterogeneous tools.
- A care home data platform requires understanding of the rationale for data collection, and the reality of how staff collect data.
- A care home data platform needs to be built on strong foundations of individual level data, with robust infrastructure.
- Co-production between academics, policy makers, sector representatives and residents, families and care staff is essential.

Introduction

Care homes collect a large amount of data to support residents' care, but improved data flow within and between care homes and health and social care providers is needed to enhance residents' quality of care, better evidence practice and more robustly inform regional and national policies [1]. In Scotland, 30,000–40,000 older people live in over 800 care homes, most of which are privately owned, or run by voluntary or not-for-profit providers [2, 3].

Pre-COVID, international and UK programmes were in progress to develop common data elements (CDEs)—a set of data elements to measure concepts that can be used across studies for data sharing and comparisons—[4,5] and a Minimum Data Set (MDS)—an agreed selection of the elements required to create a comprehensive, standardised assessment of each resident's functional capabilities and health needs—[6] for care homes. There are mandated systems for MDS in place in some countries, with financial implications: e.g. the Inter-RAI LTCF [7], the Dutch National Measurement of Care Problems 'LPZ' [8] and MDS 3.0 [9].

Focussing on the UK, there is currently no agreed MDS or CDEs for care homes which limits the potential for data linkage, which at present is minimal [10,11]. Studies which have tried to implement interRAI and LPZ in the UK have had mixed results [12,13]. The current DACHA (developing resources and minimum data set for Care Homes' Adoption) study [6] aims to establish the data needed to support care home service, research and innovation and to develop an agreed MDS. The COVID-19 pandemic has highlighted the consequences of these data deficits and intensified focus on how best to address these limitations [1,14].

In Scotland, there are several data sources relating to care homes: the Social Care Survey (SCS) and Scottish Care Home Census (SCHC) had mandatory centralised data collection [15], now been superseded by the SOURCE data collection curated by Public Health Scotland [16]. A 'Safety Huddle Template' (SHT) was created during the COVID-19 pandemic to present an overview of activity and staffing requirements [15–17] (Appendix A describes the data included in each of these).

There is now a unique opportunity to develop the data capture infrastructure in care homes in Scotland, with a new National Care Service (NCS) Bill introduced [18], and a Health and Social Care Data Strategy including consideration of a National Health and Social Care Data Platform [19] out for consultation.

Care homes collect data in a range of ways to support, monitor and record care, and to report to regulatory authorities. Any strategy to improve data collection and analytic capacity must build on what is currently recorded in individual care homes, understand their capacity to provide useable data, and consider all data users' needs, inside and outside the care home [6].

This project was undertaken to inform the development of a care home 'data platform': to outline the foundations of what is required for a person-centred interoperable data framework that can link between social care and health for care home residents. It aimed to (i) identify what data are routinely collected as part of resident care in six different care homes in Scotland and (ii) collate care home managers' views and experiences of collecting, using and sharing data. We use these findings to make recommendations for the considerations of individual-level data as part of the development of a national care home data platform.

Methods

We performed a mixed methods study with six care homes, which comprised the Scottish Lothian Care Home Innovation Partnership (CHiP Lothian). These homes were recruited in Autumn 2018 to represent different types of care homes as part of a wider vision for a teaching/research-based care home centre in the region [20].

Between July 2019 and January 2020, a Research Fellow (L. J.) visited each care home to (a) identify and document data items, systems/software in use and data recording and sharing processes and (b) conduct interviews with each care home manager using a topic guide (Appendix B) to gather views and experiences of current data use and management.

The data items identified were categorised, compared and cross-referenced between care homes and with Scottish and international data sets. Field notes for interviews were written up electronically. The qualitative interview data was coded using the key aims of the study and the interview schedule/topic lists as a framework. L. J. generated initial codes from the data; and identified preliminary themes, then presented these at a group discussion of all managers which was audio recorded and transcribed. A thematic analysis approach was adopted to further define and name key themes and develop a narrative description. These were shared with all authors who further scrutinised their meaning and relevance to reach consensus on two high level, overarching themes.

Ethical approval was given by the Edinburgh Napier University School of Health and Social Care Ethics Committee (Ref/SHSC2007).

Results

The six care homes were under different ownership, had an average capacity of 70 beds and used various data collection methods (Table 1).

Care home data collected

All care homes collected information on admission on Demographics and Diagnoses (date of birth, gender, ethnicity, spiritual beliefs, next of kin and key medical diagnoses).

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Table 1. Characteristics of care homes (CH) in the study

CH	Sector	No. of beds	Data collection method
1	Independent 'for profit'	72	Caresys [21]
2	Charity	72	iCareHealth [22]
3	Independent 'not for profit'	63	Person Centred Software [23]
4	Charity	70	Person Centred Software [23]
5	Local authority	61	Paper + manual entry to in-house spreadsheet
6	Independent* 'for profit'	80	Paper + manual entry to in-house spreadsheet

*CH6 was part of a large 'for profit' chain, none of the others was part of a large chain.

Most data collected included information on the individual's functioning and care needs (physical, emotional, social and spiritual), forming the basis of a personalised care plan. We have used the term Detailed Care Planning Information (DCPI) to describe these. This information was gathered on admission and then reviewed, and updated according to the home's policies, the resident's condition and regulatory requirements: (more than) daily, weekly, monthly or quarterly.

We identified 15 key items of DCPI that are most regularly or routinely collected or used (Table 2): six domains recorded routinely for all residents (dependency, nutrition, weight, incidence and risk of falls, incidence and risk of pressure sores and prevalence of infections); four items regularly used and gathered as required (wounds, frailty, bowel movements and fluid intake); five additional items most likely to be collected when a resident's condition changed (mood/behaviour, pain, movement, mobility, sleep and observations (pulse, blood pressure etc)). There was significant heterogeneity in the tools and measures used (see Table 2), and also in how frequently; e.g. temperature or bowel movements may be recorded daily in some homes, but only in response to a change in condition in others (e.g. see Appendix C).

Some of the assessments relied on observation, care staff intuition and prior knowledge of a resident, rather than formal tools, e.g. identification of delirium or pain. Other assessments, although widely used, were not universally standardised, e.g. falls: recording method varied depending on the f data collection purpose i.e. for regulatory purposes or internal audit.

We mapped these key DCPI to the data elements used by the SCS and SCHC, Safety Huddle Template, MDS-RAI and LPZ (Figure 1). There was good overlap only for nutrition, falls and pressure sores, with some overlap for dependency, weight, infections, frailty, fluid intake, mood and movement. However, there was no overlap for wounds, pain, sleep or observations.

Care home managers' views

Six interviews were performed with seven people (care home managers from each home, and in one home the director of care was interviewed with the manager).

Our analysis identified two high-level, overarching themes that illustrate the current weak foundations of a care home data platform relating to individual-resident level data and are (i) the *rationale* for collecting data, and (ii) the *reality* of data collection and use by care home staff and managers.

Rationale for collecting care home data

The main reasons care home managers gave for collecting residents' data were to

(a) support and deliver person-centred care (the predominant reason), both for care planning and delivery, and to identify a change in a resident's condition;
(b) share information with internal staff and external professionals;
(c) manage workforce and budget;
(d) record and evidence care for regulatory bodies, for inspection compliance and national administrative data such as the care home census.

The rationale affects data collection and use in three main ways: the frequency of collection/use; different data required by different organisations and the lack of ability to share data.

The managers highlighted fluid intake, mood, pain, movement, sleep and vital signs as most useful in monitoring a change in a resident's condition, and six items as key to indicate quality of care or those who need enhanced care: urine/chest infection, weight loss, pressure sores, falls and incidents of 'challenging behaviour'.

The frequency of data collection/use   The collection of DCPI data is driven by three different underlying rationales, which impact collection frequency

• Care Planning overall (and each assessment component) is *reviewed formally* at regular intervals.
• Specific aspects of functioning and care provided are re-assessed *as required,* e.g. in response to a change in the condition of the resident.
• Certain DCPI is gathered *routinely*—i.e. weekly, monthly or annually irrespective of review timeframes or 'as required' triggers.

Different data for different organisations   Individual data items often served more than one purpose and were required by different organisations, with regulatory bodies and the Scottish Government requesting similar data in different

Table 2. Detailed Care Planning Information (DCPI)—assessment tools/measures for each data item regularly used in six care homes

	Area assessed	Care home 1	Care home 2	Care home 3	Care home 4	Care home 5	Care home 6
1	Dependency/indicator of need	Augmented IoRN	IoRN	Dependency assessment	IoRN	IoRN	In-house form
2	Nutrition	MUST	MUST	MUST	MUST	Eating well in care homes/cook safe	In-house
3	Weight	kg and BMI	kg and BMI	kg and BMI	kg and BMI	kg and BMI	kg and BMI
4	Incidence and risk of falls	FRASE	In-house form	–	–	In-house form	In-house form
5	Incidence and risk of pressure sores	Braden	Pressure ulcer cross/PU checklist/waterlow	Waterlow	Waterlow	Waterlow	Skin integrity care Plan
6	Infections	Count and type of infection	Count and type of infection	Count and type of infection	Count and type of infection on PCS	Count and type of infection	Count and type of infection
7	Wounds (new and ongoing)	In-house form	STAR Classification	In-house form	on PCS	NHS wound assessment chart	In-house form
8	Frailty	CIRC	SPAR Tool	Edmonton Frailty Scale	Clinical frailty Scale	Not collected	Not collected
9	Bowel movement(s)	Bristol stool chart	Bristol stool chart	on PCS	Bristol stoolchart on PCS	Bristol stool chart	In-house form
10	Fluid intake	In-house form	In-house form	on PCS	on PCS	In-house form	In-house form
11(a)	Mood: Depression	GDS and/or Cornell scale for depression in dementia	–	–	Cornell scale for depression in dementia	–	–
11(b)	Mood: Delirium	4AT	4AT	–	–	Care plan	–
12	Pain	PAINAD DOLOPLUS-2 Abbey pain scale	Abbey pain scale	Abbey pain scale	Abbey pain scale	Abbey pain scale	Abbey pain scale
13	Movement	R-L-T; Nolan's senses f/work	CarePlan	–	–	Careplan	Careplan
14	Sleep	–	Careplan	Careplan	In-house form	In-house form	In-house form
15	Observations/vital signs	–	–	–	–	–	–

4AT, 4As test; ADL, Activities of Daily Living; CIRC, Change in Resident's Condition; FRASE, Falls Risk Assessment Scale for the Elderly; GDS, Geriatric Depression Scale; IoRN, Indicator of Relative Need [24]; MUST, Malnutrition Universal Screening Tool; PAINAD, Pain in Advanced Dementia Scale; PCS, Person Centred Software; SPAR, Supportive and Palliative Action Register; STAR, Skin Tear Audit Research; R-L-T = Roper, Logan, Tierney model of ADL [25]; Nolan's senses framework [26]. 'in-house', A form developed by the individual care home to collect information on that item. '–', No measure/tool reported, data may be collected as part of the individual's care plan; where respondents specifically stated that information was collected in care support plan this is included in the table.

	Domain of DCPI	MDS-RAI and LPZ	Safety Huddle Template	SCS and SCHC
1	Dependency/ indicator of need	Physical Functioning (RAI) Prevalence of bedfast residents		
2	Nutrition	Nutrition and Eating (RAI) Malnutrition (LPZ)	FFN MUST Score	
3	Weight	Prevalence of weight loss (RAI)		
4	Incidence and risk of falls	Falls (RAI & LPZ)	Number of falls with harm	
5	Incidence and risk of pressure sores	Prevalence of stage 1-4 pressure ulcers (RAI)	Number of new pressure ulcers Grade 2 and above	
6	Infections	Prevalence of urinary tract infections (RAI)		
7	Wounds (new and ongoing)			
8	Frailty		Frailty score >= 7	Problems arising due to infirmity of age (SCS)
9	Bowel Movement(s)			
10	Fluid intake	Prevalence of dehydration (RAI)		
11(a)	Mood: Depression	Prevalence of -behavioural symptoms affecting others - symptoms of depression - symptoms of depression without antidepressant therapy (RAI)		Mental Health Problems (SCS and SCHC)
11(b)	Mood: Delirium			
12	Pain			
13	Movement	Incidence of decline in - late-loss ADLs; - range of motion		
14	Sleep			
15	Observations/ Vital Signs			

Colours denote agreement across sources:

Green = good overlap, Amber = some overlap, Red = no overlap.

MDS-RAI = Minimum Data Set Inter-RAI LTCF [8] ; LPZ = Dutch National Measurement of Care Problems [9]

Figure 1. Domains of Detailed Care Planning Information (DCPI) and overlap with other datasets (colours denote agreement across sources: green = good, amber = some and red = none).
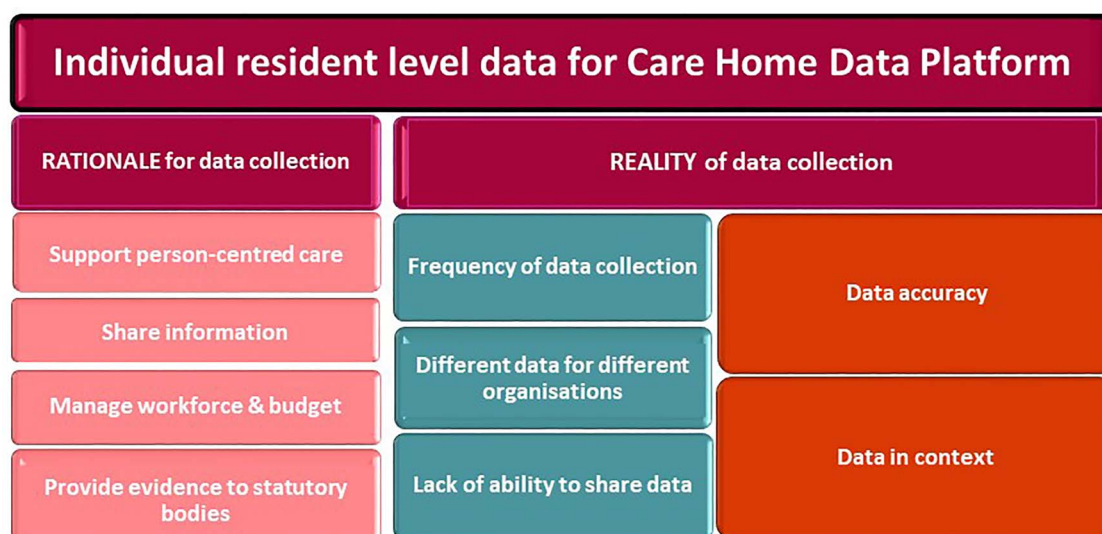
Figure 2. Considerations for individual resident level data as the foundation for a care home data platform.

ways: one manager commented 'they all ask for different things'.

Lack of ability to share data Care home managers explained that external data linking and sharing was limited, resulting in data being entered more than once, onto different systems, or shared verbally and recorded retrospectively. One manager suggested 'it would be great to put the data in once and be able to share it with GP, hospital and other staff'.

Reality of data collection and use in care homes

Our analysis identified two issues relating to the reality of care home data collection and use that care home managers consider important to address to ensure they do not weaken the foundations of the developing of a care home data platform. These are data accuracy and data in context.

Data accuracy Data collection was reported as time-consuming for frontline staff and managers and, therefore, often done retrospectively (at end of shift), which may affect data accuracy. Depending on the data collection processes (paper or electronic), some DCPI could be over or under recorded by staff. The accuracy of care home data may also be affected by how individual staff apply the varied definitions of each DCPI (e.g. fall, witnessed fall, fall resulting in fracture); staff understanding of terminology particularly where English is not their first language and illegible writing and spelling on paper records.

Care home data being used out of context Care home managers considered it important for a developing care home data platform to have context built in to ensure appropriate analysis and interpretation.

Several suggested that the current data prioritised recording of care tasks, fuelling a task-orientated culture and over-reliance on more readily quantified aspects of care home service. One manager hoped that any new data platform would contribute to the needed cultural shift from task-orientated care to resident/relationship orientated care, not work against it.

Managers felt that the lived experience of residents and causal factors relevant to resident outcomes ('softer/qualitative' data) are under-recorded and less well understood. Some felt that pre-scripted data fields limit the recording of social/emotional activities and care provision, and can result in the data about care homes and residents/families being clinically focussed.

In addition, items of care home data are often interpreted in isolation, limited in their ability to construct a holistic understanding of a resident's changing needs. We summarise the issues relating to individual resident-level data for a care home data platform in Figure 2.

Discussion

This survey of six diverse care homes from the Lothian Care Home Innovation Partnership has shown the heterogeneity of the data collected by staff. We identified 15 core data items—DCPI—regularly collected and used by care home staff which are the foundations of care home data sets. Care home managers reported that they used this information to inform person-centred care, to inform workforce planning and respond to the organisational context. At present, the foundational content of a care home data platform, data on individual residents, is recorded in heterogeneous ways across the care homes and there is limited overlap with the data elements recorded by InterRAI, LPZ, Safety Huddle Template, Social Care Survey and Scottish Care Home Census.

This study has several strengths, using a mixed methods approach to outline in detail the reality of data collection about individual residents, and exploring the views of care home managers on data use. The Scottish context with the

imminent introduction of a NCS [18] and associated Data Strategy [19] provides specific opportunities. The Community Health Index (CHI) unique identifier could enable easier linkage, if its use is extended to social care settings [19,27]. The NCS could mandate specific aspects of data collection, such as a minimum data set, and thus highlight the Scottish Government's priorities for the care home sector. The data strategy clearly outlines the need to include social care users, and care home residents, in the use of data for better services and innovation to improve care [19]. The existence of a Scottish national data-collection framework with high completion rates since 2003—the Scottish Care Home Census [15]—suggests that care home managers in Scotland would be willing to work with the relevant authorities to collect data [15,28].

The limitations of this study include its small size; therefore, these findings may not be replicated elsewhere. The homes included may atypical, as, they are larger than average size [29], and the managers volunteered to participate in a Care Home Innovation Partnership. Many of the challenges of data entry and system implementation identified here are widely recognised [6]. We reviewed the main sources of data suggested by the care home manager, and did not view individual residents' notes, or search other locations e.g. family information, key information summary, which can include important data. We could not distinguish information that *could* be collected from information that *was* collected, although the interviews provided feedback on what the managers said were generally collected and used.

The presentation of these 15 items as a list belies the complexity and context-specific nature of care home data. It is important that the reality of data collection—why it is collected, and by whom it is used—is understood, including the nuances of each individual data item.

Several systems exist to collect data electronically e.g. [21–23], which can link to external information sources such as GP data or relatives, and care homes decide whether to purchase these. The priority given to clinically related data can create a task-orientated culture, preoccupied with physical and mental health. Data should include wider aspects of well-being, always maintaining a person-centred approach [30]. The ongoing DACHA study [6], and work on CDEs [4,5], will inform how this could be achieved.

Data linking and interoperability is extremely limited both inside care homes and with external organisations [6,11,19,31]. Ongoing efforts to improve this must focus both on the collection of individual resident-level data and summarising this as aggregate data, avoiding duplication (e.g. DCPI such as falls must be entered separately in aggregate as number of falls with harm to external agencies; [31]).

It important that studies consider not only how data are captured meaningfully [6,32] but also how care home staff use these data [33]. Data collection must take account of two key factors: the *rationale* of those who want to use the data and the *reality* of how the data is actually collected and recorded. This relates to different outcome levels—resident, staff, service-use and relationships/integration [34]. We suggest that whether data are collected at individual or aggregate level, and why, must be reviewed regularly to ensure that data collection is fit for purpose and changes according to local, national and other priorities.

The impact of COVID-19 has highlighted limitations in care home data. Firstly, in the key issue of identifying who lives in a care home: COVID-19 studies used institutional codes in national death records [35], but also required manual verification; or gained access to a cohort from an individual care home chain [36]. The development of new methods to identify residents is particularly welcome, e.g. this method based on the CHI and the Unique Property Reference Number (UPRN), CURL [27] or guidance on how to combine different aspects of the Electronic Health Record [37], although these still do not identify all care home residents. There is therefore an urgent need for e.g. Care Episode Statistics to accurately identify care home residents, in combination with a unique identifier to allow linkage to other existing data [19,28,38], and adequate resource to support staff to collect data, and to see the benefits of doing so [14].

This paper concentrates on the foundations of a care home data platform: information collected at the individual resident level in the domains of demographics, diagnoses and detailed care planning information in a robust, standardised and person-centred way using appropriate data collection approaches. These results identify how the rationale for data collection and the reality of how it is collected is undermining the much-needed strong foundations of individual resident level data. The proposed structure of a MDS [6] includes individual data on residents as one of its key components. We have proposed a model (Appendix D) of the various pillars of data and systems to visualise the additional components that are all required to provide a stable foundation for a care home data platform. This aims to highlight how a robust data platform builds on the foundation of data on individual residents (Figure 2), including clear governance processes for the internal and external use of data. This will allow enhanced interoperability between care homes and other health/social care stakeholders, particularly if data can be standardised/harmonised. Data should also be collected about the workforce, and the physical infrastructure of the care home. Then all aspects of care home data—about residents and their needs, the workforce and the building (with appropriate consents/anonymisation)—can be linked to outcome data. This proposed platform can form the basis for further development and co-production with key stakeholders; it could combine with ongoing work to define a National Minimum Data Set [6] to identify the core information required to provide person-centred care that is responsive to a change in condition, including opportunities for innovation and data-driven approaches.

It is essential that we collect what is important, and do not attribute importance to items just because they are

measurable. Documentation must be able to record care-related, as well as health-related aspects, and relate to the individual's quality of life. Future work must also not only document what data are collected, but how staff use data to provide care. We therefore recommend that a truly robust data platform for care homes must be co-produced, from the foundations up, starting with individual-level data—not just by academics with clinical and technical expertise, policy makers and sector representatives—but collectively, including residents, their families and friends, and staff to construct a whole-system care home data platform.

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