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Who lives in Scotland's care homes? Descriptive analysis using routinely collected social care data 2012–16

ORIGINAL RESEARCH PAPER

Who lives in Scotland's care homes? Descriptive analysis using routinely collected social care data 2012–16

Jennifer K Burton[1], Ellen Lynch[2], Sharon Love[3], Julie Rintoul[4], John M Starr[5], Susan D Shenkin[6]

Abstract

Background Adults living in long-term care are a significant and complex population who are under-represented in research using traditional methodologies.

Methods The aim of this study was to provide the first description of the adult care home population and their homes, using routinely collected data. A retrospective descriptive analysis was performed using the Scottish Care Home Census (SCHC) between 1 April 2012 and 31 March 2016.

Results Data are from 1,299 care home services (79.3–89.7% completeness), including 34,399–39,311 residents per year across all regions of Scotland. A total of 68% of residents are female, with median age 84 years. 27% fund their own care. Over 85% of self-funded residents receive free personal care allowance. Around 60% require care from a registered nurse and 49% have a formal diagnosis of dementia.

The majority of admissions come from hospital (46%). Between 13 and 17% of residents die annually, with a median time to death of 596–653 days.

Conclusions This study provides the most comprehensive descriptive data of UK care home residents available. There is scope to enhance the information available through linkage to other routine sources.

Correspondence to:

Jennifer K Burton
Academic Geriatric Medicine
Institute of Cardiovascular and Medical Sciences
New Lister Building
Glasgow G31 2ER
UK

Email:
Jenni.Burton@glasgow.ac.uk

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Introduction

Between 2 and 5% of the older adult population worldwide receive 24-hour care in an institutional long-term setting.[1] The UK care home population has been comparatively under-represented in research, including that using administrative data.[2] Care homes in the UK do not typically use the large international care data systems,[3] such as the InterRAI (international resident assessment instrument)[4] and Minimum Dataset (MDS).[5] These data systems collect multidomain assessments about residents and have provided a rich repository for research in the USA, Canada and across Europe.

Knowledge about UK care home residents, therefore, comes from survey data,[6] longitudinal cohort studies[7,8] or from recruited participants in intervention studies.[9,10] Both the Cognitive Function and Ageing Study and English Longitudinal Study of Ageing have reported data on care home residents in UK care homes; totalling 543 and 303 residents, respectively.[7,8] Individual studies have yielded valuable in-depth data characterising residents, but again are limited by small numbers of residents in relatively few homes, with 227 residents from 11 care homes included from a single region represented in the most cited UK care home cohort data.[11] The challenges of research in the care home sector are well described, including issues around capacity

[1]SCREDS Clinical Lecturer and Speciality Trainee Year 3, Academic Geriatric Medicine, Institute of Cardiovascular and Medical Sciences, Glasgow Royal Infirmary, University of Glasgow, Glasgow, UK; [2]Statistician, Health and Social Care Analysis Division, Directorate for Population Health, Scottish Government, Edinburgh, UK; [3]Geographic Information Science Analyst, Geographic Information Science & Analysis Team, Data, Statistics, and Outcomes, Scottish Government, Edinburgh, UK; [4]Senior Statistician, Health and Social Care Analysis Division, Directorate for Population Health, Scottish Government, Edinburgh, UK; [5]Director, Honorary Professor and Consultant Geriatrician, Alzheimer Scotland Dementia Research Centre, University of Edinburgh and NHS Lothian, Edinburgh, UK; [6]Senior Clinical Lecturer and Honorary Consultant Geriatrician, Centre for Clinical Brain Sciences, University of Edinburgh and NHS Lothian, Edinburgh, UK
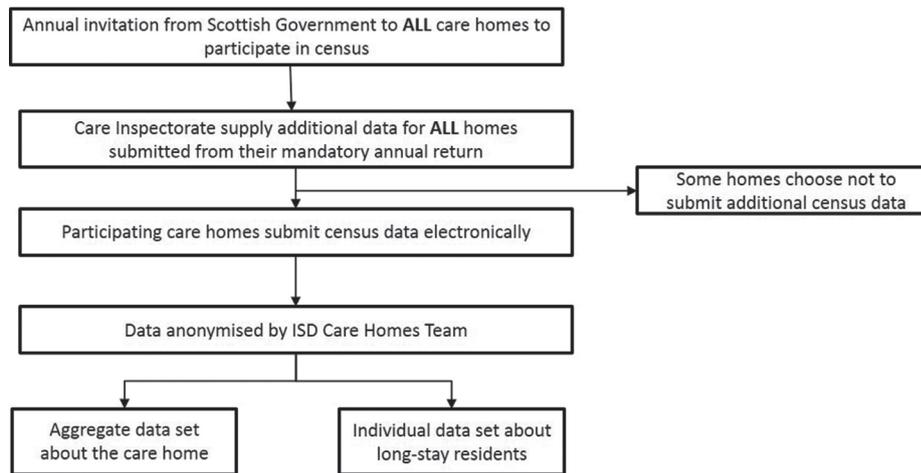
to consent, pressures of the care home environment, and the need to ensure all research is planned and conducted with the support of residents, relatives and staff as key stakeholders.[12]

An alternative, novel approach is to make use of existing data collected for nonresearch reasons to add visibility to the needs of this under-represented population. Care homes collect and generate significant amounts of data as part of everyday care and regulatory compliance. This routinely collected data has a potential utility as a research tool. Scotland has an infrastructure to utilise routinely collected data and combine information from health and administrative sources.[13] The use of routinely collected social care data for research is novel[14] and its feasibility and usefulness has not yet been explored.

Methods

The aim of this study was to provide the first description of the long-stay adult care home resident population in Scotland and the homes in which they live.

Design

This was a retrospective descriptive analysis using routinely collected social care data from the annual Scottish Care Home Census (SCHC) of residents within the care home between 1 April 2012 and 31 March 2016.

Setting and participants

There is significant heterogeneity in terminology and care services provided in long-term care settings across the world.[15,16] For this analysis, a 'care home' is defined as a nursing or residential care facility that provides 24-hour care to its residents. Care home residents within the same care home may receive residential care or residential and nursing care if this is required by the individual.[17]

All care home services in Scotland, whether privately owned or local authority funded, are registered with the national regulator, the Care Inspectorate.[18] Only adult care home services, with long-stay residents,[19] were included in this analysis. The number of adult care home services in

Scotland fluctuates annually as some homes close, new homes open and other services change ownership and are re-registered.

Data sources

The SCHC has been collected annually by the Care Inspectorate and the Scottish Government Health and Social Care Analysis Division (SGHSCAD) since 2003. Data are submitted electronically through an e-form open from July to May by individual care homes to the Care Inspectorate. Submission is not mandatory but is actively encouraged. Updated guidance is produced to aid completion.[20]

Data are requested on the activity of the care home over the preceding financial year (1 April–31 March). The submission is structured in two parts: aggregate information about the care home and individual resident information on long-stay residents. The aggregate data submitted by individual homes are supplemented by data provided by the Care Inspectorate from their separate annual return, which all homes must submit data towards.[21] This means there is some basic data available on all care home services each year.

Data are securely transferred from the Care Inspectorate to the NHS National Services Scotland Information Services Division (ISD) Care Homes Team who collate, quality assure and analyse them. A copy of the final dataset is also securely held by SGHSCAD for further analysis. The flow of data is summarised in Figure 1. An anonymised copy of the data can be made available for use by researchers, with project-specific permission.

Care home variables

Descriptive data were reported about the care home, including the registered subtype of care provided, sector providing care and the registered capacity of beds. Health Board Area was matched into the dataset using electronic lookup tables based on the location of the care home. Care home services open at any point during the study period are reported by Health Board Area, with the approximate adult population in 2015 to provide context. Scottish Index of Multiple Deprivation (SIMD) is a measure of area-based deprivation and was reported in quintiles, from one representing the most deprived area to five

Table 1 Descriptive analysis of the adult care home services 2012–16 that submitted resident data

Census year	Open homes 31 March	n (%) submitting data*
2012/13	1,204	1,141 (89.7)
2013/14	1,171	1,021 (81.2)
2014/15	1,147	956 (79.7)
2015/16	1,103	941 (79.3)

Care home services in Scotland (2012–16)	Included total n = 1,299	
Registered subtype	**n (%)**	
Older people	957 (73.7)	
Learning disabilities	215 (16.6)	
Mental health problems	66 (5.1)	
Physical and sensory impairment	42 (3.2)	
Other**	19 (1.5)	
Sector	**n (%)**	
Private	761 (58.6)	
Voluntary or not for profit	352 (27.1)	
Local authority or Health Board	186 (14.3)	
Capacity	**Places**	
Mean (SD)	34.6 (25.6)	
Median (IQR)	31.0 (33.0)	
Range	1–225	
Average weekly charge	**£**	
Mean older people care homes (SD)	624.7 (138.7)	
Median older people care homes (IQR)	587.0 (111.5)	
Range	326–1,422	
Mean other care homes (SD)	991.5 (500.7)	
Median other care homes (IQR)	872.0 (534.0)	
Range	301–2,976	
MISSING (%)	122 (9.4)	
Health Board Area	**Number care home services (%)**	**Adult population 2016†**
Greater Glasgow & Clyde	249 (19.2)	963,937
Grampian	184 (14.2)	488,123
Lothian	170 (13.1)	730,400
Tayside	121 (9.3)	348,994
Highland	107 (8.2)	267,177
Lanarkshire	105 (8.1)	538,322
Fife	92 (7.1)	307,373
Ayrshire & Arran	86 (6.6)	307,565
Forth Valley	77 (5.9)	252,718
Dumfries & Galloway	46 (3.5)	125,596
Borders	34 (2.6)	95,059
Shetland	11 (0.8)	19,024
Western Isles	11 (0.8)	22,596
Orkney	6 (0.5)	18,354
Area-based deprivation††	**n (%)**	
SIMD 1 (most deprived area)	229 (17.6)	
SIMD 2	233 (17.9)	
SIMD 3	310 (23.9)	
SIMD 4	292 (22.5)	
SIMD 5 (least deprived area)	235 (18.1)	

Table 1 Continued

Main provision within the care home	n (%)
Older people	805 (62.0)
Learning disabilities	206 (15.9)
Dementia	121 (9.3)
Mental health (not dementia)	68 (5.2)
Physical disability or illness	35 (2.7)
Autism spectrum disorders	11 (0.9)
Alcohol dependency	9 (0.7)
Acquired brain injury	7 (0.6)
Drug dependency	6 (0.5)
Alcohol-related brain injury	5 (0.4)
Other[†]	10 (0.8)
MISSING	16 (1.2)

Client needs care home can accommodate	n (%)
Older people[††]	1,018 (78.4)
Dementia[#]	957 (73.7)
Physical disability or illness	942 (72.5)
Visual impairment	935 (72.0)
Hearing impairment	845 (65.1)
Sensory impairment	836 (64.4)
Palliative and end of life care	813 (62.6)
Other mental health problems	759 (58.4)
Learning difficulties	579 (44.6)
Korsakoff's syndrome	286 (22.0)
Autism spectrum disorders	183 (14.1)
Alcohol dependency	174 (13.4)
Alcohol-related brain injury	152 (11.7)
Acquired brain injury	151 (11.6)
Blood-borne viruses	121 (9.3)
Drug dependency	81 (6.2)
MISSING	16 (1.2)

*Denominator is care home services open at any point in the year, not just at end of census year.
**Category 'Other' includes alcohol misuse, drug misuse.
[†]Using National Records of Scotland Mid-Year Estimates.[41]
[††]Area-based deprivation based on SIMD Quintile 2011.
[†]Category 'Other' includes: palliative and end of life care, sensory impairment, visual impairment, hearing impairment.
[††]Older people includes categories older people and older people – frailty.
[#]Dementia includes categories dementia and older people – dementia.
IQR: interquartile range; SD: standard deviation; SIMD: Scottish Index of Multiple Deprivation

representing the least deprived area.[22] SIMD was matched into the dataset using electronic lookup tables based on the datazone (small area geography) of the care home. Care homes report both the main provision their service can care for and all the client needs that can be accommodated within the service. Main provision is thus reported as a single response per care home service, whereas homes can record as many client need categories as they can support. This client need category does not necessarily correspond to the residents currently living in the care home service, rather it indicates the provision that could be offered if required.

Resident-level variables

Resident demographic information was calculated, including sex, age at admission to care home and age at census date for those still resident in the home at the end of census year. Funding status is based on the main or whole source of funding for the individual's place, based on the care home records. The 'Local Authority' category will include individuals who are funding their own care but choose to pay their fees via their Local Authority, and those who the Local Authority are funding their care.

In Scotland, all adults aged ≥65 years are entitled to free personal care allowance of up to £171 per week (£8,892/year) if they are assessed as requiring it.[23] This allowance is used towards the costs of personal care within the care home setting. The proportion of those aged ≥65 years claiming personal care allowance was calculated. An additional £78 per week (£4,056/year) is available to adults of any age who are assessed as requiring nursing care, which is used towards the total costs of the care home place.[23] The proportion of care home residents claiming nursing care allowance was calculated.

A targeted list of resident care needs (e.g. dementia, acquired brain injury, etc.) is recorded as present or absent for all long-stay residents, which are defined for care home staff in the census guidance.[20] As many as apply to each resident can be recorded, providing proportions of all residents with each 'need'.

Location of Adult Care Homes in Scotland 2012-2016

- Older People
- Learning Disabilities
- Mental Health Problems
- Physical and Sensory Impairment
- Other

Health Board Boundaries

1. Ayrshire & Arran
2. Borders
3. Dumfries & Galloway
4. Fife
5. Forth Valley
6. Grampian
7. Greater Glasgow & Clyde
8. Highland
9. Lanarkshire
10. Lothian
11. Orkney
12. Shetland
13. Tayside
14. Western Isles

Scottish Government
Riaghaltas na h-Alba
gov.scot

Figure 2 Map visualising the location of adult care homes by registered subtype and Health Board Area
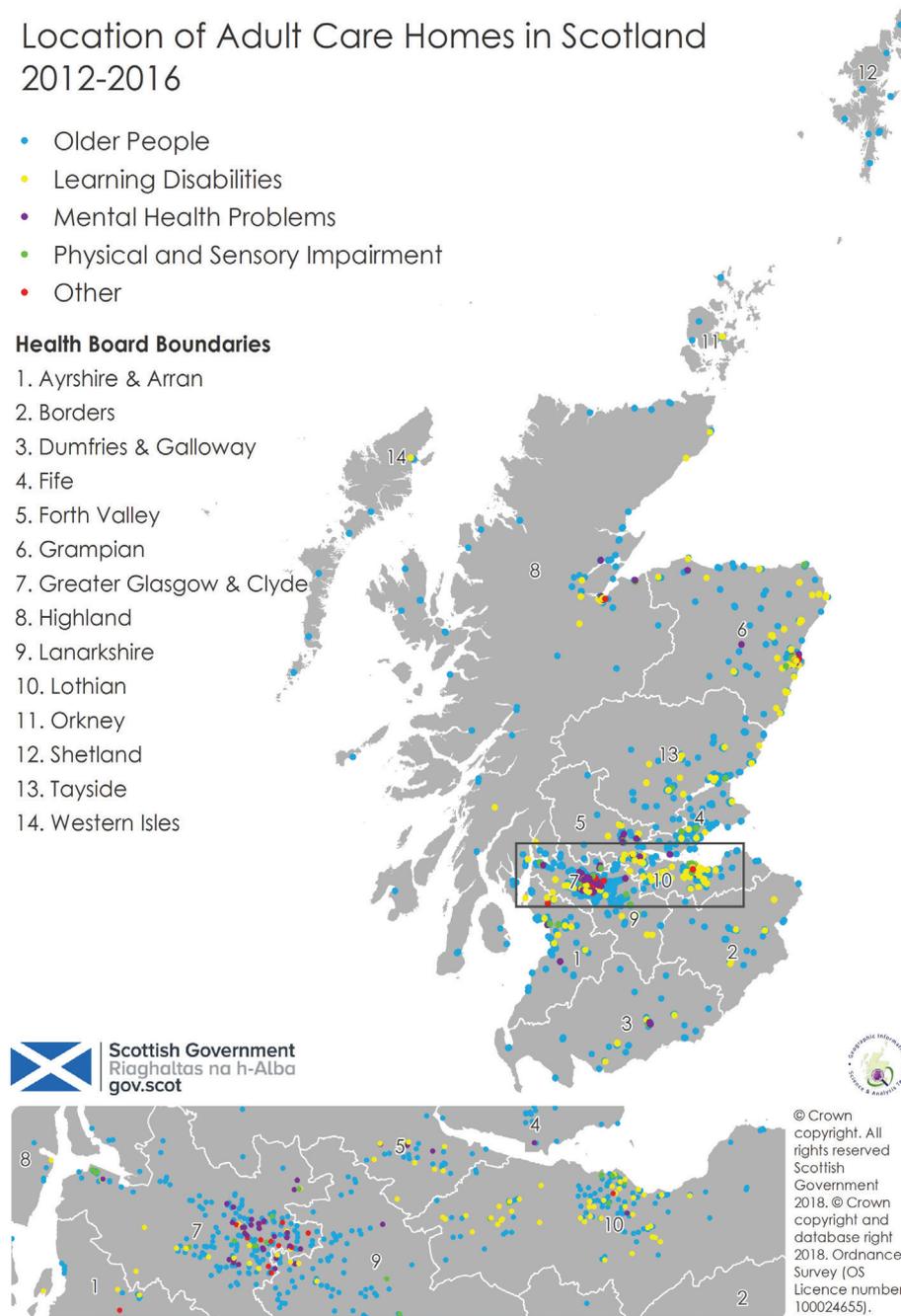
Outcome variables

Admissions and discharges were reported for each census year, based on having a valid date between 1 April and 31 March. All categories of source of admission and discharge destination were reported. Time to event was calculated in days for those who died, were transferred to another care home, were discharged home or to sheltered/supported accommodation, using cases with a valid date of admission and date of discharge.

Bias

Not all care homes submit long-stay resident data to the SCHC as submission is not mandatory. This is likely to introduce bias into the estimates produced. It is possible to describe open homes that do not submit resident data and describe potential bias at the care home level. It is not possible to evaluate the potential bias around resident data that is not submitted.

Study size

The data have not been used previously for research, thus no sample size calculation was performed. All available data were included in the study.

Statistical methods

The data were cleaned and analysed using SAS® Enterprise Guide 7.1 (SAS Institute Inc., Buckinghamshire, UK).

The census contains a consistent service identifier variable, so care home level analyses could be combined across the study period 2012–16. If data were submitted for at least 1 year, then the care home service was included.

Table 2 Adult long-stay care home resident characteristics, analysed by census year 2012–16

	2012/13 n = 39,311 n (%)	2013/14 n = 35,456 n (%)	2014/15 n = 34,389 n (%)	2015/16 n = 35,431 n (%)
Male	12,541 (31.9)	11,297 (31.9)	11,161 (32.5)	11,583 (32.7)
Female	26,724 (68.0)	24,076 (67.9)	23,171 (67.4)	23,824 (67.2)
MISSING	46 (0.1)	83 (0.2)	57 (0.2)	24 (0.1)
Mean age at admission (SD)	78.8 (14.7)	78.9 (14.8)	78.8 (15.1)	79.3 (14.6)
Median age at admission (IQR)	82.6 (13.2)	82.7 (13.3)	82.8 (13.4)	83.0 (13.2)
Range	16–106 years	16–106 years	16–106 years	16–106 years
MISSING (date of admission or date of birth)	5,039	1,933	936	319
Mean age at end of census year (SD)*	80.6 (13.9)	81.1 (13.7)	81.0 (13.9)	81.3 (13.6)
Median age at end of census year (IQR)*	84.0 (14.0)	84.0 (13.0)	84.0 (13.0)	85.0 (13.0)
Range	16–109 years	16–110 years	17–108 years	18–107 years
MISSING (date of birth)	4,985	1,906	906	297
Local authority mainly/wholly funding care	28,127 (71.5)	25,054 (70.7)	24,425 (71.0)	24,492 (69.1)
Privately mainly/wholly funding care	10,373 (26.4)	9,679 (27.3)	9,340 (27.2)	10,354 (29.2)
NHS mainly/wholly funding care	694 (1.8)	635 (1.8)	486 (1.4)	525 (1.5)
MISSING	117 (0.3)	88 (0.2)	138 (0.4)	60 (0.2)
If privately funded and ≥65 years, receiving free personal care	7,701 (86.2)	7,944 (87.6)	7,929 (87.9)	8,914 (87.4)
MISSING	10 (0.1)	0	5 (0.1)	3 (0.03)
If privately funded, receiving free nursing care	5,992 (57.8)	5,510 (56.9)	5,263 (56.3)	5,834 (56.3)
MISSING	15 (0.1)	27 (0.3)	17 (0.2)	42 (0.4)
Nursing care	24,286 (61.8)	21,496 (60.6)	20,844 (60.6)	21,832 (61.6)
Other physical disability or chronic illness	15,483 (39.4)	13,988 (39.5)	13,111 (38.1)	13,655 (38.5)
Dementia – medically diagnosed**	18,793 (47.8)	17,179 (48.5)	16,897 (49.1)	17,814 (50.3)
Dementia – not medically diagnosed**	2,861 (7.3)	2,497 (7.0)	2,360 (6.9)	2,498 (7.1)
Visual impairment	6,204 (15.8)	5,555 (15.7)	5,127 (14.9)	5,291 (14.9)
Hearing impairment	4,222 (10.7)	3,641 (10.3)	3,233 (9.4)	3,362 (9.5)
Mental health problem (excluding dementia)	3,673 (9.3)	3,239 (9.1)	2,924 (8.5)	2,972 (8.4)
Learning disabilities	2,606 (6.6)	2,336 (6.6)	2,262 (6.6)	2,071 (5.8)
Acquired brain injury	1,285 (3.3)	1,074 (3.0)	968 (2.8)	905 (2.6)
Alcohol dependency	1,882 (4.8)	1,727 (4.9)	1,581 (4.5)	1,539 (4.3)
Drug dependency	132 (0.3)	123 (0.3)	150 (0.4)	171 (0.5)

*Age at census only calculated for residents in care home at end of census year (31 March) with valid date of birth.
**Dementia variables – only one variable should be selected, if both are positive only counted as medically diagnosed.
IQR: interquartile range; SD: standard deviation

Completeness was calculated annually using the denominator of care home services open at the end of the previous census year plus the new services registered in the census year. This was used because care homes that are open at any point in the year can submit resident data.

Illustrative analysis of missing data is presented for the open care home services that did not submit data in 2015/16, given the similarities in data between years. Resident analysis was reported per year of census as no unique identifier variable was present to allow aggregation.

Sample characteristics were described as means and standard deviations, medians and interquartile ranges or frequencies and percentages as appropriate. Calculations or characteristics in which data are missing are indicated in the tables. Adults were defined as those aged ≥16 years, and 110 years was used as the upper accepted limit for age calculations. Cost estimates <£300 per week or >£3,000 per week were censored. Cost data were examined based on care home subtype – comparing older people care home charges with all other care home charges based on the different populations served. Time to death, discharge and

Table 3 Summary of admissions, deaths, transfers and discharges by census year

		2012/13 n = 39,311 n (%)	% all residents	2013/14 n = 35,456 n (%)	% all residents	2014/15 n = 34,389 n (%)	% all residents	2015/16 n = 35,431 n (%)	% all residents
Admissions	Total admissions	9,704 (24.7)		8,408 (23.7)		8,543 (24.8)		9,742 (27.5)	
	Source of admission								
	Another care home	1,181 (12.2)		1,143 (13.6)		1,206 (14.1)		1,599 (16.4)	
	Hospital	4,768 (49.1)		3,853 (45.8)		3,983 (46.6)		4,282 (44.0)	
	Own home	3,183 (32.8)		2,809 (33.4)		2,664 (31.2)		3,100 (31.8)	
	Sheltered/supported accommodation	234 (2.4)		232 (2.8)		208 (2.4)		253 (2.6)	
	Other/not known	338 (3.5)		371 (4.4)		482 (5.6)		508 (5.2)	
Discharges	Total discharges	8,921 (22.7)		6,665 (18.8)		7,498 (21.8)		7,550 (21.3)	
	Reason for discharge								
	Death	5,941 (66.6)	15.1	4,899 (73.5)	13.8	5,844 (77.9)	17.0	5,985 (79.3)	16.9
	Transfer to another care home	828 (9.3)	2.1	697 (10.5)	2.0	680 (9.1)	2.0	634 (8.4)	1.8
	Hospital	590 (6.6)	1.5	445 (6.7)	1.3	392 (5.2)	1.1	366 (4.8)	1.0
	Discharge home	333 (3.7)	0.9	332 (5.0)	0.9	328 (4.4)	1.0	317 (4.3)	0.9
	Other/not known	1,229 (13.8)	3.1	292 (4.4)	0.8	254 (3.4)	0.7	248 (3.3)	0.7
Deaths	Number with valid date	5,784 (97.4)		4,719 (96.3)		5,844 (100)		5,985 (100)	
	Mean days to death (SD)	955.6 (1031.4)		938.2 (1132.9)		977.5 (1091.5)		922.7 (1,076.5)	
	Median days to death (IQR)	639.0 (1165.0)		596.0 (1098.0)		653.0 (1143.5)		605.0 (1,072.0)	
	MISSING	157		180		132		136	
Transfers to another care home	Number with valid date	763 (92.1)		618 (88.7)		680		634	
	Mean days to transfer (SD)	528.0 (884.6)		513.9 (1002.5)		536.0 (1009.7)		575.1 (1,004.6)	
	Median days to transfer (IQR)	209.0 (642.0)		149.5 (533.0)		178.0 (565.0)		246.0 (624.0)	
	MISSING	65		79		77		69	
Discharges home	Number with valid date	295 (88.6)		289 (87.0)		328		317	
	Mean days to discharge (SD)	382.6 (833.1)		466.8 (1,064.3)		461.2 (888.1)		356.4 (837.2)	
	Median days to discharge (IQR)	90.0 (368.0)		128.0 (412.0)		150.0 (477.0)		72.5 (290.0)	
	MISSING	38		43		36		41	

IQR: interquartile range; SD: standard deviation

transfer were calculated where date of admission and date of event were present and plausible.

Approvals and permissions

Participation in the SCHC is voluntary and all care homes receive a privacy notice and information for residents and families about the purpose of data collection and the uses of the data. Individual resident consent is not obtained as data are collected and used on an anonymised basis as part of routine care.

Permission to use the data was granted by the SGHSCAD for a single researcher (JKB) to analyse the data under supervision and evaluate quality and completeness. All data were accessed and analysed within the Scottish Government Health and Care Analysis Division, Edinburgh, UK. Geographical analysis was performed by SL at the Scottish Government Geographic Information Service, Edinburgh, UK, on a limited dataset with no identifiable variables. Results were subject to statistical disclosure control by the SGHSCAD Senior Statisticians (EL and JR), to prevent release of potentially identifiable or sensitive data.

Results

Care home services

In Scotland in 2012/13 there were 1,204 care home services with long-stay residents open at census year end, falling to 1,103 in 2015/16, a reduction of 8.4%. The number of care home services submitting data to the SCHC each year varied from 941 to 1,141 (79.3–89.7% completeness, including all homes open at any point during the census year) (Table 1).

The majority of care homes (72.8%) are registered for older people, followed by learning disabilities (16.2%) and mental health problems (5.0%). For 62.0% of care homes the main provision offered is for older people, followed by 15.9% for people with learning disabilities, 9.3% for dementia and 5.2% for other mental health problems. Two-thirds of all Scottish care homes can accommodate the following client groups: older people; people living with dementia; those with physical disability or illness; and, people with visual impairment.

Most Scottish care homes are privately owned (58.6%), with voluntary or not-for-profit providers accounting for 27.1% of the sector and local authority or Health Board provision for 14.3%. Care home capacity varied from 1–225 beds with a median of 31 beds. Older people care homes had a lower mean and median weekly charge compared to other care home types.

There are care homes in every Health Board Area and care home numbers vary across Health Board Areas from six in Orkney to 249 in Greater Glasgow and Clyde, broadly in keeping with population size. Figure 2 visualises the location of homes by their registered subtype. There is little variability in care home provision by deprivation: 17.6% of care homes

are in the most deprived areas of Scotland and 18.1% are in the least deprived areas.

Long-stay residents

Each year there are between 34,389 and 39,311 long-stay residents in care homes in Scotland, depending on the number of open services and proportion of care homes submitting data. Table 2 summarises the resident characteristics per year. More than two-thirds of residents are female. Age at admission ranges from 16 to 106 years, with a mean age of 79 years and median of 83 years. Age at census ranges from 16 to 108 years, mean age is 81 years and median age of 84 years.

Around 70% of residents (range: 69.1–71.5%) have local authority as the main or whole funder of care with 26.4–29.2% of residents privately funding their care and the NHS funding 1.4–1.8% of resident places. Around 87% of self-funders aged ≥65 years are receiving free personal care allowance (range: 86.2–87.9%). Between 56.3 and 57.8% of self-funders receive nursing care allowance.

The distribution of care needs among long-stay residents is comparable across the 4 years of data. Between 60.6 and 61.8% require nursing care; 38.1–39.5% have a physical disability or chronic illness; and, 47.8–50.3% have a diagnosis of dementia. A further 6.9–7.3% are considered by care home staff to have dementia, without a formal diagnosis. Sensory impairment not corrected by aids is common – 14.9–15.8% have visual impairment and 9.4–10.7% have hearing impairment. Mental health problems (excluding dementia) affect 8.4–9.3% of residents and 5.8–6.6% have a learning disability. Acquired brain injury is recorded in 2.6–3.3% of residents. Substance misuse is uncommon, with 4.3–4.9% of residents dependent on alcohol and 0.3–0.5% dependent on drugs.

Outcomes

Table 3 summarises the admissions, deaths, transfers and discharges among the long-stay residents. There were 8,408–9,742 admissions recorded in each census year, representing 23.7–27.5% of resident records. Hospital was the most common source of admission (44–49.1%); followed by admissions from an individual's own home (31.2–33.4%) and transfers from another care home (12.2–16.4%).

There were 6,665–8,921 discharges recorded in each census year, representing 18.8–22.7% of resident records. Between 13.8 and 17.0% of residents died each year, with median time to death of approximately 1.7 years, and mean time to death of approximately 2.6 years. Between 1.8 and 2.1% were transferred to another care home and 0.9–1.0% were discharged home annually.

Non-returning care home services 2015/16

There were 245 care home services (20.7%) that did not submit long-stay resident data in 2015/16 (Supplementary Table 1). Non-returning homes were more likely to specialise in learning disabilities and mental health problems and be

smaller, with a mean of 13 fewer places. Privately owned care homes were more likely to return data than local authority homes.

Discussion

Key findings in context

This report using the Care Home Census provides the most comprehensive descriptive data of UK care home residents available, including data from 1,299 care home services (79.3–89.7% completeness) open at any point over a 4-year period. This includes the spectrum of adult care home services available, providing a home for older adults, those with learning disabilities, mental health problems and substance misuse. Although these services primarily provide care for an older adult population, this work emphasises the heterogeneity present in the care home population and use of these data linked, at an individual level, to other sources could offer potential to explore this further. Our findings demonstrate that Scottish care homes can and do accommodate residents with a broad range of care needs, emphasising the complexity of health needs among this population and need for support.[24]

Provision is largely from private care providers and local authority provision represents the smallest part of the sector. This is in-keeping with wider UK trends in predominant privatisation.[25] Care homes for older people have lower weekly charges than other services and this may reflect the use of a National Care Home Contract rate for older people agreed by local authorities and the Convention of Scottish Local Authorities.[26]

The majority of admissions come from hospital (46%), despite national policy directives advising against new care home admissions from acute settings.[27,28] There has been little prior research about those admitted to care homes from hospital.[29] Transfers between care homes are common. Discharge home is rare but happens to approximately 1% of residents annually. All these transitions in care are poorly explored in the literature,[30] but represent significant events in the lives of the individuals involved, particularly those with cognitive impairment and those approaching the end of their lives.[31]

Between 13 and 17% of residents die annually, with a median time to death of 596–653 days after admission. Time to death was a mean of 922–977 days (approximately 2.7 years) and median of 596–653 days (approximately 1.6 years) after admission. These estimates are skewed by this analysis being of all adult care homes, thus including younger residents who have a significantly longer stay, and lower risk of death, than the older population. These data are similar to those reported in an analysis of 11,565 residents who died between 2008 and 2011, which found half of the residents in a chain of English care homes had median time to death of 1.6 years.[32] However, they differ from more contemporary UK data that found 56% of deaths in English nursing home residents were within a year of care home admission.[33] Our data include a broader case mix

as all care home provision is included, including residential and nursing provision. It is possible that residents who are admitted and die within days or weeks are not included in the census return, as they have not stayed for 6 weeks, as referenced in the definition of long-stay residents.[19] Accurate data about length of stay in Scottish care homes would be helpful to inform service planning and capacity. Such data could be used to inform modelling of social care need and costs, exploring variation across regions.[34]

Strengths

This is the largest study of UK care home residents and the first to use routinely collected social care data, with appropriate confidentiality safeguards, as a source. Data are inclusive and, as individual resident consent was not required by the methodology, will include individuals with and without capacity who are often excluded from research. The data provide valuable descriptive epidemiology of a significant predominantly older adult population, which can inform the planning of services. Additional variables, such as Health Board Area and SIMD, to evaluate deprivation were matched into the dataset, based on care home location, enriching the data. Levels of missing data were low across the included variables and an illustrative description is provided of the care homes that do not participate from the most recent year of data. This allowed an assessment of bias at the care home level.

Limitations

Data are missing from 10.3–20.7% of all care home services. Homes not returning data are smaller, more likely to care for individuals with a learning disability or mental health problem, and more likely to be under Local Authority ownership. This will affect the representativeness of the summary data as the residents of these homes may be different. However, this provides the first characterisation of completeness and a target to improve and incentivise data submission.

As the analysis considers all care home services over the whole 4-year period, the number by Health Board Area may not represent services open simultaneously, thus the data comparing the adult population is provided as an illustration, rather than the number of homes per head of population.

No individual data are collected on those using the care home for short-stay, respite or intermediate care.

The lack of a resident-level identifier within the SCHC dataset meant resident data had to be reported by year, rather than across the study period. This means the total numbers of residents each year are likely to include the same residents. However, all calculations of time to events such as death or transfer were recorded based on actual recorded dates and so extend beyond the study period.

There are other parameters about the care home population that would be helpful to describe their needs, which are captured in more comprehensive international datasets.[5,35] This may include health data such as comorbidities and

medication use and specific information around frailty, continence and dependency, etc. The former could be made available through data linkage of the SCHC to other national data sources. Examples of the latter group can feasibly be evaluated in UK care settings[36,37] but these are not available nationally or routinely collected in the UK. Any expansion in data collected would need to be justifiable to residents, relatives and staff, and feasible with the care home setting.

Future research

This analysis has identified an untapped research resource that provides insights into the Scottish Care Home population. The information collected in the Census data can be enhanced through linkage to other data sources, to help investigate issues around pathways into care, predictors of care home admission and variations in practice. Accurate identification of care home residents in routine data sources is a priority to facilitate data-driven research.[38–40] The availability of individual-level anonymised data could facilitate understanding around the care trajectories of the different resident populations and to compare those receiving residential care and those who require nursing care.

Conclusions

Making use of routinely collected data to inform practice is an efficient methodology, provided the data are accurate and representative. Analysing the SCHC data provides valuable descriptive epidemiology about the Scottish care home population, at a scale unique in UK research. Attention should now be focused on enhancing the value of these data through record linkage and using this to improve the care of people currently in care homes, and those who may be admitted in future. ◑

Declarations

Individual resident consent was not obtained but care homes were supplied with privacy notices to explain to residents and their families how their data may be used for statistics and research: http://www.gov.scot/Topics/Statistics/Browse/Health/ScottishCareHomeCensusB

Availability of data and material

The dataset supporting the conclusions of this article are available from the Scottish Government Health and Social Care Analysis Division, but restrictions apply to the availability of these data, which were used under direct supervision and so are not publicly available. Data are, however, available upon reasonable request with permission of the Scottish Government Health and Social Care Analysis Division.

Online Supplementary Material

Supplementary Table 1 is available with the online version of this paper, which can be accessed at https://www.rcpe.ac.uk/journal

References

1 Ribbe MW, Ljunggren G, Steel K et al. Nursing homes in 10 nations: a comparison between countries and settings. *Age Ageing* 1997; 26: 3–12.

2 Moore DC, Hanratty B. Out of sight, out of mind? A review of data available on the health of care home residents in longitudinal and nationally representative cross-sectional studies in the UK and Ireland. *Age Ageing* 2013; 42: 798–803.

3 Stosz L, Carpenter I. Developing the use of MDS/RAI reports for UK care homes 2008. https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/2308-care-assessment-standards.pdf (accessed 31/10/17).

4 Gray LC, Bernabei R, Berg K et al. Standardizing assessment of elderly people in acute care: the interRAI acute care instrument. *J Am Geriatr Soc* 2008; 56: 536–41.

5 Rahman AN, Applebaum RA. The nursing home Minimum Data Set assessment instrument: manifest functions and unintended consequences–past, present, and future. *Gerontologist* 2009; 49: 727–35.

6 Gage H, Dickinson A, Victor C et al. Integrated working between residential care homes and primary care: a survey of care homes in England. *BMC Geriatr* 2012; 12: 71.

7 Green I, Stow D, Matthews FE et al. Changes over time in the health and functioning of older people moving into care homes: analysis of data from the English Longitudinal Study of Ageing. *Age Ageing* 2017; 46: 693–6.

8 Matthews FE, Bennett H, Wittenberg R et al. Who lives where and does it matter? Changes in the health profiles of older people living in long term care and the community over two decades in a high income country. *PLoS One* 2016; 11: e0161705.

9 Teale EA, Munyombwe T, Schuurmans M et al. A prospective observational study to investigate utility of the Delirium Observational Screening Scale (DOSS) to detect delirium in care home residents. *Age Ageing* 2018; 47: 56–61.

10 Siddiqi N, Cheater F, Collinson M et al. The PiTSTOP study: a feasibility cluster randomized trial of delirium prevention in care homes for older people. *Age Ageing* 2016; 45: 652–61.

11 Gordon A, Franklin M, Bradshaw L et al. Health status of UK care home residents: a cohort study. *Age Ageing* 2014; 43: 97–103.

12 Luff R, Ferreira Z, Meyer J. Care homes 2011. http://eprints.lse.ac.uk/41191/1/SSCR_Methods_Review_8_web.pdf (accessed 18/05/18).

13 Walesby KE, Harrison JK, Russ TC. What big data could achieve in Scotland. *J R Coll Physicians Edinb* 2017; 47: 114–9.

14 Witham MD, Frost H, McMurdo M et al. Construction of a linked health and social care database resource–lessons on process, content and culture. *Inform Health Soc Care* 2015; 40: 229–39.

15 Burton JK, Quinn TJ, Gordon AL et al. Identifying published studies of care home research: an international survey of researchers. *J Nurs Home Res* 2017; 3: 99–102.

16 Sanford AM, Orrell M, Tolson D et al. An international definition for "nursing home". *J Am Med Dir Assoc* 2015; 16: 181–4.

17 Care Inspectorate. Care homes for adults 2015. http://www.careinspectorate.com/index.php/care-homes-for-adults (accessed 18/01/19).

18 Care Inspectorate. Care Inspectorate 2015. http://www.careinspectorate.com/index.php (accessed 15/02/18).

19 Information Services Division Scotland, NHS National Services Scotland. Care Home Census for Adults in Scotland 2016. https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-10-25/2016-10-25-CHCensus-Report.pdf (accessed 25/07/17).

20 Scottish Government. Guidance for 2015 Scottish Care Homes Census 2015. http://www.gov.scot/Topics/Statistics/Browse/Health/ScottishCareHomeCensusB/GuidSCHC15 (accessed 20/07/16).

21 Care Inspectorate. Why your annual returns are so important 2015. http://www.careinspectorate.com/index.php/annual-returns/why-your-annual-returns-are-so-important (accessed 21/12/17).

22 NHS National Services Scotland. Scottish Index of Multiple Deprivation (SIMD). https://nhsnss.org/services/practitioner/dental/scottish-index-of-multiple-deprivation-simd/ (accessed 13/02/18).

23 Scottish Government. Free Personal & Nursing Care 2015. http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Older-People/Free-Personal-Nursing-Care (accessed 29/09/15).

24 Goodman C, Dening T, Gordon AL et al. Effective health care for older people living and dying in care homes: a realist review. *BMC Health Serv Res* 2016; 16: 269.

25 Sutaria S, Roderick P, Pollock AM. Are radical changes to health and social care paving the way for fewer services and new user charges? *Br Med J* 2017; 358: j4279.

26 Care Information Scotland. Paying care home fees: Standard rates 2018. http://www.careinfoscotland.scot/topics/care-homes/paying-care-home-fees/standard-rates/ (accessed 05/06/18).

27 NHS England. Safe, compassionate care for frail older people using an integrated care pathway: practical guidance for commissioners, providers and nursing, medical and allied health professional leaders. 2014. p. 21. https://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf (accessed 16/10/15).

28 Audit Scotland. Reshaping care for older people. p. 29. http://www.audit-scotland.gov.uk/docs/central/2014/nr_140206_reshaping_care.pdf (accessed 23/11/15).

29 Harrison JK, Garrido AG, Rhynas SJ et al. New institutionalisation following acute hospital admission: a retrospective cohort study. *Age Ageing* 2017; 46: 238–44.

30 Steventon A, Roberts A. Estimating length of stay in publicly-funded residential and nursing care homes: a retrospective analysis using linked administrative data sets. *BMC Health Serv Res* 2012; 12: 377.

31 Perrels A, Fleming J, Zhao J et al. Place of death and end-of-life transitions experienced by very old people with differing cognitive status: retrospective analysis of a prospective population-based cohort aged 85 and over. *Palliat Med* 2014; 28: 220–33.

32 Forder J, Fernandez J-L. Length of stay in care homes. Report commissioned by Bupa Care Services, PSSRU Discussion Paper 27692011. http://eprints.lse.ac.uk/33895/ (accessed 06/06/18).

33 Kinley J, Hockley J, Stone L et al. The provision of care for residents dying in U.K. nursing care homes. *Age Ageing* 2014; 43: 375–9.

34 Steventon A, Roberts A. Estimating lifetime costs of social care: a bayesian approach using linked administrative datasets from three geographical areas. *Health Econ* 2014; 24: 1573–87.

35 Onder G, Carpenter I, Finne-Soveri H et al. Assessment of nursing home residents in Europe: the Services and Health for Elderly in Long TERm care (SHELTER) study. *BMC Health Serv Res* 2012; 12: 5.

36 Darby J, Horne J, Lewin J et al. Benchmarking the prevalence of care problems in UK care homes using the LPZ-i: a feasibility study. *East Midlands Research into Ageing Network (EMRAN) Discussion Paper Series.* 2017: 1–17.

37 NHS National Services Scotland. The changing functional needs and dependency of people living in care homes 2016. http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2017-02-28/2017-02-28-The-changing-functional-needs-and-dependency-of-people-living-in-care-homes-Report.pdf (accessed 01/03/17).

38 Burton JK, Guthrie B. Identifying who lives in a care home – a challenge to be conquered. *Age Ageing* 2018; 47: 322–3.

39 Housley G, Lewis S, Usman A et al. Accurate identification of hospital admissions from care homes: development and validation of an automated algorithm. *Age Ageing* 2018; 47: 387–91.

40 Burton JK, Marwick CA, Galloway J et al. Identifying care-home residents in routine healthcare datasets: a diagnostic test accuracy study of five methods. *Age Ageing* 2019; 48: 114–21.

41 National Records of Scotland. Mid-Year Population Estimates Scotland, Mid-2016 Edinburgh: National Statistics; 2017. https://www.nrscotland.gov.uk/files//statistics/population-estimates/mid-year-2016/16mype-cahb.pdf (accessed 25/07/17).