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

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Abstract

Background: care home residents are aged, many have multiple co-morbidities and low levels of functioning. Yet, the UK has no routinely available, national data on health in care homes. The aim of this study is to identify longitudinal or nationally representative cross-sectional sources of information on the health and wellbeing of older adults residing in care homes in the UK and Ireland.

Methods: searches were made of health databases (Medline, Embase), websites of the Economic and Social Data Service and UK Office for National Statistics, and selected journals. On-going longitudinal or repeated cross-sectional studies were sought in the UK and Ireland, that included participants aged over 65 and reported one or more health-related variables. Data were extracted on studies that included older adults in care homes. If necessary, study teams were contacted for information.

Results: we identified 42 longitudinal cohort or repeated cross-sectional studies in the UK that involved older adults. Of these, 17 studies provided data from care home residents. The time period of data collection ranged from 2 to 40 years. Proxy interviews were used to capture the majority of data in care homes.
Introduction

Promoting the health and wellbeing of care home residents will be an important challenge for health services in the future. In the 2011 census, one in six (16.4%, 9.2 million) people in England and Wales were aged over 65 years [1]. By 2050, there are expected to be 19 million in this age group in the UK [2]. Although there are just under 400,000 older adults in England and Wales resident in care homes at any one time [3], the throughput is rapid, with a median length of stay in a UK care home of 15 months before death [4]. Overall, it is estimated that >80% of adults aged over 65 will require some kind of care, including admission to care homes, in their later years [5].

The UK has no routine, national data collection specific to the health and wellbeing of care home residents, despite suggestions that residents of nursing homes receive lower quality health care than people living at home [6]. Information on the health of care recipients over time would inform policy making and provide a means of evaluating the quality and outcomes of services provided. Better data could answer important questions about the way NHS services are delivered to care homes, the impact of different models of care on patients’ health, or which services are most needed by residents. Bowman et al. [7] developed a census for use within the largest provider of care homes in the UK, collecting data on care type, functional problems and diagnoses at admission. This census has been repeated on four occasions, but the model has not yet been copied by other providers [8, 9]. When care home residents are admitted to hospital, their place of residence is recorded in the Hospital Episode Statistics, which should allow separate analyses for the care home population. Similarly, treatment provided by general practices is documented in medical records and may be included in primary care databases in England and Wales that collate data from samples of general practices. At present, primary care data sets including The Health Improvement Network (THIN) and Clinical Practice Research Datalink (CPRD) cover just over half of the UK population [10–15]. However, extracting data on care home patients from the primary care databases is neither straightforward nor without financial cost. Shah et al. [16] have developed a method for identifying care home residents within THIN database, which could be applied to others. At a national level, the information collected by general practices for the voluntary incentive scheme, the Quality and Outcomes Framework should encompass all care home residents. In practice, a high proportion of patients in care homes are excluded from data collection on clinical grounds [17].

In the absence of any easily accessible or comprehensive health service data on care home residents, it is useful to consider surveys and censuses that have broader scope, but include information on health and wellbeing. The UK and Ireland have a number of government supported nationally representative data sets, and a range of cohort studies. These have the potential to provide valuable information on older adults living in institutions and fill the gaps left by routine health service data collection. The aim of this study is to identify and describe current (non-NHS) sources of information on the health and wellbeing of older adults in care homes, available in the UK and Ireland.

Methods

On-going sources of data on the health and wellbeing of older adults were sought that met the following criteria:

- Participants were aged 65 years and older at the time of the last wave of data collection, and were either a complete population sample (e.g. a census) or representative of the source population.
- Studies that focused on people with a specific medical condition were excluded unless the original sample members were unaffected members of the source population.
- Data on at least one measure of health status were included.
- Data were available from more than one point in time

These criteria encompass repeated cross-sectional studies, prospective and retrospective longitudinal designs including cohort studies. Intervention studies, such as randomised controlled trials, were not included.

Data sources were identified in five different ways:

1. The UK Office for National Statistics and the Economic and Social Data Service (ESDS) websites were searched to identify any longitudinal and cross-sectional studies which met inclusion criteria. The ESDS is a national data archiving and dissemination service containing key economic and social data from the UK.
2. Medline (Ovid) and Embase (Ovid) were searched using a strategy designed to identify research with care home residents, using longitudinal or repeated cross-sectional methods. The search was restricted to the UK and Ireland, no language or time limitations were imposed (Supplementary data are available in Age and Ageing online, Appendix 2).
3. The journals that appeared most often in the results of the Medline and Embase searches were identified and tables
of contents examined from 1990 (or earliest available if later) to January 2013. The journals were either general medical publications or specialist journals relating to the health care of older adults, and included Age and Ageing, British Medical Journal, British Journal of General Practice, British Journal of Psychiatry, International Journal of Geriatric Psychiatry, International Journal of Epidemiology and Community Health and Palliative Medicine.

(4) Cohort profiles published in the International Journal of Epidemiology were located and scrutinised for descriptions of relevant data sets.

(5) A Google search was conducted using a shortened version of the Medline (Ovid) and Embase (Ovid) search strategies.

For all the data sources that met the inclusion criteria, information was sought from the study website and publications based on the data set, on whether residents of care homes were included in the data collection. For the purpose of this study, care home refers to both residential and nursing homes. Residential homes provide accommodation, meals and help with personal care such as washing and eating. In addition, nursing homes have registered nurses who can provide care for more complex health needs.

Data were then extracted using a specially designed form. If any items of information were unavailable, the named study person was contacted by email or telephone. The study design, baseline characteristics of participants including age and geographical location and total number of respondents at the most recent wave of data collection were all noted. In addition, the number of care home respondents, and health variables used were also recorded. In cohort studies, the age of participants was estimated using the most recent wave of data. The last available wave of data collection was also used to derive the total number of participants and the number in care homes. In longitudinal studies, where the sample has been boosted over the lifetime of the study, this will be higher than at the start of the study. In others, where the cohort has aged over time, and attrition from death or withdrawal is likely, the overall numbers may be reduced.

Results

This review identified a total of 42 studies that met the inclusion criteria, listed in Box 1. Seventeen studies collected any data on care home residents (eight could not be contacted for clarification). For these 17 studies, the total number of participants in the most recent wave of data collection, the number recorded as residing in care homes and the items of information collected from participants are shown in Supplementary data online, Table 1. Further details on how the data were collected in care homes are listed, such as whether proxy informants were used.

Of the 17 studies that included older adults in care homes, 12 were longitudinal cohort studies, four nationally representative repeated cross-sectional studies and one repeated cross-sectional study. One study was based in the

Box 1. Data sets and cohort studies identified that met the inclusion criteria

Aberdeen Birth Cohorts of 1921 and 1936 [35]
Boyd Orr Cohort [36]
The British Regional Heart Study (BRHS) [37]
British Household Panel Survey [38]
British Women's Heart and Health Study [39]
Caerphilly Health and Social Needs Electronic Cohort Study (E-CATALyST) [40]
Caerphilly Prospective Study (CAPS) [41]
Cambridge City over-75s Cohort [19]
Census for England and Wales/ONS Longitudinal Study (ONS LS) [42, 43]
Census of Population of Ireland [44]
Cognitive Function and Ageing Study I [45]
Cork and Kerry Diabetes and Heart Disease Study [46]
Edinburgh Artery Study (1988–94) [47]*
English Longitudinal Study of Ageing (ELSA) [18]
European Male Ageing Study [48]
Generation Scotland: Scottish Family Health Study [49]
Gospel Oak Study (1988–90) [50]*
Health and Lifestyle Survey [51]
Health Survey for England (HSE) [20]
Hertfordshire Ageing Study (HAS) [52]
Hertfordshire Cohort Study (HCS) [53]
Housing Regeneration and Health Study [54]
Leicestershire cohort (1979–90) [55]*
Life Opportunities Survey [56]
Lothian Birth Cohorts of 1921 and 1936 [57]
Million Women Study [58]
Melton Mowbray Cohort (1980–88) [59]*
Melton Osteoporotic Fracture Study (1990–92 to 1995–97) [60]*
National Survey of Health and Development [61]
Newcastle 85+ Study [62]
Northern Ireland Census/Northern Ireland Longitudinal Study [63] (NILS) [64]
North Yorkshire, Nottinghamshire, Derbyshire and Kirklees Cohort (1980–81) [65]*
Nottingham Cohort (1998–99) [66]*
Nottingham Longitudinal Study of Activity and Ageing [67]
Scottish Health and Ethnicity Linkage Study [30]
Scottish Health Surveys Cohort [68]
Scotland's Census/Scottish Longitudinal Study (SLS) [69, 70]
Southall and Brent Revisited (SABRE) [71]
Southampton Ageing Project (1977–02) [72]*
West of Scotland Twenty-07 Study [73]
Whitehall II study [74]
Understanding Society [75]

Studies providing data on care home residents shown in bold.

*Data sets identified that met the inclusion criteria but which are not on-going, with dates.
UK, four in Great Britain, eight in England and Wales, two in Scotland, one in Northern Ireland and one in the Republic of Ireland. The time period of data collection ranged from 2 to 40 years, excluding cohorts that followed up participants from birth.

The proportion of care home respondents ranged from 70 out of 10,274 in the English Longitudinal Study of Ageing (ELSA) [18] to five out of seven participants in the Cambridge City over-75s Cohort [19]. In the nationally representative repeated cross-sectional studies, between 0.5 and 0.7% of participants were care home residents, with the exception of the 2000 Health Survey for England that included a sample of 2,493 care home residents [20]. In six studies, participants in care homes were not specifically excluded from this study, but no data were collected on place of residence.

In ten of the studies that included care home residents, data collection took place through a proxy informant when it was not possible to conduct an interview with the participant. For example, in the last wave of the ELSA [18], 58 of the 70 interviews in institutions were conducted with a proxy. Proxy interviews within ELSA omit certain questions, and do not include the nurse visit or any physical measurements or estimations. The proxy was usually an adult who knew enough about the participant to answer the questions, most often a member of the care home staff or friend or relative aged over 16 years.

**Discussion**

**Summary findings**

Few data are available on the health of care home residents from studies in the UK and Ireland. Our review has shown that the majority of studies being conducted either exclude care home residents at baseline or censor their data by not following community-dwelling participants into institutions. When data from people in care homes are available, they are often collected through a proxy. Most studies did not publish their approach to data collection in care homes.

**Comparison with other studies**

Seematter-Bagnoud and Santos-Eggimann published an international review of cohorts that included older adults, but they did not identify the proportion of older adults in institutions [21]. There is an extensive literature on care home residents from the USA, using analyses of the national minimum data set [22, 23]. This collects information on the physical, psychological and psychosocial functioning of all residents of long-term facilities that are certified by Medicare or Medicaid, and it is used to monitor the quality of nursing home care [24]. Elsewhere, the Australian Institute of Health and Welfare regularly publish information on age, sex, length of stay and needs of residents in aged care facilities [25]. Other authors have described the challenges of conducting research in care homes [26], but we are not aware of other studies that have collated the sources of information on care home residents in longitudinal and related studies for an international or local population.

**Strengths and limitation**

Obtaining information on care home residents’ participation in longitudinal studies was not straightforward, and we contacted study organisers to ensure that the information presented is correct. This study was restricted to older people, which led to the exclusion of two studies whose participants were under 65 at the time of the last wave. Both the Newcastle Thousand Families 1947 Birth Cohort and the Aberdeen Children of 1950s Study will provide data on institutionalised older adults as their participants age [27, 28]. The Irish Longitudinal Study on Ageing also plans to follow-up care home residents [29]. Data linkage studies, such as the Scottish Health and Ethnicity Linkage Study [30], have the potential to include care home residents in the future. This review focused on the UK and Ireland, as previous work had identified these countries as one of the main sources of relevant studies in Europe [21]. Of the longitudinal studies that we identified, the English Longitudinal Study of Ageing provided data on the largest number of care home residents [18]. It has sister studies in Europe (Survey of Health, Ageing and Retirement) and in the USA (Health and Retirement Study) [31, 32].

**Implications**

The paucity of data available from participants in care homes is understandable, when the challenges to conducting research are considered. Many residents have poor mental and physical health; levels of cognitive impairment and dementia are high. Careful assessment of adults’ capacity to consent to participate in research is particularly important in this setting. Recommendations of research ethics committees and appropriate legislation provide a framework for researchers. The principle underpinning such guidance is that any action should be in the best interests of the person who lacks capacity [33].

Care home staff, health professionals or family may all act as gatekeepers to ensure that residents do not participate in research that may be burdensome or detrimental to their health and wellbeing. Interviews in care homes are also likely to be time consuming and resource-intensive, if participants have poor hearing, or a proxy informant has to be identified and accessed, for example [34]. The use of proxy respondents may also raise questions over the comparability, validity and reliability of data collected.

Care home residents are aged; many have multiple comorbidities or significant deficiencies in functioning. The absence of systematic data collection compromises our ability to monitor the outcome of health care in this population. However, as the proportion of older adults in the population rises and the number of people receiving institutional care grows, the need for systematic data on health in care homes will become more important. In the future, funders of research should take into account the extra resources that
will be needed to include care home residents in surveys. Researchers may wish to look critically at the current use of proxy informants and consider whether this is an area ripe for methodological development.

Key points

- There are no routinely available sources of information on the health of care home residents, despite their high levels of frailty, comorbidities and functional impairments.
- In the UK and Ireland, most nationally representative studies do not include or follow-up older adults in care homes.
- Data collection in care homes is most often via a proxy respondent.
- Consideration should be given to supporting systematic collection of information on the health of older adults in care homes, to inform policy and practice.

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Conflicts of interest

None declared

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Supplementary data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

References

Due to the number of references supporting this review only the most important are listed here and are represented by bold type throughout the text. The full list of references is available in Supplementary data *Age and Ageing* online, Appendix 1.

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Prognosis of hospitalised older people with different levels of functioning: a prospective cohort study

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Abstract

Background: hospitalised older people are at risk for poor functioning after hospital discharge. We aimed to validate the predictive ability of the Identification Seniors At Risk-Hospitalized Patients (ISAR-HP) screening questionnaire to identify older patients at risk for functional dependence by comparing groups with different ISAR-HP scores on cognitive and physical functioning, mortality, health-related quality of life (HRQoL) and loneliness.

Design: a longitudinal prospective cohort study.

Setting: a 450-bed hospital in the Netherlands.

Subjects: four hundred and sixty patients 65 years or older admitted between June 2010 and October 2010.

Methods: participants were classified into five risk groups at hospital admission using the ISAR-HP. We interviewed patients at hospital admission and at 3 and 12 months after admission using validated questionnaires to score HRQoL, physical functioning, cognitive functioning and loneliness. Differences in survival were quantified by a concordance statistic (c).