CHIEF SCIENTIST OFFICE

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RESEARCH PROJECT BRIEFING



IMPROVING UNDERSTANDING OF THE POPULATION LIVING IN SCOTLAND'S CARE HOMES USING DATA

AIMS

Adults living in care homes have complex health and social care needs and are under-represented in research. Data collected through everyday use of services (*known as routinely collected data*) offers the potential to involve an inclusive sample of residents, without additional burden to them or to their caregivers. Care home staff take time to collect these data and yet their usefulness as a research tool has not been explored. This study aimed to make use of these data to address the following questions:

- To establish if care home data can be linked to health and administrative data sources to build a more complete picture of pathways into care homes
- To understand how people move-in to care homes, including whether they move-in from hospital or from home
- To compare the characteristics, costs and outcomes of people moving-in to care homes from hospital to those moving-in from home
- To explore national data about people living in care homes, describing how different data sources can be used to identify dementia in this population

This programme of research was designed to improve understanding of this life-changing move for the resident and their family, generating evidence from real-world experience to improve understanding.

KEY FINDINGS

- Linking care home data from the Scottish Care Home Census to other national data resources was feasible and informative, bringing additional insights not available in the original data collection
- People moving-in to care homes from hospital are clinically different from those moving-in from home, with higher rates of frailty, dependency and often long or multiple admissions in the previous six months
- NHS costs are significantly higher in the year before moving-in to a care home, compared to the year after (*average £8323 versus £1670*)
- Average time to death is significantly (both clinically and statistically) shorter among people moving-in to care homes from hospital (*23 versus 32 months from home*)
- Care home data provides information on the numbers of residents living with dementia which are not consistently captured in health datasets

WHAT DID THE STUDY INVOLVE?

We used data from the Scottish Care Home Census and linked this to national health and administrative data. For the comparative analysis, this included data on adult care home residents moving-in between 2013-2016. For the dementia analysis, this included data on all adult care home residents from 2012-2016. Mortality data was available until end of May 2020.

The Scottish Care Home Census involves care homes submitting data to the Care Inspectorate (*national care regulator*) which are shared with Public Health Scotland for analysis and official statistics publication. Data are requested annually, summarising the activity of the care home over the preceding financial year.

Care home data were linked to general and psychiatric hospital admissions, community prescribing and mortality records to identify other health conditions, significant diagnoses, hospital resource use, numbers of prescribed medicines, frailty, dementia and mortality. We also used the Scottish Index of Multiple Deprivation; Urban/Rural look-up tables and NHS Scotland Costbook for additional information.

Data cleaning was required to enable use, including identifying the first care home move for each resident. We described the resident cohorts included in the analyses and then looked to identify

predictors of moving-in from hospital compared to from community. Economic modelling was done to estimate costs with different pathways and to estimate the differences in costs for the one-year period preceding and following moving-in to the care-home. Time to death analysis was adjusted for age, sex and frailty status.

The research was supported by a multi-professional steering committee with expertise from care home representatives, the Care Inspectorate, data analysts in Public Health Scotland and representation from the Scottish Government Social Care Analysis Team.

Following easing of public health restrictions, a series of care home engagement events were held in October-December 2022 in three Scottish care homes to discuss findings with care home residents, families and friends and care home staff. This helped make sense of findings, affirm the relevance of the research and identify key next steps.

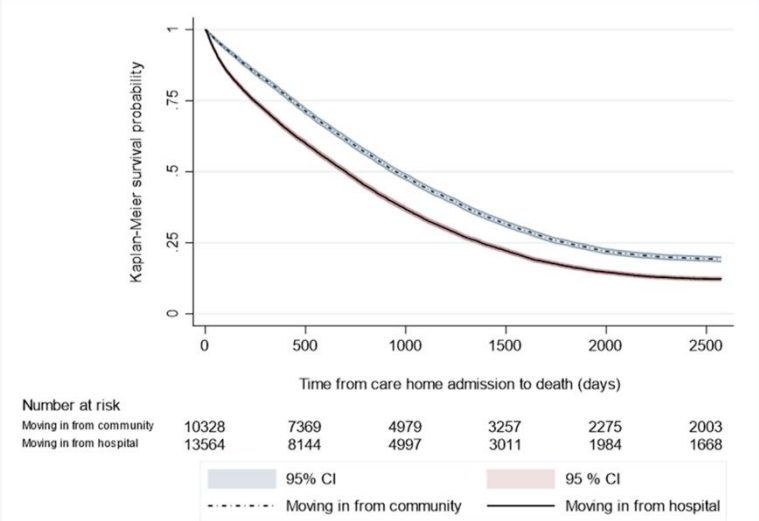
WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

- Our study comparing pathways into care homes included 23,892 people moving-in to a care home, 13,564 (56.8%) from hospital and 10,328 (43.2%) from the community. Individuals with high frailty risk, hospital discharge with diagnosis of fracture or stroke were associated with moving-in from hospital. Discharge from in-patient psychiatry was also a highly significant predictor of moving-in to a care home from hospital. This study compares care home pathways in terms of resident characteristics, finding clinically important differences to inform national policy, which currently advocates avoiding moves from acute hospital settings.

- Our study on mortality after moving-in to care home found average age at death of 87 years (range 19-109 years). Most deaths (77.5%) occurred in the care home, a further 20.5% died in hospital. Dementia, in various forms accounts for the single most common reason (35.6% of all deaths). Time to death was varied with 0.1% dying the day they moved-in, 3.2% dying within a month, 24.2% dying within a year and 85% dying by 7 years. Survival analysis is reported in the Figure below. These data provide novel insights into usual care home mortality in Scotland, previously not explored beyond national population statistics.

Our survival analysis shows that those who move-in from hospital (*shown in the lower red line*) are at higher risk of death compared to those moving-in from the community (*top, blue dashed line*), at all time points of follow-up

This result was unchanged by removing younger adults from the analysis and checking the result.



- Our study on dementia data across national datasets included 63,308 adults living in 1,231 care homes Care home data identified 36,275 (57.3%) with dementia. In total, 14,269 (22.5%) had a prior prescription for a dementia medication, 13,920 (22.0%) had a general hospital discharge diagnosis of dementia, 2,750 (4.3%) had a psychiatric hospital discharge diagnosis of dementia and 31,825 (50.3%) had dementia recorded on their death certificate. We found 30.2% of the cohort had no dementia data in any national data sources and 25.3% had dementia data in all three sources and 5.1% only had dementia included in death data. This study is the first to look at dementia among care home residents in Scotland using national data resources.

WHAT IMPACT COULD THE FINDINGS HAVE?

- People moving-in to care homes from hospital have distinct needs including greater levels of frailty and dependency. They have a shorter survival in the care home. Therefore, opportunities should be proactively sought to offer this group and their families Future Care Planning conversations to support preferences and person-centred care

- Death and dying are core parts of care home life. Professionals working in care homes require support and greater recognition for the pivotal role they play in providing end of life care.

- Care home data identifies individuals living with dementia who are not captured by other health and administrative datasets. Relying on health and administrative data alone risks significantly under-estimating the impact of the condition in the care home population.
- Care home residents are under-represented in research. Linking data between social care, health and administrative sources can improve their participation, but is not without challenges to ensure data are interpreted aware of the context of their collection
- Making more effective use of care home data could inform more robust long-term care service planning and policy-making around pathways into care homes.

HOW WILL THE OUTCOMES BE DISSEMINATED?

This work has been widely shared with care home providers, clinicians, academics, methodologists and decision-makers in national government. This includes both lay and academic publications; poster and oral presentations and contribution to national reports. Key findings have been specifically shared with residents, families and care home staff in workshops, discussion and a short leaflet.

Having demonstrated the feasibility of using the data for research, extending the analysis to look at trends over time and expanding geographical analysis to look at different approaches to care and support would be informative and timely. It would be beneficial to look at the care home data linked to the national social care data to look at prior social care use contribution to care home pathways. This could also help generate evidence around the role of respite care. Specific work focusing on adults in in-patient psychiatry settings would be informative to address specific challenges contributing to delayed discharges from hospital.

CONCLUSION

Linking routinely collected care home data provides insights into the pathways, needs and outcomes of a complex and vulnerable population in an inclusive and minimally disruptive way. This research provides an impetus to make more effective use of linked national care home data as a tool for practice, research and long-term care policymaking. The ultimate aim is to improve understanding of the needs of people living in care homes to deliver more effective evidence-informed care, planning and support for residents.

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Additional Information
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