Identifying Scotland's Care Home Population Living with Dementia: Is Data Linkage Useful?

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Background

People living with dementia are more likely to move into care homes. **The true prevalence of dementia in Scottish care homes is unknown.** Correctly identifying Scottish care home residents living with dementia can improve standards of care and quality of life.

Routinely collected data could offer unique insight into this difficult to research population.

Aim

To **compare national data sources of dementia** status among care home residents in Scotland using cross-sectoral linked data.

Methods

Design: retrospective cohort study
Population: adult (≥ 18 years) care home residents in Scotland during financial years 2012/13 and 2013/14
Data access & indexing: Anonymised individual data was accessed within the National Safe Haven. An indexing process linked Scottish Care Home Census data to Community Health Index numbers. This permitted linkage to healthcare data sources.

Data sources:
- acute/general and psychiatric hospital admissions (**SMR01 and 04**) – 5-year lookback on data (2007-13 and 2008-14)
- prescriptions (**Prescribing Information System**) – data from 2012-14
- Scottish Patients at Risk of Admission and Readmission (**SPARRA**) - data from 2012-14
- National Records of Scotland (**NRS**) mortality records – 5-year follow-up data (2012-18 and 2013-19)

Data analysis:
- Comparison of dementia ascertainment rate across national routine datasets;
- Analysis of SMR01 and 04 dementia subtype;

Results

N (2012/13) = 31,589 **N (2013/14) = 31,504**

Results (2012/13):
- **17,548 (55.5%)** residents have SCHC-recorded dementia
  - PIS confirms **4,701 (26.8%)** cases
  - SMR01 confirms **4,254 (24.3%)** cases
  - SMR04 confirms **1,830 (10.4%)** cases
  - SPARRA confirms **964 (5.5%)** cases
- **10,445 (53.3%)** residents have one dementia record (**Fig.1**):
  -> 83.9% in SCHC, 7.3% in SMR01, 5.0% in PIS, 1.5% in SMR04, 1.3% in SPARRA. (**Fig.2**)
- Of 18,683 residents with dementia in SMR01 or SCHC:
  -> 5,031 (26.9%) have one dementia subtype in SMR01;
- Of 17,866 residents with dementia in SMR04 or SCHC:
  -> 2,079 (11.6%) have one dementia subtype in SMR04;
- **6,984 (44.3%)** residents have death records confirming dementia (of residents who die in 2012-18);

Results in 2013/14 are similar.

Fig. 1

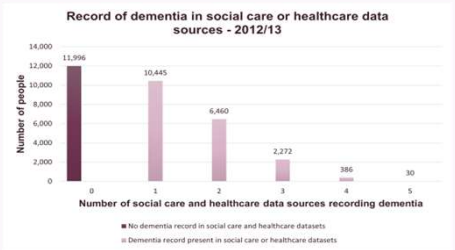
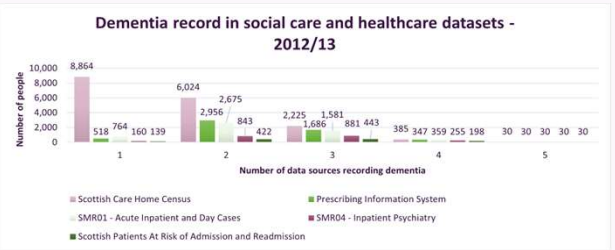


Fig. 2



Discussion

Linkage between SCHC and national health data can enhance dementia identification in the care home population.
- SCHC most commonly records dementia amongst care home residents.
- General hospitalisations and prescriptions most often confirm SCHC diagnoses and are highly accurate.[1,2]
- SMR01 records subtypes more often that SMR04. SMR04 has higher reliability due to specialist input.
- Mortality records confirm half of diagnoses of residents with SCHC dementia who die within the follow-up period.

Data from more financial years will further our understanding of the usefulness of linking social care and healthcare data to identify dementia in care homes.

References:
1. NHS National Services Scotland: ISD Scotland. Data Quality Assurance: Assessment of SMR01 Data Scotland 2014-2015. 2014-2015.
2. Public Health Scotland. Community Dispensing - Mental Health 2020 [cited 2021 2nd December]. Available from: https://www.isdscotland.org/Health-Topics/Prescribing-and-Medicines/Community-Dispensing/Mental-Health/.