

The Secure Anonymised Information Linkage databank Dementia e-cohort (SAIL-DeC)

Schnier, C^{1*}, Wilkinson, T², Orton, C³, North, L³, Rochford, R³, and Sudlow, C²

¹UK Biobank / Edinburgh University

²The University of Edinburgh

³Swansea University

Introduction

Dementia Platform UK (DPUK) brings together over 50 different dementia-related cohorts. Most studies have restricted follow-up times and all are based on information from people who volunteer time and data for research. Participants are therefore often not representative of the 'wider population' and generalization of results is complicated. The Secure Anonymised Information Linkage databank (SAIL) holds long-time information on every person in Wales registered with the national health service, so generalization of study results is easier; however, data management and analysis of SAIL data is not trivial. We used data from SAIL to construct an easily accessible, well described dementia e-cohort.

subtype codes. Seventy-nine percent of participants who developed dementia died during follow-up. Median survival was 12.3 years for participants diagnosed with dementia when aged 50-60, 6.8 years when aged 60-70, 4.2 years when aged 70-80 and 2.4 years when aged 80-90.

Conclusions

We have created a generalisable, national dementia e-cohort, aimed at facilitating epidemiological dementia research.

Methods

With some age restrictions, all Welsh residents for whom primary care data were available were included. Within SAIL, a table was created holding demographic information for every participant including follow-up times and several dementia indicators. Using validated diagnostic code lists, this table was linked to information on every dementia-related diagnostic event and several covariates and co-morbidities. SAIL-DeC can be modified according to varying study designs using annotated SQL-based scripts. Information on SAIL-DeC can easily be updated and linked to additional data on the SAIL database. Interactive visualisations effectively summarise cohort characteristics, aiding researchers to quickly determine cohort eligibility for dementia studies.

Results

From 4.4 million participants in SAIL, 1.2 million met the cohort inclusion criteria, resulting in 18.8 million person-years of follow-up. Of these, 129,650 (10%) developed all-cause dementia during follow-up, with 77,978 (60%) having dementia

*Corresponding Author:

Email Address: christian.schnier@ed.ac.uk (C Schnier)

