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Generation Scotland: using data linkage for longitudinal studies

Campbell, Archie¹

¹Generation Scotland

Objectives

Generation Scotland: Scottish Family Health Study (GS:SFHS) is a family-based genetic epidemiology study of ~24,000 volunteers from ~7000 families recruited across Scotland between 2006 and 2011 with the capacity for follow-up through record linkage and re-contact.

Approach

Participants completed a demographic, health and lifestyle questionnaire and provided biological samples including DNA, and 90% underwent detailed clinical assessment, including anthropometric, cardiovascular, respiratory, cognition and mental health. The biological samples, phenotype and genotype data collected form a resource with broad consent for academic and commercial research on the genetics of health, disease and quantitative traits of current and projected public health importance. Features include the family-based recruitment; breadth and depth of phenotype information, with detailed data on cognition, personality and mental health. GWAS and exome genotype data is available on most of the cohort. These features maximise the power of the resource to identify, replicate or control for genetic factors associated with a wide spectrum of illnesses and risk factors. By linkage to routine NHS hospital, lab tests, prescribing and dental records this has become a longitudinal dataset, using the Scottish Community Health Index (CHI).

Results

Researchers are now able to use the dataset to find prevalent and incidental disease cases, and healthy controls, to test research hypotheses on a stratified population. They can also do targeted recruitment of participants to new studies, utilising the NHS CHI register for up to date contact details. There are 6 published papers on a variety of conditions and currently around 10 ongoing studies based on our record linkage capabilities.

Conclusion

We have thoroughly tested the linkage process and plan to extend it to include primary care data (GP records) in the next year. There are current or planned collaborations looking into heart disease, diabetes, breast and colon cancers, depression, neuropathic pain, Alzheimer's disease and dementia. Generation Scotland is also a contributor to major international consortia. The resources are available to academic and commercial researchers through a managed access process.

*Corresponding Author:

Email Address: archie.campbell@igmm.ed.ac.uk (A. Campbell)