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Generation Scotland - Using Electronic Health Records for Research

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¹Generation Scotland

Background

Generation Scotland is a family-based genetic epidemiology study of ~24,000 volunteers from ~7000 families recruited across Scotland with the capacity for follow-up through record linkage and re-contact. Broad consent was obtained for linkage to “medical records” for 98% of the cohort. This created a resource for investigation of the genetics of common conditions, available to researchers worldwide.

Methods

Participants completed a demographic, health and lifestyle questionnaire, provided samples, and underwent detailed clinical assessment. The samples and data collected form a resource with broad consent for research on the genetics of conditions of current and projected public health importance. This has become a longitudinal dataset by linkage to routine NHS hospital, maternity, lab tests, prescribing, dentistry, and mortality data.

Results

Researchers can use the linked datasets to find prevalent and incident disease cases, and healthy controls, in a stratified population. They can also do targeted recruitment of participants to new studies, including recall by genotype. We have established and validated EHR linkage, overcoming technical and governance issues in the process. Using consented data avoids some limitations of safe havens for analysis.

Genome-wide association studies (GWAS) have been done on a wide range of quantitative traits and biomarker measurements. Generation Scotland is a contributor to major international consortia and has collaborated with Dementia Platforms UK and Health Data Research UK to make the resources more widely known. There have been over 300 research collaborations, and GS data has contributed to 200 publications, with more in the pipeline.

Conclusions

Generation Scotland has thoroughly tested the linkage process and is extending it to include primary care data and scanned images, with plans to collect more samples and data. The resources are available to academic and commercial researchers through a managed access process (www.generationscotland.org).

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