

Generation Scotland - Using Electronic Health Records for Research

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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. Broad consent was obtained for linkage to “medical records” for 98% of the cohort.

Participants completed a questionnaire, provided samples, and underwent clinical assessment. The samples and data collected form a resource with consent for research on the genetics of health, becoming a longitudinal dataset by linkage to routine NHS hospital, maternity, lab test, prescribing, dentistry and mortality data.

Researchers can use the linked datasets to test research hypotheses on a stratified population and target recruitment to new studies. We have established and validated EHR linkage, overcoming technical and governance issues in the process. We plan to collaborate with UK Biobank, creating a combined cohort of over 50,000 people in Scotland, and using the SHARE register to obtain new research samples from routine NHS tests.

We will extend linkage to include primary care data and scanned images in the next year. The resources are available to academic and commercial researchers through a managed access process.

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