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Generation Scotland – Linking all the records we can

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We started a family-based genetic epidemiology study in 2006-11 which recruited 24,000 adult volunteers from 7000 families across Scotland with consent for follow-up through medical record linkage and re-contact. In 2022-25 we have recruited a further 16,000 volunteers, with consent extended to administrative records, and age range now 12+. Original volunteers completed demographic, health and lifestyle questionnaires, provided biological samples, and underwent detailed clinical assessment. The samples, phenotype and genotype data form a resource for research on the genetics of conditions of public health importance. This has become a longitudinal dataset by linkage to routine NHS records: hospital, maternity, lab test, prescriptions, dentistry, mortality, imaging, cancer screening, GP data, Covid-19 testing and vaccinations, as

well as follow-up questionnaires. The new wave of recruitment is all online with DNA from saliva collected by post. Teenagers aged 12-15 can join with parental consent. Researchers can find prevalent and incident disease cases and controls to test research hypotheses on a stratified population. They can also do targeted recruitment of participants to new studies, including recall by genotype. We have established and validated E-HR linkage with the NHS Scotland CHI Register, overcoming technical and governance issues in the process. We contribute to major international consortia, with collaborators from institutions worldwide, both academic and commercial. The Research Tissue Bank resources are available to academic and commercial researchers through a managed access process.

