

Generation Scotland – Transparency in the data access process



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Generation Scotland (GS)

GS is large family-based cohort study established as a resource for research into the genetic and environmental determinants of physical and mental health. Participants completed a baseline questionnaire and clinic visit in **2006-2011**.

24,084

 Participants

5,501

 Families

- **NHS data linkage** 22,402 (93%)
- **Genotype array data** 20,026 (83%)
- **DNA methylation data** 18,876 (78%)

New recruitment - 2022-2025

In 2019 funding was obtained to expand the existing GS cohort. NextGenScot aims to:

- Recruit **20,000 new participants** online
- Expand eligibility to **12-17 year olds**
- Collect saliva samples by post for genotyping
- Linkage to NHS and other administrative data

Details on how to join at www.gen.scot

Data linkage

Participants consented to linkage to NHS medical records which offer longitudinal phenotype information. Linkage is conducted using the Community Health Index (CHI).

19,787 SMR01 Hospital admissions

21,838 Dispensed prescriptions

19,675 GP Records

4,336 Cancer Registry records

Data access for research

GS receives 30-40 requests for access to data and/or samples every year, and has been included in over 380 publications.

Research proposals are subject to review by the GS Access Committee. Details of the application process terms and conditions for access are available on the GS website, and now on the new research access website.

Data access transparency

The previous GS access process was based on an application form in Word, downloaded from the main GS website.

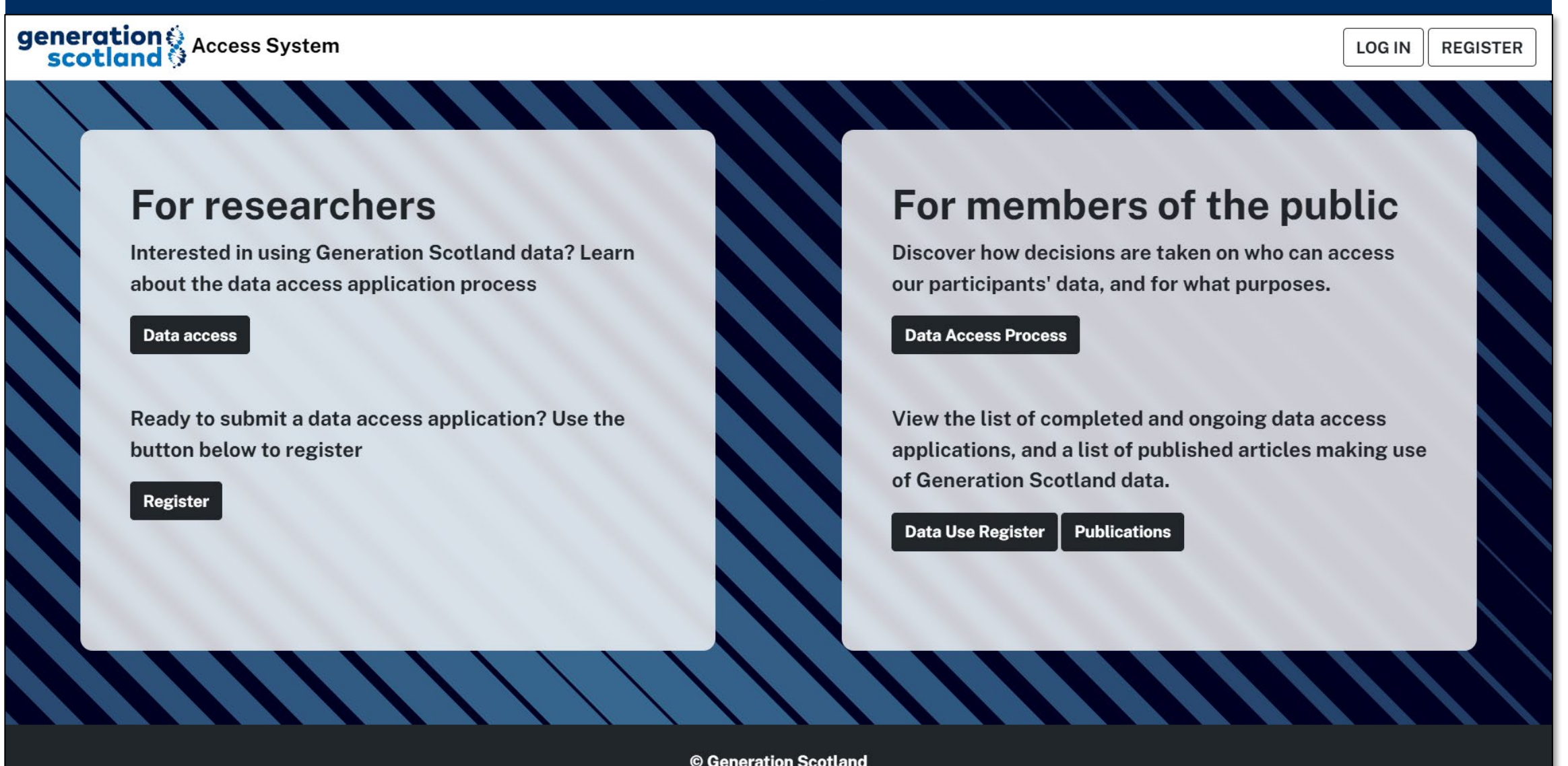
We are replacing this with a new online research access system, adhering to transparency standards, helped by HDR funding.

Publications

After researchers publish their results, a link to the publication and a lay summary is currently posted on the GS website, with a spreadsheet listing papers.

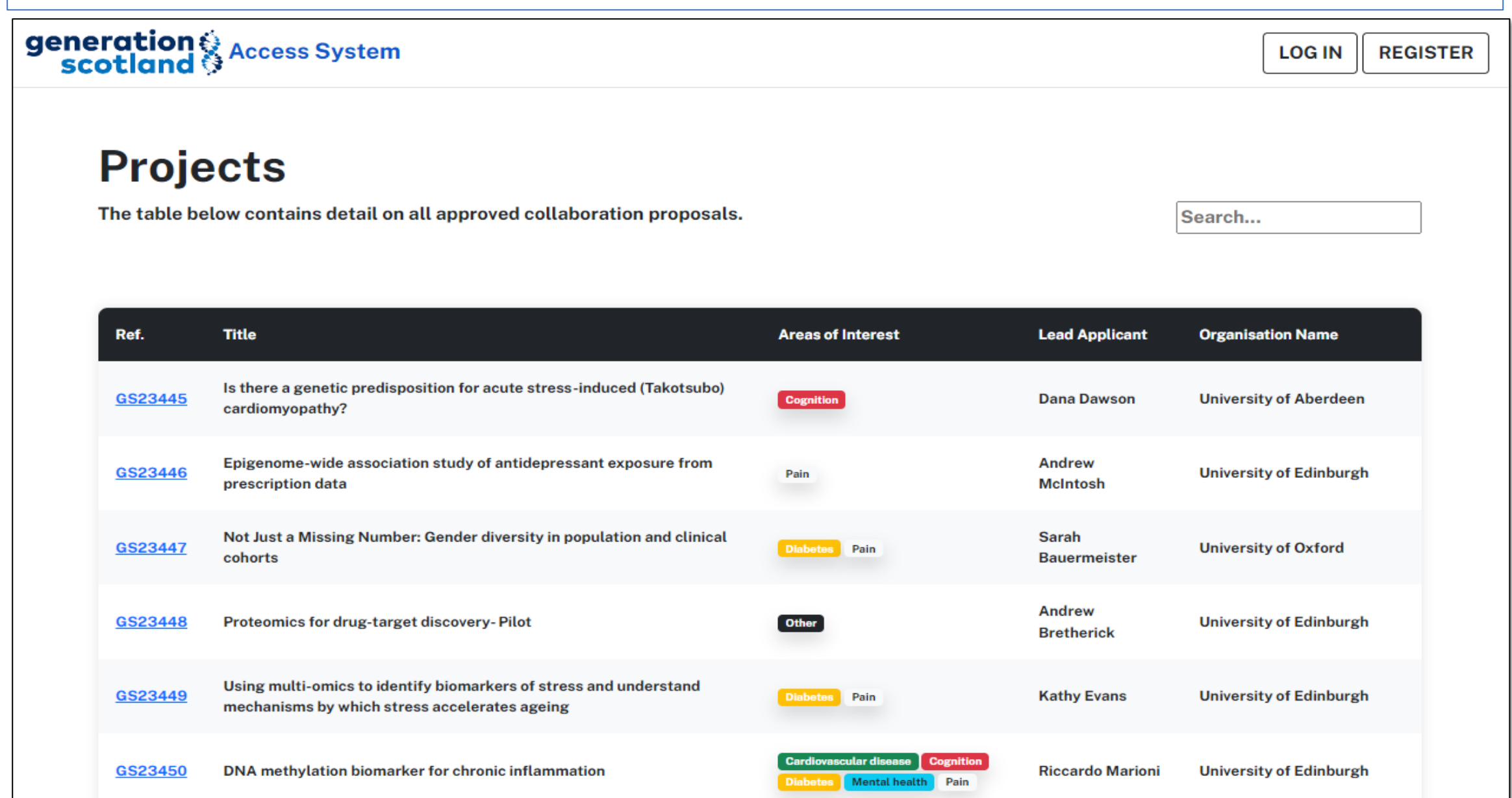
We will now make this information available and searchable for researchers, participants and the public on the new research access website.

New research access system www.gsaccess.org



Transparent access to GS data for registered users

- View summary of data available
- Query the summary data to see if it fits research requirements
- Select data requested
- Get a detailed quote for access charges
- Complete application form showing the project complies with the Five Safes
- Upload supporting documentation (e.g. protocol, DPIA, ethics, etc)
- Track progress of their application review, approval and delivery
- Researchers will be required to submit a lay summary of their application



GS participants, researchers and the public can view:

- List of approved applications with lay summaries
- Summaries of ongoing projects which will link to eventual publications
- Searchable list of publications