



Dear Generation Scotland participant,

We want to thank you for your involvement with GS and would like to take this opportunity to update you on our activities.

It has been 11 years since the first recruits answered our call to take part in Generation Scotland, and we would like to thank you for all the participation you have given over the years. You may remember that you completed a questionnaire about your lifestyle and medical history, attended a clinic for an examination and donated samples of blood and urine for research. You also agreed to let us link all of this data to NHS routine medical records. Thanks to this linkage we did not have to keep getting back to you for health updates, but be assured your data is still being used and we have many updates for you.

As promised, we have kept all of your information confidential and we use it to learn as much as we can about the current and future health of individuals, families and the population as a whole.

In June 2018 we are planning a meeting where you can speak to our researchers and find out what has been going on behind the scenes. We hope to send out further details to you shortly, so keep an eye out for your invitation!

When we started the project, smart phone and internet use was not as widespread as it is today. All that has changed and we still hope to use these new ways to communicate and make on-going active participation easier. Any involvement would be completely voluntary, but watch out for letters and emails from Generation Scotland about new studies that you might want to help us with. As always, full information will be given on our website, www.generationscotland.org.

We are delighted with our progress and excited about the future and we hope you will be too. The following newsletter contains more detail on what we have achieved in the last year.

General Summary

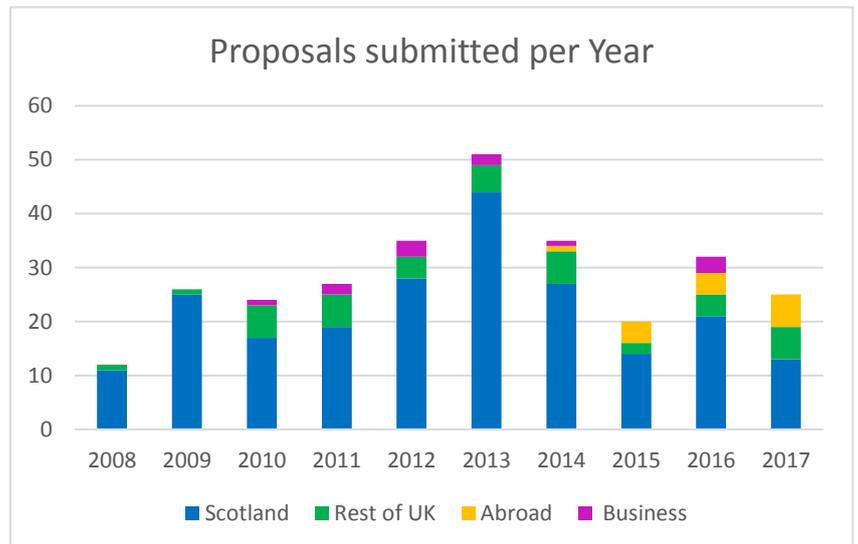
Since 2007, we have received more than 280 proposals from researchers interested in using the Generation Scotland (GS) resource. You have helped us understand, in more detail, how lifestyle, diet and genes combine to affect individual risks of obesity, diabetes, heart disease, stroke, dementia amongst others, and on cognitive, personality and mental health traits.

Since 2007, more than
280 collaboration proposals
have been submitted

Research interests are diverse



Most GS research is being conducted within Scotland, however we have seen an increase in research interest from abroad, over recent years. Your data is not only helping research in Scotland but is being used worldwide and we expect this trend to continue in 2018. For many studies GS is a contributing cohort to research domain focussed consortia.



SMR02	Maternity
SMR06	Cancer Registry
SMR04	Mental Health
Died	Mortality (NRS)
Presc	Prescriptions
Dental	NHS Dentistry
Lab	SCI Store lab tests
GP	Primary care data

Future Plans

In June 2018 we are planning a public engagement event where you can speak to our researchers and find out more about how your participation is helping medical research progress. Further details will appear shortly.

When we started the project, smart phone and internet use was not as widespread as it is today. All that has changed and we hope to use these new ways to communicate and make on-going active participation easier. Any involvement would be voluntary and we hope the recontact process will be made faster and more efficient for your participation. Full information will be given on our website, www.generationscotland.org.

2017 Meetings and Conferences

March

NHS Lothian R&D Conference – We presented a poster summarising what we do at this annual conference for NHS and University staff involved in research.

Pharmacogenetics and Stratified Medicine Framework – We attended the 4th annual open meeting in London.



April

Informatics for Health – We attended the Informatics for Health conference in Manchester, and presented talks on data linkage and electronic health records.

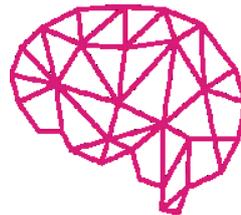
May



EPAD Trial Centre Launch – The European Prevention of Alzheimer's Dementia (EPAD) is a major EU funded project, led by Craig Ritchie, Edinburgh, looking to recruit volunteers to a long-term study of the early signs of Alzheimer's and its prevention. In May 2016 EPAD launched its first centre in Edinburgh and in May 2017 announced plans to open three more Trial Delivery Centres in Glasgow, Dundee and Aberdeen.

GS are one of the cohorts involved with this project. So far over 60 GS:SFHS participants have been recruited. EPAD have now added our GS:21CGH cohort to their invitee list. We look forward to the future where we hope to see more of you getting involved. If you receive an email from the EPAD team we would be grateful for your response.

DPUK Conference – Dementias Platform UK (DPUK) is the biggest UK funded research initiative into dementia. GS attended their annual conference in London, where members of the DPUK research community shared their findings and plans. DPUK includes over 40 cohorts, including GS who are one of the largest. Since May 2017 we have received 4 new study proposals via DPUK. Data has been uploaded to the SAIL data safe haven in Swansea ready for joint collaborations on their new research platform. DPUK have now made a call for proposals to apply for their Discovery Awards funding. We are currently encouraging researchers to come up with new ways to use GS data along with other cohorts for innovative dementia research.



**Dementias
Platform^{UK}**
Medical Research Council

June

ADRN Conference – Generation Scotland presented a poster at the Administrative Data Research Network Conference in Edinburgh.

MRC Festival – We showed the public what can be achieved through biobank research and provided examples of current ongoing research. Despite GS recruitment being closed, we pointed those interested in the direction of SHARE (www.goshare.org.uk) which is a recent Scottish Government Health Department initiative, that allows anyone to sign up for involvement in future research. We would also encourage you to join SHARE, if you are interested.

STRADL Symposium – Stratifying Resilience and Depression Longitudinally (STRADL) is a research group which focuses on the study of depression using the Scottish Family Health Study (GS:SFHS), funded by the Wellcome Trust. The project invited you to complete new questionnaires on their mental health and resilience, with almost 10,000 responses, thank you to all of you who took part.

To date, 850 of you who took part have been invited to attend clinics in Aberdeen and Dundee, for further data collection including MRI brain scans. STRADL have now started analysing this data and publishing results, and they presented findings at their symposium.

November



NRS Conference – At the NHS Research Scotland conference in Perth we gave a snapshot of our research and presented a summary poster.

Biodata World Congress – This meeting in Cambridge brought together academia, industry and healthcare representatives, GS was able to meet with pharma companies and international researchers to raise our profile.

Dealing with Data – Researchers from across the University of Edinburgh came together to discuss how to deal with “big data”. Cate Heeney gave a talk about governance, and GS presented a poster.

Infectious Diseases Workshop – The workshop held on 29th November has developed some interesting potential future collaborations which we hope to progress with through 2018.



Preventing Dementia – The public were invited to attend a meeting to discuss the current progress of dementia prevention research. This event included talks from EPAD and DPUK. GS supports both EPAD and DPUK (see above).

1. You have helped show the enormous value of detailed medical, household and personal information for the ~24,000 participants in ~7,000 family groups. This is a key feature of Generation Scotland that few other studies in the world can match. It really helps us to understand why some illnesses cluster together and others don't. Importantly for treatment, it is telling us a lot about the different causes and types of apparently the 'same' disease, such as diabetes. In the future this might make it possible to tailor treatment on a more person-by-person basis. This is often referred to as 'stratified' or 'precision' medicine.
2. You have also shown how important it was that you agreed to share information not just about physical illnesses, but also about your personality, mood and thinking skills, and if and where you feel pain. Our research has shown just how important it is to take these factors into account across a wide spectrum of conditions.
3. Thanks to you, we can see much more clearly how this affects how you feel and cope with conditions such as diabetes, obesity, lung disease, joint disease or cancer.
4. Since 2007, we have received more than 240 formal requests from researchers interested in using the Generation Scotland resource. You have helped understand in more detail how lifestyle, diet and genes combine to affect individual risks of obesity, diabetes, heart disease, stroke, dementia and other conditions.

Scottish Family Health Study (SFHS)



~24,000



Blood, serum, DNA, urine, cryo-preserved blood, biochemical data



Intensive phenotype, clinical measures, mental health, cognition



Identify genetic variants, enhanced power for linkage & association studies, CNV inheritance testing

Since 2007, more than **240** collaboration proposals have been submitted

Research interests are diverse



Bone and joint disease



Diabetes



Cancer



Mental Health



Cardiovascular disease



Pain



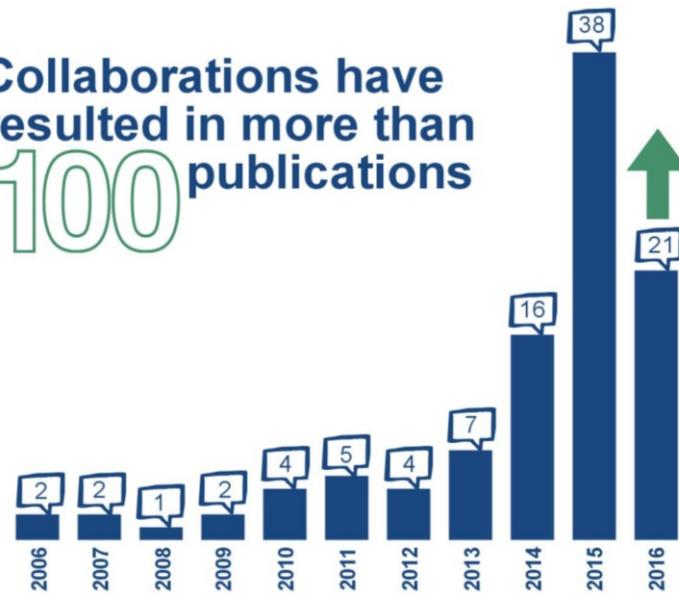
Cognition



Other

5. You have helped discover new genes that affect a) lung function and the risk of Chronic Obstructive Pulmonary Disease, b) kidney function and circulation, c) clinical depression or dementia, and d) how we develop and how we age. Researchers have published these findings in a variety of high-ranking academic journals, such as *Nature*, *Nature Genetics*, *Nature Neuroscience*, *Molecular Psychiatry*, *International Journal of Epidemiology*, *PLoS Medicine* and *PLoS Genetics*.

Collaborations have resulted in more than 100 publications



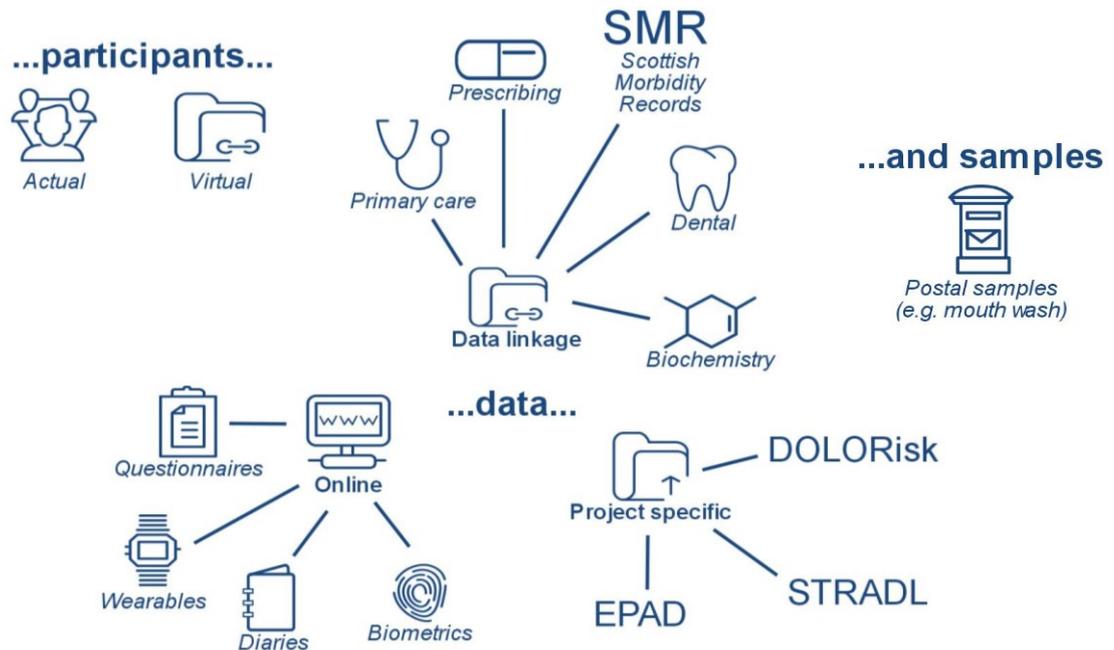
6. When the H1N1 flu outbreak occurred in 2009, you helped assess how many people in the adult Scottish population had been exposed – almost half!
7. You helped show just how closely related we Scots are to the peoples of continental Europe, but also the subtle differences and distinctive features that might help explain why some conditions, such as Multiple Sclerosis, are more common in Scotland than in England and Wales or the mainland of Europe.
8. Importantly, you have stimulated research across the Scottish University Medical Schools, enhancing our international reputation and sharing new knowledge with the world.
9. The Generation Scotland study data has been combined with those of 15 leading health studies internationally. By doing so, Generation Scotland is helping to answer questions that no single study is large enough to answer on its own. For a small nation, thanks to this very special study, we are more than making our mark!

Generation Scotland is part of various consortia



10. In the future, we would like to expand the Generation Scotland resource even further. As mentioned before, technological advances have made it easier to communicate with you and to collect more information from you if you wish to participate in future studies. The more information we can gather and the larger the cohort, the more powerful it becomes to ask and answer health related questions.

Future plans: to expand the resource by adding...



The Generation Scotland 10 Year Report gives a more detailed overview on what we have achieved over the past decade. You can download the report from our website [here](#).

With sincere thanks from the Generation Scotland team and to your continuing, greatly valued contribution.

Yours sincerely,

Professor David J. Porteous, University of Edinburgh
on behalf of the Generation Scotland team.

Website: <http://www.generationscotland.org/>

Facebook: <http://www.facebook.com/generationscotland>

Twitter: [@genscot](https://twitter.com/genscot)