

Written evidence submitted by CLOSER, the home of longitudinal research (UCL Social Research Institute) (SS0009)

Scottish Affairs Committee 'Science and Scotland' Inquiry

Response from CLOSER, the home of longitudinal research (UCL Social Research Institute)

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Inquiry Terms of Reference

Our response focuses on the following questions in the Terms of Reference:

- Could you showcase the international influence Scottish scientific research and development has had in the last ten years?
- What are the scope and nature of the opportunities and challenges surrounding the scientific community in Scotland?

This submission showcases Scottish longitudinal population studies and the impact they have had over the last ten years. It also proposes recommendations to ensure these world-class scientific assets continue to provide vital data and insights on the lives of Scottish people for years to come.

Summary

- Longitudinal Population Studies follow the same people and households over time, often from birth, collecting a wide array of data and information about study participants, which enable researchers and policymakers to explore people's complex lives and how changes in society affect them.
- Scotland is unique in having several longitudinal population studies following the lives of different generations across the country. The lives of around 40,000 people living in Scotland are being followed by two of CLOSER's partner studies: Generation Scotland and Growing Up in Scotland.
- Data and research findings from these studies have had national and international reach, leading to new insights and discoveries. The studies have informed policies in Scotland across several domains, including education, health, mental health, inequalities, genetic research, and predictive medicine. Additionally, during the COVID-19 pandemic, the studies provided immediate and crucial insights into the impacts of the pandemic and lockdown measures on the general population, young people and those living in rural areas.

- Historically, there has been piecemeal funding of the Scottish longitudinal population studies – these national scientific assets need sustained, long-term funding to understand the impact of interventions across the life course and ensure policy decisions are informed by the best available evidence.

1. About us

1.1 CLOSER, the home of longitudinal research, is the UK's partnership of leading social and biomedical longitudinal population studies, the UK Data Service and The British Library. Our mission is to increase the visibility, use and impact of longitudinal population studies, data, and research to ensure that longitudinal evidence is used to address the health, social, economic, and environmental challenges facing the UK, now and in the future.¹

1.2 CLOSER, which is based at the UCL Social Research Institute, has been funded by the UKRI Economic and Social Research Council (ESRC) since 2012. Our partner studies comprise national and regional longitudinal population studies from across the UK. CLOSER partner studies include the British Birth Cohort Studies, ONS Longitudinal Study, English Longitudinal Study of Ageing, Born in Bradford, Southampton Women's Survey, Avon Longitudinal Study of Parents and Children, Generation Scotland, Growing up in Scotland, Understanding Society – the UK Household Longitudinal Study, and more.²

1.3 These national scientific assets follow the same people and households over time, often from birth, collecting a wide array of data and information about study participants, which enable researchers and policymakers to explore people's complex lives and how changes in society affect them. The lives of around 40,000 people living in Scotland are being followed by two of CLOSER's partner studies: Generation Scotland and Growing Up in Scotland.

2. Longitudinal Population Study Showcase: Generation Scotland³

2.1 Generation Scotland is a Scotland-wide family-based study following over 30,000 people from around 7,000 families from childhood to old age. It is a collaboration between the Scottish university medical schools and NHS Scotland.

2.2 Baseline data were collected at the study recruitment stage (2006-2011), with participants giving broad consent to genetic studies, linkage to medical records and willingness to be recontacted for future research. Study participants attended a clinic in Glasgow, Tayside, or Aberdeen, or sent a saliva sample kit and questionnaire by post. The study was converted from cross-sectional to longitudinal through anonymous data linkage to both retrospective and prospective Scottish medical records and through supported follow up studies. Recruitment is currently underway to increase the size of the cohort to 40,000, including teenagers from the age of 12 upwards via online consent and questionnaire and postal saliva sample collection.

¹ <https://closer.ac.uk/>

² <https://closer.ac.uk/explore-the-studies/>

³ <https://closer.ac.uk/study/generation-scotland/>

- 2.3 Research from the Generation Scotland study has informed health policy in Scotland across several domains, including mental health, genetic research, and predictive medicine. Additionally, during the COVID-19 pandemic, three new surveys — CovidLife, TeenCovidLife and RuralCovidLife — provided widespread insight into the impacts of the pandemic and lockdown measures on the general population, young people and those living in rural areas.
- 2.4 Research using Generation Scotland’s COVID-19 survey data has provided evidence of the pandemic’s impact on people’s mental health, including increased anxiety, depression and loneliness during lockdowns. It identified that certain groups – young people, women, those living alone and those with pre-existing health conditions – were more susceptible to poorer mental health during the pandemic and suggested a link between severe COVID-19 illness and long-term mental health outcomes.
- 2.5 Findings from Generation Scotland’s genetic research that have had an international reach, include identifying new genes affecting kidney function, gallstone disease, reproductive lifespan in women, and depression and brain health.
- 2.6 Generation Scotland has pioneered the use of novel molecular approaches to measuring disease relevant mechanisms and predicting future illness onset in currently unaffected individuals. The DNA methylation dataset is currently the largest epigenetic cohort dataset in the world. The dataset includes measures of DNA methylation and expression (proteomics), yielding potential drugs targets and predictors of future morbidity and mortality.^{4,5,6}
- 2.7 Research using the data collected by Generation Scotland has also led to the discovery of potential predictive markers for certain health conditions, including Alzheimer’s Disease, non-alcoholic fatty liver disease and cerebral blood vessel disease. The Generation Scotland data are used by many international research consortia including the international Psychiatric Genomics Consortium, CHARGE, Cardiogram and many others.
- 2.8 Generation Scotland has also had significant policy impact, informing numerous Scottish government strategic policy documents. The study’s successful matching of Guthrie cards (newborn blood spot collection) to demonstrate the feasibility of historical DNA analysis has been critical to the policy debate around the continued collection and storage of newborn screening collection and the use of these biological data for research.
- 2.9 Generation Scotland’s ongoing genetic research has fed into the Scottish government’s ‘Informing the Future of Genomic Medicine in Scotland’ report⁷ and their subsequent Genomics Plan⁸ and Rare Disease Action Plan⁹. Generation Scotland is also cited in the

⁴ <https://genomemedicine.biomedcentral.com/articles/10.1186/s13073-023-01161-y>

⁵ <https://journals.plos.org/Plosmedicine/article?id=10.1371/journal.pmed.1004247>

⁶ <https://www.nature.com/articles/s43587-023-00391-4>

⁷ <https://scottishscience.org.uk/article/genomic-medicine-full-report>

⁸ <https://www.gov.scot/publications/genomics-scotland-building-future/documents/>

UK-wide policy paper on the Future of UK Clinical Research Delivery¹⁰ as one of several key data assets that need to be supported to expand its accessibility. Research from the CovidLife and TeenCovidLife surveys has informed the Scottish Government's Coronavirus (COVID-19): mental health - transition and recovery plan¹¹, especially in relation to young people.

3. Longitudinal Population Study Showcase: Growing Up in Scotland (GUS)¹²

3.1 Growing up in Scotland (GUS) is a longitudinal population study which tracks the lives of thousands of children born in Scotland from birth through to their teenage years and beyond. Commissioned by the Scottish Government and hosted at the Scottish Centre for Social Research, GUS began in 2005, with families from every local authority area in Scotland taking part in the study.

3.2 The families of these cohort children have been interviewed regularly (mostly annually or biennially) since the children were aged 10 months, with parents answering questions on a range of topics including family circumstances and experiences, child health and development, parenting and family relationships, support and use of services, diet and physical activity, school, and peer relationships. Information from interviews has been supplemented with data from objective measurements of the children's height and weight and cognitive ability as well as linked health and education administrative data.

3.3 Three groups or 'cohorts' of children have been taking part in GUS:

- Birth cohort 1: This cohort contains around 5,000 children, born between June 2004 and May 2005. Data was collected annually from their families when these children were aged between 10 months to just under 6 years, then every two years until the children reached their first year of secondary school. In 2018, as part of sweep 9/age 12 fieldwork, an additional group of 502 children were recruited to the cohort to improve the representativeness of the data. During 2020, children in this cohort were mostly due to sit their National 5 (GCSE-equivalent) exams. With the school closures and related restrictions occurring as a result of the COVID-19 pandemic, these children therefore had a crucial period in their education severely disrupted. GUS offers an opportunity to explore the long-term impact of this disruption.
- Birth cohort 2: This cohort contained around 6000 children born between March 2010 and February 2011. Data was collected from their families when these children were 10 months old, just under 3 years old, and just under 5 years old.
- Child cohort: This cohort contained around 3000 children born between June 2002 and May 2003. Four 'sweeps' of data were collected from their families, from between the ages of just under 3 years to just under 6 years.

⁹ <https://www.gov.scot/publications/rare-disease-action-plan/documents/>

¹⁰ <https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery>

¹¹ <https://www.gov.scot/publications/mental-health-scotlands-transition-recovery/documents/>

¹² <https://closer.ac.uk/study/growing-up-in-scotland/>

3.4 Altogether, information has been collected on around 14,000 children, making GUS the largest longitudinal population study of its kind in Scotland. The sample for each cohort was drawn on a random probability basis from Child Benefit records. As a result, findings from the study can be generalised to all children of the equivalent age in Scotland.

3.5 GUS collects a wide range of information about children and their families. The primary areas covered include:

- Cognitive, social, emotional, and behavioural development
- Physical and mental health and wellbeing
- Childcare, education, and employment
- Home, parenting, family, community, and social networks
- Involvement in offending and risky behaviour

3.6 The study provides crucial evidence to help the Scottish Government and others develop and monitor policies for children, young people, and their families, particularly in the areas of education and health. GUS has played a significant role in demonstrating how inequalities in Scotland are evident from an early age, spanning a range of health and developmental areas. Importantly, GUS has also contributed to our understanding of which early circumstances and experiences may help improve outcomes for children – especially those growing up in less-advantaged circumstances.

3.7 All data from GUS is made available to researchers via the ESRC-funded UK Data Service¹³. The data are widely used by a range of researchers, analysts and policymakers in central and local government, government bodies, academia, and the voluntary sector. Findings from GUS have informed the development of Scottish Government policies on addressing educational inequalities, home-learning activities, parenting and parental support, early learning and childcare, child health and child poverty. Information from the study has also informed the revision of national guidance for practitioners working with young children in Scotland.

3.8 GUS is one of several ‘Growing Up’ studies around the world launched in the first decade of the new millennium. As well as the UK-wide Millennium Cohort Study, similar projects exist, for example, in the Republic of Ireland, France, Australia and New Zealand. GUS has established firm links with its international partners – including through European cohort study networks – leading to collaborative, comparative research projects.

4. Beyond the CLOSER Scottish partner studies

4.1 Whilst this submission focuses on CLOSER’s Scottish partner studies, there are several other longitudinal population studies following the lives of Scottish people that are worth noting:

4.2 Longitudinal Population Study Showcase: Scottish Longitudinal Study

¹³ <https://ukdataservice.ac.uk/>

The Scottish Longitudinal Study (SLS)¹⁴ is a large-scale linkage study created using data from administrative and statistical sources. These include census data from 1991 onwards; vital events data (births, deaths, marriages); NHS Central Register data (gives information on migration into or out of Scotland); and education data (including Schools Census and Scottish Qualifications Authority data). The SLS includes cultural, demographic, economic, health, education, ecological, housing, and social data. To create the SLS approximately 274,000 individuals were selected using 20 random birthdates, and this data has now been linked to other datasets including vital events, school data, weather and pollution data, and census data from 2001 and 2011.

4.3 Longitudinal Population Study Showcase: The Lothian Birth Cohorts

The Lothian Birth Cohort 1921 (LBC1921) study and the Lothian Birth Cohort 1936 (LBC1936)¹⁵ study are two longitudinal population studies of cognitive, brain and general ageing. They aim to understand how our brain and thinking skills change throughout life, and why some brains age better than others. The studies collect a range of data, including cognitive, lifestyle, social and psychological, genetic and epigenetic, health and physical fitness, biological, brain and vascular imaging data. The data collected resulted in hundreds of peer-reviewed publications, and the studies continue to make novel and significant contributions to our understanding of the ageing process from a variety of perspectives.

4.4 Longitudinal Population Study Showcase: HAGIS

Healthy AGEing in Scotland (HAGIS)¹⁶ is a longitudinal study of people aged 50+ in Scotland. It collects data on their health, economic and social circumstances and uses this information to help researchers understand the lives and improve the health and wellbeing of Scotland's older people. HAGIS is the first comprehensive Scottish study to follow older people over time. HAGIS is part of the Health and Retirement study family of longitudinal ageing studies. Together, these studies cover more than half the world's population aged 50+. By bringing them together, it is possible to compare the lives of older people in Scotland with those of older people across Europe, or in the USA or China. These comparisons provide many opportunities for cross-country learning and shaping better policies and practices.

4.5 In addition, investigators in Scotland have been instrumental in increasing the diversity of longitudinal studies throughout the world. Examples include Healthy Lives Malawi (Crampin Glasgow),¹⁷ Generation Malawi,¹⁸ and DepGenAfrica (McIntosh).¹⁹

5. Recommendations

¹⁴ <https://sls.lscs.ac.uk/about/>

¹⁵ <https://www.ed.ac.uk/lothian-birth-cohorts>

¹⁶ <https://www.hagis.scot/>

¹⁷ <https://www.meiru.info/healthy-lives-malawi/>

¹⁸ <https://www.meiru.info/generation-malawi/>

¹⁹ <https://wellcome.org/grant-funding/people-and-projects/grants-awarded/depression-genetics-africa-depgenafrica>

5.1 Historically, there has been piecemeal funding of the Scottish longitudinal population studies – these national scientific assets need sustained, long-term funding to understand the impact of interventions across the life course and ensure policy decisions are informed by the best available evidence.

5.2 Sufficient coverage of Scotland in any new UK-wide longitudinal population study needs to be better assured too. Funding of UK studies needs to be large enough to ensure a large Scottish sample. With enough Scottish data, Scotland/England comparisons can be made, offering unique opportunity for consideration of the impact of different policy contexts and potential learning for governments and policymakers in both countries.

5.3 While many funding opportunities are UK-wide, it is essential that funders make demonstrable efforts to adequately engage with researchers in Scotland, as well as Wales and Northern Ireland. This will help ensure the longitudinal research community in Scotland is fully aware of the funding opportunities available to them.

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