

Genetic Health in the 21st Century Participant Information Leaflet (Centres 3 and 4)

You are invited to take part in an additional Generation Scotland project, Genetic Health in the 21st Century (21CGH). It is a lot like the Scottish Family Health Study (SFHS) in relation to identifying risk of Cancer, Heart Disease and Stroke. The main differences are that for 21CGH we need people whose parents (and preferably grandparents) were born in Scotland and we don't need other family members.

What would you need to do?

At your SFHS appointment, you would be asked to provide an additional 20ml of blood and for your consent for some of the information obtained by the SFHS study to be used in the 21CGH project. The additional blood would be taken at the same time as the SFHS sample. This would be used to extract DNA, plasma and cells. The cells will be modified to produce a cell line. Cell lines are capable of continuously renewing themselves, providing an inexhaustible resource for future research. In addition, these cell lines yield DNA that is better for specific research methods than DNA isolated from blood. We may also wish to contact you in future to ask if you would be willing to participate in follow-up research. You won't be asked to commit to this just now, but we will ask for your permission to contact you again (you will be free to refuse permission).

Do you have to take part?

No, taking part in this additional project is entirely voluntary. You can say no to taking part at any time. If you decide you do not want to take part, you won't be asked to give a reason and your decision will have no effect on your future medical care. You can still take part in SFHS only. We may ask another member of your family if they wish to take part instead.

So, is this project just like the Scottish Family Health Study?

Yes, 21CGH is being conducted by the Generation Scotland Scientists who also run SFHS. The Generation Scotland Scientific team will be the custodians of your samples and all material and information from them. Samples and information will be initially processed at laboratories in Edinburgh (DNA and data) and Salisbury (plasma and cells). Blood and DNA samples may then be distributed to laboratories in Hospitals and Universities around Scotland for further research. Your samples and information will be treated with the maximum level of confidentiality and security. Information about any relevant health issues, confidentiality, commercial interests and access to the data are contained in the SFHS Participant Information Sheet. Please also feel free to ask a member of the research team. Like SFHS, insurance companies and employers will not have access to data held by Generation Scotland and you can withdraw from the project having given blood.

The Tayside Committee on Medical Research Ethics, which has responsibility for looking at proposals for medical research on humans, has reviewed the proposal for this project and has not raised any objections from the point of view of medical ethics.

Who do you contact for further information?

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For more information visit www.generationscotland.org or write to: Generation Scotland, The University of Edinburgh, Molecular Medicine Centre, Western General Hospital, Crewe Road South, Edinburgh, EH4 2XU.