

21CGH Newsletter

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Three research posts are funded through 21CGH to address ethical, legal and social aspects



The WTCRF Genetics Core, Edinburgh (above) is one of three sites that will generate 21CGH genotyping data – the others are in Glasgow and Aberdeen (below)



Genetics & Healthcare Initiative (GHI)

An informative meeting was held at the Scottish Executive on 24th May with the CSO Panel put in place to review submissions to the GHI. This has led to a helpful clarification of the key elements of the original guidance on which a full submission should be based. The revised guidance is on the CSO web site, <http://www.show.scot.nhs.uk/cso/> so that all can see how they might engage with the GHI process. The deadline for full applications is August 30th.

Individuals or groups who feel that they are particularly well placed to respond to specific aspects of the revised guidelines are encouraged to contact one of the lead applicants on the original outline. The 21CGH Science Management Group (Professors A Dominiczak, A Morris, D Porteous, and S Ralston) will also be consulting locally and nationally. Time is short to respond to the deadline and the revision process is already underway.



Ethical, Legal & Social Aspects

The ethical, legal and social aspects associated with the development of Generation Scotland are being investigated by a team of lawyers and social scientists based at the University of Edinburgh.

One important part of this is to conduct research with and involve a range of public groups in discussions about Generation Scotland. Public engagement and consultation is not the same as public relations as the idea is to identify a range of public views and opinions and to try to increase interest and involvement in social, legal and ethical debates and the possible resolutions of expressed concerns. This should then feed

back and shape the way that Generation Scotland will develop. Our aim is for participation and dialogue across Scotland.

How do we do this? We are currently reviewing the range of ways in which such engagement can be promoted and with whom; ideas include public events, small group discussions, citizen panels and juries. Some preliminary work has already begun involving three components: sixteen interviews with a range of “specialist” stakeholders (geneticists, theologians, lawyers etc); ten focus groups held in different parts of the country to reflect a range of demographics

(gender, ethnicity and age), interests (patient, voluntary and civic) and localities (rural/city); a public event bringing together members of the Generation Scotland team, other interested parties and members of the public. A combination of short presentations, small group discussions and a panel discussion made for a full day. Reports on each of these components will be available shortly and will be sent to all who participated. In the meantime, if you have any ideas or want to discuss aspects of the public engagement programme, please contact:

Dr Gill Haddow 0131 650 2389 or e-mail: gill.haddow@ed.ac.uk

21CGH Career Opportunity

There is an opportunity for a Data Manager to join 21CGH. The area of responsibility of the Data Manager is in co-ordination and development of all IT aspects of the project.

The successful applicant will develop applications for database storage of genotype and phenotype (clinical) data. 21CGH research outputs (patient sensitive health information and sample identifier data) will be collected and stored electronically, following appropriate levels of security and confidentiality.

The data manager will specify and develop data entry forms for research nurses to input phenotype data using mobile devices for entry into the phenotype (clinical) database. Genotype data will be produced

at three locations and emailed to the data manager for entry into the genotype database.

The data that will be generated and managed in 21CGH are not particularly extensive or complicated, but the solutions designed should be scalable for future additional work, so that the successful applicant will play a key role in data management infrastructure building for Generation Scotland and (in the longer term) the Scottish Spoke of the UK Biobank.

The position is based at the Western General Hospital in Edinburgh.

See <https://www.jobs.ed.ac.uk/> Ref No 3001900

Publication Alert:

21CGH Research Fellow R Gertz “Analysis of the Icelandic Supreme Court judgement on the Health Sector Database Act”, (2004) 1:2 SCRIPT-ed, @ <http://www.law.ed.ac.uk/ahrb/script-ed/issue2/iceland.asp>