

Genetic Health in the 21st Century (21CGH) - building the infrastructure, developing the science, enhancing the knowledge base, engaging the public

Researchers

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Background

Most, if not all, medical disorders of public health importance have a significant heritable component. Indeed, the list includes and extends beyond the 'big three' health priorities in Scotland - cancer, heart disease / stroke and mental health, encompassing, for example, inflammatory bowel disease and osteoporosis, both major causes of morbidity and mortality in Scotland and other developed countries.

With few exceptions, the genes selectively responsible for elevated risk of one or another of these diseases remains unclear. To address this question of fundamental relevance to citizens and society, 21CGH has been structured as a multi-HEI, pan-Scottish, cross-disciplinary Consortium proposal that brings together existing and complementary Scottish strengths in medical and social science research strategy in relation to common disorders with a heritable component.

21CGH will establish an enabling platform for translational application of the new genetic knowledge, backed by a multi-disciplinary and self-sustaining skill network in genetic epidemiology and health informatics. It will put Scotland at the forefront of genetic database creation, analysis and utilisation. Crucially and uniquely, it will bring together from the outset the social, ethical and legal aspects as well as the scientific aspects of this challenge and opportunity.

Aims of the study

- To establish a baseline for prospective research by establishing the genetic profile of Scots in relation to health and disease and thus ensure that future studies are structured appropriately and cost-effectively
- The studies proposed will generate substantial and cumulative data sets at all stages from medical histories to genetic profiles for individuals, families and groups
- Engage actively with the people of Scotland, public interests groups, elected representatives and the media in order to articulate the objectives, solicit opinion and respond to concerns about genetic research
- To establish a structured programme of networking and research planning to ensure a coherent Scottish identity and responsiveness to the priorities of citizens and of government; and to establish and disseminate best practice in the field

Methods of working

The 21CGH is led by David Porteous (Edinburgh) and involves collaborators from many Scottish universities. Dundee and St Andrews are represented through the SDHI. The work of the group will involve the collection of biological samples and preparatory work to allow for genetic analysis. A major part of the work will be to engage the public and address the social, legal and ethical issues that such studies raise.

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