

Press Release

Thurs 21st August, 2008

Electronic genetic profiling: Your genome on a chip?

We fully accept that our medical records should be kept on file. But what about information about your personal genetic make-up? As DNA sequencing becomes ever cheaper, the idea that everyone's genetic profile could be stored on a central database seems increasingly possible. So too does the likelihood that genetic profiles could be electronically linked to other records. But how far should this technology be taken? Linkage between genetic and medical records could lead to smarter diagnosing, and aid research into the causes of disease. But should such information be made available to the police, or to insurance companies? Is a personal genetic database really such a good idea? Will it help us to improve our health, or will it endanger our privacy and even our security?

Scotland's young people will be able to have their say at the Edinburgh International Book Festival, when the Scottish Youth Parliament (SYP) and the ESRC Genomics Forum host a debate on "Electronic Genetic Profiling". The debate will be chaired by MSYP Fiona Beaton, who will be joined on the platform by journalist and broadcaster Lesley Riddoch and by Dr Claudia Pagliari, a Senior Lecturer in Primary Care at the University of Edinburgh and Convenor of the eHealth Interdisciplinary Research Group. The debate promises to be engaging, complex and informative.

The "Electronic Genetic Profiling" event takes place at the Spiegeltent on Thursday 21 August 2008 at 8 pm.

Tickets are available either through the Edinburgh International Book Festival website (www.edbookfest.co.uk) or by phone on 0845 373 5888.

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Note to Editors:

Fiona Beaton is Member of the Scottish Youth Parliament for Cumbernauld and Kilsyth and a member of the SYP Health Committee.

Lesley Riddoch is one of Scotland's best-known journalists and broadcasters. She runs her own independent radio, and podcast company, Feisty Ltd, which produces *Riddoch*

Questions, a weekly topical phone-in programme fronted by Lesley every Friday lunchtime on BBC Radio Scotland. She also writes a weekly columnist for *The Scotsman*, which was short listed in 2006 for the Orwell prize for political writing.

Dr Claudia Pagliari is Senior Lecturer in Primary Care at The University of Edinburgh's Centre for Public Health & Primary Care Research, and Convenor of the University's eHealth Interdisciplinary Research Group. She researches the risks and benefits of eHealth interventions and their implications for policy.

Established in August 2004, the ESRC Genomics Policy and Research Forum is a novel initiative in the field of social science research.

As part of the ESRC Genomics Network (EGN), the Forum acts to integrate the diverse strands of social science research within and beyond the EGN; to develop links between social scientists and scientists working across the entire range of genomic science and technology; and to connect research in this area to policy makers, business, the media and civil society in the UK and abroad.

This is a novel and challenging role, but one which presents huge opportunities. Under the Directorship of Professor Steve Yearley and the Deputy Directorship of Dr Steve Sturdy, the Forum is widening the reception of social science research beyond existing audiences, and building capacity amongst social scientists for public and policy engagement.

The Genomics Forum aims:

- to exploit synergies across the EGN and other relevant ESRC initiatives
- to encourage fruitful interaction between social scientists and scientists working on genomics, both nationally and globally
- to connect social science research on genomics with public policy debates and decision making, and with policy makers, business, the media and civil society, in the UK and abroad
- to develop new lines of engagement between social scientists, biomedical scientists, policy-makers and publics

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