

4th December 2009

Principles Consultation
Human Genetics Commission
Department of Health
6th Floor North
Wellington House
133-155 Waterloo Road
London SE1 8UG

Dear Sir or Madam

Call for views on a Common Framework of Principles for direct-to-consumer genetic testing services

Thank you for the opportunity to contribute to the Human Genetics Commission's work on direct-to-consumer genetic testing.

Although we are not currently in a position to comment on the specifics of the proposed Framework of Principles, we would like to welcome the fact that the Commission is seeking to promote high standards and consistency in the provision of genetic tests amongst commercial providers at an international level in order to safeguard the interests of people seeking genetic testing and their families.

As you know, the Council is considering the ethical issues raised by direct-to-consumer genetic testing as part of its Working Party, set up in October 2008, on *Medical profiling and online medicine: the ethics of 'personalised' healthcare in a consumer age*. These issues might include, for example:

- autonomy, choice, freedom of expression, and the right not to know;
- the impact on the doctor-patient relationship;
- privacy and confidentiality;
- trustworthiness of information and services, safety, quality;

Chair

Professor Albert Weale FBA

Deputy Chairman

Professor Hugh Perry FMedSci

Members

Professor Steve Brown FMedSci
Professor Roger Brownsword
Dr Amanda Burls
Professor Robin Gill
Professor Sian Harding FAHA FESC
Professor Peter Harper
Professor Ray Hill FMedSci
Professor Søren Holm
Professor Christopher Hood FBA
Dr Rhona Knight FRCGP
Professor Graeme Laurie FRSE
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Professor Ottoline Leyser CBE FRS
Professor Anneke Lucassen
Professor Alison Murdoch FRCOG
Dr Bronwyn Parry
Professor Nikolas Rose
Professor Joyce Tait
Professor Jonathan Wolff

Director

Hugh Whittall

Assistant Directors

Dr Alena Buyx
Katharine Wright

- fair and prudent use of public resources;
- social solidarity; and
- protecting consumers from harm.

The Working Party, of which Professor Sir John Sulston is a member, also includes others with expertise in medicine, science, law, philosophy and sociology. It held a public consultation from April to July 2009, and a programme of evidence gathering meetings with stakeholders is underway. The group is also looking at issues raised by predictive scanning tests, telemedicine, and online health information, health records and purchasing of pharmaceuticals. The Terms of Reference and a full list of members are at **Annex A**.

A report will be published in June 2010, which will include conclusions and recommendations for policy and future practice.

The outcomes of the HGC's consultation, and the final Common Framework of Principles for direct-to-consumer genetic testing services, would be valuable for the discussions of the Working Party. If timings allow, the Working Party will take these into consideration in the development of its recommendations, but in any event it would be helpful if we could keep in touch as our respective projects progress.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Hugh Whittall'.

Hugh Whittall
Director

Annex A

Medical profiling and online medicine: the ethics of 'personalised' healthcare in a consumer age

Terms of Reference

- 1 To identify and consider the ethical, legal, social and economic issues that arise in the application of new health and medical technologies that aim to deliver highly individualised diagnostic and other services.
- 2 To describe and analyse, by means of case studies, developments in medical research and practice and other factors giving rise to the development of personalised healthcare.
- 3 To consider, in particular:
 - a arguments about the scientific significance, reliability and predictive value of particular personalised services;
 - b implications for equity in health in relation to who will benefit most from particular personalised services, and for whom they may be harmful;
 - c the impact of personalised services offered by private providers;
 - d the tensions that might arise between increasing expectations for highly tailored care with the need to provide healthcare for all in the NHS;
 - e the extent to which personalised services can be offered as part of a fair and efficient operation of private and public healthcare systems;
 - f confidentiality and privacy issues in relation to the ownership, transmission, storage and access to personal health data;
 - g any impacts on the doctor-patient relationship; and
 - h whether current regulation is appropriate.

Working Party Members

Professor Christopher Hood FBA (Chair)

Gladstone Professor of Government and Fellow, All Souls College, University of Oxford and Director, ESRC Public Services Research Programme

Professor Kay-Tee Khaw CBE FRCP

Professor of Clinical Gerontology, University of Cambridge School of Clinical Medicine, Addenbrooke's Hospital

Dr Kathy Liddell

Lecturer, Faculty of Law, University of Cambridge

Professor Susan Mendus FBA

Professor of Political Philosophy, University of York

Professor Nikolas Rose

Martin White Professor of Sociology, BIOS Centre for the Study of Bioscience, London School of Economics and Political Science

Professor Peter C Smith

Professor of Health Policy, Imperial College Business School, London

Professor Sir John Sulston FRS

Chair, Institute of Science, Ethics and Innovation, University of Manchester

Professor Jonathan Wolff

Head of the Department of Philosophy, University College London

Professor Richard Wootton

Director, The Scottish Centre for Telehealth