

*Advanced Courses and Scientific Conferences*

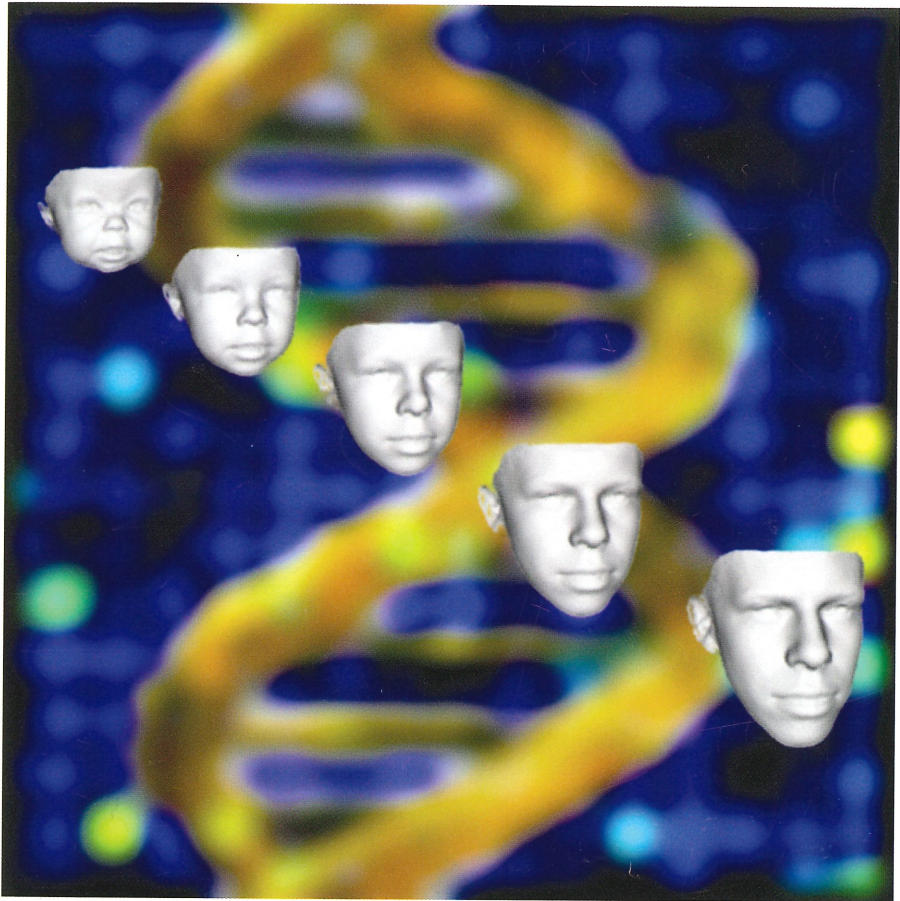
---

# Genomic Disorders 2013

From 60 years of DNA to human genomes in the clinic

10-12 April 2013

A Wellcome Trust Scientific Conference



## **Ethical implications of sharing incidental findings: preliminary findings from an International study**

**Anna Middleton<sup>1</sup>, Michael Parker<sup>2</sup>, Eugene Bragin<sup>1</sup>, Caroline Wright<sup>1</sup>, Andrew Paul Bevan<sup>1</sup>, Helen Firth<sup>1</sup>, Matt Hurles<sup>1</sup> on behalf of the DDD Study**

<sup>1</sup>Wellcome Trust Sanger Institute, Hinxton, Cambridge, UK; <sup>2</sup>Ethox Centre, University of Oxford, Oxford, UK

Empirical data on the attitudes, values and beliefs of research participants towards receiving results from whole genome/exome sequencing studies is limited. There have been several small-scale qualitative interview studies as well as discussion about the feedback of genomic results within the context of biobanks and an evaluation of the attitudes of genetic health professionals. Such research has emphasised the need for further and larger scale studies in this area. Although much has been written about incidental findings in medical imaging, to our knowledge, there are no large-scale (n = 1000+) mixed-methods studies that clearly evaluate attitudes towards the sharing of genomic incidental findings within a research or clinical setting. To address this gap, we have designed a questionnaire and interview study to ascertain the views of families recruited to the DDD project, genomic researchers, genetic health professionals, laboratory staff and members of the public; as the questionnaire is online it is not limited by geography and thus people participating may be from anywhere in the world. The questionnaire is available at <http://www.genomethics.org>; film and animation are used to explain the concepts needed to answer the questions. The first 2,000 completed questionnaires have been analysed and data from this subset will be presented. Attitudinal differences - that exist between genomic researchers, health professionals and lay members of the public - will be shared.