

Human Variome Project 3, Session 1 - Ethics

Sue Povey¹, Arleen D. Auerbach², Carol Isaacson Barash³

¹ Division of Life Sciences, UCL, London NW1 2HE, UK; s.povey@ucl.ac.uk

² Program in Human Genetics and Hematology, The Rockefeller University, New York, NY 10065, USA; auerbac@rockefeller.edu

³ Boston University, Boston, MA 02130, USA; cbarash@gepci.com

Additional existing ethics group members before HVP 3

Aida I Al Aqeel, Anne Cambon-Thomsen, Ruth Chadwick, Raymond Dalglish, Johan T den Dunnen, Marc S Greenblatt, Finlay Macrae, George P Patrinos, Judith Savige, Maria-Jesus Sobrido, Ingrid Winship, Richard Cotton. Help has also been given by Dr Helen V Firth and Dr Michael Parker

New members already recruited

Jumana Y Aama (Saudi Arabia), Inge Bernstein (Denmark), Gabrielle Bertier (France) Suzanne A Al Bustan (Kuwait), Joanna Elson (UK), Aida B Falcon de Vargas (Venezuela), Jim Kaput (USA), Ilkka Lappalainen, (EBI, UK), Hyun Young Park (South Korea), Ming Qi (China), David Quin (Australia), Raj Ramesar (South Africa), Graeme Suthers (Australia), BA Zilfalil (Malaysia)

The first resolution of the ethics group in the previous Human Variome Project meeting required that the HVP should be carried out with highest ethical standards combined with the sharing of intellectual property among all participating countries. This required identification of the legal and ethical issues and a determination to work towards an internationally acceptable database policy statement covering ethical and privacy issues for collection and sharing of data.

Because a major activity of many scientists within the HVP is the curation of locus-specific or disease-specific variation databases (LSDBs), the HVP working group has produced detailed guidelines intended to help the curators of LSDBs resolve ethical issues and achieve the high standards that should be the goal of all curators (Povey et al, Human Mutation, in press). The authorship of 14 includes individuals from eight countries, which are mostly Western with one author from Saudi Arabia. In the light of presentations at the meeting in Paris and extended discussion from the floor the following resolutions were adopted.

H1 The twelve major headings in the guidelines form an appropriate basis for future work (See ethics Box 1).

H2 The HVP should request volunteers from a wider range of countries to join the ethics group. The existing members of the ethics group and the new volunteers so far recruited are listed at the end of this summary.

The tasks of the ethics group will be

H3 Make some assessment of the utility and implementation of the published guidelines before the next meeting. This will involve contact with LSDB curators.

H4 Explore the diverse needs of different cultures with a view to modification of future guidelines. In particular it may be that acceptable forms of consent (not