

Ethical Aspects of Participant-Centred Research Initiatives

Organizers: HC Howard, E. Vayena, P. Borry

DAY 1. Oct 1, 2015, 9h00 to 17h30

Welcome and Introduction to Workshop

9h00-9h30 Heidi C. Howard

Session 1: Identification and mapping of participant-centred genomic research initiatives

Chair session: Jacqui Beckmann (University of Lausanne, Switzerland)

9h30-9h55 Greg Biggers (Genomera)

9h55-10h20 Sharon Terry (Genetic Alliance)

10h20-10h40 **Break**

10h40-11h05 Caroline Kant (EspeRare Foundation)

11h05-11h30 Sohini Chowdhury (Michael J. Fox Foundation)

11h30-12h30 **Discussion**

12h30-13h45 LUNCH (and group photo)

Session 2: Research ethics in participant-centred genomic research initiatives: recruitment strategied, informed consent , oversight mechanisms

Chair session: Effy Vayena (University of Zürich, Switzerland)

13h45-14h10 Deborah Macalzoni (University of Uppsala, Sweden)

14h10-14h35 Gaia Barazzetti (University of Lausanne, Switzerland)

14h35-15h00 Sigrid Sterckx (Ghent University, Belgium)

15h00-15h25 Misha Angrist (Duke University, USA)

15h20-15h50 **Break**

15h50-17h30 **Discussion and Day 1 Wrap up**

Diner and CHIPME Session (more info to come)

DAY 2 Oct. 2, 2015, 9h30-16h00

Session 3: Research ethics in participant-centred genomic research initiatives: return of results

Chair session: Pascal Borry (University of Leuven, Belgium)

9h30-9h55	Leigh Jackson (Plymouth University, U.K.)
9h55-10h20	Anna Middleton (Wellcome Trust Sanger Institute, UK)
10h20-10h45	Regine Kollek (University of Hamburg, Germany)
10h45-11h10	Martina Cornel (VU University Medical Center Amsterdam, The Netherland)
11h10-11h30	Break
11h30-12h30	Discussion

12h30-13h45 LUNCH

Session 4: Next steps discussion and debate, CHIPME SESSION

Chair session: Heidi Howard, Effy Vayena, Pascal Borry

14h00-16h00 Structured Discussion

In this session the focus will be on an interactive group discussion regarding: 1) the article to be published, and 2) the important ethical questions that still necessitate answers and the steps to find these answers.