

Personal Genomes: accessing, sharing and interpretation

Wellcome Genome Campus,
Hinxton, Cambridge, UK

11-12 April 2019

Conference Programme

Thursday, 11 April

- 11:30-12:30 **Registration** with lunch
- 12:30-12:40 **Welcome and Introductions**
Stephan Beck, University College London, UK
- 12:40-13:30 **Keynote Lecture:**
New Technologies & Sharing Comprehensive Personal Precision-Medicine Data
George Church, Harvard University, USA
- 13:30-15:30 **Session I: Personal genetic testing: opportunities and limitations**
Chair: Manuel Corpas
- 13:30 Personal genomes and beyond for the Indian population
Anu Acharya
Mapmygenome, India
- 14:00 **Codigo46: Bridging the gap between the promises and realities of personalized medicine in Mexico**
Lorenza Haddad
Codigo46, Mexico
- 14:30 From biobanking to precision medicine
Andres Metspalu
Estonian Genome Centre, Estonia
- 15:00 The Personal Genome Project Canada: findings from whole genome sequences of the inaugural cohort
Naveed Aziz
CGEn, Canada
- 15:15 *Korean personal genome project*
Sungwon Jeon
Ulsan National Institute of Science and Technology, South Korea

- 15:30-16:00 **Afternoon Tea**
- 16:00-17:30 **Session 2: Interpretation of personal genomes**
Chair: Bastian Greshake Tzouvaras
- 16:00 Analyzing personal genomes, phenomes and electronic health records at scale
Gustavo Glusman
Institute of Systems Biology, USA
- 16:30 Empowering the public to use personal genomic information: a genetic counsellor perspective
Nicki Taverner
University of Cardiff, UK
- 17:00 Using personal genomes to calculate and interpret polygenic risk scores in preparation for genomic medicine
Cathryn Lewis
King's College London, UK
- 17:15 Leveraging phenome-wide information to improve accuracy and applicability of genetic risk predictions for complex traits
Vincent Plagnol
GenomicsPlc, UK
- 17:30-18:30 **Panel discussion: benefits from testing and sharing personal genome data**
Session Chair: Mahsa Shabani
Panellists: some speakers from earlier sessions will be joined by Fiona Nelson Repositve, UK and Tom Stubbs Chronomics, UK
- 18:30 -19:30 Poster Session with drinks reception
- 19:30 Dinner
- *19.00 There will be a lecture and Q&A on personal genomes in the Auditorium for members of the public - *pre-booking essential

Friday, 12 April

- 09:00-10:30 **Session 3: Citizen science and personal genomics: users, customers and patients**
Chair: Stephan Beck
- 09:00 Harnessing the power of open crowdsourcing for personal genomics
Bastian Greshake Tzouvaras
Open Humans, USA
- 09:30 Open donation of personal genome sequence data from the perspective of a hybrid scientist/citizen scientist
Colin Smith
University of Brighton, UK

10:00 Genomics Aotearoa, a platform for best practice genomic science in partnership with indigenous people
Ben Te Aika
Genomics Aotearoa, New Zealand

10:15 The rise of genetic genealogy as a citizen science
Maurice Gleeson
International Society of Genetic Genealogy

10:30-11:00

Morning Coffee

11:00-12:30

Session 4: Return of data to research participants and personal data access

Chair: Fiona Nielsen

11:00 What is the behavioral impact of personal genomic information, and why does it matter?
Saskia Sanderson
University College London, UK

11:30 Genomics England - treating data with care
Joanne Hackett
Genomics England, UK

12:00 Health data sharing and data protection law in Africa: a South African perspective
Ciara Staunton
Middlesex University, UK

12:15 Evaluating utility of patient-centered deep phenotyping
Monica Munoz-Torres
Oregon State University, USA

12:30-14:00

Lunch

14:00-15:30

Session 5: Society challenges: data protection and privacy and the ethics of data sharing

Chair: Mahsa Shabani

14:00 Personal genomes and the police: public opinion and ethical considerations
Christi Guerrini
Baylor College of Medicine, USA

14:30 Access, Storage, and Sharing of personal genomic information
Pascal Borry
University of Leuven, Belgium

15:00 Accessing IM Genomes transnationally across Europe by 2022
Gary Saunders
ELIXIR Europe, UK

15:15 Genomics as a personalized medicine approach in disease risk prediction - P5.fi FinHealth
Heidi Marjonen
National Institute for Health and Welfare, Finland

15:30-16:00

Afternoon Tea

16:00-17:00

Session 6: Clinical perspective – from patients to the public

Chair: Johan den Dunnen

16:00 Knowns and unknowns in genomic testing; a clinician's eye view
Frances Elmslie
St George's, University of London

16.30 Embedding genomics into routine health care
Reecha Sofat
University College London, UK

17:00-18:00

Keynote Lecture:

Genetic privacy: friend or foe?

Yaniv Erlich

MyHeritage, Israel

18:00-18:15

Concluding remarks

Programme committee

18:30

Coaches depart to Cambridge City Centre and Train Station, Heathrow Airport via Stansted Airport