

World Congress on Genetic Counselling

2 - 4 October 2019
Wellcome Genome Campus

Provisional Conference Programme

Wednesday, 2 October

- 12:30-13:50 Registration with lunch
- 13:50-14:00 Welcome and Introduction
Anna Middleton, Wellcome Genome Campus, UK
- 14:00-14:45 **Keynote lecture**
Chair: Anna Middleton, Wellcome Genome Campus, UK
- Genetic Counsellors: imagining the next 10 years
Laura Hercher
Sarah Lawrence College, USA
- 14:45-15:45 **Session 1: Genetic Counselling: countries with an established profession**
Chair: Jehannine Austin, University of British Columbia, Canada
- 14:45 Client-Centred genetic counselling in Japan
Chieko Tamara
FMC Tokyo Clinic, Japan
- 15:15 Models for the provision of additional genomic findings
Clara Gaff
Melbourne Genomics Health Alliance, Australia
- 15:45-16:15 Afternoon tea
- 16:15-17:30 **Session 2: Genetic Counselling: countries with an emerging profession**
Chair: Michelle Bishop, Health Education England, UK
- 16:15 The delivery of genetic counselling in Hong Kong from a counsellor's perspective
Olga Zayts
The University of Hong Kong, Hong Kong

- 16:45 Genetic counselling in Portugal: enduring challenges, emerging research
Alvaro Mendes
i3S, University of Porto, Portugal
- 17:15 LEADERS: A culturally tailored approach to genetic counseling for Arab communities in northern Israel
Naama Nahama Cohen Kfir
Bar Ilan University, Israel
- 17:30-18:30 **Panel led discussion: The ‘therapeutic alliance’ in genetic counselling, what is it and how do we translate this to non-specialist colleagues?**
Chair: Anna Middleton, Wellcome Genome Campus, UK
 1. *Barbara Biesecker, RTI International, USA*
 2. *Jehannine Austin, University of British Columbia, Canada*
 3. *Clara Gaff, Melbourne Genomics Health Alliance, Australia*
- 18:30-19:30 **Poster session I (odd numbers) with drinks reception**
- 19:30 Dinner & cash bar

Thursday, 3 October

- 09:00-10:30 **Session 3: Advocating for Genetic Counselling**
Chair: Chris Patch, Genomics England, UK
- 09:00 Selling what genetic counsellors do to policy makers
Michelle Bishop
Health Education England, UK
- 09:30 Embedding genomics into clinical care – Meeting the needs of policy makers
Elly Lynch
Melbourne Genomics Health Alliance, Australia
- 09:45 Views from the Transgender Community about Genetic Counselling
Speaker tbc
Gender Identity Research and Education Society (GIRES)
- 10.15 High risk – what’s next? decisional conflict, regret and satisfaction among pregnant women making choices about further prenatal testing
Charlotta Ingvoldstad Malmgren
Karolinska University Hospital, Sweden
- 10:30-11:00 Morning coffee

11:00-12:30

Session 4: What changes as a consequence of genetic counselling?

Chair: Galen Joseph, University of California, San Francisco, USA

- 11:00 Behaviour change as an outcome of psychiatric genetic counseling
Jehannine Austin
University of British Columbia, Canada
- 11:30 Experience as knowledge: Perceptions of Screening amongst Families Living with Genetic Disease
Felicity Boardman
Warwick Medical School, UK
- 12:00 Improving the communication of genomic results to patients with rare diseases and their families using Experience-based Co-design (EBCD)
Alessia Costa
King's College London, UK
- 12:15 Parent experiences with ultra-rapid genomic sequencing in paediatric acute care
Samantha Ayres
Victorian Clinical Genetics Services, Australia

12:30-14:00

Lunch

14:00-15:15

Session 5: Achieving valued outcomes for genetic counselling patients

Chair: Barbara Biesecker, RTI International, USA

- 14:00 The Genomics Outcome Scale: A short form of the Genetic Counselling Outcome Scale
Marion McAllister
Cardiff University, UK
- 14:30 Communicating Polygenic Disease Risk for Coronary Artery Disease: Design and Optimization of a Polygenic Score Report
Deanna Brockman
Massachusetts General Hospital, USA
- 14:45 Pretest Chatbots: Is Information Value Neutral?
Kelly C Donahue
Genetic Support Foundation, USA
- 15:00 Effect of Providing Education about Carrier Results via Web versus Genetic Counselor on the Subsequent Therapeutic Relationship
Lori Erby
National Human Genome Research Institute, USA

15:15-16:00

Afternoon tea

- 16:00-16:45 **Keynote lecture**
Chair: Christine Patch, Genomics England, UK
- Futuristic models of genetic counselling
Shivani Nazareth
Clear Genetics, USA
- 16:45-18:00 **Panel led discussion: Technology and Genetic Counselling: how do we combine the two?**
Chair:
 1. *Shivani Nazareth, Clear Genetics, USA*
 2. *Patricia Birch, University of British Columbia, Canada*
 3. *Laura Hercher, Sarah Lawrence College, USA*
 4. *Jon Roberts, Wellcome Genome Campus/Addenbrooke's, UK*
- 17:30-19:00 **Poster session 2 (even numbers) with drinks reception**
- 19:00 Conference dinner & cash bar

Friday 4 October

- 09:00-10:30 **Session 6: Research into the Counselling Process**
Chair: Alvaro Mendes, i3S, University of Porto, Portugal
- 09:00 A family systems approach to genetic counselling; development of interventions
Rhona MacLeod
Manchester Centre for Genomic Medicine, UK
- 09:30 Communication of clinical uncertainties: A systematic literature review
Barbara Biesecker
RTI International, USA
- 10:00 An anthropological view of genetic counselling
Galen Joseph
University of California, San Francisco, USA
- 10:30-11:00 Morning coffee
- 11:00-12:15 **Session 7: Leadership in genetic counselling**
Chair: Shivani Nazareth, Clear Genetics, USA
- 11:00 Preparing a genetic counselling workforce of the future
Alison McEwen
University of Technology Sydney, Australia

- 11:30 International Genetic Counseling
Jon Weil
California St Univ. Stanislaus, USA
- 11:45 Developing a nationally agreed cross-professional competency framework to facilitate consent for genomic testing
Amanda Pichini
University Hospitals Bristol NHS Foundation Trust, UK
- 12:00 Patient and counselor perceptions of a telehealth genetic counseling model. Can high efficiency co-exist with high satisfaction?
Kiley Johnson
GeneMatters, USA
- 12:15-13:15 **Panel led discussion: The evolution of genetic counselling practice**
1. Chieko Tamara, FMC Tokyo Clinic, Japan
2. Marion McAllister, Cardiff University, UK
3. Gemma Chandratillake, Eastern Genomic Lab Hub, UK
- 13:15-13:20 Closing remarks and conference summary
Programme Committee
- 13:20-14:20 Lunch
- 14:20 Coaches depart to Cambridge city centre and train station & Heathrow airport via Stansted airport