# World Congress on Genetic Counselling

**2 - 4 October 2019**  
*Wellcome Genome Campus*

## Provisional Conference Programme

### Wednesday, 2 October

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>12:30-13:50</td>
<td>Registration with lunch</td>
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</tbody>
</table>
| 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 1 (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
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

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

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**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

  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