World Congress on Genetic Counselling

4-6 October 2017
Wellcome Genome Campus

Conference Programme

Wednesday, 4 October

12:30-13:50 Registration with lunch

13:50-14:00 Welcome and Introduction
Anna Middleton
Wellcome Genome Campus, UK

14:00-15:00 Keynote lecture
Chair: Anna Middleton, Wellcome Genome Campus, UK

What have genetic counselors been doing and have they been any good at it?
Bob Resta
Swedish Medical Centre, USA

15:00-16:00 Session 1: The public: understanding of genomics – before becoming a patient
Chair: Christine Patch, King’s College London and Genomics England, UK

15:00 Socialising the genome – how to make genomics resonate for the public
Anna Middleton
Wellcome Genome Campus, UK

15:30 Genomics in society – attitudes of the Australian public to personal genomics
Sylvia Metcalfe,
MCRI & University of Melbourne, Australia

16:00-16:30 Afternoon tea

16:30-17:45 Session 2: Becoming a patient: the first conversations about genomics
Chair: Clara Gaff, University of Melbourne, Australia

16:30 The UK 100,000 genomes project: views, expectations, and experiences of the first patients recruited
Sandi Dheensa
CELS, University of Southampton, UK
17:00 Parents’ and adolescents’ reasoning related to receiving secondary variants from whole genome sequencing  
Robin Hayeems  
The Hospital for Sick Children Research Institute, Canada

17:30 Parental interest in genomic sequencing of newborns: Enrollment experience in the BabySeq project  
Shawn Fayer  
Brigham and Women's Hospital, Boston, USA

17:45 How do consent forms for diagnostic next-generation sequencing address unsolicited and secondary findings? A qualitative content analysis  
Danya Vears  
KU Leuven, Belgium

18:00-19:30 Poster Session 1 (odd numbers) with Drinks Reception

19:30 Dinner & cash bar

Thursday, 5 October

09:00-10:30 Session 3: Counselling under scrutiny  
Chair: Tara Clancy, University of Manchester, UK

09:00 Adapting evidence based strategies for effective communication in cancer genetic counseling  
Robin Lee  
University of California, San Francisco, USA

09:30 The ‘counselling’ in genetic counselling: empirical evidence  
Tina-Marie Wessles  
University of Cape Town, South Africa

10:00 Counselors’ experiences with uncertainties in counseling about multigene panel testing for cancer. A focus group study  
Niki Medendorp  
Academic Medical Center, Netherlands

10:15 Next-generation counseling: a model for non-invasive prenatal screening results disclosure and patient management  
Carrie Haverty  
Counsyl, USA

10:30-11:00 Morning coffee
**Session 4: Inside genetic counselling**
*Chair: Barbara Biesecker, NIH, USA*

11:00 New interventions to facilitate family communication about genetic risk and preparing the workforce
*Alison Metcalfe*
*Kings College London, UK*

11:30 Facilitating personalized communication in genetic counselling for Cancer
*Eveline Bleiker*
*Netherlands Cancer Institute, The Netherlands*

12:00 Challenges for genetic counseling of families with dilated cardiomyopathy and truncating titin mutations
*Renee Johnson*
*Victor Chang Cardiac Research Institute, Australia*

12:15 Psychological impact and genetic counselling preferences of multi-gene cancer testing in a Spanish multi-centric cohort: a 12-month analysis
*Irene Esteban*
*Ninewells Hospital, UK*

12:30-14:00 Lunch

**Session 5: Outcome measurements**
*Chair: Marion McAllister, Cardiff University, UK*

14:00 What counts as ‘success’ in genetic counselling?
Systematic review of RTCs in assessing outcomes in genetic counselling?
*Barbara Biesecker*
*NIH, USA*

14:30 Measuring the economic value of genetic counselling
*Katherine Payne*
*University of Manchester, UK*

15:00 Using data collected using patient-reported outcome measures for quality improvement in clinical genetics
*Marion McAllister*
*Cardiff University, UK*

15:15 The ongoing search for a patient reported outcome measure (PROM) in genetic counseling: the psychometric properties of the Genetic Counseling Outcome Scale for a Dutch study sample
*Jan Voorwinden*
*University Medical Center Groningen, Netherlands*

15:30-16:00 Afternoon tea
16:00-17:30  
**Session 6: Debate session – How & when are psychotherapeutic models relevant in the genomic era**  
*Chair: Anna Middleton, Wellcome Genome Campus, UK*

Jehannine Austin, University of British Columbia, Canada  
Tara Clancy, University of Manchester, UK

17:30-19:00  
**Poster session 2 (even numbers) with drinks reception**

19:00  
Conference dinner & cash bar

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**Friday 6 October**

09:00-10:30  
**Session 7: Ethical, legal and social issues**  
*Chair: Christine Patch, King’s College London and Genomics England, UK*

09:00  
Bioethics and genetic counselling  
*Heidi Howard*  
Uppsala University, Sweden

09:30  
The duty to inform: HD case legal going through the English courts  
*Vicky Chico*  
University of Sheffield & Wellcome Genome Campus, UK

10:00  
BME women’s decision-making for risk-reduction after BRCA testing  
*Mavis Machirori*  
King's College London, UK

10:15  
Reporting clinical whole genome sequencing results via telephone genetic counseling in a diverse healthy population  
*Molly McGinniss*  
Illumina, USA

10:30-11:00  
Morning coffee

11:00-12:00  
**Keynote lecture**  
*Chair: Christine Patch, King’s College London and Genomics England, UK*

The priorities for research in genomic counselling  
*Clara Gaff*  
University of Melbourne, Australia
12:00-13:35 **Session 8: Spreading the word post consultation**  
*Chair: Bob Resta*

12:00  Genetics in popular culture  
*Jon Roberts*  
*Wellcome Genome Campus, UK*

12:30  Personal Genomic Screening: how best to facilitate preparedness of future clients  
*Jane Flemming,*  
*Sydney University Medical School – Northern*

12:45  Panel discussion: The future of the genetic counselling profession  
*Clara Gaff, Tina-Maria Wessles, Christine Patch, Jehannine Austin*

13:30  Closing remarks and conference summary  
*Programme Committee*

13:35 -14:45 Lunch

14:45 Coaches depart to Cambridge city centre and train station & Heathrow airport via Stansted airport