## PROGRAM

**Wednesday 26th May 2021**

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<th>Time</th>
<th>Vancouver</th>
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<td>Welcome and Introductions</td>
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**Plenary 1 (1h)**

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"Solve-RD - on the impact of diagnostic rare disease research on the diffusion of genomic medicine"

Holm GRAESSNER (Centre for Rare Diseases, University Hospital Tübingen, Germany)

**Session A (1h)**

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- A - Implementation of exome and genome sequencing: who has access, who pays, and what are solutions for implementation challenges?

Proposed by Deborah Marshall

Deborah MARSHALL, Kathryn A. PHILLIPS, Sarah WORDSWORTH, James BUCHANAN, Dean REGIER
### Thursday 27th May 2021

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Details</th>
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<tr>
<td><strong>Plenary 2 (1h)</strong></td>
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<td>07:00 a.m.</td>
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<td><strong>Sessions B (1h15)</strong></td>
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<td><strong>Short break (10min)</strong></td>
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<td><strong>Sessions C (1h15)</strong></td>
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**Plenary 2 (1h)**

- **07:00 a.m.**
  - Sessions A (Vancouver)
  - Short break
- **08:00 a.m.**
  - "What's important to you in the delivery of health care... and what does this mean for valuing Next Generation Sequencing?"
  - Mandy Ryan (Health Economics Research Unit, University of Aberdeen, United Kingdom)
- **09:30 a.m.**
  - Sessions C (Melbourne, Sydney)

**Sessions B (1h15)**

- **08:10 a.m.**
  - B1 - How to assess the cost effectiveness of WES/WGS?
  - Systematic review or meta-analysis: how to consider the high heterogeneity of studies to access the clinical utility of WGS/WES?
  - Camille Level
- **09:30 a.m.**
  - C1 - Methodological considerations for measuring preferences for genome sequencing
  - Proposed by Wendy Ungar (CA)
  - Family matters: measuring the preferences of family members for genome sequencing
  - Wendy Ungar
  - Demand for precision medicine: a discrete choice experiment and external validation study
  - Dean Regier
- **10:00 a.m.**
  - Sessions D (Melbourne, Sydney)

**Sessions C (1h15)**

- **09:30 a.m.**
  - C2 - What place and articulation for professionals?
  - Clinical utility of genomic sequencing: a measurement toolkit
  - Robin Hayeems
  - The development of the clinician-reported genetic testing utility index (C-GUIDE): a novel strategy for measuring the clinical utility of genetic testing
  - Robin Hayeems
- **10:30 a.m.**
  - Sessions E (Melbourne, Sydney)
### Sessions D (1h15)

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**D1 - Cost effectiveness of genomic medicine: Beyond the cost of diagnosis**

Proposed by Deborah SCHOFIELD (AUST)

Capturing the widespread ripple effects of familial intellectual disability and potential benefits of genomics – Deborah SCHOFIELD

An economic modelling framework to assess the impact of population-wide preconception carrier screening for genetic disease with specific reference to spinal muscular atrophy – Evelyn LEE and Rupendra SHRESTHA

Modelling the economic impact of next generation sequencing on childhood cancer management – Owen TAN

**D2 - Implementing new generation sequencing in care for pediatric cancers: impacts for patients, healthcare providers and public policies**

Proposed by Sandrine DE MONGOLFIER and Sylvain BESLE

Negotiating the regulation of routine genome sequencing in care setting - Catherine BOURGAIN

Routinization of sequencing techniques: what impact on patient care pathways in oncopediatrics? – Solenne CAROF and Lucile HERVOUET

Legally assure minors' rights in oncopediatric: between rights and practices – Emmanuelle RIAL SEBBAG

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*“Introducing Next Generation Sequencing in healthcare: challenges for patients’ rights and for public health”*

Emmanuelle RIAL-SEBBAG (Laboratoire d’épidémiologie et de santé publique, Université de Toulouse, France)

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**Sessions E (1h15)**

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**E1 - Comparative evaluation of two strategies**

Accurate and comprehensive microcosting of genome sequencing in pediatric populations - Wendy UNGAR

Time-varying effects of genomics-informed treatment in patients with advanced cancers: a difference-in-difference analysis - Deirdre WEYMANN

The GenoVA Study: design of a pragmatic randomized trial of polygenic risk scoring for common diseases in primary care - Jason VASSY

A cost-effective model for the pathway of care of CDH1-related hereditary diffuse gastric cancer syndrome - Liliana SOUSA

**E2 - Genome sequencing: new evidence on costs, and challenges for health technology assessment**

Proposed by James BUCHANAN (UK)

Estimating the diagnostic pathway costs of patients with suspected rare genetic diseases - John BUCKELL

Casting genome sequencing in large-scale, national initiatives: challenges and opportunities - Patrick FAHR

Considerations for cost-effectiveness analysis of genome sequencing - Wendy UNGAR

**E3 - Theoretical microeconomics in genomic medicine**

Welfare impacts of genetic testing in health insurance markets will cross-subsidies survive? - Philippe DE DONDER

Implementation of personalized medicine in a context of moral hazard and uncertainty about treatment efficacy - Stéphane ALCENAT

Physicians' incentives to adopt personalized medicine: experimental evidence - Samuel KEMBOU NZALE

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**Sessions F (1h15)**

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**F - Perspectives on Genomic Medicine: Between Public Policy and Citizens**

Stakeholders perspectives for precision oncology: balancing patient and public support with evidentiary uncertainty - Samantha POLLARD

DNA debate: engaging citizens on genomics - Chloé MAYEUR

Health technology assessment and funding of genomic medicine technologies in Ontario, Canada - Wendy UNGAR

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**Close of the conference**
The Solve-RD project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement N° 779257

The conference also benefits from the financial support of:

- the Burgundy Franche-Comté region, within the framework of the regional call for projects 2020 dedicated to "International Scientific Colloquium"

- the University of Burgundy, as part of the call for project named "BQR 2020"