EUROPEAN CONFERENCE

ON THE DIFFUSION OF GENOMIC MEDICINE

HEALTH ECONOMICS & POLICY

VIRTUAL EVENT

MAY 26-28, 2021

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

PROGRAM

Wednesday 26th May 2021

-9 (Vancouver)	-6 Quebec, NY, …)	-1 (London, Lisbon)	Paris (ref.)	+8 (Melbourne, Sydney)	
06:30 a.m.	09:30 a.m.	02:30 p.m.	***03:30 p.m.***	11:30 p.m.	***Welcome and Introductions***
Plenary 1 (1h)					
07:00 a.m.	10:00 a.m.	03:00 p.m.	***04:00 p.m.***	00:00 p.m.	**"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)					
08:00 a.m.	11:00 a.m.	04:00 p.m.	***05:00 p.m.***	(Day +1) 01:00 a.m.	*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

-9 (Vancouver)	-6 Quebec, NY, …)	-1 (London, Lisbon)	Paris (ref.)	+8 (Melbourne, Sydney)			
Plenary 2 (1h)							
07:00 a.m.	10:00 a.m.	03:00 p.m.	***04:00 p.m.***	00:00 p.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)*		
Short break (10min)							
Sessions B (1h15)							
08:10 a.m.	11:10 a.m.	04:10 p.m.	***05:10 p.m.***	01:10 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** *Genomic testing in the field of developmental disorders: the added value of human and social sciences studies* - **Catherine LEJEUNE** *Next Generation Sequencing for the next generation of patients: building the economic evidence base* - **Michael ABBOTT**	*B2 - Preferences, expectations, representations of patients, professionals and general population* *"Anything to make things a bit better for my child": parental preferences for genomic testing in rare childhood diseases* - **Samantha POLLARD** *Quantifying how individuals trade health for non-health value deriving from genomic-based diagnostic information* - **Martin EDEN** *Simulation modeling methods for economic evaluation in precision medicine that consider patient preferences* - **Deborah MARSHALL** *"It is written in our genes! What we would like to know?" Understanding the demand for genetic testing using a discrete choice experiment to assess the French populations' preferences* - **Aurore PELISSIER**	*B3 - Addressing evidentiary uncertainty in precision medicine health technology assessment* **Proposed by Dean REGIER (CA)** *Can Big Data from Precision Medicine Observational Cohorts Reduce Evidentiary Uncertainty? A Perspective from the UK 100.000 Genomes Project* - **James BUCHANAN** *Quasi-experimental Methods for Evaluating Precision Medicine: Case Studies in Personalized OncoGenomics* - **Deirdre WEYMANN** *Life-cycle Health Technology Assessment to Enable Sustainable Precision Medicine Diffusion* - **Dean REGIER**
Short break (5min)							
Sessions C (1h15)							
09:30 a.m.	12:30 p.m.	05:30 p.m.	***06:30 p.m.***	02:30 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** *Defining and mesuring the value of genetic testing from patients' perspectives: developing the patient-reported genetic testing utility InDEx (P-GUIDE)* - **Robin HAYEEMS**	*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** *The evolution of the profession of clinical geneticist and genetic counsellors with the arrival of new technologies in genetics* - **Lea GAUDILLAT**	*C3 - Use and value of genetic information* *My DNA, everybody's business? A citizen forum on the use of genomic information in society* - **Wannes VAN HOOF** *Additional data obtained from exome/genome sequencing : two national studies to discuss the risk-benefit balance for implementation in France* - **Laurence FAIVRE** *Donation, free and informed consent, genetic data* - **Sarah CARVALLO** *Next Generation Sequencing techniques and the "information illusion"* - **Marie DARRASON**

Friday 28th May 2021

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Sessions D (1h15)						
01:00 a.m.	04:00 a.m.	09:00 a.m.	*10:00 a.m.*	18:00 p.m.	*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 – a microsimulation approach* – **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 patients'right in oncopediatric: between rights and practices* – **Emmanuelle RIAL SEBBAG**
Long break						
Plenary 3 (1h)						
07:00 a.m.	10:00 a.m.	03:00 p.m.	*04:00 p.m.*	24:00 p.m.	***"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)*	
Short break (5min)						
Sessions E (1h15)						
08:05 a.m.	11:05 a.m.	04:05 p.m.	*05:05 p.m.*	(Day +1) 01:05 a.m.	*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** *Costing 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**
Short break (10min)						
Sessions F (1h15)						
09:30 a.m.	12:30 p.m.	05:30 p.m.	*06:30 p.m.*	02:30 a.m.	*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 assesment and funding of genomic medicine technologies in Ontario, Canada* - **Wendy UNGAR**	
10:45 a.m.	01:45 p.m.	06:45 p.m.	***07:45 p.m.***	03:45 a.m.	***Close of the conference***	

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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"

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

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