Integrating genomics into personalised healthcare: a science-for-policy perspective

My genome: our future

CONFERENCE PROGRAMME

12-13 February 2019
Brussels, Belgium
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Conference Programme
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Scientific Steering Committee Members

Tit Albreht
National Institute of Public Health (NIJZ), Slovenia

Rolf Apweiler
The European Molecular Biology Laboratory - European Bioinformatics Institute (EMBL-EBI), United Kingdom

Mauro Giacca
King’s College London, United Kingdom

Peter Goodhand
Ontario Institute for Cancer Research, Canada

Jan Korbel
European Molecular Biology Laboratory (EMBL), Germany

Jacques Simard
Université Laval, Canada

Rita Schmutzler
Uniklinik Köln, Germany

Giorgio Stanta
University of Trieste, Italy

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European Commission, Joint Research Centre, Italy

Guy Van den Eede
European Commission, Joint Research Centre, Belgium
AM

Tuesday 12 February 2019

8:00 - 9:15 Participants registration and welcome coffee

9:30 - 10:00 Institutional addresses

Chair: Vladimír Šucha
Director-General, European Commission, Directorate-General Joint Research Centre, Belgium

Martin Seychell
Deputy Director-General, European Commission, Directorate-General for Health and Food Safety, Belgium

Irene Norstedt
Acting Director, European Commission, Directorate-General for Communications Networks, Content and Technology, Belgium

10:00 - 13:15 Session I: Setting the stage

Chair: Joris Vermeesch
University of Leuven, Belgium

Co-chair: Marco Marsella
European Commission, Directorate-General for Communications Networks, Content and Technology, Luxembourg

Rapporteur: Jacques Simard
Université Laval, Canada

10:00 - 11:00 Keynote presentations

10:00 - 10:30 Big data in healthcare and biology, opportunities and challenges
Ewan Birney
European Molecular Biology Laboratory - European Bioinformatics Institute (EMBL-EBI), United Kingdom

10:30 - 11:00 From clinical genetics to genomic medicine: a brief history
Sir John Burn
Newcastle University, United Kingdom

11:00 - 11:30 Coffee break

11:30 - 13:15 Moderated panel discussion with

Peter Devilee
Leiden University Medical Center, The Netherlands

Mark Bale
Genomics England, United Kingdom

Denis Horgan
European Alliance for Personalised Medicine, Belgium

Peter Kapitein
Inspire2live, The Netherlands

13:15 - 14:15 Lunch break
PM

14:15 - 14:45 Flash talks by young health innovators

Chair: Mauro Giacca
King's College London, United Kingdom

14:15 - 14:30 Reinventing ADCs - Catalyzing the discovery and development of next-generation Antibody Drug Conjugates (ADCs) for targeted therapies
Dominik Schumacher
Tubulis Technologies, Germany

14:30 - 14:45 From genetics to metabolism, a translational effort towards cancer diagnostics
Francesco Gatto
Elypta, Sweden

14:45 - 18:00 Session II: Genomics - opportunities and challenges

Chair: Giorgio Stanta
University of Trieste, Italy
Co-chair: Irene Norstedt
European Commission, Directorate-General for Research and Innovation, Belgium
Rapporteur: Rolf Apweiler
European Molecular Biology Laboratory - European Bioinformatics Institute (EMBL-EBI), United Kingdom

14:45 - 15:45 Keynote presentations

14:45 - 15:15 Data sharing in genomic medicine: opportunities and challenges
Jan Korbel
European Molecular Biology Laboratory (EMBL), Germany

15:15 - 15:45 The internet for social machines
Barend Mons
Leiden University Medical Center (LUMC), The Netherlands

15:45 - 16:15 Break

16:15 - 18:00 Moderated panel discussion with
Rodrigo Dienstmann
Vall d’Hebron Institute of Oncology (VHIO), Spain
Stefan Fröhling
National Center for Tumor Diseases (NCT), Germany
Serena Scollen
European Life-Science Infrastructure For Biological Information (ELIXIR), United Kingdom

18:00 End of day 1
18:00 - 19:00 Refreshments
8:00 - 8:45 Participants registration

8:45 - 12:00 Session III: The public health perspective

**Chair:** Tit Albreht  
National Institute of Public Health (NIJZ), Slovenia

**Co-chair:** Elke Anklam  
European Commission, Directorate-General Joint Research Centre, Belgium

**Rapporteur:** Marc Van den Bulcke  
Sciensano, Belgium

8:45 - 9:45 Keynote presentation

**The future of oncology research in Horizon Europe**  
Thierry Philip  
Institut Curie and Organisation of European Cancer Institutes (OECI), France

9:45 - 10:15 Coffee break

10:15 - 12:00 Moderated panel discussion with

**Nazneen Rahman**  
Independent healthcare consultant, United Kingdom

**Jacek Gronwald**  
Pomeranian Medical University (PMU), Poland

**Jan-Ingvar Jönsson**  
Swedish Research Council, Sweden

**Laura van’t Veer**  
University of California San Francisco (UCSF), Helen Diller Family Comprehensive Cancer Center, USA

12:00 - 13:00 Lunch break

13:00 - 13:30 Flash talks: A focus on genomics for rare diseases

**Chair:** Julia Wilson  
Wellcome Trust Sanger Institute, United Kingdom

13:00 - 13:15 **SOLVE-RD: a diagnosis for every rare disease patient**  
Han Brunner  
Radboud University Medical Center (Radboudumc), The Netherlands

13:15 - 13:30 **European joint programme on rare diseases – bringing genomic tools and discoveries to clinics**  
Daria Julkowska  
National Institute of Health and Medical Research (INSERM), France
Session IV: The citizen and patient perspective

Chair: Peter Goodhand
Global Alliance for Genomics and Health, Canada

Co-chair: Ioana-Maria Gligor
European Commission, Directorate-General for Health and Food Safety, Belgium

Rapporteur: Rita Schmutzler
Uniklinik Köln, Germany

13:30 - 14:30 Keynote presentations

13:30 - 14:00 Citizen and patient perspectives: The Quebec experience
Bartha Knoppers
McGill University, Canada

14:00 - 14:30 How biobanking can help deliver on the promises of personalised medicine
Francesco Florindi
Biobanking and Biomolecular Resources Research Infrastructure - European Research Infrastructure Consortium (BBMRI-ERIC), Austria

14:30 - 15:00 Break

15:00 - 16:45 Moderated panel discussion with
Jane Kaye
Centre for Law, Health and Emerging Technologies (HeLEX), University of Oxford, United Kingdom

Bettina Borisch
University of Geneva, Switzerland

Jean-Pierre Hubaux
Ecole Polytechnique Fédérale de Lausanne (EPFL), Switzerland

Andres Metspalu
University of Tartu, Institute of Genomics, Estonia

16:45 - 17:30 Final keynote presentation

Chair: Guy Van den Eede
European Commission, Directorate-General for Health and Food Safety, Belgium

Final keynote presentation:
Genomic medicine programs of the National Human Genome Research Institute
Teri Manolio
National Human Genome Research Institute, National Institutes of Health (NIH), USA

17:30 Closing of the conference
Institutional addresses

Chair

Vladimír Šucha
Director-General, European Commission, Directorate-General Joint Research Centre, Belgium

Vladimír Šucha is Director-General of the Joint Research Centre of the European Commission, its in-house scientific service. He was Deputy Director-General of the JRC between 2012 and 2013. Prior to that, he spent 6 years serving as Director of Culture and Media in the Directorate-General for Education and Culture of the European Commission. Before joining the European Commission, he held various positions in the area of European and international affairs. Between 2005 and 2006, he was Director of the Slovak Research and Development Agency, the national body responsible for funding research. He was the principal advisor for European affairs to the minister of education of the Slovak Republic (2004-2005). He worked at the Slovak Representation to the EU in Brussels as research, education and culture counselor (2000-2004). In parallel, he has followed a long-term academic and research career, being a full professor in Slovakia and visiting professor/scientist at different academic institutions in many countries. He has published more than 100 scientific papers in peer reviewed journals.

Speaker

Martin Seychell
Deputy Director-General, European Commission, Directorate-General for Health and Food Safety, Belgium

Martin Seychell is Deputy Director-General of Health in the Health and Food Safety Directorate-General (SANTE) since 2014. He is a graduate in chemistry and pharmaceutical technology with specialization in chemical analysis. He has held various important positions on several government Boards and Commissions in Malta, including the Food Safety Commission and the Pesticides Board. Between 2001 and 2006, Mr Seychell occupied the post of Head of Directorate at the Malta Standards Authority. He has been responsible for the implementation of a number of EU directives in the areas of risk assessment, food safety, chemicals and cosmetic products legislation, and has actively participated in negotiations on major technical proposals such as the new chemicals legislation, REACH, and in screening processes in the areas of free movement of goods, environment and agriculture during the process leading to Malta’s accession to the EU. Between 2006 and 2011, he held the post of Director of Environment in Malta and was responsible for a broad range of functions arising from the Maltese Environment Protection Act. In March 2011, he was appointed Deputy Director-General for Health and Consumers at the European Commission and was responsible for the Directorates dealing with Consumer affairs, Public health and Health systems and products (SANCO).
Irene Norstedt is the Acting Director responsible for the Health Directorate of the DG for Research and Innovation at the European Commission. She is also Head of the Innovative and Personalised Medicine Unit. She has served at the European Commission since 1996 and was instrumental in the creation of the Innovative Medicines Initiative (IMI) in 2008. From 16 December 2014 to 15 September 2015, Irene served as Acting Executive Director of the Innovative Medicines Initiative. Before joining the European Commission, she worked for the Swedish Life Science company, Biacore AB and at the Swedish Embassy in London. Irene studied biotechnology and polymer science, and holds a Master of Science (MSc) in Chemical Engineering.
Session I:
Setting the stage

Chair
Joris Vermeesch
Department Chair, University of Leuven, Belgium

The Vermeesch laboratory is focused on developing technologies for rare disease analysis, understanding the causes and mechanisms underlying rare developmental disorders and it primarily focuses on structural variation and mosaicism detection. The laboratory has been translating those technologies to leverage postnatal diagnosis, as well as preimplantation and prenatal to avoid transmission of disease alleles. The laboratory has also been focusing on embryonic development and early placentation and aims to unravel the mutational mechanisms active during those early developmental stages. Joris Vermeesch is the founder of Cartagenia, a start-up company specialized in genomic data analysis for clinical diagnostic laboratories, founder and coordinator of Genomics core Leuven and founder and president of the Leuven Institute of Genomics and Society (LIGAS). He has published over 300 papers and an H-index of 51.

Co-chair
Marco Marsella
Head of Unit, European Commission, Directorate-General for Communications Networks, Content and Technology, Luxembourg

Marco Marsella is Head of the “eHealth, Well-being, and Ageing” Unit of the Directorate General for Communications Networks, Content and Technology (DG CONNECT) of the European Commission. From 2016 to June 2018, Marco Marsella headed the Unit responsible for the Web Accessibility Directive, Safer Internet and Language Technologies. He has worked on policy development, innovation and research implementation in the areas of digital content, technologies for learning, e-inclusion and assistive technologies.

Rapporteur
Jacques Simard
Vice-Dean of Research and Graduate Studies, Université Laval, Canada

Jacques Simard holds a Canadian Research Chair in Oncogenetics and is Vice-Dean of Research and Graduate Studies at the Faculty of Medicine of Université Laval. He was the lead investigator (Bartha M. Knoppers co-lead) of the project Personalized Risk Stratification for Prevention and Early Detection of Breast Cancer (PERSPECTIVE) (2013-2018), designed to develop the tools needed to implement a risk stratification approach that would target breast cancer screening in women most likely to develop the disease. He leads (Anna Chiarelli co-lead) PERSPECTIVE: Integration and Implementation (2018-2022) to further improve personalized risk assessment, to provide risk-based prevention and early detection of breast cancer, and to determine the optimal implementation approaches in the Canadian health system.
**Keynote speaker**

**Ewan Birney**  
Director, European Molecular Biology Laboratory - European Bioinformatics Institute (EMBL-EBI), United Kingdom

Ewan Birney is Director of EMBL-EBI, together with Rolf Apweiler, and runs a small research group. He is also EMBL-EBI’s Joint Head of Research, alongside Nick Goldman. Ewan Birney led the analysis of the Human Genome gene set, mouse and chicken genomes and the ENCODE project, focusing on non-coding elements of the human genome. Ewan Birney’s main areas of research include functional genomics, DNA algorithms, statistical methods to analyse genomic information (in particular, information associated with individual differences in humans and Medaka fish) and use of images for chromatin structure. Ewan Birney is a non-executive Director of Genomics England, and a consultant and advisor to a number of companies, including Oxford Nanopore Technologies, Dovetail Genomics and GSK. Ewan Birney was elected an EMBO member in 2012, a Fellow of the Royal Society in 2014 and a Fellow of the Academy of Medical Sciences in 2015.

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**Keynote speaker**

**Sir John Burn**  
Professor of Clinical Genetics, Newcastle University, United Kingdom

Sir John Burn has been a registered specialist in clinical genetics since 1982 and Professor since 1991. He helped construct, and led for two decades, the NHS genetic services in the Northern region of England. He helped conceive and brought to the forefront, the International Centre for Life to celebrate and advance genomics. He has been chair of the British Society of Human Genetics, a scientific advisor to the Department of Health, the Science and Technology Committee, the DDD project at the Sanger Centre and the UK 100,000 genome project. He has been a member of the Board of NHS England and now Chair of Newcastle Hospitals, responsible for one of the 7 genomic laboratory hubs. He helped create and currently Chair of QuantuMDx Ltd, a company developing point of care DNA testing devices suitable for low and middle-income countries.

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**Panellist**

**Peter Devilee**  
Head of Section, Leiden University Medical Center, The Netherlands

Peter Devilee has 35 years’ experience in cancer genetics, including somatic genetics of tumors and the genetics of familial clustering of cancer, primarily breast and colorectal cancer, and paragangliomas. Since 2003, he is a professor of Tumor Genetics at the Leiden University Medical Center (Department of Human Genetics and the Department of Pathology). In the late nineties, he was the coordinator of the worldwide Breast Cancer Linkage Consortium, which made significant contributions to the understanding of the genetics of familial breast cancer. In 1995, he was co-discoverer of the BRCA2 gene, and in 2000, of the gene-defect underlying hereditary paragangliomas. His current works include searches for new cancer susceptibility and risk modifier genes in selected families and patient populations, studies directed towards understanding the polygenic nature of cancer susceptibility and the pathogenicity of unclassified variants in the BRCA1/2 genes. Since 2015, he has been coordinating the BRIDGES project, an EU-program aimed at developing a personalized breast cancer risk-estimation tool.
Panelist

Mark Bale
Head of Science Partnerships, Genomics England, United Kingdom

Mark Bale is the senior genomics policy expert at the Department of Health & Social Care and Head of Science Partnerships at Genomics England. He has had responsibility for several emerging areas of science and their ethical, legal and policy implications. The current emphasis is on genomics (particularly, the 100,000 Genomes Project) and emerging areas such as genome editing. At Genomics England, he coordinates the various partnerships within England, Scotland, Wales, and Northern Ireland, and links with other international partners. These include the EU 1 Million Genomes Initiative and representation at the Council of Europe and OECD.

Panelist

Denis Horgan
Executive Director, European Alliance for Personalised Medicine, Belgium

Denis Horgan is the Executive Director of the European Alliance for Personalised Medicine (EAPM). Horgan’s background blends extensive expertise in health policy and issues advocacy with a unique understanding of how civil society interacts with today’s political arena at the European and Member State level. Prior to working for the EAPM, he worked at the European Cancer Patient Coalition and in the European Parliament on a broad array of health issues relating to the pharmaceutical area and patient issues and for international NGOs on health development projects in Afghanistan, Mexico and Palestine. Throughout his career, Denis Horgan has developed numerous public affairs initiatives in the areas of advocacy, social marketing, policy support and launch, policy development and media relations. As a senior policy affairs manager, he has actively been involved in coalition building, grassroots advocacy, conferences development and development of policy platforms to support access to reimbursement/treatment at the political level and for institutions/bodies. Specialities: European Union policy and legislation, government affairs, lobbying, patient relations, patients sector, communication, advocacy, NGO sector, Development sector.

Panelist

Peter Kapitein
Patient Advocate, Inspire2Live, The Netherlands

As a Patient Advocate of Inspire2Live, Peter Kapitein connects patients, researchers and clinicians to further research, treatments and care in The Netherlands, as well as globally. He organises congresses, lobbies the matrix of public authorities, health care organizations, insurance companies and health research institutes. Peter Kapitein also gives lectures and talks to help patients and society fight cancer, where possible and to live with it with a good quality of life. He writes blogs, articles and books that contribute to these topics. He has studied the Medical Industrial Complex, the complex in which the stakeholders in healthcare work together in a way that does not necessarily benefit the patient. Health care is (without bad intention) distracted from its essence, the patient. Peter Kapitein is the co-founder of Alpe d’Huez, the foundation that is most famous for the annual cycling event on Mount Alpe d’Huez and that raised over 150 million euro for the fight against cancer. He works at the Central Bank of the Netherlands as a program manager and advisor for complex and politically difficult problems. His employer facilitates him in this job. His job enables him to be genuinely independent and to work tirelessly for the interests of all patients globally. He was honoured with a doctorate in October 2012 at the Free University in Amsterdam for connecting patients, researchers and clinicians all over the world.
Flash talks
by young health innovators

Chair
Mauro Giacca
Professor of Cardiovascular Sciences, King’s College London, United Kingdom

Mauro Giacca is a Professor of Cardiovascular Sciences at the School of Cardiovascular Medicine & Sciences, King’s College London. Until 2018, he served as the Director-General of the International Centre for Genetic Engineering and Biotechnology (ICGEB), an international organization in the United Nations Common System. He is the President-Elect of the International Society for Heart Research (ISHR) – European Section and has served in the scientific councils of several biotechnology centres internationally. A medical doctor by training, he is a scientist active in the field of molecular medicine. His research interests focus on the development of novel biotherapeutics for degenerative disorders, in particular, myocardial infarction and heart failure.

Speaker
Dominik Schumacher
Group Leader and Founder, Tubulis Technologies, Germany

Dominik Schumacher studied business chemistry and chemistry at the University of Düsseldorf and conducted his PhD under the supervision of Christian Hackenberger at the Leibniz-Institut für Molekulare Pharmakologie and the Humboldt Universität zu Berlin. Together with his business partner, Jonas Helma-Smets, he is co-leading the award-winning start-up Tubulis, which has created a new technology-driven approach to accelerate and de-risk drug development with a specific focus on Antibody Drug Conjugates (ADCs) for targeted therapies. Dominik Schumacher filed several patents and is the first and corresponding author of publications in renowned journals including Angewandte Chemie, Chemical Science and Nature Chemistry. He received several prizes and was recently awarded as one of Europe’s top innovators under 35.

Speaker
Francesco Gatto
Co-Founder, Chief Scientific Officer, Elypta, Sweden

Francesco Gatto is the co-founder and Chief Scientific Officer at Elypta, a molecular diagnostics company based in Stockholm, Sweden. Francesco obtained an M.Sc. in Chemical Engineering from the University of Padova, Italy in 2011 and a PhD. in Systems Biology and Bioinformatics from Chalmers University of Technology, Sweden in 2015. He was a visiting scholar at University of California, San Diego in 2016. In 2017, he co-founded Elypta. Francesco Gatto is a co-inventor in the 3 patent applications that culminated in the creation of Elypta, whose core technology revolves around an innovative liquid biopsy for cancer, possibly the first one based on metabolism. For this venture, he attracted over €5M in research grants and private equity. He is the first author of 10 scientific publications since 2014. For his achievements with Elypta, Francesco was named MIT Technology Review Innovators Under 35 Europe in 2018, with a special mention as Pioneer of the Year 2018.
Session II: Genomics – Opportunities and challenges

Chair
Giorgio Stanta
Professor of Pathology, University of Trieste, Italy

Giorgio Stanta is the head of the Molecular Histopathology Lab at the University of Trieste. He is the coordinator of the European group “Archive Tissues: Improving Molecular Medicine Research and Clinical Practice – IMPACTS” (www.impactsnetwork.eu). Also, he is the chairman of the “Biobanking and Molecular Pathobiology Working Group” of the OECI (Organisation of European Cancer Institutes – www.oeci.eu) and chairman of the “Molecular Pathology Working Group” of the ESP (European Society of Pathology – www.esp-pathology.org). He is a member of the managing board of BBMRI.IT (Italian Biobanking Infrastructure) and a member of the Committee of CEN (European Committee for Standardization) for molecular in-vitro diagnostic examinations.

Co-chair
Irene Norstedt
Acting Director, European Commission, Directorate-General for Research and Innovation, Belgium

Irene Norstedt is the Acting Director responsible for the Health Directorate of the DG for Research and Innovation at the European Commission. She is also Head of the Innovative and Personalised Medicine Unit. She has served at the European Commission since 1996 and was instrumental in the creation of the Innovative Medicines Initiative (IMI) in 2008. From 16 December 2014 to 15 September 2015, Irene served as Acting Executive Director of the Innovative Medicines Initiative. Before joining the European Commission, she worked for the Swedish Life Science company, Biacore AB and at the Swedish Embassy in London. Irene studied biotechnology and polymer science, and holds a Master of Science (MSc) in Chemical Engineering.
### Rapporteur

**Rolf Apweiler**

Director, The European Molecular Biology Laboratory - European Bioinformatics Institute (EMBL-EBI), United Kingdom

Rolf Apweiler is Director of EMBL-EBI, together with Ewan Birney. Prior to this position, he was a Joint Associate Director, after many years of leading protein resources such as UniProt. Rolf Apweiler has made a major contribution to methods for the automatic annotation of proteins, making it possible to add relevant information to proteome sets for entire organisms. He spearheaded the development of standards for proteomics data, and his teams have maintained significant collections of protein identifications from proteomics experiments (PRIDE) and molecular interactions (IntAct). He also led EMBL-EBI’s contribution to the Gene Ontology and is the current Director of Open Targets. Rolf received his PhD from the University of Heidelberg in 1994, and has been at EMBL since 1987. His major contribution to the field of proteomics was recognised by the Human Proteomics Organisation’s “Distinguished Achievement Award in Proteomics” in 2004 and he was elected as President of the Human Proteomics Organisation, which he held in 2007 and 2008. In 2012, he was elected as a member of EMBO and in 2015 he was elected to the ISCB (International Society for Computational Biology) as a fellow. Rolf Apweiler also served for many years on a multitude of Editorial Boards and Scientific Advisory Boards.

### Keynote speaker

**Jan Korbel**

Group Leader, European Molecular Biology Laboratory (EMBL), Germany

Jan Korbel is a Group Leader and Senior Scientist at the EMBL. He holds a PhD in Molecular Biology, and during his postdoc at Yale University, he developed the paired-end mapping methodology for characterizing structural variations by next-generation sequencing. Jan Korbel has expertise in Human Genetics and Computational Biology and his research interests focus on understanding the determinants of genomic DNA rearrangement formation and selection in the germline, as well as in cancer genomes. He has had leading roles in the 1000 Genomes Project and the PCAWG Initiative. Also, he is significantly involved in a project dealing with scientific self-regulation in the context of whole-genome sequencing in patients and associated bioethical and normative aspects. Jan Korbel was elected into the German National Academy of Sciences Leopoldina in 2015 and into EMBO in 2016. He received the EACR – Pezcoller Foundation Cancer Research Award in 2018.

### Keynote speaker

**Barend Mons**

Professor of BioSemantics, Leiden University Medical Center (LUMC), The Netherlands

Barend Mons is a global expert on FAIR principles. Originally a molecular biologist, he refocused in 2000 on semantic technologies and later on Open Science. In 2014, Barend Mons initiated the FAIR data initiative, and in 2015, he was appointed Chair of the European Commission’s High-Level Expert Group for the “European Open Science Cloud”, where he retired by the end of 2016. He continues to be active towards the practical realisation of the EOSC, defined as the Internet of FAIR data and services. Presently, Barend Mons is co-leading the GO FAIR initiative, an initiative to kick start developments towards the Internet of FAIR data and services, which will also contribute to the implementation of components of the European Open Science Cloud.
Panellist
Rodrigo Dienstmann
Principal Investigator, Vall d’Hebron Institute of Oncology (VHIO), Spain

Rodrigo Dienstmann is a medical oncologist with expertise in drug-biomarker co-development, computational research and real-world data analysis. He currently leads the Oncology Data Science Group of Vall d’Hebron Institute of Oncology, integrating clinical and translational research with genomics and immunophenotyping of tumors for precision cancer therapy. Rodrigo Dienstmann coordinates the Molecular Prescreening program of the institution, one of the largest in Europe, matching patients’ tumor molecular alterations with targeted therapies and immunotherapies in early clinical trials. In parallel, he collaborates with Sage Bionetworks on biomedical research projects that bring cognitive computing closer to the clinics.

Panellist
Stefan Fröhling
Acting Managing Director, National Center for Tumor Diseases (NCT), Germany

Stefan Fröhling heads the Division of Translational Medical Oncology at DKFZ and is Acting Managing Director of NCT Heidelberg. Stefan Fröhling’s research aims at providing patients with individually tailored cancer treatments. As part of the cross-institutional MASTER initiative of NCT Heidelberg/Dresden and the German Cancer Consortium, much of his work is centred on the development of tools for the comprehensive molecular and functional characterization of individual tumors, and the conception of clinical studies examining the efficacy of modern, molecularly targeted treatment approaches. In addition to his research in the precision oncology field, Stefan Fröhling particularly focuses on the biology of bone and soft-tissue sarcomas, as well as acute forms of leukaemia.

Panellist
Serena Scollen
Head of Department, European Life-Science Infrastructure For Biological Information (ELIXIR), United Kingdom

Serena Scollen is the Head of Human Genomics and Translational Data at ELIXIR, the European infrastructure for bioinformatics and life-science data, based in Hinxton, UK. Her vision is to ensure data that can be shared, will be shared responsibly. She works with scientists across Europe to establish standards and infrastructure to facilitate discoverability, access, sharing and analysis of genomics data, linked to other data types and at a scale that has not previously been achieved. Developing infrastructure will unleash new possibilities for genomics and health. Serena is a PI for the Innovative Medicine Initiative (IMI) FAIRplus project, an €8.3M collaboration that sets out to improve data sharing and reuse in life science research. Prior to joining ELIXIR, she was a Director within the Human Genetics and Computational Biomedicine group at Pfizer. In this role, she led and implemented a genetic and precision medicine strategy to support drug target selection and clinical programmes for the Pain and Sensory Disorders Research Unit. She was also a member of the ABPI Stratified Medicine Working Group. Earlier in her career, she worked within the Toxicogenomics group at GlaxoSmithKline. She gained postdoctoral experience at the University of Cambridge and Imperial College London and a PhD from the University of Cambridge, with a focus on the genetic susceptibility to disease.
Session III: The public health perspective

Chair

Tit Albreht
Head of Centre, National Institute of Public Health (NIJZ), Slovenia

Tit Albreht is a Senior Health Services and Health Systems Researcher at the National Institute of Public Health of Slovenia and specialises in Social Medicine. He received his PhD from the University of Amsterdam, focussing his research on the exploration of the health services nationally and internationally. His research interests include the performance of health systems, evidence-based health policy, health workforce planning and mobility and development of more efficient health care, especially in the field of non-communicable diseases. He is an associate professor of public health in the Medical Faculty in Ljubljana and a member of the Scientific Committee of the European Public Health Association. He is a reviewer in several international and national medical and public health scientific journals. Since 2006 he has been actively involved in the development of cancer policies at the European level – during the Slovenian presidency to the Council of the EU and later as coordinator of Joint Actions on cancer policies at the EU level – European Partnership for Action Against Cancer (EPAAC), Cancer Control (CanCon) and the most recent one, innovative Partnership for Action Against Cancer (iPAAC). He worked in a number of projects for policy support in different countries in South-eastern Europe, e.g. Bosnia and Herzegovina, Macedonia, Moldova, Montenegro, Serbia and also in Kazakhstan. These consultancies included: support in the development of legal acts in the area of public health, cancer control and public health intervention. All of these aimed at supporting the policies of the respective ministries of health.

Co-chair

Elke Anklam
Director, European Commission, Directorate-General Joint Research Centre, Belgium

Elke Anklam is a chemist, with specialisation in food, organic and radiation chemistry. After obtaining her PhD from the University Hamburg (Germany), she worked in various European Research Institutions and was a Teaching Professor at the Applied University of Fulda (Germany). Since 1991, she has been working at the European Commission’s Joint Research Centre (EC-JRC) where since 2006, she has been a Director at the JRC. Currently, she is the Director of the JRC-Geel site and Director of JRC Directorate F: Health, Consumers & Reference Material, located at the JRC-Geel and JRC-Ispra sites.
Marc Van den Bulcke obtained his PhD in sciences at the Laboratory of Genetics, University of Ghent (Belgium). He worked for about 7 years within the biotech industry at Plant Genetic Systems (now Bayer Crop Science) where he was involved in regulatory affairs and biotech product quality assurance. During this period, he gained real-life experience with global registration processes, accreditation, product quality control/assurance and business relationships. Since 2003, he works at the Scientific Institute of Public Health (Brussels, Belgium), now Sciensano, where he supported the establishment of the National Reference Laboratory on GMO detection. He worked for 3 years as a contract agent at the ‘Institute of Health and Consumer Protection’ at the Joint Research Centre of the European Commission where he coordinated policy-support research in molecular detection. Since 2013, he heads the Cancer Centre, a unit dedicated to the monitoring and evaluation of the activities on cancer control in Belgium. Current key activities of the Cancer Centre focus on the introduction of Next-Generation-Sequencing (NGS) in routine diagnostics in Belgium; on models to support the socio-professional reintegration of cancer patients; on screening and early detection (expert focus on cervical cancer) and on integrating patients, citizens and general practitioners views in the policy support activities of the Cancer Centre.

Thierry Philip is a Paediatrician and a specialist in bone marrow transplantation and immunology. Currently, he doubles as the Head of Curie Institute and President of the European Organisation of Cancer Institutes (OECI) and the Vice President of the Rhone Alpes Region and Lyon Metropole. Prior to this position, Thierry Philip was the Director of the Cancer Centre Lyon between 1989 and 2009.

Nazneen Rahman’s research integrates her medical and scientific expertise to identify and clinically implement human disease genes, with a major focus on cancer predisposition genes. She was Head of the Division of Genetics and Epidemiology at the Institute of Cancer Research, London and Head of Cancer Genetics at the Royal Marsden NHS Trust for 10 years, spanning to 2018. Nazneen Rahman was also Founder and Director of TGLclinical, a genetic testing lab using new sequencing and analytic technologies to deliver fast, affordable, cancer gene testing to the NHS. Nazneen Rahman has a strong commitment to open science and science communication and has garnered numerous awards, including a CBE. Nazneen Rahman is an AstraZeneca Non-Executive Director and chairs its Science Committee and is an independent healthcare consultant.
Panellist

Jacek Gronwald
Professor, Pomeranian Medical University (PMU), Poland

Jacek Gronwald is a professor at the Pomeranian Medical University, Poland and a specialist in gynaecology-obstetrics and clinical genetics. He is also a Regional Consultant in Clinical Genetics. From 2008 to 2016, he was the Dean of the Faculty of Medicine, Biotechnology and Laboratory Medicine at the Pomeranian Medical University (PMU). In 2008, he researched on Habilitation in the field of oncological genetics at the Pomeranian Medical University. Jacek Gronwald received his PhD in the field of oncological genetics from the Pomeranian Medical University, Poland in 1997. His research interests include cancer genetics, risk estimation, prevention and treatment of hereditary breast and ovarian cancer. Jacek Gronwald is an author and co-author of more than 250 papers mainly in the field of cancer genetics with IF of over 1500, and more than 9000 citations, including 43 h-index. He was born on 07 August 1965 in Koszalin, Poland.

Panellist

Jan-Ingvar Jönsson
Secretary General, Chair ICPeRMed, Swedish Research Council, Sweden

Jan-Ingvar Jönsson obtained his PhD from Max-Planck-Institute in Freiburg, Germany, in 1990. After working as a postdoc at a Hospital for Sick Children in Toronto, he established a career as an independent investigator in experimental hematology and cancer biology in Sweden in the mid-90’s. Jan-Ingvar is currently the Secretary-General for Medicine and Health at the Swedish Research Council. His main responsibilities are the development of high-quality research programs and funding schemes in medicine, life science and clinical research. He is also involved in different aspects of assessment and impact of research within the health care sector. Since 2016, Jan-Ingvar is vice-chair of Joint Programming Initiative on Antimicrobial Resistance (JPIAMR). He was elected the new Chair of International Consortium of Personalised Medicine in November 2018. He is also chair of the joint committee of the Nordic medical research councils (NOS-M).

Panellist

Laura van’t Veer
Director, University of California San Francisco (UCSF), Helen Diller Family Comprehensive Cancer Center, USA

Laura van ‘t Veer has a 25-year track record in molecular oncology research and over 280 scientific publications. She is Chair of the AACR Diagnostic Policy Committee and Chair of the Scientific Advisory Committee of the National Biomarker Development Alliance. She received the European Society Medical Oncology (ESMO) Lifetime Achievement Award for Translational Research in Breast Cancer in 2007, the 2014 European Union Prize for Women Innovators and the EPO European Inventor Award in 2015. In 2017, she received the European CanCer Organization (ECCO) Clinical Research Award. Last year, 2018, she was recognized by 24/7 Wall Street as one of ‘32 Amazing Women Inventors’. Laura van ‘t Veer holds a PhD in Medicine from the University of Leiden and has held several positions at the Cancer Center of Harvard Medical School, Massachusetts General Hospital in Boston and The Netherlands Cancer Institute where she headed the Diagnostic Oncology department. She is a Professor of Laboratory Medicine at UCSF since 2010. Laura van ‘t Veer is best known for her work that originated at the Netherlands Cancer Institute (NKI) on a 70-gene activity signature which distinguishes whether breast cancer has a low or high risk of recurrence. This was the basis for the MammaPrint® test (Agendia, co-founded by Dr van’t Veer). MammaPrint® obtained clearance from the FDA in 2007 and is included in many national and international guidelines.
Flash talks: A focus on genomics for rare diseases

Chair

Julia Wilson
Associate Director, Wellcome Trust Sanger Institute, United Kingdom

Julia builds and supports the relationships to support the strategic vision of the Sanger Institute. These activities range from interactions with the academic scientific community, commercial partners, funders and other key stakeholders. She increases awareness of the Sanger Institute’s research, explores new collaborations and areas of research. She works in the position of serving as a source of translational opportunities, raises awareness of the importance and impact of genomics research with government and policymakers, and facilitates the translation of genomics research into clinical practice at the Sanger Institute. Previously, Julia was Assistant Director of Research at Breakthrough Breast Cancer and Science Programme Manager at the World Cancer Research Fund. As a scientist, she was a post-doc at the Karolinska Institute in Sweden and then worked as a cancer researcher at Cancer Research UK and the Queen Mary University of London.

Speaker

Han Brunner
Head of Department, Radboud University Medical Center (Radboudumc), The Netherlands

Han Brunner is a full professor and Head of the Department of Human Genetics at Nijmegen University Hospital, and Maastricht University Medical Center, in the Netherlands. He served as board member of the Dutch, European (president in 2014–2015) and American Societies of Human Genetics. He was elected member of the Royal Netherlands Academy of Arts and Sciences, and the Academia Europaea. He is a Knight in the Order of the Dutch Lion since 2013. He received the King Faisal International Prize in Medicine 2016, the 2017 Carter medal of the British Clinical Genetics Society, and the Medal of Honour of the German Society of Human Genetics. Han Brunner discovered a large number of disease genes, and by applying cutting-technologies (genomic microarrays, exome sequencing, and whole genome sequencing) to understand genetic diseases. Much of his work is on neurodevelopmental conditions such as intellectual disability and abnormal behaviour. His work has established that in non-consanguineous populations, the major cause of intellectual disability lies in spontaneous new mutations.

Speaker

Daria Julkowska
Assistant Director, National Institute of Health and Medical Research (INSERM), France

Daria Julkowska is the Assistant Director of the Institute of Genetics, Genomics and Bioinformatics at INSERM. She is also the coordinator of the European Joint Programme Cofund on Rare Diseases (EJP RD) that brings together 130 institutions from 35 European, Associated countries and Canada. Previously, she was the Scientific Coordinator at ANR responsible for the management of several EU and international funding programmes, including the ERA-Net E-Rare. She developed and implemented a set of collaborations facilitating rare diseases research, including partnerships with EU Research Infrastructures and Patients’ Organizations. She has extensive knowledge of the European funding schemes and programmes. Since February 2017, she has been serving as Chair of the Funders Constituent Committee of IRDIRC.
Session IV:
The citizen and patient perspective

Chair
Peter Goodhand
Chief Executive Officer, Global Alliance for Genomics and Health, Canada

Peter Goodhand is a leader in the global health sector as a senior executive and board member. He played a key role in the creation of the Global Alliance for Genomics and Health (GA4GH) and was appointed as its founding Executive Director in 2014, and as Chief Executive Officer in 2018. From May 2016 to April 2018, he also served as the President of the Ontario Institute for Cancer Research (OICR). Prior to the GA4GH and OICR, he was the President and Chief Executive Officer of the Canadian Cancer Society, Canada’s largest health charity. Before joining the charitable sector, Goodhand had a 20 year career in the global medical technology industry, including strategic leadership roles with multinational healthcare companies such as American Cyanamid and Johnson & Johnson; Board Chair and President of Canada’s Medical Device Industry association (MEDEC); and as the founding Managing Director and then Board Chair of the Health Technology Exchange (HTX). Peter Goodhand is currently a member of the Occupational Cancer Research Centre Steering Committee, Co-chair of the Medical and Scientific Advisory Board of Global Genes, Co-chair of the International 100K+ Cohorts Consortium (IHCC), and a member of the of the Global Genomic Medicine Collaboration (G2MC) Steering Committee. He chaired the Government of Canada’s Expert working group on the future of medical isotope production, and was a member of the Canadian delegation to the UN summit on non-communicable diseases.

Co-chair
Ioana-Maria Gligor
Head of Unit, European Commission, Directorate-General for Health and Food Safety, Belgium

Ioana-Maria Gligor is Head of Unit of the European Reference Networks and Digital Health at the European Commission, in DG Health and Food Safety (SANTE). Before joining SANTE, Ioana was Deputy Head of Unit in the Secretariat General of the Commission and at DG Employment and Social Affairs (EMPL) and assistant to the Director General of DG EMPL. She began her career at the European Commission in the cabinet of Commissioner Orban. Before joining the European administration, she was the spokesperson for the Romanian Chief Negotiator with the EU. Her background is in EU affairs and political sciences, combined with an IT- high school acquired expertise.

Rapporteur
Rita Schmutzler
Head of Department, University Hospital Cologne, Germany

Rita Schmutzler is Director of the Center for Familial Breast and Ovarian Cancer, University Hospital Cologne and coordinator of the German Consortium for Hereditary Breast and Ovarian Cancer. She did her specialist training in Obstetrics and Gynecology and received her postdoctoral lecturing qualification (Habilitation) from the University of Bonn in 1998 and the Federal Licensing Examination (FLEX) USA in 1997. She is a member of numerous committees such as the expert panel of the National Cancer Plan at the Federal Ministry of Health, the S3 guideline committee on breast cancer and the committee of the gene diagnostic act at the Robert-Koch Institute, as well as a member of some scientific advisory boards e.g. at the Federal Institute for Drugs and Medical Devices (BfArM) and the Institute for Quality and Efficiency in Health Care (IQWiG). Her main research focus is to understand the hereditary basis of breast and ovarian cancer, identify genotype-phenotype correlations and translate these findings into risk-adjusted clinical prevention programs.
Keynote speaker

Bartha Knoppers
Director, McGill University, Canada

Bartha Maria Knoppers, PhD (Comparative Medical Law), is a Full Professor, Canada Research Chair in Law and Medicine and Director of the Centre of Genomics and Policy of the Faculty of Medicine at McGill University. She is Chair of the Ethics and Governance Committee of the International Cancer Genome Consortium (2009-2017), as well as the Ethics Advisory Panel of WADA (2015– ). She is Co-Chair of the Regulatory and Ethics Workstream of the Global Alliance for Genomics and Health (2013– ). From 2015-2016, she was a member of the Drafting Group for the Recommendation of the OECD Council on Health Data Governance and gave The Galton Lecture in November 2017. She holds four Doctorates Honoris Causa and is a Fellow of the American Association for the Advancement of Science (AAAS), the Hastings Center (bioethics), the Canadian Academy Health Sciences (CAHS), and, the Royal Society of Canada. She is also an Officer of the Order of Canada and of Quebec.

Keynote speaker

Francesco Florindi
Engagement Officer, Biobanking and Biomolecular Resources Research Infrastructure - European Research Infrastructure Consortium (BBMRI-ERIC), Austria

Francesco Florindi obtained a cum laude Master’s degree in International Relations and Diplomacy from the University of Trieste-Gorizia with a thesis on EU enlargement. In 2011, he started working for regional representatives, NGOs, and the European Commission’s Joint Research Centre (JRC) in Brussels. He went on to join the European Cancer Patient Coalition as Public Affairs Coordinator and became Head of EU Affairs in 2016. His experience working in healthcare dates back to 2013 when he joined the ECCO and SIOPE Public Affairs team. Francesco has worked on a number of key European issues such as data protection, health technology assessment, access to quality healthcare, eHealth/mHealth and patient advocacy. These experiences made him understand how patients and healthcare professionals can fruitfully collaborate at European and international level in order to reach common goals. Francesco Florindi is a fellow Young Gasteiner and a Member of the European Health Parliament. He is an Italian and speaks English and French.

Panellist

Jane Kaye
Director, Centre for Law, Health and Emerging Technologies (HeLEX), University of Oxford, United Kingdom

Jane Kaye is the Director of the Centre for Law, Health and Emerging Technologies (HeLEX) at the University of Oxford. She is also a part-time Professor at the University of Melbourne, Australia where she has a research team. She obtained her degrees from the Australian National University (BA); University of Melbourne (LLB); and University of Oxford (DPhil). She serves on several international expert committees and scientific advisory boards and is on the editorial boards of Law, Innovation and Technology, of the Journal of Law, Information and Science, of New Genetics & Society and of Life Sciences, Society and Policy. Her team are leading on the Dynamic Consent project, and she is one of the leaders in the ELSI 2.0 Global Initiative. Her research focuses on the relationships between law, ethics and the emerging technologies in health. The main focus of her research is on genomics with an emphasis on biobanks, privacy, data-sharing frameworks, global governance and translational research.
Panellist

Bettina Borisch
Professor of Social and Preventive Medicine, University of Geneva, Switzerland

Bettina Borisch is an MD and a Histopathologist, MPH and Fellow of the Royal College of Pathology (UK). Her scientific research work delves into neoplastic lesions of the immune system and breast cancer. Her interests also include community-based oncology, as well as health communication and global health. She is the Editor in Chief of “Pathobiology” and the Co-Editor of “Journal of Public Health Policy”. In addition to her academic work, she serves as the Director of the World Federation of Public Health Associations and holds positions at several Committees of Public Health-oriented institutions. She was president of Europa Donna – The European Breast Cancer Forum – and Founding President of the Swiss Forum of Europa Donna. She teaches at the University of Geneva, the Swiss School of Public Health and she also teaches patient support groups. She is an author of more than 120 scientific papers and 2 books.

Panellist

Jean-Pierre Hubaux
Professor, Ecole Polytechnique Fédérale de Lausanne (EPFL), Switzerland

Jean-Pierre Hubaux is a Full Professor at Ecole Polytechnique Fédérale de Lausanne (EPFL). Through his research, he contributes to laying the foundations and developing the tools for protecting privacy in tomorrow’s hyper-connected world. He has pioneered the areas of privacy and security in mobile/wireless networks and in genomics. He is the academic director of the recently created Center for Digital Trust (C4DT). He leads the ETH-funded project, Data Protection in Personalized Health (DPPH) and is a co-chair of the Data Security Work Stream of the Global Alliance for Genomics and Health (GA4GH). He is one of the seven commissioners of the Swiss FCC and is a Fellow at both IEEE (2008) and ACM (2010). He is among the most cited researchers in privacy protection and information security.

Panellist

Andres Metspalu
Head of Department, University of Tartu, Institute of Genomics, Estonia

Andres Metspalu obtained his MD in 1976, PhD in 1979 and did his postdoc at Colombia University and Yale University from 1981-1982. His main scientific interests are human genetics, genomics of complex diseases and population-based biobanks and application of the precision medicine in health care. From 1993-1994, he served as a visiting faculty staff at Baylor College of Medicine, Houston, and in 2000 he was a recipient of the International Visiting Senior Scientist Award offered by IARC, Lyon, France. From 1996 to 2008, Andres Metspalu was also the Head and founder of the Molecular Diagnostic Center of the Tartu University Hospital. Andres Metspalu was previously the president of the ESHG in 2006. In 2010, he was elected to the Estonian Academy of Sciences. He serves in several national and international committees and has received among other awards and honours the Order of the Estonian Red Cross 3rd Class and L’Ordre des Palmes Académiques from the Republic of France. From 2010 he was awarded Doctor Honoris Causa from Vilnius University.
Final keynote presentation

Chair
Guy Van den Eede
Head of Unit, European Commission, Directorate-General Joint Research Centre, Belgium

Guy Van den Eede is an agricultural engineer, specialized in plant molecular biology. He has been appointed at the Joint Research Centre of the European Commission in 1990 to provide technical support to the implementation of the EU policies on GMOs; later he has set up and managed the European Union Reference Laboratory for GMOs. In 2016, he was appointed Unit Head Knowledge for Health and Consumer Safety, covering life science-related files in the field of e.g. public health, food safety and security, toxicology, molecular biology and GMOs. Attention is given to anticipating knowledge needs and mapping knowledge gaps. The Unit has staff on both the Belgian site in Geel and the Italian site in Ispra.

Keynote speaker
Teri Manolio
Director, National Human Genome Research Institute, National Institutes of Health (NIH), USA

Teri Manolio directs the NHGRI’s Division of Genomic Medicine, where she leads programs to develop and implement genomic applications in clinical care. She came to NHGRI in 2005 to lead efforts in applying genomic technologies to population research, including the Electronic Medical Records and Genetics (eMERGE) Network, the NHGRI Genome-Wide Association Catalog, and the Clinical Genome (ClinGen) Resource. She continues to practice and teach internal medicine at the Walter Reed National Military Medical Center and the Uniformed Services University of the Health Sciences. She is the author of over 280 research publications and has research interests in genome-wide association studies of complex diseases, ethnic differences in disease risk, and incorporating genomic findings into clinical care.
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