European Commission

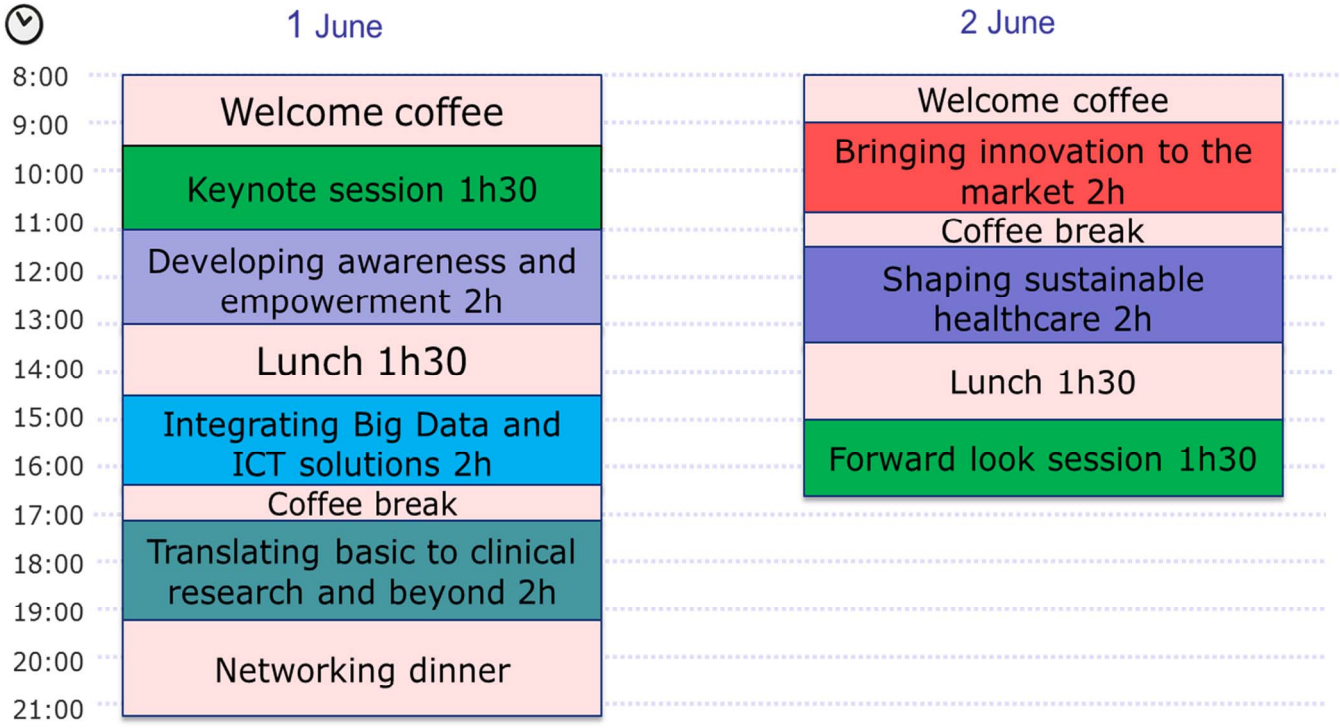
Personalised Medicine Conference

1 – 2 June 2016

Programme

Research and Innovation

Programme overview



Keynote session

1 June – 09:30 – 11:00

The Personalised Medicine Conference 2016 will explore personalised medicine through a research policy lens. It aims to showcase the current state-of-the-art in the area and explore research and innovation challenges for advancing the field to the benefit of patients and citizens.

The keynote session will give an introduction to the area and to the aims of the conference. It will also present a new initiative, involving funding and policy making organisations from Europe and beyond, called the International Consortium for Personalised Medicine (IC PerMed).

Video message	**Carlos Moedas,** Commissioner for Research, Science and Innovation
Chair: introduction	**Ruxandra Draghia-Akli**, Director of the Health Directorate, Directorate-General for Research and Innovation, European Commission
Opening statements	**Robert-Jan Smits**, Director-General for Research and Innovation, European Commission **Xavier Prats Monné**, Director-General for Health and Food Safety, European Commission **Lowri Evans**, Director-General for Internal Market, Industry, Entrepreneurship and SMEs, European Commission **Roberto Viola**, Director-General for Communications Networks, Content and Technology, European Commission
Keynote	**Paulo Lisboa,** Professor and Head of Department of Applied Mathematics, John Moores University, Liverpool **Anders Olauson** , Honorary President, European Patients' Forum

Challenge 1 - Developing awareness and Empowerment

1 June – 11:00 – 13:00

Personalised Medicine (PM) promises more effective prevention and prediction of diseases, and earlier and safer treatment. It will change our approach to public health and the way we care for patients in the future. However, to successfully implement PM, all stakeholders, including patients and healthcare professionals, need to be empowered and aware of its potential. In modern societies, health care systems are increasingly difficult to navigate and education systems too often fail to provide people with adequate skills to access, understand, assess and use information to improve their health. We need to improve knowledge and understanding of PM, encourage public engagement, and provide evidence that PM will benefit patients and society.

The aims of this session are to promote health literacy, citizen engagement and cultural changes in patient care and education of healthcare professionals. It will address patient's information and participation, responsible sharing of health data, curricula changes at academic health centres, and interaction between healthcare providers, patients and researchers. The overall objective is to facilitate the move towards a patient centric healthcare model by developing common principles and practices that enable sharing of patient-level data for research in a way that is ethical and acceptable to patients and the public.

Chair: Introduction	**Maria Judit Molnar**, Professor, Semmelweis University
Plenary talks Patient perspective on Personalised Medicine and how patient organisations empower the community Educational strategies in the era of PM - EIT-Health Educational Pillar The role of patients and healthcare provider in translational medicine The health economic impact of increasing patient engagement	 **Peter Kapitein**, Patient Advocate, Inspire2Live, Amsterdam **Rudi Westendorp,** University of Copenhagen **Jan Geissler**, Director, European Patients' Academy, Riemerling, Germany **Panos Kanavos**, Associate Professor, London School of Economics
Moderator: **Panel discussion** The effect of citizen and patient engagement in the health care	**Andrzej Rys**, Director of Health systems, medical products and innovation, Directorate-General for Health and Food Safety, European Commission **Panel:** **Jan Geissler**, Director, European Patients' Academy **Jan Hazelzet**, Chief medical information officer Professor in Health Care Qualify & Outcome Erasmus Medical Center, Rotterdam **Maired O'Driscoll**, Director, Strategy and Funding Health Research Board Ireland **György Németh**, Chief Medical Officer, Gedeon Richter Plc., Budapest **Antonija Poplas Susič**, Community Health Centre Ljubljana

Challenge 2 – Integrating Big Data and ICT solutions

1 June – 14:30 – 16:30

The datasets generated by large-scale sequencing and "omics" technologies are extensive and when combined with clinical, imaging, nutritional, life style and environmental exposure data they produce 'big data' of great value. These developments need further research efforts to fully develop their great potential, e.g. in improving disease stratification and paving the way of a more personalised medicine. In parallel, analytical methods, medical informatics and modelling approaches should be further developed to make use of individual datasets and support the decision-making process on all levels of health care. To translate these efforts into a real added value in practise, healthcare professionals and providers will need to strengthen their ICT proficiency. In parallel they will need suitable decision-support tools for their routine with an easy-to-use interface. With all of these efforts other research aspects should not be neglected, e.g. data security and ownership, privacy, ethical and social challenges and needs, patient's benefit, transparency as well as the practicability for the doctors, other providers and patients, the economic value and the sustainability of our healthcare systems. These developments will be the essential basis for more personalised approaches in diagnosis, treatment and prevention within the health care.

The session will investigate how 'big data' and related ICT solutions can be best used for the development and reasonable implementation of personalised medicine. The presentations will highlight examples of the data sets which are and will be available, how they could be processed, in which way they can support research and eventually how citizens/patients will benefit. The talks as well as moderated discussion with the speakers and the audience will highlight opportunities and restraints of these innovations for research, health systems as well as the personal and research data management.

Chair: Introduction	**Wolfgang Ballensiefen**, Project and Programme Manager, German Aerospace Centre
Moderator:	**Paul Timmers**, Director of Digital Society, Trust and Security Directorate, Directorate-General for Communications Networks, Content and Technology, European Commission
	Speakers:
The power of data	**Michal Rosen-Zvi**, Director of Healthcare informatics, IBM Research, Haifa Research Labs, Israel
Holistic data and citizen data ownership	**Ernst Hafen**, Head of Institute of Molecular Systems Biology, ETH Zurich
Options and opportunities in health data science	**Andrew Morris**, Director of the Usher Institute of Population Health Sciences and Informatics, University of Edinburgh
Tech and the Human Touch	**Mitzi László**, Entrepreneur and Co-Founder of the Innit Foundation, Amsterdam
Interpreting Genome Data for Personalised Medicine	**Janet Thornton**, Senior Scientist and Director Emeritus at the European Bioinformatics Institute (EBI), European Molecular Biology Laboratory (EMBL), Hinxton
(Big) Health Data for Research	**Vilo Jaak**, Head of the Institute of Computer Science, University of Tartu
Discussion:	Moderated discussion with the speakers and the audience

Challenge 3 – Translating basic to clinical research and beyond

1 June – 17:00 – 19:00

In order for personalised medicine to reach its anticipated impact on human health and wellbeing, the collaboration and communication across the continuum of research is required. This starts with the establishment of cohorts of healthy people and patients in standardised platforms, which integrate all 'omics' data as well as complex information including life history, life style, environment, etc. The overall challenge is the efficient cross-talk of basic researchers, clinicians and public health experts during the long-term follow-up of healthy individuals and patients, which is a prerequisite for understanding the effect of genetic variations in diseases and for discovering robust biomarkers. The development of new methods, tools and services for preclinical and clinical research in personalized medicine with a focus on data integration and security is also required.

The talks will cover the research efforts that need to be done by researchers and clinicians to make personalized medicine possible in most medical fields. Success stories will also be presented. The panel discussion will tackle the ways of addressing these challenges in the most effective ways, especially from the point of view of funding policies.

Chairs: Introduction	**Hemma Bauer**, Austrian Ministry of Science, Research and Economy, Vienna **Daria Julkowska**, French National Research Agency, Paris **Natalia Martin**, French National Research Agency, Paris
Keynote talk Challenges of translating basic to clinical research in personalised medicine	**Nicholas Katsanis**, Director, Center for Human Disease Modeling, Duke University, Durham, NC
TED talks From retrospective patient cohorts into prospective patient cohorts to clinical validation Designing clinical trials for personalised medicine Stratified medicine in primary biliary cirrhosis: understanding disease mechanisms and targeting therapies	 **Markus Perola**, Research Professor, National Institute for Health and Welfare, Helsinki **Sabine Tejpar**, University Hospital Leuven **Dave Jones**, Professor, Newcastle University
Moderator: **Panel discussion** Exchange and dissemination of research and outcomes in both directions between basic research and clinicians, as well as the interdisciplinary collaboration is key to further enhance and promote personalised medicine. What are the best models of cross-sectorial	**Ruxandra Draghia-Akli**, Director of the Health Directorate, Directorate-General for Research and Innovation, European Commission **Panel:** **Jan-Eric Litton**, Director General, Biobanking and Biomolecular Resources Research Infrastructure, Stockholm **Fabien Calvo**, Chief Scientific Officer, Cancer

collaborations? European health research infrastructures (BBMRI, ELIXIR, EATRIS, EuroBioImaging, etc.) play a central role in providing access to samples, data and infrastructure. An important task is to standardize procedures, data sets and analyses in order to improve quality of services and research. How to improve the visibility and promote the use of existing research infrastructures within the basic and clinical research community? Biomarker validation is the process with low success rate. How to define the criteria for biomarker validation and how to ensure they are used? How to address the emerging challenge of validating biomarkers to be used for health promotion and disease prevention?	Core Europe, Paris **Astrid Vicente**, Principal Investigator Head, Department of Health promotion and Non Communicable Disease Prevention National Health Institute Doutor Ricardo Jorge, Lisbon **Marc Schiltz**, Secretary General and Executive Head, National Research Fund of Luxembourg **Christine Mayer-Nicolai**, Head Global Regulatory & Scientific Policy (GRASP), Merck KGaA, Darmstadt **Jacques S. Beckmann**, Head of Clinical Bioinformatics at SIB Swiss Institute of Bioinformatics, Lausanne

Challenge 4 – Bringing innovation to the market

2 June – 09:00 – 11:00

Personalised Medicine has the potential to radically change the way citizens learn and care about their health, both in terms of disease prevention and management. However, bringing innovation to the market has several challenges which need to be addressed. It is moreover important to understand the drivers and enablers behind innovation so that they can be fully exploited. These topics could be further explored through research. The outcome of such research could for example help to inform new market policies, business models and regulatory frameworks.

This session will look at challenges and drivers for bringing innovative personalised medicine approaches to the market. It will address a number of aspects, including how a better understanding of value can drive innovation and what the role of regulators should be. It will also look at examples of how early dialogue between all players involved in the innovation ecosystem can help getting new treatments to the market faster. Since personalised medicine is a patient centred approach, the session will moreover ask what role patients play in getting innovation to the market.

Chair: Introduction	**Peter Høngaard Andersen**, Chief Executive Officer, Innovation Fund Denmark, Copenhagen
Keynote talk Bringing innovative personalised medicine approaches to the market: lessons learned and future challenges	**Peter Høngaard Andersen**, Chief Executive Officer, Innovation Fund Denmark, Copenhagen
Moderator:	**Pierre Meulien**, Executive Director, Innovative Medicines Initiative (IMI)
Panel discussion Drivers and challenges in getting personalised medicine to the market **Topics to be discussed**	**Panel:**
Cancer - barriers and drivers for innovation	**Bianca Wittig,** Medical Lead, Region North, Global Medical Affairs, AbbVie, Wiesbaden
Diseases of the Central Nervous System - challenges for personalised treatments	**Raj Long**, Senior Advisor, Integrated Delivery - Global Health Bill & Melinda Gates Foundation, London
Regulatory perspective and early dialogue	**Marisa Papaluca**, Senior Scientific Advisor, European Medicines Agency, London
Prediction and prevention - driving innovation	**Brian O'Connor**, Chairperson, European Connected Health Alliance, Belfast
The patient's role - partner and leader	**Virginie Hivert**, Therapeutic Development Director, EURORDIS - Rare Diseases Europe, Paris
Personalised therapies and diagnostics - the challenges to market entry	**Catherine Larue**, Chief Executive Officer , Luxembourg Institute of Health

Challenge 5 – Shaping sustainable healthcare

2 June – 11:30 – 13:30

Personalised medicine presents both opportunities and challenges for health care systems. By making sure that only the patients who will benefit from treatments receive them, it could help contain costs. By focusing on prediction and prevention, it could also help to reduce healthcare spending in the long term. However targeted medicines are often very expensive and can strain the budgets of health care systems. Today, we lack a comprehensive framework for determining the value of interventions for health care systems and how to ensure the sustainability of these systems in view of new approaches for preventing, diagnosing and treating disease. Furthermore, it is not yet clear how personalised medicine approaches can best be put into practice in healthcare systems.

This session will look at what hurdles must be overcome to implement personalised medicine in health care systems in a sustainable manner. Examples of personalised medicine approaches currently being applied will be presented and opportunities for collaboration between academia, industry and health care providers will be explored. Furthermore, health economic research and health system management and social collaboration will be discussed.

Chair: Introduction	**Gaetano Guglielmi**, Deputy Director General, General Directorate for Research and Innovation in Healthcare, Italian ministry of health, Rome
Keynote talks: A framework on impact of PM in National Health Systems Experience of implementing personalised medicine approaches in EU countries	 **Walter Ricciardi**, President, Istituto Superiore di Sanita, Rome **Andres Metspalu**, Director, Estonian Genome Center at the University of Tartu **Frédérique Nowak**, Institut national du cancer (INCa), Paris
Moderator: **Round table discussion** Health economic research Opportunity for collaborative research and collaboration between academia and industry and health providers for sustainability Health system management research and social collaboration	**Mary Harney**, former Irish health Minister and Deputy Prime Minister **Panel:** **Maarten J. IJzerman**, Professor, University of Twente, Enschede **Varda Shalev**, Director, Institute for Health Research and Innovation, Maccabi Health Systems, Tel Aviv **Maria Aguirre Rueda**, Director for Health Research and Innovation, Basque Government **Roberto Salgado**, GasthuisZusters Antwerpen Hospitals, Institut Jules Bordet, Brussels **Matthias Perleth**, Gemeinsamer Bundesausschuss, Berlin
Final remarks:	**Walter Ricciardi**, President, Istituto Superiore di Sanita, Rome

Forward look session

15:00 – 16:30

The Forward Look session will be a panel discussion moderated by Brussels-based journalist Peter O'Donnell. The panellists and moderator will take stock of two days of information-rich exchanges and use the information to look forward at what research and innovation actions should be prioritised to progress the area of personalised medicine in Europe and beyond.

Moderator: **Round table summary discussion**	**Peter O'Donnell**, Journalist, Brussels **Panel:** **Antoni Andreu**, Director General of Research and Innovation of the Regional Ministry of Health of Catalonia, Barcelona **Maria Beatriz Da Silva Lima**, Chair IMI Scientific Committee, Universidade de Lisboa **Ruxandra Draghia-Akli**, Director of the Health Directorate, Directorate-General for Research and Innovation, European Commission **Ilias Iakovidis**, Acting Head of Unit of the Digital Social Platforms Unit, Directorate-General for Communications Networks, Content and Technology, European Commission **Ildikó Horváth** – Vice Chair Scientific panel for Health and Semmelweis University, Budapest