



B1MG Stakeholders Meeting Agenda Wednesday, 21st October 2020

Beyond 1 Million Genomes (B1MG) Stakeholders VIRTUAL Meeting.

08:00 - 16:00 BST/09:00 - 16:00 CET

Registration:

<https://attendee.gotowebinar.com/register/4335341772837182988>

Overview

The aim of Beyond 1 Million Genomes (B1MG) is establish the support and coordination structure for the European 1+ Million Genomes initiative (1+MG), which is based upon the commitment of 22 European Member States and Norway that have signed the Declaration 'Towards access to at least 1 million sequenced genomes in the EU by 2022'. Collectively, these countries have committed to establish a cross-border federated network of national genome collections associated with phenotypic data, consented for advancing health and medicine practices across Europe. Europe is uniquely placed to take on this challenge and position itself as a global leader in this field.

Objective of Meeting

One of essential aims of the project is to collaborate with an array of international initiatives and consult a range of stakeholders to support the creation of a pan-European genome-based health data infrastructure, encompassing data quality and exchange standards, access protocols and legal guidance. The aim is to provide concrete guidance on the steps required to implement personalised medicine, a healthcare approach that takes into account a person's genetic make-up, at local, regional and national-scale.

As such, the purpose is to set the framework for this engagement through the lense of the Working Packages which include sessions that address the topics of: Session 1: Setting the Framework for Cooperation; Session II: Ethics, Legal, Societal Impact; Session III: Standards & Quality Guidelines; Session IV: Federated Secure Cross-border Technical Infrastructure; Session V: Session V: Delivering Personalised Medicine cross-borders: Implementation in Healthcare systems and Societal Impact and finally, Session VI: Communication, Governance and Sustainability

Target Audience

Attendees will be drawn from key stakeholders from the community whose interaction will create a cross-sectoral, highly relevant and dynamic discussion forum. These participants will include healthcare professionals, decision makers, patient organisations, and European umbrella organizations representing interest groups and associations actively engaged in the field of Personalised Medicine. Each session will comprise panel discussions as well as Q&A sessions to allow best possible involvement of all participants

Expected outcomes

It is absolutely clear that it is necessary to formulate a personalised healthcare-centred strategy involving decision makers and regulators in the arena of public health, to enable the EU and Member States to contribute to integrating personalised medicine into clinical practice while enabling much-greater access for patients. In order to provide a clear focus and to devote sufficient space to analysis, discussions during the conference will concentrate on how

- to assess and address obstacles to the integration of personalised medicine into Europe's healthcare systems
- to identify best practices and their added value
- to outline the potential benefits of personalised medicine on public health and its impact on policy making



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We sincerely hope you will be able to join us for this vital, high-level stakeholder virtual gathering on 21 October, and with that in mind please find the agenda below.

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09:00 09:10	Opening B1MG Stakeholders Meeting	
09:10	<p>Welcome and Setting the Scene: Denis Horgan, WP 1 Leader (5 minutes) & Ruben Kok, Director, Dutch Techcentre for Life Science (DTL) (5 minutes)</p>	
09:20 10:25	<p><u>Session I: Setting the Framework for Cooperation</u></p> <p>Chair: Denis Horgan, WP 1 Leader</p> <p><u>Member States Alignment and I+MG</u> Speaker: Ruben Kok, Director, Dutch Techcentre for Life Science (DTL) (10 minutes)</p> <p><u>Stakeholder Portal: Gateway to the Alliance</u> Speaker: Toni Andreu, Scientific Director, EATRIS (5 minutes)</p> <p><u>Stakeholder Alignment: Stakeholder Coordination</u> Speaker: Jan Korbel, Head of Data Science, EMBL Heidelberg (5 minutes)</p> <p><u>Discussion with Stakeholders:</u> Daria Julkowska, Coordinator EJP RD. (5 Minutes) (Confirmed) Andrew Biankin, Executive Director, International Cancer Genome Consortium (5 Minutes) (Confirmed) Marcus Guardian, Chief Operating Officer, EUnetHTA. (5 minutes) Benjamin Horbach, Health Systems Strategy Leader -- Personalised Healthcare (PHC) (5 minutes) (Confirmed) Tit Albreht, Joint Action on Cancer (5 minutes) (Confirmed) Francesco Florindi, Strategy and Partnership Manager, BBMRI-ERIC (5 minutes) (Confirmed) Mario Romao, Global Director – Health & Data Policy, Intel (5 minutes)</p> <p>Q&A (10 minutes)</p>	
10:25 11:05	<p><u>Session II: Ethics, Legal, Societal Impact</u></p> <p>Chair: Regina Becker, Research Scientist, Luxembourg Centre for Systems Biomedicine, UNILU</p> <p><u>Setting the Scene by WP Leads:</u> Jasper Bovenberg, founder and director of the Legal Pathways (5 minutes)</p> <p><u>Discussion with Stakeholder (25 Minutes)</u> Virginie Bros-Facer, Scientific Director, EURORDIS (5 minutes) (Confirmed) Kathi Apostolidis, President European Cancer Patient Coalition (ECPC). (5 minutes) (Confirmed)</p>	



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	<p>Anna Middleton, Wellcome Trust Sanger Institute; "Your DNA, Your Say" Project (5 minutes) (Confirmed)</p> <p>Hans Peter Dauben, Director/Head, DAHTA – German Agency for Health Technology Assessment (5 minutes) (Confirmed)</p> <p>Dirk Lanzerath, Secretary General, EUREC (5 minutes) (Confirmed)</p> <p>Q&A (10 minutes)</p>	
<p>11:05 11:20</p>	<p>Coffee Break</p>	
<p>11:20 12:00</p>	<p><u>Session III: Standards & Quality Guidelines</u></p> <p>Chair: Jeroen Belien, Associate Professor, VU University Medical Centre</p> <p><u>Setting the Scene by WP Leads:</u> Andres Metspaltu, full professor of Biotechnology and Head of the Estonian Biobank in the Institute of Genomics of the University of Tartu (5 minutes)</p> <p><u>Discussion with Stakeholder (25 minutes)</u> Yves Verboven, Director, Market Access & Economic Policies, MedTech (5 Minutes) (Confirmed) David Marrow, Senior Scientific Programme Manager, EATRIS (Confirmed) Ana Rath, Director, ORPHANET (5 minutes) (Confirmed) Gennaro Ciliberto, Scientific Director IRCCS, Istituto Tumori Regina Elena Rome (5 minutes) (confirmed) Carin Smand, Executive Director, European Hematology Association (5 minutes) (confirmed)</p> <p>Q&A (10 minutes)</p>	
<p>12:00 12:15</p>	<p>Coffee Break</p>	
<p>12:15 13:00</p>	<p><u>Session IV: Federated Secure Cross-border Technical Infrastructure</u></p> <p>Chair: Tommi Nyrönen, Programme Director, CSC – IT Center for Science</p> <p><u>Setting the Scene by WP Leads:</u> Ilkka Lappalainen, Biomedical Service Development Manager, CSC – IT Center for Science (5 minutes) Bengt Persson, Professor at Department of Cell and Molecular Biology, Computational Biology and Bioinformatics, University of Uppsala (UU) (5 minutes) Sergi Beltran, Head of the Bioinformatics Unit, CNAG-CRG (5 minutes)</p> <p><u>Discussion with Stakeholder (20 Minutes)</u> Mark Caulfield, Chief Scientist, Genomics England (5 minutes) (Confirmed) Thomas Keane, Team Leader, EGA and Archive Infrastructure, EMBL-EBI (5 minutes) (Confirmed) Alfonso Valencia, Group Leader and Director of the Life Sciences Department of the Barcelona Supercomputing Center (5 minutes) (Confirmed) Birute Tumiene, Clinical geneticist, Vilnius University Hospital Santaros Clinics (5 minutes) (Confirmed)</p> <p>Q&A (10 minutes)</p>	



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13:00 13:50	Lunch break	
13:50 14:25	<p><u>Session V: Delivering Personalised Medicine cross-borders: Implementation in Healthcare systems and Societal Impact</u></p> <p>Chair: Serena Scollen, <i>Head of Human Genomics and Translational Data, ELIXIR Hub</i></p> <p><u>Setting the Scene by WP Leads:</u> Astrid Vicente, <i>Coordinator of the Department of Health Promotion and Prevention of Non-communicable Diseases Principal Investigator, Instituto Nacional de Saude Doutor Ricardo Jorge (INSA) (5 minutes)</i></p> <p><u>Discussion with Stakeholder (20 Minutes)</u> Ejner Moltzen, <i>Chair, ICPeMed (5 minutes) (Confirmed)</i> Marco Greco, <i>President, European Patient's Forum (5 minutes)</i> Jasmina Koeva, <i>Chair, Bulgarian Alliance for Personalised and Precision Medicine (5 minutes) (Confirmed)</i> Dr Joaquin Mateo, <i>Chair of the European Society for Medical Oncology's (ESMO) Translational Research and Precision Medicine Working Group; Principal Investigator, Prostate Cancer Translational Research Group, Vall d'Hebron Institute of Oncology (VHIO) (5 Minutes) (Confirmed)</i></p> <p><i>Q&A (10 minutes)</i></p>	
14:25 14:40	Coffee Break	
14:40 15:20	<p><u>Session VI: Communication, Governance and Sustainability</u></p> <p><u>Chair: Juan Arenas</u>, <i>Head of Project Management Unit, ELIXIR Hub</i></p> <p>Juan Arenas, <i>Head of Project Management Unit, ELIXIR Hub (5 minutes)</i> Esther Rodriguez, <i>European Project Office Coordinator, Research Infrastructures NCP, Instituto de Salud Carlos III (ISCIII) (5 minutes)</i></p> <p><u>Discussion with Stakeholder (20 Minutes)</u> Stefania Boccia, <i>full professor of Hygiene and Public Health at the Università Cattolica del Sacro Cuore (UCSC) (5 minutes) (Confirmed)</i> Tuula Helander, <i>Ministry of Social Affairs and Health, Finland (5 minutes)</i> Richard Rosenquist Brandell, <i>Professor of Clinical Genetics, Karolinska Institutet (5 minutes) (Confirmed)</i> Eva Suhren, <i>VDI-VDE-IT (5 minutes)</i></p> <p><i>Q&A (10 minutes)</i></p>	
15:20 15:40	<p>Conclusions: Outcomes from today & Next Steps: Chair: D. Horgan, Executive Director, EAPM</p> <p><u>Member States Alignment and I+MG</u> Speaker: Ruben Kok, <i>Director, Dutch Techcentre for Life Science (DTL) (10 minutes)</i></p>	



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	<p><u>Stakeholder Portal: Gateway to the Alliance</u> Speaker: Toni Andreu, <i>Scientific Director, EATRIS (5 minutes)</i></p> <p><u>Stakeholder Alignment: Stakeholder Coordination</u> Jan Korbel, <i>Head of Data Science, EMBL Heidelberg (5 minutes)</i></p>	
16:00	<p>Concluding Remarks: Stakeholder Declaration Denis Horgan, WP 1 Leader (10 minutes) & Ruben Kok, <i>Director, Dutch Techcentre for Life Science (DTL) (10 minutes)</i></p>	

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