OECD Workshop
“Collaborative platforms for personalized health: realizing the potential of genomics and biobanks”
17-18 September 2019
Vinnova – Swedish Governmental Agency for Innovation Systems, Stockholm, Sweden

The purpose of the Workshop is to re-examine the institutional arrangements and business models underlying collaborative platforms in genomics and biobanks for personalized health. It will pool ideas and best practices from representatives of major national and international platforms in genomics and biobanks, and from a diverse range of experts at the triple interface between IP and data policy, business, health systems.

National and international biobanks and genomic initiatives are at the heart of the development and use of personalized medicine. Co-creative processes across public and private actors are supporting transformative change in research and health-care while simultaneously addressing issues around implementation, sustainability, and wider adoption. Government investment and cross-sectoral collaboration have been key drivers for the translation of shared R&D assets and common-pool resources such as genomic, and phenotypic data as well as collections of bio-specimens into clinical practice.

Key policy questions to be addressed at the Workshop:
1. What are the goals, best practices, and standards in IP licensing, data ownership and sharing of major genomic platforms and biobanks?
2. What are the approaches to fund and resource collaborative platforms for personalized medicine? What can be learnt from the most successful, and sustainable business models in both public and private sectors?
3. What are the options to uphold the social contract and value sharing among funders, innovators, and society?

Workshop Agenda

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<th>First half-day</th>
<th>Tuesday, 17 September 2019</th>
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<tr>
<td>11:00-12:15</td>
<td>Registration &amp; light lunch</td>
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<td>Vinnova, Swedish Governmental Agency for Innovation Systems, Mäster Samuelsgatan 56, Stockholm</td>
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<td>12:15-12:25</td>
<td>Welcome messages &amp; introduction to workshop</td>
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<td>Workshop Moderator: Dr David Winickoff, Senior Policy Analyst, Secretary, Working Party on Bio-, Nano- and Converging Technologies (BNCT), Science and Technology Policy Division, OECD, Paris, France</td>
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<td>12:25-12:55</td>
<td>Keynote</td>
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<td>Dr Jenni Nordborg, Director, National Coordinator Life Sciences, Office for Life Sciences, Government Offices of Sweden, Stockholm, Sweden</td>
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12:55-15:00 ► **Session 1**

**Connecting genomic data and biobanks with human health – realizing digital opportunities in personalized medicine**

The opening Session will provide insights and experiences from genomic research, integrated biobanks, and new approaches to accelerate the translation of big health data into personalized medicines and clinical practice.

Chair: Dr Shelley Epstein, Vice President, Corporate and Public Affairs, Imagia, Montreal, Canada

Rapporteur: Ms Helen Stevens, Genomics Clinical Science Adviser from the Centre for Genomics Research, AstraZeneca, UK

Panellists:

- Dr Maria Chatzou, CEO & Co-Founder, Lifebit, London, UK
- Dr Stefan Foser, Head of Medical Market Development, F. Hoffmann-La Roche, Basel, Switzerland
- Dr Peter Frommolt, Global Head of Bioinformatics and Data Management at Indivumed Group (Indivumed GmbH), CECAD Building, Köln, Germany
- Dr Dianne Nicol, Professor of Law, Director of the Centre for Law and Genetics, Faculty of Law University of Tasmania, Australia
- Dr Mike Vella, Deep learning and genomics engineer, NVIDIA, UK

Discussion questions:

1. What will be the next breakthroughs in genomic research and deep medicine that drive the delivery of novel, innovative diagnostics and therapies?
2. What is the potential of digital technology for integrating clinical/health data and genomic big data to implement precision medicine?
3. What are the key obstacles for companies in genomics and product development? How can a better integration of companies into large national programmes help?

15:00-15:20 ► **Coffee break**

15:20-15:40 ► **Presentation**

Dr Mark Bale, Head of Science Partnerships, Genomics England; Dr Nick Maltby, General Counsel, Company Secretary and Data Protection Officer, Genomics England

15:40-18:00 ► **Session 2**

**Governance in light of international collaboration: addressing real-world issues in data sharing**

The second Session will elaborate on governance issues in genomic and health data sharing internationally and across the public and private sectors: lack of clarity, legal barriers, regulatory uncertainty.

Chair: Dr Jane Kaye, Professor of Health, Law and Policy & Director, Centre for Health, Law and Emerging Technologies (HeLEX), Oxford, UK

Rapporteur: Dr Naomi Hawkins, Associate Professor, University of Exeter Law School, Amory Building, Rennes Drive, Exeter, UK

Panellists:

- Dr Emilia Niemiec, Post-doc, Centre for Research Ethics & Bioethics, Upsala University, Sweden
- Dr Elettra Ronchi, Senior Policy Analyst, Committee on Digital Economy Policy, Directorate for Science, Technology and Innovation, OECD, Paris, France
- Dr Irene Schlünder, Wissenschaftliche Referentin Recht & Bioethik, TMF – Technologie- und Methodenplattform für die vernetzte medizinische Forschung e.V., Germany
- Dr Sirpa Soini, Director of the THL Biobank, Helsinki, Finland
- Dr Evert-Ben van Veen, Partner, Senior Consultant, MedLawconsult, Den Haag, The Netherlands
Discussion questions:

1. What are the options for closer integration and alignment with other national and international infrastructures through the development of agreed standards, protocols, and ethical and legal frameworks for data and bio-specimen collection and sharing?

2. How can collaborative platforms in personalized health support interdisciplinary and multicultural debates about the ethical, legal, and societal implications of data sharing?

3. How to balance the need of increased data fluidity with higher demands on data privacy?

18:00-19:30 ► Reception

Second half-day Wednesday, 18 September 2019

09:00-09:30 ► Keynote
Mr Peter Goodhand, Chief Executive Officer, Global Alliance for Genomics and Health (GA4GH), Canada

09:30-11:30 ► Session 3
Business models of genomic platforms and biobanks

The third Session will focus on successful, and sustainable business models in genomics and biobanks. Collaborative platforms could offer an approach to sustainable innovation by forming a bridge between profit-driven investment, funding models that delink profits from R&D, and upholding the social contract. Participants will pool experiences around the dynamics of collaboration and contractual agreements: novel funding models and IP licensing practices to address population –omics challenges.

Chair: Dr Richard Rosenquist Brandell, Project leader Genomic Medicine Sweden, Professor of Clinical Genetics, Dept of Molecular Medicine and Surgery, Karolinska Institutet, Sweden

Rapporteur: Dr Kathy Liddell, Director Centre for Law, Medicine and Life Sciences; University Senior Lecturer, University of Cambridge, UK

Panellists:

- Dr Inês Amado, Deputy Director General of the Health Technologies Institute at INSERM, Deputy director of the Plan France Medicine Genomic, Paris, France
- Dr Christian Jonasson, Senior Researcher, HUNT Research Center and the K. G. Jebsen Center for Genetic Epidemiology, Dept of Public Health, Faculty of Medicine, Norwegian University of Science and Technology (NTNU), Biobank Norway, Norway
- Dr Paul Jones, Director, Population Genomics, Illumina, London, Greater London, UK
- Dr Lotta Lungqvist, CEO GE Nordic & Testa center, former Head of R&D Life Sciences, GE Healthcare, Sweden
- Dr Jessica Nordlund, Facility Director, NGI Uppsala (SNP&SEQ Technology Platform), Dept. of Medical Sciences, Uppsala University, National Genomics Infrastructure (NGI), Sweden
- Dr Cornelia Specht, Geschäftsführung, German Biobank Node, Berlin, Germany

Discussion questions:

1. How to support collaborative and responsible research and product development – in line with public interests and business needs?

2. How does the growing importance of health data and biobanks as currencies of innovation affect traditional patenting and commercialization strategies? Should practices of monetizing health data be allowed and under which conditions?

3. How to define barriers to investment, translation, and access in more granularity?
11:30-12:30 ➤ Session 4

Mission-oriented innovation strategies

The fourth Session explores the potential of mission-oriented research and innovation policies (MOIPs) in genomics and biobanks to make significant progress in personalized health. These bold initiatives are result-oriented and wide-spanning coordinated sets of policy measures supporting the whole innovation chain to achieve common ambitious objectives.

Chair: Dr Philippe Larrue, Policy Analyst, Science and Technology Policy Division, Directorate for Science, Technology and Innovation, OECD, Paris, France

Rapporteur: Dr Jenni Nordborg, Director, National Coordinator Life Sciences, Office for Life Sciences, Government Offices of Sweden, Stockholm, Sweden

Panellists:
- Dr Björn Arvidsson, Managing Director, Uppsala BIO, Sweden
- Dr Julio Celis, Associated Scientific Director of the Danish Cancer Society Research Center, Copenhagen, Denmark
- Dr Francesco Florindi, Strategy & Partnership Manager, BBMRI-ERIC, Neue Stiftungtalstrasse, Graz, Austria
- Dr Göran Marklund, Director, vice-GD, Sweden

Discussion questions:
1. Is there a need for a more mission-oriented – i.e. more directional and coordinated – policy approach in genomics and biobanks?
2. What can be learned from MOIPs (in theory and other areas of practice) regarding the design, governance, and business models of genomics and biobanks?

12:30-13:00 ➤ Summary by Session Rapporteurs

13:00-13:30 ➤ Light lunch and end of workshop

Contact: Dr Hermann Garden, Policy Analyst Health Innovation, Science and Technology Policy Division, Directorate for Science, Technology and Innovation, OECD, Paris, France (hermann.garden@oecd.org)