



DANISH NATIONAL
GENOME CENTER

novo nordisk
foundation

Personalised medicine and beyond: Supporting a data- driven healthcare system

Programme

Programme

Monday, 8 September 2025

8.00-8.45

Registration and breakfast

8.45-8.50

Welcome

by Bettina Lundgren, Center Director, Danish National Genome Center, Denmark

8.50-9.00

Personalised Medicine: Political Priorities in Denmark and Europe

by Sophie Løhde, Minister for Interior and Health, Denmark

Session 1: From Genomic Data to Personalised Medicine: Where Are We and What Is the Goal?

Moderator: Bettina Lundgren, Center Director, Danish National Genome Center, Denmark

9.00-9.10

Implementing WGS in Healthcare – Insights from the Danish National Genome Center

by Bettina Lundgren, Center Director, Danish National Genome Center, Denmark

9.10-9.15

The Treatment of the Future Is Tailored to the Individual Patient

Film with a patient perspective produced by the Danish National Genome Center

9.15-9.45

Dream Scenarios for a Data-Driven Healthcare System

- **Clinician's Perspective: Putting the Patient at the Center of Clinical Care**

by Britt Elmedal Laursen, Consultant, Associate Professor, Department of Molecular Medicine & Department of Oncology, Aarhus University Hospital, Institute of Biomedicine, Pharmacology & Precision Medicine, Aarhus University, Denmark

- **Researcher's Perspective: Unleashing the Potential of Danish Health Data for Precision Healthcare**
by Sisse Rye Ostrowski, Professor, Consultant, Head of Research, Head of Studies for Master's programme in personalised medicine, Rigshospitalet and University of Copenhagen, Denmark
- **Industrial Perspective: Conditions for an Effective Implementation of Personalised Medicine**
by Ida Sofie Jensen, CEO, Danish Association of the Pharmaceutical Industry (Lif), Denmark

9.45-10.30

Barriers and Strategies for Designing a Data-Driven Healthcare System

- **Digital Health Denmark and the Vision for Better Use of Healthcare Data**
by Thomas Fredenslund, Director General, and Jacob Hartmann Sørensen, Head of Programme, Danish Health Data Authority, Denmark
- **Data-Driven Healthcare: Experience of the NHS Genomic Medicine Service**
by Dame Sue Hill, Professor, Chief Scientific Officer for England & Senior Responsible Officer for Genomics in the NHS, NHS England, United Kingdom
- **Data-Driven Personalised Medicine in Sweden**
by Richard Rosenquist Brandell, Professor, Clinical Genetics at Department of Molecular Medicine and Surgery, Karolinska Institutet, Sweden
- **Building a Data-Driven Healthcare System: Challenges, Strategies, and Insights from the Health Data Hub**
by Emmanuel Bacry, Scientific Director, Health Data Hub, France

10.30-10.40

Summing Up the Common European Challenges

by Stinus Lindgreen, Researcher and Member of Parliament, Social Liberal Party, Denmark

10.40-11.00

Q&A

Speakers from "Barriers and Strategies for Designing a Data-Driven Healthcare System" and "Summing Up the Common European Challenges".

11.00-11.30

Coffee Break

Session 2: Infrastructure Requirements, Data Standards and Competencies to Support Personalised Medicine and a Data-Driven Healthcare System

Moderator: Lene Cividanes, Head of Health, Research and International Relations, Danish National Genome Center, Denmark

11.30-12.30

Collecting and Utilising Data in the Hospital

- **Back to Basics: Using Data to Meet Clinical Needs**
by Dr Laura Anne Whelan, PhD, Lecturer in Human Genetics and Genomics, Project Management Lead, Genomic Data Infrastructure Ireland and Genome of Ireland, RCSI University of Medicine and Health Sciences, Ireland
- **The Value of Data Sharing: A Health Economics Perspective**
by James Buchanan, Senior Lecturer, Health Economics and Policy Research Unit (HEPRU), Queen Mary University of London, United Kingdom
- **New (and Existing) Competencies When Moving to a Data-Driven Healthcare System**
by Bodil Ørkild, Deputy Director, University Hospital at Herlev and Gentofte, Denmark
- **Intensified Data Sourcing in Practice**
by Klaus Hoeyer, Professor, Department of Public Health, Section of Health Services Research, University of Copenhagen, Denmark
- **Questions**

12.30-13.00

Best Practices from National IT Infrastructures

- **Infrastructure Requirements, Data Standards and Competencies to Support Personalised Medicine and a Data-Driven Healthcare System**
by Henrik Ullum, CEO, Statens Serum Institut, Denmark
- **FinnGen and the Finnish Opportunities for Data-Driven Discoveries**
by Aarno Palotie, Research Director, Institute for Molecular Medicine Finland FIMM, University of Helsinki, Finland
- **How to Combine Data Across Infrastructures and Sectors: Insights from a National Center of Excellence**
by Tine Jess, Professor, Center Director, PREDICT National Center of Excellence, Aalborg University Copenhagen, Denmark

13.00-14.00

Lunch

14.00-14.30

The Value of Cross-Border Collaboration

- **Is EHDS the Answer to All Our Dreams? [Provisional title]**
by DG SANTE, EU [To be confirmed]
- **Precision Health National Initiatives**
by Peter Goodhand, CEO, Global Alliance for Genomics and Health (GA4GH), Canada
- **Digital Europe and Genomic Data [Provisional title]**
by Saila Rinne, Head of Unit, Artificial Intelligence in Health and Life Sciences, European Commission, DG CNECT, EU
- **European Genomic Data Infrastructure – How Far Have We Got and What Is the Potential?**
by Serena Scollen, Head of Human Genomics and Translational Data,

ELIXIR (Intergovernmental)

- **Bridging Borders, Cultures and Interests - GDI from a Member State Perspective**

by Troels Tvedegaard Rasmussen, Senior Adviser, Danish National Genome Center, Denmark

- **Personalised Medicine – Collaboration Across the Public and Private Sectors**

by Diana Arsovic Nielsen, CEO, Danish Life Science Cluster, Denmark

14.30-15.00

Panel Debate: Is Interoperability the Solution to Realise our Ambitions?

- Speakers from “The Value of Cross-Border Collaboration”

15.00-15.20

Coffee Break

Session 3: Exploring Ethical Perspectives in the Development of Personalised Medicine and a Data-Driven Healthcare System

Moderator: Lisbeth Knudsen, Strategic Director, Mandag Morgen, Denmark

15.20-15.30

Introduction

by Lisbeth Knudsen, Strategic Director, Mandag Morgen, Denmark

15.30-16.30

Ethical Dilemma Game

- **Genetic Data Across Borders**

Panelists:

- Klaus Hoeyer, Professor, Department of Public Health, Section of Health Services Research, University of Copenhagen, Denmark
- Dr. Regina Becker, ELSI Fellow, Luxembourg National Data Service (LNDS), Luxembourg
- Richard Rosenquist Brandell, Professor, Clinical Genetics at the Department of Molecular Medicine and Surgery,

Karolinska Institutet, Sweden

- **Private Access to Public Genetic Data**

Panelists:

- Ida Sofie Jensen, CEO, Danish Association of the Pharmaceutical Industry (Lif), Denmark
- Aarno Palotie, Research Director, Institute for Molecular Medicine Finland FIMM, University of Helsinki, Finland
- Speaker [To be confirmed]

- **AI and Genetic Data: Maintaining Public Trust**

Panelists:

- Dr. Anne Cambon-Thomsen, Emeritus Research Director at CNRS, Inserm and University of Toulouse, France
- Francisca Nordfalk, PhD, Project Manager, National Center for Ethics / Danish Data Ethics Council, Denmark
- Gry Hasselbalch, PhD, Academic Director, DataEthics.eu, Denmark

Session 4: Looking Forward

Moderator: Lene Cividanes, Head of Health, Research and International Relations, Danish National Genome Center, Denmark

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| 16.30-16.45 | ThinkRare: Harnessing AI for the Early Identification of Patients with Undiagnosed Rare Genetic Diseases
by Dr. Kym Boycott, Professor, Senior Scientist, Children's Hospital of Eastern Ontario Research Institute, Canada |
| 16.45-17.00 | The Future of PM and a Data-Driven Healthcare System
by Bogi Eliassen, Executive Director, Movement Health Foundation, Switzerland / Honorary Fellow, Copenhagen Institute for Futures Studies, Denmark |
| 17.00-17.15 | How Does the Novo Nordisk Foundation See the Future?
by Mads Krogsgaard Thomsen, CEO, Novo Nordisk Foundation, Denmark |

17.15-17.20

Thank You for Today

by Bettina Lundgren, Center Director, Danish National Genome Center,
Denmark

17.20-18.30

Drinks and Networking