



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

Programme



# Programme

Monday, September 8 2025

- 8.00-8.45      **Registration and breakfast**
- 8.45-8.50      **Welcome**  
Bettina Lundgren, Center Director, Danish National Genome Center,  
Denmark
- 8.50-9.00      **Personalised Medicine: Political Priorities in Denmark and Europe**  
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**  
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 for 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**  
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**

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**

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**

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**

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**

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**

Emmanuel Bacry, Scientific Director, Health Data Hub, France

10.30-10.40

### **Summing Up the Common European Challenges**

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**  
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**  
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**  
Bodil Ørkild, Deputy Director, University Hospital at Herlev and Gentofte, Denmark
- **Intensified Data Sourcing in Practice**  
Klaus Hoeyer, Professor, Department of Public Health, Section of Health Services Research, University of Copenhagen, Denmark
- **Q&A**  
Speakers from “Collecting and Utilising Data in the Hospital”

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**  
Henrik Ullum, CEO, Statens Serum Institut, Denmark
- **FinnGen and the Finnish Opportunities for Data-Driven Discoveries**  
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**  
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?**  
Fulvia Raffaelli, Head of Digital Health, European Commission, Director General on Health & Food Safety, DG SANTE, EU
- **Precision Health National Initiatives**  
Peter Goodhand, CEO, Global Alliance for Genomics and Health (GA4GH), Canada
- **Digital Europe and Genomic Data**  
Saila Rinne, Head of Artificial Intelligence in Health and Life Sciences, European Commission, DG CNECT, EU
- **European Genomic Data Infrastructure: Achievements and Future Potential**  
Serena Scollen, Head of Human Genomics and Translational Data, ELIXIR (Intergovernmental)

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

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

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

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

14.30-15.00

**Panel Debate: Is Interoperability the Key to Realizing 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**

Lisbeth Knudsen, Strategic Director, Mandag Morgen, Denmark

15.30-16.30

**Ethical Dilemma Game**

- **Genetic Data Across Borders**

- 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 National Genomic Databases**
  - 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
  - Katharina O’Cathaoir, PhD, Associate Professor, Faculty of Law, University of Copenhagen, Denmark
- **AI and Genetic Data: Maintaining Public Trust**
  - 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
  - Frederik Otzen Bagger, PhD, Head of Bioinformatics, Rigshospitalet, Denmark

#### Session 4: Looking Forward

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

- 16.30-16.45      **ThinkRare: Harnessing AI for the Early Identification of Patients with Undiagnosed Rare Genetic Diseases**  
Dr. Kym Boycott, Professor, Senior Scientist, Children’s Hospital of Eastern Ontario Research Institute, Canada
- 16.45-17.00      **The Future of Personalised Medicine and a Data-Driven Healthcare System**  
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?**  
Mads Krogsgaard Thomsen, Prof., DVM, PhD, DSc and CEO, Novo Nordisk Foundation, Denmark

17.15-17.20

**Thank You for Today**

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

17.20-18.30

Drinks and Networking