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

## Programme

# Programme

**Monday, 8 September 2025**

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| 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** |
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- **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 |
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| 14.00-14.30 | **The Value of Cross-Border Collaboration** |
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- **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 Boarders**
  by Klaus Hoeyer, Professor, Department of Public Health, Section of Health Services Research, University of Copenhagen, Denmark
  by speaker [To be confirmed]
  by Richard Rosenquist Brandell, Professor, Clinical Genetics at the Department of Molecular Medicine and Surgery, Karolinska Institutet, Sweden

- **Private Access to Public Genetic Data**
  by Ida Sofie Jensen, CEO, Danish Association of the Pharmaceutical Industry (Lif), Denmark

by Aarno Palotie, Research Director, Institute for Molecular Medicine Finland FIMM, University of Helsinki, Finland
by speaker [To be confirmed]

- **AI and Genetic Data: Maintaining Public Trust**
  by speaker [To be confirmed]
  by Francisca Nordfalk, PhD, Project Manager, National Center for Ethics / Danish Data Ethics Council, Denmark
  by Gry Hasselbalch, PhD, Academic Director, DataEthics.eu, Denmark

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## 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 Eliasen, 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