

# Nordic Networks for Precision Medicine Research

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# Nordic Advantages



\* 40+ million if you count  
deceased individuals

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- Personal identifier number links
  - Health registries
  - Population surveys
  - Research cohorts: disorders, twins, blood donors
  - Large biobanks
  - Pharmacy records
- Public health systems
- Public supports research
- Transnational cultural, historical ties



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Ability to integrate research,  
innovation, and healthcare



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# Roadmap for a precision-medicine initiative in the Nordic region

The Nordic region, comprising primarily Denmark, Estonia, Finland, Iceland, Norway and Sweden, has many of the necessary characteristics for being at the forefront of genome-based precision medicine. These include egalitarian and universal healthcare, expertly curated patient and population registries, biobanks, large population-based prospective cohorts linked to registries and biobanks, and a widely embraced sense of social responsibility that motivates public engagement in biomedical research. However, genome-based precision medicine can be achieved only through coordinated action involving all actors in the healthcare sector. Now is an opportune time to organize scientists in the Nordic region, together with other stakeholders including patient representatives, governments, pharmaceutical companies, academic institutions and funding agencies, to initiate a Nordic Precision Medicine Initiative. We present a roadmap for how this organization can be created. The Initiative should facilitate research, clinical trials and knowledge transfer to meet regional and global health challenges.

**Pål Rasmus Njølstad, Ole Andreas Andreassen, Søren Brunak, Anders D. Børghlum, Joakim Dillner, Tõnu Esko, Paul W. Franks, Nelson Freimer, Leif Groop, Hakon Heimer, David M. Hougaard, Eivind Hovig, Kristian Hveem, Anu Jalanko, Jaakko Kaprio, Gun Peggy Knudsen, Mads Melbye, Andres Metspalu, Preben Bo Mortensen, Juni Palmgren, Aarno Palotie, Wenche Reed, Hreinn Stefánsson, Nathan O. Stitzel, Patrick F. Sullivan, Unnur Thorsteinsdóttir, Marc Vaudel, Eero Vuorio, Thomas Werge, Camilla Stoltenberg and Kári Stefánsson**

# Nordic Society of Human Genetics and Precision Medicine



- Founded 2018 in Reykjavik
- Conferences, workshops
- Legal working group
- Education working group
- Stakeholder network
- Communication



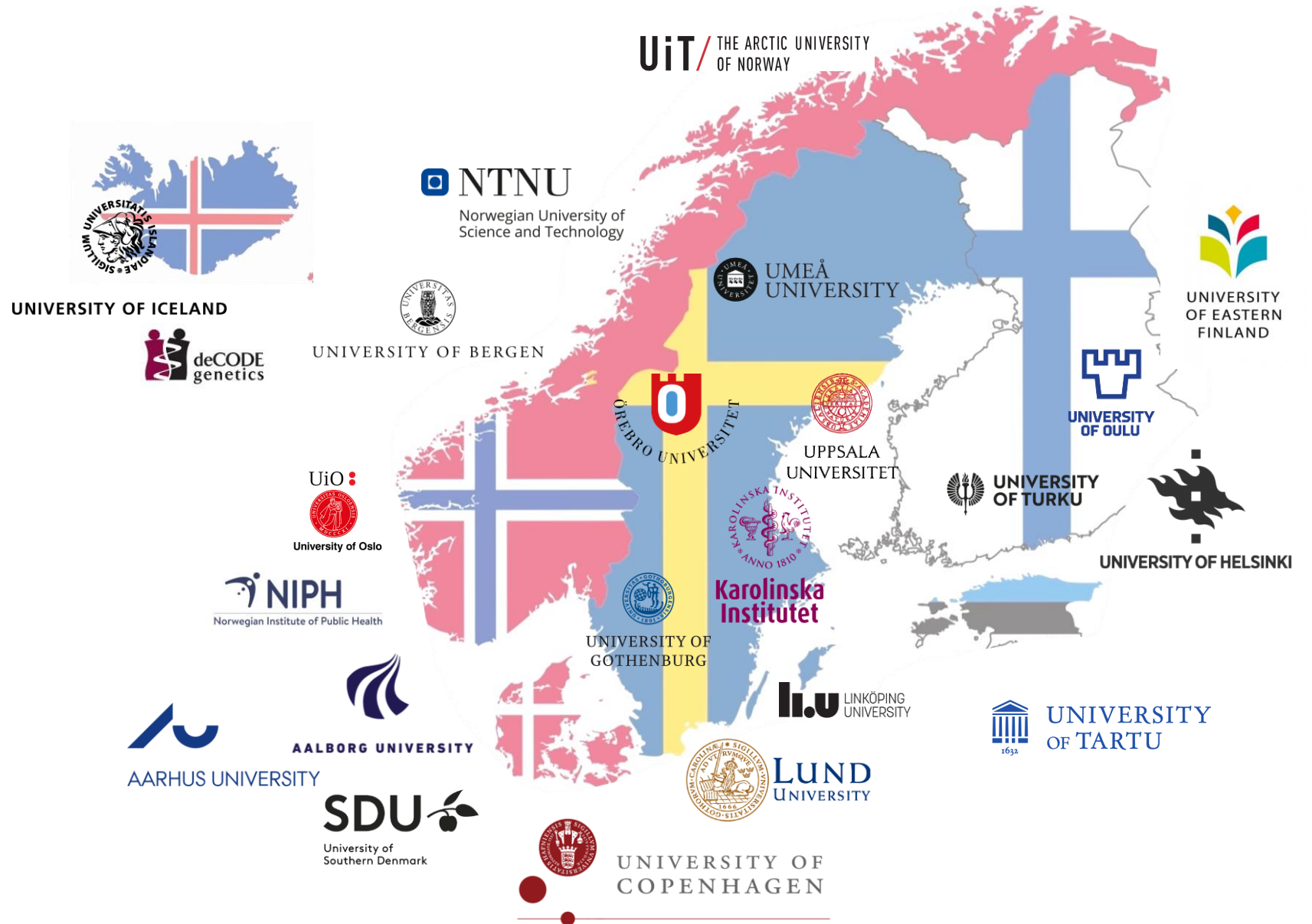
# Nordic Academic Research Stakeholders

## The Faculties of Health and Medical Science of the Nordic Countries

In collaboration with:



With support from:



# The wider Nordic public stakeholder network








# Nordic resources for precision medicine research

100+ Registries, Cohorts and Biobanks

Genotyping and other Omics  
(estimates by end of 2024)

COUNTRY	TYPE	COHORT/BIOBANK	DESCRIPTION/SIZE
DENMARK 	Population	CAMB - Copenhagen Aging and Midlife Biobank	7,191 subjects
		COLOSMA: Copenhagen Longitudinal Study of Male Cognitive Aging	Subsample of CAMB
		Copenhagen Hospital Biobank	50,000 samples collected annually
		DBDS - Danish Blood Donor Study	110 000 subjects
		DNBC - Danish National Birth Cohort	100,000 children born 1996-2002. More than 1 million new samples per year + PKU cards: blood spots from

COUNTRY	TYPE	COHORT/BIOBANK	DESCRIPTION/SIZE
NORWAY 	Clinical	NOPSC - Norwegian biobank for primary sclerosing cholangitis	From 2008 wide range of biological samples from patients with primary sclerosing cholangitis (PSC) and other liver related diseases. Samples and clinical data from patients with other autoimmune diseases are included
		Norwegian Research Biobank for Multiple Myeloma	The multiple myeloma biobank started in the early 1990s. The biobank includes serial serum, cells and bone marrow aspirates from 3,000 patients and data from all neurological departments in Norway are included
		Norwegian register and biobank for multiple sclerosis	ongoing register and biobank that comprises all women with multiple sclerosis in the Oslo area. Blood and fresh frozen tissue samples and phenotypic data are retrieved from 2,400 women so far
		Oslo-2 Breast Cancer	The Prospective Breast Cancer is a longitudinal prospective cohort study in Western Norway that include 1,200 newly diagnosed breast cancer patients. The cohort is followed with yearly visits and unique cohort for the study of breast cancer development
		Prospective Breast Cancer Biobank	samples and data from men undergoing radical prostatectomy from 1994 and onward. The biobank includes 3,000 prostate cancer patients. The biobank includes formalin-fixed paraffin-embedded tissue, fresh frozen tissue and phenotypic data longitudinally.
		Prostate Cancer Biobank	collection of 4,500 patients recruited from psychiatric hospitals and biobank of serious psychiatric illnesses
		TOP - Thematic study and biobank of serious psychiatric illnesses	prospective cohort study on the health of children, 17 years old. The cohort includes children with diabetes and immune-related disease
SWEDEN 	Population	ABIS ( All Babies in Southeast Sweden)	prospective longitudinal cohort study in Skåne. 100 000 individuals summoned to undergo examinations. about 50% of smokers in the cohort.
		BIG3 - chronic obstructive pulmonary disease (COPD), cardiovascular diseases and lung cancer	110k subjects; 8k w/GWAS, 50k w/DNA
		Central Sweden Cohorts & Biobank	The DiPiS study is prospective study that involved scanning in Scania (Skåne) county in southern Sweden for risk of type 2 diabetes (T2D)
		DiPiS - Diabetes Prevention in Skåne	

	GWAS	WGS/WES
Denmark	1,000,000	60,000
Estonia	210,000	3,000
Finland	500,000	5,200
Iceland	180,000	60,000
Norway	500,000	6,000
Sweden	350,000	50,000
<b>Totals</b>	<b>2,740,000</b>	<b>184,200</b>

# Nordic Networks for Research in Precision Medicine

Nordic Research Network		<i>For more information, contact:</i>
Alzheimer's disease	NordNetPM-AD	Hreinn Stefánsson, deCODE genetics, Iceland
Cardiometabolic disorders	NordNetPM-CMD	Søren Brunak, University of Copenhagen, Denmark Pål Njølstad, University of Bergen, Norway
Vaccine effects	NordNETPM-VACCINE	Per Magnus, Norwegian Institute of Public Health
Mental illness	NordNetPM-MENT	Thomas Werge, Region Hovedstaden, Denmark Ole Andreassen, University of Oslo, Norway
Multiple sclerosis	NordNetPM-MS	Ingrid Kockum, Karolinska Institutet, Sweden

# NordNetPM-Mental Illness



**REALMENT:** Using real-world big data from eHealth, biobanks and national registries, integrated with clinical trial data to improve outcome of severe mental disorders. *Funding: EU HORIZON*



**CoMorMent:** Using a 'big data' approach, we investigate how & why mental ill-health interacts with cardiovascular disease. *Funding: EU HORIZON*



**COVIDMENT**

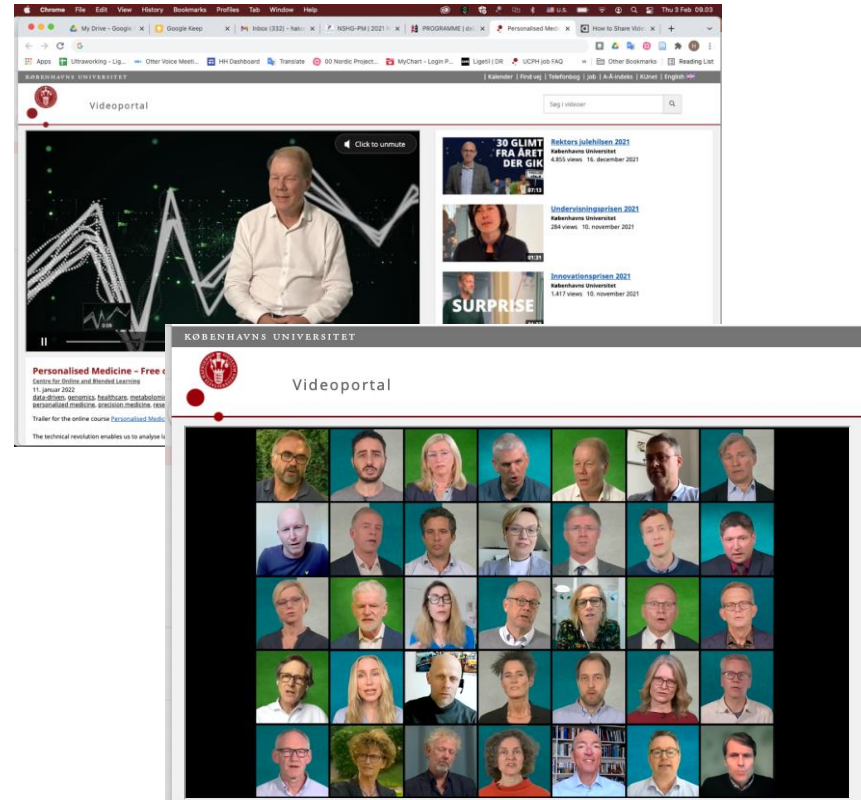
**COVIDMENT:** Mental morbidity trajectories in COVID-19 across risk populations in five nations. *Funding: NordForsk*

**NEW in 2024!!**  
**PreciMENT**

**PreciMENT:** Leveraging Nordic opportunities to transform mental health care through precision medicine. *Funding: NordForsk*

# Education: Precision medicine course

- MOOC for medical students
- Secondary audiences include masters/PhD programs in medicine, biosciences, data science, social science, law
- Launched at University of Iceland in January 2022 to very positive reviews
- Foundation for future summer schools, practitioner training



**coursera**



**SAEDIS  
SAEVARSDOTTIR**



**SISSE RYE  
OSTROWSKI**



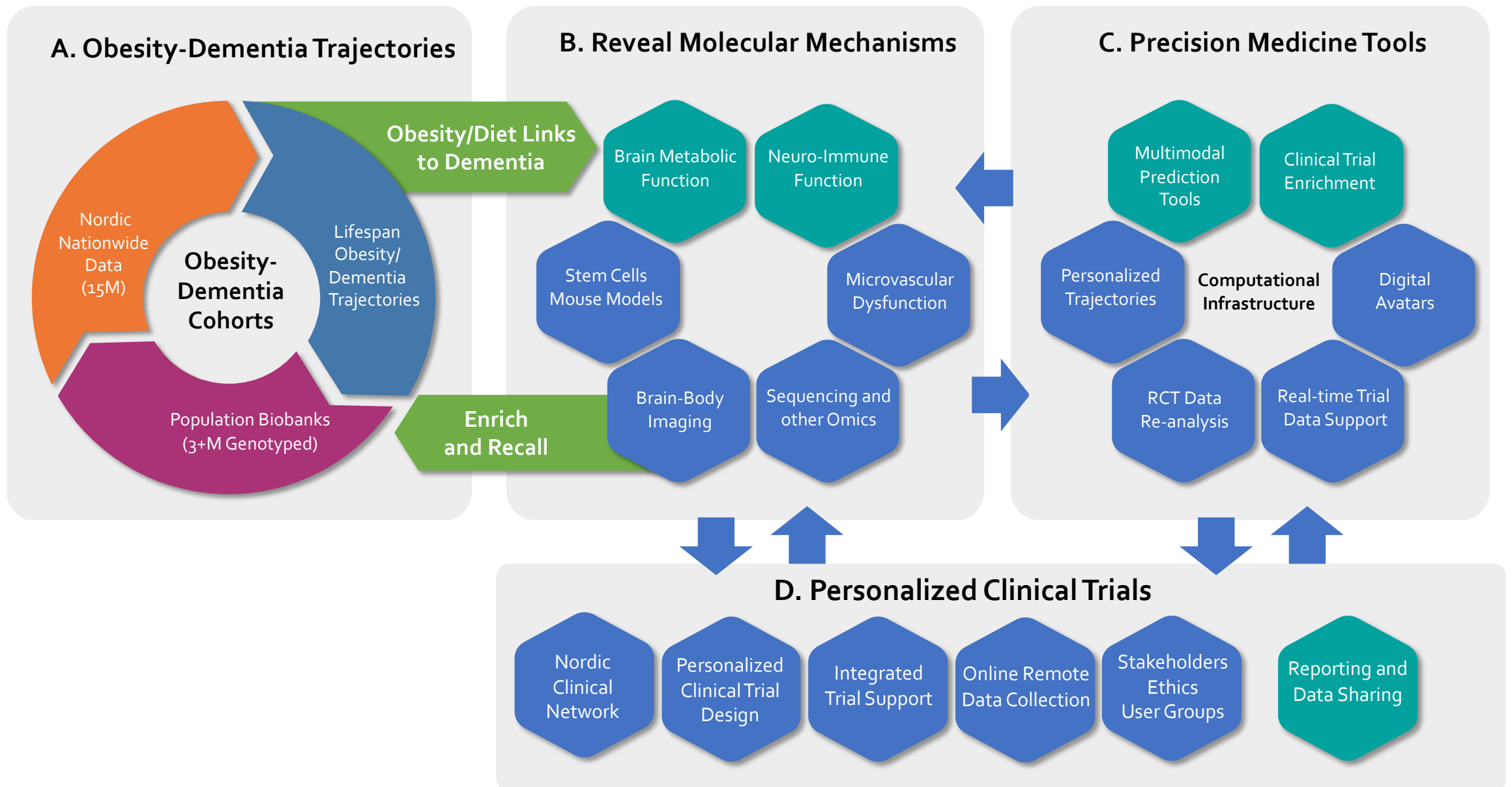
**ENGILBERT  
SIGURDSSON**



**HAKON  
HEIMER**



# Data-driven personalized interventions





# Nordic Precision Psychiatry: Addressing Challenges

**Dedicated, consistent funding for research and infrastructure**

- Active engagement with public, private funders, other stakeholders
- Show feasibility with exemplars

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**Access to sensitive data for domestic, Nordic, European (GDPR), international collaboration**

- TRYGGVE framework: Distributed analysis with high-performance computing (HPC) tools
- Elixir: secure storage and analysis nodes in each country

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**Coordination across Nordic countries**

- Nordic Commons for Health Data
- NSHG-PM and other Nordic societies

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**Public, clinicians' perceptions of risk**

- Secure infrastructure for data storage and analysis
- Communication, education

# NORDIC CONFERENCE ON FUTURE HEALTH

## Biobanks, Research, Innovation, and Precision Medicine

September 10-12, 2024 ❖ Trondheim, Norway

Nordic Society of Human Genetics  
and Precision Medicine  
3<sup>rd</sup> Biennial Conference



Nordic Biobank Conference  
2<sup>nd</sup> Biennial Conference  
Hosted by



[NSHG-PM.org](https://NSHG-PM.org)

[BBMRI.no](https://BBMRI.no)



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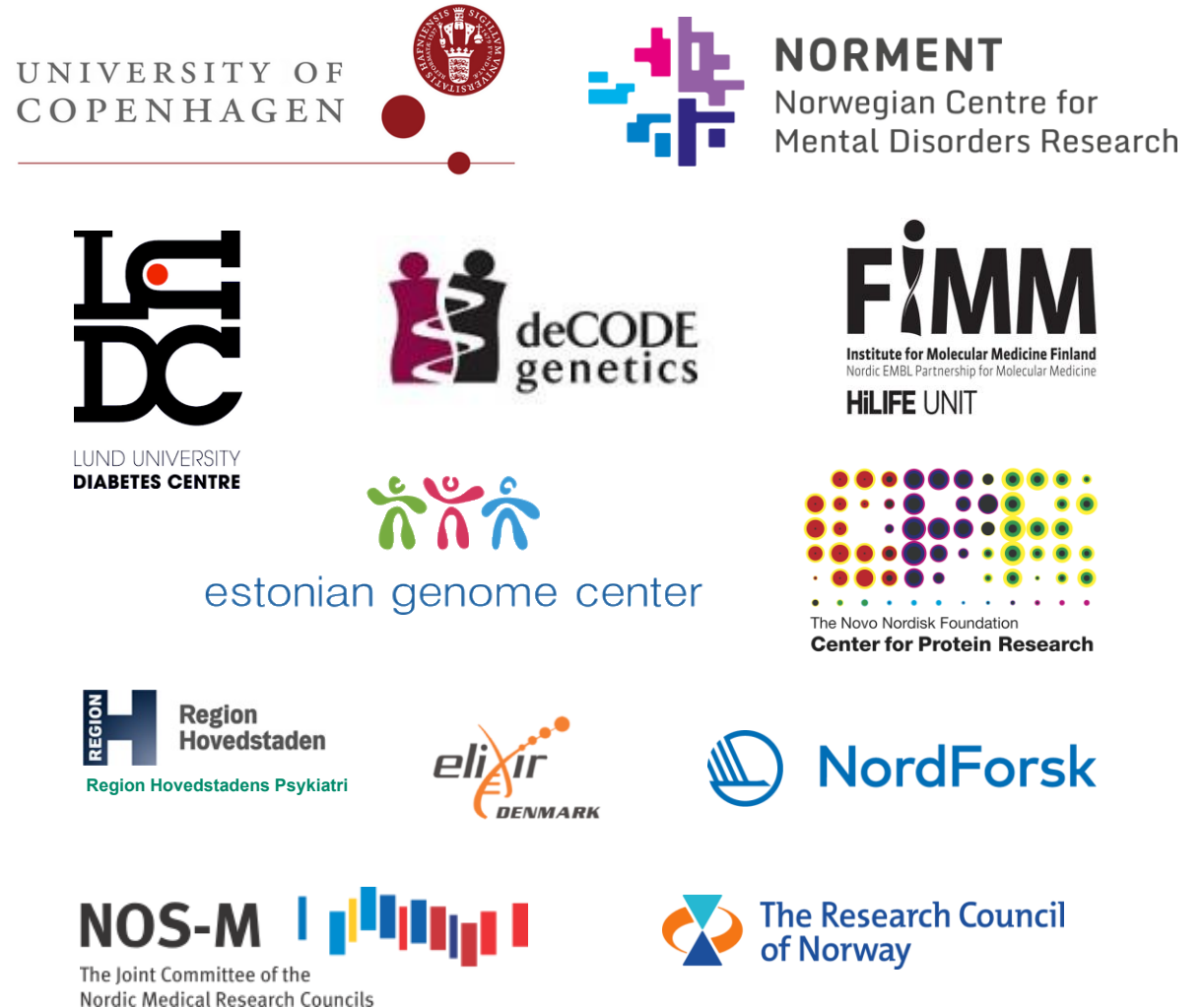
# Key Initiators and Supporters

## Current Council

- Ole Andreassen, University of Oslo, Norway (President)
- Ingrid Kockum, Karolinska Institutet, Sweden (Vice-President)
- Søren Brunak, University of Copenhagen, Denmark (Treasurer)
- Bo Jacobsson, University of Gothenburg, Sweden
- Andres Metspalu, Estonian Genome Center
- Lili Milani, Estonian Genome Center
- Pål Njølstad, University of Bergen, Norway
- Aarno Palotie, Institute for Molecular Medicine Finland
- Samuli Ripatti, Institute for Molecular Medicine Finland
- Hreinn Stefánsson, deCODE Genetics, Iceland
- Kári Stefánsson, deCODE Genetics and University of Iceland
- Thomas Werge, Mental Health Centre Sct. Hans, Denmark

## Other key initiators

- Anders Børghlum, Aarhus University, Denmark
- Mark Daly, Institute for Molecular Medicine Finland
- Paul Franks, Lund University Diabetes Center, Sweden
- Leif Groop, Lund University Diabetes Center, Sweden
- Hakon Heimer, University of Oslo, Norway
- Kristian Hveem, NTNU, Norway
- Juni Palmgren, Karolinska Institutet, Sweden
- Camilla Stoltenberg, Norwegian Institute of Public Health, Norway
- Patrick Sullivan, Karolinska Institutet, Sweden



**Thanks for your attention!**