Nordic Alliance for Sequencing and Personalized Medicine

Policy statement for Nordic Alliance Meeting

The Nordic Alliance for Sequencing and Personalized Medicine is an independent, non-governmental, not-for-profit, Nordic association that has received initial funding from Nordforsk.

Our overall mission is to share trustworthy genomics data and technology competence for improved diagnosis and treatment, and as a resource for research.

Specific goals include:

- Facilitate the responsible sharing of genomic data, bioinformatics tools, sequencing methods and best practices for interpretation of genomic data.
- Enhance quality of genomic data and processes, and explore methodologies to provide assurance.
- Understand legal barriers to the implementation of personalised medicine and to engage with key stakeholders that influence these barriers
- Develop demonstration projects that challenge perceived legal barriers that limit responsible and ethical sharing of genomic and health data.
- Build bridges between research and clinical communities, technologies and practices to foster innovation

To this end we are building Nordic alliance of key national research infrastructures in genomics as well as key clinical environments for implementing genomic medicine in the Nordic countries. The alliance is a result of a realization that the Nordic countries with its high trust in government, transparent societies and similar health care systems based upon the ideal of equal access to care for all members of society, have the potential to become leading countries in the sustainable implementation of personalized medicine. However, this requires Nordic collaboration as the Nordic countries individually are too small.

Following three informal workshops we now plan an inaugural meeting of the alliance and we wish to bring together key stakeholders in the Nordic countries to identify specific action points for the future of the alliance. We also want to bring in international expertise with the aim of identifying best practices and state of the art for the field.

Tentative agenda
15th november

12:00 – 12:40	Registration
12:40 – 12:45	Welcome: Remi Eriksen, Group CEO, DNV GL
12:45 – 13:00	Introduction:

Session 1: State of the art of personalized medicine
Chair: Dag Undlien

13:00 – 14:00	Genomics England 100,000 Genomes Project: Delivering genomic medicine in cancer and rare diseases. Clare Turnbull
14:00 – 14:30	Nordic collaboration for Personalized Medicine – why this matters for industry. Steinar Thoresen.
14:30 – 15:00	Coffee break

Session 2: Personalized Medicine – Nordic initiatives
Chair: Valtteri Wirta

15:00 – 15:20	The Danish Genome Centre. Status and plans. Gert Sørensen, Director of the Danish Genome Center
15:20 – 15:40	Genomic Medicine Sweden initiative. Richard Rosenquist Brandell , Karolinska Institutet.
15:40 – 16:00	Norwegian strategy for personalized medicine. Status and plans. Maiken Engelstad, Norwegian Ministry of Health and Care Services
16:00 – 16:20	Finnish plans for personalized medicine - Implementation status. Jaakko Yrjö-Koskinen, Ministry of Social Affairs and Health, Finland
16:20 – 16:40	The Nordic Alliance for Sequencing and Personalized Medicine
16:40 – 17:00	Break
17:00 – 17:40	Panel discussion on Nordic collaboration in Personalized Medicine Chair: Stephen McAdam Panelists: Clare Turnbull Gert Sørensen Steinar Thoresen Richard Rosenquist Brandell Maiken Engelstad Jaakko Yrjö-Koskinen
17:45	Reception and Dinner at DNV GL (Buses leave for Sandvika, Lysaker, Skøyen and Oslo S at 21:00)

Tentative agenda
16th november

Session 1: Personalized Medicine – data sharing and big data
Chair: Karin Wadt/Morten Dunø

8:30 – 9:00	Data sharing and privacy. Thomas Keane, Global Alliance for Genomics and Health
9:00 – 9:30	Sharing variant classifications at a National level – experiences from the Netherlands, Morris Swertz, Groningen University Medical Centre
9:30 – 10:00	Big Data and Personalized Medicine, Søren Brunak, University of Copenhagen
10:00 – 10:30	Discussion
10:30 - 11:00	Break
11:00 – 11:30	P5.fi: Precision Medicine Finally Implemented, Pia Heikkurinen, SITRA, the Finnish Innovation Fund
11:30 – 12:00	BigMED Lighthouse Project, Thomas Smedsrud, Oslo University Hospital
12:00	Lunch
13:00	Start of workshop 1: Inaugural general assembly for Nordic Alliance for Sequencing and Personalized Medicine.
13:45	Start 4th Nordic Workshop on implementation of genomic medicine in health care. Standardization and data sharing. (by invitation only)
13:45	Start 1st Nordic workshop for National Genomic research infrastructures (by invitation only)

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This Nordic Alliance Meeting is arranged in cooperation NordForsk.