

Nordic Common Strengths and Future Potential in the Field of Personalised Medicine

**NOS-M Workshop 23rd November 2016
Stockholm Waterfront**

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Background on NOS-M

- The Joint Committee of the Nordic Medical Research Councils (**NOS-M**) is a cooperative body for the medical research councils of Denmark, Finland, Iceland, Norway and Sweden.
- Aims of NOS-M:
 - Coordinate/promote medical research in the Nordic countries
 - Monitor progress of Nordic medical research
 - Facilitate information exchange among the countries

Background on the Workshop

The 2011 Nordic White Paper

- In **2011** NOS-M published a Nordic white paper on medical research, aiming to identify opportunities for strengthening medical research jointly and individually amongst the Nordic countries.
- The white paper highlighted actions needed in the Nordic region to maintain a competitive position globally and respond to scientific, healthcare and economic challenges.



**Present Status and Future Potential
for Medical Research
in the Nordic Countries**

Nordic White Paper
on Medical Research



Nordic White Paper 2011

“Present Status and Future Potential for Medical Research in the Nordic Countries”

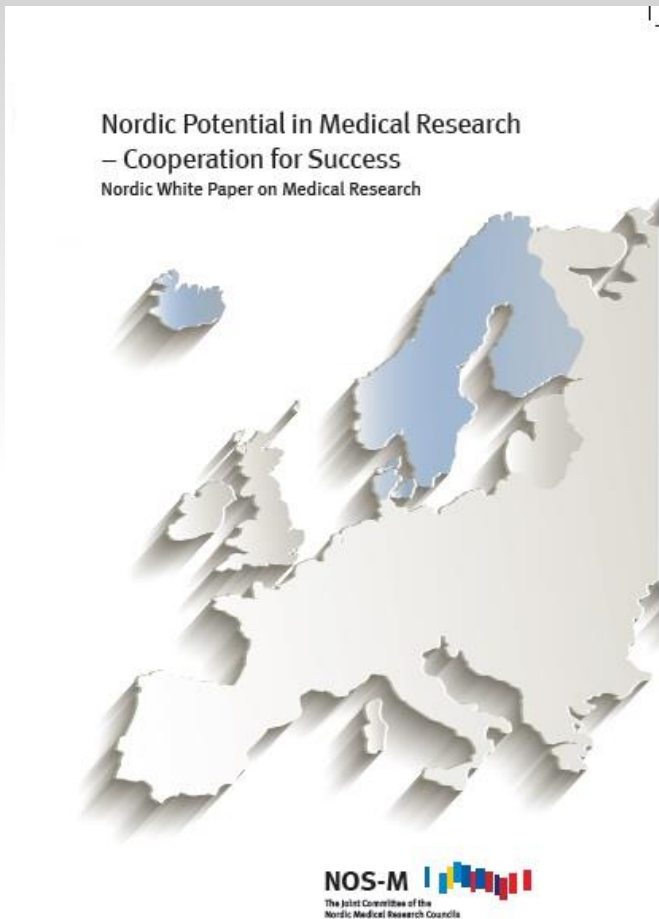
Recommendations:

- Better incentives for Nordic cooperation are needed
- Innovations require good basic research
- Clinical research requires increased attention

Background on the Workshop

The 2014 Nordic White Paper

- A second white paper was published in **2014**, aiming to advance the discussion on the *added value* of Nordic cooperation in medical research and to recommend concrete actions needed to be taken.
- In this second white paper, *biobanks and registers* and *personalised medicine* were identified as areas where the Nordic countries - through cooperation - have an opportunity to become world leaders.



Nordic White Paper 2014

“Nordic Potential in Medical Research – Cooperation for Success”

Recommendations:

- Biobanks and Registers
- Personalised Medicine
- Gender Equality

Background on the Workshop

- *As a result of the recommendations of the white paper, NOS-M decided at the meeting 1/2016 in Reykjavik to arrange a workshop in Stockholm on the theme personalised medicine.*

Aims of the Workshop

- To discuss the potential of and common Nordic strengths in personalised medicine
- NOS-M's set of recommendations as starting point
- Target group: research councils, universities and ministries
- Identify how to move forward and potential joint Nordic actions

Workshop Programme

- The meeting was opened by Prof. Jan-Ingvar Jönsson, chair of NOS-M.
- The following presentations were divided into two sections:
 - 1) Personalised medicine in the Nordic countries and Europe
 - 2) Nordic added value and future potential in personalised medicine

The final part of the workshop was a panel discussion on the Nordic common strengths and the way forward

Personalised Medicine in the Nordic countries and in Europe

Personalised medicine may radically improve health care within the next decade

Speaker: Prof. Mikael Benson, Director of the Centre for Personalised Medicine at Linköping University.

- Current key healthcare problem: up to 90 % of all medications are ineffective in 50 % of the patients.
- Personalised medicine aims to solve these problems by enabling early diagnosis and treatment, as well as individualised treatment.
- The emergence of omics technologies has been of crucial importance for the diagnosis and treatment of multigenic disorders.
- By combining information from multiple sources, e.g. proteins, mRNA, DNA, environmental factors into groups of networks, one can understand disease mechanisms, find biomarkers and therapeutic agents, etc.

Personalised medicine may radically improve health care within the next decade (cont.)

- Several factors affect the risk of a complex disease and *individual variations* in these factors are of major importance in personalised medicine
- In summary, personalised medicine may lead to major improvement of health care within next decade. However, there are a number of major ethical, societal and legal challenges that need to be tackled before this can be accomplished.

Report on Personalised Medicine initiatives in the Nordic countries

- **Denmark** (Prof. Torben Falck Ørntoft, Aarhus University Hospital)
 - Political initiatives included a total of DK 5 million for a pre-analysis of the state of personalised medicine in Denmark and internationally.
- **Finland** (Dr. Jarmo Wahlfors, Academy of Finland)
 - Long tradition of international top-level genetic research, excellent registries and biobanks, citizens (still relatively) pro-research and improved political support
- **Iceland** (Prof. Magnús Karl Magnússon, University of Iceland)
 - Over half of the adult population has been genotyped and 25 000 whole genomes have been sequenced. Together with detailed genealogy data this enables *imputation of the genotypes of the whole population*.
 - A number of cancer risk genes have been mapped to the genotype data. Whether the health care system need to *proactively intervene* in these cases is currently being discussed by the Ministry of Health.

Report on Personalised Medicine initiatives in the Nordic countries

- **Norway** (Senior advisers Hege Wang and Kari Steig, Norwegian Directorate of Health)
 - A Norwegian Strategy for Personalised Medicine in Healthcare 2017–2021.
 - The focus of the strategy is on treatment and diagnostics, not on research.
- **Sweden** (Prof. Mikael Benson)
 - Many resources are available for personalised medicine in the country, but they are split between different funders. There is thus a need for *national coordination of funding*.
 - Current major initiatives include the national programme in protein research and biopharmaceutical drugs, with a total budget of SEK 320 million for 2016–2023.

Report on European Personalised Medicine initiatives

Speaker: Irene Norstedt, Head of Innovative and personalised medicine, DG Research and Innovation, European Commission.

- The EC was an early mover in personalised medicine: workshops in 2010 and a conference in 2011.
- IC PerMed, was launched in June 2016. The consortium is a collaboration of research funders and policy makers from EU Member States and beyond, and the vision is to establish Europe as a global leader in personalised medicine research.
- A SRIA was published in June 2015 and the first action plan is to be published in late 2016.
- EU definition of personalised medicine is broader than the US *precision medicine*. A more holistic view involving multiple information sources. Requires working together across disciplines, organisations and countries

Nordic Added Value and Future Potential in Personalised Medicine

Personalised medicine and the development of Life Science

Speaker: Anders G. Lönnberg, Swedish Life Science Coordinator.

- Life science is among the government's top priorities.
- The goals of the work are threefold:
 - Increase the quality of health care
 - Increase the speed by which new innovations are implemented in health care.
 - Increase the level of Swedish innovation being translated.
- So far, 5 priorities have been suggested:
 - Digitalisation.
 - Reimbursement system (hospitals have to consider short-term budget).
 - Meriting system (research/healthcare/industry).
 - Government has to be clear in its priority. Too often, the healthcare system sees research as an obstacle.
 - New knowhow.

Infrastructures for personalised medicine

Speaker: Janna Saarela, Research Director at Institute for Molecular Medicine Finland, FIMM

- FIMM: part of the Nordic EMBL Partnership for Molecular Medicine
- Harbours a biobank infrastructure, as well as a technology centre enabling various aspects of molecular medicine research beyond genomics, e.g. metabolomics, imaging and clinical informatics.
- FIMM coordinates the Sequencing Initiative Suomi (SISu) search engine which offers a way to search for data on sequence variants in Finns <http://sisuproject.fi/>
- *A common Nordic database would be very useful because of accumulation of patients with rare diseases.*

Nordic Commons for Register and Biobank Data

Speaker: Prof. Juni Palmgren, Karolinska Institutet

- A vision of an integrated Nordic research platform
- Nordic advantages include: a number of *unique registers, cohorts* and *biobanks*, high quality *epidemiology* and *clinical* research, and a population that is generally very positive towards participating in research.
- Lack of Nordic perspective → Potential risk that policy directives are developed which are not aligned on the Nordic level

Nordic Commons for Register and Biobank Data (cont.)

Speaker: Prof. Juni Palmgren, Karolinska Institutet

- A Nordic commons would rely on:
 - A clear legal and ethical framework for sharing data and tools across borders.
 - Transparency and an open access policy.
 - Involvement of a broad range of Nordic key stakeholders (political level, research funding level, national data-owner institutions, e-Science/e-infrastructure experts, scientists).
- Challenges and obstacles for Nordic cooperation on data resources: *political, organisational, legal, financial, ethical and technical.*

Risk screening and personalised therapy in cancer: a personalised medicine example

Speaker: Prof. Torben Falck Ørntoft, Aarhus University

- Genomic medicine: the use of genomic information in the clinic to enable a more precise stratification of patients and citizens, for the purpose of surveillance, prevention, diagnosis and treatment. Seq
- Next-generation sequencing is used at Aarhus university hospital to identify various inherited diseases, identify certain bacterial infections, select treatment of cancer of unknown primary, etc.
- Examples include GWAS to identify risk SNPs for prostate cancer in individuals with elevated PSA levels.

Panel Discussion – Nordic common strengths and the Way Forward

Moderator: Prof. Jan-Ingvar Jönsson

Panel members: *Mia Bengtström*, Senior Adviser at Pharma Industry Finland; *Magnus Karl Magnusson*, Dean, Faculty of Medicine, University of Iceland; *Irene Norstedt*; *Troels Rasmussen*, Special Adviser, Danish Agency for Science Technology and Innovation; *Dag Erik Undlien*, Professor, Department of Medical Genetics, Oslo University Hospital; and *Anders G. Lönnberg*

CONCLUSIONS

- Personalised medicine may lead to major improvement of health care, but there are a number of major ethical, societal and legal challenges that need to be tackled before this can be accomplished.
- Policy directives need to be aligned on the Nordic level.
- Several Nordic advantages, including: a number of *unique registers, cohorts and biobanks*, high quality *epidemiology and clinical* research, *public-funded healthcare* and a population that is generally very positive towards participating in research.
- Rare diseases and cancer are appropriate focus areas for Nordic cooperation.