A vision of a Nordic secure digital Infrastructure for health data:

The Nordic Commons

Recommendations, status and first steps

NordForsk

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21 April 2021

Nordic strengths in health research

- Similar health care systems available to all citizens
- Publicly funded universities
- Extraordinary research infrastructures (registers and biobanks)
- Long history of Nordic cooperation between scientists and political stakeholders
- Citizens have trust in research and authorities collecting data
- Established research and research infrastructure networks (e.g. cancer registries, biobanks, precision medicine, epidemiology)
- Population +27 Million
- The Personal Identification Number (PIN)

Unique Nordic data resources

The Nordic registers are **unique** because of their

- detailed curation
- depth of information
- longitudinal nature and long history
- ease of linkage (?)

The registers contain **longitudinal data** on

- disease risk factors
- etiological factors
- drug prescriptions
- medical therapies
- disease outcomes
- socioeconomic variables

Data at population level "**from the cradle to the grave**"

Photo by Joshua Sortino on Unsplash

Similar health data sources in each country for secondary use in research and innovation

Data producers
- authorities
- health care
- research
- patients/individuals

Data types
-register
-biobank
-genomics
-survey
-other health data

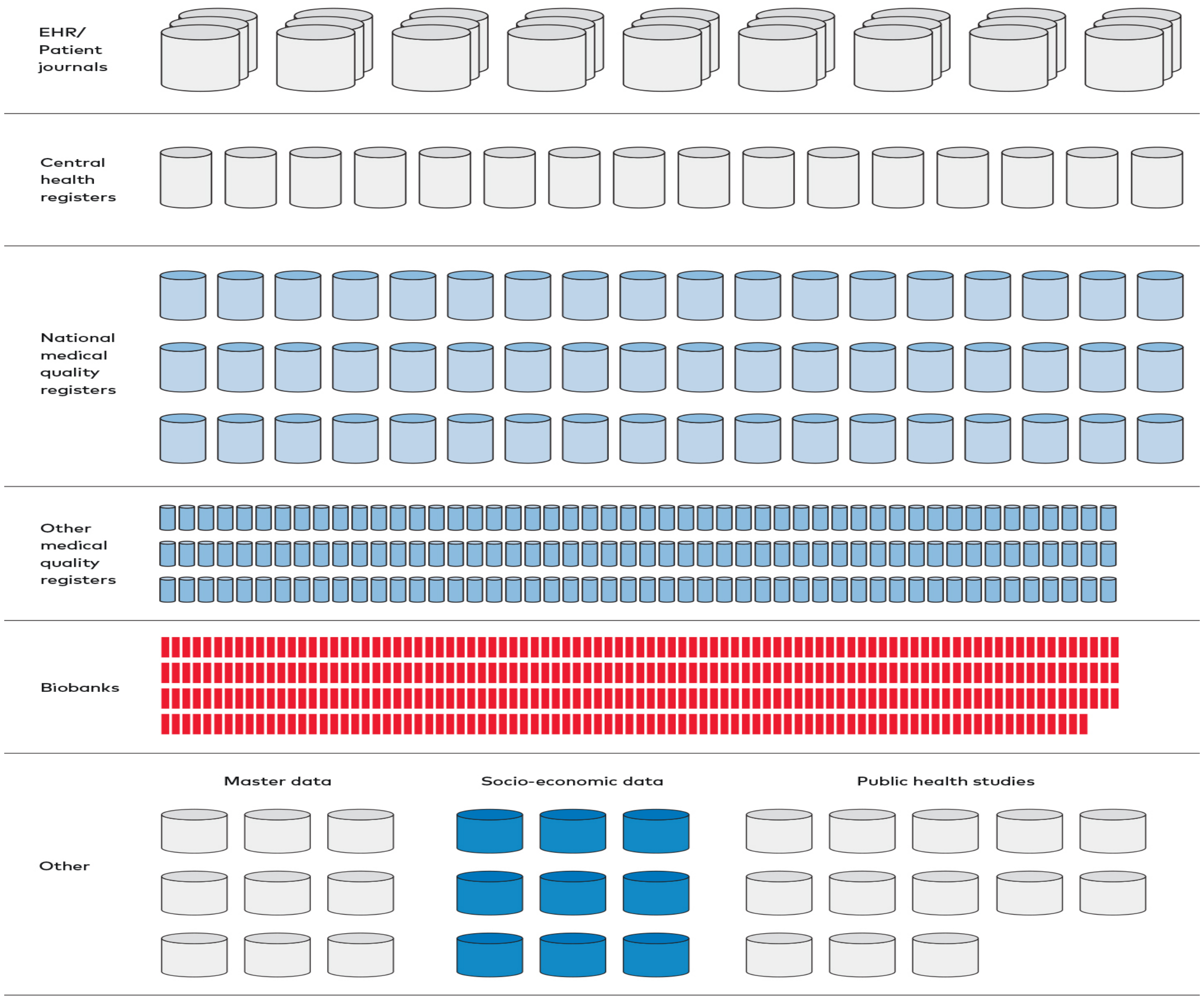


Figure from Nordic Commons report
nordforsk.org/publications

Many national actors within health data…

NASJONALT SERVICEMILJØ FOR
MEDISINSKE KVALITETSREGISTRE

helsedata

Helsedirektoratet

Biobank Norway

Direktoratet for
e-helse

Kreft
registeret

FHI
Folkehelseinstituttet

VINNOVA

Sveriges
Kommuner
och Regioner

Socialstyrelsen

vård- och
omsorgsanalys

eHälsomyndigheten

SWElife

BIOBANK
SVERIGE

SITRA

Finnish institute for
health and welfare

FINDATA
Social and Health Data Permit Authority

FINBB
FinBioBank

ICT Solutions for Brilliant Minds
CSC

KOR
Det Koordinerende Organ
for Registerforskning

STATISTICS
DENMARK

DANMARKS
NATIONALE
BIOBANK

rkkp
regionernes kliniske kvalitetsudviklingsprogram

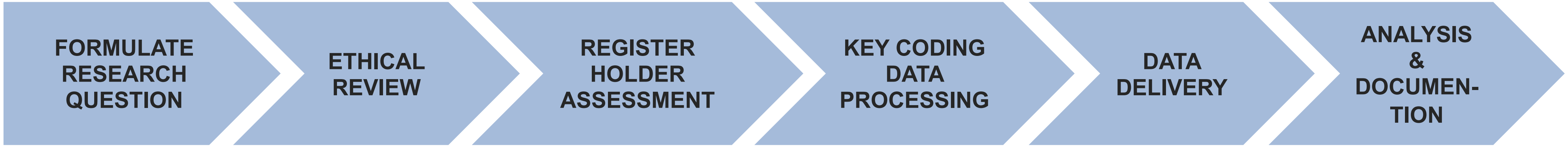
SUNDHEDSDATA-
STYRELSEN

DANISH NATIONAL
GENOME CENTER

In addition…
E-infrastructure providers
Research Infrastructures
Industry cooperation
Legal and regulatory initiatives
etc

Needs and potentials exceed system readiness

At present, Nordic collaborative projects are complex to manage and extremely time-consuming



FORMULATE RESEARCH QUESTION

ETHICAL REVIEW

REGISTER HOLDER ASSESSMENT

KEY CODING DATA PROCESSING

DATA DELIVERY

ANALYSIS & DOCUMEN-TION

- Limited knowledge of **what data exists**, where and its meaning – issues of comparability
- Limited knowledge of what **permits** are needed and what **procedures** are in place, even among researchers in the field
- Need to apply for **ethical permissions and data in each individual country**
- Data owners explicitly prohibit storage of data outside national institutions

Risks?

- Research not being performed or sub-optimally
- Nordic countries losing a competetive edge

(Horror) Stories from Nordic research projects

Overview

	Denmark	Finland[b]	Norway	Sweden
Net processing time (days)	100/150[a]	210	774/237	399
Costs in 1000s €	6	25	36	10
Number of decision makers	2(5)	3	6/7	3(4)
Number of data retrievers	1(2)	3	5	2

[a] The processing time was approximately 100 days from submission of first application and approximately 150 days including consultancy and processing time together with the Public Health Database staff.

[b] The figures represent approximate net processing time and costs of updating and extending data set (2).

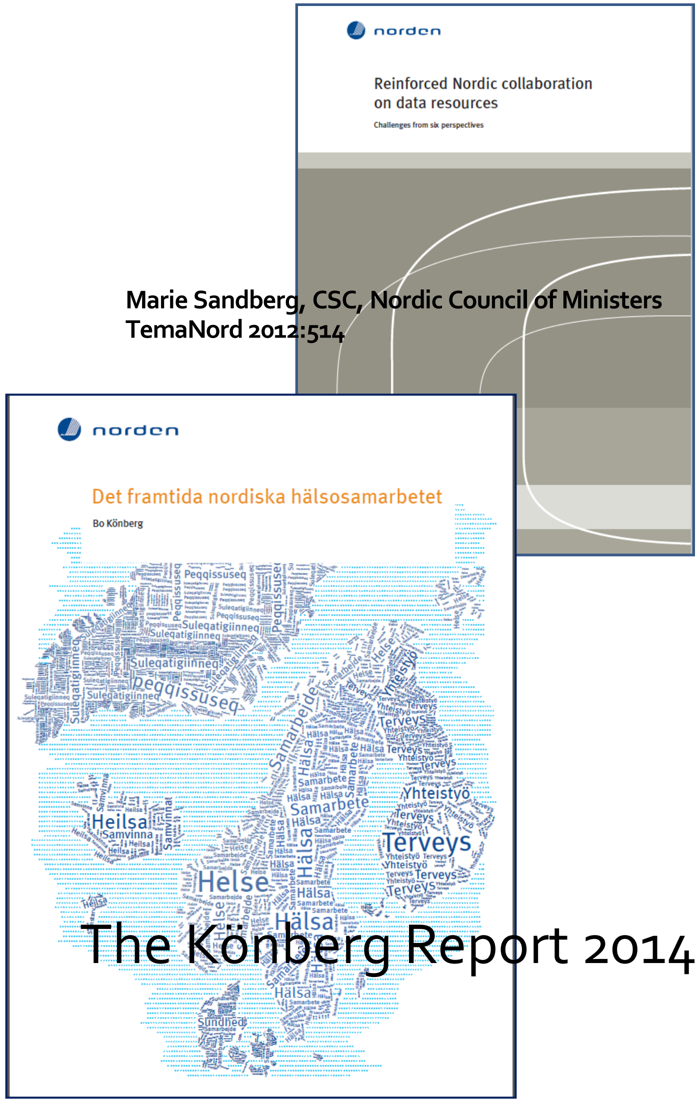
A gold mine, but still no Klondike: Nordic register data in health inequalities research.
Kjetil van der Wel *et al.* Scandinavian Journal of Public Health, 2019; 47: 618–630

The Nordic political perspective

- Health cooperation is high on the Nordic political agenda
- Already in 2012 challenges from different perspectives were identified

political - organisational - legal – financial – ethical - technical

- Könberg Report 2014 - Proposal 4: Register-based research (A Nordic virtual center is set up for register-based research)
- The Norwegian Priority Project 2017
  'Nordic cooperation for better health'
  - Ethical Review
  - Clinical Trials
  - Health Data



norden

Reinforced Nordic collaboration
on data resources

Challenges from six perspectives

Marie Sandberg, CSC, Nordic Council of Ministers
TemaNord 2012:514

norden

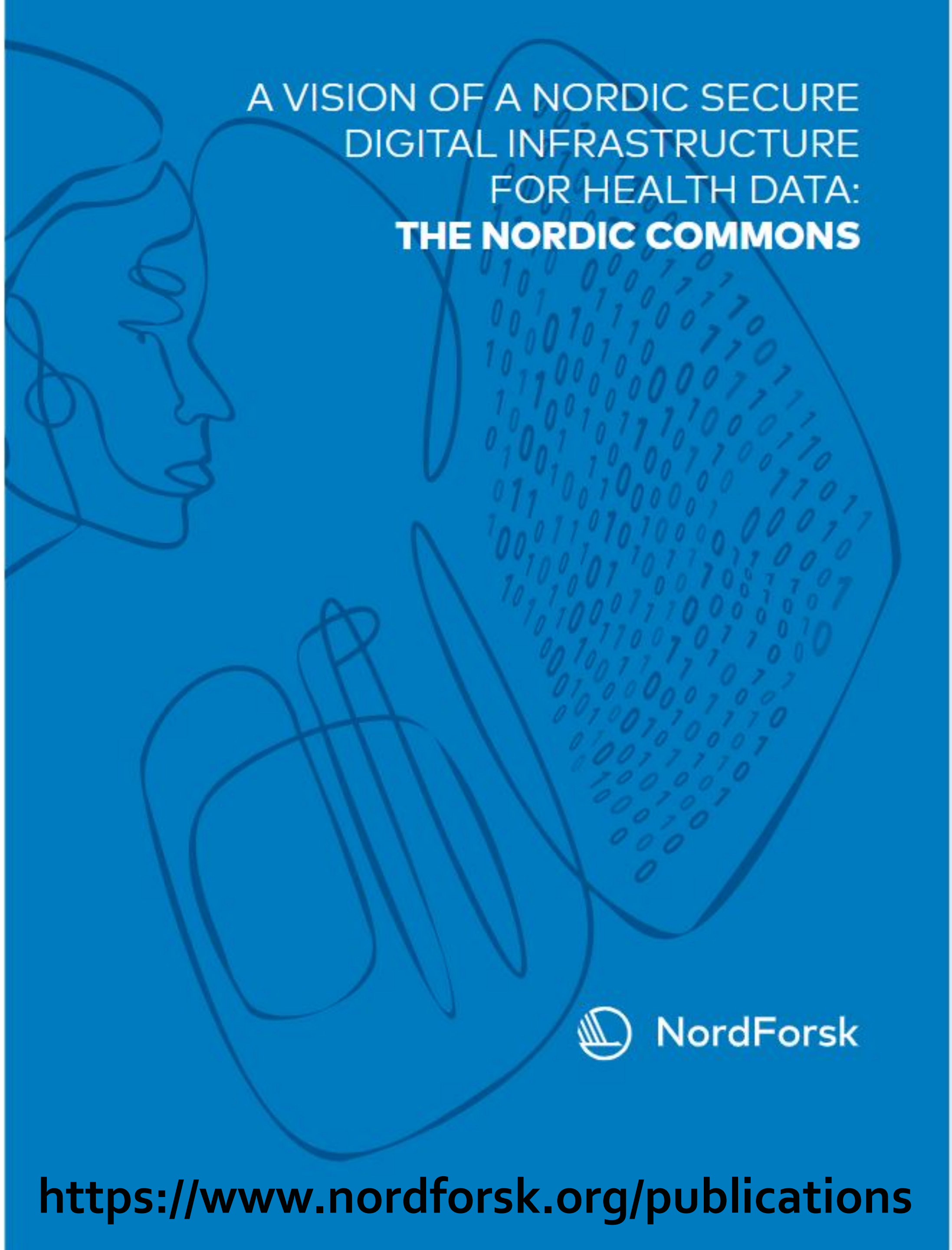
Det framtida nordiska hälsosamarbetet

Bo Könberg

The Könberg Report 2014

Norwegian Priority Project
'Nordic Cooperation for Better Health' 2017-2019

The Nordic Health Data Commons



A VISION OF A NORDIC SECURE
DIGITAL INFRASTRUCTURE
FOR HEALTH DATA:
THE NORDIC COMMONS

NordForsk

https://www.nordforsk.org/publications

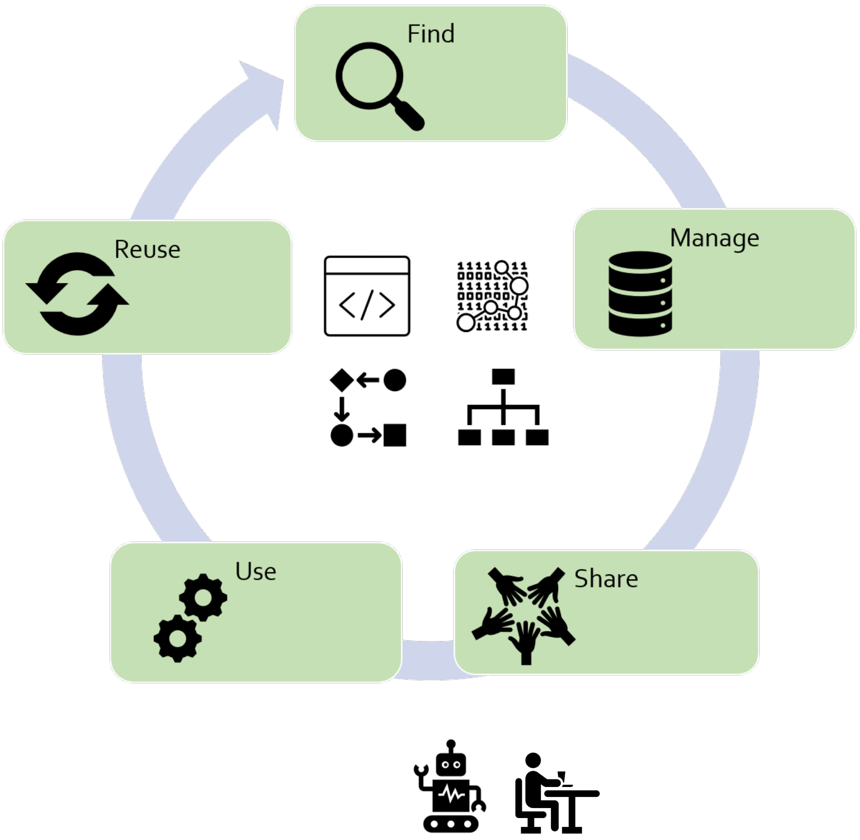
A Nordic Health Data Commons

Vision: the Nordic region as a leading region for secondary use of health data

○ The **Nordic Commons** is a virtual space where scientists can

- **find** health data
- understand its **meaning**
- understand how it could be **used and re-used**
- have access to the right **software** and **services**
- **link** data from different sources
- use data at the **Nordic** level
- work in a **secure environment**
- ...according to **legal** and **ethical frameworks**

○ **FAIR** data and data management is central – (meta)data should be **F**indable-**A**ccessible-**I**nteroperable-**R**eusable



Find

Manage

Share

Use

Reuse

Icons:
Software/coding: By shuai tawf - https://thenounproject.com/search/?q=2752876&i=2752876, CC BY 3.0, https://commons.wikimedia.org/w/index.php?curid=90009811
Data: By priyanka - https://thenounproject.com/search/?q=data&i=2223266, CC BY 4.0, https://commons.wikimedia.org/w/index.php?curid=99909171

Key technical components needed in each country

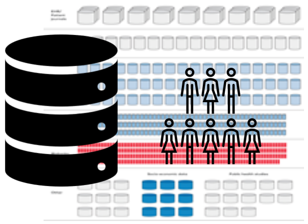
Find
Evaluate
Reuse

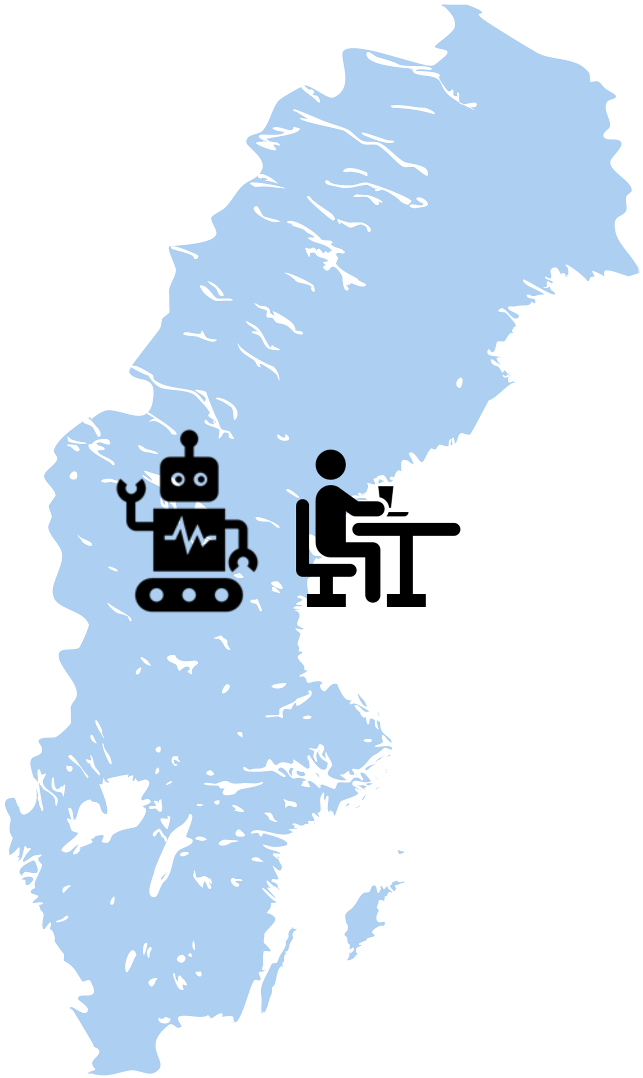
National metadata hub

Collect metadata and provenance

National data sources

Secure storage at data owner





Data Linkage

Key Management

Secure disclosure

Secure compute infra-structure

Process
Compute
Analyse

Vision for the Nordic Commons

“The Nordic region as a leading region for secondary use of health data”

This requires:

1. Nordic health data described with rich metadata according to the FAIR* criteria – a federated Nordic Health Metadata Repository
2. A Nordic federated secure platform for processing sensitive personal data – a Nordic Health Cloud
3. A coherent legal and ethical framework supporting the above
4. A funding programme for technology and competence development (proof-of-value)

The Nordic Commons report elaborates on items 1 and 2 and gives recommendations on all four items.

** Findable, Accessible, Interoperable, Re-usable*

Photo by Markus Spiske on Unsplash

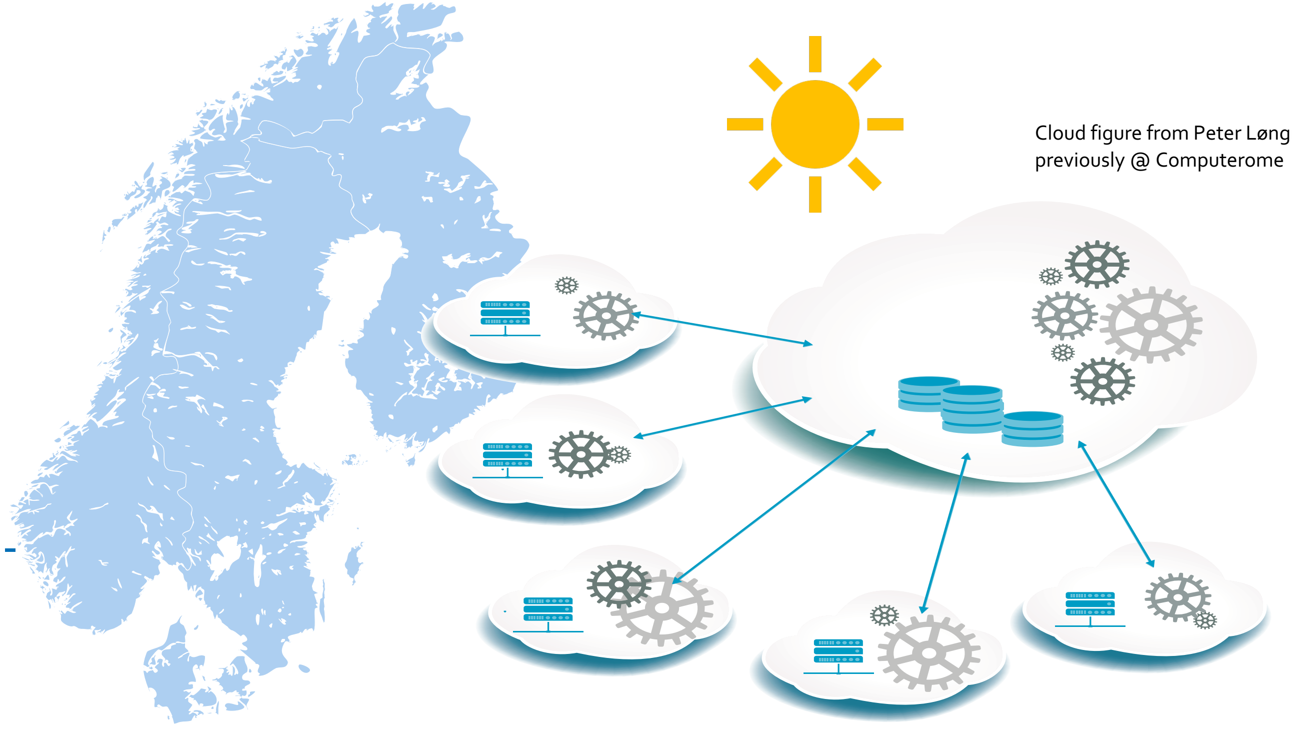
Data management

Metadata hub

Secure key management

Secure national source data

Secure compute infrastructure



Cloud figure from Peter Løngreen,
previously @ Computerome

Foundation

Guidelines

Governance frameworks incl. consent models

Legal and regulatory frameworks

Organisational coordination

National and regional leadership – ambitions, milestones

Interoperability framework

Recommendations

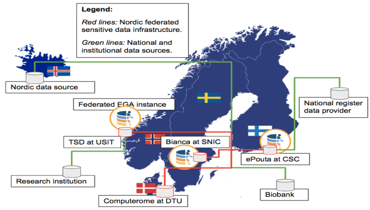
A. To establish a **high-level policy board** comprised of national actors from the health, research and innovation sectors.

- ❑ aligning national initiatives
- ❑ access to resources
- ❑ promote funding mechanisms and calls
- ❑ support of development, proof-of-value projects
- ❑ establish future governance

B. To secure **sustainable funding** from national and Nordic research/innovation and research infrastructure funders.

- ❑ *support research to test, utilise and contribute to* the Nordic Health Data *technology* solution and to the Nordic metadata standards framework.

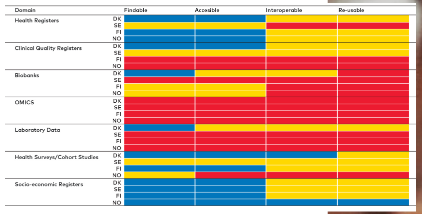
Recommendations (continued)



C. To establish a **technology expert group** comprised of national representatives of digital infrastructures on health data.

- ❑ outlining the *design and implementation of a Nordic Health Cloud*
- ❑ setting up use-cases/proof of values

D. To establish a **metadata expert group** comprised of the national health data hosting organisations and relevant national metadata initiatives.



Domain		Findable	Accesible	Interoperable	Re-usable
Health Registers	DK	🟦	🟦	🟨	🟨
	SE	🟨	🟨	🟥	🟥
	FI	🟦	🟦	🟨	🟨
	NO	🟦	🟦	🟨	🟨
Clinical Quality Registers	DK	🟦	🟦	🟨	🟨
	SE	🟨	🟨	🟨	🟨
	FI	🟥	🟥	🟥	🟥
	NO	🟥	🟥	🟥	🟥
Biobanks	DK	🟦	🟨	🟨	🟥
	SE	🟥	🟥	🟥	🟥
	FI	🟨	🟨	🟥	🟥
	NO	🟨	🟨	🟥	🟥
OMICS	DK	🟥	🟥	🟥	🟥
	SE	🟥	🟥	🟥	🟥
	FI	🟥	🟥	🟥	🟥
	NO	🟥	🟥	🟥	🟥
Laboratory Data	DK	🟦	🟨	🟨	🟨
	SE	🟥	🟥	🟥	🟥
	FI	🟥	🟥	🟥	🟥
	NO	🟥	🟥	🟥	🟥
Health Surveys/Cohort Studies	DK	🟦	🟦	🟦	🟨
	SE	🟨	🟨	🟨	🟨
	FI	🟦	🟦	🟨	🟨
	NO	🟨	🟥	🟥	🟥
Socio-economic Registers	DK	🟦	🟦	🟨	🟨
	SE	🟦	🟦	🟨	🟨
	FI	🟦	🟦	🟨	🟨
	NO	🟦	🟦	🟦	🟦

- ❑ *set up a Nordic health metadata repository ecosystem*
- ❑ i.e. a digitalised system for data documentation using established standards.

E. To establish an **expert group on legislation, ethics and trust** comprised of competencies in and perspectives on international legislation and policies.

- ❑ *national legislation should meet the technology demands* of the Nordic Health Cloud.

Photo by Maarten van den Heuvel on Unsplash

Aspects of interoperability

Nordic Commons

Political

High-level policy board

Establish governance model

Legal

Expert group on legislation, ethics and trust

Organisational

Alignment of the actors capabilities, Common goals, Agreed principles etc

Technical

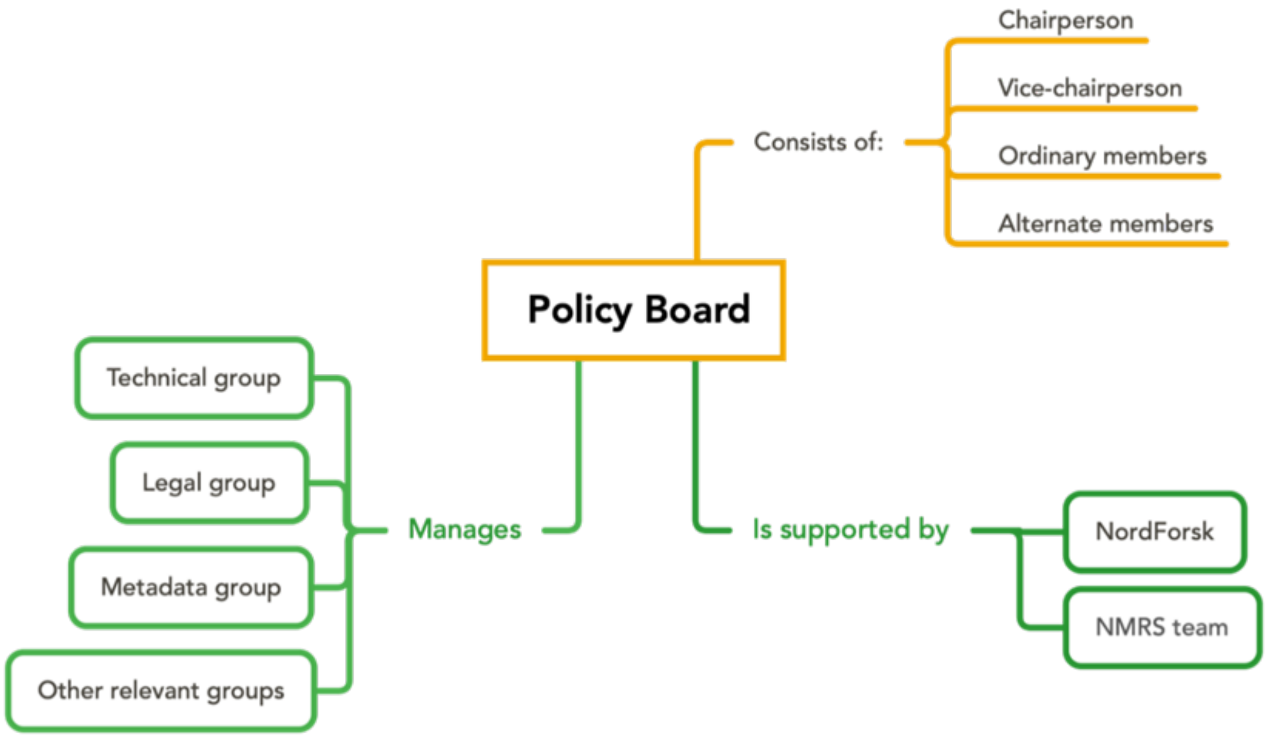
Technology expert group

Semantic

Metadata expert group

The initiative is being set up

- The Nordic Commons Project has been funded with 22 MDKK 2021-2024
- Letter of Appropriation to NordForsk to provide administrative support to Policy Board and coordinating function (March 2021)
- Norway and Finland Lead countries
- Mandate for Policy Board to be decided in June by MR-S and ÄK-S
- Nominations by Nordic countries of members and deputies to Policy Board later this spring



Policy Board

Consists of:

- Chairperson
- Vice-chairperson
- Ordinary members
- Alternate members

Manages

- Technical group
- Legal group
- Metadata group
- Other relevant groups

Is supported by

- NordForsk
- NMRS team

Ongoing international activities

Activities within the Nordic Commons project must align with ongoing initiatives

- European Open Science Cloud (research data)
- European Health Data Space
- 1+Million Genomes
- Covid-19 data platform
- etc

ERA PerMed

B1MG Beyond one Million Genomes

TEHDAS
Towards
European
Health
Data
Space

EOSC-Life

elixir

EUROPEAN OPEN SCIENCE CLOUD


European Commission

eHealth:
connecting health systems in Europe

OUR CHALLENGES

Increasing pressures and demands on European countries' health systems call for a change in the way of organising and managing the delivery of health services:

#DigitalSingleMarket #DigitalHealth @eHealth_EU @EU_Health

A Nordic Schengen for Health Data?

- Activities under the Nordic Commons have great potential
  - Several ongoing initiatives at Nordic level could be built upon
  - long tradition of cooperation (NeIC umbrella, at register and biobank level etc)
  - Strong Nordic added value

- Potential to develop
  - proof of values
  - Nordic proposals/pilots under TEHDAS and beyond

- Essential to involve key national actors + mandate + resources

- Existing hurdles and bottlenecks mapped in Nordic collaboration projects (ongoing)

Nordic Alliance for Clinical Genomics

EOSC NORDIC

Nordic Society of Human Genetics and Precision Medicine

neic
NORDIC E-INFRASTRUCTURE COLLABORATION

> The use of personal identity numbers and the many registries give us fantastic research opportunities in the Nordic region. This unsurpassed level of detail enables us to track the population from cradle to grave, and merging the data from the Nordic countries gives the analysis statistical strength.
>
> - Professor Jeanette Falck Winther

Thank you for your attention!

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