

Juni Palmgren  
NeIC Open Science with Sensitive Data  
May 15, 2019

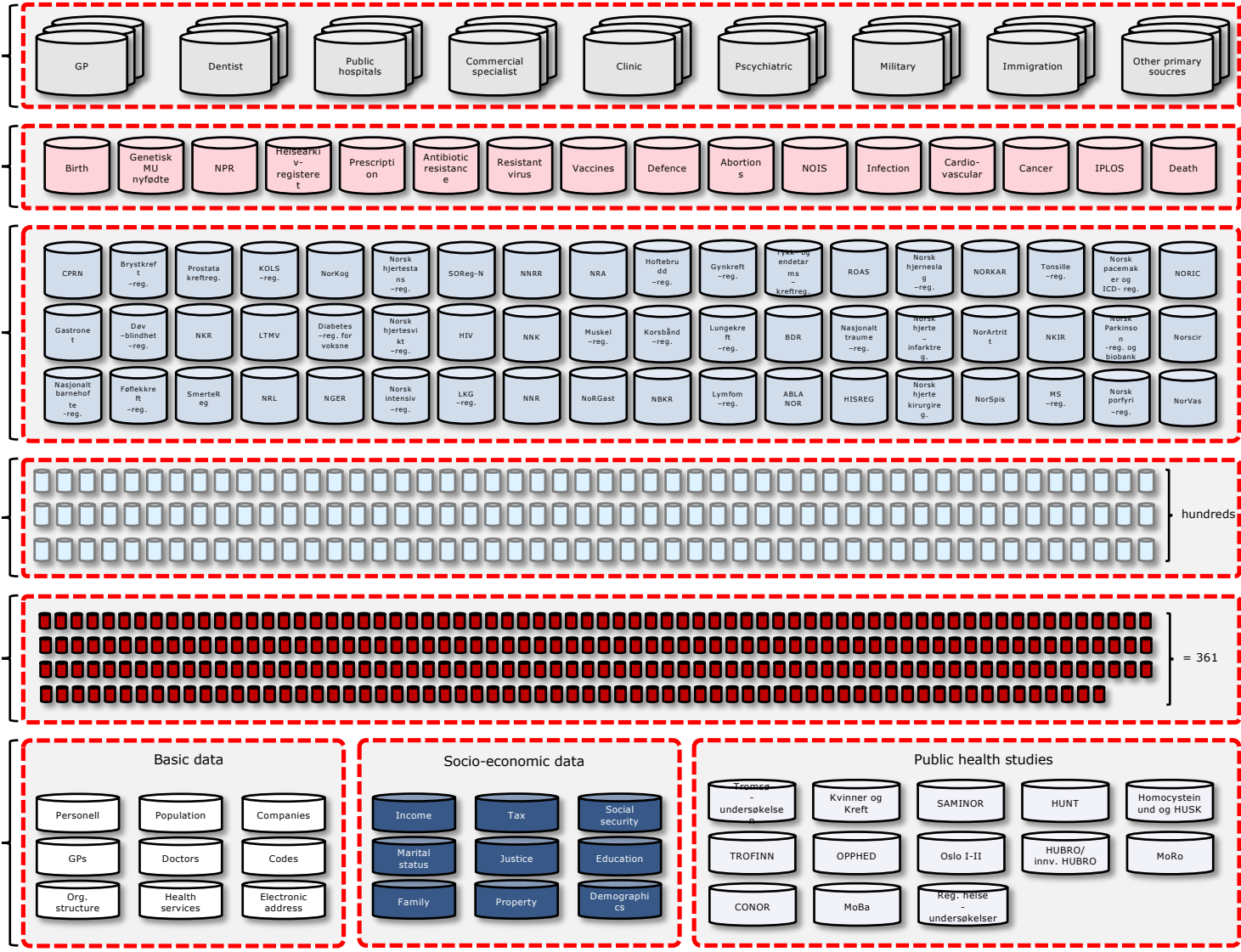
# Nordic Commons for Health Data

## Challenges and opportunities

The Norwegian Priority Project 2017: "Norden i omstilling"  
Ministry of Health, Norway

Nordic Council of Ministers EK-S →  
NordForsk Programme for Health and Welfare

# Broad scope: Health data sources in Norway



EHRs

Central health registers

National medical quality registers

Other medical quality registers

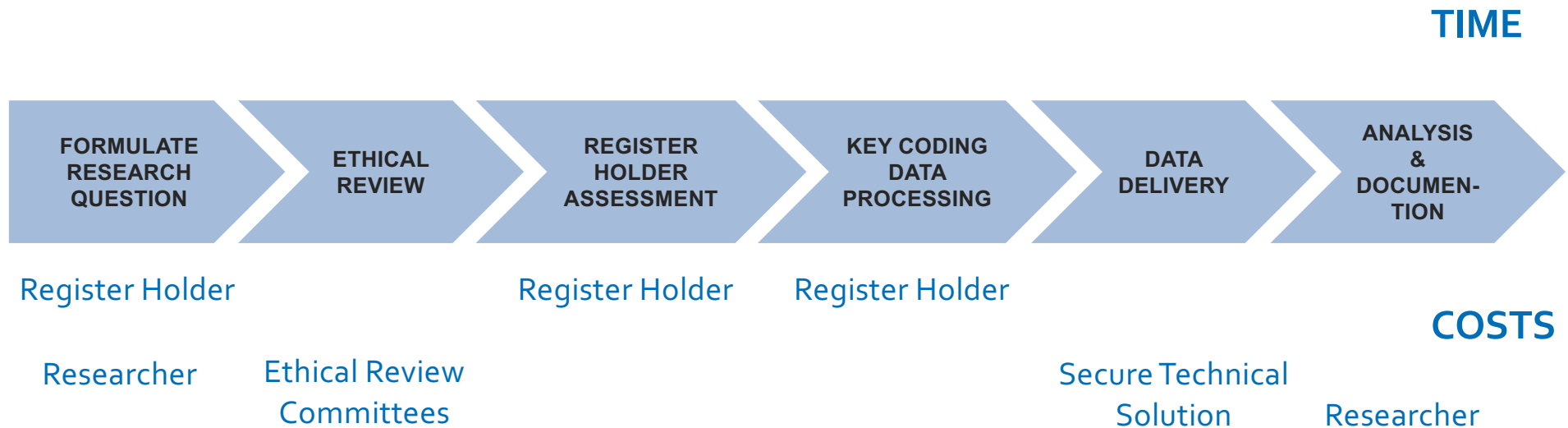
Biobanks

Other

From eHelsedir.



# The data retrieval process: key steps and actors



- The process is similar in the Nordic countries
- The time and costs vary - increase with a Nordic study



FORMULATE RESEARCH  
QUESTION

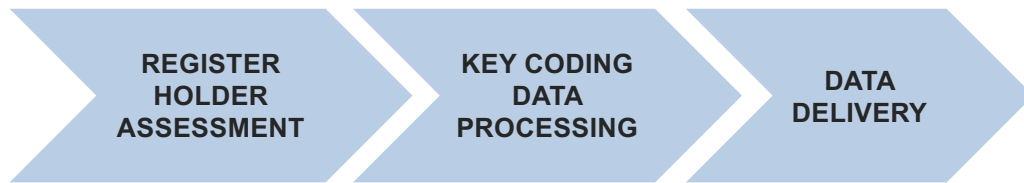
ETHICAL  
REVIEW

# Challenge: Lack of information

- What data exist? In which registers? Meaning?
- Can data in different registers be linked?
- How do I request data? Do I need any specific permissions?
- What legislation is applicable?

- **Limited knowledge of what permits are needed and what procedures are in place, even among researchers in the field**
- **Long and time-consuming dialogues with the register holders**
- **Need to apply for ethical permissions and data in each individual country**





## Challenge: Logistics

- Lack of coordinated processes between register holders both within countries and between Nordic countries
- Each national Statistics Agency inclined to lock-up their data at their own facility
- Need for secure technical environments for joint analysis

- **The researcher is dependent on a good dialogue between the register holders**
- **The researcher often needs to facilitate the process**
- **The register holders need to trust each other's technical platforms**

# Nordic Commons - vision

“A shared virtual space where scientists can work with the digital objects of **biomedical** research.

This is a system that will allow investigators to find, manage, share, use and reuse data, software, metadata and workflows”.

From Data Science at NIH

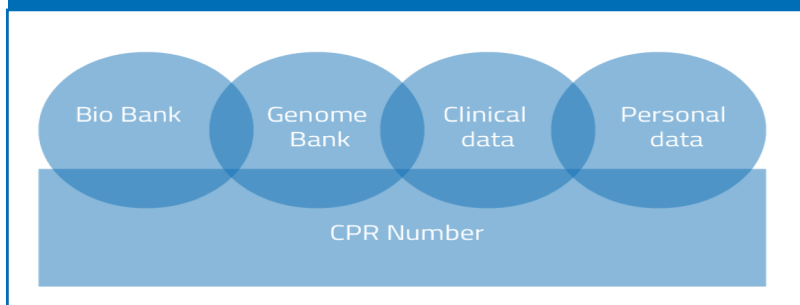


# National programs for Integrated Health Data

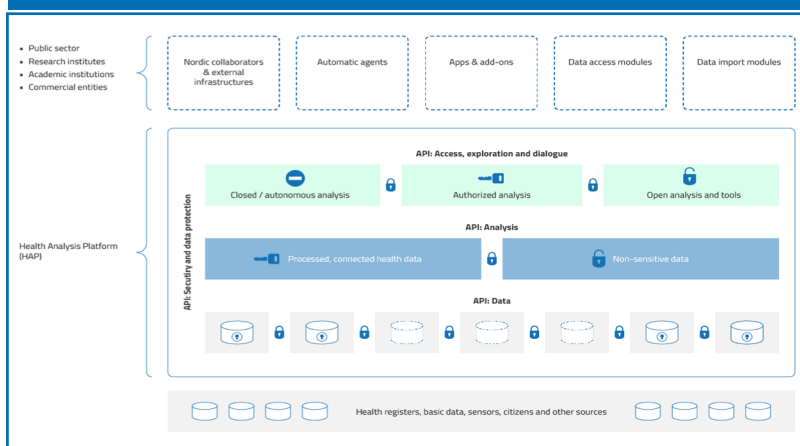
National organizational, legal, financial and ethical perspective

Focus on research, health care and industry

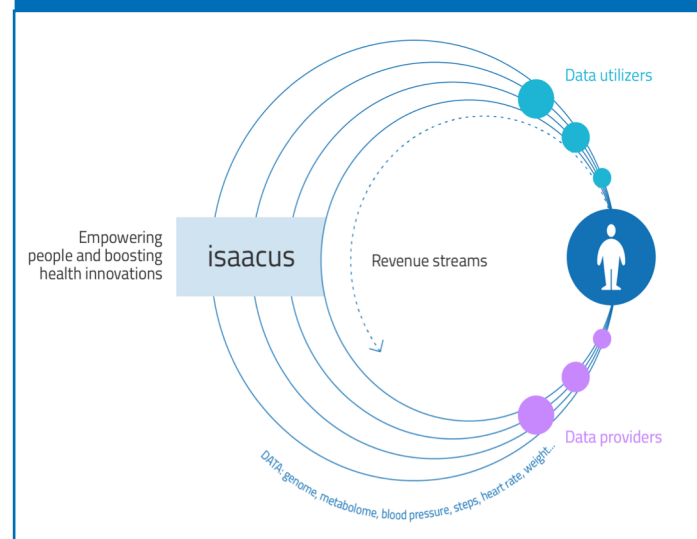
## Denmark - Unique position with Integrated Health Data



## Norway - The Norwegian Health Data Program is working on concepts for a national health analysis platform



## Finland - Isaacus programme



## Sweden – No specific national health data program

To date, there is no specific national health data program for Sweden. The landscape is rather fragmented.

Vetenskapsrådet has a **Register Infrastructure Programme** with a **RUT** data interface. Vinnova has a strategic innovation program **SweLife** and a recent initiative **Genomic Medicine Sweden**.

# Ongoing Nordic activities

## Nordic working groups under the Norwegian Priority project of the Nordic Council of Ministers 2017

- **TECHNICAL SOLUTIONS:** Synchronizing national e-infrastructures for secure federated storage, sharing and analyses of sensitive personal data
- **METADATA:** Focus on how to describe Nordic health data according to the FAIR\* principles
- **LEGAL FRAMEWORK:** Focus on legal questions related to technical solutions

\* Data being **F**indable-**A**ccessible-**I**nteroperable-**R**e-usable (**FAIR**)

## EOSC Nordic 2019

- NordForsk, through NeIC coordinates EOSC-NORDIC,
- a regional project aimed at implementation of European Commission European Open Science Cloud (EOSC)
- EOSC-NORDIC was approved in February 2019 with start September 2019.





# Technical solutions

The goal is to establish a federated, secure, scalable environment for using Nordic sensitive health datasets in research.

## *Working group*

- Peter Løngreen, Danish Technical University DTU, DK (Chair)
- Ali Syed, Danish Technical University DTU, DK
- Antti Pursula, Nordic e-Infrastructure Cooperation, FI
- Tommi Nyrönen, CSC, Elixir Finland, FI
- Hanne Cecilie Otterdal, Helsedataplattformen, NO
- Maria Francesca Lozzi, SIGMA2, NO
- Ann-Charlotte Sonnhhammer, SNIC Uppsala University, SE
- Hanifeh Khayerri, Swedish Research Council, SE

# Suggested action B: *A Technology Board*

## Initial tasks:

—To set up a detailed *design plan* for the architecture of the Nordic secure digital infrastructure solution. This needs to be agreed on by national e-infrastructures involved in the processing of sensitive data – possibly in collaboration with NeIC - and adopted by the strategic steering board in action A.

—To identify hosting institutions that represent national secure cloud performers in the Nordic setting

—To map existing national e-infrastructures that could serve as building blocks for the Nordic solution

—To define a set of authorization and authentication procedures

—To clarify legal prerequisites (e.g. for streaming data to a temporary joint virtual Nordic space)

—To identify risks and mismatches in a systematic way from the technical point of view

—To establish proof of concept for the infrastructure solution in collaboration with health data hosting organisations. By utilizing national and Nordic metadata repositories this will contribute to their development and to making national registries FAIR and useful for the



Nordic research community.

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# Suggested Action A: *A high-level Nordic strategic steering board covering health, research and innovation*

Set up with representatives from the national health data initiatives.

## Tasks:

- To oversee the work of the technology board and of the meta-data groups in order to **ensure a balanced focus on health, research and innovation.**
- To provide input to national legislation and ethics processes from a Nordic perspective
- To assess governance, risk management, and compliance of the Nordic solution
- To provide input on the formulation of **calls for funding for Nordic use-cases**, which drive the development of the digital infrastructure

**Responsible institutions:** Ministries of health, education and enterprise in the Nordic countries and the Nordic Council of Ministers

**Timeline:** 2020-2021



**CRUCIAL:**

**TO BUILD TRUST BETWEEN**

**NATIONAL TECHNOLOGY PROVIDERS**

**AND**

**NATIONAL HEALTH DATA HOSTING**

**INSTITUTIONS!**



# Summary VISION:

To shape the Nordic Region as a world-leading region for secondary use of health data. This requires:

- Adequate Nordic regional political steering (A)
- A secure **technology platform** for analysing and storing sensitive data (B)
- A Nordic health data population cohort of 27 million data subjects described with rich **metadata ecosystem** according to the FAIR principles (C).
- A clearly formulated legal and ethical framework for sharing data (D)
- Competence development and education (E)

*B and C form the **Nordic Secure Digital Infrastructure for Health Data (Nordic Commons)**. A, D and E are equally important.*



# Thank you for your attention!

**Juni Palmgren**

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Chair of NordForsk Expert group on Health Data Infrastructure

Coordinator

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## *Part II – additional slides*



# Health metadata

The goal is to create a Nordic common metadata repository ecosystem for harvesting and consuming Nordic health data resources.




## *Working group*

- Magnus Eriksson, Swedish Research Council, SE (Chair)
- Jeppe Klok Due, Det koordinerende organ  
för registerforskning, KOR, DK
- Arto Vuori, National Institute for Health and Welfare, FI
- Truls Korsgaard, Directorate for e-Health, NO



# Status in the Nordics – rough estimate (Fall-2018)

Domain	Country	Findable	Accesible	Interoperable	Reusable
Health Registers		Green	Green	Yellow	Yellow
		Yellow	Yellow	Red	Red
Green		Green	Yellow	Yellow	
Green		Green	Yellow	Yellow	
Registries of Clinical Quality		Yellow	Yellow	Yellow	Yellow
		Red	Red	Red	Red
Biobanks		Green	Yellow	Yellow	Yellow
		Red	Red	Red	Red
OMICS		Yellow	Yellow	Yellow	Yellow
		Red	Red	Red	Red
Laboratory data		Green	Yellow	Yellow	Yellow
		Red	Red	Red	Red
Health Surveys/Cohort studies		Green	Green	Green	Yellow
		Yellow	Yellow	Yellow	Yellow
Socioeconomic registries	Green	Green	Yellow	Red	
	Green	Green	Yellow	Yellow	
	Green	Green	Yellow	Yellow	



# Suggested Action C: A Nordic common metadata repository ecosystem

*Initial task to set up:*

- A Standards Group which works on how data should be described in order to be effectively interpreted, understood and exchanged by machines and humans.. The standards group works with the technology board to create proof of concept for a Nordic metadata ecosystem by participating in the realization of *use cases*.
- A Domain Expertise Group, which sets up a common foundation for a *clinical and health language*, which describes and defines data in the health domain terminologies for health registers, biobanks, electronic journals, laboratory results, population registers etc. *International standards* and international domain terminology are used where possible.



**CRUCIAL:**

TO BUILD TRUST BETWEEN  
**HEALTH DATA HOSTING INSTITUTIONS**  
WITHIN AND BETWEEN COUNTRIES



# Summary VISION:

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# Note 1: A use case based approach

Given the complexity, a use case based step-wise approach is proposed

- End users drive the incremental construction of the Nordic system through software development and relevant APIs
- The prioritisation of use cases needs careful attention and high-level coordination
- The data hosting institutions only give access to data to researchers under specific security protocols (harms assessment) and after an approval by an ethical review committee in some countries. These institutional security protocols need to be acknowledged in a coherent and trusted digital system.

**Example:** Collaboration between the Lundbeck Foundation Initiative for Integrative Psychiatric Research (iPSYCH at Aalborg University) and Statistics Denmark (DST).

- iPSYCH could access their own data and the DST data jointly through a dedicated link at the highly secure Computerome cloud infrastructure at the Danish Technical University. The DST could restrict and give access to their data for research use for one research project. For more information see <http://www.registerforskning.dk/projekter/store-datamaengder/>



## Note 2: The pace is fast!

- The building of common national IT-infrastructure and collaborative processes for health data in the respective Nordic countries is currently developing very rapidly.
- Technical capabilities, analytical understanding and collaboration practices in each Nordic country are developed in a fast moving environment and work is carried out in diverse projects between academia, IT-providers and healthcare organizations.
- **Common Nordic activities should be designed to keep up with this fast pace of development.**
- Funding mechanisms and calls for project proposals should be well adapted to the ongoing national activities and support also agile development projects, experimentation and proof-of-concept (POC) type projects.



# Thank you for your attention!

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