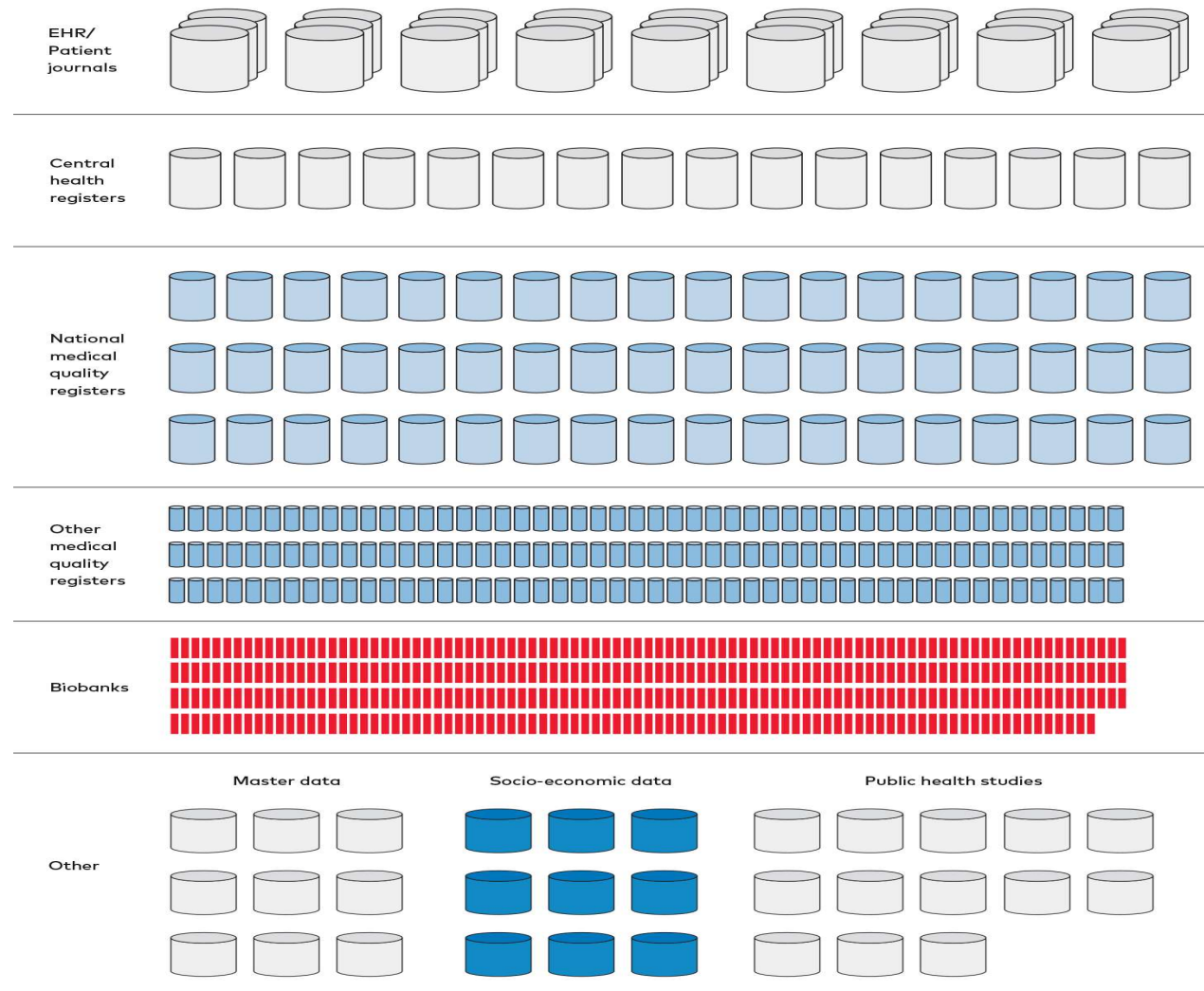# Health Data in Norway

Status November 2022

Health data in Norway

A lot of data…

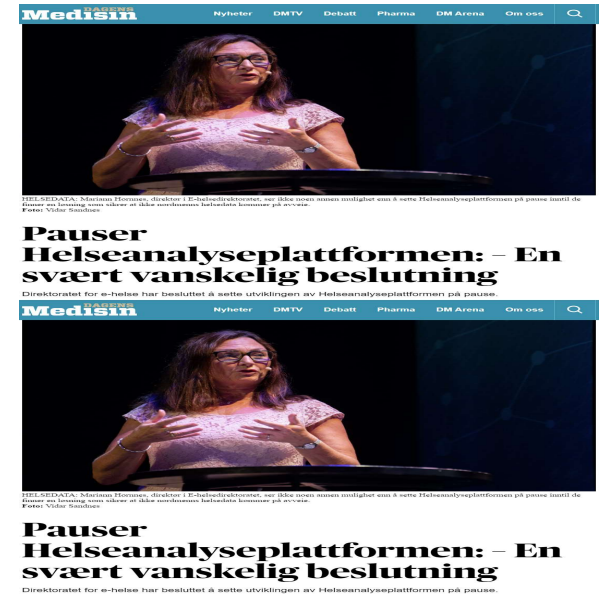…but difficult to access for secondary purposes

EHR/Patient journals

Central health registers

National medical quality registers

Other medical quality registers

Biobanks

Other

Master data   Socio-economic data   Public health studies

The Health Data Program

	1	2	3	4	5	6	7	8
	Søknadsveilederen	Helsedataportalen	Saksbehandlingen	Det enkle analyserommet	Den eksplorative analysen	Det enkle økosystemet	Avansert helseanalyse	Analyseøkosystemet
	Application guidance	Health data portal	Case handling	The simple analytics platform	The explorative analysis	The simple eco system	Advanced health analysis	Analytics eco system
	A) Webpage helsedata.no	B) Application and case handling services		C) Data and analytics platform		D) Analytics eco system		
	A) Helsedata.no	B) SØKNADS- OG SAKSBEHANDLINGSTJENESTER		C) DATA- OG ANALYSEPLATTFORM		D) ANALYSEØKOSYSTEM		

December 2021

What has happened in 2022

After the decision in December 2021 to pause development of the Health Analytics Platform
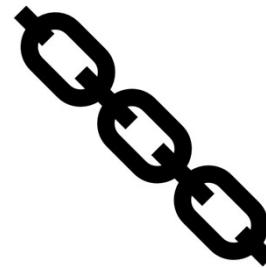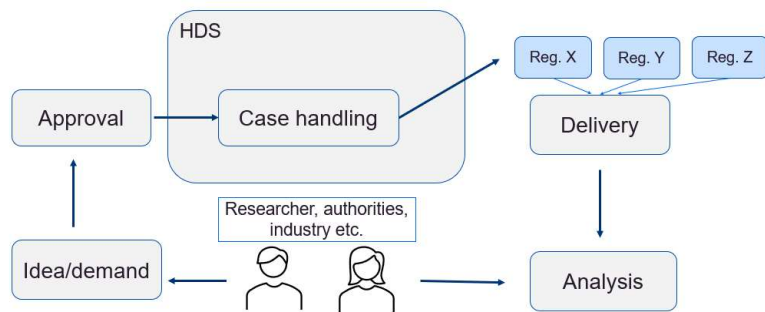
General
- Permit authority without data ownership
- Case handling IT solution (Pega)
- Ongoing work with meta data and variable catalogue
- Supporting register owners to decrease the back log
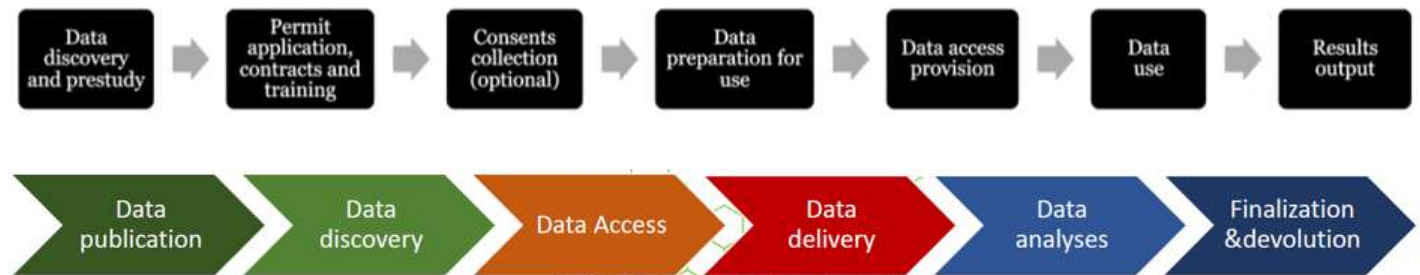
Data and analysis services
- «Packing down» the IT solution developed in the program
- Suggestion for solution in hybrid cloud
- Schrems II evaluations together with other public entities
- Evaluating decentralised model based on existing infrastructures
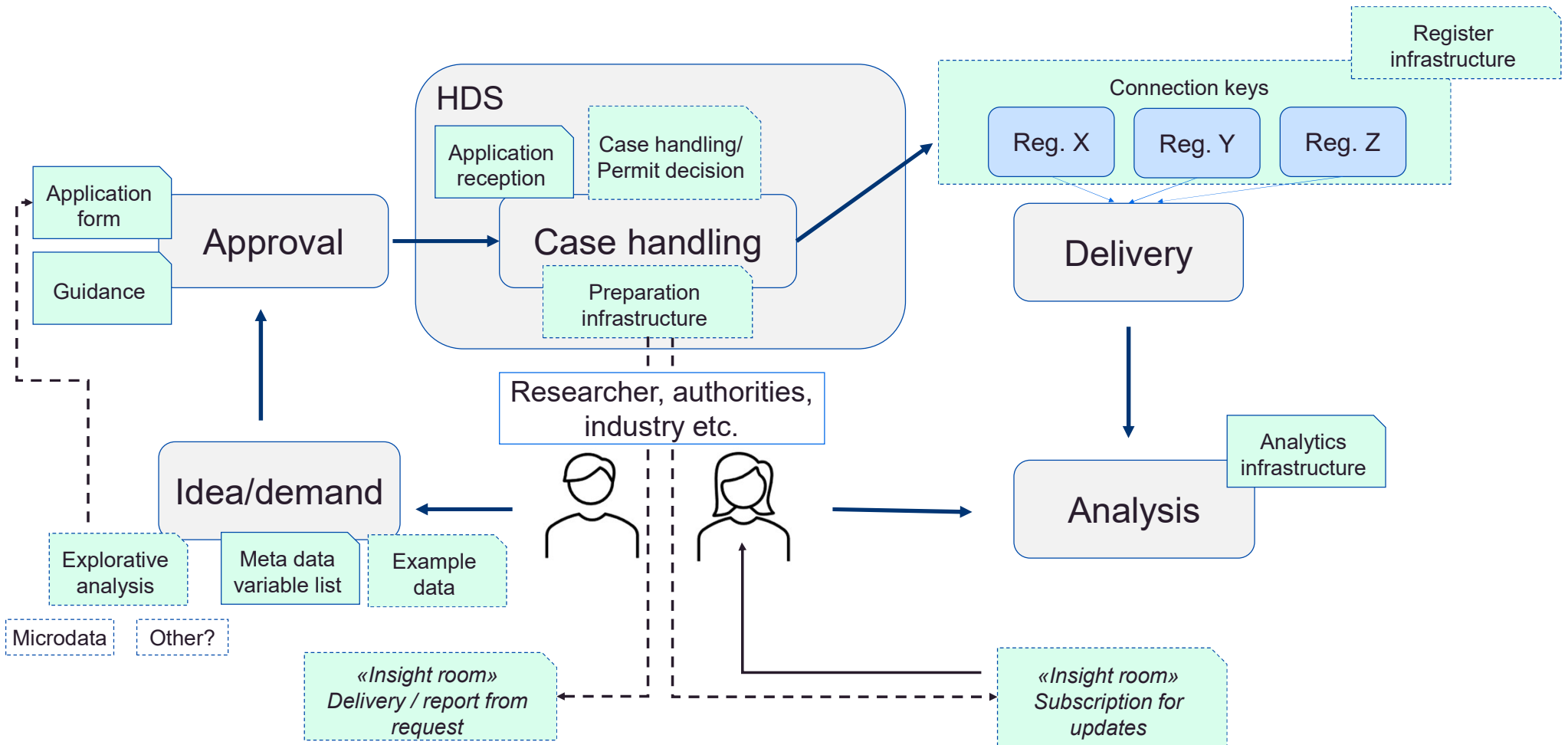
Eco system Norway vs Europe

HDS

TEHDAS/EHDS

Directorate of e-health

Building blocks in a distributed eco system

HDS

Application reception

Case handling/ Permit decision

Case handling

Preparation infrastructure

Application form

Guidance

Approval

Connection keys

Register infrastructure

Reg. X

Reg. Y

Reg. Z

Delivery

Researcher, authorities, industry etc.

Idea/demand

Explorative analysis

Meta data variable list

Example data

Microdata

Other?

Analytics infrastructure

Analysis

«Insight room» Delivery / report from request

«Insight room» Subscription for updates

Directorate of e-health

Status in Norway (as-is August 2022)

Established

Ongoing work/existing plan

No concrete initiative

- Based on mapping performed in the Nordic Commons initiative
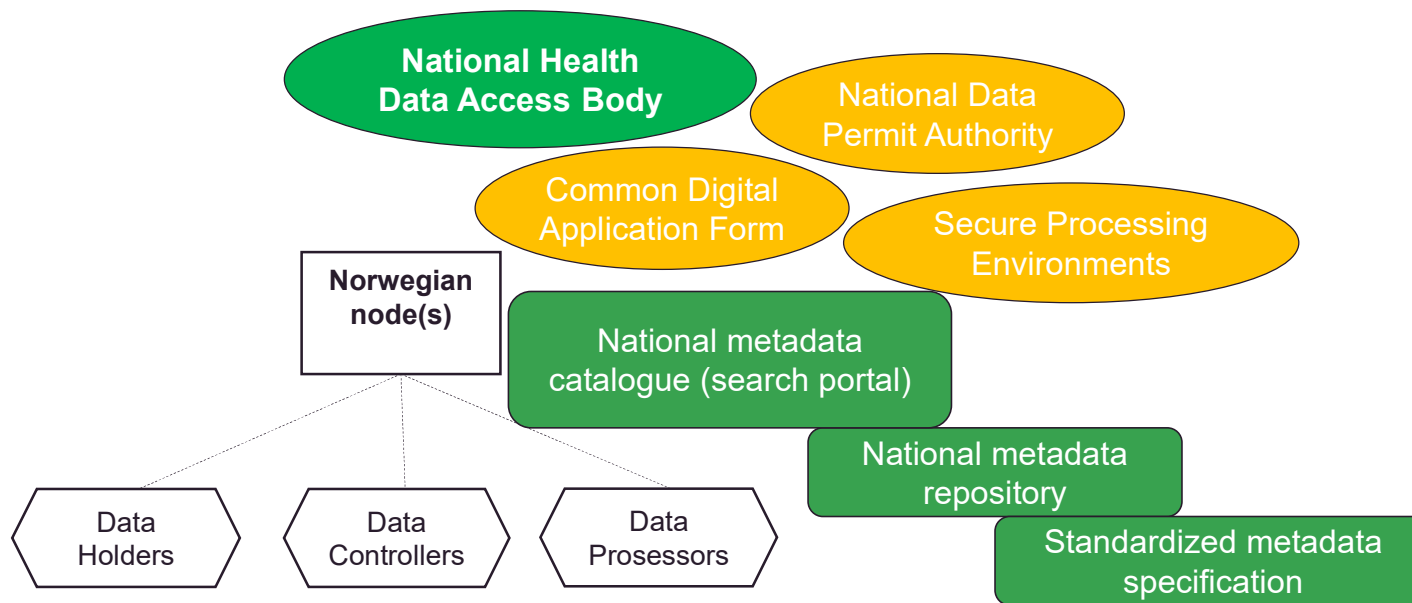
Priorities in 2023

Health data services (HDS) as a data permit authority

- Regulatory work
- Establish common processes and routines
- Introduce payment models

Further development of helsedata.no

- Common digital application form
- Case handling system
- Metadata and variable catalogue
- Guidance and support services

Further development of existing infrastructures

- Analytics infrastructures
- Data transfer processes
- Explorative analysis and access to anonymous data

Questions from Health Data Hub
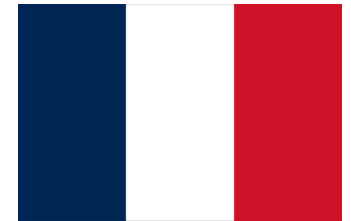
Interoperability

1. Which data standards are currently used in Norway?
2. What is the adoption level of international standards, for the three following levels : common data model, terminology, data sharing. What is the strategic mindset behind these adoptions ?
3. Personal health data anonymisation : How advanced is Norway on these questions ? What are the current processes deployed ? How public and shared is it ? Has any national definition / regulation around data anonymisation been adopted ?
4. How advanced is Norway in terms of synthetic data ? Which strategy/governance do you adopt for this type of data?
5. Regarding health data warehouses what is your technological infrastructure ? How well is Norway provided ? What is the national strategy to provide health centers with the adequate equipment?

Questions from Health Data Hub
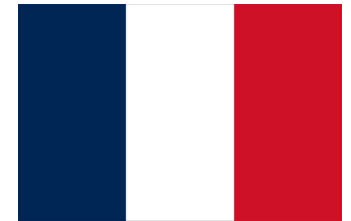
Europe

1. What is the current Norwegian State of play regarding secondary use of data ? How developed is its' interest for AI, and its' use of health databases ?

2. What are the current public policies regarding access to health data by researchers in Norway ? By other stakeholders (e.g. industry) ?

3. What is the current strategy on health data warehouses, community medicine, hospitals, specialized medicine (oncology in particular), etc. ?

4. Which organisations are the main actors for primary and secondary use of data ? How is the strategy articulated around these two types of use ? In France, it represents two detached strategies, one for each kind of use.

5. Does the Norwegian Center for eHealth Research interact with the Norway Directorate for eHealth (which is part of the EHDS pilot) ?

6. How much is your governance interested in European and international actions ? In which areas are you mostly interested in the actions from abroad ?

Questions from Health Data Center

1. What is the overall process for applying, approving and providing health data for secondary use? What are the main actors, who does what and where is health data stored and processed?

2. How has the use of Health data warehouses (infrastructure for analysis of health data) been regulated, including mandatory use and requirements for such environments? Including the standard on health data warehouses adopted by the French data protection authority (CNIL).

3. How has the certification process for such infrastructures been implemented in practice? Who is responsible for what, what's the process and where are things documented?

4. What is the process for following up compliance with requirements for such infrastructures, including audit procedures? Who is responsible for what, what's the process and where are things documented?

5. What are the available (certified) Health data warehouses and who are the providers?

6. What is the role and responsibility of Health data hub related to Health data warehouses?

7. How is the data transfer between the data providers and data users performed? How is Health data hub involved in this process?

8. How is the data responsibility set up throughout the process? Where in the process do responsibilities change? How is the responsibility regarding use of Health data warehouses set up between the data users and regulating bodies when a certificated infrastructure is used? (I.e. does this move/remove responsibilities from the data user?)

Questions from Health Data Center
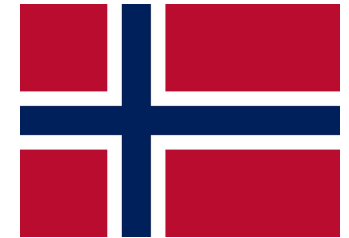
If there is time…

What is the status of use of public cloud provided by service providers subject to FISA702?
- Are you still allowed to use the third country cloud provider?
- Is your assessment to migrate to another solution still valid?
- Is an alternative solution in place?
- Is security measures in an alternative solution sufficient?
- Has there been need for use of analysis tools from providers in third countries?

More details on the solutions in the process for applying, approving and providing health data for secondary use.
- Solution for sending application, including level of detail
- Process for guidance to applicants and dialogue with data owners in the case handling process
- Focus on clarifications on details early in the process
- What type of data is handled, and from which sources
- What are the main benefits of establishing the HDH and what challenges remain
- Invoicing, e.g. what's the basis for calculating what to be invoiced