Co-funded by the
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NIPH
Norwegian Institute of Public Health

# SPUHiN

FAIR Secure Provision and Use of Health data in Norway
Project number: 101128232

## Deliverable number: D20/D91
## Deliverable title: Annual report of status of new and updated metadata

Date: March 2024

Co-funded by the European Union

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# 1. Background

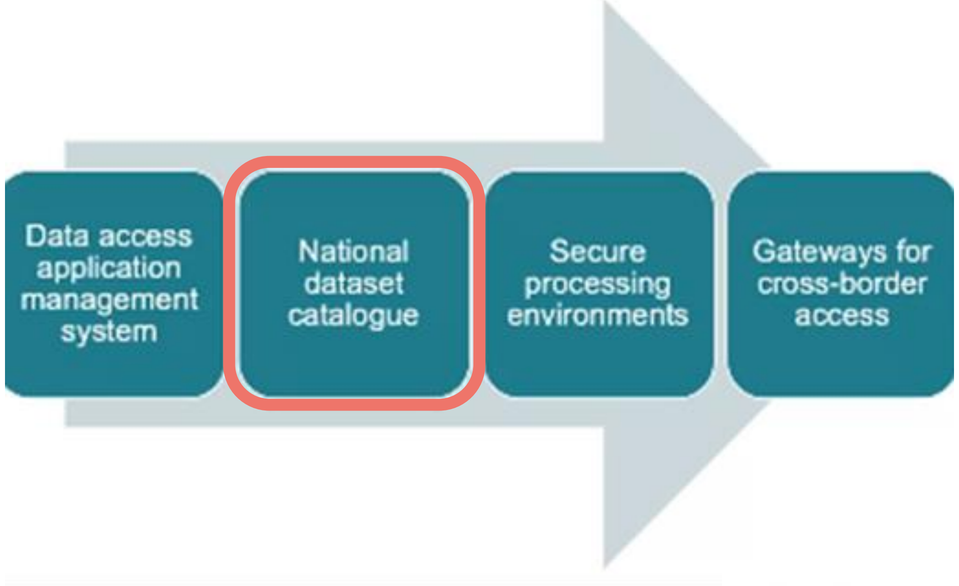
# Introduction to the SPUHiN project

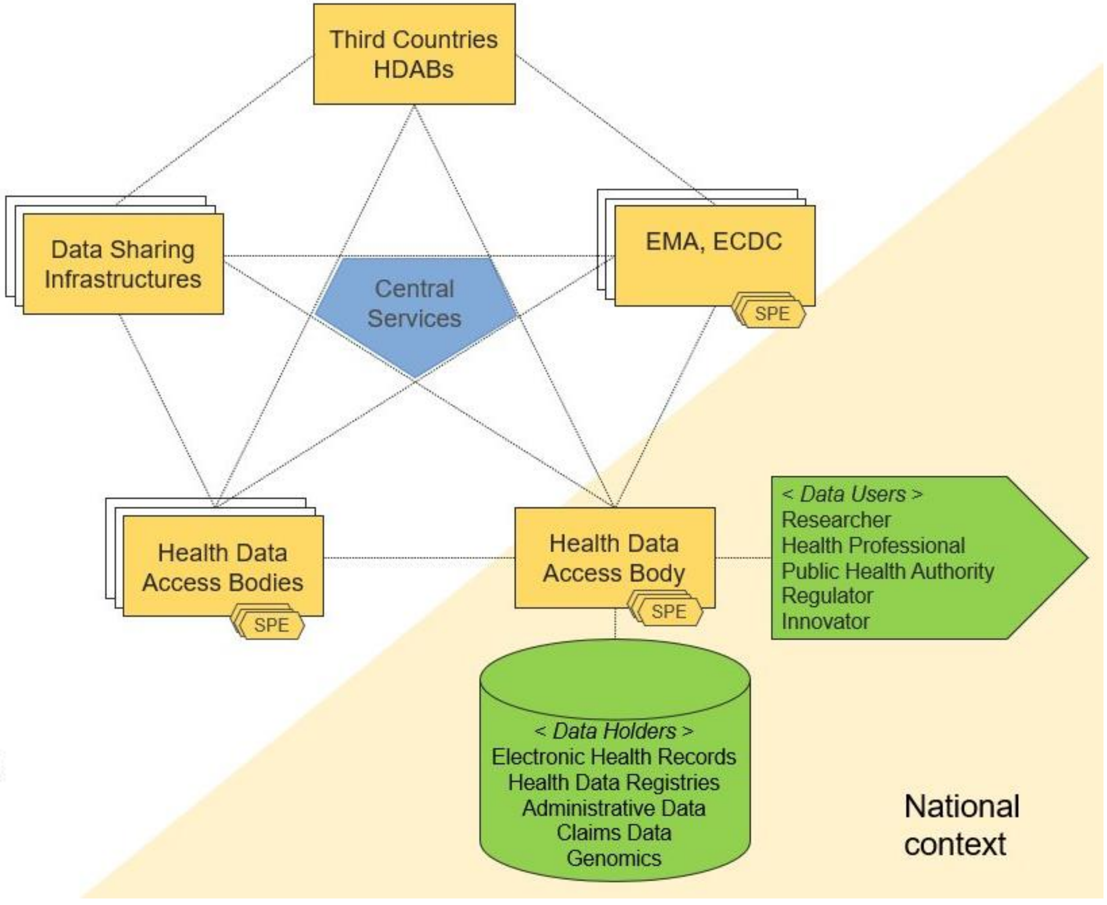
- The European Health Data Space (EHDS) proposes that Health Data Access Bodies (HDAB) are established in each EU/EEA country
- Health Data Service (HDS) in the Norwegian Institute of Public Health is established as the Norwegian HDAB
- Each HDAB is expected to implement a set of defined capabilities:
  - Data access application management system
  - National dataset catalogue
  - Secure processing environments
  - Gateways for cross-border access
- *See related illustration in the next page*

- The SPUHiN project has been granted funds via a Direct Grant from the EU4Health program to further develop the following capabilities:
  - Secure processing environments (SPE) – covered in WP5 and WP6
  - Gateway for cross-border access – covered in WP7 and WP8
  - National dataset catalogue – covered in WP9
- Article 50 in the proposed EHDS regulation is specifically relevant for Secure Processing Environments
- The development of a Data access application management system is part of the Norwegian HDAB activities, but not as scope of the SPUHiN project

# HDAB role and capabilites

**Four Digital Business Capabilities to be deployed:**





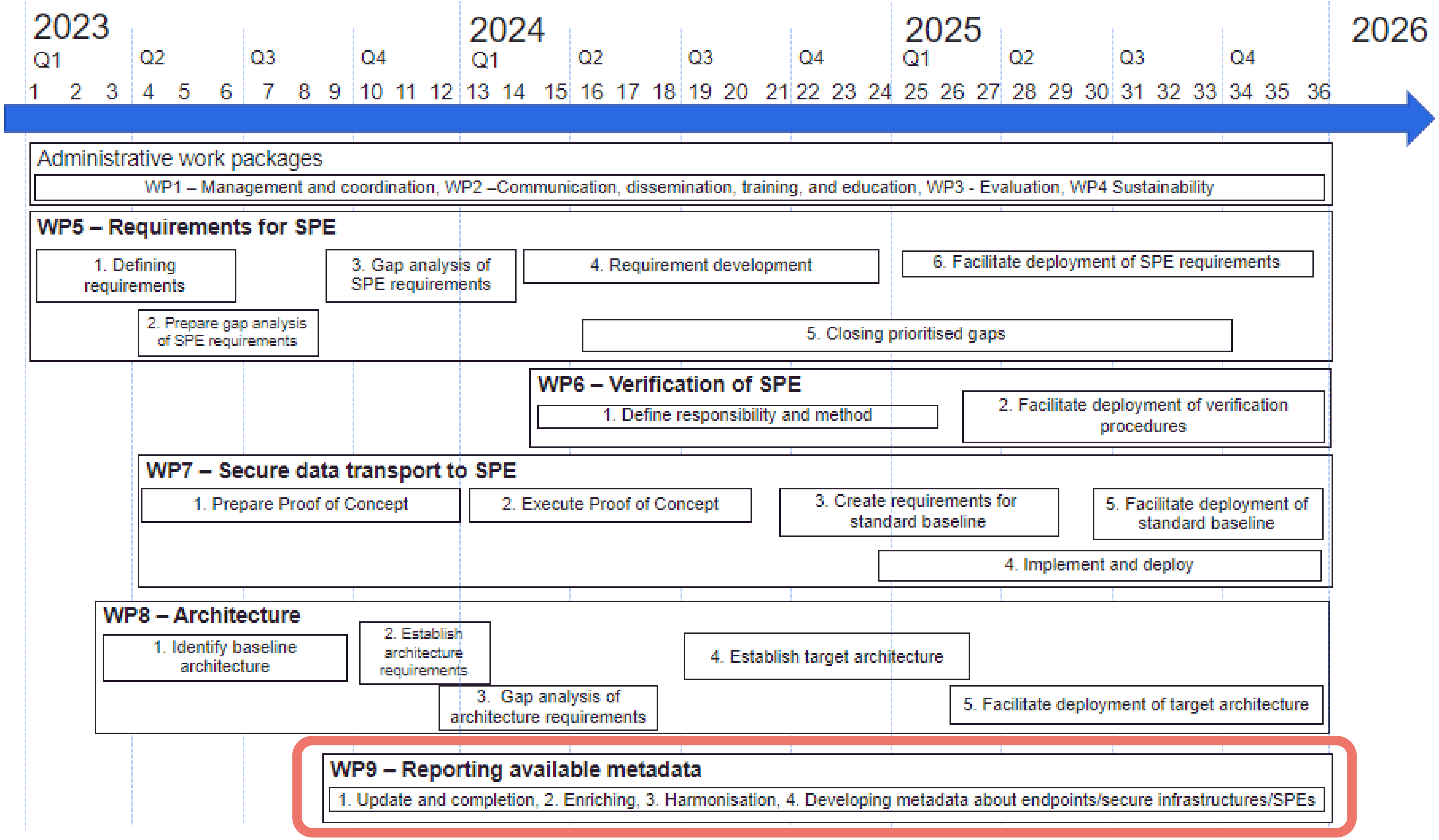
⬟ Central support services provided by EC

🟨 National data management services provided by authorised participants

SPE Secure Processing Environments

🟩 Local services provided by/to local partners

# SPUHiN project plan



Administrative work packages

WP1 – Management and coordination, WP2 –Communication, dissemination, training, and education, WP3 - Evaluation, WP4 Sustainability

**WP5 – Requirements for SPE**

1. Defining requirements
2. Prepare gap analysis of SPE requirements
3. Gap analysis of SPE requirements
4. Requirement development
5. Closing prioritised gaps
6. Facilitate deployment of SPE requirements

**WP6 – Verification of SPE**

1. Define responsibility and method
2. Facilitate deployment of verification procedures

**WP7 – Secure data transport to SPE**

1. Prepare Proof of Concept
2. Execute Proof of Concept
3. Create requirements for standard baseline
4. Implement and deploy
5. Facilitate deployment of standard baseline

**WP8 – Architecture**

1. Identify baseline architecture
2. Establish architecture requirements
3. Gap analysis of architecture requirements
4. Establish target architecture
5. Facilitate deployment of target architecture

**WP9 – Reporting available metadata**

1. Update and completion, 2. Enriching, 3. Harmonisation, 4. Developing metadata about endpoints/secure infrastructures/SPEs

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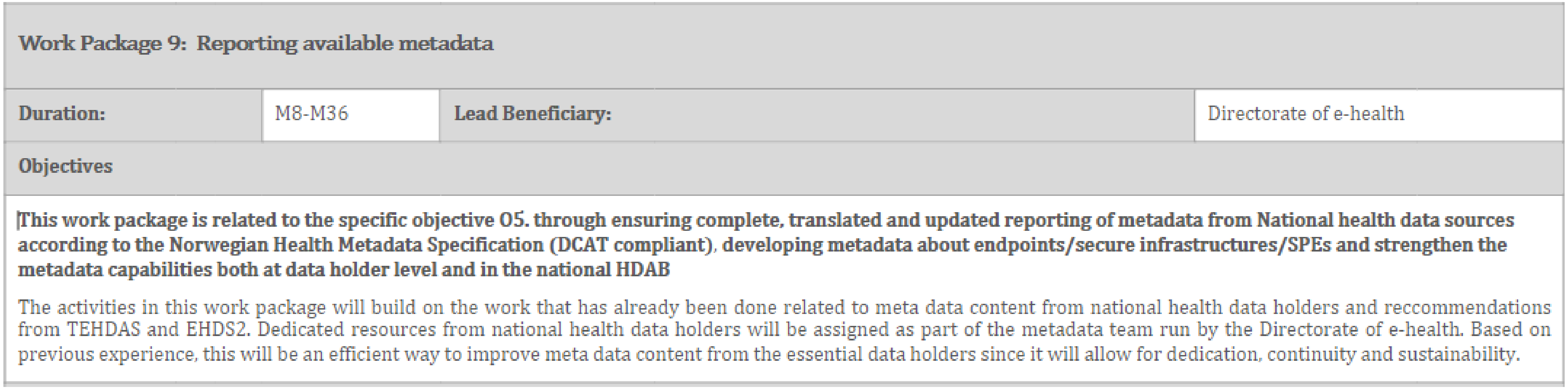
# WP9

## Reporting available metadata

# Objectives



| **Work Package 9: Reporting available metadata** | | | |
|---|---|---|---|
| **Duration:** | M8-M36 | **Lead Beneficiary:** | Directorate of e-health |
| **Objectives** | | | |
| **This work package is related to the specific objective O5. through ensuring complete, translated and updated reporting of metadata from National health data sources according to the Norwegian Health Metadata Specification (DCAT compliant), developing metadata about endpoints/secure infrastructures/SPEs and strengthen the metadata capabilities both at data holder level and in the national HDAB**<br>The activities in this work package will build on the work that has already been done related to meta data content from national health data holders and reccommendations from TEHDAS and EHDS2. Dedicated resources from national health data holders will be assigned as part of the metadata team run by the Directorate of e-health. Based on previous experience, this will be an efficient way to improve meta data content from the essential data holders since it will allow for dedication, continuity and sustainability. | | | |

**Guideline and evaluation tool FAIR priciples**

Direktoratet for e-helse

Veileder for bruk av FAIR prinsippene for helsedatakilder

Hvordan tilrettelegge for deling og gjenbruk av helsedata

**National Health Metadata Specification**

Direktoratet for e-helse

Nasjonal spesifikasjon for metadata om helsedata

Versjon 1.1

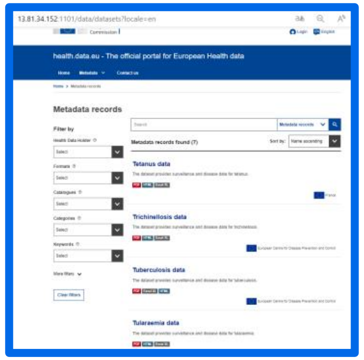
HITS 1230:2021

## Fill the gap…and more

- Prepare dataset description (Art. 41)
- Provide data quality and utility label for datasets (Art. 56)
- Make national datasets catalogue description publicly available (Art. 57)

**The pilot HealthDCAT-AP Editor**

**The pilot live version of the EU Health Metadata Catalogue**



# Activities and division of work (WP description)

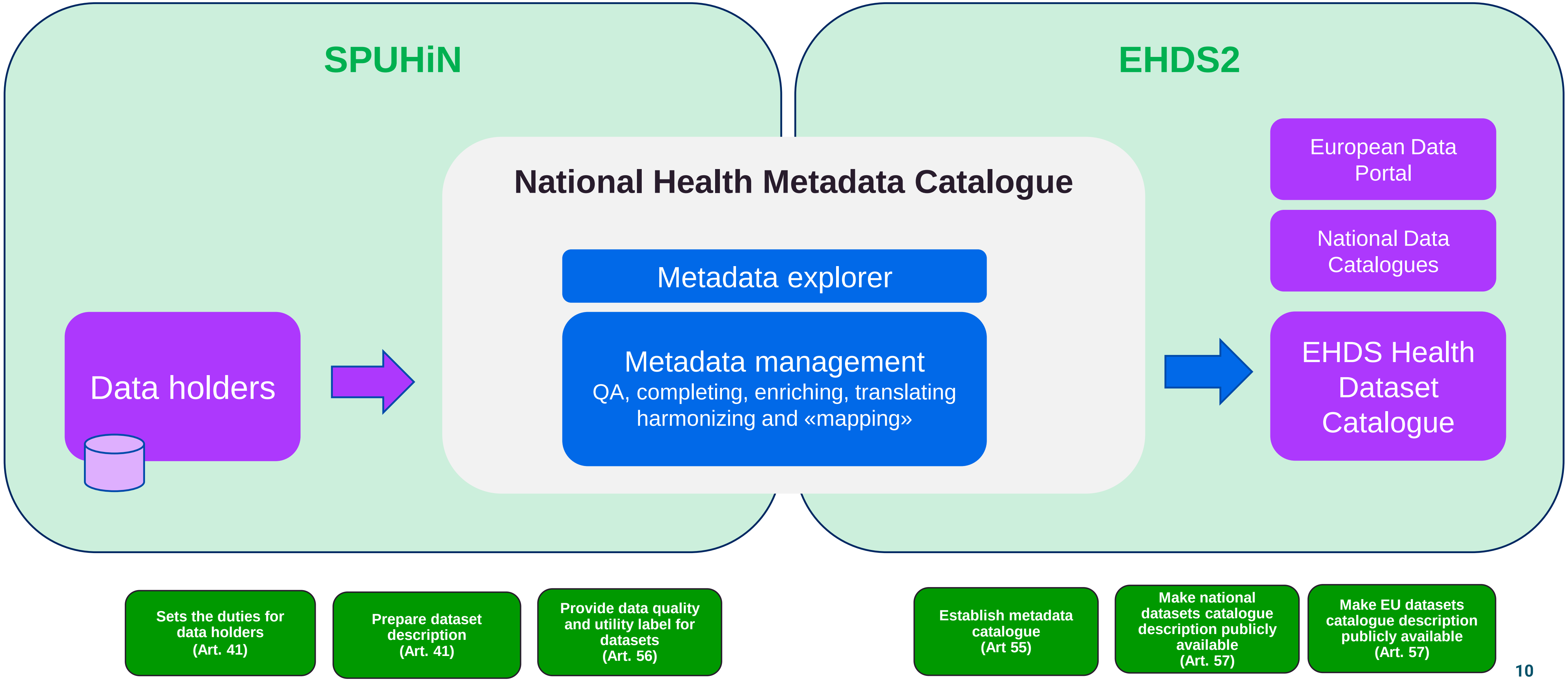
| Task Number | Task Name | Description | Comments |
|---|---|---|---|
| T9.1 | Completion, translation and updating. | Completion, translation and updating **mandatory metadata** about data sources, belonging variables and code lists/value sets according to the Norwegian Health Metadata Specification and the upcoming HealthDCAT-AP. | Only for the National Health Registries in scope (Slide 15).<br>To be completed in the data holders metadata management tools AND in the EHDS2/WP6 pilot HealthDCAT-AP editor. |
| T9.2 | Enriching | Adding more metadata about Accessibility, Interoperability and Re-useability to make the data sources (datasets) more findable and discoverable. | **Recommended properties** according to the National Health Metadata Specification and the HealthDCAT-AP. |
| T9.3 | Harmonization | Contribute to categorization and harmonization of themes and key variables across specifc domains and data sources using for example OMOP as common information model. | Thematization according to the classes in the OMOP information model. Only the defined key variables. |
| T9.4 | Developing metadata about endpoints/secure infrastructures/SPEs. | Define key properties for endpoints/secure infrastrctures/SPEs based on DCAT, and publish this in the Norwegian Health Metadata Catalogue to make them more findable and discoverable. | |

# Related EU activities

- **The work in SPUHiN will be done coordinated and in close co-operation with the other ongoing initiatives in EHDS**
  - EHDS2/WP6 Metadata standards (Co-chair)
  - CoP/Subgroup Datasets Catalogue (Contributer)
  - TEHDAS2/WP5 Data Discover (Major contributor)
  - QUANTUM (Contributor)
  - European Open Science Cloud (EOSC)

- **Interface to EHDS2**
  - EHDS/WP6 is focusing on preparing and sharing metadata with the EU Dataset Catalogue according to the HealthDCAT-AP specification.
  - SPUHiN/WP9 is focusing on rising the FAIRness, the quality, of the metadata reported from the data holders to the National Health Metadata Catalogue according to the National Health metadata specification.

# The Norwegian metadata value chain



**SPUHiN**

**EHDS2**

**National Health Metadata Catalogue**

Metadata explorer

Metadata management
QA, completing, enriching, translating harmonizing and «mapping»

Data holders

European Data Portal

National Data Catalogues

EHDS Health Dataset Catalogue

**Sets the duties for data holders (Art. 41)**

**Prepare dataset description (Art. 41)**

**Provide data quality and utility label for datasets (Art. 56)**

**Establish metadata catalogue (Art 55)**

**Make national datasets catalogue description publicly available (Art. 57)**

**Make EU datasets catalogue description publicly available (Art. 57)**

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# 2. Methodology and considerations

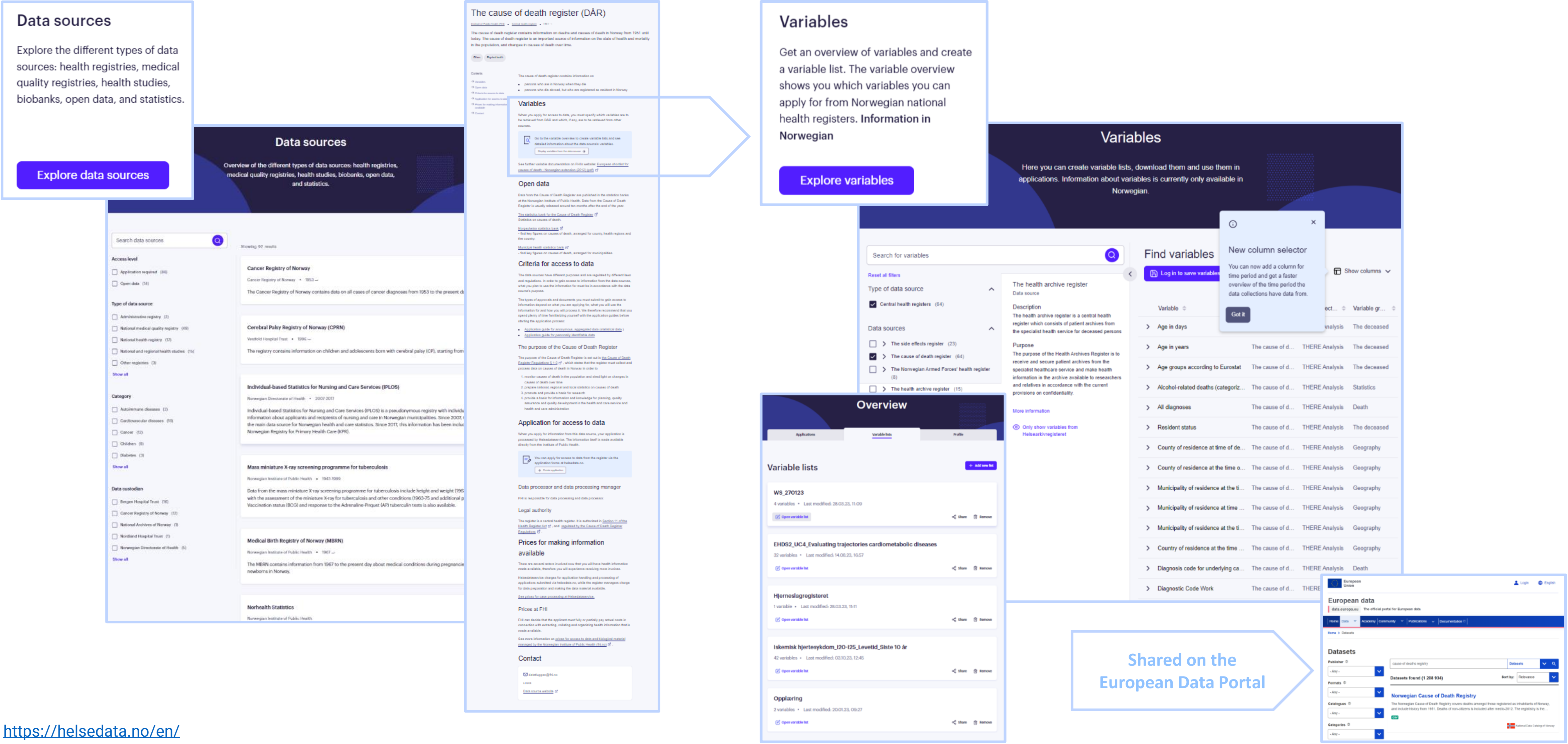
# Norwegian data sources and metadata management

- The Norwegian Health Metadata Catalogue has been operational for nearly 5 years and consist of a data source (datasets) explorer with «descriptive» metadata and a variable explorer with «structured» metadata, for example metadata about variables, value sets and statistics (Slide 14).
- The data source explorer contains information (metadata) about most data sources from which you can apply for data from. Most of the information is translated to English.
- The variable and value set explorer so far contains information (metadata) from many national health data registries, about 30% of national medical quality registries, three health surveys and a selection of metadata from Statiscs Norway.
- The variable explorer also contains a service where applicants can discuss, define and specify the variables and values they will apply for (their data model).

# Norwegian data sources and metadata management

- The metadata management process starts at data holder level and ends in different external metadata catalogues like the National Common Data Catalogue and the official European Open Datasets Catalogue (slide 14, 16).
  - The process starts at dataholder level with their internal metadata- and data management («Order in own house»).
  - The data holders report their metadata according to the National Health Metadata Specification and the duties in their assignment documents.
  - The National HDAB manage the metadata reported by the dataholders in a national metadata repository.
  - The metadata are shared and loaded into an EPI-server and customized for the presentation in the National Health Metadata Catalogue.
  - The «descritive metadata» are transformed to DCAT-AP-NO and shared with the Norwegian Common Data Catalogue and from there to the official European Data Portal.
  - SPUHiN/WP9 will enable the National Health Registries to provide high quality metadata to meet the expectations of both the National Health Metadata Specification and the standard HealthDCAT-AP (in process) and improve the FAIRness of the Norwegain National Health Registries (within the scope) in both the Norwegian Health Metadata Catalogue and the EU Health Dataset Catalogue (in process).
- The national Norwegain «Metadata-team» work closely together with the data holders and has over the years established national health metadata commuinty that has regularly meetings and workhops.
- Additionally, the «Metadata-team» has been, and is, a major and engaged contributor in a number of Nordic and European initiatives:
  - National Initaitives Network
  - Nordic Commons
  - EHDS2/QUANTUM
  - TEHDAS 1 and 2
  - EHDS CoP

# Norwegian National Health Metadata Catalogue



## Data sources

Explore the different types of data sources: health registries, medical quality registries, health studies, biobanks, open data, and statistics.

**Data sources**

Overview of the different types of data sources: health registries, medical quality registries, health studies, biobanks, open data, and statistics.

Access level
- ☐ Application required (86)
- ☐ Open data (14)

Type of data source
- ☐ Administrative registry (2)
- ☐ National medical quality registry (49)
- ☐ National health registry (17)
- ☐ National and regional health studies (15)
- ☐ Other registries (3)

Category
- ☐ Autoimmune diseases (2)
- ☐ Cardiovascular diseases (18)
- ☐ Cancer (12)
- ☐ Children (9)
- ☐ Diabetes (3)

Data custodian
- ☐ Bergen Hospital Trust (16)
- ☐ Cancer Registry of Norway (12)
- ☐ National Archives of Norway (1)
- ☐ Nordland Hospital Trust (1)
- ☐ Norwegian Directorate of Health (5)

Showing 92 results

**Cancer Registry of Norway**
Cancer Registry of Norway • 1953 –
The Cancer Registry of Norway contains data on all cases of cancer diagnoses from 1953 to the present d

**Cerebral Palsy Registry of Norway (CPRN)**
Vestfold Hospital Trust • 1996 –
The registry contains information on children and adolescents born with cerebral palsy (CP), starting from

**Individual-based Statistics for Nursing and Care Services (IPLOS)**
Norwegian Directorate of Health • 2007-2017
Individual-based Statistics for Nursing and Care Services (IPLOS) is a pseudonymous registry with individu information about applicants and recipients of nursing and care in Norwegian municipalities. Since 2007, t the main data source for Norwegian health and care statistics. Since 2017, this information has been incluc Norwegian Registry for Primary Health Care (KPR).

**Mass miniature X-ray screening programme for tuberculosis**
Norwegian Institute of Public Health • 1943-1999
Data from the mass miniature X-ray screening programme for tuberculosis include height and weight (196 with the assessment of the miniature X-ray for tuberculosis and other conditions (1963-75 and additional p Vaccination status (BCG) and response to the Adrenaline-Pirquet (AP) tuberculin tests is also available.

**Medical Birth Registry of Norway (MBRN)**
Norwegian Institute of Public Health • 1967 –
The MBRN contains information from 1967 to the present day about medical conditions during pregnancie newborns in Norway.

**Norhealth Statistics**
Norwegian Institute of Public Health

## The cause of death register (DÅR)

The cause of death register contains information on deaths and causes of death in Norway from 1951 until today. The cause of death register is an important source of information on the state of health and mortality in the population, and changes in causes of death over time.

Contents

The cause of death register contains information on
- persons who are in Norway when they die
- persons who die abroad, but who are registered as resident in Norway

### Variables

When you apply for access to data, you must specify which variables are to be retrieved from DÅR and which, if any, are to be retrieved from other sources.

Go to the variable overview to create variable lists and see detailed information about the data source's variables.

See further variable documentation on FHI's website: European shortlist for causes of death - Norwegian extension (2012) (pdf)

### Open data

Data from the Cause of Death Register are published in the statistics banks at the Norwegian Institute of Public Health. Data from the Cause of Death Register is usually released around ten months after the end of the year.

The statistics bank for the Cause of Death Register
Statistics on causes of death.

Norgeshelsa statistics bank
- find key figures on causes of death, arranged for county, health regions and the country.

Municipal health statistics bank
- find key figures on causes of death, arranged for municipalities.

### Criteria for access to data

The data sources have different purposes and are regulated by different laws and regulations. In order to gain access to information from the data sources, what you plan to use the information for must be in accordance with the data source's purpose.

The types of approvals and documents you must submit to gain access to information depend on what you are applying for, what you will use the information for and how you will process it. We therefore recommend that you spend plenty of time familiarizing yourself with the application guides before starting the application process:

- Application guide for anonymous, aggregated data (statistical data )
- Application guide for personally identifiable data

The purpose of the Cause of Death Register

The purpose of the Cause of Death Register is set out in the Cause of Death Register Regulations § 1-3, which states that the register must collect and process data on causes of death in Norway in order to

1. monitor causes of death in the population and shed light on changes in causes of death over time
2. prepare national, regional and local statistics on causes of death
3. promote and provide a basis for research
4. provide a basis for information and knowledge for planning, quality assurance and quality development in the health and care service and health and care administration

### Application for access to data

When you apply for information from this data source, your application is processed by Helsedataservice. The information itself is made available directly from the Institute of Public Health.

You can apply for access to data from the register via the application forms at helsedata.no.

Data processor and data processing manager

FHI is responsible for data processing and data processor.

Legal authority

The register is a central health register. It is authorized in Section 11 of the Health Register Act, and regulated by the Cause of Death Register Regulations.

### Prices for making information available

There are several actors involved now that you will have health information made available, therefore you will experience receiving more invoices.

Helsedataservice charges for application handling and processing of applications submitted via helsedata.no, while the register managers charge for data preparation and making the data material available.

See prices for case processing at Helsedataservice.

Prices at FHI

FHI can decide that the applicant must fully or partially pay actual costs in connection with extracting, collating and organizing health information that is made available.

See more information on prices for access to data and biological material managed by the Norwegian Institute of Public Health (fhi.no).

### Contact

datatilgang@fhi.no

Links

Data source website

## Variables

Get an overview of variables and create a variable list. The variable overview shows you which variables you can apply for from Norwegian national health registers. **Information in Norwegian**

**Variables**

Here you can create variable lists, download them and use them in applications. Information about variables is currently only available in Norwegian.

Reset all filters

Type of data source
- ☑ Central health registers (64)

Data sources
- ☐ The side effects register (23)
- ☑ The cause of death register (64)
- ☐ The Norwegian Armed Forces' health register (8)
- ☐ The health archive register (15)

The health archive register
Data source

Description
The health archive register is a central health register which consists of patient archives from the specialist health service for deceased persons

Purpose
The purpose of the Health Archives Register is to receive and secure patient archives from the specialist healthcare service and make health information in the archive available to researchers and relatives in accordance with the current provisions on confidentiality.

More information

Only show variables from Helsearkivregisteret

**Find variables**

New column selector

You can now add a column for time period and get a faster overview of the time period the data collections have data from.

| Variable | | ect... | Variable gr... |
|---|---|---|---|
| Age in days | | nalysis | The deceased |
| Age in years | The cause of d... | THERE Analysis | The deceased |
| Age groups according to Eurostat | The cause of d... | THERE Analysis | The deceased |
| Alcohol-related deaths (categoriz... | The cause of d... | THERE Analysis | Statistics |
| All diagnoses | The cause of d... | THERE Analysis | Death |
| Resident status | The cause of d... | THERE Analysis | The deceased |
| County of residence at time of de... | The cause of d... | THERE Analysis | Geography |
| County of residence at the time o... | The cause of d... | THERE Analysis | Geography |
| Municipality of residence at the ti... | The cause of d... | THERE Analysis | Geography |
| Municipality of residence at time ... | The cause of d... | THERE Analysis | Geography |
| Municipality of residence at the ti... | The cause of d... | THERE Analysis | Geography |
| Country of residence at the time ... | The cause of d... | THERE Analysis | Geography |
| Diagnosis code for underlying ca... | The cause of d... | THERE Analysis | Death |
| Diagnostic Code Work | The cause of d... | THERE | |

**Overview**

**Variable lists**

**WS_270123**
4 variables • Last modified: 28.03.23, 11:09

**EHDS2_UC4_Evaluating trajectories cardiometabolic diseases**
32 variables • Last modified: 14.08.23, 16:57

**Hjerneslagregisteret**
1 variable • Last modified: 28.03.23, 11:11

**Iskemisk hjertesykdom_I20-I25_Levetid_Siste 10 år**
42 variables • Last modified: 03.10.23, 12:45

**Opplæring**
2 variables • Last modified: 20.01.23, 09:27

Shared on the European Data Portal

**European data**

data.europa.eu The official portal for European data

**Datasets**

Datasets found (1 208 934)

**Norwegian Cause of Death Registry**
The Norwegian Cause of Death Registry covers deaths amongst those registered as inhabitants of Norway, and include history from 1951. Deaths of non-citizens is included after medio-2012. The registry is the...

https://helsedata.no/en/

# National health registries in scope

### Norwegian Patient Registry (NPR)

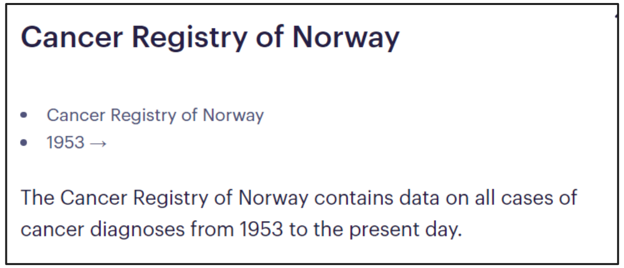
- Norwegian Directorate of Health
- 1997 →

The Norwegian Patient Registry contains information on everyone who is referred for or has received specialized healthcare at a hospital, outpatients' clinic or from contract specialists.

### Norwegian Registry for Primary Health Care (KPR)

- Norwegian Directorate of Health
- 2016 →

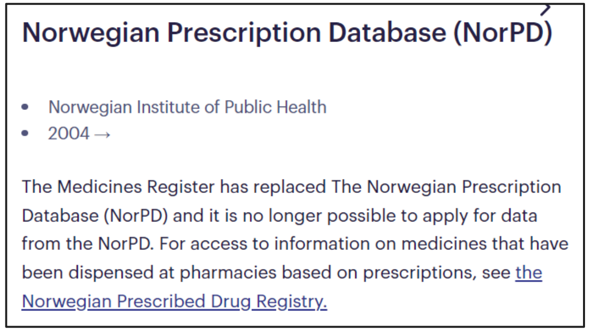
The Norwegian Registry for Primary Health Care is a collection of registries with personally identifiable information. It contains information on applicants and recipients of healthcare in Norwegian municipalities.



### Cancer Registry of Norway

- Cancer Registry of Norway
- 1953 →

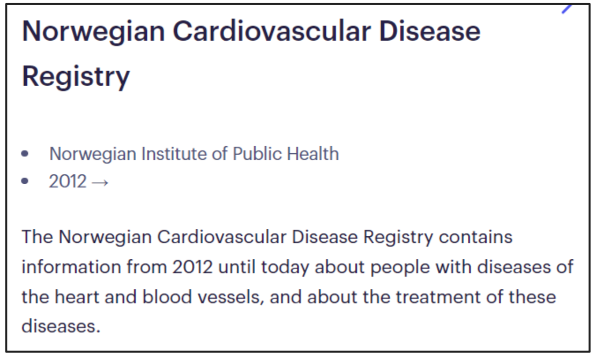
The Cancer Registry of Norway contains data on all cases of cancer diagnoses from 1953 to the present day.



### Norwegian Prescription Database (NorPD)

- Norwegian Institute of Public Health
- 2004 →

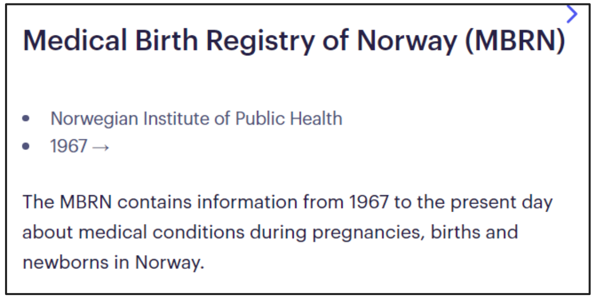
The Medicines Register has replaced The Norwegian Prescription Database (NorPD) and it is no longer possible to apply for data from the NorPD. For access to information on medicines that have been dispensed at pharmacies based on prescriptions, see the Norwegian Prescribed Drug Registry.



### Norwegian Cardiovascular Disease Registry

- Norwegian Institute of Public Health
- 2012 →

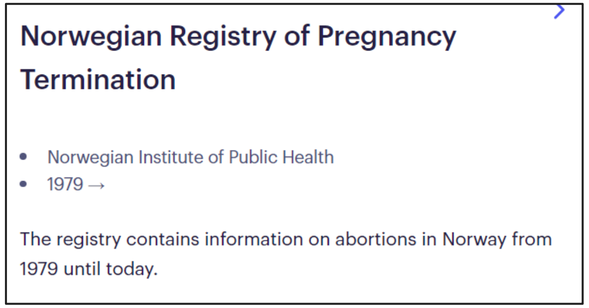
The Norwegian Cardiovascular Disease Registry contains information from 2012 until today about people with diseases of the heart and blood vessels, and about the treatment of these diseases.



### Medical Birth Registry of Norway (MBRN)

- Norwegian Institute of Public Health
- 1967 →

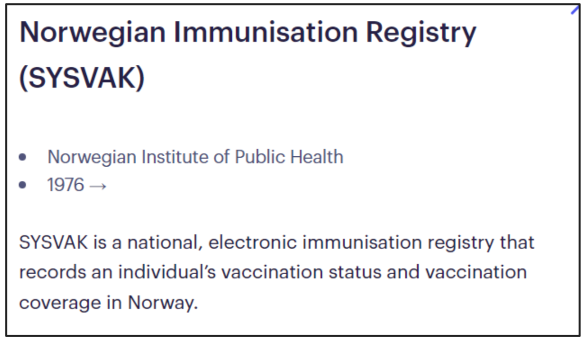
The MBRN contains information from 1967 to the present day about medical conditions during pregnancies, births and newborns in Norway.



### Norwegian Registry of Pregnancy Termination

- Norwegian Institute of Public Health
- 1979 →

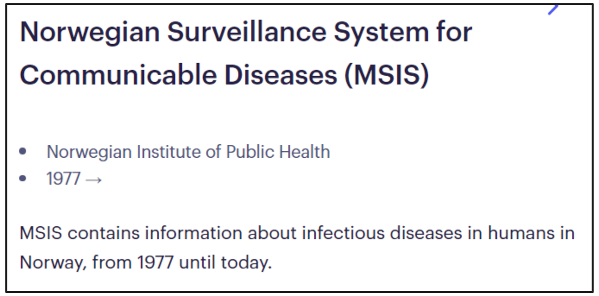
The registry contains information on abortions in Norway from 1979 until today.



### Norwegian Immunisation Registry (SYSVAK)

- Norwegian Institute of Public Health
- 1976 →

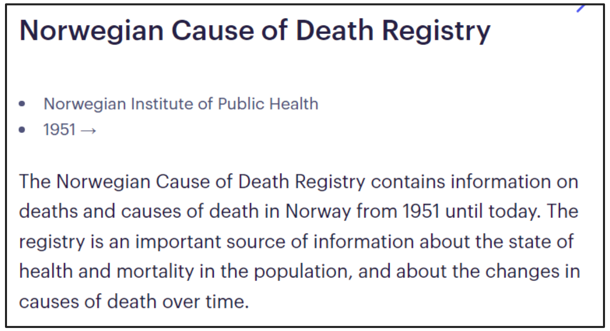
SYSVAK is a national, electronic immunisation registry that records an individual's vaccination status and vaccination coverage in Norway.



### Norwegian Surveillance System for Communicable Diseases (MSIS)

- Norwegian Institute of Public Health
- 1977 →

MSIS contains information about infectious diseases in humans in Norway, from 1977 until today.



### Norwegian Cause of Death Registry

- Norwegian Institute of Public Health
- 1951 →

The Norwegian Cause of Death Registry contains information on deaths and causes of death in Norway from 1951 until today. The registry is an important source of information about the state of health and mortality in the population, and about the changes in causes of death over time.

# The Norwegian metadata management process

**Normed National Health Metadata Specification (v.1.1)**

Nasjonal spesifikasjon for metadata om helsedata

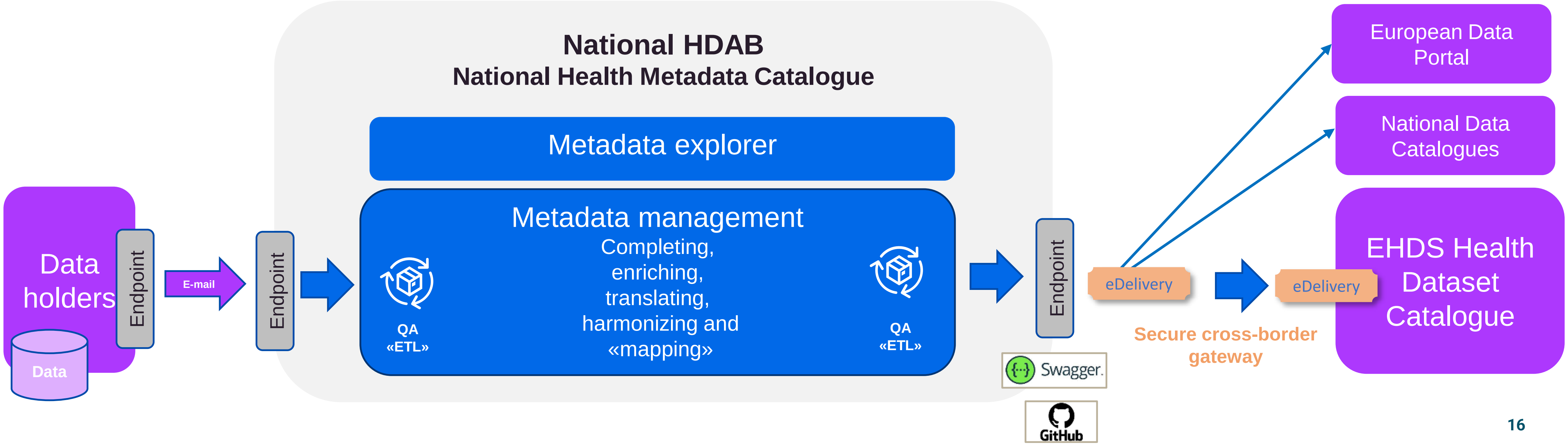
HITS 1230:2021

**Normed FAIR guideline and self evaluation tool**

Veileder for bruk av FAIR prinsippene for helsedatakilder

Hvordan tilrettelegge for deling og gjenbruk av helsedata

**HealthDCAT-AP Extension**



## National HDAB
## National Health Metadata Catalogue

Metadata explorer

Metadata management
Completing,
enriching,
translating,
harmonizing and
«mapping»

# 3. Results and outcomes

# Assessment of status – Task 9.1-9.3

- Due to the upcoming re-organization and limited resources, HDIR and NIPH have not been able to provide resources for task 1-3 as planned to start up in August 2023.
- Re-planning has been performed with the following outline:
  - All relevant resources were gathered in the same organization from 1.1.2024.
  - Q1-Q2 in 2024 will be used to mobilize and train relevant meta data resources.
  - The main activities of task 1-3 will start in Q2-3 2024.
  - Limited work will be done prior to start-up with a selection of registers that are behind.
- The project expect to be able to work more focused with task 1-3 in the new organization and budget revision will not be considered until end of 2024 despite later start-up.
- See updated detailed plan for task 1-3 on the next pages (Slide 19).

**Outcome:**

- Overview of completeness of reported data finalized.
- Limited DCAT-based metadata of 9 National Health Registries are shared at data.europa.eu and will be shared at the EU Health Metadata Catalogue when this is ready for testing spring 2024.

**T9.1 Completion, translation and updating**

**T9.2 Enriching**

**T9.3 Harmonisation**

# Progress plan

## - Deliverables Task 9.1 – 9.3

🟨 Definition/start up

🟩 Production

| | 2023 Q4 | 2024 Q1 | 2024 Q2 | 2024 Q3 | 2024 Q4 | 2024 Q1 | 2025 Q2 | 2025 Q3 | 2025 Q4 |
|---|---|---|---|---|---|---|---|---|---|
| Create overview of the completeness of reported meta data | 🟩 | | | | | | | | |
| Mobilise and train meta data resources | | 🟨 Advertisment | 🟨 Employ<br>Train | 🟩 Produce | | | | | |
| Complement properties with status «Mandatory» | | | 🟨 MSIS | 🟩 | 🟩 | | | | |
| Complement properties with status «Recommended» | | | 🟨 MSIS | 🟩 | 🟩 | | | | |
| Translate mandatory meta data for **key variables** to English | | | 🟨 MSIS | 🟩 | 🟩 | | | | |
| Translate remaining mandatory meta data to English | | | 🟨 MSIS | 🟩 | 🟩 | | | | |
| (Test and evaluate to implement automatic translation on helsedata.no) | | | | | | ? | | | |
| Define and specify content in the classes «Variable groups», «Filter» and «Instrument» | | | | | 🟨 | 🟩 | 🟩 | | |
| Complement the classes «Variable groups», «Filter» and «Instrument» and related map set | | | | | 🟨 | 🟩 | 🟩 | | |
| Define (key registres) and key variables | | 🟨 V.0.3 | 🟩 V.0.7 | 🟩 V.0.9 | | | | | |
| Map key variables to a common information model (OMOP) | | | | | 🟨 | 🟩 | 🟩 | 🟩 | |
| Enrich metadata to make sources and variables that are mapped to OMOP «Findable» and «Reusable» (Define «OMOP-properties») | | | | | | | 🟨 | 🟩 | 🟩 |
| Recommendations about the way forward | | | | | | | | | 🟩 |

# Assessment of status – Task 9.4

**Outcome:**

- First version (V.0.3) logical model based on DCAT described for meta data on SPE/infrastructures/end point.
- Draft definition of key variables from key registries prepared (V.0.3).
- Proof of Concept (V.0.3) harvesting metadata from the Secure Processing Environment (SPE) provider TSD (University of Oslo) in the demo version of the National Data Catalogue (DCAT-based cross sectorial data catalogues).
- See updated detailed plan for task 4 on the next page (Slide 21).

# Progress plan

## - Deliverables Task 9.4

🟨 Definition/start up

🟩 Production

**T9.4 Developing meta data about endpoints/secure infrastructures/SPEs**

| | 2023 Q4 | 2024 Q1 | 2024 Q2 | 2024 Q3 | 2024 Q4 | 2025 Q1 | 2025 Q2 | 2025 Q3 | 2025 Q4 |
|---|---|---|---|---|---|---|---|---|---|
| Describe a logical model based on DCAT-AP-NO 3.0 | | 🟨 V.0.3 | 🟩 V.0.5 | 🟩 V.0.7 | 🟩 V.0.9 | | | | |
| Define and specify metadata properties about SPE’s | | 🟨 V.0.3 | 🟩 V.0.5 | 🟩 V.0.7 | 🟩 V.0.9 | | | | |
| Publish initial mandatory properties of the SPE’s in scope in the demo environment of the Norwegian Common Data Catalogue (DCAT-based) | | 🟨 V.0.3 | 🟩 V.0.5 | 🟩 V.07 | 🟩 V.0.9 | | | | |
| Workshop with WP8 | | | | 🟩 | | | | | |
| Plan and execute demo day in April | | | 🟩 | | | | | | |
| Plan and execute demo day in October | | | | | 🟩 | | | | |
| Propose a specification based on V.0.9 and send on a hearing (In ASCIdoc)? | | | | | 🟨 | 🟩 | 🟩 | | |
| Norm and distribute the V.1.0 of the specification? | | | | | | | | 🟩 | |

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# 4. Next steps

# Executive Summary

## What has been done:

- A detailed overview of metadata properties to be completed per registry has been prepared.
- Limited metadata about 9 National Health Registries is  updated and shared with European Open Datasets Catalogue.
- Identified need for capacity in the registries to maintain and complete their metadata.
- A first draft of DCAT-based properties for SPE's has been developed.
- Identified need of an extended editor the EHDS2/WP6 pilot editor for completing, enriching translation and harmonise meta data.

## Outcome and next steps:

- Initiated hiring process for more resources to maintain and complete meta data from the different registries.
- Annual report for 2023 describing the baseline (D9.1)(March).
- Mobilisation and training of resources.
- The editing of metadata for the Norwegian Surveillance System for Communicable Diseases (MSIS) will start within April/May.
- Completion of metadata from the other registries will start in September 2024 when newly hired employee is operative.

Helsedirektoratet

# Appendix

# Glossary and abbreviations

| Phrase/Abbreviation | Description |
|---|---|
| SPE | Secure Processing Environment as specified in the EHDS regulation, article 50. |
| TRE | Trusted Research Environment. Term that is used for environments with similar use as an SPE but more generally for all type research. |
| Analysis infrastructure | Term used in this report for providers of secure services to process health data for secondary use. Research infrastructure is a similar term that is also used elsewhere. When an analysis infrastructure complies with the minimum requirements of an SPE they can be referred to as an SPE. |
| EHDS | European Health Data Space |
| TEHDAS | The European Health Data Space project |
| HDAB | Health Data Access Bodies |
| SPUHiN | Abbreviation of the project FAIR Secure Procurement and Use of Health data in Norway, co-funded by the EU4Health program |
| ISMS | Information Security Management System |
| Project owner | The person responsible for the project that is using an analysis infrastructure. They are also data responsible according to GDPR. This role is in practice referred to as project responsible, principal investigator etc. but we in this report we have decided to use project owner to describe this role. |
| Review access | Possibility to check who has access at this moment |
| Access log | Possibility to see who has logged on and when |
| Machine to machine transfer | Possibility to transfer data without users having to do a manual operation |
| | |