

EUROPEAN HEALTH DATA SPACE

Discovering datasets in the National Health Dataset Catalogue

How metadata helps data users find,
understand and access data.



THE GOVERNMENT
OF THE GRAND DUCHY OF LUXEMBOURG
Ministry for Digitalisation

Government commission for data sovereignty

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Scope

Key elements.

01

What metadata tells you

How it helps you find and understand available health datasets.

02

How to assess relevance

Using National Health Dataset catalogue information to evaluate a dataset against your purpose.

03

Which access path applies

The access paths and conditions associated with datasets.

PART ONE

The data user's questions

A simple starting point to understand
the National Health Dataset Catalogue

01

The data user's starting point

A new public health question may need data from hospitals, laboratories, registries or other institutions.

What data is
available?



Where can I
find it?



Can I
re-use it?



It starts with...



Search datasets

PART TWO

What is the National Health Dataset Catalogue

What the catalogue is and what it contains.

02

What the National Health Dataset Catalogue is

A central place where people can discover information about health-related datasets.

It never stores the data itself.

It stores structured descriptions of datasets, metadata, so people can understand what exists, where it comes from, and how it may be accessed.

REMEMBER

**Metadata is data about data
Not the data itself.**

Descriptions are public

The data stays with its holder

Access conditions are visible up front



The National Health Dataset Catalogue will be published on letzdata.lu.

PART THREE

Searching the National Health Dataset Catalogue

What a metadata record contains, and how to narrow a search down to candidates.

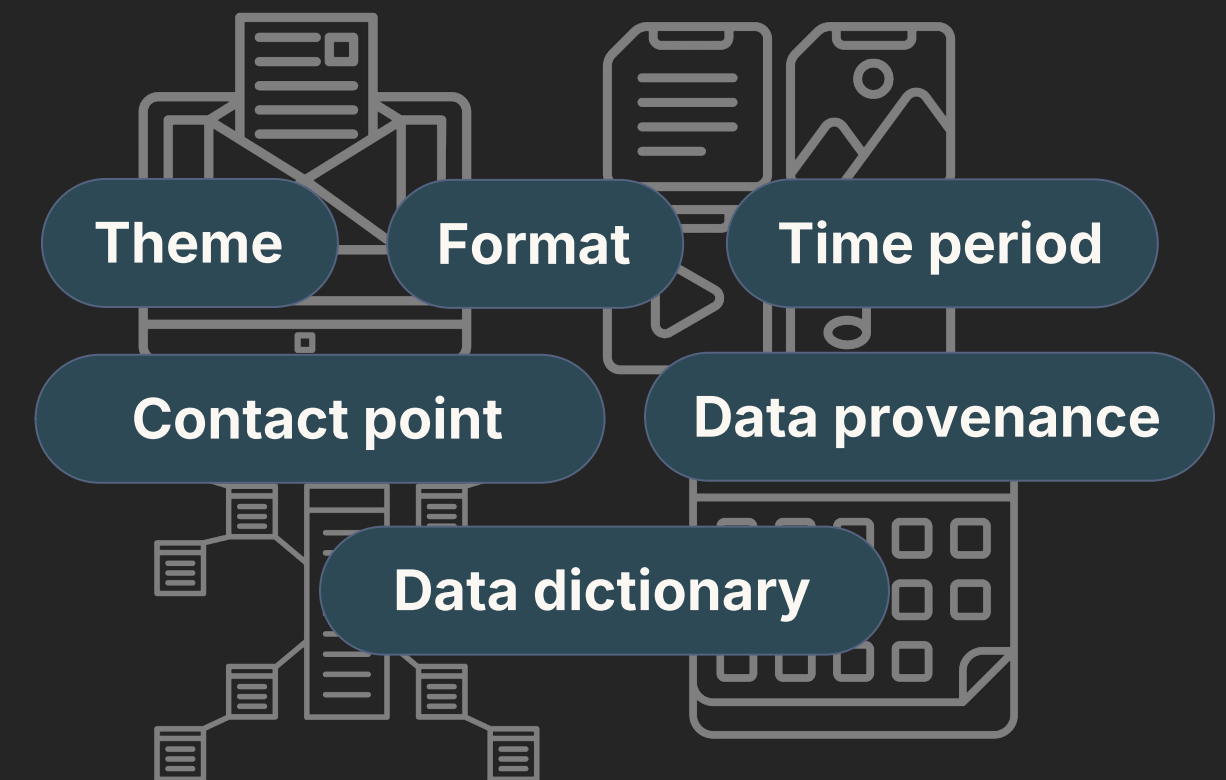
03

Inside a metadata record

Every dataset in the catalogue is described by the same structured fields.

National health dataset catalogue – record	
TITLE	National Diabetes Registry 2018–2025
DESCRIPTION	Registry records of diagnosed diabetes cases, with treatment and follow-up indicators
PUBLISHER	National disease registry
ACCESS CONDITIONS	Request procedure through the HDAB

FURTHER CONTEXT FIELDS



The record describes the dataset. It is not the dataset.

Inside a metadata record

PREVIEW

Every dataset in the catalogue is

National health d

TITLE

DESCRIPTION

PUBLISHER

ACCESS CONDITIONS

JB

Metabolic Statistic Registry ...

Health

Dataset Types

Statistical data

Test data

Who can access this data?

Public

Registry records of metabolic statistics, with treatment and follow-up indicators

Keywords

chronic disease management

health

Themes

Health

Population and society

Health Category

Other health data from med...

Data from medical registrie...

Health Theme

Nutrition Security

Applicable Legislations

Regulation (EU) 2025/327 (European Health Data Space)

Publisher

Luxemb

and Endocrine Research

0

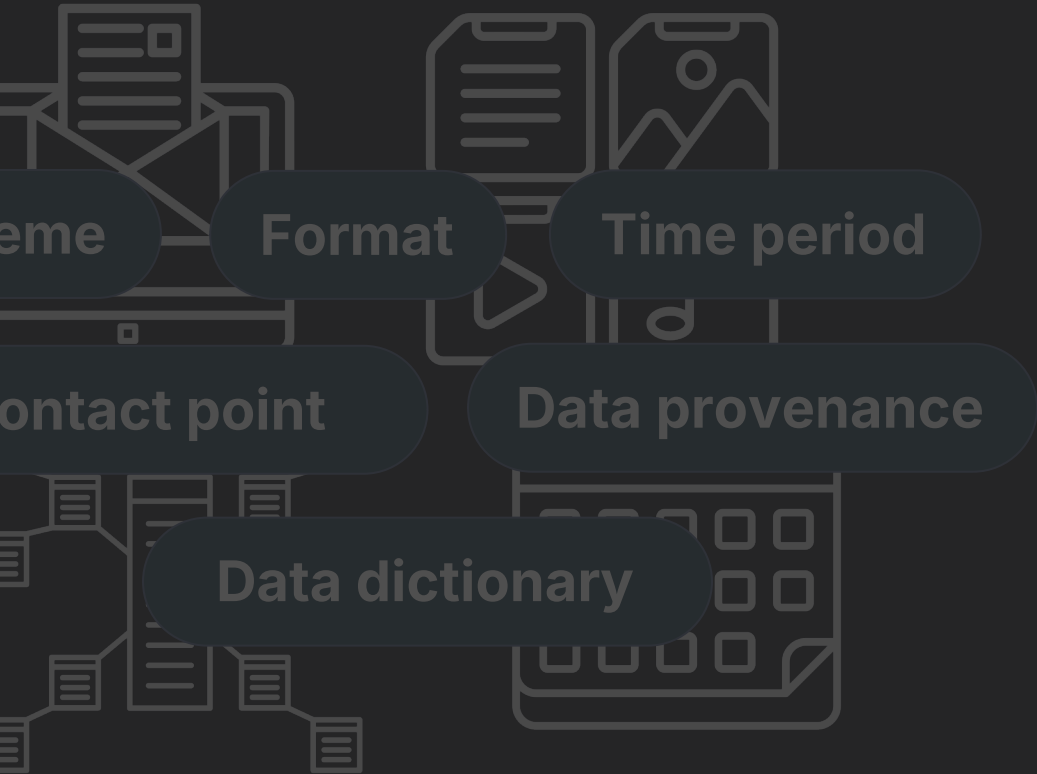
Distributions

0

Dictionary Entries

MOCK UP OF THE CATALOGUE TOOL

ER CONTEXT FIELDS



ne dataset.

Search & filter

Search by keyword or browse by category, then narrow the results.

National health dataset catalogue — search

Diabetes registry data

FILTERS

Publisher

Theme

Format

Access rights

Temporal coverage

RESULTS

National Diabetes Registry 2018–2025

Non-public

Primary Care HbA1c Indicators

Public

Hospital Endocrinology Activity Dataset

Non-public

Search & filter

PREVIEW

HDAB METADATA CAPTURE

+ Add Dataset



JB

Filters

✕ Reset all

Dataset Types

Select... | ▾

Rights Statement

☐ Public

☐ Restricted (Health)

☐ Non-Public

Publishers

Select... | ▾

Keywords

Type to search keywords... | ▾

Themes

Select... | ▾

Applicable Legislations

Search Dataset

🔍

Draft 21

Completed 1

Validated 0

Approved 5

Published 19

Internal Only 0

Deprecated 10

JB

Metabolic Statistic Registry ...

 Health

⋮

Dataset Types

Statistical data

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Who can access this data?

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Keywords

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Nutrition Security

Applicable Legislations

Regulation (EU) 2025/327 (European Health Data Space)

▾

JB

National Diabetes Registry ...

 Health

⋮

Dataset Types

Test data

Who can access this data?

Restricted

Restricted access registry records of diagnosed diabetes cases, with treatment and follow-up indicators

Keywords

mental health

health

Themes

Health

Population and society

Applicable Legislations

Regulation (EU) 2025/327 (European Health Data Space)

▾

MOCK UP OF THE CATALOGUE TOOL

Why public metadata matters

Self-service discovery, without putting the real data at risk.

SELF-SERVICE

Understand a dataset without opening it

Descriptions and attributes answer most questions before any request is made; restricted data is never exposed.



CONTACT POINT

Ask information directly to the health data holder

If more information is needed, the catalogue provides the health data holder's contact details for follow-up questions.



MONITORING

Come back and see what changed

New datasets published, existing ones updated, one central place to monitor the health data landscape.



PART FOUR

Assessing relevance

Discovering datasets is not only about finding a record, it is about judging whether it fits the purpose.

04

Questions answered by metadata

Who published it?

What does it describe?

**What period
does it cover?**

**In what format
is it available?**

**How was it collected?
Which methods, tools,
and protocols?**

**What variables
and data types exist?**

**What are the
conditions for access?**

Answered from the record
before any access request



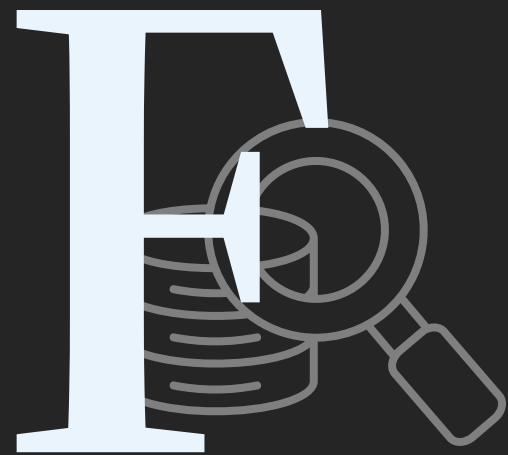
Relevant for the purpose



Not relevant yet — refine the search

Aligned with the FAIR principles

A widely recognised framework across research and policy communities.



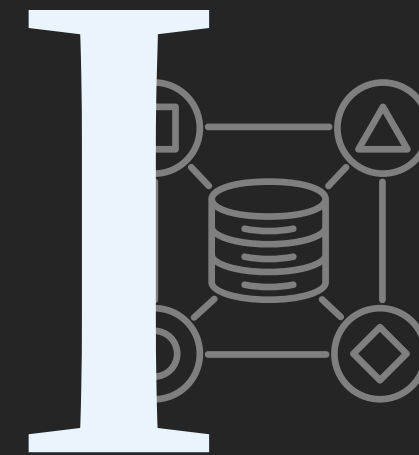
Findable

through clear metadata



Accessible

with access conditions



Interoperable

with shared standards



Reusable

with governance rules

PART FIVE

Understanding access paths

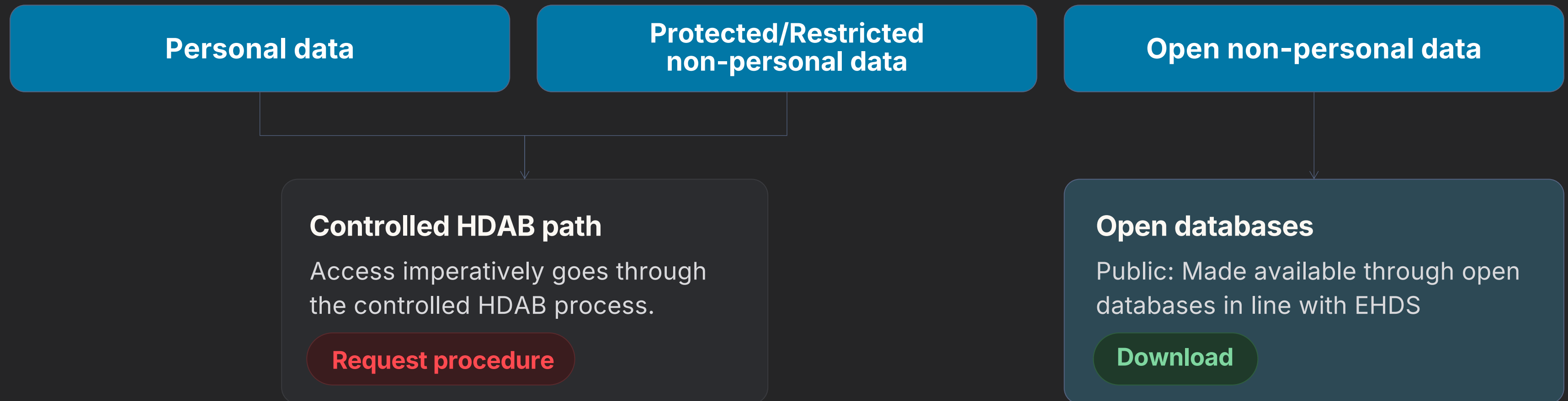
The catalogue never replaces governance,
it makes the access path visible.



05

Three access paths

In EHDS-aligned catalogue terminology, access is described as personal, restricted non-personal and public data.

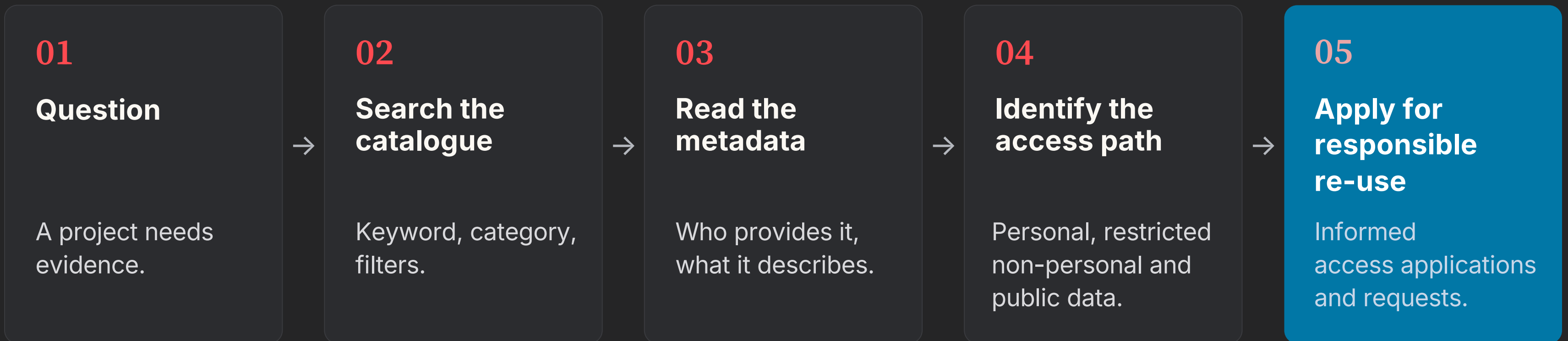


WHEN A REQUEST IS NEEDED Access is granted only after the relevant governance checks are completed.

Summary:

From a question to an access application and request

The National Health Dataset Catalogue is the starting point for data discovery.



Questions?

Related training on EHDS secondary use:

What is the EHDS?

What is the HDAB?

What secondary use makes possible

What is an SPE?

Health data holder obligations



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