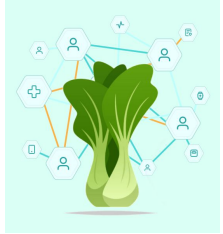

Semantic Framework for Legally-aligned Health Data Exchanges

Beatriz Esteves, Ruben Dedecker, Wout Slabbinck,
Filip Pattyn, Ruben Verborgh

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beatriz.esteves@ugent.be | w3id.org/people/besteves

Semantic Framework for Legally-aligned Health Data Exchanges

Motivation

Related work

Health data exchange policy framework

    Agreement Instantiation

Conclusions & future work

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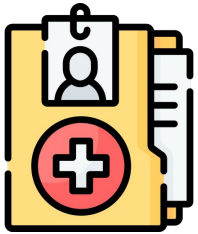
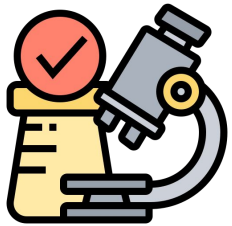


Interoperability
Data Integration
Accuracy
Accessibility
Reusability

Public health initiatives

Healthcare delivery



Health-related R&D

Icons from Freepik, smalllikeart, Icon home, pojok d, Smashicons, Eucalyp

EU Recognised
Data Altruism
Organisation

- Data subject ↔ Data controller
- Personal data
  - ➢ Personal electronic health data
- Processing operation
- Purpose
  - ➢ Primary/Secondary use
- Legal basis
- Recipient
- Anonymisation
- Duration/Frequency
- Data source

Techno-legal requirements

R1. Ability to model policies for both data subjects/holders and data controllers/users.

R2. Support legal requirements for health data exchange.

R3. Define the necessity of these requirements according to the identified legal framework.

R4. Specify ‘pre-defined’ templates for common exchanges.

R5. Generate agreements for specific health-related data exchanges between 2 parties.

Semantic Framework for Legally-aligned Health Data Exchanges

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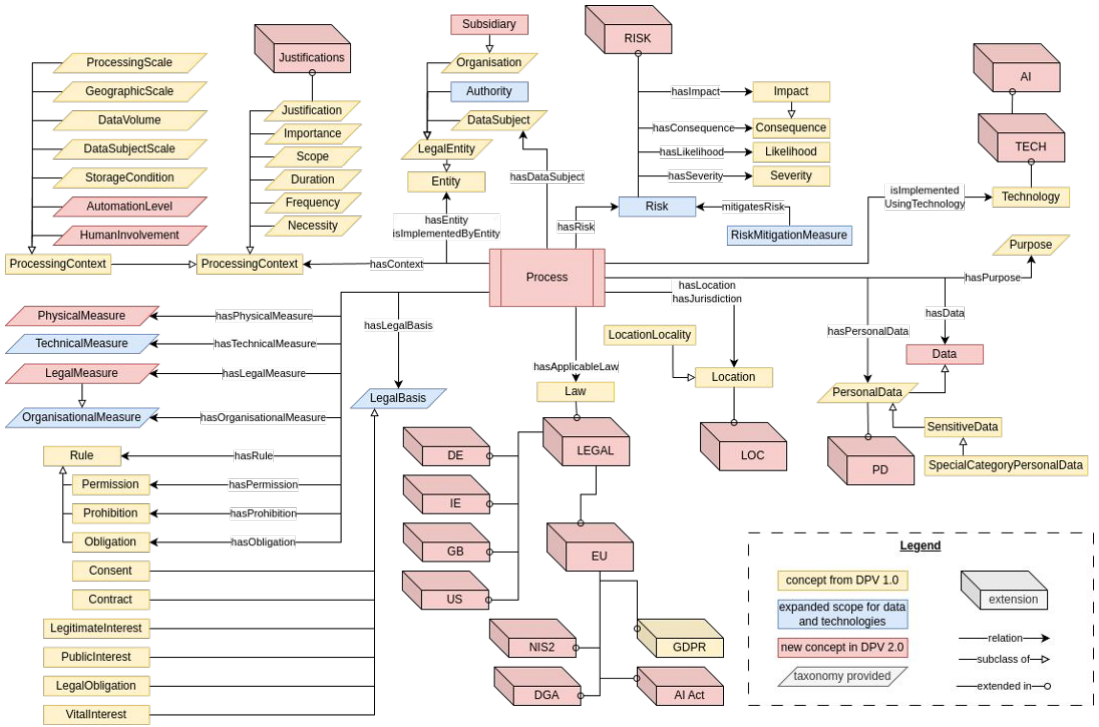
Data Privacy Vocabulary (DPV)

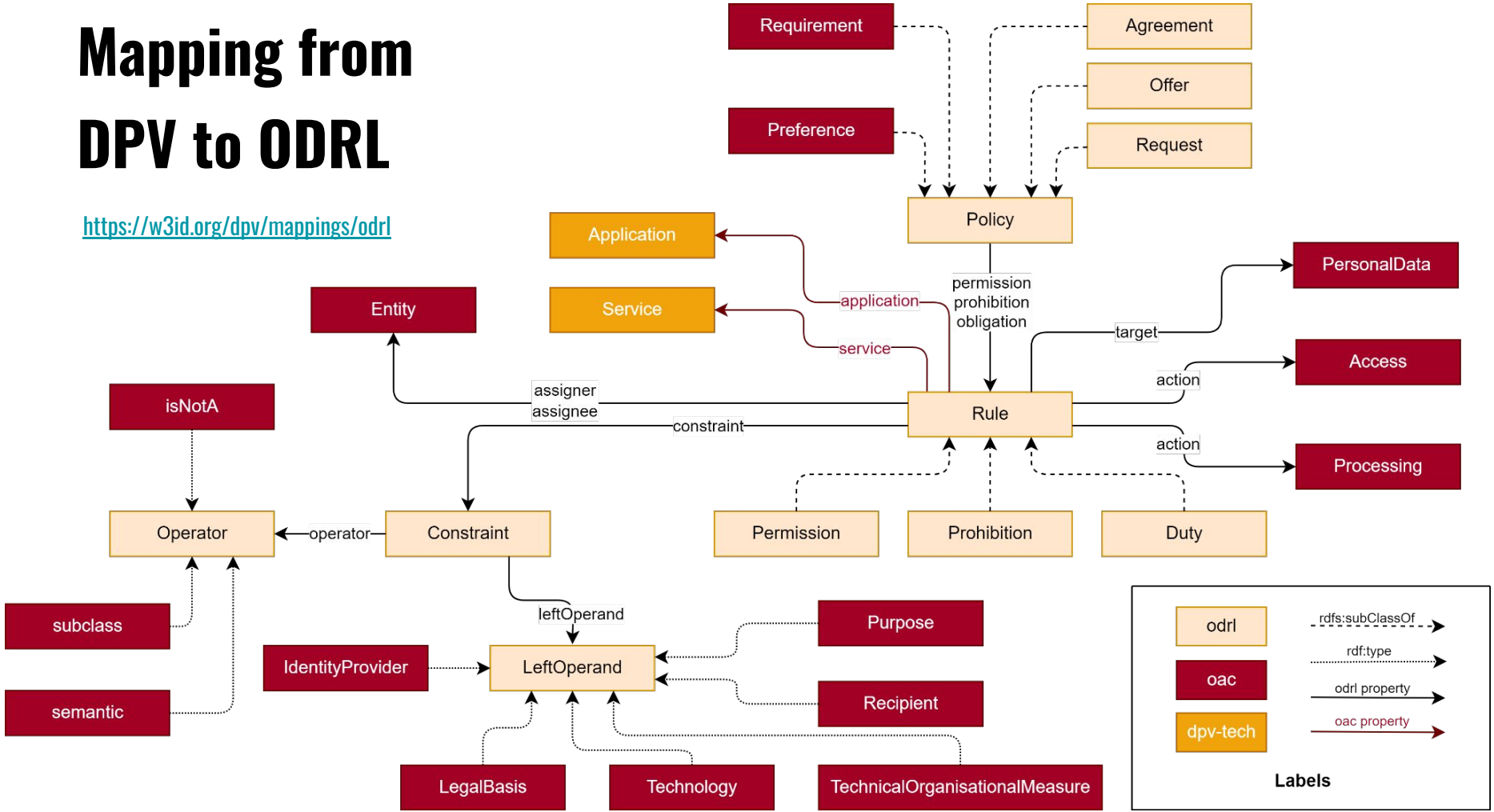


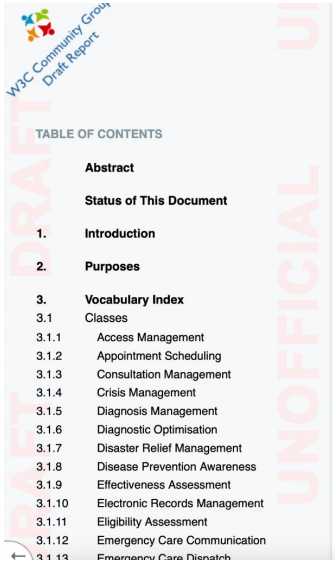
https://w3id.org/dpv

- Developed by the **W3C** Data Privacy Vocabularies and Controls Community Group (**DPVCG**)
- Defines a **jurisdiction-agnostic** ontology for expressing metadata about the processing of personal data
- Provides **hierarchical taxonomies**, from abstract to more specific concepts, to instantiate specific concepts in practical use-cases
- Has **law-specific extensions**

Mapping from DPV to ODRL

https://w3id.org/dpv/mappings/odrl





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3.1.2 Appointment Scheduling

3.1.3 Consultation Management

3.1.4 Crisis Management

3.1.5 Diagnosis Management

3.1.6 Diagnostic Optimisation

3.1.7 Disaster Relief Management

3.1.8 Disease Prevention Awareness

3.1.9 Effectiveness Assessment

3.1.10 Electronic Records Management

3.1.11 Eligibility Assessment

3.1.12 Emergency Care Communication

Health Sector Concepts (SECTOR-HEALTH)

version 2.1

Draft Community Group Report 16 March 2025

Latest published version:
https://w3id.org/dpv/sector/health

Latest editor's draft:
https://dev.dpvcg.org/sector/health

Editor:
Harshvardhan J. Pandit (ADAPT Centre, Dublin City University)

Author:
Harshvardhan J. Pandit (ADAPT Centre, Dublin City University)

Feedback:
GitHub w3c/dpv (pull requests, new issue, open issues)

This Release
https://w3id.org/dpv/sector/health

Key Publications
Data Privacy Vocabulary (DPV) -- Version 2.0 (2024)

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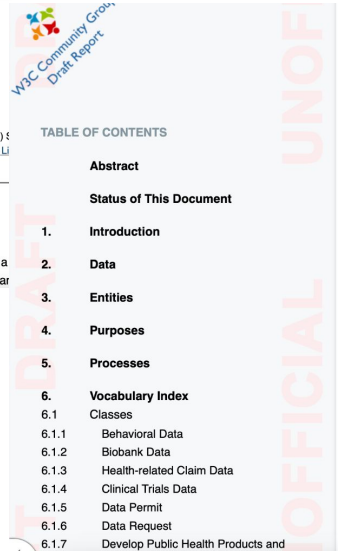
Vocabularies and Controls Community Group under the W3C Community Contributor Li
summary is available.

Abstract

The Health Sector Concepts (SECTOR-HEALTH) extension provides a
Vocabulary (DPV) Specification and other extension concepts . The nar

https://w3id.org/dpv/sector/health



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EU European Health Data Spaces (EHDS)

version 2.1

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https://w3id.org/dpv/legal/eu/ehds

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Authors:
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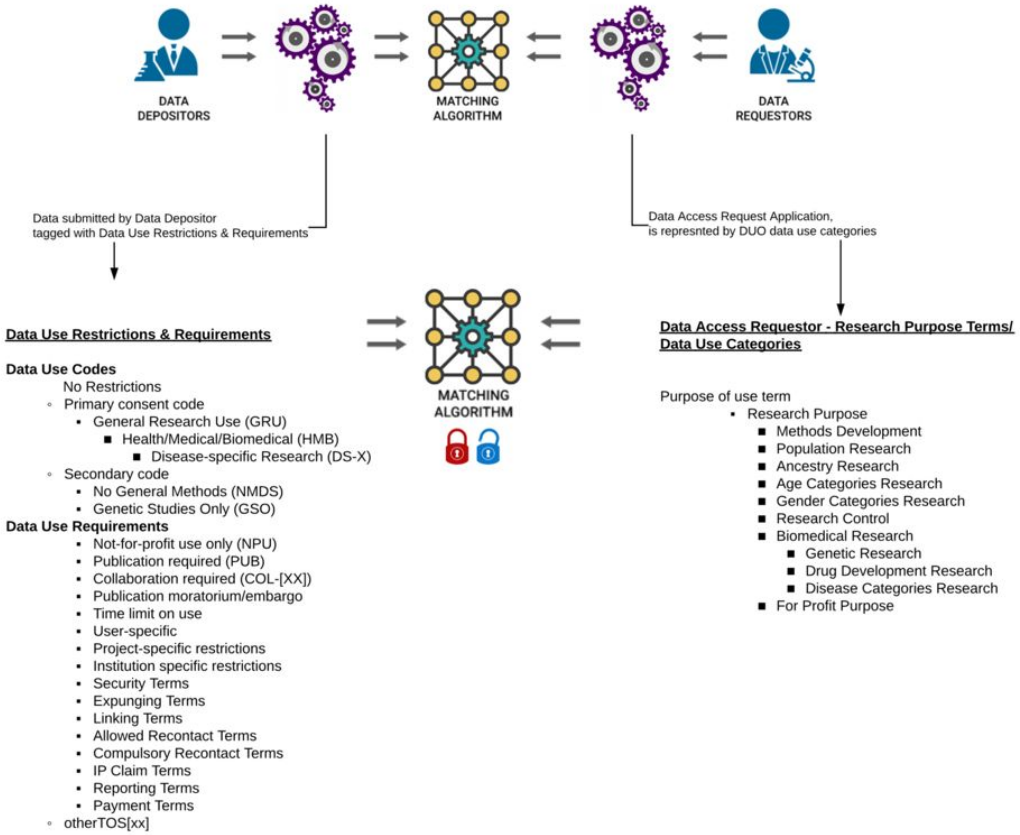
Key Publications
Data Privacy Vocabulary (DPV) -- Version 2.0 (2024)

Copyright © 2025 the Contributors to the EU European Health Data Spaces (EHDS) Specification, published by the Data Privacy Vocabularies and Controls Community Group under the W3C Community Contributor License Agreement (CLA). A human-readable summary is available.

Contributors: (ordered alphabetically) **Beatriz Esteves** *(IDLab, IMEC, Ghent University).* NOTE: The affiliations are informative, do not represent formal endorsements, and may be outdated as this list is generated automatically from existing data.

https://w3id.org/dpv/legal/eu/ehds



http://purl.obolibrary.org/obo/duo

EHDS
HealthData@EU Pilot

https://healthdcat-ap.github.io/

EUROPEAN ELECTRONIC HEALTH RECORD EXCHANGE FORMAT

https://ehr-exchange-format.eu

Semantic Framework for Legally-aligned Health Data Exchanges

Motivation

Related work

Health data exchange policy framework

    Agreement Instantiation

Conclusions & future work

Health data exchange policy framework

- Provide minimal set of terms to define access and usage control rules for data subjects and health data holders
- Fulfil GDPR and EHDS requirements
- Provide additional user controls, e.g., anonymisation

Term	Concept	Relation / Constraint
Data subject	URI	odrl:assigner
Personal data	URI / subclass of dpv:PersonalData	odrl:target
Processing operation	subclass of odrl:Action or dpv:Processing	odrl:action
Purpose	subclass of dpv:Purpose	dpv-odrl:Purpose
Pseudo/Anonymisation	dpv-odrl:Pseudonymise, dpv-odrl:Anonymise	odrl:action
Recipient	URI / subclass of dpv:Organisation	dpv-odrl:Recipient
Duration	xsd:duration	dpv-odrl:Duration
Frequency	xsd:positiveInteger	dpv-odrl:Frequency

Unofficial Draft

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3.2 Requests

4. Agreement Instantiation

5. Using different legal grounds

6. Health data sharing policy catalogs
6.1 Alignment with HealthDCAT-AP
6.2 Alignment with EHRxF

A. Issue summary

HEalth Data exchanGE policy framework (HEDGE)

Work in Progress

Unofficial Draft 20 May 2025

▼ **More details about this document**

Latest published version:
https://w3id.org/hedge

Editor:

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Abstract

This document defines a framework for modelling and cataloguing health data exchange conditions, aligned with legal requirements, e.g., from the European Union's General Data Protection Regulation (GDPR) and the European Health Data Spaces (EHDS) regulation, using semantic standards and specifications such as the Open Digital Rights Language (ODRL) and the Data Privacy Vocabulary (DPV).

§ 1. Introduction

The increasing digitalisation of healthcare has led to the generation of vast amounts of health-related data from multiple sources, including clinical records, wearable devices, and patient-generated data. However, the

https://w3id.org/hedge

```
ex:physician-request a odrl:Request ;
    odrl:uid ex:physician-request ;
    dcterms:description """Physician requests patient to read health data for primary care
        without time restriction and also for non-direct encounters (e.g. remote monitoring).""" ;
    odrl:permission [
        odrl:action odrl:read ;
        odrl:target ex:health-data ;
        odrl:assignee ex:physician ;
        odrl:constraint [
            odrl:leftOperand dpv-odrl:Purpose ;
            odrl:operator odrl:isAnyOf ;
            odrl:rightOperand sector-health:PrimaryCareManagement, sector-health:PatientMonitoring ],[
            odrl:leftOperand dpv-odrl:LegalBasis ;
            odrl:operator odrl:eq ;
            odrl:rightOperand eu-gdpr:A9-2-a ] ] .
```

PACSOI

PATIENT CENTRIC SOLID

FAQIR FOUNDATION

FAQIR
HEALTH DATA ... SIMPLIFIED

IDLab imec
INTERNET & DATA LAB

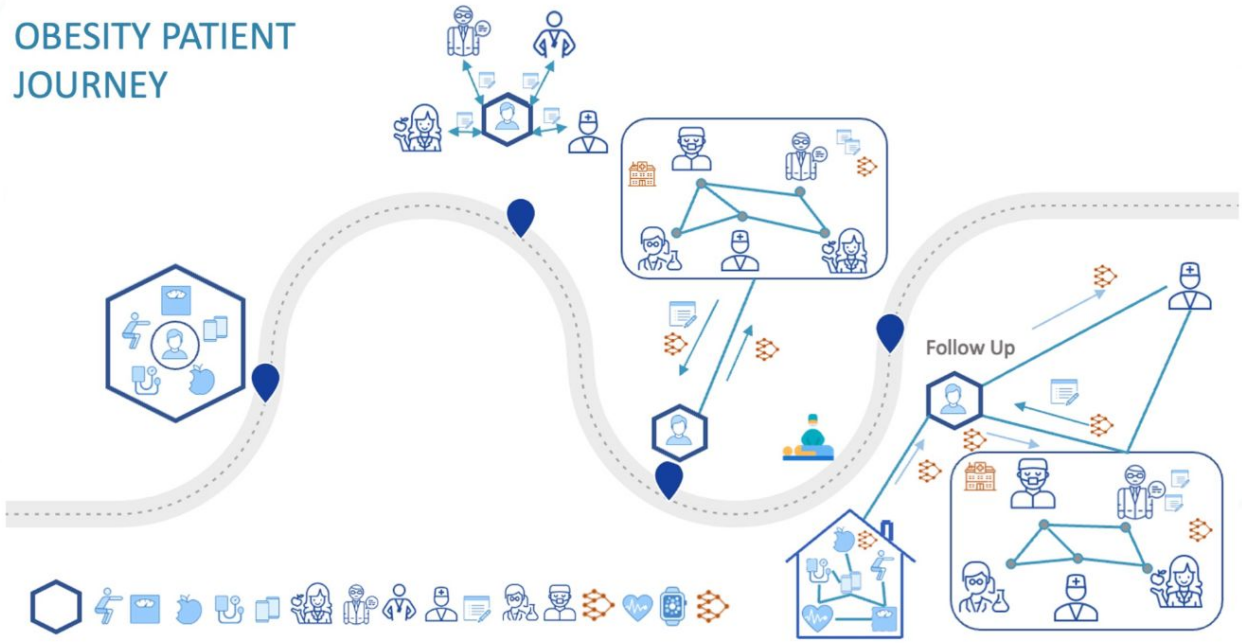
Byteflies

moveUP

ACONTRARIO

VLAIO

OBESITY PATIENT JOURNEY



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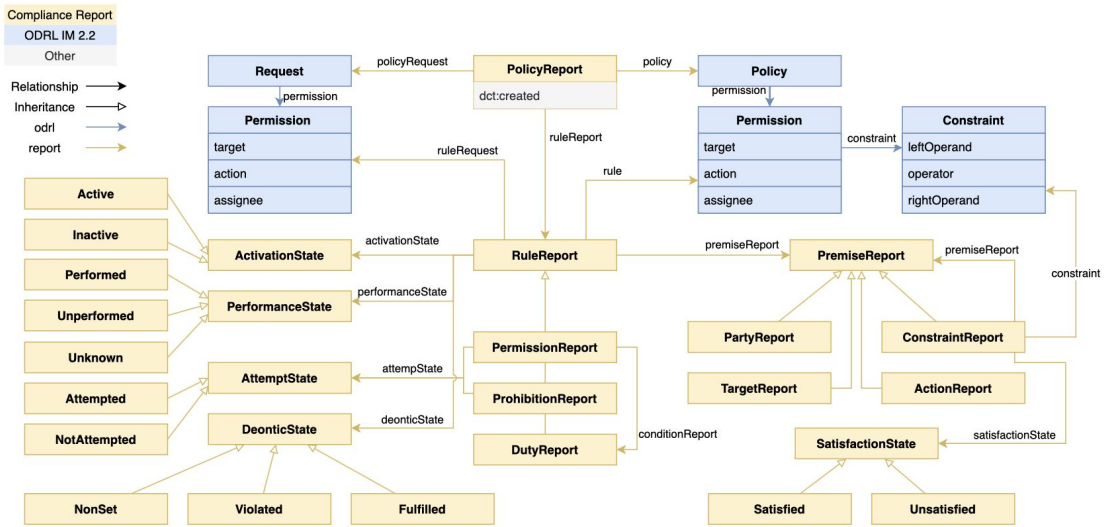
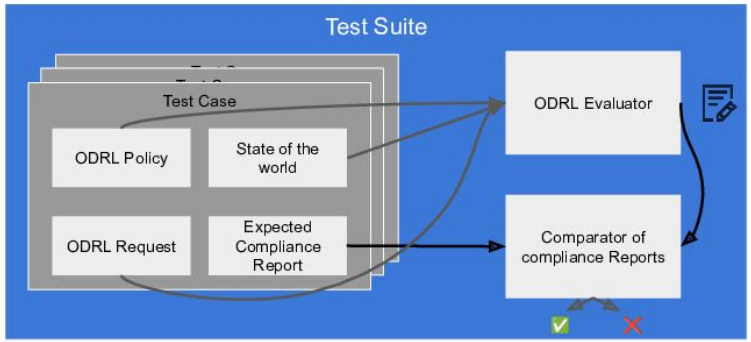
Interoperable Interpretation and Evaluation of ODRL Policies





Session 4 – Privacy and Security: **Tuesday, June 3rd 2025, 14h20 - 14h40** – Mediteranea hall Floor 11

Agreement Instantiation

- Validate the proper modelling of the odrl:Policy, odrl:Request and SoTW information.
- Convert compact policies into their atomic equivalents.
- Remove the rules that are not relevant for the request.
- Reference the ODRL request that triggered the agreement instantiation and the policies from the data subject/holder.
- Instantiate the concrete assigner and assignee of the agreement.
- Include relevant rules with concrete actions, targets and constraints.

https://w3id.org/force/policy-instantiation

https://w3id.org/force/policy-instantiation/poc

Semantic Framework for Legally-aligned Health Data Exchanges

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Conclusions & future work

Conclusions & future work

Secondary usage of health data for public interest and research

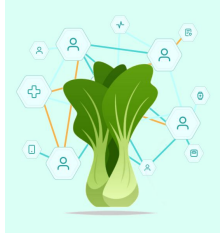
Alignment with legal requirements from GDPR & EHDS

Validated by legal experts in DPV and PACSOI project

Use different legal grounds to share health data

Benchmark agreement instantiation algorithm

Integrate with standards (DCAT, EHRxF)



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