

Data spaces: experience from the European Health and Common Energy data spaces

Unin. europo academy 22 November 2024 10.00 — 11.30 CET

Rules of the game



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Introduction













Flora Kopelou Data.europa.eu Publications Office of the EU Melodie Bernaux, Policy officer Digital Health, European Commission Pascal Derycke Data Engineer, Sciensano Stavros Stamatoukos Policy Officer at DG Energy, European Commission

Antonello Monti Professor, Institute Director, RWTH Aachen University

Shievam Kashyap Research Associate and Project Manager, University of Applied Sciences Upper Austria



Agenda

10.00 - 10.05	Opening and introduction – Flora Kopelou		
10.05 - 10.35	European Health Data Space and Health-DCAT – <i>Melodie Bernaux and Pascal Derycl</i>		
10.35 - 11.05	Common European Energy Data Space and use cases – <i>Stavros Stamatoukos, Antonello</i> Monti and Shievam Kashyap		
11.05 – 11.25	Q&A session		
11.25 – 11.30	Closing remarks – Flora Kopelou		





European Health Data Space

Harnessing the power of health data for people and innovation

Data spaces: experience from the European Health and Common Energy data spaces 22/11/2024

EC – SANTE C1





European Commission - Press release

Commission welcomes European Parliament's adoption of the European Health Data Space and regulation on substances of human origin

Brussels, 24 April 2024

The Commission welcomes the adoption by the European Parliament today of the European Health Data Space (EHDS) and new rules to increase the safety and quality of <u>substances of human</u> origin (SoHO). These are two cornerstones of a strong European Health Union which protects the health of citizens and improves the resilience of healthcare systems.

The European Health Data Space (EHDS)

This groundbreaking initiative, put forward by the Commission in May 2022, has two main aims:

- to place citizens at the centre of their healthcare, granting them full control over their data, with the goal of achieving better healthcare across the EU;
- to allow the use of health data for research and public health purposes, under strict conditions.

Thanks to the new rules, citizens will benefit from immediate and simple access to their digital health data when in the EU, regardless of their location. For instance, when a patient seeks healthcare abroad, healthcare professionals will be able, when necessary, to access key information from the patient's home Member State. This will improve evidence-based decision making, reduce repetition of tests and examinations and enhance patient care.

The EHDS also establishes a **strong legal framework for the re-use of health data** for research, innovation and public health purposes in full compliance with strict EU data security and access criteria, fundamental rights and cybersecurity rules. The data will help **develop life-saving treatments and personalised medicines** and improve European crisis **preparedness**.

Substances of human origin

The new regulation, proposed by the Commission in July 2022, provides a holistic approach for the regulation of substances of human origin. The new rules notably include better protection of recipients and donors of substances of human origin, as well as children born from medically assisted reproduction. The new framework foresees:

- Clear rules covering all substances of human origin except solid organs, such as faecal microbiota and human breast milk;
- Registration of all entities that carry out activities that could affect the safety and quality of SoHO;
- Reinforced expertise, building on existing technical bodies, notably the European Centre for Disease Prevention and Control (ECDC) and the European Directorate for the Quality of Medicines & HealthCare (Council of Europe), to keep technical guidelines up to date;
- More innovation, with a common procedure to assess and authorise SoHO preparations, proportionate to the risks these bring;
- Strengthened national oversight, and EU support for national authorities (such as training and IT);
- New measures supporting supply continuity that will help Member States to take action when the supply of critical SoHO is threatened;
- A SoHO Coordination Board (SCB) will be established, with and for Member States. It will support the implementation of the new regulation and provide legal clarity;
- Finally, the digital EU SoHO Platform will be created, to gather all required information, streamline reporting and increase visibility to citizens.





EHDS in a nutshell

What? To create a unified framework to facilitate the exchange of electronic health data across Europe for secondary use.

Why?

- Enable large-scale health research and innovation.
- Support evidence-based policy making and public health interventions.
- Cross-Border collaboration, promote interoperability and data sharing across EU member states.

How?

- Data governance: clear policies and regulations for data access and use.
- Technical infrastructure: robust platforms for secure data exchange and analysis.
- Stakeholder engagement: involvement of healthcare providers, researchers, policymakers, and patients.



Policy context

Secondary use in practice

Common European rules on who has to make which data available for

which purposes and under which conditions

How?

A mandatory connexion of all MS to a common infrastructure

Data catalogues of available datasets

Permits for data use, common safeguards



What's in it for *data users*?

Increased data discoverability

- Access to a rich, diverse, and high-quality dataset that supports research and public health actions.
- A single platform / EU catalogue

A streamlined procedure to access data across EU

- Single application form
- Single permit template
- Fees determination based on the complexity and duration of data access.
- Timely access



European data

data.europa.eu The official portal for European data Data 🗸 Academy Community ∨ Publications ∨ Documentation ^[2] Home > Datasets **Datasets** Data scope ③ Search Any - $\mathbf{\vee}$ Datasets found (1 729 857) Provenance ③ - Any -Bornes de Recharge pour Véhicules Électriq Publisher ② Data Bornes de Recharge pour Véhicules Électriques Wattzhub

Obligations

- Approved Purposes: Use data only for the purposes defined in the data permit
- Data Protection: Process data in secure environments, ensuring privacy and protection (anonymization/pseudonymization)
- Strictly adhere to security and ethical standards, and avoid any reidentification attempts.
- **Transparency**: Publish results in a way that contributes to public knowledge while respecting privacy rules.



What's in it for *data holders*?

OBLIGATIONS

Dataset description

- communicate to the HDAB a description of their datasets
- accurate and kept up to date
- Compliant with EHDS metadata standards
- + data quality and utility label

Make data available

- upon request of the HDAB according to a data access
- Timely provision : within a reasonable time frame (3 months)

Respect obligations towards natural persons



Benefits

- Contribution to advancing public health and research
- **Recognition** and potential collaborations within the EHDS network.
- Participation in building a resilient European health system.
- Increased visibility of their datasets.

Protection

- Charge fees
- Protection of trade secrets and IP rights



The need for a health-specific metadata standard





European Commission

The path towards healthDCAT-AP

Idea of EHDS 2



Implementing act

Choosing and extending DCAT-AP

Proven framework

- Established Standard: widely adopted for data cataloging, ensuring reliability and robustness.
- Flexible / easily adapted to meet specific needs.
- Interoperability and compatibility
 - Ensures compatibility with existing data catalogs and systems.
 - Facilitates data sharing and promotes data exchange within and across sectors.
- HealthDCAT-AP
 - Adds health-specific properties and vocabularies to DCAT.
 - Improved Metadata Quality: Provides detailed and relevant metadata for health datasets.

DCAT Application Profile for data portals in Europe | ISA²



DCAT Application Profile for Data Portals in Europe (DCAT-AP)



EHDS2 – Legislative process

Timelines are indicative.



• 24/04/2024 EP plenary





EHDS Regulation

How can you make your voice heard?

TEHDAS2

- Public consultation on all milestones (three waves)
- External advisory board with stakeholder representatives (closed)
- Save the date: Open TEHDAS2 stakeholder forum (hybrid) on 31/01/25
- Two others stakeholder forum aligned with the public consultations





Welcome to Have your say Public Consultations and Feedback

Citizens and businesses can share their views on new EU policies and existing laws.

Search for initiatives Search All initiatives >

- Implementing/delegated acts
 - standard better regulation rules apply,
 - Expect public 4-week public consultations



Thank you



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Data discovery in the European Health Data Space: HealthDCAT-AP for findable health data

Pascal DERYCKE, Data & Semantic Engineer

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• Why HealthDCAT-AP?

- EHDS User Journey
- Data in scope of the European Health Data Space Regulation
- Extending DCAT-AP
- EU health Datasets catalogue

HealthDCAT-AP in a nutshell

- New properties from existing vocabularies
- New HealthDCAT-AP properties
- New Controlled Vocabularies (Standardised Terms)
- New rules for the minimum metadata elements for describing datasets

• <u>https://healthdcat-ap.github.io</u>

• Q&A



Agenda





Why HealthDCAT-AP?

European Health Data Space



User journey of the European Health Data Space for secondary use



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Data in scope of the European Health Data Space Regulation

EHDS Regulation Article 33 Minimum categories of electronic data for secondary use

Health data holders shall make the following categories of electronic data available for secondary use in accordance with the provisions of this Chapter:

(a) electronic health data from EHRs;

(b) data on factors impacting on health, including socio-economic, environmental and behavioural determinants of health:

ba) aggregated data on healthcare needs, resources allocated to healthcare, the provision of and access to healthcare, healthcare expenditure and financing;

(c) pathogen data, impacting on human health;

(d) healthcare-related administrative data, including dispensation, claims and

reimbursement data:

(e) human genetic, epigenomic and genomic data;

(ea) other human molecular data such as proteomic transcriptomic, metabolomic,

lipidomic and other omic data;

(f) automatically generated personal electronic health data, through medical devices ;

(fa) data from wellness applications;

(g) data on professional status, specialisation and institution of health professionals involved in the treatment of a natural person;

(h population-based health data registries (public health registries);

(i) data from medical registries and mortality registries;

(j) data from clinical trials, clinical studies and clinical investigations subject to Regulation (EU) 536/2014,

Regulation [SOHO], Regulation (EU) 2017/745 and Regulation (EU) 2017/746, respectively;

(k) other health data from medical devices ;

(ka) data from registries for medicinal products and medical devices;

(1) data from research cohorts, questionnaires and surveys related to health, after the first publication of results; (m) health data from biobanks and associated databases. □.

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EU health Datasets catalogue

Categories 3 https://acceptance.data.health.europa.eu/ [Adapted] Finnish Care Register for Health Care (Terveys-Hilmo, Hilmo) Select \sim The purpose of the register is to collect data on the activities of health centres, PDF CSV Coding Systems 3 HealthData@EU EU Dataset Catalogue hospitals and other institutions providing inpatient care and on the clients treated in them as well as on home-nursing clients for the purposes of statistics, research Home EU Dataset Records EU Dataset Catalogues Select \sim and planning. The Care Register for Health Care started in 1994 as a continuatio... Home > EU Dataset Records Data models ③ Updated: 29 February 2024 [Test] Finnish National HDAB Select \sim EU Dataset Records [Adapted] Linking of registers for COVID-19 vaccine surveillance Age Range 💿 Formats 3 Q Search Select \mathbf{v} Last modified Relevance Name ascending -EU Dataset Records EU Dataset Catalogues The LINK-VACC project links selected variables from existing registries for COVID-CSV Clear 0 - 120 19 vaccine surveillance, in order to ensure the monitoring of COVID- 19 vaccines Catalogues ③ in the phase following their marketing authorization (post-authorization 4 dataset records found Select \mathbf{v} surveillance). This includes the measurement of uptake and coverage of the... Population size 2 EHDS2 Pilot - Demo - National Dataset 0 Keywords 3 Updated: 09 October 2024 Created: 20 January 2023 [Test] Belgian National HDAB \mathbf{v} Select 0 - 10.000.000 Clear Example description of the dataset record. PDF Data scope @ Update frequency (2) \mathbf{v} Select Select \mathbf{v} Updated: 07 October 2024 Created: 07 October 2024 EHDS2 Pilot node Licences 3 HealthDCAT-AP extends Quality and utility label ⁽²⁾ \sim Select [Adapted] Antimicrobial resistance in the ECDC atlas **DCAT-AP data catalogues with** Select Health Data Access Body ③ Data covering EU/EEA countries, currently from 2000 and onward, and collected Excel XL HTML new health-centric properties! More filters [∨] Select by the European Antimicrobial Resistance Surveillance System (EARSS), and later, from 2010 by the European Centre for Disease Prevention and Control (ECDC) through the European Antimicrobial Resistance Surveillance Network (EARS-Net., Publisher 3 Clear filters Select Updated: 09 October 2024 Created: 22 September 2022 [Test] EU datasets Previous 1 Next > Items per Page: 10



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Draft HealthDCAT-AP

in a nutshell:

- New properties added to DCAT-AP
- New Controlled Vocabularies
- New rules for the minimum metadata elements

New properties added to DCAT-AP from existing vocabularies

NEW PROPERTIES



NEW CONTROLLED VOCABULORIES

Based on Art. 51 (datasets in scope of the EHDS Regulation)

Contact Point Registry of the Health Data Access Bodies, the Union data access service and authorised participants of the healthData@EU infrastructure

Wikidata as an ontological health database

Health Publisher type

NEW CARDINALITIES & USAGE NOTES

General increase of the cardinalities to create rich metadata:

- Open data
- Protected Data
- Sensitive data

Mandatory Sample Distributions for sensitive data:

- use of synthetic or anonymized subsets
- use of CSVW terms for RDF-izing variable descriptions





New HealthDCAT-AP properties





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New Controlled Vocabularies (EHDS Standardised Terms)





New minimum metadata elements for describing datasets

NEW PROPERTIES

alternative analytics (DCAT-AP Distribution) code values coding system health category health data access body health theme legal basis max typical age min typical age number of records number of unique individuals personal data population coverage publisher note, publisher type purpose quality annotation retention period

NEW CONTROLLED VOCABULORIES

Based on Art. 51 (datasets in scope of the EHDS Regulation)

Contact Point **Registry** of the Health Data Access Bodies, the Union data access service and authorised participants of the healthData@EU infrastructure

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Health Data Holders must provide information on Access Rights



EHDS HealthData@EU Pilot

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HealthDCAT-AP Mandatory Properties by Access Rights



SENSITIVE DATA

At least one Dataset Distribution is mandatory, regardless of the Access Rights.



Sensitive data (Personal electronic health data)





Sensitive data (Personal electronic health data)





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HealthDCAT-AP draft specification

W3C ReSpec



Draft version of HealthDCAT-AP: https://healthdcat-ap.github.io

$\leftarrow \rightarrow$ (p.github.io/#personal-electronic-health-data	⊗ ±
10.1 10.2 10.3 10.3 11.	Requirements for controlled vocabularies Controlled vocabularies to be used Wikidata as an ontological medical database Support for implementation	HealthDCAT-AP Unofficial Draft 22 December 2023	ReSpec
11.1	In scope of EHDS	▼ More details about this document	
5 11.2 11.3 11.4	Denoting a health Dataset Health data categories Access rights	Latest published version: https://healthdcat-ap.github.io/	
11.4.1 11.4.2	Non-personal electronic health data Personal electronic health data	Latest editor's draft: https://healthDCAT-AP.github.io	
11.5 11.6	Distribution Sample distribution	History: Commit history	
11.7 12. 13.	Identifiers as persistent URIs RDF Examples Validation	Editors: <u>Pascal Derycke</u> (Sciensano) Charles-Andrew Vande Catsyne (Sciensano) Truls Korsgaard (Folkehelseinstituttet)	
		Hans Aage Huru (Folkehelseinstituttet) Author:	
Α.	Quick Reference of Classes and Properties	Pascal Derycke (Sciensano)	
A.1 A.2	HealthDCAT-AP tabular overview DCAT-AP 2.x vs 3.0 deprecated properties and classes	Feedback: GitHub healthDCAT-AP/draft (pull requests, <u>new issue</u> , open issues)	

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Thank you!



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www

in

https://www.ehds2pilot.eu/

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Common European Energy Data Space - CEEDS

Stavros STAMATOUKOS

DG ENER.B4 – Digitalisation, Competitiveness, Research & Innovation

Digitalisation of energy Action Plan





CEEDS - vision and objectives

Vision: Develop a European data sharing framework to support innovative energy services

Objectives: 3 high level use cases

- Flexibility services
- Smart and bidirectional charging
- Energy efficiency in buildings



Example: Smart charging ecosystem



Developed by the Sustainable Transport Forum, a formal Commission expert group

CEEDS - architecture

Components:

- distributed data exchange platforms layer: regulated or non-regulated infrastructures
- Federated layer: access and usage policies, identity management, logs, vocabulary hub, contracting, discovery
- data space connector" orchestrates interconnection and exchanges of data and metadata

Actors: DSOs, TSOs, market operators, OEMs, energy communities, charge point operators, customers, BRPs, BSPs etc.



Figure 12 - Complete CEEDS architecture.



CEEDS - timeline

ETIP SNET





Smart Energy Expert Group

- Announced in the DoEAP as a successor to the Smart Grids Task Force (SGTF)
- Coordinated by ENER / CNECT
- Established in Oct 2024
- 3 subgroups: Data for energy (D4E), Cybersecurity, Consumers
- 69 members
 - Type C: 37 associations from energy and digital domains
 - Type D: 27 Member States
 - Type E: ENTSO-E, ENTSO-G, EU-DSO ENTITY, ACER, BEREC
 - Observers & invited experts



Type C members of SEEG

- AIOTI (Alliance for Internet of Things and Edge Computing Innovation)
- CEDEC (European Federation of Local and Regional Energy Companies)
- CEER (Council of European Energy Regulators)
- CEN CENELEC ETSI CG
- ChargeUp Europe
- COGEN Europe (Association for the Promotion of Cogeneration)
- CurrENT
- DLMS UA (DLMS User Association)
- DR4Eu (Demand Response for Europe)
- EASE (European Association for Storage of Energy)
- ECOS (Ecostandard: environmental coalition on standards)
- E.DSO for smart grids

- ElaadNL
- ESMIG (The European Smart Energy Solution Providers)
- EU.BAC (European Building Automation and Controls Association)
- EUREC (European research and development in renewable energy technologies)
- Eurelectric
- Eurogas
- Euroheat & Power
- European Heating Industry
- E.V.V.E (European Association for the consumption-based billing of energy costs)
- European Energy Retailers
- European Heat Pump Association
- European Energy Information sharing and analysis Centre (EE-ISAC)

- European Network for Cybersecurity
- EUTC (European utilities telecom Council)
- Fraunhofer-Gesellschaft
- GAIA-X
- Gas Infrastructure Europe (GIE)
- GEODE
- IEEE
- ORGALIM
- SmartEN
- Solar Power Europe
- T&D Europe
- TNO
- VTT Technical Research Centre of Finland



D4E working group: objectives

• Overall objective

"to assist the Commission in developing a comprehensive and coherent data exchange framework in the energy sector"

- Concrete objectives
 - To elaborate the 3 high-level use cases identified in the Digitalisation action plan and
 - To develop the technical building blocks for the defined use cases
 - To agree on the potential pathways for the governance of the data sharing framework
 - To support Member States exchange best practices, learn from each other and seek
 technical assistance in implementing national data exchange standards



Member States workstream

- Objective: to facilitate the exchange of best practices among Member States
- Indicative actions:
 - Webinars presenting national practices
 - Maintain a database of data sharing infrastructures
 - Twinning/matchmaking actions



Thank you



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Developing an interoperability community: the int:net project

Prof. Antonello Monti

Fraunhofer FIT – Center for Digital Energy Aachen, Germany

This project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101070086

Interoperability Network for the Energy Transition

- Horizon Europe call HORIZON-CL5-2021-D3-01-03
 - Coordination & Support Action (CSA)
 - Duration: 36 months
 - Runtime: 01.05.2022 30.04.2025
 - Consortium: 12 Partners
 - 7 Countries
 - 1 Associated Partner
 - Budget: 5 M€

t:net



Project objectives

- Consolidating a <u>common knowledge base</u> for interoperability activities on energy services in Europe
- Developing a comprehensive and accepted Interoperability Maturity Model (IMM)
- Deploying a <u>framework for interoperability testing</u> in a network of laboratories and testing facilities
- Fostering a <u>community network of standards and</u> <u>regulatory environment</u> for a European interoperability ecosystem





Analysis of interoperability initiatives

Repository with more than 100 international initiatives analyzed and described



What is **EMINENT**?

EMINENT (Evaluating the **M**aturity of **IN**teroperability for the **EN**ergy **T**ransition)



EMINENT allows organizations to assess and improve their interoperability capabilities over time, ensuring that they can keep pace with the rapidly changing energy landscape.



Community of interoperability testing facilities

Identification IOP enablers for harmonization



"WHAT needs to be covered by IOP testing?"

"WHICH testing infrastructure (physical/virtual) is required for IOP testing?"

"HOW should IOP testing be done?"



int:net project

6th SGAM layer: Frameworks





Community network for a European interoperability ecosystem

- Horizontal coordination, support, up-take of energy services related to interoperability, data spaces and digital twins:
 - Legal and regulatory framework setters in cross-domain modelling and interoperability testing exercises (e.g., connectathons)
 - Cross-fertilization process for regional testing infrastructures
 - Initiatives external to the project (Gaia-X, ISGAN, ETIP SNET, BRIDGE, EIRIE, etc.)
- int:net community as formal institution (association) to be self-maintained in the long term



Engage Stakeholders

:net



Disseminate Results



Create a Community



Blueprint of the CEEDS

Goal: from Innovation Actions to national initiatives and large-scale deployments of data spaces

Content:

- Business use-cases:
 - Scenarios, Actors, Exchanged Data
- Architecture for data exchange
- Interoperability:
 - Technical
 - Semantic
 - Governance





Use cases for Common European Energy Data Space (CEEDS)





Energy Data Space Cluster

::net

Proposed Architecture



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Dataset and Semantic Model

- Focus on smart meter data exchange
- EUMED Metering and Market as common EDSCP data model
- Strongly linked to European My Energy Data Initiative
- EUMED has been integrated in Omega-X
 Common Semantic Data Model (CSDM)





Semantic Interoperability

- Definition of Mapping between Data Models of different projects into common EDSCP data model
 - Allow different formats (JSON using UML, JSON-LD, XML)

Next Steps:

- Projects are defining mapping between their data model and EUMED
- Live Demo in Q1 '25







Thank you for your attention

Prof. Antonello Monti Fraunhofer FIT antonello.monti@fit.fraunhofer.de





SELECTED USE CASES

Shievam Kashyap

Research Associate & Project Manager

University of Applied Sciences Upper Austria

22nd November 2024

Project Consortium





EDDIE Core Vision – An Integrated Distributed Energy Data Space





Overview



Selected Use Cases





Use case -1

ENERGY DATASPACE

for Residential Energy Optimisation in future NetZero homes

Integrating PV self-consumption, storage and V2X

Dataspace for Implicit Prosumer Participation







Use case -2

ENERGY DATASPACE

for Granular Carbon Accounting

24x7 Carbon-free Energy Matching

Dataspace for Granular Carbon Accounting













Use case -3

ENERGY DATASPACE

for Virtual Power Plants

Facilitating Renewable Integration and Demand side flexibility




Facilitation of Virtual Power Plants and Demand-side Flexibility





Facilitation of Virtual Power Plants and Demand-side Flexibility

Current State

Envisioned State





Facilitation of Virtual Power Plants and Demand-side Flexibility







Facilitation of Virtual Power Plants and Demand-side Flexibility







Facilitation of Virtual Power Plants and Demand-side Flexibility







Facilitation of Virtual Power Plants and Demand-side Flexibility

















14 deployments across 16 countries

60 European Partners € 16 M Budget

EDDDE EUROPEAN DISTRIBUTED DATA INFRASTRUCTURE FOR ENERGY

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Co-funded by the European Union

Q&A













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Antonello Monti Professor, Institute Director, RWTH Aachen University

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WEBINAR

Smart cities and digital twin technology: the case of Rotterdam

Unin. europo academy

6 December 2024 10.00 – 11.00 CET









Thank you!



