



D5.11 Rome dissemination event

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QUANTUM summary	QUANTUM aims at developing and implementing a label mechanism that could be ideally adopted in the future HealthData@EU. QUANTUM builds on 5 technical work packages (WPs). WP1 conceptualises and provides technical specifications for a data quality, utility, and maturity label. WP2 designs and tests, at small-scale, the label. WP3 implements the labelling mechanism in a number of data holders. WP4 engages the data quality users' community; and, WP5 outreaches other interested parties, including other initiatives building HealthData@EU.
Deliverable abstract	This deliverable provides an overview of the QUANTUM Dissemination Event held in Rome, focusing on building a high-quality health data ecosystem within the European Health Data Space. The event showcased the QUANTUM project's progress, highlighting the development of data quality labels and their importance for enhancing trust and usability of health data. Key discussions covered data holder challenges, patient trust, and the technical specifications and implementation of the QUANTUM tool. The document summarizes main takeaways from each Work Package and overall considerations for future developments.
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QUANTUM CONSORTIUM			
#	Short Name	Organisation Name	Country
1	IACS	INSTITUTO ARAGONES DE CIENCIAS DE LA SALUD	ES
2	Sciensano	SCIENSANO	BE
3	Health Data Hub	PLATEFORME DES DONNEES DE SANTE	FR
3.1	HOSPICES LYON	HOSPICES CIVILS DE LYON	FR
3.2	HOSP TOULOUSE	CENTRE HOSPITALIER UNIVERSITAIRE DE TOULOUSE	FR
3.3	CHU Bordeaux	CHU HOPITAUX DE BORDEAUX	FR
4	I-HD	THE EUROPEAN INSTITUTE FOR INNOVATION THROUGH HEALTH DATA	BE
5	UCSC	UNIVERSITA CATTOLICA DEL SACRO CUORE	IT
6	BBMRI-ERIC	BIOBANKS AND BIOMOLECULAR RESOURCES RESEARCH INFRASTRUCTURE CONSORTIUM	AT
7	DIGITALEUROPE	DIGITALEUROPE AISBL	BE
8	GÖG	GESUNDHEIT OSTERREICH GMBH	AT
9	UPV	UNIVERSITAT POLITECNICA DE VALENCIA	ES
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13	VIB	VIB VZW	BE
14	CIPH	HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO	HR
15	HUS	HUS-YHTYMA	FI
16	THL	TERVEYDEN JA HYVINVOINNIN LAITOS	FI
17	ECRIN	ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK	FR
18	BFARM	BUNDESINSTITUT FÜR ARZNEIMITTEL UND MEDIZINPRODUKTE	DE
19	HIQA	HEALTH INFORMATION AND QUALITY AUTHORITY	IE
20	ISS	ISTITUTO SUPERIORE DI SANITA	IT
21	CESSDA ERIC	CESSDA ERIC	NO
21.1	KNAW	KONINKLIJKE NEDERLANDSE AKADEMIE VAN WETENSCHAPPEN - KNAW	NL
21.2	EKKE	ETHNIKO KENTRO KOINONIKON EREVNON	EL
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29	UESSEX	UNIVERSITY OF ESSEX	UK
30	INSERM	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE	FR
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Developing a data quality and utility label for the European Health Data Space.

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List of Abbreviations and Acronyms

EHDS	European Health Data Space
EC	European Commission
UCSC	Università Cattolica del Sacro Cuore
CoP	Community of Practice

1 Introduction

This deliverable provides an overview of the QUANTUM Dissemination Event: Building a High-Quality Health Data Ecosystem, which served as a crucial gathering for partners and stakeholders to discuss, review, and advance the goals of the QUANTUM project. This event focused on developing a data quality and utility label for the European Health Data Space (EHDS) and fostering collaboration within the community..

2 Programme of the event

The events took place in person over two half days at Hotel The Building in Rome:

Day 1: April 9, 2025 Afternoon (15:00-18:00 CEST)

Day 2: April 10, 2025 Morning (09:00-13:30 CEST)

The event was strategically designed to showcase the progress and findings of the QUANTUM project, which is dedicated to building a high-quality health data ecosystem. The core rationale was to inform stakeholders, foster collaboration, and gather feedback on the project's key output: establishing data quality labels for health data systems within the European Health Data Space (EHDS). The event aimed to highlight the importance of data quality in enabling effective and trustworthy use of health data across Europe.

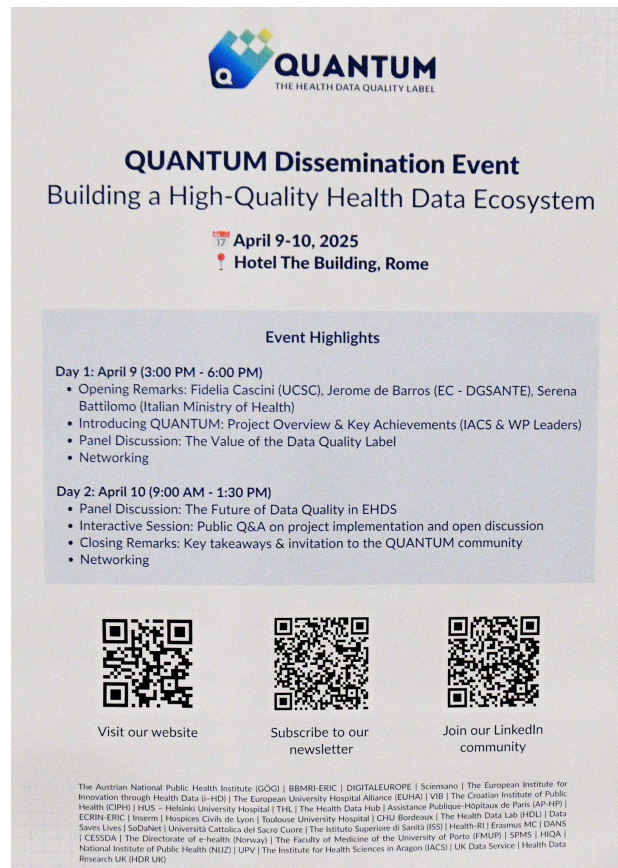


Figure 1: Poster of the Dissemination Event

Day 1 - April 9, 2025 (15:00-18:00 CEST)

Day 1 was designed to lay the groundwork for understanding the QUANTUM project. The rationale was to introduce the project's vision, its significance within the EHDS, and to present the foundational achievements from each work package. This day aimed to provide attendees with a comprehensive overview of the project's scope and the critical need for data quality in health data systems, stimulating the discussion around the value of data quality labels.



Figure 2: Plenary session of the first day

Sessions Overview

15:00 - 15:20: Welcome and Opening Remarks

- Welcome by WP5 Co-leader and host of the event (Fidelia Cascini).
- Institutional remarks by the Director of the Information System of the Italian Ministry of Health (Serena Battilomo).
- Setting the Stage: Importance of Data Quality in the EHDS by EC - DG SANTE (Jerome de Barros).

This session set a welcoming tone and underscored the vital role of data quality in the EHDS, featuring insights from the event host, the Italian Ministry of Health, and the European Commission.

15:20 - 16:45: Introducing QUANTUM: vision and achievements

- Overview of the project and its goals by IACS (Enrique Bernal-Delgado, Project Coordinator).

Key achievements of each Work Package (WPs Leaders including Q&A from the public):

- WP1: Focused presentation of the data quality, utility, and maturity criteria - HDH, GöG.
- WP2: Design, development, and testing of the label - Sciensano, UPV.

- WP3: Mid-scale implementation of the label - IACS.
- WP4: Capacity building, community engagement and scale up - i~HD, BBMRI.
- WP5: Dissemination and outreach - DIGITAL EUROPE, Sciensano.

This session delved into the heart of the QUANTUM project, outlining its overarching goals and presenting key accomplishments from each Work Package (WP). Each WP leader provided specific details on their contributions, covering areas such as data quality criteria development, label design, implementation strategies, capacity building initiatives, and dissemination efforts. The presentations can be found here:

https://drive.google.com/drive/folders/1jtjSVdkvxaXUqPmmPTVYCoyZipoo5_SG?usp=sharing

16:45-17:00: Coffee and Networking

17:00 - 18:00: Panel Discussion: The value of data quality labels in health data systems

- Moderator: Label to enable (Petra Hoogendoorn).
- Speakers: EOSC (Ignacio Blanquer), FINDATA (Peija Haaramo), University of Pavia (Riccardo Bellazzi), EMA (Ana Cochino).

Discussion Points:

- Value of data quality labels for stakeholders.
- FINDATA's experience with data quality labels.
- Data quality labels in AI and innovative health technologies.
- Benefits of data quality labels for data holders in clinical research.
- Future applications and implementation.

This discussion brought together experts from prominent organizations like EOSC, FINDATA, the University of Pavia, and EMA to explore and articulate the broader impact and inherent value of data quality labels in enhancing the reliability and usability of health data systems.

Day 2 - April 10, 2025 (09:00-13:30 CEST)

The second day was designed with a focus on the future trajectory of data quality within the EHDS and on actively engaging participants. The rationale was to move beyond presentations to interactive discussions, gather valuable feedback on the project's implementation, and foster a sense of community among stakeholders. This day aimed to explore the practical application and future development of data quality initiatives.



Figure 3: Results' roundtable session

Sessions Overview

09:00 - 09:15: Welcome and introduction to the day

The day commenced with a brief welcome and an outline of the key objectives for the day, preparing participants for the interactive sessions ahead.

09:15 - 11:00: The Future of Data Quality in the EHDS

- Moderator: HDRUK (Monica Jones).
- Speakers: EHDS CoP Steering Board (Fidelia Cascini), EHDS CoP SG2 (Truls Korsgaard), EFPIA (Pamela Dobay), ESPM (Giampaolo Brichetto), ELIXIR Europe /GDI (Juan Arenas), IHE Catalyst (Claudio Saccavini), Giuseppe D'Avenio (Italian National Institute of Health).

Discussion Points:

- Significant data quality hurdles in EHDS implementation.
- Role of TEF health.
- Prioritizing standards for data quality, interoperability, and cross-border data exchange.

This session featured speakers from diverse organizations, including the Community of Practice (CoP), industry representatives, and research institutions, who shared their perspectives on the evolving landscape of data quality and its future within the EHDS.

Coffee and Networking 11:00 - 11:30 AM

11:30 AM - 12:15 PM: Interactive Session

- Moderator: Regina Valenzano (UCSC)
- WP leader asking questions (pre-submitted) and the public answer (questions were related to: public consultation, issues over the project implementation etc.).

12:15-13:00 Results' round-table discussing the interactive sessions

- Moderator: Fidelia Cascini (UCSC)
- Panel: QUANTUM Work Package leaders discussing the main outcomes of the interactive session carried out over Mentimeter.

13:00 - 13.30 PM: Closing Remarks

- Evaluation of the event by UCSC (Regina Valenzano)
- Invitation to join the QUANTUM community and contribute to the future of health data by Sciensano (Barthelemy Moreaux)
- Summary of key takeaways and next steps by IACS (Enrique Bernal-Delgado) and UCSC (Fidelia Cascini)



Figure 4: Dissemination event final group picture

3 Main takeaways

The Dissemination event successfully communicated the benefits of using quality data to a broad range of stakeholders. Key topics included the value of data quality labels, the future of data quality in the EHDS, and engaging citizens and patients.

Progress was highlighted on the development of the QUANTUM tool for assessing data quality, utility, and maturity. Interactive sessions using Mentimeter provided insights for further improvements.

Furthermore, the event facilitated collaboration and networking among project partners, AB members, and stakeholders.

3.1 Main takeaways by WPLs

WP1: Specification Data Quality & Utility - Maturity Label

Tool Improvement: the results of the mentimeter (QUANTUM Interactive session: Gathering insights for improvement) raised some issues related to the QUANTUM tool and its specifications (to be more specific and less generic). The need for more explanations regarding the underlying reasons for the agnostic approach was expressed and pros (adaptability, standardization) and cons (potential for being too broad, misinterpretation) were highlighted.

Domain-Specific Labels: Suggestions were made to create specific labels for different use cases or domains within the EHDS, building on the initial generic label.

Non-Tabular Data: The usability of specifications for non-tabular data (e.g., cancer images, biobanking data) is a significant challenge. There's a need for clear documentation, metadata evaluation at the catalog level, and possibly sector-specific standards.

WP2: Design, Development & Testing of Label

Data Holder Implementation: Data holders need guidance and tools (like open-source options) to implement and justify reported data quality measurements. A methodical approach, starting with simpler datasets, was recommended.

Data User Feedback: Data users emphasize "fitness for purpose" and need clear, timely, and easy-to-understand data quality information. However, some users may be reluctant to provide feedback due to time constraints or data use agreements.

Tool Accessibility: Preferences vary for accessing the QUANTUM labeling tool: some want a secure online web application, others want local installation, and some want both. There's also interest in contributing to and extending the open-source tool locally.

WP3: Mid-Scale Implementation of the Label

Pilot Participation: A diverse range of professional profiles should be involved in the mid-scale

pilot (IT staff, data quality specialists, data stewards, etc.). Selection criteria should include expertise, willingness, and data diversity.

Direct Data Access: There is interest in future versions of the QUANTUM tool directly accessing data to calculate quality metrics.

HDAB Label Revocation: The process for Health Data Access Bodies (HDABs) to revoke a quality label needs to be transparent, well-defined, and potentially involve independent verification.

WP4: Capacity Building, Community Engagement & Scale Up

QUANTUM Evolution: Future phases of QUANTUM should focus on user feedback, verification of label specifications, integration within the EHDS platform, and extensive training and capacity building.

Data Quality Dimensions: The usefulness of a data quality dimension weighting system is debated. Suggestions include archotyping user purposes or monitoring usage to better understand needs.

Stakeholder Upskilling: QUANTUM can help upscale stakeholders' data quality through training, awareness initiatives, and clear feedback mechanisms.

QUANTUM Academy: Stakeholders want practical, accessible, user-friendly, and modular training from the QUANTUM Academy.

WP5: Dissemination & Outreach

Communication: Various channels are used to stay informed about QUANTUM. Suggestions were made for more efficient and clear communication, including video materials and aligning with other EHDS initiatives.

Overall Challenges and Considerations

The document highlights several key challenges and considerations that are crucial for the successful implementation and adoption of the QUANTUM tool and the broader concept of data quality labels within the European Health Data Space (EHDS). These can be summarized as follows:

1. Data Holder Challenges:

- **Maintenance:** Data holders are concerned about the ongoing maintenance required to keep the data quality labels up-to-date and accurate. This includes regular checks, updates, and adjustments as data changes and new requirements emerge.
- **Resources:** Implementing and maintaining a data quality labeling system demands resources, both in terms of personnel and technology. Data holders may lack the dedicated staff or the necessary infrastructure to effectively adopt the tool.
- **Time:** The process of assessing data quality, assigning labels, and maintaining the system takes time. Data holders may be hesitant to invest significant time, especially if

they don't immediately see the value.

- Understanding the Value of the Tool: Some data holders might not fully grasp the benefits of the QUANTUM tool and data quality labels. They need clear explanations and demonstrations of how it can improve data usage, transparency, and trust.

2. Patient Trust:

- Transparency: Data labeling can significantly enhance patient trust by providing transparency about how their data is being used and the quality of that data. When patients understand that data is being managed responsibly and accurately, they are more likely to trust secondary data use for research and other purposes.
- Accountability: Data quality labels imply accountability. Data holders who assign and maintain labels are taking responsibility for the quality of their data. This accountability can reassure patients about the integrity of data handling.
- Clear Communication of Benefits: It's crucial to communicate the benefits of secondary data use to patients effectively. When patients understand how their data contributes to advancements in healthcare, they are more likely to support data sharing initiatives.

In essence, these challenges and considerations underscore the need for a comprehensive approach that includes not just the technical aspects of the QUANTUM tool, but also the organizational, educational, and ethical dimensions of data quality in the EHDS.

4 Concluding remarks

In conclusion, the QUANTUM Dissemination Event in Rome served as a pivotal moment for advancing the dialogue and collaboration around data quality within the European Health Data Space. The event successfully highlighted the project's vision, key achievements, and the critical importance of data quality labels for enhancing trust and usability of health data. Through informative sessions, engaging discussions, and valuable feedback from stakeholders, the event not only showcased the progress of the QUANTUM project but also laid a strong foundation for future developments and implementation efforts. The insights gathered, particularly regarding data holder challenges, patient trust, and the need for specific tool improvements, will be instrumental in shaping the next phases of the project and ensuring its continued success in building a robust and reliable health data ecosystem across Europe.