



# D5.3 Newsletter

1st Newsletter edition (June 2024)

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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 (WP). 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 several 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 presents the content of the first QUANTUM newsletter.
Keywords	Newsletter, EHDS

Document Revision History			
Date	Version	Author/Contributor/Reviewer	Summary of Main Changes
28/05/2024	0.1	Barthélemy Moreau de Lizoreux	Initial document
28/05/2024	0.2	Daniella Manassero (DIGITALEUROPE), Fidelia Cascini (UCSC)	Slight modifications of the introduction, proofreading and addition of visuals
30/05/2024	1	-	Final version

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
10	HEALTH-RI	STICHTING HEALTH-RI	NL
11	EUHA	EUROPEAN UNIVERSITY HOSPITAL ALLIANCE	BE
12	AP-HP	ASSISTANCE PUBLIQUE HOPITAUX DE PARIS	FR
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
22	e-helse	DIREKTORAT FOR E-HELSE	NO
23	U.PORTO	UNIVERSIDADE DO PORTO	PT
24	SPMS	SERVICOS PARTILHADOS DO MINISTERIO DA SAUDE EPE	PT
25	NIJZ	NACIONALNI INSTITUT ZA JAVNO ZDRAVJE	SI
26	ERASMUS MC	ERASMUS UNIVERSITAIR MEDISCH CENTRUM ROTTERDAM	NL
27	EDHA	EUROPEAN DIGITAL HEALTH ACADEMY GGMBH	DE
28	HDR UK	HEALTH DATA RESEARCH UK	UK
29	UESSEX	UNIVERSITY OF ESSEX	UK
30	INSERM	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE	FR

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**QUANTUM**  
THE HEALTH DATA QUALITY LABEL

Developing a data quality and utility label for the European Health Data Space.

Project number: 101137057  
Call: HORIZON-HLTH-2023-TOOL-05  
Topic: HORIZON-HLTH-2023-TOOL-05-09  
Type of Action: Horizon-CSA  
Start Date of Project: 01 January 2024  
Duration: 30 months

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## Introduction

The deliverable D4.3 presents the content of the first QUANTUM newsletter, which will be displayed in a newsletter format to the subscribers, through the online tool [MailerLite](#). The different sections (topics) of this first issue are:

1. Editorial: Welcome to QUANTUM
2. Successful kick-off meeting for QUANTUM
3. NEW IN: QUANTUM website launched
4. pen consultations
5. QUANTUM events
6. Discover the QUANTUM work areas
7. Related projects
8. What we're reading - interesting publications

# Editorial

Subject line: Welcome to the QUANTUM project! | Newsletter no. 1 (June 24)







Figure 1: Newsletter header

Dear readers,

Welcome to the very first newsletter of the QUANTUM project, where you will receive regular updates on the project and other initiatives related to the topic of data quality, health data, and the European Health Data Space (EHDS).

**TALKING ABOUT THE EHDS...** the recent [adoption of the regulation proposal by the European Parliament](#) reinforces our commitment to contribute to the EHDS, and especially to its requirement (article 56) of labelling health datasets within the EU for secondary purposes, benefiting research, innovation, and the healthcare systems as a whole.

## What do we have for you in this edition?

-  NEW IN: QUANTUM website
-  Open consultations
-  **17 July** QUANTUM Events
-  QUANTUM work areas...and more!

Keep scrolling down to learn more!

Happy reading,

The QUANTUM coordination team

## Successful kick-off meeting for QUANTUM!



Figure 2: QUANTUM kick-off meeting photo

On the 20<sup>th</sup> and 21<sup>st</sup> of February, the consortium of QUANTUM: “Developing a Data Quality and Utility Label” met in Brussels for the first time to officially launch the Horizon Europe-funded project. All the partners discussed the various activities and highlighted the way forward for this ambitious and strategic project to unlock the full potential of new tools, technologies and digital solutions for a data-driven healthy society.

[Read the press release here!](#)

## NEW IN: QUANTUM website launched!

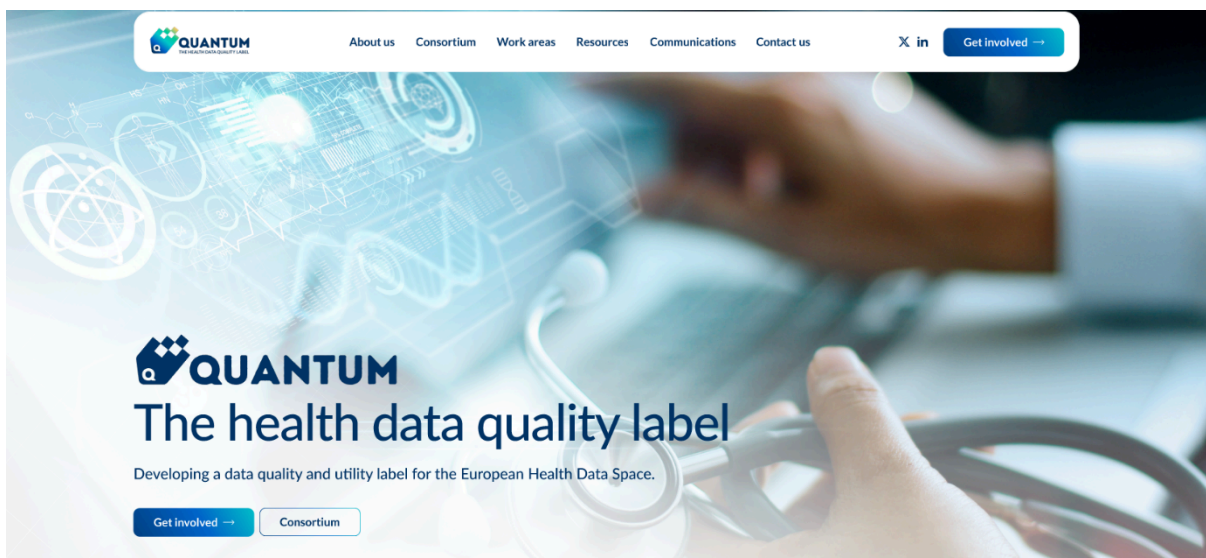


Figure 3: QUANTUM website screenshot

We are very excited to announce that the QUANTUM website is now online! The content will continue to be enriched in the coming weeks, but it already provides interesting information about the project’s activities, objectives, partners and news.

[Visit our website!](#)



## QUANTUM open consultations

In the framework of the QUANTUM work package 1 (see below for more information about the different work packages for the project), several open consultations are conducted to develop the specifications of the QUANTUM data quality, utility and maturity labelling system.

### QUANTUM Delphi study

To gather expert insights and achieve consensus on the different dimensions for the data quality and utility label, we are conducting a Delphi exercise, which will consist of 2 rounds of surveys (with the possibility of a third round). The final purpose is to rate, on a 9-point Likert scale, the relevance of each data quality dimension for the assessment of the quality and utility of health data. **After a successful first round gathering 109 experts among data holders, users and Health Data Access Bodies, the second round will start on June 3<sup>rd</sup>! Get ready, if you participated in the first round!**

### QUANTUM nominal group workshop

**On July 4<sup>th</sup> and 5<sup>th</sup> in Brussels, we are organising a nominal group workshop in Brussels with a list of 16 experts from QUANTUM partner organisations. The aim is to reach a consensus on the specifications of data quality & utility metrics (definition, measurement unit, weight and thresholds) of the QUANTUM label.**

### QUANTUM focus group meetings

The QUANTUM's quality and utility labelling system aims to also cover the data holder's maturity process and to propose levels of maturity for the Capability Maturity Model dimensions affecting data and data quality management. To this aim, a dedicated focus group with data managers and data quality managers from the participating data holders will be asked to assess key processes in data management, goals in each process, features, key practices, and levels of maturity. Participants will represent different levels of maturity in the primary collection of data. **The QUANTUM first focus group meetings will take place on the 29<sup>th</sup> of May and the 19<sup>th</sup> of June 2024.**

## QUANTUM events

Since the launch of the project in February, we already had several occasions to present QUANTUM and to liaise with relevant stakeholders and international or European initiatives. Our coordinator, Enrique Bernal Delgado (IACS), participated for instance in an event dedicated to **the European Medicines Agency's Data Quality Framework for EU medicines regulation** on the 24<sup>th</sup> of April. Our colleague Jens Declerck, data quality manager at the European Institute for Innovation Through Health Data (i~HD) also participated in a symposium "[The Arisal of Data Spaces: Big Data in Health and Care](#)" in Hasselt, Belgium,



where he delved into the challenges and methodologies of evaluating data quality within the European Health Data Space (EHDS) by introducing the QUANTUM project. On the 27<sup>th</sup> of May, Jens also presented QUANTUM at the **Belgian Data Spaces Day 2024**.

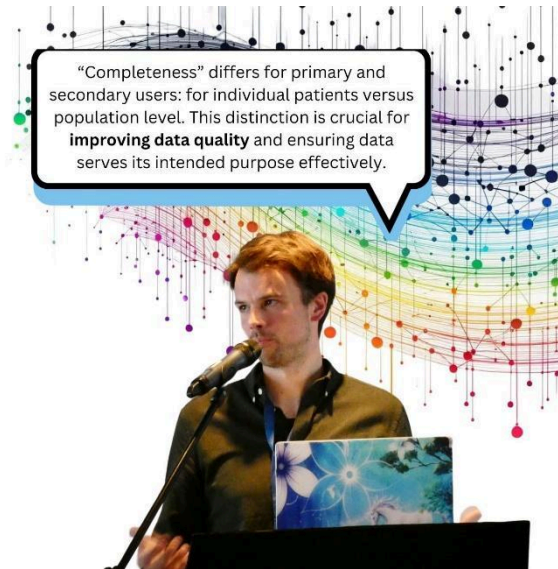


Figure 4: Jens Declarck at the symposium "The Arisal of Data Spaces: Big Data in Health and Care" in Hasselt, Belgium

## Discover the QUANTUM work areas



Figure 5: QUANTUM Work packages overview

### WP1 Specification of the data quality and utility, and maturity label

**Lead:** Health Data Hub; **co-lead:** Gesundheit Österreich

This work package has the aim to bring together the necessary conceptual grounds and evidence for an EHDS data quality and utility label focusing on evaluating the quality of the data per se and the maturity levels of data holder’s organisations. It will perform the following tasks:

- Conceptualisation of data quality & utility. **This task, led by GÖG and co-led by THL has just reached a successful conclusion.** This initial phase was dedicated to conceptualising data quality and utility across various dimensions. A comprehensive literature review, coupled with expert consultations - including data quality managers,

data holders, data analysts, and data users - has culminated in a collection of terms and definitions. These will be critically evaluated in the recently started Delphi process (see hereafter).

- Carry out the selection of a relevant and consensual set of criteria for data quality and utility assessment (via the ongoing Delphi study).
- Operationalise the consensus reached through the Delphi process into a specification of the data quality and utility metrics
- Propose levels of maturity for the Capability Maturity Model dimensions affecting data and data quality management

## WP2 Design, development and testing of the label

**Lead:** Sciensano; **co-lead:** Universitat Politècnica de València (UPV)

The main objectives of this work package are to design, develop and test a tool to enable data holders to: share standardised data quality and utility information; report on maturity elements; and include data access bodies and user experiences. It will perform the following tasks:

- Landscape analysis of the technical requirements
- Design and development of the label
- Small-scale testing of the tool on a small selection of data holders
- Labelling upgrading

## WP 3 Mid-scale implementation of the label

**Lead:** Instituto Aragonés de Ciencias de la Salud (IACS); **co-lead:** Health-RI

Based on the work performed by the work packages 1 and 2, the mid-scale testing of the labelling tool will be implemented following the tasks below:

- Preparation of the implementation plan of the tool
- Mid-scale label implementation pilot
- Assessment of the experience of data holders involved in piloting the label
- Transfer and sustainability for the implementation of the label for the HealthData@EU infrastructure.

## WP 4 Capacity building, community engagement and scale up

**Lead:** The European Institute for Innovation through Health Data (i-HD); **co-lead:** Biobanks and biomolecular resources research infrastructure consortium (BBMRI)

The QUANTUM work package 4 will address the capacity building and training needs of the health data access bodies, as so far as entry-point to the HealthData@EU infrastructure data, and expected supervisors of the labelling mechanism; data holders as implementers of the labelling mechanism; and health data users, typically the research community and innovators,

the EU and National and Regional Agencies, as well as decision makers. It will perform the following tasks:

- Capacity needs assessment: This task will engage with data holders, data access bodies, data users and evidence decision-making stakeholders, in order to explain the expectations on each of them for creating or making use of the QUANTUM labelling tool.
- Development and provision of data quality labelling education and adoption resources, such as online training tailored to the different stakeholders whose capacity gaps were identified.
- Sustainable community of practice and repository of best practice resources. This repository will establish a community of practice that can provide peer support and exchange experiences in scaling up data quality labelling and making use of data quality labels.

## WP 5 Dissemination and outreach

**Lead:** Università Cattolica del Sacro Cuore (UCSC); **co-lead:** DIGITAL EUROPE

This work package aims to contribute to one of the main objectives of the QUANTUM project which is to develop a capacity-building and outreach programme that allows a broad engagement of the data quality professional community, patients and citizens. The following tasks will be performed:

- Elaboration of a dissemination and outreach plan
- Building the identity and branding of the project
- Access to a wider audience (social media, newsletter, layperson reports and visuals...)
- Engagement with other international initiatives
- Engagement with citizens and patients
- The organisation of dissemination events

## WP 6 Project management

**Lead:** IACS;

The aim of this work package is to efficiently manage the project and to monitor its activities in order to support the achievements of the project's objectives. This includes the day-to-day follow-up of the scientific, administrative and financial aspects of the project. WP6 will ensure that the contractual obligations are fulfilled and the expected results are delivered as planned. It includes a specific task dedicated to the project's monitoring and risk management.

## Related projects

### HealthData@EU pilot



HealthData@EU Pilot project is building a pilot version of the European Health Data Space (EHDS) infrastructure for the secondary use of health data which will serve research, innovation, policy-making and regulatory purposes.

[Learn more](#)

## Second Joint Action Towards the European Health Data Space – TEHDAS2



The TEHDAS2 joint action prepares the ground for the harmonised implementation of the secondary use of health data in the European Health Data Space – EHDS. The TEHDAS2 joint action started in 2024 and it will build on the work of previous [TEHDAS1](#) and other European projects. TEHDAS2 is carried out by 30 European countries and co-ordinated by the Finnish Innovation Fund, Sitra. The project started in May 2024, and it will end in December 2026. It is based on the European Commission’s EU4Health Programme.

[Learn more](#)

## xShare



xShare is a three-year Horizon Europe project envisioning everyone sharing their health data in European Electronic Health Record Exchange Format (EEHRxF), with a click-of-a-button. With its consortium of 40 partners, xShare aims to introduce the xShare ‘yellow’ button and industry label to the European market. This yellow button will enable people to share their health data through the European Electronic Health Records Exchange Format. The project’s work forms an important element of the upcoming European Health Data Space (EHDS) regulation.

[Learn more](#)

## What we are reading - interesting publications



[Frameworks, Dimensions, Definitions of Aspects, and Assessment Methods for the Appraisal of Quality of Health Data for Secondary Use: Comprehensive Overview of Reviews](#)

JMIR Medical Informatics | Vol 12 (2024)

This review aims to offer a comprehensive overview of the existing frameworks for data quality dimensions and assessment methods for the secondary use of health data. In addition, it aims to consolidate the results into a unified framework. Authors of this paper Jens Declerck and Dipak Kalra are also colleagues from the QUANTUM consortium.

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