



Intelligent ecosystem to improve  
the Governance, the sharing, and the re-use  
of health data for rare cancers

# Data Altruism Manager

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MAY 21<sup>st</sup>, 2025



## Component

**Data Altruism Manager**

## Partner

**CERTH – Centre for Research and Technology Hellas**

## Brief description

A tool for individual patients to voluntarily provide data for research related with rare cancers with dynamic consent as to how and by whom these data can be used. Aligned with the Data Governance Act and the IDEA4RC platform governance options, it innovates with its trust-enhancing blockchain log for consent versions and its helpful LLM-based chatbot.

## Intended users

- Data altruism organisations as administrators
- Patients

## Functionality

- cancer data donation
- dynamic, blockchain-based granular consent mechanism
- consent history log
- chatbot to boost digital literacy of the data subjects
- administrator dashboard (pseudonymised history log, statistics)

## Comparison with competing approaches (business value)

- granular options for consent: purposes of data use, data user categories
- dynamic digital consent: can be modified or withdrawn
- exportable content
- chatbot enabling users to better understand how their contribution matters and how their digital rights are protected, motivating them to participate
- immutability and non-repudiation of the consent records, so that both the patients can be confident that their consent choices are safeguarded against alteration and the researchers using the data through IDEA4RC can be confident that they are respecting patient rights and will avoid legal disputes

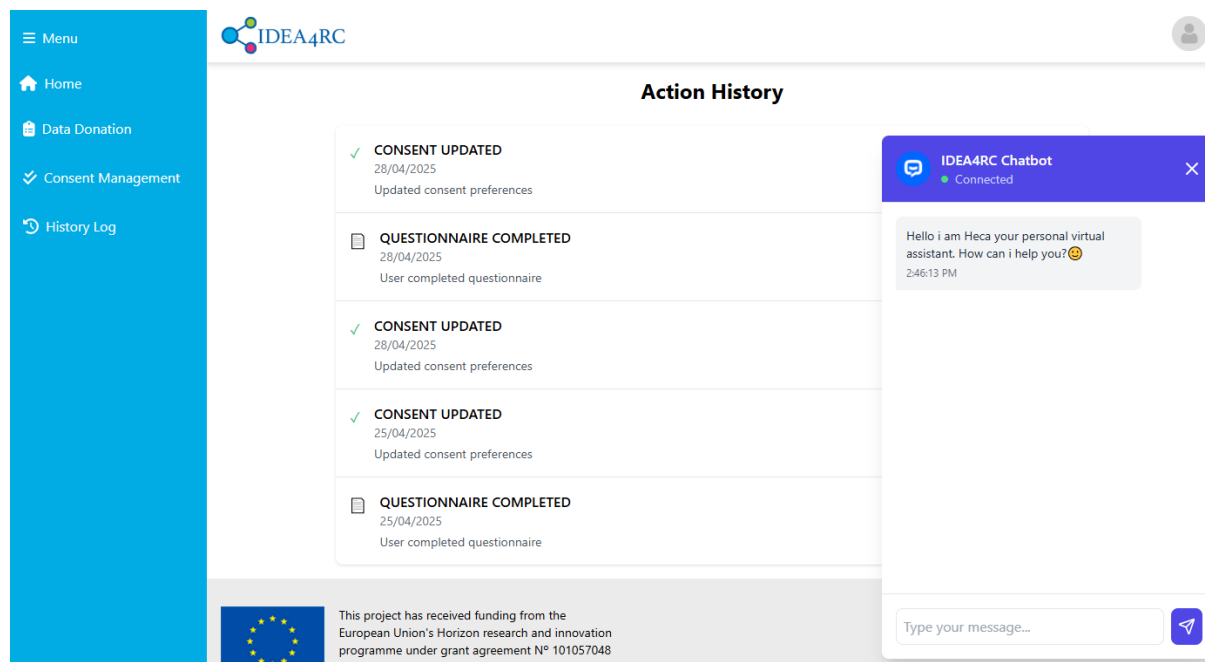
## Development status

Released

## Imagery



Figure 1- Data Altruism Manager targeted users



The screenshot displays the IDEA4RC web application interface. On the left is a blue sidebar menu with options: Menu, Home, Data Donation, Consent Management, and History Log. The main content area is titled 'Action History' and lists several actions:

- ✓ CONSENT UPDATED** (28/04/2025): Updated consent preferences
- 📄 QUESTIONNAIRE COMPLETED** (28/04/2025): User completed questionnaire
- ✓ CONSENT UPDATED** (28/04/2025): Updated consent preferences
- ✓ CONSENT UPDATED** (25/04/2025): Updated consent preferences
- 📄 QUESTIONNAIRE COMPLETED** (25/04/2025): User completed questionnaire

At the bottom left, there is a European Union flag and a text box stating: 'This project has received funding from the European Union's Horizon research and innovation programme under grant agreement N° 101057048'. On the right side, there is a chatbot window titled 'IDEA4RC Chatbot' with a 'Connected' status. The chatbot message reads: 'Hello i am Heca your personal virtual assistant. How can i help you? 😊' (2:46:13 PM). Below the chatbot is a text input field labeled 'Type your message...' and a send button.

Figure 2 – Blockchain-powered history log of consent records and versions of the data

Menu
Home
Data Donation
Consent Management
History Log

I consent for the use of my data for the following purposes and areas of research and by the following data users:

### Purposes

☒ Public interest in the area of public and occupational health, such as activities for protection against serious cross-border threats to health and public health surveillance or activities ensuring high levels of quality and safety of healthcare, including patient safety, and of medicinal products or medical devices.
☒ Policy making and regulatory activities to support public sector bodies or Union institutions, agencies and bodies, including regulatory authorities, in the health or care sector to carry out their tasks defined in their mandates.
☐ Statistics, such as national, multi-national and Union level official statistics defined in Regulation (EU) No 223/200928 related to health or care sectors.
☐ Education or teaching activities in health or care sectors at the level of vocational or higher education.

☐ Scientific research related to health or care sectors, contributing to public health or health technology assessment, or ensuring high levels of quality and safety of health care, of medicinal products or of medical devices, with the aim of benefitting the end-users, such as patients, health professionals and health administrators, including (i) development and innovation activities for products or services.
☐ Training, testing and evaluating of algorithms, including in medical devices, in-vitro diagnostic medical devices, AI systems and digital health applications.
☐ Improving delivery of care, treatment optimization and providing healthcare, based on the electronic health data of other natural persons.

### Research Areas

☐ Development and innovation activities for products or services.
☒ Training, testing and evaluating of algorithms, including in medical devices, in-vitro diagnostic medical devices, AI systems and digital health applications.

### Data Users

Figure 3 – Granular consent options in the Data Altruism Manager



# IDEA4RC

