

Trust by design: data governance becomes real

September 2023

Welcome to the seventh CRANE newsletter. This autumn brings a milestone at the very heart of what CRANE is building: on **24 September 2023**, the EU's **Data Governance Act** entered into application, introducing for the first time across Europe a legal framework for **trusted data intermediaries** and **data altruism** — the very ingredients our project has worked with since day one. We look at what changes, why it matters for citizen-centred health, and where CRANE stands as our suppliers move through the prototype phase.

— A NEW EUROPEAN WAY TO SHARE DATA

The Data Governance Act enters into application

The Data Governance Act (DGA) creates a safe environment for sharing data across sectors and Member States, with the explicit aim of **increasing trust** in how data is shared. Rather than opening the floodgates, it builds the institutions that make sharing trustworthy in the first place — and that is a shift CRANE recognises well.

- 1 Trusted data intermediaries.** A new category of neutral actors can broker data between those who hold it and those who want to use it, without taking ownership of it.
- 2 Data altruism.** Individuals and organisations can donate their data for goals that serve society — from research to tackling a pandemic — through registered, trustworthy organisations.
- 3 A European Data Innovation Board.** A new body will guide the development of common European data spaces, including the health data space, and set interoperability standards.

— WHY THIS MATTERS FOR CITIZEN-CENTRED HEALTH

Rights need institutions to make them real

CRANE set out from a simple conviction: giving citizens control over their health data is not only a technical question, but a question of **trust and governance**. The DGA puts that same idea into European law. Trusted intermediaries and data altruism are precisely the mechanisms through which a citizen can share health data with confidence — knowing who governs the exchange, and on what terms.

For a project piloting citizen-controlled data sharing across three rural regions, this alignment is encouraging: the framework now forming at European level is the one our suppliers are building working solutions for — at the same time, and in the same direction.

The common thread: *what the Data Governance Act regulates at European scale — trustworthy intermediation for data sharing — is exactly the layer CRANE's suppliers are designing and testing on the ground.*

— WHERE CRANE STANDS: THE PROTOTYPE PHASE

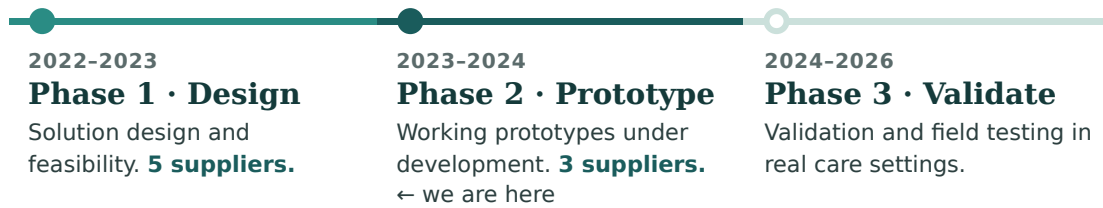
From design to working prototypes

CRANE is now in **Phase 2** of its three-phase competition, where suppliers turn their designs into working prototypes. A recurring theme has already emerged: before anything else can function, each

solution has to build a **citizen-side governance layer** — the part that manages consent and lets data be used without being surrendered. That the European legislator and our suppliers are converging on the same need, independently, is a strong signal — and CRANE will keep testing what it takes to make this work in real care settings.

— CRANE AT A GLANCE

A three-phase journey, now in prototyping



WHAT'S NEXT

As Phase 2 advances, the suppliers will finalise their working prototypes and prepare for the validation phase, where the solutions meet real citizens and professionals across the three regions. We will report on prototype progress in the next issue — and keep tracking how Europe's data-sharing framework develops alongside the project.

Visit our website and follow us to keep up with CRANE as the prototypes take shape and Europe's data framework comes to life: crane-pcp.eu · LinkedIn @crane-pcp

All the best, and let's CRANE!



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