

EUROPEAN HEART NETWORK

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PATIENT INVOLVEMENT IN EU-FUNDED PROJECTS: AIDAVA

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EHN & EU-funded projects

EHN participates in EU-funded projects aimed at improving cardiovascular care through the Horizon 2020 and Horizon Europe funding programme



(2017 - 2023)



(2022 - 2026)



(2023 - 2027)



(2023 - 2027)

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EHN facilitates structured patient involvement in research to enable patients to be active partners in large-scale research and innovation projects.

What is Patient and Public Involvement (PPI)?



Value of PPI in research

- Strengthens the relevance and impact of project results.
- Leads to better recruitment and follow-up rates
- Communication and dissemination are more patient-friendly and accessible to the public

Barriers to PPI

- Access to resources: financial, human, know-how
- Language and communication
- Lack of mechanisms for planning and including meaningful PPI

How and when to involve patients in research



- Through a PPI advisory board or as a patient consultant
- The duration, frequency and regularity of PPI can range from ad hoc task-based contributions to long-term engagement for the entire duration of a project.
- Contribute throughout the life cycle of the research project from reviewing funding applications to supporting dissemination activities.

What enables successful PPI?



- Ensure there are specified PPI goals in the project and role clarity
 - *When? What? How?*
- Establish mechanisms to involve patients early on to build a sense of shared ownership and partnership
- Ensure enough time for patients to contribute to tasks
- Providing feedback to patients on the impact of their contributions
- Provide learning and development opportunities for patients
- Ensuring sufficient resources for PPI activities

AIDAVA:

A Horizon Europe Project

AIDAVA

AI Powered Data Curation and Publishing Virtual Assistant



Funding: Horizon Europe work programme



Consortium: 14 partners from 9 European countries



Budget: € 8.6 million



Duration: 4 years



AIDAVA: The Problem

The availability of high-quality health data is an essential basis for improving preventive medicine, quality of care and clinical research.

Current problem:

- Patients' health data are scattered across different sources and there is no reliable conduit for the data to become interoperable, AI-ready and reuse-ready at scale
- Patients do not have easy access to and full control of their health data
- Costly and recurring manual data cleaning work is still required

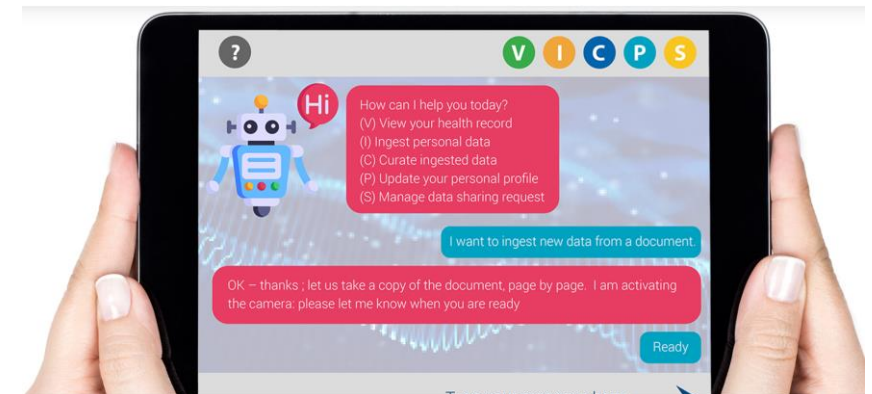


AIDAVA: The Solution

AIDAVA will develop & test two versions of an AI-powered virtual assistant prototype around CVD longitudinal health records & breast cancer registries.

This “**automatic health data cleaning machine**” will support patients and data curators by maximizing the automation of data curation and publishing in **two steps**:

1. **POOLING**: integrate heterogeneous health data from different sources via a Health Data Intermediary
2. **CURATING**: increase the quality of data to make them reuse-ready and interoperable.



AIDAVA: Involvement of Patient Consultants

AIDAVA: Practical information



Type of PPI: 8 patient consultants (4 CVD patients / 4 cancer patients)

Recruitment: Patients with diverse backgrounds (gender, country of residence, age, education, etc.) that meet the inclusion/exclusion criteria

Duration: To participate for the entire life cycle of the project (4 years)

Methods: Online and in-person meetings and workshops

Compensation: 350 euros per one day of work (8 hours), plus full reimbursement for any travel expenses incurred

Administrative: Memorandum of Understanding between the patient organisation and patient consultant.

AIDAVA: Example of patient activities

The development of personas: The aim was to follow human-centred design principles to develop future typical users of the AIDAVA tool, called *personas*.

Step 1



- Online semi-structured interviews were conducted with each patient (\approx 45mins)
- Then the patients reviewed their transcript to ensure the interviewer captured the patient's needs, abilities, skills, constraints and preferences.

Step 2



- Partners aggregated the interview results to form the basis of the personas - 2 profiles were derived.
- The patient consultants reviewed the profiles to provide feedback on:
 - *Is the persona realistic from your point of view? Is any important aspect missing?*

AIDAVA: Example of patient activities

User requirements workshop: the aim was to understand how the system can provide an intuitive interaction, considering different levels of digital and health literacy.

- One day in-person workshop to ensure that the system meets patients' expectations and needs
- Discuss the 'User Journey' from *Registration* to *Deleting Account*
- Project partners collected user requirements from the discussion



Example of the 118 user requirement collected:

Actor	Action	Description	Rationale	Source
Patient	having my data in AIDAVA	I want the system to show me my personal health data by categories, which I want to define by myself (self-defined data filter)	so that I can easily get an overview of my health data (e. g. by type of data such as blood test)	Workshop with patients consultants

AIDAVA: Example of patient activities

Prototype Assessment: the aim is for patient consultants to contribute to the design and implementation of the AIDAVA prototype evaluation study.

Role of patient consultants:



- Provide **feedback on the acceptability of the study schedule and activities** for site patients and suggest any improvement (critical changes vs. 'nice-to-have')
- **Proofread and comment on material** that will be given to site patients
 - *Study Information Package, Informed Consent Form, etc.*
- **Revise the training material** for site patients before they test the system
- **Pre-test the system** before it is deployed in hospitals

AIDAVA: Consultant's overall feedback

The patient consultants are very heterogeneous, yet the work on AIDAVA is very effective, interesting and peaceful despite stimulating discussions.

- AIDAVA is well organised, and as the patient consultants are well-integrated into the project, we can clearly see the progress over time.
- It is interesting and an honor to be part of a partnership between patients, organisations, and researchers throughout the project's life cycle.
- AIDAVA will be made with and by patients and not just for them- which is not an easy task since the patient consultants have a lot of ideas and dreams which are not always in scope of this project.





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