

Project Intro



AIDAVA is a Horizon Project, which started on September 2022 with 14 partners including 2 patient associations: the European Health Network (EHN) and the European Patient Coalition for Cancer (ECPC).

AIDAVA objective is to develop “a data cleansing machine“ for patients, enabling them to maintain a high-quality personal medical record, including data collected by the patients (devices, PROMS). To minimize patient effort, the system will maximize automation in the cleansing process by orchestrating multiple AI technologies.

During a requirement workshop with patients from both associations in February, we gathered the following reactions.



Patient's Incentives

As a patient with a complex medical condition, the main incentive to clean my data is to ensure my treating physician has smooth access to my complete medical record, so that I can receive the most appropriate care.

I am happy for others to access and use my data, but in a controlled way.



Using and Sharing Data

1. I want to know who will access my data and if possible, to obscure some information.
2. I am ready to share my data, but I want to give consent in an easy way for all parties.
3. When I share my data, I want to know who will use these data and for what purpose.
4. A reward should be envisioned, when I share my data for developing a commercial product.
5. I am not sure about data donation – does it mean I lose control of my data ?

The project will keep working with patients – and hospital data curators - to clarify the requirements of the tool.
A first release of the system will be deployed in the summer of 2024 and will undergo a formal evaluation.
A second version of the prototype will be deployed and tested mid 2026.

Next Steps

