Introduction

AIDAVA's goal is to make it easy for patients to maintain a personal medical record that is complete, accurate, and reusable - with as much automation as possible. Your feedback has been essential in shaping the next version of the prototype (Generation 2 - G2), which will be released to patients later this year. In this issue, we look back at recent patient and ethics activities that are guiding G2's development and share what's coming next for you.

Ethics Advisory Board Update

The AIDAVA Ethics Advisory Board (EAB] plays a key role in ensuring the project respects ethical principles, safeguards data privacy, and delivers real value for patients. We also want to highlight the **increased partnership between the Patient Advisory Group and the EAB**. The EAB has an overall ethics and data protection oversight role in AIDAVA, and the Chair provided valuable input for the design of our recent Patients' Workshop.

This collaboration strengthens our commitment to responsible, transparent, and patient-centred development, and we look forward to partnering even more closely with the EAB in the months ahead.

Learn more on the AIDAVA EAB here: https://aidava.eu/about/boards

Patient Workshop

On 26 February 2025, we held a Patients' Workshop in Brussels, where patient consultants, advocates, and AIDAVA consortium partners came together to discuss:

1. The value of AIDAVA for patients
2. How to tailor the tool for different levels of health and data literacy
3. Patient perspectives on data quality scores
4. Launching the AIDAVA Ambassador initiative

The event is summarised on LinkedIn and on the AIDAVA website.

Patient Interview

We also feature an interview with Caius Mersha, EHN Patient Consultant, filmed at the European Parliament on 7 April 2025, where he reflects on how participating in clinical data curation deepens his understanding of health, supports research, and benefits future patients. Watch the interview here: https://youtu.be/g3_Dg1xT-8w

Insights from AIDAVA Patient Consultants

"AIDAVA represents an important tool in the healthcare system to manage data efficiently."
Wendy Davis, EHN Patient Consultant

"AIDAVA is the first step in introducing the importance of data to everyday people in their health data management."
Krisztina Toth, Patient Advocate, Syreon Research InstitutE

Next Steps

The next key milestone is the **Prototype Generation 2 (G2) testing workshop** for patient consultants in Split this October. This will take place 6–8 weeks before G2 is released to patients in the ongoing study, giving our patient consultants the opportunity to provide feedback before wider testing begins. Your involvement will help us ensure G2 is as clear, useful, and patient-friendly as possible.

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