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AI powered Data Curation & Publishing Virtual Assistant

Deliverable No. 6.1

Public Project Website

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the European Union**

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Document History

Version	Date	Description
V1	19/12/2022	1st submission

¹ **Type:** Use one of the following codes (in consistence with the Description of the Action):

R: Document, report (excluding the periodic and final reports)
 DEM: Demonstrator, pilot, prototype, plan designs
 DEC: Websites, patents filing, press & media actions, videos, etc.

² **Dissemination level:** Use one of the following codes (in consistence with the Description of the Action)

PU: Public, fully open, e.g. web
 SEN: Sensitive, limited under conditions of the Grant Agreement

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Summary

This deliverable shortly describes the initial set-up of the AIDAVA public project website with screenshots of the main pages attached in the annex.

1 Introduction

Providing information about AIDAVA's objectives and work as well as the results achieved over the course of the project's lifetime is of utmost importance to foster the project's success.

The AIDAVA public website is the project's predominant tool for communication about the project and, in the end, for disseminating results aiming at reaching the broader public, as well as stakeholders and scientists in the field, and creating continuous awareness of the project's activities. The public project website is part of **WP6: "Innovation Management: Communication, Dissemination, Exploitation"**.

2 Description of Activities

The AIDAVA website is directed at the general public as well as different stakeholders with an interest in the project, its activities as well as its progress, outcomes and innovations. Such stakeholders include the scientific community, hospitals (medical staff and clinicians), patients and their families, further interest groups such as governments/ministries of health, the pharma industry, or regulatory bodies.

At the time of its launch, the website offers a project introduction including key facts about AIDAVA. In addition, it offers background information about the research and the consortium members, as well as on the planned impact and the project's approach on empowering citizens. A helpdesk section summarizes the contact details and provides access to a special feature, the Glossary, which explains the terminology used in the AIDAVA project and its meaning. The website also includes a section on project-related events and news, as well as links to AIDAVA's social media channel on Twitter. The funding acknowledgement, imprint (including the mandatory disclaimer), privacy statement and entry point to the password protected intranet (Project Management Platform, see D7.2) are accessible at the bottom of the website on all pages.

The different sections are available in tabs in the main navigation panel with drop-down menus to subpages or in boxes on the home page.

The project website currently offers the following main features and information (provided as screenshots in the annex):

1. **Home:** Main page and entry point to the AIDAVA website providing the key facts and a short intro to the project;
2. **About:** Provides information about the project's vision & key facts, its aim & objectives, a presentation of the AIDAVA partner institutions and their teams - including a visualization of the partner locations - as well as of the Advisory Boards (in constitution);
3. **Research:** Provides information about the project's approach, i.e., the problem, the suggested solution, the use cases, and the project's individual work packages;
4. **Impact:** Provides information about the project's impact on various groups of stakeholders, e.g., patients, data stewards, health care providers;
5. **Resources:** This is a repository with public project-related information materials, such as the Periodic flash for patients & clinicians;
6. **News & Events:** Frequently updated section with news and events from within the consortium and generated from subject-related content;
7. **Helpdesk:** Provides contacts as well as the project's glossary.

The public website went online on 16/12/2022. It has been developed by a professional communications team at EURICE together with the coordinator UM, co-coordinator b!lo and with the feedback from the AIDAVA Communication Committee. The website can be accessed via <https://aidava.eu/>.

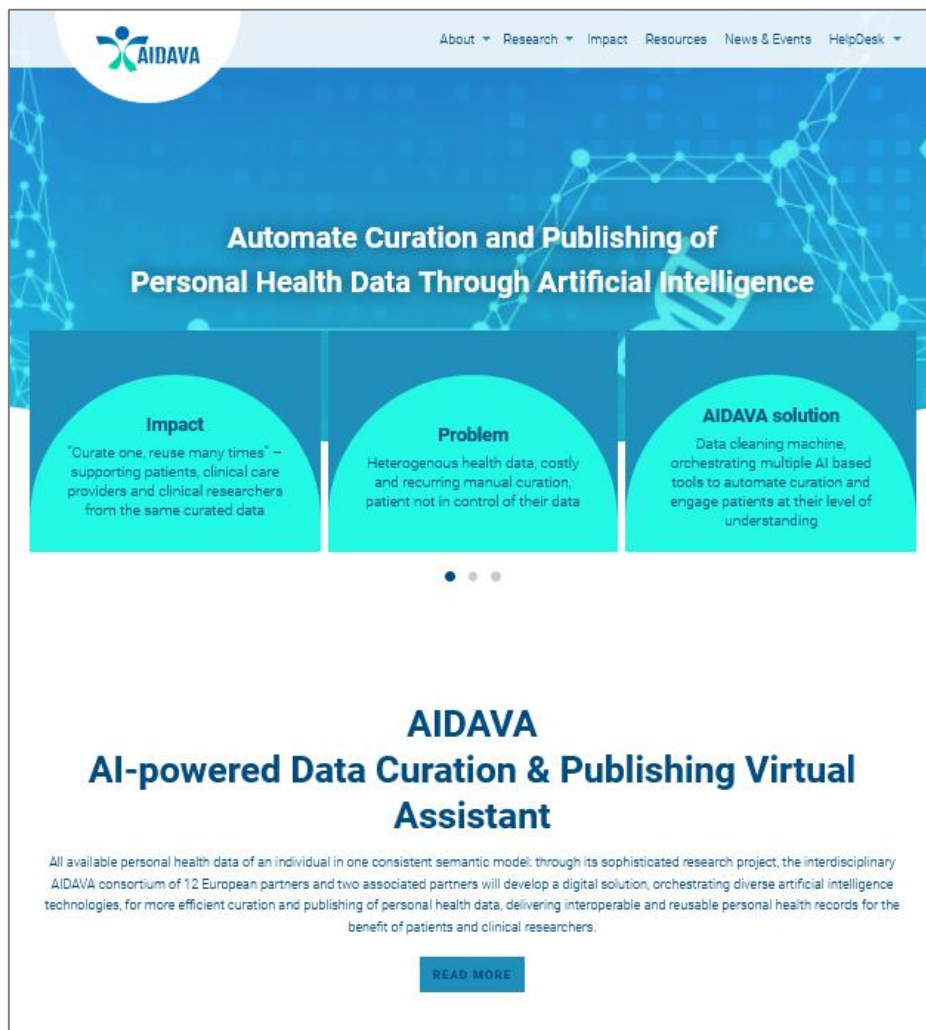
3 Conclusion


The website as well as the social media account Twitter are online and ready to provide information to the interested user. They are in line with the project's corporate identity.


The website's set-up ensures that the site is appealing, efficient and intuitive. Since the development of the website is a continuous task, the website as presented in this deliverable must be considered as a 'snapshot'. Content will be regularly updated. Additional information and subpages will be introduced in the course of the project.


4 Annex 1 – Screenshots website


(1) Home



**01 SEP 2022**
START DATE

**4 YEARS**
DURATION

**8.6 MIO €**
BUDGET

**14 PARTNERS**
FROM 9 COUNTRIES

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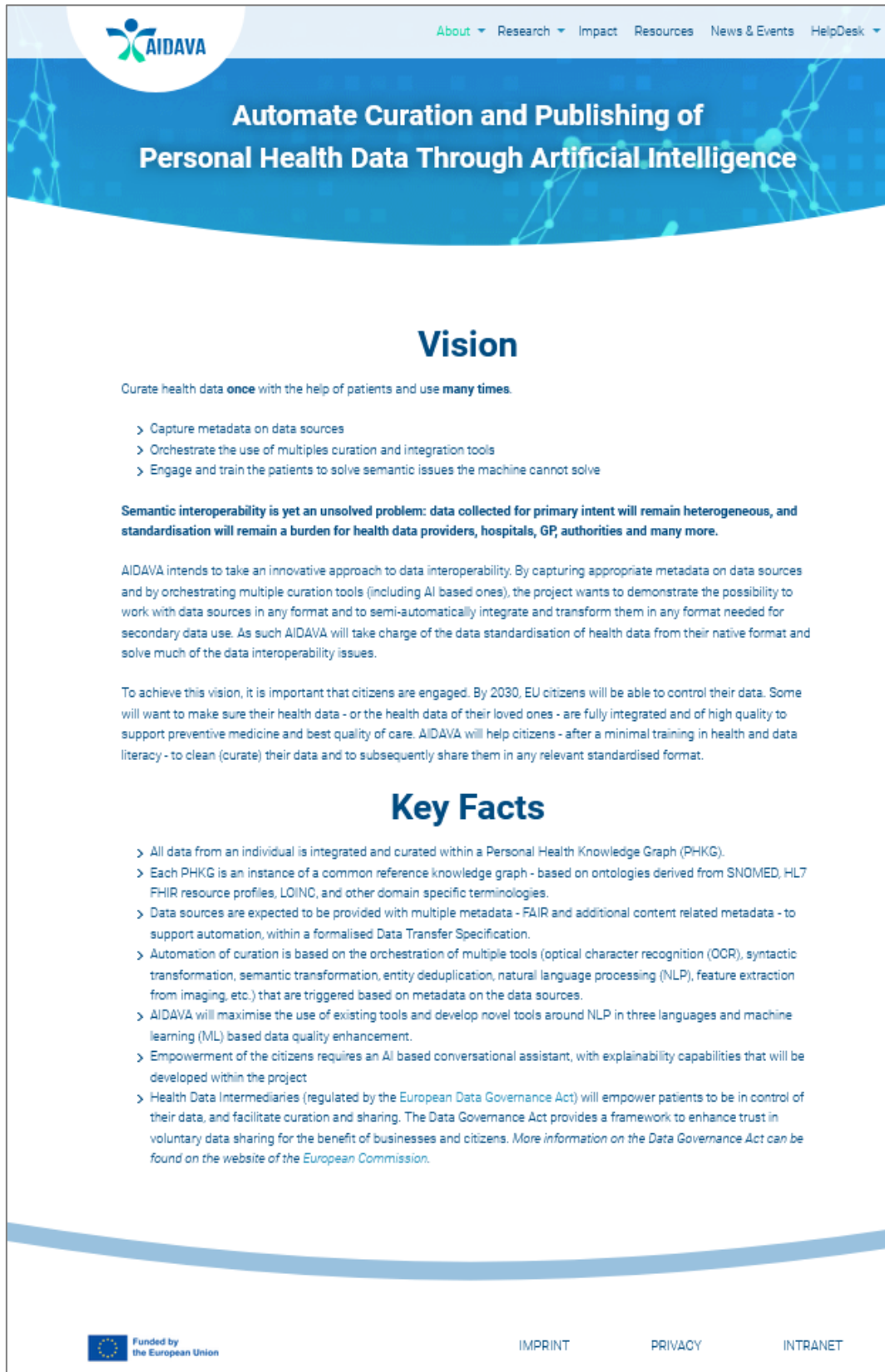
IMPRINT

PRIVACY

INTRANET

2) About

(2a) Vision and Key Facts



The screenshot shows the AIDAVA project website. The header includes the AIDAVA logo and a navigation menu with links: About, Research, Impact, Resources, News & Events, and HelpDesk. The main banner features the title "Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence". Below this, the "Vision" section is highlighted, followed by a list of key facts.

Vision

Curate health data **once** with the help of patients and use **many times**.

- > Capture metadata on data sources
- > Orchestrate the use of multiples curation and integration tools
- > Engage and train the patients to solve semantic issues the machine cannot solve

Semantic interoperability is yet an unsolved problem: data collected for primary intent will remain heterogeneous, and standardisation will remain a burden for health data providers, hospitals, GP, authorities and many more.

AIDAVA intends to take an innovative approach to data interoperability. By capturing appropriate metadata on data sources and by orchestrating multiple curation tools (including AI based ones), the project wants to demonstrate the possibility to work with data sources in any format and to semi-automatically integrate and transform them in any format needed for secondary data use. As such AIDAVA will take charge of the data standardisation of health data from their native format and solve much of the data interoperability issues.

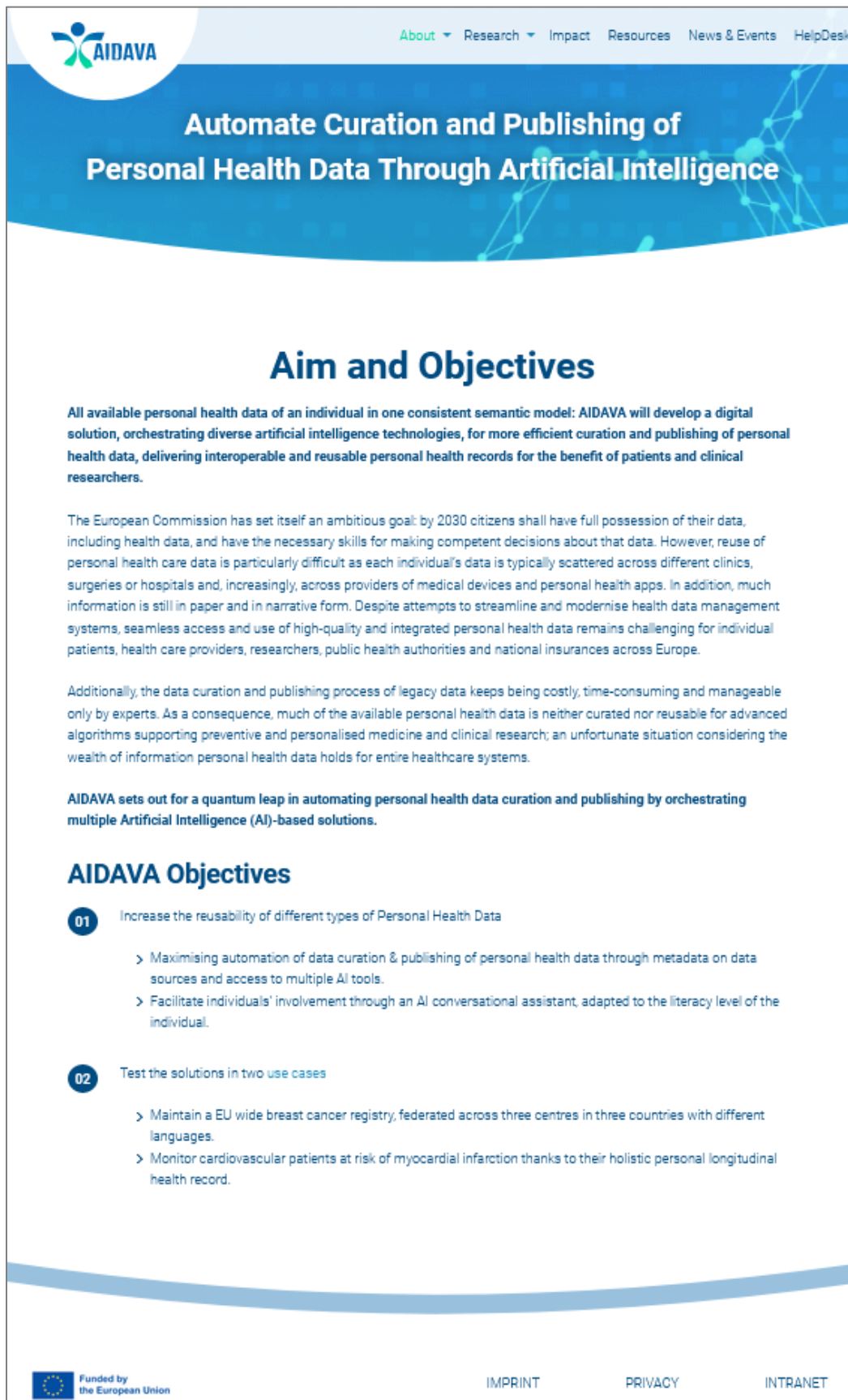
To achieve this vision, it is important that citizens are engaged. By 2030, EU citizens will be able to control their data. Some will want to make sure their health data - or the health data of their loved ones - are fully integrated and of high quality to support preventive medicine and best quality of care. AIDAVA will help citizens - after a minimal training in health and data literacy - to clean (curate) their data and to subsequently share them in any relevant standardised format.

Key Facts

- > All data from an individual is integrated and curated within a Personal Health Knowledge Graph (PHKG).
- > Each PHKG is an instance of a common reference knowledge graph - based on ontologies derived from SNOMED, HL7 FHIR resource profiles, LOINC, and other domain specific terminologies.
- > Data sources are expected to be provided with multiple metadata - FAIR and additional content related metadata - to support automation, within a formalised Data Transfer Specification.
- > Automation of curation is based on the orchestration of multiple tools (optical character recognition (OCR), syntactic transformation, semantic transformation, entity deduplication, natural language processing (NLP), feature extraction from imaging, etc.) that are triggered based on metadata on the data sources.
- > AIDAVA will maximise the use of existing tools and develop novel tools around NLP in three languages and machine learning (ML) based data quality enhancement.
- > Empowerment of the citizens requires an AI based conversational assistant, with explainability capabilities that will be developed within the project
- > Health Data Intermediaries (regulated by the European Data Governance Act) will empower patients to be in control of their data, and facilitate curation and sharing. The Data Governance Act provides a framework to enhance trust in voluntary data sharing for the benefit of businesses and citizens. *More information on the Data Governance Act can be found on the website of the European Commission.*

The footer contains the European Union funding logo, and links for IMPRINT, PRIVACY, and INTRANET.

(2b) Aim and Objectives



Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence

Aim and Objectives

All available personal health data of an individual in one consistent semantic model: AIDAVA will develop a digital solution, orchestrating diverse artificial intelligence technologies, for more efficient curation and publishing of personal health data, delivering interoperable and reusable personal health records for the benefit of patients and clinical researchers.

The European Commission has set itself an ambitious goal: by 2030 citizens shall have full possession of their data, including health data, and have the necessary skills for making competent decisions about that data. However, reuse of personal health care data is particularly difficult as each individual's data is typically scattered across different clinics, surgeries or hospitals and, increasingly, across providers of medical devices and personal health apps. In addition, much information is still in paper and in narrative form. Despite attempts to streamline and modernise health data management systems, seamless access and use of high-quality and integrated personal health data remains challenging for individual patients, health care providers, researchers, public health authorities and national insurances across Europe.

Additionally, the data curation and publishing process of legacy data keeps being costly, time-consuming and manageable only by experts. As a consequence, much of the available personal health data is neither curated nor reusable for advanced algorithms supporting preventive and personalised medicine and clinical research; an unfortunate situation considering the wealth of information personal health data holds for entire healthcare systems.

AIDAVA sets out for a quantum leap in automating personal health data curation and publishing by orchestrating multiple Artificial Intelligence (AI)-based solutions.

AIDAVA Objectives

- 01** Increase the reusability of different types of Personal Health Data
 - > Maximising automation of data curation & publishing of personal health data through metadata on data sources and access to multiple AI tools.
 - > Facilitate individuals' involvement through an AI conversational assistant, adapted to the literacy level of the individual.
- 02** Test the solutions in two use cases
 - > Maintain a EU wide breast cancer registry, federated across three centres in three countries with different languages.
 - > Monitor cardiovascular patients at risk of myocardial infarction thanks to their holistic personal longitudinal health record.

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(2c) Project Partners



Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence

Project Partners

Austria

- > MUG - Medizinische Universität Graz

Belgium

- > blio - biloba
- > KUL - KU Leuven
- > IHD - The European Institute for Innovation through Health Data
- > ECPC - European Cancer Patient Coalition
- > EHN - European Heart Network AISBL

Bulgaria

- > ONTO - Sirma AI EAD

Estonia

- > NEMO - Sihtasutus Põhja-Eesti Regionaalhaigla

Germany

- > AVERBIS - Averbis GmbH
- > EURICE - European Research and Project Office GmbH

Netherlands

- > UM - Maastricht University

Romania

- > GND - Egnosis by Gnome Design Srl

Switzerland

- > MID - Midata Cooperative

United Kingdom

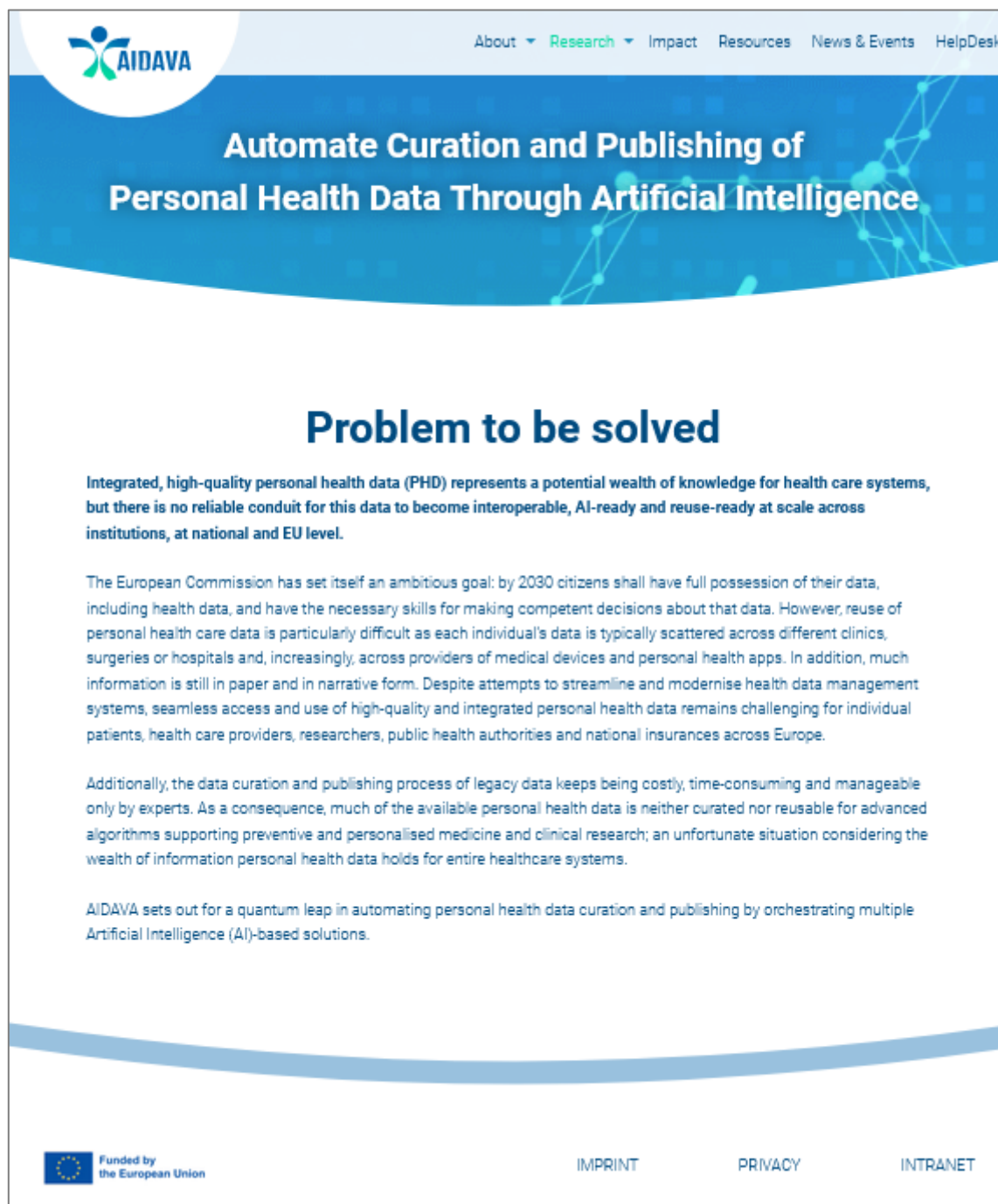
- > DME - Digi.me Ltd

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(3) Research

(3a) Problem



The screenshot displays the AIDAVA project website. The header features the AIDAVA logo on the left and a navigation menu with links for 'About', 'Research', 'Impact', 'Resources', 'News & Events', and 'HelpDesk'. The main banner has a blue background with a network diagram and the title 'Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence'. Below the banner, the section 'Problem to be solved' is highlighted. The text describes the challenges of integrating high-quality personal health data (PHD) for interoperability and reuse at scale. It mentions the European Commission's goal for 2030 and the current difficulties in data integration and management. The AIDAVA project's aim to automate this process using AI is also stated. The footer includes the European Union funding logo, and links for 'IMPRINT', 'PRIVACY', and 'INTRANET'.

Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence

Problem to be solved

Integrated, high-quality personal health data (PHD) represents a potential wealth of knowledge for health care systems, but there is no reliable conduit for this data to become interoperable, AI-ready and reuse-ready at scale across institutions, at national and EU level.

The European Commission has set itself an ambitious goal: by 2030 citizens shall have full possession of their data, including health data, and have the necessary skills for making competent decisions about that data. However, reuse of personal health care data is particularly difficult as each individual's data is typically scattered across different clinics, surgeries or hospitals and, increasingly, across providers of medical devices and personal health apps. In addition, much information is still in paper and in narrative form. Despite attempts to streamline and modernise health data management systems, seamless access and use of high-quality and integrated personal health data remains challenging for individual patients, health care providers, researchers, public health authorities and national insurances across Europe.

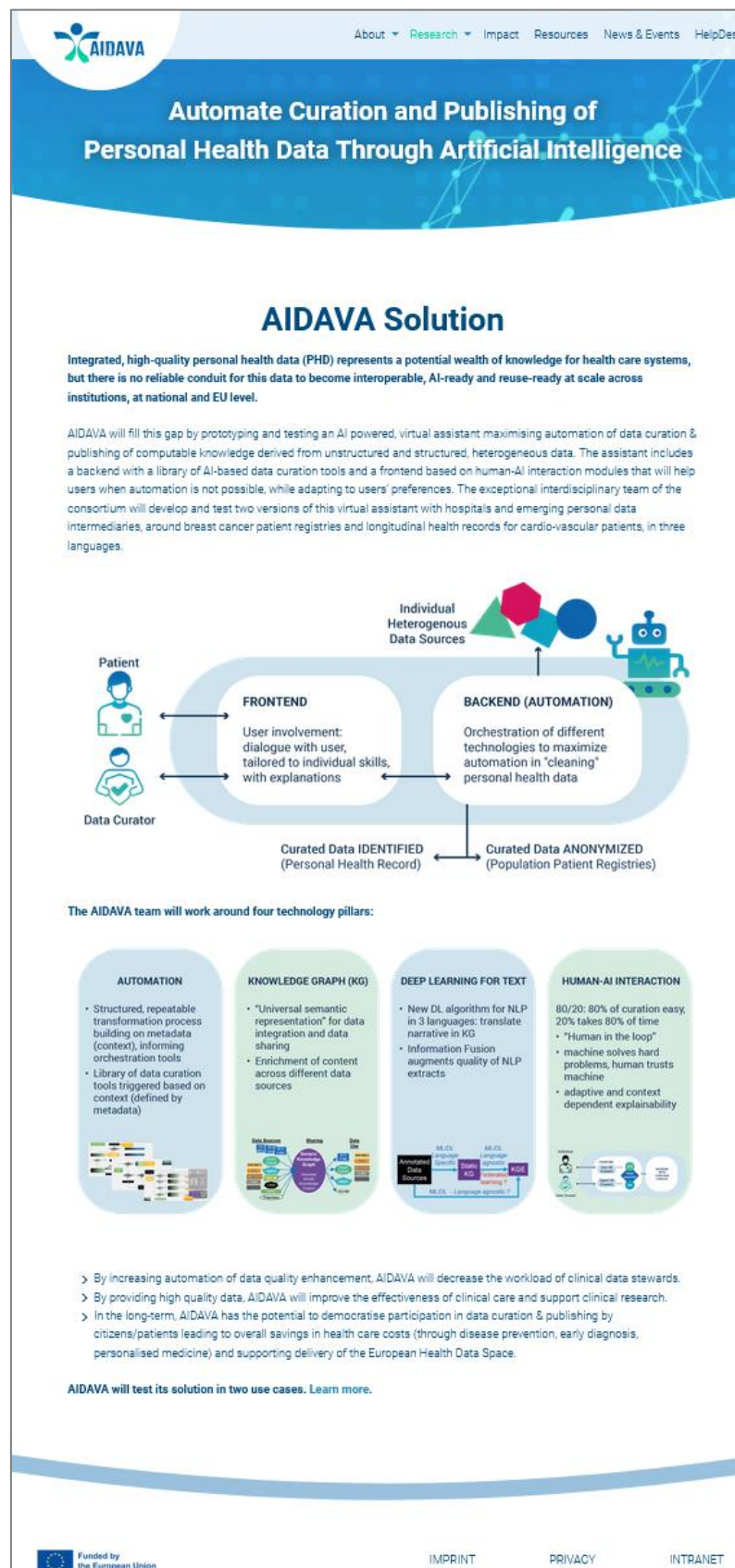
Additionally, the data curation and publishing process of legacy data keeps being costly, time-consuming and manageable only by experts. As a consequence, much of the available personal health data is neither curated nor reusable for advanced algorithms supporting preventive and personalised medicine and clinical research; an unfortunate situation considering the wealth of information personal health data holds for entire healthcare systems.

AIDAVA sets out for a quantum leap in automating personal health data curation and publishing by orchestrating multiple Artificial Intelligence (AI)-based solutions.


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(3b) Solution



(3c) Use Cases


About ▾ Research ▾ Impact Resources News & Events HelpDesk ▾

Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence

AIDAVA Use Cases

Availability of integrated, high-quality personal health data (PHD) remains limited, with impact on quality and costs of care and limiting possibilities for research and analytics. Indeed, PHD is currently distributed, heterogeneous, captured through different modalities, with variable quality. Interoperability and reuse of PHD remains a major challenge that will be addressed in AIDAVA. AIDAVA wants to address interoperability and reusability of PHD by working on two use cases and demonstrating the principle of "curate once, use many times".

Use Case 1: Breast Cancer Registry (*Hospital Centric*)

Development and maintenance of an **EU Breast Cancer registry** by defining a set of data elements that can be derived from AIDAVA to form a federated registry. Each clinical site will provide these extracts; a federated query across all three sites will demonstrate interoperability and reuse.

Use Case 2: CVD Longitudinal Health Record (*Patient Centric*)

Management of longitudinal health records of CVD patients with display of the record for the patient through the same application across sites; and with computation of the SMART Risk Score, a 10-year risk score for vascular events. The score will be computed automatically in the three sites with the same algorithm, based on the extract issued from AIDAVA.

AIDAVA will work through the following steps:

Data Ingestion

Transfer and pooling of data from different data sources, from the hospital or from the health data intermediary acting on behalf of the patient

Data Curation

Harmonisation and integration of heterogeneous data sources and transformation into a Personal Health Knowledge Graph (PHKG). AIDAVA will maximise automation on this step by orchestrating multiple (AI based) curation tools based on the interoperability issue to be solved; patients and expert data curators will be asked to complement information whenever relevant. Data quality checks will be performed on the resulting PHKG.

Data Publishing

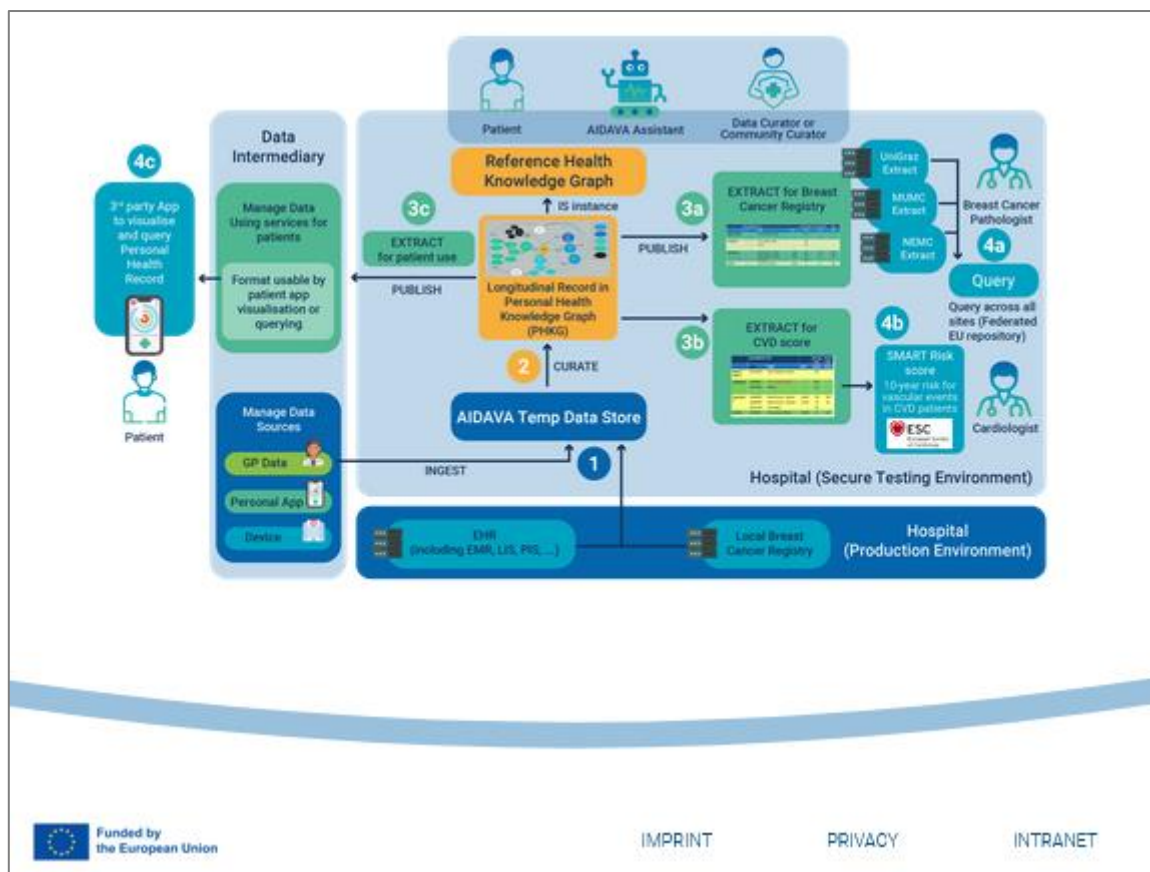
Transformation of the PHKG into a format required for data consumption and secondary data use. From the PHKG, many transformations are possible supporting different use cases enabling the "curate once, use many times" principle of the AIDAVA project.

- > Extract for local instance of an "EU" Breast Cancer Registry (Use Case 1)
- > Extract to compute the SMART risk score (Use Case 2)
- > Extract to visualise and query the patient longitudinal record (Use Case 2 – also provided in Use Case 1 as an option to the patients); to be done across three sites with a 3rd party app being identified

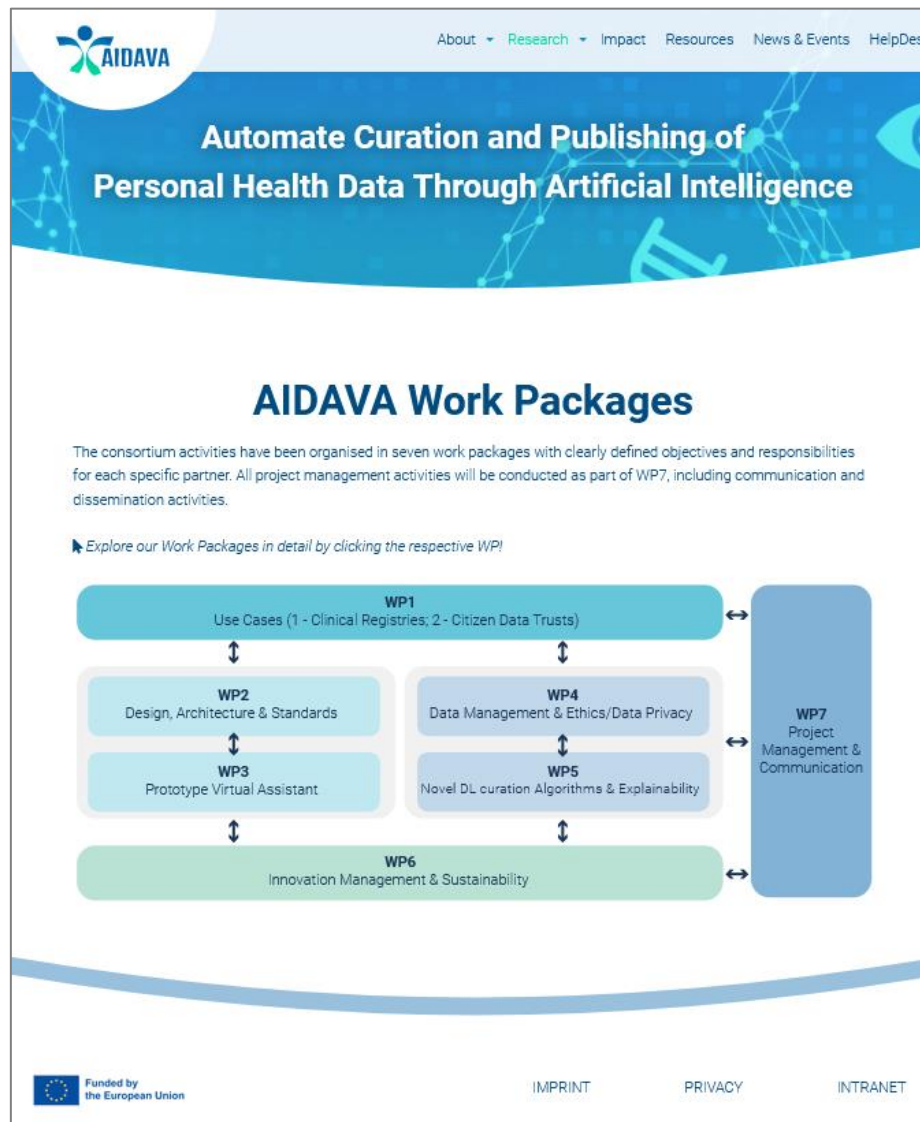
Data Use

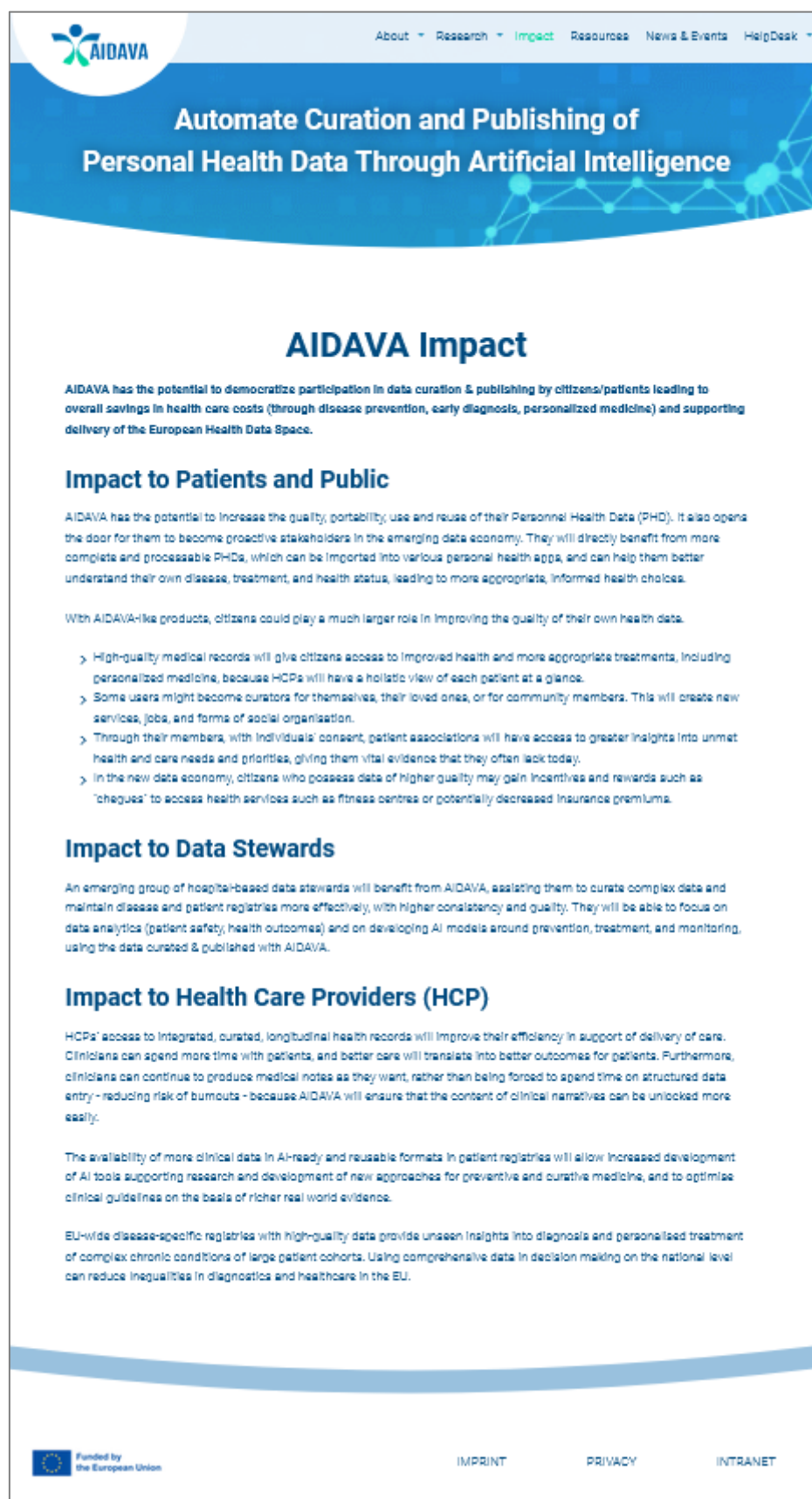
Usage of the respective extracts to meet a specific need

- > Federated query across the three sites mimicking a "Federated EU registry" (Use Case 1)
- > Computation, display and comparison over time of the SMART risk score of the related patient (Use Case 2)
- > Display of the patient longitudinal record with selected 3rd party app



(3d) Work Packages



(4) Impact


Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence

AIDAVA Impact

AIDAVA has the potential to democratize participation in data curation & publishing by citizens/patients leading to overall savings in health care costs (through disease prevention, early diagnosis, personalized medicine) and supporting delivery of the European Health Data Space.

Impact to Patients and Public

AIDAVA has the potential to increase the quality, portability, use and reuse of their Personal Health Data (PHD). It also opens the door for them to become proactive stakeholders in the emerging data economy. They will directly benefit from more complete and processable PHDs, which can be imported into various personal health apps, and can help them better understand their own disease, treatment, and health status, leading to more appropriate, informed health choices.

With AIDAVA-like products, citizens could play a much larger role in improving the quality of their own health data.

- > High-quality medical records will give citizens access to improved health and more appropriate treatments, including personalized medicine, because HCPs will have a holistic view of each patient at a glance.
- > Some users might become curators for themselves, their loved ones, or for community members. This will create new services, jobs, and forms of social organization.
- > Through their members, with individuals' consent, patient associations will have access to greater insights into unmet health and care needs and priorities, giving them vital evidence that they often lack today.
- > In the new data economy, citizens who possess data of higher quality may gain incentives and rewards such as "cheques" to access health services such as fitness centres or potentially decreased insurance premiums.

Impact to Data Stewards

An emerging group of hospital-based data stewards will benefit from AIDAVA, assisting them to curate complex data and maintain disease and patient registries more effectively, with higher consistency and quality. They will be able to focus on data analytics (patient safety, health outcomes) and on developing AI models around prevention, treatment, and monitoring, using the data curated & published with AIDAVA.

Impact to Health Care Providers (HCP)

HCPs' access to integrated, curated, longitudinal health records will improve their efficiency in support of delivery of care. Clinicians can spend more time with patients, and better care will translate into better outcomes for patients. Furthermore, clinicians can continue to produce medical notes as they want, rather than being forced to spend time on structured data entry - reducing risk of burnout - because AIDAVA will ensure that the content of clinical narratives can be unlocked more easily.

The availability of more clinical data in AI-ready and reusable formats in patient registries will allow increased development of AI tools supporting research and development of new approaches for preventive and curative medicine, and to optimise clinical guidelines on the basis of richer real world evidence.

EU-wide disease-specific registries with high-quality data provide unseen insights into diagnosis and personalised treatment of complex chronic conditions of large patient cohorts. Using comprehensive data in decision making on the national level can reduce inequalities in diagnostics and healthcare in the EU.

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(5) Resources

(6) News & Events

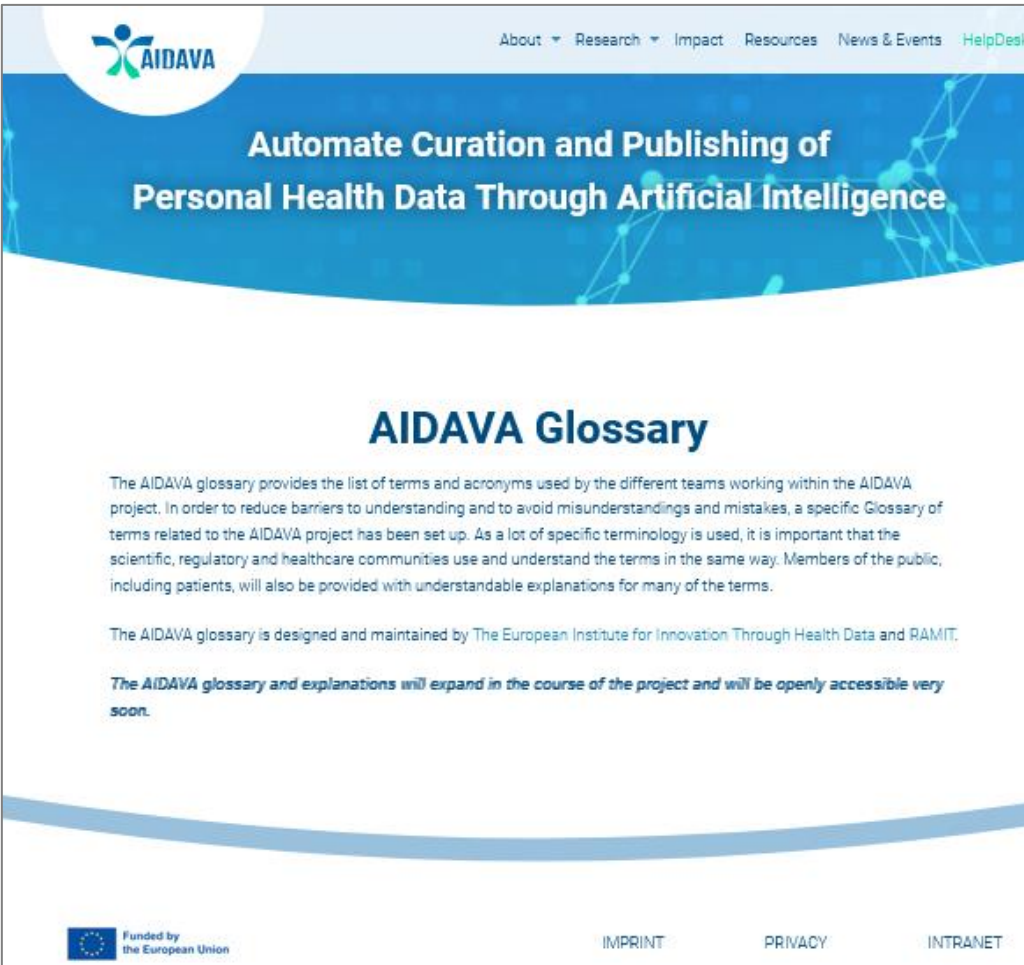
The screenshot shows the AIDAVA website's 'News & Events' page. At the top, there is a navigation bar with links: About, Research, Impact, Resources, News & Events (highlighted), and HelpDesk. Below the navigation bar is a blue banner with the text 'Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence'. The main heading is 'News'. There are two news items listed:

- Periodic Flash for Patients and Clinicians**
13/12/2022
On a regular basis, AIDAVA is publishing a periodic flash to maintain communication with patients and clinicians working with the project.
Please download the first issue here.
[READ MORE](#)
- New Project "AIDAVA"**
05/10/2022
AIDAVA: New EU Research Project Launches to Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence
All available personal health data of an individual in one consis...
[READ MORE](#)

At the bottom of the page, there is a footer with the European Union logo and text 'Funded by the European Union', and links for IMPRINT, PRIVACY, and INTRANET.

(7) Helpdesk**(7a) Contact**

(7b) Glossary



The screenshot shows the AIDAVA Glossary page. At the top, there is a navigation bar with the AIDAVA logo on the left and links for About, Research, Impact, Resources, News & Events, and HelpDesk on the right. Below the navigation bar is a blue banner with the text "Automate Curation and Publishing of Personal Health Data Through Artificial Intelligence". The main heading is "AIDAVA Glossary". The text explains that the glossary provides a list of terms and acronyms used by the different teams working within the AIDAVA project, aiming to reduce barriers to understanding and avoid misunderstandings. It states that the glossary is designed and maintained by The European Institute for Innovation Through Health Data and RAMIT. A note mentions that the glossary and explanations will expand in the course of the project and will be openly accessible very soon. The footer includes the European Union logo and text "Funded by the European Union", along with links for IMPRINT, PRIVACY, and INTRANET.

AIDAVA

About ▾ Research ▾ Impact Resources News & Events HelpDesk


**Automate Curation and Publishing of
Personal Health Data Through Artificial Intelligence**

AIDAVA Glossary

The AIDAVA glossary provides the list of terms and acronyms used by the different teams working within the AIDAVA project. In order to reduce barriers to understanding and to avoid misunderstandings and mistakes, a specific Glossary of terms related to the AIDAVA project has been set up. As a lot of specific terminology is used, it is important that the scientific, regulatory and healthcare communities use and understand the terms in the same way. Members of the public, including patients, will also be provided with understandable explanations for many of the terms.

The AIDAVA glossary is designed and maintained by The European Institute for Innovation Through Health Data and RAMIT.

The AIDAVA glossary and explanations will expand in the course of the project and will be openly accessible very soon.

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