

CRANE 6th Newsletter Latest EHDS Updates

September 2023

Data Spaces are gaining mometum all across Europe, with many ongoing research and related deployment activities. We devote our latest newsletter to highlight some of the hottest related news.

HEALTH DATA LAKE TENDER IN SPAIN



45M€ for Health Data Lake Services

Spain is opening, in short time, a public tender for the provision of a solution to implement the national Health Data Lake services.

The upcoming tender goal is the instantiation of a National Health Data Lake and the provision of support services for it.

The solution should be able to collect data from the health related information systems and carry out big data processing and analysis on it, with the final objective of pathologies identification and improvement of diagnosis and treatment, always with the citizen in mind.

The pre-anouncement can be found in the <u>Ted's platform</u> while all the details will be published in the <u>Spanish electronic tendering platfrom</u>.

According to the Spanish government, this is the first step in a long term strategy, the provision of the tecnology infrastructure needed by the regional health authorities. Then projects for the big data processing of the generated health data will be launched, looking for synergies between public and private sectors as well as the engagement of research centers.

The final objective is to obtain health massive analysis capability able to identify risk factors, trends and potential health risk situations.

In line with the above, the Spanish Data Protection Agency published in May 2023 a comprehensive guideline in order to help private and public stakeholders fulfilling their obligations related to the design and implementation of Data Spaces. It can be found in Spanish here.

EHDS TENDER FROM HADEA



1.5M€ for Capacity Building services

Deadline extended until the 24th of October 2023 16.00 (CEST)

HaDEA has published the call for tenders HADEA/2023/OP/0024 "Capacity building for secondary uses of health data for the European Health Data Space"

The capacity building activities target staff in health data access bodies (HDABs) and people with a platform to reach out to stakeholders involved in the secondary use of health data (EHDS2 ambassadors).

The purpose of the call is to strengthen and standardise their skills through the transfer and creation of knowledge and the exchange of best practices on five digital business capabilities, all of which are crucial for the secondary use of health data.

The requested services include the:

- Preparation of training materials and delivery of trainings;
- Preparation of materials to support local implementations;
- Verification and monitoring of local implementations.

You can access the tender portal directly from here.

RECOMMENDATIONS FROM THE DANISH HEALTH ROBUSTHEDSKOMMISSIONENS

The Danish Commission for robustness in the healthcare system was established in the summer of 2022 in continuation of the political agreement of 20 May 2022 on a healthcare reform.



The Commission's main task has been to point to initiatives that in the future can ensure more staff and staff with more time for the core task close to citizens and patients, e.g. through better organization of training courses, better transition from training to practice, strengthened attachment to the workplace and more flexible and interdisciplinary solution of tasks.

The Commission has also focused on initiatives such as prioritization and smarter task solving as well as better use of technologies, all of which can give staff more time and space to solve the core task.

Many of the identified challenges as well as proposed recommendations are born from the same rational as CRANE, ageing societies and the need to provide adequate health services with limited human resources by relying on technology innovations.

To know more, read the full report <u>here</u> (in Danish).

BDVA POSITION PAPER ON HEALTH DATA SPACES

Opt-in and opt-out mechanisms?



The Big Data Value Association (BDVA) has recently published in July 2023 a Position Paper on the European Health Data Space. Read below to know more

BDVA is an industry-driven association focussed on data-driven research and innovation, fully committed to European values. As part of its values, it stresses the importance of providing feedback to the regulators on specific matters of concert to the industry and research areas.

In its possition paper the association welcomes the ambitious objectives of the European Health Data Space and highlights some of the detected issues as well as suggested improvements.

The overall objective is to address the debate of opt-in and opt-out for patients in the secondary use of healthcare data, to suggest further improvements on the balance between regulation and innovation, as well as recommending for legal interoperability and clear terminology.

In fact, according to BDVA to ensure that natural persons in the EU have increased control in practice over their electronic health data, the discussion should rather be about the governance supporting the control over data and for what purpose those are used. Therefore, BDVA suggests that no opt-in nor opt-out mechanisms should be foreseen. The obligation to comply with additional safeguards should preferably fall under the responsibility of data users rather than being imposed on data holders or subjects.

Moreover, BDVA voices the concern of the risk of data and algorithmic bias resulting in unreliable research results due to the introduction of any opt-in or opt-out mechanisms for secondary use of data.

The full position paper with more relevant insights can be downloaded from the BDVA website <u>here</u>.

Visit our <u>website</u> and follow us on our <u>LinkedIn</u> and <u>Twitter</u> social networks for the latest updates

All the best and let's CRANE!

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