



WORKSHOP ON HEALTH DATA ALTRUISM

Workshop summary – TEHDAS WP8 Deliverable 8.2 Brussels 27/04/2023

The conclusions of the workshop discussions

Capturing key points and takeaways from the various topics discussed during the workshop

The workshop discussions shed light on several crucial aspects that require careful consideration during the establishment of the European Health Data Space (EHDS). One key takeaway is the need for a common understanding of the concept of public good which is not solely limited to public or private sectors. Another key message is that ethical considerations must always be at the forefront of discussions to maintain transparency and societal trust. There is also a shift towards data processing based on public interest in the secondary use of health data therefore, individuals should be allowed to retain control over the use of their data.

Furthermore, there is a need to address data control challenges and ensure cooperation between sectors for successful secondary use. Moreover, the role of consent in the EHDS framework and the importance of clear and practical consent mechanisms should be carefully considered to uphold citizen control over personal data.

While the GDPR provides solid legal basis for data protection, its implementation and practical application present certain challenges. New concepts and legal interpretations will continue to evolve. The discussions emphasised that cultural and ethical differences should be understood and respected to ensure successful data sharing and secondary use of data.

Building and implementing solutions with citizens' trust in mind is essential for the EHDS to be effective and widely accepted. The discussion highlights the need for a nuanced approach to data altruism and consent, considering various factors such as data sources, cultural norms, and practicalities. A balanced and trust-based consent mechanism is essential to foster participation in research while respecting individuals' data protection rights.

In conclusion, the discussions underscore the complexity surrounding data altruism organisations within the EHDS ecosystem including their unique contributions, overlapping data access, market viability, fees, data quality, and legal aspects.

Regarding data altruism, participants expressed reassurance that voluntary data sharing, including data altruism, will play a relevant role within the EHDS alongside other data sharing models. It will be important to examine the added value data altruism organisations can provide e.g., in terms of data types, and improving data quality.

In conclusion, the workshop calls for nuanced approaches, ethics-driven decisions, and an appreciation of cultural diversity while establishing the EHDS. Building trust among citizens and offering voluntary data sharing options, including data altruism, will be pivotal in realising the potential of the EHDS to benefit public health, health research and society as a whole.

Summary of the poll results

Based on the discussions and poll results, the workshop highlighted a range of stakeholder views on various topics, including compliance with GDPR, the role of broad consent in data altruism, the necessity of opt-in/consent requirements, and the importance of transparency and accountability in data altruism organisations.

Compliance with GDPR:

The majority of respondents (18 out of 25) agree that private sector entities should be encouraged to increase their participation in and contribution to the secondary use of health data, which suggests a positive outlook towards data sharing in the private sector.

Data altruism and public interest:

A significant number of respondents (14 out of 23) agree that data altruism, where data subjects consent to the processing of their personal data, should be processed based on public interest in the EHDS framework. This indicates a recognition of the importance of public interest in utilizing health data for secondary purposes.

Opt-in/consent in EHDS legislative framework:

While there is some agreement (13 out of 23) that opt-in/consent should be part of the EHDS legislative framework to ensure citizens' control over their personal data, there are also doubts (7 out of 23) and disagreements (3 out of 23). This suggests a lack of consensus regarding the necessity of opt-in/consent requirements for certain data categories.

Broad consent in data altruism:

There is a notable level of doubt (14 out of 22) regarding the use of broad consent as the main rule for secondary use of health data in the context of data altruism. A smaller portion of respondents (8 out of 22) disagreed with this approach, indicating concerns or reservations about the risks involved.

Balancing broad consent:

The opinions regarding the balance between scientific research for the common good and the protection of individuals' data protection rights are divided. While some respondents agree (3 out of 24), others have doubts (12 out of 24) or disagree (9 out of 24). This suggests a complex and nuanced perspective on finding the right balance between research benefits and data protection.

Opt-out for privacy concerns:

A significant number of respondents (9 out of 23) agree that the privacy concerns related to the secondary use of health data can be addressed through opt-out mechanisms. However, there are also doubts (11 out of 23) and disagreements (3 out of 23), indicating differing views on the effectiveness of opt-out as a privacy protection measure.

Data altruism organisations and business models:

The majority of respondents (18 out of 24) agree that data altruism organisations should define their roles in the future legal framework and offer understandable and practical business models. This suggests a recognition of the importance of clear roles and practical approaches in utilizing health data for altruistic purposes.

Rulebook for data altruism organisations:

A large majority of respondents (19 out of 22) agree that the Rulebook for Data altruism organisations should be prepared and updated in close cooperation with stakeholders, particularly EHDS stakeholders, projects, and initiatives. This highlights the importance of collaborative efforts and involving relevant parties in shaping the regulatory framework.

Transparency and accountability of data altruism organisations:

The majority of respondents (21 out of 21) strongly agree that transparency and accountability of data altruism organisations are crucial for building public trust in data use. This highlights the consensus on the importance of ensuring transparency and accountability to maintain public confidence in the utilization of health data.

In summary, while there is general agreement on certain aspects, such as the need for transparency and accountability, there are varying opinions and doubts regarding the use of broad consent, opt-in/consent requirements, and addressing privacy concerns. These results highlight the complex nature of balancing data utilization for public interest and scientific research while safeguarding individuals' data protection rights.

The project is funded by the Third EU Health Programme

Further information: [TEHDAS](https://tehdas.eu)



Co-ordinated by the Finnish
Innovation Fund Sitra

SITRA



www.tehdas.eu



[@tehdas](https://twitter.com/tehdas)