



Towards
European
Health
Data
Space

TEHDAS outlines key issues and considerations on data altruism

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<https://tehdas.eu/app/uploads/2022/12/primary-recommendations-to-foster-gdpr-compliant-data-altruism-mechanisms-for-the-ehds.pdf>

National Directorate General for Hospitals (OKFŐ) participates in the TEHDAS project since February 2021 and with the professional support of Semmelweis University Health Services Management Training Centre, leads Work package 8 (WP8) dealing with national data altruism definitions and systems as well as preparing recommendations for GDPR-compliant data altruism mechanisms and methods for the development of EHDS.

In the future data altruism will make new data sources available for research and innovation. TEHDAS has published preliminary requirements to enable voluntary data sharing for the European health data space.

A recent report by the joint action Towards the European Health Data Space (TEHDAS) presents preliminary recommendations to foster 'data altruism' which was defined in the [Data Governance Act](#) (open in new window). Due to the [unique specificities of health data](#) compared to data in many other sectors, the report studies data altruism in the context of health data.

Data altruism refers to people and organisations making health data voluntarily available for the public interest thereby enabling new data sources for secondary purposes such as research and innovation without seeking reward. An example is data gathered by an individual's smartwatch or other smart devices.

The report identifies the key requirements TEHDAS will continue to work on. These include:

- to develop health data consent forms
- to clarify the roles and responsibilities of actors in data altruism such as individuals, data altruism organisations and data users
- to develop data altruism mechanisms.

TEHDAS has already published [a summary of stakeholders' views](#) on defining data altruism and best practices in involving the public in data sharing for the upcoming European health data space and conducted [a literature review](#) on data altruism definitions.

TEHDAS outlines preliminary requirements to enable voluntary data sharing for the European health data space.

TEHDAS will issue recommendations on data altruism in spring 2023.

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