

# TEHDAS consultation: Citizens support the secondary use of health data when it matches their ethical values

Citizens support the use of health data if it accords with their values and if its benefits outweigh the risks. People also think that they should be considered as a partner in the governance of data. These are among the main recommendations from a public consultation organised by TEHDAS.

A recent report of the joint action Towards the European Health Data Space (TEHDAS) summarises people's views on how their health data could be used in the future for secondary purposes. The opinions were sought via an online consultation conducted between December 2021 and May 2022 mainly in France, Belgium and the UK. Participants contributed close to [6,000 suggestions](#) concerning the use of health data.

The [online consultation](#) took place before the European Commission's proposal on the EHDS was published in May 2022. The issues raised by the individuals during the consultation concern the secondary use of health data in general and not the Commission's proposal.

## Data to be used transparently



Many respondents supported the secondary use of health data and its potential benefits, but only if some key conditions are met. In general, citizens highlighted the need to acknowledge their relationship with their health data. They want responsible bodies to communicate openly and quickly, and for this information to be accessible and understandable. Some citizens also expressed an interest in accessing their health data and information about how such data could be used for secondary purposes such as research, innovation and policymaking. Citizens also felt the decision-making process should rely on a range of views and actors to increase trustworthiness.



The second major public perception is the need to maximise the benefits of the secondary use of health data, while mitigating its potential risks TEHDAS considers it important that those responsible for health data governance in the European health data space understand public attitudes to the use of their health data for secondary purposes. TEHDAS has previously proposed that the European Health Data Space Board, which will determine the implementation of EHDS, will [liaise with external stakeholders](#) in a dedicated forum to ensure the board benefits from their expertise. The findings of the consultation were discussed at four stakeholder workshops organised by TEHDAS in the participating countries in autumn 2022.



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*The report has been approved by the project steering group. The European Commission gives final approval to all joint action's deliverables.*