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Consumers uneasy with sharing their health data, survey shows

A [survey](#) across eight European countries¹ shows that consumers are more cautious about sharing their health data than legislation currently under discussion at EU level proposes. The findings underline that EU legislators urgently need to better reflect people's preferences in the European Health Data Space Regulation which is already under discussion by the EU institutions. This is essential for people to feel confident about sharing their health data to improve healthcare provision and make their data available for research and public health purposes.

Snapshot of [main findings](#):

- The **vast majority** of people surveyed are **already using health platforms**, ranging from the highest rate of use in France (96%) to the lowest in Germany (70%).
- However, people are **very selective about the health data they are willing to share**: 61% are willing to share their health status (e.g. allergies) for care purposes, while a large majority does not want to share data related to their health habits (67-70% depending on the purpose), genetic data (77-80%) or sexual and reproductive health data (85-87%).
- Consumer willingness to share their health data with an entity **strongly mirrors the level of trust** they place in them: 88% are willing to share their data with their general practitioners (88%) but only 8% are willing to share their data with insurance or wellness apps companies. Only 5% are willing to share their health data with digital technology companies.
- An overwhelming majority of people (81%) **prefer to choose what personal data they give access to, who they give access to, and for what purposes**. Yet only 19% have currently limited the access of some professionals to their health data, which strongly suggests the current privacy settings in health platforms do not allow people to apply their preferences or people are not aware they can choose and how.
- **Only half** of respondents (51%) are willing to share their health data with healthcare practitioners across EU member states to secure good treatment when they are abroad.

Monique Goyens, Director General of the European Consumer Organisation (BEUC) said: "These survey results should provide a reality check to the EU. While the European Health Data Space is well-intentioned, setting it up should not come at the detriment of people's protection and preferences regarding how much they want to share, with whom and for what purpose."

¹ The survey took place in February 2023 with 8,067 consumers surveyed across Belgium, Czech Republic, France, Germany, Greece, Italy, Spain and Portugal. The consumer organisations which contributed to the survey are Test Achats/Test Aankoop (Belgium), dTest (Czech Republic), UFC-Que Choisir (France), vzbv (Germany), EKPIZO and KEPKA (Greece), Altroconsumo (Italy) and OCU (Spain) and DECO Proteste (Portugal). Euroconsumers contributed to developing the questionnaire, and carried out the data collection and statistical analysis that serves as the basis for this report.

“Health data is incredibly sensitive and our survey shows people do not want to share it all or share it out blindly. People are generally happy to share their data with their doctors but not with tech or insurance companies. There are also clear differences in the type of data people are willing to share. For example, they are clearly uncomfortable sharing health habits, genetic data or sexual and reproductive health data.

“It is therefore crucial that EU decision-makers integrate the right protections in the legislation so that consumers are better protected and their health data is not misused. That includes an opt-in mechanism for patients to share their data for care purposes. There should also be at the very least an opt-out one for sharing their data for scientific or public health purposes, and some data exclusions and purpose restrictions. That is how to build trust in this health data space.”

Background on the European Health Data Space

The European Commission proposed the creation of a European Health Data Space in May 2022 and the European Parliament and national governments are currently poring over its details. Its objectives are to more systematically record people’s health data so that healthcare professionals and patients have access to it, while health data beyond those included in electronic health records, such as genetic data and clinical trials’ data, can become available for research, innovation, policy-making and regulatory activities.

BEUC main recommendations for the European Health Data Space

- Create an opt-in mechanism with granular settings for patients to share their data for care purposes.
- Ensure consumers are better protected when it comes to the use of their data for secondary purposes, such as health research or public health purposes. This requires:
 - Creating at the very least an opt-out mechanism for consumers sharing their health data for scientific research or public health purposes;
 - Excluding genetic data, and person-generated data from wellness applications and digital health applications for scientific or public health purposes (secondary use of data) from the scope of the regulation; and
 - Restricting which purposes for secondary uses of health data are legitimate.

More information on the survey

You can find the full report [here](#) and a link to a stand-alone executive summary [here](#).

