

Consumer attitudes to health data sharing

Survey results from eight EU countries

Executive summary

With the European Union institutions currently working to create a European health data space, which would allow the **access and sharing of people's health data across the EU**, nine consumer organisations from eight EU countries¹ have surveyed people to get a better insight on what they think about sharing their health data. This survey sheds light on consumer attitudes and unveils **what type of data they are willing to share, with whom and for what purpose** (for provision of healthcare, for scientific research, or for public health reasons).

Our survey reveals that **consumers are generally cautious about sharing their health data** through online health platforms and want to decide for themselves what data they share and with whom.

Health data is rightly regarded as both extremely sensitive and of great value by all kinds of entities, from public health authorities and businesses to people themselves. As a result, it is crucial that EU legislators respect consumers' interests, and our evidence-based recommendations should provide food for thought at this critical juncture.

1

People are very selective about the health data they are willing to share.

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 their attitudes vary significantly regarding the data they are willing to share.

Attitudes range from being fairly positive about sharing their **health status** when it is for care purposes (61% of them are willing to do that) to being guarded when it relates to their **health habits** – between 67% and 70% do not want to share it – and are generally opposed to sharing their **genetic data** (between 77% and 80% do not want to share it).

2

Consumer willingness to share data depends on the entity with whom it is shared.

Our survey shows that consumers' willingness to share their health data strongly mirrors the **level of trust** they place in the receiving entity and how close that entity is to the **direct provision of healthcare**.

¹ 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).

Among people willing to share their data, those with whom they are most open to sharing it with are their **general practitioners** (88%). Less than one in five is willing to share their data with pharma companies (17%), and less than one in ten is willing to share their health data with insurance companies or companies developing wellness apps (8%). Only 5% are willing to share their health data with digital technology companies.

3 People want to choose what happens to their data and prefer to be asked for their explicit consent to share it.

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**. However, consumers tend not to adjust their privacy settings on online health portals and platforms at the moment. Only 19% have limited the access of some professionals or entities to their health data. This strongly suggests that people are not sufficiently aware of the choices available or the impact that their privacy settings could have on the sharing of data on health platforms. After all, the take-up of these online health platforms is both recent and greatly linked to the COVID-19 pandemic. As a result, there must be clearer and better options to manage one's health data.

As for data that cannot be anonymised, such as genetic data, a large majority of respondents (69%) think that it should not be used for research purposes **without the patients' explicit consent**.

4 Consumers are split about sharing their data across borders in the EU.

People are **lukewarm** when it comes to granting access to their health data to entities **in other EU countries**. Fewer than half of the respondents (from 39% to 49% according to the purpose) are willing to do so. Only just over half of respondents are willing to share their health data with healthcare practitioners across EU member states (51%) to secure good treatment when they are abroad.

5 People can see benefits, but also have concerns when they share their health data electronically.

The benefit that people most commonly see in sharing their health data is that it can lead to the **development of new or better diagnostic systems** (39% of all respondents). Consumers also see the benefits of **easier access for patients to treatment** across the EU or **easier access to health records** (32%).

Most respondents believe that the profit created by companies through the use of citizens' health data should be **reflected in more affordable and accessible healthcare services and medicines** (68%).

The greatest concerns respondents had related to the possibility of **data theft** (44%) or **unauthorised access/use of data** (40%/39%).

Policy recommendations for the European Health Data Space (EHDS) Regulation currently under discussion at EU level

- 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.
- Introduce third-party assessment of Electronic Health Record Systems and maximise cybersecurity requirements.
- Introduce the right to compensation and add the EHDS regulation in the Annex of the Representative Actions Directive.
- Tie the use of data from the EHDS with transparency obligations and a return on public investment.

