

Consumer attitudes to health data sharing

Survey results from eight EU countries



Acknowledgements

We would like to thank Euroconsumers¹, which contributed to developing the questionnaire, and carried out the data collection and statistical analysis that serves as the basis for this report.

We also wish to thank the BEUC members which contributed to the survey: Test Achats/Test Aankoop (Belgium), dTest (Czech Republic), UFC-Que Choisir (France), vzbv (Germany), EKPIZO and KEPKA (Greece), Altroconsumo (Italy) and OCU (Spain). We are grateful to DECO Proteste (Portugal) which also contributed to this survey.

Publishing Bureau designed this report and the visuals associated with this survey.

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Published in May 2023



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¹ Gathering five national consumer organisations and giving voice to a total of more than 1,5 million people in Italy, Belgium, Spain, Portugal and Brazil, Euroconsumers is the world's leading consumer cluster in innovative information, personalised services and defence of consumer rights. Its European member organisations are part of the umbrella network of BEUC, the European Consumer Organisation. Together they advocate for EU policies that benefit consumers in their daily lives.

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Terminology

Throughout this report, we refer mostly to ‘people’ and occasionally to ‘consumers’. Although the term ‘data subject’ would be a more specific, and perhaps more accurate, term given the subject matter, we use the term ‘consumer’ in a broad sense to reflect that we are a consumer organisation.

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 countries² 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**.

² 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 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.



Introduction

Everything related to our health, such as the latest ailments we had, our medical prescriptions, or our blood pressure says something about the state of our bodies and minds. This data is undoubtedly of **great value** to ourselves and to healthcare professionals, but it can also help **researchers, public health authorities, governments, and drug developers** and different types of industries.

If health data is more systematically recorded and available for use, it can serve all kinds of purposes, from providing **better informed healthcare** when we go abroad and fall ill, to making it easier to monitor medicines' adverse effects which in turn improves their safety, or **helping scientific research** and the development of novel treatments. To make the most of health data across borders, the European Commission proposed the creation of a **European Health Data Space** (EHDS) in May 2022.

The aim of the proposal is to provide both healthcare professionals and patients with access to their **electronic portable health data**, which would improve healthcare provision and make national electronic health records interoperable across Member State. Besides care purposes, the proposal foresees that 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.

Legislation to create a European Health Data Space could radically alter the way health data is treated in the European Union. Much has been made of the benefits to companies and public authorities if people's health data is more accessible across borders, but are people themselves willing to share it and under what conditions? Surprisingly little research has been carried out to explore consumer attitudes towards the sharing of their health data.

In light of the Commission's proposal, nine consumer organisations³ from eight EU countries have surveyed people to get a better insight on what they think. This survey sheds light on **consumer attitudes** and unveils **what type of data they are willing to share, with whom and for what purpose**. The three purposes that consumers were surveyed on regarding sharing their health data were for provision of healthcare, for scientific research, or for public health reasons (for example, contraction of infectious diseases or vaccination status).

The survey also reveals how the **level of trust** they place in different entities affects their willingness to share their data. Crucially, it also looks at whether people want to be **active or passive** in the way their data is handled. It comes at an immensely important time, as the European legislation is entering the critical phase when both the Parliament and Member States work out their positions on the file.

This report provides an overview of the key results of the survey, followed by their assessment and BEUC's policy recommendations, while an explanation of the methodology behind the survey can be found at the end of the report.

³ 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), OCU (Spain) and DECO Proteste (Portugal).

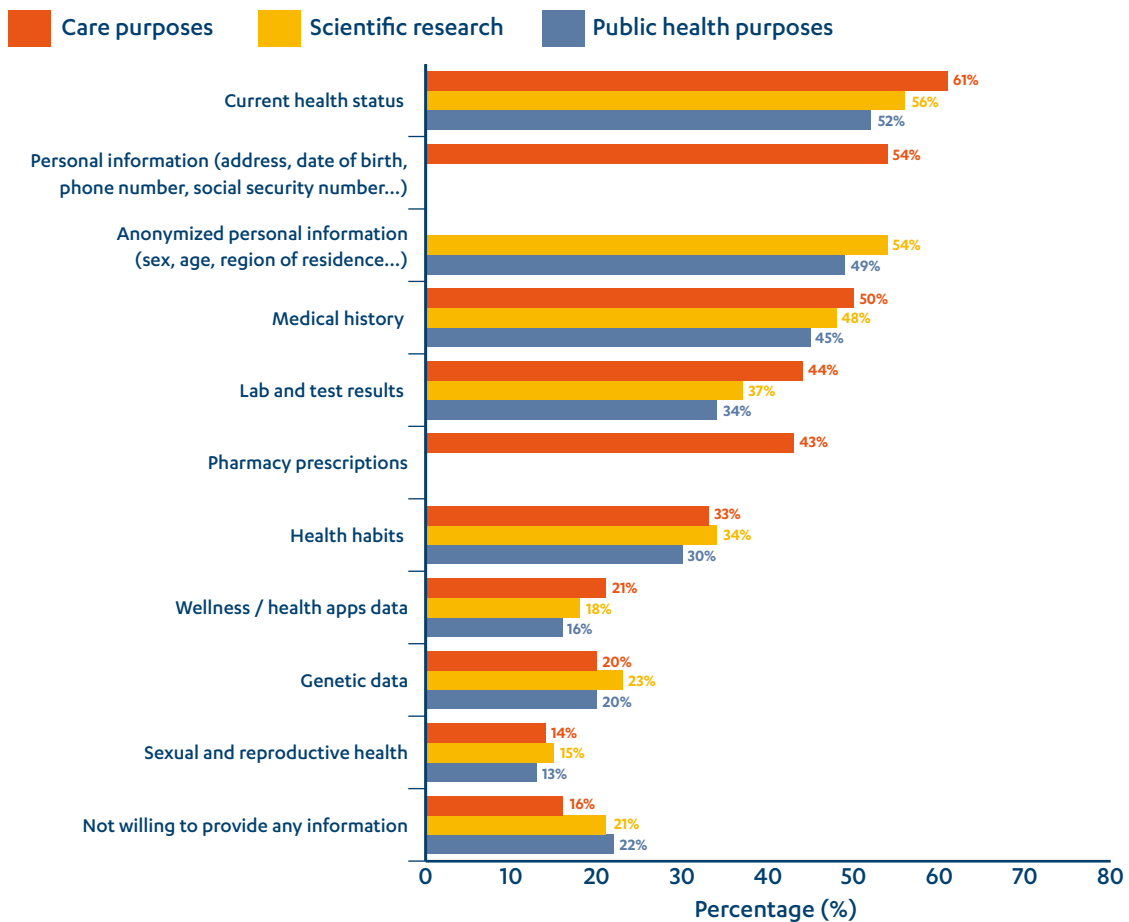
Survey results & policy recommendations

1

Although most consumers are familiar with online health platforms, their willingness to share health data through them varies greatly according to the type of data.

- More than **8 in 10** people **use online health platforms** to manage their health data. The most common reasons for doing so are fixing an appointment (64%), and for accessing their medical records (45%).
- Use of online health platforms is high in all countries surveyed, ranging from a very high rate in **France** (96%) to the lowest level in **Germany** (70%), where 21% of people do not use them because they do not trust the providers of those digital services. On average, those who use online health platforms the most tend to be people with a **high or at least medium education level**.
- The health data people are most willing to share electronically relates to their **health status**, with just over half willing to share it for **care purposes** (61%), and less than half want to share it for **scientific research** (44%) and for **public health reasons** (48%).
- Approximately half of the respondents are **unwilling to share their personal information** such as their address and date of birth for care purposes (46%), and their anonymised personal information, such as sex and age, for scientific research (46%) or for public health reasons (51%). The majority of respondents do not want to share data that relates to their **health habits** (between 67% and 70% depending on the purpose), **wellness and health applications data** (between 79% and 84% depending on the purpose), **genetic data** (between 77% and 80% depending on the purpose) and **sexual and reproductive health data** (between 87% and 85%).

Which of the following types of personal information would you be willing to provide through an online healthcare platform for...?



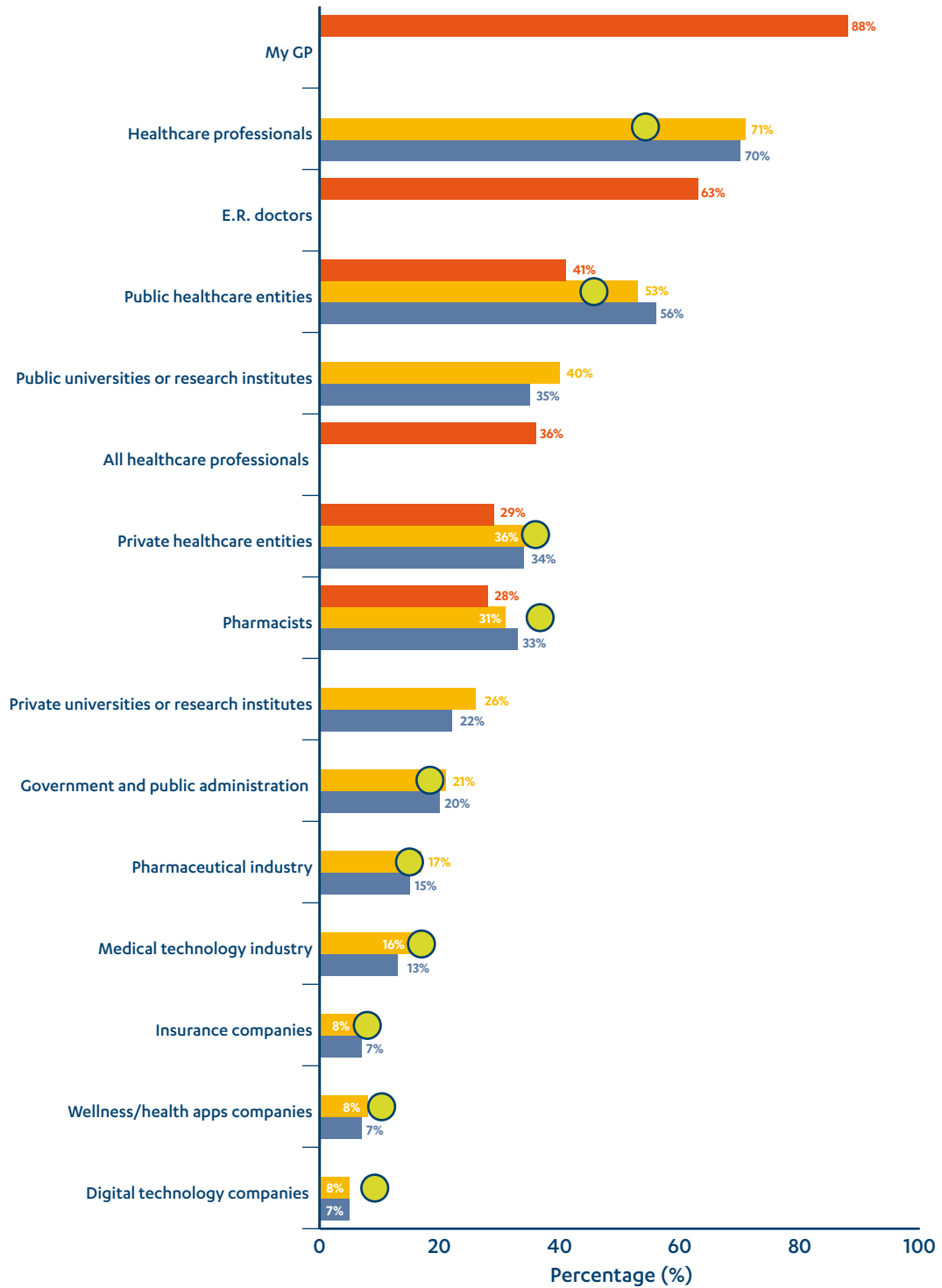
2

People's willingness to share their data depends on the level of proximity and trust they place in the receiving entity: happy to share with their general practitioners, opposed to sharing it with the pharmaceutical industry, digital technology, insurance or wellness app companies.

- Amongst the people willing to share their health data, the **vast majority** are happy to give access to their **general practitioner for care purposes** (88%) though they are less willing to share it with emergency room doctors (63%), and significantly less disposed to share it with all healthcare entities (36%) or even pharmacists (28%).
- **Health professionals**, with whom consumers enter into contact the most on their health, are the **most trusted category** with over half (54%) of respondents placing complete or high trust in them. Seven in ten respondents would share their health data with healthcare professionals for both scientific research and public health purposes.
- Only 17% would share their data with the **pharmaceutical industry**, in whom only 15% of respondents gave a high or complete level of trust. Consumers were even less willing to share their data with **insurance companies** and companies developing **health/medical apps** (8% each), with just 8% and 11% of respondents placing their complete or high trust in them respectively.
- A tiny 5% are willing to share their health data with **digital technology companies** for scientific research, in whom a **low level or absence of trust** is shared by 59% of people.

Who would you be willing to give access to your health data, through an online healthcare platform, for...?

■ Care purposes
 ■ Scientific research
 ■ Public health purposes
 ● High/complete consumer trust level



3

People want to choose what happens to their data, prefer to opt in to share their health data, but their privacy settings today do not reflect that.

- An **overwhelming majority of people** (81%) prefer to choose which personal data they give access to, whom they give access to, and for what purposes.
- More specifically and for all the purposes investigated, over half of the survey respondents think that their health data should be accessible only **after they provide their explicit consent** (between 51% and 57% depending on the purpose).
- A smaller share of people prefer their data to be **accessible by default**, varying from 34% for scientific research, 41% for public health purposes and 45% for care purposes. When it comes to very sensitive data which 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**.
- When it comes to **adjusting their privacy settings** on online health portals and platforms, a mere 19% have **limited** the access of some professionals or entities to their health data, while 17% granted access to all professionals and entities. One in ten said they would have adjusted their privacy but didn't know how to or found it impossible to do so, while more than four in ten (41%) did not take any action.



Assessment and policy recommendations for the EHDS Regulation

Enable consumers to choose what data they share, with whom and for what purpose in the European Health Data Space (EHDS) Regulation.

- Despite the fact that most respondents have used online health platforms, they are **very reluctant** to share certain categories of health data, regardless of the purpose in question. The results also show that **consumers' willingness** to share their health data with an entity reflects the **level of trust** they have in that entity. For example, people are happier to share their data with healthcare professionals they have a personal relationship with, such as their general practitioners, rather than all healthcare professionals or emergency room doctors. Trust and, consequently, willingness to share drop as the entity is less and less linked to direct healthcare provision, such as insurance companies or the tech industry, showing that people fear their health data will be misused.

On this basis, it is clear that **consumers' data should not be made available by default** but should instead reflect consumers' wishes.

Create an opt-in mechanism for patients to share their data for care purposes.

- The use of health data for care purposes both at national level and across borders should be subject to the **explicit consent of individuals** given the very sensitive and personal nature of the health data. Incorporating an opt-in mechanism with granular settings as to what types of health data patients wish to share and with which categories of healthcare professionals is essential to fully address their concerns.

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 all the following recommendations to be reflected in the European Health Data Space (EHDS) Regulation:

- **Create at the very least an opt-out mechanism for consumers sharing their health data for scientific research or public health purposes.**

The added value that health data sharing has for the public interest is enormous. However, it is essential that the regulation accommodates **both the interests of society and individuals**. Given the high degree of caution that consumers have about sharing their health data with entities they mistrust, such as tech or insurance companies, their concerns need to be reflected in the regulation.

There must, **at the very least**, be an easy to use **opt-out mechanism** that consumers can rely on if they do not want their data to be used for **secondary purposes** via the European Health Data Space. This ability to at least opt out should be combined with further safeguards to ensure that consumers' data is not misused.⁴

- **Exclude from the scope of the regulation genetic data and person-generated data from wellness apps and digital health applications for scientific or public health purposes (secondary use of data).**

People are most reluctant to share **genetic data, health habits, sexual and reproductive health data, and data from wellness and health applications**. Certain categories of health data, such as genetic data, are too revealing and can never be anonymised. If we combine this with data coming from wellness and health applications, reidentification of individuals would be trivial, leading to serious privacy breaches. **This type of data should not be available.**⁵

- **Restrict certain purposes for secondary uses of health data.**

Given the level of mistrust in companies that are more removed from direct healthcare provision, certain secondary uses of data, such as for **product or service development activities, personalised medicine and AI training**, should **not be allowed**, as people are unwilling to share their data with these entities.

Invest in improving consumer awareness and digital literacy.

- The use of online health platforms and portals is very common. However, today, these platforms are mostly used to carry out simple tasks such as fixing medical appointments or accessing one's medical record, while their uptake is highest among people with a higher or at least medium educational level. In addition, even though most consumers want to be actively involved in managing their health data, the percentage of people who proactively adjust their privacy settings is much lower. This suggests that **proactively adjusting privacy settings is not always easy or straightforward**. Authorities should therefore provide help to people who will need to use these platforms for complex tasks or who want to adjust their settings but do not feel sufficiently confident or know how to do so.

⁴ As the survey showed that so many consumers are hesitant to share their data for purposes other than the initial ones, an alternative considered by some BEUC members is to foresee an opt-in to put consumers in the driving seat with regard to the use of their health data.

⁵ Test Achats/Test Aankoop (Belgium), Altroconsumo (Italy) and OCU (Spain) consider that an opt-in for genetic data could be an alternative solution as some consumers may see the benefit of for instance these new treatments or benefit from it themselves and are therefore more willing to share their data for scientific or public health purposes.

4

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

- **Fewer than half** of the respondents (from 39% to 49% according to the purpose) are willing to grant access to their health data to entities in **other EU countries**.
- The rest of the sample is almost equally divided between those who do not want to give access to their data in other EU countries (between 27% and 29% depending on the purpose) and those who are not sure or don't have an opinion about it (between 24% and 28% based on the purpose).
- The percentages vary according to whether the data would be shared for **care purposes** (43%), for instance if somebody breaks their leg and needs medical treatment abroad, or for **scientific research** (39%) or **public health reasons** (49%).
- **Just over half** of respondents are willing to share their health data with healthcare practitioners across EU member states (51%) to secure good treatment in case of medical emergencies abroad.
- The willingness to share their data with other countries **varied widely between countries**, with Portuguese people most open to sharing their data (74% for care purposes), while French and German respondents are least open to sharing their data (34% in both countries).

5

People can see the benefits but also have concerns about sharing 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).
- Easier access for patients to **treatment across the EU** (32%), **easier access to health records** and **lower risk of losing documents** (32%), and **better medical follow-up**, for example booster shots for vaccination (30%) are also commonly identified as potential benefits of sharing health data electronically.
- Nevertheless, some people (7%) did not see any benefits to the sharing of their health data electronically.
- The greatest concerns respondents had related to the possibility of **data theft** (44%), **unauthorised access/use of data** (40%/39%), or insurance companies getting their hands on the data which could lead to a **refusal to insure** or to an **increase in insurance premiums** (27%). Data theft scored particularly high as a source of concern in France (47%) and Spain (44%).
- On average, half of the respondents are willing to give access to **their anonymised health data** to help develop new medicines and treatment.
- 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%).
- Very few people do not have any concerns about sharing their health data electronically (3%).

Assessment and policy recommendations for the EHDS Regulation

Improve consumer awareness of the benefits of health data sharing for care purposes through awareness-raising campaigns.

While people do tend to see the value of their health data, they do not always see the direct benefits that come from sharing it with **different healthcare professionals** other than their general practitioners. This is reflected by the fact that only **one third** of respondents see better medical follow-up, such as booster shots for vaccination, as an important benefit of sharing their data electronically.

The **reluctance to share health data across borders** is pronounced, with only half of respondents willing to give health practitioners from other countries access to their health data in case of medical emergencies and only a third see easier access to treatment across the EU as a direct benefit.

Introduce third-party assessment of European Health Record Systems and maximise cybersecurity requirements.

- Consumers are **deeply concerned** about their health data being stolen, as was the case in the multiple cyberattacks recorded in hospitals in France, Spain and Germany in the recent months, where respondents indicated data breaches as their major concern. To ensure the highest level of protection, **European Health Record Systems** must be assessed by notified bodies before being placed on the market, instead of relying on the self-assessment carried out by the economic operators involved. **Maximising cybersecurity requirements** is also essential to build trust in those systems.

Introduce minimum quality requirements for mandatory anonymisation and pseudonymisation.

- The proposal foresees the use of anonymised or pseudonymised data for secondary uses. However, there are no relevant quality requirements as to how anonymisation and pseudonymisation will be carried out in practice. Effective anonymisation is difficult to achieve and requires know-how and resources, while its poor application can lead to the **re-identification of individuals**. **Moreover, pseudonymised data is by definition personal data**, subject to the General Data Protection Regulation (GDPR). As people wish to share their anonymised health data to improve health treatment, it is important the regulation **delineates the minimum requirements** for those techniques, ensuring that their data is adequately protected.

Introduce the right to compensation and add the European Health Data Space Regulation to the Annex of the Representative Actions Directive.

- Given that respondents are very concerned about their health data being breached, accessed or used without their authorisation, they should be given access to an **effective redress mechanism** if any data misuse takes place. Consumers must have a right to compensation for damages for not respecting the EHDS Regulation. To benefit from the existing collective redress mechanism, the EHDS Regulation must be added to the Annex of the Representative Actions Directive (EU) 2020/1828.

Tie the use of data from the European Health Data Space with transparency obligations and a return on public investment.

- Consumers make it clear that they want their data to be exploited for their **benefit** and **not against them**. This is why they want to make sure that the profit generated by those making use on their health data is reflected in more affordable and more accessible healthcare services and medicines.



Methodology

The survey aimed to assess and measure a variety of aspects:

- what type of data consumers are willing to share for primary use (for care purposes) and what type of data for secondary use (for scientific research and public health purposes). The types of data included amongst others basic health information, genetic data, pharmaceutical prescriptions or medical and lab results.
- With whom consumers are willing to share this data, for example family physicians, doctors in emergency services, other health professionals, researchers, private companies, policy makers, regulators) and for what purposes.
- Consumers' attitudes towards 'opting in' to share their data versus 'opting out' including by type of data/actor/purposes.
- The level of awareness about the current situation in their country.
- The level of awareness about the European Health Data Space initiative.
- The level of trust in various entities including health practitioners, pharma companies or insurance companies
- The benefits and concerns consumers perceived regarding sharing their health data with online platforms.

Along with the above information, the survey collected socio-economic data relating to respondents to be able to segment them.

The countries covered in the survey were Belgium, the Czech Republic, France, Germany, Greece, Italy, Portugal, Spain.

The European Consumer Organisation (BEUC) produced the survey, developing the questionnaire together with Euroconsumers, which was then adapted to the national context and translated by Test Achats/Test Aankoop (Belgium), dTest (Czech Republic), UFC-Que Choisir (France), vzbv (Germany), EKPIZO and KEPKA (Greece), Altroconsumo (Italy), DECO Proteste (Portugal) and OCU (Spain). Euroconsumers carried out the data collection and statistical analysis that serves as the basis for this report.

The fieldwork took place in all countries between 21 February and 27 February 2023. The answers were collected through an external provider which specialises in panel provision and whose products comply with ESOMAR, MRS, ARF, MRIA, AMA, AMSRO, Insights Association standards and ISO 20252. Panellists were recruited by registration pages and validated by a double opt in procedure, with anti-duplication and Geo-IP control. The survey took place online.

Participants to the survey ranged from 18 to 74 years old and stratified using quotas by age, gender and geographical area. Afterwards a weighting procedure was applied to the samples in order to reflect the distribution of the national populations in terms of gender, age, educational level and geographical area. Test questions were included in the questionnaire to screen out cheaters and people who tried to complete the questionnaire too fast. For each of the samples, respondents who took less than half of the median time to answer the questionnaire (by country) were dropped and substituted.

Number of valid questionnaires collected by country:

Belgium	Czech Republic	France	Germany	Greece	Italy	Portugal	Spain	TOTAL
1,012	1,003	1,002	1,009	1,008	1,013	1,015	1,005	8,067



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