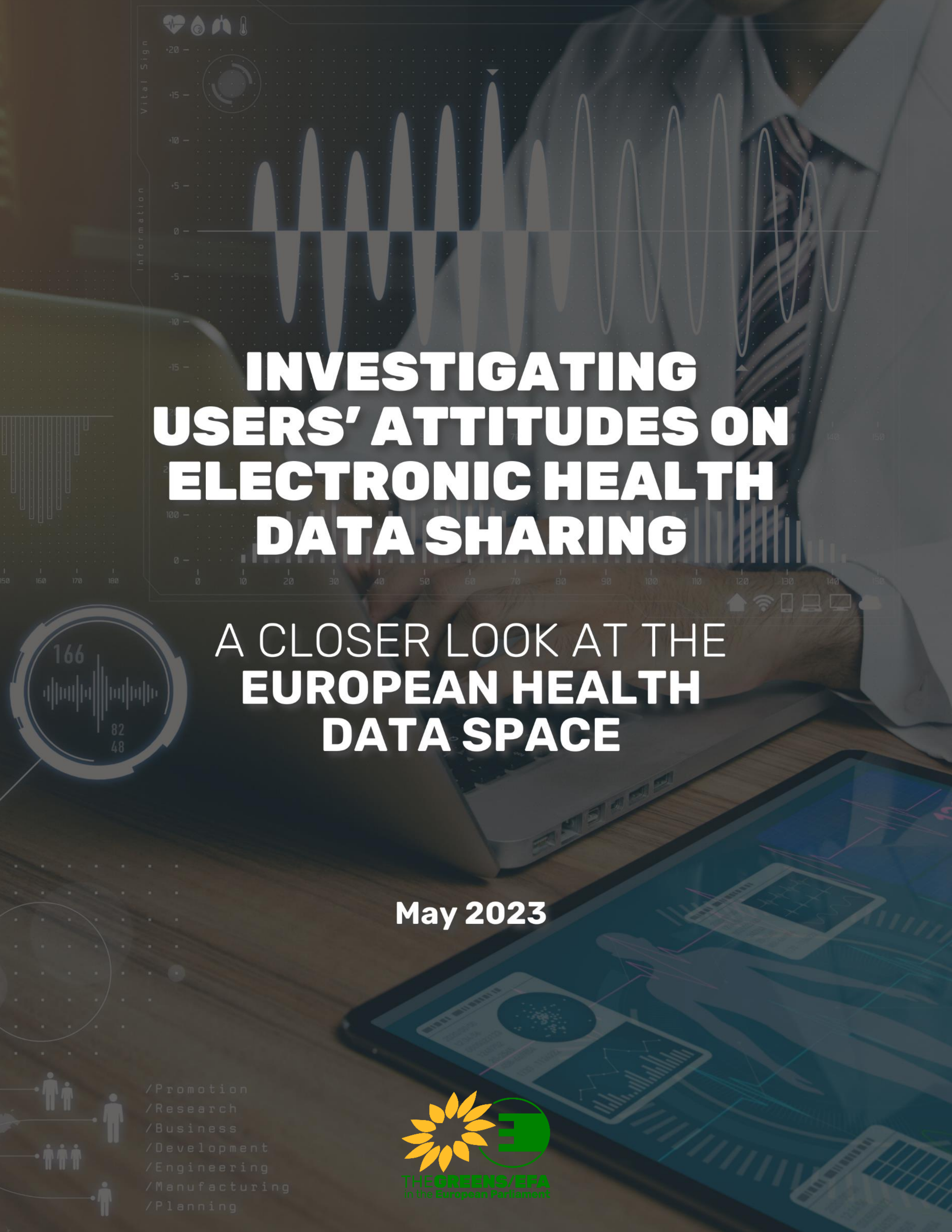


INVESTIGATING USERS' ATTITUDES ON ELECTRONIC HEALTH DATA SHARING

A CLOSER LOOK AT THE **EUROPEAN HEALTH DATA SPACE**

May 2023

THE GREENS/EFA
in the European Parliament

Contents

1. Introduction

On the 3rd of May 2022, the European Commission published a proposal for a Regulation on the European Health Data Space (EHDS). The proposal is a key stepping-stone of the 2020 European strategy for data as it aims to facilitate data sharing of electronic health data across different players by:

1. increasing data subjects' rights to data portability and interoperability to strengthen their control and access to data in cross-border situations;
2. provide legal certainty via horizontal and harmonized rules for economic operators that introduce digital health products, such as electronic health record (EHR) systems, including electronic health records (EHR);
3. strengthen secondary access and use of electronic health data by private and public bodies to, inter alia, develop new products, innovative practices, conduct research, and regulatory practices in the field of public and occupational health.

At the time of writing, the Commission proposal is currently under scrutiny in the European Parliament (EP) and Council of Ministers. In the EP, the proposal has been assigned to the LIBE-ENVI committees under a joint committee procedure (rule 58). Respectively, IMCO and ITRE committees have shared competences for EHR systems and wellness applications (Chapter III), and secondary uses of data (Chapter IV). The co-rapporteurs on the file are Annalisa Tardino (LIBE - ID) and Tomislav Sokol (ENVI - EPP)

In light of the strategic importance of this file, the Greens/EFA group in the European Parliament has requested Ipsos to conduct a survey to investigate EU citizens' attitudes to primary and secondary data sharing as well as to measure their levels of digital literary and trust to public authorities in the field of health. This report provides an overview of these findings across four variables to investigate more in-depth country-level, gender-level, age-level, and education-level differences.

Overall, it emerges the need for greater user-level control to make available their electronic health data shared via the EHDS. In particular, the findings highlight that

1. Respondents overwhelmingly prefer to make their electronic patient records accessible to third parties based on explicit consent;
2. Respondents prefer to grant access to their electronic health records to scientists and researchers.
3. A strong majority of respondents wish to express consent before giving access to scientists and researchers;
4. Most respondents prefer to share their personal data only for general or specific health-related purposes and not for commercial ones;
5. Respondents feel more protected when health public health authorities protect their data, contrary to government private actors;

6. Respondents claim to understand “well” the risks and benefits associated with sharing data via their electronic health records.

This report proceeds as follows: First, it outlines the survey methodology by providing more information on the adopted variables, sample size, and statistical methods to conduct the survey. Second, it shows the findings of the study by dividing the results across country-level, age-level, gender-level, and education-level variables. Finally, it summarizes the results by reflecting on the importance of the findings in light of the current Commission proposal.

2. Survey

The survey was commissioned to Ipsos on the 13th of February 2023 and the results were delivered on the 14th of March of the same year, in the form of data tabulations. As previously mentioned, the survey aimed at investigating citizens' attitudes to primary and secondary uses of electronic health data as well as to measure their levels of digital literacy and trust to public authorities in the field of health. To quantify these objectives, the survey consisted of six questions, followed by two socio-demographic questions to collect data on respondents' levels of education and potential disabilities that affect their abilities to carry out day-to-day activities. At the beginning of the survey, base questions on gender identification and regional provenance were included.

The survey had a total sample size of 5073 participants, equally distributed across five countries - Estonia (EE), Germany (DE), France (FR), Spain (ES), and Croatia (HR) - that are representative of geographical and population differences in the Union while taking into account different levels of digital health advancement. The respondents' age target was between 18 and 65 years of age, and the questions were asked in five languages: Estonian, German, French, Spanish, and Croatian. The fieldwork started on 6 March.

Findings

3.1 Horizontal findings

In this section, the study reports the results of the six questions without accounting for the four specific variables of the study.

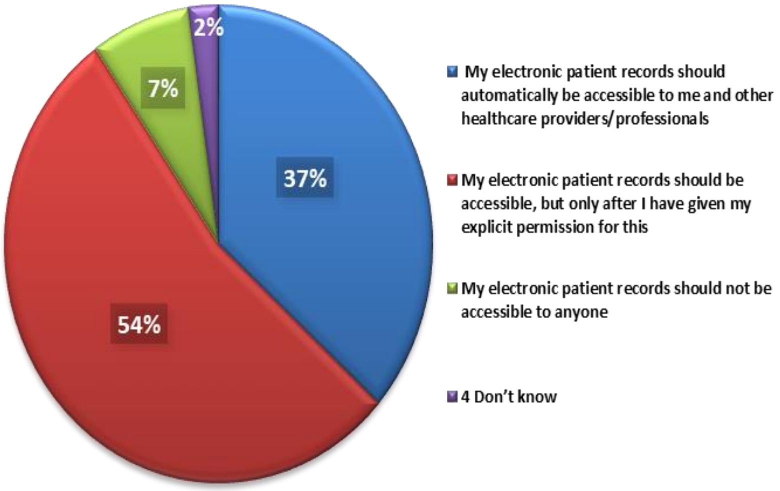


Figure 1.1 Which of the following comes closest to your own view?

To investigate users' attitudes towards granting access to their electronic health records, *Figure 1.1* reports that a slight majority of participants (54%) wishes to give explicit consent to make their records accessible while 37% agrees of making them automatically. A sharp minority would not grant accessibility under any circumstances (7%).

In this regard, *Figure 1.2* illustrates a different preference by citizens to authorize scientific and/or research bodies to access their records. Most notably, 25% of overall respondents would give access to almost all reported entities in the survey. Similarly, 24% of participants have no objection concerning whom should get access to their records. On the contrary, 14% of them would only grant direct access to scientists/researchers while just 10% would authorize university researchers alone. Finally, and in sharp contrast with the previous figure that displayed a generic willingness to grant patient data, 22% would not allow access to any of the selected entities in the survey.

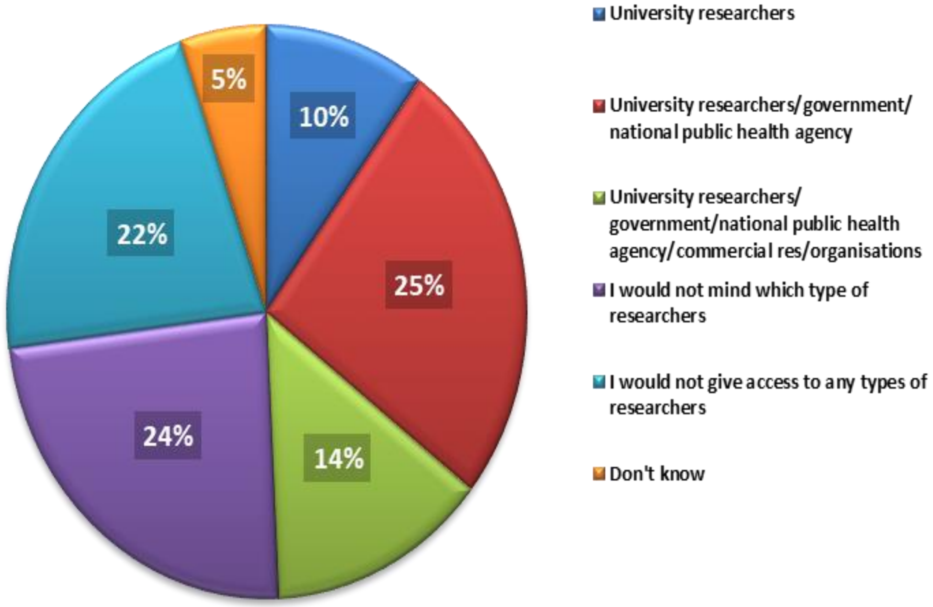


Figure 1.2 What types of scientists/researchers would you be happy with being able to access your electronic patient records for research purposes?

Concerning whether scientists and researchers should have access or not to their health records, *Figure 1.3* overwhelmingly reports a desire by patients to be consulted before requesting access to their data. Accordingly, 46% of respondents demands prior consent while even 29% argues that users should even be able to express prior consent on the specific project. Still, 20% of the survey base would automatically give access to their patient records.

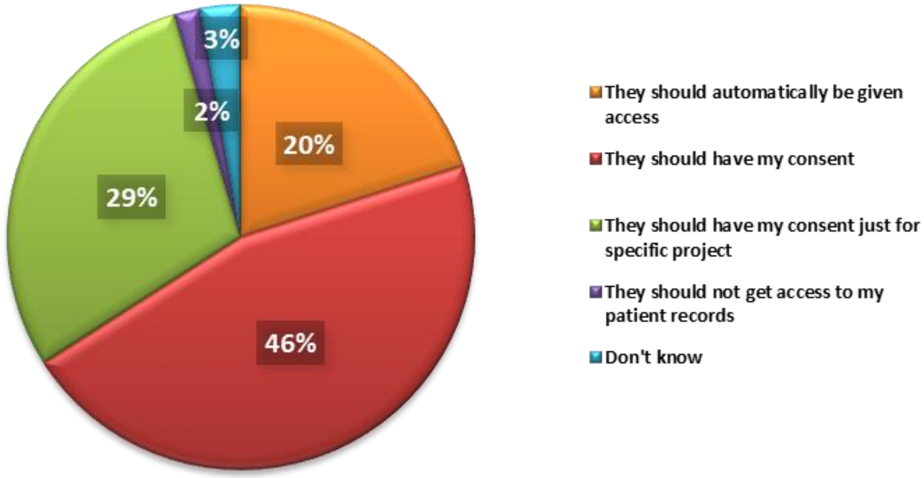


Figure 1.3 How these scientists/researchers would gain access to your electronic patient records for research purposes?

In addition, as *Figure 1.4* reports, 65% of respondents report that third parties should be allowed to gain access to their data for general public health benefits while a limited 20%

believe that there has to be a direct health benefit aim related to giving access to scientists and researchers. Furthermore, the amount of respondents in favour of sharing their records for any reason is higher than those who do not want to share their data at all.

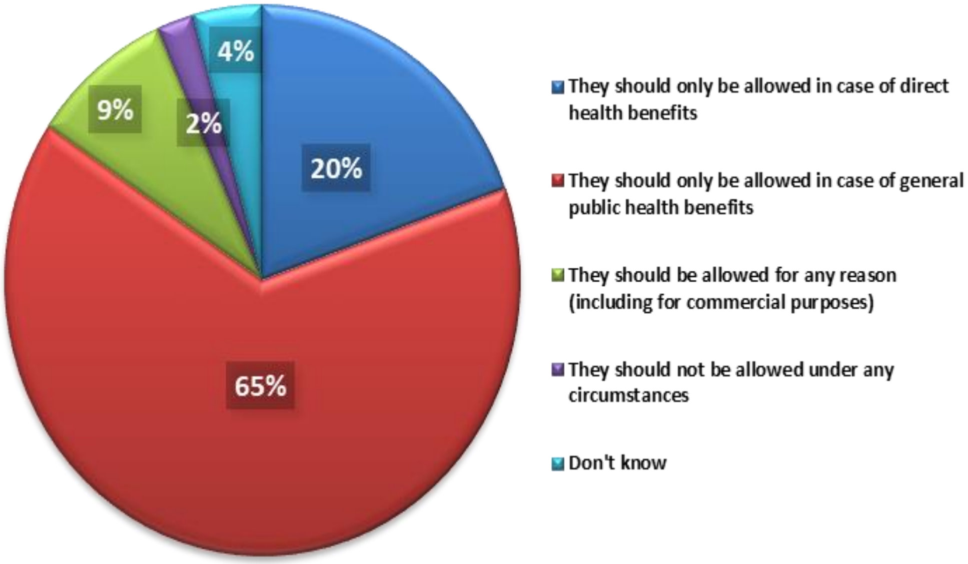


Figure 1.4 For what purpose would scientists/researchers be given electronic patient records?

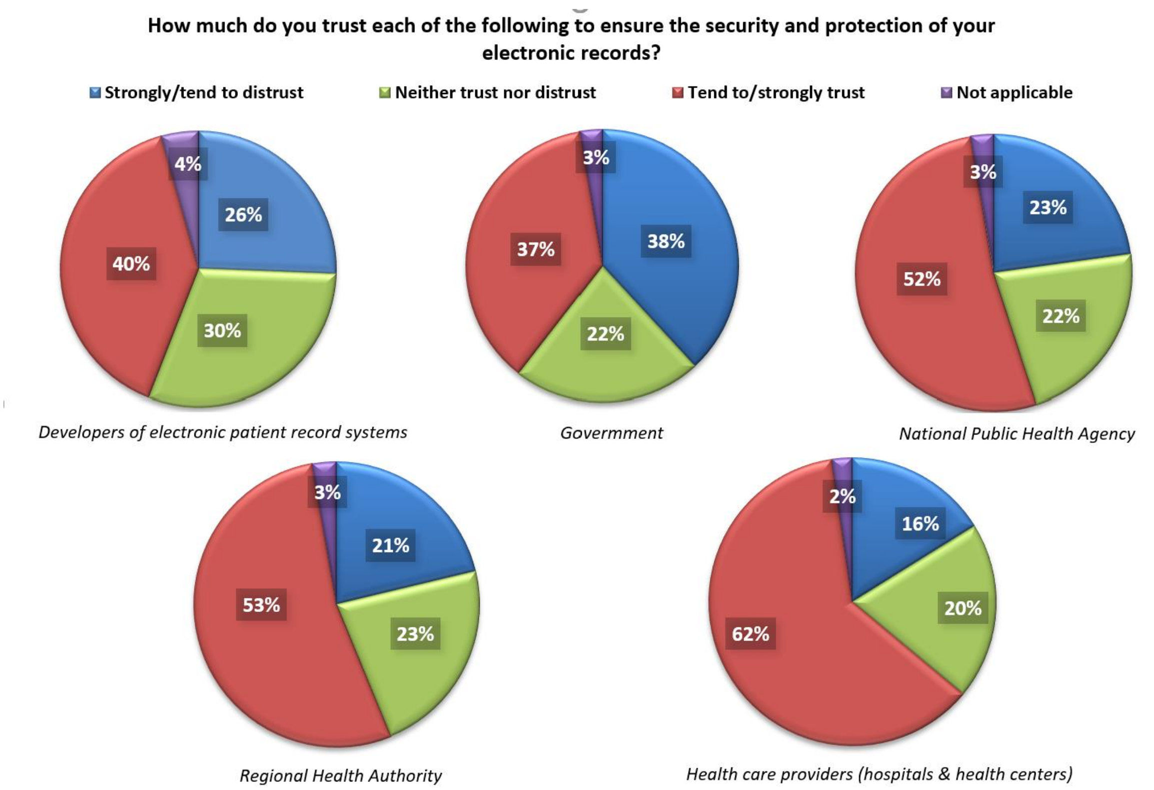


Figure 1.5 How much do you trust each of the following to ensure the security and protection of your electronic records?

Figure 1.5 also reports different level of trust towards developers of electronic patient records, government, national public health agencies, regional health authorities, and health care providers. Accordingly, patients tend to trust health care provider the most (62%) while national governments enjoy the lowest levels of trust (38%). Largely, there is more trust in public authorities in the health sector than in private bodies, in particular for developers of electronic patient records (40%).

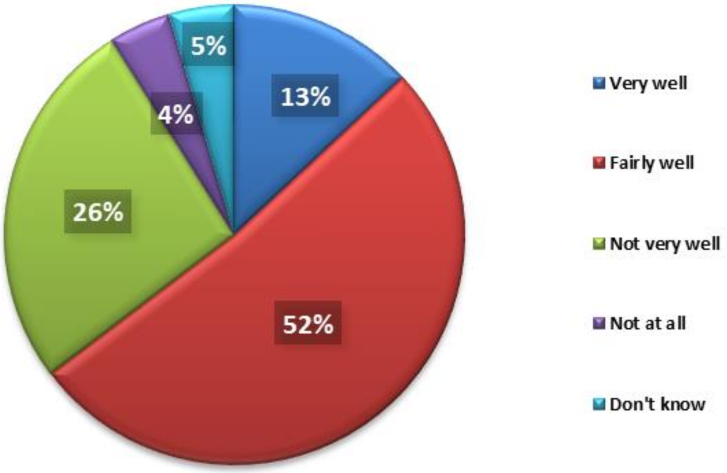


Figure 1.6 How well do you feel understand the benefits and risks associated with the sharing of electronic patient records?

Finally, concerning the benefits and risks associated with the sharing of electronic patient records, *Figure 1.6* depicts an overall positive attitude (65%) among respondents on sharing health data via electronic patient records. On the contrary, 26% indicates claims not to understand well the risks and benefits while just the 4% reports not to understand the associated risks and benefits at all.

3.1.1 Key takeaways

- Most respondents expressed their preferences to grant accessibility of their electronic patient records by being asked for consent prior access authorization (*Figure 1.1*);
- Most of the respondents would grant access to any scientists/researchers (*Figure 1.2*);
- Most patients would prefer to be consulted to give access to scientists/researchers (*Figure 1.3*);
- Most respondents consider that personal data should be shared for health-related purposes (general or specific) *(Figure 1.4*);
- Respondents feel more protected when health public authorities secure their data (*Figure 1.5*);
- Respondents report to understand well the risks and benefits associated with sharing data via their electronic health records have an overall well feel in sharing their data without associating risks (*Figure 1.6*).

3.2 Country-level differences

This section reports the results on citizens' attitudes to primary and secondary uses of electronic heath data across the five selected countries.

It is against this backdrop that *Figure 2.1* depicts a general positive trend towards citizens' acceptance to grant access to their health data, albeit with some minor variations. All the five selected countries report a preference on granting access based on users' explicit permission - the lowest indicator here is Estonia with 48%. In terms of automatic access, there are some notable country-level differences: Estonia holds the highest rate of trust to healthcare providers and professionals, reporting an almost identical level of accessibility both for automatic access and access based on consent (49%). On the contrary, there is an opposite trend for Germany (58%) and France (57%) where respondents indicate that their records should only become accessible to third parties after explicit consent. In particular, Germany reveals the highest trend in favour of not giving access to electronic patient records at all (13%). This trend is in sharp contrast with Estonia which reports that just 2.5% would not grant access to their data in any circumstances.

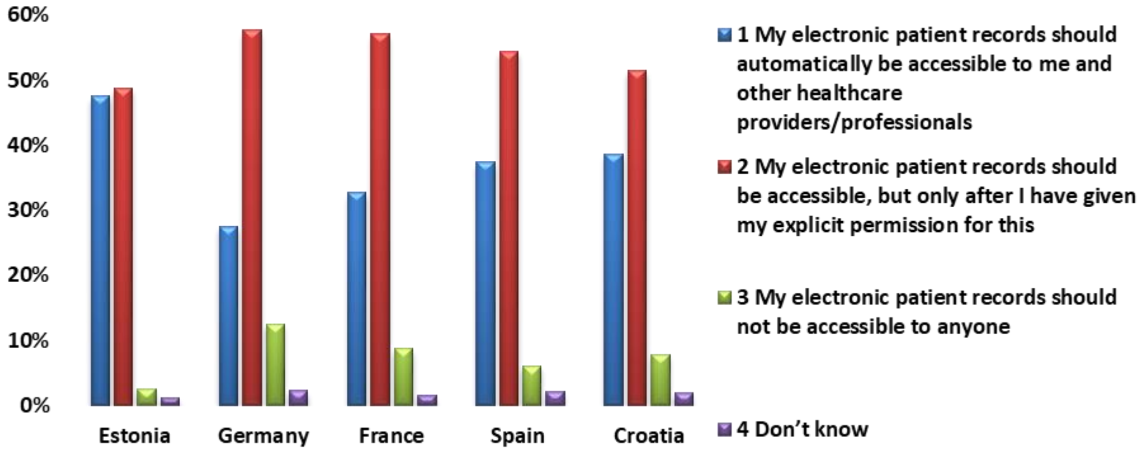


Figure 2.1 Which of the following comes closest to your own view?

Similarly, in relation to which scientists and researchers should have access to patients for research purposes, Estonia once again reports a more favorable attitude. As depicted in *Figure 2.2*, Estonia holds the highest level of trust (35%) for sharing electronic health data with universities, government bodies and national health authorities for research purposes. On the contrary, German and French respondents appear very skeptical on sharing their personal health data, as 26% and 28% of respondents would not grant access to any researcher, respectively. Distinctly from France and Germany, Spanish and Croatian respondents displayed a comparable trust towards university, government, national public health agency scientists/researchers (Spain 23%, Croatia 26%), albeit Croatia relies more on the nature of university researchers (16%) whereas Spanish respondents would generally give access to any organization (21%), including commercial ones.

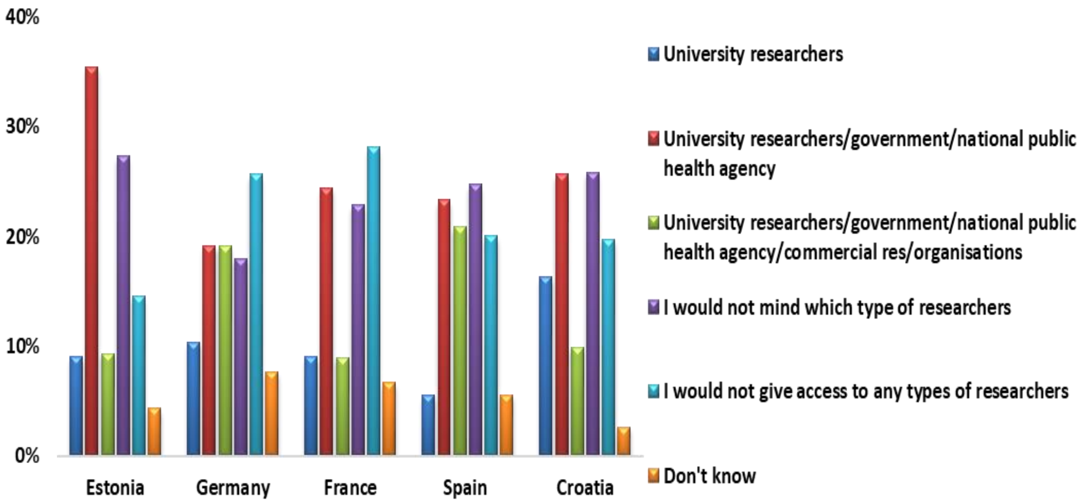


Figure 2.2 What types of scientists/researchers would you be happy with being able to access your electronic patient records for research purposes?

Concerning the terms on how to give access, *Figure 2.3* clearly points a preference among respondents to give require consent before authorizing access to their electronic health records for research purposes - the lowest value is Estonia here with 40%. Furthermore, in line with the above-mentioned findings, Estonian respondents generally reveal a higher level of confidence for research than German respondents: 25% of Estonian respondents would be in favor of automatic access while, on the other, 26% of German respondents highlight a preference for allowing access just for specific research projects.

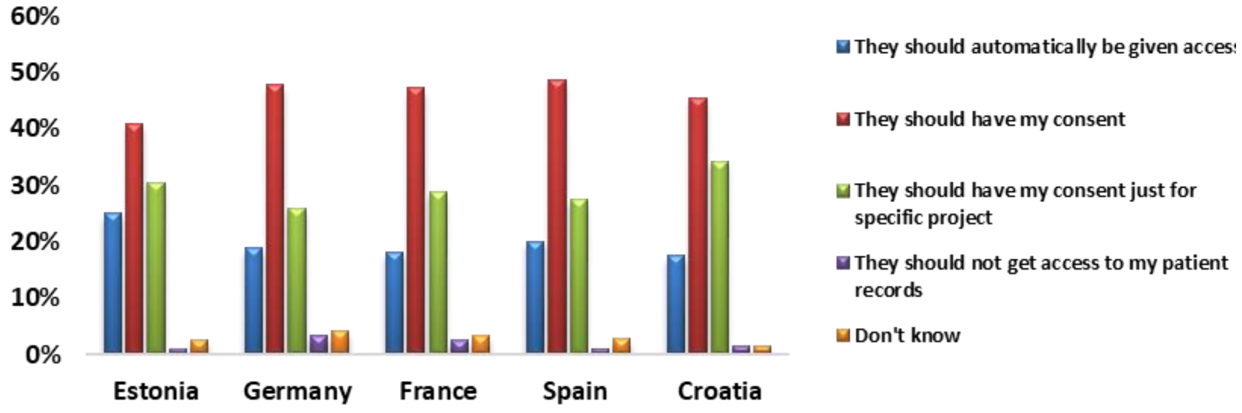


Figure 2.3 How these scientists/researchers would gain access to your electronic patient records for research purposes?

Figure 2.4 reports an overall preference amongst users to give access to scientists and researchers to their anonymous electronic patient records for general public health benefits. These values range from 75% in Estonia to 58% in the case of France. Not only that, the figure reveals that in the cases of Spain (24%), Germany (23%), and France (21%), respondents would give access to scientists and researchers for direct health benefits only.

Furthermore, each of the five country depicts a poor tendency to allow their electronic patient records access for unrelated health benefit reasons such as commercial purposes (France 11%, Croatia 10%, Estonia 9%, Germany 8%, Spain 7%).

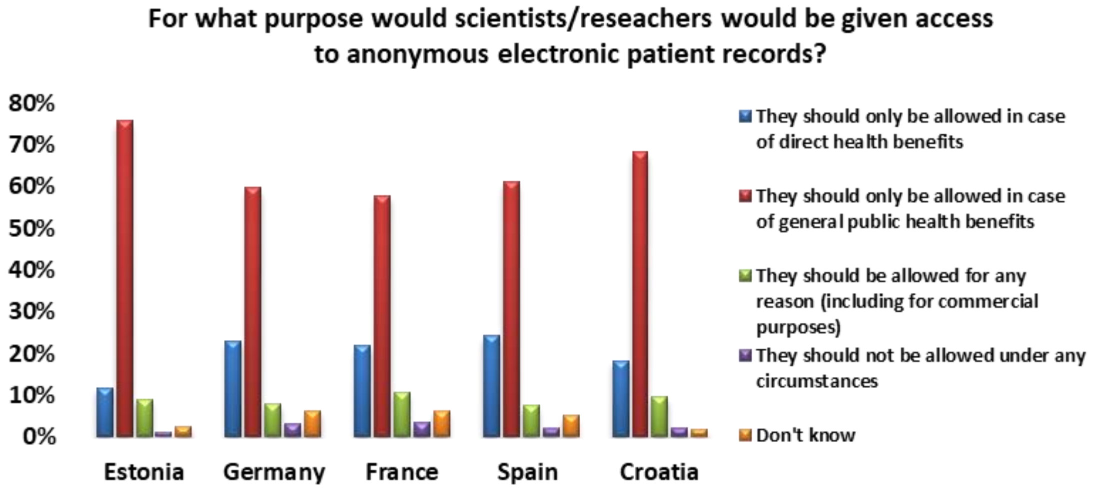
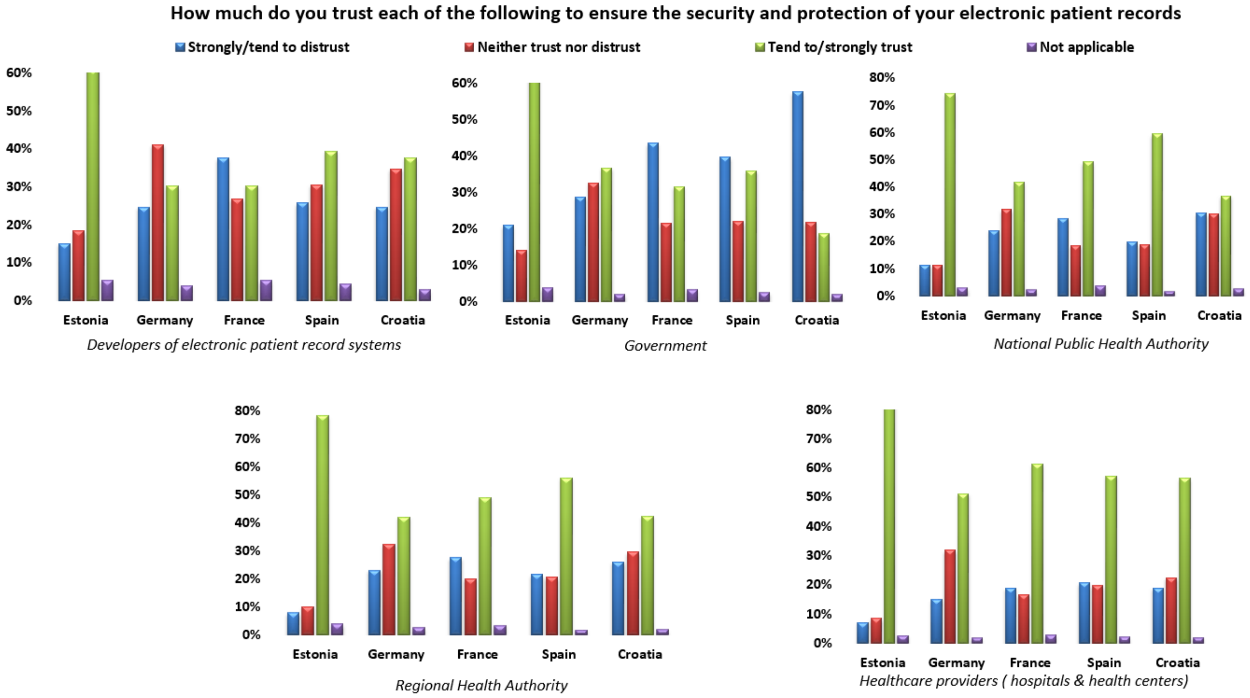


Figure 2.4 For what purpose would scientists/researchers would be given access to anonymous electronic patient records?



Developers of electronic patient record systems

Government

National Public Health Authority

Regional Health Authority

Healthcare providers (hospitals & health centers)

Figure 2.5 How much do you trust each of the following to ensure the security and protection of your electronic records?

Figure 2.5 reports different levels of trust across countries for five different actors about ensuring the security and protection of electronic patient records: developers of electronic patient record system, governments, national public authorities, regional health authorities, and healthcare providers. Compared to the other countries, Estonia holds the highest rate of trust as well as the lowest rate of distrust for all the selected actors. On the contrary, Germany registers a general distrust towards developers' capacity to secure and protect patients records (25%) while reporting the highest level of confidence towards healthcare providers (51%). On average, German respondents also tend to trust more authorities that are public the most than other countries (37% for Government and 42% for both National and Regional Public Health Authority). Overall, Croatia reports the highest level of mistrust towards the government in ensuring the protection and security of electronic patient records (58%), followed by 44% in France and 40% for Spain. More modest instead is the mistrust of the state in Germany (29%) and Estonia (21%). Likewise, the most trusted actors are regional health authorities and healthcare providers.

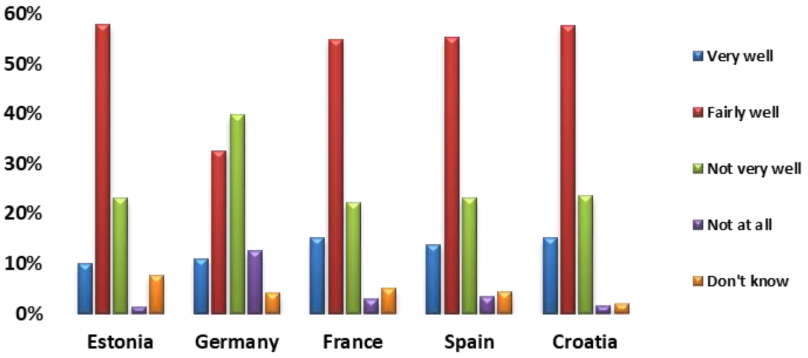


Figure 2.6 How well do you feel understand the benefits and risks associated with the sharing of electronic patient records?

In terms of perceived security and protection at country level, *Figure 2.6* reports that respondents across countries tend to indicate that they understand “fairly well” the benefits and risks associated with sharing of electronic patient records, with the exception of Germany (33%).

3.2.1 Key takeaways

- **Respondents across the five selected countries prefer to give accessibility to their electronic patient records only via their explicit permission *(Figure 2.1);***
- The notion of who should have access to electronic health data for research purposes is different in each of the four countries. Estonia trusts universities, government bodies and national health authorities the most. Germany and France would prefer not opening up their records to any type of researcher; Spain and Croatia are instead divided between those who would give access to researchers and those who would not *(Figure 2.2);*
- Across the five selected countries, respondents prefer being consulted before giving access to their electronic patient records *(Figure 2.3);*

- Across the five selected countries, there is an overall preference amongst users to give access to scientists and researchers to their anonymous electronic patient records for general public health benefits *(Figure 2.4);*
- Across the five selected countries, respondents indicate stronger levels of trust and security towards healthcare providers to secure and protect their clinical records *(Figure 2.5);*
- Across the five selected countries, respondents indicate to understand the benefits and risks of sharing electronic health data “fairly well”, with the exception of Germany *(Figure 2.6).*

3.3 Gender-level differences

This section elaborates on respondents' preferences for sharing data stemming from their electronic patient records across the gender variable.[1]

In terms of attitudes towards granting accessibility to electronic health records *Figure 3.1* depicts a similar trend across both-gender groups in granting access to their electronic patient records only after giving explicit permission.

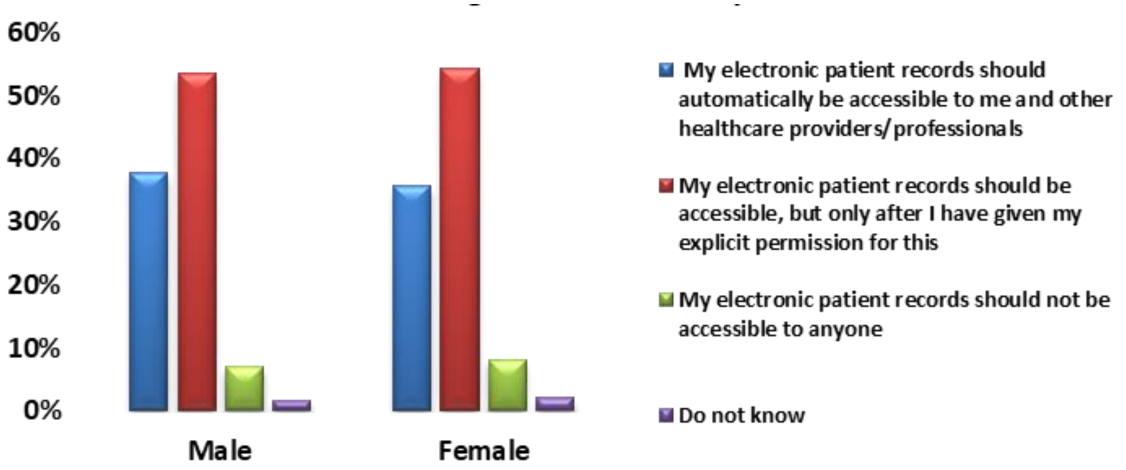


Figure 3.1 Which of the following comes closest to your own view?

Likewise, *Figure 3.2* reports similar preferences across gender-groups for what concerns granting access to scientists and researchers to their electronic patient records. However, there is no significant difference across the preferred reported options. First, around 26% of respondents across both groups indicate their preference for granting access to university researchers, governments, and national public agencies. Second, respondents indicate general acceptance for automatic access to patient records, irrespective of the kind of involved actor (23% for male respondents and 24% for female respondents). Third, 20% of male respondents and 23% of female respondents prefer not giving access to any types of researchers.

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[11] Respondents only indicated "male" and "female" gender identification.

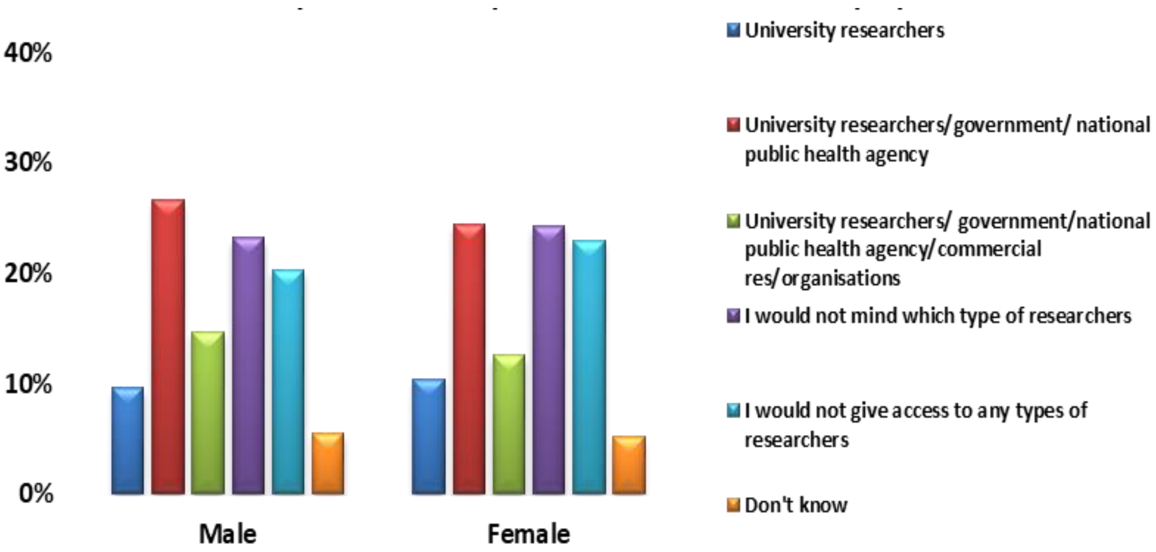


Figure 3.2 What types of scientists/researchers would you be happy with being able to access your electronic patient records for research purposes?

Concerning the alternatives of gaining access provided by *Figure 3.3*, both gender-groups prefer to give consent before giving access to scientists and researchers (both 46%). On the contrary, for what concerns expressing consent for specific projects, female respondents tend to be more in favour of this option (32%) while male respondents report higher rates of acceptance for granting automatic accessibility (22%).

Similarly, for what concerns the purposes behind giving access to anonymous electronic patient records, *Figure 3.4* emphasizes an overwhelming preference for general public health benefits.

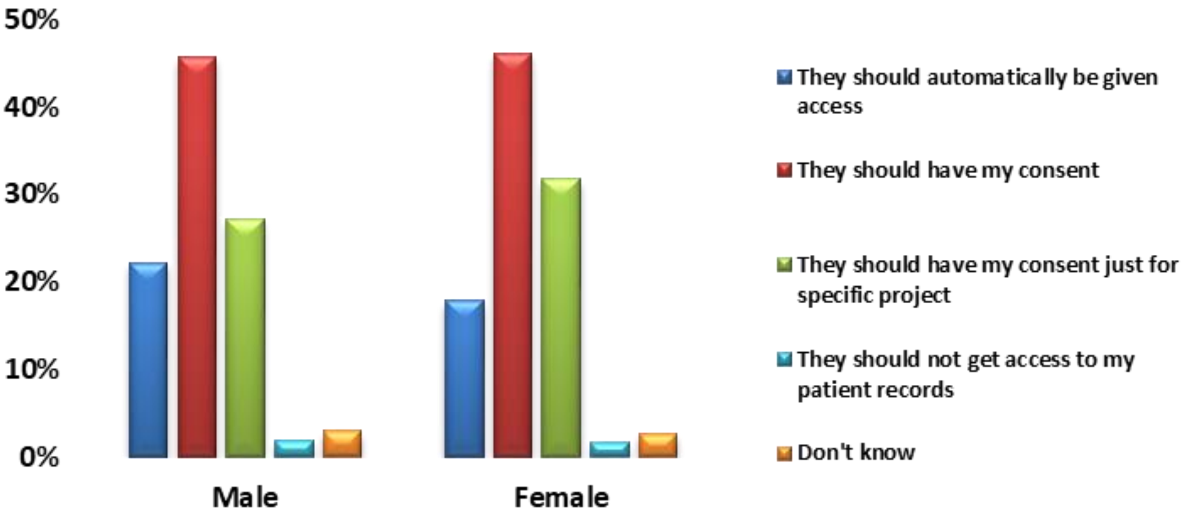
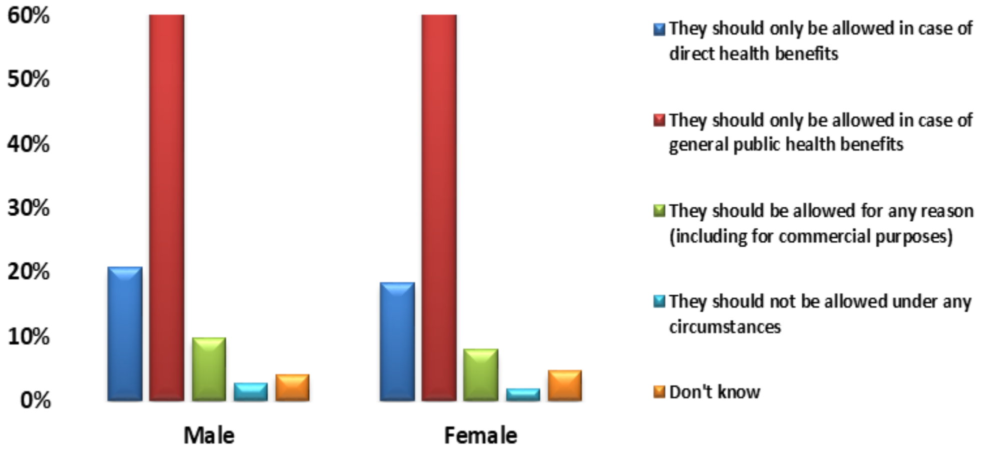


Figure 3.3 How these scientists/researchers would gain access to your electronic patient records for research purposes?



<u>Figure 3.4</u> For what purpose would scientists/researchers would be given access to anonymous electronic patient records?

On the question of trust and mistrust towards private and public actors in ensuring the security and protection of electronic records, there is significant difference across gender-groups. As *<u>Figure 3.5</u>* reports, both gender-groups tend to trust national public health authorities, regional health authorities and health care providers the most. On the contrary, and in line with previous findings, they tend to trust their national governments and developers of electronic patient record systems the least.

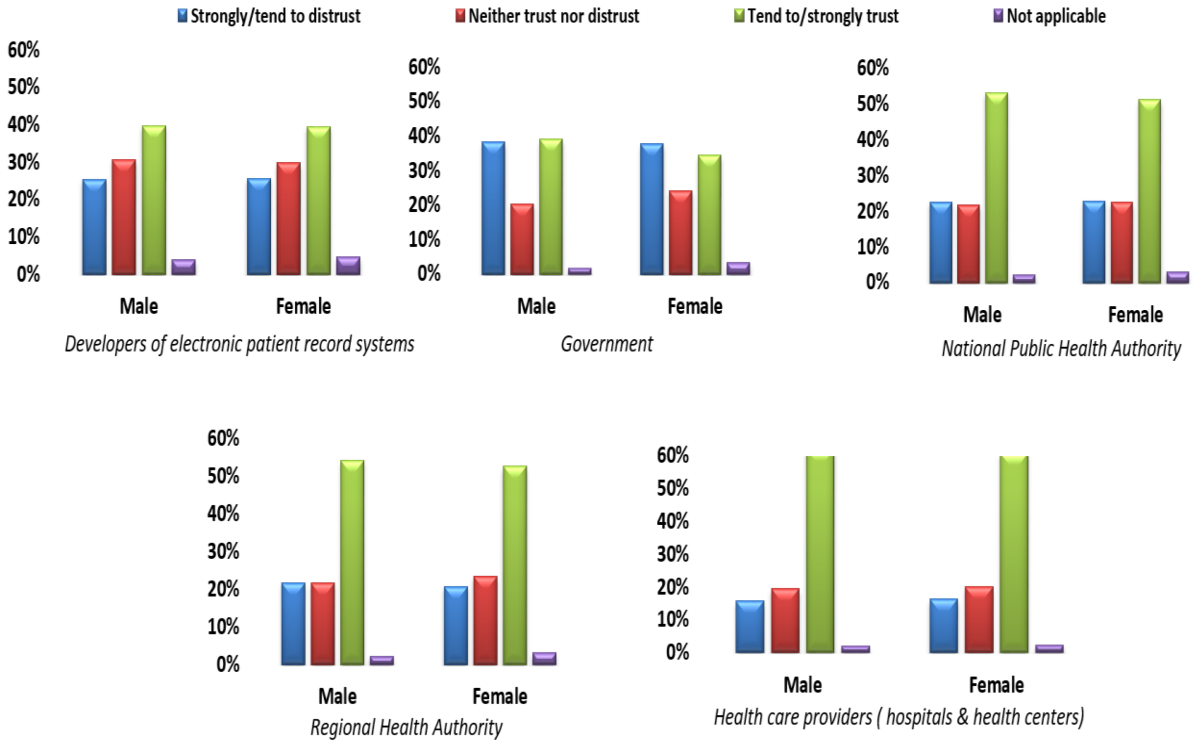


Figure 3.5 How much do you trust each of the following to ensure the security and protection of your electronic records?

Finally, as *Figure 3.6* depicts, both genders report to understand “fairly well” the risks and benefits associated with the sharing of electronic patient records (54% for male and 49% for female), although female respondents claim to not understanding potential circumstances stemming from sharing data while the male age group reports to be more aware.

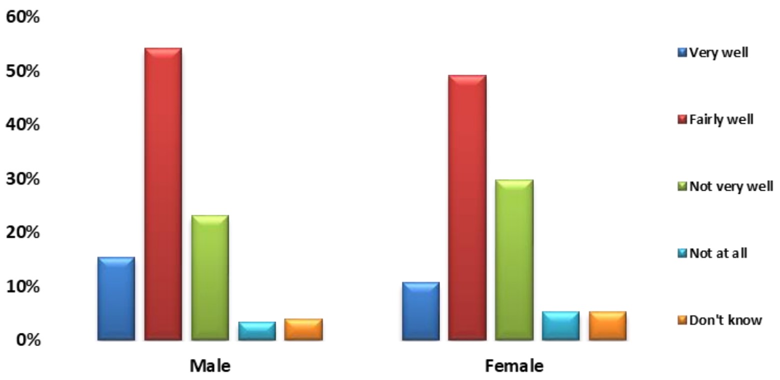


Figure 3.6 How well do you feel understand the benefits and risks associate with the sharing of electronic patient records?

3.3.1 Key takeaways

- Both gender-groups express their preferences to grant accessibility of their electronic patient records only after giving an explicit permission *(Figure 3.1);*
- Both gender-groups show a very balanced outcome in percentage terms for most of the options *(Figure 3.2);*
- Both gender-groups prefer to be consulted before giving their access to electronic patient records *(Figure 3.3);*
- Both gender-groups consider that personal data should be mainly shared for health-related purposes, both general and specific *(Figure 3.4);*
- Both gender-groups indicate a clear trust towards health-related actors while they mistrust governments there is no marked position of trust or mistrust towards governments and developers of electronic patient records the least *(Figure 3.5);*
- Both genders assume to have an overall well understanding of the benefits and risks of sharing their data without associating risks *(Figure 3.6).*

3.4 Age-level differences

This section analyses the use and the attitudes of electronic health data according to the variable of age, divided into four categories: 18-24 years old; 25-39 years old; 40-54 years old; and 55-65 years old.

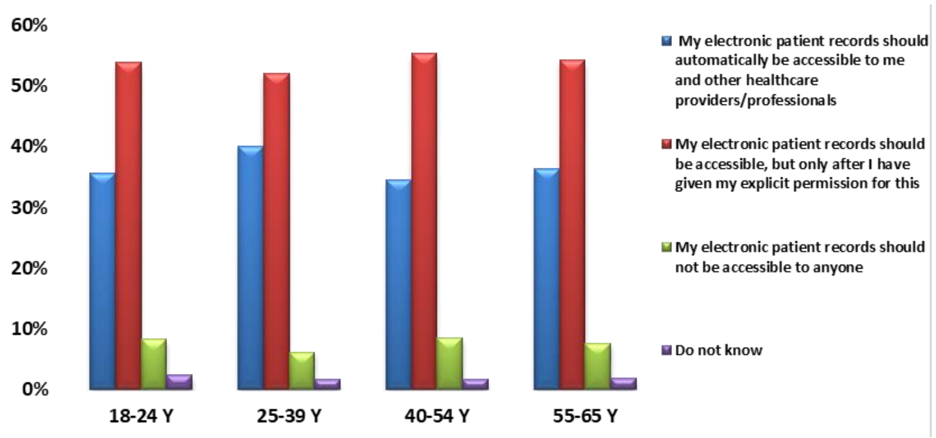


Figure 4.1 Which of the following comes closest to your own view?

As shown in *Figure 4.1,* all four categories reveal a strong preference for granting access to their electronic health records only after giving explicit permission. However, respondents aged 25-39 slightly indicate a higher preference than the other age groups for the automatic accessibility option, reaching 40% of the desired.

On the level of trust towards scientists/researchers, *Figure 4.2* illustrates a dissimilar preference compared to the previous question. The figure reports that the youngest age categories report the highest rate of preference for researchers and scientists. Most notably, 18-24 and 25-39 age categories wish to grant access to university researchers/government/national public health agency, by 18% and 28% respectively. On the contrary, 40-54 age category indicates a significantly higher preference for not sharing data at all compared to other groups (25%). Furthermore, the oldest age group also stresses a strong disregard for knowing who has access to their data - 28% indicate not to mind the kind of research at stake.

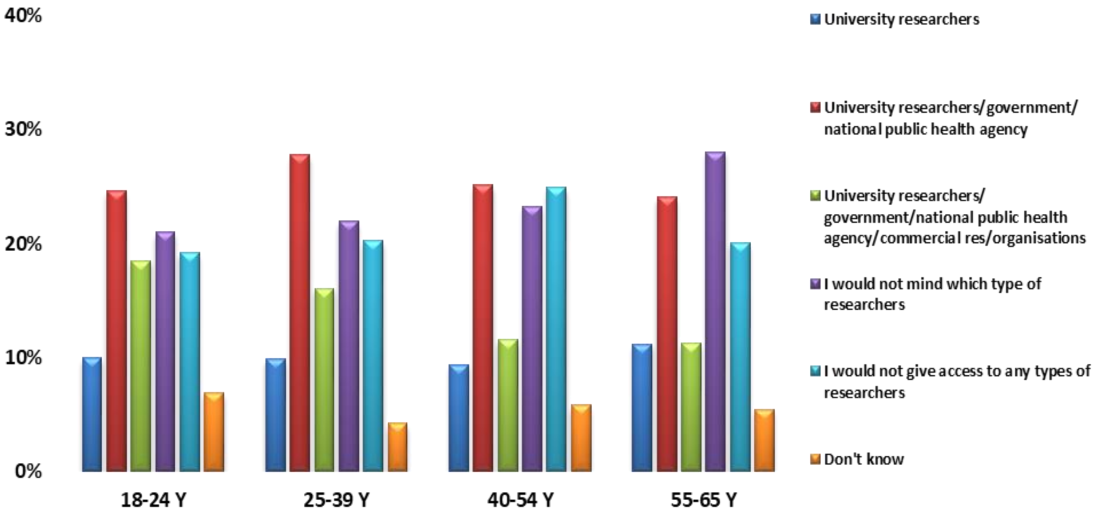


Figure 4.2 What types of scientists/researchers would you be happy with being able to access your electronic patient records for research purposes?

Furthermore, *Figure 4.3* outlines a clear preference across all age categories to grant access to their data only after giving their explicit consent, which goes above 40% each age category. In particular, among all, the youngest category is the least favorable to consent automatic access (16%) and consequently the most willing to allow access only for specific projects (33%).

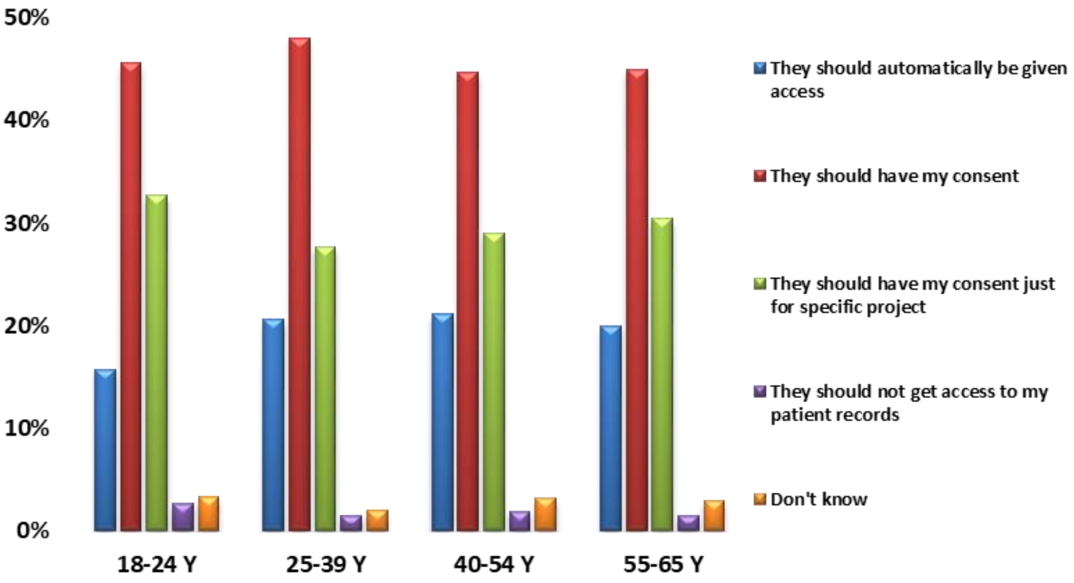
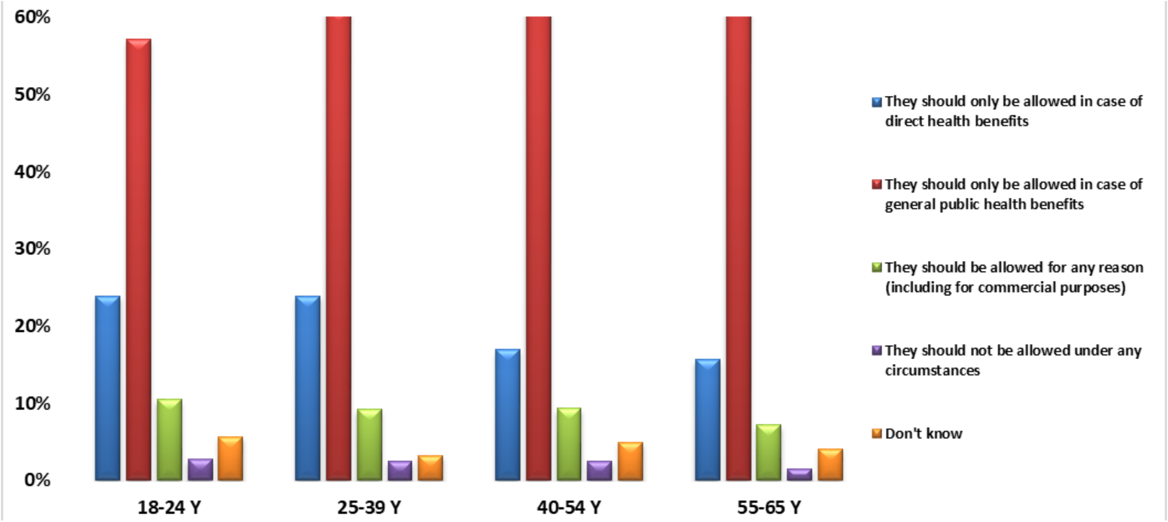
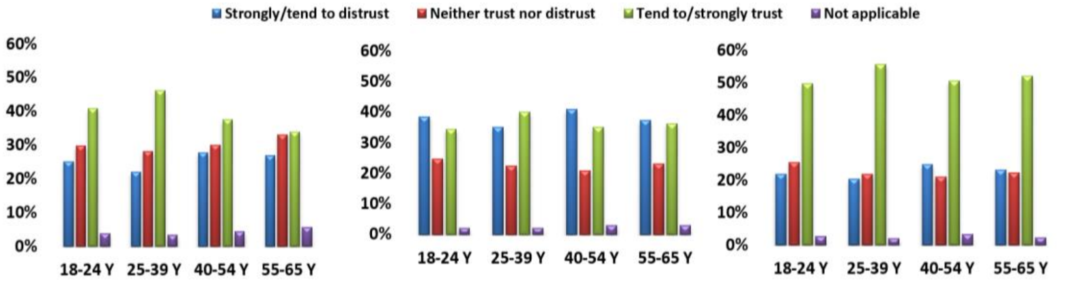


Figure 4.3 How these scientists/researchers would gain access to your electronic patient records for research purposes?



<u>Figure 4.4</u> For what purpose would scientists/researchers be given electronic patient records?

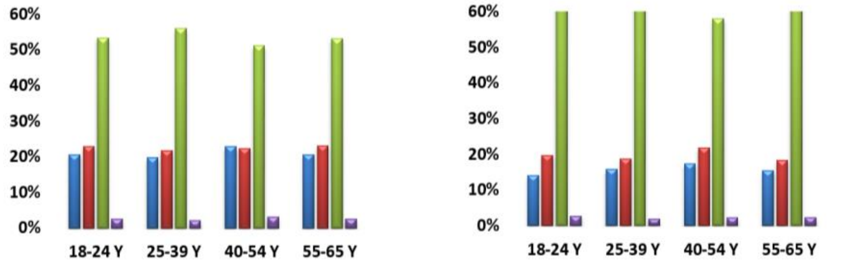
As to the reasons behind granting access to their data, *<u>Figure 4.4</u>* illustrates that the entirety of respondents independently from the age-level, would allow access for general public health benefits. Specifically, the oldest age group reports the highest rating with 72% of preferences. Although the already mentioned preference for general public health benefits, younger categories (18-24 and 25-30 age groups) account for a fair level of 24% preferences when it comes to sharing data for direct health benefits.



Developers of electronic patient record systems

Government

National Public Health Agency



Regional Health Authority

Heath care providers (hospitals & health centers)

<u>Figure 4.5</u> How much trust each of the following to ensure the security and protection of your electronic records?

Figure 4.5 portrays the level of trust across the four age categories for developers of electronic patient record systems, governments, national public health agencies, regional health authorities, and health care providers. At first glance, all the categories, independently of their ages, strongly exhibit preferences for the three healthcare authorities, with levels of trust varying from 58% to 64% of votes. In contrast to the category of 25–39-year-olds, which reveals a comparatively level of trust in government (40%) to the other age categories. Particularly, the 40-54 age group reports a very high level of distrust, almost reaching 41%.

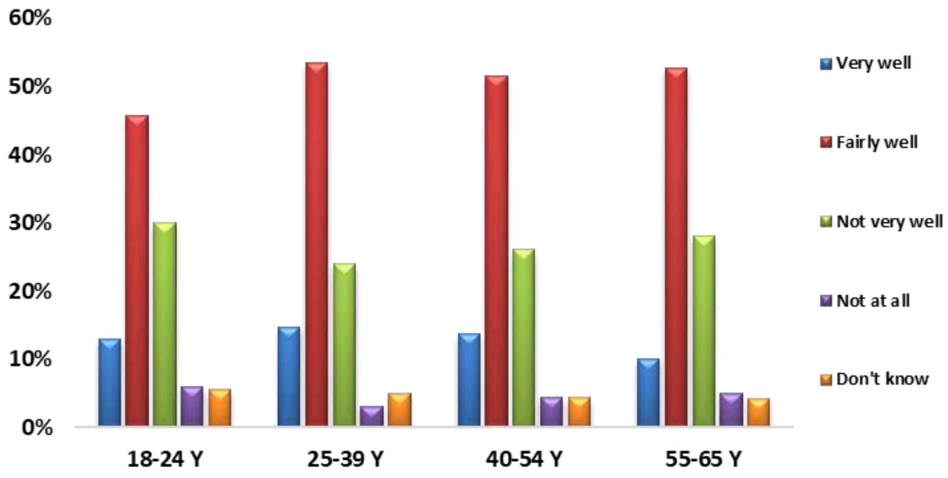


Figure 4.6 How well do you feel understand the benefits and risks associated with the sharing of electronic patient records?

Again, all the four age categories claim to understand "fairly well" the benefits and risks associated with the sharing of electronic patient records (*Figure 4.6*). The youngest age category reports the most uncertainty on this aspect.

3.4.1 Key takeaways

- All the four age categories display a strong preference for granting access to their electronic health records only after giving explicit consent. *(Figure 4.1);*
- The youngest age group (18-24 and 25-39) prefer granting access to researchers and scientists while older age categories (40-54 and 55-56) showed such reluctance on granting access for research purposes *(Figure 4.2);*
- All the four categories display a clear preference for only allowing access to their data on an explicit consent basis *(Figure 4.3);*
- All the four categories would rather allow access for general public health benefits *(Figure 4.4);*
- All the four categories trust healthcare actors the most in protecting their electronic health data while they trust governments the least, with the exception of the category of 29- to 35-year-olds *(Figure 4.5);*

- All the four age categories claim to understand fairly well the benefits and risks associated with the sharing of electronic patient records *(Figure 4.6)*.

3.5 Education-level differences

This section reports the result on citizens' attitudes to primary and secondary uses of electronic heath data. It also assesses their levels of digital literacy and trust on public authorities based on the education-level variable, which is further decomposed into three sub-categories: high, middle, and low.

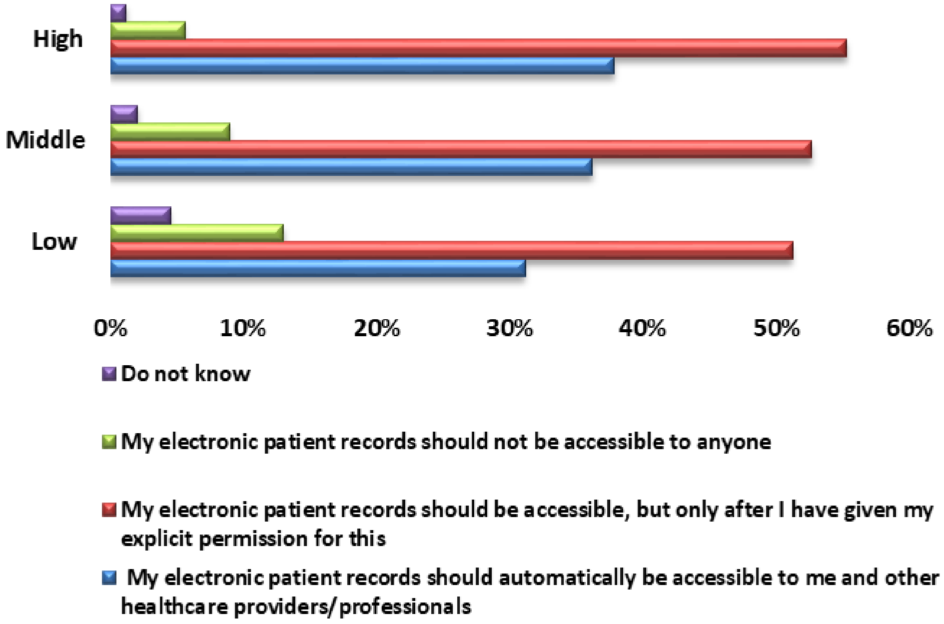


Figure 5.1 Which of the following comes closest to your own idea?

As in the case of the previous categorical variable, the results of *Figure 5.1* confirm the general preference for granting access to electronic patient records based on explicit consent. Nevertheless, there is a strong preference for highly educated respondents to favor automatic access (38%) while there is resistance from low-educated groups, with 13% of respondents that would not grant access under any circumstances.

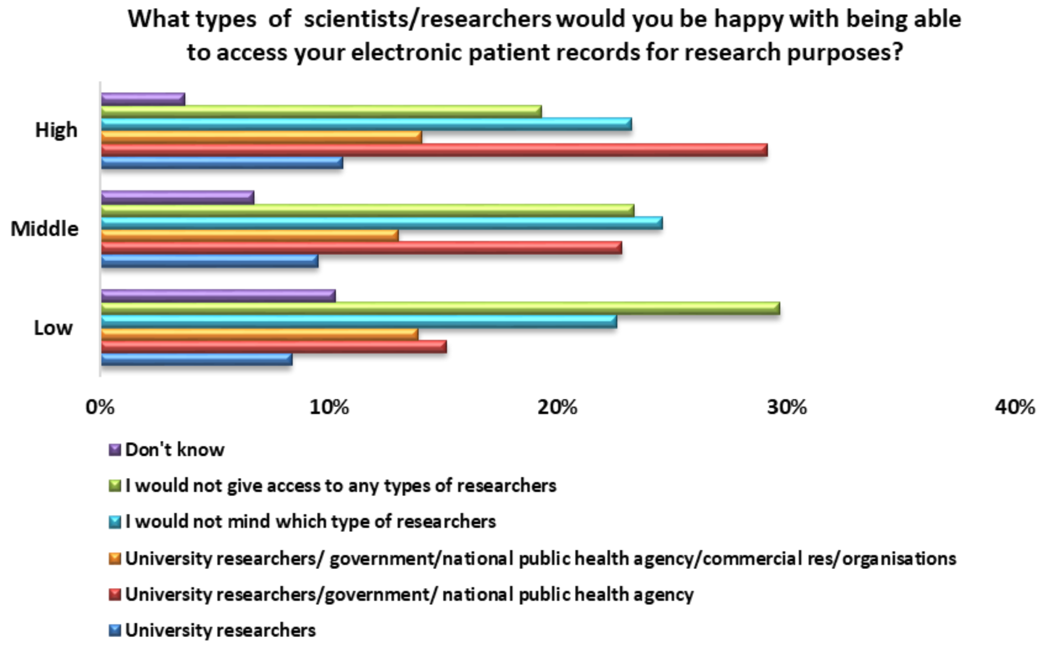


Figure 5.2 What type of scientists/researchers would you be happy with being able to access your electronic patient records for research purposes?

Educational attainment also illustrates differing preferences on granting access to researchers and scientists for research purposes (*Figure 5.2*). Speaking of which, the voting preferences of low educated respondents reflect misgiving on scientific research, where 30% of respondents are not in favor of giving access to any type of research, whereas only 15% are in favor. Similarly, for the middle-level education category, there are more respondents contrary to granting access (23%). Higher educated people are reversely more propended to grant access with 29%. Therefore, the higher the level of education, the more likely respondents agree to having their health data accessed for scientific research.

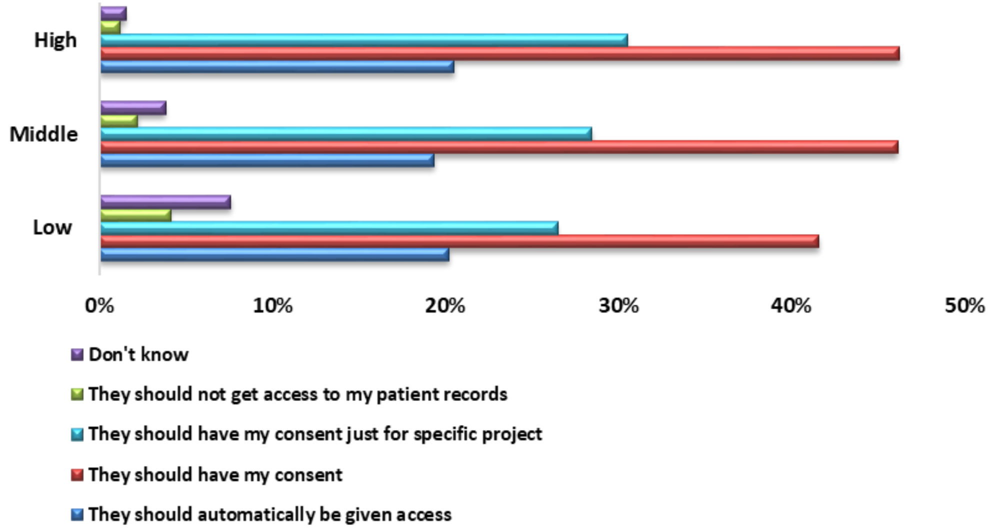


Figure 5.3 How these scientists/researchers you would gain access to your electronic patient records for research purposes?

Likewise, when it comes to the terms of accessing data, *Figure 5.3* clearly points a preference to first obtain patient consent across different groups, with the percentage remaining stable between 42 and 46%. However, a distinct minority (4%) of the low educated group would not grant access to researchers and scientists in any circumstances.

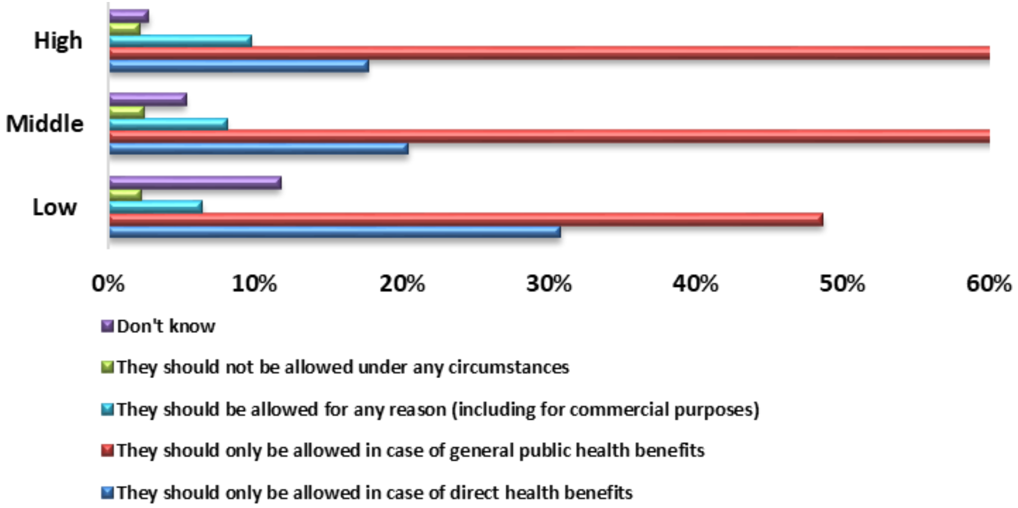
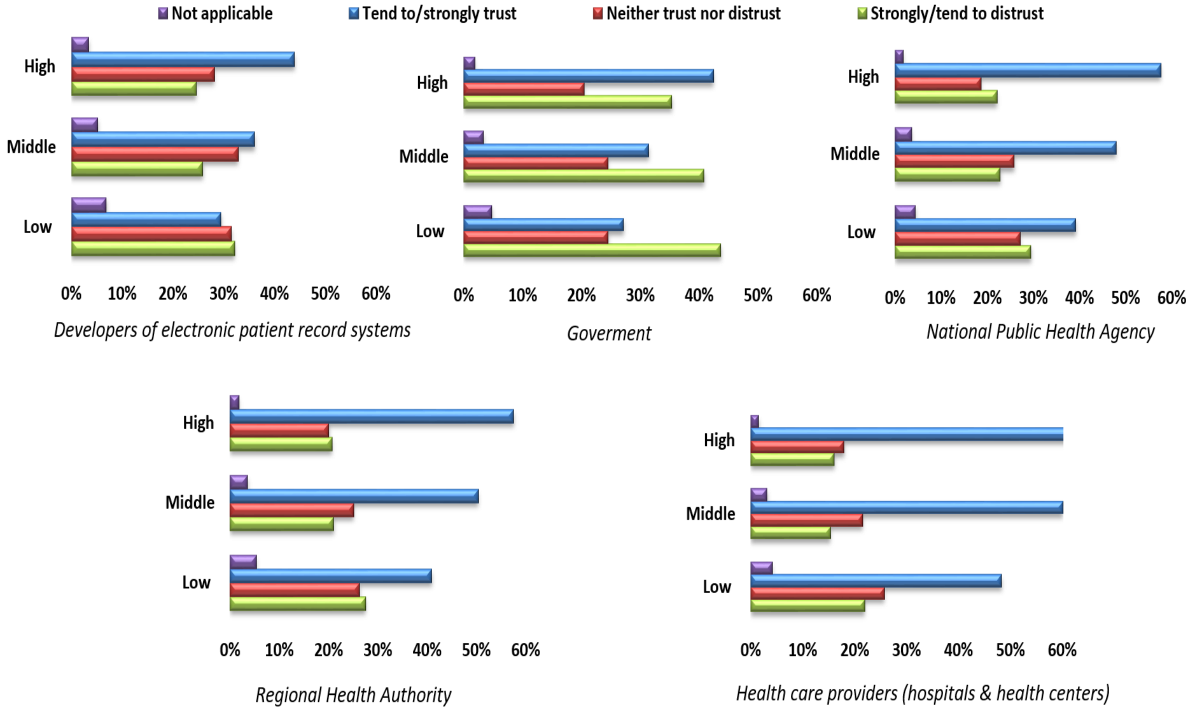


Figure 5.4 For what purpose would scientists/researchers be given electronic patient records?

Figure 5.4 discloses a global trend in favor of allowing records' access in case of general public health benefits, spanning from a major favorability of 68% for the highly educated group to 48% for the low educated group. In addition, 31% of less educated respondents would only allow scientists and researchers only in the case of direct health benefit.



Developers of electronic patient record systems

Goverment

National Public Health Agency

Regional Health Authority

Health care providers (hospitals & health centers)

Figure 5.5 How much do you trust each of the following to ensure the security and protection of your electronic records?

Figure 5.5 shows the level of trust in the usual five different actors to protect patient records. As in the case of previous variables, there is general reliability for health care actors - i.e., national public agencies, regional health authorities, and health care providers. Notably, highly educated respondents register 65% of trust towards health care providers and 58% for national and regional health care authorities. Considering the trend of trust in the developers of electronic patient record systems, high and middle educated people tend to trust rather than distrust them, whereas low educated people tend to distrust (32%). As with the previous variables, the role of government in ensuring the security and protection of electronic records is not well perceived: 43% of respondents belonging to the low educated category assesses the government as a non-reliable actor to protect their data, as well as middle educated respondents with 41% of votes.

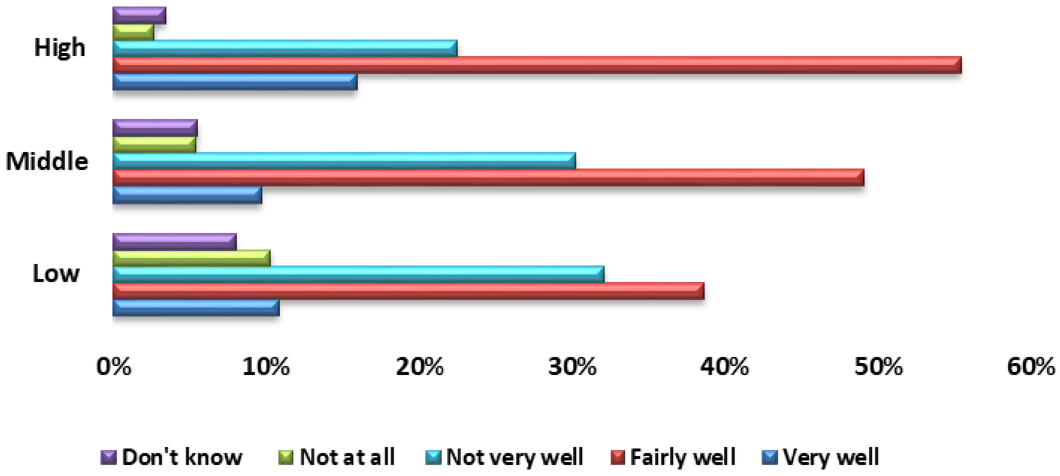


Figure 5.6 How well do you feel understand the benefits and risks associated with the sharing of electronic payment records?

Finally, with regard to the benefits and risks associated with sharing electronic health records, *Figure 5.6* shows a clear difference across educational groups. However, in each of the three categories, a majority of respondents report to "fairly well" understanding associated benefits and risks, ranging from 55% for highly educated respondents, 49% for the middle-educated group, and 39% for low educated group. Instead, under the heading "not very well", the values are reversed so that the least educated report to understand "not very well" the associated risks than most educated segments of the population.

3.5.1 Key takeaways

- Independently from the education level, there is a generic preference for granting access to electronic patient records by expressing just right after an explicit consent. However, highly educated groups have a slight tendency in favor of granting automatic access while low educated groups are more resistant. *(Figure 5.1);*
- There is different level of preference for granting access to researchers and scientists based on respondents' levels of education *(Figure 5.2);*
- Independently from the education level, there is an overall preference to first consult patients for their authorization to grant their electronic records for research purposes *(Figure 5.3);*
- There is a global trend of preference for allowing access to patient records in case of general public health benefits *(Figure 5.4);*
- All the three categories report an overall higher level of trust towards healthcare related actors, with the slight difference that highly educated segments report a positive net trust for developers and governments (*Figure 5.5);*
- The findings outline a clear difference where highly educated segments of the population tend to understand more the risks and benefits associated with

sharing electronic health records and *vice versa* with low educated groups *(Figure 5.6).*

3.6 Conclusion

This report has provided an overview about the users' attitudes on sharing electronic health data as part of the proposed EHDS Regulation. It has done so by looking at four variables that could account for country, gender, age, and education-level differences. The results can nevertheless be held constant across these four dimensions as users demand for greater centricity in deciding when, how, and with whom sharing their data.

To summarize, it emerges that:

- Respondents overwhelmingly prefer to make their electronic patient records accessible to third parties based on explicit consent. This finding is particularly relevant for low educated segments of society;
- Respondents prefer to grant access to their electronic health records to scientists and researchers. Spanish and French respondents would even prefer not opening up their records to any type of researcher. The same finding is holds for the youngest segments of society while old-age groups are reluctant on granting access for research purposes. Highly educated groups are more in favour of automatic access than low-educated respondents;
- A strong majority of respondents wish to express consent before giving access to scientists and researchers;
- Most respondents prefer to share their personal data only for general or specific health-related purposes and not for commercial ones;
- Respondents feel more protected when health public health authorities protect their data, contrary to government private actors, with the exception of the 29-35 age group;
- Respondents claim to well understand the risks and benefits associated with sharing data via their electronic health records, with the exception of Germany and of low educated groups.

These findings need to be taken into account by the co-legislators working on the EHDS Regulation.