

ID

QUESTIONNAIRE

Health data governance

This study aims to assess the opinions of patients, informal carers, health professionals and technical staff regarding lay citizens' participation in the governance of health data, in the field of rare diseases. Health data governance comprises the policies, procedures and practices related to the collection, protection, share and use of health data.

There are no right or wrong answers. We are interested in knowing your honest opinion.
Thank you in advance for your collaboration and for taking the time to answer this questionnaire.

Date: |_|_|/|_|_|/|_|_|_|_|
(day) (month) (year)

1. Do you have a rare disease?

- No 0

- Yes 1 Which? _____

2. Are you an informal carer of a person with a rare disease?

- No 0

- Yes 1 What is the disease of the person you care for? _____

3. Currently, you are responding to this questionnaire as: (please choose only one option)

- Patient 1

- Informal carer 2

- Health professional 3 Professional category: _____

- Other 4 Which? _____

4. The General Data Protection Regulation (GDPR) from the European Union came into force on May 25, 2018.

How do you feel about the information you have about this Regulation?

- Not informed at all 0 (please go to question 6)

- Little informed 1

- Neutral 2

- Informed 3

- Highly informed 4

5. Please state the **two main sources** where you got information on the General Data Protection Regulation:

- | | | | |
|------------------------|----------------------------|---------------------------------|----------------------------|
| - Television | <input type="checkbox"/> 1 | - Patient association | <input type="checkbox"/> 6 |
| - Newspapers | <input type="checkbox"/> 2 | - Family, friends or colleagues | <input type="checkbox"/> 7 |
| - Radio | <input type="checkbox"/> 3 | - Other | |
| - Internet | <input type="checkbox"/> 4 | Which? _____ | <input type="checkbox"/> 8 |
| - Health professionals | <input type="checkbox"/> 5 | | |

Willingness to share data, with whom and for what purposes

6. There are several types of health data that can be used for scientific research purposes. **How willing would you be to share the following types of data for research purposes:**

- | | Very unwilling | | | Very willing | | |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|--|
| - Personal data (e.g. educational level, age) | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Individual medical history | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Familial medical history | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Biological samples (e.g. blood, urine) | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Genetic data (e.g. DNA) | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |

6.1. It is important for us to understand the reason(s) for your answers above. **Please give a brief explanation.**

7. **To what extent is it important for you to be able to decide on the sharing of your health data for research purposes?**

- | | |
|----------------------|----------------------------|
| - Not important | <input type="checkbox"/> 0 |
| - Slightly important | <input type="checkbox"/> 1 |
| - Neutral | <input type="checkbox"/> 2 |
| - Important | <input type="checkbox"/> 3 |
| - Very important | <input type="checkbox"/> 4 |

8. Scientific research can be carried out by several institutions. **How willing would you be to share your health data with the following institutions?**

- | | Very unwilling | | | Very willing | | |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|--|
| - Health institutions where I receive care | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Portuguese universities | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Universities outside Portugal | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Portuguese companies (e.g. pharmaceutical or insurance companies) | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Companies outside Portugal (e.g. pharmaceutical companies) | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - Portuguese patient associations | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| - International patient associations | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |

9. To what extent is it important for you to be able to decide with whom your health data is shared?

- Not important 0
- Slightly important 1
- Neutral 2
- Important 3
- Very important 4

10. How willing would you be to share your health data for the following purposes?

- | | Very unwilling | | | Very willing | |
|-----------------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| - Non-profit research | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - For-profit research | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - National databases | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - International databases | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Use of insurance companies | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Use of pharmaceutical companies | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

11. To what extent is it important for you to be able to decide on the purposes of sharing your health data?

- Not important 0
- Slightly important 1
- Neutral 2
- Important 3
- Very important 4

12. Suppose that you have authorized the use of your health data in research projects. **If your data will be used for that purpose, would you like to be notified about it?**

- Yes, always 1
- Yes, once a month 2
- Yes, once a year 3
- No 4

13. There are some aspects people may consider important to decide if they will share their health data for scientific research. **If you had to make such a decision, how important would you rate the following aspects:**

- | | Not important | | | Very important | |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| - Knowing the research objectives | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Ensuring the privacy of my data | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Ensuring the security of my data | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Trusting in the organisation hosting the research | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Trusting in the team that will conduct the research | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Being able to withdraw consent at any time | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| - Having access to the results at the end of the study | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

14. Health data collected for medical treatment or for research purposes can be reused for other purposes (for example, quality assessment and services or policy planning). **To what extent is it important for you to be able to decide on the reuse of your health data for purposes other than the ones for which they were initially collected?**

- Not important ₀
- Slightly important ₁
- Neutral ₂
- Important ₃
- Very important ₄

Positions on informed consent

15. The sharing of health data for research purposes can only occur with prior consent of the holder. **Please specify which type of consent do you prefer regarding the sharing of genetic and non-genetic information:**

15.1. A **broad consent** (given once for any kind of research project) or a **specific consent** (given for each specific research project).

- | | Broad consent | Specific consent |
|---|--|---------------------------------------|
| - Genetic data (e.g. DNA) | <input type="checkbox"/> ₁ (please go to question 16) | <input type="checkbox"/> ₂ |
| - Non-genetic data (e.g. personal data) | <input type="checkbox"/> ₁ (please go to question 16) | <input type="checkbox"/> ₂ |

15.2. A specific consent for **all dimensions** of the research project or a specific consent for **each dimension** of the research project (for example, data use and protection).

- | | All dimensions | Each dimension |
|---|---------------------------------------|---------------------------------------|
| - Genetic data (e.g. DNA) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| - Non-genetic data (e.g. personal data) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

16. **Select the two most important risks that, in your opinion, may be associated with the sharing of genetic information for research purposes.**

- Lack of security and control regarding access to information ₁
- Restrictions to citizens' rights of privacy and autonomy ₂
- Possibility of extracting information that exceeds the research objectives ₃
- Performing genetic studies which can discriminate citizens ₄
- Other. Which? _____ ₅

17. **Select the two most important benefits that, in your opinion, may be associated with the sharing of genetic information for research purposes.**

- Discover a cure for untreatable diseases ₁
- Development of strategies to control diseases dissemination ₂
- Development of new drugs and treatments ₃
- Development of personalized treatments, considering the characteristics of each patient ₄
- Other. Which? _____ ₅

18. If you had to decide about sharing your health data for research purposes, you would like to: (please choose only one option)

- Decide by myself ₁ (please go to question 19)
- Decide with the help of another person(s) ₂
- Delegate the decision to another person(s) ₃

18.1. Which person(s)?

- Family and friends ₁
- A professional specifically trained to provide health data counselling ₂
- A non-specifically trained professional to provide health data counselling ₃
- Other. Which? _____ ₄

Opinions about participation

There are several ways by which citizens can participate in the governance of health data. For example, they can attend meetings where procedures to collect, protect, share and use of health data are defined, in collaboration with professionals in charge for the management of information and other citizens.

19. If you had all the necessary conditions to participate in the governance of health data within a public hospital, would you be willing to participate in:

- | | Yes | Maybe | No |
|--|---------------------------------------|---------------------------------------|---------------------------------------|
| - Periodic meetings (e.g. every 3 or 4 months), giving opinions | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| - Periodic meetings (e.g. every 3 or 4 months), taking part in decision-making | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| - Sporadic meetings, giving opinions | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| - Sporadic meetings, taking part in decision-making | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |

20. In your opinion, what advantages may result from citizens' participation in the governance of health data in a public hospital?

21. In your opinion, what disadvantages may result from citizens' participation in the governance of health data in a public hospital?

22. Assuming that you have given permission for using your health data in a research project, **how important would it be for you to participate in...**

	Not important					Very important				
- Defining research objectives	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Recruiting participants	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Collecting data	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Discussing the results	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Writing the project's report	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- The dissemination of results	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

23. The collection of health data can be performed by citizens themselves, for example, through an application on their mobile phone, tablet or computer. **Would you be willing to participate in the collection of your own health data?**

- No 1 (please go to question 24)
- Maybe 2
- Yes 3

23.1. How willing would you be to share your self-collected health data for the following purposes?

	Very unwilling					Very willing				
- Contributing for the diagnosis and treatment of your disease, considering your personal characteristics and needs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Conducting non-profit research related with:										
1) your own disease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2) other diseases	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Conducting for-profit research related with:										
1) your own disease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2) other diseases	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

24. How much do you personally trust each of the institutions presented below?

	No trust at all										Complete trust	Refusal	Don't know
- Parliament	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>
- Legal system	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>
- Police	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>
- Politicians	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>
- Political parties	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>
- European Parliament	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>
- United Nations	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10	<input type="checkbox"/>	<input type="checkbox"/>

25. **Generally speaking, would you say that you can't be too careful in dealing with people, or that most people can be trusted?**

You can't be too careful 0 1 2 3 4 5 6 7 8 9 Most people can be trusted 10 Refusal Don't know

26. **Do you think that most people would try to take advantage of you if they got the chance, or would they try to be fair?**

Most people try to take advantage of me 0 1 2 3 4 5 6 7 8 9 Most people try to be fair 10 Refusal Don't know

27. **Would you say that most of the time people are mostly looking out for themselves or that they try to be helpful?**

People mostly look out for themselves 0 1 2 3 4 5 6 7 8 9 People mostly try to be helpful 10 Refusal Don't know

Sociodemographic characteristics

28. **Sex:**

- Female 0
- Male 1

29. **Year of birth:** |__|__|__|__|

30. **Country of origin:**

- Portugal 1
- Other country 2

Which? _____

31. **Where do you currently live? Municipality:** _____

32. **What is your marital status?**

- Single 1 - Widow/widower 4
- Married 2 - Divorced 5
- Living with a partner 3 - Separated (married, but does not live with partner) 6

33. **What is the highest educational level you have completed?**

- None, but can read and write 1 - Bachelor's degree 6
- 1st cycle of basic education (4th grade) 2 - Licentiate degree 7
- 2nd cycle of basic education (6th grade) 3 - Master's/Integrated Master's 8
- 3rd cycle of basic education (9th grade) 4 - PhD 9
- Secondary education (12th grade) 5

34. At this moment, what is your main occupation? (please choose only one option)

- | | | | | | |
|----------------------|--------------------------|---|--|--------------------------|---|
| - Full-time employee | <input type="checkbox"/> | 1 | - Student/At school/Professional qualification | <input type="checkbox"/> | 5 |
| - Part-time employee | <input type="checkbox"/> | 2 | - Doing housework | <input type="checkbox"/> | 6 |
| - Unemployed | <input type="checkbox"/> | 3 | - Other. Which? _____ | <input type="checkbox"/> | 7 |
| - Retired | <input type="checkbox"/> | 4 | | | |

35. What is your current job? (if in the previous question you answered unemployed, retired, doing housework or other, please consider your last job)

36. Thinking of your household income, would you say that your household is able to make ends meet?

- | | | |
|----------------------------|--------------------------|---|
| - Insufficient | <input type="checkbox"/> | 1 |
| - Caution with expenses | <input type="checkbox"/> | 2 |
| - Enough to make ends meet | <input type="checkbox"/> | 3 |
| - Comfortable | <input type="checkbox"/> | 4 |

37. Are you involved in any patient associations?

- | | | |
|--|--------------------------|------------------------------|
| - No | <input type="checkbox"/> | 0 (please go to question 38) |
| - Yes, I am involved in ... | | |
| A local or national association | <input type="checkbox"/> | 1 |
| Several local or national associations | <input type="checkbox"/> | 2 |
| An international association | <input type="checkbox"/> | 3 |
| Several international associations | <input type="checkbox"/> | 4 |

37.1. How long have you been involved in a patient association?

- | | | |
|-------------------------|--------------------------|---|
| - Less than a year | <input type="checkbox"/> | 1 |
| - Between 1 and 5 years | <input type="checkbox"/> | 2 |
| - More than 5 years | <input type="checkbox"/> | 3 |

38. How satisfied are you with your health?

- | | | |
|--------------------------------------|--------------------------|---|
| - Very dissatisfied | <input type="checkbox"/> | 0 |
| - Dissatisfied | <input type="checkbox"/> | 1 |
| - Neither satisfied nor dissatisfied | <input type="checkbox"/> | 2 |
| - Satisfied | <input type="checkbox"/> | 3 |
| - Very satisfied | <input type="checkbox"/> | 4 |

Thank you for your collaboration!