

Open Survey on cultural barriers using FAIR data for health research

April 2019

Objectives:

Purpose of the research study: The purpose of this survey is to gather opinions and attitudes about sharing of health data.

What you will do in the study: You are asked to complete a short survey, 12 questions in order to understand your opinion and / or degree of agreement about health data sharing. There are no mandatory questions. You may skip any question that makes you uncomfortable and/or stop the survey at any time.

Time required: About 7-10 minutes.

Confidentiality: The information that you provide us within this survey will be handled confidentially. Your data will be anonymous, which means that your name will not be collected or linked to the data. Your data will be recorded, stored, and shared anonymously using an individually assigned identification number.

The results of this survey will be used as input that will be included in the report "*Guidelines for implementing FAIR open data policy in health research*" as part of the work developed within the [FAIR4Health project](#) and will be released later this year (2019).

In case you have further questions we encourage you to contact the FAIR4Health coordination team making use of the form embedded in this link: <https://www.fair4health.eu/en/contact>

Questions:

1. Gender:

- ❖ Male
- ❖ Female
- ❖ Other
- ❖ Prefer not to say

2. Age range:

- ❖ 18-24
- ❖ 25-34
- ❖ 35-44
- ❖ 45-54
- ❖ 55-64
- ❖ Over 65

3. Which of the following countries is your primary place of employment? (list of countries- taken from surveys)

4. What is your profile

- ❖ Researcher
- ❖ Clinical researcher
- ❖ Medical Doctor
- ❖ Health professional
- ❖ Patient advocate
- ❖ Other

5. Do you reuse data shared from others?

- ❖ Never
- ❖ Occasionally
- ❖ Often
- ❖ Always

6. To what extent do you agree with the following statements? Please rate from 1 (Strongly Disagree) to 5 (Strongly agree)

Attitudes towards sharing / not sharing data					
	1	2	3	4	5
I have no desire to share my research data					

I don't usually share my data but have no problems to do it if someone or a funding agency asks for it					
I only share my data upon request (from other researchers, agencies)					
I usually share my data via repositories					
I usually share my data with other researchers via e-mail or files sharing services					

7. To what extent do you agree with the following statements? Please rate from 1 (Strongly Disagree) to 5 (Strongly agree)

Barriers for sharing					
	1	2	3	4	5
I do not have time to share my data					
My research data are too small or unimportant					
Too costly. I do not have funds to support sharing data.					
I do not know how to package/manage/share my research data appropriately					
I am not sure about which repository to use					
I am not sure about the correct license to apply					
My research data are too large to share					

8. How concerned are you regarding the following questions about data sharing. Please rate from 1 (not very concerned) to 5 (very concerned)

Concerns for Data Reuse					
	1	2	3	4	5
My research data might be misused by companies (laboratories, insurance companies, etc.)					
My research data might be misused for political proposals (intentional abuse of data)					
My research data might be misinterpreted due to their complexity.					
My research data might be misinterpreted due to their poor quality.					

My research data might be criticized for errors found during secondary use					
Secondary use of my research data might be detrimental to me					
Secondary use of my research data might benefit me					
I would be willing to reuse open data for my own research in the future					
My research data would not get proper credit when shared					
Others with more resources might be able to do more with my research data					
There is no reward of any kind for sharing data					

9. For others to use my data, I would expect the following in exchange. Please rate from 1 (Strongly Disagree) to 5 (Strongly agree)

Overcoming barriers					
	1	2	3	4	5
Co-authorship on publications resulting from my data use.					
Citation in all disseminated work making use of my data.					
The opportunity to collaborate on a project using my data.					
Contribution toward at least part of the cost of data acquisition, retrieval or provision					
Easy access to all products that make use of my data					
Signing an agreement that states clear conditions of use of my data					

10. To what extent do you agree with the following statements? Please rate from 1 (Strongly Disagree) to 5 (Strongly agree)

Management data					
	1	2	3	4	5
My institution/organization provides training, support and advice in regard to research data management					

I would like assistance to manage research data					
I need support to share research data					
I feel the work required to package the data for sharing is too onerous					
If I had clear guidelines and/or help I would be willing to share my data					
I am not familiar with the FAIR data principles					

11. Which of the FAIR data principles do you think are more important for Research Data. Please rate them from 1 (very low) to 5 (very high).

FAIR principles					
F indable	1	2	3	4	5
A ccessible	1	2	3	4	5
I nteroperable	1	2	3	4	5
R e-usable	1	2	3	4	5

12. Any other comments will be appreciated and welcome

THANK YOU!