

# TRIEM

by SalusCoop & IdeasForChange

JANUARY 2018

IDEAS  
FOR  
CHANGE



Ajuntament  
de Barcelona

The study outlined in this document was partially funded by Barcelona City Council through the grant Subvencions d'Impuls Socioeconòmic del Territori 2017.

We would like to thank the following for their collaboration:

*Andrea Barbiero, Lluís Muns, Joan Guanyabens, Josep Picas (Salus.coop), Marco Straccia (FRESCI), Ferran Jornet (Derecho.com)* for participating as experts in the workshops;  
Gui Seiz, Lucas Peña and James Oconnell for designing the online tool; and  
Kubik, OuiShare and el Col·legi Oficial d'Infermeres i Infermers de Barcelona for offering us the chance to hold the co-design workshops at their spaces and events.

We would also like to give special thanks to everyone who participated in the co-design workshops and used the online tool. Their results are outlined in this document.



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"In 1854, as cholera swept through London, John Snow, the father of modern epidemiology, painstakingly recorded the locations of affected homes. After long, laborious work, he implicated the Broad Street water pump as the source of the outbreak, even without knowing what bacteria caused cholera. Today, Snow might have crunched Global Positioning System (GPS) information and disease prevalence data, solving the problem within hours."

*(Khoury and Ioannidis, 2014)*

01

# Our data

Opportunities, risks  
and governance



**We are living in the midst of a data explosion** Digital records, the growing use of smart phones and portable devices to record personal health data and the new generation of biosensors reaching the market mean that the amount of data is growing by orders of magnitude.

The health sector, for example, generates one of the highest volumes of data related to the public's health and lifestyles. The sector has data from different sources, such as Electronic Health Record (EHR), Personal Health Record (PHR), Hospital Information Systems (HIS), Laboratory Information Systems (LIS) and Radiological Information Systems and Picture Archiving and Communication Systems (RIS-PACS).

The future of medical research lies in being able to combine and integrate all data sources, from medical records to social media data. The benefits of using data in research and medical service provision are tangible and significant: they represent an opportunity "that changes the game" (Briody, 2011) and, undoubtedly accelerate research (Groves et al., 2013).

However, data can include information about some of the most private aspects of our lives and can expose us to various risks, for example, the risk to being discriminated against or even being manipulated.

Information systems are increasingly able to process larger amounts of data, which become more and more useful and valuable information. On one hand, more and more companies see huge value in obtaining our data, and that is why they offer low-cost or free services. In exchange, they ask users to accept their legal agreements (generally known as Terms of Service and Privacy Policy) which are often very long-winded and difficult to understand.

On the other hand, sometimes the data that the public wants to use or share are stuck in data silos because they are in the hands of the companies or academic institutions that are in competition with each other, slowing down research.

These factors contribute to an environment that lacks transparency and leads to companies making unethical use of data or deters the public from sharing data that could contribute to a significant collective benefit, for example discovering new treatments or medicines.

How can the general public make informed decisions about the conditions under which they share their data?

When we decide to share our data, we need to take balance of many risks, including privacy and security and the potential improper use of the data, related to the huge potential value of accelerating innovation in medicine and even improving public service planning and provision.

Only members of the general public can make these decisions, in line with their beliefs, fears and incentives. And the more knowledge they have about the nature of the data and the technological operations that extract their value, the more capable they will be to make decisions that minimise the risks and increase the collective benefit.

From May 2018, according to the General Data Protection Regulation (GDPR), European citizens will have the right to data portability, which includes making their health data available for research. In view of this great opportunity, we need to understand and discuss the great ethical dilemmas, risks and opportunities associated with data sharing.

### Legally, we own our data

- 1 As members of the general public, we own data of a personal nature, in any case.
- 2 As the data owners, we have the right to access our data and obtain a copy of them, in a regular format (e.g. PDF).
- 3 We have the right to data portability. If we change companies, we can ask for our data to be transferred to the new company, through a mechanism that is similar to the one that is used when we change telephone operators and keep the same number.
- 4 We have to give explicit consent to donate data to third parties. This consent must outline the conditions under which the data are to be transferred and the purpose of such.
- 5 If third parties use our data, they must only treat those data that are relevant for analysis purposes and, where possible, dissociate our personal data.



**Ferran Jornet**

*Lawyer at Derecho.com*

The TRIEM project aims to prepare the general public with the right tools so that they can take a leading role in controlling their health data by judging critical variables needed to design new licences for data access and use. This involves individually and collectively considering their preferences and deciding what data to share, who with, under which conditions and for what purpose.

The project was developed through a collaborative process and consists of two stages:



The **FIRST STAGE**'s objective was to examine the elements that most stimulate or worry the general public when sharing health data through debates and co-design workshops.

*(See chapter 2).*



The **SECOND STAGE** sought large-scale validation of the knowledge obtained in the previous stage. To this end, we developed an online tool to collate the Stage 1 results and anonymously collect the preferences of a large number of people. The tool content, which includes a survey, was created in line with the results from the workshops.

*(See chapter 3).*

Although the results from these two stages do not intend to be scientifically valid, they are an important step towards a new way of addressing complex subjects that cause controversy. TRIEM provides a new perspective on the mechanisms through which decisions are made. If data are a key asset in producing wealth in the 21st century, the general public must have the right to decide how they are used, under which conditions and for what purposes, especially, if they are going to be used for an individual or collective benefit.



### The importance of data in understanding illnesses

Without data there would be no medical advances. However, at present, many data that are potentially useful for understanding diseases are difficult for researchers to access.

With the growing use of information and communication technologies, the data that is generated about us has increased exponentially. Our social interactions measured by technologies produce data. We produce data when we go from one place to another with our mobile phone in our pocket and the GPS turned on, when we share a photo of our lunch on social media or a poem on WhatsApp, or buy our food shopping online. These data say a lot about us, about our habits and our environment. This information is key to understanding aspects about our health. We are used to thinking that only the clinical data produced when we have a doctor's appointment is useful for research. However, there are many factors that contribute to an illness developing, among which is lifestyle and environmental exposure. In many cases, the information about these factors can come from analysing our interactions on the Internet and on social media. Many of these data are saved in the databases of technological companies that offer us services (apps, websites and social networks) and are not shared with researchers. Defining the rules associated with sharing our data is an important step in producing new medical knowledge.



**Marco Straccia**

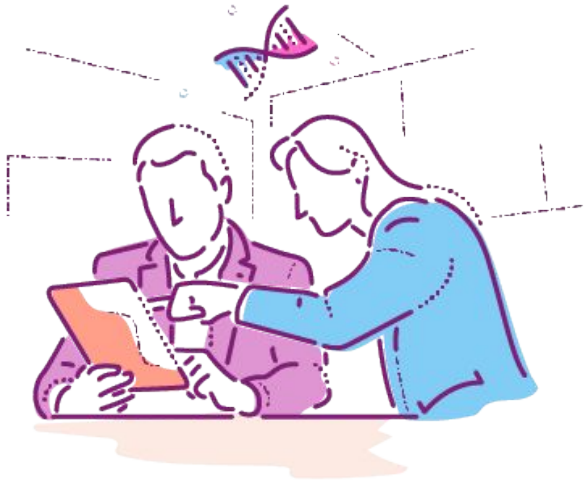
*Biomedical researcher and FRESCI founder*



02

# Under what conditions are we willing to share our data?

Co-design workshops



### Under what conditions are we willing to share our health data?

This question was discussed as a group through three workshops with people from the general public. In each workshop, we aimed to reflect on the consequences related with the fact that citizens can exercise their ownership rights over their health data and can share them to accelerate medical innovation.

Three workshops were organised, during which a total of 60 people with different profiles participated, including people from the general public, law experts, researchers, healthcare professionals and facilitators. Each workshop consisted of three stages:

1. **INFORMATION AND AWARENESS**
  - Welcome survey
  - Presentations
2. **CO-DESIGNING**
  - Brainstorming influencing elements
  - Discussing and organising elements
3. **DISCUSSION AND CONCLUSION**
  - Feedback
  - Concluding survey

Some of the activities varied slightly between the workshops, as we had to adapt to the circumstances of the events where the workshops were held. Furthermore, the co-design activities were adapted from workshop to workshop to include the contributions made by the participants and the lessons learnt at each event.

#### Workshop 1



20 participants: members of the general public  
3 experts in law, health and research  
5 facilitators



09 November 2017  
@Kubik, coworking space in Gracia (Barcelona)

#### Workshop 2



17 participants: general public  
5 facilitators



15 November 2017  
@OuiShareFest 2017

#### Workshop 3



6 participants: health experts and  
healthcare professionals.  
4 facilitators



22 November 2017  
@COIB, 1st Spinner d'emprenedoria, innovació i  
tecnologia

## 1 | INFORMATION AND AWARENESS

### Expert presentations

The workshops started with a presentation that addressed three areas: i) the value of data for medical research, ii) the legal framework that establishes data ownership, and iii) description of archives and access to health data.

In workshop 1, we had help from three experts in the following fields:

Marco Straccia, biomedical researcher and FRESCI founder. He made us reflect on the importance of knowing people's everyday habits and their environment in order to understand how diseases are born and evolve. He showed us different types of data that could contribute to this cause. (See page 9)

Ferran Jornet, lawyer at Derecho.com, presented five key points on the data protection law and the new European directive. (See page 7)

Andrea Barbiero, co-founder of the citizen data cooperative Salus.coop, presented us with several types of archives that contain (some of) our clinical data, such as La Meva Salut or the Sanitas platform, etc.

In workshops 2 and 3, Javier Creus and Joan Guanyabens presented the most relevant aspects of each of the three areas.



## 1 | INFORMATION AND AWARENESS

### Welcome survey

The first part of the workshop aimed to inform the participants but we also wanted to find out how much they knew about these areas. To this end, we asked the participants to answer a brief survey before starting the workshop:

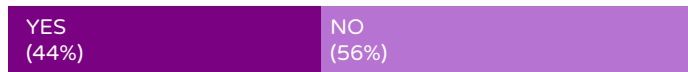
1. Have you ever participated in a medical research study?



2. Have you ever donated blood or are you registered as an organ donor?



3. Do you know how to access your health data?



4. Would you share your health data for a medical research study?



5. Citizens legally own their health data. True or false?



### The most important findings from the results are:

- 77% of participants know that citizens legally own their data, however, only 44% know how to access them. This figure drops to 29% if we only consider workshop 2 results, which had no health experts present. Only 16% of workshop 1 participants confirm that they currently have access to their personal La Meva Salut folder.
- A high percentage of participants would be willing to share their data with researchers: 60% said they would do so without reservations, compared to 5% that would not. The remaining 35% consider the possibility of sharing their data, depending on other factors.
- Although most of the participants report that they have contributed to the medical sector before (70% have donated blood or are registered organ donors), only 40% have contributed to a research study. This figure drops to 11% if we only consider the workshop 2 results where there were no participants from the health sector, and therefore less likely to have contact with researchers. This lack of participation can be explained by the fact that, unlike blood and organ donation, which have well-established participation structures, there is no clear structure or process that lets the general public be in contact with researchers and participate in their studies by donating their data.
- These results must be carefully interpreted, as the sample of participants is not representative of the population. The fact alone that participants volunteered themselves for this type of event, displays their interest and prior knowledge of the subject matters discussed.

# Welcome

1. Have you ever participated in a medical research study?

Yes ☒ No ☐

2. Have you ever donated blood or are you registered as an organ donor?

Yes ☒ No ☐

3. Do you know how to access your health data?

Yes ☒ No ☒

5. Would you share your health data for a medical research study?

Yes ☐ No ☒ Depends ☐

6. Citizens legally own their health data.

True ☐ False ☒



## 2 | CO-DESIGNING

### Jigsaw Technique

The objective of the workshop's co-design activity was to identify the aspects that influence us when deciding to share our data.

This activity was carried out using the Jigsaw technique.<sup>1</sup> It is a method that makes participants dependent on each other, as each participant has a piece of information needed to complete a task, making them an "expert" in their area. The activity consisted of two parts:

**Part 1** - each table examined and brainstormed a subject.

**Part 2** - elements are presented, discussed and classified.

<sup>1</sup> Jigsaw (teaching technique). Wikipedia  
[https://en.wikipedia.org/wiki/Jigsaw\\_\(teaching\\_technique\)](https://en.wikipedia.org/wiki/Jigsaw_(teaching_technique))



## 2 | CO-DESIGNING

### Jigsaw part 1: Brainstorming influencing elements

For this exercise, the participants were put in groups of 6 people. Each group reflected on a condition category. Then the members of each group discussed the elements they considered the most important when weighing out their preferences on data sharing.

They examined the following 6 categories\*:

- **Data types:** What data can we share to help medical research?
- **Agents** - Who asks for or wants to use data?
- **Research subjects:** What different research projects can be developed with our data?
- **Results or access:** What results can be produced from the research conducted with our data? Who can have access to the results?
- **Risks:** What type of risks are there when we share our health data?
- **Individual incentives:** What could we receive in exchange for sharing our health data?

\*Some of the 6 categories changed over the 3 workshops, with the aim of clarifying some of the aspects that were initially not very clear for participants.





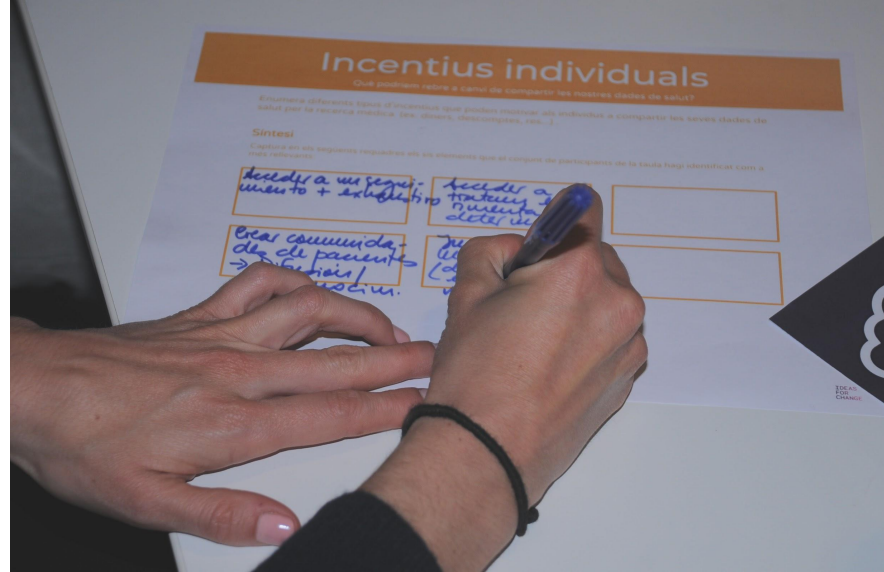
## 2 | CO-DESIGNING

### Jigsaw part 2: Organising the elements

In the second stage of the Jigsaw technique, the participants that are considered "experts" in one of the categories, change groups. The new groups are therefore made up of 6 participants, each one an "expert" in a different category. As such, each table has a data type expert, a risk expert, an incentives expert, etc.

Each expert presented what they had learnt in previous group and the elements selected. Then, each member at the table organised the elements in accordance with how much they influence them deciding to share their health data.

In workshop 1, we tried a variant of this activity. In addition to presenting and discussing the elements, each table combined the elements to create two data sharing scenarios: a desirable scenario where they would feel comfortable sharing their data and an undesirable scenario where they would not want to share their data.



## 2 | CO-DESIGNING

### Co-design activity results

We are now going to present some of the elements identified by the participants. These elements appeared in all 3 workshops. The participants were able to easily identify the elements for the different conditions, except the condition category "results and access" as most participants did not know how to clearly identify the alternatives. This shows a lack of knowledge regarding the different research stages, what is produced with the research and the ownership of the results. This aspect can be considered problematic as it does not allow the general public to set conditions to be part of a medical study.

#### DATA TYPES

- DNA
- Data on stigmatised illnesses (e.g. infectious)
- Eating habits
- Harmful habits
- Sex habits
- Sleep routines
- Mental (psychological, traumas)
- Medication
- Socio-demographic
- App and social media user data

#### AGENTS

- University researchers
- Public administration
- Private medical centre
- Technological companies (app, wearable)
- Pharmaceutical industry
- Food industry
- Foundations
- Insurance companies
- Entrepreneurs and individuals

#### RESEARCH SUBJECTS

- Broadening approach to medicine
- Education on the sovereignty of health data and promoting awareness of their value
- Change in the Doctor-Patient relationship and promoting Patient-Patient relationship
- New questions and perspectives (in research, consumption, etc.)
- More inclusive medicine: Reducing inequality to health access
- Empowering citizens: Innovating social participation.

## 2 | CO-DESIGNING

### Co-design activity results

#### RESULTS OR ACCESS

- Publications
- Data models / patterns
- Interests to reject results
- Laws and action protocols / Clinical guidelines
- Advice and training: changing habits
- Clinical tests
- Patents

#### RISKS

- Not being able to revoke authorisation for data use
- Using data for profit
- Losing control of data
- Potential misuse in a social, reputational, image and political area.
- Problems associated with employment contracts
- Legal and political control
- Risk of being unaware of the power of each data
- Third parties reusing data for unauthorised or unknown purposes

#### INDIVIDUAL INCENTIVES

- Health area services
- Have personalised follow-up of an illness
- Discounts
- Healthy products
- Money
- Acknowledgment
- Create patient communities to share information

## 2 | CO-DESIGNING

### Co-design activity results

In workshop 1, the participants had to combine the pre-identified elements to create data sharing scenarios. In the first stage, they were asked to create an "undesirable" scenario, where none of the group members would feel comfortable sharing their data. Then, based on this scenario, they were asked to make it a "desirable" scenario by changing one or more elements. The results show that they found it difficult to make a scenario go from being "undesirable" to "desirable" by only changing one element. In most cases, participants created a new scenario from scratch.

Example of a "DESIRABLE" scenario  
created by Workshop 1 participants

### Creating scenarios

A scenario where we would be willing to donate our data



A PUBLIC HEALTH ENTITY is developing a  
research process/product/service for  
CHRONIC ILLNESSES.

During the research process RELEVANT ASPECTS  
will be generated and shared FOR HEALTH IMPROVEMENTS.

The results will be PUBLIC/ACCESSIBLE.

That's why it wants to access data about your ALL DATA.

There may be risks associated with NOT HAVING  
CONTROL OVER YOUR DATA.

In exchange for sharing your data, you will receive  
PERSONALISED INFORMATION ON YOUR RISKS.

Example of an "UNDESIRABLE" scenario  
created by Workshop 1 participants

### Creating scenarios

A scenario where we would be willing to donate our data



A PRIVATE INSURANCE COMPANY is developing a  
research process/product/service for  
BEHAVIOUR PREDICTION.

During the research process ALGORITHMS be generated  
and shared EGD RESEARCH/PHARMACEUTICAL INDUSTRY.

The results will NOT BE ACCESSIBLE.

That's why it wants to access data about your HABITS.

There may be risks associated with EXCLUSION.

In exchange for sharing your data, you will receive  
ECONOMIC INCENTIVES.

### 3 | DISCUSSION AND CONCLUSION

#### Concluding survey

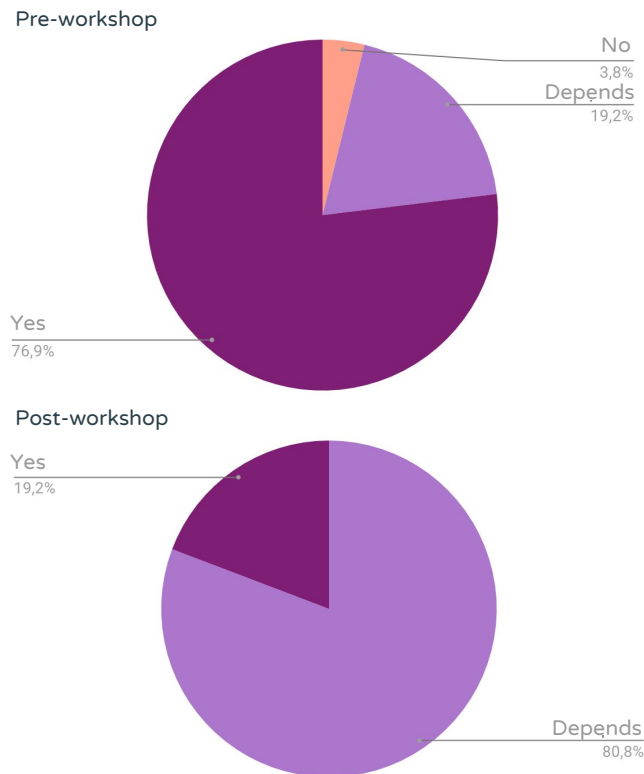
The workshops ended with participants sharing the most interesting discussions that they had had at the tables with the rest of the groups.

A recurring reflection among participants was that the co-design activities allowed them to reflect on aspects that they had never considered before. This can be observed in the end survey, which repeated the questions from the welcome survey: Would you share your health data for a medical research study?

The results\* show a clear change of opinion. Most people who had previously answered that they would share their data without reservations, changed their mind after evaluating the importance of being able to decide some of the aspects related to the sharing process.

In this regard, three aspects were considered the most important when influencing our decisions: i) agents, or those who ask for our data, ii) collective benefits, i.e. what type of research is going to use the data and how can society benefit from it, and iii) what types of data are required.

#### Would you share your health data for a medical research study?



\*Results from Workshops 1 and 3. For logistical problems, we were not able to complete the concluding survey at the end of Workshop 2.

## Conclusions and reflections on co-design workshops

The workshops gave us the chance to find out what aspects could influence the decision to share our data, from the general public's perspective.

The activity results show that there is not just one element that clearly defines our decisions. Each person tends to base their decision on their personal experience and especially their previous knowledge of a subject. In this sense, a lack of knowledge is seen as a possible risk. For example, the participants showed that such a case can exist where they share their data without really understanding the consequences and what they can reveal.

It is important to note that some highly sensitive data, such as DNA, were not perceived as such. There is a general willingness to share data because they could be greatly beneficial in terms of knowledge. In contrast, other, less sensitive data, such as (poor) habits (e.g. smoking, medication, etc.), are not shared as much they perceive the risk that they are used to discriminate.

The results show a positive attitude towards sharing data provided that it generates a collective benefit for society. The risk is perceived that data can be used for commercial purposes where only the few benefit from them. However, how the collective benefit is controlled and guaranteed is a difficult task to resolve.

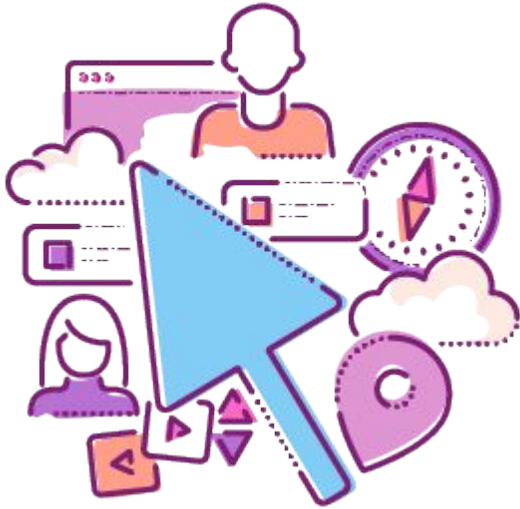
Most participants seem unaware of the way that research results can be used and the licence types that can be assigned to them to limit/accelerate their use. These licences determine how results are shared, who can use them and how they can be used for research, products or services, e.g., for other researchers, companies, the general public, etc.

Data literacy and understanding about research impact and circuits are two important skills that should be promoted among the general public if we want them to be able to make informed decisions about whether to share their data or not.

03

# Large-scale, anonymous survey

First steps towards creating fairer  
data licences





## 1 | Facilitating decision-making

### Towards data literacy and creating clear, accessible licences

The workshop results show how the lack of knowledge on the data-related opportunities and consequences can lead to excessive leniency or restrictiveness, depending on each person's personality or previous experience. We therefore have an important challenge: to empower citizens so that they can control their data and make informed decisions on sharing them.

*How can we empower the general public so that they can take control of their data?*

**Data literacy** When we talk about data literacy, we are mainly referring to being able to read and analyse data to extract useful information. However, the results from the workshops show that there is a necessary stage before this: we need to help the general public understand how data are used by different players in our society, what added value they create and who benefits from using our data. Without this knowledge, the general public run the risk of underestimating the importance of controlling their data, and are susceptible to the decisions made by others.

**Creating data licences** As Creative Commons licences have allowed content writers to decide how their work can be used, data licences would allow the general public to grant legal permission to use the data (that they own) and therefore decide on restrictions of use. This would promote sharing knowledge based on our data, respecting our rights. Following the Creative Commons example, data licences would consist of several layers of information so that lawyers, the general public and machines are able to understand and read them. By using plain language, the licences will speed up the decision process for data owners. They would also help make use circuits more transparent, therefore boosting data literacy.



The three design layers that Creative Commons licences have, are a reference when creating data licences.

Source: [creativecommons.org](https://creativecommons.org)



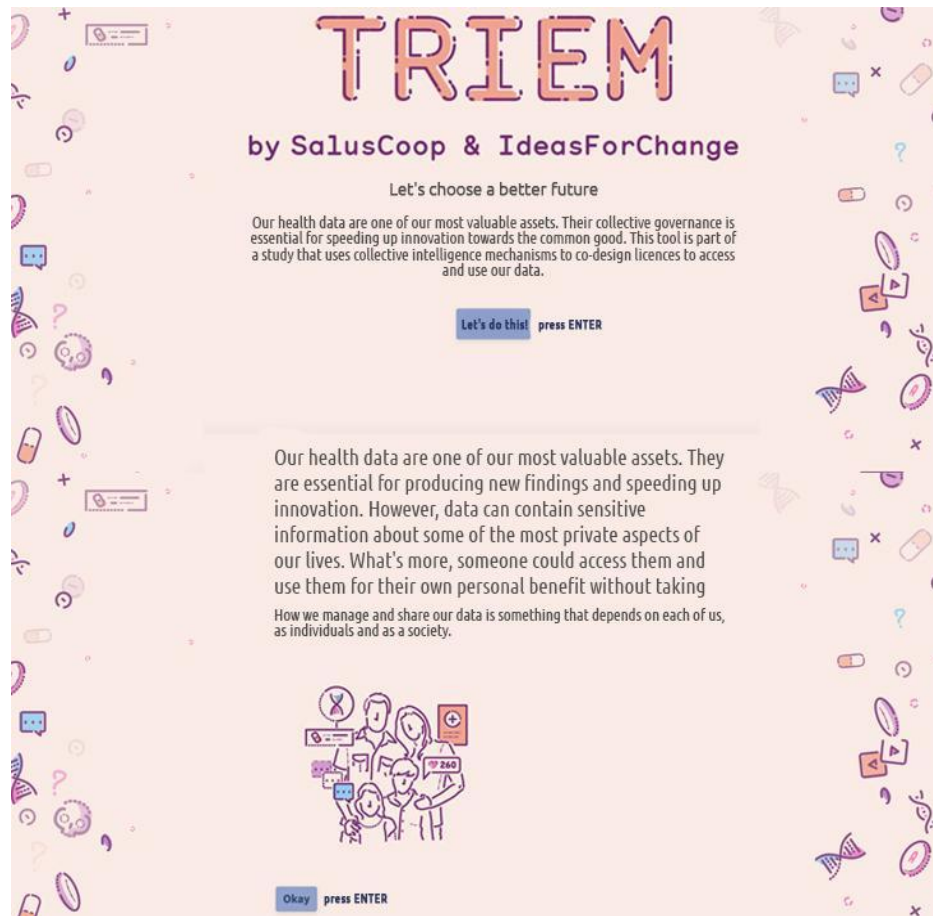
## 2 | TRIEM

### *A beta research tool*

To start to address the previously mentioned objectives, we created the TRIEM tool, which aims to:

- collect the preferences of potential data donors on a broader scale to the workshops,
- be educational and provide complementary information, so that more informed decisions can be made.

TRIEM is a first step towards designing data licences. Using plain language for the general public, the TRIEM tool lets us experiment with new ways of deciding how our data can be used, while collecting information on the critical aspects that need to be considered for future licences. The first version of the tool employs two ways to interact/communicate with the data donor: i) questions based on individual elements, ii) questions based on scenarios, which are a combination of elements.



TRIEM consists of three blocks of questions:

#### BLOCK 1 Elements

The first block consists of a set of questions based on the 6 condition categories that were examined in the workshops (agents, data types, research subjects, access to results, individual incentives, and risks). Each category consists of some of the elements that were mainly mentioned by the workshop participants.

The respondent has to evaluate each element on a scale of 1 to 6, where 1 means the respondent would not share their data and 6 is the maximum level, where the respondent would share their data. So, for example, if the element about who is asking for your data is "University Researcher", the respondent should indicate how willing they would be to share their data with this agent.

The question is presented with an explanatory text that outlines the benefits and consequences associated with the element.

#### 6 → DNA

Your DNA is the cornerstone of your life. DNA tests are very useful for understanding illnesses. They reveal a lot of information about a person, such as their family history, vulnerability to certain diseases and even the risk of diseases that can be inherited.

How willing would you be to share your DNA data?\*



1	2	3	4	5	6
I would definitely not do it			I would definitely do it		

Sample question for the DNA element belonging to the category 'data types'

## BLOCK 1 Elements

### AGENTS, WHO IS ASKING FOR YOUR DATA

- University researcher
- Pharmaceutical company
- Technological company
- Public administration

### DATA TYPES

- DNA
- Social media
- Blood tests

### RESEARCH SUBJECTS

- Chronic diseases
- Acute diseases
- Aesthetic conditions
- Rare diseases

### ACCESS TO RESULTS

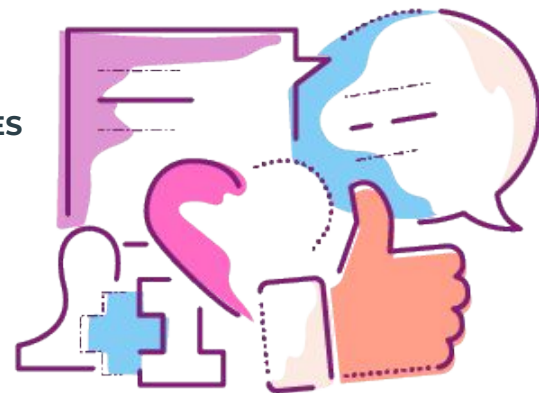
- Paid access
- Partially published results
- Open access

### POSSIBLE RISK

- Being identified
- Reveal information about your family members
- Loss of control
- Discrimination

### INDIVIDUAL INCENTIVES

- No reward
- Discounts
- Money



## BLOCK 2 Combination of elements

Deciding whether to share our data or not does not often depend only on one factor, but on a combination of several factors. With the objective of understanding how to change the preferences for a combination of variables, we have created 3 scenarios, combining elements from the 6 categories. Each scenario represents a possible situation where an agent asks someone from the general public to use their data with a health-related objective in exchange for collective benefits, risks and individual incentives.

### 28 → \* Scenario 1

**A UNIVERSITY RESEARCHER asks for your SOCIAL MEDIA user data to research a RARE DISEASE. At the end of their research they discover a new finding that is published in an academic article that has a COMMERCIAL LICENCE, i.e. it is not free to access it. If you share your data, there is a risk that you could BE IDENTIFIED. In exchange for sharing your data, YOU WILL NOT RECEIVE ANYTHING\***

Would you share your data?

☒ Yes

☐ No

## BLOCK 3 Demographics

The willingness to share data can be influenced by personal experiences, such as for example, the state of our health, our religion or age. The last block of the questionnaire includes socio-demographic questions with the objective of understanding the sample of people that participated and examine the possible correlations between the willingness to share data and personal aspects.

### 34 → About you

a. What is your age group?

☐ A 18-27

☐ B 28-37

☐ C 38-47

☐ D 48-64

☐ E ≥65

d. What is your gross annual wage?

☐ A €0 - €8,000

☐ B €8,000 - €18,000

☐ C €18,000 - €30,000

☐ D €30,000 - €50,000

☐ E More than €50,000

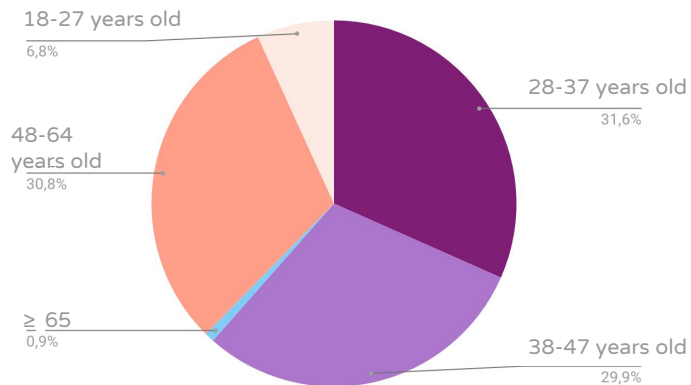
☐ F I would prefer not to answer

## 3 | RESULTS

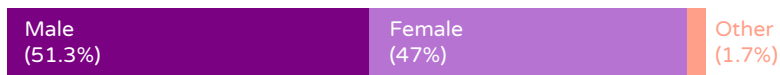
### BLOCK 3 TRIEM questionnaire respondent profiles

Total participants: **117**

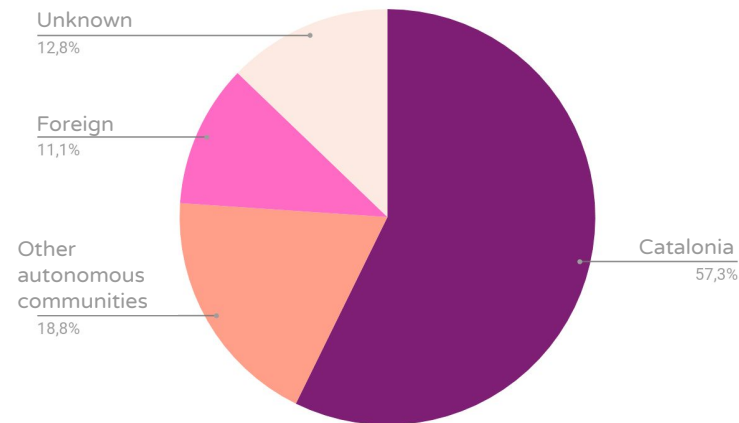
#### 1. Age



#### 2. Gender



#### 3. Origin



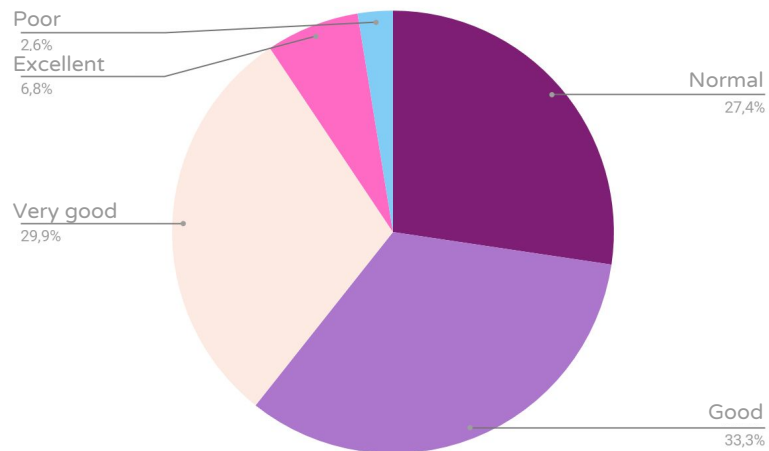
#### 4. Religion



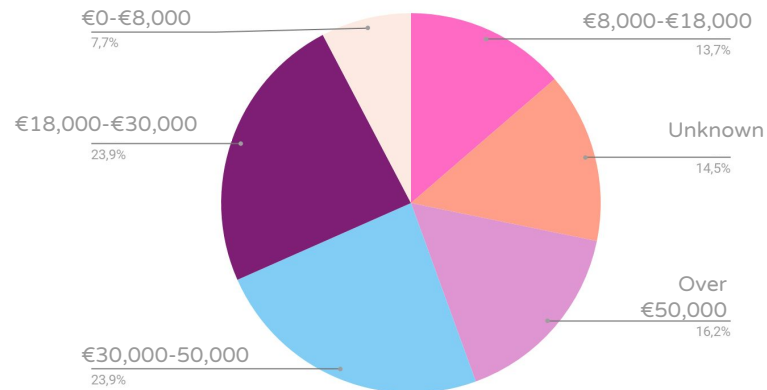
### 5. Volunteer



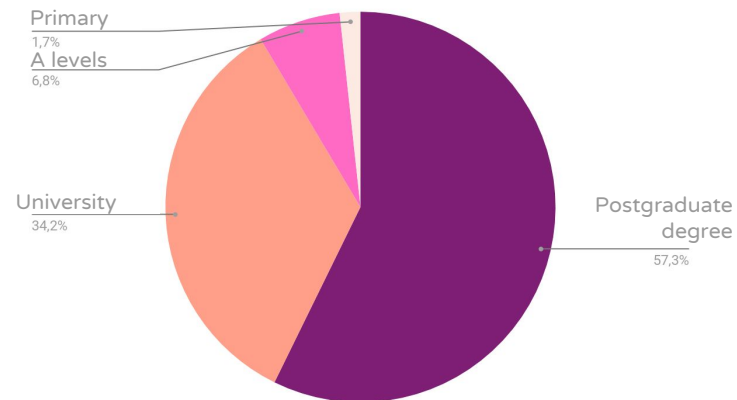
### 6. State of health



### 7. Salary range



### 8. Level of education



## 3 | RESULTS

### TRIEM questionnaire respondent profiles

The survey has mainly been shared on the Internet and social media. That is why it is important to highlight that the sample of participants is not representative of the general population. In fact, the participants display a high level of education (57% are postgraduates), salary range (40% over €30,000) and participate in volunteer activities (69%). All of these characteristics could affect their willingness to share data.

Male/female participation was almost even, and there was a range of ages and states of health. However, there were not enough older people (+65 years), younger people (-27 years) and people with a poor state of health.

That is why we believe it is important to highlight that **the results presented do not intend on being representative. This survey does however have to be taken as a first experiment that enables us to validate the research mechanisms.**

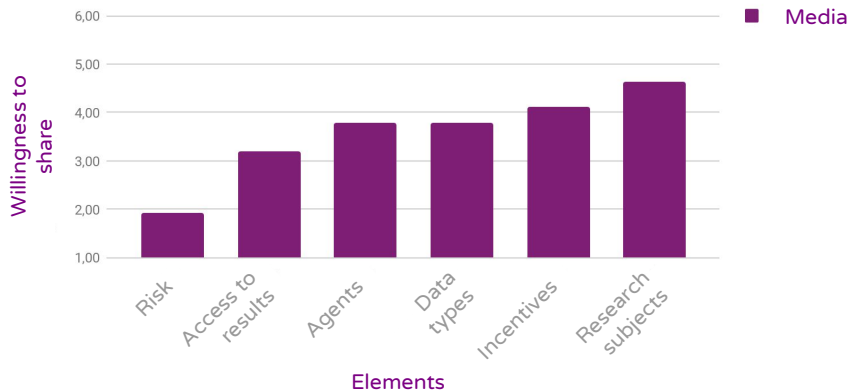


### 3 | RESULTS

#### Block 1 - General willingness to share

The table to the right shows the averages obtained from the Block 1 answers. It shows how the risk elements reduce the willingness to share and, on the other hand, how there is a high willingness to share data regardless of the research subject.

The second obstacle associated with sharing data is determined by the way the results obtained from the research produced with our data are shared. If a commercial licence is linked to the results, the willingness to share drops considerably when compared to an open-access licence, which would mean the results would reach a wider audience.



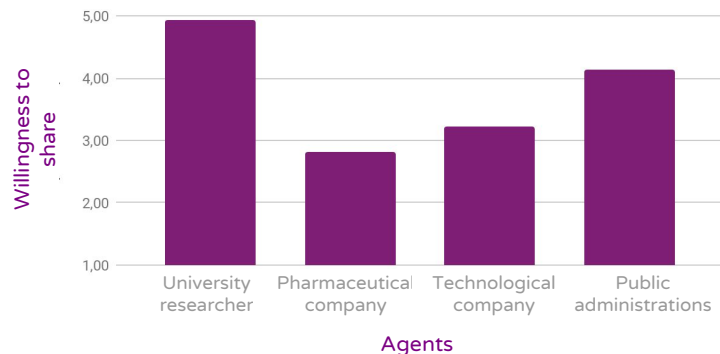
Elements	Media	Standard deviation
AGENTS	3.78	1.69
University researcher	4.92	1.24
Pharmaceutical company	2.82	1.56
Technological company	3.23	1.50
Public administrations	4.15	1.60
DATA TYPES	3.78	1.82
DNA	3.91	1.82
Social media	3.28	1.82
Blood tests	4.15	1.74
RESEARCH SUBJECTS	4.62	1.62
Chronic diseases	5	1.33
Acute diseases	4.85	1.41
Aesthetic conditions	3.44	1.84
Rare diseases	5.21	1.20
ACCESS TO RESULTS	3.20	1.86
Commercial licence	2.09	1.27
Partially published results	2.66	1.54
Open access	4.85	1.48
RISK	1.92	1.28
Being identified	2.32	1.46
Revealing info. about family members	2.17	1.30
Loss of control	1.77	1.23
Discrimination	1.43	0.87
INCENTIVES	4.13	1.69
No reward	4.68	1.39
Discount	4.06	1.73
Money	3.63	1.76



### 3 | RESULTS

#### Block 1 - Willingness to share according to elements

Do you mind what type of AGENT asks for data?



There is more willingness to share data with non-profit entities, such as universities and public administrations, as it is perceived that the data will be used for the common good.

*"I would give my data to entities that are seeking to benefit society or for public research or medical advances. For private companies, I would ask them to consult me beforehand, as it would depend on the project that they want to develop or the purpose."* Open response to a survey question

*"It makes me really angry that the initial research is paid for with public funding and then during the last leg, they end up going around the pharmaceutical companies, agreeing on patents without returning anything to the preliminary research."*

Do you think it is important to RECEIVE SOMETHING IN EXCHANGE for donating data?



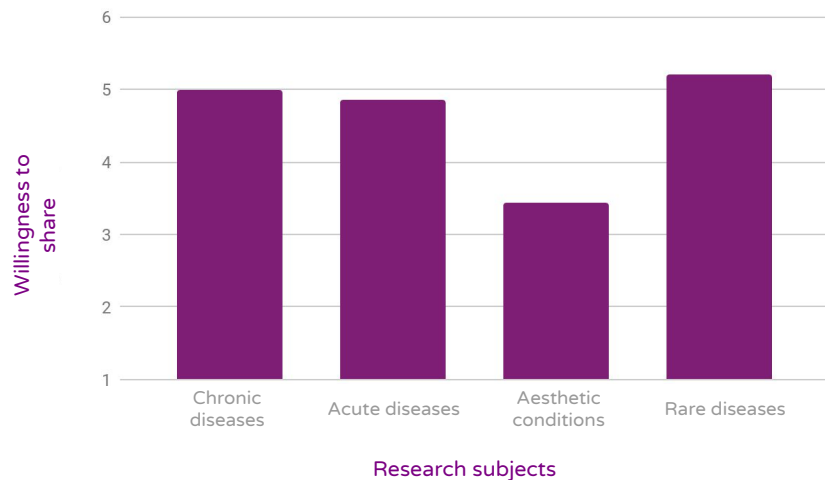
Money is not the main reason that people choose to share their data. However, some respondents state that it is important to acknowledge the donor, whether through social acknowledgment or applying another type of reward. It is important to better understand what types of rewards are considered most appropriate. Some of the respondents' answers are: access to the research and its follow up, results-based personalised feedback.

*"I wouldn't want to be rewarded with money, I would be more interested in other type of reward."*

*"I think if I am giving my data, some of the health or social services that I receive could be paid with my data contribution."*

### 03 Large-scale, anonymous survey

Do you mind what TYPE OF RESEARCH uses your data?

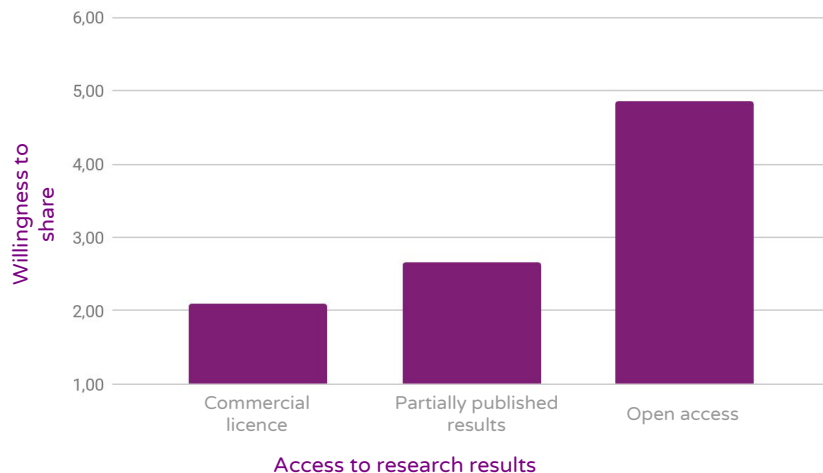


Willingness to share does not change greatly depending on the research subject, provided that the gain does not exceed the collective benefit. To this end, research related to aesthetic conditions was rated lower because it is often associated with marketing mechanisms.

*"I would donate my data if it helps society but I do not want anyone to make profit from them"*

*"More willing to share the longer term or more complex the disease is"*

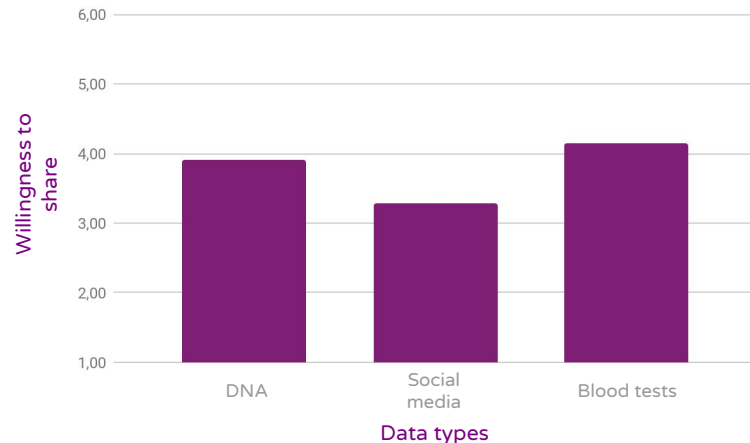
Do you mind how the research results are shared with everyone else?



*"If the person who shares their data does not get paid, they should not be able to charge to access the research results." Science only advances within the framework of open-access publications, if not, there are only closed areas where science stops being, or has already stopped being verifiable and reproducible as the processes to achieve such turn out to be part of the knowledge economy."*

### 03 Large-scale, anonymous survey

#### Which DATA do you feel more comfortable sharing?

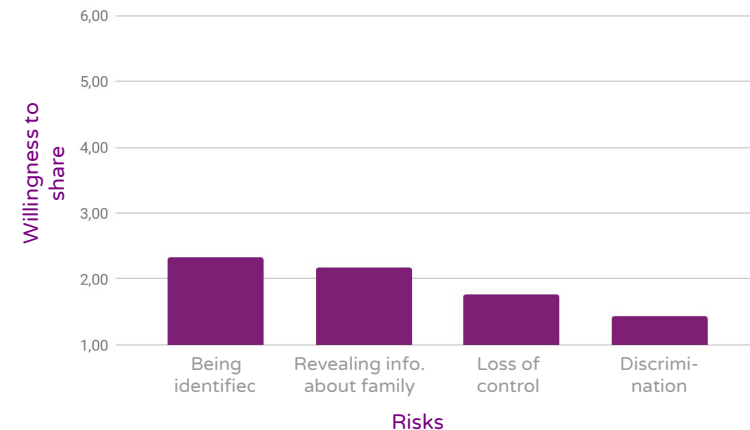


Respondents showed that they were very willing to share DNA data, even though these data can reveal sensitive information about them or even their family members. However, when asked about risks, willingness to share drops considerably if there is a risk that information about their family could be revealed. This contradiction may be explained by the fact that there is no clear knowledge on data-related consequences, which the workshop results confirm.

*"Social media, since we are sharing everything anyway, and it's a commercial and political monopoly. So we may as well do it for something good, right? If a family member had died of a particular cause, I would also share their data."*

*"If these data are relevant to obtain more information to research anything generally health-related, I think it is absolutely necessary to share them."*

#### How willing are you to share your data if there were any kind of RISK?



*"This part is critical! Non-discrimination and identification of people are essential"*

*"The key is in guaranteeing that data protection is offered."*

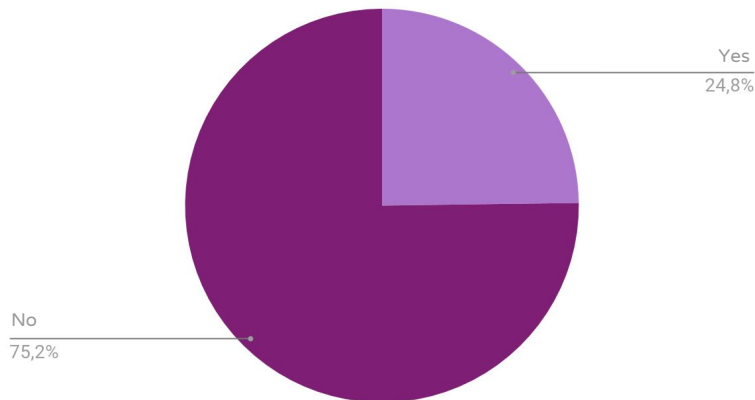
*"Security and guarantees are indispensable here"*

## 3 | RESULTS

### Block 2 - Willingness to share according to scenarios

#### Scenario 1

A UNIVERSITY RESEARCHER asks for your SOCIAL MEDIA user data to research a RARE DISEASE. At the end of their research they discover a new finding that is published in an academic article that has a COMMERCIAL LICENCE, i.e. it is not free to access. If you share your data, there is a risk that you could BE IDENTIFIED. In exchange for sharing your data, YOU WILL NOT RECEIVE ANYTHING.



#### Yes, they would share data

*"The data type and risk is small and how they are going to be used is more important in my opinion"*

*"Because it is for research related to rare diseases. Although I do not agree that the results have a commercial licence or that I could be identified, it is not so bad if it helps cure a rare disease."*

*"My social media activity is public and I wouldn't mind if my data were used for health-related research. Even more so if it is for rare diseases, as it is harder to collect data for them."*

#### No, they wouldn't share data

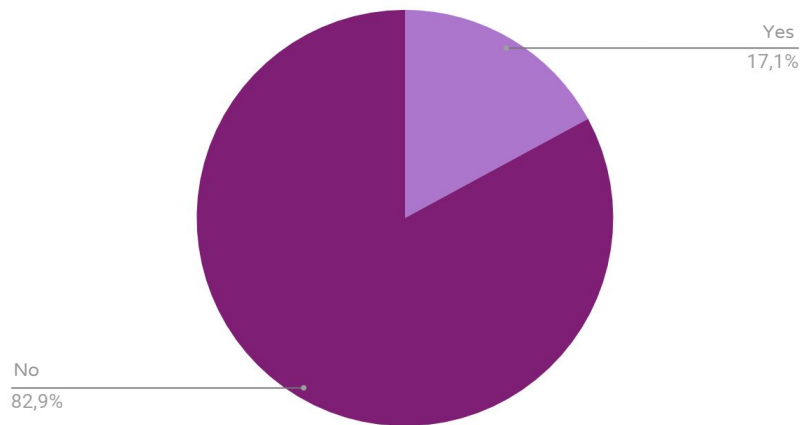
*"I would not share if the benefit is not open and free. We must think about different ways that the investment into research can be returned, we remember that although the data are essential, they are only a part of it."*

*"There is no acknowledgment for sharing my data. Or at least nothing in return."*

*"I would not feel comfortable sharing something that could expose me"*

#### Scenario 2

A PHARMACEUTICAL COMPANY asks for your BLOOD TEST data to conduct a study about ACUTE DISEASES. At the end of the study it discovers a new treatment that is protected by a COMMERCIAL LICENCE. If you share your data, there is a risk that you could BE DISCRIMINATED AGAINST. In exchange for sharing your data, you will receive DISCOUNTS\* on products and services.



#### Yes, they would share data

*"It should not be like that, but it is a way that we can change our culture to use data to benefit everyone. It's OK..."*

*"I wouldn't have any problems if the objective is to discover a treatment for acute diseases which benefits the society"*

*"My answer would depend on the incentive that I receive (if the discounts are good or not), I wouldn't mind sharing my blood test data. But if they are for a commercial purpose, it would be fair if there were a reward for participating."*

#### No, they wouldn't share data

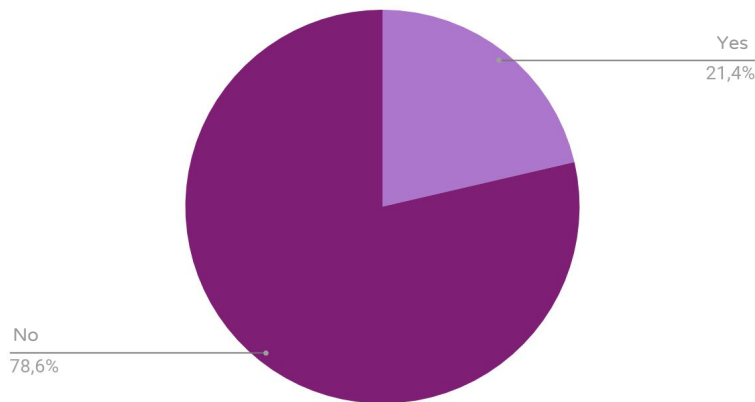
*"Commercial licence and discrimination are more important than discounts."*

*"Discounts do not matter if the risks involve being discriminated against, and on top of that, they end up with my blood test data."*

*"No, because it is a pharmaceutical company and you're not telling me what results it obtains"*

#### Scenario 3

A PHARMACEUTICAL COMPANY asks for your DNA data to study AESTHETIC CONDITIONS. At the end of the study, it discovers a new solution that it shares as an OPEN ACCESS resource. If you share your data, there is a risk that you could BE DISCRIMINATED AGAINST. In exchange for donating your data, YOU WILL NOT RECEIVE ANYTHING.



#### Yes, they would share data

*"I feel like I am contributing to the common good, despite the risk that I could be identified."*

*"I understand that the common good may be more than my own harm, which is why I would share them. I am contradicting myself because in a previous answer I said I wouldn't share my data with a pharmaceutical company. If the pharmaceutical company is going to publish the solutions it obtains with open access, I would be for that pharmaceutical company"*

*"Data are shared as open-access resources, although it is for aesthetics purposes, it could be important for other people and it is not for commercial purposes"*

#### No, they wouldn't share data

*"The same as the other two. The collective benefit does not remove the individual risks"*

*"Because it is related to an aesthetic condition and I could be discriminated against (if I were not identified I wouldn't mind opening up my data)."*

*"I think there is a lot of money and research involved in aesthetic conditions. But, if they were to give me free treatment for that condition, as opposed to nothing, then I would think about it."*

## REFLECTIONS ON THE SURVEY RESULTS

The results offer a general view of the general public's preferences. However, they do not explain the correlations between the 3 blocks of questions in depth. They must, therefore, be understood to be preliminary results.

In this first version of the survey, we should highlight the difference in answers between the questions based on individual elements (Block 1) and scenario-based questions (Block 2).

The respondents show that they are fairly positive about sharing their data when asked about their position on the elements -each variable.<sup>1</sup> However, the willingness to share drops considerably when they are asked about scenarios that combine several variables.<sup>2</sup>

This result shows that people's decision should be understood within a real scenario that combines several elements. One element could weigh more than another or influence the end decision. For example, a person who is willing to share data for a study on rare diseases could back out if there is a risk of being discriminated against.

Understanding the weight of the variables for a scenario would mean isolating the most critical variable, which could turn an undesirable scenario into one where more people would be willing to share their data. For example, although respondents were not very willing to share their data with a pharmaceutical company, many of them commented that their opinion could change if the pharmaceutical companies were to adopt mechanisms that guarantee and prioritise providing a benefit for society as opposed to financial gain.

In this sense, the results of this study show that medical advances produced from data (collective benefit) is the main driving element for data sharing, and which should minimise those mechanisms that may hinder disseminating this benefit (commercial licences to access the results, partial publication, high medication prices).

<sup>1</sup> 3.55 out of 6 is the average of all the questions in Block 1

<sup>2</sup> Only 21% of the scenario answers were positive

The results also show that there are variables that can represent a strong obstacle when sharing data. Risks are the most critical variable. Declaring, controlling and minimising the possible risks associated with data sharing is essential for encouraging people to donate their data.

However, we must consider that data sharing is not risk-free and anonymity cannot be 100% guaranteed in any case. At present, we are used to using certain products or services that misuse our data because we do not know the consequences or we believe that the benefit obtained from using these products is greater.

*Where is the middle ground between risk and the value generated?*

**How can collective benefit be guaranteed?**





## STUDY LIMITATIONS AND FUTURE OPPORTUNITIES

The results of this study must be considered with caution, since the sample of participants is small and biased. On one hand, people with a very defined profile participated in the survey, suggesting that there is certain interest in the subject from a segment of the population. This could act as a driving force in a first stage of the awareness and taking control process, which can then be scaled to more of the general public.

On one hand, it is important to understand the preferences of the whole population, and identify how socio-economic factors, life experiences and state of health can influence decision-making.

Only 3 scenarios with a combination of variables have been presented. However, as previously shown, people's decisions to share data must be understood in the context of the scenarios. Three is a very limited number to be able to extract significant conclusions.

In the future, we would like to design crowdsourcing mechanisms that can auto-generate scenarios based on people's input. This would, on one hand, exponentially increase the number of scenarios over the base of preferences. On the other hand, it would mean that scenarios could be created that are made up of more condition categories than those we have examined in the study.

We understand this study to be the first experiment that uses the co-design method to design data governance processes. We would like to broaden the study presented here with the aim to increase the participant base, extend the number of scenarios and consolidate analysis of the results.

# TRIEM

by SalusCoop & IdeasForChange

[info@ideasforchange.com](mailto:info@ideasforchange.com)

[www.ideasforchange.com](http://www.ideasforchange.com)

[www.saluscoop.org](http://www.saluscoop.org)



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