SHARE AND PROTECT OUR HEALTH DATA!

Results from Rare Barometer Data Protection and Sharing survey

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3 March 2020

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Multiple approaches to securing patient preferences on data sharing

Patient Advisory Council (PAC) (16 members), 2012-2018

Webinar + follow up discussion on concerns of GDPR, 50 participants, 2017

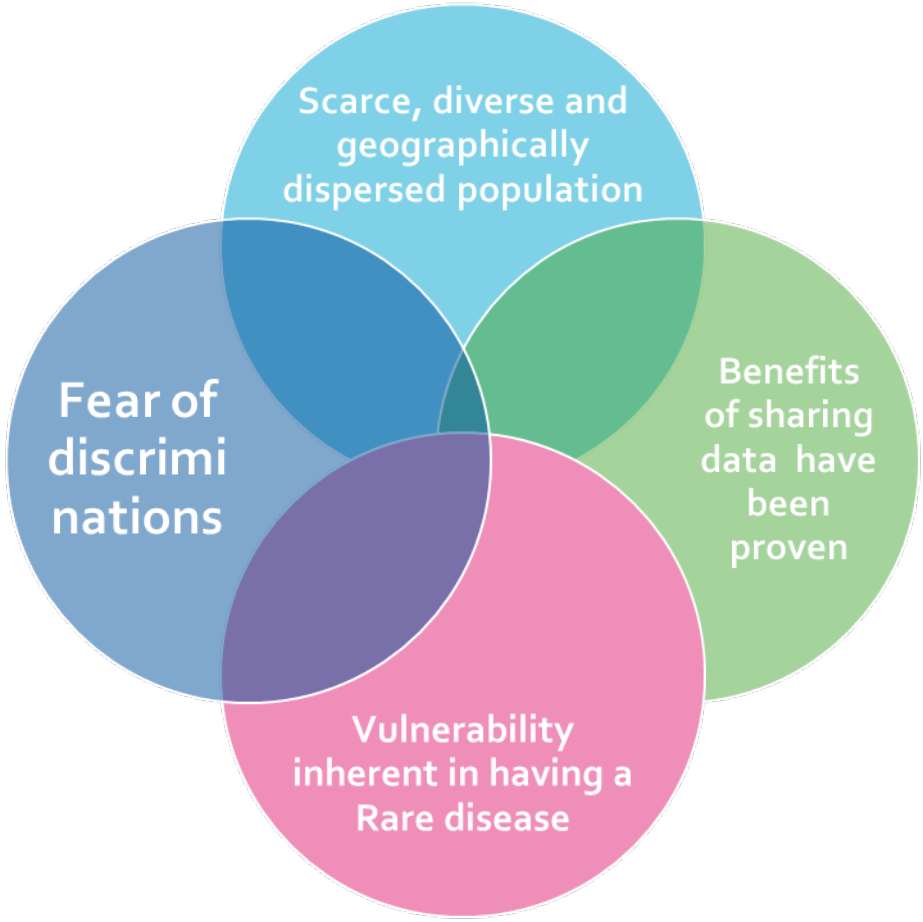
Quantitative survey on rare disease patients participation in research (3213 patients), 2017

Focus groups on rare diseases patients perspectives on use and sharing of genomic data (22 patients), 2017

Delphi exercise with expert patients on data sharing and data protection (16 patients), 2016)

Participation in focus groups on data sharing for international research (52 patients) 'You should at least ask' (McCormack P1, Kole A, 2016)

Rare Disease population specificities



Project goal

- Encourage researchers and healthcare stakeholders in charge of or participating in data-sharing initiatives to **recognise the importance of understanding rare disease patient perspectives**
- **Encourage discussion** about data sharing best practices

First large scale, multi-country survey on data sharing

- **Target population**: patients living with a rare disease or family members (parents and close relatives) of over 16 years old
- Questionnaire designed : Topic expert Committee, sociology, legal, computational biology, rare disease patient advocacy, ethics, patient reported outcome measurement
- 66 countries and 664 diseases represented

Rare disease patients are clearly willing to share their data

To foster research on their disease...

97% would be ready to share their data to **better understand the mechanisms and causes** of their disease

97% to **develop new treatments** for their disease

97% to **improve diagnosis** of their disease

or to improve their healthcare

95% to receive **additional specialist advice** on their care

> *"We are only 6 families in [country] affected by this. If we don't offer our database, I think it's impossible for someone to help us, to know much about us"*
>
> **Rare disease patient**

> *"It is difficult to get the diagnosis. Doctors don't know about my disease because it is very rare. We need to share all the information about this disease – how it is manifested, how it progresses, all the experience the patients and doctors have"*
>
> **Rare disease patient**

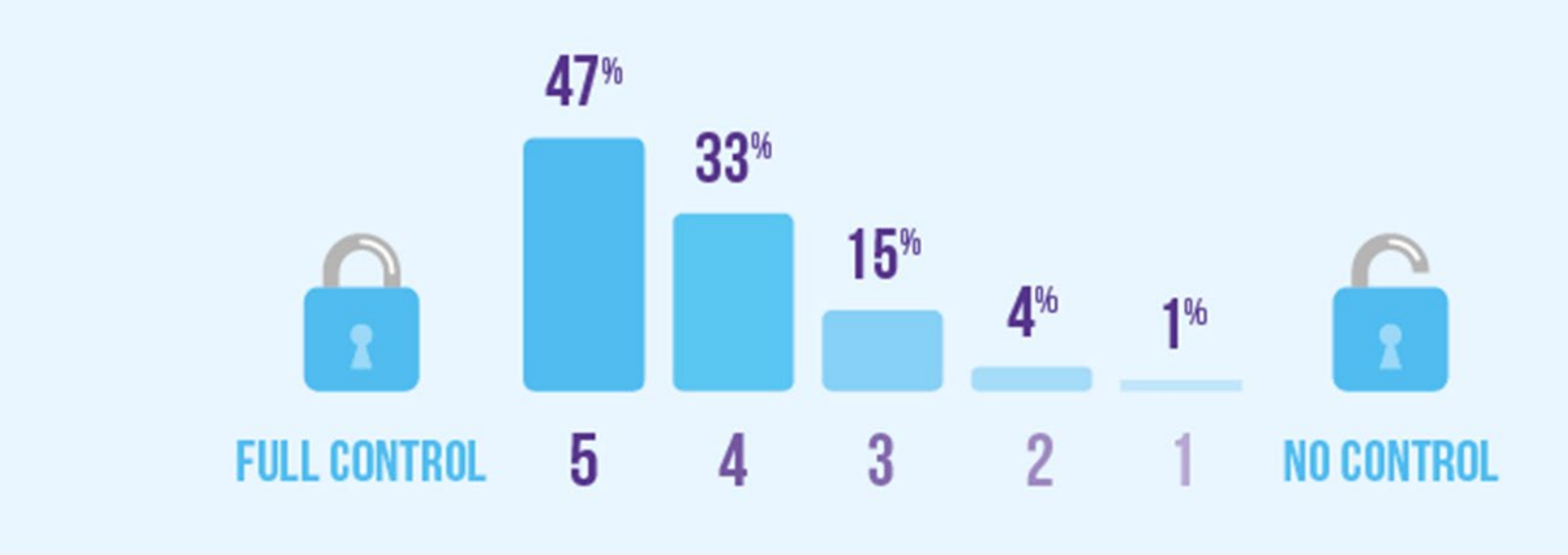
They also support data sharing for wider scientific interest

are also willing to share their data to improve research on diseases other than theirs.

"I agree to share my data if the rare disease community gets benefit from it"
Rare disease patient

Rare disease patients seem more inclined to share their data than the general population: depending on the study, between 37% and 80% of the general population declare that they would be ready to share their health data[1].

Patients want to have control over the data they are sharing



Q *On a scale from 1 to 5, how much control would you like to have over this information?*

Top three incentives encouraging participation

1  **69%** The possibility to **learn more information** about their disease

2  **66%** The possibility to **discuss and ask questions** directly to professionals involved in the project

3  **62%** The possibility to **be informed on the results** of the project

Q *From the list below, what are the three main options that would encourage you to participate in a project involving the sharing of your/the person you care for health information?*

Top four risks associated with sharing data

1. **50%** Their information being **shared with 3rd parties** without their consent
2. **47%** Their information being **used in a different context** from the ones where they disclosed it
3. **35%** Their information being **used without their knowledge**
4. **34%** Becoming the **victim of discrimination**

Comparison with general population:

5% view becoming a victim of discrimination as a risk[2]

Q *According to you, what are the most important risks connected with disclosure of your personal or health information?*

Higher levels of confidence in not-for-profit stakeholders

NOT-FOR-PROFIT AND HEALTHCARE PROFESSIONALS

89% **Medical doctor** involved in their healthcare

79% **Researcher** from a non-profit organisation

77% **Patient organisation**

69% **Other healthcare professionals** (dentists, pharmacists, nurses)

48% **Government from their country**

FOR-PROFIT

47% **Researcher** from a private **genetic testing company**

45% **Researcher** from a **pharmaceutical or medical device company**

16% **Insurance company**

Only 48% of respondents reported confidence in government entities that are frequent initiators and custodians of data sharing initiatives

People involved in the project can belong to different types of organisations. How much confidence do you have in each of them to handle and use your health information carefully?

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Top three most important pieces of information

1 **80%** **Details on how the project could be beneficial** for their disease or other diseases

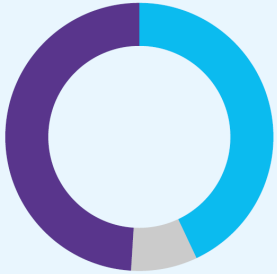
2 **51%** **Brief summary of the key information** necessary to understand the main aspects of the project

3 **49%** **Information about the data management rules** (eg. how access to health information will be granted or is there an ethical review?)

Q *What are the three main pieces of information about the project that would be important for you to receive?*

Opinions are fragmented on whether responsibility could be delegated to ethic committee

are in favour **49%**



43% are against the idea

8% don't know

Q *Would you allow an ethics committee to decide on your behalf with whom your information will be shared, how and why?*

Email and face-to-face discussion favoured ways of receiving information

93% Email

86% **Face-to-face discussion** with professionals involved in the project

85%

A dedicated **website**

67%

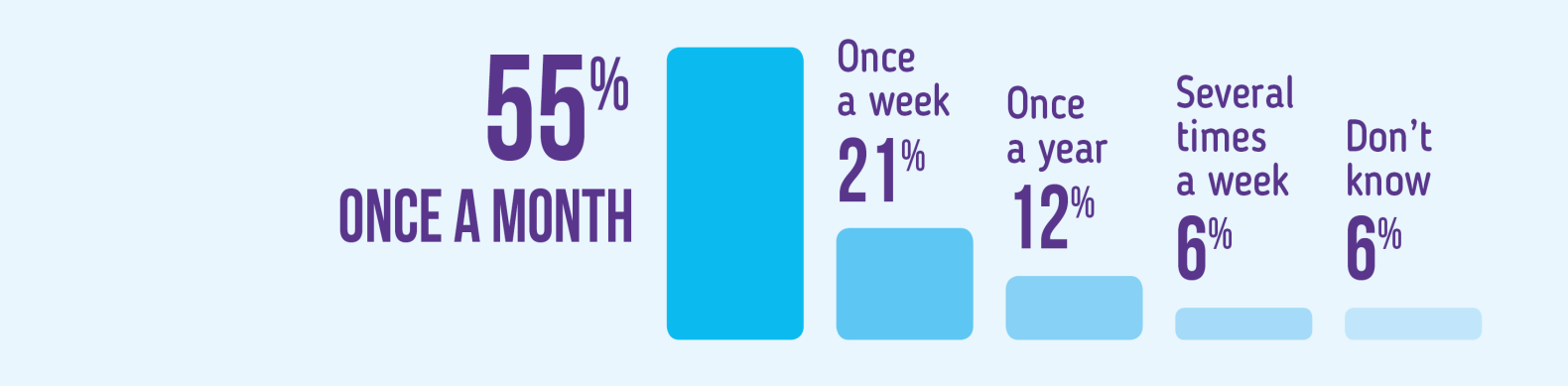
Attending **conferences**

56%

A mobile app

Q *Would you like to be informed about the outcome of the project through each of the following means?*

The ideal frequency to be informed for a majority of respondents is once a month



Q *How often would you like to be informed about the outcome of the project?*

Recommendations . . . .

1 Ensure implementation of appropriate legislation

Policy makers should ensure implementation of appropriate legislations at European and national levels and pursue efforts to foster cultural, technological and infrastructural changes to further develop international data sharing initiatives in health and research for rare diseases.

2 & 3 Include trusted representatives and implement robust safeguards

Governing structures of data-sharing initiatives should:

- Develop and implement robust standards to ensure secure, ethical and responsible data sharing whilst putting in place safeguards around data protection
- Include representatives from trusted advocacy organisations, i.e. patient organisations and non-profit organisations as well as clinicians and healthcare professionals

Recommendations . . . .

4 Promote dynamic systems

All stakeholders involved in data sharing initiatives need to promote the development of, and implement, dynamic systems enabling:

- The possibility to express different attitudes and preferences
- Access to updated information on research outcomes to increase patient participation in research and stimulate data sharing whilst respecting patients' preferences

5 Dedicate finance to educational resources

All stakeholders involved in data sharing initiatives including healthcare systems and other relevant authorities should allocate resources at national and regional levels to enable the development of, and facilitate access to, relevant educational resources to enable informed choices for patients to share or not to share their health-related data.

Recommendations . . . .

6 Dedicate finance to educational resources

Funders and sponsors of data sharing activities should ensure that adequate financial resources are allocated to improve communication and increase transparency on the purpose and outcomes of data sharing initiatives to maximise the benefits of the project outcomes.

7 Emphasise potential health benefits of studies

Funders, clinicians and researchers need to emphasise potential health benefits of research studies and healthcare initiatives on future generations and other disease areas, as an incentive for wider participation in data sharing initiatives.

Data survey outcomes

❖ **Peer-reviewed publication**

Share and protect our health data

An evidence based approach to rare disease patients' perspectives on data sharing and data protection - Quantitative survey and recommendations

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Published in **Orphanet Journal of Rare Diseases**, 12 July 2019

Available online at: https://doi.org/10.1186/s13023-019-1123-4


Courbier et al. Orphanet Journal of Rare Diseases (2019) 14:175
https://doi.org/10.1186/s13023-019-1123-4

Orphanet Journal of Rare Diseases

RESEARCH Open Access

Share and protect our health data: an evidence based approach to rare disease patients' perspectives on data sharing and data protection - quantitative survey and recommendations

Sandra Courbier[1*], Rebecca Dimond[2] and Virginie Bros-Facer[1]

Abstract

Background: The needs and benefits of sharing health data to advance scientific research and improve clinical benefits have been well documented in recent years, specifically in the field of rare diseases where knowledge and expertise are limited and patient populations are geographically dispersed. Understanding what patients want and need from rare disease research and data sharing is important to ensure their participation and engagement in the process, and to ensure that these wishes and needs are embedded within research design. EURORDIS-Rare Diseases Europe regularly surveys the rare disease community to identify its perspectives and needs on a number of issues in order to represent rare disease patients and be their voice within European and International initiatives and policy developments.
Here, we present key findings from a large quantitative survey conducted with patients with rare diseases and family members as part of a continuous evidence-based advocacy process developed at EURORDIS. The aim of this survey was to explore patient and family perspectives on data sharing and data protection in research and healthcare settings and develop relevant recommendations to support shaping of future data sharing initiatives in rare disease research.
This survey, translated into 23 languages, was carried out via the Rare Barometer Programme and was designed to be accessible to a diverse population with a wide range of education backgrounds. It was widely disseminated via patient organisations worldwide to ensure that a wide range of voices and experiences were represented.

Main findings: Rare disease patients, regardless of the severity of their disease and their socio-demographic profile, are clearly supportive of data sharing to foster research and improve healthcare. However, rare disease patients' willingness to share their data does come with specific requirements in order to respect their privacy, choices and needs for information regarding the use of their data.

Conclusions: To ensure sustainability and success of international data sharing initiatives in health and research for rare diseases, appropriate legislations need to be implemented and multi-stakeholder efforts need to be pursued to foster cultural and technological changes enabling the systematic integration of patients' preferences regarding sharing of their own health data.

Keywords: Rare diseases, quantitative survey, Data sharing, Data protection, Patient engagement, Recommendations, Evidence-based approach, Patient organisation, Public trust, Healthcare, Research

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Rare Barometer
A EURORDIS INITIATIVE

SHARE AND PROTECT OUR HEALTH DATA!

Rare disease patients' preferences on data sharing and protection

October 2019

30 MILLION
people are living with a rare disease in Europe and 300 million worldwide

NO CURE
for the vast majority of diseases and few treatments available

Sharing health data to advance scientific research and improve clinical benefits are of particular importance in the **field of rare diseases** where knowledge and expertise are limited and **patient populations are geographically dispersed.**

Understanding what patients want and need from rare disease research and data sharing is **important to ensure their participation and engagement in the process**, and to ensure that these wishes and needs are embedded within research design.

WITHIN THIS REPORT YOU WILL FIND:

1 Key results from research conducted by EURORDIS, outlining rare disease patients' preferences with regards to data sharing

2 Six recommendations designed to inform and support stakeholders involved in data sharing initiatives

3 Research and recommendations methodology

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Rare Barometer Voices

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Thank you to all Rare Barometer partners:

This project is co-funded by the European Union
Call for Proposals VP/2014/008; EaSI PROGRESS, DG Employment, Social Affairs and Inclusion

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