

Key findings from research conducted by EURORDIS–Rare Diseases Europe on rare disease patients’ preferences on data sharing and protection:

1 WHY SHARE HEALTH RELATED DATA?

Rare disease patients, regardless of the severity of their disease and their socio-demographic profile are clearly willing to share their data:

To foster research on their disease...

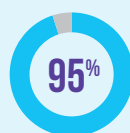
97% would be ready to share their data to better understand the mechanisms and causes of their disease

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



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

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 data¹.



If given the opportunity, would you be willing to make your/the person you care for health information available for the purpose of:

The possibility to discuss and learn information about the disease and the project are the main incentives to participate in such initiatives.

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

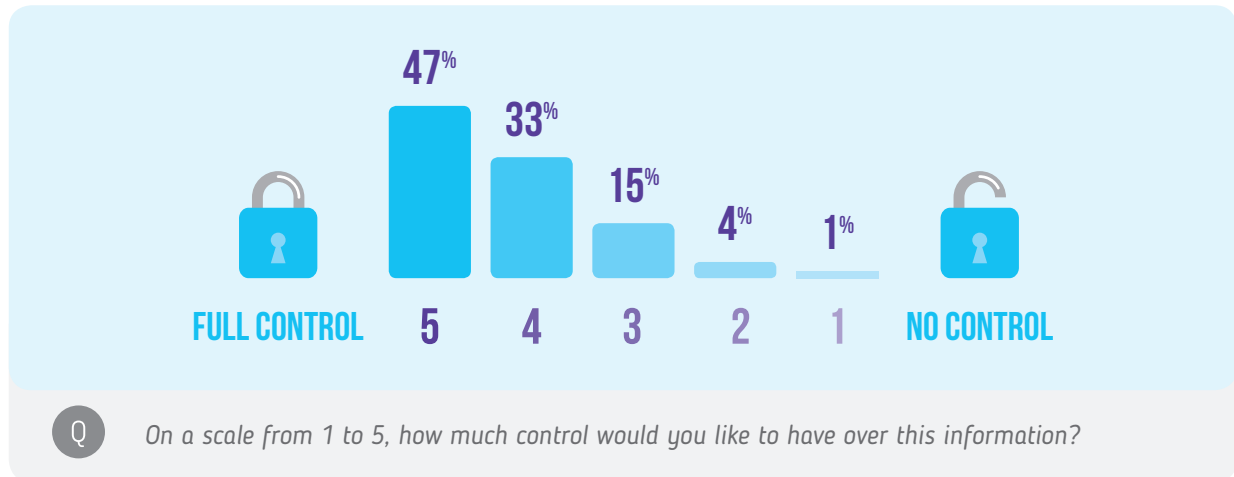


From the list below, what are the three main options that would encourage you to participate in a project involving the sharing of your/the person you care for health information?

2 DATA SHARING: RISK AND LEVEL OF CONTROL

Rare disease patients want to have control over the data they are sharing.

80% said they wanted to have full (47%) or near to full (33%) control. Being in favour of sharing data and calling for more control are not contradictory, they are clearly stated as two parallel requirements.



According to rare disease patients, the main risks associated with data sharing are:



THANK YOU to all people living with a rare disease who participated in the survey and discussion groups and to Rare Barometer partners!

2: European Commission: Data Protection Report. Special Eurobarometer 431; 2015 https://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_431_sum_en.pdf