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.

- **To improve their healthcare:**
  - 95% to receive additional specialist advice on their care.
  - 95% 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 data.

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.

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

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

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

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

Comparison with general population: 5% view becoming a victim of discrimination as a risk.

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