

EURORDIS Rare Barometer privacy notice

I, hereby, consent to the processing of my personal data for the purpose of the conduct of Rare Barometer surveys and studies by EURORDIS-Rare Diseases Europe, a non-profit alliance of over 1000 rare disease patient organisations from over 70 countries (hereafter 'EURORDIS').

Rare Barometer is a survey initiative that robustly collects the experiences and opinions of people living with a rare disease and their close family members on topics that directly affect them.

This programme is owned independently by EURORDIS-Rare Diseases Europe and is a non-profit initiative; no commercial use of your details will be made at any time.

It conducts 1 to 3 studies each year, and global online surveys are translated in at least 23 languages.

Rare Barometer also hosts a survey panel of more than 20,000 people who agreed to receive email invitations to participate in surveys and studies conducted by EURORDIS.

More information:

- EURORDIS: eurordis.org
- Rare Barometer: eurordis.org/voices

I understand that:

- EURORDIS only collects the data that I willingly share in the Rare Barometer registration form and/or surveys and that EURORDIS does not use cookies or tracking techniques for the Rare Barometer surveys and studies. The data collected can include personal and sensitive data, including health data (such as the name of my rare disease).
- No personal data will be shared outside the Rare Barometer team, and the person responsible for the management of my personal data is Jessie Dubief, Social Research Director and Rare Barometer Lead at EURORDIS (jessie.dubief@eurordis.org).
- Rare Barometer complies with the General Data Protection Regulation (GDPR). My data is collected through the Sphinx survey software, saved on secured servers in France, password protected and pseudonymised.
- My data will only be used for research and advocacy purposes - no marketing use of my data will be made.
- EURORDIS will only share collective survey results with survey participants, patient organisations, decision-makers, researchers and the wider public, to bring about change for the rare disease community and under the condition that respondents' anonymity can be ensured (for instance by sharing only collective results with a sufficient number of responses).
- I have the right to stop answering surveys, to access the data I shared with Rare Barometer, to withdraw my data, and to unsubscribe from the Rare Barometer panel at any time without suffering any retaliation, discrimination or being harmed in any way. To do so, I can send an email to rare.barometer@eurordis.org