**Email for Patient Organisations to share with members**

Subject: **Make your voice heard: take the new Rare Barometer Voices survey on rare disease patients’ experience of treatments**

The new [**Rare Barometer Voices survey**](http://bit.ly/eurordis-survey) on rare disease patients’ experience of treatments is now live!

This global survey is open to anyone from any country in the world who is living with a rare disease, as well their family members and carers. The survey is available in 23 languages and your responses will help to provide an up-to-date insight into the unmet treatment needs of people like yourself who are living with a rare disease.

Through asking questions such as whether treatments are available, whether these treatments are accessible and if these treatments have resulted in positive or negative experiences, we will be able to better measure and understand your experience of treatment.

Where possible, the results will be available for your country, disease and disease grouping. They will be shared with everyone who responded to the survey as well as patient organisations, policy makers and the general public and used in advocacy work to drive real change for the rare disease community.

**You can access the online survey** [**here**](http://bit.ly/eurordis-survey)**.**

It should take no more than 10 minutes to complete. All responses are anonymous and will be kept in secure storage only accessible to the Rare Barometer research team.

You can find more information on this survey, and the Rare Barometer Voices initiative [here](https://www.eurordis.org/voices).

The survey closes on Tuesday 30 April.

Thanks in advance for your participation – the more people who respond and share their experiences, the more powerful our voice will be!