



MAKE YOUR VOICE HEARD!

A guide for members of EURORDIS-Rare Disease Europe on how they can participate in Rare Barometer surveys and use their results for action



A EURORDIS INITIATIVE

**EURORDIS-Rare Diseases Europe,
Plateforme Maladies Rares,
96, rue Didot, 75014 Paris, France
Tel: +33 1 56 53 52 10**



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What is this guide for?

This guide aims to help member organisations of EURORDIS-Rare Diseases Europe understand how to best capture their community's experiences and opinions through Rare Barometer surveys. We give you a sneak peek into the Rare Barometer methodology and provide examples on:

- 1** How you can take part in shaping questionnaires to make sure that our surveys best answer the needs of the rare disease community.
- 2** How you can motivate your community to participate in Rare Barometer surveys, and receive your own results.
- 3** How you can best use the survey results for actions at national, European and international levels.
- 4** Which useful resources you can access.

About Rare Barometer

Rare Barometer is a survey initiative created in 2016 to robustly collect the experiences and opinions of people living with a rare disease and their close family members on topics that directly affects them. This programme is **run independently by EURORDIS-Rare Diseases Europe and is a not-for-profit initiative.**

As part of EURORDIS' **evidence-based advocacy**, the organisation conducts 1 to 3 global online surveys in 23 languages every year. Rare Barometer also hosts a survey **panel** of more than 20,000 people who agreed to receive email invitations to participate in EURORDIS' surveys and studies.

Survey results are shared with the Rare Barometer panel, patient organisations, decision-makers and the wider public to feed the advocacy work of the rare disease community and drive real change for people living with rare diseases.



1-3 surveys a year



All surveys are translated into **23 languages**



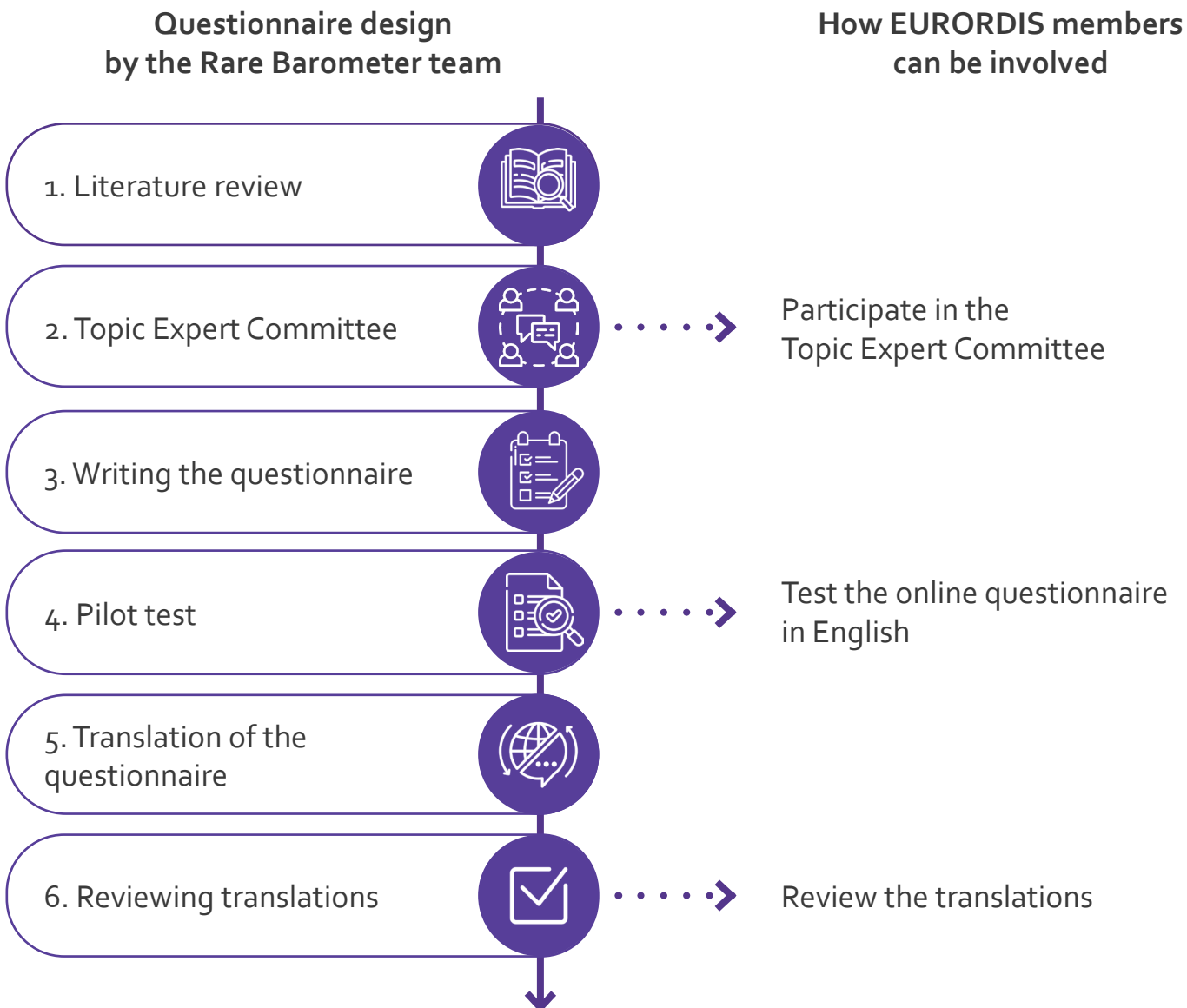
Surveys are **available worldwide**



20,000+ people living with a rare disease have joined our panel

1 Designing Rare Barometer questionnaires

To understand and represent the priorities, needs and preferences of our community, we invite members of EURORDIS-Rare Diseases Europe to be involved in the survey design and implementation process. You can send us suggestions of topics to be explored in our surveys, or express your interest in participating in some or all of the activities described below, by sending an email to rare.barometer@eurordis.org.



Information on new surveys and requests for your support are communicated through the EURORDIS Member News, Council of National Alliances (CNA) updates and CNA catch-up meetings. Please make sure to keep up to date on the information we send out to follow any news on Rare Barometer surveys and how you can be involved.



Participate in the Topic Expert Committee

The role of the Topic Expert Committee is to contribute to identifying issues and indicators that should be included in the questionnaire. Committee members will be asked to participate in an online meeting and later provide input on the questionnaire via email or a short survey. Committee members will also be invited to discuss preliminary results and how to use them for action.



Test the questionnaire

After testing the survey internally, we invite our members to provide feedback on the questionnaire through a pilot test. This is an opportunity to provide input on the structure and the questions included in the questionnaire. It is important to note that once the questionnaire has been sent for translations, we cannot make new changes. It is therefore important that you provide your feedback within the given deadline.



Review the translations

Rare Barometer surveys are translated in 23 languages. The English questionnaire is sent to professional translators specialised in health-related issues, but having native speakers involved in rare diseases reviewing the final version ensures that the questionnaires are easy to understand and adapted to the local context.

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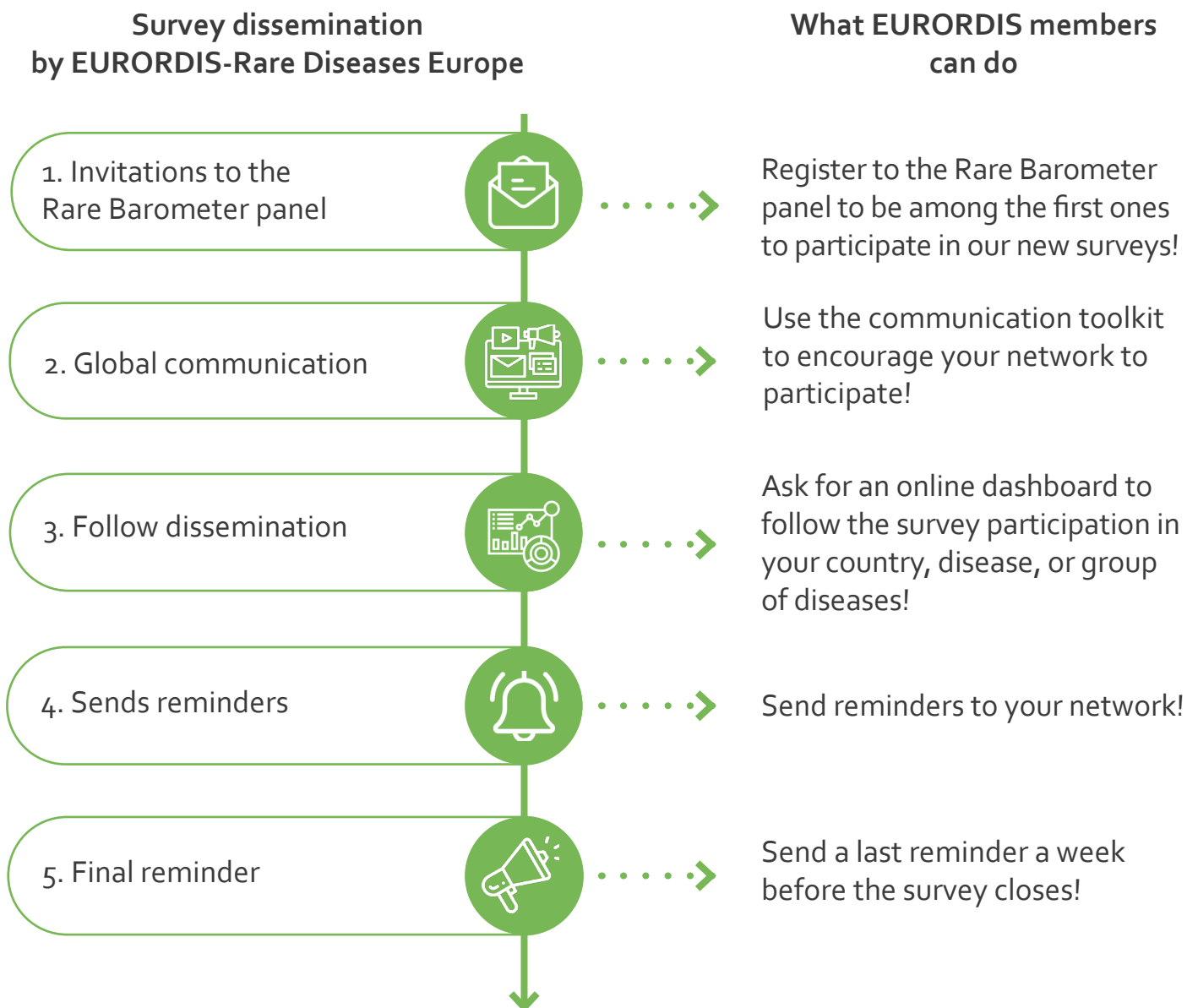
Being involved in the design of the questionnaire since the beginning allowed me to provide input on the questions and adapting them to my national context. This is important because it will make people from my country feel more involved, and it will be easier to reach out to them.

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Simona Bellagambi, UNIAMO - Italian Federation for Rare Diseases

2 Disseminating Rare Barometer surveys

The more people participate, the stronger our voice will be at the European, national and international levels! To get robust and actionable findings, we rely on a strong collaboration with members of EURORDIS-Rare Diseases Europe to disseminate Rare Barometer surveys and better represent the views, needs, priorities and experiences of the rare disease community while truly reflecting the diversity of our community.



If you are interested in receiving a dashboard for your country, a specific disease or group of diseases, you can send an email request to rare.barometer@eurordis.org with the country, disease(s) or orphacode(s) of the disease(s) you would like to see included.

To support you in your communications efforts, we provide you with tailored communications materials:



Communication toolkit

For every survey, we provide a communications toolkit in 7 to 23 languages to help the rare diseases community spread the word about our surveys.

This toolkit includes:

- an email template,
- suggested social media messages,
- social media visuals where you can add your own logo.

We advise you to send out reminders to participate half-way through the survey fieldwork, and a last call for action a week before the deadline. You are free to make your own visual and messages, adding the Rare Barometer logo and using the hashtag #RareBarometer in all messages.



Online dashboards

During fieldwork, we provide you with an online dashboard updated every day so that you can follow the number of respondents in your community and access some preliminary results. Set yourself a goal of how many members of your community you wish to survey and use the dashboard to guide your communication efforts! You can receive your consolidated results if you have at least 30 respondents.



Communication checklist

- ✓ If you make your own visuals, always include the Rare Barometer logo.
- ✓ Remember to use the hashtag **#RareBarometer** in messages on social media.
- ✓ Remember to include the link to the survey or to the Rare Barometer website in any messages about our surveys.
- ✓ Specify the deadline of the survey.

There is no 'one way' of doing effective communication. Every context is different, and the time and resources you have within your reach may vary. The most efficient communication actions are often the simplest ones, such as encouraging your network to take the survey in your day-to-day communications (emails, newsletters...). To make the most of your organisation's communication channels and of the material provided by Rare Barometer, you can consider the following questions:

- **Who do you want to encourage to take the survey, and who can support you in disseminating it?** Make an overview of your internal and external communication channels to map which channel is the most efficient in reaching out to your target audience. Reach out to your partners.
- **Who is your main target audience and what do they need to know?** You can create content directed to their needs and interests to maximise your reach.

Here are some tips and tricks on how to encourage your network to participate in our surveys, ranging from the less time-consuming to the more time-consuming actions.

General communication:

- **Newsletters:** inform your network about the survey and why they should participate. Share the link to the survey and invite them to take it and to share it with their network.
- **Social media:** use the social media visual and suggested messages in the communication toolkit (or make your own) to encourage your followers on social media to participate in our surveys.
- **Personalised emails:** in our experience, this remains the most efficient way to reach out to your community for online surveys.
- **Meetings/calls/webinars:** remind your network to participate in the survey during regular calls with your members and partners. This can be relevant events and webinars, or regular check-ins. Include a slide with information about the survey and share the link to participate.

When inviting people to participate in a new survey, emphasise why the survey is important to your community and remind them that they will receive the results of the survey, and how you intend to use the results.

Additional communication:

- Invite the Rare Barometer team to come and speak about the survey at any relevant events or regular check-ins with your members. Make recordings and share them with people who could not attend.
- Make video recordings explaining the survey topic and how people can participate. Share this with your members on social media or through your newsletters.
- Reach out to different partners, including healthcare professionals specialised in rare diseases, who can help you reach 'hard-to-reach' or underrepresented members of your community.
- Use Facebook ads to reach out to your network or target a new audience.
- Encourage your network to sign up to the Rare Barometer panel. Although it is not compulsory to sign up to participate in our surveys, people registered in our database are always the first ones to receive invitations about new and upcoming surveys in their local language.

3 Using Rare Barometer survey results

What better way to draw the attention to a topic than by using numbers and statistics?

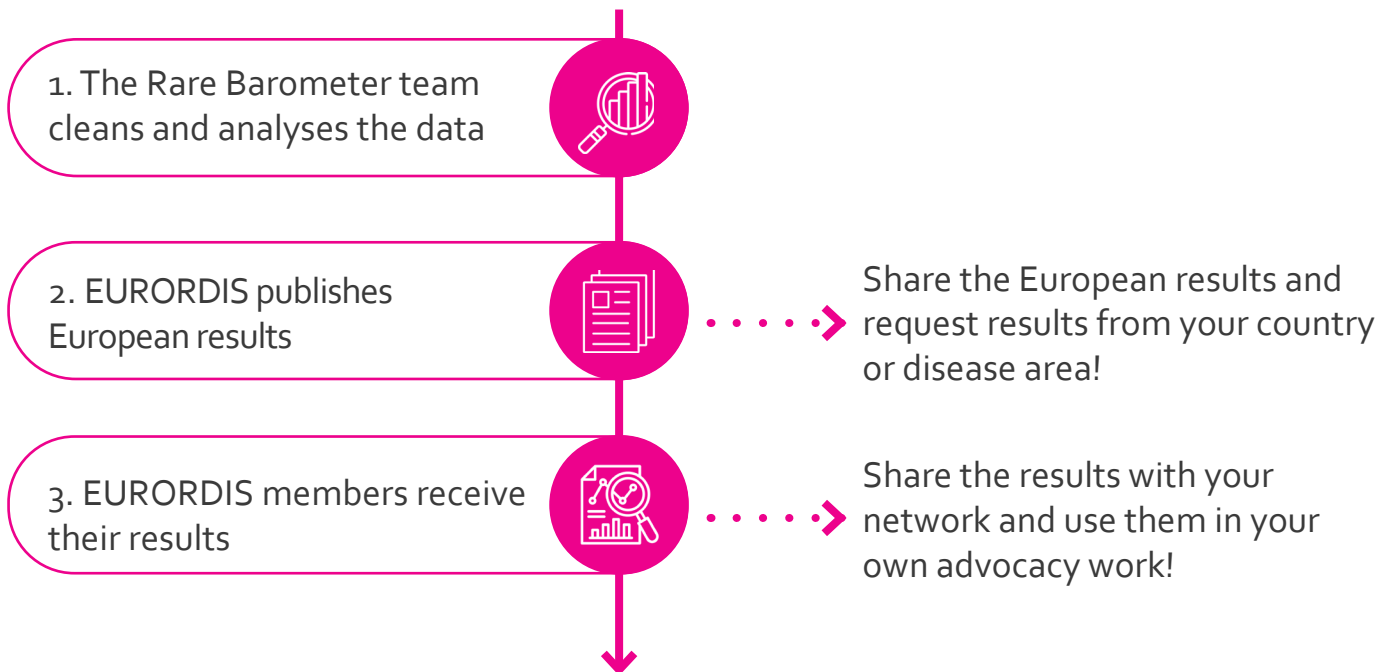
EURORDIS-Rare Diseases Europe uses Rare Barometer survey results to advocate for policies and innovative solutions for all rare diseases in Europe, while our members can freely use and communicate their results for their country, disease or disease group. The Rare Barometer team provides three types of supports to present Rare Barometer survey results:

- Reports or peer-reviewed articles with in-depth information about the survey methodology and European results, available in English.
- Factsheets with key information presented in a short and visual manner, available at least into the 7 EURORDIS languages and in other languages on request.
- Dashboards consisting of tables and figures for each question of the survey, available in 23 languages.

Once the overall European results have been published, members of EURORDIS-Rare Diseases Europe with at least 30 respondents in their community and from anywhere in the world can ask to receive the tailored dashboards and factsheets presenting their own results: send us an email at rare.barometer@eurordis.org

Analysing and publishing survey results

What EURORDIS members can do





Report or peer-reviewed article

In-depth description and analysis of European results are published either in a report or a peer-reviewed article in English, allowing you to dive deeper into the different dimensions of the survey, guiding your own analysis.



Factsheets

For every survey, key results are published as factsheets available in 7 languages, and more languages on demand. The factsheets are designed to provide key results concisely and graphically, and can be used for:

- **Advocacy:** the factsheets can be shared with decision-makers, providing them with the knowledge and overview only patients and their advocates can bring to the table.
- **Press:** numbers and figures draw the attention of journalists and decision-makers. Share the factsheets with relevant national or local newspapers to generate awareness on a specific topic.
- **Events:** the factsheets can be disseminated in relevant meetings and conferences to highlight the situation on a particular topic.

EURORDIS-Rare Diseases Europe published factsheets with key European results, and EURORDIS members with more than 30 respondents in their community and from anywhere in the world can ask for a factsheet with key results from their community.



Dashboards

Once the data has been consolidated, we create dashboards presenting the final results for each question of the survey, and we can create specific dashboards for all our members with least 30 respondents in their community and from anywhere in the world.

The dashboards contain the data you need to make your own analysis based on the results from your country, disease, or group of diseases. You can compare your analysis with the one conducted by the Rare Barometer team to check how the situation in your country or disease area contrasts with the European results. You are also free to draft your own publication based on the results of your analysis (e.g. a scientific paper, a detailed report), and mention Rare Barometer!

European results of Rare Barometer surveys are shared with everyone who responded to the survey, and communicated to patient organisations, decision-makers and the wider public, to drive real change for the rare disease community: our publications are available on our website eurordis.org/voices

Members of EURORDIS-Rare Diseases Europe with more than 30 respondents can receive a factsheet and a dashboard with their own results.

		European results	European results for one disease or group of diseases	Country results (any country in the world)	Specific results (results from one disease or group of diseases from a specific country)
	Everyone	X			
EURORDIS MEMBERS	European Federations	X	X		
	National Alliances	X		X	
	Other EURORDIS members	X			X

Tips for you:

- Have a look at our publications on our website: eurordis.org/voices
- Ask the Rare Barometer team if you have enough respondents to receive the results from your country, disease, or group of diseases and use the results in your own advocacy work!
- If you are interested in the results from a specific country or European results for a specific disease, you can reach out to the respective EURORDIS National Alliance or European Federation and ask for the results.
- Always communicate survey results to your community and tell them how you have used them or intend to use them – it will encourage your community to participate in future surveys!

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We took part in the COVID-19 survey, and shared the infographics with our politicians to push the case and advocate for the inclusion of people living with a rare disease, facing the challenge and risk of COVID. This was priceless, and a lot of benefit for us to make our work easier.

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Lisa Foster, Former Chief Executive, Rare Disorders New Zealand

4 Useful resources

Visit our website to register to the Rare Barometer panel, access European survey results and have more information on the programme:

eurordis.org/voices

If you plan to conduct your own research, you can scan the QR code below to access the resources developed by EURORDIS-Rare Diseases Europe:

- The Listen Up. Follow-Up guide: A brief guide for rare disease patient organisations on how to listen to the community;
- An online course on 'Survey design for rare disease patient organisations';
- A repository of questions useful for any survey on rare diseases, with their translation in 23 languages.

Previous Rare Barometer questionnaires are available upon request to rare.barometer@eurordis.org

