



Rare Barometer Programme

EURORDIS - European
network of help lines for rare
diseases - Face to face meeting



What is Rare Barometer Programme ?



- EURORDIS survey programme
- Launched in June 2015

What is the aim of Rare Barometer programme ?

Context : Necessity for rare disease patients to be involved in health, research and social decision making

Facilitate and streamline the inclusion of patient perspectives



Provide a high quality evidence base

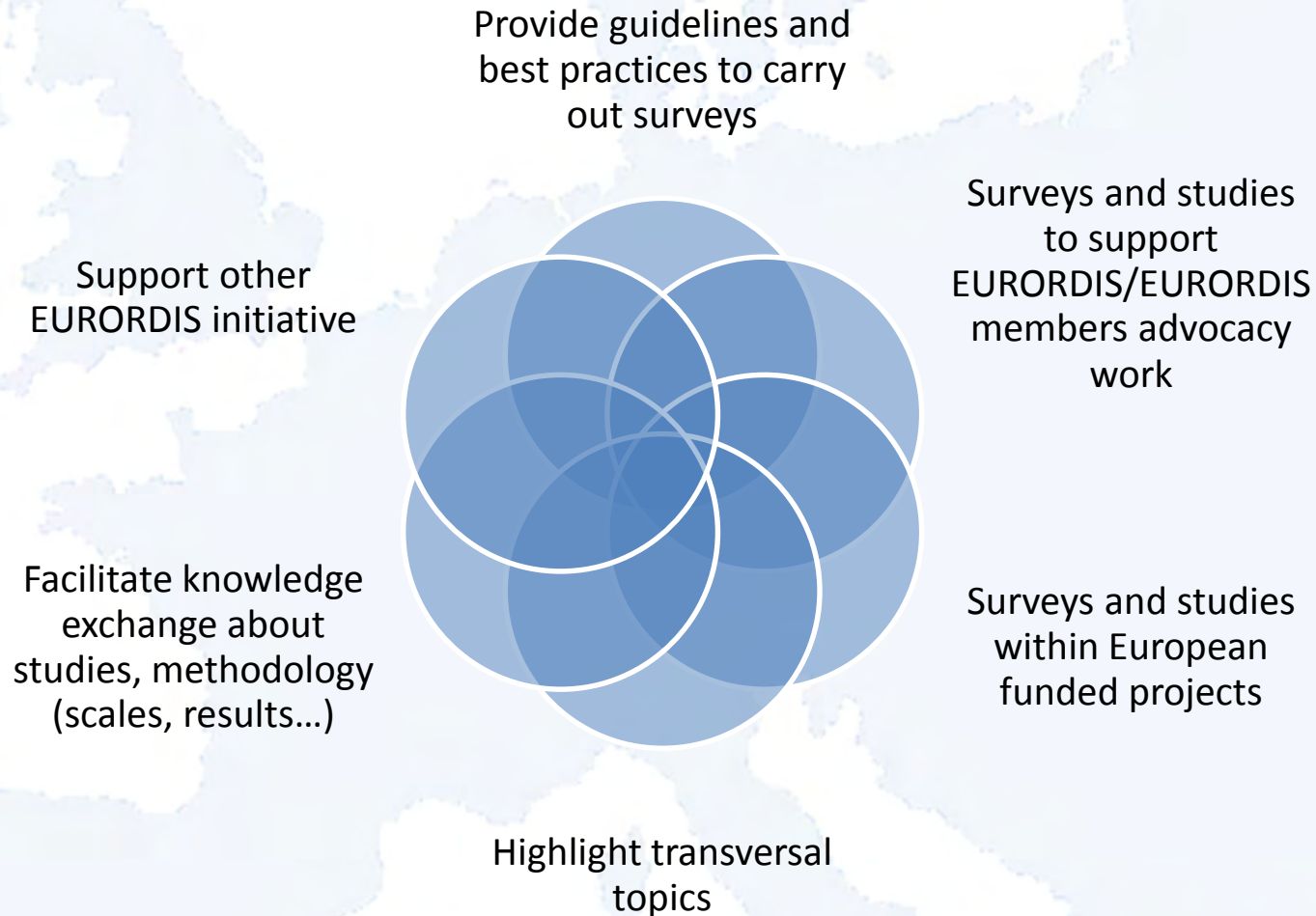


Support advocacy and policy making activities at EURORDIS



Promote and improve further research on patient perspectives

Rare Barometer : An interactive project



RareConnect template

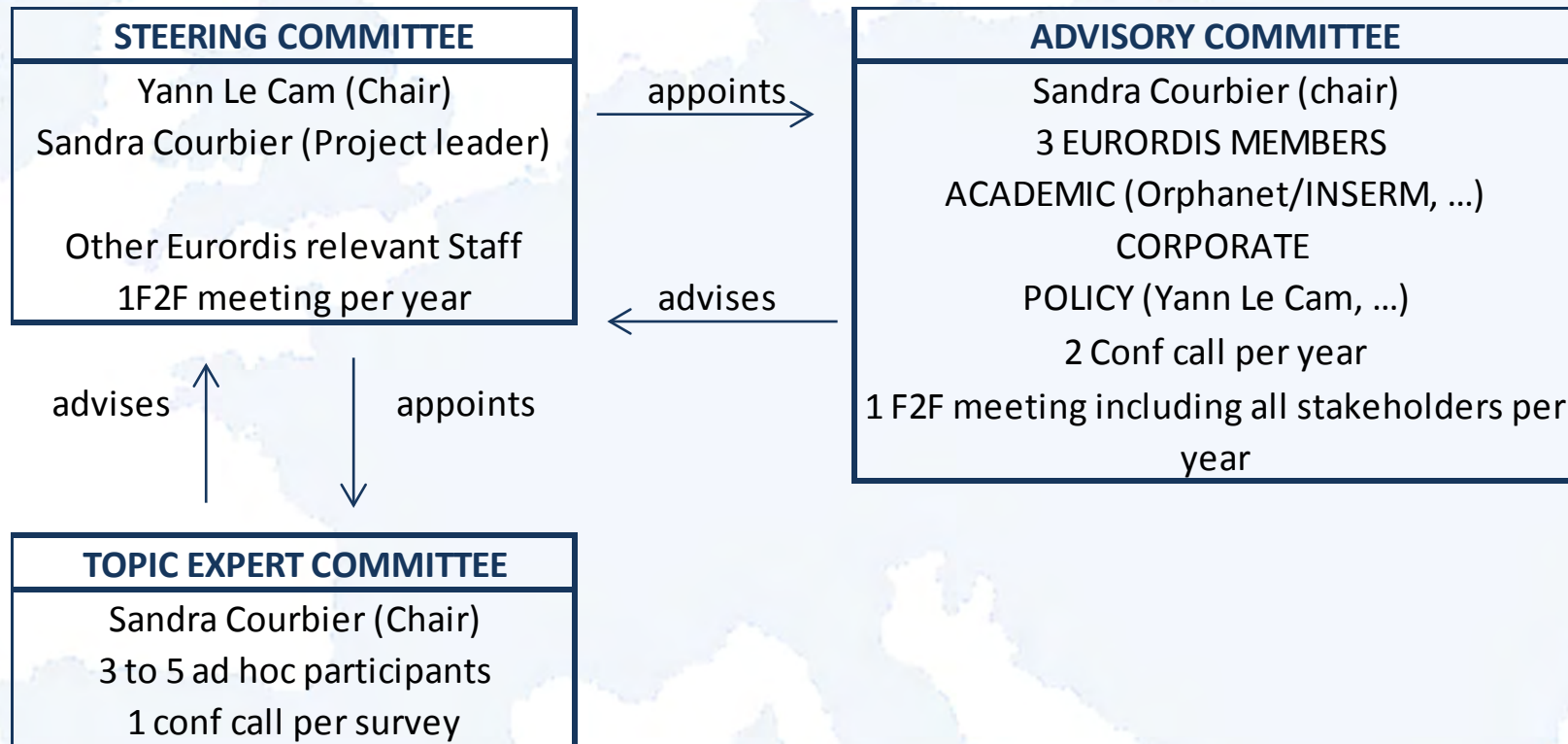
Survey template
Applicable to any
disease



What kind of methods?



Rare Barometer's governance



Scope of the surveys

- EURORDIS's Advocacy priorities

- Genetics & Data sharing :

- 2015/2016 - RD Connect :



Delphi exercise with expert patients

- 2016 - Genetic Clinic of the Future : Patient perspectives about genetic data sharing

- Diagnosis

- Social care provision :

- 2016 : INNOVCare : Study on the needs of patients/families in their social and daily life

Tools



- Sphinx, all in one survey software :
 - ✓ Data collection, enabling multicountry surveys
 - ✓ Responsive
 - ✓ App available for face to face data collection
 - ✓ Online dissemination (emailing, profile selection)
 - ✓ Analysis of the survey, qualitative and quantitative
 - ✓ Data storage in France : online platform with high security level

Sophisticated web forms

- Response control
- Conditions (go to question...), restrictions (show only if...)
- Insertion of image, pictogramme

The screenshot shows a configuration window for a web form, with the 'Presentation' tab selected. The window is divided into three main sections:

- Visual / Shape:**
 - Presentation of modalities: Pictograms
 - Pictograms: A row of five emoticon-like pictograms (angry, sad, neutral, happy, surprised) with a 'Size: Auto' dropdown.
 - Number of columns: 2, with a dropdown 'from top to bottom'.
 - Text of modalities: Right
 - ☐ Number of modalities
 - ☐ Ignore controls on modalities
- Contents:**
 - ☒ Show title
 - ☒ Label (dropdown) ☐ Variable
 - ☐ Fixed width: 0.1 cm
 - ☐ Display the instruction: Below input zone
- Data entry zone:**
 - Layout: Below question
 - ☐ Read-only

At the bottom, there are buttons for 'New question', 'Library', 'OK', and 'Cancel'.

Reporting

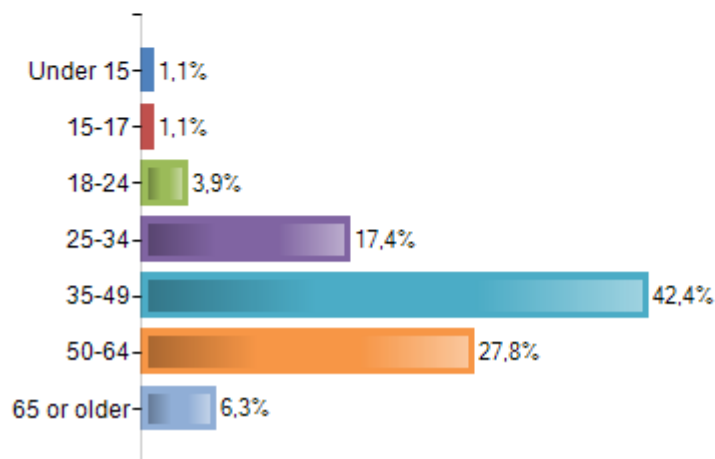
- Automatic report
- Webreporting

1. How old are you?

	Frequencies	% Obs.
Under 15	6	1,1%
15-17	6	1,1%
18-24	22	3,9%
25-34	97	17,4%
35-49	236	42,4%
50-64	155	27,8%
65 or older	35	6,3%
Total	557	100%

Effective responses : 557
Response rate : 100%

Non-response(s) : 0
The most quoted modalities : 35-49; 50-64; 25-34



Quantitative surveys are the biggest challenge

- Statistics about rare disease population don't exist (except prevalence)
- Small number of people per disease
- A « list of people » affected by rare disease doesn't exist

➡ Usual methods for sampling and contacting participants by phone or face to face (by quota or random) are not applicable

Rare Barometer Voices



Group of pre-screened patients who have offered to provide personal information on an on-going basis



Patients, family member and patient representative




Contact list (email) with useful sociodemographic information (disease, gender...) combined with an emailing tool

Give the possibility to select the contact you want to interrogate






Exclusive tool, constant check by data management, protected by a password with access limited to one person only

eurordis.org/voices

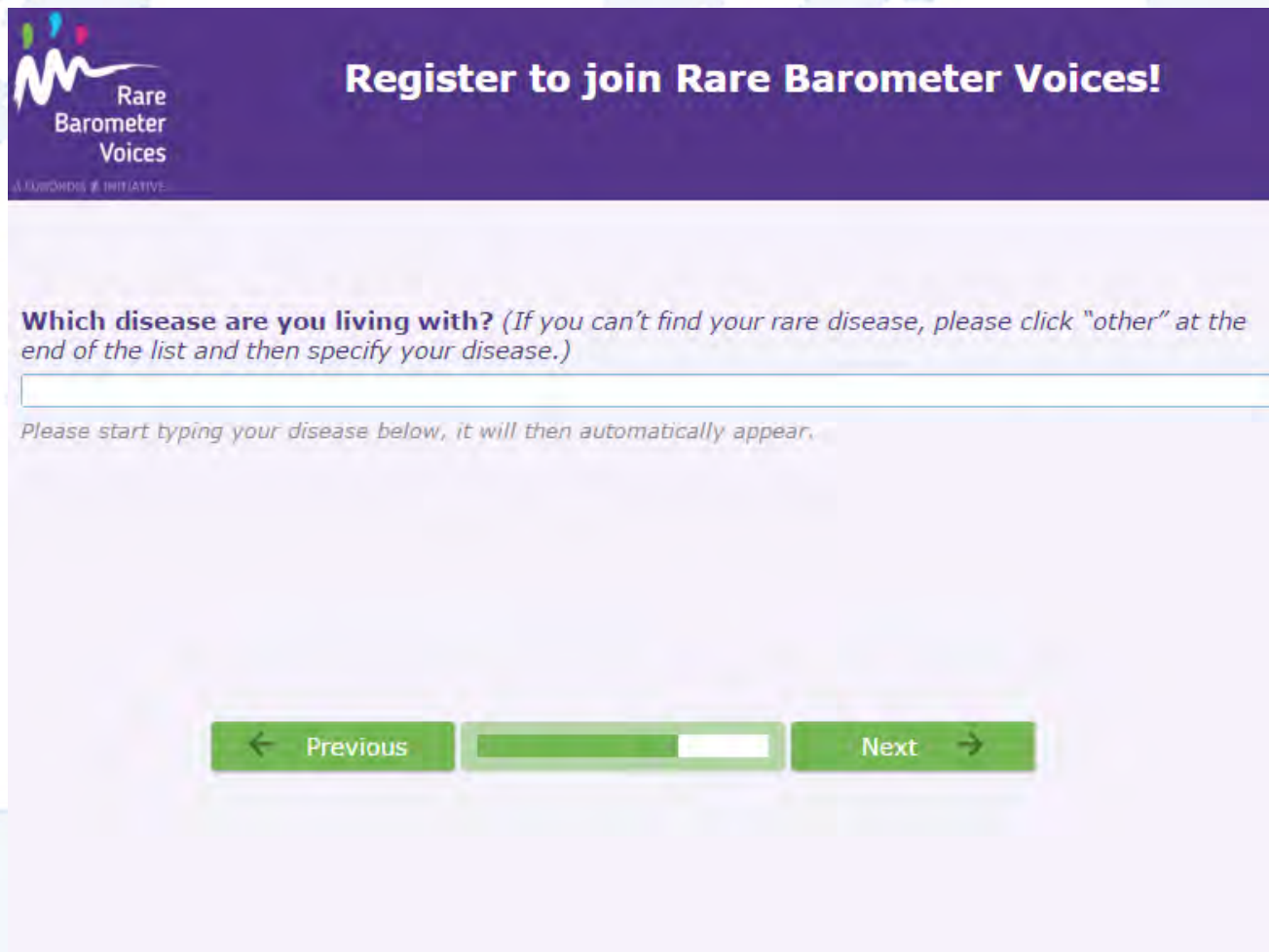


"Make your voice heard!"

- 
1
Register to Rare Barometer Voices
- 
2
Receive invitations to surveys
- 
3
Take part in the surveys

[Register now](#)

Registration questionnaire



Register to join Rare Barometer Voices!

Rare Barometer Voices
EURORDIS INITIATIVE

Which disease are you living with? *(If you can't find your rare disease, please click "other" at the end of the list and then specify your disease.)*

Please start typing your disease below, it will then automatically appear.

← Previous Next →

Rare Barometer Voices characteristics

- Website and surveys available in 23 languages (main EU languages + Russian)
- 48 countries covered (EURORDIS membership criteria)
- List of diseases : 7 Orphanet languages
- Short results available in 23 languages, full analysis in 7 languages

Rare Barometer Voices recruitment

First step:

- Social media
- Through EURORDIS member

Next step:

Center of expertise

 Diversify respondent profile

EURORDIS survey panel objectives

- Represent the diversity of rare disease population (diseases, country, socio-demographic profile..)
- Carry out longitudinal studies
- Consider the rare disease community as a whole
- Statistical adjustment : by countries and disease prevalence (Orphanet data)