RARE BAROMETER VOICES

A new international Advocacy tool?

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What is Rare Barometer Voices?
What is the objective of the tool?

Collect patient experiences and opinions
Through validated methods
Generate fact and figures
Feed the rare disease community’s advocacy work
Rare Barometer Voices

Rare Barometer Voices is a group of people living with a rare disease who participate in EURORDIS surveys and studies.

Patients, families, patient representatives can register

Participants provide useful information for future surveys (disease, gender, age ...)

Rare Disease patients can register from any country of the world
Surveys and registration page are available in 23 languages

High level of data protection (Sphinx survey software)
Advantages of building a panel

- Quality of the data
- Carry out longitudinal studies
- Inform participants on the results of the survey
- More detailed analysis
Description and possibilities of the sample
7500 patients and families have registered for Rare Barometer Voices!
Distribution by country

Countries outside of Europe
USA: 196
South Africa: 42
Australia: 39
Brazil: 35
Canada: 32
...

EURORDIS.ORG

EUROPEAN RARE DISEASES ALLIANCE

www.eurordis.org
### 1420 different diseases in total

<table>
<thead>
<tr>
<th>Disease</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ehlers-Danlos syndrome</td>
<td>178</td>
</tr>
<tr>
<td>22q11.2 deletion syndrome</td>
<td>125</td>
</tr>
<tr>
<td>Cystic fibrosis</td>
<td>116</td>
</tr>
<tr>
<td>Duchenne muscular dystrophy</td>
<td>106</td>
</tr>
<tr>
<td>Neurofibromatosis type 1</td>
<td>102</td>
</tr>
<tr>
<td>Systemic sclerosis</td>
<td>91</td>
</tr>
<tr>
<td>Sarcoidosis</td>
<td>86</td>
</tr>
<tr>
<td>Tuberous sclerosis complex</td>
<td>77</td>
</tr>
<tr>
<td>Behçet disease</td>
<td>73</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td>70</td>
</tr>
</tbody>
</table>
### Participants’ profile

#### Diagnosis Status

<table>
<thead>
<tr>
<th>Diagnosis Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed</td>
<td>92</td>
</tr>
<tr>
<td>Undiagnosed</td>
<td>8</td>
</tr>
</tbody>
</table>

#### Respondent Status *(Several answers possible)*

<table>
<thead>
<tr>
<th>Respondent Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>55</td>
</tr>
<tr>
<td>Parent of a child living with a rare disease</td>
<td>42</td>
</tr>
<tr>
<td>Other family members</td>
<td>5</td>
</tr>
<tr>
<td>Sibling of a person living with a rare disease</td>
<td>4</td>
</tr>
<tr>
<td>Grandparent of a person living with a rare disease</td>
<td>1</td>
</tr>
<tr>
<td>Patient representative</td>
<td>6</td>
</tr>
</tbody>
</table>

- High proportion of patients and families not engaged in advocacy activities
All results are made available to the Rare Disease community

- 72% for patients
- 69% for carers
- 78% in the UK
- 69% in France
- 73% of women
- 63% of men
Example of what a ‘RDI’ survey could be
Choosing the topic

Context:
- International event focusing on inequalities
- Survey Topic Expert committee (RDI volunteers, experts on the topic)
During the past 12 months did it ever happen that you did not get the medical treatment you needed because...

- The treatment was not available where you live?
- You could not pay for it
- The waiting list was too long

- Yes
- No it didn’t happened
- No need of medical treatment
- Don’t know
Analysing and creating awareness through powerful advocacy tools

Comparison with the general population

During the past 12 months did it ever happen that you did not get the medical treatment you needed because...
... The treatment you needed was not available where you live (n=1350)

Infographic based on the results

- FOR 24%, Vs 7% in the general population, the treatment was not available where they live
- FOR 15%, Vs 6% in the general population, they could not pay for it
- FOR 19%, Vs 9% in the general population, the waiting list was too long

- Rare Barometer Voices
- International Social Survey Programme