

RARE BAROMETER VOICES

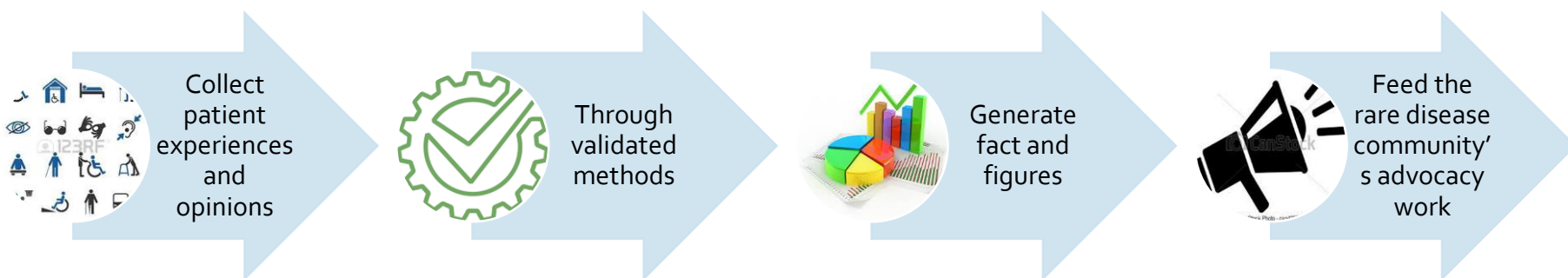
**A new international Advocacy
tool?**

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Manager

9th Mai 2018

What is Rare Barometer Voices?

What is the objective of the tool?



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

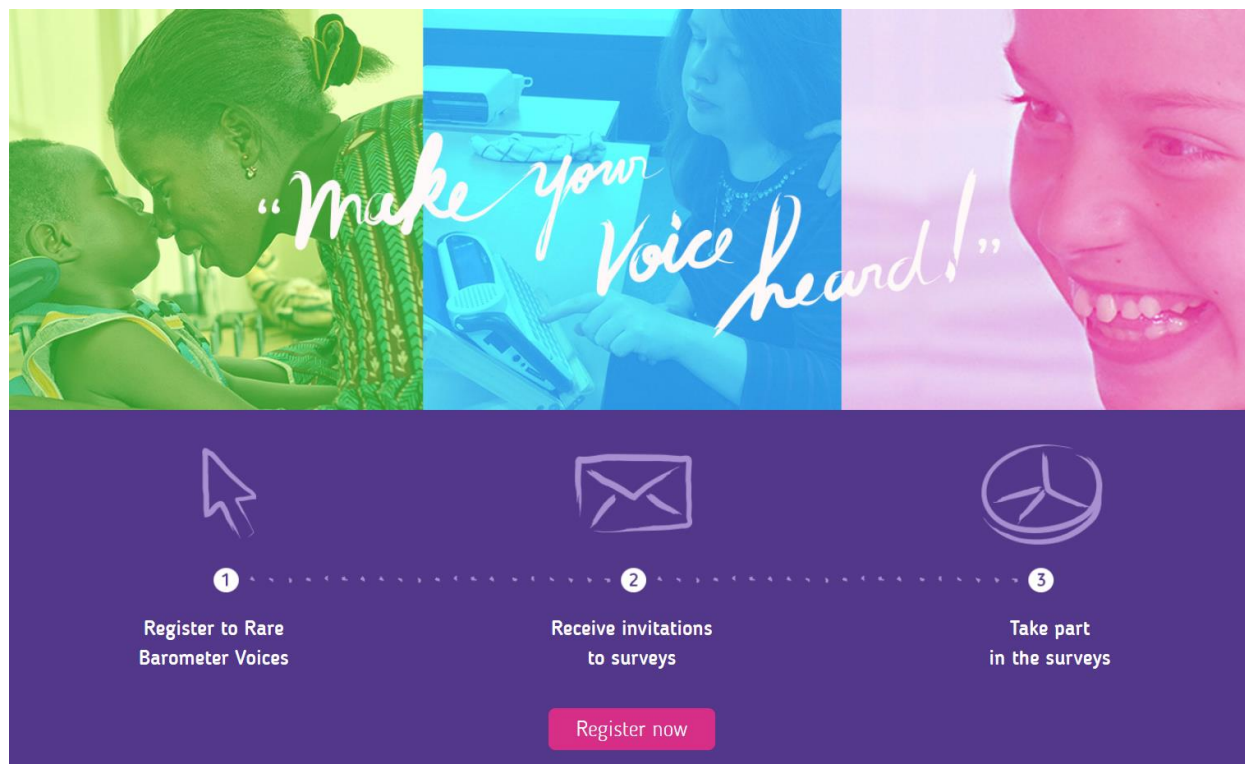


Participants provide useful information for future surveys (disease, gender, age ...)



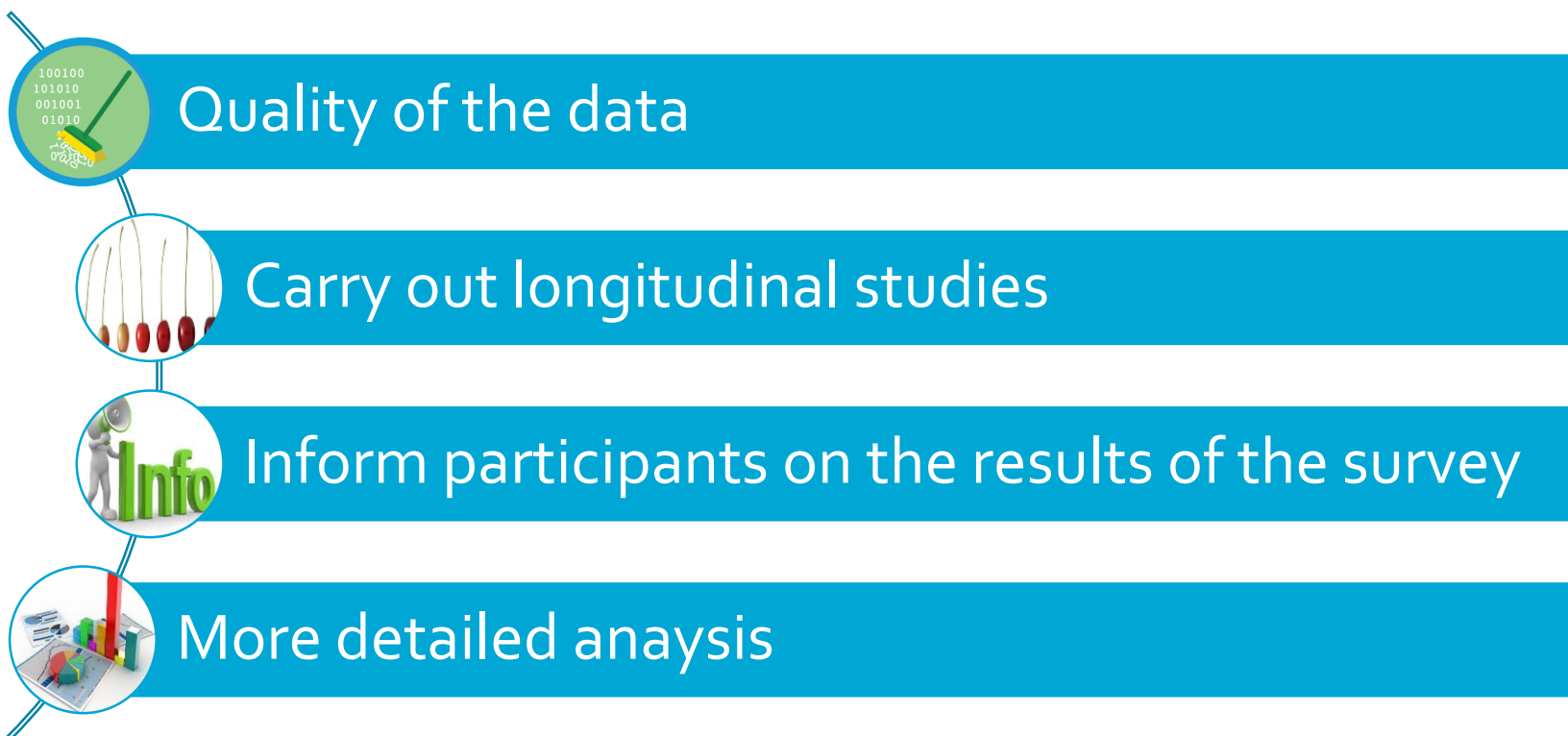
Rare Disease patients can register from any country of the world

eurordis.org/voices



- Surveys and registration page are available in 23 languages
- High level of data protection (Sphinx survey software)

Advantages of building a panel

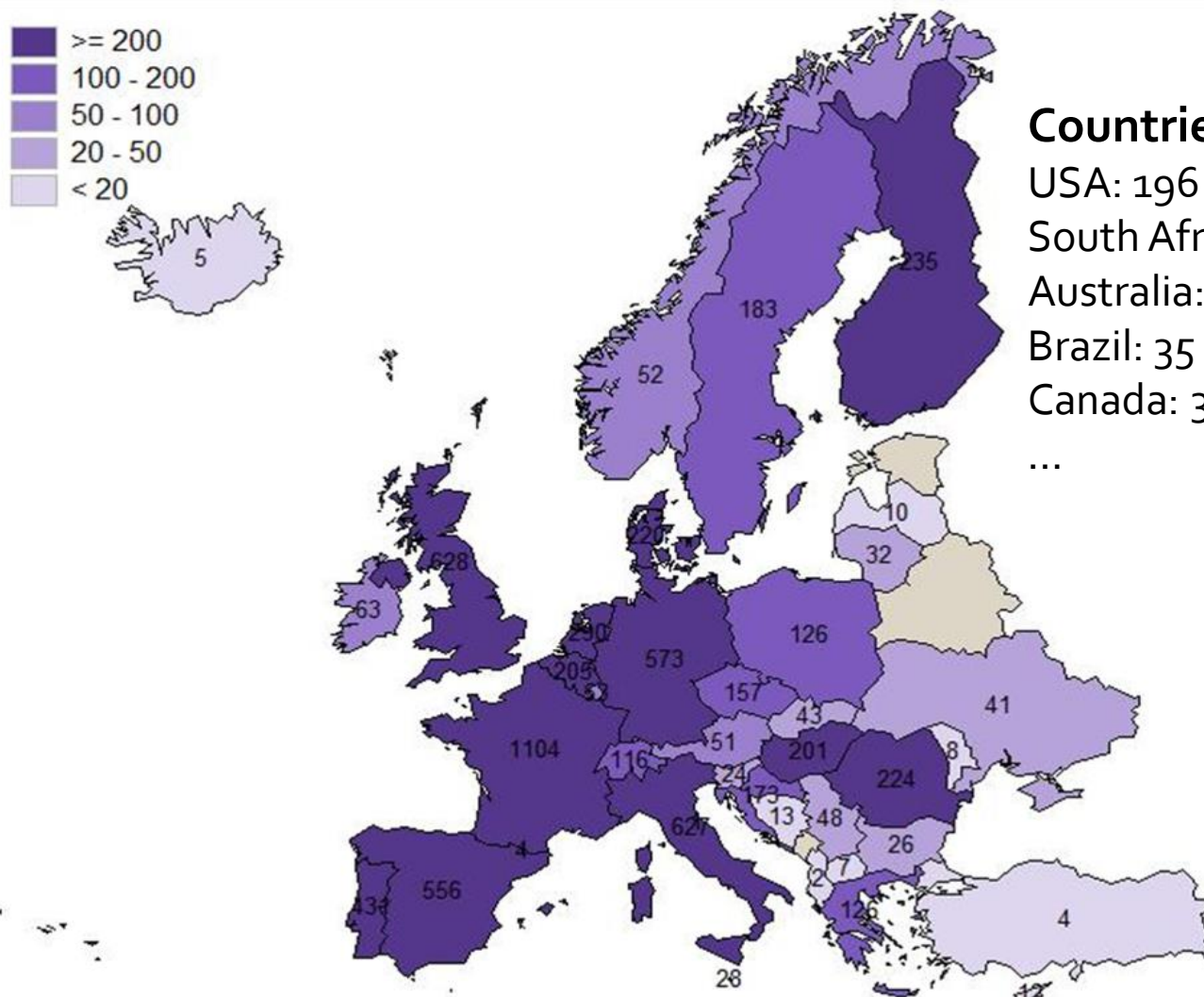


Description and possibilities of the sample

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

...

1420 different diseases in total

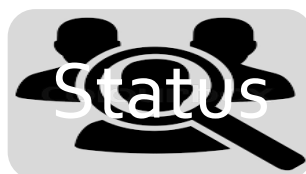
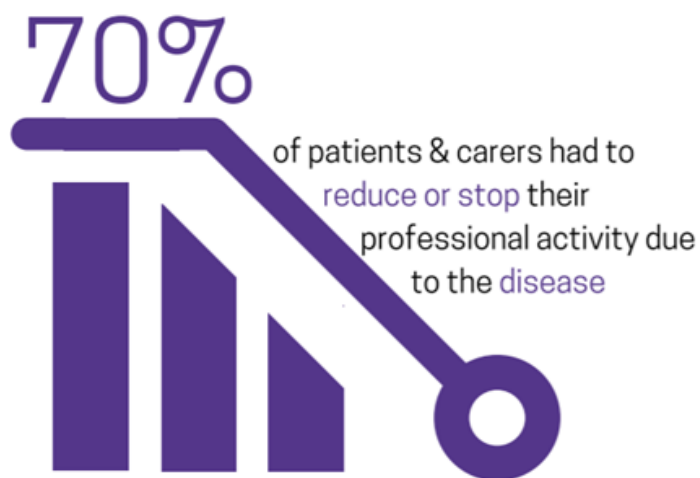
Disease	Frequency
Ehlers-Danlos syndrome	178
22q11.2 deletion syndrome	125
Cystic fibrosis	116
Duchenne muscular dystrophy	106
Neurofibromatosis type 1	102
Systemic sclerosis	91
Sarcoidosis	86
Tuberous sclerosis complex	77
Behçet disease	73
Myasthenia gravis	70

Participants' profile

Diagnosis Status	
Diagnosed	92 %
Undiagnosed	8 %
Respondent Status (<i>Several answers possible</i>)	
Patient	55 %
Parent of a child living with a rare disease	42 %
Other family members	5 %
Sibling of a person living with a rare disease	4 %
Grandparent of a person living with a rare disease	1 %
Patient representative	6 %

- High proportion of patients and families not engaged in advocacy activities

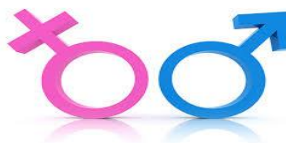
All results are made available to the Rare Disease community



- 72% for patients
- 69% for carers



- 78% in the UK
- 69% in France



- 73% of women
- 63% of men

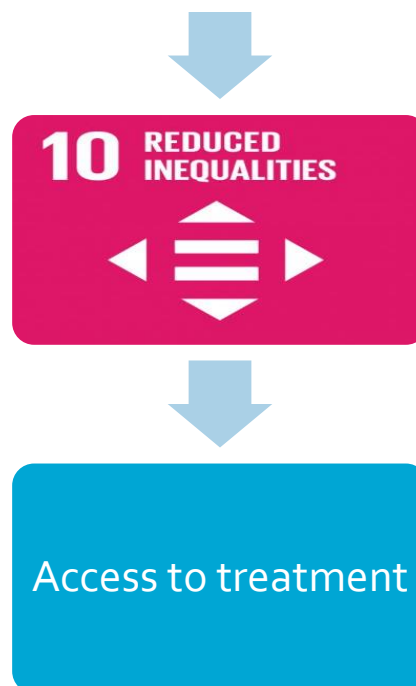
Example of what a 'RDI' survey could be

Choosing the topic



Context:

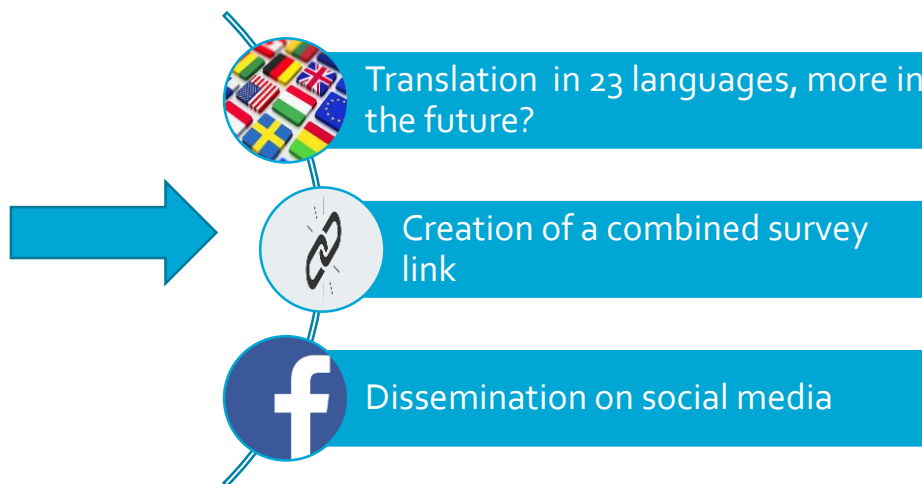
- International event focusing on inequalities
- Survey Topic Expert committee (RDI volunteers, experts on the topic)



Creating and disseminating the survey

During the past 12 months did it ever happen that you did not get the medical treatment you needed because...

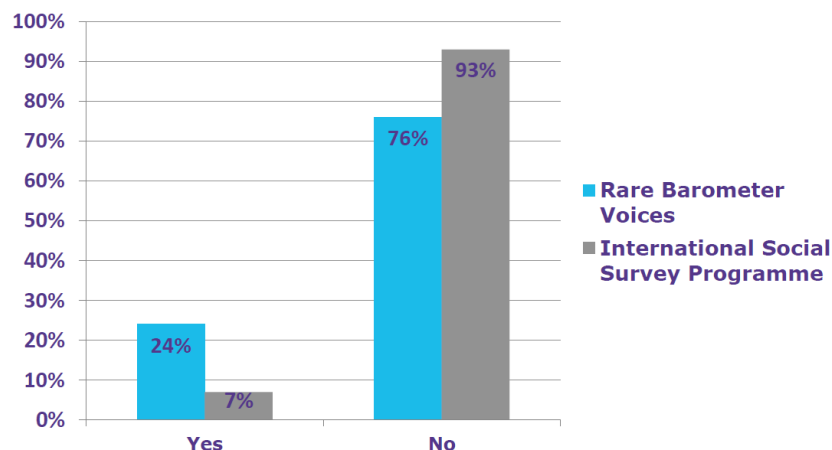
- The treatment was not available where you live?
- You could not pay for it
- The waiting list was too long
- Yes
- No it didn't happened
- No need of medical treatment
- Don't know



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

