



UPDATE ON RARE BAROMETER /HOW TO USE THE NEW SURVEY ON RARE DISEASE RESEARCH

CNA/CEF meeting

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EURORDIS.ORG

Rare Barometer Voices – Quick reminder

Group of people living with a rare disease who participate in EURORDIS surveys

➔ **Transforming opinions and experiences** about topics that directly affect rare disease patient into **figures and facts** to feed the rare disease community's advocacy work



Patients, families, patient representatives can register



At registration participants provide useful information for future surveys (disease, gender, age ...)



Registration page (eurordis.org/voices) and surveys are available in 23 EU languages



Results are **available to patient organisations: by country, by ERN, by disease** when possible

Rare Barometer Voices is now available to participants around the world

Make your voice heard!

Rare Barometer Voices

EURORDIS & INITIATIVE

Which country do you live in?

Afghanistan
Albania
Algeria
Andorra
Angola
Antigua and Barbuda
Argentina
Armenia
Australia
Austria
Azerbaijan
Bahamas
Bahrain
Bangladesh
Barbados
Belarus
Belgium
Belize
Benin

Next →

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August 2017



More than 7000 patients and families have registered for Rare Barometer Voices !



Thank you for spreading the word about Rare Barometer Voices!

Elena Mora Navas @ElenaMoraNavas · 17 oct.

La experiencia de los pacientes, un valor incalculable para a info que manejamos. Nueva #infografía de @eurordis gracias a #RareBarometer.

Rare Diseases Europe @eurordis

New! Our #infographic on social impact of #raredisease, the focus of today's launch event #ParliamentAdvocate4Rare download.eurordis.org/rbv/juggling_c...

1 retweet 1 like

NFSD #sällsyntliv @NFSDse · 5 oct.

Ny #RareBarometer enkät inför #sällsyntdagen2018 där temat "Forskning". eurordis.org/voices #sällsyntliv

1 retweet 1 like

Marios Rossides @mrossidescy · 7 sept.

Living with a #RareDisease? Tell your thoughts about #research! This is important! #RareBarometer

Rare Diseases Europe @eurordis

What type of #raredisease #research have you participated in? Tell us about your experience ow.ly/jDu330eFt7B #RareBarometer

1 retweet 1 like

Genetic Alliance UK @GeneticAll_UK · 6 sept.

Make your voice heard! #RareBarometer is now global, register wherever you are to respond to @eurordis surveys ow.ly/7a6E30eQhYP

5 retweets 2 likes

HPEspaña @HPE_ORG · 3 sept.

Eres paciente, cuidador o familiar con una #enfermedadrara? #Rarebarometer regístrate donde quiera que estés buff.ly/2eLvfnq

3 retweets 2 likes

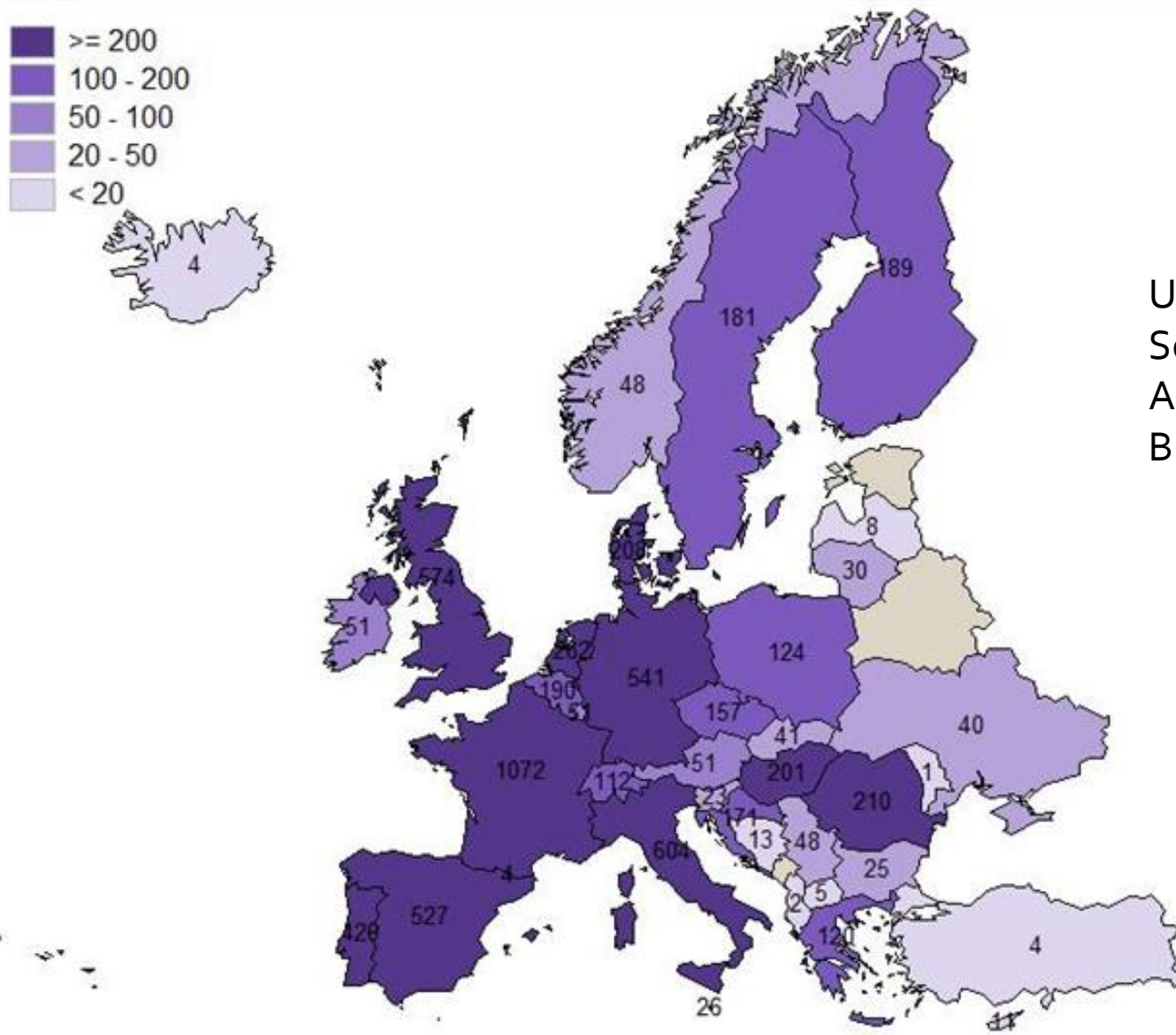
Mollarets Meningitis @MM_Assoc · 21 août

Check out eurordis.org/voices to participate in rare disease surveys. Europe Only.

#RareBarometer #CureMollarets

1 retweet 1 like

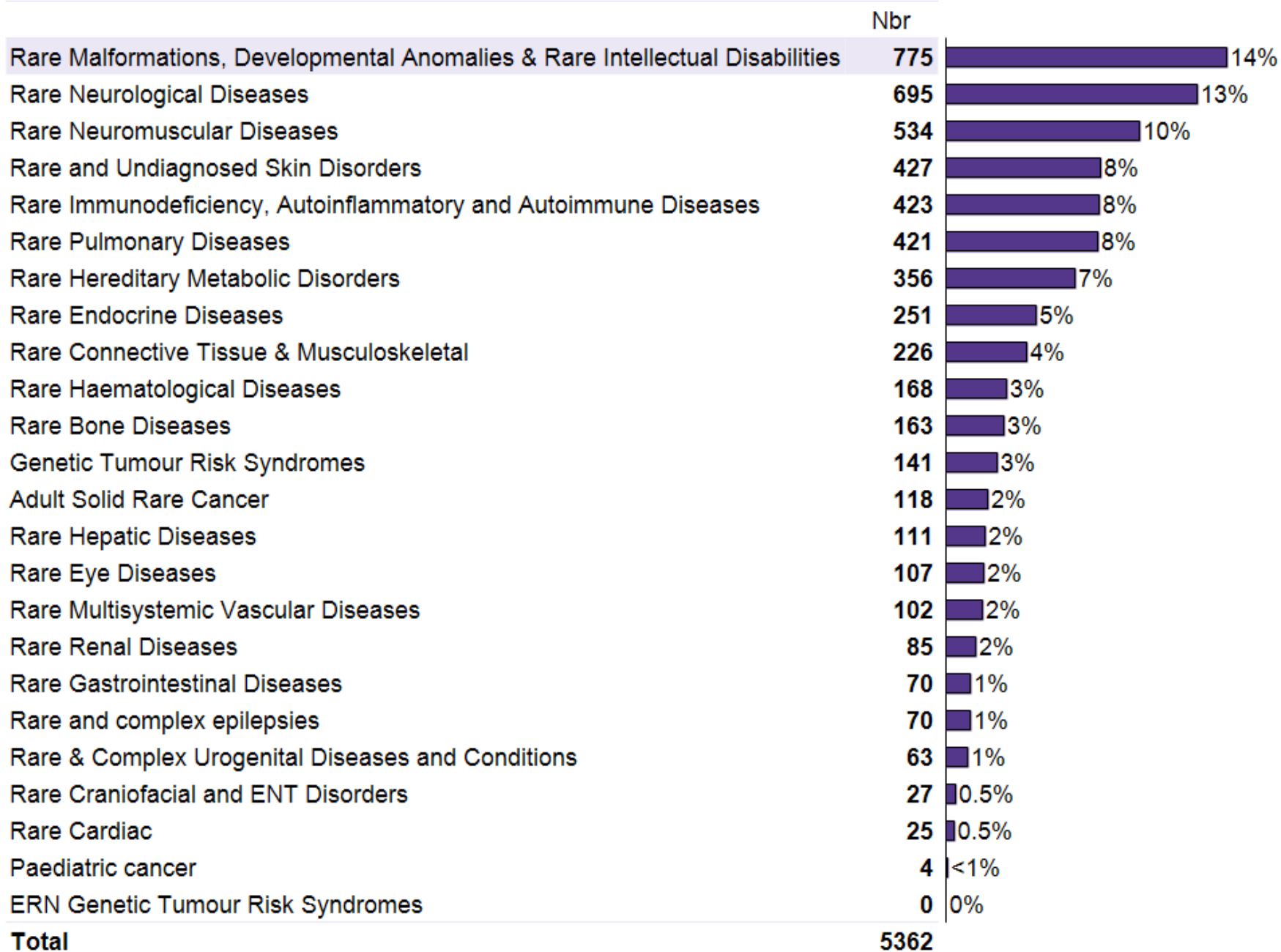
The number of respondents by country is progressing



USA: 153
South Africa: 40
Australia: 34
Brasil: 33

1306 different diseases in total

166	Ehlers-Danlos syndrome, hypermobility type
123	22q11.2 deletion syndrome
113	Cystic fibrosis
100	Duchenne muscular dystrophy
98	Neurofibromatosis type 1
89	Systemic sclerosis
84	Sarcoidosis
75	Tuberous sclerosis complex
65	Williams syndrome
63	Myasthenia gravis



New: Paper leaflets!

Confidentiality & protection of your data

All of the information you share with us is **completely confidential** and **anonymous**.

- The programme is run independently by EURORDIS and is a **non-profit initiative**. Your data will not be used for commercial purposes.
- **You can unsubscribe at any time** by clicking the link in the survey email.

Rare Barometer Surveys

Previous Rare Barometer Voices surveys have been carried out on **topics including:**

Access to treatment

Alternative & complementary therapies

Juggling care & daily life

How to register?

Please provide your email below and we will send you our invitations to participate in each new survey:

Email

Do you agree to be contacted on this e-mail address?

Yes

No

If you write "no", you will not receive invitations to participate in surveys.

How to send back your registration?

→ **Via your patient organisation:**

Give the form to your patient organisation and they will pass it on to EURORDIS.

→ **Email:**

Scan this page and send it to: rare.barometer@eurordis.org

THANK YOU FOR JOINING!

First Europe-wide survey on social impact of rare diseases

Juggling care and daily life:

The balancing act of the rare disease community

- Scope of the EU-funded INNOVCare project
- 3071 patients and carers participated
- 802 diseases, 42 countries
- Performed in 23 languages



http://download.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20ofinal.pdf

First Europe-wide survey on social impact of rare diseases

Results were presented during the Launch of European Network of Parliamentary Advocates for RDs



Heavy time burden for patients & carers

42% Of patients & carers spend **more than 2h/day** on illness-related tasks

Hygiene



Administration of treatments



Helping with house chores



Helping patients to move



Lack of flexibility and adaptation of tasks

Rare disease patients and carers in employment face certain needs that are not always met by employers:

- People living with a rare disease often need to stop working during most challenging times:

58% absent from work over 15 days/year

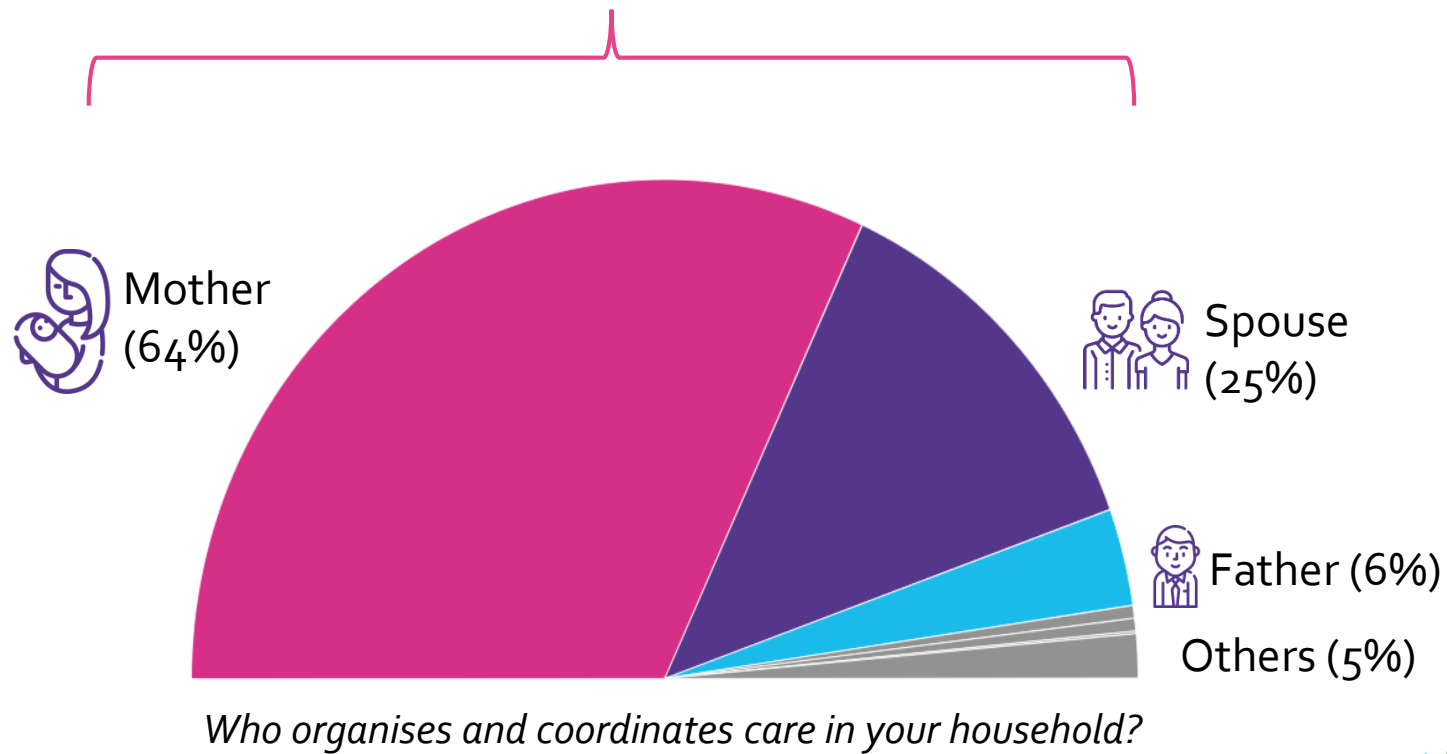
21% absent from work over 90 days/year

- The possibility of asking for special leave is a high unmet need for rare disease patients:

41% asked but could not obtain it

A burden that heavily falls on women

The role of the primary carer for people living with a rare disease is primarily assumed by women



New infographic

Rare diseases seriously impact everyday life

7 in 10 patients & carers

reduced or stopped professional activity due to their or their family member's rare disease.



8 in 10 patients & carers

have difficulties completing daily tasks (household chores, preparing meals, shopping etc.)



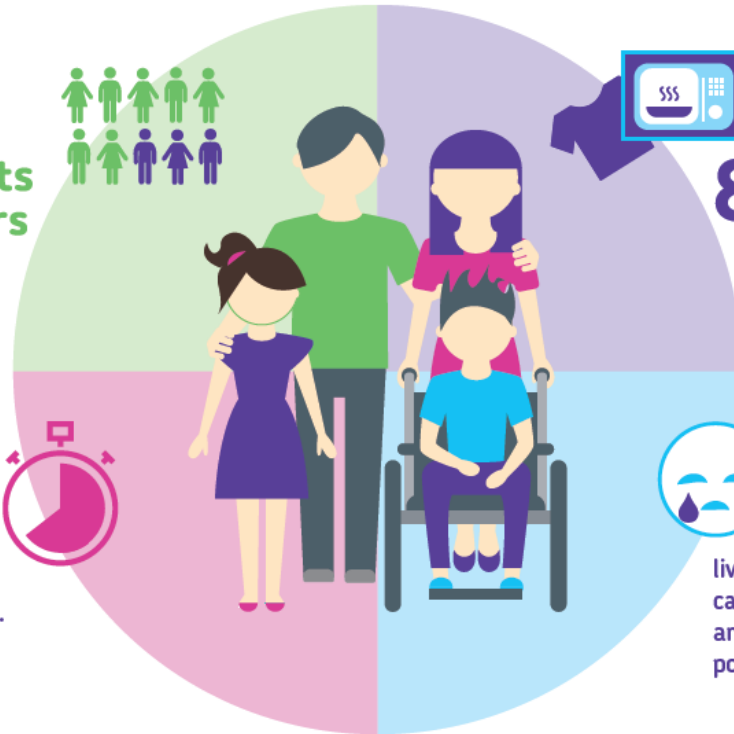
2/3 of carers

spend more than 2 hours a day on disease-related tasks.



3 times more people

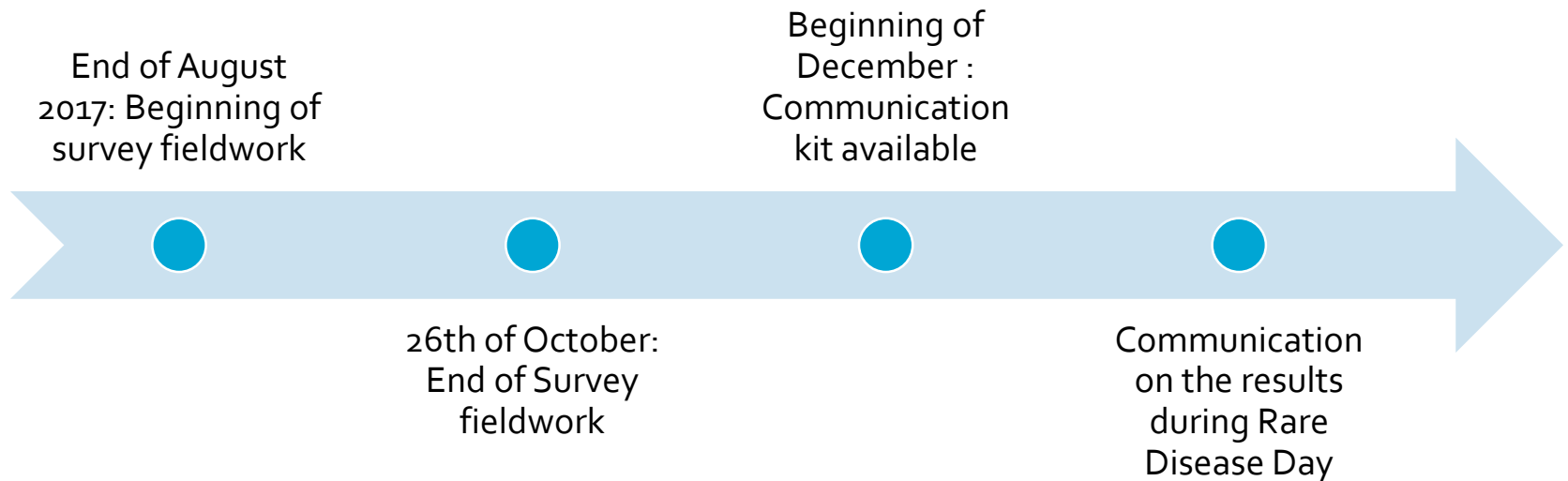
living with a rare disease and carers report being unhappy and depressed than the general population*



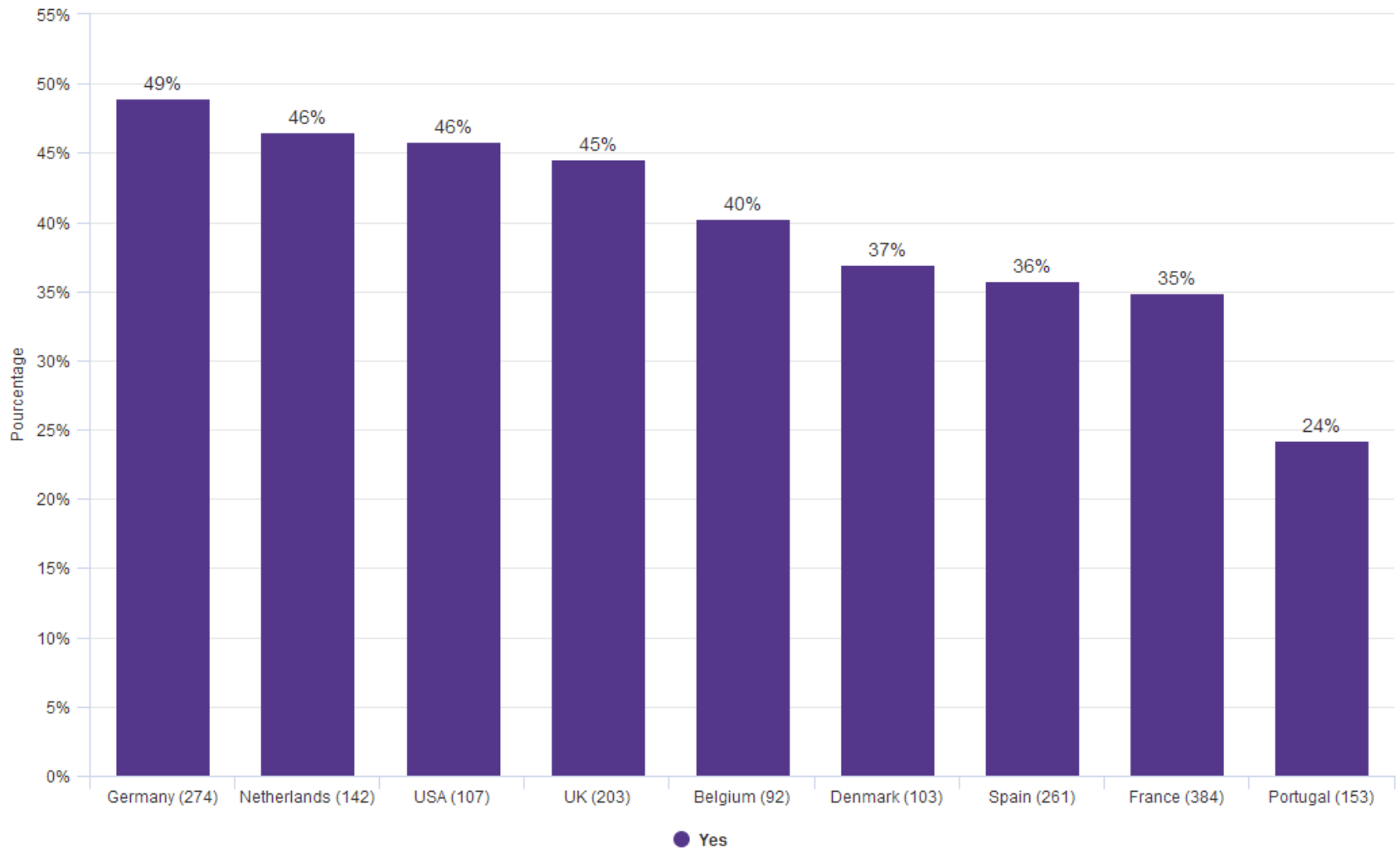
New survey on participation in Rare Disease research

➔ **Provide content** (in particular for National Alliances) to advocate on theme of Rare Disease Day 2018: Research

3176 respondents, 62 countries

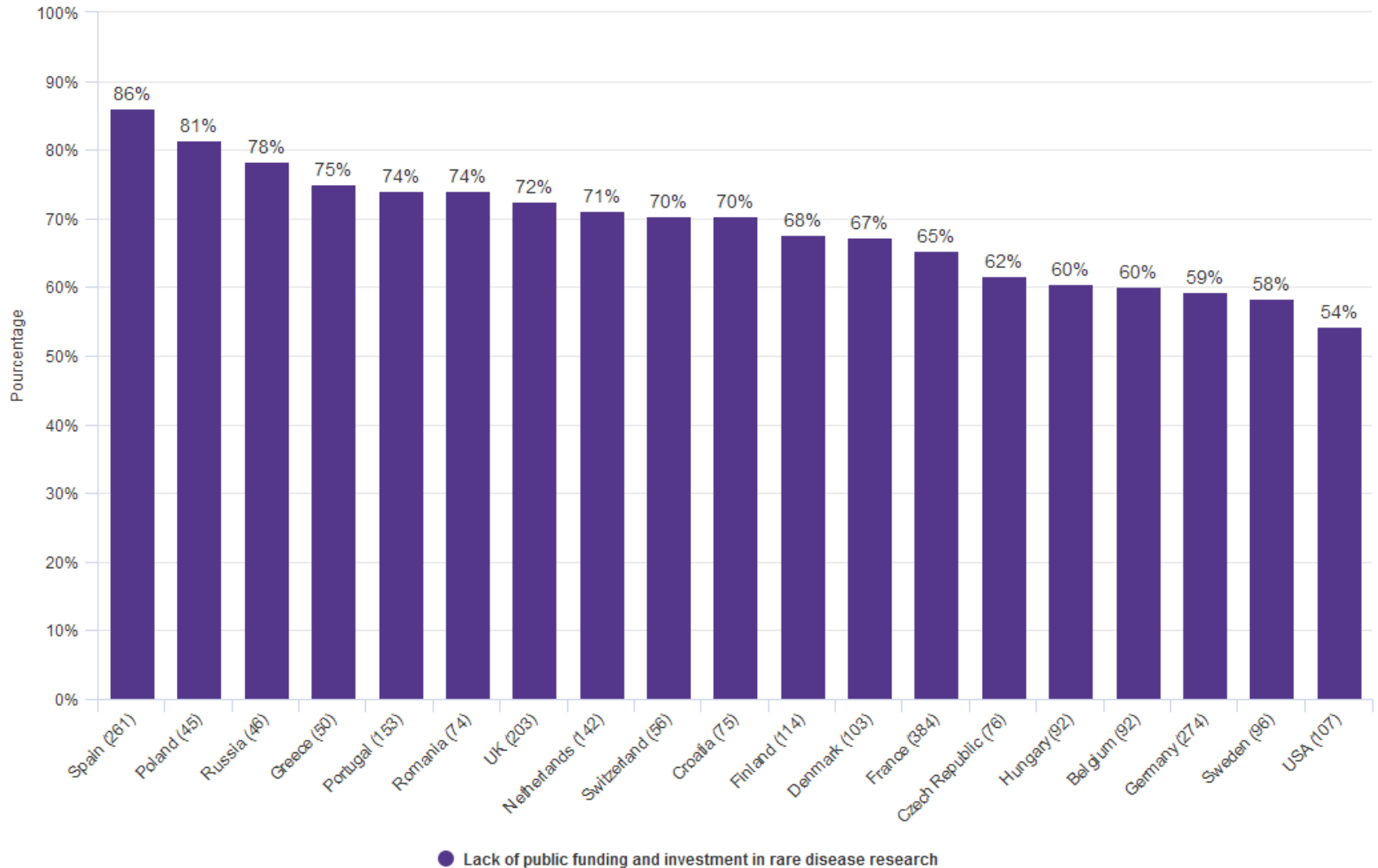


35% of RBV participants have participated in Rare Disease Research





Lack of public investment in RD research is seen as the main obstacle to rare disease research



My Rare Barometer Voices survey reports

Example for Spain:



Rare Disease Day survey Communication kit



Survey report in English



Facebook posts



Power point with main messages by country with graphs in your languages

My health-related data: to share or not to share?



- Test hypothesis from the Focus groups and the Delphi style exercise
- Come up with patients views on data sharing for **research and healthcare** purposes

RD  Connect

Data survey Topic Expert Committee

Patient organisations

- Avril Daly
- Julian Isla
- Anne-Sophie Lapointe

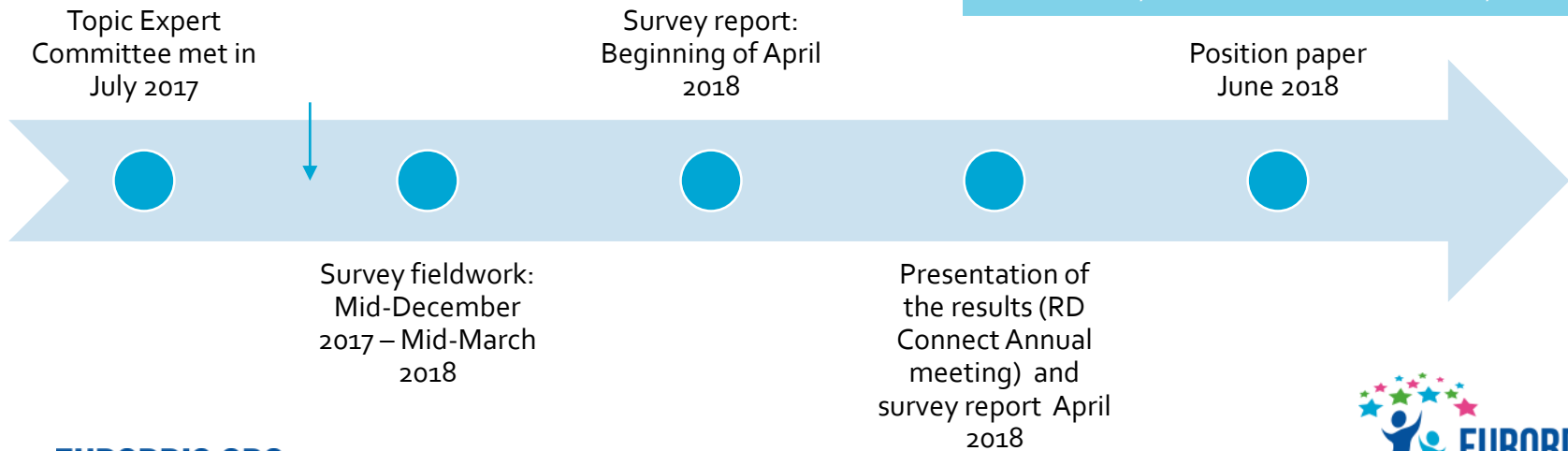
Experts

- Nathalie Banner (Wellcome Trust, Policy Adviser)
- Orion Buske (Sick Kids)
- Rebecca Dimond (Cardiff University, Medical Sociologist)
- Xavier Fourmi (MAPI)
- Deborah Mascalzoni (Upsala, Ethicist)

Policy Experts

- EURORDIS relevant staff
- Victoria Hedley (RD Action, Newcastle University)

Timing:



Participating in Rare Barometer

Register now

Register yourself in the database



Distribute the paper leaflet during events



Share the link of the survey on data protection and data sharing from the EURORDIS Facebook and Twitter account



Participate in Topic Expert Committees



Suggest topics

Thanks for your attention!

