



# RARE BAROMETER VOICES INFOGRAPHICS

CNA-CEF meeting, 11th  
December 2018

Sandra Courbier, Rare Barometer survey  
programme Senior Manager

[EURORDIS.ORG](http://EURORDIS.ORG)



# Rare Barometer Voices Infographics available

# 1st Rare Barometer survey on the impact of rare diseases on daily life, May 2017



## JUGGLING CARE AND DAILY LIFE: THE BALANCING ACT OF THE RARE DISEASE COMMUNITY

Through its survey initiative Rare Barometer Voices, EURORDIS-Rare Diseases Europe carried out the first European-wide survey on the impact of rare diseases on everyday life. The survey covered issues including coordination of care, mental health, employment and economic impact. See the full survey report at [eurordis.org/voices#studies](http://eurordis.org/voices#studies)



**30 million**  
people are living with a rare disease in Europe and 300 million worldwide



No cure for the vast majority of diseases and few treatments available

### 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\*



\* Rare Barometer Voices sample compared to International Social Survey Programme, 2011



Rare Barometer Voices is a EURORDIS-Rare Diseases Europe online survey initiative. It brings together over 6,000 patients, carers and family members to make the voice of the rare disease community stronger. Results are shared with policy decision makers to bring about change for people living with a rare disease.

**3,071**  
people responded to the survey.

The survey was conducted in **23 languages** across **42 countries**

Thank you to all Rare Barometer Voices participants and partners!

[www.eurordis.org/content/contribute-rare-barometer-programme](http://www.eurordis.org/content/contribute-rare-barometer-programme)

For more information visit [eurordis.org/voices](http://eurordis.org/voices) or email [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)



# Rare Disease patients' participation in research, February 2018



## An insight into the participation of rare disease patients in research



**30 million** people are living with a rare disease in Europe and 300 million worldwide

No cure for the vast majority of diseases and few treatments available

**3213** rare disease patients and their families responded to the survey, conducted in 23 languages across 42 countries worldwide

### Key findings of a Rare Barometer Voices survey on the participation of rare disease patients in research:

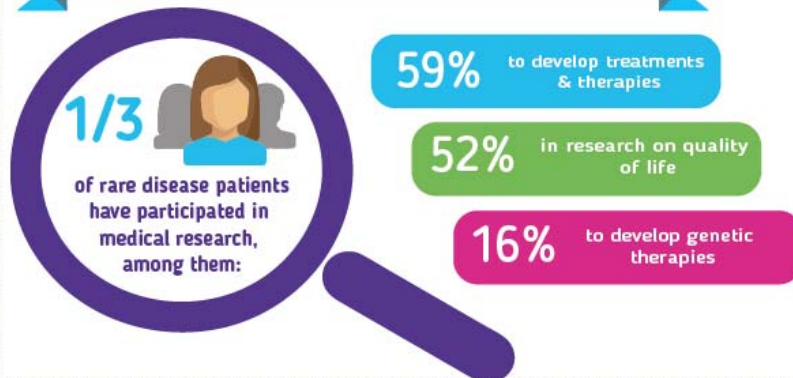
#### Top 3 obstacles to rare disease research



#### Top 3 priorities for patients



#### What type of research do patients participate in?



#### What matters to patients?



Rare Barometer Voices is a EURORDIS–Rare Diseases Europe online survey initiative. It brings together over 8,000 patients, carers and family members to make the voice of the rare disease community stronger.

Thank you to all Rare Barometer Voices participants and partners! To read the full report, register to participate in future surveys or for more information, visit: [eurordis.org/voices](http://eurordis.org/voices).

# Why are we designing infographics?

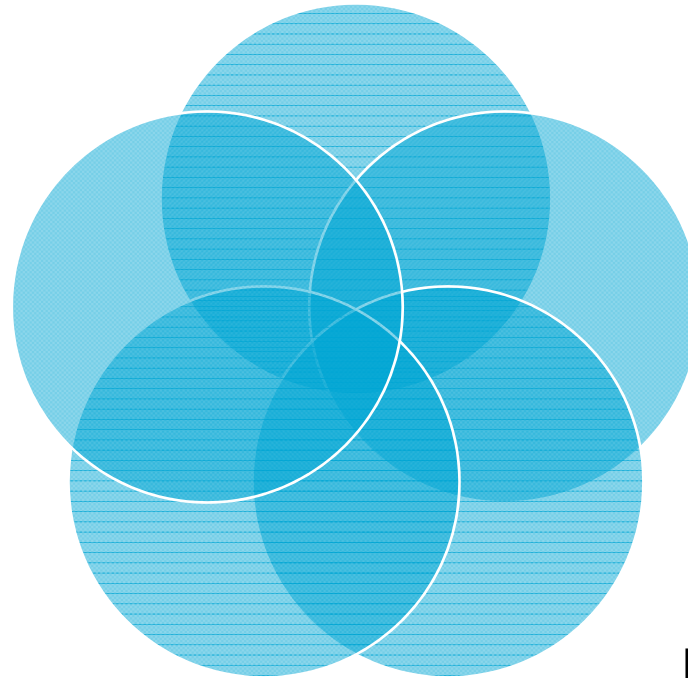
Summarise the info to reach a wider audience

Help your advocacy work and fundraising activities

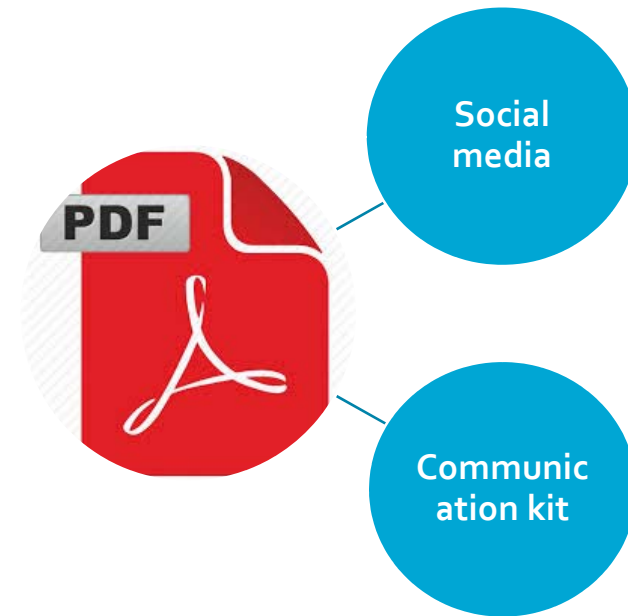
Raise awareness about Rare Diseases

Value and thank your participation

Encourage participation in future surveys



# How can you use these infographics?





# Images based on infographics for social media and presentations (ex. 1)

**EURORDIS**  
RARE DISEASES EUROPE

## JUGGLING CARE AND DAILY LIFE

Through its survey initiative Rare Barometer Voices, EURORDIS–Rare Diseases Europe carried out the first European-wide survey on the impact of rare diseases on everyday life.

**7 in 10** patients & carers

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

If you would like to participate in future rare disease surveys visit [eurordis.org/voices](http://eurordis.org/voices)

This survey was conducted in the scope of the EU-funded INNOVCare project. This project is co-funded by the European Union

Rare Barometer Voices  
A EURORDIS INITIATIVE

EURORDIS  
RARE DISEASES EUROPE

# Images based on infographics for social media and presentations (ex.2)








\*Findings of a Rare Barometer Voices survey on the participation of rare disease patients in research. 3213 rare disease patients and their families responded to the survey, conducted in 23 languages across 42 countries worldwide.



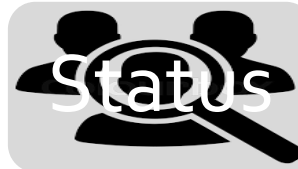
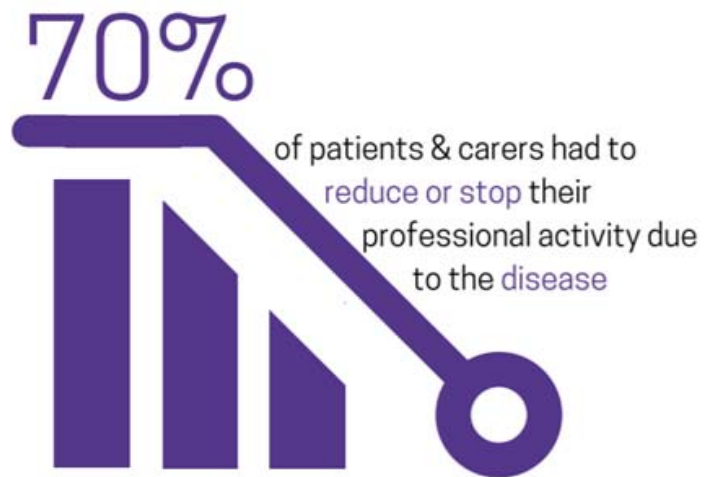
# What kind of visuals are available for you now?

## Results:

-  Per country
-  Per group of disease (ERN grouping)
-  Per disease
-  Any other relevant category (young people, carers, eg.)
-  For any Rare Barometer Voices language

when possible and upon request, contact [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)

# What is a subset of data?



- 72% for patients
- 69% for carers



- 78% in the UK
- 69% in France

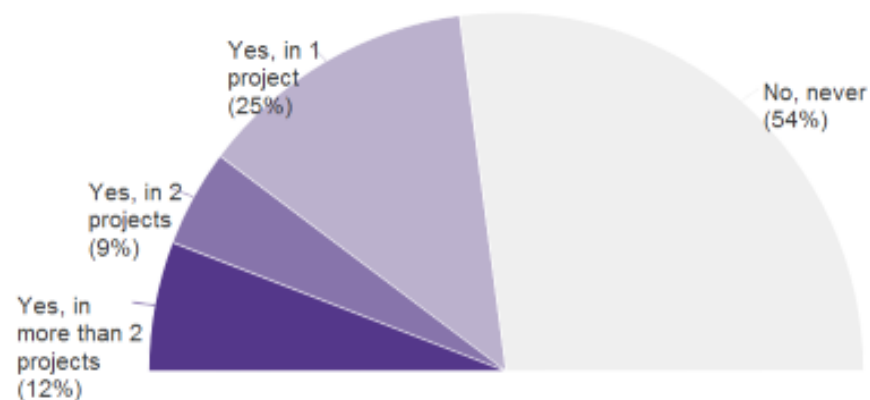


- 73% of women
- 63% of men

# Threshold per category : 30 respondents minimum per question !

Example: Rare Disease research, UK results

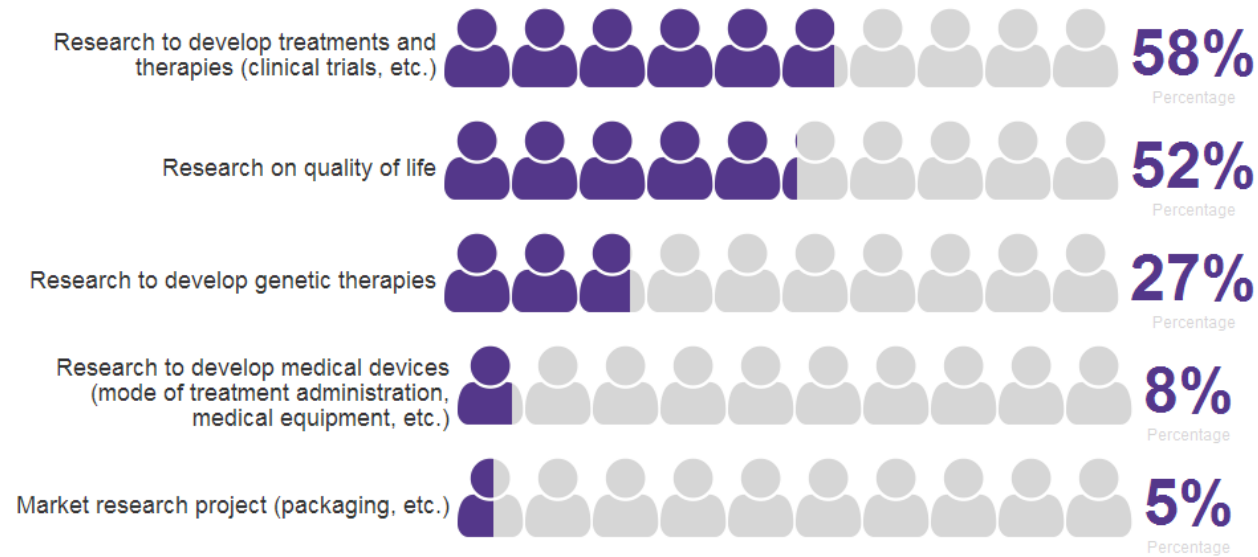
Have you ever participated in rare disease research (including for example, clinical trials, quality of life studies, research projects on genetic therapies or medical devices)? n=214



# Example: Rare Disease research : UK results



What type of research did you participate in? (Several answers possible), n=94



# Ex: Infographic in Spanish, for the results in Spain



## ENCUESTA SOBRE EL IMPACTO DE LAS ENFERMEDADES RARAS EN LA VIDA DIARIA

A través de su iniciativa de encuesta Rare Barometer Voices, EURORDIS-Rare Diseases Europe llevó a cabo la primera encuesta a nivel europeo sobre el impacto de las enfermedades raras en la vida cotidiana. La encuesta cubrió temas que incluyen la coordinación de la atención, la salud mental, el empleo y el impacto económico. Este documento presenta los resultados para España.



**3 millones**

Se estima que 3 millones de personas conviven con una enfermedad rara en España



No hay cura para la gran mayoría de enfermedades y, además, existen pocos tratamientos disponibles

Las enfermedades raras tienen un gran impacto en el día a día de las personas con estas patologías, y sus familias

**7/10** pacientes y familiares

reducen su actividad profesional, o dejan de trabajar, con motivo de la ER.

**1/2** cuidadores

dedican más de 2 horas al día a las tareas relacionadas con la ER



**8/10** pacientes y cuidadores

tienen dificultades para completar las tareas diarias relacionadas con tareas domésticas, preparación de comidas, compras, etc.

**3x**

Las personas con ER y sus cuidadores refieren estar infelices o tener depresión hasta tres veces más que el conjunto de la población\*

\* Muestra del Rare Barometer Voices en España, comparada con los resultados del Programa Internacional de Encuestas Sociales en España, 2011



Rare Barometer Voices es una iniciativa de encuesta en línea de EURORDIS-Rare Diseases Europe. Reúne a más de 8,000 pacientes, cuidadores y familiares para fortalecer la voz de la comunidad de enfermedades raras.



¡Gracias a todos los participantes del Rare Barometer Voices y colaboradores!

[www.eurordis.org/content/contribute-rare-barometer-programme](http://www.eurordis.org/content/contribute-rare-barometer-programme)

**3,071** personas han respondido a esta encuesta

Esta encuesta ha sido traducida a 23 idiomas alrededor de 42 países.

Para más información visita [eurordis.org/voices](http://eurordis.org/voices)

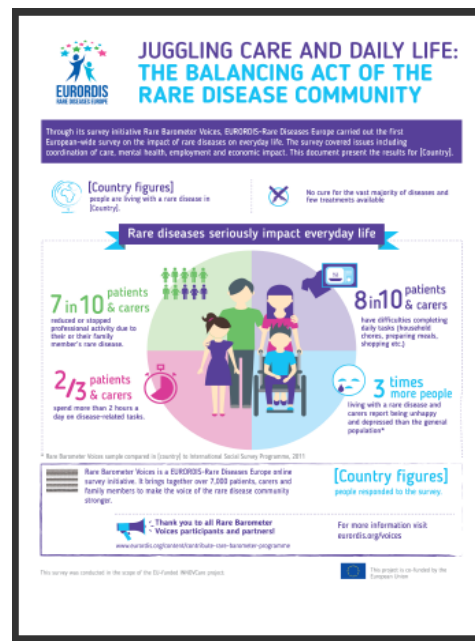


# Sharing Insights: Rare Barometer Voices Juggling Care Infographic Engagement

5 country-specific  
infographics  
created



Infographic  
translated into  
6 languages



Over 400 likes, shares and  
comments on social media



Shared at numerous  
conferences and events



# Communicating the results to the Voices

**New:** Results from the last survey were communicated through the research infographic, translated in 23 languages



# International days : Communication of RBV results on social media

International Right to Know Day, 28th September



of rare disease patients and their families do not feel well informed about social rights or the help they could be entitled to\*

\*Results of first Europe-wide survey on the impact of rare diseases on daily life, conducted via Rare Barometer Voices. Over 3,000 people responded to the survey.



Thanks for your attention!

