



CNA/CEF meeting 2nd November 2016
How to use the INNOVCare survey results for
your advocacy work?
Sandra Courbier (Surveys and social study
Manager)



Impact of rare diseases on daily life

Stage 1 – Social care needs and coordination of care

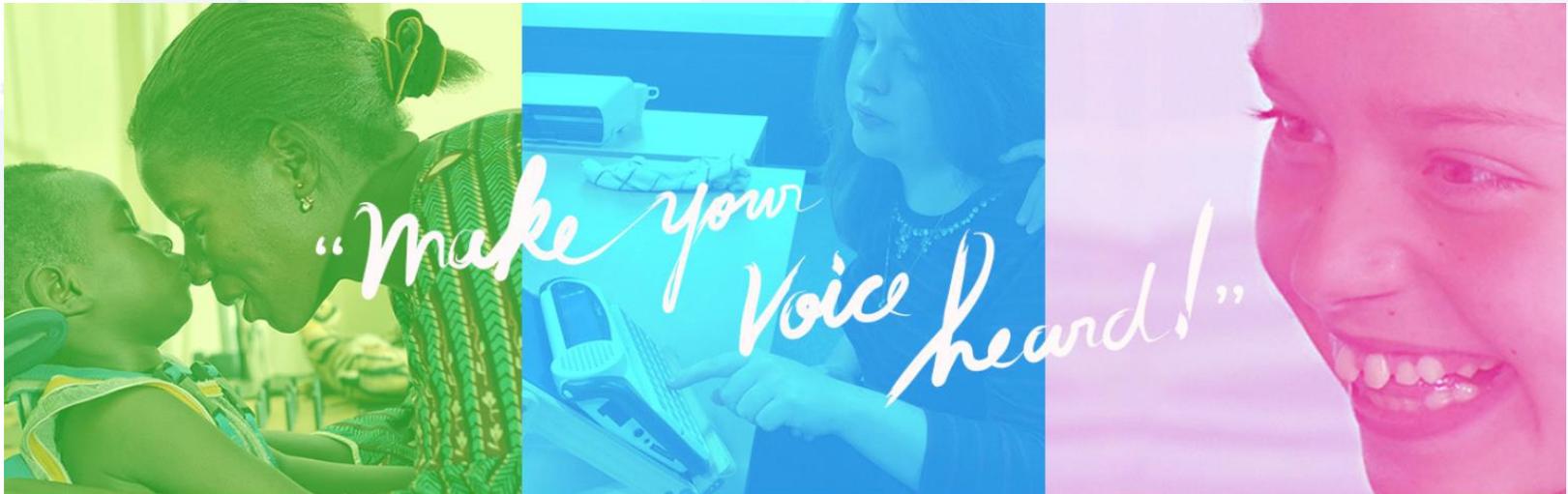
1. Rare Barometer Voices: reminder



Rare Barometer Voices framework

- Group of people living with a rare diseases who participate in EURORDIS surveys and studies
- Rare Barometer Voices members receive an invitation to participate in the INNOVCare survey
- New participants have to register for Rare Barometer Voices first
- High level of data protection (data storage in France, anonymised data, approved by French data protection authority)
- Covers 48 countries (European Continent)
- Survey translated in 23 languages

eurordis.org/voices



1

Register to Rare
Barometer Voices



2

Receive invitations
to surveys



3

Take part
in the surveys

Register now

Available in 23 languages



Make your voice heard!

Čeština

Dansk

Deutsch

Eesti

English

Español

Français

Hrvatski

Latviešu

Italiano

Lietuvių

Magyar

Nederlands

Polskie

Português

Română

Slovenčina

Slovenščina

Suomi

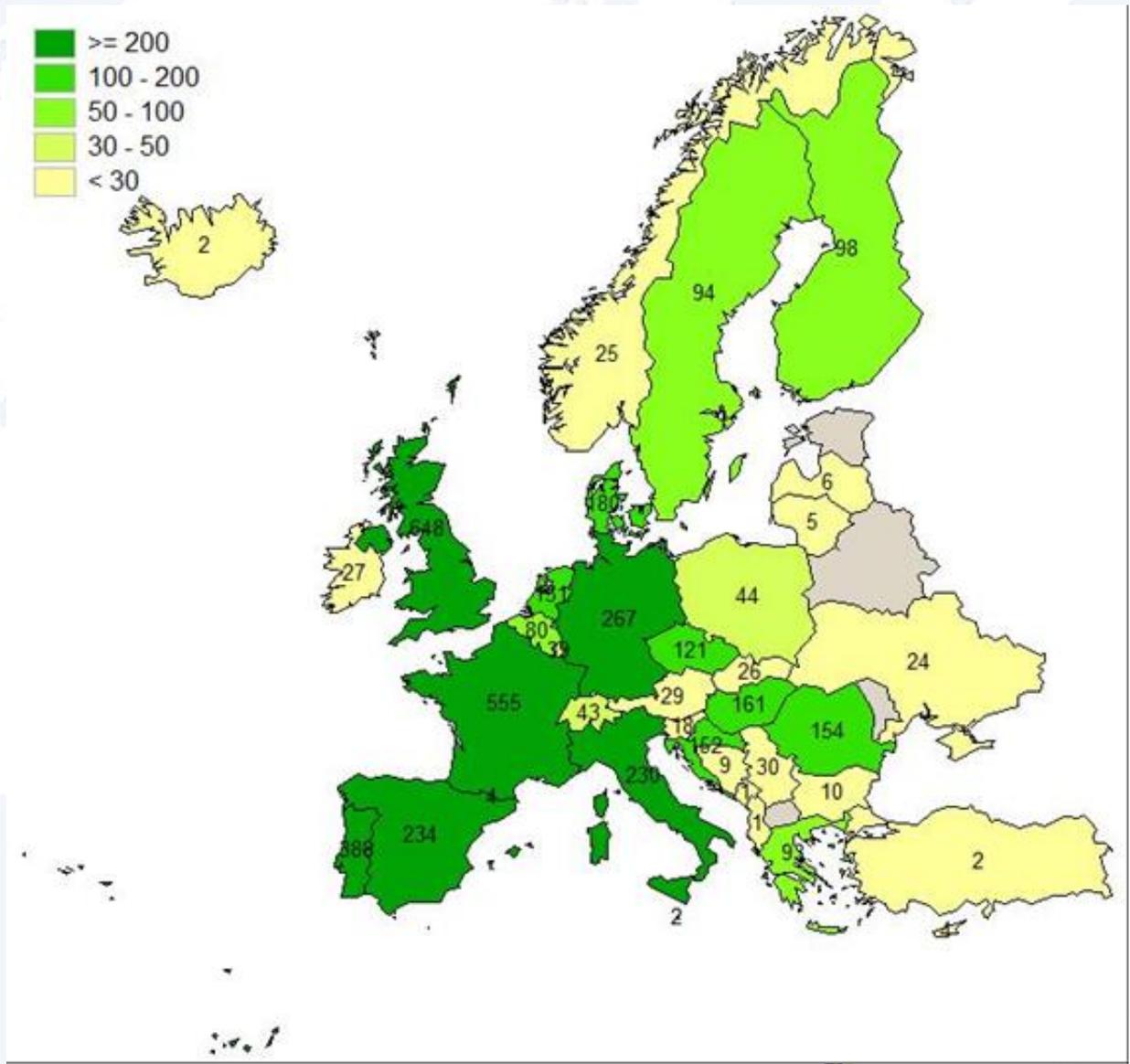
Svenska

Ελληνικά

Български

Русский

3850 Voices!



INNOCare

2. Survey on the impact of rare disease on daily life - INNOCare

An interactive project

Questions raised by patient organisations

Focus groups (Oct. 2015) with the EURORDIS Council of National Alliance (CNA)

Feedback from the EURORDIS Social Policy Action Group ([SPAG](#))

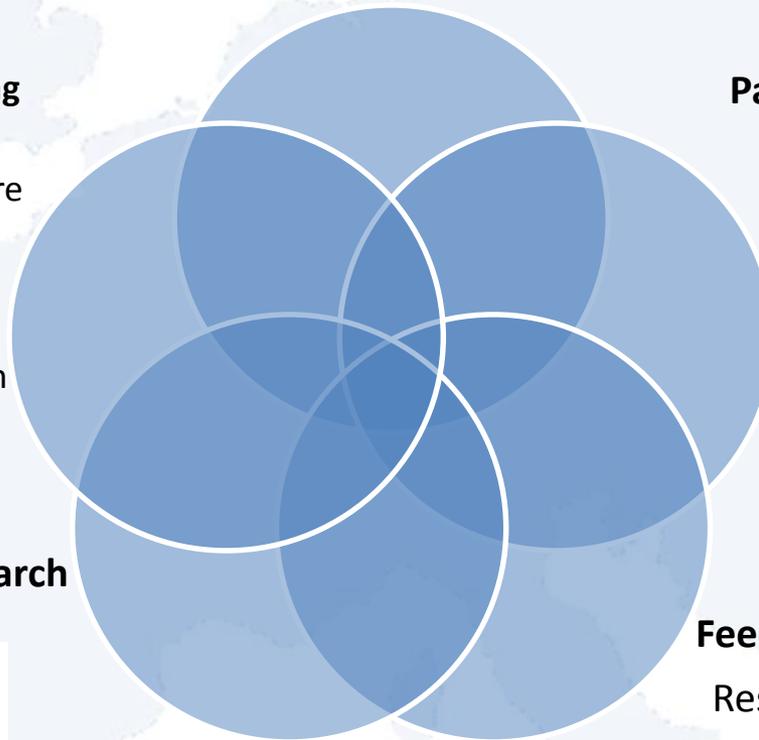
Questions based on existing literature

Only the strong survive (Rare Disease Denmark, 2013)

ENSERIO (Feder, 2009)

Users Experience of Health Services (Frambu, 2008)

Public and private research involvement



Patient organisations involvement in project design



Feedback to participants

Results in 23 languages

Information about the use of the results

Timing and organisation



- Stage 1: Started in August - questions care needs, access, costs and coordination.
- Stage 2: Starting in November - questions on employment, school and well-being
- Fieldwork will end mid-December
- January 2017: Full INNOVCare survey report available
- February 2017: Results available for patient organisations and participants

Participants' profile



People concerned by rare diseases, diagnosed/undiagnosed



Patients, families (siblings, parents, spouse...)



More than 18 years old



Only one person per household can answer

A user friendly survey

- Stage 1: 20-25 min to be filled in
- Stage 2: 10 minutes
- The respondent can stop and go back to the survey without losing his responses
- No need for any document or medication
- Attractive design (clickable items, attractive colours...)

Rare Barometer Voices
A EURORDIS INITIATIVE

Impact of rare diseases on daily life

Stage 1 – Social care needs and coordination of care

Who is the main carer in your household?

The first carer >

The patient himself The mother The father The grandparents The spouse of the person living with a rare disease

Uncle/aunt of the person living with a rare disease Sibling of the person living with a rare disease Other

← Previous Next →

3. Insight into the survey questions

Care profile



To what extent does the person living with a rare disease have difficulties with:

	No difficulty	Some difficulty	A lot of difficulty	Completely unable
Communicating with others (participating in conversations, sending emails)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking care of finances and handling everyday administrative tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daily activities and tasks (household chores, preparing meals, shopping, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social life and relations with other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Controlling general behaviour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motor and sensorial functioning (visual, hearing, difficulties in maintaining body positions, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care activities (personal hygiene, dressing/undressing, eating, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Access to services



Does your family currently benefit or have access to ... (1/2)

	Yes and it covers my needs	Yes but it is not enough to cover my needs	Yes but I don't need to	No but I would need to	No but I don't need to	Don't know
Support for house chores and daily tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Day care (access to a day centre, occupational activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home care (nurse, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social worker support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychological support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rehabilitation services and therapies (ergotherapy, speech or physical therapy etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Information about the disease



What is your primary source of information about your disease, treatment and care?

The first source of information



Health care
professionals in
hospital

General practitioner

Social worker

Patient organisation

The internet

Family and friends

Other

How well informed do you feel about ...

Relevant health specialists and services for the
disease



Very well informed



Fairly well informed



Fairly not well
informed



Not informed at all



Time spent in disease-related tasks



Do you feel that...

The time you spend in health related administrative procedures represents...



A little time and it is easy to manage

A little time and it is not possible to manage

Some time and it is easy to manage

Some time and it is difficult to manage

A lot of time and it is easy to manage

A lot of time and it is difficult to manage

How much time do you invest in a average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)?

- Between 0 to 1 hour a day
- More than 1 hour and up to 2 hours a day
- More than 2 hours and up to 4 hours a day
- More than 4 hours and up to 6 hours a day
- More than 6 hours a day

Impact on employment (stage 2)

Has the fact that your life is affected by a rare disease...
(several answers possible)

- Prevented you from accessing higher education
 - Limited your professional choices
 - Limited your opportunities to get a job
 - Led you to reduce or stop professional activity
 - Limited you from being promoted
 - Led you to more fulfilling professional opportunities
 - Caused a decrease in your income
-
- ✓ Yes
 - ✓ No
 - ✓ Not applicable



Impact on schooling

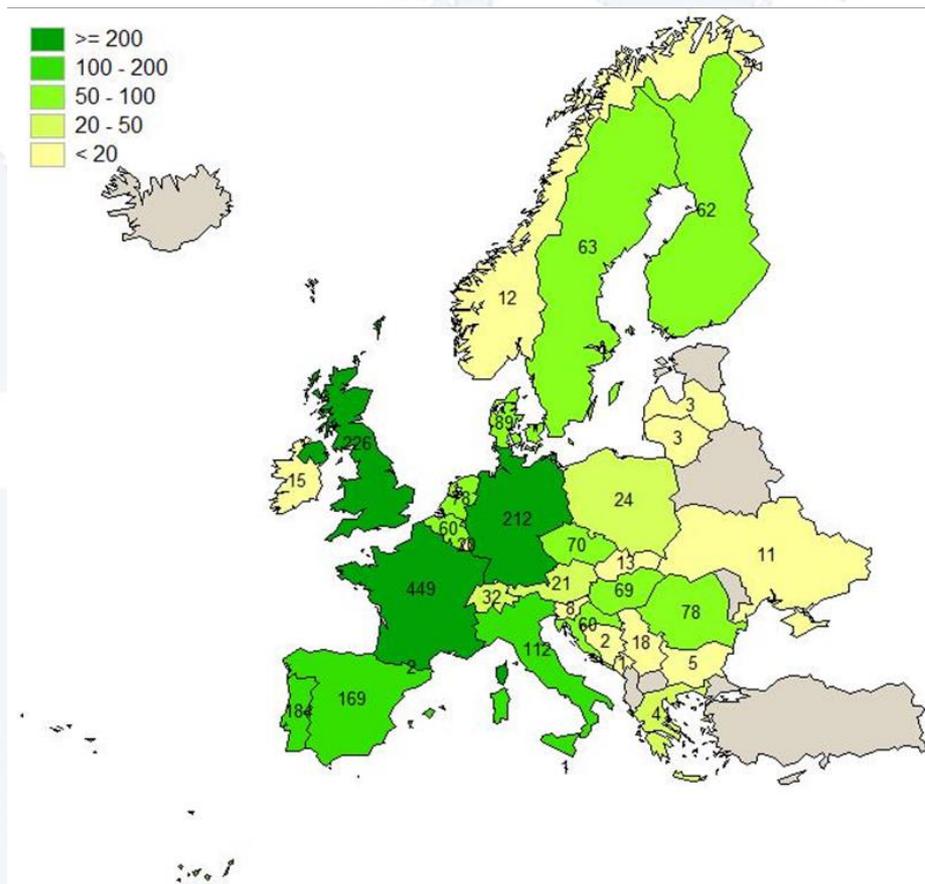
How many days per year is the child you care for absent from school? (Based on 1993 WA Child Health Survey)

- Fewer than 20 days a year
- Between 21 and 40 days a year
- Between 41 and 70 days a year
- More than 70 days a year



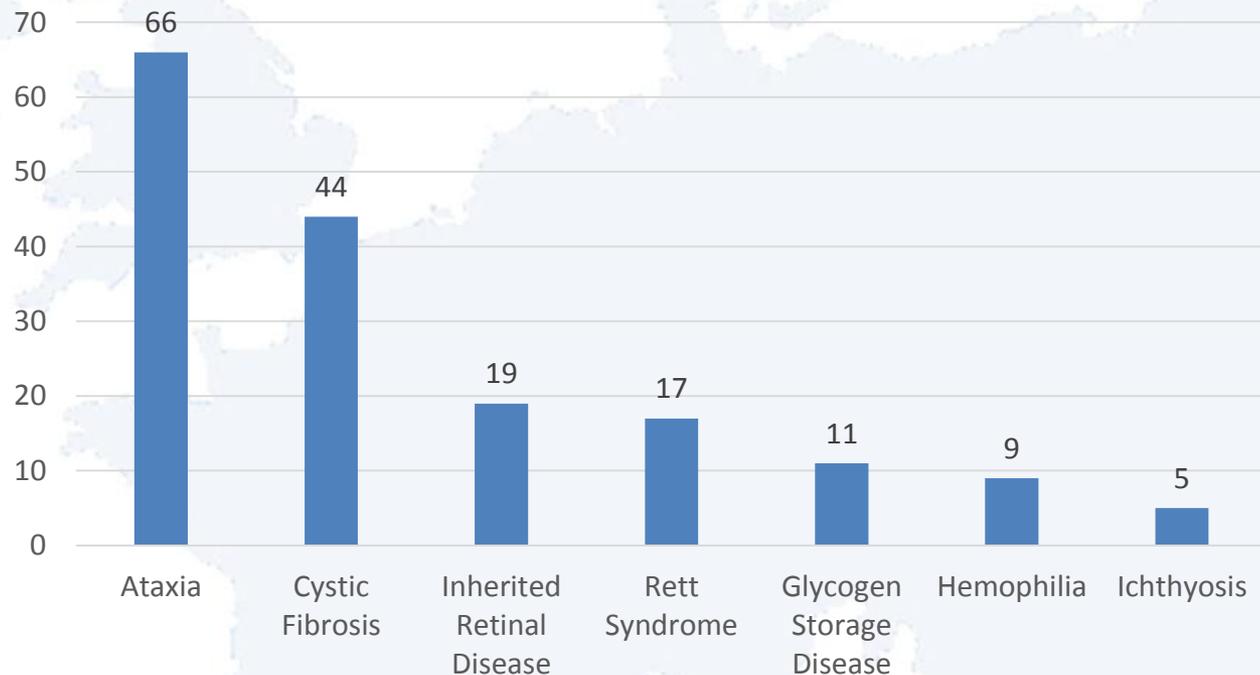
4. Use and availability of the results

Results available per countries (Survey : 2300 respondents)



- Need for a sufficient number of people per country to be able to use the results
- Upon request

Results available per disease



- We need the list of diseases covered by your association
- Sample size to be determined by a case by case strategy
- Upon request

How can you use the results?



Our experience and aim at EURORDIS

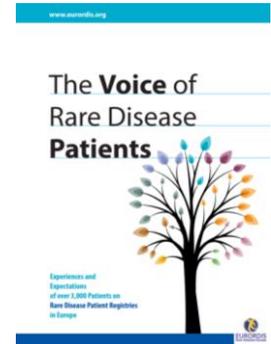
- ✓ Significant number of respondents
- ✓ Comparative analysis
- ✓ Comparison with the general population (Eurostat, International Social Survey)
- ✓ Comparison with other chronic diseases

Have proven to be huge awareness & advocacy tool

Example: EURORDISCare Survey -> supported advocacy, elaboration of recommendations to Member States, applications for EU grants

This survey will

- ✓ Raise awareness of the impact of rare diseases on daily life
- ✓ Support future positions of EURORDIS and advocacy work: for better access and quality of social care & integrated care



Encourage people around you to fill in the survey!



eurordis.org/voices

4. How to communicate about the survey

Spread the word!

- Share the link eurordis.org/voices on social media (Twitter, facebook) : communication material available (translated posts, images)
- Share it with your members via blog and/or newsletters (translated text available)

Thank you to our partners!



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EaSI PROGRESS



Co-funded by
the Health Programme
of the European Union



Contact me if you want to:

- Recruit actively in order for you to use country or disease-specific results
- Be involved in the Rare Barometer Programme
- Ask any other question on Rare Barometer Programme

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