

NEW RARE BAROMETER SURVEY: SOCIAL PARTICIPATION AND INDEPENDENT LIVING

CNA Monthly call
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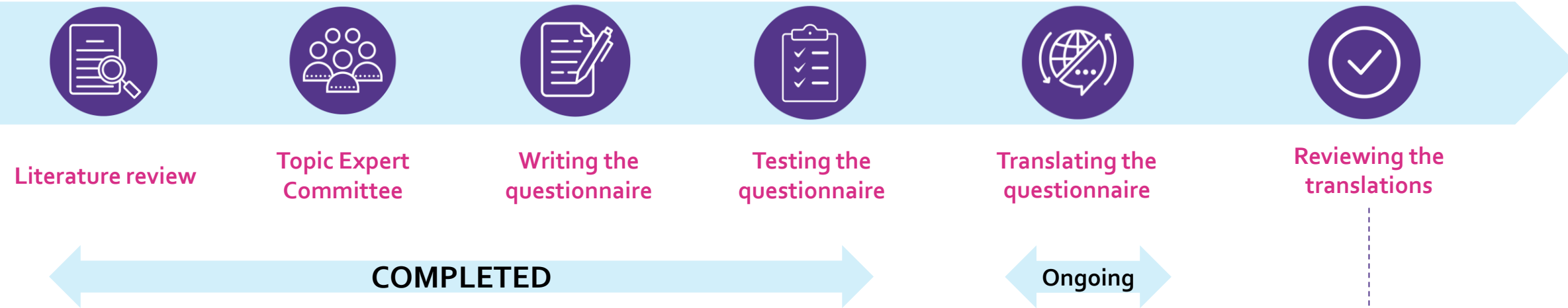
OBJECTIVES OF THE SURVEY

- Estimate the level of **participation in social activities** such as education, work or leisure.
- Identify **barriers or facilitators** in doing those social activities.
- Understand **preferences and needs** regarding **living arrangements and personal assistance**.
- Collect **experiences with disability assessment**.
- Identify the main difficulties in accessing **social and disability rights**.

More information: tiny.cc/RB_DailyLife



SURVEY PREPARATION



The Survey is translated into Czech, Danish, Greek, Croatian, Dutch, Polish, Romanian, Bulgarian, Finnish, Hungarian, Lithuanian, Latvian, Swedish, Slovenian, Slovakian, Norwegian, Russian, Turkish, German, Spanish, Italian, Portuguese, Ukrainian, French.

Contact rare.barometer@eurordis.org if you want to volunteer to review the questionnaire in your native language.

Review the translation in your native language (sent out in the week of June 24)

SURVEY LAUNCH AND FIELDWORK

10 JULY



8 SEPTEMBER 2024

TARGET POPULATION

All people living with a rare disease and their family members

WORLDWIDE

25 languages

ALL rare diseases

SURVEY LAUNCH AND FIELDWORK

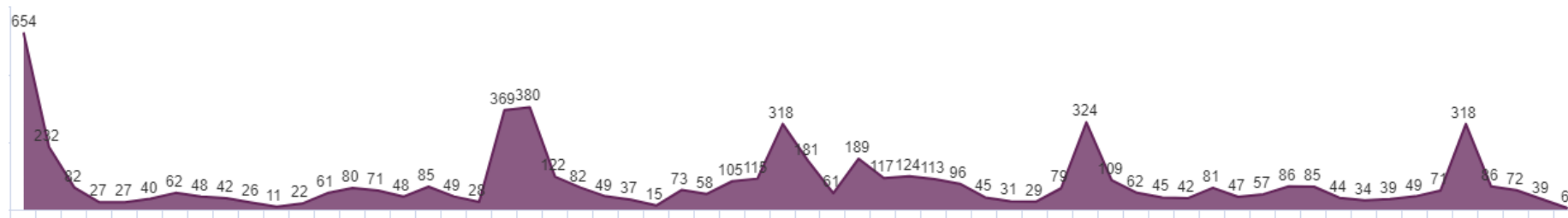
Invitations sent to the **Rare Barometer panel** a few days before the official survey launch.

Survey launch on July 10th:

- Information webinar at **2:30 PM CET**. Register: tiny.cc/daily_life_RD_webinar
- Start of the social media campaign

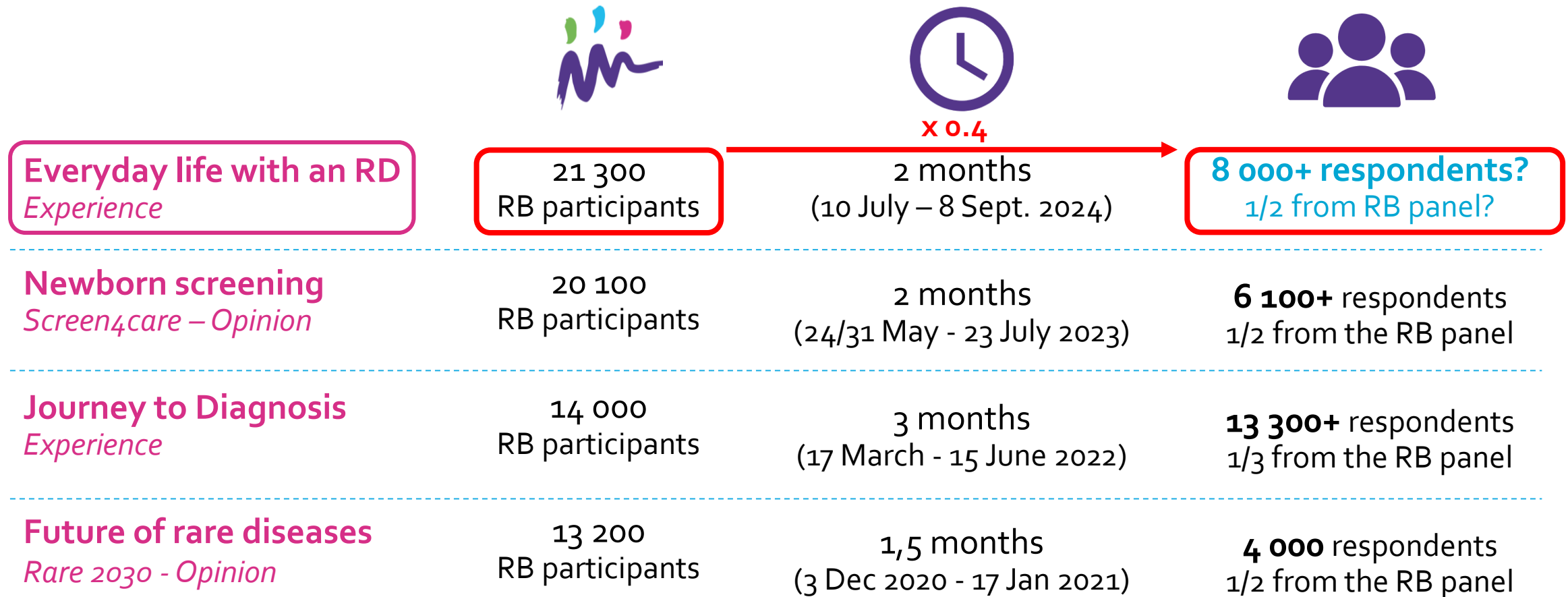
Follow survey dissemination with your online dashboard (updated everyday)

- CNA members will receive a dashboard to follow dissemination 1-2 weeks after official launch
- Monitor the impact of your communication on the number of respondents!





PARTICIPATION IN PREVIOUS SURVEYS & OBJECTIVES



RARE BAROMETER PANEL

JUNE 2024

Multiply by 0.4

to estimate the number of respondents to the new survey
> adapt communication actions

Eastern and Central Europe

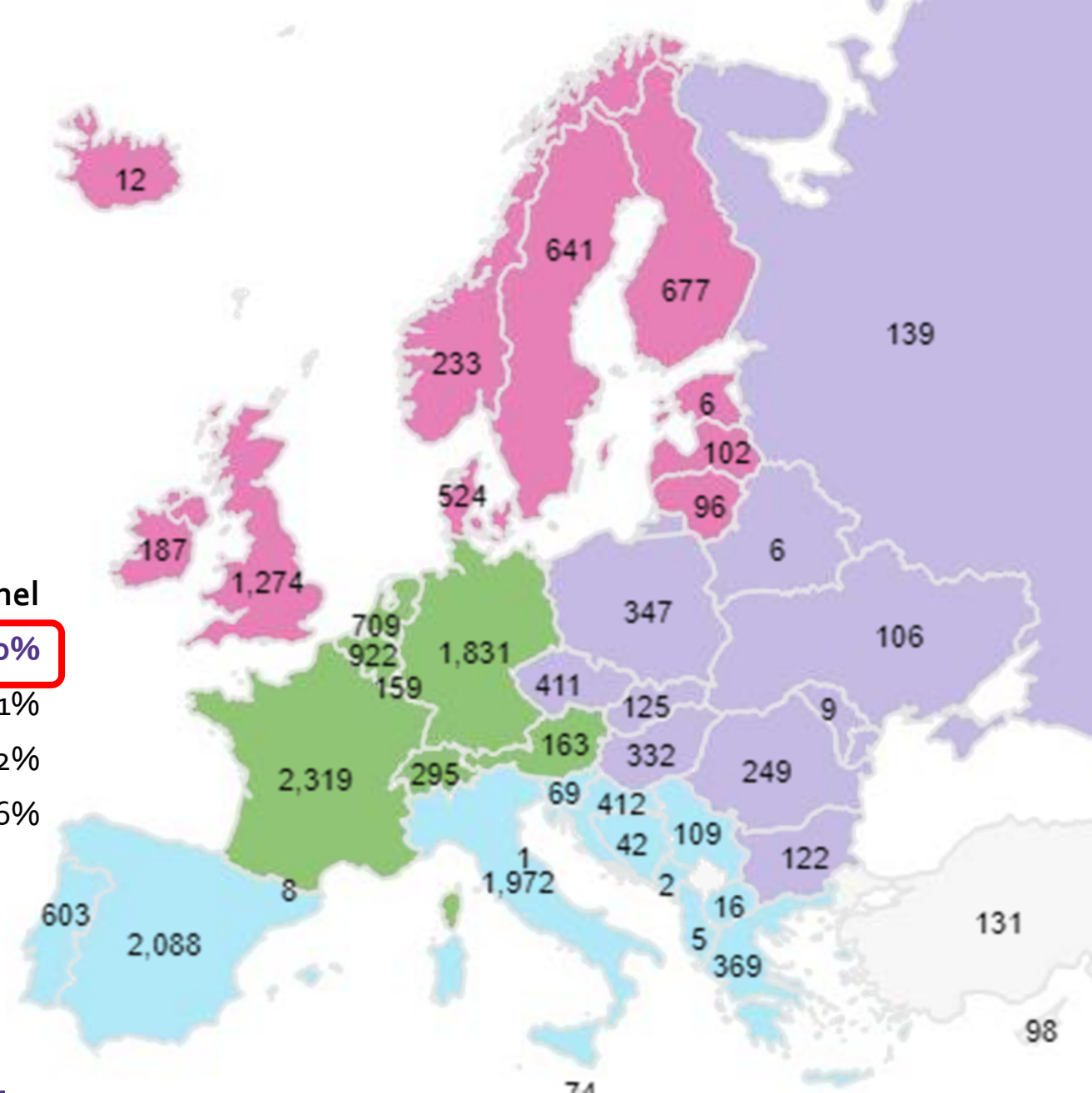
Northern Europe

Southern Europe

Western Europe

Population	RB panel
39%	10%
14%	21%
20%	32%
26%	36%

Dissemination by patient organisations
> comms. toolkit available in 25 languages



COMMUNICATION ACTIONS: GET PREPARED!

Theme: staying 'catchy' and relevant:

- **Everyday life / daily life:** avoiding conceptual terms, e.g. 'social participation', 'independent living' (+ translation issues)
- **Impact** of the RD on everyday life: same as juggling care but also more catchy
- **Not focusing on disability:** avoid using *only* pictures of PLWRD and a disability, to encourage everyone to participate (sample diversification)

Communications toolkit with email template
& suggested social media messages and visuals



How does your rare disease impact your daily life?
Tell us about it in the new #RareBarometer survey!
What would it take for you to live your everyday life to its fullest?
The #RareBarometer survey on the impact of rare diseases on
daily life closes on 8 September!
Tell us how your rare disease impacts your life!

COMMUNICATION ACTIONS: GET PREPARED!

Targeted social media posts included in the communication toolkit to encourage participation of **young adults**

You are between 18 and 30 years old and living with a rare disease?

Tell us how your condition impacts your life!

Share your experience to help all people living with a rare disease live life to its fullest!

How is school/university with a rare condition?

Your voice is powerful and can drive positive change!

  #RareBarometer #RareDisease #YoungAdvocates #MakeADifference #EURORDIS

COMMUNICATION ACTIONS: GET PREPARED!

Keep the engagement high during the fieldwork

- with videos, Instagram reels and stories about the content of the survey
- Encourage RD ambassadors and influencers from different countries to promote the survey
- Regular posts, tweets... on social media (once a week until the survey closes)

EURORDIS communication only in English

ANALYSIS AND PUBLICATION OF RESULTS

Involvement of the Council of National Alliances

September-November



Data management
and curation



Data analysis

November



Discussing preliminary
results and advocacy
messages

Meeting

End 2024



Publication of
European results;
EURORDIS members
and ERNs receive
their results



Communicate the
results – help us
spread the word!

Rare Barometer guide for EURORDIS members: tiny.cc/RB_guide

PUBLICATIONS

REPORT

English



FACTSHEET

2/4 pages - 7 languages
+ on demand

PARTAGEZ ET PROTÉGEZ NOS DONNÉES DE SANTÉ!

Principaux résultats de la recherche menée par EURORDIS-Rare Diseases Europe portant sur les préférences des personnes atteintes de maladies rares quant au partage et à la protection de leurs données de santé.

1 POURQUOI PARTAGER CES DONNÉES ?

Les personnes atteintes de maladies rares, quelle que soit la sévérité de leur maladie et leur profil sociodémographique, souhaitent partager leurs données :

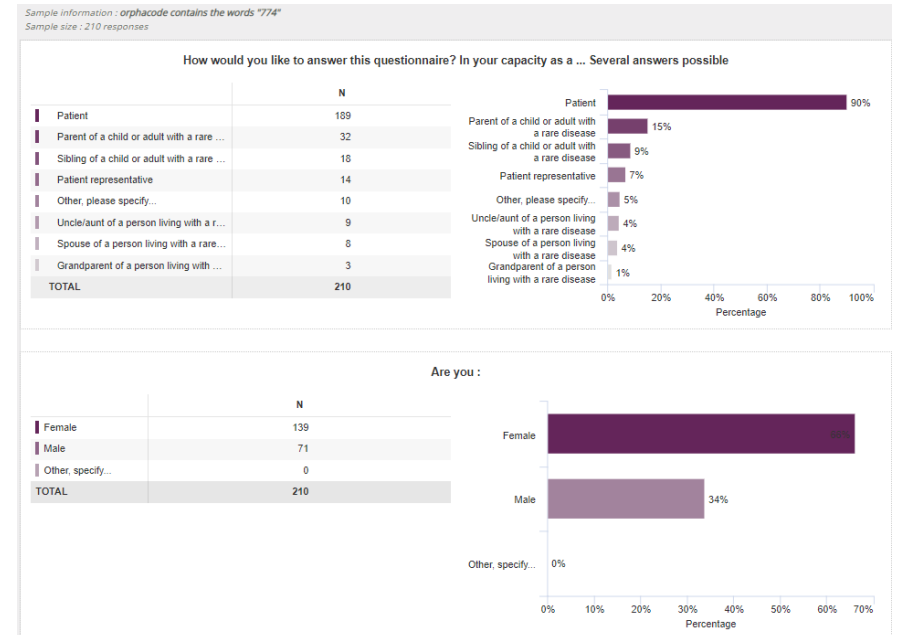
- 97% seraient prêtes à partager leurs données pour mieux comprendre les mécanismes et les causes de leur maladie
- 97% pour développer de nouveaux traitements pour leur maladie
- 97% pour mieux diagnostiquer leur maladie
- 95% ou pour améliorer leurs soins
- 95% pour recevoir davantage de conseils spécialisés à propos de leurs soins
- 95% sont aussi prêtes à partager leurs données pour améliorer la recherche sur des maladies autres que les leurs

Les personnes atteintes de maladies rares semblent plus enclines à partager leurs données de santé que la population générale : selon les études existantes, entre 37% et 80% de la population générale déclarent être prêts à partager leurs données de santé.

Si on vous le proposait, seriez-vous prêt à rendre vos informations de santé/ celles de la personne dont vous vous occupez disponibles pour :

DASHBOARD

Each question of the questionnaire
Frequency and percentages
25 languages





THANK YOU!

To the Rare Barometer participants, partners and corporate donors in 2023!

rare.barometer@eurordis.org



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