

# Website

## Deliverable 2.3

31 March 2019



<b>WP Participants:</b> EURORDIS
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V1	7 February 2019	EURORDIS
V2	13 March 2019	All partners
Final version	31 March 2019	All partners



The Rare2030 project is co-funded by the European Union Pilot Projects and Preparatory Actions Programme (2014- 2020). This leaflet is part of the pilot project PP-1-2-2018-Rare 2030. The content represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission or any other body of the European Union.

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# About [www.rare2030.eu](http://www.rare2030.eu)

[www.rare2030.eu](http://www.rare2030.eu) is the main point of communication for this project and other communication tools (social media, newsletters) can be channelled to the website. The website communicates all the project aims and objectives, in addition to providing information on the structural organisation of the project. News and announcements will be available on the website and it will be updated regularly to reflect the deliverables achieved. The website is accessible to all stakeholders and will provide an introduction for those who are not familiar with the project in addition to all the material produced by Rare2030.


Key points of interest on the website:

- 'What is Rare 2030' provides a brief introductory summary of the work that the project aims to achieve, making it accessible to a wider pool of stakeholders;
- 'How it Works' describes the stages of the Rare2030 Foresight study
- 'Governance' lets visitors know about the partners and people involved in the project
- 'Our Work' provides a more in depth view of the project deliverables by Work Package and indicating who is coordinating them;
- 'Key events' includes information about conferences, workshops and online tools through which stakeholders can make their opinions about the future of rare disease policy heard;
- 'Contact' allow people to reach out the project coordinator. A sign up function for the bi-annual Newsletter is also available on the home page.
- Live Tweets allow visitors to see the latest news and follow @rare2030

The Project Coordinator is responsible for the creation, content and maintenance of the Rare2030 website. Partners send updates, new information and material to the Project Coordinator who will take care of uploading the information on the Rare2030 website once validated.


[www.rare2030.eu](http://www.rare2030.eu) went live on Rare Disease Day 28 February 2019 and is updated regularly. Links with partnering websites and relevant projects and initiatives in the rare disease community will be progressively added.

# Sample Screen shots



What is Rare2030? | How It Works | Governance | Key Events | Our Work | Contact

Preparing a better future for people living with a rare disease through 2030 and beyond




Rare2030 is a foresight study that gathers the input of a large group of patients, practitioners and key opinion leaders to identify what drives change in the field of rare diseases, construct potential futures scenarios based on these drivers and propose policy recommendations that lead us for a better future for people living with a rare disease in Europe based on preferred scenarios.

Since the adoption of the Council Recommendation on European Action in the field of Rare Diseases in 2009, the European Union has fostered tremendous progress to improve the lives of people living with rare diseases. Rare2030 will guide a reflection on rare disease policy in Europe through the next ten years and beyond.

Tweets by @rare2030

Foresight in Rare E...  
@rare2030

RD-CODE to support Member States in improving gathering information on rare diseases by implementation of #orphanet @neurards @Orphanet @APHF @Insem rd-code eu/vip-content/act...

RD CODE  
Code Europe for rare diseases  
2019-2021

Embed | View on Twitter


Newsletter

Your email (required)

Sign Up

The health of 30 million people living with a rare disease in Europe should not be left to luck or chance. Rare2030 prepares a better future for people living with a rare disease in Europe with foresight.

Partners

Rare2030 is a project that applies **foresight** to the future of rare disease policy in Europe. Foresight is a tool that provides us with different future **scenarios** and sets out road maps for how we can reach them through changes in policies and strategies so to better shape our tomorrow.

In Rare2030, policies aimed at lessening the impact of rare diseases will be identified through a review of literature and European and national level initiatives in rare diseases—for example, national plans for rare diseases, patient data collection, research networks, health care organisation, access to treatments, empowerment of patients, social support and health care budgets. This **knowledge base** will allow a **Panel of Experts** to consider what new **trends** (both specific and not specific to rare diseases) will **drive** change.



Through a number of workshops, interviews and surveys throughout 2019 and 2020, we will ask a **Panel of Experts**, representing all **stakeholders** in the rare disease community including patients and young citizens, to participate at every step of the foresight

<https://www.rare2030.eu>



Rare2030 is led by EURORDIS-Rare Diseases Europe who is tasked with the strategic/scientific coordination of the project. ISINNOVA is responsible for the administrative and operative management – together representatives from these institutions making up the Management Board.

Six additional partners complement the Management Board making up the Executive Management Committee in executing the project's objectives.



Project partners include:



Contact Us

Your Name:

Your Email:

Subject:

Message: