



## Project Update

September 2020

### What is Rare 2030 and Why?

Rare 2030 is a foresight study that gathers the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations that will lead us to improved policy and a better future for people living with a rare disease in Europe. This a two year project that will end in a presentation to parliament at the end of 2020 with recommendations on the most critical areas needing sound policy.



In the last decade the European Union, its Member States and all the dedicated actors in the rare disease community have fostered tremendous progress to improve the lives of people living with rare diseases. As major challenges remain, and the opportunities to overcome them have and continue to quickly evolve, the Rare 2030 project uses the method of foresight to guide a reflection on rare disease policy in Europe through the next ten years and beyond.

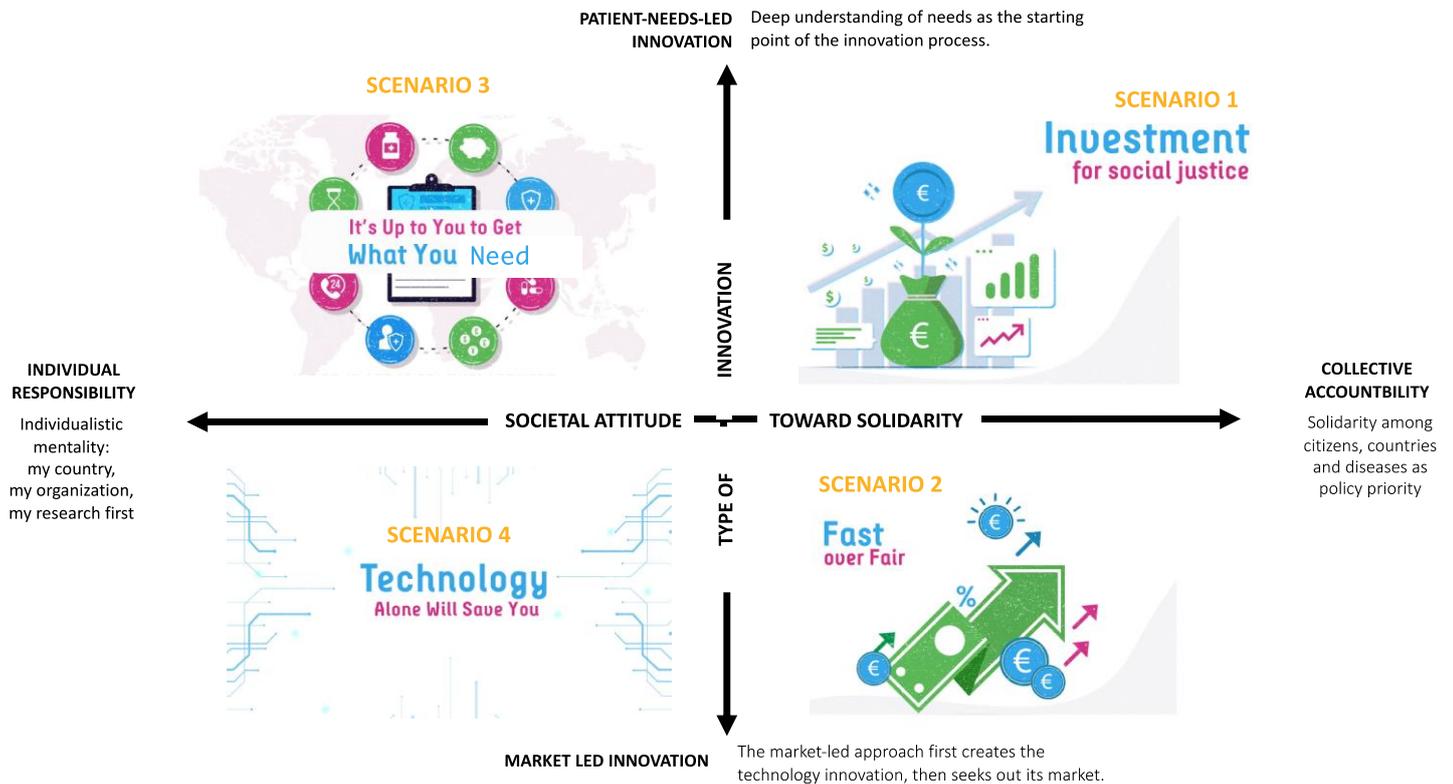
### How Does it Work?

The Rare 2030 Foresight Project includes 4 major stages detailed below. The first 18 months of the project focused on stages 1 to 3. For more details on these steps read the [May 2020 Rare 2030 Project update](#).



## 1. WHERE WE ARE NOW

Since our last update in May 2020 the project’s multiple panels of stakeholders have considered 4 possible future scenarios that were constructed through a year-long iterative and participatory process. Opinions on those that are most preferred (Scenario 1 “Investment for Social Justice” and most likely (Scenario 2 “Fast over Fair”) are now guiding the transition from Step 3 (Create Future Scenarios) to Step 4 (Propose Policy Recommendations).



## A Young Citizens Conference

Following a series of workshops and assignments spread from March to July, a two-day online meeting was organized on July 7<sup>th</sup> and 8<sup>th</sup> with 10 experts and 23 young citizens – bridging the gap between the next generation public and experts to contribute to and validate a series of future policy scenarios at the 2030 horizon of rare disease policy.

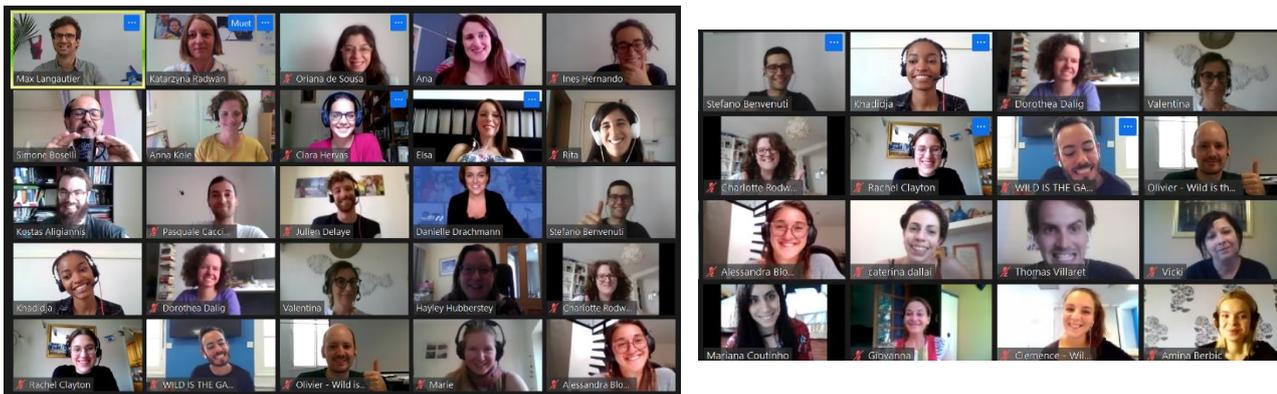
Background information on this new generation of advocates in the field of rare diseases can be found here: [Rare 2030 Young Citizens](#)

On the occasion of the conference, the participants focused 8 topics of discussion identified in earlier stages of the Rare2030 project:

1. Political & strategic frameworks relevant to RD
2. Data collection and utilization
3. Availability and accessibility of OMP and medical devices
4. Basic, clinical and translational research
5. Diagnostics

6. Social integration of RD and holistic care
7. Patient engagement
8. Accessing healthcare

The participants discussed and debated over these topics through the lens of the Rare2030 policy scenarios, with a particular emphasis on scenario 1 (*'Investment for Social Justice'*) and scenario 2 (*'Fast over Fair'*) as these were the scenarios the rare disease community voted on as being the most preferred (*'Investment for Social Justice'*) and the most likely if we continue as we are now (*'Fast over Fair'*).



This young generation’s recommendations will be presented during an online debate with a selected jury in November 2020 and incorporated into the projects final recommendations.

A behind the scenes [VIDEO](#) provides some visual feedback from the event.

## 2. NEXT STEPS

Project partners are currently working with several streams of stakeholders (young citizens, HCPs in ERNs, patient advocates and patients) to collectively consider the policy proposals that will allow us to arrive at a scenario that these same stakeholders have deemed as most preferable for the future of people living with rare diseases in Europe. A culmination of policy recommendations from this vast group of opinion leaders and decision makers will be reflected in the projects final recommendations presented at the Parliament on the occasion of Rare Disease Week 2021.

### 1) Regional Workshops aligned with upcoming EU presidencies Oct-Nov 2020

- Croatia
- Germany
- Spain
- Slovenia
- France
- Czech Republic
- Sweden

### 2) European Policy Back-casting Workshop (with European Reference Networks and other European level KOLs)

- Session 1: Governance and Strategic positioning of ERNs (21 September 4-6:30 CEST)
- Session 2: Integrating ERNs to national systems and frameworks (28 September 4-6:30 CEST)

- Session 3: Role of ERNs in virtual care delivery and cross-border healthcare (29 September 4-6:30 CEST)
- Session 4: ERNs, research, and the data ecosystem of the future (12 October 4-6:30 CEST)
- Closing Plenary : 26 October 9-12 CEST

3) Rare Barometer Voices Survey Nov/Dec 2020

4) Policy Conference @Parliament 23 February 2021