Rare 2030

Foresight in Rare Disease Policy

A foresight study preparing a better future for people living with a rare disease in Europe

A European Pilot Project

January 2019 – December 2020

www.rare2030.eu

Rare2030 will gather the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations that lead us to a better future for people living with a rare disease in Europe.

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.

4 Steps
in a Foresight Study

BUILDING A KNOWLEDGE BASE

1

Critically review existing knowledge and emerging issues at national and EU levels to identify trends and drivers of change that affect the future of rare diseases and inform policy options.

SCANNING THE HORIZON

2

A structured stakeholder dialogue enriches the list of trends and drivers of change and ranks them to identify those considered of high importance/high uncertainty and thus most relevant for policy recommendations.

BUILDING FUTURE SCENARIOS

3

Consistent and plausible alternative futures scenarios of the state of health and care for people living with a rare disease in 2030 and beyond are constructed on the basis of the most relevant trends and drivers. A debate among key stakeholders on preferred scenarios helps refine and complete scenarios with their implications to gather consensus around them.

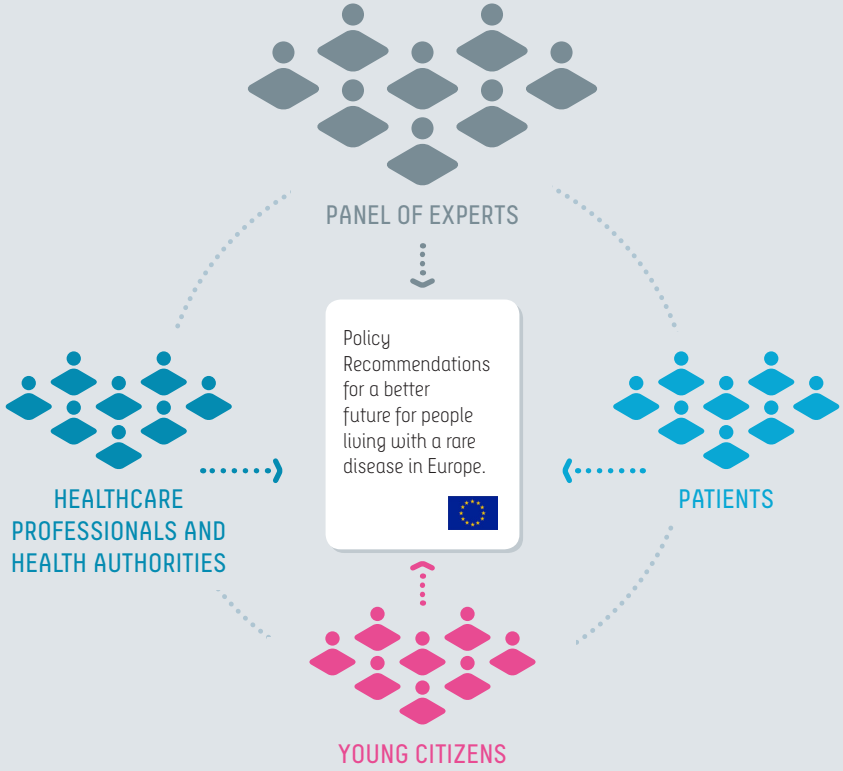
BACK-CASTING POLICY OPTIONS AND RECOMMENDATIONS

4

In a process of "back-casting", patients, the public and experts at EU and national levels propose policy options that can pave the way towards preferred future scenarios. Final policy recommendations are presented at the European Parliament.

Stakeholders

consulted at every step



Panel of Experts

A large panel of experts (up to 250 members) representing a full range of stakeholders in the field of rare diseases will serve as the core consultative body throughout the project.

Patients

Through numerous workshops and the EURORDIS Rare Barometer Voices platform, patients will make their voice heard about preferences they have for future policies that affect them.

Young Citizens

To integrate the perspective of the next generation of citizens, young students and advocates will be asked to contribute their point of view.

European and National Healthcare Professionals and Health Authorities

Coordinators and healthcare professionals of European Reference Networks and national level stakeholders will take part in a series of workshops to propose policies options that reflect their experience and expectations and lead to the preferred futures identified in the project.

@rare2030

Partners

Non-profit alliance of rare disease patient organisations that work together to improve the lives of 30 million people living with a rare disease in Europe

Knowledge base and information portal for rare diseases and orphan drugs

John Walton Muscular Dystrophy Research Center: translational research to bring diagnosis, care and therapy to people with neuromuscular disease

Non-profit organisation fostering research that leads to cures for rare genetic diseases

Research institute working in the field of policy design, analysis and impact assessment with a particular expertise in forward looking methods

European Reference Network for Hereditary Metabolic Disorders (University of Udine)

European Reference Network on Rare Bone Disorders (Istituto Ortopedico Rizzoli)

Centre for Health Economics and Policy Innovation: assessing impacts of public policies on chronic diseases and other areas of health

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.

www.rare2030.eu | @rare2030

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.

For more information contact: **Anna Kole**
anna.kole@eurordis.org