

Rare 2030

Foresight in Rare Disease Policy



Victoria Hedley
Rare Disease Policy
Manager
Newcastle University

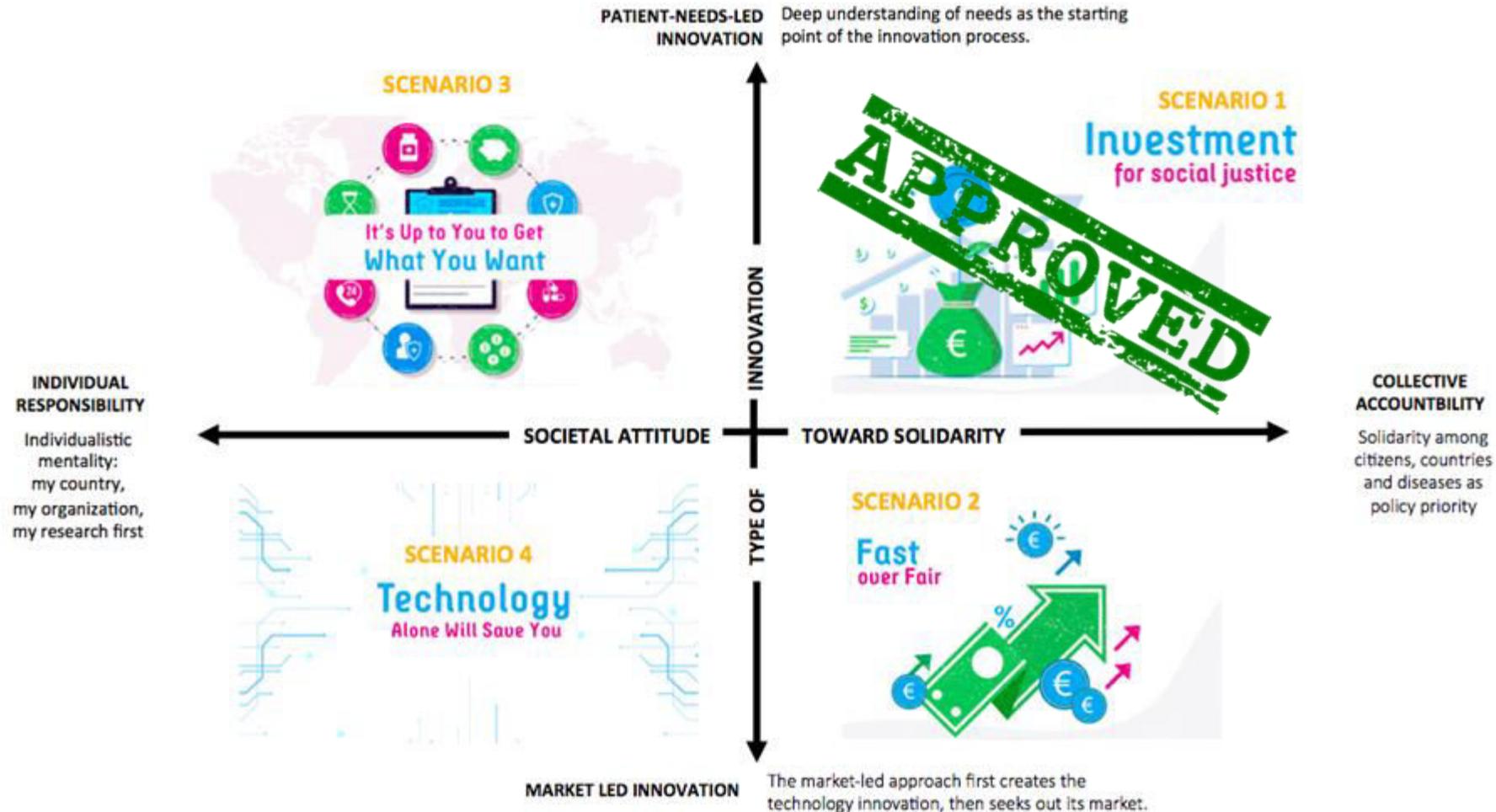
2nd March 2021

**Policy
Recommendations
from the Rare 2030
Foresight Study**

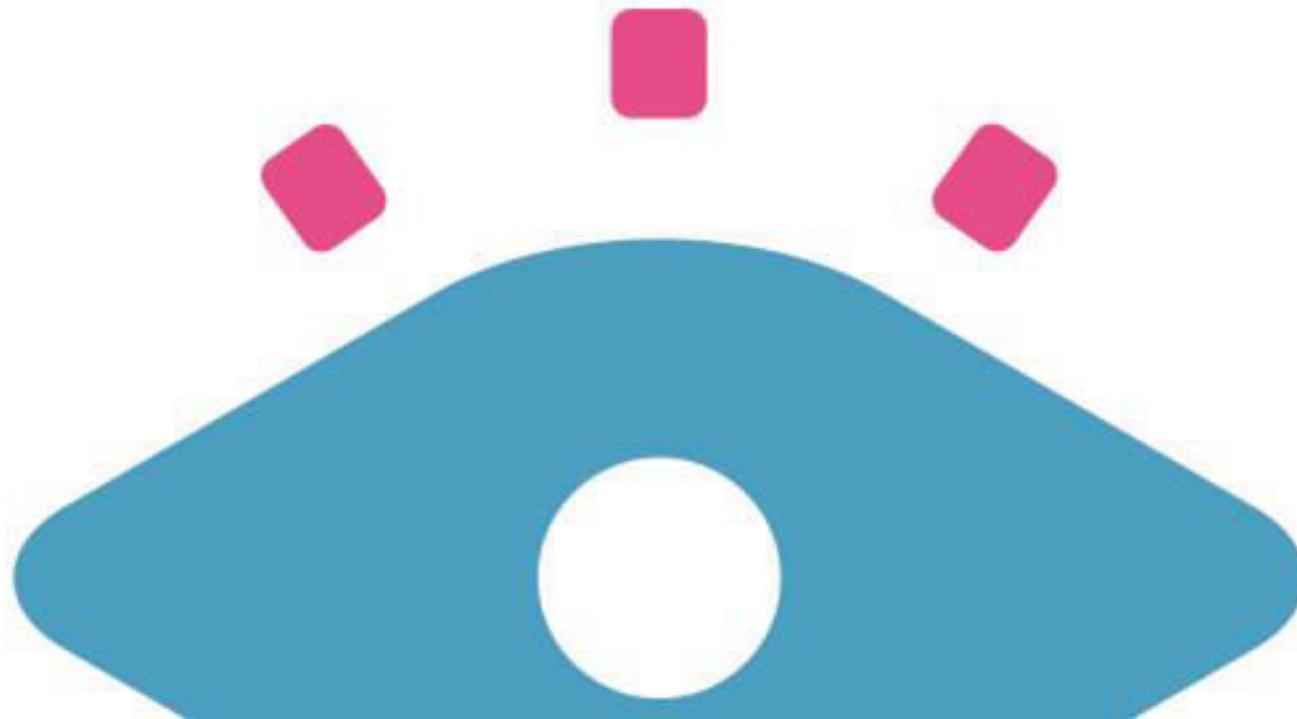
Why this project? Why a new policy framework

- Past policies for RD at EU level have left to many successes
 - Commission Communication: Rare Diseases: Europe's Challenge 2008
 - Council Recommendation on an action in the field of RD 2009
 - Cross-Border Healthcare Directive
 - Etc
- A sense that many of these policies have been either implemented or have stalled a little, or else are no longer sufficiently up to date
- European Parliament funded a foresight study 2019-March 2021 – Rare 2030

Where are we trying to go?



After two years of extensive consultation, the Rare 2030 Foresight study recommends a new policy framework for rare diseases

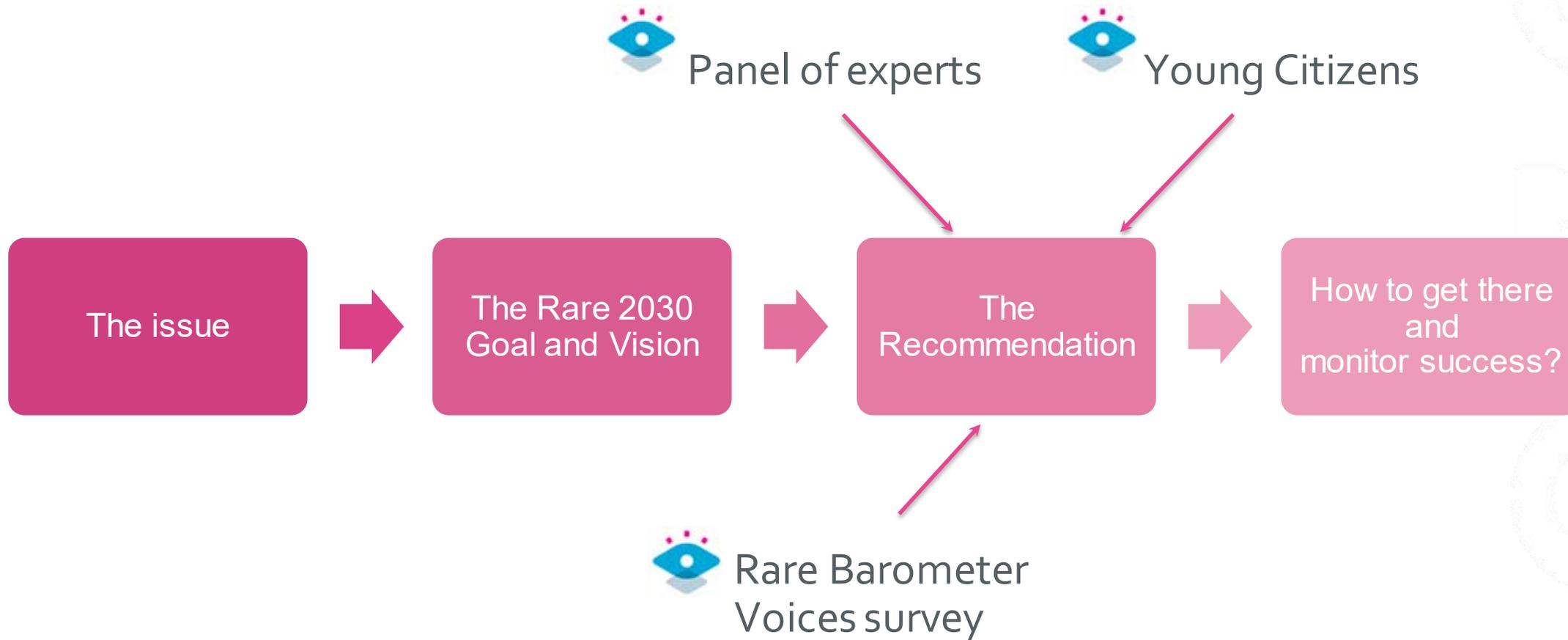


8 Recommendations

<https://www.rare2030.eu/recommendations/>



For each recommendation...





Recommendation 1

*Long-term, integrated
European and National
Plans and Strategies*



- 'A European policy framework for RD defined by societal responsibility, equity and driven by the needs of people living with a rare disease should guide the implementation of consistent national plans and strategies, secure major investments at both the European level and by governments that are fairly shared across Europe in order to pool scarce resources, share expertise and information, scale-up good practices and provide access to timely and accurate diagnosis and the highest available quality of treatment and care for people living with a rare disease, no matter where they live in Europe.
- Both EU and national policies are supported by measurable outcomes that are monitored and assessed by a multistakeholder body on a regular basis

Specifically:

- + this framework should be aligned with other European and national strategies (e.g. cancer, data, research, access, social rights)
- + it should support a harmonisation of the definition of rare diseases and rare cancers in European and national plans, strategies and policies
- + this European policy framework should be aligned with the international objectives established in Sustainable Development Goals, Universal Healthcare and other UN system policies relevant to rare diseases.
- + a new focus should be placed on EU level monitoring of rare disease diagnostics, treatment, care, research, and holistic wellbeing, with countries encouraged to collect and pool such data to publically and transparently illuminate the status quo and enable benchmarking
- + European and national plans and strategies should be sustained on a long-term basis, with adequate funding, and should be monitored by the appropriate authorities and key opinion leaders in the field
- + a renewed focus should be placed on the state of the art of current national plans and strategies and the adoption of renewed national plans and strategies
- + a suitable forum should be created or designated to advance multistakeholder policy-oriented debate on rare diseases, enabling the identification of good practices and support for implementation to suit national realities

