



Rare 2030

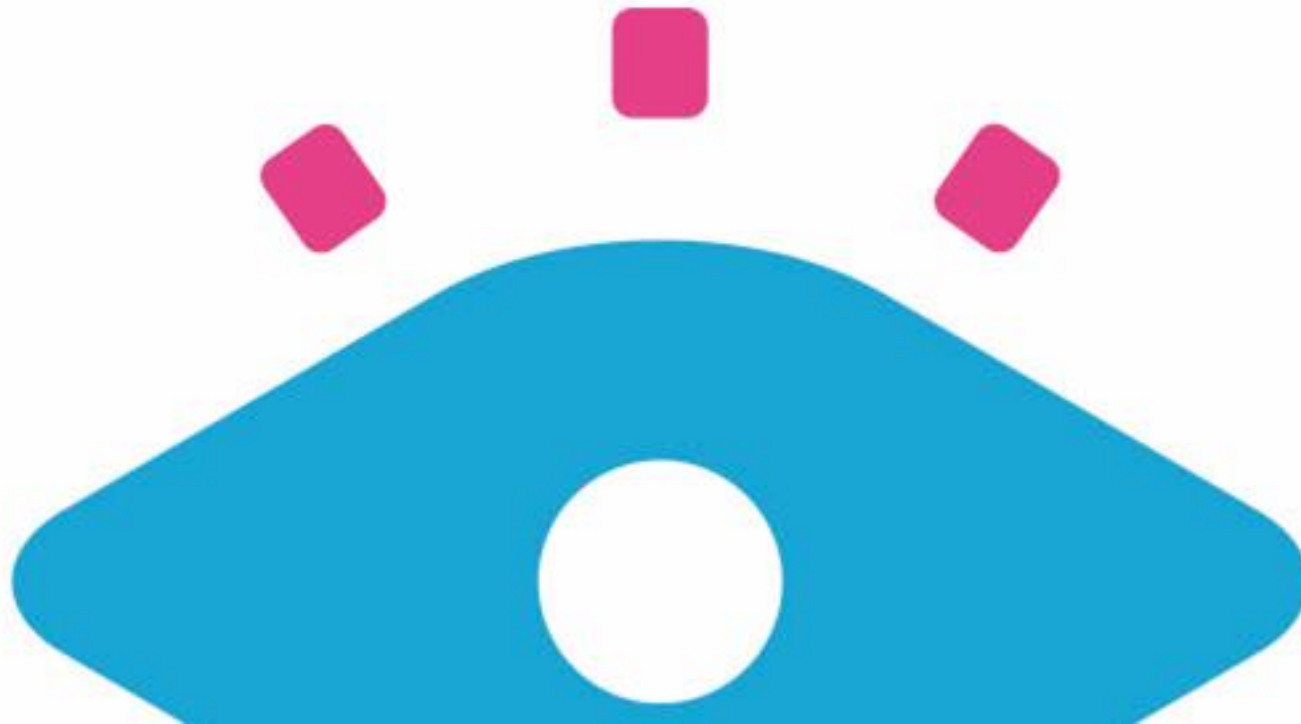
Foresight in Rare Disease Policy



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Recommendations from the Rare 2030 Foresight Study

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





**RECOMMENDATIONS
FROM THE RARE 2030
FORESIGHT STUDY**

THE FUTURE
OF RARE DISEASES
STARTS TODAY

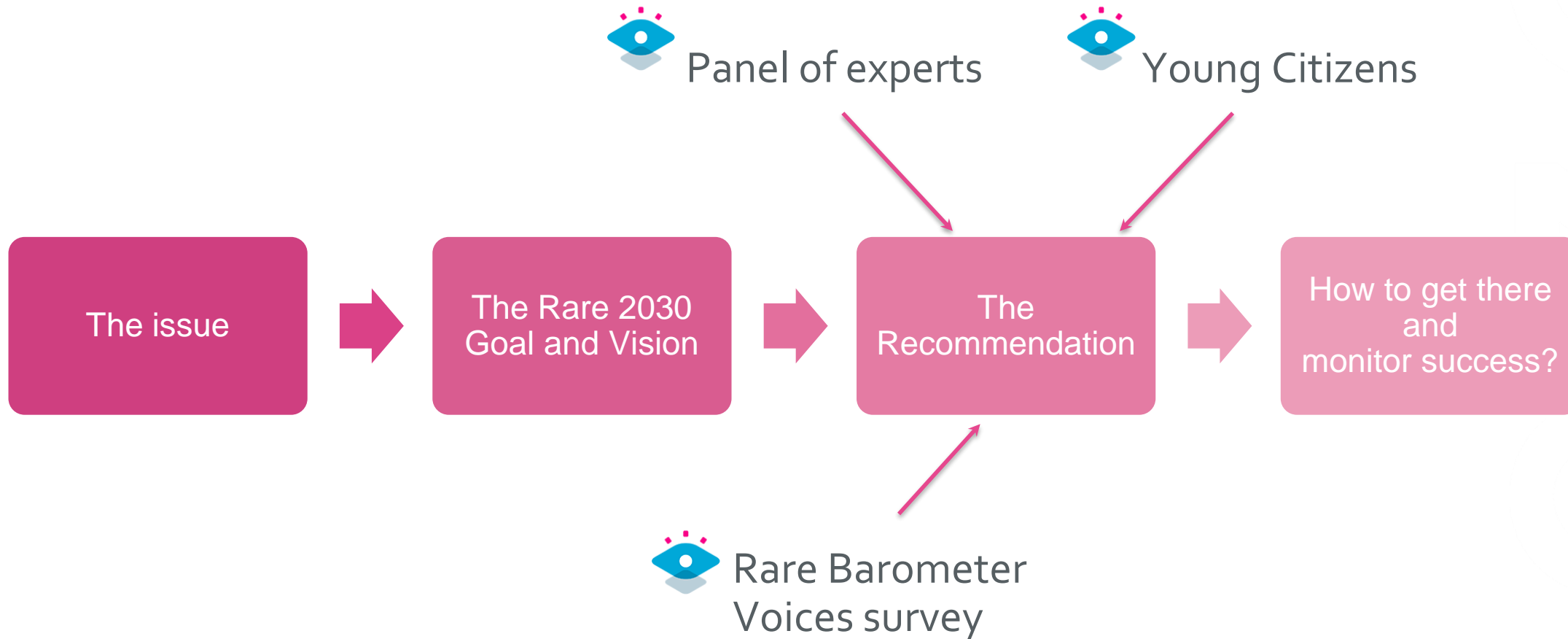
www.rare2030.eu



8 Recommendations



For each recommendation...





Recommendation 1

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



What do we recommend?



A European policy framework guiding the implementation of consistent national plans and strategies, monitored and assessed by a multistakeholder body on a regular basis.

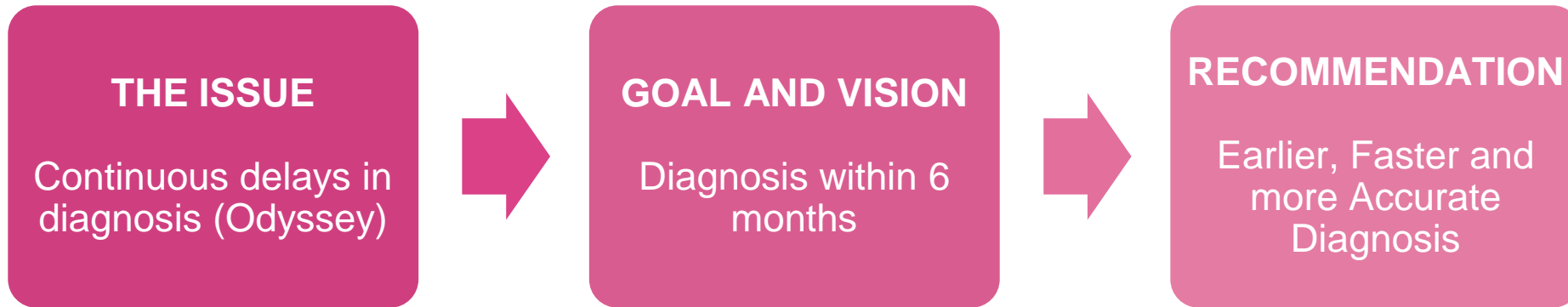


Recommendation 2

*Earlier, Faster and more
Accurate Diagnosis*



What do we recommend?



A better use of **currently effective and available tools, new technologies and innovative approaches** driven by patient-needs. **Inequalities** in access to diagnosis and care must be **eradicated** through the **harmonisation of standards**



Recommendation 3

Access to High Quality Care



What do we recommend?



Provision of **political, financial, operational and technical support** at European, national and regional levels to establish a highly specialized healthcare ecosystem that leaves no one behind

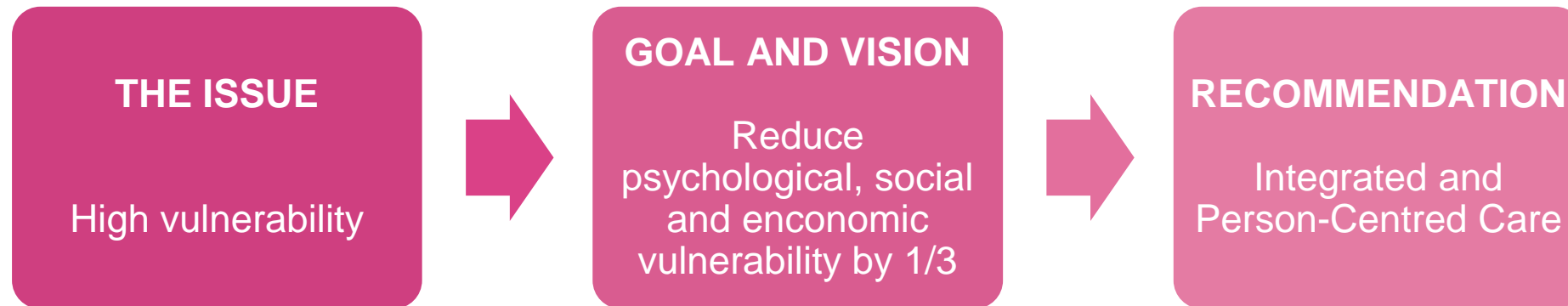


Recommendation 4

Integrated and Person-Centred Care



What do we recommend?



Implement EU-wide and national actions, **guaranteeing integration** of people living with a rare disease in **societies and economies**



Recommendation 5

Partnership with Patients



What do we recommend?



An overall culture encouraging **meaningful participation, engagement, involvement and leadership** of people living with a rare disease in both the public and private sectors.



Recommendation 6

*Innovative and Needs-Led
Research and Development*



What do we recommend?

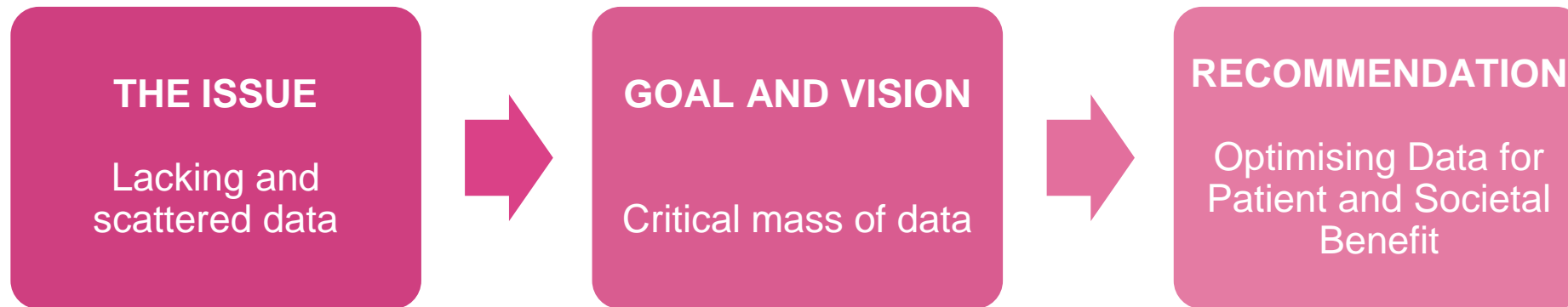


Basic, clinical, social and translational research maintained as a priority by **increasing the funds** for, **establishing greater incentives** in more neglected areas, and **supporting infrastructures** required to expedite discovery and knowledge acquisition

Recommendation 7

*Optimising Data for Patient
and Societal Benefit*

What do we recommend?



All European data sources of relevance should **be federated in a continuum** and **linked at the global level where possible**. Sharing should be optimised across infrastructures and countries and facilitated by adoption of common codification systems



Recommendation 8

*Available, Accessible and
Affordable Treatments*



What do we recommend?



Establishing **streamlined regulatory, pricing and reimbursement policies**, encouraging a continuum of evidence generation and a European ecosystem that **attracts investments, fosters innovation and addresses challenges of sustainability**

The Rare 2030 Recommendations

- Consider the full ecosystem
- Compliment and guarantee success of larger health programmes
- Contribute to the UN Sustainable Development Goals
- Aspire to leave no European citizen behind

