

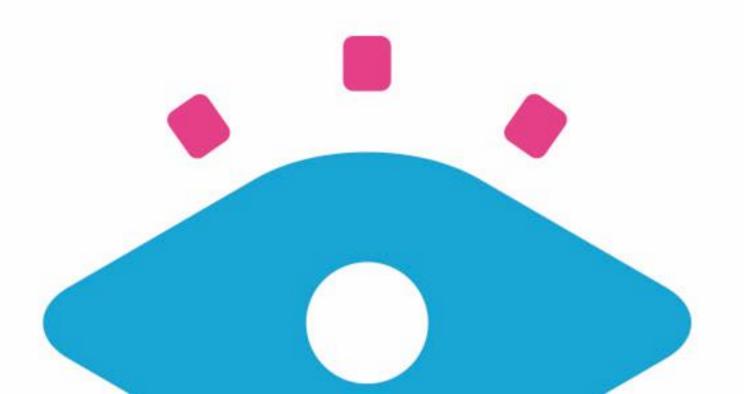


Anna Kole Rare 2030 Project Lead EURORDIS

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





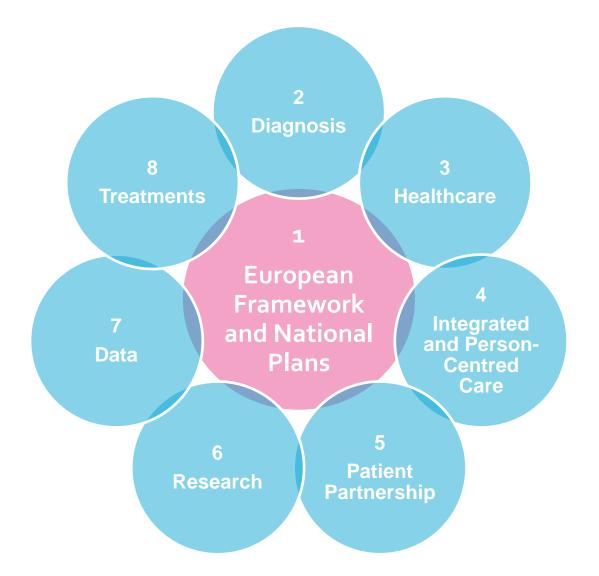






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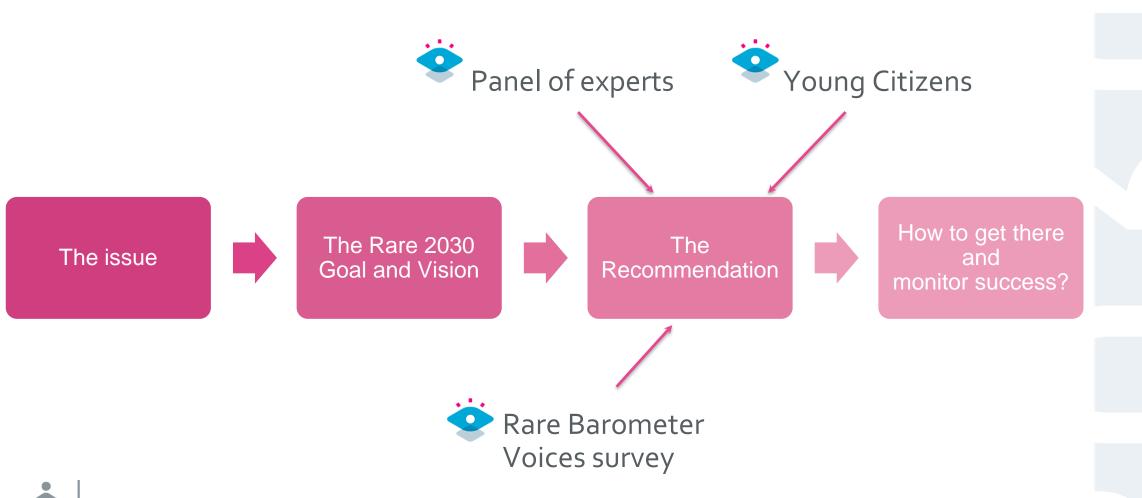




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For each recommendation...









Long-term, integrated European and National Plans and Strategies



THE ISSUE

Outdated framework and inconsistent national plans



GOAL AND VISION

Alignement, sustainability and adequate funding



RECOMMENDATION

Long-term, integrated
European and
National Plans and
Strategies

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







Earlier, Faster and more Accurate Diagnosis



THE ISSUE

Continuous delays in diagnosis (Odyssey)



GOAL AND VISION

Diagnosis within 6 months



RECOMMENDATION

Earlier, Faster and more Accurate Diagnosis

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







Access to High Quality Care



THE ISSUE

Lacking and scattered expertise and care



GOAL AND VISION

Right to health care, leaving no one behind



RECOMMENDATION

Ecosystem for access to high quality care

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







Integrated and Person-Centred Care







High vulnerability



GOAL AND VISION

Reduce psychological, social and enconomic vulnerability by 1/3



RECOMMENDATION

Integrated and Person-Centred Care

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







Partnership with Patients





Patients are experts



GOAL AND VISION

All patients and representatives can find their opportunity to provide expertise



RECOMMENDATION

Culture fostering meaningful patient partnerships

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







Innovative and Needs-Led Research and Development



THE ISSUE

Lacking investments and coordination



GOAL AND VISION

(and an in the late)

Increased and faster benefits for people living with a RD



RECOMMENDATION

Innovative and Needs-Led Research and Development

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





Optimising Data for Patient and Societal Benefit



THE ISSUE

Lacking and scattered data



GOAL AND VISION

Critical mass of data



RECOMMENDATION

Optimising Data for Patient and Societal Benefit

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 infrastures and countries and facilitated by adoption of common codification systems







Available, Accessible and Affordable Treatments



THE ISSUE

Significant unmet needs



GOAL AND VISION

1,000 new therapies, 3 to 5 times more affordable



RECOMMENDATION

Available, Accessible and Affordable Treatments

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

Rare 2030
Foresight in Rare Disease Policy

- 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

