RARE DISEASES
A major unmet medical need
R&I Projects for Policy

The majority of rare diseases lack accurate diagnosis and efficient treatment.

It takes a very long time for new treatments to become available for patients with rare diseases.

Developing solutions requires sharing data and collaborating internationally and globally as patients are dispersed widely.

Improving the lives of rare disease patients requires cooperation between research and healthcare organisations.

More than 30 million people in the EU have a rare disease.

There are 6000 to 8000 rare diseases.

80% of rare diseases are genetic diseases.

Research for new and better solutions
The EU has invested in research on rare diseases.

More than €1.4 billion
FP7 and Horizon 2020
2007-2019

More than 200 projects have produced results on:
gathering a critical mass of rare diseases cases and expertise for collaboration
prevention, treatments and diagnostics for rare diseases
tools and challenges relating to effective and ethical medical data sharing
new approaches for clinical trials in small populations

Actions for policymakers
support integration and networking among EU research, patient and healthcare organisations
adapt implementation of regulatory requirements, especially for clinical trials on rare diseases
support health technology assessment, standards and evidence-base for guiding public health policy
collaborate globally through IRDiRC* to accelerate research on improving the lives of patients with rare diseases

More than 200 projects have produced results on:

R&I Projects for Policy on Rare Diseases:
http://ec.europa.eu/research/p4p

*International Rare Diseases Research Consortium

More than 200 projects have produced results on:
prevention, treatments and diagnostics for rare diseases
tools and challenges relating to effective and ethical medical data sharing
new approaches for clinical trials in small populations

Research and Innovation

Supporting innovation and research

R&D spending: €2.2 billion
2007-2019

Collaboration with the private sector

Adapt implementation of regulatory requirements, especially for clinical trials on rare diseases

Supporting health technology assessment, standards and evidence-base for guiding public health policy

Collaborating globally through IRDiRC* to accelerate research on improving the lives of patients with rare diseases

MORE INFORMATION
Read the full R&I Projects for Policy report on Rare Diseases:
http://ec.europa.eu/research/p4p

Find all R&I Projects for Policy editions on:
http://ec.europa.eu/research/p4p

See also:
http://ec.europa.eu/research/healthcare
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