164 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

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

- 27–36 million people in the EU have a rare disease.
- There are 5000 to 8000 rare diseases
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- 80% of rare diseases are genetic diseases.
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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
- develop legally and ethically robust agreements for collecting and exchanging health and genetic data
- collaborate 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://europa.eu/!Nu98YP

See also:
http://ec.europa.eu/research/health/rare
http://www.irdirc.org

Find all R&I Projects for Policy editions on:
https://ec.europa.eu/info/research-and-innovation/p4p_en

\(^*\)International Rare Diseases Research Consortium