

RARE-Bestpractices: Researching rare diseases

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Clinical research needs to optimise its agenda by taking into consideration both patients' and clinicians' needs and interests. This is the goal of a four-year project funded by the EU's Seventh Framework Programme, which got underway in January 2013.

The RARE-Bestpractices project aims to improve the [clinical management](#) of rare diseases by undertaking a number of research activities that can be turned into practical solutions.

These activities include creating standards and transparent reliable procedures for the development and evaluation of clinical practice guidelines for rare diseases. Additionally, the project is working towards the identification of available notations for graphic representation of processes within clinical practice guidelines to improve user understanding and implementation.

The project also aims to build a comprehensive [public database](#) of high quality [clinical practice guidelines](#), ranging from diagnostic tests and treatments to organization of care, to help professionals, patients, policy makers with the best

and most up to date information. By December 2016, it will also have produced mechanisms to identify and prioritise rare diseases.

Finally, the project aims to define to what extent conclusions from cost-effectiveness analyses for pharmaceuticals are accounted for and implemented in best-practice guidelines across a range of countries.

Core activities will be complemented by training events organised to support stakeholders in developing and evaluating guidelines for rare diseases. To help shape its strategy and support its activities, the RARE-Bestpractices project has set up an advisory board of international experts, representing European and international organisations with a strong commitment in basic clinical research on [rare diseases](#).

More information: RARE-Bestpractices project - www.rarebestpractices.eu

Provided by CORDIS

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