

National registries of rare diseases in europe: an overview of the current situation and experiences.

[Taruscio D](#)¹, [Vittozzi L](#), [Choquet R](#), [Heimdal K](#), [Iskrov G](#), [Kodra Y](#), [Landais P](#), [Posada M](#), [Stefanov R](#), [Steinmueller C](#), [Swinnen E](#), [Van Oyen H](#).

[Author information](#)

Abstract

The European Union (EU) policy for healthcare requires the establishment of a system of European Reference Networks, union-wide information databases, and registries for rare diseases (RDs) based on shared criteria. In pursuing its goals, the 'Building Consensus and Synergies for the EU Registration of RD Patients in Europe' (EPIRARE) project convened a meeting with experts of the competent health authorities to discuss the role of national institutional RD patient registries in supporting EU patient registration and the room for international cooperation. With this aim, this paper comparatively analyses the current situation of national institutional RD registries in the EU. © 2014 S. Karger AG, Basel.

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