

Scientific monitoring of the national action plan for people with rare diseases (German acronym: WB-NAPSE)

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Summary: In 2010, the National Action League for People with Rare Diseases (NAMSE) was created by the Federal Ministry for Health (BMG), the Federal Ministry for Education and Research (BMBF) and ACHSE e. V. (Alliance of Chronic Rare Diseases). The 28 NAMSE partners (central and umbrella organisations of the key players in the health sector) have jointly developed 52 measures and proposals for a national action plan for people with rare diseases. The result, the National Action Plan, was presented to the public on 28 August 2013.

WB-NAPSE: The national action plan for people with rare diseases has been in place since 2013 and is now being scientifically monitored by the aforementioned cooperation partners.

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Duration: 2015 – 2017

Funding amount: €37,660

Organisational unit: Faculty of Public Health Services

Research area: Research on Societal Participation and Health Services Research