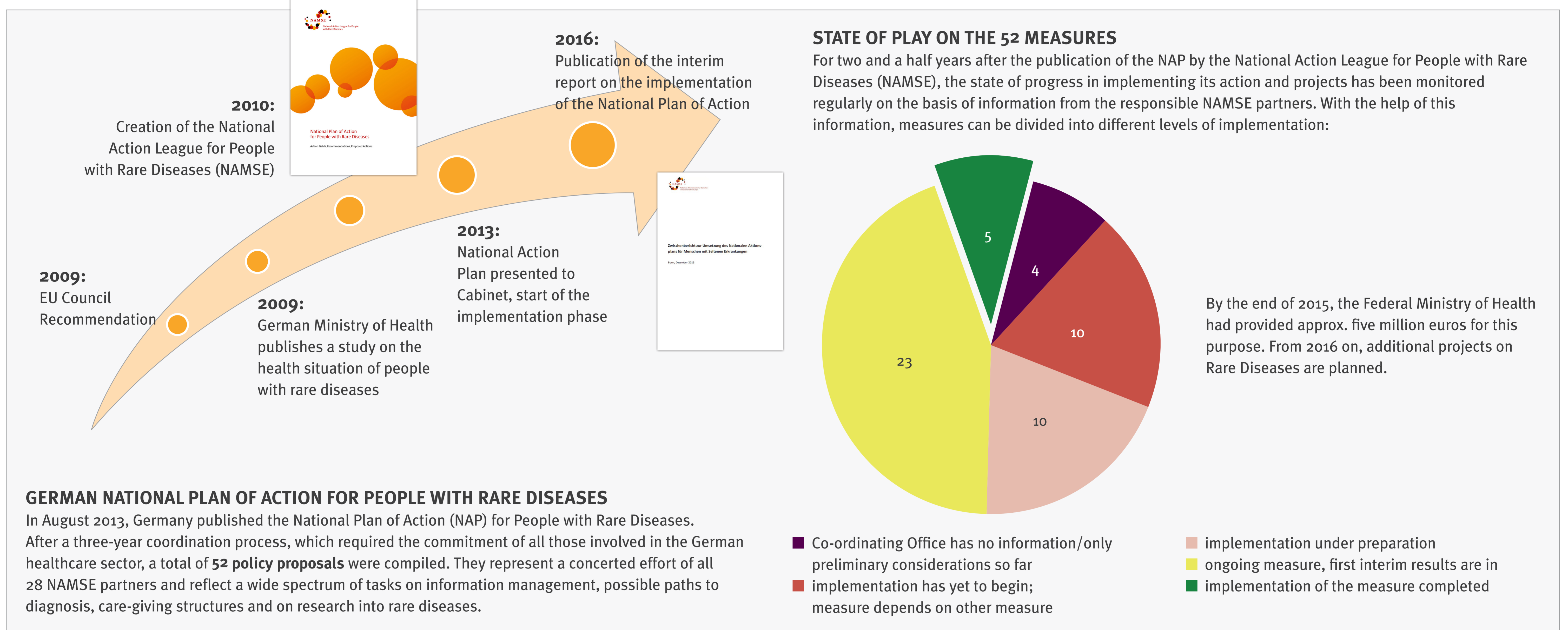


# NATIONAL PLAN OF ACTION FOR PEOPLE WITH RARE DISEASES: NEW RESULTS



## PROJECTS WITH A PARTICULAR RELEVANCE FOR EUROPEAN COOPERATION

### Highlight from the action field registries: OSSE OPEN-SOURCE-REGISTRY SYSTEM FOR RARE DISEASES IN THE EU (PROPOSAL 29)

With the project 'Open Source Registry System for Rare Diseases in the EU' (OSSE), sponsored by the Federal Ministry of Health, a free open-source software<sup>1</sup> for the development of a prototypical registry was developed for patient organizations, physicians, scientists and other parties. The project provides the complete service package (data protection concept, informed consent forms, etc.). It aims at improving the quality of German registries and assuring interoperability of those registries on a national and international level by reconciling existing and newly established registries with each other.

<sup>1</sup> [www.osse-register.de](http://www.osse-register.de)

### Highlight from the action field diagnostics: DIMDI PROJECT: „RARE DISEASES CODING GERMANY“: MATCHING OF ICD-10-GM, ALPHA-ID AND ORPHACODE IN ONE SINGLE DATABASE (PROPOSAL 19)

Sponsored by the Federal Ministry of Health, the project of the German Institute for Medical Documentation and Information (DIMDI) on 'Rare diseases coding' published the latest file of the Alpha-ID Version 2016 on 7th October 2015, which can be downloaded for free and comprises 2,646 entries on rare diseases<sup>2</sup>. It is a data set which allows a simplified, uniform and standardized coding by combining the Orpha number and the ICD-10-GM code. It aims at a proper representation of rare diseases in the German healthcare sector and a connection to the ERN for rare diseases throughout Europe.

<sup>2</sup> <https://www.dimdi.de/static/de/klassi/alpha-id/seltene-erkrankungen.htm>

### CENTER MODEL FOR RARE DISEASES

Directive 2011/24EU on the application of patients' rights in cross-border healthcare envisages the implementation of European Reference Networks (ERN). These are networks connecting highly specialised national health care providers and centers of expertise for the purpose of improving access to diagnosis, treatment and the provision of high-quality healthcare for patients.

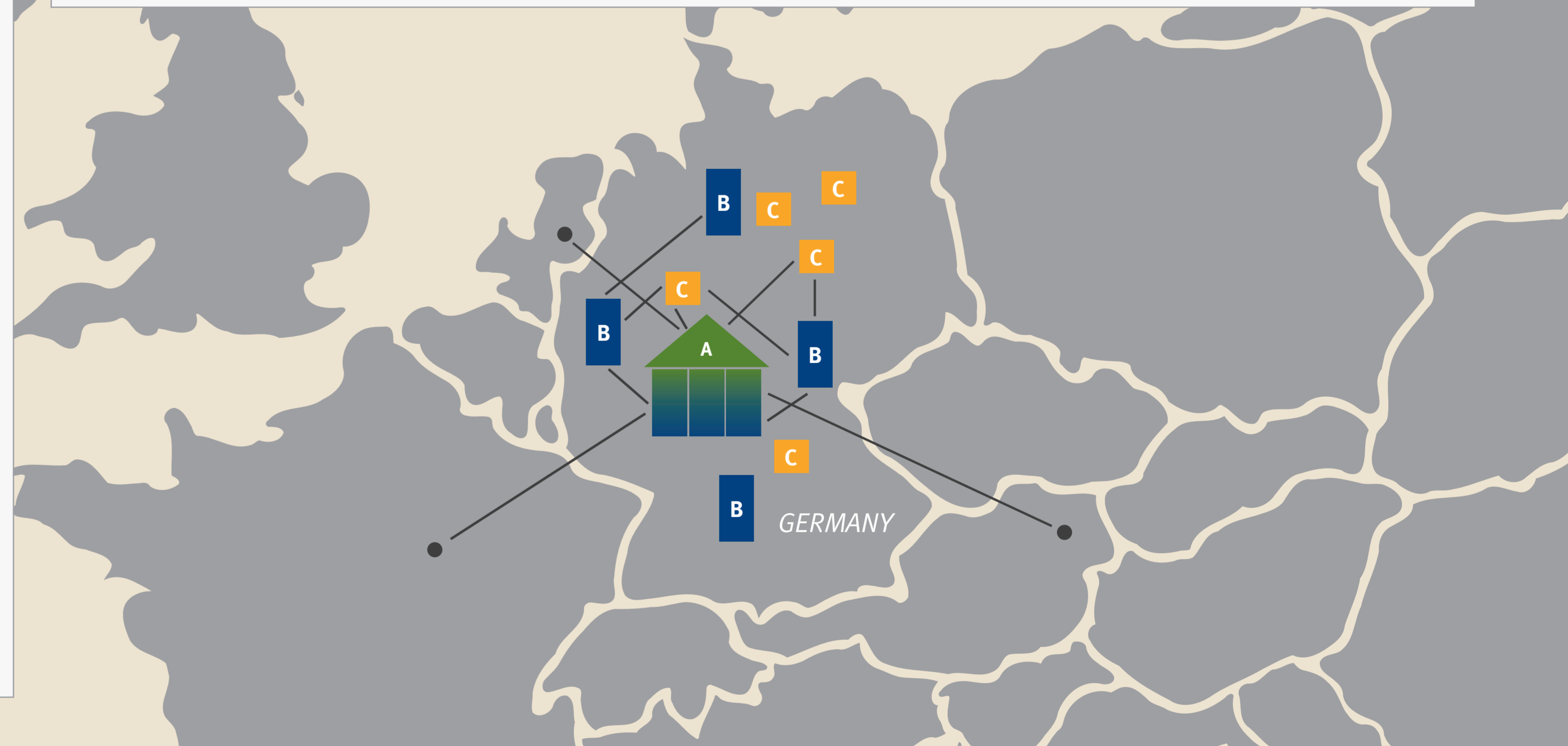
**Type A centers/Reference centers:** expertise of several thematic groups, referral center for patients with an unclear diagnosis,

**Type B centers/Centers of expertise for a specific rare disease or disease group,** for patients with a confirmed diagnosis or strongly suspected diagnosis.

**Type C centers/Cooperating centers for a specific rare disease/disease group,** exclusively close-to-home care, outpatient care.

The quality criteria catalogues are accessible online at: [www.namse.de](http://www.namse.de).

They are the basis for future certification procedures. Currently, various options are being considered for the implementation of the certification procedure.



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In 2015 and 2016, national legislation governing Rare Diseases changed:

### GKV-VERSORGUNGSSTÄRKUNGSGESETZ (ACT TO STRENGTHEN CARE PROVISION IN THE STATUTORY HEALTH INSURANCE SYSTEM)

This Act marks a major step towards enhancing the outpatient management of rare and complex diseases at university hospitals.

### KRANKENHAUSSTRUKTURGESETZ – KHSG (HOSPITAL STRUCTURES ACT)

At the same time, the Hospital Structures Act was adopted that specifies the existing provisions on Center operation subsidies (Zentrumszuschläge) in detail.

