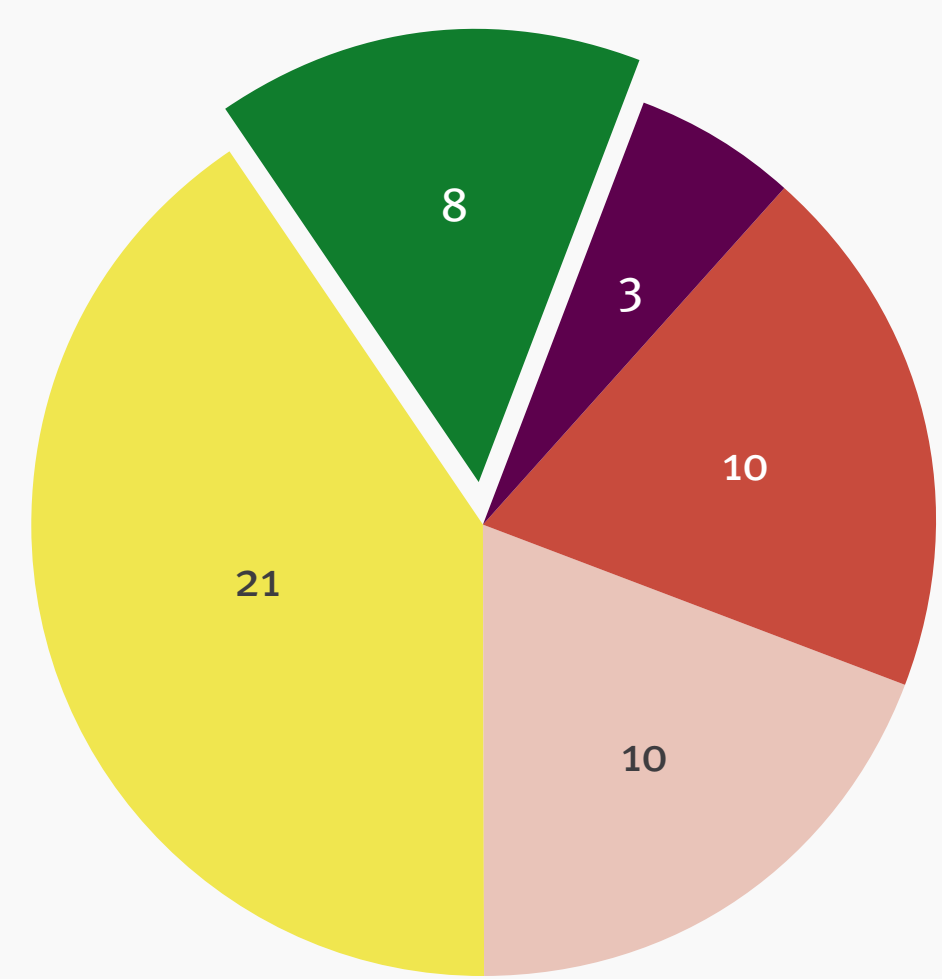


## NATIONAL PLAN OF ACTION FOR PEOPLE WITH RARE DISEASES: FURTHER DEVELOPMENTS

## STATE OF PLAY ON THE 52 MEASURES

Since the publication of the NAP by the National Action League for People with Rare Diseases, the state of progress in implementing its action and projects has been monitored regularly on the basis of information from the responsible NAMSE partners. With the help of this information, measures can be divided into different levels of implementation.

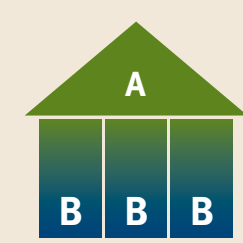


- Co-ordinating Office has no information/only preliminary considerations so far
- implementation has yet to begin; measure depends on other measure
- implementation under preparation
- ongoing measure, first interim results are in
- implementation of the measure completed

Four years after the publication of the National Action Plan half of the proposed measures have been implemented. Most of the other measures are due to the establishment of the **centers' model for rare diseases**.

## CENTER MODEL FOR RARE DISEASES

One central aim of the National Action Plan is the establishment of specialist centers at three different, cross-linked levels of specialization.



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



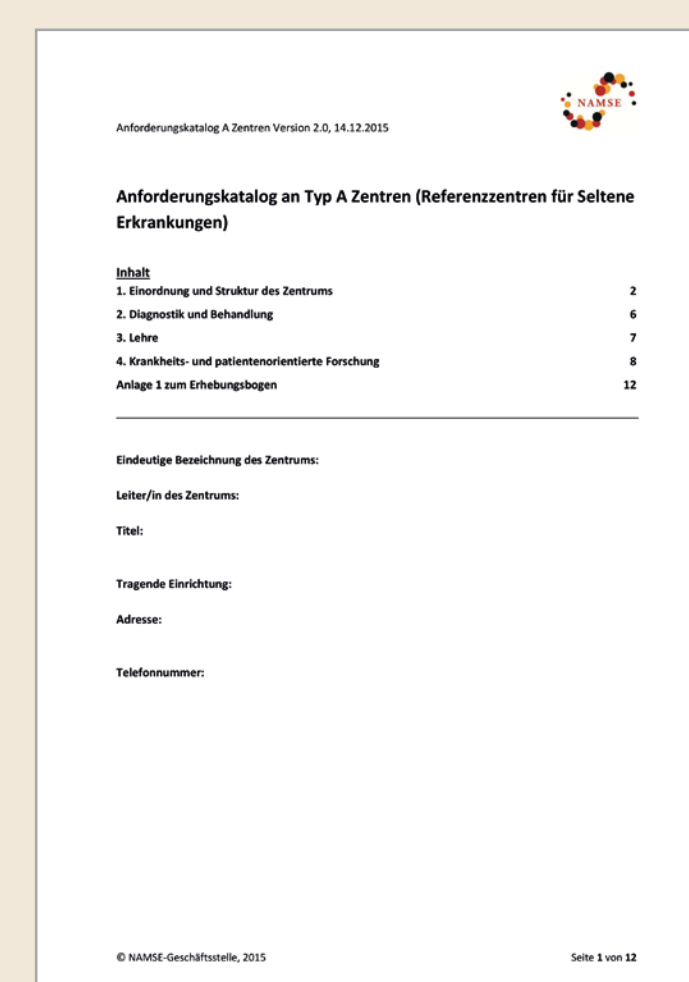
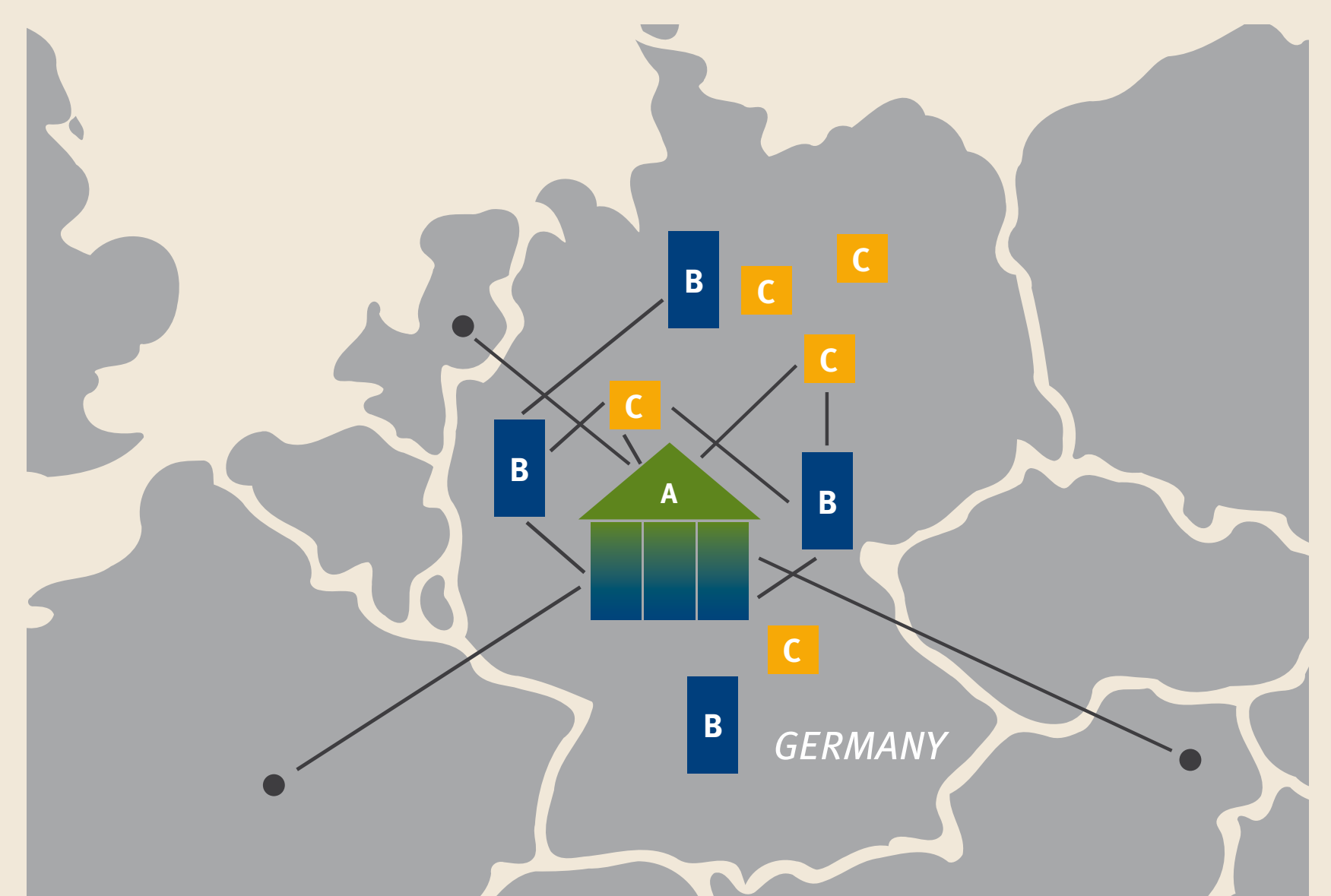
**Type B centers / Centers of expertise for a specific rare disease or disease group**, for patients with a confirmed diagnosis or strongly suspected diagnosis.



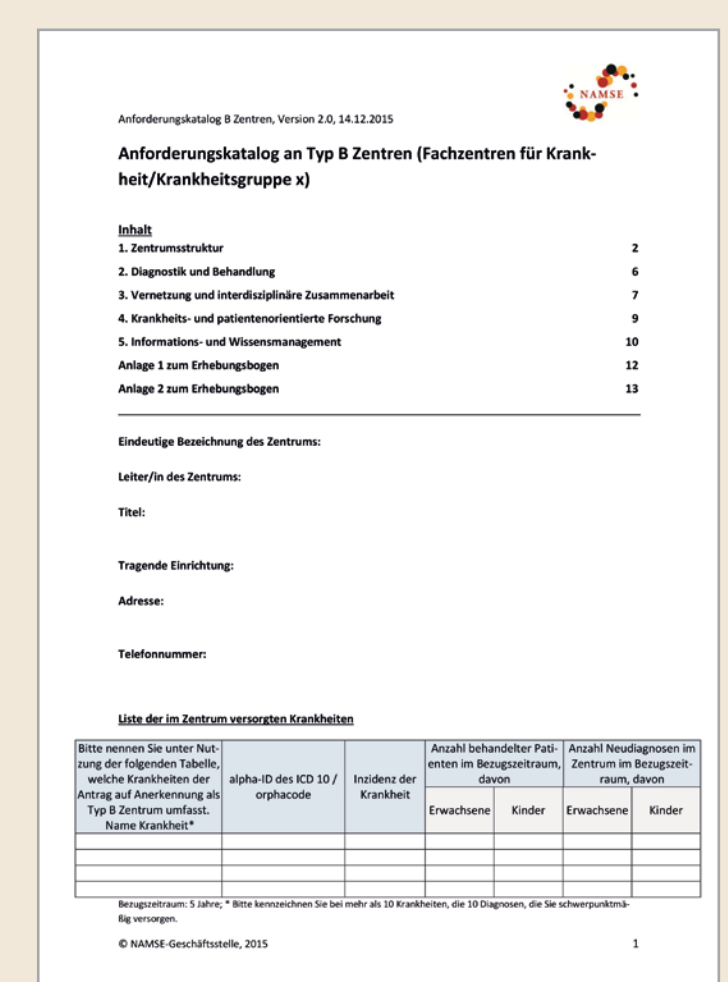
**Type C centers / Cooperating centers for a specific rare disease / disease group**, exclusively close-to-home care, outpatient care.

**Quality criteria catalogues for Type A centers and Type B centers**  
are accessible online at: [www.nam.se](http://www.nam.se)

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



## Quality criteria catalogue for Type A centers



## Quality criteria catalogue for Type B centers

## FURTHER ACTIVITIES



Graphic Recording, NAMSE-World-Café, September 2016

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**2010:**

Creation of the National Action  
League for People with Rare Diseases  
(NAMSE)



**2013:**

National Action Plan presented to Cabinet, start of the implementation phase

**2016:**

Publication of the interim report on the implementation of the National Plan of Action

**2018:**

To ensure the long-term implementation and continual further development of the Action Plan, a sustainable organizational structure for NAMSE has to be developed. Details are currently under discussion.

**2009:**

**2009:**  
EU Council  
Recommendation