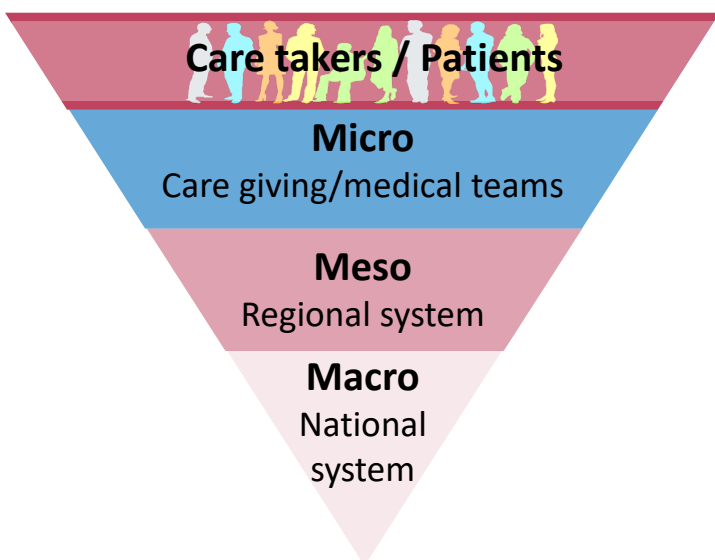


# NATIONAL PROGRAM AREA - RARE DISEASES:

## PROMOTING AND ENABLING KNOWLEDGE-BASED, EQUAL AND RESOURCE-EFFICIENT HEALTHCARE FOR RARE DISEASES IN SWEDEN

**BACKGROUND** Sweden has launched a new national structure for knowledge-based managed healthcare. The goal is to offer the population an even more equal and resource-efficient healthcare based on best available knowledge.

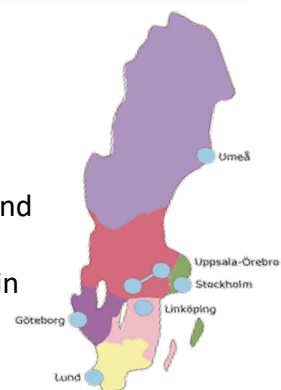


**NATIONAL PROGRAM AREAS** The new structure of knowledge-based management is centered around 25 National Program Areas. One of them covers rare diseases hence emphasizing the specific needs and requirements for this group of patients, in addition to more traditional grouping of disorders according to medical specialties. Each National Program Area should mirror the whole healthcare chain: prevention, primary care, specialist care, rehabilitation, care, etc. To support the NPAs and enable the overall goal additional National collaboration groups are formed around different themes such as National quality registers, Pharmaceuticals/MedTech and Patient safety.

**INITIAL AIMS** for the National Program Area Rare Diseases:

- Set a framework for national coordination and collaboration.
- Establish communication with patients' organizations.
- Establish a network of a large group of governmental authorities, healthcare providers, therapeutic national groups and so forth with purpose to share knowledge and interests in the field of rare disease.
- Initiate a national registry for Rare disorders.
- Initiate a working group with aim to improve the healthcare for patients with, syndromes with complex requirements.

**ORGANISATION** The Swedish healthcare system is decentralized through six national healthcare with 21 largely self-governed regions and 290 municipalities. The new national structure is operated in cooperation between all the regions. The aim is to develop common national guidelines based on scientific evidence and tested experience to be used by healthcare providers all over the country in every meeting with the patients. This is expected to increase the possibility for all the population to be offered healthcare on equal terms with respect for individual specific needs, expectations and integrity. The national structure also aims to optimize the use of resources in ensuring that best possible healthcare is offered to the population.



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