Rare Diseases Denmark

The National Landscape for Centres of Expertise
- Denmark

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The Danish system, the basics

- Denmark:
  - 5 mio. people
  - 30.000 – 50.000 patients with rare diagnosis
  - App. 800 rare diagnosis present
- Treatment at hospitals, medicin given at hospitals and acces to GPs and specialists: free of charge for all citizens independently of diagnosis and prevalence (financed by the general taxes)

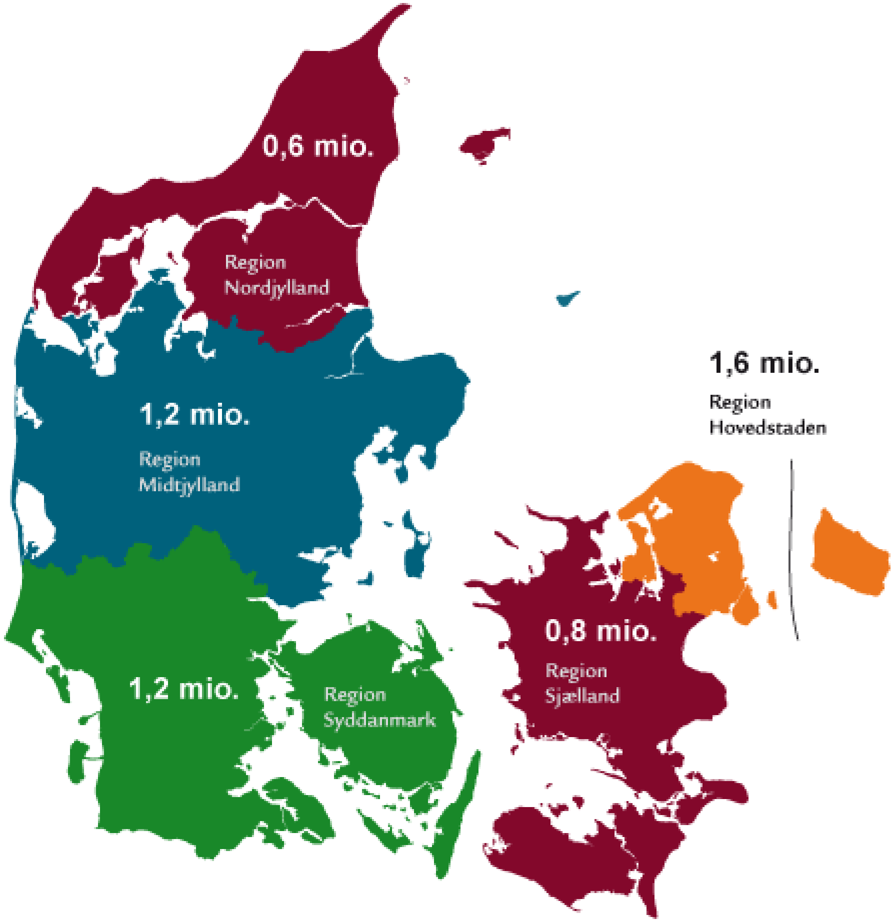
The Danish system, division of tasks

Regions:

- ➢ Operates public hospitals
- ➢ Plans health services
- ➢ Contracts private operators
- ➢ “Fixed” budget

National Authority (DHMA)

- ➢ Recommends basic functions
- ➢ Appoints specialised functions, including Centres of Expertise



Basic and specialised functions

- Basic functions: app. 90 %
- Specialised funcions: app. 10 %
  - Regional functions – 1-3 hospitals per region
  - Highly specialised funcions: 1-3 hospitals nation wide
- 36 specialties: app. 1.100 specialised functions
  - One instruction for each specialty
  - All in all: The Specialty Plan for all specialised functions

Criteria for specialised functions I

- Legal ground: Health Care Act of 2007
- Slogan: Specialise and centralise!
- When should a function be highly specialised:
  - Rarity (”practise makes perfect”)
  - Complexity (skills, multi-disciplinarity)
  - Resources

Criteria for specialised functions II

- What should ”count” when appointing a highly specialised function:
  - Core criteria
    - Capacity and stability
    - Volume, experience and expertise
    - Collaboration and facilites
    - Quality and documentation
  - Secondary criteria
    - Research, development and education
    - 24-7 services
    - Geography

The process of calls and appointment of highly specialised functions I

- The DHMA in collaboration with Learned Societies and Experts settle a catalouge of specialties
- The DHMA send out a call to the five regions to apply for specific specialised treatments in the catalouge
- Public (and private) hospitals apply to the DHMA for approval to maintain or gain specific specialised treatment (2009)
- After a process involving learned societies and other experts, the DHMA announced the appointment of regions/hospital departments in specific instructions for each specialty - the Specialty Plan (2010)

The process of calls and appointment of highly specialised functions II

- The Specialty Plan is binding – if a hospital/department is not approved, it is not allowed to carry out the specialty
- The approved departmentments are required to secure and develop their expertise – establish a quality improvement programme, document their activities and take part in teaching and research activities
- The appointment is for three years and during this period:
    - Yearly status reports, including patient satisfaction and patient safety
    - Monitoring from DHMA
- Revision of the Specialty Plan every 3 years (2014/2015)

Highly specialised functions, status for rare diseases

- Rare diseases can be found in almost all of the 36 specialties
- App. 100 – 120 highly specialised functions are related to various rare diseases or groups of rare diseases
- App. 75 highly specialised functions in only one hospital/department/center
- Two Centres for Rare Diseases at the University Hospitals in Copenhagen and Aarhus sees more than 3.000 patients, representing more than 400 different rare diagnoses

Revision of the Specialty Plan

- General results of centralisation: better care, better coordination
- Revision of the Specialty Plan: Rare Diseases Denmark made a statement, supported by examples of experience from 21 of our member organisations

The future

- The Future, our challenges:
  - Need to have: An even more specific Specialty Plan
  - Need to asses: if the Danish understanding of CoE is the same (and as good as) the European one
  - Need to reveal: how the DK CoE will find their way to ERN
  - Need to fight for: More patient involvement in the Specialty Plan and in evaluation of the Centres

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Thank you for your attention

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