

# Denmark & ERN – Status and foresight



05 March 2020

Danish Health Authority  
Status of ERN Networks

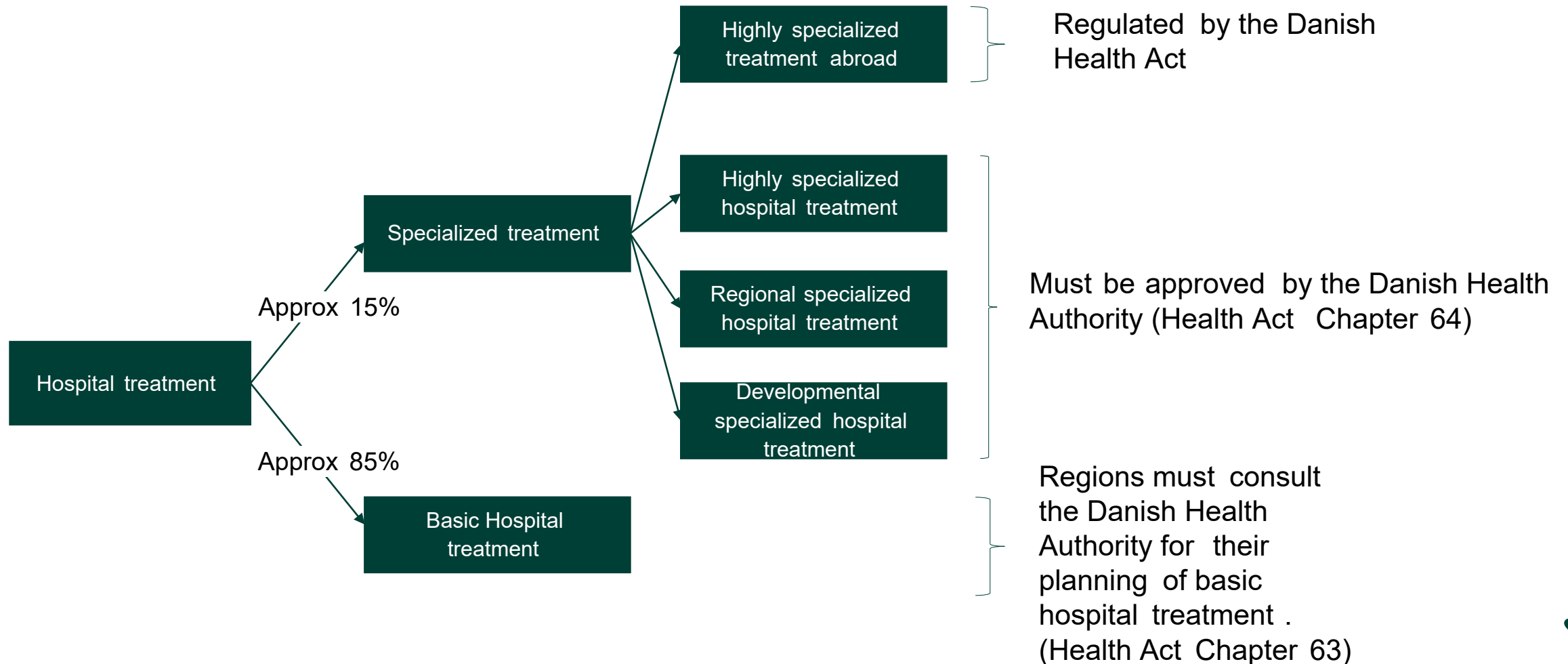
# Agenda

- A short introduction of the guiding principle of specialty planning in Denmark
- The Danish Health Authoritys participation in Board of Member states
- Current members and Affiliated partner in Denmark
- Applications for full membership from Denmark in 2019.
- Perspectives on the Danish participation in ERNs

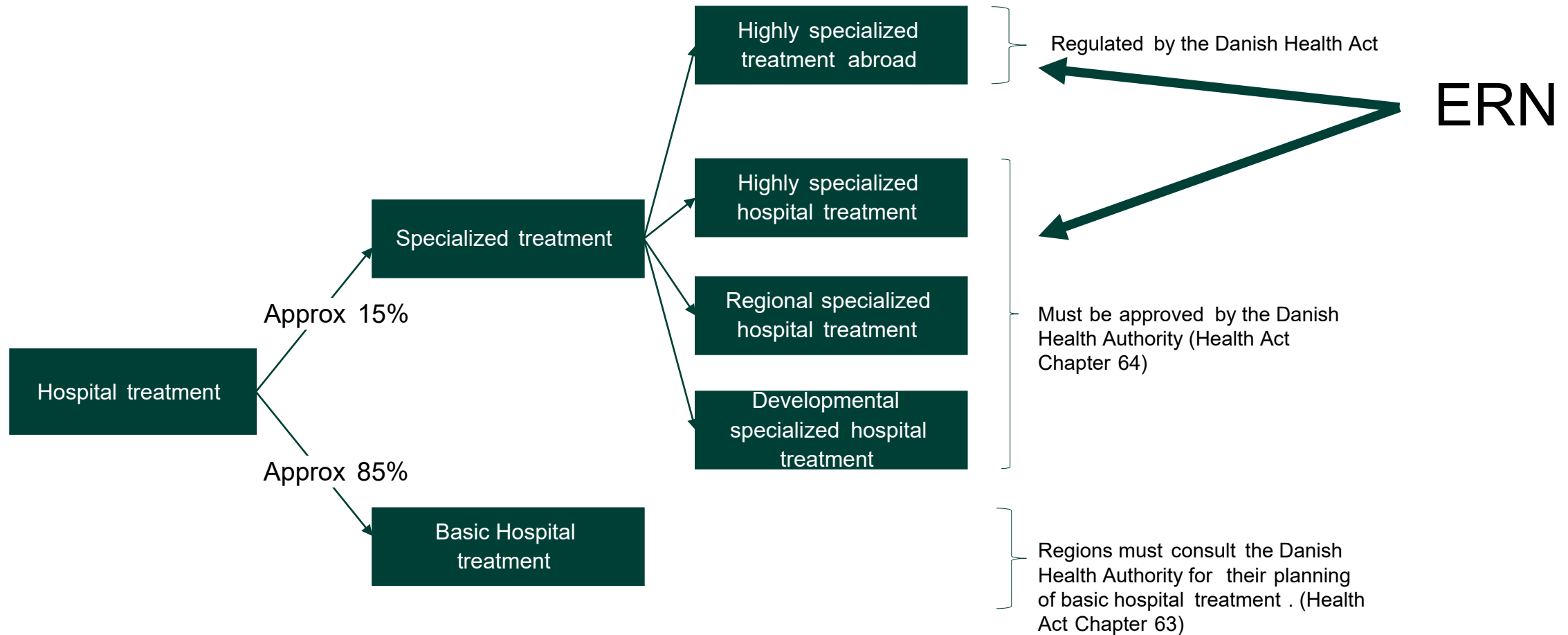
# Guiding principles of Specialty Planning in Denmark

- Practice makes perfect.
- Citizens must receive uniform, high-quality treatment across the country
- Cooperation between centers of expertise, both concerning treatment and research, is vital.

# Specialty Planning in Denmark



# Specialty Planning in Denmark



# Clinical patients pathways in Denmark for highly specialized treatment

- Centers of expertise for rare diseases/ highly specialized treatment is established
- A centralized specialty planning gives strong centers of expertise, compared to other EU-members with same size population.
- A clear pathway is established for almost all highly specialized treatments (GP referral and/ or referral from basic hospital level )

# Danish representation in the Board of Member States (BOMS)

- Board of member states is the guiding body of the European Reference Networks
- The purpose is to ensure the development of the networks and ensure integration across the member states.
- The Danish Health Authority represents Denmark in these full day meetings, that takes place 2-3 times a year in Bruxelles.
- All member states of EU is represented at the meetings.
- Decisions are made in consensus.

# Current Danish Memberships of the 24 ERN's

- 17 Full members
- 28 Affiliated partners
- All information and contact points available on Danish Health Authority webpage:  
<https://www.sst.dk/da/Opgaver/Sundhedsvaesen/Sygehusplanlaegning/Specialeplanlaegning/Europaeiske-referencenetvaerk/Oversigt-over-danske-medlemsskaber>
- Current referral structure is to contact relevant network center closest to patients place of residence.
- In the future a guide for subnetworks of Danish Representation in the ERN-networks might be added to ensure better patient pathways.



Network	AF	FM
Endo-ERN		2
EpiCARE		2
ERKNET		3
ERN BOND		3
ERN CRANIO		2
ERN-EYE		1
ERNICA		2
ERN-LUNG		2
ERN-RND		2
ERN-SKIN		2
EURACAN		1
EuroBloodNet		2
eUROGEN		2
EURO-NMD		2
GENTURIS		3
GUARD-HEART		1
ITHACA		3
MetabERN		1
PaedCan		1
RARE-LIVER		1
ReCONNET		2
RITA		2
TransplantChild		2
VASCERN		1
Total	28	17

# Current Danish coverage of networks

- Denmark has a 100% coverage of all 24 network, either in the form of full membership(s) or Affiliated partnerships.
- Current applications for turning Affiliated partnerships and other applications into full memberships is currently under review by the EU-Commission.

## Conclusion - Current status of the ERN

- ERN's are a great asset for treatment of rare and highly specialized treatments for all patients.
- The structure of, and guiding principles of ERN\*s are comparable to the principles of Danish Specialty planning (practice makes perfect).
- Danish Health Authority will continue to support the further development of the networks in collaboration with the Regions.

# Perspectives

- The enlargement process of the networks currently underway challenges the governance structure of some of the networks (potentially +700 new members).
- Higher requirements for participation might be needed.
- Legal challenges and practical exists in the development of European registries of rare diseases.
- Further national integration of the ERN's in the Danish Healthcare system will be a focus of Danish Health Authority and Regions in the coming years to ensure equal access to ERN's for all relevant citizens of Denmark.

# Questions ?



# Contact information:

– [Mail - specialeplanlaegning@sst.dk](mailto:specialeplanlaegning@sst.dk)

– Søren Neermark

Tlf +45 93518531



