



THE WAY FORWARD: FROM CENTRES OF EXPERTISE TO NATIONAL NETWORKS OF EXPERTISE

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Objective/background

Improving care for patients with a rare disease requires concentration of knowledge and resources in designated Centres of Expertise (CoE), dissemination, cooperation and knowledge sharing. At the European level, European Reference Networks (ERN's) stimulate Centres of Expertise to exchange knowledge and research between countries. However, there is a missing link if the ERN's are not connected to national Networks of Expertise (NoE). The Dutch government stresses the importance of such national Networks of Expertise and intends to make it a major criterion for being recognized as a designated Centre of Expertise. To facilitate this process, the VSOP is developing a generic roadmap for the development of national Networks of expertise by Dutch patient-organisations and Centres of Expertise.

Method/summary of work

Based on several VSOP-initiated pilots, a roadmap with standards for cooperation, knowledge sharing, communication and research is developed. A format for vision of organisation of care is included, describing the role of CoE and other medical centres. Also, the financing and continuity of a CoE is explored. The roadmap is currently tested by 10 patient-organisations and Centres of Expertise. These pilot-partners represent the variety in organisation of care for rare diseases.

Overview of participating pilot partners

Rare Disease	Patient Organisation	Centre of Expertise
ACNES	Stichting ACNES	SolviMáx, Expertisecentrum voor ACNES
Haemophilia	Nederlandse Vereniging Hemofilie patiënten	Van Creveldkliniek
Juvenile arthritis	Jeugdreuma vereniging Nederland	WKZ/ UMC Utrecht
Pulmonary fibrosis	Belangenvereniging Longfibrose patiënten	Erasmus Expertisecentrum Interstiële Longziekten
Vasculitis	Vasculitis stichting	UMC Groningen, Vasculitis Expertise Centrum
Mastocytosis	Mastocytosevereniging Nederland	Nederlands Mastocytose Centrum Groningen (NMCG)
Neurofibromatosis	Neurofibromatose vereniging Nederland	Erasmus, Sophia Kinderziekenhuis, Expertisecentrum ENCORE
Prader Willi-syndrome	Stichting Prader-Willi Syndroom Nederland	PWS Expertise Centrum Nederland, Erasmus UMC/ Stichting Kind en Groei
Marfan syndrome	Contactgroep Marfan Nederland	Expertisecentrum AMC Marfan syndroom
Von Hippel Lindau	Belangenvereniging Von Hippel-Lindau	UMC Groningen, afdeling Endocrinologie

Results

First results show that the pilot-partners appreciate the methodology of the roadmap as appropriate and useful. The patient organisations emphasize the importance of cooperation with designated Centres of Expertise. An important feature of the roadmap is the development of a shared vision on the organisation of care at a national level. This process has been started in the participating pilot-organisations. Involvement of other medical centres (not the CoE) and defining their (formal) role in the national Network of Expertise, is required to create clarity between hospitals and transparency for patients.

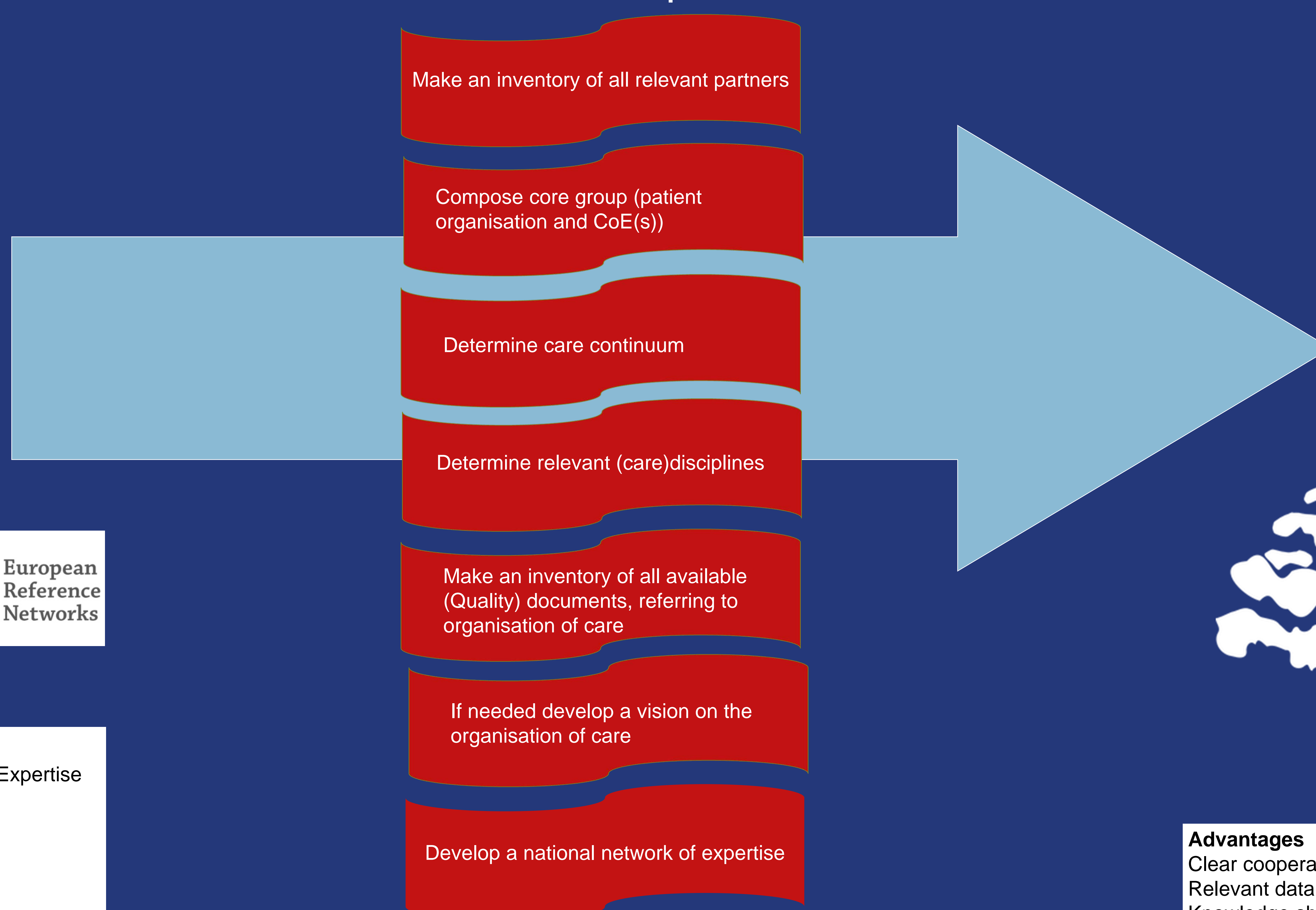
Conclusion

Clearly defined national Networks of Expertise will support the involvement of Centres of Expertise, in the related ERN. The developed generic roadmap provides Centres of Expertise and patient-organisations with knowledge and experience to initiate a national network. The roadmap is useful for all various organised (clusters of) rare diseases. Creating a national network fosters collaboration and knowledge sharing between medical centres and patient-organisations. This will contribute to quality of care for rare diseases.

Current



Roadmap



Future



Advantages

Clear cooperation between healthcare professionals
Relevant data sharing
Knowledge sharing
Improved care