

## Meet 'Expertise mapped'

Patients with rare diseases are often faced with:

- \* a late diagnosis
- \* lack of knowledge among specialists and healthcare workers
- \* a lack of effective treatments
- \* insufficient attention for scientific research.

To provide proper care for these patients it is important to cluster the expertise for these diseases. This insight has already led to the formation of so-called centres of expertise in The Netherlands. It also leads to developments at the European level, such as the European Reference Networks. In the process of designating centres of expertise hospitals and healthcare workers generally indicate their expertise. The perception of patients is often not incorporated.

### Project 'Expertise mapped'

The common problems experienced by patients with different rare diseases and the developments at the European level have resulted in the project 'Expertise mapped'.

### Goal

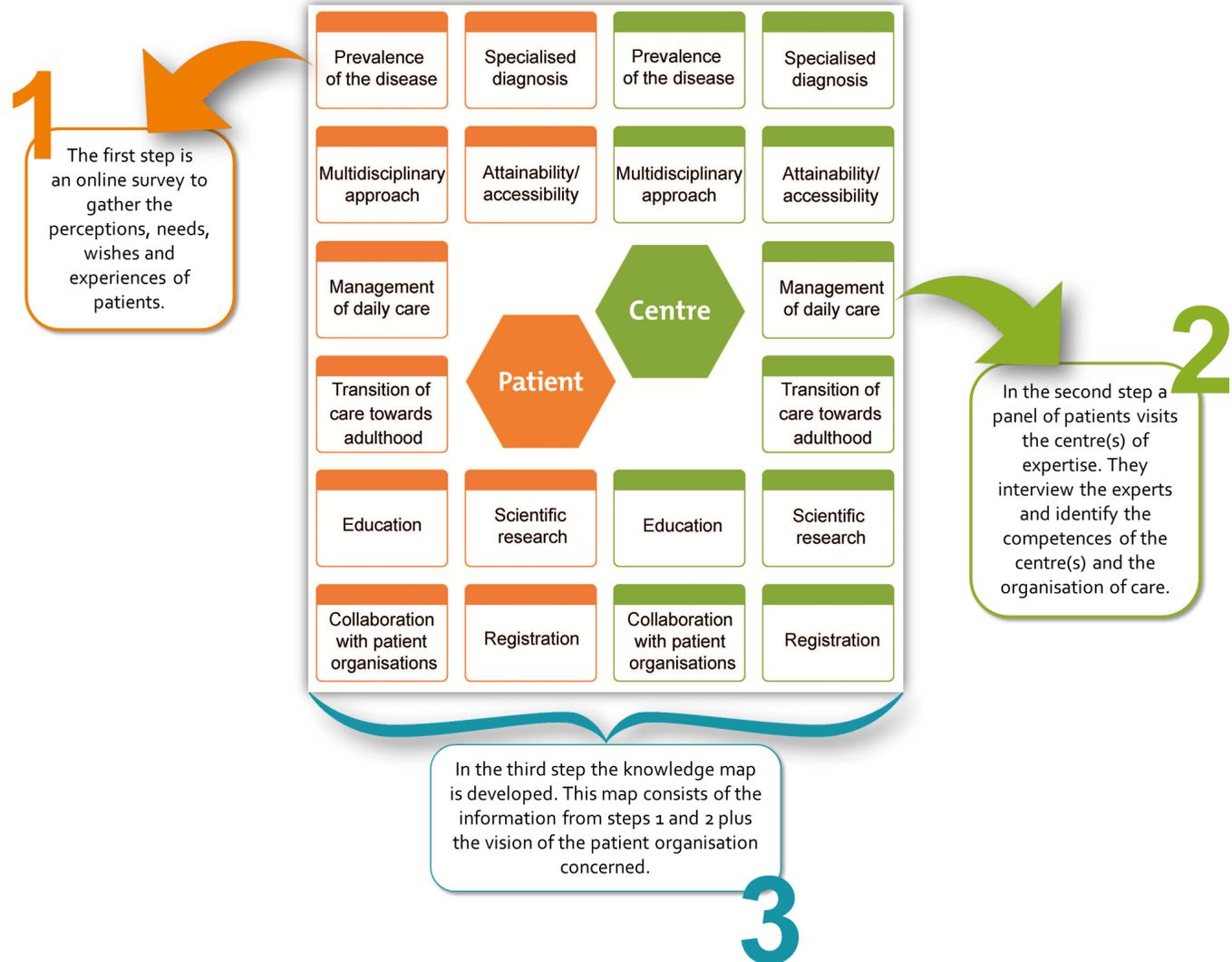
'Expertise Mapped' visualises the organisation of care for patients with rare diseases from the patient's perspective in knowledge maps.

## About knowledge maps

Knowledge maps are divided in two sections: the experiences of patients (orange section) and the organisation of care (green section). In both sections ten topics are discussed, based on the Quality Criteria for

Centres of Rare Diseases (EUCERD). The ten topics are shown in the figure below.

If there are more centres of expertise for one rare disease, each centre will get their own knowledge map.



A panel of patients is visiting  
the centre of expertise for X-ALD  
in The Netherlands (AMC Amsterdam)



Marc Engelen, paediatric neurologist:  
"The knowledge maps clearly show  
patients the outline of health care  
in centres of expertise."

## Stronger together

Different patient organisations for rare diseases collaborate in this project to generate a large and diverse overview of rare diseases and their centres of expertise. Every patient organisation for rare diseases is invited to join us, both in The Netherlands and abroad. Together we stand strong!

We hope to inspire other countries to incorporate the patient's perspective in the expertise for rare diseases.

## Benefits

Knowledge maps:

- \* show where expertise is located and how health care is organised
- \* give patients the opportunity to choose the centre that best fits their needs
- \* provide insight into the perspective on proper care and actual care needs of patients
- \* give centres of expertise the opportunity to show their expertise
- \* give centres of expertise the opportunity to improve and customize their health care by informing them about the patients' experiences, needs and wishes
- \* show healthcare professionals where they can refer their patients and where they can ask their questions about the treatment for their patients

'Expertise mapped' strengthens the position of patients by listening to patients and providing them a voice.

Interested or questions  
about 'Expertise mapped'?  
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