

P13**Expertise for rare diseases mapped**

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Background

Patients with rare diseases often have to endure a late diagnosis, a lack of knowledge among specialists and healthcare workers, a lack of effective treatments, and insufficient attention to scientific research. To provide proper care, it is important to cluster expertise for these diseases. This insight has led to the formation of centres of expertise and also leads to the establishment of European Reference Networks. In the process of identifying and designating expertise in rare diseases at national level, hospitals and healthcare workers generally indicate their expertise. The perception of patients is often not incorporated. The goal of the project 'Expertise Mapped' is to visualise the organisation of care for patients with rare diseases, from patients' perspective.

Method

The knowledge maps are based on the EUCERD Quality Criteria, summarized in ten topics (Fig. 1). These maps show on the left side the perceptions, needs and wishes of patients (gathered by online surveys) and on the right side the competences of the centre (gathered from visiting the experts by a panel of patients). If there are more centres of expertise for one rare disease, each centre will get their own knowledge map.

Results

We produced knowledge maps for 15 different rare diseases, corresponding 27 centres of expertise in the Netherlands. In the next 3 years we will continue producing knowledge maps with the intention to generate a large and diverse overview of rare diseases and their centres of expertise. They are published on the website Expertise Mapped [<http://www.expertisemapped.org>].

Conclusions

It is important to acknowledge centres of expertise for rare diseases from patients' perspective and to visualise the organisation of care. 'Expertise Mapped' provides patients, patient organisations and healthcare workers more insight in the organisation of care, and an overview of the expertise for rare diseases from patients' perspective. Knowledge maps have many advantages:

1. Knowledge maps show where expertise is located and how healthcare is organised;
2. If there are more centres for the same disease, knowledge maps give patients the opportunity to choose what fits their needs;
3. The online survey provides insight into patients' perspective on proper care and their actual care needs;
4. Knowledge maps give centres of expertise the opportunity to show their expertise.

'Expertise Mapped' strengthens the position of patients by bundling and showing the expertise for different rare diseases from the patients' perspective. The more knowledge maps are published, the stronger the patients' voice.

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