

Patients experiences are essential for improving the quality of health care

Background

Metabolic diseases (MD) are rare and specific care for them is insufficiently developed. Because of the complexity and severity of MD, patients' opinions about care needs are essential. We inventoried the patient's perspective on health care and centres of expertise (CEs) in The Netherlands through an online survey as part of the project Expertise Mapped. This provides a picture of the organisation of care for rare diseases from the patients' perspective. From these data we have distilled shared opinions to advocate the needs of patients with MD.

Method

Between 2013-2018 the online survey was conducted among 1802 Dutch patients with 191 different rare diseases as part of the project Expertise Mapped. For this poster the data for MD only were extracted. With the use of descriptive statistics the data of 401 Dutch patients with 97 different MD were analysed.

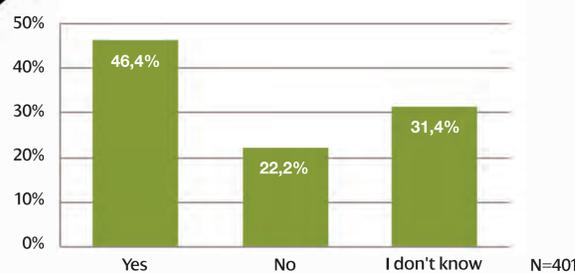
About Expertise Mapped

Expertise Mapped visualises the organisation of care for patients with rare diseases from the patient's perspective in knowledge maps based on EUCERD Quality Criteria. The first step to develop a knowledge map is an online survey to gather the perceptions, needs, wishes and experiences of patients. In the second step a panel of patients visits the centre(s) of expertise. They interview the experts and identify the competences of the centre(s) and the organisation of care. In the third and last step, all the information from the online survey and the interview is put together in a knowledge map en published online at www.expertisemapped.org.

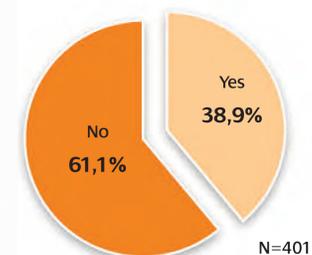
At this moment there are 44 knowledge maps published for 26 different rare diseases. Among the published knowledge maps there are 13 knowledge maps for 11 different groups of MD.

Results

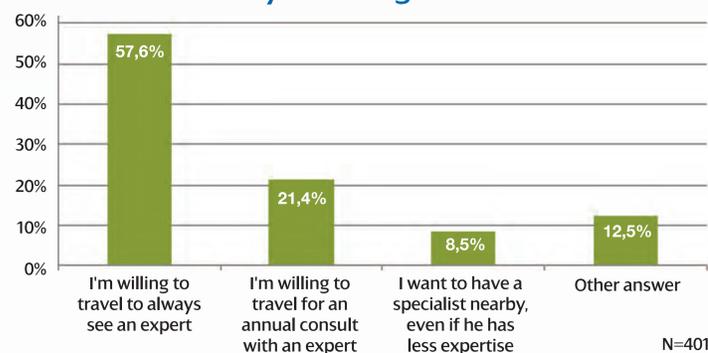
Is there a centre of expertise?



Do you experience problems in health care?



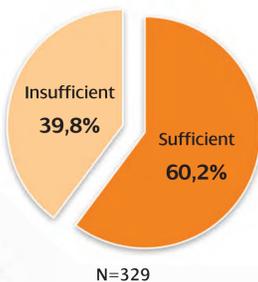
Are you willing to travel?



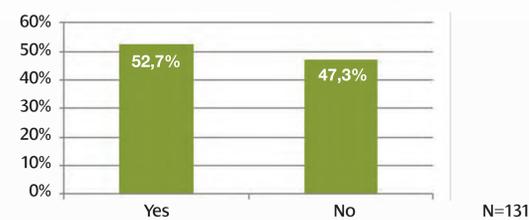
Top 3 problems (N=156):

1. A lack of knowledge among healthcare professionals regarding their disease (62,8%).
2. A lack of collaboration between specialists and healthcare professionals (42,9%).
3. Insufficient reimbursement for medicine and medical aids (30,8%).

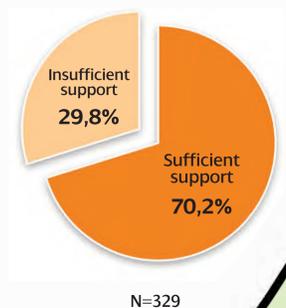
Psychological support



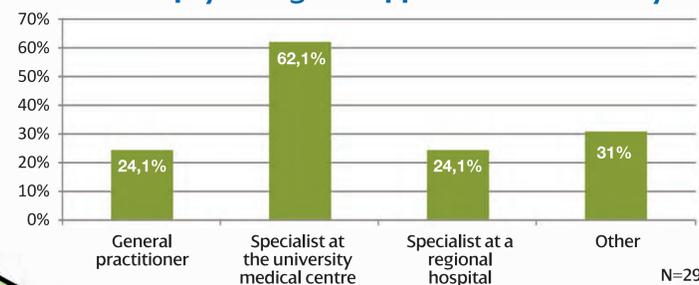
Do you have a need for psychological support?



Support regarding the organisation of care



I would like psychological support to be offered by:



Conclusion

CEs should increase their visibility for patients, emphasize their added value and involve patients in the organisation of care. When a larger proportion of patients is seen in a CE, the knowledge of MD will increase and the quality of care will improve. Simultaneously, experts must pass along their expertise to other healthcare professionals to decrease the knowledge gap.

Support for patients in the CE's in the coordination of their care is indispensable and collaboration between healthcare professionals should be stimulated. All these data suggest there is a larger role for the CE's, and possibly for the MetabERN as well, to fill the gaps that patients experience. The use of the method from Expertise Mapped may help in this process.

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