

Patients experiences are essential for improving the quality of health care

Background

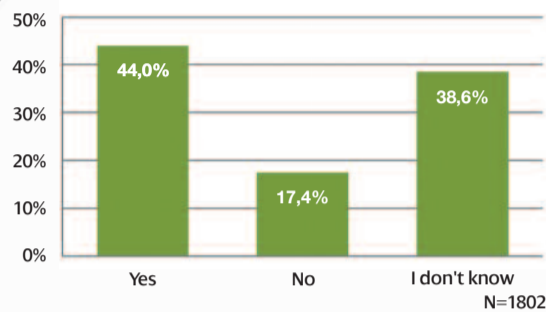
Most patients with rare diseases feel they do not receive the attention they deserve. 'Expertise mapped' was therefore set up to visualise the organisation of care for rare diseases from the patients' perspective. 'Expertise mapped' develops knowledge maps (based on EUCERD Quality Criteria) in which both the patients' perspective on health care (gathered from an online survey) and the organisation of care in the centre of expertise (gathered from interviews with the experts by a panel of patients) is presented. In total our online survey represents almost two hundred rare diseases. From these data we have distilled common interests that can be used by patient organisations to jointly advocate the needs of patients with rare diseases.

Method

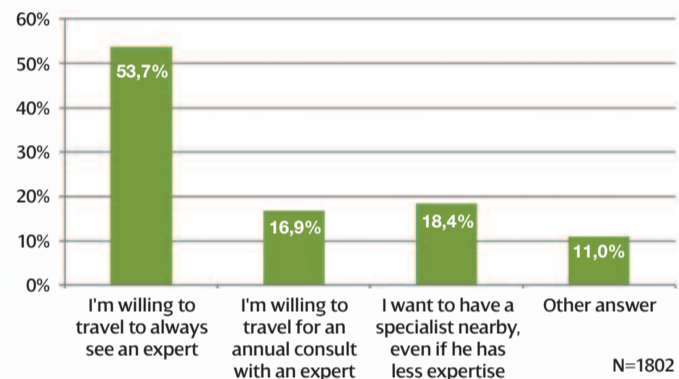
Between 2013 and 2017 1802 Dutch patients with 191 different rare diseases filled in the online survey. Distinctive characteristics and similarities were identified and analysed with the one-way ANOVA and the Paired Samples T-Test.

Results

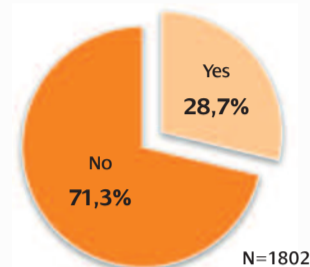
Is there a centre of expertise?



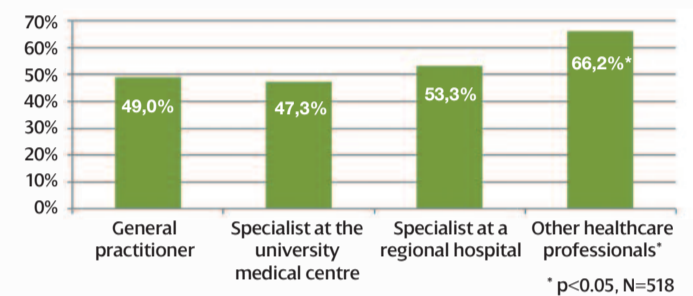
Are you willing to travel?



Do you experience problems in health care?



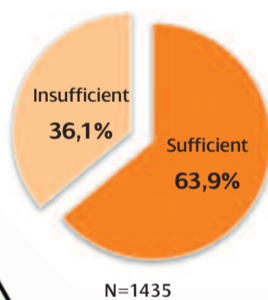
Patients experience difficulties with:



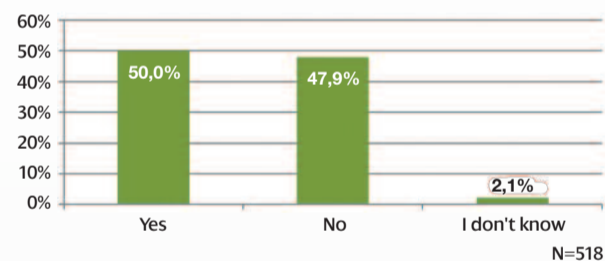
Top 3 problems (N=518):

1. A lack of knowledge among healthcare professionals regarding their disease (57.5%).
2. A lack of collaboration between specialists and healthcare professionals (42.5%).
3. Insufficient reimbursement for medicine and medical aids (27.6%).

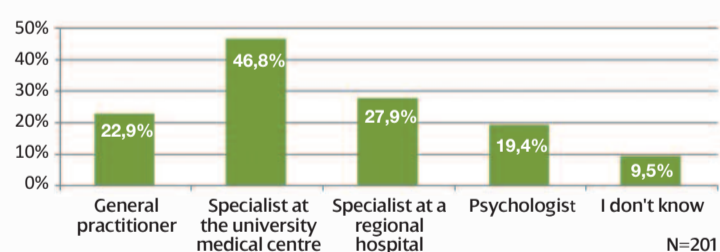
Psychological support



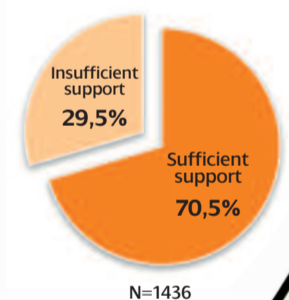
Do you have a need for psychological support?



I would like psychological support to be offered by:



Support regarding the organisation of care



Conclusion

Despite the introduction of government-designated centres of expertise for rare diseases in The Netherlands in 2014, less than half of the patients is aware of their existence. Centres of expertise should thus increase their visibility for patients and emphasize their added value. 'Expertise mapped' brings experts and patients together with the aim to improve the care for rare diseases. And by giving them a voice, patients will be able to exert influence on the care they receive as well as on the (re-)designation of centres of expertise. Our data show that most patients are willing to travel to an expert. When a larger proportion of patients is seen in a centre of expertise, the knowledge of rare diseases at

this site 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 organisation and coordination of their care is another key issue. This support should preferably be provided by someone connected to the centre of expertise, who should also stimulate the collaboration between different specialists and healthcare professionals. Psychological support also deserves more attention. All these data suggest there is a larger role for the centres of expertise to fill the gaps that patients experience.

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