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OBJECTIVE

Healthcare is about people, their quality of life and experience with medical services. In the Netherlands patient organisations participated formally in the designation of Centres of Expertise (CoE), making sure patient perspective was included in addition to the medical/scientific perspective.

METHOD

- The expertise of a candidate CoE was assessed by - EUCERD criteria based - questionnaires.
- One had to be filled out by the candidate CoE itself
- One by the patient organisations representing the rare disease(s) declared by the CoE.
- The Scientific Board of Orphanet NL filled out an assessment form.

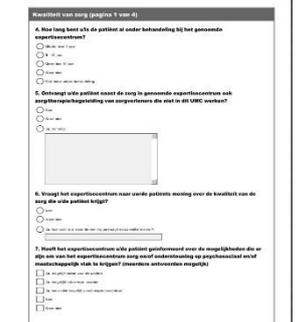
RESULTS

- In total 302 designated Centres of Expertise in the Netherlands on January 2016
- Participating patient organisations were facilitated and supported by VSOP, including:
 - Instructional meetings;
 - A telephone and e-mail helpline;
 - Q&A and other information on www.vsop.nl;
 - Basic questionnaire for membership consultation.
- For information on a specific CoE in the Netherlands, see: www.zichtopzeldzaam.nl



GENERAL NUMBERS

Number of applied candidate Centres of Expertise	417
Number of unique participating patient organisations	85
Number of questionnaires filled out by patient organisations	298
Number of questionnaires filled out per patient organisation	1 to 19



CONCLUSIONS

- The assessment of candidate CoE's from the patients' perspective was of great added value in the process of designation.
- Patient organisations gave their own unique perspective based on their experiences with the CoE's and the patients (and/or their parents) experience with these elements of healthcare.
- It also became clear from patient perspective- which candidate CoE's were already performing good on criteria like (international) collaboration and which candidate CoE's could improve.
- As a result, the collaboration between the CoE's and patient organisations improved and resulted in a better mutual understanding and cooperation, to work together and improve the quality of healthcare and research.