

Health-related quality of life measurement strategy for solid rare cancers

Team: Msc Catarina Simões Padilla, Dr. Olga Husson, Dr. Margot Tesselaar & Prof. Dr. Winette van der Graaf
The Netherlands Cancer Institute Amsterdam, The Netherlands

Outline of project:

Rare cancers are defined as those with fewer than six cases per 100,000 people/year. More than any other single malignancy, they account collectively for around 24% of all diagnosed cancer cases. As a result, rare cancers pose a severe burden to public health and should be recognised as a priority. Also, compared to the general cancer patient population, rare cancer individuals report poorer psychosocial outcomes and worse health quality of life (HRQoL). Due to several obstacles with access to care and information, many patients with rare cancer have (unmet) supportive care needs.

This project aims to improve HRQoL measuring practices for individuals with solid rare cancer diagnoses. Due to the diversity of tumours, therapies and patient experiences, developing a single HRQoL score for all rare malignancies will be hard. Understanding these variations is crucial when developing an HRQoL measuring technique.

We will employ a mixed-methods approach in this study. We conduct two systematic literature reviews, moving to a qualitative section in which two rounds of interviews with patients and healthcare professionals (HCPs) are held, then a quantitative analysis of the interviews and output of questionnaires. Considering how diverse rare cancers can be, the team chose two diagnosis per EURACAN group (see below).

We hope to bring more awareness and knowledge to a challenging and tricky area of research. The project's primary outcome will be to develop a measurement strategy (i.e. guidance document) for HRQoL assessment for research in solid rare cancers focused on content.

