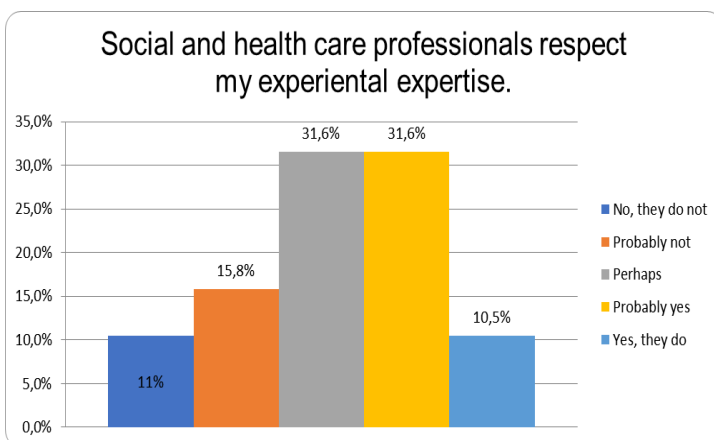
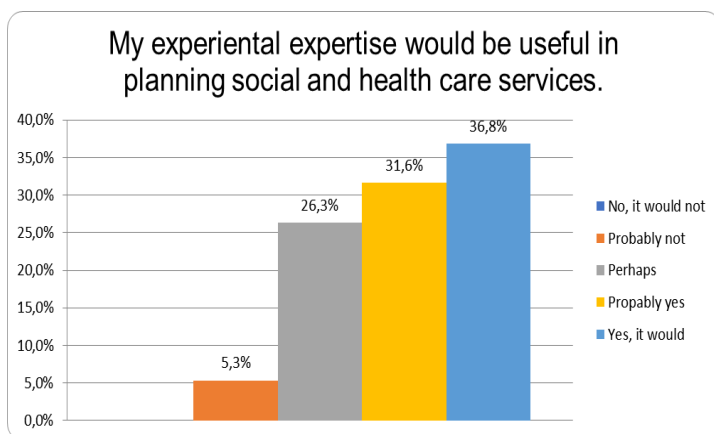


Survey on rare disease patients' experiences of participation and possibilities of influencing in social and health care service structures

Authors: Maija Airos, Kristina Franck, Risto Heikkinen, Marika Kiikala-Siuko, Kati Saari and Päivi Vataja.

OBJECTIVE

The Finnish national plan for rare diseases emphasizes participation of rare disease patients and patient organisations throughout the implementation. However, the execution of patient participation is still in progress and the policies are gradually shaping. The aim of the survey was to examine rare disease patients' experiences of participation in planning, decision making and evaluation in the field of rare diseases.



BACKGROUND

The survey was carried out by the Finnish Network for Rare Diseases, which consists of 20 independent, non-governmental organisations and foundations working for the interests of rare disease patients. The main goal of the network is to improve the conditions of people with a rare disease or disability by raising awareness and sharing information, and by influencing and co-operating with decision makers, professionals and experts nationally and internationally.

The working group (Harkko) gathers the experiential expertise of 25 rare disease patients and their families. The group is established by the Finnish Network for Rare Diseases, and the representatives are appointed to the working group by the member organisations of the network.

The Finnish Network for Rare Diseases, 2018.

METHODS

A webropol survey was sent to the 25 members of the working group of experiential expertise. A total of 19 replies were received. In addition, theme interviews were executed for the five experiential expertise representatives participating in the steering groups of Rare Disease Units in three University Hospitals.

RESULTS

The hypothesis was that there already exist possibilities of participating and influencing in social and health care service structures for rare disease patients and their families, but not yet in sufficient extent.

The rare disease patients do often know a lot about their disease and are familiar with everyday challenges.

Allowing experiential expertise to complement the professional expertise would lead to a more holistic approach.

Social and health care professionals should utilize better the holistic information regarding rare diseases. Furthermore, they should be aware of the supportive services and measures provided by both public and private sector and NGOs. The exchange of information should be uninterrupted and transparent. Furthermore, the information disseminated should be simple, clear and universally comprehensible.

According to the survey patient organisations provide the easiest way to be active and to get your ideas through. The working group is seen as a key instrument in creating new opportunities of influencing and participation. It also offers rare disease patients a platform for sharing information and experiences.

"Even though the experiential expertise is quite well taken on by the professionals, their understanding of the challenges of everyday life is still inadequate."

"The working group provides information and helps in comprehending the diversity of rare diseases."

CONCLUSIONS

Based on the survey the role of rare disease patients as experts in their own care and services should be respected and seen as an asset. The rare disease patients' participation and possibilities of influencing need to be executed better and throughout the social and health care service structures. The results point out key issues and critical points for intervention. It is essential to genuinely and systematically involve rare disease patients in planning, decision making and evaluation in the field of rare diseases, and to find new ways of participation. In this process the supportive role of the Finnish Network for Rare Diseases will continue to be significant.



THE FINNISH NETWORK
FOR RARE DISEASES



Member of
EURODIS
Rare Diseases Europe

