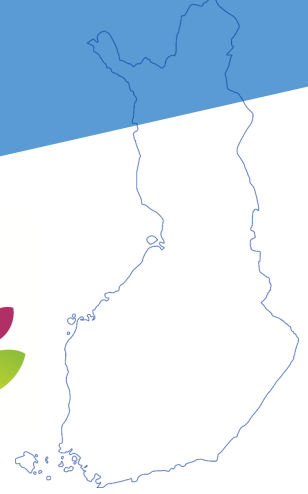


Advancing meaningful patient involvement: case Harkko patient advocacy group

HARKKO



INTRODUCTION

From a rare disease patient's perspective, the health care systems are often unable to cope well with rare conditions because they do not meet patients' needs. A major problem for rare disease patients is fragmentation of care and the lack of feedback systems. This is due to the disease-centred approach which does not recognise the holistic perspective. Therefore, patient involvement takes a great value in the field of rare diseases.

To achieve a genuine co-operation with the health care professionals, it is necessary to support rare disease patients to build critical awareness and forward the active involvement of patients throughout the processes. There is a need for well-organized and easily adaptable engaging models to allow the active involvement of rare patients and their families in planning and implementing change.

Harkko patient advocacy group encompasses



16 patient organisations



28 rare disease patients or family members



over 40 rare diagnoses

GOAL OF HARKKO ADVOCACY GROUP

Harkko patient advocacy group was founded by the Finnish Network for Rare Diseases in 2015 as an opening towards greater rare patient engagement in the Finnish health care system. The goal was to create a patient advocacy group, which equips rare patients and their families with the capacity to participate in decisions related to services targeted to rare disease patients, in collaborative partnership with health care professionals. Harkko group focuses on common themes, which affect all rare disease patients regardless of the diagnosis.

Rare disease patients are more than just their health condition: they have individual lives, needs and experiences. While each disease has its own characteristics, people living with a rare disease share similar challenges. Harkko forms a framework for patient engagement, which successfully involves a diverse group of rare disease patients. Harkko framework for structured rare patient involvement model has proven to be effective: it provides meaningful patient feedback and is easily adjustable in different environments.

In the Finnish National Plan for Rare Diseases (2019 - 2023) Harkko patient advocacy group is described as an example of well-organized model of rare patient participation.

CONCLUSIONS

Involving a diverse group of rare disease patients leads to collective intelligence to solve complex problems. They will be able to benefit and learn from each other's expertise and, thus, formulate a comprehensive picture of the needs of rare patients. At its best can patient engagement influence organizational transformation and policy change, and lead to better health outcomes and health care systems. By establishing similar groups as Harkko, e.g. in the rare disease units in university hospitals will help to generate meaningful and holistic insight into and impact on quality improvement in the health care service and delivery for the rare disease patients.

Harkko patient advocacy group acts as a driver for bringing patient engagement to the next level in the Finnish social and health care system. At present several members of Harkko patient advocacy group act as representatives e.g. in steering committees and equivalent bodies in the university hospitals overseeing the implementation and the monitoring and evaluation of services. Harkko patient advocacy group has proven to be a game changer in building rare patient participation.



THE FINNISH NETWORK
FOR RARE DISEASES



Member of
EURORDIS
Rare Diseases Europe

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