

The Importance of Patient Organisations Involvement in HTA

Authors

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Patient organisations offer unique insights, identify unmet needs, and can help to produce practical recommendations for HTA. The European Cancer Patient Coalition's Value of Innovation in Oncology paper contains recommendations for a more patient-centric HTA process. The Coalition also has a role in the Innovative Medicines Initiative's PREFER study, which will develop guidelines on patient preference studies in HTA.

Introduction

Patient organisations want to get involved in HTA but they realize they need to learn more so that they are able to contribute in assessing new health technology, in developing research priorities and making submissions. In Europe, the work done by the European Commission and EUnetHTA have consolidated the role of HTA, and promise to better harmonise its impact across EU countries. However, they need to institutionally include patient organizations in their activities and offer educational opportunities.

Methods

The European Cancer Patient Coalition (ECPC), aiming to empower its membership for involvement in HTA, raised awareness and offered capacity building lectures and workshops already since its early years. ECPC developed a model for engagement of patient organizations in HTA based on the experience from:

- From its long standing interest in capacity building in HTA and input from its membership
- ECPC's involvement in organizations active or related to HTA
- ECPC's participation in the Patient and Consumer Interest Group of HTAi
- ECPC's leading role in the Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) study, funded by the Innovative Medicines Initiative, to develop guidelines on how patient-preference studies should be performed throughout the development of new medical treatments.
- ECPC's Value of Innovation in Oncology White Paper, which includes input from ECPC's membership;

Results

Through the policy and capacity building work of ECPC, more of our members got interested in HTA and sought more information and tools.

The ECPC Value of Innovation in Oncology White Paper, launched in 2017, recommends that patients should be formally and routinely included in HTA policy and operations at EU and at national level. These recommendations were also submitted to the European Commission's public consultation on strengthening EU cooperation on HTA.

Patient preferences, patient involvement in research priority setting are important areas of ECPC policy and capacity building activities. Patient preferences are concerned with measuring elements of HTA, e.g. how patients value components such as treatment end points, route of administration, treatment duration, treatment frequency, frequency of side-effects, price, and quality of life. Through its work in PREFER, ECPC is helping to improve how patient preferences are measured and valued to capture the impact of health technology on patients' daily life..

Conclusions

Patient organisation involvement in HTA is vital. Patient organisations offer unique insights, experiences, identify unmet needs, and can help to produce practical recommendations and HTA agencies should offer them training and engagement opportunities that will facilitate their institutional involvement.

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Kathi Apostolidis is the Vice President of the European Cancer Patient Coalition. She co-wrote the "Value of Innovation in Oncology" White Paper, which includes strong recommendations for the harmonization of HTA at the European level. She is also involved in the Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) study, funded by the Innovative Medicines Initiative, to develop guidelines on how patient-preference studies should be performed throughout the development of new medical treatments. Kathi is also the President of the Hellenic Cancer Federation – ELL.O.K. and a member of the PCIG Steering Committee of HTAi.