Patient involvement in HTA

Introduction

HTA bodies are not organised according to a universal structure; similarly, there is no single way to involve patients in the work of an HTA body. The way patients are involved in an HTA body depends on the political and cultural context. Patient involvement in HTA should be developed as the result of a partnership between the HTA body and patient representatives, and it should be constantly evolving in response to experience and feedback.

Patient Involvement

HTA is used to support public decisions (in other words, decisions that affect all potential users of the health system). In most health jurisdictions worldwide, ministers of health are not only accountable to patients who require immediate care, but they are also accountable to the tax paying public, which is the primary source of financing for the healthcare system. Health decisions are everybody’s business: we are all either patients or future patients.

Approaches to patient involvement in HTA vary according to the healthcare system and country. These approaches may be:

- **Bottom-up** – in which the focus is on direct participatory involvement of patients and the public
- **Top-down** – in which the public are merely represented or consulted.

Patient and public involvement in the HTA process and the act of balancing individual needs with those of the population is important. Measures should be taken in order to address inequalities between the strength of the voices of
professional and industry interests and those of citizens and patients.

Simply advocating that a new technology is ‘needed’ once it is being assessed is not enough to influence or sway the decisions of publicly accountable decision-makers and the HTA bodies that support them. Rather, a good way to put patient participation in place might be characterised as involvement (versus representation). Across HTA bodies, patients are participating in more aspects of HTA. Active patient and public involvement in HTA may include various combinations of activities such as¹:

- Serving as members of HTA boards, committees, and workgroups
- Identifying potential topics for HTA
- Early identification of potential target groups for HTA reports
- Setting priorities among HTA topics
- Identifying health outcomes and other impacts (economic, social, etc.) to be assessed
- Reviewing proposals or bids by outside organizations/contractors to conduct HTAs
- Providing expert input to an appraisal committee
- Submitting evidence for HTAs
- Reviewing draft HTA reports and recommendations
- Helping to design and prepare patient-friendly HTA report summaries
- Dissemination of HTA findings to policymakers, patient groups, and other target groups
- Evaluating the use of HTA recommendations

(Adapted from Facey, 2010)

As patient organisations become familiar with HTA, they are increasing their engagement in debates about policy priorities and access. Patient organisations are also now using HTA recommendations to inform action and lobbying to access new
therapies or improve the usage of existing therapies.

Further Resources


References


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