

VP60 The Importance Of Patient Organizations Involvement In Health Technology Assessment

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INTRODUCTION:

In Europe, the work done by the European Commission and the European Network for Health Technology Assessment (EUnetHTA) has consolidated the role of Health Technology Assessment (HTA), and promises to better harmonize its impact across European Union (EU) countries. However, more work is needed to improve patient involvement in assessing new health technology, and in developing research priorities.

METHODS:

The European Cancer Patient Coalition (ECPC) developed a model for engagement of patients in HTA based on the experience from:

- ECPC's 'Value of Innovation in Oncology' White Paper, which includes input from ECPC's membership
- 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.

RESULTS:

The ECPC 'Value of Innovation in Oncology' White Paper was launched in 2017. The paper provides ECPC's policy position on key obstacles to equitable access to meaningful innovation. The paper recommends the establishment of an EU-wide HTA body to reduce delays and variations in access and to avoid duplication of effort by individual Member States. The paper also recommends that patients should be formally and

routinely included in HTA policy and operations at EU and at national levels. These recommendations were also submitted to the European Commission's public consultation on strengthening EU cooperation on HTA.

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. Patient preferences are concerned with measuring 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.

CONCLUSIONS:

Patient organization involvement in HTA is vital. Patient organizations offer unique insights, experiences, identify unmet needs, and can help to produce practical recommendations

VP61 Patients Views Of Health Technology Assessment At The National Institute Of Health And Care Excellence (NICE): Enhancing Involvement Opportunities

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INTRODUCTION:

The National Institute for Health and Care Excellence (NICE) medicines health technology assessments (HTAs) involve patients throughout (1): scoping the topic, evidence submission, attending committee as 'patient experts', consultation and appeal. A 2013 Health Select Committee report stated "It is important for the credibility of NICE and for the decisions that it makes that the patient voice is effectively and openly represented in all its work" (2). We thus wished to build on previous evaluation projects with more formal

research into the views of patient organizations and individual patient experts on their involvement. We additionally sought to explore barriers to involvement.

METHODS:

The research was a collaboration between staff from three teams at NICE: public involvement, market research, and HTA committee support. A mix of interviews, focus groups and surveys was used to gather feedback – from patients and organizations who have engaged with NICE, but also those who had not, plus NICE committee chairs and staff. Facilitators and barriers to involvement were investigated, along with attitudes towards process and support. We used qualitative thematic analysis alongside quantitative methods.

RESULTS:

Key findings were that patients and patient organizations mostly:

- hold favourable opinions of NICE
- have a good understanding of process and expectations
- remain unsure of the impact of their inputs.

Improvements identified include clarifying communications, language and roles. Plus increasing transparency of decision making and patient impact.

CONCLUSIONS:

The research findings and action plan, although specific to NICE, hopefully can inform others in the wider HTA ecosystem. Resources developed will be shared with Health Technology Assessment International (HTAi) networks, including updated correspondence templates and new videos explaining decision making in lay language. The research further adds to discussions around appropriate use of patient organizations scarce resources, and how best to feedback to participants and demonstrate impact of patient involvement.

REFERENCES:

1. Amis L. Patient involvement in NICE technology appraisals. In: Littlejohns P, Rawlins M, eds. *Patients, the public and priorities in healthcare*. Oxford: Radcliffe, 2009.

2. Parliamentary Health Select Committee UK (2013) National Institute for Health and Clinical Excellence: Eighth Report of Session 2012–13, Vol. 1: Report, Together with Formal Minutes, Oral and Written Evidence. London: The Stationery Office. making in lay language. This research hopefully can inform the wider HTA ecosystem.

VP63 National Institute For Health And Care Excellence (NICE) Technology Appraisal Patient Expert Feedback: 15 month analysis

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INTRODUCTION:

The National Institute for Health and Care Excellence (NICE) has a formal policy stating patients, carers and citizens are involved throughout each Health Technology Assessment (HTA). One key way patient/carer organizations are involved is by nominating patient experts to participate in appraisal committee meetings.

A NICE 2014 report (1) on Patient Experts experiences identified a need to routinely survey Patient Experts. This has been ongoing since October 2015. This study highlights key findings, including new recommendations and whether previous concerns have been addressed.

METHODS:

We refined the 2012 survey to be routinely sent to all patient experts that attended a NICE technology appraisal committee meeting. Between October 2015 and December 2016 this online survey was sent to eighty-eight patient experts. After analysis the findings were compared to the previous report to identify