SP0128 THE VARIOUS ROLES OF PATIENT PARTICIPATION IN HTA BY THE EXAMPLE OF IQWiG

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Background: The involvement of affected persons in preparing systematic reviews and HTA represents an established international standard of benefit assessment. The Institute of Quality and Efficiency in Health Care (IQWiG) is a professionally independent scientific Institute founded within the framework of the German Health Care Reform of 2004 as an establishment of the Foundation for Quality and Efficiency in Health Care. IQWiG provides benefit assessments addressing issues concerning the statutory health insurance services. Its responsibilities include among others the preparation of scientific reports, expert opinions and comments on quality and efficiency issues taking age, gender, and personal circumstances into account.

Objectives: The goal of this presentation is to provide an overview on different paths of involvement of patients and affected persons at IQWiG.

Methods: IQWiG's legal basis and responsibilities are anchored in the Social Code Book Fifth Book – Statutory Health Insurance (SGB V) and have been adapted and extended several times in the course of further health care reforms. The Institute's work is commissioned by the Federal Joint Committee or by the Federal Ministry of Health. The information for this presentation stems from IQWiG's General Methods (currently in version 5.0), a publicly available paper provided on the Institute's website, which explains the groundwork for its assessments.

Results: The involvement of affected persons at IQWiG primarily takes place during the initial work on a report within the framework of patient-relevant outcomes and relevant subgroups. Moreover, involvement can also include partaking in hearings. Affected persons include in particular patients (represented by parents or relatives, when appropriate) as well as potential participants in prevention measures. Affected persons are found via the patient representation of the Federal Joint Committee, as well as national or local self-help organizations or groups, hospitals or medical practices, external experts or other routes. The involvement can consist of a personal consultation or providing information in writing (through questionnaires or reports on personal experience), in both cases with documenting potential conflicts of interest.

Conclusion: As representatives of patients or self-help groups are sometimes not patients themselves and cannot directly account for symptoms or their impact on the quality of life, focus is placed on involving persons directly affected. Different assessments require distinct types of involvement depending on the available time and the confidentiality of the topic.

Disclosure of Interests: None declared

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SP0129 A PATIENT'S VIEW ON PATIENT INVOLVEMENT

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Background: • HTA as defined by the EUPATI:

Health technology assessment aims to inform decision making by health care policy makers. It is a systematic process that considers health technologies (such as medicines) and can involve a review of: Clinical evidence compared to existing models of care, Cost effectiveness, Social and ethical impacts on the health care system and the lives of patients EUPATI Overarching principle: "We recommend close cooperation and partnership between the various stakeholders including healthcare professionals' organisations, contract research organisations, patients' and consumers' organisations, academia, scientific and academic societies, regulatory authorities and HTA bodies and the pharmaceutical industry. Experience to date demonstrates that the involvement of patients has resulted in increased transparency, trust and mutual respect between them and other stakeholders. It is acknowledged that the patients' contribution to the discovery, development and evaluation of medicines enriches the quality of the evidence and opinion available."

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1. Clinical evidence compared to existing models of care,
2. Cost effectiveness,
3. Social and ethical impacts on the health care system and the lives of patients

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has resulted in increased transparency, trust and mutual respect between them and other stakeholders. It is acknowledged that the patients' contribution to the discovery, development and evaluation of medicines enriches the quality of the evidence and opinion available."

Objectives: Areas of patient involvement: Data, Decision problem (context), Scientific judgment and analysis, Value, Recommendation, Decision, Governance EUPATI guidance: (an exercise with 150 responders from 39 countries (Academia, HTA agencies, Patients industry : Knowledge and experience of patients are unique and contribute to essential knowledge - Fairness : Patients have the same rights as any other stakeholders to be part of the process - Equity: patient perspective helps to seek equity, by bringing into the process the true needs of patients, versus fairness of distribution of resources - Legitimacy : facilitates those affected by HTA decisions to participate contributing to the transparency and equability and credibility of the process - Capacity building : addresses barriers and helps building capacity for patients and HTA Organizations to work together

Methods: EPF Survey contacted 2010-2011 which produced a report among HTA agencies, decision makers and patient Organizations. The aim of the research was to assess the state of patient involvement in HTA. Responses collected from 40 HTA agencies, 18 decision makers and 23 patient organizations through on line questionnaires. The type of involvement varies. Few HTA agencies currently involve patients perspectives in their reports and contact formal evaluation of the impact of patient involvement in HTA. Out of the 40 HTA agencies that responded, nearly half of them (18) involve patients in HTA. Out of the 23 patient organisations that completed the questionnaire, 10 indicated that their organisations have been involved in HTA. Out of 18 decision-makers, four stated that they are planning to involve patients in decision-making for health technologies and three said that they already involve patients. On the other hand, five respondents stated that they do not intend to involve patients in the future and the remaining six either stated that they did not know or did not respond to the question.

Results: There are four main challenges according to all three stakeholders to involve patients in HTA: (1) lack of an agreed and good method to obtain/provide patient evidence, (2) not knowing the stage at which patient engagement is needed and most useful, (3) patient involvement process being time intensive, and (4) lack of capacity (HTA agencies, decision-making bodies, patient organisations). These themes represent all different forms of capacity that need to be in place for a meaningful patient involvement in HTA. According to the responses from the HTA agencies, high to moderate involvement is mainly seen in the phases of diffusion and dissemination, assessment, production of information, and external review. Low to no involvement is seen in the phases of identification, filtration, and prioritization.

Conclusions: The role of patient is very important in HTA in all aspects of the process. Before the medicine is developed, within HTA and when recommendations are made.

As patients' life and health state will be affected by new technology, their input is vital in all stages of evaluating a new technology or medicinal product. Patients should be part of the process to explain WHY and HOW important is the proposed technology for the health. If there no involvement in all stages there is a risk of not deciding on the most appropriate technology and for crucial needs remain unmet. Recommendations for patient Organizations and HTA agencies exist in the EPF guide

REFERENCES:

- [1] Results of the EPF Survey
- [2] Patient involvement in the HTA decision-making process

Disclosure of Interests: None declared

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FRIDAY, 14 JUNE 2019

13:30:00 – 15:00:00

Capillaroscopy II

SP0130 STANDARDISATION OF NORMAL VERSUS ABNORMAL AND PATHOLOGICAL CAPILLAROSCOPIC IMAGES

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Medical doctors frequently get patients with Raynaud's phenomenon (RP), a frequent symptom in the general population, referred. The importance of