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 purpose 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 documented 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, the 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.


A PATIENT’S VIEW ON PATIENT INVOLVEMENT

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Background: 1. 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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3. Social and ethical impacts on the health care system and the lives of patients

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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