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Acceptability and Perceived Benefits and Risks of Public and Patient Involvement in Health Care Policy: A Delphi Survey in Belgian Stakeholders

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ABSTRACT

Background: In systems with public health insurance, coverage decisions should reflect social values. Deliberation among stakeholders could achieve this goal, but rarely involves patients and citizens directly. **Objectives:** This study aimed at evaluating the acceptability, and the perceived benefits and risks, of public and patient involvement (PPI) in coverage decision making to Belgian stakeholders. **Methods:** A two-round Delphi survey was conducted among all stakeholder groups. The survey was constructed on the basis of interviews with 10 key stakeholders and a review of the literature on participation models. Consensus was defined as 65% or more of the respondents agreeing with a statement and less than 15% disagreeing. Eighty stakeholders participated in both rounds. They were defined as the Delphi panel. **Results:** Belgian stakeholders are open toward PPI in coverage decision processes. Benefits are expected to exceed risks. The preferred model for involvement is to *consult* citizens or patients, *within* the existing decision-making structures and *at specific milestones* in the process. Consulting citizens and patients is a higher level of involvement than merely informing them and a lower level than letting them participate actively. Consultation involves asking non-binding advice on (parts of) the decision problem. According to the Delphi panel, the benefits of PPI could be increasing awareness among members of the general public and patients about the challenges and costs of health care, and enriched decision processes with expertise by experience from patients. Potential risks include subjectivity, insufficient resources to participate and weigh on the process, difficulties in finding effective ways to express a collective opinion, the risk of manipulation, and lobbying or power games of other stakeholders. **Conclusions:** PPI in coverage decision-making processes is acceptable to Belgian stakeholders, be it in different ways for different types of decisions. Benefits are expected to outweigh risks.

Keywords: Belgium, coverage decisions, patient participation, policy, public involvement.

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Introduction

Involvement of the general public and patients in the resource allocation decision-making process is a way to incorporate societal values in decisions. *Involvement* is "the spectrum of processes and activities that bring the public into the decision-making process" and is associated with activities beyond routine democratic processes [1]. Public and patient involvement (PPI) in health care decision making helps in legitimating decisions [2–4] and in dealing with societal and economic evolutions, such as increasing demand for health care and higher patient expectations in a context of budgetary constraints [5]. Moreover, it could engender the trust and confidence in the health system [6] and engage communities and individuals in health action [3,7].

Public involvement in coverage decisions implies a shift from professional dominance of technocratic experts in decision-making processes toward more empowerment of lay people [8].

In deliberation-driven models, as in Belgium and Austria, health care coverage decisions are prepared by a multistakeholder appraisal committee, consisting of scientists, sickness funds, pharmaceutical industry, medical professionals, health care institution representatives, and politicians. Patients or citizens are usually not directly represented in the committees. Nevertheless, the committees are deemed to take balanced decisions in the best interest of the citizens and patients, taking resource constraints into account.

It is unclear to what extent the committees would value PPI in decision-making processes, in which cases, and in which way

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[9–11]. Nevertheless, there seems to be an interest in the subject at different levels: the strategic level, relating to global priorities for health care resource allocation, and the operational level, relating to the reimbursement of individual products or services.

This study assesses the acceptability to stakeholders of PPI in health care resource allocation decision-making processes, possible reasons for PPI, and perceived benefits and risks of such involvement.

Methods

General Design: Delphi Approach

The aim of assessing the opinions of stakeholders in health care coverage regarding PPI calls for a qualitative research approach. We used a two-round Delphi approach, combining elements from the modified Delphi approach and elements from the policy Delphi approach [12], to survey a group of Belgian stakeholders currently involved or not (yet) involved in decision-making processes. Patient organizations are, for example, not involved (yet) in Belgium [13].

The Delphi approach uses a series of sequential questionnaires or "rounds," interspersed by controlled feedback, that seek to gain the most reliable consensus of opinion of an "expert panel" [13]. As in the modified Delphi approach, we first performed face-to-face interviews to construct the survey for the first Delphi round. As in a policy Delphi approach, we invited policymakers and other stakeholders to participate in a two-round survey. The research protocol followed the guidelines for qualitative research of the Belgian Health Care Knowledge Centre [14]. Only those respondents who participated in both Delphi rounds were considered part of the Delphi panel. *Consensus* was defined as at least 65% of the participants agreeing with a statement and a maximum of 15% disagreeing. The Delphi survey was performed by e-mail to avoid direct confrontation and the risk of excessive influence of powerful stakeholder groups. Figure 1 presents the consecutive steps of our Delphi process.

Preliminary Phase: Interviews with Key Stakeholders and Literature Review

The preliminary phase of our Delphi process consisted of semi-structured interviews with 10 stakeholders and a narrative review of the literature on PPI in resource allocation decision making. The aim of the stakeholder interviews was to identify contextual factors and experiences with PPI that were important to know for the construction of the first Delphi survey and for the interpretation of its results. An interview guide consisting of three parts was used. Part 1 consisted of nine questions relating to experience with PPI and the presumed purpose of PPI. Part 2 included six questions relating to ways to involve the public and patients. In part 3, the interviewees were asked to give examples of PPI from Belgium or elsewhere, followed by semi-structured discussion about these examples.

All interviewees had a key role in the current health care system. They consisted of politicians, civil servants, representatives of the medical profession and care institutions, patient organizations, and sickness funds. They were selected because of their expected general overview of concerns and sensitivities of stakeholders with respect to PPI in decision making. The interviewees were not excluded from the Delphi panel. After the interview, they were treated in the same way as other invited stakeholders.

The literature review was performed to be able to describe different implementation models for PPI in health care resource allocation policy. We started from existing reviews on PPI [1,5,7,15] and applied the snowballing principle to the reference lists of these reviews to select additional articles for full-text review. Articles were included if they added new information or fresh insights. These included studies on PPI and consultation methods, practice and evaluation, and theoretical and conceptual frameworks of the design and evaluation of PPI processes. The review identified the dimensions of involvement and the pros and cons of different implementation models. The dimensions used for describing PPI models were level or type of the decision [16–18], role of the citizen or patient representative [16,19,20], intensity of involvement [5,16,18,21–23], and involvement modalities.

The *level of the decision* can be the strategic or the operational level. *The strategic level* refers to general priority setting for resource allocation. It relates to questions such as "should we, as a society, give priority to the expansion of home care services for chronically ill elderly patients or to more effective curative treatments for cancer patients when allocating our limited public resources for health care." The *operational level* relates to the coverage of specific products or services for the entire population, a subgroup of patients, or individual patients. They refer, for instance, to decisions regarding the coverage of a new insulin analog for the treatment of diabetes.

The role of the public or patient representative can be that of a tax and social contributions payer (citizen), or that of an expert by experience (patient). This simplified presentation of possible roles was chosen to avoid confusion among the participants in the Delphi panel. It should be acknowledged, however, that the distinction between public and patient is in a way artificial because the public includes past and current as well as future patients. In addition, individuals easily move between roles [16,19]. We did not, as some authors do, define patient involvement as referring to "decisions about one's own care" only [20].

The intensity of involvement refers to "the extent to which individuals have control over the decision-making process" [16]. A broad range of levels of involvement has been documented in the literature [5,16,18,21–23]. We used the spectrum of the International Association for Public Participation (IAP2), but adapted the labels to avoid confusion with the general term

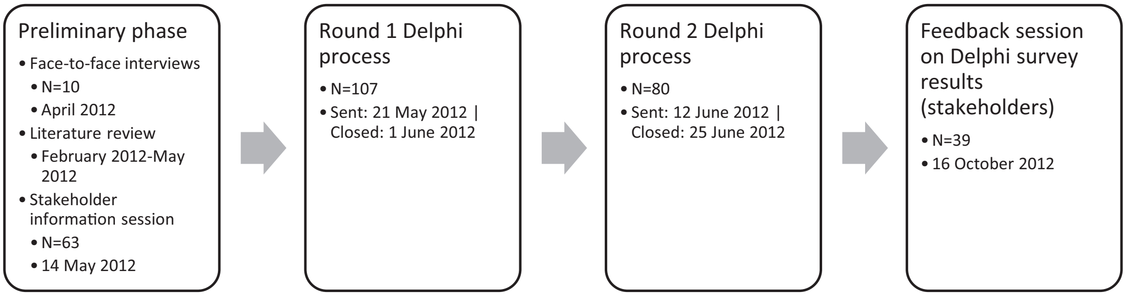

Fig. 1 – Three-round Delphi process.

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