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How to integrate research evidence on patient preferences in pharmaceutical coverage decisions and clinical practice guidelines: A qualitative study among Dutch stakeholders

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ABSTRACT

Despite the increasing number of research publications on patient preferences, their use in healthcare policy-making is limited. Integrating research evidence on patient preferences in policy-making is advocated by some, but several issues are put forward as well. There has been no systematic investigation of the stakeholders' view on this matter so far. Objective is to explore the opinions of Dutch stakeholders on how to integrate evidence on patient preferences in pharmaceutical coverage decisions and clinical practice guideline (CPG) development, and which issues may be encountered.

Methods: Qualitative study with semi-structured interviews with Dutch researchers ($N=7$), policy-makers and CPG developers ($N=4$) and patient representatives ($N=4$) involved in pharmaceutical coverage decisions and/or CPG development. The interview scheme focused on the definition of patient preferences; how to integrate evidence on patient preferences in decision-making; and barriers and facilitators.

Results: Respondents mentioned various barriers and facilitators for integration, of conceptual, normative, procedural, methodological and practical nature. There is also variety in the terms and definitions used for preferences, complicating searching and synthesising evidence. It is not clear how to integrate evidence on patient preferences in different decision contexts, and what weight preferences should have in relation to other decision criteria.

Conclusions: This study revealed important issues that need guidance when integrating evidence on patient preferences in healthcare policy decisions.

1. Introduction

The patient perspective is considered important on all levels of healthcare decision making. This view is reflected in several patient participation initiatives in healthcare research and policy-making. Examples of the latter include pharmaceutical coverage decisions and

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clinical practice guideline (CPG) development [1,2]. Various patient participation methods are advocated, of which active participation in committees is most frequently used. This has not been without problems and it is often unclear what the impact is of active participation on healthcare decision making [3,4]. In addition, to strengthen the work of patient representatives, using existing research evidence on patient preferences could be considered an additional means of participation. In general, the use of research on patient preferences may improve the quality and legitimacy of pharmaceutical coverage decisions and CPGs. Quantitative and qualitative research on patient preferences is increasingly being performed, for example by means of discrete choice experiments and interviews. However, the integration of research results on patient preferences for pharmaceutical coverage decisions and CPG development is limited [4,5]. Research on patient preferences is not systematically used in pharmaceutical coverage decisions and CPG development, and only in some cases specific research questions on this topic are formulated, as was previously found by the current authors [6]. The integration of research evidence on patient preferences is advocated by some [1,5,7–11], while others raised barriers [7,12–14]. Barriers include the ambiguity in the use of the term 'patient preferences' [9], the availability and quality of research evidence on patient preferences [7,12,13], the place of patient preferences in current procedures [7,13], and the object of patient preferences [15], which can be restricted to health or extended with aspects beyond health. There is no overall overview available on which issues we may face in the process towards systematic integration of research on patient preferences in pharmaceutical coverage decisions. Furthermore, within pharmaceutical coverage decisions and CPG development there are different stakeholders. It is unknown whether these stakeholders foresee the same issues, or that they focus on different issues. In this study, which is part of the Patient VIP study [16], we investigate the opinions of Dutch stakeholders regarding the taxonomy of preferences, and which issues may be encountered when integrating research on patient preferences in pharmaceutical coverage decisions and/or CPG. By means of interviews we aim to answer the following research questions: (1) How are patient preferences defined and conceptualised by the stakeholders; (2) Which issues need to be considered when integrating evidence on patient preferences in health care policy decisions?; and (3) How should research on patient preferences be integrated in pharmaceutical coverage decisions and CPG development?

2. Methods

2.1. General design

The study is a qualitative study using semi-structured interviews, conducted between September 2012 and March 2013. The study protocol of the Patient–VIP study (Patient Values in Policy Making Study) (including the interviews) was presented to the medical ethics committee of the Maastricht University Medical Centre. The committee concluded that formal approval was not required.

Table 1
Overview of participants.

Participant number	Primary affiliation	Role
1	None	Researcher
2	None	Researcher
5	Coverage	Researcher
9	Coverage	Researcher
13	Coverage	Policy maker/CPG developer
14	Coverage	Policy maker/CPG developer
8	CPG	Researcher
11	CPG	Researcher
15	CPG	Researcher
3	CPG	Policy maker/CPG developer
7	CPG	Policy maker/CPG developer
6	CPG	Patient/patient representative
4	CPG	Patient/patient representative
10	CPG	Patient/patient representative
12	CPG and coverage	Patient/patient representative
Number of participants with affiliation "coverage"		5
Number of participants with affiliations "CPG"		9
Number of participants with role "researcher"		7
Number of participants with role "policy maker"		4
Number of participants with role "patient/patient representative"		4

2.2. Participants

We used our network to select representatives of the relevant stakeholders involved in pharmaceutical coverage decisions and CPG development. Previously we described the Dutch procedures of coverage decisions and guideline development [17]. A summary of the procedure and stakeholders involved can be found in Appendix 1. Based on the procedures, the following stakeholders were included as participants: (1) policy makers (in case of coverage decisions) or guideline developers, who advice the deciding authority on policy and specific decisions; (2) patient representatives, who's preferences it concerns in this contribution; and (3) researchers who are producer of research evidence on patient preferences. Health insurers and health care professionals (or umbrella organisations of these) were not considered as stakeholders in the procedures, as they are, in case of coverage decisions, partially represented by the policy makers, and in both the case of coverage decisions and CPG development, are the executer of decisions in practice. The invited stakeholders were considered to be knowledgeable in their field and to be able to provide guidance as regards the research questions. Potential participants were invited by email with an introduction to the study, and were contacted within two weeks after the invitation. An appointment was made for a face-to-face or telephone interview with those who responded positively to the invitation. Participation was voluntary and confidentiality was assured. Seventeen stakeholders were invited, of whom 15 agreed to participate. Table 1 provides an overview of the participants primary affiliation and role. We interviewed more participants from the field of CPG, as during the concurrent transcribing and summarising of the interviews, interviews from this field appeared to be less