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Patient and public involvement in hospital policy-making: Identifying key elements for effective participation

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ABSTRACT

The involvement of patients and the public in healthcare decisions becomes increasingly important. Although patient involvement on the level of the individual patient-healthcare worker relationship is well studied, insight in the process of patient and public involvement on a more strategic level is limited. This study examines the involvement of patient and public (PPI) in decision-making concerning policy in six Flemish hospitals. The hospitals organized a stakeholder committee which advised the hospital on strategic policy planning. A three-phased mixed- methods study design with individual questionnaires (n = 69), observations (n = 10) and focus groups (n = 4) was used to analyze, summarize and integrate the findings. The results of this study indicate that: (1) PPI on hospital level should include the possibility to choose topics, like operational issues; (2) PPI-stakeholders should be able to have proper preparation; (3) PPI-stakeholders should be externally supported by a patient organization; (4) more autonomy should be provided for the stakeholder committee. Additionally, the study indicates that the influence of national legislation on stakeholder initiatives in different countries is limited. In combination with the growing importance of PPI and the fact that the recommendations presented are not claimed to be exhaustive, more transnational and conceptual research is needed in the future.

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1. Introduction

In the declaration of Alma Ata [1], the right and duty of public involvement in the planning of healthcare was emphasized. In the decades to follow, patient and public involvement (PPI) has had a rising importance in healthcare [2,3]. Due to demographic and epidemiological transitions, PPI has gained even more importance [4]. Because of an aging population and the upsurge of chronic illnesses, healthcare costs are increasing and shifting. This financial pressure, in combination with societal expectations, demands profound changes in healthcare systems around the world

concerning efficiency, efficacy and legitimacy [5,6]. Patient and public involvement could be one of the possible solutions. There are indications that PPI increases quality of care [7–9] and transparency and legitimacy about public funds [3], contributing to the future sustainability of healthcare systems [10]. Evidence increasingly supports the important role of involving patients on all levels of healthcare systems [6,11–13]: the individual level of the patient-healthcare worker relationship (micro-level), the collective levels of wards, patient organizations and hospitals (meso-level), and the national or international level (macro-level).

Statements that define PPI as the “holy grail of healthcare” [14] and “the blockbuster drug of the century” [15], indicate increased interest in the matter. This movement, which is led by good intentions, contrasts with the current lack of research on the implementation of PPI on the more collective level [7,16], also defined as consumer and community engagement in healthcare systems [17]. Different to patient involvement on the individual level, which has been more extensively studied across healthcare professions [18,19], the implementation and impact of consumer and community engagement in healthcare systems is understudied [3,20,21]. In the corporate industry, developing strategies to effectively deal

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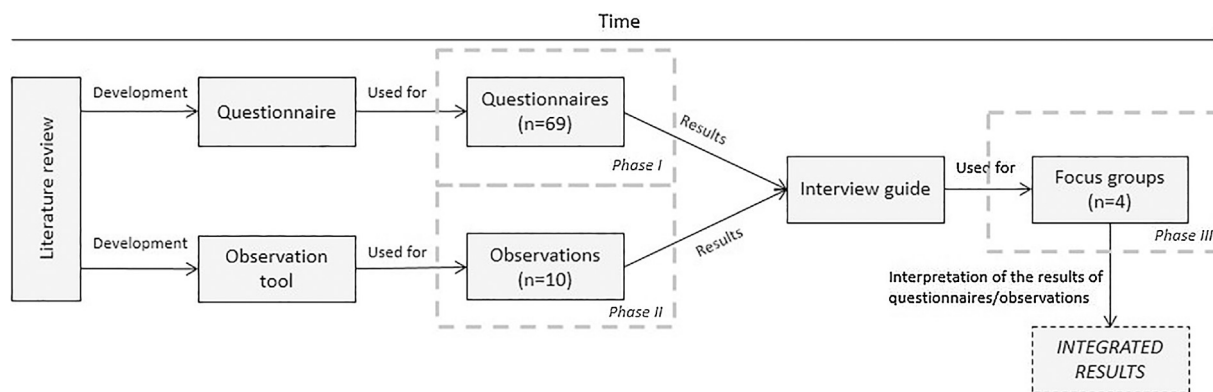


Fig. 1. Outline of the mixed-methods design of this study, based on Addo et al. [36].

with the concerns of stakeholders like consumers and the community, is a key component of the so called “stakeholder theory” [22]. This theory contrasts to the traditional view of a company, the shareholder view, in which only the owners or the shareholders are considered important as the purpose of the company is to create value for the shareholders. The stakeholder theory is new to non-profit healthcare systems and lacks an adapted conceptual framework, leaving the dynamics are poorly understood [16,23]. Research on ethical issues concerning consumer and community engagement in healthcare systems, like the burden for patients and finding adequate representation [19,24–27], is needed [28]. Such elements are important for regarding the public and patients as experts [28,29]. The combination of the lack of evidence and the increase in initiatives emphasizes the need for research on consumer and community engagement in healthcare systems, addressed more specifically in this study in hospital policy-making [16,20].

1.1. The Flemish pilot study

In contrast to surrounding countries, PPI in hospital policy in Belgium and Flanders is a new concept and lacks a model adjusted to the national legislation. Germany [30], France [31], the United Kingdom [15] and the Netherlands [32] have examples of legally regulated PPI-structures. Because of the specificity of the healthcare system in Belgium, a new model was developed [33] and implemented for a pilot study of two years [29]. In the model, PPI-stakeholders, internal stakeholders (e.g. hospital employees and members of the board), and professional external stakeholders (e.g. insurance companies or primary healthcare workers) are assembled in a stakeholder committee led by an independent president and a secretary. The group of PPI-stakeholders was composed of patients, their family members, and patient representatives. The PPI-stakeholders were supported by the Flemish Patient Organization, an independent umbrella-organization for all patient peer support groups in Flanders which also professionalizes patient representatives. Ideally, an equal number of all stakeholder groups was represented. The goal of the stakeholder committee was to discuss and advice on the annual report, the strategic options and the hospital business plan. These three elements are seen as the leading mandatory documents for hospital policy in Belgian and Flemish hospital legislation. Next to these topics, all stakeholders had the opportunity to propose new topics for the agenda. A code for interactions between the stakeholder committee and the board of directors was also established. The stakeholder committee had six annual meetings. The model was described in more detail by Malfait et al. [29].

2. Materials and methods

2.1. Aim

This study aims to identify conditions that contribute to the actual involvement of patients and the public in the decision-making processes of hospital policy through a stakeholder committee.

2.2. Study design

A three-phased sequential exploratory mixed-methods was used [34]. In mixed-methods research quantitative and qualitative research methods are combined and integrated to answer a research question. This leads to triangulation, completeness, explanation and interpretation of the findings [35]. Three research methods were used: questionnaires, observations, and focus groups. Fig. 1 provides an outline of the study.

2.3. Materials and data analysis

In the first phase a questionnaire was used to identify the opinions of the stakeholders on the stakeholder committee and to identify possible differences between groups. As no adequate questionnaire could be found in the international literature, the questionnaire had to be developed. The topics and items were based on an existing checklist [37] and were content validated [38] with a double Delphi procedure using the content validity index [39]. This process resulted in 36 questions on five topics: the composition of the stakeholder committee (3 items), the functioning of the members of the stakeholder committee (11 items), the functioning of the president (5 items), the preparation of the stakeholder committee (11 questions), and the processes and dynamics within the stakeholder committee (6 questions). All items were scored on a 5-point Likert-scale (1 = strongly disagree; 5 = strongly agree). Next to descriptive results, differences between stakeholder groups were studied using SPSS® [40]. Depending on the distribution of the data, one-way ANOVA's or Kruskal-Wallis tests were used with a significance level of 0.05.

In the second phase observations were conducted to identify additional areas of interest. As no adequate observation tool could be found, a tool had to be developed based on the available literature [38]. The observations targeted the same five topics as the questionnaire and were conducted by at least three researchers. Directly after each observation, researchers' triangulation was performed to reach consensus on the observations. Recordings of the observations were made for future use in the study (e.g. listening and clarifying ambiguities).

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