



Health Policy

journal homepage: www.elsevier.com/locate/healthpol



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

S. Malfait^{a,b,*}, A. Van Hecke^{a,b,1}, G. De Bodt^{b,3}, N. Palsterman^{c,2}, K. Eeckloo^{b,d,3}

^a Faculty of Medicine and Health Sciences, Department of Public Health, University Center for Nursing and Midwifery, Ghent University Hospital, Belgium

^b Ghent University Hospital, Belgium

^c OLV-Hospital, Aalst, Belgium

^d Faculty of Medicine and Health Sciences, Department of Public Health, Ghent University Hospital, Belgium

ARTICLE INFO

Article history:

Received 24 May 2017

Received in revised form

21 November 2017

Accepted 14 February 2018

Keywords:

Patient and public involvement

Hospital administration

Mixed methods

Community participation

Quality of healthcare

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.

© 2018 Elsevier B.V. All rights reserved.

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

* Corresponding author at: U.Z. K5, 3rd floor, De Pintelaan 185, B-9000 Ghent, Belgium.

E-mail addresses: simon.malfait@ugent.be (S. Malfait), ann.vanhecke@ugent.be (A. Van Hecke), griet.debodt@ugent.be (G. De Bodt), nele.palsterman@olvz-aalst.be (N. Palsterman), kristof.eeckloo@ugent.be (K. Eeckloo).

¹ U.Z. K5, 3rd floor, De Pintelaan 185, B-9000 Ghent, Belgium.

² OLV Hospital, Moorselbaan 164, B-9300 Aalst, Belgium.

³ U.Z. K12, 11th floor, De Pintelaan 185, B-9000 Ghent, Belgium.

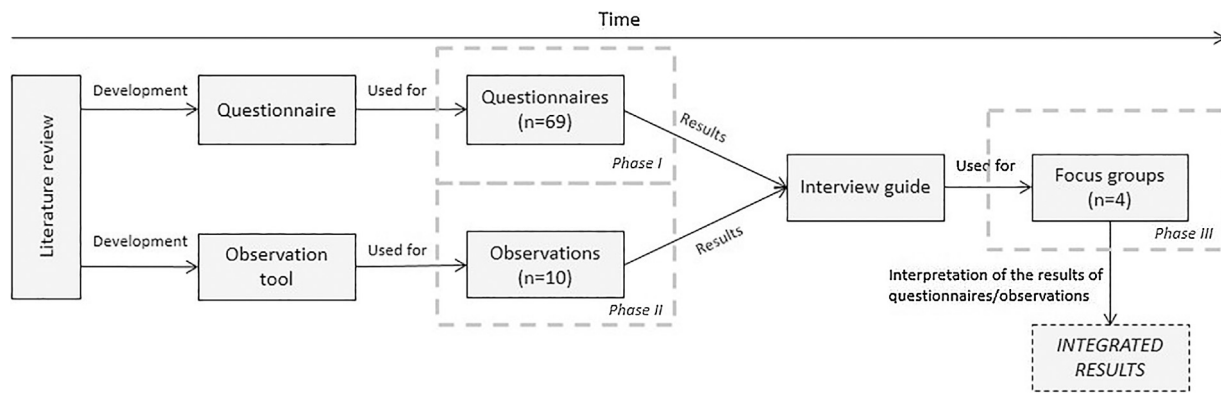


Fig. 1. Outline of the mixed-methods design of this study, based on Addo et al. [36].

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).

Table 1
Demographic characteristics of the questionnaire's respondents and response rates in the study.

| Variable | Presidents and secretaries | Internal stakeholders | Professional external stakeholders | PPI-stakeholders | Total |
|--------------------------------------|----------------------------|-----------------------|------------------------------------|------------------|-------------|
| <i>Gender</i> | | | | | |
| Male | 5 (55.6%) | 26 (76.5%) | 12 (54.5%) | 5 (33.3%) | 48 (60.0%) |
| Female | 4 (44.4%) | 8 (23.5%) | 10 (45.5%) | 10 (66.7%) | 32 (40.0%) |
| <i>Age</i> | | | | | |
| <30 years | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) | 3 (20.0%) | 3 (3.8%) |
| 30–39 years | 1 (11.1%) | 4 (11.8%) | 4 (18.2%) | 3 (20.0%) | 12 (15.0%) |
| 40–49 years | 2 (22.2%) | 8 (23.5%) | 4 (18.2%) | 3 (20.0%) | 17 (21.2%) |
| 50–59 years | 3 (33.3%) | 18 (52.9%) | 10 (45.5%) | 4 (26.7%) | 35 (43.7%) |
| 60–69 years | 0 (0.0%) | 4 (11.8%) | 4 (18.2%) | 2 (13.3%) | 10 (12.5%) |
| >69 years | 3 (33.3%) | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) | 3 (3.8%) |
| <i>Education</i> | | | | | |
| <bachelor | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) | 3 (20.0%) | 3 (3.8%) |
| Bachelor | 1 (11.1%) | 0 (0.0%) | 9 (40.9%) | 2 (13.3%) | 12 (15.0%) |
| ≥master | 8 (88.9%) | 34 (100.0%) | 13 (59.1%) | 10 (66.7%) | 65 (81.2%) |
| <i>Response rate</i> | | | | | |
| >2 participations ^a | 12 (100.0%) | 36 (100.0%) | 28 (100.0%) | 17 (100.0%) | 93 (100.0%) |
| Questionnaire (phase I) ^b | 9 (75.0%) | 34 (94.4%) | 22 (78.6%) | 15 (88.2%) | 80 (86.0%) |
| Observations (phase II) | 6 (50.0%) | 19 (52.8%) | 13 (46.4%) | 8 (47.1%) | 46 (49.5%) |
| Focus groups (phase III) | 7 (58.3%) | 7 (19.4%) | 6 (21.4%) | 13 (76.5%) | 33 (35.5%) |

^a Number of distributed questionnaires.

^b number of persons invited for the focus groups.

In the third phase, the results from the observations and the questionnaires were combined to draft a semi-structured focus group discussion guide. The focus group discussions were used to interpret the findings, reveal underlying processes and identify additional conditions for effective PPI. All focus groups were conducted by at least 2 researchers and were recorded. Afterwards, the recordings were written trans verbatim to be analyzed using NVivo® [41]. The focus groups mainly aimed at identifying underlying processes and elements not reported in the questionnaires and observations.

2.4. Recruitment and data collection

In 2013, general and psychiatric hospitals in Flanders were invited to participate in the pilot study. Five general hospitals and one psychiatric hospital were purposively selected to implement the stakeholder committee, based on the variation in hospital setting and the proposed composition of the stakeholder committee. Participating hospitals had to compose their stakeholder committee with representatives from all four stakeholder groups. In total, one-hundred and sixteen stakeholders were invited by the participating hospitals and 93 stakeholders participated at least two times in a stakeholder committee, making them eligible for the study. Each of these participants received a questionnaire in December 2014, resulting in 70 returned questionnaires. Ten observations were conducted from September to November 2014 in three of the six hospitals. Four focus groups were organized in February 2015: a focus group for presidents and secretaries, one for internal stakeholders, one for professional external stakeholders, and one for PPI-stakeholders. Each focus group lasted from one-and-a-half to two hours. Table 1 provides an overview of the demographic characteristics of the questionnaire's respondents and the overall response rates.

2.5. Ethical considerations

The study was approved by the Central Ethics Committee of [blinded for review] and by all local ethics committees of the participating hospitals. All participants gave a written informed consent.

3. Results

In the result section, the essential findings of the study are given. An overview of all results can be found in the final research report [42]. The results are presented in an integrated way, meaning that for each of the identified key elements for effective PPI, the results from different research methods are elaborated and combined. During the focus groups the results from the questionnaires and observations (Table 2) were addressed. Four key elements were identified: (1) choice of topics and operational issues, (2) proper preparation, (3) the need for external support, and (4) autonomy of the stakeholder committee. An overview of these key elements and their relation to the study findings are presented in Fig. 2.

3.1. Choice of topics and operational issues

In phase 1 of the study (questionnaires; Table 2), the internal stakeholders reported they noticed more changes within the organization as a consequence of the stakeholder committee in comparison to both PPI-stakeholders and external professional stakeholders.

The observations (Table 2) made apparent that PPI-stakeholders took a less active role during the discussions, and internal stakeholders reacted mostly upon the opinions of the other stakeholders. The initiative to address the agenda was mostly taken by the secretary as stakeholders did not stimulate each other to formulate their personal opinion. The goals of the stakeholder committee were seldomly elaborated at the beginning, and strategic advice was seldomly formulated. It was common practice to start the meetings with the practical issues on the agenda (e.g. adaption of the website and road signs on the hospital campus). These topics were put on the agenda by both internal stakeholders and PPI-stakeholders.

It became apparent in the focus groups that the exclusive focus on strategic issues was possibly an ineffective way for a stakeholder committee to be initiated. Respondents indicated that all stakeholders needed time to get acquainted with each other. Operational, and thus more practical issues, were perceived as less threatening than strategic issues. This gave everybody the opportunity and time to get used to each other, which empowered them to also undertake discussions on a more strategic level.

Table 2
Overview of the (selected) results from the first phase (questionnaire) and second phase (observations) of the study.

| Focus | Questionnaire statement | Results |
|---|--|---|
| Composition of the stakeholder committee | Demographics | Internal stakeholders were higher educated than the group of PPI stakeholder ($\chi^2 = 13.623$; $df = 3$; $p = .003$) PPI-stakeholders were less convinced of the fact that they were represented enough ($\chi^2 = 10.419$; $p = .015$) |
| | The stakeholder groups are equally represented in the stakeholder committee | |
| Functioning of the members of the stakeholder committee | I feel competent to participate in the stakeholder committee | Respondents with lower education had lower scores ($F = 0.285$; $p = .028$) felt less competent to participate |
| | I feel competent to express my opinion | Respondents with lower education had lower scores ($t = -2.230$; $p < 0.001$) felt less competent to express their opinion |
| Functioning of the president | The president was prepared | Younger stakeholders had lower scores ($F = 3.256$; $p = .046$) |
| | The president divided speaking time equally under all the participants | Younger stakeholders had lower scores ($F = 4.403$; $p = .016$) |
| | The president led the discussion | Younger stakeholders had lower scores ($\chi^2 = 15.135$; $p < 0.001$) |
| | Overall score for the presidents | Younger stakeholders had lower scores ($\chi^2 = 10.621$; $p = .005$) |
| Preparation of the stakeholder committee | The agenda was delivered on time | PPI-stakeholders have lower scores ($F = 9.155$; $p < 0.001$) |
| | The documents were delivered on time | PPI-stakeholders have lower scores ($F = 7.429$; $p < 0.001$) |
| | The documents contain enough information | PPI-stakeholders have lower scores ($F = 3.597$; $p = .018$) |
| Processes and dynamics within the stakeholder committee | The information in the documents is comprehensive | PPI-stakeholders have lower scores ($F = 3.658$; $p = .017$) |
| | I have more information than other stakeholders | Internal stakeholders have more information than PPI-stakeholders ($F = 3.38$; $p = .023$) |
| | Based on the stakeholder committee, there are changes in the organization | Internal stakeholder report more changes ($\chi^2 = 13.798$; $p < 0.032$) than PPI-stakeholders and external professional stakeholders |
| | The stakeholder committee leads to concrete and practical changes | Younger stakeholders scored lower ($\chi^2 = 14.181$; $p = .001$) |
| | Changes based on advice were followed-up | Younger stakeholders scored lower ($\chi^2 = 7.114$; $p = .029$) |
| Focus | Observation | |
| Composition of the stakeholder committee | Professional external stakeholder and PPI-stakeholders sit opposite each other The number of professional external stakeholders is higher than the number of PPI | |
| Functioning of the members of the stakeholder committee | Internal stakeholders more often respond/react to the opinion of PPI-stakeholders The stakeholder groups do not stimulate each other to formulate their own opinion PPI-stakeholders take on a passive role | |
| Functioning of the president | The president gives no additional background information when this is needed The president is involved in content discussions making it difficult for PPI to make a statement The president is an acquaintance of some of the internal stakeholders. | |
| Preparation of the stakeholder committee | The goals of the stakeholder committee are not elaborated at the beginning | |
| Processes and dynamics within the stakeholder committee | During almost all stakeholder committees, no strategic advice was formulated. Practical topics were put on the agenda by both internal stakeholders and PPI-stakeholders. | |

“Big policy decisions...we’re not quite there yet, but I have the feeling that we’re moving towards it.” [Internal stakeholders focus group]

Furthermore, PPI-stakeholders indicated that the effects of strategic changes take longer to become visible, which could demoralize and discourage them to take further part in the stakeholder committee as they feel non-influential. They preferred operational issues because of the faster and more visible success, giving them the necessary stimulant. PPI-stakeholders also emphasized the importance of including staff nurses in the stakeholder committee. PPI-stakeholders define this group as ‘easy-to-relate-to’ and approachable healthcare workers, often related to PPI-stakeholders’ personal problems.

“Personally, I thought that nurses were underrepresented. They are the most visible connection between us and the hospital.” [PPI-focus group]

Finally, PPI-stakeholders explained during the focus groups that the initially proposed topics in the model (e.g. the annual report, the strategic options and the hospital business plan) were perceived as distant for PPI-members. PPI-stakeholders indicated having insufficient knowledge on these topics, and expressed the will to also be involved in topics that are more related to their personal environment as they felt to be more expert on those topics.

“For us, the focus of these committees is perhaps less strategic oriented, but more oriented on the patient as a unique person.” [PPI-focus group]

All focus groups agreed to the fact that strategic issues were not discussed, or at least not at the start of the pilot study. Still, none had the feeling that the project had failed. Overall, stakeholders designated time as an essential element for the success of a stakeholder committee as there should be a personal (e.g. “getting acquainted with the topics”), interpersonal (“getting to know each other”), and

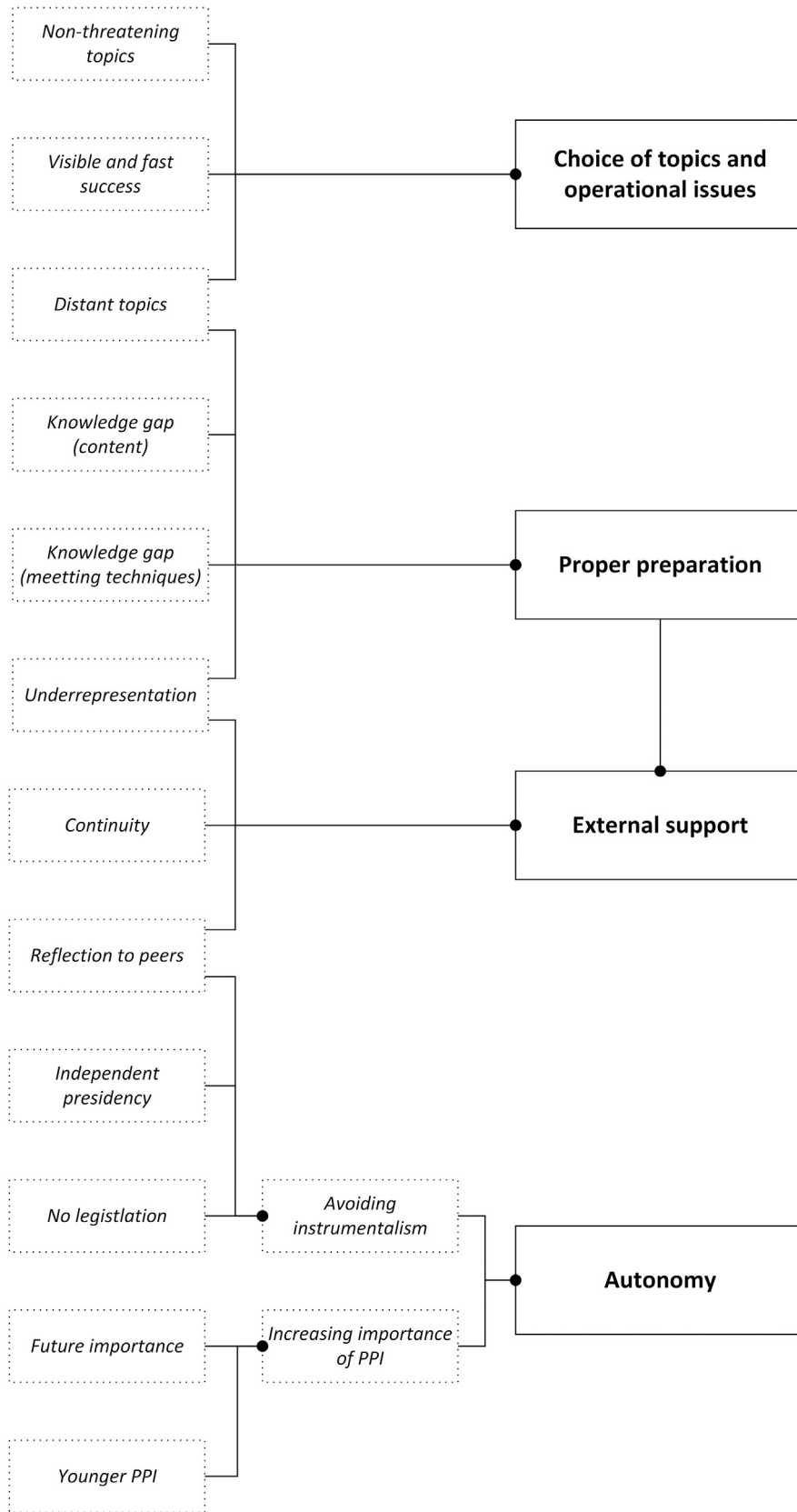


Fig. 2. Identification of key elements for effective PPI.

organizational (“from small to big changes”) growth before results could be expected.

“Perhaps one of the most important effects of the stakeholder committee is that they have introduced patient involvement at the

highest level of the hospital, perhaps initiating its inclusion in a hospital culture” [Internal stakeholder focus group]

3.2. Proper preparation

The results of the questionnaire (Table 2) showed that the group of internal stakeholders was higher educated than the group of PPI-stakeholders. The latter respondents, with often a lower educational level, felt less capable of participating in the stakeholder committee and expressing their opinions. PPI-stakeholders reported (Table 2) they had the feeling that the agenda and documents were not delivered in time before the meetings, did not contain sufficient information and were not always comprehensive. These results are in contrast with the other stakeholder groups. Moreover, the questionnaires displayed that internal stakeholders felt that they had more information than the PPI-stakeholders.

In the focus groups, PPI-stakeholders indicated that they have insufficient knowledge to cope with strategic questions and inclusion of operational themes was preferred. Next to addressing issues of a more practical nature, PPI-stakeholders argued that they should have the opportunity to thoroughly prepare themselves for the meetings. Three elements of preparation were mentioned.

First, in order to make sufficient and thorough preparations and understand the topics, important documents and the meeting’s agenda should be delivered well in advance, and should provide comprehensive and additional information. Often, the topics were described too briefly described, leading to a knowledge gap. Not addressing this inequality could compromise the role of the PPI stakeholders.

“It was necessary to receive the necessary documents well in advance in order to be able to sufficiently prepare for the stakeholder meetings.” [PPI-focus group]

Second, PPI-stakeholders indicated they also needed information and training on meetings techniques as PPI-stakeholders felt less competent to express their opinions in an organized manner.

Third, receiving information well in advance enabled PPI-stakeholders to consult their peers. This was necessary in order to have the feeling to express the opinion of a population of peers and not solely their own opinion.

“I could not take a stand on some issues as I was only expressing my own feeling and did not want to be held responsible for the consequences for everybody.” [PPI-focus group]

3.3. External support

The results of the questionnaires (Table 2) indicated that PPI-stakeholders felt underrepresented in comparison to the internal stakeholders. The observations (Table 2) confirmed this feeling. In all stakeholder committees, internal stakeholders were more present than external stakeholders although initially an equal number of stakeholders in each group was anticipated. During the focus groups, all four stakeholder groups supported the statement that the group of PPI-stakeholders was too small. The focus groups made clear that including more PPI-stakeholders was difficult as the financial, organizational and staff resources of the supporting patient organization were insufficient. This is in contrast with the perceived importance of an organization that was not affiliated to the government or the hospital as expressed by PPI-stakeholders during the focus groups. They deemed the support of an organization as essential for three reasons.

First, such organization enabled PPI-stakeholders to reflect with their peers on a regular bases, giving them the feeling they were representing a whole patient population. An essential element for PPI-stakeholders.

“It was useful to have a formal organization that supported us in making connection with our peers in a structural way” [PPI-focus group]

Second, such peer groups were also important to provide continuity. Most participating patients had a chronic illness and could not always be present due to acute sickness. Peer groups enabled patients to pass on information to possible substitutes in case of acute sickness.

Finally, external support by a patient organization was designated by the PPI-stakeholders as one of the essential elements enabling the patients to have a proper preparation for the stakeholder committee. PPI-stakeholders indicated that this organization organizes training on meetings techniques and provides additional content information on hospital topics if needed.

3.4. Autonomy

The results from the questionnaire (Table 2) indicate that younger stakeholders perceived the president more often as not well prepared, not dividing speaking time equally, and not adequately leading the discussion. Overall, they judged the actions of the presidents during the committees less appropriate than the older age groups. The younger group also felt that the stakeholder committee did not lead to concrete and practical advice and that follow-up of their advice was lacking. The observations (Table 2) showed that the presidents often were acquaintances of the internal stakeholders. With exception of one hospital, the president used to be a former internal stakeholder. This often led to involvement of the president in content discussion, making it difficult, especially for PPI-stakeholders, to express disagreements or contrasting opinions and to put new issues on the agenda. This feeling could be strengthened by the fact that, according to the observations (Table 2), most meeting rooms were organized in a non-inclusive U-shape. Consequentially, internal stakeholders and PPI-stakeholders always took place opposite to each other.

During the focus groups, it was concluded by all stakeholder groups that PPI is an important topic for the future of healthcare and hospital policy, especially in competitive environments. It is perceived as an inevitable future demand of which no escape is possible.

“It will be, or maybe already is, the duty of hospital to have a form of accountability to society by including a number of partners.” [Internal stakeholders focus group]

For all stakeholders it was important to avoid stakeholders with no actual impact on hospitals (i.e. instrumentalism). This feeling was particular present in younger stakeholders. They had a more critical view towards the stakeholder committee, and more specific towards the actions of the president. They regard themselves as the generation who will benefit from these initiatives and emphasized that if, in case of failure to comply with elements of autonomy, the stakeholder committee will fail and disappear in the hospital. Two important elements to avoid instrumentalism were mentioned.

First, it became clear that the fact PPI stakeholders were underrepresented in numbers and felt to have insufficient knowledge and competence. This created the expectancy that the president would support or protect them during discussions, making the neutrality of the president important. PPI-stakeholders expressed their concerns that, if a president does not remain independent during discussions, the stakeholder committee tends to become instrumental and dependent. If so, PPI-stakeholders will no longer have the feeling of being involved and actually being heard. These feelings could make them considering leaving, leading to a non-representative stakeholder committee.

“Our president was an independent person, with no connection to the hospital or any hospital-related organization. Perhaps this made it easier to express an opinion.” [PPI-focus group]

Second, it was suggested to not legally embed the stakeholder committee in hospital structures. This made the organization of a stakeholder committee a free and deliberate choice, and forces the hospitals to actually endorse recommendations of their stakeholder committee, making PPI-stakeholders an equal partner. Not endorsing recommendations would lead to the disappearance of these committees, and a competitive disadvantage as no PPI will be found to be part of the stakeholder committee. In case of legally embedding stakeholder committees, the respondents of the focus group fear that the stakeholder committee will be a formality for most hospitals, negatively affecting the position of PPI-stakeholders.

“If not [actually endorsed], the stakeholder committee will gather once a year, purely formal, with no results as a consequence. This will lead to absenteeism of stakeholders, and finally extinction. I’m convinced that the importance of a stakeholder committee will increase in the near future. (...) It will be a strategic and competitive advantage to have and to retain.” [PPI-focus group]

4. Discussion

4.1. Explanation of the study findings

In this study, several interconnected key elements of successfully involving patient and the public in hospital policy-making could be identified. In this discussion, each of these key elements is discussed and put into international perspective.

4.1.1. Choice of topics and operational issues

Strategic issues were occasionally discussed during the stakeholder committees although this was the goal of the initial model [29,33], which means an inherent shortcoming within the model. The study findings suggest that topics of a more operational nature should be addressed (1) to initiate the first contact as these are non-threatening, (2) to give patients an expert position, (3) to address topics that are more closely linked to the PPI-stakeholders environment, (4) to stimulate PPI-involvement, and (5) to address a possible problem with the PPI-stakeholders’ feeling of representativeness (e.g. not feeling adequate to represent a population in case of strategic issues). These findings match with the findings of previous studies on PPI-involvement in research [43] that indicate that a flexibility in PPI-models on how engagement should take place is necessary.

4.1.2. Proper preparation

The study shows that a knowledge gap for PPI-stakeholders is to be bridged before effective PPI-involvement is possible. First, PPI-stakeholders report a lack of competence on meeting techniques. Research indicates that lacking such skills could exclude important PPI-groups from participating [20]. Second, PPI-stakeholders report a lack of knowledge about the functioning of hospitals. In order to prepare they have to have access to the necessary sources of information. Third, PPI-stakeholders want to discuss possible topics with their peers in order to truly be ‘a representative’. These three elements take time. Studies on PPI in research have proven that lacking proper preparation leads to feelings of incompetence, inability or overburdening [22].

4.1.3. External support

Next to proper preparation, PPI-stakeholders indicate they lack the resources to be a true representative. An independent organization could provide information, support peer groups, and train

PPI-stakeholders. During this study, there was such a patient organization, but they indicated a lack in resources to provide the necessary support for all the PPI-stakeholders. Van de Bovenkamp et al. [10] have described the necessary, but delicate position of such organizations. These should professionalize, in order to have sufficient capacity and funds, but should not replace actual patients with professionalized representatives in order to maintain legitimacy.

4.1.4. Autonomy

International studies [10,16,20] emphasize that citizen participation is increasingly important, also in healthcare services. According to our findings, PPI is going to be a strategic advantage in the near future and should not be made compulsory. A similar consideration on the difficult and balanced role of governments on not undermining initiatives of PPI with too much legislation was expressed previously by Baggot [19]. Our findings suggest that non-legislation could provide in a positive redistribution effect (e.g. only hospitals with effective PPI-involvement will find PPI-stakeholders for their committee) perhaps resulting in true autonomy and increased power for stakeholder committees, leaving hospitals with merely instrumental involvement of PPI with no stakeholder committee at all. The results from younger participants in this study confirm these future expectations. It is possible that the societal call for more opportunities to participate was expressed by this age group as they grew up with these ideals and consider it as the future paradigm [44]. By not legally embedding the stakeholder committee, this committee will have increased ownership and power, making them more autonomous.

When looking at these findings from the perspective of the stakeholder theory, which is derived from corporate structures, a difference can be noticed. The stakeholder theory states that the salience of a stakeholder is determined by the power, legitimacy and urgency a stakeholder possesses [45–47]. Based on the discussion above, the identified conditions for actual involvement seem strategies mainly aimed at overcoming imbalances of power in the stakeholder committee. Concerning power imbalances, such imbalances do exist and are perhaps consciously installed, possibly reflected by the small group of patients and the public in the stakeholder committees. As pointed out before, interaction between professionals and patients starts from an inherent power imbalance as healthcare professionals have a strong professional dominance over patients due to a comprehensive knowledge on practices and professional expertise and knowledge [48]. It is only when healthcare professionals have a preparedness to share this power, that PPI is possible [21,27]. The conditions identified in this study seem installed to avoid or overcome such imbalance. The strong emphasis on power, and the limited connection to legitimacy and urgency, indicates that a power shift is the first step to be taken in installing stakeholder committees in hospital settings. Legitimacy is perhaps addressed less, as patients are the *raison d’être* of hospitals and are self-evident [49]. Urgency seems to be lacking, in the behavior of both hospital- and PPI-stakeholders. This could be an indication that members of the stakeholder committee are still exploring and accepting their new roles. This behavior would be similar to patient participation on the individual level [27]. Overall, great similarities can be seen with patient involvement on the individual level.

4.2. Contribution to the existing literature/fitting to the existing literature

Most of the key elements described in this study, have been partially identified in the limited amount of previous studies on PPI [7,10,16,20,21,43,44]. However, our study further unraveled the rationale behind these key elements and discussed their possible relation to power imbalances. Therefore, this study has three important consequences. First, by providing deeper insight in the

process of effective PPI, future endeavors have more chance on success. From an ethical point of view, as described in the introduction, this is important for not harming the expert position of patients. These findings contribute to establishing actual PPI, avoiding instrumentalism and consolidating the equal position that patients deserve. Second, PPI-involvement on the hospital level shows to have transnational communalities. Most key elements identified in this study have been reported separately before. This indicates that governmental laws and jurisdictions have perhaps a more limited effect than previously stated [10]. Third, PPI on a more collective level shows strong similarities to patient involvement on the individual level, indicating that a conceptual framework can be based on frameworks from patient involvement and participation on micro-level.

4.3. Recommendations on future research regarding PPI in hospital policy decision-making

It should be acknowledged that PPI in hospital policy is of growing importance. The combination of lack in current research on the topic, the ethical consideration and the popularity of the topic indicate that more research is needed [23]. Especially, a concept analysis of PPI on hospital level could be useful to provide a common conceptual framework and scientific language on the topic [16]. The lack of such a framework has put restraints on the depths of the analyses of this study. Also, because of possible problems with the transferability of findings and policy between countries [49,50], research on PPI initiatives –including this study- is almost exclusively executed in one country. It is important to acknowledge that this study identifies universal concepts (e.g. proper preparation) which are probably identical between modern healthcare systems and are less dependent on local legislation, which makes transferability more likely [51]. Thus, future research should target to implement a similar intervention in multiple countries, and not be held back by concerns about local legislations or transferability. Such comparative studies are one of the future challenges of the health policy and systems research [12]. Finally, the indication that power imbalances, as described on micro-level, are also applicable and of great importance to the meso-level can inform future studies on aiming the scope of their analysis towards power imbalances on the meso-level. As a specific framework is currently still missing for analyses [16], frameworks from individual patient-healthcare worker relationships can be used to guide.

4.4. Limitations of the study design

Two points of discussion can be identified. First, the number of participants and settings is low which has implications on the generalizability of the results. Due to the limited numbers, bias in representation could be present. In contrast, it could be ethically hazardous to include a larger sample of hospitals. In case of negative results, the position of included patients could be negatively affected [27]. Therefore, a pilot study model was used here. The deep analyses by using a mixed-methods study design partially overcomes the issue of generalizability by the application of thick description, which possibly increased the value of the findings [52]. Still, although the use of mixed-methods studies is increasing, the use in studying healthcare services is still limited [53]. A perfect method for analyzing and reporting the findings of mixed method studies is still in development [12]. Second, this study used self-developed tools (e.g. questionnaire and observation checklist) because no applicable tools were available, another indication that healthcare service structures are understudied.

5. Conclusions

The results of this study confirm that PPI in hospital policy decision making is a complex process, and should not be taken lightly. Based on the findings of this study, four recommendations for effective and meaningful patient and public involvement on hospital level can be made. First, PPI on hospital level should also have the possibility to choose topics and address operational issues and not merely strategic questions. Second, PPI-stakeholders should have the resources, knowledge and opportunity to prepare. Third, PPI-stakeholders should be supported by an external patient organization. Fourth, the stakeholder committee should be provided with more autonomy. In the light of increasing civic participation, a stakeholder committee is expected to become an important asset of a hospital's policy and could be a strategic advantage. This strategic advantage will be minimized if PPI is made compulsory or is being instrumentalized. Furthermore, this study showed that initiatives are perhaps less dependent on national legislation than previously presumed. The conditions presented here are not exhaustive, and future transnational research is needed. Future research should also be targeted a providing a conceptual framework which can be, according on our results, based on model of patient involvement on the individual level.

Conflict of interest

No conflict of interest has been declared by the authors.

Funding statement

This research was partially made possible by funding of ICURO, the Flemish federation of public hospitals, and The King Baudouin Foundation [Koning Boudewijn Stichting]. There was no involvement of these funding bodies in the study design, collection and analysis of the data or writing of the report. The choice of journal for publication was made by the authors. This research has received no further grants from any funding agency in the public, commercial or social-profit sectors.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.healthpol.2018.02.007>.

References

- [1] World Health Organisation. Declaration of Alma Ata, International conference on primary healthcare. 1978.
- [2] Staniszewska S. Patient and public involvement in health services and health research: a brief overview of evidence, policy and activity. *Journal of Nursing Research* 2006;14(4):295–8.
- [3] Boivin A, Lehoux P, Lacombe R, Burgers J, Grol R. Involving patients in setting priorities for healthcare improvement: a cluster randomized trial. *Implementation Science* 2014;20:9–24.
- [4] Goodwin N. Integrated care in Europe: challenges, progress and the future agenda. A personal view. In: *Progress and challenges on integrated care around the world. The experience of Europe, the Americas and Western Specific Regions*. In: International Hospital Federation, 38th World Hospital Congress. 2013.
- [5] Kluge H. Roadmap for the Development of a framework for action and coordinated/integrated health service delivery in the WHO European Region. In: *Progress and challenges on integrated care around the world. The experience of Europe, the Americas and Western Specific Regions*. In: International hospital federation, 38th world hospital congress. 2013.
- [6] Kickbush I, Gleicher D. Governance for health in the 21st century. Copenhagen: WHO regional Office for Europe; 2012.
- [7] Groene O, Sunol R, Klazinga NS, Wang A, Dersarkissian M, Thompson CA. Involvement of patients or their representatives in quality management functions in EU hospitals: implementation and impact on patient-centred care

- strategies. *International Journal for Quality in Health Care* 2014;26(Suppl. 1):81–91.
- [8] Crawford MJ, Aldridge T, Bhui K, Rutter D, Manley C, Weaver T, et al. User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica* 2003;107(6):410–4.
- [9] Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* 2006;3:1–25.
- [10] Van de Bovenkamp HM, Trappenburg MJ. Government influence on patient organizations. *Health Care Analysis* 2011;19(4):329–51.
- [11] Staniszevska S, Herron-Marx S, Mockford C. Measuring the impact of patient and public involvement: the need for an evidence base. *International Journal for Quality in Health Care* 2008;20(6):373–4.
- [12] Mills A. Health policy and systems research: defining the terrain; identifying the methods. *Health Policy Plan* 2012;27(1):1–7.
- [13] Mockford C, Staniszevska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care* 2011;24(1):28–38.
- [14] Wilkins S. Patient engagement is the holy grail of health care [blog on the Internet, cited 2013 Jan 7]. Available from: goo.gl/pNiXAo.
- [15] Dentzer S. Rx for the 'blockbuster drug' of patient engagement. *Health Affairs* 2013;32(2):202.
- [16] Stewart E. What is the point of citizen participation in health care. *Journal of Health Services Research & Policy* 2013;18(2):124–6.
- [17] Sarrami-Foroushani P, Travaglia J, Debono D, Braithwaite J. Key concepts in consumer and community engagement: a scoping meta-review. *BMC Health Services Research* 2014;14:250.
- [18] Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, VanHecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Education and Counseling* 2016;99(12):1923–39.
- [19] Clemens B, Nowak P. Consumer participation and organizational development in healthcare: a systematic review. *Wiener klinische Wochenschrift* 2010;123:408–14.
- [20] Baggot R. A funny thing happened on the way to the forum? Reforming patient and public involvement in the NHS in England. *Public Administration* 2010;78(3):533–51.
- [21] Sarrami-Foroushani P, Travaglia J, Debono D, Braithwaite J. Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review. *BMC Health Services Research* 2014;14:402.
- [22] Freeman RE, Harrison JS, Parmar BL, Wicks AC, de Colle S. Stakeholder theory. In: *The State of the Art*. Cambridge University Press; 2010. p. 362.
- [23] Cornforth C, Hayes JP, Vangen S. Nonprofit–public collaborations understanding governance dynamics. *Nonprofit and Voluntary Sector Quarterly* 2014;44(4):775–9.
- [24] Brett J, Staniszevska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect* 2014;17:637–50.
- [25] Litva A, Coast J, Donovan J, Eyles J, Shepherd M, Tacchi J, et al. The public is too subjective': public involvement at different levels of health-care decision making. *Social Science & Medicine* 2002;54(12):1825–37.
- [26] Martin GP. Representativeness, legitimacy and power in public involvement in health-service management. *Social Science & Medicine* 2008;67(11):1757–65.
- [27] Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. *Mayo Clinic Proceedings* 2010;85(1):53–62.
- [28] Williamson L. Patient and citizen participation in health: the need for improved ethical support. *American Journal of Bioethics* 2014;14(6):4–16.
- [29] Malfait S, Van Hecke A, Hellings J, De Bodt G, Eeckloo K. The impact of stakeholder involvement in hospital policy decision-making: a study of the hospital's business processes. *Acta Clinica Belgica* 2017;72(1):63–71.
- [30] Newman J, Kuhlmann E. Consumers enter the political stage? The modernization of health care in Britain and Germany. *Journal of European Social Policy* 2007;17(2):99–111.
- [31] Ministère des Affaires Sociales. La commission des relations avec les usagers et de la qualité de la prise en charge (CRUQPC). Paris, France: MAS; 2010.
- [32] Van der Weijden T, van Veenendaal H, Drenthen T, Versluis M, Stalmeier P, Koelwijn-van Loon A, et al. Shared decision making in the Netherlands, is the time ripe for nationwide, structural implementation? *Zeitschrift Fur Evidenz, Fortbildung Und Qualitat Gesundheitswes* 2011;105(4):283–8.
- [33] Hellings J. Hospital governance recommendations [hospital governance aanbevelingen]. Brussel, Belgium: ICURO; 2012.
- [34] Kettles AM, Creswell JW, Zhang W. Mixed methods research in mental health nursing. *International Journal of Mental Health Nursing* 2011;18:535–42.
- [35] Tashakkori A, Creswell JW. The new era of mixed methods. *Journal of Mixed Methods Research* 2007;1:3–7.
- [36] Addo MA, McKie A, Kettles AM, Gibb J, Gass J, Yule M. Are nurses to empowered to make decisions about levels of patient observation in mental health? *Nursing Times* 2010;106(9):26–8.
- [37] Denis A, Teller M. Levers to improve patient participation. New practices and opportunities for recognition and funding [Hefbomen voor een betere patiëntenparticipatie. Nieuwe praktijken en mogelijkheden voor erkenning en financiering]. Brussels, Belgium: King Baudouin Foundation; 2011.
- [38] Daniels L, Diouani Z, Eeckloo K, VanHecke A. The degree of patient participation in the (strategic) policy of healthcare organizations: development and psychometric validation of a questionnaire [Mate van patiëntenparticipatie in het (strategisch) beleid van gezondheidsinstellingen: ontwikkeling en psychometrische validering van een vragenlijst]. Ghent University; 2014. Unpublished masterthesis, 2014.
- [39] Lynn M. Determination and quantification of content validity. *Nursing Research* 1986;35(6):382–5.
- [40] IBM SPSS statistics for windows, version 21. Armonk, New York, USA: IBM Corp.; 2013.
- [41] NVivo® qualitative data analysis software, version 10. QSR International Pty Ltd; 2012.
- [42] Eeckloo K, Malfait S, De Bodt G, Van Hecke. Patient participation in the strategic policy of hospitals by use of stakeholder committee, an evaluation of six pilot studies: final report. [Patiëntenparticipatie in het (strategisch) beleid van gezondheidsinstellingen via stakeholdersoverleg: een evaluatieonderzoek van 6 pilootprojecten: eindrapport]. Brussels, Belgium: ICURO; 2015.
- [43] Pearson M, Monks T, Gibson A, Allen M, Komashie A, Fordyce A, et al. Involving patients and the public in healthcare operational research: the challenges and opportunities. *Operations Research for Health Care* 2013;2(4):86–9.
- [44] Mirra N, Morrell ED, Cain E, Scorza D, Ford A. Educating for a critical democracy: civic participation reimagined in the council of youth research. *Democracy and Education* 2013;21(1). Article 3.
- [45] Mitchell RK, Angle BR, Wood DJ. Towards a theory of stakeholder identification and salience: defining the principles of who and what really counts. *Academy of Management Review* 1997;22:853–86.
- [46] Neville BA, Bell SJ, Whitwall G. Stakeholder salience Revisited: towards an actionable tool for the management of stakeholders. *Academy of Management Proceedings* 2004:D1–6.
- [47] Winn MI, Keller LR. A modeling methodology for multiobjective stakeholder decisions: implications for research. *Journal of Management Inquiry* 2001;10:166–82, 2001.
- [48] Angel S, Norup Frederiksen K. Challenges in achieving patient participation: a review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies* 2015;52:1525–38.
- [49] Eeckloo K, Van Herck G, Van Hulle C, Vleugels A. From corporate governance to hospital governance. Authority: transparency and accountability of Belgian non-profit hospitals' board and management. *Health Policy* 2004;68(1):1–15.
- [50] Dolowitz DP, Marsh D. Learning from abroad: the role of policy transfer in contemporary policy-making. *Governance* 2000;13:5–23.
- [51] Lavis JN, Possada FB, Haines A, Osei E. Use of research to inform public policy-making. *Lancet* 2004;364(9445):1615–21.
- [52] Coyle CE, Schulman-Green D, Feder S, Toraman S, Prust ML, Plano Clark VL, et al. Federal funding for mixed methods research in the health sciences in the United States. *Journal of Mixed Methods Research* 2016:1–20.
- [53] O' Cathain A. Mixed methods research in the health sciences: a quiet revolution. *Journal of Mixed Methods Research* 2009;3(1):3–6.