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Organising and managing patient and public involvement to enhance quality improvement—Comparing a Swedish and a Dutch hospital

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ARTICLE INFO

Article history:

Received 17 May 2021

Revised 7 March 2022

Accepted 6 April 2022

Keywords:

Co-production

Critical realism

Healthcare

Management

Patient involvement

Quality improvement

Thematic analysis

ABSTRACT

As co-production approaches to quality improvement (QI) gain importance in healthcare, hospital leaders and managers are expected to organise and support such efforts. Yet, patient and public involvement (PPI) can be challenging. Hospital organisations, emphasising knowledge and evidence domains, are characterised by operational-professional rather than patient-preference led management. Thus, PPI adds aspects of influence and responsibility that are not clearly defined or understood, with limited knowledge about how it can be orchestrated. This study, therefore, aimed to explore hospital leaders' and managers' contextualised experiences of managing QI efforts involving patients, by comparing two European hospitals.

The study draws on field observations and qualitative interviews with a total of 21 QI team leaders and hospital managers in a Swedish and a Dutch hospital organisation. The data were subjected to thematic analysis with a critical realist approach.

Results define seven themes, or areas, in which mechanisms are at play: (1) patient involvement in hospital QI, and (2) improving outcomes for patients, originating from the strategic view of achieving the hospital vision. Furthermore, (3) societal influence, (4) knowledge and evidence, (5) complexity, (6) individual resources, and (7) cooperation are areas in which mechanisms operate in the process. These areas are equally relevant for both hospitals, yet the mechanisms involved play out differently depending on contextual structure and local means of action.

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1. Introduction

Co-production [1] and co-design [2] approaches to quality improvement (QI) [3,4] are increasingly developing in healthcare, and have a high priority for QI leaders, managers, policy makers, and researchers [5,6]. Moreover, the involvement of patients and/or their representatives (designated, in the following, as 'patients') in healthcare QI is being emphasised, encouraging patients and healthcare professionals (designated, in the following, as 'professionals') to collaborate in new, co-productive ways [7,8,9].

As patient and public involvement (PPI) [10] is a relatively uncharted area in research and clinical practice, attempts are made to define and delimit its different approaches. For example, PPI is described in degrees of: (1) patients being consulted as consumers of healthcare (choice), (2) patients being deliberately involved

(voice), and (3) patients actively participating in co-produced activities (partnership and shared leadership) [7,11]. Patients are also described to be involved at multiple levels of the healthcare organisation—in direct care, in organisational design and governance, and in policy making [11,12]. Furthermore, theoretical constructs of legitimacy, credibility, and power are proposed to explain variations of PPI [13]. Nevertheless, PPI, [10] co-design [2] and co-production [1] approaches are considered essential to guide healthcare organisations towards focusing on more collaborative approaches to QI [14].

This study rests on the premise that the healthcare system consists of clinical microsystems (CMSs) nested in mesosystems and overarching macro-systems [15]. Formed around common purposes and needs, CMSs are the smallest functional units in which patients and professionals interact and exchange information. At the CMS level, patients and professionals work interdependently to co-produce quality, safety, and cost outcomes. For example, it can be in a delivery room, a primary care centre or in the patient's home. In this study, the CMS encompasses patients and professionals that are engaged in QI efforts.

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It is suggested that PPI in clinical practice needs to be tailored to each specific QI context to be successful [6,16]. Different approaches are observed across Europe, and variations in the commitment to and character of PPI are much attributed to the existing context and history of each specific healthcare system [7]. The availability of infrastructure, guidance, and support are suggested as some of the mechanisms at play. However, and equally for all European healthcare systems, societal expectations, social networks, and digital technology drive and facilitate the movement [17,18]. Consequently, QI leaders and hospital managers are expected to organise and support QI efforts to be co-produced with patients [19,20].

However, organising and promoting PPI in QI can be challenging. QI efforts require systematic planning and need to be informed by research evidence and best practices [21]. Additionally, healthcare organisations are complex, adaptive systems [22] with main elements of operational-professional led, rather than patient-preference led, management [23]. In such contexts, PPI risks being considered time consuming and resource demanding [24]. Moreover, healthcare organisations are domains strongly grounded in evidence, knowledge, and best practices [25], and PPI in QI adds aspects of influence and responsibility that, to date, are not clearly defined or understood [24,26]. Thus, the research is limited and the clinical performance is unevenly implemented. The UK and the USA are in the lead in publishing work on frameworks for supporting PPI [6]. In the rest of Europe, the UK excluded, relatively small groups of researchers account for most of the publications. The highest research activity is noted in the Netherlands [17].

Despite the relative lack of consensus on the approach, there is some evidence that PPI in QI makes a difference. For example, patients can contribute with experiential knowledge that professionals do not have, leading to better results for individual and public health, improved service and system performance, professional development, and behavioural change [14]. However, there is very little knowledge about what aspects to consider in the process of introducing PPI in QI efforts at different levels of healthcare and how it can best be organised and managed in hospital organisations. Recent attempts to explore how it can be optimised in hospital QI have described differences in practices between hospitals and countries in Canada [27,28,29] and Europe [30,31]. However, the introduction and management of PPI in QI efforts has implications for hospital managers and leaders, and this former research does not gather any specific information on the contextual factors and mechanisms that might impact on the process. Furthermore, there is, to our knowledge, no comprehensive research on what leaders, managers and policy makers need to consider in their local context, why it needs consideration and how. In light of this, we set out to explore QI team leaders' and hospital managers' experiences of and beliefs about organising and managing PPI in QI efforts. The main focus of this study was to identify the mechanisms involved and how they play out in different hospital contexts.

2. Materials and methods

The study has a qualitative design with a critical realist (CR) ontology and epistemology approach [32]. The choice CR was guided by the aim to explore and offer descriptions of individual experiences and beliefs in a relatively under-researched field, and simultaneously account for organisational and other contextual factors.

The empirical data are based on field notes from QI team leader and management meetings in a Swedish hospital, and from study visits (with meetings focusing on PPI in QI efforts) in a Dutch hospital. Furthermore, 21 semi-structured individual interviews were conducted with QI team leaders and hospital managers (designated, in the following, as 'leaders' and 'managers') in both hospitals. All respondents had experience with organising and manag-

ing PPI in QI efforts. Data were collected from March 2016 to April 2019. This research is part of a larger project studying PPI in the QI efforts of hospital organisations from the CMS [15] and leadership [33] perspectives.

2.1. The two cases

The contexts of the two cases are (1) a patient process organisation in a hospital in Sweden (SWE) and (2) a hospital organisation in the Netherlands (NL). They were included as a result of the first author's access to them through her work and an international exchange programme (i.e. a form of convenience sample).

In the SWE case, the context is a tax-financed, decentralised, and politically steered healthcare system. Twenty-one county councils/regions finance almost all healthcare in Sweden and also provide most of the services. The health and welfare system covers all residents, with costs being heavily subsidised, and additional private healthcare insurance is not required. The role of the state is to legislate and establish principles/guidelines, distribute responsibilities, allocate government grants, supervise, and decide on local government financial equalisation and national high-cost protection/maximum fees [34].

The case under study is a mid-size, non-academic regional hospital. It provides healthcare within all specialities to approximately 300,000 citizens. The hospital has 320 beds, about 4100 employees, and a yearly budget of approximately €400 million. The hospital organisation applies the Hoshin Kanri [35] approach for its strategic planning and follow-up. Organisations that use Hoshin Kanri often follow a plan comparable to Deming's PDSA cycle [36]. It is a top-down approach, with goals mandated by the management and the implementation performed by professionals on the floor. An X-matrix is applied to ensure that the focus areas identified by the management are effectively visualised all the way through the organisational levels. At the time of the study, five focus areas were communicated and acted upon, of which one was phrased as 'the patient should be involved'.

In this hospital, the patient process organisation is a model applied for patient groups with common, serious diagnoses whose outcomes are identified as dependent on the inter-professional cooperation across departments and related community-based services. During the research period, it consisted of 12 different defined patient processes based on diagnoses, such as multi-diagnosed older people, pneumonia, and stroke. A patient process is often identified from the hospital's patient safety work. It is formalised in an application procedure and mandated by the management. The QI efforts performed by each patient process aim at improving the care process for the defined group of patients. QI efforts are carried out at the group and organisational levels [12,15] and focus on areas of patient safety and information, care path efficiency, accessibility, and clinical outcomes. Each defined patient process consists of one inter-professional QI team led by a process leader, referred to as the leader (in most cases a physician). The patient process organisation is, in turn, led by representatives from the hospital's management. At the time of the study, patients were involved in six of the 12 teams. The degree of PPI was decided by each team. On some of the teams, patients actively participated as representatives, while on other teams, they were consulted with or interviewed by professionals but did not regularly attend the team meetings.

In the NL case, a model for regulated competition, the Health Insurance Act, was introduced in the healthcare system in 2006. The model combines mandatory universal healthcare insurance with competition among private insurers [37]. This has led to three different healthcare markets in the Netherlands: a procurement market, an insurer market, and a delivery market. The assumption behind this is that competition will help increase efficiency as well

as quality in healthcare. Based on income, residents are insured on a compulsory basis by private insurance companies to a standard level of 80% of available healthcare, and they can voluntarily add supplementary insurance coverage. Insurance companies and hospitals compete to attract patients. The government does not take part in the provision of healthcare, but determines the yearly macro budget and income-related contributions and allowances, and is responsible for accessibility, affordability, and quality [38].

The case under study is a larger, non-academic regional hospital. It provides healthcare within all specialities to approximately 675,000 residents in 20 surrounding municipalities. The hospital has 1100 beds, 7000 employees, and a yearly budget of almost €700 million. The hospital organisation has adapted the value-based healthcare framework [39] for its QI within defined patient processes and also involves patients in other ways. At the time of the study, ‘patient value’ was put at the top of the hospital’s strategy plan, and patients were involved in QI efforts at the individual, group, and governance and management levels of the organisation [12,15]. For example, the hospital had an established client council collaborating with the hospital board, and patients were actively involved on the hospital’s Quality and Safety Committee. Furthermore, hospital departments were requested and supported in regularly involving patients in their QI efforts by, for example, so-called ‘mirror conversations’ [40].

2.2. Finances and quality

At the time of the data collection, both hospitals were experiencing a negative financial situation. There were problems with staff turn-over and restrictions on managers recruiting new staff members.

In the Euro Health Consumer Index (EHCI) [41], data on healthcare performance indicators have been collected from European healthcare systems since 2006. Both Sweden and the Netherlands have exhibited very high quality in this index. In 2018, six sub-disciplines with a total of 46 indicators were monitored: (1) patient rights, information and e-Health, (2) accessibility, (3) outcomes, (4) range and reach of services, (5) prevention, and (6) pharmaceuticals. In the same year, the Netherlands was ranked second and Sweden eighth. Historically, the Netherlands has performed very well and appeared in the top positions regardless of what aspects of healthcare have been covered. The Swedish performance has been lowered by significant problems with accessibility, a problem that remains in the form of waiting times, despite national efforts [34].

2.3. Procedure

2.3.1. Field notes

During the study period, one of the authors (CB) attended 40 meetings between leaders and the hospital management in SWE and made, in total, 20 days of study visits in NL. The field notes were spontaneous and free, written with a focus on PPI in social interactions, communication, considerations, and decision procedures. The author had the opportunity to interact with participants and, in this way, was able to observe the different contexts of the meanings, actions, routines, and practices involved. The field notes complemented the interviews and were also used during the data analysis.

2.3.2. Interviews and participants

A total of 21 semi-structured individual interviews were conducted with leaders and managers by one author (CB) (Table 1). In SWE, all six leaders of the patient process teams that involved or sought to involve patients in their QI efforts, and the four managers involved in the patient process organisation, were asked and

Table 1
Description of the participants (SWE and NL) and the interviews.

Participants	QI team leaders (n = 13)		Hospital managers (n = 8)	
	SWE (n = 6)	NL (n = 7)	SWE (n = 4)	NL (n = 4)
Female	n = 3	n = 3	n = 2	n = 3
Male	n = 3	n = 4	n = 2	n = 1
Age range	45–65 years		45–64 years	
Interview range	40–75 minutes		40–57 minutes	

agreed to participate in individual interviews. Interviews were performed in Swedish and conducted between March 2016 and April 2019. In NL, the participants were informed about the study with interview questions sent out in advance, asked to participate, and scheduled for the interview by a hospital development leader. One author (CB) visited NL on two different occasions in 2018 and 2019. Interviews were performed in English.

The interviews took place at the participants’ workplaces. All interviews, except for one, were digitally recorded and transcribed verbatim. One participant approved the interview but not the digital recording of it. In this particular case, the answers to the interview questions were documented by the participant beforehand. Additional notes were taken by the author during the interview.

2.3.3. Analysis

The interview data underwent thematic analysis (TA), following Braun and Clarke’s [42,43] guidelines. TA was chosen due to its flexibility and theoretical freedom, along with the well-established guidelines for performing it. Furthermore, the philosophical framework of CR [32] informed the data collection and analysis, and guided the reporting of the results.

The CR approach [32] treats the world as theory-laden, but not theory-determined. The approach admits a real social world we can attempt to understand or access, but proponents argue that some knowledge about it is closer to reality than other knowledge. In this perspective, individual meanings, beliefs, and values are as equally real to physical objects and processes, and part of the reality. Furthermore, in CR, the actual mechanisms (some observable and others not) and processes, that result in particular outcomes, are understood as dependent on context. Consequently, the mechanisms identified in a CR causal theory are considered situationally dependent – with their actual context entangled in the causal process [44]. Thus, CRs can gain knowledge ‘in terms of theories, which can be more or less truthlike’ [45]. In other words, the theories that help identify the causal mechanisms driving *structure* (i.e. social events, activities, phenomena), are selected and formed by *agency* (i.e. the rational judgment influenced by culture, history, language, political interests, and more) [46]. The choice of adapting the CR approach to this study was guided by the aim to explore and offer descriptions of individual experiences and beliefs in a relatively under-researched field, and simultaneously account for organisational and other contextual factors.

The two data sets (SWE and NL) were analysed separately, yet in parallel. Field notes were not included in the coding process but added information about context throughout the analysis. The phases of TA were applied [42]. Familiarisation involved transcribing the interviews (CB) and reading the transcripts several times in order to become familiar with the depth and breadth of the data (CB and MW). In the first data coding cycle, each data set was worked through systematically and labelled with codes (CB). The codes generated were both descriptive and interpretative. After coding all data, two compiled lists of codes (SWE and NL) were transferred to an Excel spread-sheet and discussed within the research group. At this stage, the SWE list of codes was translated into English. The second coding cycle involved distinguishing codes

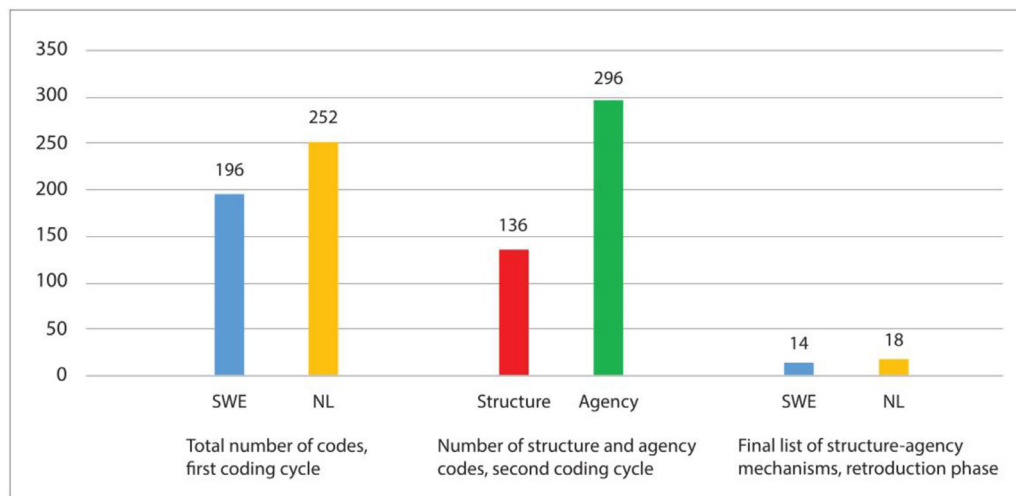


Fig. 1. Comparisons of the number of codes and structure–agency mechanisms that were generated in the analysis.

representing social *structures* (i.e., the way things are constructed or organised) from codes representing *agency* (i.e., the means of action through which things are done) [32]. All codes were considered important, however, the most prominent codes were used as starting points to identify the structure–agency mechanisms (demi-regularities) [42] in the next phase of theme development. These structure–agency mechanisms were reorganised and clustered together into bigger patterns for further analysis. In the next phase of review and definition of the candidate themes, causal mechanisms and conditions were investigated through retrodution [32]. Retrodution is a form of logical inference, iteratively repeated, that leads to the formulation of a theory that provides the most likely explanation. It involved a thought process of moving from concrete to abstract, followed by a return to the concrete again. By doing so, the authors aimed to identify the necessary contextual conditions for particular mechanisms to have certain effects and to cause the observed tendencies, trends and patterns [32]. Efforts were made to constantly move between empirical and deeper levels of reality to derive predictions and to search for facts verifying or falsifying the assumptions. The goal was to achieve a full understanding and refinement of the themes.

3. Results

In the first coding cycle of the analysis, more codes were generated from the NL than from the SWE data set. In the second coding cycle of distinguishing structure and agency codes, there were more agency codes than structure codes generated across both data sets. Finally, when comparing the two ultimate lists of structure–agency mechanisms, there were almost the same number of mechanisms in both data sets (Fig. 1).

Seven interconnected yet distinct themes (designated, in the following, as ‘areas’) in which the structure–agency mechanisms are at play were generated and defined: (1) *patient involvement in hospital QI*, (2) *improving outcomes for patients*, (3) *societal influence*, (4) *knowledge and evidence*, (5) *complexity*, (6) *individual resources*, and (7) *cooperation*. In Supplement 1, the areas are displayed with their structure–agency mechanisms and examples of quotes from the participant interviews (Supplement 1). Areas 1 and 2 constitute the context of the process and the expected outcome, and areas 3 – 7 describe the areas in which structure–agency mechanisms are at play in the process. Fig. 2 illustrates the interconnectedness of the seven areas from a CMS perspective (Fig. 2). Based on this fig-

ure, the results are discussed in the following sections, and implications for practice are given at the end.

4. Discussion

The aim of this study was to explore leaders’ and managers’ experiences of, and beliefs about organising and managing QI involving patients and/or patient representatives. The study is part of a larger research project, and patients’ and professionals’ perspectives on PPI in QI efforts have been reported elsewhere [16,47].

4.1. Improving outcomes for patients by incorporating PPI in QI efforts

All areas were equally relevant for both hospitals, yet the analysis revealed that the mechanisms play out differently in the two organisations. At the time of the study, both hospitals’ strategy plans included strategies for (1) *patient involvement in hospital QI*, to achieve the vision of (2) *improving outcomes for patients*. Nevertheless, when reasoning about how to actually organise and manage PPI in QI, leaders and managers were struggling with issues of how to transform it into action [24].

4.1.1. The SWE strategy

In SWE, there were few examples of PPI in QI efforts, and the attempts made had not been explored or evaluated to any extent. Consequently, the few lessons learned were not systematically disseminated in the organisation, and in interviews, leaders and managers took an overall reasoning stance to the question. Rather than expressing their actual experiences, they elaborated on beliefs about how PPI in QI may be managed. There was consensus that improved outcomes for patients should be created in healthcare. However, ideas of the actual definition of improved outcomes differed—why, how, and under what circumstances it should be created, who decides upon it, how to measure it, and so on [26]. Most notable were the differences in opinions between leaders and managers. These observations compared well with a gap between hospital management and frontline clinicians’ perspectives described in earlier research [47,48]. In many hospitals, the management argue for improved outcomes and experiences for patients, whereas frontline professionals and/or leaders see little formal planning or support to promote such efforts [47,48]. One leader described experiencing such a disagreement in follow-up

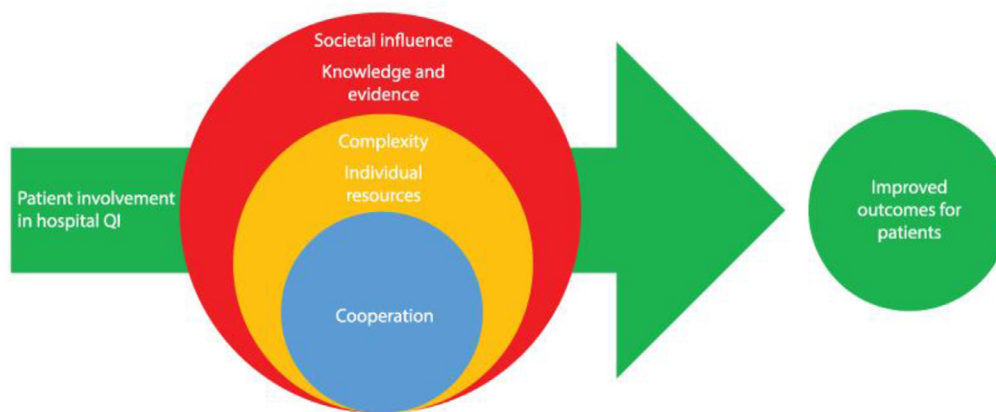


Fig. 2. Improving patient outcomes by organising and promoting patient involvement in hospital QI efforts, with the five areas in which mechanisms are at play in the process.

meetings with the hospital management (Supplement 1: *Improving outcomes for patients, SWE 7*).

Managers argued over the importance of institutionalising PPI as one of the standards for the hospital's quality management. However, no concrete structure or strategy for it was elaborated upon. Leaders expressed considerable uncertainty about how to interpret the formulation of the hospital strategy plan, how to act upon it in QI efforts, and what outcomes to expect. Consequently, PPI was not consistently included in the continuous QI efforts but treated as a detached approach to QI (Supplement 1: *Patient involvement in hospital QI, SWE 6*).

4.1.2. The NL strategy

In NL, where PPI has been on the national agenda since the model for regulated competition was introduced, [37,38] PPI was an integral part of the hospital structure and was organised at different levels. Insights were discussed and reasoned about, and strategic support was provided by the management to test new ways of involving patients. Leaders and managers expressed extended knowledge about how patients could best be involved depending on circumstances such as diagnosis, purpose, type of involvement, and organisational level. Consequently, the development of PPI in QI had progressed further in this context. However, leaders and managers still found it difficult to define the notion 'patient value' [49] from the hospital strategy, and leaders did not always experience that it was the primary course followed (Supplement 1: *Patient involvement in hospital QI, NL 1*).

Both leaders and managers acknowledged the organisational dilemma that occurred when improved outcomes for patients and the economy were, in theory, seen to benefit each other, but in practice became conflicting interests. In this matter, the influence of quality management systems initiated by insurance companies in healthcare was strongly criticised (Supplement 1: *Improving outcomes for patients, NL 7*). Thus, this study revealed, in line with earlier research, a fundamental uncertainty of what actually constitutes PPI in both cases [24,26]. Furthermore, leaders and managers agreed on the common vision of improving outcomes for patients but struggled with questions of how to monitor it and how to decide when it was achieved [14,49]. Throughout the data, a conflict between leaders and managers in their views of how improved patient outcomes and costs were to be prioritised in practice was also noted [14]. It was reasoned that the organising of economy with financial measurements and metrics is easier to control and follow up strategically, and, subsequently, becomes the focus for steering. Leaders, who were experiencing cooperation with patients, were, on the one hand, more inclined to put a pos-

itive financial development as a secondary outcome of successful PPI [49,50]. On the other hand, managers, who carried the financial responsibility, viewed improved patient outcomes as more of a vision than a substantial goal. Their counterargument was that a good financial situation is fundamentally good for patients as well [49]. Therefore, in line with other research, [14,23,48,49] this study points to the importance of agreeing on carefully defined visions and goals with metrics to monitor patient outcomes alongside costs, and visualising it throughout the organisation.

4.2. Areas with mechanisms that matter for management

In many ways, the two cases were similar, both being European hospitals with comparable quality outcomes and challenges [41]. However, the mechanisms for leading and managing PPI in QI played out differently due to differences in structure and agency interplay. In the following, the areas in which mechanisms were experienced to promote and/or impede the management of PPI are discussed. Put in a CMS perspective, [15] mechanisms concerning (3) *societal influence* and (4) *knowledge and evidence* played out at the macro-system level; (5) *complexity* and (6) *individual resources* at the mesosystem level; and (7) *cooperation* at the microsystem level (Fig. 2).

4.2.1. Mechanisms of societal influence

In both cases, evolving public expectations of healthcare are affected by changing expectations of life itself, affecting how PPI in QI is perceived [17]. Additionally, a history of ever-changing trends and concepts is increasingly being questioned by professionals, influencing their attitudes toward behaviour change and testing new models.

In Sweden, with a politically steered and government-funded healthcare organisation, [34] patient organisations work in parallel with healthcare. Subsequently, there were examples of patient processes in SWE in which patients had more influence in the overall society than others. These circumstances were reflected in the development of QI team cooperation. For example, the diabetes, breast cancer, and neuropsychiatric diagnoses had well-established patient organisations from years of collaboration with healthcare, both nationally and locally. Diabetes and neuropsychiatric diagnoses also offered examples of patient groups that encompassed patients with chronic diagnoses of all ages—patients who need to live with and adapt to their illness in their daily lives. Thus, there was longer experience with PPI on these QI teams, and it had been continuously developed. Digitalisation and social media were explored as means for PPI [18], and the attitude was to learn from

testing different approaches (Supplement 1: *Societal influence, SWE 5*).

In NL, PPI had developed favourably in a process from being question-based to becoming client-focused, and the hospital had recently adopted the value-based care approach [39]. Digitalisation worked as an enabler of PPI in QI [18]. In addition, the market orientation of healthcare, the statutory nature of client councils, and the organisation of family doctors were national incentives that seem to have had positive impact on the management to initiate and develop means for PPI [38]. However, leaders and managers expressed that the hospital reimbursement created from market orientation was not actually based on reducing costs and improving outcomes for patients, but on diagnosis treatment combinations and operational production outcomes. Subsequently, the competition between hospitals, which was meant to favour patients, was reasoned to lead to overtreatment and unnecessary costs. Furthermore, insurance companies were involved in the granting of QI projects, which added conflicts of interest. Hospitals were totally dependent on reimbursement from the patients who chose them, yet insurance companies were believed to exercise their control function in order to save costs without involving any patient preferences. In Dutch healthcare, there were examples of hospitals going bankrupt, and it was argued how deeply this may affect public trust in healthcare (Supplement 1: *Societal influence, NL 6*).

4.2.2. Mechanisms of knowledge and evidence

Knowledge and evidence are central concerns in healthcare [25]. Thus, the clarification of underlying reasoning and attitudes and how the current knowledge base is acted upon is important [51]. In SWE, leaders and managers indeed recognised that patients carry knowledge about themselves and their own care, and emphasised the importance of including patients' experiential knowledge in QI [52]. Just like in NL, their underlying reasoning was that holistic approaches to identify gaps between patients' needs and the actual care delivered represented key opportunities for improvement [14,47].

In NL, patient, professional, and improvement knowledge were acknowledged by leaders as interdependent and forming a joint knowledge base, however, many professionals were determined to lack skills in how to unite and act upon this base [51]. Leaders reasoned professionals were mainly trained in evidence-based education and guideline-based treatment, and not in exploring the patient perspective. Thus, QI was often experienced as operationalised without input from patients. However, the management were of a different view and emphasised that patients' experiential knowledge certainly was inquired about in QI and support systems. In SWE, the holistic approach to QI was debated, but neither completely acted upon nor fully followed up. Rather, the professional knowledge tended to take precedence over the more uncharted experiential and improvement knowledge [47,53]. The representativeness of patients on QI teams was questioned with reference to it not being empirical, although gaining different perspectives was argued to be the goal of PPI. In both cases, leaders and managers were of different professions, and some of them experienced others as lacking knowledge about and passion for optimising the system from the patients' point of view [49] (Supplement 1: *Knowledge and evidence, NL 11*).

A big issue for leaders and managers in both cases was the well-known struggle to identify proper measurements and metrics to improve and learn from [23,54,55]. Measures were reasoned to require tangible results to be understandable, and it was experienced as difficult to display the explicit results of soft and 'blurry' improvements. There were no examples of simple, tangible measurements that covered the complexity of diagnoses or care processes. Subsequently, most measurements were kept medical and

operational, illustrating, for example, the use of antibiotics, in-hospital length of stay, and waiting times. Unless empirical or operational evidence to support change was clear, QI areas were often experienced as neglected. As an example, the monitoring of complex diagnoses or care processes was experienced as too standardised or oversimplified to follow up the target of improving outcomes for patients. Consequently, some leaders believed that relevant knowledge for QI risked being missed out on (Supplement 1: *Knowledge and evidence, SWE 7*).

In NL, leaders believed that the standardisation of care helped reduce variation between individual patients and/or professionals, yet argued that it became an issue when applied in cases where patients' individual choices deviated from standardised guidelines. Instead, patient-initiated variation was proposed to be accepted as the standard procedure.

4.2.3. Mechanisms of complexity

Hospitals are considered complex organisations [22], and in such contexts several mechanisms between people and between organisational levels are triggered. These mechanisms may be dealt with by efforts to establish clarity [24,56,57].

In Sweden, PPI is regulated by national law, and there are relatively simple, overarching governance and policy documents to clarify and give directions [19,20,34]. However, the closer to clinical practice, the more complex the change process gets, and overarching directions were not believed to give proper implications for introducing PPI in QI [47]. This contributed to a lack of clarity and transparency. As argued in the knowledge and evidence section, complexity issues were, in some aspects, believed to be overlooked in favour of more tangible models for standardisation. A conflict was expressed in that, to be prioritised by the management, QI measurements and metrics had to function for operational performance [23,49]. Thus, patient processes with complexity issues, such as multi-diagnosed older people or people with neuropsychiatric diagnoses, risked getting a lower priority. Leaders argued that simple measurements and metrics may even be counterproductive to the achievement of improved outcomes for some patient groups. The nationally applied, standardised quality management system for monitoring breast cancer patient process outcomes was given as an example. In this system, predetermined lead times were sometimes experienced to limit local QI efforts because they were the national indicators connected to benchmarking. For example, the standardised lead times could become obstacles to what patients and professionals viewed as the most appropriate timing for exchanging certain information. Furthermore, patients' individual decisions for treatments were not always in line with national, standardised procedures. These oppositions across organisational levels have been highlighted in earlier research [49], and were experienced as demanding. Especially in SWE, expectations from the management were not experienced by leaders to correspond to the support given [47]. In general, there seemed to be a lack of direction and support for PPI in QI throughout the SWE hospital organisation [48]. However, in this case the management were somewhat aware of this issue (Supplement 1: *Complexity, SWE 9*).

In NL, QI interventions and support systems had developed towards being more patient-centred. The hospital had introduced a new, electronic patient dossier that enabled increased PPI. Complementary functions, such as a PREM (Patient Reported Experience Measures) and PROM (Patient Reported Outcome Measures) survey [58], video meetings, and educational films, were being developed. Outcome monitoring had developed from rating only doctors to capturing patient experiences. As mentioned, patient value was incorporated into the hospital strategy, and the management emphasised value-based healthcare [39] by putting it into action in QI efforts and support systems. The issue raised now was that the

operational and cost monitoring had not developed in the same, patient-centred way. Leaders still believed the focus was mainly to monitor for the sake of quality management systems and hospital reimbursement. It was proposed that this might have an adverse effect on the strategy of improving outcomes for patients, and thereby, the management could risk losing credibility among professionals.

As found in earlier research, hierarchy, culture, behaviour, conflicting interests, administration, and too many QI projects at one time were other complex obstacles that both leaders and managers said they were facing [47]. Similarly to SWE, the knowledge exchange between organisational levels was experienced as too limited to enable proper support, creating a gap in mutual understanding and cooperation. Value-based healthcare [39] was argued to require joint facilitation from leaders, IT, and finance and control departments in order to succeed. Additionally, as leaders and managers emphasised the importance of time, opportunity, and a formal decision, these resources were simultaneously experienced as their most limited ones [47] (Supplement 1: *Complexity, NL 11*).

4.2.4. Mechanisms of individual resources

Furthermore, and strongly connected to the mechanisms in the area of complexity, were the mechanisms of individual resources. At the mesosystem level, [15] the aspects of complexity and individual resources, therefore, are noticeable and influence other areas. In SWE, both patients and professionals were believed to carry individual resources to be involved, or to involve others, in QI. Leaders and managers argued that patients had individual capabilities according to diagnoses, age, frailty, social connection and support, etc. It was also proposed that patients had to feel safe to represent their patient group and needed a realistic approach to their ambitions. Prolonged assignments could risk giving them a pre-understanding that forced them to compromise between patient and organisational needs [24,47]. Their involvement in QI should, therefore, be adjusted accordingly.

In self-criticism, leaders reasoned that they themselves as professionals were the major obstacle to PPI in QI. Depending on individual experiences and knowledge, the involvement of patients as experts in their field could be experienced as being put in a reversed and uncomfortable position [24,47]. One leader described it as a relatively uncharted approach that initially created uncertainty (Supplement 1: *Individual resources, SWE 4*).

In NL, leaders and managers had come to the same realisation: however, they were acting strategically upon it. For example, different adjustments to involve chronically ill and frail patients in QI were explored. As examples, some patients were involved bedside to identify improvement areas that they could gain experience of themselves before discharge. At the clinic level, patient preferences were collected through so-called mirror conversations, [40] gathering patients and professionals around specific QI topics. When it came to chronic obstructive pulmonary disease patients, a group of patients that hesitated in coming to the hospital unless critically ill, digital ways of involving them in QI were explored.

As expressed in SWE, PPI was believed to be an underestimated and sometimes threatening resource. It was also discussed that professionals tended to overcomplicate it. Thus, in NL, intrinsic motivation to change behaviour was being addressed. For example, a shared decision-making research project for physicians and an initiative on hospitality for all employees were two projects that were being implemented. PPI in QI was seen as a joint responsibility to be tailored to each unique situation [16,21]. Yet, as leaders and managers in the SWE case also concluded, the final responsibility lies in healthcare [26,47]. Due to patients' diverse capabilities to be involved, professionals need to help prioritise and synchronise QI efforts to make them manageable and worthwhile. This

was considered one of the keys to success (Supplement 1: *Individual resources, NL 9*).

This study also revealed a sense of moral injury [59,60] expressed by leaders in situations when operational and financial outcomes were experienced as favoured over achievements in being patient oriented. This needs to be addressed by management, or it may become a major barrier to the pursuit of the organisation's vision. Thus, leaders and managers need to recognise that professionals have individual resources to involve patients. Experiences, knowledge, and engagement may differ [47,51]. Their involvement should, therefore, be supported accordingly.

4.2.5. Mechanisms of cooperation

In line with other research, [47,50,61] this study identified a key leverage point for PPI in QI at the microsystem level [15]. However, the way mechanisms played out at this level depended on how other areas of structure–agency mechanisms played out at the other levels.

In both cases, the general agreement was that PPI in QI is a successful approach that contributes to a common view of what matters to both patients and professionals, and which creates mutual trust. The notion of 'trust' stood out as a central prerequisite to achieving cooperation and was also reasoned to be one of the secondary outcomes of co-produced QI. Cooperation, leaders and managers said, depended on well-functioning dialogue and trust, regardless of whether it concerned individual treatment, co-produced QI efforts, or policy making [24,26,47]. Subsequently, most models for PPI were believed to be successful if trusted by the people involved.

In NL, experiences were that proposing and reaching agreements with patients, for example through shared decision making [62] or mirror conversations, [40] was a successful approach to reach adherence to advice, treatments, medication, guidelines, and QI efforts. Leaders and managers, in both cases, believed such trust could only be earned by hard work. In SWE, leaders reasoned that when the patient becomes an equal member of the team, top-down governance could be replaced by dialogue [47]. In such a dialogue, the patient could act as a two-way link, bringing direct feedback from interconnected QI teams or between the QI team and the patient organisation. Under these conditions, attitudes within the QI team were believed to transform into a mutual kind of openness, in which governance or policy documents on PPI should not be needed anymore. In line with this, leaders in the NL further emphasised that agreements with patients could only be reached in co-production [1] (Supplement 1: *Cooperation, NL 1*).

In SWE, leaders and managers were more occupied with how to achieve a proper balance between professional-operational and patient-oriented approaches to QI. Worries about dependency situations and tokenism [24,47] were much elaborated upon. Equal involvement was believed to be a question of hierarchy and society, and of the maturity of the organisation [31]. One manager ambiguously described it as a major cultural shift to equalise QI from being healthcare-mandated to being shared between patients and professionals (Supplement 1: *Cooperation, SWE 10*).

In NL, where the active presence of patients and patient representatives is mandatory [37,38], these challenges were not emphasised in the same way. Though there were different views of the actual degree of PPI in the organisation, patients still had an established function and a defined task to perform. For example, even though the client council understood there were economic issues that the management had to consider and prioritise, it was still clear to them that their assignment was to guard patient interests in every decision. Subsequently, it was reasoned to be an organisational failure when the client council was not involved in hospital decisions.

Finally, and also worth highlighting, this study found a reversed mechanism in which dialogue and trust were believed to be secondary outcomes of co-produced QI efforts. In such situations, structure–agency mechanisms might influence each other synergistically and contribute to institutionalising PPI in QI.

4.3. Implications for practice

This study illuminates QI leaders' and hospital managers' contextualised experiences of, and beliefs about, managing PPI in QI efforts, by comparing two hospital organisations in two different countries in Europe. Despite the two countries having different healthcare financial systems, basic preconditions of the hospitals were similar. Both countries were spending approximately the same percentage (10–11%) of Gross National Product (GNP) on national healthcare in 2018 [63]. Both hospital organisations were also, at the time of the study, experiencing a negative financial situation, had problems with staff turn-over and restrictions for managers to employ. Nevertheless, both countries (and hospitals) exhibited high quality, according to EHCI [41].

However, this study shows that the mechanisms of organising and managing PPI to enhance QI played out differently in the two settings depending on local structure and agency. The mechanisms at play were interconnected and interacted at various organisational levels. Based on these observations, we argue that, to facilitate PPI in hospital QI, leaders and managers can benefit from anticipating what the mechanisms may be at the various levels of their own organisation and how they may play out in their own context. Thus, leaders and managers may wish to map their local organisation to identify, raise awareness of, and act upon the mechanisms that promote, or risk counteracting, PPI.

As known, the commitment to and character of PPI are attributed to the existing context and history of each healthcare organisation [7]. This study confirmed such mechanisms. Thus, at the macro system level [15], and taking mechanisms regarding *societal influence* into account, the suggested mapping regards consideration of (a) what the main foundations for the healthcare organisation are, (b) who the main actors and stakeholders are, and what their objectives and choices are, (c) what the effects of healthcare reimbursement and quality management systems are, (d) how patients and the public influence healthcare, (e) what the trends and societal expectations on healthcare are, and (f) if there are any emergent effects, long-term adaptations or unintended consequences that can be predicted. Furthermore, taking *knowledge and evidence* into account is essential in the mapping procedure because knowledge and evidence are central concerns in healthcare [25]. In some contexts, a holistic approach, including professional, patient and improvement knowledge [14] may be acknowledged, however, not acted upon. Rather, the expert knowledge tends to take precedence over the uncharted experiential and improvement knowledge [53]. In view of this, the mapping regards consideration of (a) what professionals' attitudes to patients' experiential knowledge are, (b) what support in improvement knowledge is provided or lacking, (c) what patients and professionals know about how to unite, measure, and learn from interrelated knowledge domains, and (d) what the relevant outcome measurements and metrics to generate knowledge and evidence are.

Furthermore, mechanisms also were at play at the mesosystem level [15] of the organisation. Results highlighted how the *complexity* of PPI in hospital QI efforts was managed in both similar and different ways in the two hospitals. Hospital organisations are considered to be complex adaptive systems [22] and as such, several mechanisms between people and between organisational levels are constantly triggered. Hierarchy, culture, behaviour, conflicting interests, administration, and many ongoing QI efforts in parallel are obstacles that patients, professionals, leaders and man-

agers say they are facing [47]. To deal with this, efforts to establish clarity [24,56,57] may prevent some of the counteracting mechanisms. Thus, the mapping suggested here regards consideration of (a) what time, opportunity, and formal decision is needed to support each specific QI intervention, (b) which institutions or individuals that carry responsibilities, and for what, (c) how policy documents can be translated into means for action, (d) what monitoring systems that are applicable, (e) what set of metrics that enable the relevant monitoring, patient-reported or not, of patient outcomes, (f) if standardisation is beneficial, and (g) how the flow of knowledge exchange between hospital levels can support cooperation, understanding, and learnings. Moreover, and due to *individual resources* such as patients' and professionals' various capabilities to be involved, and professionals' various capabilities to involve patients, support is needed in prioritising and synchronising QI efforts to make them manageable and worthwhile [24,47]. Consequently, the mapping suggests consideration of (a) what choices and volitions patients and professionals have, and how they can be guided, and (b) if there are any expressed moral or ethical conflicts that may occur.

The interconnectedness of the mechanisms at the macro- and mesosystem levels [15] influenced the mechanisms of *cooperation* at the microsystem level [15], and had significant impact on its success. General experiences are that PPI in QI efforts is a successful approach and that learnings should permeate the hospital organisation [47]. Leaders and managers argued that cooperation depend on well-functioning dialogue and trust, regardless of whether it concerns individual treatment, co-produced QI efforts, or policy making [24,26,47]. Thus, the suggested mapping considers (a) what is needed to support the cooperation of patients and professionals in practice, for example in the identification of significant QI outcome measures, and (b) how attention can be directed to PPI in QI efforts in hospital organisations, and how to spread the knowledge gained from doing so. Supplement 2 proposes guidance on how the mechanisms can be mapped (Supplement 2).

4.4. Methodological considerations

There are several key limitations to this study which also suggest important areas for future research. First, a small sample of purposively recruited participants was used, so the findings need to be considered from the perspective of this specific context to be applicable to other hospital organisations. A further limitation is that all participants were collected from two purposively chosen European hospitals and, subsequently, other possible hospital contexts were not accounted for. However, the authors did attempt to include leaders and managers from different contexts so that diverse experiences could be captured. Thus, authors believe this study does add knowledge and implications for practice that may benefit other hospital contexts. Additionally, interviews in the SWE case were conducted in the participants' and authors' native language, whilst in the NL case, interviews were conducted in English. However, despite the risk of participants not being able to fully express themselves, the sample consisted of motivated respondents in face-to-face interviews and meetings, and possible misunderstandings were quickly sorted out and corrected. Although the analysis generated more codes in NL, only a few more structure–agency mechanisms were generated from the NL than the SWE data set, indicating a relative balance of the two data sets.

As with all qualitative research, the authors cannot claim to have been separated from the research process, and the results presented in this study are the authors' interpretation of the data. However, in an effort to overcome this, all transcribed interviews were read several times, and the analysis was performed transparently by using a shared Excel spread-sheet. The results were discussed repeatedly during the process to increase credibility. Addi-

tionally, there was an abundance of examples in the respondents' own words in order to support the thematic structure presented. The SWE quotes included in this report were translated and back-translated by English and Swedish native speakers, respectively.

Despite the limitations, we believe this study offers insight into individual experiences and beliefs about the process of organising and managing PPI in QI, which has not previously been studied extensively from an insider's perspective. Findings appear to offer some further insights into, and implications for, policy makers, managers, and QI team leaders in the process of organising and managing PPI in QI. Future research should focus on applying and evaluating these lessons in local contexts to further develop the management of PPI in hospital QI.

5. Conclusions

Hospital leaders' and managers' experiences of and beliefs about organising PPI in QI efforts start in a process of establishing PPI that aims to improve patient outcomes and hospital operations. In the process, mechanisms in areas of societal influence, knowledge and evidence, complexity, individual resources, and co-operation are at play. Depending on the contextual structure and means of action, these mechanisms play out differently in the two hospital organisations under study. By raising awareness of different mechanisms, giving examples of how they may play out in different contexts, and proposing how they may be identified, this study contributes to an understanding of how to manage, develop and sustain PPI in hospital QI efforts.

Authors' contributions

CB conducted the interviews and field studies, analysed the interviews and field notes, developed the tables and figures, and wrote the draft and final version of the manuscript. MW and JT read the interview transcripts, took part in the analysis process, and the development of figures. MW checked the analysis to ensure that the content of the interviews and field notes was adequately represented. All authors contributed to the manuscript, and approved the final version.

Declaration of Competing Interest

The authors have nothing to disclose.

Source(s) of support/funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The study is part of a PhD research project funded by the University of Borås, Sweden. The University of Borås had no role in the design of the study, in collection, analysis, interpretation of data, or in writing the manuscript.

Ethical approval

The Central Ethical Review Board, Gothenburg, Sweden, approved the research.

Acknowledgements

Authors would like to thank the QI leaders and hospital managers in the two hospital organisations under study for their contributions to this article. Authors would also like to thank both the native speakers involved in translating and back-translating the quotes. The study is part of a larger research project at University of Borås and Jönköping University, Sweden.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.healthpol.2022.04.002](https://doi.org/10.1016/j.healthpol.2022.04.002).

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