

BMJ Open Quality 'We are data rich but information poor': how do patient-reported measures stimulate patient involvement in quality improvement interventions in Swedish hospital departments?

Carolina Bergerum ¹, Christina Petersson,² Johan Thor ^{2,3}, Maria Wolmesjö¹

To cite: Bergerum C, Petersson C, Thor J, *et al.* 'We are data rich but information poor': how do patient-reported measures stimulate patient involvement in quality improvement interventions in Swedish hospital departments? *BMJ Open Quality* 2022;**11**:e001850. doi:10.1136/bmjopen-2022-001850

Received 9 February 2022
Accepted 24 July 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Faculty of Caring Science, Work Life and Social Welfare, Högskolan i Borås, Borås, Sweden

²The Jönköping Academy for Improvement of Health and Welfare, Jönköping University, Jönköping, Sweden

³The Medical Management Center, Karolinska Institutet, Stockholm, Sweden

Correspondence to

Dr Carolina Bergerum;
carolina.bergerum@vgregion.se

ABSTRACT

Objective This study aimed to investigate if and how patient-reported measures from national and local monitoring stimulate patient involvement in hospital quality improvement (QI) interventions. We were also interested in the factors that influence the level and degree of patient involvement in the QI interventions.

Methods The study used a qualitative, descriptive design. Inspired by the Framework Method, we created a working analytical framework. Four hospital departments participated in the data collection. Collaborating with a QI leader from each department, we identified the monitoring systems for the patient-reported measures that were used to initiate or evaluate QI interventions. Thereafter, the level and degree of patient involvement and the factors that influenced this involvement were analysed for all QI interventions. Data were mapped in an Excel spreadsheet to analyse connections and differences.

Results Departments used patient-reported measures from both national and local monitoring systems to initiate or evaluate their QI interventions. Thirty-one QI interventions were identified and analysed. These interventions were mainly conducted at the direct care and organisational levels. By participating in questionnaires, patients were involved to the degree of consultation. Patients were not involved to the degree of partnership and shared leadership for the identified QI interventions.

Conclusions Overall, hospital departments have limited knowledge regarding patient-reported measures and how they are best applied in QI interventions and how they support improvements. Applying patient-reported measures to hospital QI interventions does not enhance patient involvement beyond the degree of consultation.

INTRODUCTION

Healthcare organisations have increased discussions regarding the evaluation and monitoring of healthcare performance from patients' perspectives^{1–3} and the transformation of these data into quality improvement (QI)^{4 5} and safety improvement interventions.^{1 6} It is well established that healthcare is experiencing challenging times in balancing the population's increasing and

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Patients and the public are key contributors to identifying areas of quality improvement (QI) that meet patient priorities and improve healthcare outcomes. Furthermore, the monitoring of hospital performance from patients' perspectives, and the transformation of these data into QI interventions, are increasingly evaluated and discussed topics in healthcare.

WHAT THIS STUDY ADDS

⇒ Hospital departments have limited knowledge regarding patient-reported measures and how they are best used in QI interventions. National patient-reported measures and local patient surveys do not yet encourage patient involvement to the degree of partnership and shared leadership in hospital QI interventions.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ To establish the patient-reported input data relevant for each QI intervention, further research and knowledge regarding the inter-relationships between patient-reported experience measures and patient-reported outcome measures and the ways in which they constitute relevant feedback for QI interventions need priority.

changing demands with limited finances for digital and scientific development. During the past decades, healthcare objectives have transformed from mostly managing patients with acute injuries or illnesses to providing long-term support of patients with multiple chronic conditions and managing public health at the governance level. Consequently, healthcare outcomes are no longer clearly demarcated, and they extend beyond medical goals.⁷ Thus, current approaches to QI constantly need revision.⁸

Therefore, patients and the public are key contributors to identifying areas of QI^{4 9} that meet patient priorities and improve

healthcare outcomes.^{17 10 11} Despite the lack of consensus on the definitions of patient and public involvement,^{12 13} it is an important component that makes a difference in high-quality healthcare.¹⁴ In direct care, patient priorities combine individuals' specific realistic health goals based on what matters most with the healthcare activities they are willing and able to perform to achieve their goals.⁷ However, patients are involved in their own care and at multiple levels of healthcare; in direct care, organisational design and governance, and policy-making. QI interventions must be executed at multiple levels of healthcare,^{15 16} and therefore, different collaborative approaches to patient involvement in QI, such as co-design and co-production of healthcare services, are being explored.^{16–19}

Discussion regarding the importance of relevant monitoring, control and agreement of the proper standards and measurable indicators has followed the development towards a more participative era within healthcare.^{14 20 21} Simple and crude patient satisfaction scales have advanced to become more patient centred, including the use of patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs).^{1–3} Patient-reported measures collect health outcomes directly from the patients and the public who experience them to support clinical decision-making and prioritisation of patients, compare outcomes of healthcare providers, stimulate QI and evaluate practices and policies.²² However, this strategy is not without opposition, and it has been argued that measurements risk becoming too excessive, standardised or generalised to identify QI areas from patient and population perspectives.^{6 8} Furthermore, there is little knowledge regarding the distinctions and associations between PREMs and PROMs²³ and their actual effect on patient outcomes.²⁴ Thus, reliable and valid tools for measuring patient and public involvement are also being investigated.^{5 25}

In Sweden, the healthcare system is tax financed, decentralised and politically steered. The health and welfare system finances and provides almost all healthcare services covering all residents, with costs heavily subsidised and no additional private healthcare insurances required. The role of the state is to legislate and establish principles or guidelines, distribute responsibilities, allocate government grants and supervise and decide on local government financial equalisation and high-cost protection/maximum fees.²⁶ Since 2009, the National Patient Survey (NPS) has consistently collected PREMs at the national level in Sweden.²⁷ The purpose of the NPS monitoring is to initiate QI only and enable healthcare development from the patient perspective, to facilitate evaluations of healthcare settings and provide tools for quality management. County councils, regions and local healthcare units also conduct 'in-between measurements', which are additional patient-reported measurements in their own contexts. Furthermore, national quality registries (NQRs) continuously report PREMs and PROMs.²⁸ In Sweden, there are more than 100 NQRs. An

NQR contains structured, individualised medical data for a specific patient population or for patients undergoing a specific healthcare process. Healthcare providers routinely collect data to initiate and monitor QI.²⁹ For an NQR to be certified at a high level, PROMs are obligatory. To capture the patients' perspectives, it is recommended that an organisation of patient representatives and professionals support each registry and share joint responsibility for its development. Approximately 90% of the NQRs include some form of PROMs (generic or disease/symptom specific), and about 40% include PREMs. These measures potentially impact QI at different organisational levels of healthcare.

However, there is significant opportunity for improvement.^{3 30} Research shows there is limited evidence regarding the ways that aggregated patient-reported measures inform QI interventions in practice.¹ Some barriers exist, such as if and how patient-reported measures actually contribute to patients' active choices and the perceived scepticism of professionals. In addition, there lacks explicability and timeliness of the patient-reported measures as well as structure, support and guidance in the transformation process.^{1 31} Research also highlights problems with identifying the monitoring systems that can be applied in practice and the patient-reported measures that provide the relevant input for each QI context when organising and managing patient involvement in hospital QI interventions.³² Thus, the objectives of this study were to identify the national and local monitoring systems containing patient-reported measures that are available in hospital departments and to investigate how they are applied to QI. Furthermore, we sought to explore how patient-reported measures stimulate patient involvement in QI interventions in practice. We used the following research questions:

- ▶ What monitoring systems of patient-reported measures are used?
- ▶ What QI interventions have been initiated or evaluated in applying patient-reported measures?
- ▶ How do patient-reported measures stimulate patient involvement in hospital QI interventions?

METHODS

Patient and public involvement

This qualitative study has an explorative, descriptive design. The study is part of and informed by a larger research project to study patient and public involvement in the QI interventions of hospital organisations from the clinical microsystem³³ and leadership³⁴ perspectives. Patients were not involved in the design, recruitment to or conduct of this study. However, patients participated in the larger research project. Results from this study will be disseminated to participants of the research project on publication.

Participating settings and departments

Two mid-size, non-academic hospitals in two different regions in southern Sweden (hospital 1 and hospital 2)

Table 1 The working analysis framework adapted from the ‘Multidimensional Framework for Patient and Family Engagement in Health and Health Care’¹⁵

Analysis framework		
Dimension	Definition	Analysis questions
Level of involvement	The level of the healthcare system at which the QI intervention is carried out.	At which level of the healthcare system is the QI intervention carried out? 1. Direct care (eg, individual patient care). 2. Organisational design and governance (eg, QI team, patient safety team, hospital-wide project, leadership and management). 3. Society (eg, national health programme, policy-making, research).
Degree of involvement	The place on the continuum of patient involvement where the QI intervention is carried out.	Where on the continuum of patient involvement is the QI intervention carried out? 0. No patient involvement. 1. Consultation (eg, informed, survey, focus group). 2. Involvement (eg, invited to give feedback, active involvement, patient representative, QI team member, steering groups, research). 3. Partnership and shared leadership (codesign and coproduction, coleadership in QI).
Factors influencing involvement	The factors that influence patient involvement in the local QI intervention.	What factors may have influenced the adaptation of patient involvement in the local QI intervention? ▶ Patient (beliefs about the patient role, health literacy, education). ▶ Organisation (policies and practices, culture). ▶ Society (social norms, regulations, policy).

QI, quality improvement.

were initially considered for the study. Hospital 1 provides healthcare in all specialties to approximately 300 000 citizens in the region. At the time of the study, the hospital applied the Hoshin Kanri³⁵ approach to its strategic planning and follow-up. Organisations that use Hoshin Kanri often follow a plan comparable to Deming’s Plan-Do-Study-Act cycle.³⁶ The hospital applied an X-matrix to ensure that all the organisational levels effectively visualised management’s three focus areas, of which one was phrased, ‘Together with the patient—for the patient’. Hospital 2 provides healthcare in all specialties to approximately 365 000 citizens. Aligning with the region in general, the hospital applied the balanced scorecard³⁷ to its performance management, which provides strategic financial and non-financial performance measures that enable the hospital to better accomplish its objectives. The balanced scorecard defined five perspectives, of which one was phrased ‘The citizen and customer perspective’.

Procedure

Using the Framework Method³⁸ as a starting point, two authors (CB and CP) created a working analysis framework (table 1) adapted from the ‘Multidimensional Framework for Patient and Family Engagement in Health and Health Care’ framework.¹⁵ Stages 4–7³⁸ were completed to develop and apply the analysis framework, chart the data in the framework matrix and interpret the data.

To identify departments eligible for inclusion and their local QI leaders, we contacted the development managers (n=5) for the two hospitals, informed them about the study and asked them to forward our request to their local QI leaders or provide us with their contact information.

Subsequently, each department’s QI leader(s) were informed about the study and asked to participate, and the analysis framework was provided to them in advance. Seven departments agreed to participate from hospital 1 (n=2) and hospital 2 (n=5). After a closer review, three of the departments had no practical experience with applying patient-reported measures to their local QI interventions, and consequently, they were excluded from participation. Eventually, four departments (and their QI leaders) from hospital 2 participated in the study. The participating departments represented internal medicine, oncology, paediatric and rehabilitation. All QI leaders had experience with QI interventions that were initiated or evaluated with patient-reported measures monitored at different levels in their departments.

Before commencing the data collection, the analysis framework was tested with the QI leader from the first department to participate. Specifically, a QI intervention with no degree of patient involvement on the engagement continuum was identified, and the analysis framework was adjusted accordingly. No further adjustments were made. Thereafter, one author (CB) collected data in collaboration with the QI leaders from the other three departments. These data collection meetings occurred at the QI leaders’ worksites and were digitally recorded in July and August 2021. In these meetings, we identified the monitoring systems containing patient-reported measures used. Next, we analysed the information to determine if the patient-reported measures had initiated or evaluated any QI interventions. Each QI intervention was analysed to determine the level and degree of patient involvement on the engagement continuum. Finally, we discussed the factors that influenced patient involvement

in QI interventions (table 1).¹⁵ The digital recordings were 64–106 min. The author (CB) took additional notes.

To organise and manage the data, the authors used the Framework Method,³⁸ which provides a system to categorise data and identify areas that need further attention. This method was developed for large-scale policy research³⁹ and is not aligned with any particular epistemological viewpoint or theoretical approach. An Excel spreadsheet was used to chart the data. Ratings were assigned to each patient involvement dimension¹⁵ and QI intervention coding cell and transferred to the spreadsheet. The identified influencing factors were also transferred to the spreadsheet. To systematically organise the data, the columns in the matrix included the patient involvement dimensions,¹⁵ and the rows included the QI interventions. Thus, we were able to compare vertically within each dimension¹⁵ and horizontally across each intervention for the analysis. The matrix also included author notes from the meetings, the recordings and the analysis. Connections and differences between the patient involvement dimensions and QI interventions were analysed in the matrix.

RESULTS

Monitoring systems with PREMs and PROMs and their connections to QI interventions

The four departments applied patient-reported measures from nine different national monitoring systems (seven NQRs, one Patient Care Bundles monitoring and one from the NPS) and several local measures and patient surveys to initiate or evaluate their QI interventions (table 2). The departments applied national and local monitoring to the same extent, but the oncology department used local monitoring more frequently. A total of 31 (range 5–11) QI interventions were identified (table 2, table 3), three of which applied a combination of national and local monitoring.

The analysis of the ratings for each QI intervention (table 4) indicated that the internal medicine department performed all QI interventions at the level of direct care.¹⁵ To initiate or evaluate QI interventions, outcomes from the national guidelines for the standardisation of care paths (Patient Care Bundles) and local patient surveys were applied. Thus, patients were consultatively involved in QI interventions. The rehabilitation department performed QI interventions at the direct care level and the organisational level.¹⁵ Patients were mainly involved to the degree of consultation¹⁵ and represented by the outcomes of NQR monitoring, but in one QI intervention, patients were not involved at all. The oncology department conducted QI interventions at all hospital levels but mainly at the organisational level.¹⁵ Patients were consultatively¹⁵ involved in QI interventions from the outcomes of NPS and local patient surveys. However, patients were not represented in any degree¹⁵ in two cases. The paediatric department performed QI interventions at the organisational and policy-making levels.¹⁵

Patients were consulted¹⁵ regarding outcomes of NQR monitoring, NPS and local patient surveys. Unlike the other departments, paediatric patients (ie, their family members) were actively involved in QI interventions, such as a breastfeeding project in the neonatal intensive care unit and a project to improve at-home paediatric healthcare. Patients were not involved in QI interventions to the degree of partnership and shared leadership in any of the four departments.¹⁵

Factors that influence patient involvement

In the data collection meetings with QI leaders, the factors they believed influenced patient involvement in the local QI interventions were discussed from the perspective of the patient, the organisation and society.¹⁵

QI leaders highlighted their beliefs about health literacy and the patient's role in QI interventions when discussing factors from the patient perspective. They believed the patient's role in QI was unclear, and this led to both patients and professionals questioning why and how to involve patients. On the one hand, patients were considered mostly satisfied with their individual care because they did not understand their diagnoses or healthcare system shortcomings to realise the importance of giving feedback and contributing to QI. The QI leaders provided examples of patients who misunderstood and ignored opportunities to contribute and how the professionals tried to address these situations. On the other hand, QI leaders attributed the patients' lack of engagement to the professionals' scepticism in including patients as presumptive partners in QI. Many QI interventions focused more on professionals' attitudes and motivations, mainly in direct care. As an example, the internal medicine department implemented a shared decision-making programme to encourage professionals to involve patients in their own care. Consequently, PROMs were mostly used to provide direct care and to adjust treatment based on individual feedback, and in these cases, patients were expected to be engaged.

From the organisation's perspective, which includes its policies, practices and culture, the limited resources available to the hospital departments were considered major influences. The QI leaders mentioned time constraints, targeted financial incentives, top-down management and limited support systems as some of the practical factors. When poor patient outcomes were illuminated in the organisation, rapid attention and action was required. Often QI interventions did not consider patient involvement and had strict deadlines. For example, a QI intervention initiated from NQR outcomes tried to increase patients' satisfaction with their rehabilitation programme, but patients were not involved in the intervention. Furthermore, if patient outcomes were considered good enough, they were not prioritised, and no actions were taken.

Some patient processes incorporated many measurements and monitoring systems. Thus, NQRs were perceived as input systems that required administration, rather than

Table 2 QI interventions initiated or evaluated from monitoring systems of patient-reported measures

Monitoring system	QI interventions initiated or evaluated
National Quality Registers (n=7): <ul style="list-style-type: none"> ▶ The National Quality Registry for Pain Rehabilitation (NRS). ▶ The WebRehab. ▶ The Swedish National Diabetes Register (NDR). ▶ The Swedish Rheumatology Quality Register (SRQ). ▶ The Swedish Web System for Enhancement and Development of Evidence-based Care in Heart Disease Evaluated According to Recommended Therapies (SWEDEHEART). ▶ The Neonatal Quality Register (SNQ). ▶ The Swedish National Airway Register (SNAR). 	<ul style="list-style-type: none"> ▶ Improving the pain rehabilitation process. ▶ Increasing patient satisfaction with the rehabilitation programme. ▶ Increasing involvement of next of kin in the rehabilitation programme. ▶ Mapping the clinical microsystem as part of a reorganisation (rehabilitation). ▶ Diabetes project—improving diabetes care. ▶ Development of register questionnaire (rheumatology). ▶ Improved, person-centred medical treatment process (heart diseases). ▶ Breastfeeding project (neonatal intensive care unit). ▶ Improving cooperation of health and welfare providers (asthma, COPD).
National Patient Survey	<ul style="list-style-type: none"> ▶ Improving the information to patients about medical students in the department. ▶ Improving patient-centredness by implementing standardised questions of ‘what matters to you’. ▶ Evaluation of the local ‘My care plan’. ▶ Improving the care for children with failure to thrive. ▶ Improving healthcare at home.
Patient Care Bundles—lung cancer	<ul style="list-style-type: none"> ▶ Increasing patient involvement and shared decision-making. ▶ Improving outcomes of health self-assessment. ▶ Improving the emotional support.
Local monitoring of operations	<ul style="list-style-type: none"> ▶ Benchmarking to decrease variation between local practices’ goal formulation with patients. ▶ Improvement project concerning integrated care for children with complex needs.
Local monitoring—direct patient care	<ul style="list-style-type: none"> ▶ Improving the identification of what matters to each individual patient.
Local monitoring—self-assessed health	<ul style="list-style-type: none"> ▶ Improving the identification of individual care needs of each patient. ▶ Implementation of a ‘Fatigue school’. ▶ Development of a programme for physical activity and training. ▶ Development of an information process to patients about physical activity and training.
Local patient survey	<ul style="list-style-type: none"> ▶ Radiation therapy ‘drop-in’ project. ▶ Improving the patient’s physical path in the radiation treatment reception. ▶ Evaluation of local ‘My care plan’. ▶ Person-centred care project: improving patient admission routines by coordinating doctors and nurses. ▶ Person-centred care project: improving information of appointed contact nurse. ▶ Implementation of an introductory conversation about the radiation therapy. ▶ Children with failure to thrive—improving care. ▶ Improving healthcare at home. ▶ Improving discharge routines.
Local patient surveys on the national website ‘1177’ for public healthcare guidance	<ul style="list-style-type: none"> ▶ Improving the use of the online patient dossier platform for communication between patients and professionals.

COPD, chronic obstructive pulmonary disease; QI, quality improvement.

systems to retrieve information, initiate QI interventions and enable learning. National and local monitoring were occasionally inconsistent. Patient-reported measures at

the national level were excessively aggregated, and consequently, professionals questioned them as indicators for local QI interventions and suggested that the measures

**Table 3** Number of QI interventions initiated or evaluated with patient-reported measures that were identified in each department

Hospital department	Monitoring system and number of QI interventions	Total number of QI interventions (n=31)
Internal medicine	Patient Care Bundles (n=3) Local monitoring (n=4)	n=7
Oncology	National Patient Survey (n=2) National Patient Survey and local monitoring combined (n=1) Local monitoring (n=8)	n=11
Paediatric	National Quality Registers (n=5) National Patient Survey and local monitoring combined (n=2) Local monitoring (n=1)	n=8
Rehabilitation	National Quality Registers (n=4) Local monitoring (n=1)	n=5

QI, quality improvement.

be used only for benchmarking. Therefore, local patient surveys were preferred to evaluate QI interventions. QI leaders suggested that departments focus more on the complex PREMs (satisfaction scales) than the PROMs, and do not consider the use of a combination of the two. Furthermore, it was difficult to connect local QI interventions to improved patient-reported outcomes and obtain reliable evidence bases. In most QI interventions patients were not actively involved because their preferences were believed already identified from the registries and surveys. Overall, departments had limited knowledge on how to apply the various patient-reported measures and how to actively involve patients in QI interventions.

From the perspective of society, which includes social norms, regulations and policy, the accreditation systems were highlighted as important factors that controlled which patient-reported measures the departments addressed and which QI interventions the departments initiated. Furthermore, the QI leaders considered the scientific evidence and monitoring grounded in nationally established policies and programmes as significant factors. However, the national goal to standardise patient processes, measurements and monitoring to simplify and make them more homogeneous could, according to the QI leaders, potentially undermine other healthcare goals, such as equitable care for citizens and more participative, co-produced healthcare.

DISCUSSION

Hospital departments are data rich but information poor

This study aimed to investigate how patient-reported measures from national or local monitoring stimulate patient involvement in hospital QI interventions. We were also interested in the factors that influence patient involvement in the QI interventions. The data collection reflected that hospital departments are data rich but information poor because they have a significant amount of data available from national and local monitoring systems yet limited resources (time, knowledge and motivation)

to transform the data into QI practice and knowledge. As previously mentioned, there are more than a hundred NQRs in the Swedish healthcare context.²⁸ Approximately 90% of the NQRs include PROMs, and about 40% include PREMs to which NPS²⁷ and innumerable local measurements can be added. These measures potentially influence QI interventions, but this study corroborates previous research³³⁰ and illustrates significant opportunity for improvement. Earlier research indicates that hospital professionals do not request large amounts of data as they need only the relevant data for guidance, recommendations and prioritisation of each case.⁴⁰ Patient-reported measures must help professionals focus on what matters most in QI rather than overwhelm them with information or demanding administration. Professionals need to be informed of the actions that leverage their time and attention and increase patient value.¹ Without relevant monitoring, the feedback loop to inform and learn from QI interventions and evaluate the effectiveness of the outcomes is missing.⁴¹

Similarly, other research also shows that monitoring must be relevant from the patient perspective. Patients are unwilling to provide large amounts of data if they do not understand the purpose.⁴⁰ Patients are more interested in whether the data reflect their needs, and they are concerned that their personal data may be neglected if only professionals define, choose or prioritise the data.⁴⁰ Furthermore, patients feel they are excluded from contributing their knowledge in QI interventions because they lack professional, technical or organisational understanding.^{10 40}

The nebulous connection between PREMs and PROMs and hospital QI interventions

Conducting this research meant exploring a nebulous, complicated area with no linear connections between patient-reported measures and QI interventions. When applied, departments used patient-reported measures to initiate or evaluate QI interventions or to do both in

Table 4 Ratings, according to the analysis framework (table 1), assigned to each QI intervention and ordered according to the level and degree of patient involvement

Hospital department	QI intervention	Level of patient involvement*	Degree of patient involvement†
Internal medicine	Increasing patient involvement and shared decision-making	1	1
	Improving outcomes of health self-assessment	1	1
	Improving the emotional support	1	1
	Improving the identification of what matters to each individual patient	1	1
	Improving the identification of individual care needs of each patient	1	1
	Improving discharge routines	1	1
	Improving the use of the online patient Dossier platform for communication between patients and professionals	1	1
Rehabilitation	Improving the pain rehabilitation process	1	1
	Increasing patient satisfaction with the rehabilitation programme	1	1
	Increasing involvement of next of kin in the rehabilitation programme	1	No information
	Benchmarking to decrease variation between practices in goal formulation with patients	2	0
	Mapping the clinical microsystem as part of a reorganisation	2	1
Oncology	Development of a programme for physical activity and training	1	1
	Improving the patient's physical path in the radiation treatment practice	1	1
	Implementation of a 'Fatigue school'	2	0
	Development of an information process to patients about physical activity and training	2	1
	Improving the information to patients about medical students in the clinic	2	1
	Improving patient-centredness by implementing standardised questions of 'what matters to you'	2	1
	Radiation therapy 'drop-in' project	2	1
	Person-centred care project: improving patient admission routines by coordinating doctors and nurses	2	1
	Person-centred care project: improving information of appointed contact nurse	2	1
	Implementation of an introductory conversation about the radiation therapy	2	1
Paediatric	Evaluation of local 'My care plan'	3	0
	Improved, person-centred medical treatment process (heart diseases)	2	1
	Improvement project concerning integrated care for children with complex needs	2	1
	Improving cooperation of health and welfare providers (asthma, COPD)	2	1
	Breastfeeding project in the NICU	2	1, 2
	Children with failure to thrive—improving care	2	2
	Diabetes project—improving diabetes care	2, 3	2
	Improving healthcare at home	3	2
	Development of the NQR questionnaire	3	2

*1. Direct care. 2. Organisational design and governance. 3. Society.

†0. No patient involvement. 1. Consultation. 2. Involvement. 3. Partnership and shared leadership.

COPD, chronic obstructive pulmonary disease; NICU, neonatal intensive care unit; NQR, national quality registry; QI, quality improvement.



some situations. This study did not map the total number of patient-reported measures available to each department. Thus, it is impossible to discuss compliance with all existing monitoring. Furthermore, we did not distinguish between the PROMs and PREMs applied. However, the results illustrate some patterns.

Hospital care for adults used QI interventions at the direct care and organisational levels, while paediatric care used QI interventions at the organisational and societal levels of healthcare (table 4). For example, the internal medicine department consistently performed QI interventions at the level of direct care and involved patients by using the survey outcomes. The oncology department predominantly used local monitoring (table 3). In the paediatric department, patients (or their family members) were consistently more actively involved. However, using the analysis framework,¹⁵ the examples of active involvement in the paediatric department were not different from other QI interventions mapped to the second degree of involvement (table 4). No direct conclusions can be drawn from this result. However, different departments had various levels and degrees of patient involvement in QI interventions, and it would be interesting to analyse these differences through additional research.

None of the departments involved patients to the degree of partnership and shared leadership¹⁵⁻¹⁷ in their QI interventions (table 4). Although this outcome is disappointing, it is not surprising. Swedish hospitals rarely involve patients in co-design and co-production activities^{16 17} with QI interventions.

This study speculated that a connection exists between the departments' application of patient-reported measures to QI interventions and higher degrees of patient involvement. However, the results did not indicate any such connections. Rather, the analysis indicated that the QI intervention already considers the patients' preferences by using information from the monitoring systems. Although it may be a good starting point to incorporate PREMs and PROMs from the systems, many QI interventions have local objectives. Thus, professionals should also consider the degree of patient involvement that supports the purpose of each QI intervention.¹⁸ Merely using reported data from systems does not constitute patient involvement.

Both QI leaders and development managers highlighted the low response rate from patients on local surveys as one of the influencing factors related to the patient perspective. They believed patients did not understand their own importance of giving feedback to improve the services. Similar to previous research, the leaders and managers argued that the patient's limited feedback affects the motivation of the professionals to incorporate patient involvement in QI interventions.¹⁸ The lack of knowledge about how patients view the patient-reported indicators and how relevant the indicators are to their concerns justifies this position. Furthermore, the patient's role in various QI interventions (and in various

healthcare contexts) needs clarification.^{10 18 40 42} Thus, the results of this study highlight the importance studying active patient involvement in QI more intensely, and in such research, patients should be actively included.

Moreover, major influencing factors relate to the organisational and societal levels of healthcare. National regulations, programmes and accreditations significantly impact the prioritising of QI interventions.³² Obviously, a gap exists in understanding the role of the patient and the public in QI interventions, monitoring and follow-up of outcomes at all levels.^{10 13 32 40} Even though patient involvement in QI interventions may be a complex activity in practice, knowledge regarding QI is necessary and requires supervision and management.³² This 'black box' must be opened if healthcare is to become more participative and co-produced, equitable and suitable for the public's purposes.^{14 16} To establish the input data relevant for each QI intervention, whether patient reported or not, further research and knowledge regarding the inter-relationships between PREMs and PROMs and the ways in which they constitute relevant input and feedback for QI interventions must be prioritised.^{23 43 44} Are PREMs more suitable for monitoring at the group level and PROMs more suitable for guiding individual treatments? Are PREMs and PROMs appropriate incentives and tools to enhance patient involvement in QI interventions or are other approaches more appropriate?^{5 16 17} Is it helpful to measure patient involvement in QI interventions, and if so, how?⁵ These questions need further study.

Strengths and limitations

This study provides valuable input regarding patient involvement in QI interventions. We experienced some challenges in applying the working analysis framework to organise and manage data (table 1) in the complex context of hospital QI interventions. However, we focused on the aims of the research questions throughout the data collection and analysis. To minimise misunderstanding during the data collection, individual meetings were held with the department's QI leaders and digitally recorded. Using the Framework Method³⁸ provided a systematic and flexible structure to manage and guide the data analysis and reporting and counteracted the challenges.

Some of the issues in conducting the research need elaboration. It became apparent at the beginning of the study that hospital departments generally had limited knowledge regarding patient-reported measures and the concepts of PREM and PROM. We approached QI leaders after contacting the development managers, but despite reminders, only seven departments responded positively. Moreover, only four of the responding departments (all from hospital 2) had practical experience applying patient-reported measures in their QI interventions. At the time for the study, hospital 1 implemented a major organisational change that may have affected its response rate. Furthermore, we contacted the leaders during the summertime and the ongoing COVID-19 pandemic.

However, we were not convinced that these circumstances explained the significant lack of responsiveness.

Therefore, we contacted the development managers again, and their responses confirmed our presumptions that attributing the lack of responsiveness to the ongoing COVID-19 pandemic was a simplified explanation. Instead, the general opinion was that hospitals are consistently under significant pressure, and QI leaders do not have time to routinely reflect on overarching, strategic questions. Furthermore, QI leaders are not educated to systematically apply and learn from healthcare outcome monitoring and QI interventions. The development managers also indicated that using the patient involvement approach for QI further complicated the study assignment for QI leaders because patient involvement is neither well defined nor fully applied in hospital organisations.⁴² The feedback from the development managers corroborates earlier research that indicates current measurements and monitoring are problematic to apply and enact in complex healthcare settings.³² Consequently, hospital organisations do not maximise their potential for QI. Patient processes, measurements and monitoring are being standardised to address these issues,^{6,8} but this standardisation adds a risk of information being oversimplified and professionals underusing it.³² QI interventions (and patient involvement in QI interventions) are afterthoughts to the daily work and knowledge, learning and improvement in this area stay limited.¹⁴

CONCLUSIONS

The results from this study indicate that hospital departments generally have limited knowledge regarding patient-reported measures, how best to apply them in QI interventions and how the measures contribute to improvements. If applied at all, patient-reported measures are mainly used in QI interventions performed at the direct care and organisational levels. Patients are involved to the degree of consultation mainly by participating in surveys. However, paediatrics provides examples of patients (or family members) being actively involved in QI interventions that patient-reported measures initiated or evaluated. National patient-reported measures and local patient surveys do not yet encourage patient involvement to the degree of partnership and shared leadership in hospital QI interventions.

Acknowledgements The authors would like to thank the development managers and QI leaders in the two hospital settings under study for their contributions to this study.

Contributors CB and CP designed the study and created the analytical framework. CB conducted the data collection meetings. CB and CP analysed the data and wrote the draft and final version of the manuscript. JT and MW took part in the analysis process. All authors contributed to the manuscript and approved the final version. CB is responsible for the overall content as the guarantor.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval The study is part of a larger research project at the University of Borås and Jönköping University. Because individuals were involved in the data collection of this study, efforts were made to carry it out according to current laws, regulations and codes of research ethics. Therefore, and prior to commencing the research project, permission was obtained from the Regional Ethical Review Board in Gothenburg, Sweden (Dnr: 1006-16) with a complementary permission from this study (Dnr: 2021-01456). Informed, written consent was obtained from the participants.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Carolina Bergerum <http://orcid.org/0000-0003-1281-7918>

Johan Thor <http://orcid.org/0000-0003-1814-4478>

REFERENCES

- Greenhalgh J, Dalkin S, Gibbons E, *et al*. How do aggregated patient-reported outcome measures data stimulate health care improvement? A realist synthesis. *J Health Serv Res Policy* 2018;23:57–65.
- Kingsley C, Patel S. Patient-Reported outcome measures and patient-reported experience measures. *BJA Educ* 2017;17:137–44.
- Nilsson E, Orwelius L, Kristenson M. Patient-Reported outcomes in the Swedish national quality registers. *J Intern Med* 2016;279:141–53.
- Berwick DM. The science of improvement. *JAMA* 2008;299:1182–4.
- Phillips NM, Street M, Haesler E. A systematic review of reliable and valid tools for the measurement of patient participation in healthcare. *BMJ Qual Saf* 2016;25:110–7.
- Iedema RA, Angell B. What are patients' care experience priorities? *BMJ Qual Saf* 2015;24:356–9.
- Naik AD, Catic A. Achieving patient priorities: an alternative to patient-reported outcome measures (PROMs) for promoting patient-centred care. *BMJ Qual Saf* 2021;30:92–5.
- Berwick DM. Era 3 for medicine and health care. *JAMA* 2016;315:1329–30.
- Bergman B, Hellström A, Lifvergren S, *et al*. An emerging science of improvement in health care. *Qual Eng* 2015;27:17–34.
- Armstrong N, Herbert G, Aveling E-L, *et al*. Optimizing patient involvement in quality improvement. *Health Expect* 2013;16:e36–47.
- Bombard Y, Baker GR, Orlando E, *et al*. Engaging patients to improve quality of care: a systematic review. *Implementation Sci* 2018;13:1–22.
- Brett J, Staniszewska S, Mockford 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.
- Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf* 2016;25:626–32.
- Batalden P. Getting more health from healthcare: quality improvement must acknowledge patient coproduction—an essay by Paul Batalden. *BMJ* 2018;1:k3617.
- Carman KL, Dardess P, Maurer M, *et al*. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff* 2013;32:223–31.
- Batalden M, Batalden P, Margolis P, *et al*. Coproduction of healthcare service. *BMJ Qual Saf* 2016;25:1–9.
- Bate P, Robert G. Experience-Based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care* 2006;15:307–10.
- Bergerum C, Thor J, Josefsson K, *et al*. How might patient involvement in healthcare quality improvement efforts work—A realist literature review. *Health Expect* 2019;22:952–64.
- Kjellström S, Areskoug-Josefsson K, Andersson Gäre B, *et al*. Exploring, measuring and enhancing the coproduction of health and well-being at the national, regional and local levels through



- comparative case studies in Sweden and England: the 'Samskapa' research programme protocol. *BMJ Open* 2019;9:e029723.
- 20 Brandsen T, Steen T, Verschuere B, eds. *Co-production and co-creation. Engaging citizens in public services*. New York, NY: Routledge, 2018.
 - 21 Palmer VJ, Weavell W, Callander R, et al. The participatory Zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Med Humanit* 2019;45:247–57.
 - 22 Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346:f167.
 - 23 Black N, Varaganum M, Hutchings A. Relationship between patient reported experience (PREMs) and patient reported outcomes (PROMs) in elective surgery. *BMJ Qual Saf* 2014;23:534–42.
 - 24 SBU (Statens beredning för medicinsk och social utvärdering). [The Swedish Agency for Health Technology Assessment and Assessment of Social Services]. Patientdelaktighet i hälso- och sjukvården. En sammanställning av vetenskapliga utvärderingar av metoder som kan påverka patientens förutsättningar för delaktighet. SBU-rapport 260/2017, 2022. Available: https://www.sbu.se/contentassets/4065ec45df9c4859852d2e358d5b8dc6/patientdelaktighet_i_halso_och_sjukvarden.pdf
 - 25 Churrua K, Pomare C, Ellis LA, et al. Patient-Reported outcome measures (PROMs): a review of generic and condition-specific measures and a discussion of trends and issues. *Health Expect* 2021;24:1015–24.
 - 26 SKR (Sveriges Kommuner och Regioner). *The Swedish association of local authorities and regions*. SKR, 2022.
 - 27 SKR (Sveriges Kommuner och Regioner). [The Swedish Association of Local Authorities and Regions]. Nationell Patientenkät. Available: <https://skr.se/skr/halsasjukvard/patientinflytande/nationellpatientenkät.617.html> [Accessed Jan 2022].
 - 28 SKR (Sveriges Kommuner och Regioner). [The Swedish Association of Local Authorities and Regions]. Quality Registries. Available: <https://skr.se/en/kvalitetsregister/omnationellakvalitetsregister.52218.html> [Accessed Jan 2022].
 - 29 Jacobsson Ekman G, Lindahl B, Nordin A, eds. *National Quality Registries in Swedish health care*. Stockholm: Karolinska Institutet University Press, 2016.
 - 30 Ernstsson O, Janssen MF, Heintz E. Collection and use of EQ-5D for follow-up, decision-making, and quality improvement in health care - the case of the Swedish National Quality Registries. *J Patient Rep Outcomes* 2020;4:78.
 - 31 Wiering B, de Boer D, Delnoij D. Patient involvement in the development of patient-reported outcome measures: a scoping review. *Health Expect* 2017;20:11–23.
 - 32 Bergerum C, Wolmesjö M, Thor J. *Organising and managing patient and public involvement to enhance quality improvement – comparing a Swedish and a Dutch Hospital*. . Högskolan i Borås and Jönköping University, 2022: 126. 603–12.
 - 33 Nelson EC, Batalden PB, Godfrey MM. Quality by design. In: *A clinical microsystems approach*. 1st ed. San Fransisco, CA: Jossey-Bass, 2007.
 - 34 Drew JR, Pandit M. Why healthcare leadership should embrace quality improvement. *BMJ* 2020;368:m872.
 - 35 Hutchins D, Kanri H. *The strategic approach to continuous improvement*. Routledge, 2008.
 - 36 Deming WE. *Out of the crisis*. Massachusetts Institute of Technology, Center for Advanced Engineering Study, 1986.
 - 37 Kaplan RS, Norton DP. The balanced scorecard--measures that drive performance. *Harv Bus Rev* 1992;70:71–9 <https://hbr.org/1992/01/the-balanced-scorecard-measures-that-drive-performance-2>
 - 38 Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117.
 - 39 Ritchie J, Lewis J. *Qualitative research practice: a guide for social science students and researchers*. London: SAGE, 2013.
 - 40 Knowles SE, Allen D, Donnelly A, et al. Participatory codesign of patient involvement in a learning health system: how can data-driven care be patient-driven care? *Health Expect* 2022;25:103–15.
 - 41 Lim S, Morris H, Pizzirani B, et al. Evaluating Hospital tools and services that were co-produced with patients: a rapid review. *Int J Qual Health Care* 2020;32:231–9.
 - 42 European Commission. Eurobarometer qualitative study. patient involvement. aggregate report, 2012. Available: https://ec.europa.eu/health/sites/default/files/systems_performance_assessment/docs/eurobaro_patient_involvement_2012_en.pdf [Accessed Jan 2022].
 - 43 Manary MP, Boulding W, Staelin R, et al. The patient experience and health outcomes. *N Engl J Med* 2013;368:3.
 - 44 Sparring V, Granström E, Andreen Sachs M, et al. One size fits none - a qualitative study investigating nine national quality registries' conditions for use in quality improvement, research and interaction with patients. *BMC Health Serv Res* 2018;18:802.