

RESEARCH ARTICLE

Including patient-reported measures in performance evaluation systems: Patient contribution in assessing and improving the healthcare systems

Sabina De Rosis  | Francesca Ferrè  | Francesca Pennucci 

Management and Healthcare Laboratory,
Institute of Management and Department
EMbeDS, Scuola Superiore Sant'Anna, Pisa,
Italy

Correspondence

Francesca Pennucci, Management and
Healthcare Laboratory, Institute of
Management and Department EMbeDS,
Scuola Superiore Sant'Anna, Pisa, Italy.
Email: francesca.pennucci@santannapisa.it

Funding information

Regione Toscana

Abstract

In healthcare, the introduction of quality standards and indicators to assess performance triggered the development of multidimensional Performance Management Systems (PMSs). The concept of performance in healthcare has recently evolved and broadened its scope. One of the current challenges of PMSs is measuring and integrating the patient perspective into traditional measures. In the regional healthcare system of Tuscany (Italy), a PMS has been implemented and used since 2005. The PMS counts on the systematic involvement of clinicians and managers. Furthermore, the PMS also includes patients' perspective. Moreover, Tuscany has recently implemented the first regional permanent Patient-Reported Outcome and Experience Measures (PROMs and PREMs) Observatory in Italy. This paper presents the results of an action research aimed at analysing the integration of patient-reported outcome and experience indicators into a consolidated PMS. The study describes the process of identifying and discussing of patient-reported indicators with practitioners and categorising findings into three domains: design of patient-reported indicators, integration process into the PMS, and goal of adoption of the patient-related indicators. The paper also

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. The International Journal of Health Planning and Management published by John Wiley & Sons Ltd.

describes facilitators, challenges, and lessons learnt with respect to organisational, methodological, cultural, and responsibility-linked factors. The study discusses the ability to agree on how to transform patient data, especially PROMs, into effective performance indicators. The integration of patient-reported indicators into the PMS poses two main challenges: one in terms of sustainability of the performance system itself, and another regarding the attribution of the responsibility for patient outcomes between care settings and providers. This paper provides initial insights on how the integration of patient-reported indicators can make PMSs more inclusive and focussed on the patient-centred perspective.

KEYWORDS

action research, healthcare management, patient-reported indicators, performance evaluation, PREMs, PROMs

Highlights

- A key challenge in the Performance Management Systems' evolution is integrating the patient perspective.
- This action research provides insights from the process of actual integration of patient-indicators into a consolidated Performance Management System.
- The process of identification, discussion with practitioners, and integration of patient-indicators is complex.
- Organisational, methodological, cultural, and responsibility-linked determinants and lessons learnt are presented.

1 | INTRODUCTION: PERFORMANCE MANAGEMENT AND THE ROLE OF PATIENTS

Multidimensional Performance Management Systems (PMSs) are dominant in the public sector agenda as essential components for steering and controlling, as well as for learning and decision-making, or for simply monitoring and accountability purposes.¹ In healthcare, PMSs have been greatly adopted and used for budget purposes at their inception. They used to measure merely input and volumes of services' produced (output), and they focussed mainly on relying on past performance and punishing loss in revenue, inefficiency, and under-productivity. Over time, the evolution of the concept of performance in healthcare has determined an evolution of PMSs in response to a wide range of weaknesses and unintended consequences occurring in different settings of care.^{2,3} This led to more comprehensive performance systems aimed at considering of foremost importance health outcomes, incorporating the multi-level (or multi-setting) and multi-stakeholder activities performed by healthcare organisations, following a population perspective,⁴⁻⁶ and including the users' voice.⁷

The introduction of the patients' perspective into PMSs follows the evolution of healthcare performance linked to value, where technical, allocative, personal, and societal value are key components to be measured and evaluated for effective and high-quality healthcare systems.⁸⁻¹¹ To follow this conceptualisation of value-based healthcare (VBHC), PMSs are expected to assess not only achievement of quality standards (technical value) and the correct distribution of resources among subgroups to minimise inequity (allocative value), but also patient's preferences (personal value) and the contribution of healthcare to social participation and connectedness (societal value).⁹

This broader definition of VBHC balances individual quality of care, patient experience, population health and wellbeing outcomes with sustainability (financial, resource and environmental) and equity considerations. From the VBHC perspective, the core aim of healthcare systems is to maximise patient health benefits and to improve care experience. The latter can be achieved through the design and implementation of integrated care pathways, which are also cost-effective and equitable in distributing resources according to needs and population subgroups. To this end, the assessment of value should be incorporated in PMSs. Value can be assessed by comparing costs and patient outcomes along the care pathway.^{12,13} There are recent examples of patient perspective integrated into performance systems, both as a dimension of performance, using indicators based on patient experience surveys^{7,14,15} and patient-reported outcomes,¹⁶ and as a mechanism to present performance information following the main phases of the patient care pathway.⁶ However, current PMSs generally lack comprehensive measures able to reflect the different values that come into play in determining performance; naturally, this depends also on different stakeholder interests.^{17,18}

Embracing the value-based approach implies measuring the value produced for people, also from the people's perspective, by considering what patients, citizens, and the society value most for their health in terms of experience, satisfaction, preferences, and self-reported outcomes. Engaging with patients is of foremost importance in service systems where the patient often plays a co-design (patient consultation) and co-delivery role (for example, peer-support groups) supporting the creation of public value.¹⁹⁻²⁴

Moreover, listening to the voice of patients is fundamental for accounting for the collaboration dynamics among clinicians engaged in the care pathways. Care pathways entail multi-professional and multi-disciplinary collaboration. Collaboration is often created informally through referral networks,^{25,26} or managed through virtual organisations (e.g., clinical networks) based on the sharing of clinical management tools such as clinical guidelines and pathways.

Traditionally, PMSs were designed to account for a single organisation ('silos vision') for which only results within a specific area were reported and acted upon instead of focussing on the creation of value across the whole system and for the entire population.^{7,26} Putting the people's voices at the core of PMSs has also the potential of assessing the collective achievements and interconnections occurring between the different parts of the care pathway. In fact, patients move between care levels and settings, and can therefore provide feedback regarding the different services and professionals encountered.

Notwithstanding the potential gains in including the patient's voice into PMSs, there are numerous challenges in successfully incorporating patient-reported information into a PMS; these challenges may explain their current rather limited use - despite the increased attention on collecting patient-reported data.¹⁸ This study aims at providing a synthesis of the opportunities and challenges of the systematic inclusion of the patient's voice (or patient-reported metrics) in PMSs. This is done by using the case study of a well-established multidimensional performance evaluation system currently used by the regional healthcare system in Tuscany.

2 | METRICS TO COLLECT PATIENTS' VOICE

Indicators generated by patient-reported data are increasingly adopted in measuring and monitoring quality. They are often used alongside process and structure indicators in healthcare PMSs following the VBHC paradigm. Patient-reported information has been traditionally measured by collecting data about people's satisfaction with the quality and type of healthcare received or with the healthcare system in general. In the seminal work of Donabedian

dealing with performance measurement in healthcare, patient satisfaction is reported as an outcome indicator of quality of care.²⁷ However, no globally accepted formulation of patient satisfaction and measurement system exists yet - also due to the subjective nature of satisfaction.^{28,29} Satisfaction is influenced by patients' individual expectations as well as by their preferences during the use of healthcare services.¹⁴ Nonetheless, researchers have developed several instruments to measure patient satisfaction, and satisfaction has become an endpoint in outcome research and benchmarking of health services, and it is often used as an evaluation of the perceived quality of services.

To partially overcome the limits of patient satisfaction measures, patient experience measures has gained attention as one of the six pillars of healthcare quality, together with patient safety, clinical effectiveness, timely, efficient, and equitable care.³⁰ Patient-reported experience measures (PREMs) are collected through instruments that provide the patient's view on the delivery of services. They are not a satisfaction score, but on the contrary they seek to elicit what actually occurred to patients while receiving care, with respect to specific experiences, as well as in relation to what they have experienced along their care pathway. Experience scales are designed and validated to minimise the impact of patients' expectations and make measures objective. Thus, PREMs provide managers and clinicians with specific information on what 'does and does not work' from the perspective of their patients.¹⁴ Patient experience questionnaires can be used to measure the experience of patients with the same service (i.e., hospital stay) delivered by different providers for different health conditions in different phases of the care pathway. They are not disease-specific; therefore, they can be widely and transversely used across patient subgroups, healthcare organisations, and systems. PREMs are being increasingly used within quality improvement in relation to care delivery, even if some barriers persist with respect to an effective use of data.^{31,32} Since PREMs refer to service-provision in the patients' perspective, they provide key performance measures about the process (how the service is provided in the patients' perspective), and about the outcomes (to what extent is care patient-centred). The definition of patient-centredness refers to activities that can be measured by using PREMs, such as patient involvement, emotional support, and informative support.³³

Another valuable patient-reported information are patient-reported outcomes (PROs) that typically addresses self-reported symptoms, and the functional and emotional status. While PREMs can be collected referring to a single service, patient-reported outcome measures (PROMs) are usually administered longitudinally at different points in time to evaluate outcomes trends. A number of validated and standard PROs surveys are available. They collect the patients' point of view on the outcomes of care pathways or conditions such as cancer or elective surgery, or measure the general health status and well-being of patients suffering from different health conditions.³⁴ While generic instruments for measuring quality of life can be extensively proposed, one of the characteristics of PROMs is that they are disease-specific, often implying a limited number of eligible patients. The number of respondents generally decreases over time, due to the longitudinal nature of these surveys. Although they were originally developed to measure health outcomes in the context of clinical trials or cost-effectiveness studies, since the early 2000s the systematic use of PROMs in clinical practice has been increasingly proposed to promote value-based patient-centred care and, along with PREMs, as a quality evaluation measure for healthcare services.³⁵ Moreover, healthcare systems can use PROs data to compare the outcomes of different providers, or to estimate health outcomes and cost-effectiveness of interventions and treatments.

The joint collection of PREMs and PROMs for measuring and evaluating the results of the care delivery, especially along care pathways, although appearing promising in literature, is rarely observed in practice.³⁶ There is evidence that patients' experience is associated with several variables, including clinical safety, outcomes (both clinical and patient-reported), and cost.³⁷

The link between PROMs and PREMs suggest that their parallel improvement can lead to higher quality of care.³⁸

In addition, looking at outcomes from the patients' perspective and recognising the relevance of patients' experience with care is key for adopting and deploying the patient-centred approach in practice.^{17,36}

Patient-reported information can be used on a large scale within PMSs as a foundation for quality improvement, supporting providers to identify areas in which they underperform - and to improve their performance accordingly.

3 | SETTING

The paper provides suggestions on opportunities and challenges for the development, implementation, and systematic use of patient-reported information in PMSs by relying on the experience of the multidimensional performance evaluation system (PES) established in 2005 in Tuscany. The Italian National Health System is a decentralised system that follows a Beveridge model, financed mainly by general taxation, and based on the principle of universal coverage. Tuscany is a large region in central Italy comprising three local health authorities, four teaching hospitals, and 26 health districts, which oversee the organisation and delivery of public health care and prevention, primary care, outpatient/walk-in care as well as hospital services and long-term care.

The Tuscan PES was implemented in 2005 as a decision support tool at both the regional and the local management level and was based on a specific willingness of the Regional Health Councilor. It was intended to measure the quality of services and their capacity to meet citizens' needs, to achieve better health and quality of life, and to preserve financial equilibrium.³⁹ The PES was developed by professionals from the health authorities and the Regional Administration with the support and guidance of a group of researchers based within a public university in Tuscany, that currently runs the PES.

The Tuscan PES measures and evaluates multiple health care performance dimensions of public health care organisations, from financial viability to quality and patient satisfaction, through a systematic and publicly disclosed benchmarking of data.^{40,41} The PES is designed to allow a user-friendly and practical reporting system based on a dashboard with the identification and inclusion of performance targets/trends.

To date, the system includes 70 composite indicators and about 700 simple indicators which measure the performance of each health care organisation. The measured dimensions include population's health status, capacity to timely pursue regional strategies, clinical performance, efficiency and financial performance, patient satisfaction, and staff satisfaction.⁴² Indicators are calculated yearly for each public health organisation by using anonymised administrative data. Each indicator is benchmarked considering international or national and local standards, and it is evaluated by using five coloured bands (best performance is dark green while worst performance corresponds to red). As a result, for each evaluated indicator, five different levels define the performance of each health organisation, from worst to best on a scale from 0 (worst) to 5 (best). The performance information allows intra- and inter-organisational comparison, and therefore it eases the identification of unwarranted variation and of performance improvement actions.

The Tuscan PES is dynamic - it allows updates and the development of new indicators and settings of evaluation. Clinical professionals, managers, and regional policy makers are involved in the proposal of new indicators, suggestions for measurement, and interpretation.

Some patient-reported indicators have been included into the Tuscan PES since its establishment. Patient-reported indicators were used mainly to measure quality of care, with the goal to make care more patient-centred. Patient-reported indicators initially included in the PES assessed performance in terms of general satisfaction (i.e., overall assessment of the care assistance received), patients' experience with some dimensions of care (i.e., evaluation of team working between doctors and nurses), and specific domains of care (i.e., access, waiting time, pain management, patient-doctor relation, patient-nurse relation, communication between patients, families and healthcare providers, ward condition and discharge). Some risk-adjustment at individual and organisation level were applied to allow comparison (age, gender, perceived health status, previous care experience and type of health organisation).⁴³⁻⁴⁵

Starting from 2017, the PES has gone under a revision regarding the collection and use of patient-reported data.^{17,46} A permanent and digital observatory on patient experience and outcomes measures was established. Its aim is to include all eligible patients in giving feedback on services and their health status and quality of life over time (census-like surveys). The healthcare organisations of the Tuscan regional healthcare system, as well as of other regional systems or single organisations, have progressively adhered to the Observatory. PREMs and PROMs surveys within the Observatory have different extensions in terms of number of healthcare organisations and professionals involved, and reference patient populations as well.

The PREMs survey currently regards the experience with hospitalisation. 28 hospitals in Tuscany joined the Observatory. Patients discharged from an ordinary hospital stay are the reference population. Each patient is informed during the hospital stay that she can take part to the survey; after the discharge, a personal invitation to an online questionnaire is sent by email or SMS; while the patient is filling in the questionnaire, data are digitally collected and reported real-time to healthcare organisations.¹⁷ The magnitude of the PREMs survey, in terms of number of hospitals, units, professionals and patients involved, is large, as reported in De Rosis and colleagues.¹⁷ In 2020, the number of involved units of Tuscan hospitals in the PREMs survey was 433 out of 699; eligible patients, meant as the number of patients discharged alive by the involved units, were more than 245,000 (<https://performance.santannapisa.it/pes/start/start.php>). The PREMs questionnaire on hospital stay includes questions related to aspects that are relevant to patients,^{14,47} and namely: access to care (i.e. reasons for choosing a specific provider, waiting time for access); informative support from healthcare professionals to patients; patient involvement (i.e. shared decision-making between patient and healthcare professionals); coordination and teamworking (i.e. between doctors and nurses); comfort of the environment (i.e. ward hygiene and silence); pain management; and emotional support and relational aspects (i.e. respect and dignity of the person; anxiety and fear management). The questionnaire and the kind of patient-reported information collected are described in-depth by De Rosis and colleagues.¹⁷

The PROMs survey in the Observatory encompasses different surveys targeted to specific groups of patients: those suffering from cancer, specific chronic conditions, as well as patients undergoing hip or knee replacement surgery.⁴⁸⁻⁵⁰ For this reason, PROMs surveys are carried on by involving single clinicians instead of whole hospitals. Clinicians are those who take care of patients involved in the specific care pathways, and these patients are the reference population for the data collection. Currently, 49 clinicians are actively involved in the PROMs surveys. In the surgical pathways, each clinician, or her relative surgical unit, is responsible for informing and enrolling patients before surgery; after the enrolment, the patient receives a personal invitation to the online questionnaire by email or SMS; since PROMs are longitudinal surveys, patients receive different invitations over time; while the patient fills in the questionnaire, data are digitally collected and reported real-time to healthcare professionals. In this paper, the focus on PROMs will be on orthopaedic and breast cancer surveys because of their well-established use both in Tuscany and internationally, and according to their advancements in terms of integration inside the Tuscan PES.^{48,49} The patient-reported information collected includes specific scores of health outcomes (i.e., functional status, relational wellbeing, mental health), and are computed and reported also in terms of health gain or loss over time. The questionnaires and the kind of patient-related information collected are in-depth described in De Rosis and colleagues⁴³ and Ferrè and colleagues.⁴⁴

Over time, the tools for collecting and reporting patient-reported measures evolved following the growth of health information technologies that provide today unprecedented opportunities to systematically collect patient-reported surveys across the whole targeted population.¹⁷ All surveys within the Observatory are web-based, and data are reported real-time in aggregated form to clinicians and managers. This allows the prompt use of information. The available data includes raw PREMs data on hospitalisation and crude scores of PROMs, and raw PREMs covering experiences throughout the care pathway and services. The transition from periodic, sample-based surveys to continuous and systematic surveys is aimed at making patient-reported data available for developing performance indicators and for supporting improving actions as well.⁴⁶ Moreover, the availability of real-time updated data from the Observatory allows managers and professionals to monitor both the progress (i.e., how much it is extended, how many patients are involved) and the outcome of surveys (i.e., how patients are evaluating their experience or outcome).

The systematic collection and reporting of patient-reported experience/outcome at system level aims at encouraging the use of measures across the full pathway of patients' care, consistently with the fact that the systematic inclusion of the patients' voice in PMSs is considered relevant to VBHC.⁸⁻¹⁰

Consequently, the identification and agreement on new measures of the patients' voice is a key step forward towards a multi-stakeholder PMS.

4 | METHODS

This paper is based on an action research design aiming at reviewing challenges and opportunities that emerged when designing the systematic integration of patient-reported measures into the Tuscan PES. Action research is a strategy for social research based on intense interactions between researchers and stakeholders/experts/practitioners in a cyclical process aiming at applying findings of the research to improve practical, real-world issues.⁵¹ In the first phase, researchers gathered input from several sources on the topic of patient-report measures, design, implementation, and use, by exploring peer-reviewed articles as well as books and grey literature. As a second step, practitioners and managers were involved by the researchers in workshops to design, implement, and discuss the results of patient-reported measures, and to reach an agreement for the integration of patient-reported indicators within the Tuscan PES—while not forgetting the role of these measures for quality improvement actions. Several workshops have taken place periodically in the 2018–2021 period. The following table (Table 1) reports the meetings that were organised to define and integrate patient-reported indicators into the PES.

A process of identification and discussion of patient-reported indicators for performance evaluation was conducted with practitioners during the workshops. The discussion process was aimed at providing professionals with resources that they could use to improve practice by using patient-centred information included in the PMS. This is aligned with the need to support changes in practice—one of the main features of action research.⁵² Two kinds of indicators were proposed and discussed, namely process and outcome indicators based on both PREMs and PROMs. As reported by Noto and colleagues,⁴ in performance measurement and evaluation, process metrics are one of the pillars due to their capacity of measuring outputs, and their importance in the efficiency and productivity perspective; at the same time, outcome measures have increasingly gained relevance for organisational performance evaluation and management in healthcare and to ensure the application of VBHC principles.

A comparative analysis has been conducted to highlight similarities and differences among the process of development and introduction of indicators based on patient-reported outcomes and experience measures within the Tuscan PES.

The analysis of the clinicians' feedback collected during the workshops focuses on three main aspects:

- a) Design of the system in terms of indicators' definition in two perspectives:
 - i. Technical aspects
 - ii. Reporting aspects
- b) Process of integration of patient-reported indicators into the PMS
- c) Goals of patient-reported indicators

5 | RESULTS

Two kinds of indicators were presented and discussed by researchers and practitioners, and analysed to understand how they could be useful for performance evaluation:

TABLE 1 Number of meetings conducted to discuss the introduction of patient indicators inside the PMS and total number of participants to this process

	Number of workshops	Mean number of participants	Total number of participants
PROMs	3	17	27
PREMs	21	45	945
Overall	24	62	972

- process indicators - related to the survey roll out and aimed at monitoring survey extension as well as patients' response to the survey;
- outcome indicators - related to the specific patients' evaluations of experience (PREMs) with care and health outcomes (PROMs).

Process indicators collect, on the one side, the level of reach (hereafter extension) of the surveys and, on the other side, the response rate by patients. The first aims at monitoring and evaluating the engagement of clinicians in collecting the patients' perspective. The extension of the survey measures both the managerial commitment in the initiative - since the engagement of units or professionals in enrolling patients depends also on the willingness of the management and on the importance given to the collection of patient-reported data by the management - and the level of engagement of single practitioners to the initiative, the agreement on its goals and potential outcomes, including changing the practice according to patient-reported indicators. Previous research on organisational climate surveys showed that indicators measuring clinicians' participation to the survey (i.e., the response rate) is a proxy measure of organisational commitment, since evidence suggests that organisations with best performance are often those that invest more on professional engagement.⁵³

The process indicator on patients' participation to the surveys are proxies of their level of involvement in the process of contributing to performance evaluation, or co-assessment process.⁴⁶ Public participation in surveys can have different determinants.⁵⁴ One of the key levers is the role that professionals play in informing patients and presenting the survey. This depends on their trust and attitude towards patient-centredness. Indicators of patient participation and extensions of the survey are a good proxy of both patients' involvement in this co-assessment initiative and of the potential impact of the initiative.

Outcome indicators aim at measuring results in terms of patients' feedback on care quality. Outcome indicators derived from patient experience surveys measure the experience of care in several standard care dimensions.^{14,17,46} Outcome indicators include a few indicators of satisfaction with care, such as a general evaluation of the care received and the willingness to recommend the ward.¹⁷ Outcome indicators from the PRO survey regard the final outcome of care, and consist of the health condition and wellbeing of patients.^{50,55} Since PROs use disease-specific questionnaires, indicators are specific for healthcare pathways (i.e. orthopaedic and breast cancer). Moreover, each disease-specific PRO questionnaire can provide a global score or several scores measuring different dimensions such as health, well-being, and psycho-social status. In the latter case, the selection of the most informative PRO score for the creation of indicators can be a complex process. The process can be informed by both literature (i.e., most used indicators in other systems) and clinical practice (i.e., most useful indicators).

Table 2 includes the list of indicators that were proposed to practitioners and managers, with the last column indicating their eventual inclusion in the PES. Currently, only a part of patient-reported measures is integrated in the Tuscan PES. The discussion with professionals led to the introduction of 23 indicators, namely:

- 17 indicators from PREMs proposed by the researchers, with some indicators listed that were also computed as sub-indicators for specific healthcare professional groups (i.e., doctors, nurses, physical therapist, health-social care workers);
- 6 indicators from PROMs, all declined for single care pathway. The orthopaedic PROMs questionnaire provides one single score; the breast cancer PROMs questionnaire provides different scores for the different dimensions of outcome. In this latter case, one specific score has been selected for the integration within the PMS, since it is the most commonly used at the international level, and is more relevant at the regional level.

During the workshops, participants discussed about the introduction of patient-reported measures into the PES. Table 3 reports a classification and summary of topics, with some quotes, around the three dimensions: indicators design, process of indicators' introduction, and goals of the indicators' integration into the PES.

TABLE 2 List of patient-reported indicators which could be included into the Tuscan PES

Measures	Type of indicator	What is it measuring	Indicator name	Integration into the PMS
PREMs	Process	Managerial commitment	Extension rate (n. of invited patients/total patients in population)	Yes
		Professionals and patients' participation	Participation rate (n. of respondent patients/n. of invited patients)	Yes
PREMs	Outcome	Emotional support	Experience of being respected as a human being?	Yes
			Healthcare professionals talking in front of the patient as s/he was not present	Yes
			Fear and anxiety management by healthcare professionals	Yes
			Kindness of welcoming in the ward	Yes
		Informative support	Clear answers by healthcare professionals	Yes
			Communication with caregivers	Yes
			Involvement of patients	Yes
			Clearness of information at discharge about education and self-management	Yes
		Physical environment	Clearness of information at discharge about pharmacological treatments	Yes
			Quietness of the ward	Yes
			Cleanliness of the ward	Yes
			Technical and competence aspects	Pain management by the healthcare professionals
		Teamwork between clinicians and nurses		Yes
		Satisfaction	Overall evaluation	Yes
Willingness to recommend	Yes			
PROMs (per each pathway)	Process	Professionals and patients' participation	Enrolment rate	Yes
			Response rate at baseline (first questionnaire)	Yes
PROMs Orthopaedic surgery	Outcome (OXFORD Hip/Knee survey)		Percentage of patients who reported an improved outcome 6 months after the surgical procedure	No

(Continues)

TABLE 2 (Continued)

Measures	Type of indicator	What is it measuring	Indicator name	Integration into the PMS
			Percentage of patients who reported an improved outcome 12 months after the surgical procedure	No
			Health gain index 6 months after the surgical procedure	No
			Health gain index 12 months after the surgical procedure	No
PROMs Breast cancer	Outcome (BREAST-Q survey)		Satisfaction with breast 3 and 12 months after breast reconstruction	No
			Psychosocial well-being 3 and 12 months after breast reconstruction	No
			Physical well-being 3 and 12 months after breast reconstruction	No
			Satisfaction with care 3 and 12 months after breast reconstruction	No

6 | FACILITATORS

The findings from the action research, supported by observations collected during the workshops and by concrete integration of patient-indicators within the PES, showed that PREMs indicators are more acceptable than PROMs ones. Previous national and international experiences were a key reference for professionals, as they were aware of the importance of having the patients' point of view in the PESs. Professionals are used to handling patient satisfaction and experience indicators, since these measures have been being collected, reported, and evaluated within the Tuscan PES for years. This made the integration of patient experience indicators highly acceptable. Moreover, PREMs seemed more acceptable to practitioners since they are generally measures of processes of care, referring to a specific service. PREMs indicators appear to healthcare professionals as less close to their core mission that is saving lives and caring for diseases. Experience measures within a performance evaluation system can affect organisational models and processes within wards and units, but potentially cannot affect clinical practice.

PROMs appear of great interest for professionals and managers, with positive reactions to the possibility of having additional longitudinal and more granular data on outcomes reported directly by patients, which cannot be measured in other ways. In fact, outcome measures already used by healthcare professionals are only those computed from health administrative data, such as hospital readmission rates and reintervention rates, mortality rates, and complications rates. Those hard endpoints are not able to catch the outcomes of care before a readmission or a reintervention. Conversely, PROMs provide information over time on the various aspects of the patient's recovery of functionality, daily activities, specific health conditions and quality of life, and psychosocial well-being.

TABLE 3 List of topics that were discussed about the introduction of patient measures into the PES and comparison between PREMs and PROMs.

Topic	PREMs	PROMs
Design		
Previous international experiences	<p>Professionals were aware of international experiences of PREMs use for computing indicators of performance evaluation, in healthcare systems that are either similar to the Italian one (i.e., UK) or very different (i.e., USA).</p> <p><i>'We can measure patient-centredness as the UK'</i></p>	<p>Professionals were aware of international experiences of PROMs use for computing indicators of performance evaluation, particularly in the UK.</p> <p><i>'For research purpose, we already use Oxford scales as a parameter to evaluate individual patient recovery or to compare different prostheses'</i></p>
Previous national experiences	<p>Professionals were used to working with patient-reported indicators from satisfaction and experience surveys. PMS in Tuscany includes patient-reported measures since the early 2000s.</p> <p><i>'While using patient-indicators, we identified some problems and implemented a process of change with a specific training for professionals'</i></p>	<p>Computing patient-reported indicators from PROMs was totally new for professionals since the only outcome measures used in Italy and Tuscany are computed by using administrative healthcare data within the National Outcome Programme (Programma Nazionale Esiti - PNE).</p>
Managerial levers (i.e., targets link to incentives)	<p>Accreditation, targets, and performance evaluation in Tuscany include patient-reported measures since the early 2000s.</p> <p><i>'We need PREMs for accrediting our hospital'</i></p> <p>However, currently targets and incentives are only related to process indicators.</p> <p><i>'We have first to push professionals to increase the number of patients participating into PREMs, in order to provide them enough data on the real-time updated web platform'</i></p>	<p>Professionals tend to consider the introduction of performance targets linked to PROMs more complicated. Indeed, the responsibility of outcome improvement is shared among providers/professionals and outcome improvement depends on patients' expectations and their prior health status.</p> <p>Currently targets and incentives have been included in some hospitals only for process indicators.</p>

(Continues)

TABLE 3 (Continued)

Topic	PREMs	PROMs
Technical aspects	<p>Indicators are computed from data collected with the same questionnaire, including questions related to the specific service (i.e., hospital stay) that are valid in every hospital. Process indicators are computed using data from the PREMs survey and the consolidated administrative flow on discharge (Scheda di Dimissione Ospedaliera - SDO).</p> <p>Outcome indicators of experience are all standardised from 1 to 100. The evaluation has been computed on fixed levels of performance. However, the methodology of data collection is a concern since it is not based on a random representative sample.</p> <p><i>'Maybe only unsatisfied or very satisfied patients respond'</i></p> <p>The statistical techniques for reporting data to the reference population and risk-adjusting them for comparison are not well understood and accepted.</p> <p><i>'Yes, we have a lot of data, but can we really compare our results with other hospitals?'</i></p>	<p>Data collection is based on the fundamental role of professionals in involving patients to take part in the surveys. Therefore, especially when reference population is small for a care pathway, it can be hard to reach a minimum number of responses to make analyses robust and statistically significant.</p> <p><i>'We cannot read outcomes with this response rate, since there could be only respondents who are in a good shape'</i></p> <p>The use of a web-based survey system is often claimed to be a barrier by the professionals who assist older populations.</p> <p><i>'You will not have any response from our patients, they are not able to browse the Internet'</i></p> <p>The validity of using these measures to assess outcomes is still discussed by professionals in terms of performance evaluation.</p> <p><i>'PROMs are perceptions of patients; they cannot be used as an objective measure of our performance'</i></p>
Reporting aspects	<p>PREMs on hospital stay are punctual, relating to a single experience. Both process and outcome data are permanently collected and reported real-time on a web platform. Indicators from PREMs are computed yearly, and refer to all patients experiencing the service the past year.</p> <p>An inconsistency between crude data reported real-time and the yearly computed indicators produced some concerns in terms of actual possibilities of monitoring the performance over time by professionals and managers' staff.</p>	<p>PROMs are longitudinal surveys, with at least three questionnaires administered over time to each patient (usually 12 months follow up period). They are systematically collected and reported real-time on a web platform. The interpretation of scores over time is still a barrier to use since not all scales have a reference threshold to detect significant changes.</p> <p>Process indicators are calculated yearly, and refer to patients treated the past year.</p>

TABLE 3 (Continued)

Topic	PREMs	PROMs
Process		
Discussion with professionals before the indicators' uptake	<p>PREMs outcome indicators were already present among indicators for accreditation, evaluation, incentives. Professionals already knew them and found them fitting with their informative and managerial needs. Thus, they did not ask for discussion on the indicator computing.</p> <p><i>'Why should we change the indicators? They have always worked fine'</i></p> <p>A dialogue was opened only with regard to minor exceptions on numerators and denominators of the PREMs process indicators.</p> <p><i>'We should exclude from the denominator of the participation rate children who were discharged by the birth department, since the respondents to the questionnaire are the women discharged for the delivery, already counted in the denominator.'</i></p>	<p>PROMs process indicators were included top-down with the aim of pushing the enrolment of patients by professionals. There were no concerns about these measures.</p> <p>On the other side, PROMs outcome indicators were proposed to professionals during specific workshops and were deeply discussed to evaluate the affordability of introducing them into the Tuscan PMS and to reach a shared decision on this.</p>
Process of indicators' integration in the PMS	<p>PREMs process indicators were presented to middle managers and professionals during management control meetings. Targets to be reached were shared and discussed, for process indicators only.</p> <p>Some concerns emerged from managers of specific units, such as geriatric, psychiatry, medical care.</p> <p><i>'We cannot reach the same results in terms of patient participation of the other wards that have younger and healthier patients.'</i></p> <p>As anticipated, PREMs outcome indicators were already known to healthcare managers and professionals. The process of introduction of these indicators into the PES was already addressed in the past, while their confirmation and communication were managed through meetings with an early sharing of raw results prior to the indicators' integration within the PES and their public disclosure.</p>	<p>PROMs process indicators were presented to middle managers and professionals during management control meetings, as the PREMs indicators.</p> <p>PROMs outcome indicators were presented and discussed to professionals by researchers during specific workshops, with some concerns and doubts by professionals.</p> <p><i>'We do not have enough data to compute the indicators.'</i></p> <p><i>'How can we evaluate an improvement of 5 points on a 48-long scale? There is no clear reference on this point.'</i></p>

(Continues)

TABLE 3 (Continued)

Topic	PREMs	PROMs
Goals	<p>The purpose of PREMs indicators is to evaluate the process of services and patient satisfaction. The aggregation of these patient-reported indicators can indicate the degree of patient-centredness of a healthcare organisation, at various levels up to the ward or micro level. The benchmarking and the evaluation can help healthcare organisations identify rooms for improvements at the hospital, organisation, or system level.</p> <p>However, PREMs are mainly meant as a support for the micro-level quality improvement actions of services and processes.</p>	<p>The purpose of PROMs indicators is to evaluate the quality of life and well-being of patients after receiving a specific procedure along a care pathway. They can add longitudinal and punctual information about the consequences of receiving specific care over time, not only at 'the end of the story'.</p> <p>The aggregate use for benchmarking providers is fundamental to evaluate quality, effectiveness, and efficiency of care from the patient perspective, allowing also to monitor intermediate outcomes that are generally not measurable from the administrative flows.</p> <p><i>'One year after they are all able to walk.'</i></p>

7 | BARRIERS AND CHALLENGES

The higher degree of acceptance of PREMs did not exclude them from several challenges.

In the Tuscan experience described in this action research, managerial levers such as targets and incentives are only linked to PREMs process indicators, namely the extension and adhesion rate. The actual results of patient evaluation on experience are not included into those managerial mechanisms that can really orient professionals' behaviours.

In fact, with regard to PREMs indicators of outcome, representativeness and benchmarking are key concerns of managers and professionals. The new digital and permanent method of data collection and the related statistical techniques to be used on raw data, such as weighting methodologies, risk-adjustments, multilevel models,^{17,46} are not fully accepted yet, neither totally clear nor well understood by the potential users of this data. The credibility of the methodological robustness is a key aspect to be considered: professionals must be convinced of the scientific soundness of the method, especially when they are used to data collected with other methods, such as the sample-based surveys.

The skewed distribution of patient evaluation of experience is a critical aspect of evaluation and data use. Due to skewness, positive assessments by patients have been translated into very negative indicators, with very negative evaluations of hospitals that report a value under 80 on a scale from 1 to 100. The actual use and usability of this data is a key issue. They can push healthcare organisations to be excellent in the patient perception of the experience with services, which appeared relatively acceptable by professionals in a context of high pressure for performance results' achievement. The discussion on the possibility of changing what is being measured or the way in which evaluation is applied to indicators remained open. Another key challenge is the ability to use positive data to learn from excellence. With this regard, patient-reported indicators of experience are usually more positive for hospitals with small volumes, and more negative for hospitals with high volumes. This kind of data can be inconsistent with indicators on volumes, which generally show a positive association between outcomes and high volumes of patients. These contradictory results can reflect the fact that these indicators are measuring different dimensions of value (technical and personal dimensions).

Previous experience and known levers that allowed the introduction of PREMs measures into the PES were not enough to promote the integration of PROMs indicators into the PES. Despite professionals mainly referred to the English experience with PROMs adoption as a positive one, ignoring critics and criticisms emerged in the UK, there

was a lower agreement on introducing patient-reported measures on the intermediate and final outcomes of the care pathway. This was linked to both technical and methodological issues, for instance in terms of comparability with other measures. Moreover, issues on the validity of data collection emerged regarding the sample size and potential biases related to the digital divide effect in the older population. Some of the key issues that emerged during the discussion with professionals about the PROMs indicators of outcome are (i) How to select the patient cohorts to compute indicators; (ii) How to adjust respondents' data considering the overall reference population and the multi-level approach when adequate; (iii) What is the minimum number of responses needed to compute the indicator, as this is a critical aspect when there are small groups of eligible patients for a certain surgical procedure or condition; (iv) How to ensure comparability among providers that care different populations in terms of volumes and characteristics; (v) How to choose the PROMs score to be computed as indicator when the PROMs survey collect data on multiple dimensions, so providing multiple scores. This is the case of breast cancer where the PRO survey selected, BREAST-Q, provides from 4 up to 6 independent scores and no overall score summarises the health gains or losses perceived by patients. The same researchers found it hard to evaluate the impact of different enrolment behaviours on sample selection bias and on the computation of patient-reported indicators.

Another key barrier is the real trust of some professionals in the patients' ability to correctly report their health status and quality of life. This result is to some extent surprising, since PROMs have been usually integrated into clinical studies to evaluate different treatments or drugs, so professionals should be familiar with and use this kind of data within clinical trials and HTA studies. However, PROMs are less frequently utilised to monitor health status of individual patients over time in a performance assessment perspective. As a consequence, professionals are more sceptical about the introduction of outcome indicators from the patient's perspective as an information useful to evaluate the performance. Moreover, some of the dimensions that are measured with PROMs seem to be not directly affected by the professionals' activity. With this regard, PROMs indicators concern both the medium-term effects of the healthcare care service (i.e., therapy effectiveness, recovery of functionality after surgery) and the longer-term impacts of the healthcare care service (i.e., self-confidence, social well-being). Since PROMs are able to longitudinally capture the value produced to patients along their journey across settings and providers, they are a measure of part of the whole-life experience of the service user. For instance, a chronic patient is assisted by several services and each of these steps contributes to her/his daily life with the disease. Patients' social and emotional health status are fundamental to foster autonomy and active lifestyle and are impacted by the sum of professionals and services' interventions. Measuring this kind of long-term outcomes is interesting for professionals from a scientific point of view, while their evaluation into a performance system appears problematic, especially in terms of long-term responsibility.

8 | DISCUSSION

In Tuscany, the established PES has shown that systematic benchmarking and public disclosure of multidimensional performance data support a balanced and sustained improvement of healthcare, but only if they are integrated with the regional governance mechanisms (e.g. targets and priority setting).⁴⁰ The PES encompasses a systematic involvement of clinicians and managers in an improvement process informed by the performance results, which is fundamental to enhance performance.⁵⁶ Professionals' involvement is a key step into the process of including patient-reported indicators into a PES. However, the collaborative processes that characterised this research action were also aimed at providing and sharing knowledge and skills with professionals, which are key elements for a cultural change. Consequently, the topic of patient contribution to performance evaluation and management should be systematically integrated into the standard and continuous training of healthcare professionals and managers, as currently occurs in the mandatory executive managerial courses in Tuscany. The Tuscan PES allows for intra- and inter-organisational comparison as well, which is fundamental for patient data interpretation and actual use.³¹ The integration of patient-reported feedback with appropriateness and quality and safety indicators from administrative and clinical sources in a multi-dimensional performance evaluation system could enable a more effective use of these data.^{31,32} In addition, by incorporating feedback on outcomes and experience with care in the PES,

patients can effectively contribute to assessing the collaboration network? Of the different professions, providers and institutions involved along the care pathway, and to overcoming the silos-vision and fostering integration and continuity of care.^{6,7,27,44,57} The role of patients becomes not merely informative, but co-creative,^{6,17} supporting the enhancement of value creation in the system. This stakeholder-oriented approach implies a more collaborative orientation of the healthcare system in including patients' feedback as an information source that is valid to evaluate performance.^{36,47,58} In this sense, the integration of patient-reported indicators can make the PES more inclusive and focussed on the patient-centred perspective. The Tuscan experience analysed in this work highlights the complexity of integrating patient-reported indicators into a well-established PES.

In fact, effective inclusion of patient-reported indicators into established PESs needs to be supported both by bottom-up processes to engage practitioners and by top-down actions that encourage and sustain the adoption of a more people-centred perspective in performance evaluation and management. The integration of PES with regional and organisational governance mechanisms (e.g. targets and priority setting) is key to drive professionals' behaviour by communicating the vision and the related actions to be taken.⁴⁰

Firstly, the findings of this research suggest that computing and integrating patient-reported indicators into PESs requires a process of sharing, discussion, and consensus with practitioners and managers. Their involvement is crucial in reaching a shared definition of how to include patient-reported measures inside the PES and to foster their use in quality improvement actions.¹⁷ According to the Tuscan experience, it seems that collaborating with faithful professionals can lead the others to accomplish more in including PROMs indicators alongside traditional indicators.⁵⁹ However, the findings of the Tuscan experience show that several efforts are needed to engage healthcare professionals in each phase, especially for the PROMs survey, and, nevertheless, the process seems to be not rapid nor resolute enough for the annual evaluation purpose of the PES.

Secondly, methodological issues emerged during the discussion of patient-reported indicators with professionals. This challenging aspect is associated with the sustainability of the PMS, for instance in terms of number of indicators, time and dimensions of evaluation, patients' cohorts to be considered, pathways to be covered by patient surveys and indicators, global or specific scores to be computed as outcome indicators, and so on. These findings have a twofold implication, practical and cultural. If managers and professionals do not trust the robustness of the patient-reported indicators, doubts regarding the appropriateness to introduce outcome indicators reported by patients in the PES can emerge. Even if they believe in these measures, it can be argued that the sustainability of PES can be challenged by the integration of indicators for every dimension of experience or outcome, for all patients, for all surgeries, and for all care pathways. In fact, practitioners proposed to reflect on what is valuable and useful to measure. This is a challenge, especially with respect to disease-specific outcome indicators from PROMs. Their condition-specificity implies, on the one hand, sustainability issues for the little sample size reachable, while on the other hand, it comes with comparability concerns in a broader population perspective (i.e., comparison with outcome indicators related to other conditions or pathways). With this respect, generic or condition-independent PROMs could be more appropriate for performance evaluation, although not concretely actionable in quality improvement process at the micro level, or for individual care purposes.¹³ A large portion of money is spent on people with multiple conditions. Generic PROMs may also be more appropriate for measuring outcomes of patients with multiple health conditions. Finally, practitioners wondered if patient-reported indicators are more able to change practice if integrated into the PMS rather than outside. Further research is needed to understand how and when the call for patients' voice inclusion in performance measurement and evaluation systems will be applicable, especially for PROMs indicators of outcome.^{13,60} However, avoiding to compute patient-reported indicators for the above mentioned challenges implies the risk of 'measuring the most easily measurable' and not what is really valuable.⁶¹

Thirdly, the greater complexity entailed by the integration of patient-reported indicators into the PMS concerns the definition of responsibility for outcomes, as borders between the organisations involved in the care pathway are often blurry. This has consequences also for accountability since multi-professionals and multi-setting actors are involved in the care of the patient. Indeed, PROMs can be considered core elements of the performance both of a public service in general,⁶² of the different healthcare organisations providing the services along the pathway, and

of the single healthcare professional responsible of the diagnosis, surgery, prescription, and so on.^{6,7,13} This makes it challenging to define who is responsible for short, medium and long-term outcomes, and how to evaluate the interaction among actors providing services along and across pathways.

PREMs measures have been integrated easier into the Tuscan PES. The attribution of responsibility is easier when the evaluation refers to punctual, concrete, and factual aspects of service delivery, in a short-term perspective. Experience measures are internationally used within performance evaluation and management systems with benchmarking and public disclosure of data.^{63–65} This aspect was also relevant for the acceptability of the PREMs indicators' integration into the PES. On the PROMs side, few examples of systematic collection of patient-reported data have been available.⁶⁶ All professionals were aware of the previous key experience of PROMs integration into the English PESs,^{67–71} with systematic benchmarking and public disclosure of data,⁷² with a low awareness of the criticisms emerged also in UK.¹³ Practitioners were familiar with the experience of international benchmarking of patient-reported indicators promoted by the OECD.⁷³ Despite this, the acceptability of integrating PROMs indicators into the PES was much lower than the PREMs ones. However, we argue that among the facilitators of the PREMs integration there was a narrow cultural vision of the practitioners on experience with care.

The fourth key aspect emerged in this action research is cultural. It seems that practitioners consider the evaluation of patients' perception of their experience with services further from their core mission (that is caring for people) than the patients' perception of outcomes that are clinically, not only organisationally, produced by practitioners. The experience and satisfaction measures are not perceived as associated with the key activities of the healthcare professionals' work and only marginally to the deontological aspects of their job. Therefore, being a low performer in patient experience indicators can be a critical but acceptable consequence of the evaluation. PREMs indicators are generally meant as process and not as outcome measures. Thus, their evaluation by patients seems to be more acceptable. This result can veil a cultural problem, which is a still narrowed vision of patient-centred care. The definition of patient-centredness includes positive patient experience with care,³³ and can be meant as one of the outcomes of the care delivery that is strictly linked with the creation of personal value.^{5,9,74} On the other side, PROMs are perceived as closer to the main mission of providers: caring for people and improving their health status. Muller⁶¹ reports that the experiences of performance evaluation systems most frequently cited as effective are those more strictly linked to the deontological mission of clinicians. He wrote that 'when we dig more deeply, we find that the metrics matter because of the way they are embedded into a larger institutional culture'.⁶¹ In order to make PESs work as positive change, they should be incorporated into the deontology of professionals, and PMSs' metrics should be a support to the intrinsic motivation and the ethos of professionals (crowding in).⁷⁵ Accordingly, professionals perceive PROMs indicators of outcome as very relevant for their work and mission, mainly if used at the individual level to improve quality and personalisation of care for individual patients. However, their systematic use for evaluation purposes is not easily accepted by professionals. The main resistance is linked to the individual professionals or units evaluation, since practitioners welcomed the integration of PROMs indicators of outcome at Tuscan regional level within the OECD publication *Health at a Glance*,⁷³ which compares indicators of different countries over time. Involving professionals in the PMSs' design and implementation is necessary but not enough. Future research should investigate what are the key cultural, process, and managerial levers which can make possible a concrete, acceptable, useable, and actionable integration of PROMs measures of outcome into the PESs.

Using PROMs indicators for performance evaluation implies shifting from the individual-patient to the population-based and value-based healthcare approaches.¹⁸ Healthcare systems need to adopt and share a cultural vision that embeds the population approach and the multi-stakeholder view into the institutional culture of professionals.⁶¹ They must recognise how to 'read' PROMs in a wider view as opposed to the traditional use of these measures in clinical and cost-effectiveness contexts.^{13,34,76} To do so, practitioners should recognise that PROMs can be used to create not only personal value, but also allocative and social value as well.

Despite the few experiences of integration of patient-reported metrics into PESs, the systematic collection and reporting of outcomes and experience in Tuscany and the initial integration of patient-reported indicators into the Tuscan PES are a solid step forward that values the role of citizens in evaluating and managing healthcare performance.

ACKNOWLEDGEMENTS

The authors kindly thank health professionals, managers, and the technostucture of the Tuscan healthcare system, for participating to the Patient-Reported Outcome and Experience Measures Observatory and for sharing their expert viewpoint during workshops. A special thanks to all patients taking part into the PREMs and PROMs surveys. The authors are grateful to prof. Sabina Nuti and prof. Milena Vainieri for their vision and insights, and to the researchers of the Management and Healthcare Laboratory for their support. The authors thank all the reviewers that contributed to improving the paper and recognise the precious contribution of Daniel Adrian Lungu for the proofreading of the manuscript. The PMS and the PREMs and PROMs Observatory are funded by the 'Direzione Diritti di cittadinanza e coesione sociale' of Tuscany Region. The funding body collaborated in the design of the PMS and of the survey, by discussing indicators, questionnaires, and the administration methodology with the research team.

CONFLICT OF INTEREST

Authors declare to not have any conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

ORCID

Sabina De Rosis  <https://orcid.org/0000-0002-8781-401X>

Francesca Ferrè  <https://orcid.org/0000-0001-5781-517X>

Francesca Pennucci  <https://orcid.org/0000-0002-0580-1435>

REFERENCES

1. Dooren WV, Bouckaert G, Halligan J. *Performance Management in the Public Sector*. 2nd ed. Routledge; 2015. <https://doi.org/10.4324/9781315817590>
2. Adcroft A, Willis R. The (un)intended outcome of public sector performance measurement. *Int J Public Sect Manag*. 2005;18(5):386-400. <https://doi.org/10.1108/09513550510608859>
3. Bevan G, Hood C. What's measured is what matters: targets and gaming in the English public health care system. *Publ Adm*. 2006;84(3):517-538. <https://doi.org/10.1111/j.1467-9299.2006.00600.x>
4. Noto G, Lo Verso AC, Barresi G. What is the performance in public hospitals? A longitudinal analysis of performance plans through topic modeling. *BMC Health Serv Res*. 2021;21(1):326. <https://doi.org/10.1186/s12913-021-06332-4>
5. Gray M. The shift to personalised and population medicine. *Lancet*. 2013;382(9888):200-201. [https://doi.org/10.1016/S0140-6736\(13\)61590-1](https://doi.org/10.1016/S0140-6736(13)61590-1)
6. Nuti S, Noto G, Vola F, Vainieri M. Let's play the patients music: a new generation of performance measurement systems in healthcare. *Manag Decis*. 2018;56(10):2252-2272. <https://doi.org/10.1108/MD-09-2017-0907>
7. Nuti S, De Rosis S, Bonciani M, Murante AM. Rethinking healthcare performance evaluation systems towards the people-centredness approach: their pathways, their experience, their evaluation. *Healthc Pap*. 2017;17(2):56-64. <https://doi.org/10.12927/hcpap.2017.25408>
8. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff*. 2008;27(3):759-769. <https://doi.org/10.1377/hlthaff.27.3.759>
9. Expert Panel on effective ways of investing in Health (EXPH). *DEFINING VALUE IN "VALUE-BASED HEALTH-CARE"*. European Union; 2019. https://ec.europa.eu/health/expert_panel/sites/expertpanel/files/docsdir/024_defining-value-vbhc_en.pdf
10. Mery G, Majumder S, Brown A, Dobrow MJ. What do we mean when we talk about the Triple Aim? A systematic review of evolving definitions and adaptations of the framework at the health system level. *Health Pol*. 2017;121(6):629-636. <https://doi.org/10.1016/j.healthpol.2017.03.014>
11. O'Flynn J. From new public management to public value: paradigmatic change and managerial implications. *Aust J Publ Adm*. 2007;66(3):353-366. <https://doi.org/10.1111/j.1467-8500.2007.00545.x>
12. Porter ME. What is value in health care? *N Engl J Med*. 2010;363(26):2477-2481. <https://doi.org/10.1056/NEJMp1011024>
13. Porter I, Gonçalves-Bradley D, Ricci-Cabello I, et al. Framework and guidance for implementing patient-reported outcomes in clinical practice: evidence, challenges and opportunities. *J Comp Eff Res*. 2016;5(5):507-519. <https://doi.org/10.2217/cer-2015-0014>

14. Coulter A, Fitzpatrick R, Cornwell J. *Measures of Patients' Experience in Hospital: Purpose, Methods and Uses*. King's Fund London; 2009.
15. Van Der Wees PJ, Nijhuis-Van Der Sanden MWG, Ayanian JZ, Black N, Westert GP, Schneider EC. Integrating the use of patient-reported outcomes for both clinical practice and performance measurement: views of experts from 3 countries. *Milbank Q*. 2014;92(4):754-775. <https://doi.org/10.1111/1468-0009.12091>
16. Gibbons E, Black N, Fallowfield L, Newhouse R, Fitzpatrick R. *Patient-Reported Outcome Measures and the Evaluation of Services*. NIHR Journals Library; 2016. <https://doi.org/10.3310/hsdr04160-55>
17. De Rosis S, Pennucci F, Nuti S. From experience and outcome measurement to the health professionals' engagement. *Micro & Macro Mark*. 2019;28(3):493-520.
18. Vainieri M, Noto G, Ferrè F, Rosella L. A performance management system in healthcare for all seasons? *Int J Environ Res Publ Health*. 2020;17(15):5590. <https://doi.org/10.3390/ijerph17155590>
19. Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf*. 2016;25(7):509-517. <https://doi.org/10.1136/bmjqs-2015-004315>
20. Bovaird T, Loeffler E. From engagement to Co-production: the contribution of users and communities to outcomes and public value. *Voluntas*. 2012;23(4):1119-1138. <https://doi.org/10.1007/s11266-012-9309-6>
21. Loeffler E, Power G, Bovaird T, Hine-Hughes F. *Co-Production of Health and Wellbeing in Scotland*. Governance International; 2013. Accessed 14 March 2018. http://www.govint.org/fileadmin/user_upload/publications/Co-Production_of_Health_and_Wellbeing_in_Scotland.pdf
22. Pennucci F, De Rosis S, Murante AM, Nuti S. Behavioural and social sciences to enhance the efficacy of health promotion interventions: redesigning the role of professionals and people. *Behav Public Policy*. 2019;6:1-21. Published online. <https://doi.org/10.1017/bpp.2019.19>
23. De Rosis S, Pennucci F, Noto G, Nuti S. Healthy living and Co-production: evaluation of processes and outcomes of a health promotion initiative Co-produced with adolescents. *Int J Environ Res Publ Health*. 2020;17(21):8007. <https://doi.org/10.3390/ijerph17218007>
24. Cepiku D, Marsilio M, Sicilia M, Vainieri M. *The Co-production of Public Services: Management and Evaluation*. 1st ed. Palgrave Macmillan; 2020. <https://doi.org/10.1007/978-3-030-60710-4>
25. Stukel TA, Glazier RH, Schultz SE, et al. Multispecialty physician networks in Ontario. *Open Med*. 2013;7(2):e40-e55.
26. Nuti S, Ferrè F, Seghieri C, Foresi E, Stukel TA. Managing the performance of general practitioners and specialists referral networks: a system for evaluating the heart failure pathway. *Health Pol*. 2020;124(1):44-51. <https://doi.org/10.1016/j.healthpol.2019.11.001>
27. Donabedian A. The quality of care: how can it be assessed? *JAMA*. 1988;260(12):1743-1748. <https://doi.org/10.1001/jama.1988.03410120089033>
28. Bleich SN, Ozaltin E, Murray CKL. How does satisfaction with the health-care system relate to patient experience? *Bull World Health Organ*. 2009;87(4):271-278. <https://doi.org/10.2471/blt.07.050401>
29. Gill L, White L. A critical review of patient satisfaction. *Leader Health Serv*. 2009;22(1):8-19. <https://doi.org/10.1108/17511870910927994>
30. IOM (Institute of Medicine). In: *Crossing the Quality Chasm*. National Academy Press; 2001.
31. Flott KM, Graham C, Darzi A, Mayer E. Can we use patient-reported feedback to drive change? The challenges of using patient-reported feedback and how they might be addressed. *BMJ Qual Saf*. 2017;26(6):502-507. <https://doi.org/10.1136/bmjqs-2016-005223>
32. Gleeson H, Calderon A, Swami V, Deighton J, Wolpert M, Edbrooke-Childs J. Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. *BMJ Open*. 2016;6(8):e011907. <https://doi.org/10.1136/bmjopen-2016-011907>
33. Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness – a systematic review and concept analysis. *PLOS ONE*. 2014;9(9):e107828. <https://doi.org/10.1371/journal.pone.0107828>
34. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013;346:f167. <https://doi.org/10.1136/bmj.f167>
35. OECD. Recommendations to OECD Ministers of Health from the High Level Reflection Group on the Future of Health Statistics - Strengthening the International Comparison of Health System Performance through Patient-Reported Indicators; 2017. Published online. <https://www.oecd.org/els/health-systems/Recommendations-from-high-level-reflection-group-on-the-future-of-health-statistics.pdf>
36. Pennucci F, De Rosis S, Nuti S. Can the jointly collection of PROMs and PREMs improve integrated care? The changing process of the assessment system for the heart failure path in Tuscany Region. *Int J Integrated Care*. 2019;19(4):421. <https://doi.org/10.5334/ijic.s3421>
37. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3(1):e001570. <https://doi.org/10.1136/bmjopen-2012-001570>
38. Kingsley C, Patel S. Patient-reported outcome measures and patient-reported experience measures. *BJA Educ*. 2017;17(4):137-144. <https://doi.org/10.1093/bjaed/mkw060>

39. Nuti S, Seghieri C, Vainieri M. Assessing the effectiveness of a performance evaluation system in the public health care sector: some novel evidence from the Tuscany Region experience. *J Of Manag And Gov*. 2013;17(1):59-69. <https://doi.org/10.1007/s10997-012-9218-5>
40. Nuti S, Vola F, Bonini A, Vainieri M. Making governance work in the health care sector: evidence from a 'natural experiment' in Italy. *Health Econ Pol Law*. 2016;11(1):17-38. <https://doi.org/10.1017/S1744133115000067>
41. Nuti S, Vainieri M. Strategies and tools to manage variation in regional governance systems. In: Sobolev B, ed. *Handbook of Health Services Research*. Springer; 2015.
42. Vainieri M, Vola F, D'Orio G, Cerasuolo D, Parenti A, Nuti S. *Il Sistema Di Valutazione Della Performance Della Sanità Toscana - Report 2020*. Laboratorio Management e Sanità; 2021. <https://performance.santannapisa.it/pes/start/report.php>
43. Murante A, Nuti S. The relationship between patient involvement and hospital accreditation standards. *Int J Care Pathw*. 2012;16(2):44. <https://doi.org/10.1258/jicp.2012.012m12>
44. Murante AM, Vainieri M, Rojas D, Nuti S. Does feedback influence patient - professional communication? Empirical evidence from Italy. *Health Pol*. 2014;116(2):273-280. <https://doi.org/10.1016/j.healthpol.2014.02.001>
45. Murante AM, Seghieri C, Brown A, Nuti S. How do hospitalization experience and institutional characteristics influence inpatient satisfaction? A multilevel approach. *Int J Health Plan Manag*. 2014;29(3):e247-e260. <https://doi.org/10.1002/hpm.2201>
46. De Rosi S, Cerasuolo D, Nuti S. *Using Patient-Reported Measures to Drive Change in Healthcare: The Experience of the Digital, Continuous and Systematic PREMs Observatory in Italy*. BMC Health Services Research; 2020. Published online. <https://doi.org/10.1186/s12913-020-05099-4>
47. Coulter A. Can patients assess the quality of health care?: patients' surveys should ask about real experiences of medical care. *BMJ Br Med J*. 2006;333(7557):1-2. <https://doi.org/10.1136/bmj.333.7557.1>
48. Ferrè F, De Rosi S, Murante AM, et al. Systematic and continuous collection of patient-reported outcomes and experience in women with cancer undergoing mastectomy and immediate breast reconstruction: a study protocol for the Tuscany Region (Italy). *BMJ Open*. 2021;11(1):e042235. <https://doi.org/10.1136/bmjopen-2020-042235>
49. De Rosi S, Pennucci F, Lungu DA, Manca M, Nuti S. A continuous PREMs and PROMs Observatory for elective hip and knee arthroplasty: study protocol. *BMJ Open*. 2021;11(9):e049826. <https://doi.org/10.1136/bmjopen-2021-049826>
50. Pennucci F, De Rosi S, Passino C. Piloting a web-based systematic collection and reporting of patient-reported outcome measures and patient-reported experience measures in chronic heart failure. *BMJ Open*. 2020;10(10):e037754. <https://doi.org/10.1136/bmjopen-2020-037754>
51. Denscombe. *The Good Research Guide*, 6th ed. 6 edizione. Open University Press; 2017.
52. Somekh B. The contribution of action research to development in social endeavours: a position paper on action research methodology. *Br Educ Res J*. 1995;21(3):339-355. <https://doi.org/10.1080/O141192950210307>
53. Pizzini S, Furlan M. *L'esercizio delle competenze manageriali e il clima interno. Il caso del Servizio Sanitario della Toscana*. PC; 2012. <https://doi.org/10.1482/38445>
54. Strokosch K, Osborne SP. Debate: if citizen participation is so important, why has it not been achieved? *Publ Money Manag*. 2020;40(1):8-10. <https://doi.org/10.1080/09540962.2019.1654322>
55. Porter ME, Larsson S, Lee TH. Standardizing patient outcomes measurement. *N Engl J Med*. 2016;374(6):504-506. <https://doi.org/10.1056/nejmp1511701>
56. Bruijn Hde. *Managing Performance in the Public Sector*. Routledge; 2002. <https://doi.org/10.4324/9780203222874>
57. Kodner DL, Spreeuwenberg C. Integrated care: meaning, logic, applications, and implications – a discussion paper. *Int J Integrated Care*. 2002;2(4). Accessed 13 February 2019. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1480401/>
58. Millenson ML. When "patient centred" is no longer enough: the challenge of collaborative health: an essay by Michael L Millenson. *BMJ*. 2017;358:j3048. <https://doi.org/10.1136/bmj.j3048>
59. Lungu DA, Pennucci F, De Rosi S, Romano G, Melfi F. Implementing successful systematic Patient Reported Outcome and Experience Measures (PROMs and PREMs) in robotic oncological surgery—the role of physicians. *Int J Health Plan Manag*. 2020;35(3):773-787. <https://doi.org/10.1002/hpm.2959>
60. Pennucci F, De Rosi S, Nuti S. Closing the gap from theory to practice. The dream of a systematic implementation of patient-reported measures. In: *XXIII IRSPM Annual Conference 2019 - 15th to 18th April*; 2019.
61. Muller JZ. *The Tyranny of Metrics*. Princeton University Press; 2018. Accessed 21 January 2022. <https://press.princeton.edu/books/hardcover/9780691174952/the-tyranny-of-metrics>
62. Damanpour F, Evan WM. Organizational innovation and performance: the problem of "organizational lag". *Adm Sci Q*. 1984;29(3):392-402. <https://doi.org/10.2307/2393031>
63. NYS Health Profiles. Hospitals. Accessed 21 January 2022. <https://profiles.health.ny.gov/hospital/#5.79/42.868/-76.809>
64. Find Healthcare Providers. Compare Care Near You | Medicare. Accessed 21 January 2022. <https://www.medicare.gov/care-compare/?providerType=Hospital%26redirect=true>
65. Care Quality Commission. The London Clinic Quality Report; 2017. Published online 17 November. <https://api.cqc.org.uk/public/v1/reports/10488d95-5aa5-4df0-925a-e6f819170f6c?20210117230946>

66. Varagunam M, Hutchings A, Neuburger J, Black N. Impact on hospital performance of introducing routine patient reported outcome measures in surgery. *J Health Serv Res Pol.* 2014;19(2):77-84. <https://doi.org/10.1177/1355819613506187>
67. Judge A, Arden N, Price A, et al. Assessing patients for joint replacement: can pre-operative Oxford hip and knee scores be used to predict patient satisfaction following joint replacement surgery and to guide patient selection? *J bone Jt Surg Br Volume.* 2011;93(12):1660-1664. <https://doi.org/10.1302/0301-620x.93b12.27046>
68. Dawson J, Fitzpatrick R, Murray D, Carr A. Comparison of measures to assess outcomes in total hip replacement surgery. *BMJ Qual Saf.* 1996;5(2):81-88. <https://doi.org/10.1136/qshc.5.2.81>
69. Murray D, Fitzpatrick R, Rogers K, et al. The use of the Oxford hip and knee scores. *J bone Jt Surg Br Volume.* 2007;89(8):1010-1014. <https://doi.org/10.1302/0301-620x.89b8.19424>
70. Padua R, Zanoli G, Ceccarelli E, Romanini E, Bondi R, Campi A. The Italian version of the Oxford 12-item Knee Questionnaire—cross-cultural adaptation and validation. *Int Orthop.* 2003;27(4):214-216. <https://doi.org/10.1007/s00264-003-0453-x>
71. Martinelli N, Longo UG, Marinozzi A, Franceschetti E, Costa V, Denaro V. Cross-cultural adaptation and validation with reliability, validity, and responsiveness of the Italian version of the Oxford Hip Score in patients with hip osteoarthritis. *Qual Life Res.* 2011;20(6):923-929. <https://doi.org/10.1007/s11136-010-9811-5>
72. NHS UK. Reviews Policy; 2018. Accessed 21 January 2022. <https://www.nhs.uk/our-policies/comments-policy/>
73. OECD. *Health at a Glance 2021.* oecd.org; 2021. Accessed 21 January 2022. <https://www.oecd.org/health/health-at-a-glance/>
74. Gray M, Jani A. Promoting triple value healthcare in countries with universal healthcare. *Healthc Pap.* 2016;15(3):42-48.
75. Bowles S. *The Moral Economy: Why Good Incentives Are No Substitute for Good Citizens.* Yale University Press; 2016.
76. Slawomirski L, van den Berg M, Karmakar-Hore S. Patient-reported indicator survey (PaRIS): aligning practice and policy for better health outcomes. *World Med J.* 2018;64(3):8-13.

AUTHOR BIOGRAPHIES

Sabina De Rosi, PhD, is an assistant professor at the Institute of Management, Department EMbeDS, Scuola Superiore Sant'Anna, in the Healthcare and Management Laboratory (MeS). Her research interest regards the users' evaluation of outcome and experience with public services. Her research is aimed at investigating strategies to enhance personal and social value measurement, assessment and integration into the services' definition, provision and evaluation, by the means of coproduction processes. She is responsible and coordinates research projects on Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs) and co-production.

Francesca Ferrè, PhD in business administration is assistant professor at the Institute of Management, Department EMbeDS, Scuola Superiore Sant'Anna Pisa (Italy), in the Healthcare and Management (MeS) Laboratory. She deals with governance and performance management in healthcare. Her most recent research concerns the development and use of performance information for improving the quality and governance of health systems, with reference to the integration of care into complex care pathways and patient outcomes. At the MeS Laboratory she coordinates research projects in the oncology field. She is currently general secretary of the Italian Health Economics Association (AIES).

Francesca Pennucci, PhD, is a post-doc research fellow at the Institute of Management, Department EMbeDS, Scuola Superiore Sant'Anna. Her research focuses on the patients and general people's role into the provision and evaluation of healthcare services. She is exploring concepts, interventions and methodological tools, which can be helpful in studying how people's role can have an impact on the value creation chain in the healthcare system. She participates in the collection of PROMs measures both for orthopaedic surgery and chronic care pathways with a specific focus on the impact of behavioural and drug therapy adherence and social support. She also participated in the innovative health promotion project 'beFood', where the co-production approach was implemented to enhance adolescents' contribution to the health promotion intervention delivery.

How to cite this article: De Rosis S, Ferrè F, Pennucci F. Including patient-reported measures in performance evaluation systems: patient contribution in assessing and improving the healthcare systems. *Int J Health Plann Mgmt*. 2022;1-22. <https://doi.org/10.1002/hpm.3596>