

Exploring how to trigger the use of patient-reported information for quality improvement in multi-stakeholder governance

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Abstract

Purpose – Value-based healthcare suggested using patient-reported information to complement the information available in the medical records and administrative healthcare data to provide insights into patients' perceptions of satisfaction, experience and self-reported outcomes. However, little attention has been devoted to questions about factors fostering the use of patient-reported information to create value at the system level.

Design/methodology/approach – Action research design is carried out to elicit possible triggers using the case of patient-reported experience and outcome data for breast cancer women along their clinical pathway in the clinical breast network of Tuscany (Italy).

Findings – The case shows that communication and engagement of multi-stakeholder representation are needed for making information actionable in a multi-level, multispecialty care pathway organized in a clinical network; moreover, political and managerial support from higher level governance is a stimulus for legitimizing the use for quality improvement. At the organizational level, an external facilitator disclosing and discussing real-world uses of collected data is a trigger to link measures to action. Also, clinical champion(s) and clear goals are key success factors. Nonetheless, resource munificent and dedicated information support tools together with education and learning routines are enabling factors.

Originality/value – Current literature focuses on key factors that impact performance information use often considering unidimensional performance and internal sources of information. The use of patient/user-reported information is not yet well-studied especially in supporting quality improvement in multi-stakeholder governance. The work appears relevant for the implications it carries, especially for policymakers and public sector managers when confronting the gap in patient-reported measures for quality improvement.

Keywords Value, Performance management, Patient-report data, Collaborative governance, Action research
Paper type Research paper

1. Patient-reported information in the healthcare domain

Delivering high-value health care is aspiration of most universally accessible health care systems whereby the care provided should respond to both technical and allocative prerogative (evidence based and cost effective) but also consider what patients and the

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population value most for their health in terms of experience, satisfaction, preferences and self-reported outcomes (Expert Group on Health Systems Performance Assessment, 2016).

Activating patients and engaging with them is of paramount importance in service systems. For example, patients can play an active role for self-management when having the knowledge, skills and confidence to manage their health (Greene and Hibbard, 2012) or they can work with their peers engaging in peer-influence, peer-support, peer-education groups (Pennucci *et al.*, 2022) thus promoting high-value care. Moreover, patient involvement in healthcare can happen through feedback reporting (Coulter, 2011). Listening to the voice of patients is relevant to support a better understanding of features and characteristics that impact on service experience (which are often interrelated with clinical quality) (Coulter, 2006; Anhang Price *et al.*, 2014) and on outcome of care (Black, 2013). The latest refer to instruments measuring the multidimensional concept of patient-reported health gains where the evaluations include several social, environmental, psychological and physical values (Bonomi *et al.*, 2000) that support the assessment of changes in health-related quality of life or well-being (hereby the terms are used interchangeably). Patient feedbacks are also fundamental for understanding patients' needs and preferences and indirectly accounting for the collaboration dynamics among clinicians or organizations engaged in the care pathways (Nuti *et al.*, 2018). Indeed, much of the care provided occurs between different professionals, units, organizations or setting of care thus collecting the people's voices has also the potential of assessing the collecting achievements and interconnections occurring along the care pathways. Care pathways entail integrated, multidisciplinary and multi-specialist care and when patients and caregivers move between care levels and settings, they can provide feedback regarding the different services and professionals encountered, reducing the silo vision that characterized performance measurement. Linking customer value and evaluation of inter-organizational performance is a prominent approach (Coletta *et al.*, 2021). In this view patient-reported data can support both intra-agency and interagency collaborative performance management (Choi and Moynihan, 2019) which is yet to be fully appreciated due to its complexity. Indeed, when health care professionals and organizations become more and more interdependent, moving towards various form of horizontal or network governance and cross-boundary collaborative actions (Klijn, 2008) inclusion of innovative performance measurement framework should be developed to grasp the effects of collaborations in the healthcare domain (Vainieri *et al.*, 2020; Noto *et al.*, 2022).

For all these reasons, it is important to complement clinical and administrative data with patients-reported information (Black *et al.*, 2016) also to encourage the solving of wicked problems that no single agency has complete responsibility for (Ferlie *et al.*, 2011). Stakeholder theory suggests that performance evaluation should be based on a broader and more balanced set of criteria, that include not only measures of input and process but also stakeholders' satisfaction and direct experience and outcome, or the "stakeholder perspective on value" (Harrison and Wicks, 2013). The presence of multiple stakeholders in the healthcare domain requires balancing competing stakeholders' claims produced by professionals, managers, policy makers, patients and the population therefore there is a need to work on stakeholder salience, terms used in the literature to identify and prioritize stakeholder demands (Mitchell *et al.*, 1997). The claim around patient and person-centred care is well-established in the healthcare literature and in practice, indeed when ranking stakeholder salience patient's value creation ranks high for the legitimacy and urgency that has received over the last decade (Richards *et al.*, 2013). Much attention has been paid to some basic themes about patient-value that are now familiar in the literature, namely, how to measure patients value (Epstein and Street, 2011) or the positive impact of collecting satisfaction and experience measures on clinical outcomes, quality of life (QoL) and patient-doctor communication (Glickman *et al.*, 2010; Meterko *et al.*, 2010; Doyle *et al.*, 2013; Murante *et al.*, 2014).

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. However, due to the subjective nature of satisfaction (patients' individual expectations influenced by their preferences during the use of healthcare services) more objective measures have been proposed such as patient-reported experience (PRE) data collected through instruments that provide the patient's view on the delivery of services. They are not a satisfaction score, they seek to elicit what 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. Usually, patient experience can be studied in a wide range of ways, encompassing both narrative studies and surveys (Ziebland *et al.*, 2013). Another valuable patient-reported information is patient-reported outcome (PRO) that typically address health-related QoL including self-reported symptoms, the functional, emotional and psychosocial status and well-being of patients (Snyder and Aaronson, 2009). The subjective assessment of one's QoL in the healthcare domain is supported by generic or disease specific scales which provide assessment of the patient's level of satisfaction with treatment, outcome and health status.

As anticipated, a lot has been said about how to collect patient information and its potential value, but little attention has been devoted to questions regarding what it means to make use of the data collected to create value for the system, to improve care (Coulter *et al.*, 2014; Flott *et al.*, 2017). Studies applying continuous improvement strategies such as lean thinking have to a little extent considered patient information to improve processes and services to meet with users' satisfaction (Alowad *et al.*, 2021) but more often have focused with on reducing the efficiency gap considering the view of professionals and staff working inside the healthcare organization only (Robinson *et al.*, 2012; Williamsson *et al.*, 2016). Often satisfaction reports among patients are used to validate the implemented solutions afterwards (Al-Kaf *et al.*, 2023) and the balancing between lean thinking and stakeholder management has just received attention with the paper of Bader *et al.* (Bader *et al.*, 2020) which concludes that a disconnection between lean thinking and demands of stakeholders exists, thus reducing the value of decision making in the organizations.

This contribution aims at extending current research about factors (triggers) fostering performance information use based on patient-reported data by introducing the case of the systematic and continuous collection of PRO and PRE data for breast cancer women along their clinical pathway in Tuscany region (Italy) (Ferrè *et al.*, 2021). The study explores the combined use of both PRO and PRE measures that are systematically collected in a longitudinal fashion and reported within a clinical managed network proving a new perspective about the use of patient/user information to support changes in collaborative governance regimes.

Breast cancer is the cancer with the highest incidence among women in all OECD countries, and the second most common cause of cancer death among women. Conventional clinical outcome measures, like survival or mortality rates, are useful but only partially depict the burden caused by breast cancer. Indeed, the diagnostic and treatment for breast cancer has several physical, emotional and social effects proving to be detrimental to the QoL of many women. Also, the complexity and multidisciplinary nature of the care pathway propose an interesting case where interactions with multiple professionals and services spanning across organizations provide the ground to explore actionability of patient-reported information in a multi-stakeholder and multi-level perspective.

The article is organized as follows: Section 2 provides the current state-of-the-art in collection and use of patient-reported data in breast cancer care and summarize the challenges and way forward. Section 3 describes the research method. Section 4 reviews the main theoretical concepts supporting the study. Section 5 presents the study findings. Finally, drawing on such findings, the following sections discusses the results, offers a framework about possible triggers and provides managerial implications as well as the limitations of the study.

2. The case of patient-reported data in breast cancer care

The performance of breast cancer has traditionally considered input and process indicators following international clinical guidelines (EUSOMA, ESMO) which suggest evidence-based qualitative and quantitative quality indicators used also to support the identification of Breast Unit (BU) [1]. Performance indicators include volume of activity, surgery procedure, post-surgery assistance and timeliness of medical therapy or radiotherapy beginning. Moreover, national and European-level-based indicators monitoring the roll out of breast screening program are well established. To a lesser extent performance information about the whole care pathway have been developed. An example of multidimensional performance system for cancer care is reported in the performance management system (PMS) of Tuscany regional healthcare system [2] that adopts a patient-centred and inter-organizational perspective in the assessment of care along the patient care journey (Nutti *et al.*, 2018, 2017a, b). More recently, to have a complete and integrated vision of the patients' pathway, also PRO and PRE data are jointly collected to support quality improvement strategy in cancer care (Ferrè *et al.*, 2021; De Rosi *et al.*, 2022).

PRO for breast cancer have been collected in Tuscany starting in 2016 with a first pilot phase in the BU of the Teaching Hospital of Pisa, that collected pre-operative data in hospital using the digital version of the BREAST-Q validated survey via tablet, with follow-up surveys issued by email. Results from the preliminary study justified the scale-up to regional level (Ghilli *et al.*, 2020). At this point it was decided to additionally integrate PRE in the data collection. In 2018 clinicians were engaged via site visits about survey design and roll-out and the data platform and web-based recruitment tool were developed. A one-year pilot study occurred in 7 out of the 14 BU of Tuscany, focusing on engagement with professionals and increasing BU participation. In 2019, the survey was rolled out in all participating BUs with real-time monitoring of results. This regional-based study was designed as a regional-based continuous and routine collection of patient-reported information on breast cancer care, integrating outcome and experience data. The study protocol is publicly available (Ferrè *et al.*, 2021).

The use of PRO and/or PRE data for specific care paths is a routine that is progressively getting widespread within healthcare systems and organizations, due to the ability of these instruments to provide insights on patients' perceptions about their health status (functional, but also social and psychosocial aspects) during their care path and about their experience and satisfaction with healthcare services. Breast cancer is one of the conditions where patient-reported data have been extensively collected, as reported by recent reviews that synthesize the diffusion of studies on this topic (Char *et al.*, 2021; Seth *et al.*, 2021; OECD, 2021) and by the existence of many PRO surveys validated at an international level (e.g. BREAST-Q, EORTC QLQ BR-23). Despite this diffusion, research typically focuses its attention on the scores about patients' QoL or wellbeing, analysing their trends either comparing the outcomes for different types of surgeries (Lagendijk *et al.*, 2018; Cogliandro *et al.*, 2022; Ghilli *et al.*, 2023) or studying the recovery of the same sample over time (Gjerset *et al.*, 2022; Nelson *et al.*, 2022). Although these contributions provide interesting insights in terms of benchmarking and expectations about patients' pre- and post-operative wellbeing, their significance at system level is still limited, as they are primarily used for clinical study or for personalized medicine when informing clinical decision (Ghilli *et al.*, 2020). When exploring patient experience along the care pathway, research is concerned around assessing breast cancer women experience of care with specific services, such as chemotherapy or breast biopsy (Liu *et al.*, 2021; Soo *et al.*, 2019).

2.1 *The use of patient data: challenges and way forward*

Despite the numerous cases and studies reflecting the interest of various stakeholders to consider strategic the person-centred care model, what patient value is still unsystematically

measured and reported at system level (Rodriguez *et al.*, 2022). Difficulties are often attributed to measurement challenges and a relative lack of trials that formally incorporate measures of patient experience and outcome in quality improvement framework. It appears that patient-centred care may be overshadowed by other aspects of quality such as efficacy and safety or by individual or service-level barriers (OECD, 2019; Rodriguez *et al.*, 2022; Nguyen *et al.*, 2021). Indeed, PMSs which inform health systems and their stakeholders about the quality achieved, are multidimensional systems that hardly integrated patient-reported data thus producing limited support for addressing the patient value and have impact on system's improvement, especially when PRO are measures (De Rosis *et al.*, 2022).

Challenges arise with respect to stakeholders' engagement for data collection both considering the need to have adequate response rates from patients and enrolment rate from professionals, to goal alignment between the multiple uses of patient-reported information, a problem of attributions of responsibility for outcome, as borders between the organisations involved in the care pathway are often blurry thus creating ambiguity in accountability. In addition, surveys used for the collection of PROs—which often use condition-specific scales—require some specific knowledge for their interpretation. Also, there is the risk to select too many items or scales which can cause information overload. On a more technical side, there are measurement challenges, inadequate information technology infrastructure to enable easy collection and use of patient-reported information and questions about the sustainability of data collection to inform PMS.

These are some of the most recurrent challenges reported to have reduced or slow down the adoption on a large scale of patient-reported data (Flott *et al.*, 2017; Lungu *et al.*, 2020; Stover *et al.*, 2021; Glenwright *et al.*, 2023) thus reducing the impact to small scale clinical studies or representing formal fulfilments not contributing to improving efficiency, effectiveness and accountability of organizations (Sharifi and Bovaird, 1995). Even when patient-reported data for cancer care are collected on a large scale at international (OECD, ICHOM), national level such as in the United Kingdom, the United States, Canada, the Netherlands, Australia, Germany or Sweden, or regional level (e.g. Italy) there is a lag in the use of such information as source of intelligence for improving quality of care and designing actions by policymakers (OECD, 2021; Di Maio *et al.*, 2022; Minvielle *et al.*, 2022b). Health policy purposes is still unusual, the reporting use are for accreditation or public reporting, only to a small extent for performance-based payment initiatives (Minvielle *et al.*, 2022b).

A meta-analysis of the literature confirms that measuring performance may not be enough to improve it (Gerrish, 2016), while using performance measures may, under some conditions, contribute to enhance it. Indeed, scholars have pointed out that performance measurement adoption may rather be followed by poor implementation, resistance, manipulation (Broadbent *et al.*, 2001; De Lancer and Holzer, 2001; Moynihan *et al.*, 2012), or limited use of performance measures (Van Dooren *et al.*, 2015). Public management theory suggest that performance needs to be incorporated into the management and policy system to be used (Van Dooren *et al.*, 2015). Incorporation means the intentionally importing data in documents and procedures with the potential and purpose of using them. The purpose is to create the possibility of including patient-related information in the discourse and ultimately in the culture and the memory of professionals and organization similarly as the processes used for incorporating traditional performance-related information based on input, process and clinical outcome indicators. Tools and techniques can be used to anchor information in procedures, documents and organizations, although different organizations can displace different incorporation capacity, which makes it possible to use information functionally. The capacity of anchoring instruments to institutionalized patient-reported information will create condition for use. Examples can be incorporation in clinical health records for monitoring patient health and well-being during treatment and follow-up, in annual patient-based performance reports to professionals for whom feedback on their own delivered care

may facilitate tailoring treatment to different patient groups and to the context for process improvements, in quality improvement plan as a foundation for quality improvement, or in strategic planning to support the introduction of new models of care (e.g. digital health solution), releasing capacity for the system, thus incentivizing best practice (Stover *et al.*, 2021; Minvielle *et al.*, 2022a, b). So, there are different levels and degree of incorporation. Incorporating patient information is necessary but not sufficient for using such information. Indeed, simple formal compliance drives the development of this performance tools with limited impact on practice.

There is more at the back to have patient-reported data used for system improvement; there is a need for a “fit-for-purpose data infrastructure and for an accommodating and motivating performance culture as superstructure” (Van Dooren *et al.*, 2015, p. 8). Using the case of the Tuscany breast cancer patient, we explore the trigger for institutionalized the use of patient-reported data in breast cancer care. The interest is in looking at patient-reported information for internal use to improve system performance, so with an orientation to change.

3. Research method

The contribution is based on an action research design that aimed at discussing possible triggers for the use of patient-reported data when a systematic collection is available for a specific clinical pathway. 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 (Denscombe, 2017). The cues of action research are the involvement with practitioners about phenomena which actually matter to them and the intent to take action in the domain of study (Eden and Huxham, 1996). In the first phase, researchers gathered input from several sources on the topic of patient-report measurements, incorporation and use at system level, by exploring peer-reviewed articles as well as books and grey literature. As a second step, multidisciplinary professionals of the regional breast cancer network were involved by the researchers in exploring the real applications (so the incorporation) of patient-reported information into the real practice both as single professionals and as professionals forming a clinical network so looking both at organizational and system level. This phase was conducted during the monthly coordination meeting organized by the regional breast cancer network in 2021 and 2022: one clinical professional for each of the 14 BUs in Tuscany takes part in the meeting which are coordinated by a clinical leader. Clinical professionals included are mainly senior clinicians with a leadership/managerial role within their BU. A process of identification and discussion of incorporation tools and possible uses of patient-reported data was conducted with professionals during these meetings in an unstructured way. The discussion process was supported by PRE and PRO data collected in Tuscany for breast cancer women with the aim of providing organizations and professionals with first-hand information to be used to achieve improvement along the care pathway (Pennucci *et al.*, 2019). This is in line with the need to support changes in practice that characterizes action research (Somekh, 1995).

4. Literature review

4.1 Scan of factors supporting performance information use in public sector

The first phase included a literature search about what are key factors that have repeatedly shown a strong positive impact on performance information use in public management. In short, the literature stress that there are successful factors at environmental, organizational and individual level (Moynihan and Pandey, 2010; Taylor, 2011; Moynihan and Hawes, 2012; Moynihan and Lavertu, 2012; Saliterer and Korac, 2013; Kroll, 2015; Zhang *et al.*, 2016; Nitzl

et al., 2019). Namely, at macro level stakeholder involvement and participation. At organizational level linked to performance management measurement system maturity, trust in the source of information, information availability, leadership role, support capacity, ability to link measures to action. Other organizational determinants are an innovative (organizational) culture, a unified organizational culture, goal orientation/clarity, administrative flexibility. Finally, at individual level prosocial motivation, familiarity and attitude towards performance management.

Public management literature often considers unidimensional performance and internal source of information. The use of patient-reported or user reported information is not yet well-studied. In addition, the interest is confined to single organization or homogeneous independent organizations. This contribution considers the actionability of information from a multi-stakeholder and multi-level public organization perspective: the perspective of a clinical network thus building also on collaborative governance. Scholars interested in collaborative governance have stressed the importance of understanding the collaborative nature and measuring the collaborative endeavours thus developing framework or matrix for collaborative performance management (McGuire, 2006; Klijn *et al.*, 2010; Emerson and Nabatchi, 2015; Cepiku, 2017). Collaborative performance management is a process that help to formalize mechanisms to share goals even among cross-border actors and consequently is a way to enhance accountability both for performance management and collaboration (Choi and Moynihan, 2019). Such arrangements call for the development of performance measurement following an integrated and holistic performance systems-based framework with multiple data sources, including collection of primary data from survey, interviews or focus group, in addition to archival data (Emerson and Nabatchi, 2015) thus supporting the collection of effectiveness of outcomes information both from the judgement of the participating organizations but also from the final recipient/user of the service (Vainieri *et al.*, 2020).

4.2 Clinical network in cancer care

The organizational model for breast cancer management in Italy focuses on the development of an integrated territory-hospital network, which is organized according to specific diagnosis and treatment services (Ministry of Health, 2014), and the institution of BUs. BU entails a multidisciplinary team approach with clinical coordinator, dedicated radiologist and imaging equipment, dedicated breast surgeon guaranteeing a minimum caseload, often integrated with local services for the delivery of decentralized services including chemotherapy and supportive services to ensure homogenous level of assistance across the territory. There are different organizational models supporting intra and inter-organizational and multi-professional work required in cancer care, often resulting in the development of clinical network. The clinical network configuration has gained prominence as an innovative organizational model for coordinating services across pre-existing vertical or functional boundaries to become more “joined up” (Pettigrew and Fenton, 2000; Addicott *et al.*, 2006), by leveraging collaboration instead of market or quasi-market mechanisms. Different forms of clinical cancer network exist in Italy from simple links between professionals to managed care network where collaboration is based on organizational routines, or other more structured models based on the sharing of practices and path assistance management tools with the introduction of the clinical paths for taking charge of patients and therefore the overall management in a multidisciplinary perspective (Tozzi and Lega, 2009).

The breast clinical network coordinates the nodes that deal with the treatment of breast cancer with reference to the BUs. The regional breast cancer network in Tuscany [3] provides coordination among the 14 BUs and is included in a multi-layer structure for cancer provision.

At the top the regional health administration plays an oversight role on the organization of cancer delivery to ensure equity and high-quality care, then the regional Cancer Network is the governing body for cancer care which provides cancer care strategic and scientific directions and support appropriateness along the cancer journey. Within the Cancer Network the Breast Network is included as a dedicated clinical network for breast cancer. The leadership of the Breast Network is left to a clinical leader (breast surgeon or breast oncology) and the BUs are linked by weak ties (Granovetter, 1973) even though BUs linked to the same Local Health Authority are more goal-aligned, showing higher co-operative links.

5. Qualitative findings from the action research study

Transcripts of meetings have been analysed and coded with reference to the research objectives. Coding was open and general, proceeding to the identification of categories using the constant comparative method (Glaser, 1995). Categories were grouped together leading to the identification of key themes. Data collection continued until saturation occurred. The validity of the key categories was reviewed by showing the set of overriding themes to professionals of the Tuscany breast clinical network. In the end, five main themes related to recurrent challenges in the use of patient data in multi-stakeholder and multi-layer organization emerged.

5.1 *Overriding theme: goal setting*

What is the purpose(s) of patient-reported data? There are multiple uses of patient-reported information to tackle different needs and most often professionals are interested in the patient feedback for clinical decisions, not the aggregate information for quality improvement. At breast cancer network level, the interest is still around the clinical impact of treatment decisions more than care pathway improvement especially for clinical professionals not engaged in management practices. On the contrary, doctor-manager or hybrid professionals have a two-fold—professional and managerial—role thus they are much engaged in discourse around their unit or organization quality improvement but still under-recognize the potential use for system improvement.

5.2 *Overriding theme: measurement challenges*

How to make sense of the data and ensure they are reliable and valid? Scepticisms arise around data provided in feedback collection, especially when professionals and staff have not been trained in the method used in the collection. Even with training, understanding larger surveys is complex and demands strict, time-consuming attention to details. Professionals often raise concerns about issues of representativeness and bias in survey data collection. Namely, the response rate and selection bias are often pointed out as limiting the validity of data. In the case study, data is digitally collected thus increasing a possible digital divide effect while response rate depends a lot on the clinical professionals in charge of enrolling patients. A dual strategy to limit these challenges have been proposed over time: include a performance target related to the annual enrolment rate to stir professionals to be inclusive and increase representativeness and support patients in providing their feedback via reminders.

5.3 *Overriding theme: information overload*

What to look at? Both PRO and PRE measures are routinely collected in Tuscany for breast cancer women in four different time point, pre-operative and three follow up survey resulting in almost 200 items each patient replies in one year time-frame. The amount of information collected is huge and the longitudinal nature of data make data reporting challenging.

Different reporting instruments have been developed: a real-time data platform which provide each professional and health manager with the possibility to visualize aggregated responses (both PRE item and PRO score) for the women they have enrolled. The digital platform allows for punctual and longitudinal views and basic filters/selection. In addition, during the first year of implementation the annual performance report was produced for single BU, then it has been collated in a regional annual patient-based performance review which provides benchmarking and trend results for significant care pathways including breast cancer. Despite the different reporting instruments, it remains difficult for professionals to understand saliency in interpreting data, which requires a multidisciplinary approach and ability to look outside their organizational boundaries. Also, where to focus improvement requires some analytical skills to clearly identify space for improvement and target setting which should consider benchmarking performance, trend and variability (Vainieri *et al.*, 2021).

5.4 Overriding theme: accountability

How responsibilities for outcomes along multi-setting and multi-provider care pathways can be defined? There are still high professional boundaries along the breast cancer care path, for instance mammography screening is often insufficiently integrated into breast centres (Deandrea *et al.*, 2022), which makes the definition of responsibility for outcomes (especially not functional or clinical outcome but emotional outcome) difficult also when considering the experience for the whole care path. Indeed, PRO and PRE can be considered core elements of the performance both of a public service in general 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 (De Rosis *et al.*, 2022). Accountability to the broader network is important but can produce tensions when performance collaboration and agency performance are not aligned or have different priority (Choi and Moynihan, 2019) especially when the formal accountability dynamics continue to focus managers primarily on agency goals as in Tuscany where the multidimensional PMS is still built around organizational performance (Vainieri *et al.*, 2023) even if an inter-organizational perspective in the assessment of care along the patient care journey for cancer care has been introduced (Nuti *et al.*, 2018, 2017a, b).

5.5 Overriding theme: actionability

Who can support changes/transformations in the care pathway? The actionable nature of quality indicators reflects the ability to move from a measurement-based assessment approach to an improvement approach. Even if PRE turn out to be more exploitable than the PRO data (Zhang *et al.*, 2018; De Rosis *et al.*, 2022), in most cases, the transformation of a measure into improvement actions represents a challenge. The Tuscany breast cancer network is organized in a regional clinical network, that is characterized by interdependencies, complexity and continuous change (i.e. network instability). The network is included in a multi-layer structure with the regional health administration, the Cancer Network, the hospitals and Local Health Authorities, the BUs, the clinical leaders and patients. It has developed within the broader regional Cancer Network and is governed by a clinical leader. It should have a “goal-directed” mission, but goals are too many and attention is often limited to clinical aspects. It is multi-professionals where health administrators, clinical professionals with specific health competencies (oncologist, surgeon, etc.) should interact with each other. However, the clinical network is loosely managed, scares resources available and not all stakeholders are represented in the clinical network coordination meeting (traditionally medical oncologist or surgeon, no radiologist, pathologist, psycho-oncologist, breast nurse, nutritionist, nor patient representatives) making changes happening across discipline and across organization difficult.

6. Discussion, implications and limitations

The qualitative observation allows the identification of significant triggers for the actionability and use of patient-reported data for quality improvement in a multi-level, multi-stakeholder and inter-organizational care path. [Figure 1](#) summarized the factors for successful use at macro- and meso level based on the action research conducted in Tuscany.

Namely, at meso level the case suggests that there is a need for communication and engagement of stakeholders, professionals in the first place for PRO data collection, but multi-stakeholder engagement and representation is needed for making information actionable in a multi-level, multispecialty care pathway organized in a clinical network. Moreover, political and managerial support from higher level governance is a vital trigger for legitimizing the use of patient-reported data for quality improvement. Support must be empowering rather than directive, enabling people on the front line to innovate without fear of disincentives if things do not turn out as expected. Collaborative governance literature supports the assumption that investment in performance systems is positively associated with collaboration to achieve intra and inter-organizational priority goals ([Choi and Moynihan, 2019](#)).

At the organizational level, an external facilitator (third party) disclosing results and discussing real-world uses of patient data is deemed to provide support in the critical interpretation and use of the information collected thus providing simple and actionable solutions for quality improvements. Technical guidance also about the methodological aspects is crucial to mediate the scepticism about survey results and enhance process improvements. Overall, feedback collections must balance robust methods against a strategy that will produce timely and easily digestible results ([Flott et al., 2017](#)).

Moreover, literature already reports that dedicated champions have positive influence on changes ([Coulter, 2012](#)). In the case of breast cancer care a dynamic clinical champion that convey trust about robustness and validity of PRO and PRE surveys to other peers and whose focus is to enhance patients' value is essential for driving change at the operational and system level. In the Tuscany breast cancer network, which is characterized by infrequent interactions (low structural link) non-coercive practices (trust building, reputation and closure) should be favoured ([Milward and Provan, 2003](#); [Turrini et al., 2010](#)). In this case, a peer clinical champion is favourable since top-down decisions (coercive practice) may be detrimental to achieve mutual interests. In collaborative governance such as clinical network, also goal salience is a key feature supporting inter-agency collaboration ([Choi and Moynihan, 2019](#)). To this end, clear goals and standards on the use(s) of patient-reported data is key. Goal-setting theory has



Figure 1.
Synthesis of triggers
for activating the use of
patient-reported data
for quality
improvement

a long tradition (Latham *et al.*, 1988; Erez *et al.*, 1985). Stakeholders should be committed to shared goals, plus effective methods for communicating these at every level, help spread and reinforce patient centred values and procedures. Of course, stakeholders expected positive benefits deriving from the collection of such data, so expectations should be constructed to allow a balance trade-off between professional and system-level expectations.

On a technical side, also the availability of information tool(s) supporting the incorporation of this data for different purposes was reported to be a trigger for the effective use of such information. There is a preference to use data for monitoring activities and services provided during the care pathway, to a lesser extent to suggest hospital or system-based improvements. In the future PRO can become an instrument to aid communication about patient's health in multidisciplinary teams and can provide evidence of patients' expectations/needs when discussing service innovation with the regional breast cancer network. Another trigger of a strategic approach to improving patient's experience and outcomes is the adequate resourcing (e.g. time and human resources) for more refined understating of patient-data at organizational level and for systems that help improve care—for example, introducing new appointment and scheduling systems, improving access arrangement, enhancing clarity of discharge information, developing programs for earlier rehabilitation and so on.

Many of the key findings are intuitive but still relevant to document. For example, the health systems should invest in diffuse the desire to learn from other peers in terms of possible actions to promote. To the extent that such information is also available across professionals and/or organizations benchmarking, and bench learning could be used to upgrade systems to specific standards, to adjust standards or even to adjust systems constantly as learning how to learn. Education and learning routine to stimulate a culture around patient-related indicators is a key element support knowledge and trigger use.

The present study does not come out without limitations due to its explorative nature. First, the present research refers to a specific context where patient-reported information has received attention over time at regional level and within the healthcare organization in charge of the management and delivery of inpatient care. Tuscany region has a long tradition is monitoring and assessing patient value including traditional satisfaction and experience measures and outcome-reported information (De Rosi *et al.*, 2020). The context where the application and discussion took place is mature thus can limits its generalizability to context where the culture around patient-reported information is not well established or the collection of data is not systematic thus the purpose of information use is (probably) a mere conformance use (e.g. for accreditation purposes) or are used within clinical studies. Second limitation, the case for cancer care and the organization around a clinical network is quite specific both for the sensibility around patient-reported inform in cancer care which is quite established and the organizational model. There are different clinical network models possible (vertically integrated, hub and spoke, managed clinical networks) thus the implications found should be carefully transfer to other disciplines and organizational models. Third limitation, the perspective gathered focuses on clinical managers (senior clinicians with a managerial role in the BU) but no patient representatives, other health professionals (e.g. nurses) or regional healthcare manager have been involved, thus limiting the views. Finally, in the current study patient-reported data cannot be linked to other quality indicators like patient safety and clinical effectiveness thus restricting the potential use, for example to understand of how patients' experience is linked to clinical outcomes and service administration.

7. Conclusion

Measuring and leveraging on patient-reported performance information to stir health systems toward high-quality care becomes crucial in the era of value-based healthcare.

Patient's 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, to improve their performance accordingly and to push an increasing uptake of activities and enablers of patient-centredness. It seems that measurement is necessary, but that change will not happen without some triggers including effective leadership, goal-clarity and cultural orientation. This work is particularly relevant for the implications it carries, especially for policy-makers and public sector managers when confronting with the gap in patient-reported measure use (non-use of patient-reported data) for quality improvement. Discussion on possible incorporation strategies of patient-reported data in mature performance tools is ongoing (De Rosis *et al.*, 2022). There are complexity issues on the implementation side, but also important trade-offs in a multi-level and multi-professional context where the cultural orientation towards patient-reported data is still in its early stages.

Notes

1. BU should be the clinical reference point for the management of the diagnostic and treatment phase and indicators.
2. <https://performance.santannapisa.it/pes/start/start.php>
3. The Tuscany regional resolution 272/2014 envisaged the establishment of the network of Breast Centers within the Tuscan oncological network, providing a Breast Center with a catchment area of no less than 250,000–300,000 inhabitants.

References

- Addicott, R., McGivern, G. and Ferlie, E. (2006), "Networks, organizational learning and knowledge management: NHS cancer networks", *Public Money and Management*, Vol. 26 No. 2, pp. 87-94, doi: [10.1111/j.1467-9302.2006.00506.x](https://doi.org/10.1111/j.1467-9302.2006.00506.x).
- Al-Kaf, A., Jayaraman, R., Demirli, K., Simsekler, M.C.E., Ghalib, H., Quraini, D. and Tuzcu, M. (2023), "A critical review of implementing lean and simulation to improve resource utilization and patient experience in outpatient clinics", *The TQM Journal*, Vol. 35 No. 3, pp. 734-758, doi: [10.1108/tqm-11-2021-0337](https://doi.org/10.1108/tqm-11-2021-0337).
- Alowad, A., Samaranyake, P., Ahsan, K., Alidrisi, H. and Karim, A. (2021), "Enhancing patient flow in emergency department (ED) using lean strategies—an integrated voice of customer and voice of process perspective", *Business Process Management Journal*, Vol. 27 No. 1, pp. 75-105, doi: [10.1108/bpmj-11-2019-0457](https://doi.org/10.1108/bpmj-11-2019-0457).
- Anhang Price, R., Elliott, M.N., Zaslavsky, A.M., Hays, R.D., Lehrman, W.G., Rybowski, L., Edgman-Levitan, S. and Cleary, P.D. (2014), "Examining the role of patient experience surveys in measuring health care quality", *Med Care Res Rev*, Vol. 71 No. 5, pp. 522-554, doi: [10.1177/1077558714541480](https://doi.org/10.1177/1077558714541480).
- Bader, B.H., Badar, M.A., Rodchua, S. and McLeod, A. (2020), "A study of the balancing of lean thinking and stakeholder salience in decision-making", *The TQM Journal*, Vol. 32 No. 3, pp. 441-460, doi: [10.1108/tqm-04-2019-0108](https://doi.org/10.1108/tqm-04-2019-0108).
- Black, N. (2013), "Patient reported outcome measures could help transform healthcare", *BMJ*, Vol. 346 No. 28 f167, doi: [10.1136/bmj.f167](https://doi.org/10.1136/bmj.f167).
- Black, N., Burke, L., Forrest, C.B., Ravens Sieberer, U.H., Ahmed, S., Valderas, J.M., Bartlett, S.J. and Alonso, J. (2016), "Patient-reported outcomes: pathways to better health, better services, and better societies", *Quality of Life Research*, Vol. 25 No. 5, pp. 1103-1112, doi: [10.1007/s11136-015-1168-3](https://doi.org/10.1007/s11136-015-1168-3).
- Bonomi, A.E., Patrick, D.L., Bushnell, D.M. and Martin, M. (2000), "Validation of the United States' version of the world health organization quality of life (WHOQOL) instrument", *Journal of Clinical Epidemiology*, Vol. 53, pp. 1-12, doi: [10.1016/s0895-4356\(99\)00123-7](https://doi.org/10.1016/s0895-4356(99)00123-7).

- Broadbent, J., Jacobs, K. and Laughlin, R. (2001), "Organisational resistance strategies to unwanted accounting and finance changes: the case of general medical practice in the UK", *Accounting, Auditing and Accountability Journal*, Vol. 14 No. 5, pp. 565-586, doi: [10.1108/eum000000006263](https://doi.org/10.1108/eum000000006263).
- Cepiku, D. (2017), "Collaborative governance", *The Routledge Handbook of Global Public Policy and Administration*, Routledge Taylor & Francis Group, Oxon.
- Char, S., Bloom, J.A., Erlichman, Z., Jonczyk, M.M. and Chatterjee, A. (2021), "A comprehensive literature review of patient-reported outcome measures (PROMs) among common breast reconstruction options: what types of breast reconstruction score well?", *The Breast Journal*, Vol. 27 No. 4, pp. 322-329, doi: [10.1111/tbj.14186](https://doi.org/10.1111/tbj.14186).
- Choi, I. and Moynihan, D. (2019), "How to foster collaborative performance management? Key factors in the US federal agencies", *Public Management Review*, Vol. 21 No. 10, pp. 1538-1559, doi: [10.1080/14719037.2019.1571275](https://doi.org/10.1080/14719037.2019.1571275).
- Cogliandro, A., Salzillo, R., Barone, M., Tenna, S., Cagli, B. and Persichetti, P. (2022), "Direct-to-implant breast reconstruction after unilateral and bilateral mastectomy: cross-sectional study of patient satisfaction and quality of life with BREAST-Q", *Aesthetic Plastic Surgery*, Vol. 47, pp. 1-7, doi: [10.1007/s00266-022-02986-5](https://doi.org/10.1007/s00266-022-02986-5).
- Coletta, L., Vainieri, M., Noto, G. and Murante, A.M. (2021), "Assessing inter-organizational performance through customer value: a literature review", *Journal of Business and Industrial Marketing*, Vol. 36 No. 13, pp. 15-27, doi: [10.1108/jbim-07-2020-0353](https://doi.org/10.1108/jbim-07-2020-0353).
- Coulter, A. (2006), "Can patients assess the quality of health care? Patients' surveys should ask about real experiences of medical care", *BMJ*, Vol. 333 No. 7557, pp. 1-2, doi: [10.1136/bmj.333.7557.1](https://doi.org/10.1136/bmj.333.7557.1).
- Coulter, A. (2011), *Engaging Patients in Healthcare*, Open University Press, Maidenhead.
- Coulter, A. (2012), *Leadership for Patient Engagement*, King's Fund, London.
- Coulter, A., Locock, L., Ziebland, S. and Calabrese, J. (2014), "Collecting data on patient experience is not enough: they must be used to improve care", *BMJ*, Vol. 348.
- De Lancer, J.P. and Holzer, M. (2001), "Promoting the utilization of performance measures in public organizations: an empirical study of factors affecting adoption and implementation", *Public Administration Review*, Vol. 61 No. 6, pp. 693-708, doi: [10.1111/0033-3352.00140](https://doi.org/10.1111/0033-3352.00140).
- De Rosis, S., Cerasuolo, D. and Nuti, S. (2020), "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*, Vol. 20, pp. 1-17, doi: [10.1186/s12913-020-05099-4](https://doi.org/10.1186/s12913-020-05099-4).
- De Rosis, S., Ferrè, F. and Pennucci, F. (2022), "Including patient-reported measures in performance evaluation systems: patient contribution in assessing and improving the healthcare systems", *The International Journal of Health Planning and Management*, Vol. 37 No. 1, pp. 144-165, doi: [10.1002/hpm.3596](https://doi.org/10.1002/hpm.3596).
- Deandrea, S., Ferrè, F., D'Antona, R., Angiolini, C., Bortul, M., Bucchi, L., Caumo, F., Fortunato, L., Giordano, L., Giordano, M., Mantellini, P., Martelli, I., Melucci, G., Naldoni, C., Paci, E., Pau, L., Saguatti, G., Sestini, E., Tinterri, C., Vainieri, M. and Cataliotti, L. (2022), "Integrating mammography screening programmes into specialist breast centres in Italy: insights from a national survey of Senonetwork breast centres", *BMC Health Services Research*, Vol. 22 No. 1, pp. 1-13, doi: [10.1186/s12913-022-08111-1](https://doi.org/10.1186/s12913-022-08111-1).
- Denscombe (2017), *The Good Research Guide*, 6th ed., Open University Press, London.
- Di Maio, M., Basch, E., Denis, F., Fallowfield, L.J., Ganz, P.A., Howell, D., Kowalski, C., Perrone, F., Stover, A., Sundaresan, P., Warrington, L., Zhang, L., Apostolidis, K., Freeman-Daily, J., Ripamonti, C. and Santini, D. (2022), "The role of patient-reported outcome measures in the continuum of cancer clinical care: ESMO Clinical Practice Guideline", *Annals of Oncology*, Vol. 33 No. 9, pp. 878-892, doi: [10.1016/j.annonc.2022.04.007](https://doi.org/10.1016/j.annonc.2022.04.007).
- Doyle, C., Lennox, L. and Bell, D. (2013), "A systematic review of evidence on the links between patient experience and clinical safety and effectiveness", *BMJ Open*, Vol. 3 No. 1, e001570, doi: [10.1136/bmjopen-2012-001570](https://doi.org/10.1136/bmjopen-2012-001570).

- Eden, C. and Huxham, C. (1996), "Action research for management research", *British Journal of Management*, Vol. 7 No. 1, pp. 75-86, doi: [10.1111/j.1467-8551.1996.tb00107.x](https://doi.org/10.1111/j.1467-8551.1996.tb00107.x).
- Emerson, K. and Nabatchi, T. (2015), "Evaluating the productivity of collaborative governance regimes: a performance matrix", *Public Performance Management Revision*, Vol. 38 No. 4, pp. 717-747, doi: [10.1080/15309576.2015.1031016](https://doi.org/10.1080/15309576.2015.1031016).
- Epstein, R.M. and Street, R.L. (2011), "The values and value of patient-centered care", *The Annals of Family Medicine*, Vol. 9 No. 2, pp. 100-103, doi: [10.1370/afm.1239](https://doi.org/10.1370/afm.1239).
- Erez, M., Earley, P.C. and Hulin, C.L. (1985), "The impact of participation on goal acceptance and performance: a two-step model", *Academy of Management Journal*, Vol. 28 No. 1, pp. 50-66, doi: [10.5465/256061](https://doi.org/10.5465/256061).
- Expert Group on Health Systems Performance Assessment (2016), *So what? Strategies across Europe to Assess Quality of Care*, European Commission, Brussels, Belgium.
- Ferlie, E., Fitzgerald, L., Mcgovern, G., Dopson, S. and Bennett, C. (2011), "Public policy networks and 'wicked problems': a nascent solution?", *Public Administration*, Vol. 89 No. 2, pp. 307-324, doi: [10.1111/j.1467-9299.2010.01896.x](https://doi.org/10.1111/j.1467-9299.2010.01896.x).
- Ferrè, F., De Rosis, S., Murante, A.M., Gilmore, K.J., Ghilli, M., Mariniello, D., Nuti, S. and Roncella, M. (2021), "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*, Vol. 11 No. 1, e042235, doi: [10.1136/bmjopen-2020-042235](https://doi.org/10.1136/bmjopen-2020-042235).
- Flott, K.M., Graham, C., Darzi, A. and Mayer, E. (2017), "Can we use patient-reported feedback to drive change? The challenges of using patient-reported feedback and how they might be addressed", *BMJ Quality and Safety*, Vol. 26 No. 6, pp. 502-507, doi: [10.1136/bmjqs-2016-005223](https://doi.org/10.1136/bmjqs-2016-005223).
- Gerrish, E. (2016), "The impact of performance management on performance in public organizations: a meta-analysis", *Public Administration Review*, Vol. 76 No. 1, pp. 48-66, doi: [10.1111/puar.12433](https://doi.org/10.1111/puar.12433).
- Ghilli, M., Mariniello, M.D., Camilleri, V., Murante, A.M., Ferrè, F., Colizzi, L., Gennaro, M., Caligo, M., Scatena, C., Del Re, M., Nuti, S., Caramella, D. and Roncella, M. (2020), "PROMs in post-mastectomy care: patient self-reports (BREAST-Q™) as a powerful instrument to personalize medical services", *European Journal of Surgical Oncology*, Vol. 46 No. 6, pp. 1034-1040, doi: [10.1016/j.ejso.2019.11.504](https://doi.org/10.1016/j.ejso.2019.11.504).
- Ghilli, M., Mariniello, M.D., Ferrè, F., Morganti, R., Perre, E., Novaro, R., Colizzi, L., Camilleri, V., Baldetti, G., Rossetti, E., Coletti, L., Scatena, C., Ghilardi, M., Cossu, M.C. and Roncella, M. (2023), "Quality of life and satisfaction of patients after oncoplastic or traditional breast-conserving surgery using the BREAST-Q (BCT module): a prospective study", *Breast Cancer*, Vol. 30 No. 5, pp. 1-8, doi: [10.1007/s12282-023-01474-1](https://doi.org/10.1007/s12282-023-01474-1).
- Gjerset, G.M., Skaali, T., Seland, M. and Thorsen, L. (2022), "Health-related quality of life, fatigue, level of physical activity, and physical capacity before and after an outpatient rehabilitation program for women within working age treated for breast cancer", *Journal of Cancer Education*, Vol. 38 No. 3, pp. 1-9, doi: [10.1007/s13187-022-02211-6](https://doi.org/10.1007/s13187-022-02211-6).
- Glaser, B.G. (1995), "The constant comparative method of qualitative analysis", *Social Problem*, Vol. 12 No. 4, pp. 436-445, doi: [10.1525/sp.1965.12.4.03a00070](https://doi.org/10.1525/sp.1965.12.4.03a00070).
- Glenwright, B.G., Simmich, J., Cottrell, M., O'Leary, S.P., Sullivan, C., Pole, J.D. and Russell, T. (2023), "Facilitators and barriers to implementing electronic patient-reported outcome and experience measures in a health care setting: a systematic review", *Journal of Patient-Reported Outcomes*, Vol. 7 No. 1, 13, doi: [10.1186/s41687-023-00554-2](https://doi.org/10.1186/s41687-023-00554-2).
- Glickman, S.W., Boulding, W., Manary, M., Staelin, R., Roe, M.T., Wolosin, R.J., Ohman, E.M., Peterson, E.D. and Schulman, K.A. (2010), "Patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction", *Circulation Cardiovascular Qualification Outcomes*, Vol. 3 No. 2, pp. 188-195, doi: [10.1161/circoutcomes.109.900597](https://doi.org/10.1161/circoutcomes.109.900597).
- Granovetter, M. (1973), "The strength of weak ties", *American Journal of Sociology*, Vol. 78 No. 6, pp. 1360-1380, doi: [10.1086/225469](https://doi.org/10.1086/225469).

- Greene, J. and Hibbard, J.H. (2012), "Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes", *Journal of General Internal Medicine*, Vol. 27 No. 5, pp. 520-526, doi: [10.1007/s11606-011-1931-2](https://doi.org/10.1007/s11606-011-1931-2).
- Harrison, J.S. and Wicks, A.C. (2013), "Stakeholder theory, value, and firm performance", *Business Ethics Quarterly*, Vol. 23 No. 1, pp. 97-124, doi: [10.5840/beq20132314](https://doi.org/10.5840/beq20132314).
- Klijn, E. (2008), "Governance and governance networks in europe: an assessment of 10 years of research on the theme", *Public Management Review*, Vol. 10 No. 4, pp. 505-525, doi: [10.1080/14719030802263954](https://doi.org/10.1080/14719030802263954).
- Klijn, E.H., Steijn, B. and Edelenbos, J. (2010), "The impact of network management on outcomes in governance networks", *Public Administration*, Vol. 88 No. 4, pp. 1063-1082, doi: [10.1111/j.1467-9299.2010.01826.x](https://doi.org/10.1111/j.1467-9299.2010.01826.x).
- Kroll, A. (2015), "Drivers of performance information use: systematic literature review and directions for future research", *Public Performance and Management Review*, Vol. 38 No. 3, pp. 459-486, doi: [10.1080/15309576.2015.1006469](https://doi.org/10.1080/15309576.2015.1006469).
- Legendijk, M., Van Egdom, L.S.E., Richel, C., van Leeuwen, N., Verhoef, C., Lingsma, H.F. and Koppert, L.B. (2018), "Patient reported outcome measures in breast cancer patients", *European Journal of Surgical Oncology*, Vol. 44 No. 7, pp. 963-968, doi: [10.1016/j.ejso.2018.03.009](https://doi.org/10.1016/j.ejso.2018.03.009).
- Latham, G.P., Locke, E.A. and Erez, M. (1988), "Resolving scientific disputes by the joint design of crucial experiments by the antagonists: application to the erez-latham dispute regarding participation in goal setting", *Journal of Applied Psychology*, Vol. 73 No. 4, pp. 753-772, doi: [10.1037/0021-9010.73.4.753](https://doi.org/10.1037/0021-9010.73.4.753).
- Liu, L., Wu, Y., Cong, W., Hu, M., Li, X. and Zhou, C. (2021), "Experience of women with breast cancer undergoing chemotherapy: a systematic review of qualitative research", *Quality of Life Research*, Vol. 30 No. 5, pp. 1249-1265, doi: [10.1007/s11136-020-02754-5](https://doi.org/10.1007/s11136-020-02754-5).
- Lungu, D.A., Pennucci, F., De Rosis, S., Romano, G. and Melfi, F. (2020), "Implementing successful systematic Patient Reported Outcome and Experience Measures (PROMs and PREMs) in robotic oncological surgery-The role of physicians", *The International Journal of Health Planning and Management*, Vol. 35 No. 3, pp. 773-787, doi: [10.1002/hpm.2959](https://doi.org/10.1002/hpm.2959).
- McGuire, M. (2006), "Collaborative public management: assessing what we know and how we know it", *Public Administration Review*, Vol. 66 No. 1, pp. 33-43, doi: [10.1111/j.1540-6210.2006.00664.x](https://doi.org/10.1111/j.1540-6210.2006.00664.x).
- Meterko, M., Wright, S., Lin, H., Lowy, E. and Cleary, P.D. (2010), "Mortality among patients with acute myocardial infarction: the influences of patient-centered care and evidence-based medicine", *Health Service Research*, Vol. 45 No. 5, pp. 1188-1204, doi: [10.1111/j.1475-6773.2010.01138.x](https://doi.org/10.1111/j.1475-6773.2010.01138.x).
- Milward, B.H. and Provan, K.G. (2003), "Managing the hollow state. Collaboration and contracting", *Public Management Review*, Vol. 5 No. 1, pp. 1-18, doi: [10.1080/1461667022000028834](https://doi.org/10.1080/1461667022000028834).
- Ministry of Health (2014), "State-Regions Conference. Presidenza del Consiglio dei Ministri", N. 185, available at: https://www.osservatorionazionale screening.it/sites/default/files/allegati/DOC_045999_185%20%20CSR%20PUNTO%204.pdf (accessed 18 December 2014).
- Minvielle, E., Di Palma, M., Mir, O. and Scotté, F. (2022a), "The use of patient-reported outcomes (PROs) in cancer care: a realistic strategy", *Annals of Oncology*, Vol. 33 No. 4, pp. 357-359, doi: [10.1016/j.annonc.2021.12.010](https://doi.org/10.1016/j.annonc.2021.12.010).
- Minvielle, E., Fierobe, A., Fourcade, A., Ferrua, M., di Palma, M., Scotté, F. and Mir, O. (2022b), "The use of patient-reported outcome and experience measures for health policy purposes: a scoping review in oncology", *Health Policy*, Vol. 129, 104702, doi: [10.1016/j.healthpol.2022.12.010](https://doi.org/10.1016/j.healthpol.2022.12.010).
- Mitchell, R.K., Agle, B.R. and Wood, D.J. (1997), "Toward a theory of stakeholder identification and salience: defining the principle of who and what really counts", *The Academy of Management Review*, Vol. 22 No. 4, pp. 853-886, doi: [10.2307/259247](https://doi.org/10.2307/259247).
- Moynihan, D. and Hawes, D. (2012), "Responsiveness to reform values: the influence of the environment on performance information use", *Public Administration Review*, Vol. 72 No. 1, pp. S95-S105, doi: [10.1111/j.1540-6210.2012.02653.x](https://doi.org/10.1111/j.1540-6210.2012.02653.x).

- Moynihan, D. and Lavertu, S. (2012), "Does involvement in performance management routines encourage performance information use? Evaluating GPRA and PART", *Public Administration Review*, Vol. 72 No. 4, pp. 592-602, doi: [10.1111/j.1540-6210.2011.02539.x](https://doi.org/10.1111/j.1540-6210.2011.02539.x).
- Moynihan, D. and Pandey, S.K. (2010), "The big question for performance management: why do managers use performance information?", *Journal of Public Administration Research and Theory*, Vol. 20 No. 4, pp. 849-866, doi: [10.1093/jopart/muq004](https://doi.org/10.1093/jopart/muq004).
- Moynihan, D., Pandey, S. and Wright, B. (2012), "Setting the table: how transformational leadership fosters performance information use", *Journal of Public Administration Research and Theory*, Vol. 22 No. 1, pp. 143-164, doi: [10.1093/jopart/mur024](https://doi.org/10.1093/jopart/mur024).
- Murante, A.M., Vainieri, M., Rojas, D. and Nuti, S. (2014), "Does feedback influence patient-professional communication? Empirical evidence from Italy", *Health Policy*, Vol. 116 Nos 2-3, pp. 273-280, doi: [10.1016/j.healthpol.2014.02.001](https://doi.org/10.1016/j.healthpol.2014.02.001).
- Nelson, J.A., Chu, J.J., McCarthy, C.M., Stern, C.S., Shamsunder, M.G., Pusic, A.L. and Mehrara, B.J. (2022), "BREAST-Q react: clinical reference values for the BREAST-Q in post-mastectomy breast reconstruction patients", *Annals of Surgical Oncology*, Vol. 29 No. 8, pp. 1-14, doi: [10.1245/s10434-022-11521-4](https://doi.org/10.1245/s10434-022-11521-4).
- Nguyen, H., Butow, P., Dhillon, H. and Sundaresan, P. (2021), "A review of the barriers to using patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) in routine cancer care", *Journal of Medical Radiation Sciences*, Vol. 68 No. 2, pp. 186-195, doi: [10.1002/jmrs.421](https://doi.org/10.1002/jmrs.421).
- Nitzl, C., Sicilia, M. and Steccolini, I. (2019), "Exploring the links between different performance information uses, NPM cultural orientation, and organizational performance in the public sector", *Public Management Review*, Vol. 21 No. 5, pp. 686-710, doi: [10.1080/14719037.2018.1508609](https://doi.org/10.1080/14719037.2018.1508609).
- Noto, G., Coletta, L. and Vainieri, M. (2022), "Measuring the performance of collaborative governance in food safety management: an Italian case study", *Public Money and Management*, Vol. 42 No. 8, pp. 627-636, doi: [10.1080/09540962.2020.1840043](https://doi.org/10.1080/09540962.2020.1840043).
- Nuti, S., Vainieri, M. and Vola, F. (2017a), "Priorities and targets: supporting target-setting in healthcare", *Public Money and Management*, Vol. 37 No. 4, pp. 277-284, doi: [10.1080/09540962.2017.1295728](https://doi.org/10.1080/09540962.2017.1295728).
- Nuti, S., De Rosi, S., Bonciani, M. and Murante, A.M. (2017b), "Rethinking healthcare performance evaluation systems towards the people-centredness approach: their pathways, their experience, their evaluation", *Healthcare Paper*, Vol. 17 No. 2, pp. 56-64, doi: [10.12927/hcpap.2017.25408](https://doi.org/10.12927/hcpap.2017.25408).
- Nuti, S., Noto, G., Vola, F. and Vainieri, M. (2018), "Let's play the patients music: a new generation of performance measurement systems in healthcare", *Management Decision*, Vol. 56 No. 10, pp. 2252-2272, doi: [10.1108/md-09-2017-0907](https://doi.org/10.1108/md-09-2017-0907).
- OECD (2019), "Patient-reported indicators for assessing health system performance. Measuring what matters: the patient-reported indicator surveys", available at: <https://www.oecd.org/health/health-systems/Measuring-what-matters-the-Patient-Reported-Indicator-Surveys.pdf>
- OECD (2021), "Patient reported outcome measures (PROMs) for breast cancer care, Technical report on data collected between 2020 and 2021", available at: <https://www.oecd.org/health/paris/OECD-PaRIS-PROMs-for-breast-cancer-care.pdf>
- Pennucci, F., De Rosi, S. and Nuti, S. (2019), "Can the jointly collection of PROMs and PREMs improve integrated care? The changing process of the assessment system for the health failure path in Tuscany Region", *International Journal of Integrated Care (IJIC)*, Vol. 19 No. 4, 421, doi: [10.5334/ijic.s3421](https://doi.org/10.5334/ijic.s3421).
- Pennucci, F., De Rosi, S., Murante, A.M. and Nuti, S. (2022), "Behavioural and social sciences to enhance the efficacy of health promotion interventions: redesigning the role of professionals and people", *Behavioural Public Policy*, Vol. 6 No. 1, pp. 13-33, doi: [10.1017/bpp.2019.19](https://doi.org/10.1017/bpp.2019.19).

- Pettigrew, A. and Fenton, E. (2000), *The Innovating Organization*, Sage, London, (ISBN 9781446219379).
- Richards, T., Montori, V.M., Godlee, F., Lapsley, P. and Paul, D. (2013), "Let the patient revolution begin", *BMJ*, Vol. 346 No. 7908, pp. 1-2, doi: [10.1136/bmj.f2614](https://doi.org/10.1136/bmj.f2614).
- Robinson, S., Radnor, Z.J., Burgess, N. and Worthington, C. (2012), "SimLean: utilising simulation in the implementation of lean in healthcare", *European Journal of Operational Research*, Vol. 219 No. 1, pp. 188-197.
- Rodriguez, H.P., Kyalwazi, M.J., Lewis, V.A., Rubio, K. and Shortell, S.M. (2022), "Adoption of patient-reported outcomes by health systems and physician practices in the USA", *Journal of General Internal Medicine*, Vol. 37 No. 15, pp. 3885-3892, doi: [10.1007/s11606-022-07631-0](https://doi.org/10.1007/s11606-022-07631-0).
- Saliterer, I. and Korac, S. (2013), "Performance information use by politicians and public managers for internal control and external accountability purposes", *Critical Perspectives on Accounting*, Vol. 24 Nos 7-8, pp. 502-517, doi: [10.1016/j.cpa.2013.08.001](https://doi.org/10.1016/j.cpa.2013.08.001).
- Seth, I., Seth, N., Bulloch, G., Rozen, W.M. and Hunter-Smith, D.J. (2021), "Systematic review of breast-Q: a tool to evaluate post-mastectomy breast reconstruction", *Breast Cancer: Targets and Therapy*, Vol. 13, pp. 711-724, doi: [10.2147/bctt.s256393](https://doi.org/10.2147/bctt.s256393).
- Sharifi, S. and Bovaird, T. (1995), "The financial management initiative in the UK public sector", *International Journal of Public Administration*, Vol. 18 Nos 2-3, pp. 467-490, doi: [10.1080/01900699508525017](https://doi.org/10.1080/01900699508525017).
- Snyder, C.F. and Aaronson, N.K. (2009), "Use of patient-reported outcomes in clinical practice", *Lancet*, Vol. 374 No. 9687, pp. 369-370, doi: [10.1016/s0140-6736\(09\)61400-8](https://doi.org/10.1016/s0140-6736(09)61400-8).
- Somekh, B. (1995), "The contribution of action research to development in social endeavours: a position paper on action research methodology", *British Educational Research Journal*, Vol. 21 No. 3, pp. 339-355, doi: [10.1080/0141192950210307](https://doi.org/10.1080/0141192950210307).
- Soo, M.S., Shelby, R.A. and Johnson, K.S. (2019), "Optimizing the patient experience during breast biopsy", *Journal of Breast Imaging*, Vol. 1 No. 2, pp. 131-138, doi: [10.1093/jbi/wbz001](https://doi.org/10.1093/jbi/wbz001).
- Stover, A.M., Haverman, L., van Oers, H.A., Greenhalgh, J., Potter, C.M., Haverman, L., Manalili, K., Roberts, N., Santana, M. and van Oers, H. (2021), "Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives in routine care settings", *Quality of Life Research*, Vol. 30 No. 11, pp. 3015-3033, doi: [10.1007/s11136-020-02564-9](https://doi.org/10.1007/s11136-020-02564-9).
- Taylor, J. (2011), "Factors influencing the use of performance information for decision making in Australian state agencies", *Public Administration*, Vol. 89 No. 4, pp. 1316-1334, doi: [10.1111/j.1467-9299.2011.02008.x](https://doi.org/10.1111/j.1467-9299.2011.02008.x).
- Tozzi, V. and Lega, F. (2009), *Il cantiere delle reti cliniche in Italia: analisi e confronto di esperienze in oncologia*, Rapporto OASI, Milano, Egea.
- Turrini, A., Cristofoli, D., Frosini, F. and Nasi, G. (2010), "Networking literature about determinants of network effectiveness", *Public Administration*, Vol. 88 No. 2, pp. 528-550, doi: [10.1111/j.1467-9299.2009.01791.x](https://doi.org/10.1111/j.1467-9299.2009.01791.x).
- Vainieri, M., Noto, G., Ferre, F. and Rosella, L.C. (2020), "A performance management system in healthcare for all seasons?", *International Journal of Environmental Research and Public Health*, Vol. 17 No. 15, 5590, doi: [10.3390/ijerph17155590](https://doi.org/10.3390/ijerph17155590).
- Vainieri, M., Ferrè, F. and Manetti, S. (2021), "An integrated framework to measure the performance of inter-organizational programme on health technology assessment", *Sustainability*, Vol. 13 No. 7, 3873, doi: [10.3390/su13073873](https://doi.org/10.3390/su13073873).
- Vainieri, M., Ferrè, F., D'Orio, G., Cerasuolo, D. and Nuti, S. (2023), *Il sistema di valutazione della performance della sanità toscana*, Pacini, Pisa, ISBN: 9791254862575.
- Van Dooren, W., Bouckaert, G. and Halligan, J. (2015), *Performance Management in the Public Sector*, Routledge, London, New York, ISBN: 9780415738101.

-
- Williamsson, A., Eriksson, A. and Dellve, L. (2016), "Organization of change agents during care process redesign in Swedish health care", *Journal of Hospital Administration*, Vol. 5 No. 3, 20, doi: [10.5430/jha.v5n3p20](https://doi.org/10.5430/jha.v5n3p20).
- Zhang, H., Van de Walle, S. and Zhuo, Y. (2016), "Does trust in the performance measurement organization influence how public managers use performance information?", *Public Performance and Management Review*, Vol. 40 No. 2, pp. 409-430, doi: [10.1080/15309576.2016.1239583](https://doi.org/10.1080/15309576.2016.1239583).
- Zhang, B., Lloyd, W., Jahanzeb, M. and Hassett, M.J. (2018), "Use of patient-reported outcome measures in quality oncology practice initiative-registered practices: results of a national survey", *Journal of Oncology Practical*, Vol. 14 No. 10, pp. e602-e609, doi: [10.1200/jop.18.00088](https://doi.org/10.1200/jop.18.00088).
- Ziebland, S., Coulter, A., Calabrese, J.D. and Locock, L. (2013), *Understanding and Using Health Experiences*, Oxford University Press, Oxford, ISBN: 9780199665372.

Further reading

- Fujisawa, R. and Klazinga, N.S. (2017), "Measuring patient experiences (PREMS): progress made by the OECD and its member countries between 2006 and 2016", OECD Health Working Papers No. 102, OECD Publishing, Paris, doi: [10.1787/893a07d2-en](https://doi.org/10.1787/893a07d2-en).
- Quentin, W., Partanen, V.M., Brownwood, I. and Klazinga, N. (2019), "Measuring healthcare quality in Europe. Characteristics, effectiveness, and implementation of different strategies", *Improving Healthcare Quality in Europe*, Vol. 31.

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