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Original Investigation

Integrating the Use of Patient-Reported Outcomes for Both Clinical Practice and Performance Measurement: Views of Experts from 3 Countries

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Policy Points:

- The patient-reported outcome (PRO) is a standardized method for measuring patients' views of their health status. Our international study showed that experts in clinical practice and performance measurement supported the integrated collection of PRO data for use in both clinical care and performance measurement.
- The measurement of PROs to support patient-provider decisions and the use of PRO performance measures to evaluate health care providers have developed both separately and in parallel.
- The use of PROs would benefit from a shared vision by health care providers, purchasers of care, and patients regarding the aims and purposes of the various applications; and the establishment of trust among stakeholders concerning the prudent use of PRO performance measures.

Context: Patient-reported outcomes (PROs) can play an important role in patient-centered health care by focusing on the patient's health goals guiding therapeutic decisions. When aggregated, PROs also can be used for other purposes, including comparative effectiveness research, practice improvement,

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assessment of the performance of clinicians and organizations, and as a metric for value-based payments. The feasibility of integrating the use of PROs for these various purposes on a wide scale has not yet been demonstrated. Our study was conducted to inform policymakers of prudent next steps for implementing PROs in clinical practice and performance measurement programs in order to maximize their impact on the quality of health care.

Methods: We conducted a qualitative study, interviewing 58 experts and leaders from 37 organizations (response rate: 88%) in the United States, England, and the Netherlands. Respondents included clinical practitioners ($n = 30$), measure developers ($n = 11$), and leaders of performance measurement programs ($n = 17$). We used a qualitative content analysis to assess current strategies for applying PROs in clinical practice and performance measurement and to identify barriers to and facilitators of further implementation.

Findings: The use of PROs in clinical practice and for performance measurement has developed both separately and in parallel. Experts across the stakeholder spectrum support the collection of PRO data in an integrated manner that would enable using the data for these distinct purposes. We identified 2 main concerns about the feasibility for integrated use of PRO data: the complexity of establishing routine data collection and the tension among stakeholders when using PRO data for different purposes. These contrasting stakeholder views suggested varying interests among clinicians, measure developers, and purchasers of care.

Conclusions: Data collection approaches that support the use of PROs in health care are underdeveloped, need better integration with clinical care, and must be tailored to the characteristics of the health care system. Enabling the sustainable use of PROs will require a shared vision of clinical professionals, purchasers, and patients, with a prudent selection of the steps in implementing PROs that will maximize their impact on the quality of health care.

Keywords: patient-reported outcomes, health care policy, quality of care, performance measurement.

The patient-reported outcome (PRO) is a standardized method for measuring patients' views of their health and health-related quality of life, and the results are expected to play several roles in advancing patient-centered health care. In clinical practice, clinicians can use them to focus on a patient's individual health goals and guide diagnostic and treatment decisions. PROs are central to patient-centered comparative effectiveness research.[1,2] Aggregated across

patients, PRO results can be used to guide efforts for clinical quality improvement, for public reporting, and for value-based payments.[3] PROs also can be used in comparative performance reporting for practice improvement and made part of the continuous professional development and maintenance of certification of licensure.[4] Many observers believe that PRO methodology could be integrated, enabling the same PROs to be used for multiple purposes.[5,6]

Typically, PROs are assessed with patient-reported outcome measures (PROMs), which are collected from questionnaires containing either multi-item scales or single-item measures. PROMs can be generic, measuring the health-related quality of life, or disease specific, assessing components of patients' functioning related to a specific disease or condition.[7] For example, a well-known generic PROM, the Short Form Health Survey (SF-36), measures overall quality of life.[8] The Patient Reported Outcome Measurement Information System (PROMIS), developed over the past decade, provides item banks for measuring patient-reported outcomes for a wide variety of diseases and conditions, thus forming a hybrid of generic and disease-specific measures.[9]

If PRO measures are aggregated across patients, they can be used as performance measures (PRO-PM) to assess and compare the quality of care of health care providers or provider organizations.[10] In health care, performance measures are typically used either as a summative mechanism for accountability to payers, purchasers, and the public or as a formative mechanism to assist clinicians and organizations in quality improvement. For government and regulators, performance information is used to evaluate the quality of the health care system at an aggregate level. For purchasers, such as health insurers, insight into the comparative quality of health care providers informs selective contracting and payment incentives. Performance information also helps patients and consumers in choosing health plans and providers.[11] Several clinical quality indicators are now used to support quality improvement initiatives in hospitals, ambulatory practices, and other settings.[12-14]

To encourage the use of PROs in clinical practice and performance measurement, the National Quality Forum (NQF) in the United States has described a pathway for developing PRO-based performance measures that integrate measurements of both clinical practice and performance.[15] In addition, standards for developing PRO-PMs have been published, emphasizing the importance of aligning clinical

practice and performance measurement.[16] An important issue in the use of PROs is the application of case-mix adjustment, stratification, or risk adjustment to provide fair and meaningful comparisons.[7]

Although case studies in several countries have illustrated the use of PRO data in clinical practice settings[17,18] and their implementation at the health system level to measure performance,[19-23] these nascent efforts have not yet demonstrated the feasibility of integrating the use of PROs on a wide scale. Insights from earlier work on factors that may facilitate or impede the introduction and implementation of innovations may help designers of strategies to introduce and implement PROs.[24,25] In this article, we summarize experiences in 3 countries with using PROs in clinical practice and performance measurement. The goal is to help policymakers choose the best next steps for implementing PROs in clinical practice and performance measurement programs in order to maximize their impact on the quality of health care.

Methods

Design and Setting

We hypothesized that integrating the use of PROs for several purposes is feasible but also will confront formidable implementation barriers. To identify barriers and facilitators in the implementation of the routine use of PROs, we conducted structured interviews with selected experts working in clinical practice, quality measure development, and quality reporting programs in the United States, England, and the Netherlands. This international sample allowed us to compare the experiences implementing PROs in different health systems. We chose these 3 nations because of our knowledge of current policy developments and initiatives for using PROs in health care organizations at both the national and local levels.

Philip Van der Wees and Eric Schneider developed a structured interview guide to answer 3 key policy questions:

- What are the current approaches to using PRO measures in clinical practice and performance measurement?
- What are the facilitators of and barriers to the further implementation of PRO measures in clinical practice and performance measurement?

- Is it possible to integrate PRO data collection for use in clinical practice and performance measurement?

At the start of the interview, we described the use of PROs in clinical practice and performance measurement using the NQF's definition: "Any report of the status of a patient's health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."[15] In our interviews we focused on patient-reported—that is, self-reported—*health* outcomes. We asked the participants to describe their familiarity with 3 constructs: patient-reported outcomes (PROs), PRO measures (PROMs), and PRO performance measures (PRO-PMs).

Selection of Key Informants. We identified key informants (experts, researchers, and leaders) through purposeful sampling from 3 sources: (1) health care organizations known for implementing the routine use of PROs in clinical practice, (2) organizations developing PRO measures and studying their reliability and validity, and (3) quality-reporting programs as potential users of PRO performance measures. We then used published descriptions of organizations implementing PROs[18] to identify key informants in the 3 countries through our professional networks. A similar approach was used to find reporting programs at the health system level. By email, we invited experts and leaders in 42 organizations stratified by care setting and country. All key informants received written information about the purpose and procedure of the interviews and were asked to confirm, by email, their participation. Our study protocol was approved by the RAND Human Subjects Protection Committee.

Interviews. Our interview guide was tailored to the specific context of health care organizations, measure developers, and reporting programs. Questions were aimed at identifying the current application of PRO measures; barriers to and facilitators for the use of PROMs at the micro-, meso-, and macro-health system levels; and the use of PROMs for evaluating the quality of care. Van der Wees used the interview guide to conduct semistructured interviews either by telephone or face-to-face after obtaining oral informed consent based on a standardized consent script approved by the RAND Human Subjects Protection Committee. Interviews were audio-recorded only after obtaining the respondent's permission.

Data Analysis. Interviews were transcribed verbatim and entered into the Atlas.ti software program for qualitative data analysis. We used qualitative content analysis with a directed approach. Content analysis is suitable for concept development or model building, and a directed approach uses themes derived from existing theory or research to guide the initial coding.[26] The framework and the initial corresponding codes based on relevant aspects of the innovation process and its categories of factors[24] were developed by Van der Wees and Maria Nijhuis-van der Sanden. Independently, they coded the same 6 transcripts from key informants in clinical practice, measure developers, and reporting programs in order to identify any new codes that might have emerged from the interviews. They then used a log of these new codes to modify the coding framework. After 2 rounds of discussion, they reached a consensus on the revised framework, which was reviewed for consistency by Gert Westert and Eric Schneider. Van der Wees and Nijhuis-van der Sanden applied the final list of codes to all the interviews.

Based on the coded interview transcripts, we conducted a thematic analysis to identify current strategies for using PRO measures in clinical practice and performance measurement, as well as any barriers to and facilitators for extending and expanding implementation. The analysis, based on determinants for implementing innovations,[24,27] included (1) characteristics of the sociopolitical context, such as rules, legislation, and patient characteristics; (2) characteristics of the organization, such as information technology (IT) infrastructure; (3) characteristics of the person adopting the innovations, such as knowledge, skills, and perceived support from colleagues; and (4) characteristics of the innovation (ie, PRO measurement), such as complexity, validity, and relative advantage. We synthesized the results across interviews to identify common and disparate themes by PRO use category and setting.

Findings

Table 1 is an overview of the respondents by their involvement in PROs and setting. We received responses from 37 organizations (response rate: 88%). The key informants helped find additional experts ($n = 21$) in their organizations. As a result, we conducted interviews with 58 respondents: 30 experts in clinical practice, 11 measure developers, and 17 experts in provider performance measurement.

Table 1. Participating Organizations and Key Informants

	Reporting Programs		Measure Developers		Providers		Total	
Country	O	I	O	I	O	I	O	I
United States	6	10	3	5	7	20	16	35
England	3	3	3	3	4	4	10	10
Netherlands	3	4	3	3	5	6	11	13
Total	12	17	9	11	16	30	37	58

Participants listed in absolute numbers.
O: Organizations; I: Informants.

All the respondents were familiar with the concept of PROs and were able to describe examples of PRO measures. Most of the participants were familiar with the intended use of PRO performance measures (comparing providers or organizations based on patient-reported health outcomes). The respondents from performance measurement programs concentrated primarily on the development of performance measures. For example, a reporting program expert stated: "Our survey is not a physician-level survey. It's assessing plan performance. It's a different effort to get it at the physician level." This contrasted with the participants in clinical practice who focused on using PRO measures for clinical care. One clinical expert reported: "We are not considering the use of PROs for benchmarking yet. That might be interesting, but we first want to establish meaningful use of PROs in the clinician-patient interaction."

Current Approaches in the 3 Countries to Using PRO Measures

Our analysis identified 3 main approaches to implementing PRO measurement. The first approach is collecting data to guide clinical care decisions related to screening and diagnosis, treatment planning, and treatment evaluation. Our interviews revealed that many organizations were still trying to establish a routine approach to data collection and to integrate this into the organization's workflow and the electronic health record.

The second approach is collecting data designed and managed by national, regional, or state organizations rather than the local health care provider. The central organizations may recruit via mail or electronic communication (or a health care provider may recruit patients), returning the completed questionnaires to a central survey manager or survey vendor. The data are not used in the direct clinical care of individual patients but to calculate performance results for organizations or providers. We found 3 examples of this route: a national approach in England for patients who undergo certain elective surgical procedures, the Health Outcomes Survey (HOS) in the United States for a sample of patients in Medicare managed care, and the joint collection of PRO and patient experience data in the Netherlands, based on samples of patients who had completed their treatment.

The third approach is a hybrid of the others. Data are collected by and used in the health care organization, as in the first approach, followed by an aggregation of data at the state or national level to measure performance. In the state of Minnesota, data are routinely collected by health care organizations from electronic health records and then are used to compare the quality of state-level providers. The Group Health Cooperative in the United States uses a health risk assessment with outcomes entered by patients into their electronic health record, with the data used to facilitate clinical care and also for reporting purposes. In mental health care in the Netherlands, local routine outcome monitoring was used to establish a national measurement method. All mental health care organizations have a mandate to collect and submit PRO data to a database to create a national benchmark for the quality of care. As one expert commented: "The primary goal of routine outcome measurement is to support clinicians in diagnosis and treatment. On top of that, we said we can aggregate these data to assess the quality of care."

Integration of Data Collection for Different Purposes

We found strong support for integrated data collection, regardless of the approach, especially for using the data for different purposes (see Box 1). But experts also expressed concerns about the feasibility of integrating the use of PRO data, based on 2 main issues: (1) the complexity of

integrated data collection and (2) the tension among the stakeholders in regard to using the PRO data for different purposes (see Box 2).

Box 1. Representative Quotations From Experts Supporting Integrated PRO Data Collection

"With an electronic health record, you could start to incorporate patient-reported outcomes in your process of care, and then you could use it on a local level for clinical improvement and clinical tracking and the need for clinical intensification. You could use it for quality improvement on a health system level."

"Groups of clinicians who are responsible for some population could be the ideal unit for this sequence of local collection of data within the process of care that's then usable both for clinical uses and for quality improvement uses at the aggregated level and then stands as a legitimate marker for national reporting as well as at a more highly aggregated level."

"Aggregate data collection only allows for quality improvement at a very generic level. I hope that the clinical system will move quickly to bring bottom-up measures that are safe and acceptable for a single clinician, a group of clinicians for quality improvement, and then at aggregate level for national reporting."

Box 2. Representative Quotations Illustrating Stakeholders' Contrasting Views of Using PRO Data for Different Purposes

Complexity

"If you were collecting it at the physician level and aggregating it up to a health plan, it probably would be extremely challenging. It is probably not impossible but extremely challenging."

"So I know the National Quality Forum is beginning to look at performance measures around patient reported measures and they make a distinction between the measure, the patient reported measure and the performance measure. But as of now I don't think they even have norms, what would be good performance, what would be poor performance. And that's where we need to get to. We have a lot of work."

"I think one of the challenges probably would be understanding all of the hurdles to implementation. So clearly, patient-reported outcomes for a physician or to use in actually providing care is probably a little bit easier than getting to the point where you can use it to assess the quality of a provider type. I think that's where kind of the hurdle probably is."

Tension Among Stakeholders

"It doesn't automatically translate that those same data [collected in clinical practice] can also be used in an accountability context because I think the stakes are much, much higher and the science ought to be a whole lot stronger in those settings."

"What makes it complicated is the tension between the benchmarking organization and the health care organization. You have to engage clinicians in the added value of benchmarking for quality improvement; otherwise they will only submit data to keep the insurance company happy."

"That you're not going to bear down to an individual clinician to take responsibility for the clinical outcomes in a way that unfairly holds them responsible for things, either that happened outside of their control or happened too far temporally outside of their control or happened just because some patients, through bad luck, are sicker than others."

Complexity. Experts emphasized that integrated data collection is important to maintain the long-term involvement and sustainability of clinicians. They noted that integrated data collection strengthens the patient-clinician interaction and encourages use of the data by clinicians and patients. But the complex steps required to integrate the data for the use of PROs in both clinical practice and performance measurement were perceived as challenging. Reliable and valid data to support performance measures require integrated routine electronic data collection in clinical practice. As one expert summarized the project: "So this is hard, it's really hard to get this up and running. To get it electronically and to get it into the record is tough. There's going to be some tipping point that occurs at some point in time where everything becomes electronic. Once that happens, I think we'll make rapid progress."

Differences Among Stakeholders' Views. Interests in PRO data varied among clinicians, measure developers, and purchasers of care. Experts reported that clinicians fear that administrators will misuse the data when creating performance measures. In addition, the patients' varying

circumstances will result in differences in individual outcomes that are not attributable to care, which may lead to misinterpretation of the data. Clinicians worry that inadequate case-mix control will bias comparisons of quality and hurt their reputation and reimbursement.

Performance measure developers were concerned about the reliability and validity of data collected in clinical practice. The need to collect data according to strict protocols to ensure comparability may conflict with the day-to-day uncertainties and fluctuations in clinical practice. Therefore the participants need to agree on the selected performance measures and interpret the results cautiously. The tension among the participants on this point was most apparent in mental health care in the Netherlands, where an integrated PRO collection system is currently being implemented. One expert warned: "An important message to insurance companies is that they should be very prudent in using PRO data for reimbursement consequences. If they jump to conclusions based on the wrong interpretation of data, clinicians may be tempted to manipulate data or withdraw from participation."

Building trust between clinicians and purchasers of care was considered a key factor for success, requiring the engagement and commitment of all parties to allay concerns and gain the cooperation of stakeholders. Several experts mentioned that for public reporting, only aggregate data at the level of the organization should be used. Data on individual clinicians should be used confidentially only in quality improvement to avoid unintended consequences related to misinterpretation.

Advancing PRO Measurement: Facilitators and Barriers

Sociopolitical Context. PRO measurement is important to policymakers in the 3 countries we studied, and experts recognize it as an important motivator for quality improvement. However, we also found significant barriers. Although policymakers, payers, and purchasers of health care typically want short-term results, implementing these innovative measurement programs may take several years. Moreover, tackling the complexity of the routine collection of sufficiently valid and reliable data to profile provider performance will require a substantial investment. Using PRO data to support contracting or commissioning decisions will depend on the development of reliable and valid performance measures and the interpretation and translation of the results. How

to do this routinely has not yet been worked out fully. As one expert commented: "I think what's most important is the data are accurately analyzed, that the data actually be reflective of the practice or the individual practitioner or the population of patients. That's my biggest concern."

Experts from the United States confirmed the complex steps in the NQF pathway that are necessary for the successful integration of data collection. According to an expert, "I think they [NQF] are premature in using patient-reported outcomes as system-level performance measures. I don't think we know enough, and I think their scientific basis for doing this is inadequate, and I think they're going to get a lot of pushback about it."

Organizational Level. The respondents identified 3 main factors for successfully establishing routine data collection: (1) the availability of electronic data collection, (2) the need to avoid disrupting the workflow, and (3) the need to obtain high response rates from patients. Most of the experts regarded electronic data collection and the integration of data in electronic health records as an opportunity to provide immediate feedback to clinicians and to avoid duplication of data storage. But they also brought up the challenge of complexity: Having sophisticated IT capabilities implies a complex system, which makes it more difficult to integrate routine PRO measurement into electronic health records. Although organizations with stand-alone PRO-recording applications were interested in integrating the data collection into electronic health records, they also saw an advantage in their stand-alone approach that avoided the challenge of embedding PRO collection in the electronic health record. One expert reported: "Then we changed our electronic medical record system, which has actually set us back a few years because we had it exactly the way we wanted it, but we couldn't integrate it into the new system."

Experts considered avoiding a disruption of workflow to be crucial to establishing routine data collection. Experts envision patients being encouraged to complete questionnaires at home or in the clinic before their visit with a physician. Several health care organizations in our sample even made available computers or tablets in the waiting room, and some arranged for assistance to patients in completing the questionnaires. One expert maintained: "Workflow is one of the biggest issues. Because if you're going to integrate this, they have to change the way they do their workflow. So the schedulers who are on the phone have to instruct the

patient how to sign up for the portal and manage. There are a lot of operational details around adjusting changing workflows."

Experts saw an important barrier in the collection of longitudinal data with repeated measurements: "The hard part is if you're following patients longitudinally over time and you want to get deltas with differences, it's really hard to get a high percentage of follow-up patients at 3 months, 6 months, or a year because patients don't want to then fill out the survey, particularly if they're not being attached back to an appointment."

Role of Clinicians. Experts agreed that the meaningful use of PRO data in the patient-provider interaction requires clinicians' full engagement: "It is essential that the clinician discuss the outcomes with the patient. Patients are very responsive to filling out questionnaires if they feel that the results are actually being used for their treatment."

Opinion leaders ("champions") were viewed as necessary to advocate for the added value of collecting patient-reported outcomes and to lead the needed changes. Experts suggested that implementing PRO measures in clinical practice should start with small-scale projects with willing clinicians, rather than imposing projects on teams with limited interest or readiness. Participants emphasized that "just getting started" is a useful way to overcome initial resistance because clinicians can then see directly that PRO data reveal aspects of their patients' health that support clinical decisions. An expert pointed out: "And so it was really the team that set the questions and told me how they wanted to see the data . . . they led the process, and me allowing them to lead the process and being willing to compromise and collaborate with them was what drove this."

Experts confirmed that clinicians may have difficulty interpreting PRO data, making them reluctant to discuss the results with their patients: "The most important thing is that clinicians are able to interpret the data . . . you should teach them how to interpret the scores, about minimal important differences, and how to use the data in diagnosis and evaluation of treatment."

PRO Measurement as an Innovation. When viewing PRO measurement as an innovation, we identified 2 main themes: the relationship between the characteristics of PRO measures and the consequences of using the measures for varying purposes, and the further development of PRO performance measures. PRO measures can be described in several ways, but a key distinction is whether they are generic or disease specific,

because this may alter the value of PRO measures for specific purposes. Clinicians usually prefer disease-specific measures for use in clinical practice, and policymakers prefer generic quality-of-life measures to enable comparability across conditions, across settings of care, and across health care interventions. Experts generally agreed that the parallel use of both types of measures seems feasible as long as the burden for patients is limited. The use of PROMIS item banks with their applicability across a wide variety of diseases and conditions was considered promising for implementation in clinical practice, even though they currently are being used mainly for research purposes.

Aggregation of data, effective recruitment, and high response rates are important components of successful performance measurement. For procedures with a short-term follow-up, such as the approach in England for elective surgery, the response rates of patients is high, 75%.[28] But the experts acknowledged that response rates may fall during long-term follow-ups in managing chronic disease. One expert observed: "What we see is that it is very important that clinicians discuss the results of the PRO measurements with their patients. Patients really appreciate this interaction and are then very happy to comply with long-term follow-up."

The experts disagreed on the importance of risk adjustment. Some advocated for limited risk adjustment to avoid overadjustment and the loss of relevant differences in providers' outcomes. Others argued that risk adjustment should be as sophisticated as possible to adjust for confounders and to address the fear of clinicians that data will be misinterpreted and lead to providers' cherry-picking of patients. The stratification of patients into subgroups instead of risk- or case-mix adjustment was viewed as a way of serving both objectives.

Discussion

Our international study showed that experts from 3 key stakeholder groups support the integrated collection of PRO data and the use of PRO results for several different purposes. Many building blocks for establishing an integrated approach are already in place, such as the availability of PRO measures, data system capabilities, motivation of stakeholders, and performance-reporting systems able to use the results. The implementation of PRO measurement in the patient-provider

interaction and the use of PRO performance measures at a national or state level, however, continue to be in 2 separate worlds—the clinical care sphere and the performance measurement and reporting sphere—with limited communication between them.

We identified several examples of integrated approaches suggesting that integration is feasible, but we also described the complexity of steps necessary to establish integrated data collection. The examples also highlighted stakeholders' competing views of using PRO data for both clinical practice and performance measurement. Integrating PRO data collection has advantages. Data need to be collected only once, thereby increasing efficiency and reducing the burden for patients and clinicians. In addition, the feedback of aggregated data derived from the same source used to support clinical care for individual patients makes the results more meaningful to clinicians and promotes patient-centered care. Such meaningful use could encourage the routine collection of data and enhance patients' participation.

The integrated data collection model also has some disadvantages, chief among them being the complexity of integrating data collection into clinical practice and the imperfectly aligned requirements for the reliability and validity of measures useful in clinical practice and as performance measures.[7,10,15] The data collection should be rigorous but should not interfere with clinical practice workflow. The variability of practices' workflow will be a challenge to obtaining truly comparable PRO data. Because these different purposes appeal to different stakeholders with different interests and expectations, an integrated approach must deal not only with the reliability and validity of data, but also with choosing appropriate analyses and presentations of data. We do not know yet whether the desired alignment of collaborative objectives for PRO measurement is possible. The challenge in bridging these interests is not unique to PRO measurement but also is relevant to other types of performance measures, such as those for identifying low-value services.[29,30]

Barriers and facilitators related to the implementation of PRO measurement have been assessed in 2 published systematic reviews. One examined routine outcome measurement in allied health professions—including PRO measures—at the individual, managerial, and organizational levels.[31] The second categorized facilitators for and barriers to practical considerations, attitudes toward the value of the data, methodological concerns, and the impact of feedback on patient care.[32] Our study points to the relative priority of these barriers and facilitators

among experts currently attempting to implement PRO data collection and also looks at the challenge of integrating the use of PRO measurement for both clinical practice and performance measurement.

Implications for Policy

Our key informants identified programs in 3 countries, suggesting that the integrated collection and use of PRO data in both clinical practice and performance measurement are feasible. But we also learned that the effort to create these programs is substantial. First, providers, patients, and purchasers of care must agree on a common vision. Building trust among stakeholders that the data will not be misused seems fundamental to success. Second, integrated measurement systems have not been fully validated for evaluating the quality of care, as the science that supports the use of PROs as performance measures is still rudimentary compared with other areas of measurement. For example, little is known about the effects on quality and access to care of purchasers using PRO data for selective contracting or other incentive programs. Third, a commitment by health care providers to the collection of reliable and valid data using standardized protocols would be necessary to sustain such a program. Fourth, we believe that if patients are to become advocates, they must see this data collection as beneficial to their health and health care. Engaging patients and the public in the integrated use of PRO measurement to establish patient-centered care and accountability could be an important motivator for the other stakeholders.

Is the use of PRO data in performance measurement worth these substantial efforts? Several systematic reviews show that the feedback of PRO data to health care professionals in clinical practice can improve the quality of patient care, with stronger evidence for improvements in the care process than in health outcomes.[33-35] Given the small number of programs, there are few rigorous studies of the effects of using PRO data as a performance measurement tool. A systematic review by Boyce and Browne[34] identified only 1 study of performance feedback at the group level, and it found no effect on performance. Another recently published study suggested that hospital performance in England was not altered by the introduction of routine patient-reported outcome measures in surgery.[36] The authors concluded that the manner in which results are communicated, the need for timely feedback, and the inclusion of suggested actions to improve PRO results might be

necessary. Qualitative studies show that the use of PRO data as a quality improvement tool is complex and that feedback tailored to support the interpretation of PRO data is necessary to stimulate quality improvement. This becomes even more important with the feedback of aggregate data in understanding variation in outcomes among clinicians or provider organizations.[32,37] These findings echo studies of the use of patient experience data in performance measurement.[38] These studies suggest the need to embed performance measurement in a formal quality improvement program. In addition, the use of PROs would benefit from greater clarity regarding the aims and purposes of each application, together with a better understanding of the circumstances that are likely to enhance success. The existing evidence to inform this is currently the subject of a realist synthesis of the literature.[39]

The 3 nations we studied have different approaches to financing and organizing health care. While the themes we uncovered were common to these countries, our results suggest that policy solutions are likely to differ among health care systems. The English approach, which is relatively centralized, may be feasible in a system with a national health service but not in a health care system that relies heavily on the private sector (such as in the United States). England has enhanced the use of PRO data in clinical practice by making patient-level data available to providers for quality improvement purposes.[40] Regional organizations help providers[41] and commissioners[42] interpret and use the PRO data. The Netherlands encourages the integrated use of PRO measures in clinical practice and performance measurement for the long term by aligning local initiatives of provider organizations with a national program for data collection.[22] In the United States, initiatives are aimed at embedding PRO measurement strategies in electronic health records, an approach that carries some risk, as it depends on the cooperation of several relevant, but independent, private stakeholders.[43]

Limitations

The 3 jurisdictions we studied may not describe how PROs are collected and used in other countries that may be actively pursuing this agenda (eg, Canada, Sweden, and Australia). Our selection of organizations and key informants was based on purposive sampling informed by published research papers and reports available to us. This sampling strategy is not

designed to produce a representative sample of experts in the field but to provide a base for identifying determinants and exploring future directions for implementation and policy. Although our sample may limit the generalizability of our findings, our results do seem to align with the themes identified in a recent systematic review.[32] By design, our sample did not include patients, consumers, or payers because we were interested primarily in the dynamics among provider organizations, measure developers, and quality-reporting programs. Repeating the study with a broader set of stakeholders could be useful.

Conclusion

We found that experts in clinical practice and performance measurement supported the integrated collection of PRO data for use in both clinical care and performance measurement. At present, though, the measurement of PROs to support patient-provider decisions and the use of PRO performance measures to evaluate health care providers operate in 2 separate spheres. Several steps could advance integration, including meaningful feedback of PRO performance data to clinicians and connecting the data to clinical practice in order to stimulate quality improvement activities. The use of PROs would benefit from greater clarity regarding the aims and purposes of the various applications; a shared vision by providers, purchasers, and patients; and the establishment of trust among clinicians, provider organizations, and purchasers of care concerning the prudent use of PRO performance measures.

References

1. Ahmed S, Berzon RA, Revicki DA, et al. The use of patient-reported outcomes (PRO) within comparative effectiveness research: implications for clinical practice and health care policy. *Med Care.* 2012;50(12):1060-1070.
2. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA*. 2012;307(15):1583-1584.
3. Reuben DB, Tinetti ME. Goal-oriented patient care—an alternative health outcomes paradigm. *N Engl J Med*. 2012;366(9):777-779.

4. Chaudry H, Rhyne J, Waters S, Cain FE, Talmage L. Maintenance of licensure: evolving from framework to implementation. *J Med Regul.* 2012;97(4):8-13.
5. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013;346:f167.
6. Wu AW, Kharrazi H, Boulware LE, Snyder CF. Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research. *J Clin Epidemiol.* 2013;66(Suppl. 8):S12-S20.
7. Cella D, Hahn EA, Jensen SE, Butt Z, Nowinski J, Rothrock N. *Methodological Issues in the Selection, Administration and Use of Patient-Reported Outcomes in Perfomance Measurement in Health Care Settings*. Washington, DC: National Quality Forum (NQF); 2012.
8. Ware JE Jr, Kosinski M, Gandek B, et al. The factor structure of the SF-36 Health Survey in 10 countries: results from the IQOLA project. International Quality of Life Assessment. *J Clin Epidemiol*. 1998;51(11):1159-1165.
9. PROMIS. Patient Reported Outcomes Measurement Information System. http://www.nihpromis.org/about/overview. Accessed October 15, 2013.
10. Deutsch A, Gage B, Smith L, Kelleher C. *Patient-Reported Outcomes in Performance Measurement*. Washington, DC: National Quality Forum (NQF); 2012.
11. Van der Wees PJ, Nijhuis-van der Sanden MW, van Ginneken E, Ayanian JZ, Schneider EC, Westert GP. Governing healthcare through performance measurement in Massachusetts and the Netherlands. *Health Policy*. 2014;116(1):18-26.
12. Friedberg MW, Coltin KL, Safran DG, Dresser M, Zaslavsky AM, Schneider EC. Associations between structural capabilities of primary care practices and performance on selected quality measures. *Ann Intern Med*. 2009;151(7):456-463.
13. Sequist TD, Schneider EC, Li A, Rogers WH, Safran DG. Reliability of medical group and physician performance measurement in the primary care setting. *Med Care*. 2011;49(2):126-131.
14. Black N. Time for a new approach to assessing the quality of hospitals in England. *BMJ*. 2013;347:f4421.
15. NQF. Patient-Reported Outcomes (PROs) in performance measurement. http://www.qualityforum.org/Projects/n-r/Patient-Reported_Outcomes/Patient-Reported_Outcomes.aspx. Accessed September 15 2013.
16. Basch E, Goertz C, Adams Dudley R, et al. *Standards for Developing and Evaluating Patient-Reported Outcome (PRO) Performance Measures*.

Chicago, IL: Physician Consortium for Performance Improvement (PCPI); 2012.

17. de Beurs E, den Hollander-Gijsman ME, van Rood YR, et al. Routine outcome monitoring in the Netherlands: practical experiences with a web-based strategy for the assessment of treatment outcome in clinical practice. *Clin psychol psychother*. 2011;18(1):1-12.
18. Nelson EC, Hvitfeldt H, Reid R, et al. *Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health*. Lebanon, NH: Dartmouth Institute for Health Policy and Clinical Practice; 2012.
19. Browne J, Jamieson L, Lewsey J. et al. *Patient Reported Outcome Measures (PROMs) in Elective Surgery: Report to the Department of Health*. London: Health Services Research Unit, London School of Hygiene & Tropical Medicine & Clinical Effectiveness Unit, Royal College of Surgeons of England; 2007.
20. Jones N, Jones SL, Miller NA. The Medicare Health Outcomes Survey program: overview, context, and near-term prospects. *Health Qual Life Outcomes*. 2004;2:33.
21. KUR. Swedish Clinical Registries (KUR): outcome registries to drive development of value guided health care. http://www.kurnet.se/english/. Accessed October 2, 2012.
22. Miletus. Stichting Miletus. http://www.stichtingmiletus.nl/. Accessed March 27, 2013.
23. Devlin NJ, Appleby J. *Getting the Most out of PROMS: Putting Health Outcomes at the Heart of NHS Decision-Making*. London: King's Fund; 2010.
24. Fleuren M, Wiefferink K, Paulussen T. Determinants of innovation within health care organizations: literature review and Delphi study. *Int J Qual Health Care*. 2004;16(2):107-123.
25. Hildon Z, Allwood D, Black N. Patients' and clinicians' views of comparing the performance of providers of surgery: a qualitative study. *Health Expect*. December 20, 2012.
26. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
27. Grol R, Wensing M, Eccles MDD. *Improving Patient Care: The Implementation of Change in Clinical Practice*. 2nd ed. Oxford: Wiley Blackwell; 2013.
28. Department of Health. *Patient Reported Outcome Measures in England: A Methodology for Identifying Outliers*. London: Department of Health; 2011.
29. Baker DW, Qaseem A, Reynolds PP, Gardner LA, Schneider EC. Design and use of performance measures to decrease

low-value services and achieve cost-conscious care. *Ann Intern Med*. 2013;158(1):55-59.

30. Qaseem A, Snow V, Gosfield A, et al. Pay for performance through the lens of medical professionalism. *Ann Intern Med*. 2010;152(6):366-369.
31. Duncan EA, Murray J. The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC Health Serv Res*. 2012;12:96.
32. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf*. February 6, 2014.
33. Valderas JM, Kotzeva A, Espallargues M, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res*. 2008;17(2):179-193.
34. Boyce MB, Browne JP. Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review. *Qual Life Res*. 2013;22(9):2265-2278.
35. Kotronoulas G, Kearney N, Maguire R, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol*. 2014;32(14):1480-1501.
36. 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 Policy*. 2014;19(2):77-84.
37. Boyce MB, Browne JP, Greenhalgh J. Surgeon's experiences of receiving peer benchmarked feedback using patient-reported outcome measures: a qualitative study. *Implement Sci*. 2014;9:84.
38. Friedberg MW, Steel Fisher GK, Karp M, Schneider EC. Physician groups' use of data from patient experience surveys. *J Gen Intern Med*. 2011;26(5):498-504.
39. Greenhalgh J, Pawson R, Wright J, et al. Functionality and feedback: a protocol for a realist synthesis of the collation, interpretation and utilisation of PROMs data to improve patient care. *BMJ Open*. 2014;4(7):e005601.
40. HSCIC. Patient Reports Outcome Measures: PROMs publications. www.hscic.gov.uk/proms. Accessed November 12, 2013.
41. YHQO. *Quarterly PROMs Report*. York: Yorkshire and the Humber Quality Observatory; 2012.

42. NHS-Eastern-Cheshire. *Outcomes Benchmarking Support Pack: CCG Level*. Manchester: NHS Eastern Cheshire; 2013.
43. Basch E, Torda P, Adams K. Standards for patient-reported outcome-based performance measures. *JAMA*. 2013;310(2):139-140.

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