Measurement, Research, Transparency, and Accountability

Chapter 7

Data plays a dual role in patient and family engagement. Data can be used to inform patients and families about the success of efforts by health care providers to embrace patient and family engagement, and it can also drive consumer decision making. As health care systems and organizations engage in efforts to increase patient and family engagement, it is important to measure these efforts. Measurement is critical to conduct a successful evaluation, to determine if effort and costs yield benefits, to choose between strategies, and to develop a research base for future decision making.[1] Measurement results can be used to inform patients and families about the success of efforts by health care providers to embrace patient and family engagement. Additionally, to fully engage in and make informed decisions about their care, patients and families need access to clear and comprehensive information about cost, quality, treatment options, and their own health and health care needs.

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Measuring Patient and Family Engagement

Several tools are available for providers and health systems to use in order to measure patient and family engagement.[2] However, the validity of these tools has not been clearly established.[3] In addition, the impact of positive and negative results of such measures has not been clearly associated with outcomes such as cost and quality.[4,5] Patient and family engagement can be measured by self-assessment or inventory, and by surveying patients. The most common tool to ask patients about their engagement experiences is a patient experience survey such as the Press Ganey survey.[6] This survey may do an excellent job in assessing some aspects of the patient experience, but a more developed and nuanced assessment of engagement is not a component of the Press Ganey survey.[7] One pilot study tested questions that could be included in a patient satisfaction survey and included the following dimensions: family participation in care, explanation of staff roles, staff supported family presence, and staff respected patients culture and spiritual beliefs.[8] This type of assessment could be easily incorporated into practice and health system assessments of patient experience, but would require new or redirected resources. Other strategies for directly involving patients in an assessment of patient engagement include the use of focus groups, interviews, and input from patient advisors and patient and family advisory committees, as well as newer methods including shadowing and guided tours.[2] These tools are useful for informing decision makers about a variety of perspectives but they are qualitative assessments and have not been validated.

In addition to patient-level assessments, health systems, hospitals, and practices can administer self-assessments of patient centeredness. Self-assessment tools are available for a variety of health units and can be used to assess the presence or absence of practices or policies, as well as the implementation of practices. These tools include an assessment of leadership commitment and culture. The Institute for Patient- and Family-Centered Care has a variety of specific tools available that can be used to assess various aspects patient centeredness.[9]

As part of the Centers for Medicare and Medicaid Partnership for Patients, the North Carolina Quality Center (NCQC), within the North Carolina Hospital Association (NCHA), has supported a Hospital Engagement Network in Virginia and North Carolina. The network has hosted over a 100 learning activities, including work to decrease complications, reduce readmissions, improve quality, and increase patient centeredness and engagement to aid in all of these goals.[10] Although the networks are no longer operating, NCQC will continue to serve as a resource for hospitals, health systems, and others concerned with patient engagement and patient-centeredness.

Payers have begun to use patient satisfaction as well as quality measures to tier reimbursement. An example of tiered reimbursement is the Blue Cross Blue Shield Blue of North Carolina Quality Physician Program. Practices and providers that adopt certain quality standards and take on training programs and modules are eligible for enhanced reimbursement. Recognition as a patient-centered medical home and trainings in cultural competency start to approach patient engagement, but more direct tools, practices, and measurement of patient engagement could be adapted into tiered reimbursement.[11] As research continues to demonstrate the value of patient and family engagement initiatives, it will be in the interest of health systems in value-based arrangements to embrace patient and family engagement programs. Evolving reimbursement models will be one of the most effective ways to ensure the adoption of practices to best support patient and family engagement. As research on patient and family centered care emerges, compelling data to support improved quality and decreased cost may drive health systems to more fully embrace this work, as accountable care organizations and shared risk/shared savings become more common in our health care delivery system.

Recommendation 7.1: Measure the Impact of Patient and Family Engagement

The North Carolina Hospital Association, in partnership with the North Carolina Medical Society and organizations that provide care management services, should work with patients and families to develop, collect, and disseminate patient and family engagement measures in hospitals and ambulatory settings across the state.

Transparency and Accountability

Patient and family engagement in health care will ultimately require improved access to information. Some patients want information such as the cost of care, how often a doctor or hospital performs a certain type of procedure, and the complication rate. If patients have more information about the cost of their health care, they may make more informed decisions about treatment. As they become responsible for more out of pocket costs, patient groups have shown more readiness to partner in their care, use available tools, and find ways to lower their costs.[12] While adhering to principles of health literacy and shared decision-making, health systems and payers can provide patients with more information about costs of health care, helping them select higher value care that better meets their needs.[13]

Such data may be available for the most common procedures, but it may also be difficult to access and not always easy to understand. Further, putting insurance companies between patients and providers has made understanding data related to pricing difficult. Patients may be most interested in knowing their out of pocket cost—the cost of a unit of care after their insurance has negotiated a rate and paid the part for which the patient is not responsible. The cost of a particular unit of care to the provider varies by insurance provider and is not easily available, particularly in advance of treatment.[14] Patients are also motivated to understand the quality of a provider or a hospital for a given type of care or service, which is also not always readily available.[15,16] Complication rates are often correlated to provider experience and volume, but some types of care are provided so rarely that estimating complication rates may be unreliable predictors of quality. For example, estimating surgical quality with such data as procedure counts per year, rates of infections, and blood clots is relatively straightforward, although this data may still not be widely available. While there are now numerous measures of quality, agreeing upon the 'right' metrics for estimating quality has been more difficult.[17]

To fully engage in and make informed decisions about their care, patients and families need access to clear and comprehensive information about cost, quality, treatment options, and their own health and health care needs.

Information on facility and provider quality is increasingly available for resourceful patients with high health and computer literacy levels. The Centers for Medicare and Medicaid Services host and maintain several websites including: Hospital Compare, Physician Compare, Nursing Home Compare, Dialysis Facility Compare, and Home Health Compare.[18] One of the most complete of these websites is Hospital Compare. It includes 44 measures of hospital quality, patient experience, and cost.[19] However, data are still quite limited. It is not currently possible for an individual consumer with a particular insurance product to determine cost. Physician Compare currently contains virtually no information, except a physician's name, location, and whether or not he/she accepts Medicare. Available data for nursing homes, home health agencies, and dialysis centers are better than what is available for individual physicians, but not nearly as useful as hospital data.[18] It is also not yet clear whether or not patients use this kind of data when choosing a provider of care, or if choosing a care provider in this manner impacts quality and cost.[15,16]

Some states use a state run data system known as an all-payer claims database to report both cost and quality metrics to consumers.[20] A variety of proprietary sites disseminate information about health care quality and availability. With the exception of websites developed by commercial insurers, these generally disseminate the same publicly available information as that what is made available by the federal government, with the addition of feedback at an individual level. Feedback such as customer reviews may be posted to the websites in a non-systematic way by individual clients.

Private payers have increasingly become more involved in sharing quality and cost information with their beneficiaries. However, private payers can only produce stable estimates of cost and quality where particular payers have a large market share, and for procedures that are commonly performed. Private payers, perhaps, have the greatest opportunity to contribute to public information sharing and transparency. Private payers have claims data available, which can be used to assess aspects of quality, and can also leverage practice and facility level audits of quality. Lastly, private payers have the final say on an individual patient's financial responsibility. Blue Cross Blue Shield of North Carolina has recently launched a website (http://www.bcbsnc.com/content/providersearch/treatments) to allow patients greater access to cost and quality data.[21] If this information is complete and patients understand how to use it, they can take advantage of this data to make more informed decisions about the choice of a health care provider. This information may have a powerful effect on their health care. However, only large insurers with a significant share of the market in an individual community will be able to aggregate data in a manner that is useful to consumers.

In 2013, the North Carolina General Assembly passed the Health Care Cost Reduction and Transparency Act requiring hospitals to post the prices of their most common diagnosis-related group (DRG) admissions and surgical procedures.[a] Lawmakers are interested in pricing transparency as one means of controlling health care costs. However, hospitals have found implementation of this law challenging because price, in and of itself, is not a meaningful measure. Should hospitals be posting the raw cost of the procedure, the average adjusted charge (or contractual rate with payers), the average charge to a patient without insurance, or the average amount for which a patient is responsible, after insurance pays its share? Ideally, information on pricing should be easily available and accessible to patients both with and without Internet access, and online searching skills, however, figuring out how and where to post information to meet these qualifications has been a challenge for hospitals. To help increase transparency in health care pricing, the Task Force recommends:

Recommendation 7.2: Encourage Health Care System Transparency (PRIORITY RECOMMENDATION)

All health care systems and providers should ensure information on services, cost, and quality is easily accessible to consumers in print and electronic formats.

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[a] **NCGA § 131E-214.11—.14**

Recommendation 7.3: Encourage Health Care Payer Transparency

Payers should provide on their websites and in their written materials information that is easily understood by consumers on covered providers and common procedures, including data on costs, quality, safety, and patient experiences.

Several states have created all-payer claims data (APCD) systems to help provide the necessary state-level data that can improve price transparency. These claims data systems also support quality improvement activities, compare disease prevalence or utilization patterns across the state, identify successful cost containment measures, and evaluate health care reform efforts on costs, quality, and access. The data included in APCD systems generally consists of claims data from physicians, pharmacists, and dental care claims from public and private insurers, and includes payment information such as plan charges and member liabilities (e.g. co-pay, deductible payments, co-insurance).[22] As of 2014, 11 states had fully functional APCD systems, 6 states were in implementation, 20 states expressed strong interest, and 3 states had existing voluntary activities.[23] In 2012, the North Carolina Department of Health and Human Services created a workgroup to examine the possibility of creating a similar APCD or confederated data system to capture data from multiple existing data systems that could be used in North Carolina to examine population health, cost, and quality issues across the state. Such a system could provide important data on health care costs, including those for specific procedures, providers, or health systems. However, North Carolina's efforts are currently on hold while the state is implementing other major health information technology efforts, with several groups continuing to hold interest meetings regarding whether to move forward on APCD or a united data system.

Recommendation 7.4: Provide Health Care Cost Information to the Public

The North Carolina General Assembly should collaborate with the Department of Insurance, health care systems, and insurers to create a statewide, mandatory data reporting system to enhance pricing transparency for medical care and health care services. This collaborative effort should include input from additional stakeholders on database use and access, and participating stakeholders should include employers, health care providers, academic and industry researchers, and patient and family advocacy groups.

Collaborative Charting

Transparency around quality and costs is one method to help consumers make more informed choices about their health care; another potential method is collaborative documentation or charting. Collaborative charting refers to a spectrum of shared medical record keeping between the health care provider and the patient. Historically, patients' access to the information in their medical charts was quite limited until the the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) which states that "patients must be able to see and get copies of their records, and request amendments."[b] The Institute of Medicine and others have suggested that allowing patients access to their medical records could reduce errors and improve quality.[24,25] This type of collaboration is not new, but the potential has exploded with the development of electronic medical records and patient portals.

Historically, a patient's chart was a file folder full of their provider's documentation of their visits. Today it is more common for the chart to be electronic, which allows greater opportunities for collaboration. Under true collaborative charting a patient's medical record is about, for, and the property of the patient and they are encouraged to contribute to it and review it at will. Rather than owning the medical chart, the health care provider enters into a partnership with the patient that extends to record keeping to ensure accuracy and transparency in medical record keeping. While true collaborative charting is still quite rare, many health systems have begun to experiment with collaborative charting through the use of patient portals which allow patients access to some parts of their medical records online.

Skeptics of collaborative charting cite many reservations about its use.[25,26] Some providers consider the medical record to be a shorthand way of retaining key pieces of information about a patient, his or her health record, and for treatment planning. This information is primarily used for recall by the health care provider for ongoing care and for communication with other members of the care team. Other current uses of medical records include support of billing, in the event of an audit, and for legal protection in the event of a malpractice claim. Providers use a specialized jargon, and some fear open charting will make the process of charting more complicated and cumbersome. Other providers fear that open charting will expose them to increased litigation, with patients more readily pointing out medical errors in their care. Some providers are concerned that time will be wasted in correcting notes that are of minimal importance to caring for their patients. Still others fear that patients will be insulted by language or judgments rendered in chart—use of terms such as 'complains of' or 'denies' may seem unfair to some patients. More problematic still might be perceived diagnostic judgments such as 'drug seeker' or 'somatic disorder.'[25]

What Could Collaborative Charting Look Like?

Imagine a patient walking into an exam room, noticing his medical chart on the door, and deciding to pick up the chart on the way into the exam room. Now imagine that patient has not only reviewed the chart, but made corrections and comments in the chart. This would be the essence of collaborative charting.

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[b] Federal Health Insurance Portability and Accountability Act of 1996, Pub L. No 104 - 191

These concerns on the part of skeptics are important considerations in collaborative documentation. However, limited research to date has shown that collaborative charting is a mostly positive experience for both patients and health care providers. A study of Open Notes, a system for collaborative charting, demonstrated that most patients who used this system feel more in control of their health care, and have increased medication compliance.[27] Reports of collaborative charting show changes in the way providers document and/or required increased time for documentation. This system was tested in only three geographic areas and, given that the culture of medicine, expectations, and experiences of patients, and payment systems vary widely across the United States, further study of the spectrum of collaborative documentation will be important.[27]

While collaborative documentation is still relatively new, it holds promise as a technique for engaging patients and families in care. Therefore, the Task Force recommends:

Recommendation 7.5: Increase Collaborative Documentation

a) **Health care organizations should examine opportunities to increase collaborative documentation aimed at increasing patient and family engagement including, but not limited to, patient portals, open charting, open notes, and other models.**

b) **The North Carolina Quality Center and the North Carolina Hospital Association should continue to provide consultative support to health care organizations implementing collaborative documentation.**

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