Patient + Family Engagement in a Changing Health Care Landscape

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Executive Summary

Purpose
The current U.S. health care system is structurally and culturally provider-centered, not patient-centered—in spite of the intentions of many stakeholders. Many factors influence whether and to what extent patients are able to engage. The Patient and Family Engagement Framework groups these factors into three categories: those related to patients, organizations, and society. Each set of factors acts on its own, and in conjunction with the other sets, to affect patients’ actions and engagement. This paper describes a selected set—the societal, policy, and organizational factors—that influence whether and to what extent engagement occurs.

Societal and Policy Factors: A Changing Health Care Landscape
Recent and emerging policies and other environmental factors affect whether and to what extent patient and family engagement occurs. Such factors include the Affordable Care Act of 2010, advances in health information technology, state-level initiatives, changes in health plan design and reimbursement, and increasing choices in care options.

Organizational Factors: Facilitating System-Level Change
All health care organizations operate within the political environment. But because they are complex systems, many factors affect whether and to what extent organizations can change to support patient and family engagement. We must think about how we can change the system to support the behaviors and actions we wish to encourage. Successful system change typically requires interventions at multiple levels of the system, can be influenced by multiple individuals within the system, and must address the needs of those asked to change their behaviors and actions.

Considerations for Developing Strategies and Tactics To Move Forward on Patient and Family Engagement
Recent changes, such as increased consumer responsibility and increased provider risk-sharing and accountability, are encouraging engagement more than ever. And, in spite of implementation challenges, health information technology applications can support engagement—doing things like sharing information between IT systems and integrating technology into traditional care delivery. Yet, change cannot be facilitated by policy alone; we must make organization and system changes to fully integrate the concepts of engagement.
Introduction

Patient and family engagement is necessary to improve population health, efficiency, and the patient’s experience of care. Yet despite decades of work on increasing the patient-centeredness of health care, the health care systems of the United States and other developed nations remain resolutely provider-centric—and, too often, patients and their families are not as engaged as they want to be or should be (Fowler, Gerstein, & Barry, 2013; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012).

We can conceptualize patient and family engagement using a framework developed by Carman et al. (Figure 1). The framework articulates a vision for moving towards more shared leadership, with patients as active partners in their own care and in the organizations and structures that provide health care (Carman, Dardess, et al., 2013). The framework has three core dimensions:

1. **Continuum of engagement**: Moving from consultation through involvement to partnership and shared leadership—and even beyond

2. **The level of the system at which engagement occurs**: Direct care, organizational design and governance, and policy making

3. **Factors that influence whether and to what extent patients are able to engage (grouped into three categories)**: Those related to patients, organizations, and society. Each set of factors acts on its own and in conjunction with the other sets to affect patients’ actions and engagement.

*Figure 1. A multidimensional framework for patient and family engagement in health and health care*
While it is clear that patient, societal, policy, and organizational factors influence engagement, not all efforts at patient and family engagement address all of these factors. This paper describes a selected set of the societal, policy, and organizational factors that influence whether and to what extent engagement occurs. We first provide an overview of the current state of patient and family engagement. Then, we discuss key societal/policy trends and organizational/system-level factors that influence the adoption and implementation of patient and family engagement by individuals and health care organizations. This is not an exhaustive list of factors—rather, we aim to inform strategies and tactics that can help us move from the current state of patient and family engagement to where we would like to be.

Current State of Patient and Family Engagement: An Overview

We know a great deal about what patients and families want in their individual health care. Patients want care that is safe and results in good health outcomes and quality of life. They want good communication, emotional support, and empathy; personalization of services, coordination and continuity; information and education that is easy to understand and reliable; involvement in decisions about treatment and care; attention to privacy, confidentiality, and dignity; involvement of family and friends; and fast access to appropriate help and advice when needed (Coulter, 2011, 2012; Workman et al., 2014).

More broadly, patients want a health care system to be structured around their best interests. They want clinicians to have the flexibility to apply the best evidence to the unique situations of the patient. At the same time, patients want the system to ensure high-quality care by holding clinicians accountable for their actions. Further, patients want more education about evidence and more transparency around health care costs to help inform decision making; some even call for government mandates requiring transparent evidence-based information about health care costs, hospital quality, or treatment effectiveness (Carman, Maurer, et al., 2013). To achieve this more transparent and patient-centered system, some patients want more involvement in the organizations and policies that govern health care.

The current state: Most systems and services remain provider-centric

The dominant U.S. (and international) cultural frame is still a provider-centered frame in which patients are expected to comply with the prescribed care plans of expert providers (Coulter, 2011). This dominant frame makes important assumptions:

- A focus on illness, not health—deficits, rather than strengths.
Illness is primarily biomedical, not social or ecological.
Technology is required to treat sickness and restore health.
Patients do best when they comply with provider recommendations and prioritize provider knowledge.

Much of the work on patient and family engagement has focused on engaging patients more effectively at the level of direct care (e.g., obtaining preventive services, adherence to treatments, self care for chronic conditions), as well as on developing shared decision making tools and implementing them into routine care, albeit with limited success (Elwyn et al., 2013). Recent organizational innovations in health care have also focused on more patient and family engagement in direct care, including Accountable Care Organizations (ACOs), patient-centered medical homes, and interest in adopting patient-centered approaches to measuring health care outcomes and assessing provider performance. However, adoption of patient and family engagement efforts significantly lags behind research innovation.

Efforts have focused less on involving patients and families in all aspects of care decisions, in organizational design and governance, or in the broader policy-level issues. Indeed, most work partnering with patients and families at the organizational design and governance level has been done by a few innovative organizations with exceptional commitment to patient and family engagement. Until recently, few compelling policy or financial incentives have motivated a broader set of organizations to change and to partner at the design and governance levels.

**Policy Factors:**

**A Changing Health Care Landscape for Patient and Family Engagement**

Affordable Care Act (ACA) of 2010. Today’s focus on patient and family engagement is the result of decades of activity, but the passage of the ACA in 2010 significantly recognized patient and family engagement as an essential function of health care delivery. The ACA:

- Introduced payment reform through the creation of Medicare Pioneer and Shared Savings Accountable Care Organizations (ACOs) Programs, shifting the focus from traditional fee-for-service medicine, where higher volume means more reward, to rewarding the quality and value of services. Health care reform increases provider risk-sharing and accountability. The ACO model, for instance, is a shared-risk arrangement between payers and providers, in which the payer bears some financial risk but transfers some risk to the providers who constitute the ACO on an annual or ongoing basis. As providers become more accountable for health outcomes, it is expected they will also become more focused on patient and family engagement.

- Created the Health Insurance Marketplace and allowed states to expand coverage. This gave many people information and tools to make active choices about insurance, and created a substantially larger insured pool by giving millions access to health insurance for the first time.
Established the Patient Centered Outcomes Research Institute (PCORI), engaging patients in the creation, dissemination, and implementation of patient-centered comparative effectiveness research.

Created the Centers for Medicare and Medicaid Innovation (CMMI), funding innovation pilots and demonstration projects, many of which focus on engaging patients and families and improving the quality of care.

Introduced population-based reform efforts, (including ACOs), the success of which depend on the system’s effective management of the health of its patients. Key to this population health management is helping patients manage their own care and modify their health behavior. To succeed, then, ACOs must transform their systems to actively reach out to and engage patients, using an array of specially designed automation tools and communications systems. Further, ACOs must design nonvisit interventions for very sick patients, those who have less severe chronic diseases, and healthy patients who need preventive care (Turcan, 2012).

Other payment reform models highlighted under ACA are shifting the costs associated with health care. **Bundled payments** are a form of provider reimbursement that packages payments for multiple, related services into a “bundle” to pay for a single episode of care (e.g., a bundled payment for hip replacement surgery would include all services from the presurgical workup to the actual procedure and through rehabilitation). **Another reform is value-based purchasing** (or outcomes-based financial incentives), where payment is based on achieving predetermined clinical and service targets, improvement toward target levels, or rankings against other specific benchmarks. In 2012, for example, Medicare instituted the national hospital value-based purchasing program, in which achievement and improvement on patient experiences of care scores (based on the Consumer Assessment of Healthcare Providers and Systems [CAHPS] Hospital Survey) are used to calculate value-based incentive payments (Centers for Medicare & Medicaid Services, 2009; Centers for Medicare & Medicaid Services & U.S. Department of Health and Human Services, 2007). Reimbursement is tied to benchmarked performance on the CAHPS Hospital Survey; hospitals are rewarded or penalized based on performance on specific CAHPS measures. This change in incentives encourages organizations to focus on patient perceptions and, thus, patient and family engagement.

**Health information technology (HIT).** To encourage health care systems to move toward electronic health records (EHR), the Health Information Technology for Economic and Clinical Health (HITECH) Act—part of the American Recovery and Reinvestment Act of 2009 (United States Congress, 2009)—established the Medicare and Medicaid EHR Incentive Programs. These programs provide financial incentives for the “meaningful use” of certified EHR technology that includes giving patients and families access to and use of their medical records. The ultimate goal is to transform patients and families from the objects of health care to active participants in creating information about their health—leading to deeper engagement in care.
Further, with the advent of the Internet, social networking, and mobile wireless technology, user-generated health-related content and groups are proliferating. Thanks to this movement, dubbed “health care 2.0,” patients and families (and providers, when they choose to participate) can more rapidly learn, on their own or in collaboration with their providers, how to optimize health and functional status; manage both acute and chronic illnesses; and share what they learn with other patients and families via general or health-specific social networking websites, or in face-to-face peer-support groups. This has given rise to the early stages of an “e-Patient” movement (Bhargava & Johnmar, 2013), which could change health care by enabling patients and providers to seek information and make choices apart from traditional care venues. The result, some speculate, could be a shift away from the primary care provider one day as the key source of guidance on achieving health outcomes.

**Changes in health plan design and reimbursement.** Within the employer-sponsored health insurance market, consumer-driven plans such as health savings accounts (HSAs) and high-deductible plans, where consumers bear more of the costs associated with health care, are becoming more commonplace. Consumers are taking on more responsibility in choosing health plans and are paying higher co-insurance and co-payments, often without the information or skills to do so effectively. Consumers can face greater financial burdens and unexpected costs when they don’t choose wisely. For example, some families participating in the Massachusetts Commonwealth Health Insurance Connector Authority, a state exchange created prior to ACA, indicated significant financial burden and “higher-than-expected costs.” Enrollees with lower incomes (incomes below 400 percent FPL), increased health care needs, and more children were at a greater risk for such unexpected financial burden (Galbraith et al., 2013).

Consumers struggle with cost and medical terminology (Kleimann Communication Group & Consumers Union, 2011a, 2011b; People Talk Research & Consumers Union, 2010); have difficulty calculating their costs when presented with health plan cost structure information (Kutner, Greenburg, Jin, & Paulsen, 2006; Malbon, 2010; Quincy, 2011); find it difficult to move into an active purchasing role to weigh complex information (Carman et al., 2010; Greene & Peters, 2009; Wood et al., 2011); and have limited ability to objectively weigh risk trade-offs associated with different deductibles and copays against premium costs (Tennyson, 2011).

This is truly a multilevel issue. On one hand, patients and families lack knowledge on how to make value-based choices, especially when confronted with highly emotional concerns and life-and-death decisions. On the other hand, patients and families often lack the information needed to make these decisions, along with the skills needed to interpret this information when making decisions.

**Increasing consumerism in care options.** New kinds of providers are moving into the care delivery space and providing retail-like care delivery services—for instance, retail clinics, pharmacist-administered immunizations, and a growing array of diagnostic tests available over the counter or online. These make new care options available to consumers but also expose them to manipulation by marketing and direct-to-consumer advertising intended to promote consumption that may not be in their best interest.
State-level initiatives. Several states have developed innovative initiatives to encourage engagement. For example, shared decision making initiatives have been implemented in Washington, Vermont, Maine, and Minnesota (Frosch et al., 2011). At the organizational design and governance level, Massachusetts enacted legislation (Senate Bill No. 1277) in 2007 designed to promote health care transparency and facilitate consumer–provider partnerships. One component of this legislation requires all hospitals in the state to establish Patient and Family Advisory Councils (PFACs) to provide meaningful input into hospital policy and management.

System thinking:
Changing system design to encourage patient and family engagement

To get new results, we need new thinking and new behaviors, and viewing health care as a system can give us helpful insights. But health care organizations are large and complex, and though we can ask individuals (patients, families, providers) to change their behaviors, it is hard to change an entire system—and even harder to make changes that will have a large impact. Improving patient and family engagement requires thinking about how to change a system to support the behaviors and actions we are encouraging at an individual level. As we do so, it is helpful to consider how systems operate, as well as key focal points for system change.

Simple rules govern how systems operate and influence how we think and behave. The design principles that govern the performance of complex systems like health care are sometimes called “simple rules.” Simple rules tend to come in three varieties—goals, incentives, and boundary conditions (Plsek, 2001). All people who interact with each other in the health care system are subject to the same set of simple rules that strongly influence their behavior—their expectations, types of conversations, and how they spend their time and attention. Thus, the goals, incentives, and boundary conditions in health care today determine the degree to which, on average, care is patient- and family-centered or not.

Simple rules are not simple to change; complex systems like health care resist change. Below are some key focal points to consider when fostering system change.

Successful change typically requires interventions at multiple levels of the system. System levels (direct care, organizational, and policy) influence each other. Initiatives directed at only one level may not be effective, because they do not address or are not supported by the “simple rules” operating at the other levels. For instance, a doctor might develop more patient-centered interactions with patients, but if his/her organization is focused on the number of patients and not the level of engagement, s/he may feel discouraged and abandon the effort. Or a clinic administrator may implement rules designed to promote patient and family engagement, but if clinic providers do not understand why the goal is important and how to change their behavior, the rules may have little or no effect.

Change at one level influences others. Everyone in a system has some power to change how they operate in the system; that change, in turn, can also influence how the system operates. Individual patients or providers can start to communicate with each other in new
ways. Medical group and hospital administrators can learn new leadership skills that promote patient-centered behaviors. Policy makers can change incentives to encourage patient and family engagement. Because the different levels of the health care system are “loosely coupled” (mutually influencing each other), changes at one level of the care system (say, patients and doctors learning new ways of conversing) can influence another level (organizational adoption of new, more patient-centered procedures for communicating with patients). This works the other way, too; new organizational policies designed to promote engagement may alter the way doctors and patients communicate.

**Address the needs of those who must implement it.** Complex systems are hard to change because, for some stakeholders, the current system works. People will resist efforts at system change, even when they agree with the intended goals, if they do not understand the good reasons for making the effort to change, they are afraid the proposed changes will harm them in ways they currently care more about, or they are not provided incentives and supports to change. Discussions about system change with stakeholders can guide the process—often reducing the losses and accentuating the gains.

**Considerations of Societal and Organizational Factors for Patient and Family Engagement Efforts**

There are important societal and organizational factors to consider as we develop strategies and tactics to move closer to our goals in patient and family engagement. It is particularly helpful to think of current trends in the policy arena (e.g., better measurement systems for patient and family engagement, patient-centered HIT tools, and payment reform models such as ACOs) and what will take longer to implement (e.g., widespread adoption of new business models or changing organizational culture).

**Steps Toward Societal and Organizational Change**

Below, we highlight some considerations of the societal and organizational factors for patient and family engagement—both what is required for effective engagement to occur and how to facilitate change.

**Today’s consumers need better tools to succeed in their role.** Consumers have unprecedented access to health information on the Internet, yet they are mired in systems that lack cost and quality transparency and the tools to help them make wise choices. The cost of care can vary widely for the same procedure, but it is exceedingly difficult to find out what services cost prior to receiving them. Employers, Health Insurance Marketplaces, navigators, consumers, and public and private payers need to develop an array of tools for consumers—cost calculators and other price transparency tools to help consumers make better plan choices, and other tools to help them make informed, value-based decisions and manage their health care options. We must continue to promote transparent cost and quality information at the
treatment, provider, and organizational levels to inform decision making. We also need more public awareness of the harm that results from not engaging in health care decision making. This requires measuring and documenting that harm—making the invisible visible—at both the policy and organizational levels.

**Systems must transform to provide active, tailored outreach.** Improving quality and containing costs requires effective support and management of patients in lower-acuity, primary care settings with diverse access points. Providers must transform their systems to actively reach and engage patients using automated communications systems, personalized approaches, and other tools and interventions developed to address different population needs—“sick patients, those who have less severe chronic diseases, and healthy patients who need preventive care.” Systems must meet patients where they are, and learn what goals they wish to achieve, in order to tailored approaches and succeed (Turcan, 2012).

**Continued reform needs to align business models and incentives with health—not sick—care.** “Disruptive” innovators are already appearing to take advantage of this market opportunity (Christensen, Grossman, & Hwang, 2009; Hwang & Christensen, 2008). To support this market shift, government and private payers must continue implementing new provider compensation models aligned with patient and family engagement, linking compensation to increased engagement and new patient-centered approaches to measuring the value of health care services (Porter & Lee, 2013).

**HIT applications are promising, but there may be challenges with implementation.**

**Engaging patients at the direct care level could be revolutionized with the rapid development of HIT.** HIT applications like mobile health apps and patient portals offer patients new ways to manage their health and health care (Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013). We can see a future where engaged patients, supported by families and friends, use self-monitoring technologies and Internet-enabled information sharing to rapidly establish and maintain control of their health risks with a much lower need for medical resources. Already, HIT is helping providers keep patients and caregivers informed, educated, and literate about their personal health and medical conditions. It is supporting ongoing self-care and wellness management, including coaching from health care providers and dialogue between providers and patients. Patient portals (online and via kiosks) can provide access to EHRs and registration, appointment scheduling, and clinical support such as secure provider messaging, patient reminders, alerts, test results, and prescription refill requests. Blue-button technology lets patients transfer records to other providers, potentially streamlining the coordination of care. Portals could allow patients to connect monitoring devices, such as blood pressure cuffs, to upload data (Enders, Battani, & Zywiak, 2010). This “end-user efficiency” approach could greatly reduce the perceived primary care shortage and the costs of chronic disease care (Scarrow, 2008). But not every patient will embrace technology in the same way; it will be important to make allowances for those differences.
Information systems need to supply actionable data to patients and allow interoperability for better coordination and patient-centered care. HIT systems could promote effective care coordination and care plan development. But today’s IT systems within and across organizations are fragmented and have difficulty sharing information. System integration of information from all health care providers involved in the care of a patient would facilitate shared decision making and care plan development (Magan, 2012).

Technology must be fully integrated into traditional care delivery, with clarified roles for providers, patients, and families. At a minimum, providers should promote and facilitate patient-centered HIT so that patients can generate and use data to achieve goals for health and care. Providers and patients will need help integrating these technologies into traditional care relationships.

Change cannot be facilitated by policy alone; we need organization and system changes to fully integrate the concepts of engagement.

Organizational leaders need to support front-line change agents. Typically, our efforts to improve the health care system are focused on changing provider behavior, overlooking the opportunity to use patients as change agents—despite the fact that patient requests are a strong motivator for physician behavior change, as shown by the results of direct to consumer marketing (Kravitz et al., 2005). New approaches such as training patients to be change agents, positive deviance, citizen health, adaptive leadership, relationship-based administration, and design thinking could lead to rapid improvements in patient and family engagement and care processes by directly changing the dyadic interactions between providers and patients.

Focus on factors that will have the greatest impact on outcomes. Many organizations, for example, spend considerable resources training providers to be more patient-centered, often with minimal results. In contrast, addressing the underlying organizational factors that interfere with patient-centered care can be effective—but can also be the most challenging and time-consuming. For instance, Group Health increased the duration of patient visits in their Patient Centered Medical Home to 30 minutes by reducing provider panel size, and observed improvements in both patient experience and provider engagement (Reid et al., 2010).

Patient and family engagement needs to be incorporated into health care students’ curricula. Workforce training of pre-professional and professional students about the importance of patient and family engagement, and how to do it well, will be essential in order to make this shift sustainable.

We need clarity around concepts and reliable measures that take an interrelated systems approach to accountability, aligned incentives, and performance improvement. Patient and family engagement efforts face a critical lack of clarity around key concepts and lack of standardized measurement. Patient-centered measurement of health system performance, or of patient and family engagement specifically, is still in its infancy. As we have seen, financial
and other incentives strongly influence the behavior of the agents in the system, both directly and by influencing beliefs and attitudes. Thus, emphasizing incentives that are already aligned with PFE (say, enhanced reputation and reduced malpractice risk) while also aligning financial incentives with improvement in valid and reliable measures of engagement, will be essential to sustaining all patient and family engagement initiatives.

Imagine a world where we better understand what works and whether (and how) specific patient and family engagement interventions, actions, and behaviors affect outcomes. Such measures would represent important elements of patient engagement for individuals, teams, organizations, and systems—useful in assessing performance and progress, identifying areas for improvement, demonstrating accountability to standards of care, and informing reimbursement in payment-incentive programs. Further, they would be validated, statistically sound, and accepted by the field. Already, the National Quality Forum is building the foundation for patient-reported outcome (PRO)-based performance measures that could be applicable across multiple settings of care and/or multiple conditions. This is the first step in “developing reliable and valid performance measures eligible for NQF endorsement that can be used for accountability and to inform quality improvement” (National Quality Forum, 2013; Ricciardi et al., 2013).

Conclusion

Many current U.S. initiatives show considerable promise in creating the kinds of structural changes required to make the care system more patient-centered by reducing the information asymmetry and leveling the power imbalance between providers and citizen patients. Innovative approaches to changing care delivery—ones that leverage systems thinking—are also showing a way forward. While the environment for promoting patient and family engagement has perhaps never been more promising, the odds are that little will change unless those working to promote patient and family engagement remain vigilant, persevering, and resourceful.

When will we achieve a care system that routinely provides patient-centered care? We will see it when patient and community ownership and governance of health care delivery and financing organizations occurs. We will see it when provider PFE performance is measured, reported, and incentivized, and when providers accord their patients, and their families, the same respect they would expect for themselves and their families. This is the path to ensure that the system becomes more patient-centered and that PFE becomes the norm.
Glossary

**The following glossary terms were taken verbatim from the sources below.**

**Accountable Care Organization (ACO):** A network of health care providers that band together to provide the full continuum of health care services for patients. The network would receive a payment for all care provided to a patient, and would be held accountable for the quality and cost of care. Proposed pilot programs in Medicare and Medicaid would provide financial incentives for these organizations to improve quality and reduce costs by allowing them to share in any savings achieved as a result of these efforts.  

**Co-insurance:** A method of cost-sharing in health insurance plans in which the plan member is required to pay a defined percentage of their medical costs after the deductible has been met.

**Consumer-driven plans:** A fixed dollar amount paid by an individual at the time of receiving a covered health care service from a participating provider. The required fee varies by the service provided and by the health plan.

**Co-payment:** A fixed dollar amount paid by an individual at the time of receiving a covered health care service from a participating provider. The required fee varies by the service provided and by the health plan.

**Health Information Technology (HIT):** Systems and technologies that enable health care organizations and providers to gather, store, and share information electronically.

**Health Insurance Exchange:** A purchasing arrangement through which insurers offer and smaller employers and individuals purchase health insurance. State, regional, or national exchanges could be established to set standards for what benefits would be covered, how much insurers could charge, and the rules insurers must follow in order to participate in the insurance market. Individuals and small employers would select their coverage within this organized arrangement. An example of this arrangement is the Commonwealth Connector, created in Massachusetts in 2006.

**Health literacy:** The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

**Health Savings Account (HSA):** A tax-exempt savings account that can be used to pay for current or future qualified medical expenses. Employers may make HSAs available to their employees or individuals can obtain HSAs from most financial institutions. In order to open an HSA, an individual must have health coverage under an HSA-qualified high-deductible

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2 Ibid.

3 Ibid.


5 Ibid.

6 Ibid.

health plan. These HSA-qualified high-deductible health plans must have deductibles of at least $1,150 for an individual and $2,300 for a family in 2009.\(^8\)

**Patient-centered care:** Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.\(^9\)

**Patient-Centered Medical Home (PCMH):** The patient-centered medical home is a way of organizing primary care that emphasizes care coordination and communication to transform primary care into “what patients want it to be.” Medical homes can lead to higher quality and lower costs, and can improve patients’ and providers’ experience of care. (more information can be found: http://pcmh.ahrq.gov/page/defining-pcmh)\(^10\)

**Population health:** The health outcomes of a group of individuals, including the distribution of such outcomes within the group.\(^11\)

**Shared-decision making:** The collaboration between patients and caregivers to come to an agreement about a health care decision.\(^12\)

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