CIN Partners Share:

Shared Decisionmaking

Main Takeaway:
Although the benefits of shared decisionmaking are established, there is no clear prescription for its implementation.

The California Improvement Network (CIN) partners — public and private health care organizations actively engaged in improving care delivery — meet quarterly to share experiences and to learn from one another. Following are highlights from the partners' August 2014 meeting, which focused on shared decisionmaking (SDM). The meeting included presentations from the Gordon and Betty Moore Foundation, Humboldt-Del Norte IPA, and Sharp HealthCare. Presenters shared background research and context for SDM as well as experiences from implementing SDM programs.

Background

Gordon and Betty Moore Foundation www.moore.org

Who: As part of its work in patient care, the Gordon and Betty Moore Foundation has supported a number of programs focused on patient and family engagement, including SDM. The foundation supports work to improve measurement of SDM processes and decision quality, and the integration of measurement into clinical workflow to provide actionable feedback to clinicians.

Terms Defined

Decision aid: A tool "intended to help people participate in decisions that involve weighing the benefits and harms of treatment options."[1]

Shared decisionmaking: A process in which "both parties share information: The clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values."[2]

Preference sensitive care: Clinical care with at least two valid treatment options.[3]

The issue: Shared decisionmaking is a process of information sharing between the provider and patient. A critical component of patient engagement, SDM is viewed by experts in the field as the "pinnacle of patient-centered care."[4] (See Figure 1.)

SDM is most relevant in situations that involve preference-sensitive decisions, defined as where more than one reasonable path forward exists (including the option of doing nothing), and different paths entail varying combinations of risks and potential benefits. Examples include therapy for early-stage breast or prostate cancer, lipid-lowering medication for the prevention of coronary heart disease, and genetic and cancer screening tests.

A number of factors have contributed to the rise in SDM, including the Dartmouth Atlas Project's nationwide research findings on variation in practice patterns, such as surgery rates, that are not accounted for by differences in patient characteristics.[5] The Affordable Care Act's payment policies that reward outcomes and quality over volume have also spurred interest in and adoption of SDM techniques.

Because explaining complex medical decision to patients can be challenging, and physicians often have little time to accomplish this task, decision support interventions, which often incorporate decision aids, are a critical component of SDM. Effective interventions explain the problem in language that patients can understand and provide detailed information about treatment options and their risks and benefits. A systematic review of decision support interventions found that patients who had been given these interventions were more satisfied and had more realistic expectations of their care. Decision support also improved patients' knowledge of the treatment options, increased preferences for participation in disease management, and often led to more conservative decisions.[6]

Despite the benefits, the difficulties of achieving effective SDM have been well documented:

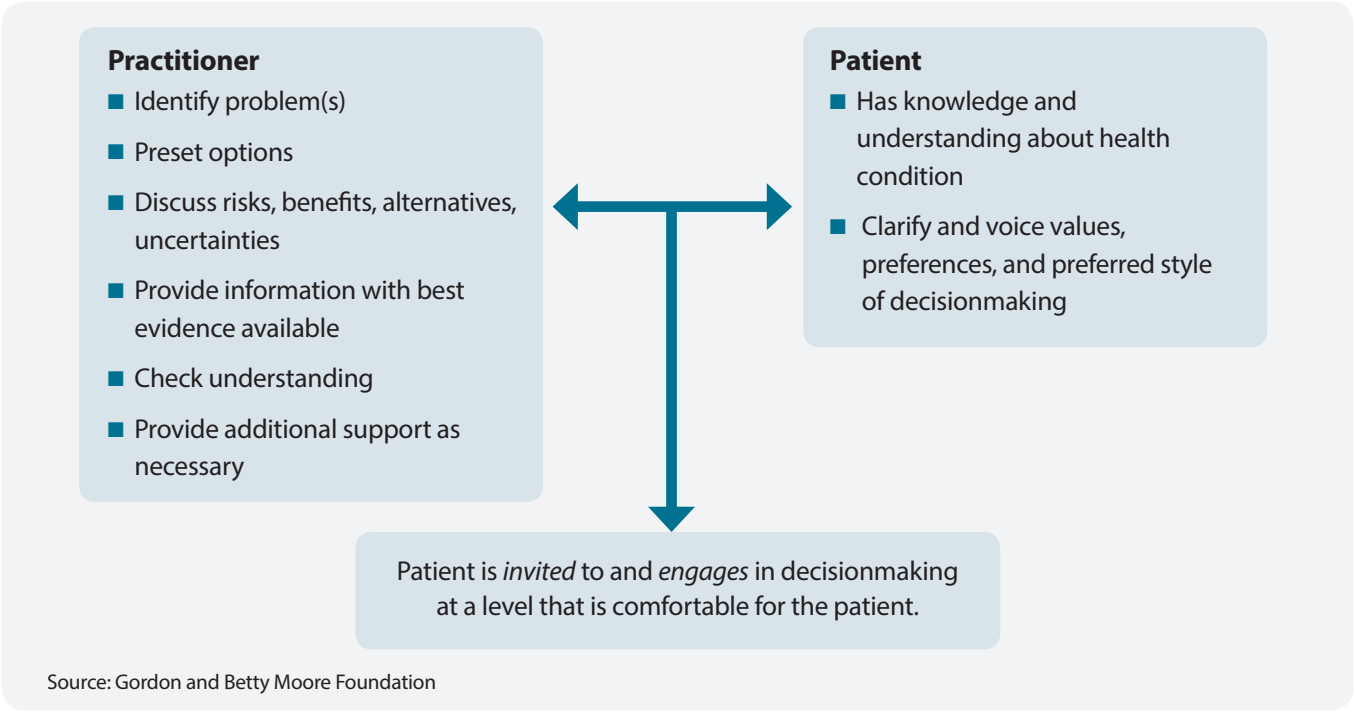
- **Quality of the interaction.** In one study of more than 1,000 clinical encounters, only 9% of decisions met the most basic definition of fully informed decisions, including a clear discussion of the clinical issue, the patient role in decisionmaking, and the exploration of patient preferences.[7] A separate study found that when patients were asked by physicians to talk about the reason for their visit, physicians interrupted patients' initial presentation of concerns in 72% of cases. The interruptions occurred after an average of 23.1 seconds.[8]
- **Patient recall.** In one study, 40%-80% of medical information provided by health care providers was forgotten immediately by patients, and almost half of the information that was remembered by patients was incorrect.[9]
- **Patient ability to express opinions.** Another study found that while over 93% of people would ask questions and 94% would discuss preference with their physicians, only 14% would disagree with a physician's recommendation, often because they feared being labeled a "difficult patient."[10]

"Shared decisionmaking is not an information dump followed by abandonment; it's a partnership. In shared decisionmaking, there are two experts — the provider and the patient. Patients are experts in what they are willing to do and what risks they are willing to take."

Many of these difficulties were observed in a project conducted by researchers at the Palo Alto Medical Foundation Research Institute that was supported by the Informed Medical Decisions Foundation, an advocacy and research organization focused on evidence-based shared decisionmaking.[11] The Partners in Medical Decision Making project studied SDM in primary care settings and found mixed results. At the end of the 21-month study of patients with back pain or who were overdue for consideration of colon cancer screening, only 12% of patients who were identified as eligible to receive a decision aid were actually provided one. This percentage peaked at over 25% in the ninth month of the project due to incentives, but this increase was not sustained.

Many providers in this study believed that they already adequately practiced SDM. Some physicians did not agree that decisions are preference sensitive, and many preferred being in control of decisions rather than sharing decisions. Providers also expressed concerns about the lack of time to engage patients in SDM, although providers who more frequently practiced SDM thought they saved time.

Figure 1. A Meeting of Experts: Roles of Provider and Patient



Source: Gordon and Betty Moore Foundation

From the Field

Humboldt-Del Norte Independent Practice Association

www.hdnfmc.com

Who: Humboldt-Del Norte Independent Practice Association (HDNIPA) is a third-party administrator for PPO/HMO health plans and a quality improvement organization for Humboldt County. The IPA and the foundation's HMO/PPO provider network consist of 98% of the health care clinicians in Humboldt County (78 primary care physicians and 108 specialty physicians). The IPA manages 5% of the total population though HMO plans and has access to an additional 33% of the total population through PPO plans.

What: After the 2011 CHCF project "All Over the Map: Elective Procedure Rates in California Vary Widely" found that Humboldt County's local elective surgery rates were outliers on the high end for 6 of the 13 procedures studied, HDNIPA initiated the Surgical Rate Project to examine why the rates were so high and to develop recommendations for action. The primary care physicians, surgeons, and community members involved in the project identified SDM for the treatment of preference-sensitive conditions as one way to address the issue.

HDNIPA created an SDM program pilot based on the following guidelines:

- SDM should start between patients and their PCPs.
- Standardize SDM so it becomes usual care.
- The program should be a centralized, referral-based service.
- Patients should choose their path to treatment.
- Use decision aid tools and trained coaches.

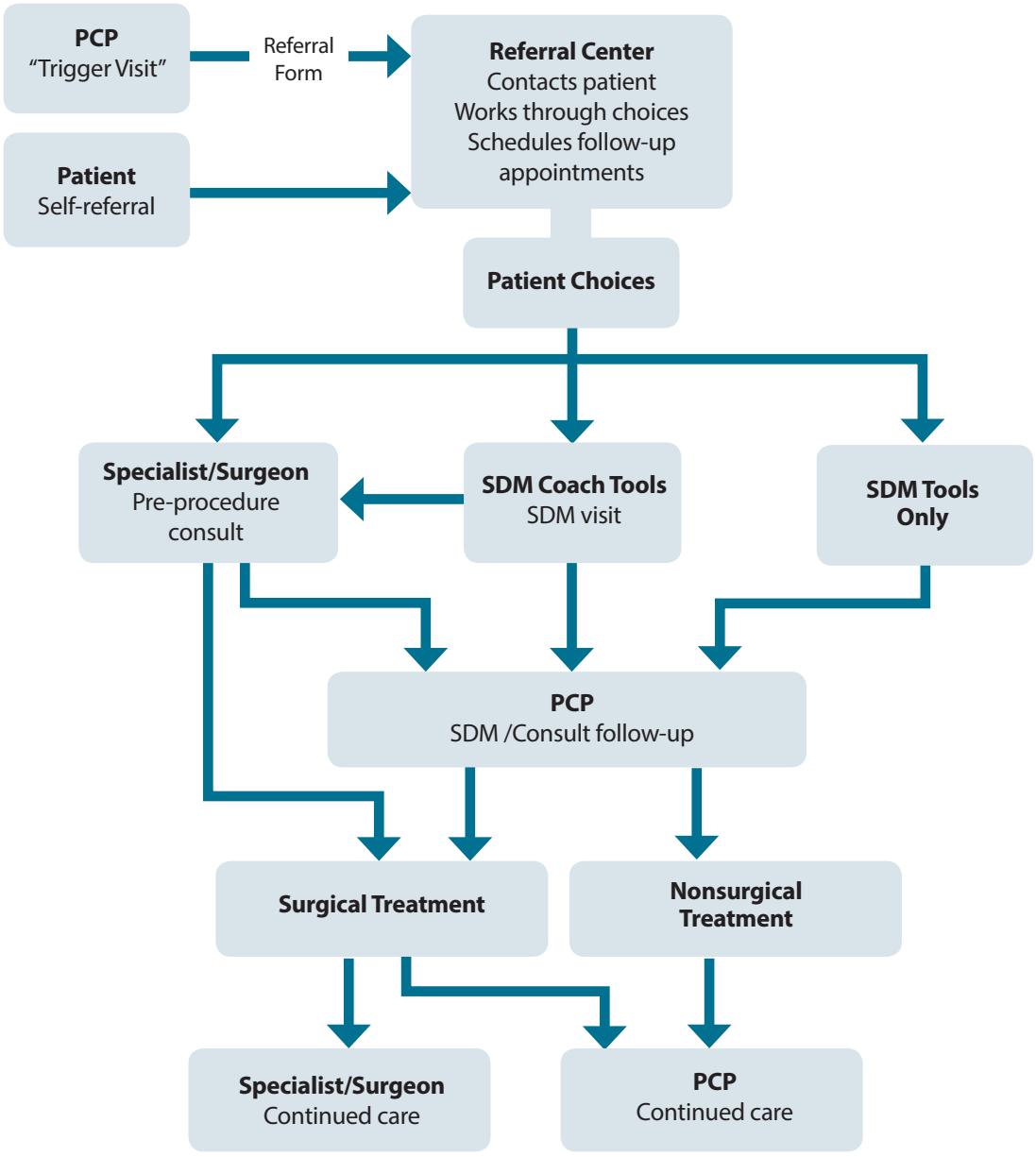
To provide input into the development of its SDM program, HDNIPA surveyed 20 PCPs (about half of all PCPs in Humboldt County). The biggest concern raised by PCPs was the lack of time to engage patients in SDM. All of the PCPs surveyed believed that patients want to participate in decisions about their care. Eighty percent of PCPs surveyed thought they could adopt SDM but worried about having all of the data and options. Survey results also indicated opportunities for improving the interface between primary and specialty care providers. More than half of surveyed PCPs wanted to see the patient again after a consult with the specialist to make a care decision, but 70% indicated that the specialist often made major treatment decisions on his or her own.

"Patient advisors played a key role in the center's development, especially in the areas of care transitions, workflow design, communication, and in ensuring that the referral center was patient centered."

Based on this feedback, HDNIPA designed an SDM process that focuses on a referral center. The process starts when a patient has a "trigger visit" (one where the patient is going to be faced with a treatment decision on any of 14 conditions or procedures identified by Humboldt for the pilot) with a PCP. Then the referral center contacts the patient to discuss care options. Patients can choose to not go through the SDM process and go straight to the specialist, to get the decision aid and review it on their own, or to get the decision aid and meet with a trained coach to discuss their options. Depending on the patient's choice, the referral center staff will send the decision aid, schedule an appointment with the coach, or send the referral on to the specialist. An HDNIPA nurse and a wellness coach who are trained on SDM techniques and tools staff the referral center. (See Figure 2.)

Patient advisors played a key role in the center's development, especially in the areas of care transitions, workflow design, communication, and in ensuring that the referral center was patient centered. HDNIPA started a pilot of this program at three primary care sites, with eight providers, for 14 conditions in October 2014.

Figure 2: Referral Center Workflow



Source: Humboldt-Del Norte Independent Practice Association

Sharp HealthCare www.sharp.com

Who: Sharp HealthCare is a nonprofit, multidisciplinary integrated health care system. It provides medical services throughout San Diego at its seven hospitals, two major medical groups, skilled nursing facilities, pharmacies, and through its home health and hospice programs. Sharp delivers care through a network of 2,600 affiliated physicians, including more than 1,100 in its two affiliated medical groups and more than 16,000 employees.

What: Sharp HealthCare integrated SDM into its end-of-life care services through its Transitions program, which was designed to extend the benefits of hospice care to patients early in their disease progression. The Transitions program is based on four principles:

1. Comprehensive in-home education with patients and their family members about the disease process and proactive medical management
2. Evidence-based prognosis

3. Professional, proactive management of family caregivers to help them participate in the care process and become advocates for the patient
4. Advance health care planning

Sharp outlined different stages of decisionmaking for patients. In stage 1, there is no disease-specific context, so decisions are theoretical. An example of a stage 1 patient is a healthy individual who comes in for a physical. For that patient, specific treatments do not have a context. In stage 2, a patient has been diagnosed with a disease and decisions can be made within the context of the disease and its natural progression. These discussions may occur months or years prior to any specific treatment decisions. In stage 3, an emergency has occurred — patients are hospitalized, and decisions are being made in chaos. The Transitions program focuses on SDM during stage 2.

Sharp has these goals for decisions that are made through SDM:

- Decisions are based on accurate and valid information.
- Decisions are usable and specific (for example, language specifically requests "do not transfer to hospital" instead of a "do not resuscitate" order).
- Provider bias has been removed.
- Uncertainty is removed so patients do not end up being admitted to the hospital against their wishes.

"We should never assume we know what our patients want. We should always ask them about their goals of care."

For effective SDM, first there must be full disclosure of all options, including a discussion of benefits, risks, and any uncertainty. Second, discussions must take place soon after diagnosis. Finally, the discussion should be placed in the context of the patient's psychosocial and physiological needs and capacity.

The Transitions program encourages family members to become patient advocates and to learn how to express the patient's goals of care to the health care system before the system makes assumptions about what is best for the patient. In addition, caregivers are encouraged to speak up for patients in times of crisis. Sharp also makes sure the multiple parties involved, including providers, patients, family members, and care institutions, share a common understanding of the patient's care plan. Since Sharp is an integrated system, the process of aligning incentives among these multiple parties is often easier for Sharp than for nonintegrated systems.

Quick Takes

- **Clinical decisions are often not one decision but a series of decisions.** It can be useful to talk about the decision tree upfront with patients so they are prepared for what's to come.
- **The language used to describe treatment options is critical.** Eliminate adjectives and simply describe the treatment options. For example, when it comes to talking about end-of-life care, describe the services available instead of asking if patients want "full care," meaning intensive intervention. Many patients won't turn down "full care" even if that goes against their wishes because they may not understand what that means or what the alternatives are.
- **Effective SDM requires significant culture change.** Patients and clinicians working together as equal partners is still a novel concept. The traditional model of clinicians doing "to patients" rather than "with patients" is still well entrenched.
- **SDM can't rely exclusively on physicians.** Organizations will need to consider workflows and roles that involve medical assistants, nurses, and care managers to effectively implement SDM.
- **Make it easy.** Something as simple as putting the decision aids in the exam room can lead to greater use.

Resources

Alston, Chuck et al. Shared Decision-Making Strategies for Best Care: Patient Decision Aids. Washington, DC: Institute of Medicine, 2014. www.iom.edu/Global/Perspectives/2014/SDMforBestCare.aspx.

Agency for Healthcare Research and Quality (AHRQ). "Patient Decision Aids." www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/patient-decision-aids.

Healthwise (health information and decision support tools for plans, hospitals, and consumer health portals). www.healthwise.org.

Mayo Clinic. "Downloads: Decision Aids." www.mayo.edu/research/labs/knowledge-evaluation-research-unit/downloads.

Option Grid Collaborative. "Option Grids: Short Tools for Comparing Health Options." www.optiongrid.org.

Ottawa Hospital Research Institute. "A to Z Inventory of Decision Aids." decisionaid.ohri.ca/azinvent.php.

Endnotes

1. Dawn Stacey et al., "Decision Aids for People Facing Health Treatment or Screening Decisions," *Cochrane Database of Systematic Reviews* 2014, no. 1 (January 28, 2014), doi:10.1002/14651858.CD001431.pub4.
2. Michael J. Barry and Susan Edgman-Levitan, "Shared Decision Making — The Pinnacle of Patient-Centered Care," *New England Journal of Medicine* 366 (March 1, 2012): 780-1, doi:10.1056/NEJMp1109283.
3. John E. Wennberg, Elliot S. Fisher, and Jonathan S. Skinner, "Geography and the Debate over Medicare Reform," *Health Affairs* (published online February 2002), doi:10.1377/hlthaff.w2.96.
4. Barry and Edgman-Levitan, "Shared Decision-Making."
5. www.dartmouthatlas.org.
6. Stacey et al., "Decision Aids."
7. Clarence Braddock III et al., "Informed Decision Making in Outpatient Practice: Time to Get Back to Basics," *JAMA* 282, no. 24 (December 22, 1999): 2313-20.
8. M. Kim Marvel et al., "Soliciting the Patient's Agenda: Have We Improved?" *JAMA* 281, no. 3 (January 20, 1999): 283-7.
9. Roy Kessels, "Patients' Memory for Medical Information," *Journal of the Royal Society of Medicine* 96, no. 5 (May 2003): 219-22.
10. Dominick Frosch et al., "Authoritarian Physicians and Patients' Fear of Being Labeled 'Difficult' Among Key Obstacles to Shared Decision Making," *Health Affairs* 31, no. 5 (May 2012): 1030-8, doi:10.1377/hlthaff.2011.0576.
11. In 2014, the Informed Medical Decisions Foundation merged with the nonprofit Healthwise.

California HealthCare Foundation

California Improvement Network Better Ideas for Care Delivery