

National Quality Partners Playbook™: Shared Decision Making in Healthcare



NATIONAL
QUALITY FORUM

NATIONAL QUALITY PARTNERS PLAYBOOK™: SHARED DECISION MAKING IN HEALTHCARE

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ABOUT NATIONAL QUALITY FORUM

Founded in 1999 and based in Washington, DC, the National Quality Forum (NQF) is the nation's resource for healthcare quality measurement and improvement. NQF is an independent, not-for-profit, membership-based organization that brings healthcare stakeholders together to recommend quality measures and improvement strategies that reduce costs and help patients get better care. Through its multistakeholder membership of more than 400 organizations, NQF facilitates an open and thorough dialogue on healthcare measurement and improvement, and strives to lead national collaboration to improve health and healthcare quality for all Americans.

National Quality Partners™

National Quality Partners™ (NQP™), an NQF initiative, is an active forum for NQF members to connect, collaborate, and provide thought leadership on quality improvement strategies to achieve national health and healthcare quality goals. NQP leads practical, action-oriented initiatives to drive meaningful and lasting change for patients and their families.

NQP addresses the nation's high-priority healthcare issues by engaging stakeholders from across the care continuum. To spur collective action to make shared decision making (SDM) a standard of care for all patients, NQP brought together experts and national stakeholders from the public and private sectors to form the NQP Shared Decision Making Action Team. Drawn from the NQF's diverse membership, the Shared Decision Making Action Team worked together to identify key barriers and solutions to advance SDM on a national scale.

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ACKNOWLEDGEMENTS

NQF gratefully acknowledges the National Quality Partners™ Shared Decision Making Action Team, its individual members, and other key contributors, who served as technical consultants as NQF developed and produced the *National Quality Partners Playbook™: Shared Decision Making in Healthcare*. A special thanks to Diana Stillwell for her contributions to this effort.

Sponsors

NQF gratefully acknowledges support from the following organizations toward the NQP's work on shared decision making:

- PhRMA
- Genentech
- Merck & Co., Inc.
- Gordon and Betty Moore Foundation

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SHARED DECISION MAKING: A HEALTHCARE IMPERATIVE

Personal decisions about healthcare are rarely straightforward. In many cases, individuals face choices about treatment options (including, at times, the option to forego treatment). Their treatment choices can differ in terms of benefits, risks or complications, and what's involved in undergoing treatment. More often than not, healthcare decisions are *preference-sensitive*, meaning that evidence does not clearly identify one treatment option as better than another, and a person's goals for care and their values and preferences for a particular set of outcomes should play a major role in their choices about which treatment option is best for them.^{1,2}

It may seem that healthcare decision making should be easier than ever. People have access to healthcare information as never before, but in reality, individuals often do not understand basic information about the risks and benefits of treatments and alternatives that are necessary to make informed decisions.³ Patients may also be reluctant to ask questions or express disagreement with their clinicians out of fear of being labelled as “difficult.”⁴ Clinicians can also have inaccurate impressions of what matters most to their patients, and both patients and clinicians can face uncertainty when making clinical decisions.⁵ Nevertheless, patients are more satisfied with their care and outcomes when their clinician listens to them, elicits their goals and concerns, explains all the options, and helps align treatment decisions with their personal preferences.^{6,7}

Many patients—though not all—prefer to make healthcare decisions in partnership with their clinicians,^{8,9} yet often patients are not asked to provide meaningful input into their healthcare decisions. Fewer than half say their clinician asked about their goals and concerns.¹⁰ Only by working in partnership can patients and clinicians identify patient values, goals, and preferences and make informed decisions about treatment and care. This model of two-way communication—known as shared decision making (SDM)—is critical to person-centered care, and has the potential to become the standard for informed consent in healthcare.¹¹

Shared decision making (SDM) is a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients. SDM requires three components:

- clear, accurate, and unbiased medical evidence about reasonable alternatives—including no medical intervention—and the risks and benefits of each;
- clinician expertise in communicating and tailoring that evidence for individual patients; and
- patient values, goals, informed preferences, and concerns, which may include treatment burdens.

– Developed by the NQP Shared Decision Making Action Team

In some cases, clinicians and patients can use high-quality, unbiased, and evidence-based patient decision aids (DAs) to support SDM. (See [Appendix B](#) for information on DAs and [Appendix C](#) for DA and SDM guide developers.) Patient decision aids are tools designed to help people better participate in healthcare decision making. These resources provide information on the risks, benefits, and alternatives as well as burdens of options and help patients clarify and communicate their personal values regarding different features of the options.

Patient decision aids do not advise people to choose one option over another, nor do they replace clinician consultation. Instead, they prepare patients to make informed decisions, together with their clinicians, that best align with their values, goals, and preferences.¹² Decision aids include but are not limited to printed booklets, videos, or web-based resources to help patients and their families and caregivers participate in decision making about their healthcare options.

Patient decision aids are tools designed to help people better participate in healthcare decision making. These resources provide information on the risks, benefits, and alternatives as well as burdens of options and help patients clarify and communicate their personal values on different features of the options. Patient decision aids do not advise people to choose one option over another, nor do they replace clinician consultation. Instead, patient decisions aids prepare patients to make informed decisions, together with their clinicians, that align with their values, goals, and preferences.

- Adapted from the International Patient Decision Aids Standards Collaboration

Clinicians and patients may find DAs valuable as part of the shared decision making process. Clinicians can also use DAs in their conversations with patients to support communication and improve the quality of the SDM process.¹³ Evidence demonstrates that using decision aids can help patients feel more prepared to discuss their treatment options with their clinicians; improve patients' understanding of their health, treatment options, potential outcomes, and risks;¹⁴ reduce the number of people who remain undecided about treatment; and result in a better match between patient values and choices.¹⁵

SDM, with the use of certified DAs, can improve the informed consent communication process,¹⁶ strengthen the patient-clinician relationship,¹⁷ and enhance patient safety by ensuring that patients have a deeper understanding of the risks and benefits inherent in treatment options.¹⁸ SDM can also improve patient experience and outcomes, help clinicians achieve optimal resource use, and reduce healthcare costs¹⁹ by better aligning care with patient values.

Finally, SDM can help healthcare organizations drive their population health strategy and advance value-based healthcare strategies that are fundamental in the shift from paying for volume to value.

A Standard of Care for All Patients

SDM can become a standard of care for all patients regardless of setting or diagnosis, but that can only happen when patients and families understand the importance of their input and engagement in healthcare decisions, and clinicians understand the importance of involving patients in decisions—and when both are supported in doing so. This is true for isolated, preference-sensitive decisions (such as whether to receive a screening test or select a treatment option for a given diagnosis), for decisions about ongoing management of chronic conditions (such as asthma, diabetes, and high blood pressure), and for decisions about transitions from one care setting to another (such as from acute care to post-acute care for rehabilitation).²⁰

Given the benefits of SDM, why has the practice been slow to take hold within healthcare organizations? Although the SDM process itself may seem straightforward, real-life clinical encounters are generally not. With many quality and performance priorities, and an evolving payment and care delivery landscape, many healthcare organizations and clinicians face challenges and need simple guidance to integrate SDM into busy clinical workflows.

Challenges to SDM within healthcare organizations can include limited leadership commitment to supporting SDM as a standard of care and limited resources (including financial support and technical expertise) to design, implement, and evaluate SDM initiatives. Clinicians may lack experience and/or confidence in how to communicate with patients about the risks, benefits, and uncertainty about the evidence concerning their treatment outcomes, particularly if patients have low health literacy or health numeracy, language challenges, differing cultural or religious beliefs, and/or medical and social complexities. Clinicians may also lack the time needed to elicit patient goals and concerns or think that they already engage in SDM with their patients.

Healthcare organizations and clinicians can and are overcoming many of these challenges every

day. SDM is a process that can be adapted to meet the unique needs and challenges of each health system as well as each patient and family. Healthcare organizations can learn from work done in other settings to establish SDM as a standard of care to

create sustainable, patient-centered models that ensure all patients are as well informed and involved in decisions about their health and their healthcare as they wish to be.

USING THE NQP PLAYBOOK

The *NQP Playbook™: Shared Decision Making in Healthcare* provides practical guidance for healthcare organizations to implement or strengthen SDM, using available resources. The *NQP Playbook* is not a list of “must do’s” but instead offers a variety of options from which to choose depending on context, resources, and needs, and strives to provide guidance on making SDM a standard of person-centered care. While intended primarily for healthcare organizations, a broad set of stakeholders, including patient advocacy organizations, educators, policy and regulatory bodies, and payers, may find it valuable in helping to support and encourage successful implementation of SDM.

The *NQP Playbook* is organized by the six SDM fundamentals for healthcare organizations. For each fundamental, the *NQP Playbook* includes a brief overview, implementation examples, potential barriers and suggested solutions, and sample tools and resources. **Appendix D** includes hyperlinks to all tools and resources by each fundamental area.

Healthcare organizations can use the implementation examples to design, refine, and extend their SDM programs and increase the potential for success.

The implementation examples progress from basic to intermediate to advanced approaches—categories that are approximate based on likely resource-intensiveness and organizational effort. Healthcare organizations can undertake basic examples relatively quickly and with limited resources, while intermediate and advanced examples may require more intensive resources and organizational effort. An organization need not begin with basic approaches before moving to intermediate and advanced approaches. Rather, organizations can determine which approaches are best for them based on their available resources and context. Given competing priorities, organizations may not be able to pursue all implementation examples across all categories. Nevertheless, the implementation examples are a broad range of what is possible and achievable.

The *NQP Playbook™* includes “snapshots” that illustrate how various organizations have put the SDM fundamentals and drivers of change into action. The snapshots are real-life, “how-to” stories of implementing shared decision making in healthcare.

SDM can become a standard of care for all patients regardless of setting or diagnosis, but that can only happen when patients and families understand the importance of their input and engagement in healthcare decisions, and clinicians understand the importance of involving patients in decisions—and when both are supported in doing so.

SHARED DECISION MAKING FUNDAMENTALS FOR HEALTHCARE ORGANIZATIONS

The National Quality Forum identified six fundamentals to guide shared decision making in healthcare organizations:

1. Promote leadership and culture
2. Enhance patient education and engagement
3. Provide healthcare team knowledge and training
4. Take concrete actions for implementation
5. Track, monitor, and report
6. Establish accountability for organizations, clinicians, and patients

Fundamental 1: Leadership and Culture

Strong leadership is essential to the success of a healthcare organization's efforts to integrate SDM as a standard of care across the healthcare continuum. Support from leadership at all levels, including the board of directors, C-suite, and departmental and team leaders, encourages broad adoption of SDM as a core value of the organization. Embracing a culture in which leaders promote SDM as a cornerstone of care enables patients and clinicians to become equal members of the care team. Further, framing SDM as part of informed consent, patient safety, and patient rights and responsibilities and promoting SDM as a way to support personalized medicine can bolster person-centered culture change.

Implementation Examples

BASIC

- Include SDM in the organization's mission, vision, and values statements
- Designate an executive and/or clinician leader to serve as a visible "champion" of SDM
- Publicly communicate the organization's commitment to SDM as a standard of care through board-approved statements, annual reports, newsletter articles from the chief executive officer, chief medical officer, and/or chief experience officer, etc
 - Include examples of actions that the organization has implemented that demonstrate this commitment
- Articulate clear expectations for SDM with targets and goals for all healthcare team members
- Share stories that highlight how SDM can improve patient experience and outcomes and the positive impact of SDM on clinician and patient relationships and the care provided
- Invest in high-quality DAs for service lines to facilitate SDM throughout the organization (see [Appendix B](#) for more information on DAs.)

INTERMEDIATE

- Establish patient and family advisory councils (PFACs) with meaningful representation and provide SDM resources to support their work
- Develop and implement a pilot or demonstration project, e.g., ask a service line to design an SDM implementation project or test the impact of financial incentives on SDM
- Design, implement, and evaluate new clinical workflows to facilitate SDM
- Include SDM measures in the organization's strategic dashboard
- Educate clinicians on SDM (see **Fundamental 3** for more information)

ADVANCED

- Prioritize funding for information technology (IT) to support SDM initiatives such as integrating DAs into electronic health record (EHR) workflows
- Allocate consistent operational resources (financial, IT, staff, etc.) to enable system-wide SDM
- Establish recognition and/or financial incentives for departments or units to promote and improve SDM
- Partner with payers to offer SDM as a benefit for health system employees and covered dependents²¹
- Collect data on SDM implementation and use, and support patient and clinician access to data on results to support continuous quality improvement efforts

Potential Barriers and Suggested Solutions

Lack of leadership support and/or buy-in for SDM*Suggested Solutions*

- Make the business case to show that SDM increases value by improving patient outcomes, and patient and clinician experience
- Provide leaders with data such as patient experience, patients' willingness to recommend a clinician or service line (i.e., net promoter score), clinician and/or patient narratives, and expert-led presentations on benefits of SDM
- Dedicate a board member to work with the SDM implementation team
- Frame and internally promote SDM interventions/approaches as healthcare organization initiatives

Skepticism about the value and importance of SDM*Suggested Solutions*

- Focus on the impact that SDM and engaged patients can have on financial goals (e.g., practice growth), patient experience, quality metrics, and regulatory standards
- Ask senior clinicians/champions to present on SDM at grand rounds
- Share clinician testimonials on positive experiences using SDM to discuss implications of different options

- Engage patients and advocates to share stories about SDM and its impact on patients and families in organizational newsletters, websites, and leadership meetings

Limited budgets to support SDM programs*Suggested Solutions*

- Explore whether existing patient education vendors provide decision aids to facilitate SDM implementation
- Leverage existing patient education and clinician continuing education (CE) budgets to purchase decision aids and SDM training
- Start with DAs that do not require significant IT integration, or use publicly available SDM and DA resources

Competing priorities, "initiative fatigue," and burnout*Suggested Solutions*

- Integrate SDM activities into existing quality improvement and/or patient engagement initiatives to gain efficiencies and avoid silos
- Start with small initiatives to demonstrate "quick wins," and use these to build momentum and gain support for larger scale implementation

Suggested Tools and Resources

Organizational resources for SDM Implementation

- [Creating a Revolution in Patient and Customer Experience](#)
- [Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care](#)
- [National Learning Consortium: Shared Decision Making](#)
- [RWJF Shared Decision-Making and Benefit Design](#)
- [Shared Decision Making in Health Care: Achieving Evidence-Based Patient Choice](#)
- [Shared Decision Making Implementation Readiness Assessment](#)

Case studies

- [Changing Culture and Delivery to Achieve Shared Decision Making at Dartmouth-Hitchcock Medical Center, New Hampshire](#)
- [Creating a Shared Vision Case Study: Stillwater Medical Group](#)
- [Group Health's Participation in a Shared Decision-Making Demonstration Yielded Lessons, Such As Role Of Culture Change](#)

Journal articles

- [Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice](#)
- [Decision Aids for People Facing Health Treatment or Screening Decisions](#)
- [Shared Decision Making—The Pinnacle of Patient-Centered Care](#)

Snapshot: Leadership and Culture in Action

At Group Health Cooperative of Puget Sound (now Kaiser Permanente Washington), senior leaders recognized the role of shared decision making supported by high-quality decision aids to improve the quality of patient decisions and enhance patient satisfaction. Having observed wide variation in rates of joint replacement across practices within their system, leaders were aware that differences in patients' clinical circumstances or preferences for care did not explain the variation. Leadership at Group Health introduced SDM and decision aids as part of a broad quality improvement initiative, with the goal of changing the culture among orthopedic clinicians and care teams. Demonstrating its strong commitment to the importance of SDM, leadership offered a ½-day SDM training program that was attended by 90 percent of orthopedic clinicians and surgeons. Group Health subsequently observed a reduction in elective surgery rates and total costs of care.

References:

Arterburn D, Wellman R, Westbrook E, et al. Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs. *Health Aff (Millwood)*. 2012;31(9):2094-2104.

Fournier A, Arterburn D, Sepucha K, et al. Implementing shared decision making in varied practice settings. Webinar presentation sponsored by Agency for Healthcare Research and Quality (AHRQ); July 15, 2015.

Fundamental 2: Patient Education and Engagement

Healthcare organizations can engage and educate patients and families about what SDM means, why SDM is beneficial to them, what their role can be, and what to expect from clinicians and the system of care. Organizations can provide educational resources and coaching for patients, families, and caregivers about SDM, including how patients can make more informed decisions and how to identify their values, goals, and preferences. With appropriate support and time to absorb information, SDM is achievable for most people: This includes those with lower health literacy and/or health numeracy and families and caregivers for those individuals unable to make decisions on their own. Once patients understand their role and have access to high-quality resources, most are enthusiastic participants in becoming informed and involved in decisions about their care.

Implementation Examples

BASIC

- Provide patient and family education on what SDM is, why it's important, what it will mean to their care, and their ability to choose to engage or not engage in SDM
- Publish newsletter or website articles including patient testimonials on the importance of sharing goals, values, and preferences and positive experiences with SDM
- Set expectations with healthcare teams to ensure they are communicating decision tradeoffs and integrating patient preferences, values, and goals into the care and/or wellness plan
- Support patients to serve on clinical committees (e.g., women's health, pediatrics, and oncology) in which SDM is particularly important
- Make available high-quality decision aids that meet the National Standards for the Certification of Patient Decision Aids (see [Appendix B](#) for details)

INTERMEDIATE

- Invite patients, families, and caregivers to participate in the redesign of workflows that incorporate SDM and decision aids
- Engage patients in creating exam room posters that depict how SDM happens in clinical settings
- Implement an ongoing process or mechanism for sharing information with patients, receiving input, and responding to input as part of the SDM program in the organization
- Ensure clinicians are co-creating care plans with the patient, family, and/or caregiver around patient goals, values, and preferences, and are regularly updating plans with patient input
- Engage patient and advisory family councils (PFACs) in planning at an organizational and program level, which could inform the selection of patient decision aids

ADVANCED

- Develop and distribute SDM rights and responsibilities to each patient, including the right to not engage in SDM
- Target patient education to facilitate SDM for preference-sensitive or specific conditions
- Leverage electronic health record (EHR) patient portals as a communication channel for SDM education and decision aids

Potential Barriers and Suggested Solutions

Patient uncertainty and/or lack of awareness about SDM, the patients' role, and the importance of sharing their preferences

Suggested Solutions

- Ensure patients understand their role in SDM; for example, when distributing decision aids, include a cover letter that clearly explains what DAs are and how they are helpful, and endorses their use to support decisions
- Ensure all members of the care team are aware of how SDM and DAs are introduced to patients
- Create clear messages about SDM, including what patients can expect, how to actively participate and engage in decision making, why it's important for them to ask questions and identify their preferences,²² and how to opt out if they choose not to participate

Patients and families with low health literacy or numeracy; nonnative speakers of English; physical disabilities (low vision, hearing impairment); or cognitive disabilities

Suggested Solutions

- Use patient decision aids and other resources that are developed using best practices for health literacy, risk communication, accessibility, and a range of visual and linguistic techniques²³

- Implement adaptive learning models to meet different learning needs and capabilities
- Use teach-back techniques—asking patients, families, and/or caregivers to state in their own words what they need to know or do—to ensure understanding
- Ensure medical interpreters are aware of SDM principles and best practices, and encourage them to share cultural insights to support SDM

Lack of patient trust in clinicians and/or healthcare system

Suggested Solutions

- Leverage all members of the care team to establish positive relationships with patients and their families
- Engage patients/families on curriculum committees
- Ensure clinicians are trained to communicate with patients, and engage trained healthcare team members to help mediate if differences arise in patient and clinician conversations
- Ensure clinicians feel safe communicating when they may not be familiar with all of the information on care options, and/or may have a perceived conflict of interest

Suggested Tools and Resources

Organizational resources

- [Healthier Washington SDM Pilots](#)
- [Shared Decisions in Cancer Care: Is Medicare Providing a Model?](#)
- [Shared Decision Making: Engaging Patients to Improve Health Care](#)

Training and toolkits for patients

- [Advance Care Planning: Multimedia Resources for Clinicians and Patients to Navigate End of Life Planning](#)
- [An Invitation to Patient and Family Engaged Care for Consumers: What it is, Why it Matters and How Patients and Families Can Engage](#)
- [SHARE Approach Curriculum Tools](#)
- [The Ottawa Hospital Decisional Conflict Scale](#)

Journal articles

- [Addressing Health Literacy in Patient Decision Aids](#)
- [Authoritarian Physicians And Patients' Fear Of Being Labeled 'Difficult' Among Key Obstacles To Shared Decision Making](#)
- [Shared Decision Making—Finding the Sweet Spot](#)
- [Shared Decision-Making Strategies for Best Care](#)
- ['That's the Doctor's Job': Overcoming Patient Reluctance to be Involved in Medical Decision Making](#)

Snapshot: Patient Education and Engagement in Action

The Virginia Piper Breast Center at Abbott Northwestern Hospital serves women in the greater Minneapolis area. As part of the Center's shared decision making program for early-stage breast cancer, an RN cancer care coordinator calls each new patient within 24 hours of her diagnosis to explain shared decision making and set up an appointment before her consult with the surgeon. During the visit, coordinators provide breast cancer education about medical terminology and common treatment options (surgery, chemotherapy, radiation therapy), and assess patient values and preferences. Angie Meillier, RN, MS, CPPM, former manager of clinical programs, describes these meetings, which are supported by a decision aid that includes key information about the condition, treatment options, and tradeoffs among them. "The decision is based on what they're looking to get out of their treatment. For many early-stage breast cancer patients, research has demonstrated that the long-term outcomes are virtually identical, so the discussion is about how the patient wants to look cosmetically, and what degree of surgery she is willing to have." Patients go home with a decision aid.

"Care coordinators found [the decision aid] decreased the number of questions and calls that came in after the initial surgical consult, and surgeons noted patients were more prepared to have informed conversations," Ms. Meillier said. Surgeons immediately saw the value in shared decision making and increased engagement with patients, and patient feedback from anonymous surveys was overwhelmingly positive.

In 2016, the Breast Center engaged 57 percent of patients in shared decision making conversations, with the goal of increasing participation to 90 percent by 2018.

Reference:

Blum K. Multipronged approach strengthens breast cancer program. *General Surgery News*, October 1, 2017.

Fundamental 3: Healthcare Team Knowledge and Training

Healthcare organizations can educate members of the healthcare team about the benefits of SDM for both their work and their patients, encourage authentic conversations about patients' preferences and concerns, and emphasize the importance of understanding a patient's level of interest or ability to engage in SDM. Training can include coaching on communicating risks and benefits; eliciting patient values, goals, and preferences; using SDM tools such as decision aids; the role of families and caregivers in supporting SDM; and incorporating what matters most to patients into care decisions. Improved knowledge and skills can foster mutual respect and trust between patients and their healthcare teams. Healthcare team members should be key stakeholders in the planning and design of SDM programs, including the thoughtful redesign of patient care workflows to incorporate use of decision aids and SDM conversations, the selection of appropriate measures of success, and ongoing process improvement.

Implementation Examples

BASIC

- Educate healthcare teams on SDM, including facts and myths about SDM, and differences between SDM, decision aids, and patient education
- Engage a skilled SDM facilitator to support and provide feedback to ensure authentic and effective SDM and strengthen communication skills
- Ensure that care team members are actively engaged in designing SDM workflows, choosing performance metrics, and selecting high-quality decision aids
- Take advantage of regular clinician staff meetings to offer brief educational sessions (e.g., “lunch and learn” model)
- Incorporate SDM concepts into orientation for new clinical staff

INTERMEDIATE

- Offer continuing education (CE) in SDM skills and competencies
- Involve clinicians in identifying gaps in skills and provide support/training to build competencies
- Integrate SDM into ongoing clinician education programs and annual competencies to ensure all staff have training in SDM to make it a part of routine care
- Engage clinicians in developing and evaluating SDM resources (e.g., orientation training, training materials, decision aids)
- Provide access to patient decision aids that meet the National Standards for the Certification of Patient Decision Aids ([Appendix B](#)) and orient healthcare teams to their content/uses
- Require training in SDM for all patient care staff, regardless of clinical discipline or role

ADVANCED

- Designate care team members who can provide ongoing SDM training and mentoring for clinicians and staff
- Integrate SDM into medical and health professional student education and training curricula to train the next generation of clinicians to implement SDM as a standard of care
- Provide team-based education on SDM, including definition of roles, training in multiple contexts, and tools such as scenario-based learning and videos
- Institute annual training on SDM, measure comprehension scores from training to track changes in knowledge, and incentivize application of knowledge in practice

Potential Barriers and Suggested Solutions

Attitude that SDM already takes place

Suggested Solutions

- Use items from the **Measurement Framework** to conduct a simple baseline survey of team and patient perceptions of SDM and compare results
- Engage team leaders in modeling and articulating SDM behavior and expectations
- Enable a culture in which individuals at all levels feel safe to discuss when SDM is not happening effectively
- Acknowledge when SDM does not happen, or does not happen optimally, and learn from failures and gaps

Lack of healthcare team skills or knowledge on SDM

Suggested Solutions

- Build clinician capacity to engage in SDM, including training in DAs to give clinicians a framework and language to use
- Increase clinician awareness of why patients may hesitate to participate in SDM and the need to create a safe and calm environment for patient communication²⁴
- Conduct team-based training sessions focused on practical skills to optimally activate and engage patients using clinical scenarios, mirroring, active listening, and role-play²⁵
- Support clinician and patient access to different types of information to help with decision making: consultations, clinician notes,

patient-directed information, data on options, and DAs

Clinicians lack confidence in key SDM competencies

Suggested Solutions

- Offer and incentivize staff training and education (e.g., continuing education credits)
- Promote cultural competence and an understanding of the different ways people make healthcare decisions
- Provide clinician training on communicating with patients, families, and/or caregivers of all backgrounds
- Have regular shared learning opportunities (e.g., clinical lead meetings, learning sets), including sessions for clinicians to discuss real world challenges
- Create learning collaboratives including executives, clinician leaders, care team members, administrators, patients, families, IT, and other stakeholders to share insights and best practices

Lack of time and resources for SDM training

Suggested Solutions

- Incorporate SDM into existing training or meeting structures and processes (e.g., continuing professional development) to engage clinicians
- Connect with other local organizations or networks to share training and educational resources

Suggested Tools and Resources

Organizational and healthcare team training

- [American Medical Association Video: Health Literacy and Patient Safety: Help Patients Understand](#)
- [Connected: Improving the Patient-Physician Experience through Communication](#)
- [Healthwise](#)
- [The Health Foundation's Shared Decision Making Skills Training Workshops](#)
- [Implementation Guide for AHRQ's Making Informed Consent an Informed Choice Training Modules](#)
- [The SHARE Approach](#)
- [Shared Decision Making—Case Studies](#)
- [Shared Decision Making & The Power of Decision Aids](#)

Decision Aids and Resources

- [Mayo Clinic Shared Decision Making National Resource Centers—Decision Aids](#)
- [MedU Shared Decision-Making Tool](#)

Journal articles

- [A Framework to Improve Surgeon Communication in High-Stakes Surgical Decisions Best Case/Worst Case](#)
- [Best Case/Worst Case: A Strategy to Manage Uncertainty in Shared Decision-Making](#)
- [Decision Aids to Help People who are Facing Health Treatment or Screening Decisions](#)
- [Implementing Shared Decision Making in the NHS: Lessons from the MAGIC Programme](#)
- [Ten Years, Forty Decision Aids, and Thousands of Patient Uses: Shared Decision Making at Massachusetts General Hospital](#)

Snapshot: Healthcare Team Knowledge and Training in Action

At Massachusetts General Hospital in Boston, the shared decision making program leadership noted that a small number of clinicians accounted for most of the total distribution of decision aids in their long-running SDM program. To increase clinician uptake of decision aids, the SDM team used the results of a survey to design a 1-hour session that could be delivered during practice meetings regularly attended by clinicians and staff. Attendees reviewed the DA content, viewed clinician- and practice-level data on the use of DAs, and were introduced to the EMR-enabled DA ordering program. Physicians who attended the session could receive continuing medical education (CME) credits, which 88 percent of survey respondents identified as a key incentive for participation.

Attendees received the sessions very positively, with attendees commenting: “After watching the video, I know what my patients will be seeing,” and “I didn’t realize the prescriptions [orders for the aids] were so easy to do.” One explained that seeing data on how many DAs were prescribed by each clinician in the department encouraged an increase in her own prescribing. Decision aid distribution more than doubled after the SDM team offered the clinician training sessions, and the improvement in rates was sustained over time. Most clinicians who used decision aids reported that the aids improved the quality of care and changed their discussions with patients.

References:

- Sephucha KR, Simmons LH, Barry MJ, et al. Ten years, forty decision aids, and thousands of patient uses: shared decision making at Massachusetts General Hospital. *Health Aff (Millwood)*. 2016;35(4):630-636.
- Fournier A, Arterburn D, Sepucha K, et al. Implementing shared decision making in varied practice settings. Webinar presentation sponsored by Agency for Healthcare Research and Quality (AHRQ); July 15, 2015.

Fundamental 4: Action and Implementation

For SDM to succeed, healthcare organizations and teams must engage in SDM with all patients who wish to do so as a central part of care decisions about interventions, procedures, tests, treatments, clinical trials, and care settings. Healthcare organizations should strive to make it easy to do the right thing through technology and thoughtful workflow redesign that can reduce time constraints for the healthcare team. Identifying a designated member of the healthcare team to document patient decisions in a standardized way into the electronic health record, deliver decision aids when appropriate, and regularly update, review, and share the care plan throughout the patient's care can also support treatment consistent with those decisions. Successful implementation includes health information technology that integrates clinical and patient information and supports SDM and process improvement.

Implementation Examples

BASIC

- Incorporate principles of SDM into care delivery in a few service lines as a pilot effort
- Designate a member of the healthcare team to document patient decisions in a standardized way and regularly update, review, and share the care plan throughout the patient's care
- Document the concept of and expectations for SDM in an organization's policies and procedures
- Establish patient preferences and identify end-points for meeting them before the healthcare team acts on the treatment plan
- Work with electronic health record (EHR) vendors to incorporate prompts for SDM into EHR platforms, and deliver and track use of DAs

INTERMEDIATE

- Select and implement high-quality decision aids that meet the National Standards for the Certification of Patient Decision Aids to help patients make informed decisions (see [Appendix B](#) for details)
- Incorporate patient decision aids into pre- and post-visit and referral workflows, and make them available in patient portals
- Implement standardized clinical pathways that include SDM
- Enable patients to have access to their care plan across the care continuum to view prior to SDM discussions and making decisions
- Evaluate clinical workflows in each service line to identify the optimal timing and process for SDM opportunities, distributing decision aids to patients (using EHR and patient portals as appropriate), and having/documenting SDM conversations
- Engage patient and family advisory committees (PFACs) in identifying high-priority areas for implementing SDM and optimal approaches for integrating SDM and DAs into routine care

ADVANCED

- Based on early program pilots, create and implement a standardized SDM framework and implementation strategy for the organization that is flexible enough for local implementation
- Create financial and professional incentives within the organization to promote SDM
- Integrate SDM into:
 - policies
 - performance evaluation processes, and
 - patient and employee satisfaction surveys.

Potential Barriers and Suggested Solutions

Workflows are not designed to accommodate SDM

Suggested Solutions

- Conduct a Plan-Do-Study-Act (PDSA) quality improvement exercise to include SDM
- Include employees from every department in designing a quality improvement plan on how to integrate decision aids and SDM into practice
- Engage patients in pre-work by providing decision support tools such as decision aids for review prior to their visit (as a supplement, not a replacement for SDM)

Lack of clinician awareness, understanding, or buy-in for SDM

Suggested Solutions

- Provide clinician-specific dashboards with de-identified peer group comparisons of SDM implementation

- Frame SDM as a component of professional integrity, mission, and excellence for clinicians
- Provide clinicians the opportunity to do trials of SDM with a few patients and provide feedback on their experience and outcomes
- Implement clinical decision support to ensure guidelines and recommended interventions are easily accessible

Clinician burden or burnout

Suggested Solutions

- Share positive outcomes from using SDM with patients, including the opportunity for efficiencies and clinician satisfaction
- Ensure SDM is not implemented as a perfunctory activity and that it is tied to observable results
- Use an interdisciplinary approach that involves other members of the healthcare team to engage in and document SDM with patients

Suggested Tools and Resources

Organizational resources

- [Evidence-Based Decision Making: Shared Decision Making](#)
- [Integrating Patient Decision Aids into Primary Care Practice: A Toolkit to Facilitate Shared Decision Making](#)
- [The Roadmap to Consumer Clarity in Health Care Decision Making: Making Person-Centered Care a Reality](#)

Toolkits and training

- [Decision Aids Implementation Worksheet](#)
- [Mayo Clinic Shared Decision Making National Resource Centers—Implementation Tool Kit](#)
- [SDM Implementation Flow Chart](#)

- [The SHARE Approach Implementing Shared Decision Making In Varied Practice Settings](#)

- [The SHARE Approach Patient-Centered Outcomes Research and the Use of Decision Aids to Facilitate Shared Decision Making Webinar](#)

Journal articles

- [A Demonstration of Shared Decision Making in Primary Care Highlights Barriers to Adoption and Potential Remedies](#)
- [Patient Activation and the Use of Information to Support Informed Health Decisions](#)
- [Shared Decision Making: A Model for Clinical Practice](#)

Snapshot: Action and Implementation in Action

Saint Agnes Healthcare, part of the Ascension Health System, serves the diverse Greater Baltimore community, where cardiovascular disease is a major health issue. The Saint Agnes Heart Failure Center (HFC) is a multidisciplinary outpatient clinic that provides ongoing, individualized care for patients with heart failure.

Advance care planning and advance directives are essential components of heart failure patient care, but these conversations can be difficult for patients, families, and providers. A 2015 record revealed that only about 15 percent of patients had a living will or an advance directive completed and easily accessible. The HFC team felt this rate was far too low, and the team recognized the need for resources and care processes to help their heart failure patients understand their options, express their preferences, and participate in healthcare decisions. The care team identified a series of short video decision aids designed to support advance care planning discussions, and with funding support from the Saint Agnes Foundation, integrated them into daily clinic workflows and documentation. Structured data fields were added to the system to help the team easily determine which patients have viewed a decision aid video and have an advance directive in place.

In general, the videos were easy to incorporate into the patient visit. As Jae Patton, RN, MSN, CRNP, nurse practitioner supervisor at HFCA points out, “Because the videos are brief, the nurse practitioners can show them while finishing up discharge paperwork.” Doing so ensures that the nurse practitioner is nearby to offer support and answer questions.

During the year following implementation of the videos, 54.2 percent of patients have completed advance directives documented in the EHR, up from 15 percent before implementation. The clinic plans to continue using the video decision aids and extend their use to the Saint Agnes Cancer Institute, COPD Clinic, and Comprehensive Care Clinic.

Reference:

ACP Decisions. Profiles website. <https://www.acpdecisions.org/profiles/>.

Fundamental 5: Tracking, Monitoring, and Reporting

Mechanisms to track, monitor, and report patient, clinician, and healthcare team engagement in SDM can help healthcare organizations identify opportunities to improve SDM implementation and results. Standardized data collection and regular sharing of performance and patient experience data with organizational leadership, clinicians, patients, and the public can strengthen these efforts. Measurement may start small with process measures and progress to patient experience measures and outcome measures as the program matures. Systems can also track when and why patients choose not to engage in SDM. To inform the shared decision making process, data collection and interpretation should add value and not unnecessarily burden healthcare teams.

Implementation Examples

BASIC

- Use the **Measurement Framework** to measure SDM implementation, considering 2-3 process measures that are most meaningful to the organization, clinicians, and patients
- Use low-cost, scalable measures such as tracking distribution and use of DAs (e.g., tracking the number of clicks on web content) or patient willingness to recommend the DA
- Ensure timely and actionable feedback, e.g., as part of daily operational dashboard reporting or team huddles
- Report on SDM metrics to all stakeholders at all levels, including patients, families, and the public

INTERMEDIATE

- Use the **Measurement Framework** to measure patient and clinician experience with SDM
 - Document patient and clinical outcome(s) of SDM
- Identify relevant outcomes via a collaborative (co-designed) process that includes patients, clinicians, administrators, and other stakeholders to ensure validity
- In high-value service lines, measure decision quality, including patient knowledge; treatment delivered according to patient values, goals, and preferences; and patient involvement in decision making

ADVANCED

- Use the **Measurement Framework** to measure SDM outcomes across key service lines, including patient decision quality
- Use real-time surveys to obtain real-time feedback in a rapid cycle approach, and summarize in a timely and usable format for group training and discussion
- Use data to assess and improve workflows and make SDM more efficient while improving outcomes
- Include SDM data collection and reporting as a core function/key performance indicator (KPI) for key service lines

Potential Barriers and Suggested Solutions

Lack of time and resources

Suggested Solutions

- Include SDM as part of standardized diagnosis and treatment protocols and incorporate the SDM model in the current workflow/process
- Leverage technology, including order sets, electronic tablets, patient portals, and other features to help automate tracking and documentation
- Engage medical assistants, nurses, and care coordinators to facilitate and document SDM

Survey burnout for patients

Suggested Solutions

- Explain that participation in surveys is voluntary, but demonstrate to patients the value of their feedback and explain how it is used
- Select decision aids that incorporate patient data collection as part of the user experience and provide patient-level and/or aggregate reporting

- Engage patients in identifying or developing the measures that matter most to them, and design surveys around these measures

Data overload and burden of measurement for clinicians

Suggested Solutions

- Focus on a small number of issues to start or consider a pilot in one clinic to demonstrate success, and then replicate for service lines
- Connect to ongoing QI initiatives/data collection
- Engage clinicians in selecting the measures that are most meaningful to improve SDM implementation and results
- Use qualitative data and stories to complement and reinforce the impact of quantitative outcomes (e.g., focus groups, storytelling)

Suggested Tools and Resources

Organizational resources

- [Shared Decision-Making Implementation Roadmap](#)

Toolkits and training

- [CollaboRATE Shared Decision Making Tool](#)
- [Integrating Patient Decision Aids into Primary Care Practice: A Toolkit to Facilitate Shared Decision Making](#)
- [Shared Decision Making Health Information Technology Tool](#)

Journal articles

- [Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument](#)
- [Decision Aids to Improve Informed Decision-Making in Pregnancy Care: A Systematic Review](#)
- [Patient and family engagement: a survey of US hospital practices](#)

Snapshot: Tracking, Monitoring, and Reporting in Action

At Group Health Cooperative of Puget Sound (now Kaiser Permanente Washington), analysis of rates of preference-sensitive interventions, such as knee and hip replacement, revealed significant variation relative to the state-wide average and between several centers. Leadership worked closely with front-line clinicians to embed shared decision making and decision aids into routine clinical workflows, including simple prescribing and documentation via the electronic health record, so that patients could receive a decision aid by mail or online through the patient portal. These steps enabled the system to monitor decision aid use and documentation of SDM conversations by clinician and clinic. Leaders and clinicians received monthly feedback, including data on the volume of decision aids ordered, the volume of surgical procedures and total costs of surgical procedures, and patient satisfaction data related to decision aid use. Senior specialty leaders also created a program measure called the ‘defect rate’—the number of patients who underwent elective surgery without having received a decision aid—and reported these rates to leaders and clinicians monthly by individual clinician and specialty, along with data showing that patients found the DAs helpful in understanding their treatment options and preparing to talk with their clinician.

Reference:

Fournier A, Arterburn D, Sepucha K, et al. Implementing shared decision making in varied practice settings. Webinar presentation sponsored by Agency for Healthcare Research and Quality (AHRQ); July 15, 2015.

Fundamental 6: Accountability

To establish accountability for the board of directors, C-suite, and department and team leaders, healthcare organizations should articulate clear expectations and establish incentives for engaging patients in SDM. Incorporating SDM measures into performance management systems can incentivize leaders to embrace SDM as a mechanism for improving person-centered outcomes and patient experience and delivering high-value, high-quality care.

Implementation Examples

BASIC

- Have a shared agreement among the healthcare team and patients on what “good” SDM looks like or what SDM is and is not
- Ensure that SDM is an organizational value that leadership reports on at the board level
- Set organizational and service line goals for SDM
- Incentivize decision quality outcomes financially and publicly, and use them as intervention targets
- Ask patients to rate their SDM experience with their clinician, and report the ratings

INTERMEDIATE

- Report on progress toward meeting all organizational goals for SDM and recommendations for future improvement
- Develop matrices or tiers of readiness so that clinicians can identify their progress on SDM
- Use tools, measures, and incentives for SDM across service lines and clinical disciplines

ADVANCED

- Distribute clinician-level data on SDM, including opportunities for improvement
- Create a platform for collecting and sharing data on SDM, including the opportunity for two-way feedback between patients and clinicians
- Integrate SDM into organizational key performance indicators (KPI) at all levels and tie to performance reviews and compensation

Potential Barriers and Suggested Solutions

Lack of alignment across team

Suggested Solutions

- Clarify roles for SDM and responsibilities for each member of the healthcare team

Misaligned financial incentives

Suggested Solutions

- Create internal incentives to reward SDM and achievement of patient experience goals
- Identify opportunities for SDM to support and reinforce quality improvement or population health initiatives

Clinician compliance with SDM

Suggested Solutions

- Create friendly competition between and within departments or service lines to meet targets on SDM, such as numbers of decision aids distributed or SDM conversations documented
- Engage clinicians in selecting SDM performance measures, and incorporate these into performance reviews

Suggested Tools and Resources

Organizational resources

- Shared Accountability—Intermountain Healthcare
- Shared Decision Making: Helping the System and Patients Make Quality Health Care Decisions
- Shared Decision Making and Benefit Design: Engaging Employees and Reducing Costs for Preference-Sensitive Conditions

Toolkits and training

- The SHARE Approach—Achieving Patient-Centered Care with Shared Decision Making: A Brief for Administrators and Practice Leaders
- Using Shared Decisionmaking and Patient Decision Aids to Engage Patients and Drive Quality: Healthier Washington Quarterly Webinar

Journal articles

- Introducing Decision Aids at Group Health Was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs

Snapshot: Accountability in Action

The UCLA Urology Department implemented shared decision making as part of a value-based care transformation initiative within the broader health system. Through in-depth interviews and focus groups with patients with benign prostatic hyperplasia (BPH), urologists, leaders, and other clinicians recognized that decision aids had the potential to meet multiple health system goals: support a better patient care experience, improve the efficiency of urology consults, and optimize use of specialists' time. The Urology Department invited men scheduled for BPH consults to use an online patient decision aid before their specialist visit. Each patient received an email invitation with a link to the decision aid. After completing the decision aid, the patient received a personalized report—also shared with the urologist—showing which options most closely suited his preferences.

Results tracked through automated reports included the percentage of invited men who completed the decision aid and treatment preferences before and after using the decision aid. Results demonstrated high completion rates and a preference of most patients to receive medical management over options provided by specialty services.

After analyzing how the use of decision aids before urology visits affected men's preferences for care, the health system redesigned the referral process for BPH patients. Now, patients who express a preference for medical therapy after using the decision aid are offered the choice of a urology referral or a return to their PCPs for follow-up care. Patients who prefer nonsurgical treatment can now avoid an unnecessary specialist referral, promoting more efficient use of health system resources and easing specialist access. By enhancing patient satisfaction and improving patients' willingness to recommend their urology provider to others, the SDM initiative is providing value to all stakeholders.

Reference:

Pollard M, Shirk J, Pagan C, et al. The impact of shared decision making software on decision quality of men undergoing treatment for BPH: an interim analysis. *J Urol.* 2017;197(4 Suppl): e196-e197.

ESTABLISHING A MEASUREMENT FRAMEWORK FOR SHARED DECISION MAKING

Performance measurement is a critical component of quality improvement and accountability. This section of the *NQP Playbook* builds on **Fundamental 5: Tracking, Monitoring, and Reporting** and dives deeper into measurement approaches. Currently, three NQF-endorsed performance measures relate to SDM. Healthcare organizations can use NQF-endorsed measures to assess performance on SDM, identify opportunities for improvement and areas to

target interventions, and monitor progress. Although the NQF-endorsed measures are specified for use at a clinician level, measure results can help inform organizational goals around SDM. Additionally, there are opportunities to consider similar approaches to measurement at an organizational level to promote alignment. Table 1 includes the specifications for each measure as described in NQF's **Quality Positioning System**.

TABLE 1. NQF-ENDORSED MEASURES FOR SHARED DECISION MAKING

| Measure | Description | Numerator | Denominator |
|--|--|---|---|
| Shared Decision Making Process (NQF #2962) Measure Steward: Massachusetts General Hospital | Assesses the extent to which healthcare providers involve patients in a decision making process when there is more than one reasonable option. Derived from the Shared Decision Making Process Survey a 4-item survey that measures discussion of 1) options, 2) reasons to have the intervention, 3) reasons not to have the intervention, and 4) patient preferences. | Patient answers to four questions are summed to a total score (0-4). | Patients who have undergone one of seven surgical procedures: back surgery for a herniated disc; back surgery for spinal stenosis; knee replacement for osteoarthritis of the knee; hip replacement for osteoarthritis of the hip; radical prostatectomy for prostate cancer; percutaneous coronary intervention (PCI) for stable angina, and mastectomy for early stage breast cancer. |
| Informed, Patient Centered (IPC) Hip and Knee Replacement Surgery (NQF #2958) Measure Steward: Massachusetts General Hospital | Derived from patient responses to the Hip or Knee Decision Quality Instruments. | Number of respondents who have an adequate knowledge score (60% or greater) and a clear preference for surgery. | Number of respondents from the target population who have undergone primary knee or hip replacement surgery for treatment of knee or hip osteoarthritis. |
| Gains in Patient Activation (PAM) Scores at 12 Months (NQF #2483) Measure Steward: Insignia Health | 10 or 13 item questionnaire that assesses an individual's knowledge, skill and confidence for managing their health and health care. The measure assesses individuals on a 0-100 scale. There are four levels of activation, from low (1) to high (4). The measure is not disease specific, but has been successfully used with a wide variety of chronic conditions, as well as with people with no conditions. | Summary score change for the aggregate of eligible patients in that unit (e.g., patients in a primary care provider's panel, or in a clinic). The change score would be calculated from a baseline score and then a second score taken within 12 months of the baseline score (but not less than six months). | All patients, except patients under the age of 19 and adults with a diagnosis of dementia or cognitive impairments. Also excluded would be patients who do not have two PAM scores and all patients who are at level 4 at baseline (as they are unlikely to gain in activation over time). |

Healthcare organizations also may find value in using measures or items from the **Consumer Assessment of Healthcare Providers and Systems (CAHPS®)** surveys, which ask patients to assess their experiences with healthcare.²⁶ The CAHPS® Survey for Accountable Care Organizations Participating in Medicare Initiatives, for example, specifically includes a performance measure focused on SDM. SDM is also the focus of supplemental item sets for the CAHPS® Clinician & Group Survey²⁷ and CAHPS® Cancer Care Survey.²⁸ The supplemental item set for the Clinician & Group Survey, for example, contains eight items derived from the Shared Decision Making Process Survey.

While most CAHPS® survey measures are not specific to SDM, most surveys include measures that assess how well clinicians communicate with patients, including whether their clinicians explained things clearly, listened carefully, gave easy-to-understand information about questions and concerns, and showed respect for what patients had to say.²⁹

Measurement Opportunities

Measuring the process and outcomes of SDM is an active area of research. Ongoing work seeks to define meaningful ways to assess patient understanding of decision-specific information, the decision making process, the quality of decisions, the impact on clinician satisfaction and efficiency, and additional patient outcomes and experience of care. As measure development and implementation often lag the rapid pace of change in healthcare, additional work is needed to identify and develop performance measures that assess the SDM outcomes that matter the most to patients, families, caregivers, and clinicians.

In addition to NQF-endorsed performance measures, healthcare organizations may find it useful to use a broader array of measures for quality improvement and accountability. Healthcare organizations should develop a measurement strategy that best fits their context, needs, and resources.

Examples of how healthcare organizations could measure SDM include:

- **Process Measures:**

- Percentage of patients who received a decision aid to support SDM
- Percentage of patients for whom SDM was documented in the care plan
- Warranted variation in intervention rates between similar service lines or specialties based on patients' clinical situation and preferences

- **Experience Measures** (*both patient and clinician*):

- Patient-reported experience of visits in which SDM was used
- Patient-reported extent to which they were engaged in decision making (e.g., NQF #2962)
- Clinician ratings of the efficiency of visits in which SDM was used
- Clinician ratings of the quality of visits in which SDM was used

- **Outcome Measures:**

- Assessments of patient understanding and confidence (including the ability of patients to summarize decisions being undertaken, options, and their expectations)
- Alignment between patient decision and care delivered
- Correlation between patient goals and treatment received
- Patient decision quality (including the degree to which patients were well informed and involved in decision making, and the extent to which care was delivered according to patients goals, preferences, and values) (e.g., NQF #2958)³⁰
- Improvement in patient-reported quality of care

Although healthcare organizations may need to begin by measuring processes, such as whether clinicians routinely deliver decision aids to patients and whether SDM is occurring, patient and clinician experience and outcome measures can help ensure that clinicians are not simply checking a box to indicate compliance, but truly engaging patients and families in SDM about their healthcare.

DRIVERS OF CHANGE

The National Quality Forum urges federal entities, accreditation agencies, patient advocacy organizations, payers, and partners in quality improvement to create an environment in which healthcare organizations can implement innovative SDM strategies and maximize impact for all patients, families, caregivers, and clinicians.

Incentivize SDM through payment

Payment is a strong incentive to stimulate change. The Centers for Medicare & Medicaid Services (CMS) and private payers can consider payment models to reimburse for SDM, beginning with preference-sensitive conditions and expanding into other areas. While some employers and health plans currently pay for SDM, others could consider reimbursing for SDM and the use of patient decision aids that meet the **National Standards for the Certification of Patient Decision Aids**. The creation of a reimbursable Current Procedural Terminology (CPT) code specific to documentation and reporting of SDM, beyond advance care planning conversations, may help stimulate broader adoption of SDM. Additional opportunities exist as payers move away from fee-for-service (FFS) models and toward value-based payment and population health models. New alternative payment models could be used to incentivize clinicians to engage in SDM as a way of achieving better patient outcomes at a lower cost, and may support the reduction of high-cost, unnecessary care or services by better aligning care delivery with patient preferences.³¹

Use high-quality decision aids in clinical practice.

Patients and clinicians need to know that patient decision aids are evidence-based and free from conflict of interest, and DA developers must ensure that tools designed to support SDM meet quality and ethical standards. Building on efforts by Washington State and the International Patient Decision Aids Standards (IPDAS) Collaboration, NQF convened an expert panel in 2016 to develop guidance on national standards for the certification of high-quality, evidence-based, and unbiased patient decision aids.

Washington State Health Care Authority currently certifies DA in end-of-life care, maternity and labor/delivery, and joint replacement/spine care, but a national certification process would augment these efforts and reinforce an expectation of a threshold of quality for DAs used in healthcare.

Support policy approaches to make SDM the standard for informed consent.

SDM has the potential to become the standard for informed consent by ensuring that patients understand their treatment options, risks, benefits, and burdens of options, and that healthcare decisions reflect patients' goals and preferences for care. Early evidence suggests that clear documentation of informed patient decisions provides more medical and legal protection for physicians, especially with the use of high-quality decision aids.³² The success of SDM relies on the two-way process of communication between clinicians and patients, and requires more than a signature on an informed consent form. SDM may help to address variations in informed consent across states concerning what information clinicians must provide to patients or to what extent they must discuss risks, alternatives, benefits, and harms.³³

Accelerate accreditation and certification opportunities.

Accreditation and certification bodies can establish standards for demonstrating and documenting SDM in healthcare settings and disciplines. As examples, The Joint Commission identifies shared decision making with patients and families as a safety action to consider³⁴; the National Committee for Quality Assurance (NCQA) requires the use of shared decision making aids for preference-sensitive conditions as part of its Patient-Centered Medical Home (PCMH) Recognition program³⁵; and emerging population health management standards include the use of certified DAs. Accreditation and certification can also help clinicians meet performance improvement requirements of federal

incentive programs, which provide financial bonuses or penalties based on their performance and quality scores.^{36,37}

Organizations that certify continuing education for clinicians can also play a stronger role in incorporating SDM and use of high-quality DAs into educational programs, emphasizing that patient engagement through SDM can help patients identify

and achieve their healthcare goals. The Hospice and Palliative Credentialing Center (HPCC), for example, includes advance care planning and shared decision making in the test content outline for two of its certifications: Certified Hospice and Palliative Nurse (CHPN) and Certified Hospice and Palliative Pediatric Nurse (CHPPN).³⁸

Snapshot: Incentivizing SDM Through Payment in Action

The Health Care Payment Learning & Action Network (LAN) recently called for SDM as a key element of episode payment models (also known as “bundled payments”) to ensure appropriate, high-quality prenatal, childbirth, and post-partum and newborn care. Health plans often pay for these services as three distinct phases, even though they are a continuum of events in the life a woman and her newborn. Separate payments miss opportunities to improve birth outcomes, and episode payment can support the goals of improving patient care; increasing coordination across services, care settings, and clinicians; and lowering healthcare costs. SDM supported by high-quality decision aids can help ensure that women clarify and express their preferences for care practices, settings, and clinician types, which all contribute to quality, outcomes, and cost of care.

Medicaid (which pays for approximately 44 percent of healthcare services related to births annually), commercial payers, and large purchasers have begun to develop episode payment initiatives for maternity care. They recognize the ways in which such reimbursement can drive higher-quality, lower-cost care. Maternity episode payment has been associated with increased use of preventive services and lower cesarean, readmission, complication, and early elective birth rates. The Catalyst for Payment Reform calls on organizations to use SDM to support women in making informed and evidence-based decisions about where and how to give birth. Efforts to inform and involve women in decisions about their maternity care are important elements of effective alternative payment models that aim to enhance health care systems’ accountability for the quality and affordability of maternity care.

References:

- Health Care Payment Learning and Action Group. Maternity care. In: *Accelerating and Aligning Clinical Episode Payment Models*. McLean, VA; Mitre Corporation; 2016: 40-63.
- Rubenstein B. Case Study: Maternity Payment and Care Redesign Pilot. San Francisco, CA: Pacific Business Group on Health; 2015.
- Catalyst for Payment Reform (CPR). *Maternity Care Payment. Issue Brief*. Berkeley, CA: CPR; 2015.
- Butcher L. Prepping for maternity care bundles. *Leadership +*. January 9, 2017.
- Lagrew DC, Low LK, Brennan R, Corry MP, Edmonds JK, Gilpin BG, et al. National Partnership for Maternal Safety: consensus bundle on safe reduction of primary cesarean births—supporting intended vaginal births. *Obstet Gynecol*. 2018;131:503-13.

CALL TO ACTION

Investment in SDM initiatives can improve patient experience and health outcomes as well as drive value-based care and population health strategies. Moving forward, it is essential for patients and clinicians to work in partnership to identify patient values, goals, and preferences so that patients can make informed decisions about their treatment and care. This *NQP Playbook™: Shared Decision Making in Healthcare* provides a range of practical solutions and strategies to implement SDM in healthcare organizations. The NQP Playbook™ and the work of the NQP Shared Decision Making Action Team mark an important milestone in making SDM a standard of care, but more work lies ahead. While this *NQP Playbook* offers general strategies and solutions to address barriers to implementing SDM, it does not contain guidance specific to particular conditions, care settings, or situations—potential topics for future NQF work.

The National Quality Forum, through this *National Quality Partners Playbook™*, is issuing a national call to action for all individuals and organizations that provide, receive, pay for, and make policies for healthcare to embrace and integrate shared decision making into clinical practice as a standard of person-centered care. This *NQP Playbook* and the work of the NQP Shared Decision Making Action Team set a national foundation for these and other activities which are essential to enabling clinicians, patients, families, and all healthcare stakeholders to understand the value of patient engagement in healthcare decisions. Join NQF and the NQP Shared Decision Making Action Team in making SDM a reality for all patients.

The National Quality Forum, through this *National Quality Partners Playbook™*, is issuing a national call to action for all individuals and organizations that provide, receive, pay for, and make policies for healthcare to embrace and integrate shared decision making into clinical practice as a standard of person-centered care.

ENDNOTES

- 1 Preference Sensitive Care from the Patient Protection and Affordable Care Act (2010)
- 2 Center for the Evaluative Clinical Sciences. *Preference-Sensitive Care*. Lebanon, NH: Dartmouth Atlas Project; 2007. Available at http://www.dartmouthatlas.org/downloads/reports/preference_sensitive.pdf. Last accessed February 2018.
- 3 Sepucha KR, Fagerlin A, Couper MP, et al. How does feeling informed relate to being informed? The DECISIONS survey. *Med Decis Making*. 2010;30(6 Suppl):77S-84S.
- 4 Frosch DL, May SG, Rendle K, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012; 31(5):1030-1038.
- 5 Berger Z. Navigating the unknown: shared decision-making in the face of uncertainty. *J Gen Intern Med*. 2015;30(5):675-678.
- 6 Arterburn D, Wellman R, Westbrook E, et al. Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs. *Health Aff (Millwood)*. 2012;31(9):2094-2104.
- 7 King J, Moulton B. Group Health's participation in a shared decision-making demonstration yielded lessons, such as role of culture change. *Health Aff (Millwood)*. 2013;32(2):294-302.
- 8 Alston C, Paget L, Halvorson GC, et al. *Communicating with Patients on Health Care Evidence. Discussion Paper*. Washington, DC: Institute of Medicine (IOM); 2012. Available at <https://nam.edu/wp-content/uploads/2015/06/VSRT-Evidence.pdf>. Last accessed February 2018.
- 9 In a survey of consumer health care options, only 7% of respondents reporting wanting the doctor to make the decision. Lynch W, Perosino K, Slover M. Altarum Institute Survey of Consumer Health Care Opinions. Ann Arbor MI: Altarum Institute; 2014. Available at http://altarum.org/sites/default/files/uploaded-related-files/Fall_2014_Survey_of_Consumer_Health_Care_Opinions_Final.pdf. Last accessed February 2018.
- 10 Alston C, Berger ZD, Brownlee S, et al. *Shared Decision-Making Strategies for Best Care: Patient Decision Aids*. Washington, DC: IOM; 2014. Available at <https://nam.edu/wp-content/uploads/2015/06/SDMforBestCare2.pdf>. Last accessed February 2018.
- 11 King JS, Moulton B. Rethinking informed consent: the case for shared medical decision-making. *Am J Law Med*. 2008;32:429-501. Available at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1284511. Last accessed February 2018.
- 12 International Patient Decision Aid Standards (IPDAS) Collaboration. Adapted from the International Patient Decision Aids Standards Collaboration website. <http://ipdas.ohri.ca/what.html>. Last accessed February 2018.
- 13 Montori VM, Kunneman M, Brito JP. Shared decision making and improving health care: the answer is not in. *JAMA*. 2017;318(7):617-618
- 14 King J, Moulton B. Group Health's Participation in a shared decision-making demonstration yielded lessons, such as role of culture change. *Health Aff (Millwood)*. 2013;32(2):294-302.
- 15 Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4:CD001431.
- 16 Washington State Legislature. RCW 7.70.060. Consent form—Contents—Prima facie evidence—Shared decision making—Patient decision aid—Failure to use. <http://app.leg.wa.gov/rcw/default.aspx?cite=7.70.060>. Last accessed February 2018.
- 17 Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4:CD001431.
- 18 Hoffman J, Raman S. Communication factors in malpractice cases. Boston, MA: CRICO; 2012. Available at <https://www.rmhf.harvard.edu/Clinician-Resources/Newsletter-and-Publication/2012/Insight-Communication-Factors-in-Mal-Cases#>. Last accessed February 2018.
- 19 Arterburn D, Wellman R, Westbrook E, et al. Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs. *Health Aff (Millwood)*. 2012;31(9):2094-2104.
- 20 Alston C, Berger ZD, Brownlee S, et al. *Shared Decision-Making Strategies for Best Care: Patient Decision Aids*. Washington, DC: IOM; 2014. Available at <https://nam.edu/wp-content/uploads/2015/06/SDMforBestCare2.pdf>. Last accessed February 2018.
- 21 Aligning Forces for Quality (AF4Q). *Shared Decision-Making and Benefit Design: Engaging Employees and Reducing Costs for Preference Sensitive Conditions*. Princeton, NJ: Robert Wood Johnson Foundation (RWJF); 2013. Available at <http://forces4quality.org/af4q/download-document/6370/Resource-rwjf405304.pdf>. Last accessed February 2018.
- 22 Frosch DL, May SG, Rendle KAS, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012;31(5):1030-1038.

- 23** McCaffrey KJ, Holmes-Rovner M, Smith SK, et al. Addressing health literacy in patient decision aids. *BMC Med Inform Decis Mak*. 2013;13(Suppl 2):S10.
- 24** Frosch DL, May SG, Rendle KAS, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012;31(5):1030-1038.
- 25** Joseph-Williams N, Lloyd A, Edwards A, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ*. 2017;357:j1744.
- 26** Agency for Healthcare Research and Quality (AHRQ). About CAHPS website. <https://www.ahrq.gov/cahps/about-cahps/index.html>. Last accessed February 2018.
- 27** AHRQ. Supplemental items for the CAHPS Clinician & Group Surveys. Adult and child website. https://www.ahrq.gov/cahps/surveys-guidance/item-sets/search.html?f%5B0%5D=field_survey_types%3A14140&f%5B1%5D=field_supplemental_topics%3A14163. Last accessed February 2018.
- 28** AHRQ. Supplemental items for the CAHPS cancer care survey shared decision making population version: adult website. <https://www.ahrq.gov/cahps/surveys-guidance/item-sets/cancer/suppl-shared-decision-making-items.html>. Last accessed February 2018.
- 29** AHRQ. *Patient Experience Measures from the CAHPS® Clinician & Group Surveys*. Rockville, MD: AHRQ; 2014. Document no. 1309. Available at https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/cg/about/measures_cg.pdf. Last accessed February 2018.
- 30** Sepucha K, Feibelman S, Chang Y, et al. Factors associated with high decision quality for treatment of hip and knee osteoarthritis. *J Am Coll Surg*. 2013 Oct;217(4):694-701.
- 31** Healthcare Payment and Action Network. *Alternative Payment Model APM Framework*. McLean, VA: Mitre Corporation; 2017. Available at <http://hcp-lan.org/workproducts/apm-refresh-whitepaper-final.pdf>. Last accessed February 2018.
- 32** Barry MJ, Wescott PH, Reifler EJ, et al. Reactions of potential jurors to hypothetical malpractice suit: alleging failure to perform a prostate-specific antigen test. *J Law Med Ethics*. 2008;36(2):396-402.
- 33** Moulton B, Collins PA, Burns-Cox N, et al. From informed consent to informed request: do we need a new gold standard? *J R Soc Med*. 2013;106(10):391-394.
- 34** The Joint Commission. Informed consent: more than getting a signature. *Quick Safety*. 2016;21:1-3. Available at https://www.jointcommission.org/assets/1/23/Quick_Safety_Issue_Twenty-One_February_2016.pdf. Last accessed February 2018.
- 35** National Committee for Quality Assurance (NCQA). *2017 Standards Review. Patient-Centered Medical Home Recognition*. Washington, DC: NCQA; 2017. Available at <http://www.ncqa.org/Portals/0/Programs/Recognition/PCMH/2017%20PCMH%20Concepts%20Overview.pdf?ver=2017-03-08-220342-490>. Last accessed February 2018.
- 36** NCQA-Recognized PCMHs automatically receive full credit in the Merit-based Incentive Payment System (MIPS) Clinical Practice Improvement Activities (CPIA) category, which makes up 15 percent of the MIPS score that determines whether clinicians get financial bonuses or penalties. NCQA. The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) and NCQA recognition programs website. <http://www.ncqa.org/public-policy/macra/the-medicare-access-and-chip-reauthorization-act-of-2015-macra-and-ncqa-recognition-programs>. Last accessed February 2018.
- 37** Clinicians also can meet performance or quality improvement expectations in MIPS by completing an accredited performance improvement continuing medical education program. CMS. Medicare Program; CY 2018 Updates to the Quality Payment Program; and Quality Payment Program: Extreme and Uncontrollable Circumstance Policy for the Transition Year. 42 *CFR* Part 414, 82 *Fed Reg* 53568-54229. Available at <https://www.federalregister.gov/documents/2017/11/16/2017-24067/medicare-program-cy-2018-updates-to-the-quality-payment-program-and-quality-payment-program-extreme>. Last accessed February 2018.
- 38** Hospice and Palliative Credentialing Center (HPCC). *CHPPN® Computer Based Examination*. Pittsburgh, PA; 2018:11-13. Available at <http://documents.goamp.com/Publications/candidateHandbooks/HPCC-CHPN-Handbook.pdf> and <http://hpcc.advancingexpertcare.org/wp-content/uploads/2015/06/HPCC-CHPPN-Test-Content-Outline.pdf>. Last accessed February 2018.

APPENDIX A: Quick Reference Guide to Shared Decision Making Fundamentals for Healthcare Organizations

Leadership and Culture

Strong leadership is essential to the success of a healthcare organization's efforts to integrate SDM as a standard of care across the healthcare continuum. Support from leadership at all levels, including the board of directors, C-suite, and departmental and team leaders, encourages broad adoption of SDM as a core value of the organization. Embracing a culture in which leaders promote SDM as a cornerstone of care enables patients and clinicians to become equal members of the care team. Further, framing SDM as part of informed consent, patient safety, and patient rights and responsibilities and promoting SDM as a way to support personalized medicine can bolster person-centered culture change.

Patient Education and Engagement

Healthcare organizations can engage and educate patients and families about what SDM means, why SDM is beneficial to them, what their role can be, and what to expect from clinicians and the system of care. Organizations can provide educational resources and coaching for patients, families, and caregivers about SDM, including how patients can make more informed decisions and how to identify their values, goals, and preferences. With appropriate support and time to absorb information, SDM is achievable for most people: This includes those with lower health literacy and/or health numeracy and families and caregivers for those individuals unable to make decisions on their own. Once patients understand their role and have access to high-quality resources, most are enthusiastic participants in becoming informed and involved in decisions about their care.

Healthcare Team Knowledge and Training

Healthcare organizations can educate members of the healthcare team about the benefits of SDM for both their work and their patients, encourage authentic conversations about patients' preferences and concerns, and emphasize the importance of understanding a patient's level of interest or ability to engage in SDM. Training can include coaching on communicating risks and benefits; eliciting patient values, goals, and preferences; using SDM tools such as decision aids; the role of families and caregivers in supporting SDM; and incorporating what matters most to patients into care decisions. Improved knowledge and skills can foster mutual respect and trust between patients and their healthcare teams. Healthcare team members should be key stakeholders in the planning and design of SDM programs, including the thoughtful redesign of patient care workflows to incorporate use of decision aids and SDM conversations, the selection of appropriate measures of success, and ongoing process improvement.

Action and Implementation

For SDM to succeed, healthcare organizations and teams must engage in SDM with all patients who wish to do so as a central part of care decisions about interventions, procedures, tests, treatments, clinical trials, and care settings. Healthcare organizations should strive to make it easy to do the right thing through technology and thoughtful workflow redesign that can reduce time constraints for the healthcare team. Identifying a designated member of the healthcare team to document patient decisions in a standardized way into the electronic health record, deliver decision aids when appropriate, and regularly update, review, and share the care plan throughout the patient's care can also support treatment consistent with those decisions. Successful implementation includes health information technology that integrates clinical and patient information and supports SDM and process improvement.

Tracking, Monitoring, and Reporting

Mechanisms to track, monitor, and report patient, clinician, and healthcare team engagement in SDM can help healthcare organizations identify opportunities to improve SDM implementation and results. Standardized data collection and regular sharing of performance and patient experience data with organizational leadership, clinicians, patients, and the public can strengthen these efforts. Measurement may start small with process measures and progress to patient experience measures and outcome measures as the program matures. Systems can also track when and why patients choose not to engage in SDM. To inform the shared decision making process, data collection and interpretation should add value and not unnecessarily burden healthcare teams.

Accountability

To establish accountability for the board of directors, C-suite, and department and team leaders, healthcare organizations should articulate clear expectations and establish incentives for engaging patients in SDM. Incorporating SDM measures into performance management systems can incentivize leaders to embrace SDM as a mechanism for improving person-centered outcomes and patient experience and delivering high-value, high-quality care.

APPENDIX B:

Patient Decision Aids to Support Shared Decision Making (SDM)

The National Quality Partners™ (NQP™) Shared Decision Making Action Team defines patient decision aids below, based on the definition of the International Patient Decision Aids Standards (IPDAS) Collaboration. Clinicians and patients can use high-quality, unbiased, and evidence-based patient decision aids (DAs) to obtain information on decision options. Decision aids include but are not limited to printed booklets, videos, or web-based resources to help patients and their families and caregivers participate in decision making about their healthcare options. Evidence demonstrates that decision aids and shared decision making have improved patients' knowledge about options and their outcomes, increased accurate risk perception, resulted in a better match between values and choices, reduced decisional conflict, and decreased the number of people who remain undecided about treatment.^{1,2}

Patient decision aids are tools designed to help people better participate in healthcare decision making. These resources provide information on the risks, benefits, and alternatives as well as burdens of options and help patients clarify and communicate their personal values on different features of the options. Patient decision aids do not advise people to choose one option over another, nor do they replace clinician consultation. Instead, patient decision aids prepare patients to make informed decisions, together with their clinicians, that align with their values, goals, and preferences.

- Adapted from the International Patient Decision Aids Standards Collaboration

National Standards for the Certification of Decision Aids

In 2016, NQF convened a multistakeholder expert panel that proposed a set of criteria that entities could incorporate into a national decision aid certification process. The Expert Panel summarized its recommendations in **National Standards for the Certification of Patient Decision Aids**. The Panel agreed on three sets of criteria for Decision Aids: (1) screening criteria, (2) certifying criteria, and (3) screening and diagnostic test criteria.

Decision Aid Screening Criteria

The Panel agreed that a decision aid should meet the following seven screening criteria before considering it for certification:

1. Describes the health condition or problem for which a decision is required.
2. Identifies the target user.
3. Explicitly states the decision under consideration.
4. Describes the options available for the decision, including nontreatment when appropriate.
5. Describes the positive features of each option.
6. Describes the negative features of each option.
7. Clarifies patient values for outcomes of options by:
 - a. asking patients to consider or rate which positive and negative features matter most to them; and/or
 - b. describing the features of options to help patients imagine the physical and/or social and/or psychological effects.

Certifying Criteria

The Expert Panel agreed that the following 12 criteria should be required for certification of patient decision aids or supporting documents:

1. Provides a balanced presentation of options.
2. Contains content based on a rigorous and documented evidence synthesis method.
3. Provides information about the evidence sources used.
4. Provides key outcome probabilities, adopting risk communication principles.
5. Provides a publication date.
6. Provides information about the update policy and next expected update.
7. Provides information about the funding sources used for development.
8. Provides information about competing interests and/or policy.

9. Provides information about the patient decision aid development process, including information about participation from target users and health professionals.
10. Provides information about user testing with target patients and health professionals.
11. Reports readability levels.
12. Follows plain language guidelines to ensure understanding of people with low literacy and/or low health literacy skills.

Screening and Diagnostic Test Criteria

The Panel agreed that the following six criteria should be required for certification for decision aids that pertain to screening and diagnostic tests:

1. Describe what the test is designed to measure.
2. Describe next steps taken if a test detects a condition/problem.
3. Describe next steps if no condition/problem detected.
4. Describe consequences of detection that would not have caused problems if the screen was not done.
5. Include information on the test's positive predictive value.
6. Include information on the test's negative predictive value.

ENDNOTES

1 King J, Moulton B. Group Health's Participation in a shared decision-making demonstration yielded lessons, such as role of culture change. *Health Aff (Millwood)*. 2013;32(2):294-302.

2 Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4:CD001431.

APPENDIX C: Decision Aid and SDM Guide Developers

- **ACP Decisions, Inc.**
 - Nonprofit foundation offering a comprehensive set of products (including patient and caregiver decision aids, and other educational materials) and services to help healthcare organizations support conversations about advance care planning.
- **Agency for Healthcare Research and Quality (AHRQ)**
 - The Effective Health Care Program has a variety of publicly available educational materials that can support shared decision making. AHRQ developed the SHARE Approach to training healthcare clinicians in SDM; training materials are available for download at <https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html>
- **Colorado Program for Patient Centered Decisions**
 - Publicly available decision aids on implanted cardiac defibrillator (ICD) placement and use of left-ventricular assist devices (LVAD).
- **ConsumerMedical**
 - Offers healthcare treatment decision support, second opinion, and other concierge services for a wide range of conditions including preference-sensitive conditions.
- **EBSCO Option Grids**
 - EBSCO Health is the commercial producer of Option Grid™) Decision Aids, web-based decision aids optimized for use in the clinical encounter.
- **Emmi Solutions**
 - Provides multimedia programs that help inform patients about treatment options for preference-sensitive conditions and prepare for procedures. Platform enables tracking and documentation of use by patients. The Emmi decision aid on prenatal genetic testing is currently certified by the State of Washington.
- **Health Decisions, LLC**
 - Decision aids integrated into the clinician's standard workflow within the EMR perform risk calculations to provide personalized estimates of risk and benefit to support shared decision making. Topics include cardiovascular and stroke risk reduction, and breast and lung cancer screening.
- **Health Dialog**
 - Provides shared decision making services, including analytics, health coaching, and decision aids on a range of preference-sensitive decisions. Online delivery options enable tracking and documentation of patient usage. Two Health Dialog decision aids (knee and hip replacement surgery) are currently certified by the State of Washington.
- **Healthwise**
 - Provides decision aids on a range of preference-sensitive decisions; some delivery options enable tracking and documentation of patient usage and preferences. Offers an online provider SDM training program and program design and implementation services. Four Healthwise decision aids are currently certified by the State of Washington: Two concern maternity decisions, and two concern knee and hip replacement surgery.
- **Health Outcomes Sciences**
 - Delivers predictive analytics at the point of care to help physicians mitigate risk and complications for individual patients, and implements personalized risk models into detailed informed consent documents, designed to be used in SDM conversations.
- **Mayo Clinic Shared Decision Making National Resource Centers**
 - Offers publicly available decision aids on several common decisions as well as implementation resources including materials to help introduce SDM and DAs to care teams.

- **Ottawa A-to-Z Patient Decision Aid Inventory**
 - Listing of decision aids that meet the seven key International Patient Decision Aid Standards (IPDAS) Collaborative criteria which define a DA (ratings are provided for the other criteria) and which the developers have agreed to make available publicly.
- **Welvie**
 - Offers shared decision making programs for health plans, employers, and government agencies that help people who are considering surgery or creating an advance care plan.
- **WiserCare**
 - Provides personalized, interactive decision aids on a range of preference-sensitive decisions; the platform enables tracking and documentation of patient usage and preferences.

APPENDIX D: URL Links to Resources

Fundamental 1: Leadership and Culture

| Resource | Address |
|--|---|
| Creating a Revolution in Patient and Customer Experience | https://www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/Creating-a-Revolution-in-Patient-and-Customer-Experience-FINAL.pdf |
| Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care | https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/ |
| National Learning Consortium: Shared Decision Making | https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf |
| RWJF Shared Decision-Making and Benefit Design | https://www.rwjf.org/content/dam/farm/reports/reports/2013/rwjf405304 |
| Shared Decision Making in Health Care: Achieving Evidence-Based Patient Choice | https://global.oup.com/academic/product/shared-decision-making-in-health-care-9780198723448?cc=us&lang=en& |
| Shared Decision Making Implementation Readiness Assessment | http://msdmc.org/3-assess/ |
| Changing Culture and Delivery to Achieve Shared Decision Making at Dartmouth-Hitchcock Medical Center, New Hampshire | http://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780198723448.001.0001/acprof-9780198723448-chapter-31 |
| Creating a Shared Vision Case Study: Stillwater Medical Group | http://msdmc.org/1-create/creating-a-shared-vision-case-study-stillwater-medical-group/ |
| Group Health's Participation in a Shared Decision-Making Demonstration Yielded Lessons, Such As Role Of Culture Change | http://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1067 |
| Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice | https://repository.uchastings.edu/cgi/viewcontent.cgi?referer=https://www.bing.com/&httpsredir=1&article=1324&context=faculty_scholarship |
| Decision Aids for People Facing Health Treatment or Screening Decisions | http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001431.pub5/full |
| Shared Decision Making—The Pinnacle of Patient-Centered Care | http://www.nejm.org/doi/full/10.1056/NEJMp1109283 |

Fundamental 2: Patient Education and Engagement

| Resource | Address |
|--|---|
| Healthier Washington SDM Pilots | https://www.hca.wa.gov/about-hca/healthier-washington/shared-decision-making |
| Shared Decisions in Cancer Care: Is Medicare Providing a Model? | https://www.urban.org/research/publication/shared-decisions-cancer-care-medicare-providing-model |
| Shared Decision Making: Engaging Patients to Improve Health Care | http://familiesusa.org/sites/default/files/product_documents/Shared-Decision-Making.pdf |

| Resource | Address |
|---|---|
| Advance Care Planning: Multimedia Resources for Clinicians and Patients to Navigate End of Life Planning | https://www.acpdecisions.org/ |
| An Invitation to Patient and Family Engaged Care for Consumers: What it is, Why it Matters and How Patients and Families Can Engage | http://www.bmj.com/content/356/bmj.j1155/rr-0 |
| SHARE Approach Curriculum Tools | https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/tools/index.html |
| The Ottawa Hospital Decisional Conflict Scale | https://decisionaid.ohri.ca/eval_dcs.html |
| Addressing Health Literacy in Patient Decision Aids | https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4042520/ |
| Authoritarian Physicians And Patients' Fear Of Being Labeled 'Difficult' Among Key Obstacles To Shared Decision Making | http://content.healthaffairs.org/content/31/5/1030.full.pdf |
| Shared Decision Making—Finding the Sweet Spot | http://www.nejm.org/doi/full/10.1056/NEJMp1510020 |
| Shared Decision-Making Strategies for Best Care | https://nam.edu/wp-content/uploads/2015/06/SDMforBestCare2.pdf |
| 'That's the Doctor's Job': Overcoming Patient Reluctance to be Involved in Medical Decision Making | https://www.ncbi.nlm.nih.gov/pubmed/27423179 |

Fundamental 3: Healthcare Team Knowledge and Training

| Resource | Address |
|---|---|
| American Medical Association Video: Health Literacy and Patient Safety: Help Patients Understand | https://youtu.be/cGtTZ_vxjyA |
| Connected: Improving the Patient-Physician Experience through Communication | https://info.physicianleaders.org/whitepapers/2017/connected-improving-patient-experience |
| Healthwise | http://www.healthwise.org/providersolutions/caretransformation.aspx |
| The Health Foundation's Shared Decision Making Skills Training Workshops | http://personcentredcare.health.org.uk/resources/shared-decision-making-skills-training-workshops |
| Implementation Guide for AHRQ's Making Informed Consent an Informed Choice Training Modules | https://www.ahrq.gov/sites/default/files/publications/files/implementation-guide-making-informed-consent-informed-choice.pdf |
| The SHARE Approach | https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html |
| Shared Decision Making—Case Studies | https://www.aquanw.nhs.uk/resources/shared-decision-making-case-studies/23202 |
| Shared Decision Making & The Power of Decision Aids | https://www.emmisolutions.com/shared-decision-making |
| Mayo Clinic Shared Decision Making National Resource Centers—Decision Aids | http://shareddecisions.mayoclinic.org/ |
| MedU Shared Decision-Making Tool | https://www.med-u.org/the-library/shared-decision-making-tool |
| A Framework to Improve Surgeon Communication in High-Stakes Surgical Decisions Best Case/Worst Case | https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5479749/ |

| Resource | Address |
|---|---|
| Best Case/Worst Case: A Strategy to Manage Uncertainty in Shared Decision-Making | http://healthliteracy.com/2017/07/01/best-caseworst-case-a-strategy-to-manage-uncertainty-in-shared-decision-making-hlol-164/ |
| Decision Aids to Help People who are Facing Health Treatment or Screening Decisions | http://www.cochrane.org/CD001431/COMMUN_decision-aids-help-people-who-are-facing-health-treatment-or-screening-decisions |
| Implementing Shared Decision Making in the NHS: Lessons from the MAGIC Programme | http://www.bmj.com/content/357/bmj.j1744 |
| Ten Years, Forty Decision Aids, and Thousands of Patient Uses: Shared Decision Making at Massachusetts General Hospital | https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2015.1376 |

Fundamental 4: Action and Implementation

| Resource | Address |
|---|---|
| Evidence-Based Decision Making: Shared Decision Making | https://www.cincinnatichildrens.org/service/j/anderson-center/evidence-based-care/shared |
| Integrating Patient Decision Aids into Primary Care Practice: A Toolkit to Facilitate Shared Decision Making | http://sdmtoolkit.org/wp-content/uploads/2013/03/SDM-DA-toolkit.pdf |
| The Roadmap to Consumer Clarity in Health Care Decision Making: Making Person-Centered Care a Reality | https://www.npaf.org/wp-content/uploads/2017/07/RoadmapWhitePaper_ecopy.pdf |
| Decision Aids Implementation Worksheet | http://sdmtoolkit.org/resources/implementation-worksheet/ |
| Mayo Clinic Shared Decision Making National Resource Centers—Implementation Tool Kit | http://shareddecisions.mayoclinic.org/resources/sharing-with-others/ |
| SDM Implementation Flow Chart | http://sdmtoolkit.org/resources/implementation-flow-chart/ |
| The SHARE Approach Implementing Shared Decision Making In Varied Practice Settings | https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/webinars/index.html |
| The SHARE Approach Patient-Centered Outcomes Research and the Use of Decision Aids to Facilitate Shared Decision Making Webinar | https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/webinars/index.html |
| A Demonstration of Shared Decision Making in Primary Care Highlights Barriers to Adoption and Potential Remedies | http://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1084 |
| Patient Activation and the Use of Information to Support Informed Health Decisions | https://www.ncbi.nlm.nih.gov/pubmed/27432014 |
| Shared Decision Making: A Model for Clinical Practice | https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3445676/ |

Fundamental 5: Tracking, Monitoring, and Reporting

| Resource | Address |
|--|---|
| Shared Decision-Making Implementation Roadmap | http://msdmc.org/pdf/MSDMCRoadmap.pdf |
| CollaboRATE Shared Decision Making Tool | http://www.collaboratescore.org/ |
| Integrating Patient Decision Aids into Primary Care Practice: A Toolkit to Facilitate Shared Decision Making | http://sdmtoolkit.org/ |
| Shared Decision Making Health Information Technology Tool | https://www.stratishealth.org/documents/HITToolkitcoordination/6-Shared-Decision-Making.pdf |
| Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument | https://www.ncbi.nlm.nih.gov/pubmed/23451939 |
| Decision Aids to Improve Informed Decision-Making in Pregnancy Care: A Systematic Review | http://onlinelibrary.wiley.com/doi/10.1111/1471-0528.12060/full |
| Patient and family engagement: a survey of US hospital practices | http://qualitysafety.bmj.com/content/early/2015/06/16/bmjqs-2015-004006 |

Fundamental 6: Accountability

| Resource | Address |
|--|---|
| Shared Accountability—Intermountain Healthcare | https://intermountainhealthcare.org/~media/Files/Trustee Resource Center/Topical Information PDFs/sa-overview.pdf |
| Shared Decision Making: Helping the System and Patients Make Quality Health Care Decisions | https://hqc.sk.ca/Portals/0/documents/Shared_DDecision_Making_Report_April_08_2010.pdf |
| Shared Decision Making and Benefit Design: Engaging Employees and Reducing Costs for Preference-Sensitive Conditions | https://www.rwjf.org/content/dam/farm/reports/reports/2013/rwjf405304 |
| The SHARE Approach—Achieving Patient-Centered Care with Shared Decision Making: A Brief for Administrators and Practice Leaders | https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-9/share-tool9.pdf |
| Using Shared Decisionmaking and Patient Decision Aids to Engage Patients and Drive Quality: Healthier Washington Quarterly Webinar | https://www.hca.wa.gov/assets/program/sdm-hw-quarterly-webinar.pdf |
| Introducing Decision Aids at Group Health Was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs | https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2011.0686 |

Additional Resources

| Resource | Address |
|--|---|
| NQF's Quality Positioning System™ | https://www.qualityforum.org/QPS/ |
| Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys | https://www.ahrq.gov/cahps/index.html |
| National Standards for the Certification of Patient Decision Aids | http://www.qualityforum.org/Publications/2016/12/National_Standards_for_the_Certification_of_Patient_Decision_Aids.aspx |
| Washington State Health Care Authority | https://www.hca.wa.gov/about-hca/healthier-washington/patient-decision-aids-pdas |

Decision Aid and SDM Guide Developers

| Developer | Address |
|--|---|
| ACP Decisions, Inc. | https://www.acpdecisions.org/products/ |
| Agency for Healthcare Research and Quality (AHRQ) | https://effectivehealthcare.ahrq.gov/health-topics |
| Colorado Program for Patient Centered Decisions | https://patientdecisionaid.org/decision-aids/ |
| ConsumerMedical | http://consumermedical.com/ |
| EBSCO Option Grids | https://health.ebsco.com/products/option-grid |
| Emmi Solutions | https://www.emmisolutions.com/product-suite/emmi-decide |
| Health Decisions, LLC | https://www.healthdecision.com/ |
| Health Dialog | https://healthdialog.com/solutions/shared-decision-making |
| Healthwise | http://www.healthwise.org/shareddecisionmaking.aspx |
| Health Outcomes Sciences | http://www.h-outcomes.com/ |
| Mayo Clinic Shared Decision Making National Resource Centers | http://shareddecisions.mayoclinic.org/ |
| Ottawa A-to-Z Patient Decision Aid Inventory | https://decisionaid.ohri.ca/AZlist.html |
| Welvie | http://www.welvie.com/ |
| WiserCare | https://www.wisercare.com/ |

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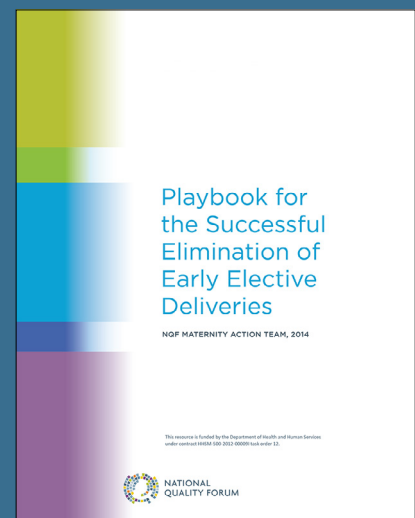
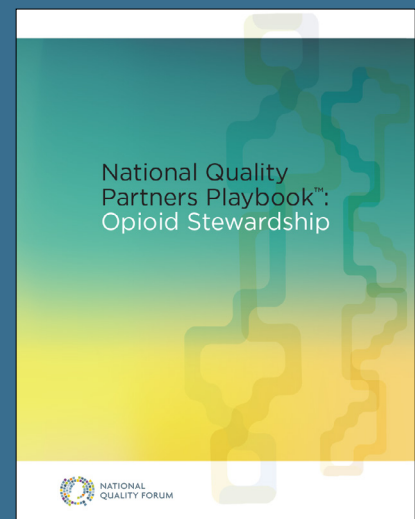
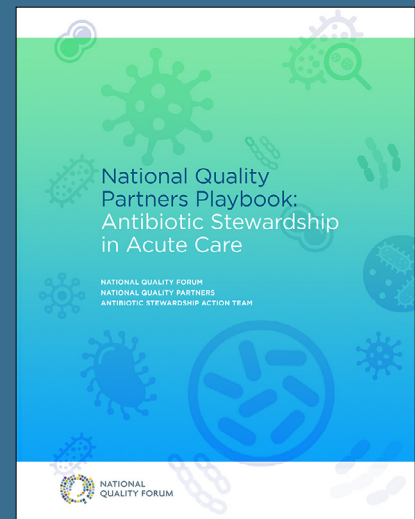
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Other Available NQP Playbooks™





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