
The Promise of Shared Decision Making in Improving Value in the US Healthcare System

12.11.17



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Funding for this analysis was provided by The Pharmaceutical Research and Manufacturers of America (PhRMA). Avalere maintained full editorial control.



Highlights

- Shared decision making (SDM) has the potential to play a critical role in the success of value-based payment models.
- Evidence suggests SDM can improve key measures of healthcare quality that matter to patients.
- Evidence also suggests SDM has the potential to drive more appropriate healthcare utilization, which could reduce unnecessary costs in the system.
- The full impact of well-done SDM remains unattained because existing evidence reflects the nascent state of SDM practice and science.
- More comprehensive, patient-centered approaches to assessing value (such as the Patient-Perspective Value Framework Initiative) can elevate SDM to the next level in supporting the evolution of a value-based healthcare system.

Background and the Current State of Shared Decision-Making Initiatives

Shared decision making (SDM) is a collaborative process used by patients and clinicians to make decisions regarding tests, treatments, and care plans based on clinical evidence as well as a patient's preferences, values, and care goals.¹ Decision aids (DAs) are evidence-based tools that supplement clinician advice and support the implementation of SDM. These tools support patients in their care decision-making by outlining treatment information and evidence, as well as helping to drive a decision grounded in patient values and preferences.² The recent drive toward greater patient-centered and value-based care has led to an increased use of SDM and accompanying DAs given their potential to improve healthcare quality while reducing unnecessary healthcare costs. Stakeholders across the healthcare spectrum are investing in SDM initiatives to infuse the patient voice into care decisions and ultimately improve patient outcomes.

¹ National Learning Consortium, "Shared Decision Making," HealthIT.gov, last modified December 2013, https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf.

² Stacey D. Légaré et al., "Decision aids for people facing health treatment or screening decisions," *Cochrane Database of Systematic Reviews*, no. 4 (April 12, 2017): [7], DOI:10.1002/14651858.CD001431.pub5.

Government organizations are increasingly funding research and providing incentives for SDM.³ The National Institutes of Health (NIH) has funded multiple studies to evaluate the use of SDM for cancer screening, management, and to guide end-of-life care. The Agency for Healthcare Research and Quality (AHRQ) is supporting SDM through several funding strategies to implement the science of comparative effectiveness and produce SDM interventions. Organizations such as the Patient-Centered Outcomes Research Institute (PCORI), are funding studies to assess the implementation of SDM across therapeutic areas including cardiovascular care, maternal-fetal health, and gastrointestinal diseases.⁴ Furthermore, the Centers for Medicare and Medicaid (CMS) mandated SDM for Medicare reimbursement coverage of two procedures: lung cancer screening with low-dose CT scan, and left atrial appendage occlusion.⁵

In addition to federal initiatives that aim to promote the uptake of SDM, other stakeholders including states, professional societies, non-profits, and health systems are also encouraging the use and integration of SDM.^{6,7} At the state level, Washington is implementing legislation passed in 2007 to encourage SDM and the use of DAs. Professional societies and health systems are embracing SDM by developing evidence-based guidelines that promote SDM and comprehensively integrate SDM and DAs into care plans.⁸ In 2016, funded by the Gordon and Betty Moore Foundation, the non-profit, National Quality Forum (NQF), developed national standards for the certification process of patient DAs to overcome SDM and DA implementation barriers and promote the widespread use of these clinician-patient tools.⁹ In October of this year, NQF also released an action brief calling on stakeholders across the healthcare industry to support and integrate SDM into clinical practice as a standard of patient-centered care. NQF will release a comprehensive playbook in March 2018 to supplement the call to action by providing solutions to remove barriers to SDM in clinical practice.¹⁰

The shift from volume- to value-based care has also led to efforts in tool development to support the patient-provider SDM process. Value framework developers, such as the American Society of Clinical Oncology (ASCO)¹¹ and the National Comprehensive Cancer Network (NCCN),¹² who aim to comparatively assess the value of different healthcare options, have pledged to support SDM uptake. In 2015, Avalere and *FasterCures* launched the Patient-Perspective Value Framework (PPVF) Initiative, to develop a value framework that incorporates the full spectrum

³ Erica Spatz et al., "Shared decision making as part of value based care: New U.S. policies challenge our readiness," *The Journal of Evidence and Quality in Healthcare* 123 (June 2017): [104-8], doi:<http://dx.doi.org/10.1016/j.zefq.2017.05.012>.

⁴ Spatz et al., "Shared decision," [105].

⁵ Spatz et al., "Shared decision," [105].

⁶ Spatz et al., "Shared decision," [104-8].

⁷ A. M. Stiggelbout et al., "Shared decision making: really putting patients at the centre of healthcare," *British Medical Journal*, January 27, 2012, [344], doi:<https://doi.org/10.1136/bmj.e256>.

⁸ Spatz et al., "Shared decision," [105].

⁹ National Quality Forum, *National Standards for the Certification of Patient Decision Aids*, [2], December 15, 2016.

http://www.qualityforum.org/Publications/2016/12/National_Standards_for_the_Certification_of_Patient_Decision_Aids.aspx.

¹⁰ National Quality Forum, "Shared Decision Making: A Standard of Care for All Patients," news release, October 2017,

https://www.qualityforum.org/Publications/2017/10/NQP_Shared_Decision_Making_Action_Brief.aspx.

¹¹ Lowell E. Schnipper et al., "Updating the American Society of Clinical Oncology Value Framework: Revisions and Reflections in Response to Comments Received," *Journal of Clinical Oncology* 34, no. 24 (August 20, 2016): [2925-34], <http://ascopubs.org/doi/abs/10.1200/jco.2016.68.2518>.

¹² National Comprehensive Cancer Network, "NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) with NCCN Evidence Blocks," <https://www.nccn.org/evidenceblocks/>.

of value considerations from the patient's perspective in the assessment of healthcare options.¹³ The PPVF Version 1.0, published in May 2017, is comprised of a set of patient-centered domains, criteria, measures, and a broad (non-condition specific) methodology for assessing value, driven by patient preferences.¹⁴ This framework has several applications, one of which is to support SDM in assessing all aspects of value to the patient, including medical and non-medical costs. The evidence presented below suggests that the PPVF and patient-centered, value-oriented SDM tools could have a positive impact on care quality, as well as patient- and system-wide costs.

Evidence Suggests that Shared Decision Making Can Improve Care Quality

The evidence base demonstrates that SDM can positively impact quality of care by improving patient knowledge, activation, and decision quality, as well as patient experience and clinical outcomes.

There is strong evidence to support that SDM and DAs increase a patient's knowledge and accuracy of risk perceptions, and that SDM is associated with improved decision quality.^{15,16,17,18,19,20} Early SDM emerged primarily in preference-sensitive conditions – where medical evidence does not clearly support a single course of treatment, and the best approach depends on a patient's values, preferences, and goals (e.g., greater certainty in the long-term in exchange for greater invasiveness in the short-term).²¹ Over time, however, clinical practice has evolved, and we gradually see broader application of SDM across various clinical areas. In a *Cochrane* review, researchers found that DAs increased participants' knowledge, accuracy of risk perceptions, and congruency between informed values and care choices compared to usual care.²² This review also found that DAs decreased decisional conflict due to feeling uninformed about treatment options, indecision about personal values, and passive decision-making.²³ Moreover, those exposed to a DA were either equally or more satisfied with their decision and

¹³ Joshua Seidman et al., "Measuring Value Based On What Matters To Patients: A New Value Assessment Framework," Health Affairs (blog), entry posted May 23, 2017, <https://www.healthaffairs.org/doi/10.1377/hblog20170523.060220/full/>.

¹⁴ Avalere and FasterCures, *Patient-Perspective Value Framework (PPVF): Version 1.0* (2017), <http://avalere.com/expertise/life-sciences/insights/avalere-health-and-fastercures-release-version-1.0-of-the-patient-perspecti>.

¹⁵ Eun Soon Park and In Young Cho, "Shared decision-making in the paediatric field: a literature review and concept analysis.," *Scandinavian Journal of Caring Sciences*, September 13, 2017, DOI:10.1111/scs.12496.

¹⁶ Ann M. Berger et al, "Preferences and actual chemotherapy decision-making in the greater plains collaborative breast cancer study," *Acta Oncologica* 56, no. 2 (September 13, 2017): [1690-97], <https://doi.org/10.1080/0284186X.2017.1374555>.

¹⁷ J. Redfern et al., "Choice of secondary prevention improves risk factors after acute coronary syndrome: 1-year follow-up of the CHOICE (Choice of Health Options In prevention of Cardiovascular Events) randomised controlled trial," *Heart* 95, no. 6 (2009): [468-75], <http://heart.bmj.com/content/95/6/468>.

¹⁸ Philippe D. Violette et al, "Decision aids for localized prostate cancer treatment choice: Systematic review and meta-analysis," *A Cancer Journal for Clinicians* 65, no. 3 (March 12, 2015): DOI:10.3322/caac.21272.

¹⁹ Sarah T. Hawley et al., "Decision Involvement and Receipt of Mastectomy Among Racially and Ethnically Diverse Breast Cancer Patients," *Journal of the National Cancer Institute* 101, no. 19 (October 7, 2009): [1337-47], doi:10.1093/jnci/djp271.

²⁰ Linda JM Oostendorp et al., "Decision aids for second-line palliative chemotherapy: a randomised phase II multicentre trial," *BMC Medical Informatics and Decision Making* 17, no. 130 (2017): <https://doi.org/10.1186/s12911-017-0529-y>.

²¹ The Centers for Medicare & Medicaid Services, "Beneficiary Engagement and Incentives Models: Shared Decision Making Model," news release, December 8, 2016, <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-12-08-2.html>.

²² Légaré et al., "Decision aids."

²³ Légaré et al., "Decision aids."

the decision-making process, compared to usual care.²⁴ In a recent *JAMA Internal Medicine* review, patient DAs increased patient knowledge of care options and were associated with enhanced decision quality when compared with patients receiving usual care.²⁵

Evidence suggests that SDM may also be associated with improvements in clinical outcomes, especially for individuals with chronic conditions, such as diabetes and asthma.^{26,27} A review of 19 randomized controlled trials (RCTs) assessing the effects of personalized care planning for adults with long-term health conditions found that personalized care planning leads to small improvements in some indicators of physical health (e.g., improved blood glucose levels and control of asthma, as well as lower blood pressure measurements among individuals with diabetes), reduced symptoms of depression, and improved patient confidence and skills to manage their health.²⁸ Additionally, the aforementioned *Cochrane* review presented several studies that identified significant benefits for patients exposed to DAs as compared to those receiving usual care. Benefits included significant improvements in general health and physical function outcome scores for men considering treatments for benign prostatic disease, as well as for women considering the treatment of abnormal uterine bleeding.²⁹

Another review assessed the association between SDM and patient-relevant, disease-related endpoints, such as improvements in cholesterol levels, body mass index (BMI), and quality of life (QOL) for individuals with post-acute coronary syndrome, or improvements in physical functioning and QOL, as well as reductions in HbA1c and illness-related days of absence from work for individuals with diabetes mellitus.³⁰ Researchers found that, in 10 articles, 57% of the endpoints were significantly improved by the SDM intervention compared to the control group. Moreover, in all 22 studies identified, 39% of the relevant outcomes significantly improved compared with the control groups.³¹ Finally, a cohort study published in *Health Affairs* compared the effects between enhanced-support and usual care when making a medical treatment decision.³² The researchers found that participants receiving enhanced support demonstrated 12.5% fewer hospital admissions than the usual-support group. This reduction was significant for heart conditions (13.9% lower), benign uterine conditions (13.9% lower), and back pain (12.8% lower).³³

²⁴ Légaré et al., "Decision aids."

²⁵ Glyn Elwyn, Nan Cochran, and Michael Pignone, "Shared Decision Making—The Importance of Diagnosing Preferences," *JAMA Internal Medicine* 177, no. 9 (September 2017): [1239-40], doi:10.1001/jamainternmed.2017.1923.

²⁶ Lisa Whitehead, "The effects of personalized care planning for adults living with chronic conditions," *International Journal of Nursing Practice* 22, no. 2 (March 8, 2016): [138-40], DOI:10.1111/ijn.12429.

²⁷ L. Aubree Shay and Jennifer Elston Lafata, "Where is the evidence? A systematic review of shared decision making and patient outcomes," *Medical Decision Making* 35, no. 1 (January 2015): [114], doi:10.1177/0272989X14551638.

²⁸ Whitehead, "The effects."

²⁹ Légaré et al., "Decision aids."

³⁰ Katarina Hauser et al., "Outcome-Relevant Effects of Shared Decision Making: A Systematic Review," *Deutsches Ärzteblatt International* 112, no. 40 (October 2, 2015): [665], doi:10.3238/arztebl.2015.0665.

³¹ Hauser et al., "Outcome-Relevant Effects," [665-671].

³² David Veroff, Amy Marr, and David E. Wennberg, "Enhanced Support For Shared Decision Making Reduced Costs Of Care For Patients With Preference-Sensitive Conditions," *Health Affairs* 32, no. 2 (February 2013): [285-93], <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2011.0941>.

³³ Veroff, Marr, and Wennberg, "Enhanced Support," [285].

There is also strong evidence to support that SDM and DAs improve medication initiation and adherence.³⁴ Researchers of an RCT comparing controller medication adherence and clinical outcomes in 612 adults with poorly controlled asthma found that, after one-year, SDM resulted in significantly better controller and long-acting β -agonist adherence, higher cumulative controller medication dose, and improved clinical outcomes, including asthma-related QOL, healthcare and rescue medication use, asthma control, and lung function.³⁵

Finally, there is strong evidence to support that SDM and DAs improve patient experience and satisfaction with care. In a qualitative study assessing diabetic patients, researchers found that patient-reported use of greater collaborative goal setting correlated with an increased level of trust in the physician.³⁶ Interestingly, both greater perceived competence and increased trust were associated with improved glycemic control. In addition, a review published in *JAMA Internal Medicine* found that, although patient DAs were linked with 7.5% longer consultations in 10 trials, patient DAs were also associated with fewer clinicians making decisions without patient participation – underscoring the role of DAs to enhance the patient-provider SDM process.³⁷

Shared Decision Making Has the Potential to Reduce Unnecessary Costs to the Healthcare System

Evidence suggests that SDM has the potential to increase appropriateness of care, reducing unnecessary costs for both patients and the broader healthcare system.

There is emerging evidence to support SDM as a driver of appropriate care as well as improved patient clinical or financial outcomes, though further research is needed in this area. In the cohort study published in *Health Affairs*, researchers assessed the association between introducing DAs for hip and knee osteoarthritis and rates of joint replacement surgery as well as costs in a large health system in Washington state.³⁸ Researchers found that patients who received enhanced support had 5.3% lower overall medical costs when compared to patients who received the usual level of support. Additionally, for patients with hip and knee osteoarthritis, DAs were associated with 12% (hip replacement cohort) to 21% (knee replacement cohort) lower costs over six months. Furthermore, researchers found that DAs reduced the number of people choosing major elective invasive surgery in favor of more conservative options, as DAs were associated with 26% fewer hip and 38% fewer knee replacement surgeries.

³⁴ Sandra R. Wilson et al., "Shared Treatment Decision Making Improves Adherence and Outcomes in Poorly Controlled Asthma," *American Journal of Respiratory and Critical Care Medicine* 181, no. 6 (June 16, 2009): [566-77], <https://doi.org/10.1164/rccm.200906-0907OC>.

³⁵ Wilson et al., "Shared Treatment," [566].

³⁶ Jennifer Elston Lafata et al., "Patient-reported use of collaborative goal setting and glycemic control among patients with diabetes," *Patient Education & Counseling* 92, no. 1 (July 2013): [94-9], DOI:<http://dx.doi.org/10.1016/j.pec.2013.01.016>.

³⁷ Dawn Stacey, France Légaré, Krystina B. Lewis. Patient Decision Aids to Engage Adults in Treatment or Screening Decisions. *JAMA* 318, no. 7 (August 2017): [657–658], doi:10.1001/jama.2017.10289.

³⁸ David Arterburn et al., "Introducing Decision Aids At Group Health Was Linked To Sharply Lower Hip And Knee Surgery Rates And Costs," *Health Affairs* 31, no. 9 (September 2012): [2094-104], <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2011.0686>.

While there is strong evidence to support that SDM and DAs reduce the number of individuals choosing major elective invasive surgery in exchange for less invasive procedures and more conservative options, more research is needed to understand the long-term cost implications of SDM.³⁹ In the short term, SDM might increase necessary costs, as the evidence shows it increases adherence to care, and the use of appropriate services. However, an increase in appropriate care might also reduce costs related to unnecessary services as well as long-term healthcare utilization, leading to potential net zero effects on costs. More research is therefore needed to better understand the long-term impact on costs associated with SDM and DAs.

In addition to long-term cost implications to the healthcare system, there is a strong need for the development and testing of SDM tools that incorporate discussion around costs of care to the patient. Most SDM tools fail to integrate a discussion component addressing the out-of-pocket (OOP) costs of care to the patient, including non-medical costs like that of travel and child or adult care, which are commonly reported as secondary reasons for not receiving recommended care. A Cancer Support Community (CSC) survey from 2016 found that most respondents who discussed costs with their doctor reported not using a guide or a decision tool during discussions (77.5%).⁴⁰ Moreover, according to a 2017 Public Agenda survey, 70% of Americans favor discussing care prices with their doctors or other practice staff members, but only 28% report having these conversations.⁴¹ Therefore, increasing the uptake of SDM will require further development and testing of tools that address the comprehensive information needs of patients when making care decisions, including the complexity of the costs they will face.

Using the PPVF To Improve Shared Decision Making Among Patients and Providers

With the evolving science around the impacts of SDM on care quality and costs, a stronger linkage between SDM and value-based care may help patients make the most appropriate care decisions, given their own values and preferences.

Though evidence suggests the positive impacts of SDM, the nascent state of SDM implementation science suggests the need for further research to understand the effects of mature SDM on outcomes and costs. This is an area that Avalere is exploring through the PPVF, as preliminary research conducted by Avalere found that the PPVF can be a useful framework from which to develop and test a patient-centered SDM resource. Focus groups that Avalere and CSC conducted with cancer patients in 2017 revealed the significant benefit a PPVF checklist could offer to patients by outlining the different aspects of value to be considered when making decisions about treatment options.⁴² Cancer patients expressed that

³⁹ Arterburn et al., "Introducing Decision," [2098-2100].

⁴⁰ Cancer Support Community, *Access to Care in Cancer 2016: Barriers and Challenges* (2016), [6-9], https://www.cancersupportcommunity.org/sites/default/files/uploads/policy-and-advocacy/patient-access/access_to_care_in_cancer_2016_barriers_and_challenges_final.pdf?v=1.

⁴¹ David Schleifer, Rebecca Silliman, and Chloe Rinehart, *How People in New York State Use Health Care Price Information* (Public Agenda, 2017), https://www.publicagenda.org/files/PublicAgenda_HowPeopleinNewYorkStateUseHealthCarePriceInformation_2017.pdf.

⁴² Avalere and *FasterCures*, Patient-Perspective Value Framework (PPVF): Version 1.0. 2017. <http://avalere.com/expertise/life-sciences/insights/avalere-health-and-fastercures-release-version-1.0-of-the-patient-perspecti>.

such a resource would have been invaluable in helping them to structure conversations with both their families and clinicians around their care decisions and to develop a roadmap for their care journeys. Research with patients and caregivers has found that treatment planning can be overwhelming for cancer patients, as they try to find a balance between knowing what questions to ask during these conversations and expressing to their clinicians the effect that their treatment has on their lives.⁴³ Given that the components of value outlined in the PPVF have gained multi-stakeholder support, and that patients and caregivers have identified them as meaningful factors to consider – or to have had considered – during their healthcare decision-making process, Avalere aims to develop a checklist building upon these components for use in SDM.

The ultimate purpose of the checklist – to be tested across different patient populations – will be to ensure that it meets the needs of patients to: 1) ask the most appropriate questions while discussing the value of different healthcare options with their clinicians and family, to make care decisions based on their personal preferences; and 2) ensure they are discussing all aspects of their potential care journeys to allow them to plan appropriately, including the financial aspects of care.

Once piloted, the PPVF checklist could be scaled by integrating it into emerging value-based payment models and public healthcare programs to improve existing care planning and SDM processes. For example, this tool could be useful to Oncology Care Model (OCM) providers, who are held accountable for documenting a care plan addressing the 13 components of the Institute of Medicine's Care Management Plan, for each participating beneficiary. The PPVF checklist could help support patients and OCM care teams to discuss these topics – including “treatment goals,” “treatment benefits and harms,” “information on QOL and patient's likely experience with treatment,” “estimated total OOP costs,” and “a plan for addressing a patient's psychosocial health needs” – in a more comprehensive and patient-centered way. Similarly, such a tool could augment the Million Hearts® Longitudinal Atherosclerotic Cardiovascular Disease (ASCVD) Risk Assessment Tool, by enhancing the information that is currently presented to the patient, as well as *how* it is presented to them, leading to the discussion of a patient-centered intervention plan.⁴⁴

Conclusion: The Future of Shared Decision Making

The evidence suggests that SDM and accompanying DAs hold promise in driving value-based care through positive impacts on care quality as well as the potential to address the healthcare system's broader challenges with costs. However, despite the evidence base that supports the

⁴³ *Patient Value Initiatives: The Many Voices of Value* (CancerCare, 2017), https://media.cancercare.org/publications/original/CancerCare_WhitePaper_053117_FINAL.pdf.

⁴⁴ "ASCVD Risk Estimator Plus," American College of Cardiology, <http://tools.acc.org/ASCVD-Risk-Estimator-Plus/#/calculate/estimate/>. The tool calculates an individual's estimated 10-year and lifetime ASCVD risk and is also accessible on the Million Hearts website.



significant benefits of SDM and DAs, the state of SDM and DA implementation science limits our current ability to fully understand their potential impact.

Providers continue to face significant barriers implementing and integrating SDM and DAs into routine clinical care. Additional barriers include challenges with tracking the long-term impact of SDM and DAs on patients and families, especially as it relates to impacts on costs.

Further research is also needed to better understand: 1) how to seamlessly incorporate SDM resources into electronic health records and the clinical workflow without posing undue burden onto providers; 2) how to integrate SDM into the patient's "life flow" and throughout their entire care journey to account for shifting preferences, contexts, and needs; 3) the needs of vulnerable patients for SDM, including those with language barriers and low health and financial literacy; and 4) the impact of SDM on patients' and families' financial burdens as well as on broader costs to the healthcare system. The further development and testing of patient- and clinician-validated SDM tools and DAs that promote evidence-based care and incorporate patient preferences will help garner multi-stakeholder support for SDM and DAs, overcoming implementation barriers, and providing the full realization of the benefits of SDM and DAs to support value-driven healthcare.

Appendix

Methodology

Avalere conducted a literature review on behalf of PhRMA to survey white and grey literature exploring the impact of SDM on driving value in healthcare including, but not limited to, its impact on improving clinical outcomes and patients' care experiences, lowering costs, and increasing the quality of care. We also included literature that explored existing gaps and barriers in research. We first conducted a broad scan of the literature and then focused on an in-depth Google and PubMed search for articles from 2015 to 2017, utilizing search terms including: "shared decision-making," "decision aids," "decision-making," and "personalized care planning" in conjunction with "clinical outcomes," "knowledge," "patient engagement," "patient activation," "utilization," "cost savings," and "care quality." Avalere outlined 31 articles in the full literature search.

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