

Co-Creating Patient Care Plans in Myelofibrosis:

A Patient/Clinician Shared Decision-Making Toolkit



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Shared Decision-Making

WHAT IS SHARED DECISION-MAKING?

Shared decision-making (SDM) occurs when a healthcare provider and a patient work together to make a healthcare decision that is best for the patient. Optimal decision making takes into account evidence-based information about available options, the provider's knowledge and experience, and the patient's values, goals and preferences. Patients and their families/caregivers who are engaged in an SDM process are more likely to arrive at a treatment decision that works best for all those involved.

WHY IS SHARED DECISION-MAKING IMPORTANT IN MYELOFIBROSIS?

Making informed decisions about treatment for myelofibrosis is challenging and can be daunting to the patient, who may be overwhelmed by therapeutic options and how they differ based on benefits, risks, and potential complications. Quite often, the choice of treatment may hinge on patient preferences. Patients and caregivers can play a collaborative and integral role with their healthcare team in determining a course of therapy that is in line with their lifestyles, goals, and desires for disease control.

Two-way communication between patients/caregivers and providers can facilitate shared decision-making, helping to improve patient adherence to therapy, enhance satisfaction with care delivery, and elevate quality of life. By successfully engaging with the healthcare team through shared decision-making, patients may experience better therapeutic outcomes and higher quality care.



National Quality Partners Playbook™ on Shared Decision Making in Healthcare

- The National Quality Forum (NQF) issued a call to action to make shared decision-making a standard of care for all patients, across all settings and conditions
- Offers vital guidance for this process of communication in which clinicians and patients work together to make healthcare decisions that align with what matters most to patients

SDM REQUIRES 3 COMPONENTS

- 1** Delivering clear, accurate, and unbiased medical evidence about reasonable alternatives/treatment options - including no medical intervention - and the risks and benefits of each.

- 2** Clinician expertise in communicating and tailoring evidence for individual patients.

- 3** Eliciting and integrating patient values, goals, informed preferences, and concerns, which may include treatment burdens, into treatment planning.

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6 FUNDAMENTALS TO GUIDE SDM IN HEALTHCARE ORGANIZATIONS

1 Promote 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.

2 Enhance 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.

3 Provide Healthcare Team Knowledge and Training

Healthcare organizations can educate members of the healthcare team about the benefits of SDM for 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.

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Take Concrete Actions for 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, 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.

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Track, Monitor, and Report

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 SDM process, data collection and interpretation should add value and not unnecessarily burden healthcare teams.

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Establish Accountability for Organizations, Clinicians, and Patients

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.

The AXIS 6 Ease (“E’s”) to SDM

ENSURE

Ensure you see and treat the patient as an individual not a disease.

ELEVATE

Elevate the patient-centric experience and improve satisfaction with care.

ENABLE

Enable a long-term personal connection with your patients.

ESTABLISH

Establish co-created treatment plans that align medical evidence with patient preferences to foster adherence and optimize outcomes.

ELICIT

Elicit patient/caregiver preferences, values, and goals for therapy.

EVALUATE

Evaluate the risk/benefits and costs of treatment so they are aligned with patient expectations.

Tips for Eliciting Patient Participation in Treatment Planning

TIPS FOR ENGAGING YOUR PATIENT

- Summarize for your patient the current status of their disease.
- Ask your patient and their caregivers to participate with the healthcare team in making treatment and disease management decisions. Explain that this open dialogue will assist the patient in selecting an option that will align with their preferences and goals of therapy.
- Ask your patient to share their feelings, challenges, and triumphs with regards to living with myelofibrosis. This can help uncover what is most important to them or barriers that may inform the selection of one treatment approach over another.
- Help your patient feel empowered to share their opinion by explaining to them that they are an important contributor to the successful management and control of their myelofibrosis.

TIPS FOR EXPLORING TREATMENT OPTIONS WITH YOUR PATIENT

- Assess what your patient already knows about his or her current treatment options.
- Provide your patient and/or caregivers with a printed list of the currently available myelofibrosis treatment options with a brief description of each in plain language; review and describe the options to them.
- Clearly communicate the risks and benefits of each option. Explain the limitations of what is known and unknown about the treatment options and what would happen with no treatment.
- Communicate numbers in a way that your patient can understand. Use simple visual aids (graphs, charts, pictographs) to help your patient understand your explanations.
- Offer evidence-based decision aid tools whenever possible and explain how to use them to arrive at a decision that reflects their preferences, goals, and values.
- Encourage patients to play an active role in treatment selection.
- Summarize by listing the treatment options for myelofibrosis again
- Use the teach-back technique to check for understanding: ask your patient to explain in his or her own words what the options are.

Tips for Eliciting Patient Participation in Treatment Planning (continued)

TIPS FOR ASSESSING VALUES AND PREFERENCES

- Encourage your patient to talk about what matters most to him or her.
- Ask open-ended questions (See sample questions below).
- Listen actively to your patient. Show empathy and interest in what is currently impacting your patients everyday life.
- Acknowledge the values and preferences that matter to your patient.
- Agree on what is important to your patient.
- Recap with your patient your interpretation of what is most important to them as a priority for consideration when mutually selecting the best treatment option.

Sample Questions

- What is your #1 priority that we accomplish during our visit today?
- How do you feel? Are you experiencing any symptoms, such as fatigue, night sweats, itching, abdominal discomfort or pain, early satiety, bone pain, inactivity, concentration problems, fever, weight loss, others?
- Are you experiencing any side effects related to your treatment? How has this impacted your lifestyle and quality of life?
- Is your condition interfering with your work, social events, or everyday activities at home?

- Do you have any questions about the benefits or risks of the different myelofibrosis treatments we are considering for your disease?
- What goals do you have regarding your myelofibrosis treatment? Have these goals changed since our last visit?

Sample goals

- Keeping the symptoms of my disease under control
 - Minimizing risks and side effects from treatment
 - Finding a treatment with a dosing option that's easy and convenient
 - Selecting a treatment that is cost effective
- What is most important to you/your family as we discuss current or new treatment options?

What is most important to your patient? It might be

- Keeping out-of-pocket costs low
- Resolving disease symptoms
- Avoiding treatment-related adverse events
- Maintaining a specific level of functionality
- Improving quality of life

TIPS FOR DECISION MAKING

- Help your patient move to a decision by asking if he or she is ready to make a decision.
- Ask if your patient would like additional information or tools such as educational materials or decision aids to help make a decision.

- Check to see if your patient needs more time to consider the options or discuss the options with others.
- Confirm the decision with your patient, if he or she is ready.
- Schedule follow-up appointments as needed.

TIPS FOR EVALUATION OF THE DECISION

- Monitor the response to the treatment that is implemented.
- Reflect with your patient on whether the decision was consistent with the patient's goals.

- Revisit the decision with your patient and determine if other decisions need to be made.

Applying Shared Decision-Making Tactics in Clinical Practice

CONSIDER THESE QUESTIONS TO ELICIT PATIENTS' PERSPECTIVES AND CONCERNS ABOUT THEIR DISEASE AND TREATMENT.

- What bothers you most about having myelofibrosis?
- What would you like most from your treatment?
- Are you able to tolerate the treatment we've chosen? If not, why not? How can we provide improved support to enhance your treatment?
- Do you understand the different treatment choices? What else would you like to know about them?
- Do you understand why we've chosen this treatment? What else would you like to know about it?
- Are you able to make a decision now, or do you need more time to think about it?
- What are the biggest challenges you face as a result of your condition? How can we better support you to cope with these challenges?
- Would you like to be involved with a patient/caregiver support group?

Documenting Shared Decision-Making

The OPTION scale, or “observing patient involvement,” was developed specifically for measuring the extent and quality of integrating SDM by clinical professionals. One clinician uses this tool to observe the other during a patient encounter and “scores” their ability to engage the patient in decision making during that visit.

The OPTION scale is one example of a tool that could be integrated into clinical practice to document that SDM occurs with each patient encounter. The OPTION scale uses items to score each patient encounter on a scale of 0 (behavior is not observed) to 4 (behavior is exemplary).

Please consider integrating the OPTION instrument below to document that SDM occurs across your myelofibrosis patient population. Documenting that SDM occurs in clinical practice can enhance your reimbursement under the Quality Payment Program (QPP) parameters.

THE OBSERVER OPTION - MEASURE SCORE SHEET

Date _____ Clinician Name _____

0 No effort (Zero effort observed)

1 Minimal effort (Effort to communicate could be implied or interpreted)

2 Moderate effort (Basic phrases or sentences used)

3 Skilled effort (Substantive phrases or sentences used)

4 Exemplary effort (Clear, accurate communication methods used)

Item 1

The clinician **draws attention to or confirms** that different myelofibrosis treatments or management options exist or that the need for a decision exists. If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need deliberation.

0 | **1** | **2** | **3** | **4**

Item 2

The clinician reassures the patient or re-affirms that the clinician **will support the patient to become informed or deliberate** about the options. If the patient states that they have sought or obtained information prior to the encounter, the clinician supports such a deliberation process.

0 | **1** | **2** | **3** | **4**

Item 3

The clinician **gives information or checks understanding about the options** that are considered reasonable (this can include taking no action), to support the patient in comparing alternatives. If the patient requests clarification, the clinician supports the process.

0 | **1** | **2** | **3** | **4**

Item 4

The clinician makes an effort to **elicit the patient's preferences** in response to the options that have been described. If the patient declares their preference(s), the clinician is supportive.

0 | **1** | **2** | **3** | **4**

Item 5

The clinician makes an **effort to integrate the patient's elicited preferences** as decisions are made. If the patient indicates how best to integrate their preferences as decisions are made, the clinician makes an effort to do so.

0 | **1** | **2** | **3** | **4**

Resources

MYELOFIBROSIS RESOURCES FOR YOUR PATIENTS

- The Leukemia & Lymphoma Society (LLS)
www.LLS.org/PatientSupport
- NCCN Guidelines for Patients®: Myeloproliferative Neoplasms
<https://www.nccn.org/patients/guidelines/content/PDF/mpn-patient.pdf>
- MPN Cancer Connection
MPNCancerConnection.org
- MPN Education Foundation
mpninfo.org
- National Cancer Institute (NCI)
cancer.gov/types/myeloproliferative
- MPN Research Foundation
mpnresearchfoundation.org

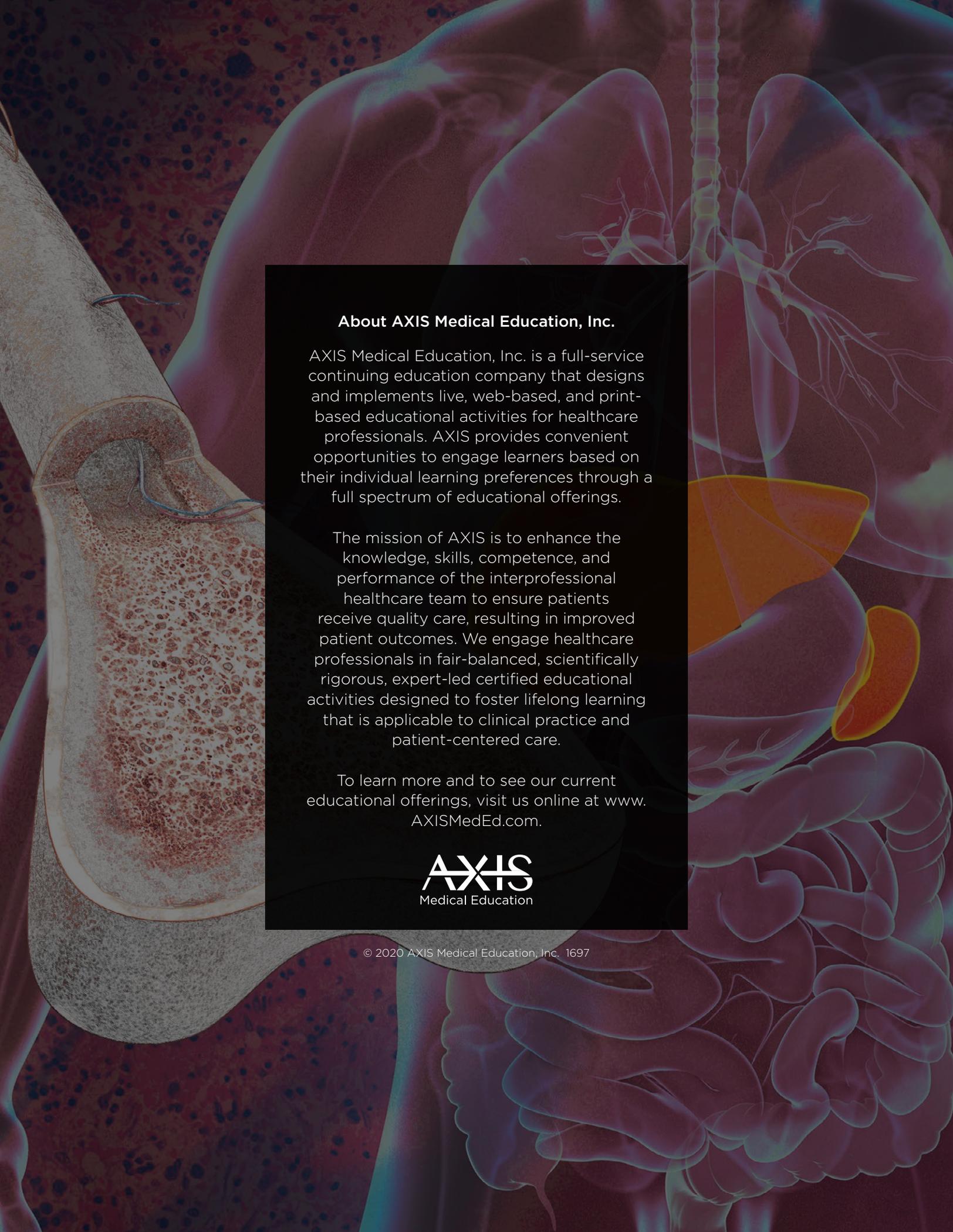
LEARN MORE ABOUT SHARED DECISION-MAKING

- National Learning Consortium: Shared Decision-Making Fact Sheet
https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf
- National Quality Partners Playbook™: Shared Decision-Making in Healthcare.
<https://store.qualityforum.org/products/national-quality-partners-playbook™-shared-decision-making>
- OPTION Training Pack: Evaluating the extent that clinicians involve patients in decisions.
http://www.glynelwyn.com/uploads/2/4/0/4/24040341/option_12_training_pack.pdf
- AXIS Oncology Shared Decision-Making Resource Center
<https://axismeded.com/portal.mainpages.aspx?OSDMR>

References

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