

Shared Decision Making: Engaging Patients to Improve Health Care



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Part of a series to help advocates understand and engage in key health system reform issues.

Fundamentally, shared decision making is about giving patients the opportunity to be active participants in their health care. When well-informed patients and caregivers team up with health professionals who are trained in effective communication, patients are more likely to receive care that meets their needs and see improved health outcomes. Advocates have an important role to play in ensuring that shared decision-making programs are consumer-friendly.

Shared decision making has the potential to help achieve better health and better care at a lower cost by giving health care consumers the tools they need to partner with their health care providers to make decisions based on medical evidence and personal preferences.¹ Encouraging shared decision making is especially important because Americans are paying more and more for their health care, often with little say in the type of care they receive. Patients rarely know or understand all of their options. As a result, they often receive care that is based more on their provider's habits than their own preferences.

Patients who are more involved in their health care are happier with their health care decisions and are more likely to follow treatment plans, which can lead to better health outcomes. It is important for advocates to be involved in the development of shared decision-making programs to ensure that they improve health and quality of care for all consumers.

This brief provides an overview of shared decision making and answers key questions about how it can improve patient care, how to design a good shared decision-making program, and how shared decision making fits into a more patient-centered health care system.

What is shared decision making?

Shared decision making can mean different things depending on the context, but in all instances it seeks to get patients and, when appropriate, families and caregivers, more involved in health care decisions. The primary objective of shared decision making is to empower patients with the knowledge and skills they need to take an active role in their health care. In the process, passive patients will transition into active health care consumers who help drive the delivery of high-quality health care.

The focus of this brief is on shared decision making as a process that occurs between patients and providers when there is more than one medically supported solution. These decisions are considered “preference-sensitive” because the best solution depends

on personal preferences and values. They can be one-time decisions, such as whether or not to get hip replacement surgery, or ongoing care decisions, such as how to manage and treat chronic low back pain. While the most effective programs will vary based on the type of patient and the type of decision being made, all shared decision-making programs should contain four fundamental elements:

1. Information

Patients should receive clear and unbiased information that describes their condition, discusses the pros and cons of different treatment options, and helps them envision how their life might change based on their decision.²

2. Support

Patients should be well supported during the decision-making process. They should get help understanding the information presented and discussing their values and preferences with their provider.³

3. Discussion

Patients and providers should share information and make a decision together that is based on the best medical evidence and tailored to the specific needs and circumstances of patients.⁴

4. Follow-Through

Care should be delivered in the agreed upon manner and in a way that aligns with patient preferences and values. Patients should remain in contact with their provider and continue to receive support for subsequent health care decisions.⁵



SHARED DECISION MAKING

All shared decision making should contain the following four elements:

- 1 Information
- 2 Support
- 3 Discussion
- 4 Follow-Through

Passive Patient vs. Active Consumer

In this brief, the term “patient” is used broadly to include both patients and their families or their caregivers. The brief emphasizes the important work that is needed to help transform passive patients who simply receive care into active consumers who play a vital role in making health care decisions. The distinction between passive patient and active consumer is important because shared decision making targets passive patients and seeks to improve their quality of care by empowering them to become active consumers.

How does shared decision making improve patient care?

Shared decision making allows patients to be more engaged in their health care.

Most patients are dissatisfied with their level of involvement in health care decisions and would like to take a more active role.⁶ The level of participation that patients want may differ by age, education level, and race or ethnicity, with younger and more educated people being the most likely to prefer a very active role. However, older, minority, and low-literacy individuals also want to become more involved in their treatment decisions.⁷ These vulnerable people tend to seek an active role when they feel knowledgeable and confident in their ability to understand, manage, and communicate health concerns.

Shared decision making improves patient satisfaction and health outcomes.

Patients who engage in shared decision making are more satisfied with their care for a number of reasons. They more fully

understand the risks and benefits associated with their decision, they are happier with the care they receive, and they feel that their decision better matches their preferences. They also feel more engaged in their care and are more likely to follow the treatment plan they agree upon with their doctor, which can lead to improved health.⁸

Shared decision making can reduce health disparities.

Shared decision making helps patients establish trust in their provider, and it helps doctors engage and communicate better with their patients. Trust and communication are two areas in which health disparities still exist in our health system.⁹ Some doctors may unknowingly hold biases toward patients who they feel are not able to understand complex medical information. Similarly, many patients do not trust or feel comfortable discussing health concerns with doctors who they cannot relate to on a personal level.¹⁰ Many people who are older Americans, speak English as a second language, or have lower literacy levels feel less engaged in the decision-making process and often have less confidence when navigating the health care system.¹¹ Shared

decision making creates a process to ensure that all patients feel empowered to express their preferences, values, and concerns, and that all providers engage their patients in a meaningful way. Shared decision-making programs employ nurses or care managers to provide additional, more appropriate support to address individual patient needs. Although providers should never force patients to participate in decision making beyond their comfort level, vulnerable individuals will benefit most from programs that increase their self-confidence and promote increased communication with their provider.

Shared decision making promotes evidence-based care.

In shared decision making, doctors or nurses often share the best medical evidence with their patients through decision tools, such as patient decision aids. These are tools that help patients understand what is known about their condition or the decision they face, as well as the options available. Patient decision aids help patients know what options are effective, and shared decision making empowers patients to make choices based on value and quality. Patients, and even doctors, often don't know that there are multiple options available and that one option isn't necessarily better than others. When shared decision making is used in everyday practice, doctors must stay up-to-date on best practices and share that information with their patients.¹² This encourages patients and providers to make health care decisions that are based on personal information and medical evidence to ensure patients receive care that is best for their unique needs and preferences.



SHARED DECISION MAKING

What makes a good decision-making program?

- It focuses on improving care.
- It keeps patients well-informed.
- It provides high-quality decision aids.
- It promotes well-trained health care teams.
- It provides access to well-designed health information technology.
- It promotes a well-integrated care delivery process.

What makes a good shared decision-making program?

Programs should focus on improving care for consumers.

There are many reasons why health care providers, practices, purchasers, and payers may want to develop shared decision-making programs. The primary objectives of a program can affect the way that it is developed and implemented and should always be consumer-oriented. Shared decision making should never be used as a means to limit patients' access to care, to limit payment for delivering necessary care, or to discriminate against patients with unique needs. Examples of consumer-friendly objectives might include:

■ Increasing Patient Engagement

After participating in shared decision making, patients seek a more active role in decision making and feel confident that they can contribute to discussions about their medical care.

■ Improving Health Outcomes

For example, a shared decision-making program that focuses on patients with diabetes would measure success based on specific health indicators, such as blood sugar level.

■ Care Delivery Transformation

Shared decision making offers individual practices and larger health systems a way to begin transitioning to patient-centered care. It can help shift how patients and doctors think about their roles in the health care system and can be tailored to meet the needs of the practice and patients.

Shared decision making is sometimes viewed as a way to control costs. Many patients who are more informed about their health care options will select less invasive and less costly care.¹³ Patients who feel more involved in their care are also more likely to make treatment plans they can realistically follow, often leading to fewer unnecessary hospital visits and better health outcomes. In this way, shared decision making has the potential to reduce unnecessary spending in the long term.

In addition, patients should be given the opportunity to factor in the out-of-pocket costs associated with various courses of treatment, as cost may be an important factor in their decision. However, consumers should not be pushed toward particular decisions or treatment options based on cost or other factors.

Successful shared decision-making programs will also require significant upfront investment in patient and provider training; health care

infrastructure; and the development of high-quality, evidence-based patient information. This means any cost savings will likely take time. Discussions of the potential for shared decision-making programs to save money will need to take these factors into account.

Patients must be well-informed in order to participate in shared decision making.

In order for patients to meaningfully engage in health care decisions with their providers, they must understand their health condition and the different options available to them. Patient decision aids are one way that this information can be provided in a consolidated, easy-to-use manner.

Patient decision aids are written, video, or web-based tools that are designed to help patients do the following:

1. Become more knowledgeable about their health condition and treatment options
2. Decide which risks and benefits are most important to them
3. Envision how the different options would affect their daily lives

Although patient decision aids are not required to create an effective shared decision-making program, it is essential that patients are well-informed and feel empowered to participate in the decision-making process to the extent they desire. When designed well, patient decision aids can help patients engage in shared decision making and make choices that align with their preferences and values. As consumer advocates, it is important that we understand what makes a good patient decision aid to ensure that they are designed and used in the best interest of consumers.

What are the elements of an effective patient decision aid?

The following is a list of the most important elements that consumers, caregivers, and advocates should look for in a high-quality patient decision aid:

1. Patient decision aids should include content that meets the following criteria:

- **Evidence-Based**
Information on the condition, treatment options, and possible outcomes is up-to-date and based on the most recent research available.
- **Balanced**
Evidence for different treatment options is presented in a balanced way, including a description of the risks and benefits for each option.
- **Understandable**
Text is written at an appropriate reading and literacy level. Risks and other numerical information are presented using easily understood rates and probabilities. All diagrams use the same scale for easy comparison.
- **Targeted**
The content and presentation is targeted for the literacy level, language or level of English proficiency, gender, age, and cultural background of the population of patients who will be using the decision aids. The content is presented in a way that is relevant. For example, some Latina patients were more responsive to a patient decision aid designed as a short soap opera that tells the story of someone in a similar situation.¹⁴ Graphics and narrative stories can often reach patients with lower literacy levels more effectively.
- **Clarifies Preferences and Values**
The material helps patients think about which risks and benefits of each option matter most to them. In addition, the materials should allow patients to indicate whether the out-of-pocket costs associated with various treatment options are of concern to them and their families. Patients can then share their preferences with their doctor to make a decision that is best for them.

What are patient decision aids?

Patient decision aids are tools that help patients understand their options and use their personal preferences and values to weigh the pros and cons of each possible course of action.

2. Patient decision aids should be developed according to the following guidelines:

■ **Consumer Input**

Patients who have experienced the same condition or who have been faced with the same health care decision can help identify what information is most valuable to patients and should be involved in testing of the patient decision aid. Consumer testing should be done in all patient populations expected to use the patient decision aid and should show that it improved patients' ability to discuss the decision with their doctor.

■ **Development Team**

In addition to consumers, the development team should include medical experts, communication and behavior specialists, and web or graphic designers.

■ **No Conflict of Interest**

Members of the development team should not have any conflicts of interest that would detract from the balance and accuracy of the information in the patient decision aid. Any conflict of interest must be clearly declared.

3. Patient decision aids should be evaluated based on the following outcomes:

■ **Patient Confidence**

Patients feel more prepared to discuss their condition and decision with their doctor after reviewing the patient decision aid.

■ **Patient Engagement**

Patients seek out a more active role in making health care decisions after viewing the patient decision aid.

■ **Patient Knowledge**

The patient decision aid provides patients with a basic understanding of their condition and improves their understanding of the options available to them.

■ **Patient Values**

The patient decision aid helps ensure that the decision aligns with values expressed by patients—including the risks and benefits that are most important to them.

For more information about evaluation measures for patient decision aids, see the Agency for Healthcare Research and Quality's patient decision aid checklist, available online at <http://www.effectivehealthcare.ahrq.gov/ehc/decisionaids/prostate-cancer/LM5/pdfs/AboutTheDecisionAid.pdf>

Well-trained health care teams are essential to the success of shared decision-making programs.

Although much of the decision-making process will occur between patients and their doctor(s), an entire team is necessary to make sure shared decision making is effective. These teams will vary based on the care setting, the condition or treatment decision, and specific patient needs. Take, for example, a patient who is making a decision about diabetes medication. The care team might also include his pharmacist and a community-based social worker to help him stick to his treatment plan. Despite variations, the most successful programs will have a core team that includes a provider, a care manager or health coach, and the patient—all trained in shared decision making and knowledgeable about the unique role that they play.

■ Provider

It is essential that all providers in a practice or in a health care system be supportive of the shared decision-making program and trained in effective communication and engagement strategies. Effective communication includes sharing health information and describing risks and benefits in a way that is relevant and understandable. Effective engagement involves establishing trusting partnerships and eliciting relevant, often non-medical, information about patients' preferences, values, and lifestyle. This also entails gauging patients' desired level of participation in the decision-making process and appropriately tailoring the dialogue.

Many practices find that identifying one provider to serve as the “champion” of



The success of a shared decision-making program depends on well-trained health care teams.

the shared decision-making program can smooth the implementation process. This “champion” will help promote the program and develop a plan to incorporate shared decision making into the care delivery process. In many practices, the “champion” will need to facilitate a culture shift to help the staff see the value of involved and informed patients. Practices with strong leadership will have greater success implementing shared decision making and improving communication between doctors and patients.

■ Care Manager

The care manager, typically a registered nurse, is responsible for tracking the health care needs of patients and coordinating with other members of the health care team. She will identify when patient decision aids might be helpful, distribute them, and make sure patients feels supported. For vulnerable patients who need additional support, she will connect them to a social worker or community health provider who then becomes part of the care team. Social workers from the local community can be a relatable and trustworthy resource for patients and help link patients with their doctors.

The care manager may also have additional training as a “health coach” and take on the additional role of supporting patients through the decision-making process. This involves helping patients communicate their desired level of participation in decision making and their knowledge, questions, and expectations regarding their health condition. To do this well, care managers must be trained to engage patients and understand the many factors that influence patient behavior.

- **Patient, Caregiver, and Family Member**

Patients also have important responsibilities in the health care team. It is the patient, often together with a caregiver or family member, who must help the doctor understand the characteristics and preferences that make them unique. This is a much easier task for some patients than others. For example, people with less education or lower English proficiency may find it more difficult to understand health information or communicate concerns to their doctor. These patients are still a critical part of the health care team and will receive better care if they are involved as much as possible and are aware of the important role that they play on the health care team.

It is important that doctors, care managers, and other members of the health care team understand patient differences when they engage in shared decision making. The care manager should first gauge the patient’s interest in shared decision making and understand the role that the caregiver or family member is willing and able to play. This person’s role will vary, and it is important that the health care team develops a care strategy that reflects the patient’s desired level of involvement and the role of the caregiver

or family member. In return, the patient and caregiver should work with the care manager to clearly express their questions and concerns and to share relevant personal information with their doctor.¹⁵

Health information technology can streamline the shared decision-making process.

Well-designed health information technology (health IT) is critical to effective and streamlined shared decision making. When developing a shared decision-making program, a practice will need to assess its health IT infrastructure. The most effective shared decision-making programs will have electronic health records (EHRs) that can track patients, increase communication between patients and providers, and give patients access to their records.

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- **Track Patients**

Health IT systems that can track patients using data in an electronic health records system can make shared decision making much more efficient and relevant to patients. If the system can identify patients who are likely to face a certain health care decision, those patients can receive

information and decision support from a care manager prior to their appointments so they feel more prepared to talk with their doctor. This can help patients and doctors make better use of their in-person visit.¹⁶

- **Alternative Communication**

Secure email gives patients an additional, faster way to ask questions and communicate with their doctor or health care team. Alternative communication can also include 24-hour access to nurse call centers for additional support. Both can help patients identify questions and clarify their preferences prior to their in-person appointments.

- **Patient Access to Records**

Patients who are able to view their health records online have a better understanding of their health condition and are more likely to engage in shared decision making with their doctors.¹⁷ Patient access to health records can also help doctors be more prepared for appointments. If patients enter their concerns or treatment preferences into the electronic health record before their appointment, doctors can provide more individualized care by addressing those concerns and preferences.

Shared decision-making programs should be well integrated in the care delivery process.

Shared decision making should occur in a way that makes sense for the practice delivering care and for the preference-sensitive decisions the practice is prepared to address. Depending on the type of decision being made, patients may be provided with a patient decision aid or another decision support tool prior to or following their initial doctor's visit. For example, a patient who must decide whether or not to have a screening test for prostate cancer should receive information prior to his initial appointment, while a patient who is deciding about diabetes management strategies should receive information after an initial appointment and diagnosis.

Payers and providers must also identify a payment and reimbursement strategy that provides incentives to effectively implement shared decision making. Some practices may choose to invest in health IT that provides reliable online communication and create a payment mechanism to reimburse care managers for the services they provide. Other providers may find that it is more effective to set up a payment structure to reimburse doctors for additional time so that patients can view patient decision aids during in-person doctor visits. It is important that shared decision making be supported by the payment structure and integrated into the care delivery process in a way that makes sense for patients, providers, and practices. Although the payment structure and delivery process may vary, both need to create the right incentives to invest in the time, training, and infrastructure necessary to do shared decision making well.

Patients who view their records online are more likely to engage in shared decision making with their doctors.

What is the future role of shared decision making?

Shared decision making is a key feature of health care reform in the Affordable Care Act.

Specific measures to promote shared decision making in the Affordable Care Act show that it is a vital part of health care reform. The law calls for the creation of national shared decision making resource centers and a body to certify patient decision aids, funding to support the development and evaluation of patient decision aids, and grants to help health care providers begin developing and using patient decision aids in their practices.¹⁸

Efforts to develop a standard definition of what shared decision making means in practical terms will help practices begin to integrate it into everyday care. Many doctors are hesitant to use shared decision making because they do not trust the quality of patient decision aids, or they do not know what shared decision making means on a practical level. Funding research and grants, as outlined in the Affordable Care Act, can help develop quality standards for patient decision aids and implementation of shared decision making. It is important that patients and advocates play a role in this process to ensure that these standards are consumer-friendly. Not all patients and care decisions are the same, and standards should allow flexibility based on patient characteristics (i.e., gender, age, cultural background) and the type of decision.

The Affordable Care Act also created several research and grant-making bodies that can test shared decision-making models and drive shared decision making in the future. The Center for Medicare and Medicaid Innovation (CMMI) was created by the Affordable Care

The Affordable Care Act calls for:

- The creation of national shared decision-making resource centers
- The creation of a body to certify patient decision aids
- Funding to support development and evaluation of patient decision aids
- Grants to help health care providers develop and use patient decision aids in their practices

Act to develop and test new ways to pay for and deliver high-quality health care. CMMI has already funded a \$26 million program to study how shared decision making can be used with patients making decisions about surgery or diabetes.¹⁹ The Patient Centered Outcomes Research Institute (PCORI) was also created by the Affordable Care Act to support research that is patient-driven and that will ultimately help patients make more informed decisions. Research from PCORI can help ensure that the information patients and providers use to make health care decisions is relevant to patients and based on the best available evidence.

Shared decision making aligns with other patient-centered health reform efforts.

Shared decision making can be integrated with other payment and delivery reform efforts to promote and advance patient-centered care. Many new payment models are

designed to promote quality over quantity of care by rewarding doctors and providers who deliver better care, rather than more care. Shared decision making works well in these models because there are opportunities to reward doctors for spending more time with their patients and to pay for additional members of the health care team.

One new delivery model, the accountable care organization (ACO), creates teams across the continuum of care that work together to make sure patients get the right care at the right time in the right setting. Many ACOs use shared decision making as a measure of quality when evaluating the care delivered to patients.²⁰ The patient-centered

medical home (PCMH) is another delivery model that uses shared decision making to evaluate quality of care. The PCMH model creates an accessible “home base” where patients can receive high-quality primary care. Shared decision making works well as an element of these care delivery models because its success depends on creating a patient-centered environment with a health care team that is focused on quality. As new health reform models are developed, it will be important for consumers and advocates to look for ways to incorporate shared decision making in ways that improve patient care and to help develop consumer-friendly standards for shared decision making.

Conclusion

Patients and providers agree that involving patients in health care decisions is the right thing to do, but it will take time and commitment to make this a reality.²¹ Investing in shared decision making will help build a high-quality health care system. It will require that providers and patients take on new roles and that delivery systems develop teams and technology to support these roles. When providers and patients work together, they make use of the best medical evidence *and* important personal preferences to make sure that patients get the best care possible. Patients deserve to have the knowledge and skills to make wiser health care decisions. Providers can deliver better care to all of their patients when they also have the tools, training, and support to communicate effectively. Shared decision making is essential to creating a health care system that values patients as partners and delivers truly patient-centered care.

Shared decision making has the potential to improve both the quality of care delivered and health outcomes. Together, patients and providers can make the health care system more effective and more efficient.

Where can I learn more about shared decision making?

- Informed Medical Decisions Foundation
<http://informedmedicaldecisions.org>
- Agency for Healthcare Quality and Research (AHRQ),
Effective Health Care Program
<http://effectivehealthcare.ahrq.gov>
- Dartmouth-Hitchcock Medical Center (DHMC),
Center for Shared Decision Making
http://patients.dartmouth-hitchcock.org/shared_decision_making.html
- International Patient Decision Aids Standards (IPDAS) Collaboration
<http://ipdas.ohri.ca>
- Ottawa Research Institute
<http://decisionaid.ohri.ca/index.html>
- Health Dialog
<http://www.healthdialog.com/Main/default>

Endnotes

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