Shared Decision Making
A Tool to Ensure Patient-Centered Care
The Value and Challenges of Shared Decision Making

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What Is Shared Decision Making?

On the surface, shared decision making (SDM) seems simple and straightforward. A clinician involves the patient in making a decision about their health. The clinician conveys the necessary medical information to the patient, explains their treatment options, and helps the patient understand how their values, goals and preferences can guide them to find the best treatment. And together they come to a preferred treatment plan. Though widely endorsed, SDM is uncommon in clinical practice.1

SDM is a process that goes beyond “informed decision making,” which is sometimes erroneously used interchangeably with SDM. But shared decision making is not simply about whether the patient has been informed and received enough information about their condition and its treatment, but a process where the provider helps the patient understand the decision, its consequences, and then helps them apply their values and preferences in order to make a decision.2

SDM is typically thought about in context of preference-sensitive decisions. That is, decisions where a patient faces two or more effective treatment options and the “best” treatment depends on how the patient values the different outcomes. However, SDM is relevant to many different types of decisions, and many argue that most health decisions are preference-based. SDM has often been studied in the context of a one-time yes/no decision – for example, whether or not to get the Shingles (Zoster) vaccine. This likely reflects the simplicity of studying such decisions.

SDM is increasingly applied to more complex and higher-stakes decisions. Take, for example, low-risk prostate cancer, where men have to choose between active surveillance, radiation, or radical prostatectomy. All treatment options have a similar impact on longevity, but the choice can have a drastic and often irreversible impact on many dimensions of a man’s quality of life. These can include incontinence, impotence and rectal symptoms.3 Therefore, a man needs to understand the short- and long-term effects of these options, and be able to integrate this knowledge into his personal values and preferences. Is it important for him to know that the cancer is removed? Is he willing to risk permanent impotence in order to obtain this peace of mind?

SDM is also highly relevant to chronic disease management. Patients with conditions, such as coronary artery disease, diabetes or asthma, are often faced with a plethora of treatment options that have similar effectiveness but different side effects and costs. Many treatments differ in their complexity or burden to the patients (e.g., taking multiple pills many times a day vs. once a day, or requiring injections). In these situations, SDM can help patients choose an initial treatment with a suitable risk/benefit profile for their particular circumstances.4 If the patient later experiences undesirable side effects, SDM can help with decisions about whether to continue the treatment or switch to a different one. It can also help with decisions about whether to intensify treatment (e.g., by adding additional medications or increasing the dosage of current medications).5

Though SDM is typically thought about in context of choosing a treatment, it may also be relevant for treatment adherence, especially when adherence to the chosen treatment plan requires daily reaffirmation of a patient’s decision about treatment. With adherence to medications for common chronic disease running as low as 40 to 50 percent,6 increased attention is given to exploring whether SDM can be used to promote adherence.

Other times patients face complex clinical situations where they need to understand the future trajectory of decisions, where one decision can set them up for a series of future decisions. For example, decisions about screening for prostate cancer using the Prostate Specific Antigen (PSA) test are complex because a positive PSA test results in a series of predictable but difficult subsequent decisions. A “decision map,” which depicts the known cascade of subsequent decisions a patient will later face, can be helpful (see Figure 1).

To use an example, consider early-stage breast cancer. Before a woman chooses between lumpectomy and mastectomy, she not only needs to understand the risks of both procedures, but if she chooses a mastectomy would she then prefer a prosthetic breast or reconstruction surgery? And if she chooses reconstruction, she will also need to choose between a breast implant vs. tissue flaps. And all of those choices and consequences emerge from and are shaped by her initial decision between mastectomy and lumpectomy.

In this case, to choose the “right” treatment, the woman needs to consider how she might feel wearing a prosthesis, how it would impact activities like swimming, and her relationship with her partner. These preferences are uniquely personal and not typically elicited as part of a standard clinical assessment.

If the patient’s doctor is not aware of how a patient feels about these matters, a treatment might be selected based on criteria that are less important to the patient. If the doctor assumed the patient wanted to preserve her breast,
whereas the patient just wanted to deal with the problem once and for all and avoid the inconvenience of radiation therapy, the doctor might recommend a lumpectomy when a mastectomy might be better for that patient. Clinicians cannot predict each patient’s unique preferences; and this is one reason SDM is crucial. An inability to predict a patient’s unique preferences is not a failing on the part of the clinician. Every patient is different and the possible reasons patients and their families may opt for counterintuitive or unexpected treatment decisions are impossible to predict. And clinicians should not try to predict this.

Research shows that when clinicians assume they know what patients prefer, they are often wrong. In one study, physicians thought most women (71 percent) with breast cancer would rank conserving their breast as a top treatment goal. But when women were surveyed, only 7 percent reported it was a top goal for them. And while no physicians in this study believed women would be very concerned about avoiding a prosthetic breast, 33 percent of patients placed great importance on this. As you can see, without SDM, the huge disconnect between clinician assumptions and reality would send many women down a treatment pathway that does not reflect their treatment goals and would potentially leave them with a greatly diminished quality of life. This mismatch is sometimes called a “preference misdiagnosis.”

**Why Is SDM Needed?**

**Awareness of Options**

Often, patients are not aware or told they have options. While this may seem surprising, it is not at all uncommon. And patients often assume that not being offered a choice implies that the treatment offered is the only one available or the best one for them. These findings have been repeatedly demonstrated in numerous clinical settings and across numerous patient demographics.

**Understanding Risks and Benefits**

Patients’ misconceptions about the severity of their condition (beliefs about prognosis), or the effectiveness of treatments, can result in inappropriate treatment. Patients who believe their condition is more serious than it is (for example, men with low-risk prostate cancer who believe that it is a life-threatening condition) may choose treatments that are inappropriately aggressive, subjecting themselves to the many known harms of treatment while accruing minimal benefit from treatment. Similarly, people who overestimate the effectiveness of treatment (e.g., chemotherapy for some cancers) may opt for overaggressive treatments and may suffer greatly as a result.

**Quality of Life**

Quality of life (QOL) is specific to each patient. For one woman, having her entire breast removed may give her better QOL if it gives her peace of mind and does not involve missing much work due to frequent radiation appointments that may require long drives. Overtreatment and undertreatment can also affect QOL. Overly aggressive treatments can lead to irreversible harms that have a significant impact on the patient’s QOL. Only when patients understand that they have a choice and that their decision affects their personal risks of serious side effects such as bowel, bladder or sexual function, do they begin to consider the tradeoffs between their options. Other times, undertreatment can lead to a longer, more drawn out treatment course. For example, with Crohn’s disease, more aggressive medications may help prevent irreversible conditions like fistulas. Once these form, even more aggressive surgical treatment may be needed. Another example is the failure to treat osteoporosis, which could lead to highly morbid hip fractures that may have been prevented by treatment.

**Provider Factors**

Some practitioners are more paternalistic in their approach and believe they can make the best decision for the patient and spare patients unnecessary stress, angst and deliberation. While some patients prefer practitioners who are paternalistic, as noted above, clinicians’ assumptions about patient preferences and values are often incorrect. And while many patients may appreciate and even ask the clinician what he or she would do if they had to make the decision, making a decision for patients is problematic unless the patient explicitly prefers this approach. Recognizing that different patients feel differently about the extent to which...
they want to be involved in decisions about their health (and these preferences change over time and in different contexts), it is best to involve the patient in decision making to the extent that the patient desires. And this can only be determined by asking the patient in the context of the decision at hand.

Providers also have their own biases, some of which are known and intentional, and some which are unrecognized or unintentional. Their training and their own past experiences with other patients (especially a case that went wrong) can misinform provider decisions in spite of what larger population studies demonstrate. It is extremely difficult to override past salient experiences, which are easily retrievable in one’s memory and tend to distort one’s perceptions about how likely they are.

Furthermore, providers are often reluctant to present or even discuss treatment options that fall outside of their own specialization or training. This is a natural response, as they may not be familiar with recent research or may not feel confident enough to discuss those options accurately. And one specialist may be less interested in discussing or giving equal discussion to procedures for which they will not be reimbursed. For example, women with symptomatic fibroids can usually choose from a variety of procedures performed by gynecologists, interventional radiologists, or other specialists. Expanding the team to include different health care professionals could potentially mitigate this problem, but introduces logistical challenges, and may be confusing for patients who try to make sense of what may appear as conflicting recommendations.

**Patient Preconceptions and Biases**

Patients do not typically enter the clinic room as blank slates. They often have preconceived notions about their condition, its severity, and its causes, all of which may interfere with how receptive they are to new information. The majority of patients search for health information on the internet, finding material of highly variable scientific quality. Many patients may make incorrect assumptions and inferences about their options or have outdated or incorrect information. For example, patients with ulcerative colitis often assume an ostomy bag will greatly diminish their quality of life and should be a last resort; when in fact, most patients are surprised by how good their QOL is with an ostomy and find that many of their concerns are nonissues.

High-profile news stories or advocacy groups may also influence people, often providing misleading information. Experiences of friends and family members can also dramatically affect how a patient perceives their condition. If they have a compelling horror story, this may lead to a very visceral and emotional response to the condition or treatment, which in turn can distort how the person perceives their risks for this outcome. It is no longer an abstract possibility, but something that affected or even ruined a friend’s quality of life. This makes these outcomes seem more likely, leading to distortion in how the patient sees their actual risk for this outcome.

**Emotional and Cognitive Load**

New diagnoses or a decline in health can be overwhelming for patients. There is often a great deal of information to understand. And the cognitive load this presents is often amplified by physical pain and stress. Often these situations require significant changes in behavior, which may mean foregoing unhealthy behaviors one enjoyed and replacing them with behaviors they otherwise would have preferred to avoid. This in itself can create ongoing stress. Additionally, coping with the uncertainty of their situation (will it get worse? will I experience side effects from the treatment?) can be challenging both for patients and their providers. Patients need time to process not only the information about their new health condition and its treatment, but their emotions and reactions to the uncertainty that surrounds them. They need to know they have the time to consider their options. And they need support throughout the difficult process of deliberation and with integrating the chosen treatment plan into their daily life.

In the case of something iconic like cancer, the word “cancer” itself is disorienting and throws many people into a state of panic. This is exacerbated by the way cancer is portrayed in movies, the media, and the “battle” language used to describe it: “war against cancer,” “fighting cancer.” The idea that certain types of cancer can be “low-risk” and not at all life-threatening is confusing. It can be challenging to counter these preconceptions and convey a legitimate option, such as active surveillance to patients who may not understand how “keeping an eye on it” could be an appropriate approach to treating a very slow-growing cancer. A partner or family member’s concerns may also drive people toward overly aggressive treatment and the need to feel like they are doing everything they can to save the person from cancer.

Going through an SDM process where patients feel fully informed of the risks, tradeoffs and information may seem

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**“Medical information can be extremely challenging.”**
as though it might make people feel uncomfortable, but this does not appear to be the case. SDM helps ensure the decision is a good one for them and patients are less likely to feel regret. Overall, SDM does not appear to have any negative impact on anxiety, and it may actually decrease anxiety for a short period of time.  

This may be because SDM helps to fill in gaps in patients’ knowledge with helpful information, which otherwise might have included incorrect inferences or beliefs. SDM consistently lowers what is called “decisional conflict,” a measure of the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret or challenge to personal life values.  

Making health decisions can be difficult, emotional and overwhelming, not only for lay people, but for doctors as well. Several studies explored the experiences of health professionals when they became patients, finding the experience left them feeling “vulnerable and disempowered.” GPs who experienced a serious illness reported feeling “anxiety, uncertainty, shock, and loss of control” and “made them realise how disempowered patients can feel…”  

Health Literacy and Numeracy  
Medical information can be extremely challenging for people to research and understand on their own. Even practitioners find it challenging to parse studies and news stories, assess the accuracy of research, and grasp why similar studies may arrive at conflicting conclusions. Experts in evidence-based medicine often come to different conclusions based on the same evidence. The sheer tonnage of health information can overwhelm people, increase stress and confusion, and decrease trust.  

Numeracy is especially challenging. Many people shut down when they see numbers. And in SDM, people need to not only understand probabilistic risk information, but weigh the risk/benefit tradeoffs, sometimes between multiple treatments that affect numerous different risks that play out over different time periods.  

It can be hard for people to understand a difference of 1 percent versus 0.001 percent, and adding terms such as “rare” and “very rare” may not clarify it in a meaningful way. Sometimes these terms may make matters worse because how they are used is not universally agreed upon.  

Distinctions between relative and absolute risks can be especially challenging. Reporting risks or benefits in relative terms tends to exaggerate their impact. For example, telling a patient a medication may reduce their risk of a heart attack by 50 percent sounds impressive and would lead a patient to opt for the medication. But if that patient’s risk for a heart attack is 2 percent, this 50 percent reduction only brings their risk down to 1 percent, making it sound like a medication that is hardly worth taking. These two ways of explaining the impact of treatment are mathematically equivalent and equally accurate, but they have a dramatically different impact on patients. Not only do patients have difficulty understanding risks, but many providers do as well.  

Aside from numeracy, tradeoffs themselves can be difficult concepts. People dislike tradeoffs and will even go so far as to choose an inferior option in order to avoid a difficult tradeoff. As Holly Witteman explains, “It’s hard to accept that there is no perfect option... What makes health tradeoffs especially tough is that they incorporate uncertainty... And yet, many medical decisions are set up precisely this way, because we never know for sure whether a treatment or therapy will work, or which people taking a drug will experience the uncommon, unpleasant side effects.”  

The Challenges of Evidence  
Physicians always struggle to keep up on the changing state of guidelines and studies, and to understand the validity of those results. There are challenges with too much evidence that may be conflicting; or the same scientific evidence may be interpreted differently by different clinicians or professional organizations. Other times there is simply a vacuum of information about a certain risk, incidence or longevity of a treatment. Often the existing evidence focuses on outcomes that may not be the main concerns of patients. While the lack of relevant data can leave patients feeling lost, SDM is still important. It can help people accept the uncertainty of their situation, and still reassure them that they have all the available information.  

What SDM Is Not  
It is important to understand what SDM is not meant to be. It is not advocacy or persuasion. Campaigns to get women to get annual mammograms or to tell all men not to get PSA tests may often be well intentioned, but SDM comes into play when there is no best answer for everyone. And it is essential that patients do not perceive the SDM process as a marketing pitch or persuasion. They may, in fact, react against any kind of pitch and suspect an underlying agenda. It is equally important that providers do not perceive decision aids (DA) as being biased towards or against one treatment, or they will not recommend it to their patients. Provider endorsement has been shown to be an important factor in disseminating DA to patients.  

While one goal of SDM is to help reduce unnecessary or harmful treatments, it is not explicitly intended to reduce overtreatment or to lower the cost of treatment. For example, while patients with chronic low back pain may be less likely to choose an invasive treatment like spinal fusion surgery after participating in SDM and understanding their options and the risks of surgery, some patients will still choose surgery. And for them it may be the right option. Maybe they have tried other options, know they cannot comply with physical therapy, or simply feel they need immediate relief and are willing to take the chance of incurring more serious side effects.
Supporting true, shared decisions means there will, at times, be conflict between what the provider feels is the best choice and what an informed patient actually chooses.

Challenges and Opportunities
Integrating SDM into care can be time-consuming. Short patient-clinician encounters do not allow the time to go over the options, risk and evidence, let alone uncertain evidence. It is challenging to stay up to date on all the relevant information. And patients need to feel there is time to comprehend the information and ample opportunities to ask questions. It is also challenging to minimize clinician and patient biases. And each patient may need different, personalized information. Viewed in this context, a straightforward SDM discussion does not seem easy to accomplish.

Decision Aids (DA)
Decision aids are tools or interventions meant to help with some of these challenges. They provide objective information to help patients understand their options and clarify their values so the provider can help them make a shared decision. They can be used during the clinical encounter or between encounters. DAs can be print materials, videos or web-based programs or tools.

Print Materials
Print materials are often used during the clinical encounter. They usually require the provider to explain and fill in the gaps – but often provide a good high-level summary so patients can wrap their heads around the information. Good examples are the diabetes cards created by Victor Montori. There are also simplified matrixes, tables or grids. These can serve as a good foundation for a patient-clinician discussion because they often summarize the pros and cons of the treatment options so patients can see all the basic information at a glance. A matrix or grid is often set up with common questions patients have about each treatment in rows with answers to these questions in columns under each treatment option.

Also, visual aids “such as icon array diagrams, bar charts, human figure representation or flow diagrams appear to aid accurate understanding of probabilities in many contexts.”

Predictive Risk Tools
Predictive risk tools can provide patients with a graphical model that helps them understand how their personal traits like age, gender, genetic markers and blood tests predict both their risk of complications from a given treatment and likelihood of benefiting from it.

Corey Siegel has developed this type of tool for patients with Crohn’s disease. After they watch a multimedia program that explains the treatments and their risks and benefits, his tool then takes their personal information and generates a graph so patients can see a straightforward visual representation of their results and whether they stratify into a high risk or low risk group (see figure 2). They can then factor this into their decision about whether or not to try more aggressive medications.

Patients often do not pay attention to population-based risks because they do not feel those risks apply to them. Often they find something about their particular situation that makes them exempt from these general risks. So a patient’s understanding of population-based risks does not necessarily entail that they understand the risks that they face. Tailoring risks and messages can therefore increase their relevance to patients and their motivation to discuss these risks. Tailored messages are more likely to be read, understood and recalled. Individualizing risks seems to increase motivation to engage in discussion and improves the accuracy of risk perceptions and results in better knowledge.

The challenge with tailoring risks, however, is ensuring that the information given is accurate for that patient (which often depends on the accuracy of data entered into the model), and that the patient truly understands this information.

Videos and Interactive Multimedia Programs
Videos and web-based multimedia programs are decision aids that can be used before, during or after clinician encounters. They can cover a large amount of information by leveraging narration and animation. This kind of standardized presentation also helps eliminate possible provider bias, and ensures the standard options are given equal weight. These presentations also allow patients to watch them at home in a more relaxed environment, when they have time to focus and absorb the information. This also allows partners and family members to watch and gain the same understanding so they can support and be part of the decision making process.

In Depth: The Emmi Program Approach
Emmi decision aid programs are web-based presentations that can be prescribed to patients to watch on any computer or mobile device. The programs attempt to address some of the challenges inherent in SDM that continue to be challenging with other DAs.

First, Emmi programs provide friendly, accessible, interesting and engaging content. A narrator speaks in plain, conversational language and takes time to empathize with their situation. Acknowledging and normalizing any anxiety also validates people and helps put them at ease.

Throughout, explanatory graphics, animations, illustrated risk explanations, and decision maps guide people through complex information, trying to simplify the process to promote understanding. For example, in the Crohn’s DA Emmi program, using animation and illustration to demonstrate 3 percent risk vs. .0002 percent, enabled patients to quickly grasp what is often a challenging distinction. (See Figures
3 and 4.) And when information is not intuitive (for example, that lumpectomy and mastectomy offer the same survival rates), we found that information often needs to be rephrased and repeated multiple times throughout the presentation. (See Figure 5.)

The tone and voice of Emmi programs proactively avoids medical jargon. Instead of sounding clinical, the experience is more like a well-informed, caring friend walking patients through the information. We find this tone helps address stress and anxiety and promotes calm deliberation. As one viewer expressed:

“I loved hearing a ‘voice’ explain the material instead of me reading it. The voice was more reassuring and calm than when I read through the booklets [my doctor had given me].” [Personal communication, from a viewer of the breast cancer program]
The programs are vetted with multi-disciplinary experts, including experts in decision science and risk communication, and tested with focus groups comprised of affected or at-risk participants. The programs attempt to anticipate patients’ common questions and points of confusion so those questions are not weighing on patients minds as they watch the programs.

Overall, we find this type of engagement approach to be very successful. Even with longer programs that exceed 40 minutes, over 90 percent of patients finish watching the full presentation.\textsuperscript{25}

Also, because patients usually watch and interact with Emmi programs at home, they are more likely to feel safe and to self-reveal. Listening to straightforward information about what are often very private and intimate topics, like sexual function, help put people at ease. In this setting, patients have time to formulate their thoughts and questions.

Questions are also interspersed throughout the programs to help patients consider their values and preferences as options. Concepts are introduced to help them to understand why they matter in the decision.

A separate question feature in the programs allows patients to type questions in for their provider, which the provider can then look at in advance and address at the next appointment.

The programs are not meant to help people make a final decision so much as to set up a more productive shared decision conversation. This saves the clinician time explaining all the foundational information patients need to know so that the clinician can focus on that patient’s specific situation and concerns.

The programs use several approaches to actively help patients think through their options, values and preferences. For example, a program about breast cancer walks women through “trying on” different decisions, from thinking about wearing a prosthetic under a dress or a swimsuit or how they might feel changing in a locker room. This information can also be printed off at the end of the program so the patient can sift through it or take it with to their appointment to discuss. And this same information is also captured for the provider so they can get a sense of the patient’s values and concerns. (See Figure 6.)

Implementation of traditional video- or pamphlet-based DAs in clinical practice has proven to be a huge challenge, with few examples of successful integration. But because Emmi programs can easily be integrated into an office or hospital’s workflow and into EMRs, this makes it easier to get the right DA to the right patient at the right time, and to confirm that the patient viewed the program. It can also be utilized as part of an intraprofessional team care to help improve care coordination as patients move from diagnosis with a primary care provider to working with a specialist or team or specialist.

Overall this approach to DA seems to promote better understanding of their options, what they mean for them in the long- and short-term, and engagement in the SDM process. While patients are used to vet and influence the programs and the programs themselves are currently being used by a large number of hospitals and health plans, formal evaluations are not completed.

\textbf{Figure 4:} Messaging regarding the equality of survival rates for mastectomy and lumpectomy from Treatment Options for Early-Stage Invasive Breast Cancer EmmiDecide program. Courtesy Emmi Solutions, LLC.

\textbf{Figure 5:} Example of preference question to help patients think about tradeoffs from the Treatment Options for Low-Risk Prostate Cancer EmmiDecide program.
Future Directions of the Field

Because of substantial challenges to integrating DAs into clinical practice, there is increasing attention on developing new approaches to promote and incentivize SDM. Innovations in the types of DAs are being seen, with recent attention to developing brief practical interventions that can be used during the clinical encounter. Attention is being given to training healthcare professions in SDM, as it appears that both patients and providers need to be primed and trained in SDM skills. SDM is increasingly being introduced into healthcare professional training programs, and in some institutions, as early as the first year of medical school (University of New England). New approaches to elicit patient preferences are emerging, as traditional approaches (standard gamble and time trade-off) are proving to be impractical beyond the research setting. These approaches include fast and frugal tools to help match a patient’s preferences with treatment.26

There has never been such interest in SDM. Patients, hospitals, professional organizations, health insurers, large employers, second-opinion companies, and even pharmaceutical companies now realize that everyone stands to benefit from true SDM. When patients understand their options, participate, and buy into their treatment pathway, and when hospitals, clinicians, and insurers understand how they can help patients be successful and choose wisely, there are likely additional benefits we cannot predict at this time. It is clear that SDM is the right thing to do with patients. The challenge now is to make it a reality by integrating it into clinical care. There will not be a one-size-fits-all option. Instead, it is about matching the appropriate approaches and DAs to various types of decisions.

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