Shared decision making: Helping the system and patients make quality health care decisions
Executive Summary

There is a growing demand in our health system for better quality of care. One way to address this is by involving patients more closely in their care. This means providing patients with more medical evidence about their condition and treatment options.

Shared decision making is a strategy for engaging patients through two-way communication and information exchange between health care providers and patients. In this way, the combination of medical evidence and patients’ preferences are more likely to support treatment decisions that lead to the health outcomes that patients value.

Shared decision making offers benefits across all health care levels. These include: a reduction in the use of health care resources (especially for elective surgeries), more valuable information exchange in patient visits, and a more responsive system catering to patients’ needs.

There are likely opportunities to incorporate shared decision making into the new initiatives aimed at improving the surgical care experience for Saskatchewan patients.

Engagement in the Health Care System

Patient-centredness is one dimension of health care quality; it is defined as care that is respectful of and responsive to patient preferences and values, and ensures that patient values guide all clinical decisions. Based on this definition, our health care system is not as patient-centred as it could be.

Do patients want to be involved in their care? Research shows that when patients receive information about their condition and treatment options, they want to be more involved in decisions about care. Furthermore, because patients now have greater access to health information through the internet, they are evolving into health care consumers who want to play a larger role in making health care decisions related to their well-being.

There is considerable evidence that patients are rarely engaged in their care. For example, studies have found that neither physicians nor patients expect to review evidence about treatment options during a routine visit. Unless patients are presented with and engaged in discussion about the best scientific evidence on treatment alternatives (where there are different options available), their decisions will not be fully informed and may not be consistent with their values.

Decision making at the patient level (micro) has implications for problems or issues at the system level (macro). Studies have found health care systems are driven by supplier-induced demand. In other words, treatment is provided, even when it is medically unnecessary, without regard for the quality of health outcomes; this is especially true of elective surgeries. Many of the elective procedures performed are not medically necessary. This is more likely to happen when patients are not involved in decisions about their care. Research shows that when patients are properly informed about their options, they are less likely to choose surgery (where other alternatives exist).
Shared Decision Making

This evidence points to the need to more closely involve patients in their care. One strategy for doing so is called shared decision making. Shared decision making (SDM) is the collaboration between the health care provider and the patient, through two-way communication and information exchange, to come to an agreement about a treatment decision. It is used primarily in cases where there are several treatment alternatives with no single “best” option.

Shared decision making effectively increases patients’ authority in interactions with health care providers by increasing their health knowledge which currently limits their role in decision-making. The more a patient’s preferences and values are incorporated into the decision-making process, the more likely the care will result in a health outcome valued by the patient. Thus, implementing shared decision making as part of specific care pathways (particularly for elective surgeries) will increase patient-centredness in the system.

SDM has three interrelated components, all of which must be used in order for the approach to succeed: decision support, decision aids, and education and training. Decision support encompasses both decision counseling and risk communication tools called decision aids. Essentially, decision support helps ensure patients have realistic expectations about their treatment when they are choosing between options. Decision counseling helps the patient participate in care decisions, but it does not make the decision for the patient. While not every patient requires decision counseling, trained professionals are available for anyone who wants or needs the help. Decision aids provide unbiased information about outcomes relevant to the patient’s specific disease or risk profile. They are usually DVDs or booklets; and unlike health education materials, decision aids focus specifically on preparing a patient to make a decision. Last, decision support is less effective without also properly educating and training health care providers about the principles and benefits associated with shared decision making. There are specific resources available for this.

The idea of engaging patients more fully in their health care decisions may seem like a daunting task because our system is currently designed to provide services, not knowledge. But we could start to change the system by making SDM the standard way we provide care. There is considerable evidence that it brings many benefits across all levels of health care:

- Increases patient knowledge;
- Helps ensure patients have realistic expectations about treatment choices;
- Stimulates patients to be more active in decision making;
- Increases overall patient engagement and empowerment;
- Creates a structured approach to reviewing options and outcomes;
- Increases agreement between providers and patients;
- Increases patient satisfaction with consultations; and,
- Aligns resource supply and demand, by decreasing rates of elective procedures.

Despite these benefits, there are also many perceived barriers to using shared decision making, the most significant being the amount of time required. While health care providers don’t think they have time to practice shared decision making in their consultations with patients, studies have shown that shared decision making does not, in fact, increase the length of these interactions. However, it does significantly change how the time is spent in a patient visit.
In studies comparing education pamphlets and decision aids, patients who received the latter were more prepared to make decisions, agreed with the physician more often, and were more aware of what they valued in their care. With shared decision making, the consultation time is more likely to be tailored to the patient’s needs and the quality of the consultation improves because the information shared is more valuable to the patient.

Opportunities to implement shared decision making in Saskatchewan

The various initiatives currently underway in this province’s health care system present opportunities to begin implementing shared decision making here. The Health Ministry has identified shared decision making as a key strategic and operational priority. As well, the inaugural Patient First Review, and a needs assessment on the topic conducted this summer by the Health Quality Council, can also serve as a platform upon which to begin more actively involving Saskatchewan patients in decisions about their care.

More specifically, the Ministry has directed the health regions to incorporate shared decision making in their efforts to improve care for patients having elective hip, knee, spine, and prostate surgery. There is plenty of research evidence and examples of how shared decision making has been applied within these specific care pathways. Combining this research with provincial initiatives, such as the multidisciplinary clinics created as part of the provincial surgery project and the decision aids available on HealthLine Online, will increase our chances of success.

There are many examples we can learn from; three of the most successful SDM programs focused on elective hip, knee, spine, and prostate surgery are The Ottawa Hip and Knee Project, Dartmouth-Hitchcock Medical Center’s Center for Shared Decision Making, and the National Health Service’s Urology Informed Decision Making Programme.

Overall, shared decision making is an excellent approach to increasing the system’s patient-centred care. Not only does it help align health care resources with medically necessary demand, but it also seeks to ensure that patients are knowledgeable, involved, and satisfied with their care.
Part I: Engagement in the Health Care System

1.1: Engagement

Health care quality improvement is complex and encompasses several inter-related dimensions. However, currently there is a growing demand for improvement in patient-centredness. Patient-centredness is one dimension of health care quality; it is defined as care that is respectful of and responsive to patient preferences, needs, and values, and also ensures that patient values guide all clinical decisions (1,2). In other words, it is a form of individualizing health care specifically for each individual patient, based on their preferences and values.

One of the biggest benefits of patient-centredness is better health outcomes: People pay more attention when information is both individualized and addresses their values related to their health problem (3). Thus, when the patient is treated as an individual they receive higher quality of care. One way to increase patient-centredness is through greater engagement.

Engaging or involving the public and patients in how care is organized and delivered and in their own care is essential for high-quality patient experiences to occur. Moreover, engagement can be practised at the macro (systems), meso (institutions), and micro (medical encounter) levels (4). Although engagement occurs in different ways at these levels, strategies are based on the same basic principle: information exchange guided by two-way communication.

It is essential that the health care system engages its patients since quality of care is really determined by its users (5). From the patient’s point of view, health care is of higher quality when it considers values and preferences (3). Therefore, engagement is fundamental in order to improve health care quality.

1.2: Public Involvement in Health Care

Public involvement/engagement is a controversial topic in health care because the evidence on its overall effectiveness is mixed. There are concerns about involving the public and patients in our ‘closed’ system. Nonetheless, engaging the public yields two significant benefits: i) It establishes an informed, accountable, and legitimate decision-making process that reflects public needs and demands; and ii) It holds the potential to create a more educated and engaged public (6). This is important because when people are educated they can more actively participate in the decision-making process. Moreover, public engagement in public services, such as tax-funded health care, should be a priority for several reasons (7):

1. The public is the most important stakeholder in the health care system.
2. Effective democratic participation requires public engagement.
3. The public can provide the information on community values and priorities.
4. Engaging the public increases the health care system’s transparency.

These points stress the fact that the public should be engaged because tax-payer funded health care is a public service, and therefore, should reflect the public’s needs. Although engaging the public in every decision is an unrealistic goal, it is essential and most pragmatic to involve them when value-dependent decisions must be made (7). For example, decisions about what the system should pay for with respect to new treatments recommended through health technology
assessments (7). In these types of sensitive situations it is particularly important to engage the public in the decision-making process.

1.3: The Lack of Public Involvement: Information Asymmetry

Engagement requires a two-way communication process and information exchange (6) - without it, the process of involvement is ineffective. Therefore, it is no surprise that public involvement is rarely practised because our system uses a paternalistic1 model based on a one-way exchange of information. In this model, health care providers are heavily relied upon for their scientific expertise, which is the primary focus of care. Meanwhile, patients are considered to be passive participants in the consultation because they have little health care knowledge. Additionally, the scientific focus of the consultation also means that patients' values and psychosocial outcomes are rarely explored despite being important pieces of information (8,9). This imbalance in knowledge and information exchange is referred to as information asymmetry (10). Ultimately, this model maintains the status quo of minimal public involvement in the health care system and can be attributed to the fact that the system is not designed to provide knowledge (11). Therefore, patients need more knowledge if they are to play a larger role in the decision-making process.

Moreover, by increasing public engagement the system will also increase its accountability. Presently, the lack of accountability can be attributed to three gaps created by the system (12):

- **Knowledge gap** between the public and the health care system's decision-makers;
- **Payment gap**: there is no financial benefit to engaging the public; and,
- **Culture gap**: patients are willing to pass their authority to both the system and its professionals.

These three gaps work synergistically in maintaining a closed system. In fact, the knowledge gap has been considered one of the system's most significant failures because of its ripple effect on health care quality (13). For example, patients can't meaningfully contribute to the decision making process because they lack health care knowledge, thus, their care providers make the decisions. Therefore, what seems like a voluntary surrender of public and patient power is actually a forced role created by a lack of knowledge. Additionally, research has found that patients want to be more involved in decision-making when they are provided with information about their treatment options (14). Finally, provider motivation to equalize the patient's role in their care is also minimal because there is limited patient demand for it and they are not currently remunerated for doing it (12,15).

Moreover, perhaps the greatest misfortune resulting from the paternalistic knowledge imbalance is that patient rights are violated. Patients have the right to know all the relevant treatment information and alternatives, as well as the right to exercise patient autonomy (11,16). Although neither Canada nor Saskatchewan currently have a Patient Bill of Rights, the World Health Organization (WHO) and the Supreme Court of Canada have both declared that patients have the right to be engaged in their care, and physicians have a legal obligation to disclose medical information regarding treatment choices before asking the patient to make a decision (9,17). Currently, these patient rights are not fully exercised. One example of how failure to fully inform a patient is an ethical violation is when they have unrealistic expectations about the effectiveness

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1This is a model where the health care providers dominate the medical encounter; meanwhile, the patients play passive roles in both care design and their own personal encounters (12).
of an elective surgery because they weren't properly informed about treatment information (18,19).

Overall, patient decision quality\(^2\) is negatively affected because patients are not provided with an adequate, or ethically appropriate, amount of information about their health care and treatment choices to make an informed choice\(^3\). Problems associated with poor decision quality are discussed in the following section.

1.4: The Lack of Patient Engagement

As with public involvement, there is also a substantial amount of evidence demonstrating that high-quality patient engagement rarely occurs in clinical practice. It has been found, in studies, that neither patients nor physicians expect to engage in a review of evidence in a routine visit (20). Studies on practice pattern variation\(^4\) in the USA show use of treatments based on provider-driven demand, not patient needs (21-23). An example of this unwarranted variation is that knee surgeries are consistently performed more often in some US states than in others despite similar demand (24). Therefore, some surgeries are unnecessarily performed, and may even be counter to patients' preferences or values. This is an example of how our paternalistic health care system exerts its power over reason, respect, and logic in order to serve its own needs rather than those of patients (25).

The overuse, underuse, and misuse of medical resources are a systemic problem that originates in the provider-patient encounter. With respect to decision making in this encounter, consumer health surveys found that less than 10% of respondents believed that the decision-making responsibility belongs solely to health care providers - but the evidence says that providers are the primary decision makers. It was also found that offering treatment alternatives rarely occurs in the consultations alongside discussion of harms and benefits of alternatives and patient uncertainties (26-28).\(^5\) In addition, a survey of patients, in six countries, found Canada ranked last in the proportion of patients that report treatment risks were clearly explained in the consultation (4). This proves that even the most basic form of patient engagement – that of informed consent – is not even well supported in patient encounters in the Canadian health care system. Finally, this has also resulted in greater patient dissatisfaction with consultations (8). The Health Quality Council’s Patient Experience Survey provides empirical evidence of a deficit of patient-centredness in Saskatchewan’s health care; Saskatchewan’s acute care patients reported lower scores for the patient-centredness of their hospital experience than did patients in American hospitals\(^6\) (29).

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\(^2\) Decision quality is the extent to which their decisions are based on the best evidence available and reflect patient preferences (6).

\(^3\) Informed choice is the practice of providing information about treatment alternatives to patients so that decisions include patient preferences and values (12). On the other hand, informed choice is part of a movement in health care known as practicing evidence-based medicine (EBM). EBM is aimed at helping health care professionals to make the best health care-related decisions based on the best evidence available (61).

\(^4\) Practice pattern variation measures the uneven distribution of health care resources (7).

\(^5\) Study found that discussion of alternatives occurred in 5.5-29.5% of interactions, pros and cons were discussed in 2.3-26.3%, and uncertainties associated with the decision in only 1.1-16.6% of consultations. Last, physicians rarely reported whether the patients understood decisions. This occurred in merely 0.9-6.9% of consultations in the study (55).

\(^6\) Two of the primary indicators for measuring patient-centredness were communication with physicians and nurses (56).
Nonetheless, the potential benefits associated with increasing the level of patient engagement could help reverse these effects.

1.5: The Benefits of Patient Engagement

Patient engagement means involving the patients in their own care as an informed consumer of health care services. In fact it is now regarded as a feature of high-quality health care (30). There are numerous benefits associated with implementing it in clinical care.

A study on the impact of patient-centredness on health outcomes found that patients’ perceptions of receiving more patient-centred care were associated with better recovery and emotional health (28). Furthermore, researchers also found a 50% reduction in the use of health care services (diagnostic testing and referrals) among patients receiving care perceived to be more patient-centred (28). Therefore, being engaged in their own treatment experiences not only improved patients’ health outcomes, but also reduces costs by aligning resource supply and demand (3,31,32). Further, better physician-patient communication (33), patient involvement, and empowerment to increase patient self-efficacy led to better adherence to treatment recommendations (34).

Patient engagement strategies are modeled similarly to chronic disease management initiatives (3), whereby the patients take on more responsibility for their health to make the most of health care system advances (35). It is based on the assumption that patients are more likely to benefit when physicians and patients share their perspectives with each other (3). Moreover, the demand for the expansion of this form of care, beyond chronic disease care, is growing as a result of increasing patient autonomy created through increased health information accessibility.

1.6: The Evolution of the Patient

In the paternalistic model, the patient is painted as a sick, powerless person who is fully dependent upon the expertise of the care providers in the health care system. This image is defined by the patient’s portrayal of the ‘sick role’ (36). The role of the patient is evolving from the powerless recipient of care into a health care consumer. (Figure 1)(30,37).

The difference between the traditional patient and the empowered consumer is that a consumer has authority and a voice in choosing the health care services that they use (12). This evolution is occurring because of information technology advances such as the internet. Presently, the internet serves as a health education tool embedded and relied upon in Western society. Moreover, the result of this increased access to information is that there is an increasing demand by patients for more decision-making authority with respect to their health care (1,11). This growing demand is essential for change to occur.

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The ‘sick role’ defines the patient in the paternalistic health care model. Specifically, patients are excused from normal activities, but have the obligation to get well by complying with medical treatment. It is primarily a passive and dependent role whereby the patient concedes their power to the physician (12, 62).
On the whole, we know that patient engagement is key to better health outcomes, optimal resource utilization, and overall improvement in health care quality. However, because of the way the system is currently designed, patients are not engaged in their care, are minimally informed about their treatment choices, and have limited decision-making authority. These are the results of a poorly designed system.
PART II: Shared Decision Making

2.1: Introduction to Shared Decision Making

One way to address the lack of patient-centredness in our health care system is to engage patients in their own care. One method for doing this is called shared decision making (SDM). By definition, SDM is “the collaboration between patients and caregivers to come to an agreement about a health care decision” (38). It is a two-way information exchange and deliberation process whereby a decision is made jointly by the patient and their health care provider. Finally, it is primarily used when a difficult health care decision must be made in situations where there is no single best treatment approach (1,26).

On a ‘patient engagement continuum’ SDM sits at the midpoint between the traditionally paternalistic model and informed patient choice. Informed patient choice occurs when the patient is educated about their health issue and subsequently becomes the sole decision-maker (36). This continuum is depicted in Figure 2, and the differences between each model are displayed in Table 1.

As previously discussed, the paternalistic model of decision-making is predominant in health care today. This is the result of an over-dependence on the system for complete care (31) which minimizes patient autonomy and allows the lack of patient-centredness to remain as an acceptable standard in care. However, adopting an SDM model will help to reverse the current negative impacts of a paternalistic model because it will aid in decreasing the knowledge gap between health care providers and patients by increasing patient knowledge and enhancing their sense of autonomy in treatment decisions that affect their well-being (34,36). Thus, SDM serves as an excellent platform from which to redefine both provider and patient roles so that both learn to practice, participate in, and expect more dialogue-centred care from the health care system (34).

SDM supports the ideal of patient-centred care because it balances the scientific knowledge of the health care provider with patient preferences and values in decision making (36). Its overarching goal is to provide health care that increases the chances of a valued health outcome for the patient (39). Hence, the idea is to create an informed patient who has authority in determining which treatment option is the most appropriate (40). Therefore, if the patient is involved in a two-way information exchange process, where decisions are based on a combination of the best scientific data available and patient values, then we can simultaneously meet patient-specific needs and provide higher quality health care.
### Table 1: Patient Engagement Models (26)

<table>
<thead>
<tr>
<th>Model</th>
<th>Informed Patient Choice</th>
<th>Shared Decision Making</th>
<th>Paternalistic</th>
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<tbody>
<tr>
<td>Information Exchange</td>
<td>One-way information exchange: medical information is passed from the health care provider to the patient.</td>
<td>Two-way information exchange: the health care provider provides the medical information, while the patient provides information about their preferences and expectations. The roles in the decision-making process are defined.</td>
<td>One-way information exchange: medical information is passed from the health care provider to the patient.</td>
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<tr>
<td>Deliberation</td>
<td>Patient alone</td>
<td>Health care provider and the patient together.</td>
<td>Health care provider alone with limited or no input from the patient.</td>
</tr>
<tr>
<td>Decision</td>
<td>Patient makes final treatment choice</td>
<td>Health care provider and the patient agree together on a treatment choice.</td>
<td>Health care provider makes the final treatment choice.</td>
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#### 2.2: The Basic Principles of Shared Decision Making

In order for SDM to occur, four necessary characteristics of decision-making must be present (26):

1. Both health care provider and patient are involved in the treatment decision-making process.
2. Both provider and patient share information with each other.
3. Both provider and patient participate in the decision-making process by expressing treatment preferences.
4. Both the provider and patient agree on the treatment to implement.

Furthermore, these characteristics remain consistent throughout the three stages of SDM (8):

1. Information exchange;
2. Deliberation; and
3. Decision.

During the *information exchange*, the physician-patient relationship is established (8). A defining part of this stage is that the patient establishes her preferences for the amount of information she wants and defines her role in the decision-making process (8). Subsequently, scientific information about the benefits, harms, and uncertainties of the different treatment alternatives are provided to the patient (1,8,41,42). This portion of information exchange is referred to as *risk communication*. One of the most important aspects of this step is that information sharing is based on evidence-based knowledge (part of EBM) (43). The non-scientific aspect of the information exchange component is the patient’s personal information exchange. This information has three
Shared decision making is best used when:

1. There are significant differences in possible treatment outcomes.
2. There are significant differences in the treatments based on the likelihood and impact of potential complications from the treatments.
3. The choices have trade-offs between short and long-term health outcomes and impacts.
4. One or more choices have the risk of mortality.
5. The different choices result in similar health outcomes.
6. Then the patient is adverse to risk taking.
7. A patient has an attachment to specific outcomes.

### Table 2: Situations for Shared Decision Making (66)

<table>
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<tr>
<th>Shared decision making is best used when:</th>
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Specifically, there are seven circumstances in which SDM should be used (see Table 2) (50). Two of the important situations to highlight (because they commonly occur) are when treatment options produce the same results (45) and when there is not enough evidence-based data to support one best treatment (45). In both of these situations there is no single best alternative to choose, so the decision will rely heavily on the patients' values and preferences. Additionally, these two circumstances are perfect examples of where provider-driven demand can be prevented through supporting patient-determined treatment necessity.

2.4: How Do We Practice Shared Decision Making?

There are three interrelated components that work together in order for SDM to successfully occur (see Figure 3):

1. Decision support;
2. Decision aids; and
3. SDM education and training.

2.4.1: Decision Support

Decision support is a means of engaging patients so they have realistic expectations when choosing a treatment option (45). It is provided using two different methods: decision counseling and decision aids. Generally, decision aids are provided to patients who need to make a treatment choice; in some cases, however, patients will require more help than what their health care provider and decision aid can provide. Just as individual disease states and risk profiles differ from one another, so do people's confidence and skills in their ability to participate in their care (13,51). In these instances, a patient would be referred to a health coach who is trained to help patients who are having difficulties with the decision-making process.

The health coach's role is to support the patient in being involved in their health care decisions; they do not make the final treatment decision for the patient (52). Health coaches are considered a ‘facilitator’ of decision-making skills in that they help by teaching the patients the skills they require to improve their confidence in making health care-related judgments based on their own preferences (53). Health coaches do this by helping the patient understand the decision aid material in a way that makes sense to them, and also help the patient to clarify their values so that they can contribute meaningfully in the consultation (13,51-53). Their role not only includes supporting individual patient needs in understanding treatment options and decision-making skills, but they also monitor the patients' progress in decision-making as well (51).

Decision support is part of the multidisciplinary approach to care which has also been a strategy shown to improve patient health outcomes (54). The role of the health coach is versatile and it fits
in with the multidisciplinary approach because of the various professionals that can fulfill this role. Typically, health coaches are trained nurses, but other health professionals also make excellent health coaches as well (e.g., social workers, psychologists and genetic counselors) (4,13,52,55). Additionally, the versatility of this role also extends past onsite health coaches as well (although onsite health coaches are the most effective (56)) because decision support can also be offered over the phone and internet as well (13). This is particularly important for non-local patients who require increased decision support.

2.4.2: Decision Aids

As previously mentioned, decision aids are risk communication tools used to help patients become informed and active participants in decision making (45). Decision aids help increase the quality of decisions patients make about medical treatments and choices by informing and empowering them (47).

Decision aids provide unbiased, balanced, and complete information about specific health issues and their associated treatment options and outcomes using the most current data (45). Additionally, the information in the decision aid is relevant to the patient’s specific disease and risk profile which makes it easier for patients to relate to (44). Last, decision aids are unlike typical health education materials since they focus on treatment options and outcomes with the explicit purpose of preparing the patient for decision-making (46).

Typically, decision aids are provided to patients after they receive their diagnosis so that they can participate in decisions about ‘next steps’ for treatment – especially if the treatment choices are preference-sensitive. It is important to note that decision aids do not replace the health care provider consultation; rather, they are complementary to it (44).

One of the most pragmatic aspects of using decision aids is that they can be paired with patient preference reports. These reports are typically completed after the patient has gone through the decision aid. By this time the patient should understand their health issue and the risks associated with its treatment choices as well. More specifically, the report allows the patient to record their knowledge about their health problem, what their values are, and also their decision status. An example of this report is the Ottawa Decision Support Guide (see Appendix A). This information, along with the patient’s clinical data, is then provided to the health care provider. Together, this information serves as a feed-forward tool for the patient’s follow-up consultation. Therefore, the consultation time can be used more effectively because the dialogue between the provider and the patient is tailored specifically to the patient’s needs (55,56). Decision aids become a valuable tool in the consultation because it helps focus the consultation on the issues that matter most to the patient.

Unlike the majority of health information available on the internet, decision aids undergo a significant amount of quality control in their development. The International Patient Decision Aid Standards Collaboration (IPDAS) has created a list of requirements that decision aids must adhere to in order to become available for public use (47,48). These standards were developed through countless systematic reviews of decision aids in clinical research. This research has identified what information is most effective for knowledge transfer (57). As a result of this research, high-quality treatment information is available in numerous formats so that patients can use the learning method that best suits them. On the whole, decision aids are reliable, high-quality tools that are essential for successful shared decision making to occur.
2.4.3: Educating Health Care Providers

In order for SDM to be successful, both health care providers and patients should be trained and skilled in its application (40,46,47,58). It is important that both parties are educated because the provider and patient bring different, but equally important, information to the partnership. As previously mentioned, the provider is considered the scientific content expert, while the patient is the expert on their own personal values and well-being (21,59). In order for this partnership to work, there needs to be a balance between both of these knowledge bases and perspectives (36). Because patients receive most of their information from providers and decision aids, it is particularly important to focus on health care provider education and training.

For physicians, there are numerous resources available to help develop their SDM communication competencies. Studies have shown that patient engagement is limited when physicians are not trained in the specific communication skills required for sharing decisions with their patients (27,60). These competencies are not currently taught in medical school, since most medical school education still follows a paternalistic model of medical decision making (9,15). Ideally, these competencies would be taught upstream, starting within medical education (15). The shared decision-making competencies physicians require are listed in Table 3. It’s not just physicians who need training; any other team members taking on the role of health coach must also be specifically trained. A study showed that nurses who were trained with SDM skills demonstrated statistically significant improvements in their knowledge and provided better quality decision support than untrained nurses (61). SDM requires providers be trained to apply the most effective communication skills.

Training for providers should include four key components (52):

1. The Ottawa Decision Support Tutorial.
2. A skill building workshop.
3. Protocols or decision aids to guide the coaching process.

Generally these strategies are implemented in the order they are listed. First, the Ottawa Decision Support Tutorial can be found online (62) and is designed to introduce SDM to health care providers (51). Next a workshop for providers is arranged. This workshop affords providers the opportunity to practice their SDM skills in a clinical setting. Third, an overview of decision aids, how they work and how to use them in a clinical setting is done. Last, the Decision Support Analysis Tool (62) is used to collect feedback on how well professionals engage patients in SDM. Each
component addresses a different aspect of SDM, all of which are essential to its successful application.

2.5: Why Choose Shared Decision Making As A Strategy to Increase Patient Engagement?

Although the concept of SDM is relatively new to both research and practice, there is a growing body of evidence that it offers numerous benefits for patients, health care providers, and the system itself.

2.5.1: Patient Impacts

Overall, SDM has been shown to improve patient decision-making outcomes. Studies have consistently shown that the number of patients who are uncertain about their health care decisions is reduced after being introduced to decision aids (44,47). SDM helps to clarify the modifiable factors in decision-making that often contribute to decisional conflict. Decisional conflict is uncertainty about what course of action to take when there isn’t one best choice (62). It arises from difficulty with choice or the modifiable factors related to choice (63). The modifiable factors involved in decision-making are: knowledge, support, unclear values, expectations, and psychological factors such as anxiety (39,42,46,51). These are the factors that decision aids are designed to address. In general, patients with lower decisional conflict are less likely to delay making their treatment decisions, be dissatisfied with their decision, or regret their choice (51).

In comparison to standard care (which does not include SDM), SDM is better at:

- Improving patient knowledge and information recall (13,46,49,64)\(^8\);
- Creating realistic expectations about the benefits and harms of treatment options (8,46)\(^9\);
- Reducing decisional conflict (42,49);
- Stimulating patients to take a more active role in decision making without increasing their anxiety (44,64); and,
- Increasing overall patient engagement and empowerment (51).

Of all these benefits, the largest and most consistent benefit of SDM over standard care is increased knowledge of treatment options (46). The strong evidence of this impact proves that SDM is helpful to balance the knowledge asymmetry that currently exists in the system. Another significant benefit is that SDM helps patients make clear, high-quality decisions that reflect the best available scientific evidence and their personal preferences (46).

Many studies have been conducted to evaluate the quality of decision making. They have shown that SDM leads to high-quality decisions by ensuring patients have realistic expectations regarding the benefits and harms of treatment choices (8,46). Researchers have had a hard time assessing SDM’s impact on patient satisfaction with their treatment results (46). Nonetheless, there is ongoing research in this specific area.

The benefits to patients alone are reason enough to implement SDM. But, there are other benefits for providers and to the system; which we present in the following sections.

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\(^8\) One study measured a 19% absolute increase in knowledge (19)
\(^9\) A 40% relative improvement in realistic expectations about treatments (19)
2.5.2: Health Care Provider Impacts

The benefits SDM has for health care providers, specifically physicians, have also been demonstrated through research. For the most part, physicians find SDM to be a useful strategy with pragmatic implications.

When SDM is practiced in the appropriate situations, physicians find that it helps them to provide:

- Relevant clinical information about treatment options and outcomes (65);
- A structured approach to reviewing options and outcomes (65);
- Higher levels of patient involvement (66);
- Increased agreement with patients (66); and,
- Increased patient satisfaction with consultations (66).

Surgeons have specifically stated that they like the feed-forward patient preference report component of SDM (55). When participating in SDM they find that the patient is better prepared for the consultation and that they themselves are also more prepared (56). Overall, when a physician is more aware of a patient’s knowledge and decision status before the consultation, the discussion can be more patient-centred and productive because it can be tailored the patient’s specific needs (55).

SDM equips patients and physicians with knowledge and skills required to make better use of time spent in consultations. This benefit at the micro and meso level has ripple effects that increase efficiency at the macro system level.

2.5.3: Systemic Impacts

Studies have found that when patients are given the choice, they sometimes make a different choice than the one that is recommended to them. For example, when provided with treatment choices, patients commonly choose less invasive procedures than the elective surgeries recommended by their provider – some of which are medically unnecessary (21). In fact, research has found that, when patients who are referred for surgery are given a treatment choice and provided with a decision aid, elective surgery rates decline between 21% and 44% (25,39,40,48,53,67). These patients are receiving the care that they value while still getting the care that they need. The results also demonstrate a direct method of minimizing practice pattern variation (47), while decreasing surgical costs and appropriately aligning the supply and demand of resources.

Research to date has clearly demonstrated that SDM is effective for creating informed patients who are active in their health care decisions (40). Studies also demonstrate that both parties are more comfortable with their decisions and their redefined roles when they participate in SDM.

10 A Cochrane systematic review found a 23% decrease in elective surgery decisions for patients opting for less invasive procedures. This study also found no adverse effects on patient health outcomes, satisfaction or anxiety (13, 28).
11 Another study found a 20% reduction in surgery opting for more conservative treatments (29).
12 Specific to 7 surgical procedures (including hip, knee, spine and prostate) found a 21-44% decline in surgery (30)
13 30-35% of individuals with a back condition will choose physical therapy or a less costly, or invasive procedure than surgery (31).
14 Decrease of surgical treatments by 25% (32).
While the evidence shows many benefits to moving from a paternalistic model to a SDM model, there are still barriers that need to be addressed.

2.6: Barriers to Implementing Shared Decision Making

In order to successfully implement SDM strategies, it is essential to address the barriers currently preventing its system-wide adoption. These barriers fall into three main categories: Patient Barriers, Health Care Provider Barriers, and Systemic Barriers.

2.6.1: Patient Barriers

Just as there are challenges to public engagement, continuing advances in getting patients to actively participate in their own care is challenging as well. Many patients are accustomed to the paternalistic model and still choose to be minimally involved in their care. However, with the technology and information, more and more patients want to be more engaged in their health care (1,11).

Patients should be given the opportunities to participate in decisions at whatever level they feel most comfortable with (11,68). This should be determined during the information exchange stage of SDM. By matching a patient's desired level of participation to her level of readiness to participate, the health care provider is practising patient-centred care. Rather than supply a standard consultation technique, the provider is tailoring the consultation to match the patient's needs (14,23). This includes accepting that a patient electing not to be the decision-maker is still a valid choice in SDM (36).

Despite the notions that certain patient demographics are more likely to participate in their care, this is not always true. For example, it has been hypothesized that younger patients with more education and of higher socioeconomic status are more likely to participate in their care (69). However, research shows that when faced with a difficult health care decision, people of all demographic categories face the same struggles associated with decision making (56). Therefore, physicians should not label some patients as decision makers and other patients as non-decision makers. Patient and physician must establish their roles during information exchanges.

Another significant patient barrier health care professionals must deal with is that some patients won’t choose the recommended treatments (3,23,69). This can present a liability issue for health care providers. However, practising SDM should be based on a documented agreement between the patient and the practitioner implemented as part of the patient preference report (56).

2.6.2: Health Care Provider Barriers

Of the three categories of barriers, those related to health care providers are the most numerous. This section focuses on physicians because most research has been based on the providers group. However, many of these barriers apply to other health provider roles that are also associated with practising SDM.

Research on physicians’ thoughts and perceptions of SDM have identified the following barriers to implementation:

- There is not enough time for SDM in the consultation (8,11,41,42,60,70,71);
• Physicians do not have the SDM competences (11,37);
• Personalizing information to individual patient characteristics is not feasible (41,70,71);
• Lack of applicability based on clinical situation (i.e. trauma situations) (70,71);
• Requires knowledge of other legitimate choices and access to technical information about the harms and benefits of treatment choices (72); and,
• Continuity of care issues (since patients often see other health professionals as well) (8).

Physicians see time as the largest barrier to adopting SDM. However, there is no evidence that SDM requires more time than the standard consult (71). Furthermore, a Canadian trial demonstrated that patients prepared with decision aids before the consult spent the same amount of time with the physician as patients who were given a simple pamphlet instead. The only difference was in how the time was spent with the physician (39). In fact, with the decision aid, patients were more prepared to make decisions, agreed with the physician more often, had increased awareness of their values, and both parties were more satisfied with the patient's preparation for decision-making (48). SDM has little effect on the quantity of time spent in the consultation, but significantly improves the quality of the time spent.

Physicians tend to be good at offering patients choices, but often have trouble asking about the patient's preferences for information and their decision-making role (27). Although it is difficult to change established practice patterns (60), providers and patients will benefit if they overcome this barrier. All of the barriers associated with health care providers can be overcome with more education about SDM, its benefits, and how to do it properly.

Although there are patient and physician barriers associated with implementing SDM, many are the result of barriers in the system. These barriers are the cornerstone for system-wide quality improvement and must therefore be addressed as well.

2.6.3: Systemic Barriers

There are three systemic barriers that impact system-wide adoption of SDM:

• No specific funding to support SDM (11);
• Delivery system is intimidating to patients because of its primary focus on biomedical issues and less focus on psychosocial issues (3,9); and,
• Practice guidelines and policies do not reflect a SDM environment.

Simply put, a system that provides no motivation, knowledge, or guidelines for change, will not improve. These barriers are the same barriers that hinder public engagement from being adopted. The current absence of financial incentives in the fee-for-service model does not support the specific aspects of SDM (e.g., health coaches). Reimbursement should be based on the quality of care, not the quantity. Second, as previously discussed, the knowledge gap between health care providers and patients intimidates patients from participating in their care. Lastly, there are no standard guidelines available at national, provincial, or regional levels for those who want to improve quality of care through SDM. The absence of supporting policies and structures required for system-wide adoption of SDM seriously inhibit implementation.

Despite the current lack of systemic support for and knowledge about SDM, there have been some advances in the past couple of years toward more widespread adoption of this new
approach. For example, new policies developed by the Registered Nurses Association of Ontario on managing chronic kidney disease outline a role for nurses in SDM (73). As well, frameworks for physician core competencies adopted by the Royal College of Physicians and Surgeons of Canada and family medicine in Canada outline competencies required for SDM (4). The groundwork for implementation of SDM is being laid down.

In the US, the state of Washington passed legislation in 2007 that recognized SDM as a high standard of informed consent (67). A demonstration project is now underway in Washington involving Group Health – a consumer-driven health care system (74).

2.7: Facilitating the Implementation of Shared Decision Making

The research literature identifies three facilitators for SDM (70,71):

1. Provider motivation;
2. Positive impact on clinical processes; and,
3. Positive impact on patient outcomes.

All three were cited as facilitators by health care providers in research studies that asked them what would help SDM implementation (70,71). Decision makers should take advantage of these facilitators and combine them with other strategies to increase stakeholder buy-in for adopting SDM. Currently, the supporting research is available, the number of best practices to follow is growing, and most importantly, the opportunity in Saskatchewan is also growing.

PART III: Shared Decision Making in Saskatchewan

3.1 : Opportunity

It is important to consider both timing and context when increasing awareness about quality improvement strategies (12). In other words, change is best promoted during ‘teachable moments.’ Saskatchewan is currently well positioned to promote SDM as a quality improvement strategy in light of three individual projects that have created a strong political platform for change: The Ministry of Health’s (MoH) Strategic and Operational Directions; the Patient First Review; and a preliminary needs assessment conducted in summer 2009 by the Health Quality Council (HQC).

Firstly, Saskatchewan’s Ministry of Health released its Strategic and Operational Directions for the Health Sector 2009-10 (75) this year; it highlights SDM as a strategic goal in the current fiscal year. Goal 1.2 in the report states that, “People have timely access to evidence-based and quality health services and supports” (75 p. 5). The strategy to achieve this goal suggests implementing “SDM methods and approaches to inform and engage patients in decisions about elective surgery” (75 p. 5). Specifically, care pathways being targeted are those for hip, knee, spine, and prostate treatment decisions. The Ministry of Health’s strategy is already on the right track, as research shows it is easier to introduce SDM in specific care pathways for invasive and costly medical interventions (40).

Secondly, the province will publically release its Patient First Review in Fall 2009. This review will report on how Saskatchewan residents feel about the way health care services are delivered in the province (76). The release of this report is anticipated to spark conversations about
implementing more patient engagement strategies within the province as a means of increasing patient satisfaction and improving the overall quality of care.

Finally, HQC conducted a basic needs assessment in the summer of 2009, to gauge the level of support among the province’s Regional Health Authorities (RHA) for implementing SDM, and determine the extent to which it is being used in RHAs. In total, 11 of the 13 RHAs participated in this assessment; respondents included senior managers and physician leaders. The assessment found that although there is considerable interest in implementing SDM, there are no specific instances where it is being used, and RHAs are unsure of how to implement SDM into their care pathways. Nonetheless, it was commonly recognized that patients do want to be more engaged in their care, and that it is essential for the system to respond to consumer demand. For more information regarding the results of the needs assessment, refer to Appendix B.

Saskatchewan has an excellent opportunity to implement SDM. Some of the leading SDM researchers have mentioned that Saskatchewan is the perfect Canadian province to start implementing SDM as a provincial strategy because of its size, historic role in health care, and its current role as a leader in health care improvement (55). However, stakeholders and strategies must work together to develop a coordinated strategy for applying SDM in this province (see Appendix C for a basic stakeholders list).

3.2: What is the Best Way to Implement Shared Decision Making?

One of the leading sources of SDM research and information is the Ottawa Hospital Research Institute’s (OHRI) decision support Implementation Toolkit (77). This toolkit lists five essential steps for implementation in clinical practice of SDM (77):

1. Assessment;
2. Decision Support Tools;
3. Education and Training;
4. Implementation; and,

The following sections provide a brief outline of each step, followed by ideas for implementing SDM in Saskatchewan with hip, knee, spine, and prostate elective surgery. The last section of this report highlights best practice examples of how SDM is being successfully applied elsewhere to these four care pathways.

3.2.1: Step One: Assessment

This step involves assessing both the patients’ and health care providers’ information and decision-making needs, and their concerns with respect to SDM (77). Hence, this step is primarily about conducting background research and needs assessments to gather information necessary to develop a strategy for implementing SDM. Specifically, this information could help planners decide where SDM best fits into different care pathways (40,77). In fact, some of the most important information will come from stakeholder concerns, which can then be used to develop strategies for overcoming barriers to implementation (55,77). Without conducting a thorough assessment, the odds of achieving successful implementation are minimal.
**Assessment in Saskatchewan:**

Within the four surgical pathways currently being targeted, there are numerous stakeholders that would need to be involved in pre-implementation assessment (refer to Appendix C). It is also important to identify the specific settings where assessment should occur. The new multidisciplinary pre-assessment clinics for orthopaedic surgery are a great example where we could incorporate this assessment step into work already underway in the province. These clinics are ideal for assessment because, as they develop new care pathways, SDM can be implemented into them as well. Furthermore, health coach training in a multidisciplinary clinic is also ideal, and there is significant opportunity to have an onsite health coach available. These ideas should be included in the initial assessment for potential SDM implementation strategies.

An example of a hip and knee care pathway that has adopted SDM can be seen in Appendix D.

### 3.2.2: Step Two: Decision Support Tools

Decision support tools, such as decision aids, are fundamental to the practice of SDM, because patients must be informed about their choices in order to make high-quality decisions. Therefore, this step focuses on choosing the decision support tools that will meet the specific needs of the targeted care pathways (77). Both health care providers and patients determine appropriateness of decision aids whereby they typically evaluate several decision aids that are related to their specific health decision. They then rate their preferred decision aids using the IPDAS decision aid criteria. The costs associated with producing and using decision aids must also be factored into your implementation strategy.

**Decision Support Tools in Saskatchewan:**

Saskatchewan has access to over 130 different decision aids through the province’s HealthLine Online program (78). The decision aids became available through the province’s collaboration with Healthwise – a leading decision aid developer in the US (79). As a start, the decision aids available online could be provided for assessment using the IPDAS decision aid criteria. The evaluators would consist of patients eligible for these surgical interventions, and the health care providers involved in these specific care pathways. Furthermore, if these decision aids do not meet the needs of the patients or providers, there are more decision aids available from other decision aid libraries such as OHRI’s A to Z decision aid index (62), the Cochrane Collaboration (80), and the Foundation for Informed Medical Decision Making (FIMDM) (81). However, decision aids from these other sources may have a cost associated with use. More information about these resources can be found in Appendix E.

### 3.2.3: Step Three: Education and Training

As previously mentioned (Section 2.4.3), educating and training health care providers involved in the specific care pathways is essential. The third key step in implementation involves giving providers opportunity to enhance their decision support skills (38,66). Research shows providers demonstrate greater involvement with patients in treatment decision making after they participate in skill development workshops.
Education and Training in Saskatchewan:

Health care providers working at the multidisciplinary clinics currently being established in the province, could fulfill the role of health coach where needed. For example, nurses could be trained as health coaches, and would fulfill this role when a patient requires further decision support.

Besides having an on-site specialist (which would only be accessible to local patients), another option would be to train the nurses who staff the province’s HealthLine call centre. Currently Health Dialog in the US is successfully providing 24/7 health coaching over both the internet and the phone (Appendix E) (82). The HealthLine nurses could be trained specifically in hip, knee, spine, and prostate treatment decision support as part of a pilot study aligned with the care pathways being targeted in Saskatchewan.

If Saskatchewan’s health care system wants to implement SDM as a province and system-wide strategy, it will be important to work closely with the Saskatchewan Medical Association (SMA) and with the College of Medicine at the University of Saskatchewan, to have SDM training incorporated in their medical school curriculum.

3.2.4: Step Four: Implementation

After all the background research has been completed and stakeholders have agreed upon a strategy for integrating SDM into the care pathways, implementation can take place. This should most likely first occur in a pilot study at a small number of sites in the targeted care pathways. However, in order for SDM to succeed, the care pathway must first be efficiently working. SDM is an improvement strategy that is incorporated into an already efficient care pathway, it is not a method for fixing a pathway (55).

There are three models; serial, group, and specialist (52). In the serial model, the patient receives decision support as they pass from one health care provider to another (52). For example, a patient considering knee surgery sees a GP for referral, and an advanced physiotherapist and a nurse to assess whether she is eligible for surgery. At each of these stages, the patient would receive decision support from each of the different providers. The group model involves a multidisciplinary team conference that includes the patient, where the treatment decision is made and decision support is provided (52). With the specialist model, a member of the team who received the necessary training fills the role of health coach (52). Most of the research evidence recommends this model (56).

It is also important to incorporate patient preference and summary reports in the care pathway as well. These reports may require supporting IT or efficiency pathways, therefore, it is important to plan for this as part of the implementation strategy.
Implementation in Saskatchewan:
It is best to have an onsite health coach available in conjunction with decision aids (56). In the multidisciplinary clinics the specialist model would have a trained health coach available onsite. Decision aids would also have to be available for patients onsite via internet or hardcopy.

However, because of the number of patients in rural areas, another implementation model for province-wide decision support accessibility would have to be considered. For example, training the HealthLine nurses to provide health coaching to patients living in rural and remote communities could increase accessibility.

3.2.5 : Step Five: Quality Monitoring Tools

This step involves using measurement and analysis tools to monitor and guide the specific aspects of SDM and quality decisions (77). A list of these resources (e.g., the Decision Support Analysis Tool) can be found on the OHRI website (62).

Quality Monitoring Tools in Saskatchewan:
After a tool is selected, the monitoring itself can be done by researchers, staff, or the Ministry of Health, to ensure that SDM is producing the desired results.

3.3: Best Practice Examples

We highlight the following best practice examples of SDM because they are innovative and also focus on the same care pathways that Saskatchewan has targeted. Furthermore, all have been successful to date, and each of them has supporting research that demonstrates the effectiveness of SDM.

3.3.1: The Ottawa Hip and Knee Project

Some of the leading researchers in SDM are right here in Canada, working at the Ottawa Hospital Research Institute. Within OHRI there is a Health Decision Centre that specializes in research on patient decision aids. As such, OHRI offers a plethora of SDM resources, including a decision aid library, implementation toolkits and health coach education and training (55,56,62).

Much of the research conducted by OHRI has also been translated into practice. More specifically, researchers have been involved with a hip and knee surgery pilot project at an orthopaedic intake clinic in Ottawa that was implementing SDM using the OHRI Implementation Toolkit (56).

In their first step towards SDM, the clinic developed a more efficient care pathway that uses a standardized patient assessment to determine a patient’s eligibility for surgery (only 50% of patients qualify for surgery after this
assessments) (83). If the patient is deemed to be suitable for surgery, she is given a decision aid (DVD and booklet). Patients who used a decision aid were more likely to make a high-quality decision, have a higher knowledge score, and overall wait times remained the same (56,83).

Although wait times did not decrease, patients were better informed about their decisions, and therefore made higher quality decisions. As well, their time in the consultation was spent differently, since the surgeon was given a summary report outlining the patient’s self-reported symptoms, clinical assessment results, knowledge results, values information, and decisional status (the last three pieces of information can be collected from the Ottawa Decision Support Guide) (55,56).

Although Ottawa has yet to permanently implement SDM into their care pathway, their pilot study has yielded the evidence and physician support upon which to back full scale implementation (56). SDM is not yet a part of the standard care pathway, but research at this site has demonstrated the benefits of SDM.

3.3.2: Dartmouth-Hitchcock Medical Center’s Center for Shared Decision Making

DHMC’s Center for Shared Decision Making is the first independent decision support center of its kind. It is located within DHMC and offers one-on-one decision support counseling, decision aids, and a health care decision guide (38). The Center is funded by and affiliated with leading decision support organizations such as the Foundation for Informed Medical Decision Making, Health Dialog Inc, and the Ottawa Hospital Research Institute.

Patients are referred to the Center after receiving their medical diagnosis. At the Center, patients fill out an intake form which gives them access to a decision aid DVD. If after viewing the DVD the patient requires additional support, they can make a follow-up appointment for one-on-one decision support counseling that is also conducted at the Center.

Since opening in 2002, the Center has become increasingly popular among both patients and providers. In fact, the Center now loans out between 4,000-4,500 decision aids per year for numerous treatment decisions (84). Health care providers are finding this service so beneficial, that referral to the center has become a standard part of some care pathways. For example, the DHMC’s renowned and innovative Spine Center (85) requires that patients visit the Center for decisions regarding elective surgery to treat spinal stenosis, herniated discs, and chronic lower back pain (21,38). Not only does this help patients make high-quality decisions about risky (and costly) elective surgeries, but the education patients receive from the decision aids has also become the Spine Center’s higher standard for informed consent (84).

DHMC is also innovative in their research and technology. In their first major study, breast cancer patients filled out intake forms using electronic tablets before they met with the surgeon. In this way all data was electronic, which increased efficiency in producing summary reports for health
care providers. This process has been further enhanced through the creation of a ‘patient portal’, through which patients can fill out the intake form over the internet, and providers have the option of viewing the results online (84). Eventually patients may have their own personal log-in portal, and be able to fill the form online from their own homes and even stream decision aid videos over the internet (84). There are obvious benefits for Saskatchewan, where many residents live in more rural settings. DHMC recommends that the best way to deliver these forms is before the patient comes into the clinic, because it saves a lot of time and makes the process more efficient (84).

The Center’s website also provides a large amount of information about implementing SDM care pathway examples, and how to start a SDM centre too (38). More specifically, DHMC has developed seven steps for integrating decision support (86) into clinical care (see Appendix F).

3.3.3: The National Healthcare Service’s Urology Informed Decision Making Programme

From 2004 to 2005 the NHS launched a pilot project that tested the impact of implementing SDM in their care pathways for prostate cancer and benign prostatic hyperplasia (BPH) (87). This project was led by a Steering Group that developed clear project goals: to improve the quality of decision making, offer decision support, implement SDM within existing care pathways, and to involve the relevant care providers and professionals (88). The steering group consisted of urologists, oncologists, nurses, patients, and professional leaders who all developed a strong sense of ownership in this project (89).

The results of the pilot project found that the SDM process was helpful in supporting the overall decision-making process (87). Based on this success, the NHS is now planning a national roll-out of their Programme which will be launched in October 2009.

The project plan for this Programme is similar to the OHRI Implementation Toolkit’s five implementation steps (detailed in Appendix G). For example, they conducted an assessment of the situation, and involved all of their key stakeholders. They also had teams design their own decision aids that were more culturally appropriate than the American ones they had used in their pilot projects. In their national plan, each patient diagnosed with prostate cancer or BPH will receive a DVD, booklet, and a personal decision guide that was specifically designed by the NHS (88,89).

Although the NHS is not using trained health coaches, or mandatory patient preference forms, they have created other options, such as speaking to a nurse over the phone, and an optional personal decision guide that will help guide consultations when needed. Because they are not conducting provider-specific SDM training, they have also developed a DVD to teach health care providers about the basic principles of SDM, with particular emphasis on its benefits (88,89). These initiatives are important for system-wide roll-out, because they make the material accessible to all the stakeholders involved.
Their plan to roll out the program nationally is linked to their cancer networks (89). This partnership will help ensure that the decision support material and expertise are distributed appropriately and are aligned with other system goals. They have also adopted the NHS Institute for Innovation and Improvement’s Sustainability Model (90) to help ensure that their program’s goals are successfully translated from project to practice (see Appendix H). Overall, the NHS's Urology Informed Decision Making Programme has been a success, and is widely regarded as a leader in its field.

3.4: Shared Decision Making for Quality Improvement in Saskatchewan

SDM is a strategy for successfully engaging patients in their health care decisions. Many of its benefits have been shown to address many patient, health care provider, and system barriers. Despite the challenge in implementing SDM, the model leads to more informed choices, better use of medical resources, and a more efficient health care system; all characteristics of a high-quality health care system.

Saskatchewan is currently well positioned to introduce SDM in its health care system. Both the timing and the context are right, since the current focus is on improving the surgical care stream. Not only will SDM improve care pathways, but it will also help make the system more responsive to the needs and demands of its consumers.
Appendix A: Ottawa Decision Support Guide

Ottawa Personal Decision Guide

**Decision:** What decision do you face?
- When do you need to make a choice?
- How far along are you with making a choice?
  - not thought about options
  - thinking about options
  - close to making a choice
  - already made a choice
  - Are you leaning toward one option?
  - No
  - Yes, which one?

**Certainty:** Do you feel sure about the best choice for you?
- No
- Yes

**Knowledge:** Do you know which options are available to you?
- No
- Yes
Do you know both the benefits and risks of each option?
- No
- Yes

**Values:** Are you clear about which benefits and risks matter most to you?
- No
- Yes

A. In the balance scale below, list the options and main benefits and risks that you already know.
B. Underline the benefits and risks that you think are most likely to happen.
C. Use stars (*) to show how much each benefit / risk matters to you: 5 stars means 'a lot', 0 star means 'not at all'.

### Benefits (reasons to choose this option) vs. Risks (reasons to avoid this option)

<table>
<thead>
<tr>
<th>Option 1</th>
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<tbody>
<tr>
<td>Option 2</td>
<td></td>
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<tr>
<td>Option 3</td>
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</tbody>
</table>

**Support:** What role do you prefer in making your choice?
- I prefer to share the decision with:
  - I prefer to decide myself after hearing the views of:
  - I prefer that someone else decides. Who?
  - Do you have enough support and advice from others to make a choice?
  - Yes
  - No
  - Are you choosing without pressure from others?
  - Yes
  - No

<table>
<thead>
<tr>
<th>Who else is involved? (name)</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Which option does this person prefer?</td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Is this person pressuring you?</td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>How can this person support you?</td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
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**Next Steps:** This section suggests some next steps based on your needs. Check any items you would like to try.

**Knowledge (if you feel you do not have enough facts):**
- List your questions.
- Note where to find answers.
  - e.g. library, health professionals, councillors
- Find out about the chances of benefits and risks.

**Values (if you are not sure what matters most to you):**
- Review stars in the balance scale to see what matters to you.
- Find people who know what it's like to experience the benefits and risks.
- Talk to others who have made the decision.
- Read stories of what mattered most to others.
- Discuss with others what matters most to you.

**Support (if you feel you do not have enough support):**
- Discuss your options with a trusted person.
  - e.g. health professional, counsellor, family, friends
- Find out what help is on hand to support your choice.
  - e.g. funds, transport, childcare
- (if you feel pressure from others):
  - Focus on opinions of others who matter most.
  - Share your guide with others.
  - Ask others to complete this guide. Find areas of agreement. When facts disagree, agree to get more information. When you disagree on what matters most, respect the other's opinion. Take turns to listen and then mirror back what the other has said that matters most to them.
  - Find a neutral person to help you and others involved.

**Other plans**
- Describe
Appendix B: Needs Assessment Results from Interviews with the RHAs

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>RHA Responses</th>
<th>Summary Points</th>
</tr>
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| Are you interested in further research about SDM?       | All regional representatives asked this question responded ‘Yes’. The reasons they provided were:  
  - SDM will help increase patient self-determination;  
  - SDM as a need;  
  - Recognize that patient-centred care is important;  
  - It is highlighted in the Ministry of Health’s (MoH) Strategic and Operational Directions Plan;  
  - Believe that patients are starting to expect more dialogue-centred care; and,  
  - Will help increase transparency.  
  Although there was consensus that SDM is important, regional leaders also do not want to be bombarded with information. | All interviewed health regions are very interested in learning more about SDM and practicing it.  
  Know that it is important to deliver patient-centred care, but aren’t sure how to go about doing it.                                                                                                                                                                                                                                                   |
| Is there any organized effort implemented right now to increase SDM in the region? |  
  - No official program, but people are trying*  
  - Nursing staff is better at this type of care  
  - Nurse practitioners (NP) have more discussion with patients  
  - Informal discussions conducted by all staff members*  
  - Staff will be interested  
  - Important to focus on groups | Overall, there are no organized efforts specifically related to SDM.  
  Recognize that patients are important and want to be more engaged in their care.  
  More discussion is probably occurring with nurses and NPs rather than physicians.                                                                                                                                                                                                                                                                   |
outside of physicians
- Trying to do what the MoH is telling them to do (hip, knee, spine, and prostate)
- Some patient promotion
- Bedside rounds
- Ask, Talk, Listen learning and care themes are practiced

<table>
<thead>
<tr>
<th>Where do you see SDM initiatives occurring within your region?</th>
<th>All of these ideas relate to the four focus areas that the MoH wants to focus on (hip, knee, spine, and prostate).</th>
</tr>
</thead>
</table>
| | • Primary Care  
| | • All physicians  
| | • Create larger roles for NPs  
| | • With specific diseases  
| | • Chronic disease management  
| | • Critical Care  
| | • MoH's four focus areas |

| What does your staff think of it? | Biggest challenge will be physician buy-in.  
| | Patients need to know their rights and responsibilities.  
| | If SDM is to be implemented it needs to be in a clear and organized effort with specific disease focus to make transition easier. |
| | • Largest challenge will be getting physician buy-in because they need to see SDM's merits  
| | • In general it will be difficult to implement because there are disconnects between how things are supposed to be done versus how they are done  
| | • It will be difficult because patients don't understand their rights and responsibilities - Perceived as more work  
| | • Patients want more control in their health care but need to understand their boundaries  
| | • Worries about who is going to do it |
| How can HQC help? | • Provide brief, simple, specific information for physicians  
• Provide clarity  
• Provide information on best practices and how to successfully implement SDM  
• Provide contacts for best practice  
• Provide SDM to leading physicians so that they can explain the benefits to patients and other physicians (SMOs)  
• Need to personalize the SDM concepts  
• Brochures  
• Align with the provincial directions  
• Provide SDM templates, guidelines, scripts  
• Send document to senior management | Provide an information package that clarifies, explains and provides best practice information to physicians and senior administration in the health regions. Moreover, in order to make the document more applicable to current improvement strategies, align this document with the MoH's strategies. |
|---|---|---|
| What communication channels would be best? | • Workshops to get CME credits  
• Yearly education sessions for specific illnesses  
• RN, LPN newsletters and magazines  
• Pair with the Patient First Review and customer service messaging  
• Education centre for physicians (use regional reps to distribute the information) | Release with the Patient First Review and MOH strategies |
Despite thinking that SDM may be occurring to some extent in health regions, research suggests that self-reported SDM does not actually meet the official SDM requirements.

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<tr>
<th>Other ideas to consider:</th>
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<tbody>
<tr>
<td>• Everybody needs to be on the same page for this to work</td>
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<tr>
<td>• Athabasca and Keewatin Yatthé have high Aboriginal populations (need to consider cultural implications)</td>
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<td>• Athabasca deals mostly with primary care (need to think about region resource capacity)</td>
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<td>• Need to consider patient participation (patients need to know how to communicate with their physicians)</td>
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<td>• In some regions not all staff are permanent residents</td>
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<td>• Expanding principles from the Chronic Disease Management Collaborative</td>
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<td>• Fewer opportunities to interact with physicians as a group</td>
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<tr>
<td>• Need to consider ways in which to provide SDM to patients in regions where the services are not available onsite (i.e., orthopedic surgery is not available in every health region, but the patients still have the right to participate in SDM).</td>
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</tbody>
</table>
### Appendix C: Stakeholder Analysis for Four Focus Areas in Saskatchewan

<table>
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<tr>
<th>Stakeholder</th>
<th>Gain/Loss from SDM</th>
<th>Support/Oppose SDM</th>
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<tbody>
<tr>
<td>Physicians/Surgeons</td>
<td>Gain: more patient information and greater efficiency in consultations</td>
<td>Mixed – some physicians have found it useful and exciting, while others are not interested</td>
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<tr>
<td></td>
<td>Lose: some authority in the decision-making process</td>
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<tr>
<td>Medical schools</td>
<td>Gain: more patient-centred curriculum</td>
<td>Mixed – SDM will require increased training, specialized workshops</td>
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<tr>
<td></td>
<td>Lose: resistance from faculty who have to change their habits and their traditional means of teaching medical students</td>
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<tr>
<td>Nurses</td>
<td>Gain: more opportunities to interact with patients, greater patient-training, opportunity to be a leader</td>
<td>Support patient-centred care, but may fear disrupting the physician-patient relationship - need to know that SDM prepares patients for their consultations</td>
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<tr>
<td></td>
<td>Lose: a bit of clinical time because of increased patient counseling</td>
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<tr>
<td>Health Care Managers</td>
<td>Gain: more efficient and effective practice</td>
<td>N/A</td>
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<tr>
<td></td>
<td>Lose: expensive to get decision aids, run pilot studies, IT updates, train staff, requires new clinical pathways</td>
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<tr>
<td>Program Delivery Staff</td>
<td>Gain: more effective and efficient service delivery</td>
<td>N/A</td>
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<tr>
<td></td>
<td>Lose: requires increased training in SDM skills</td>
<td></td>
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<tr>
<td>Government – Ministry of Health</td>
<td>Gain: increased health care efficiency that reflects patient/public needs, greater public accountability, potential cost savings</td>
<td>View SDM as valuable</td>
</tr>
<tr>
<td></td>
<td>Lose: expensive to train staff and run pilot projects</td>
<td></td>
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<tr>
<td>Regional Health Authorities</td>
<td>Gain: increased health care efficiency in their regions, potential cost savings</td>
<td>Mixed: View SDM as valuable, but aren’t sure how or where to implement it.</td>
</tr>
<tr>
<td></td>
<td>Lose:</td>
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<tr>
<td>Patients/Public</td>
<td>Gain: more power and authority for the care they want and that is right for them, greater accountability from the health care system</td>
<td>Mixed because some people don’t want to be involved in their care. However, patients who are</td>
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<tr>
<td>Lose: will spend more time on their decisions than standard care, will require more of their time and effort</td>
<td>engaged in their care are more informed, make good decisions with respect to treatment, and have a better experience with the health care system.</td>
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Appendix D: Example of a Hip & Knee Care Pathway

Hip-Knee Shared Decision Making Project
Revised Workflow Map Showing Decision Support Integration
Appendix E: Key Shared Decision Making Resources

The Cochrane Collaboration (80)

The Cochrane Collaboration is a systematic review group that has dedicated a portion of their research towards decision aids. Specifically, they use several standards in order for a decision aid to be included in their A to Z decision aid inventory.

Dartmouth-Hitchcock Medical Center’s Center for Shared Decision Making (38)

DHMC’s Center for Shared Decision Making is a unique and innovative patient engagement strategy in that this service is an independent center located within DHMC in Lebanon, NH. It is funded and partnered with the Foundation for Informed Medical Decision Making, Health Dialog Inc., and OHRI. Together, they supply decision aids and decision support counseling to patients who need to make treatment decisions. Last, DHMC also shares its services and resources with specific clinical models at DHMC including its Spine Center (85).

Key contact: Kate Clay, Program Director, MA, RN (84)

Group Health Cooperative (74)

Group Health Cooperative is a non-profit, consumer-governed health care system located in the state of Washington, US. Group Health Cooperative is the system that is leading the way for Washington to implement SDM as part of the state’s standard care.

Health Dialog Inc. (82)

Primarily, Health Dialog’s objective is to find and research ways to improve the health care system in the US as a leading care management and analytical service. Furthermore, they are heavily invested in academic research related to practice pattern variation, decision aids, and shared decision making.

One of their largest services is providing 24/7 decision support to patients with a spectrum of different needs. They provide decision aid resources and health coaching via internet and telephone services.

Healthwise (79)

Healthwise is an organization that specializes in developing consumer information focused on helping them to make the best decisions that are right for them. Specific to SDM, Healthwise is a leader in developing ‘decision points’ that are used in the decision support portion of the care pathway.

Currently, Saskatchewan’s HealthLine Online has partnered with Healthwise. In this partnership Saskatchewan gained access to more than 130 different decision aids in their HealthLine Online inventory.

International Patient Decision Aid Standards Collaboration (IPDAS) (91)
IPDAS consists of an international group of researchers, practitioners, and stakeholders from around the world. Their objective is to develop standards criteria that can be used to judge the quality of patient decision aids. This is necessary to control the quality of the hundreds of decision aids that are currently available.

Leading this research collaborative group is leading researcher Dr. Annette O’Connor who coined the term ‘decision aid’. Dr. O’Connor is the leading researcher in patient decision aids and is located in Ottawa, Canada at Ottawa Hospital Research Institute.

The Foundation for Informed Medical Decision Making (81)

This is a non-profit organization specializing in developing research, policy, and clinical models that help to improve the quality of health care by helping patients become more involved in their health care decisions. They offer numerous decision support decision aids, including some of the latest decision aid technology such as streaming decision aid videos online. Furthermore, they also offer a plentiful resource selection for clinical model implementation strategies.

The National Healthcare Service’s Urology Informed Decision Making Programme (88)

In recent years the NHS has responded to increasing patient demand for higher quality care and timeliness of care. In order to help improve care pathways the NHS conducted pilot studies to see if SDM would help increase health care quality. Based on the success of the pilot studies a national roll-out of SDM in urology is now underway.

Key contact: Johanna Finn, Project Manager (89)

Ottawa Hospital Research Institute (OHRI) (62)

The OHRI Patient Decision Aids research is a world-renowned research institute. Currently, the most successful SDM clinical models come from these researchers, as well as some of the best research evidence supporting the use of decision support tools. Moreover, OHRI also supplies quality measurement tools, a decision aid library, numerous toolkits for implementation, and even a social networking strategy for SDM available on Facebook, called iShould.

Key contacts: Dr. Annette O’Connor, MScN, Ph.D, FCAHS (55) and Dawn Stacey, RN, Ph.D (56).

University of British Columbia Division of Health Care Communication: Informed Shared Decision Making (92)

This research division at UBC specializes particularly in SDM education strategies. Currently they run numerous workshops for both patients and providers (including medical students) about how to be more engaged in care via SDM. They have done extensive research in physician competencies for SDM, as well as working on the best strategies to teach physicians. However, they are also starting to work on ways in which to motivate health care providers to practice SDM.

Key contact: Dr. William Godolphin, Co-Director of Program, Professor Emeritus of Pathology, College of Health Discipline (15)
Appendix F: DHMC Seven Implementation Steps (38)

**STEP 1: IDENTIFY A CLINICAL CHAMPION:**
Successful re-engineering of processes of care requires advocacy by an enthusiastic insider, usually a physician.

**STEP 2: PERFORM A NEEDS ASSESSMENT:**
Systematically assess decision support needs and barriers with clinicians, staff, and patients using interviews and focus groups.

**STEP 3: MAP CURRENT CLINICAL WORKFLOW**
- Map current sequence of care.
- Begin with scheduling patients for clinical appointments.
- End with the step that currently closes the decision-making loop for patient and clinician, i.e., follow-up call, return appointment, etc.

**STEP 4: SPECIFY CLINICAL CARE AND DECISION SUPPORT OBJECTIVES**
- Is this clinical quality improvement, research, or both?
- Based on results of Needs Assessment and workflow mapping

**STEP 5: REVISE CLINICAL WORKFLOW MAPPING**
Based on steps 2, 3, and 4, modify current sequence of care map to reflect:
- data capture that addresses clinical care objectives
- decision support integration points and methods

**STEP 6: DESIGN DATA COLLECTION PROCESS** to meet clinical care objectives, based on steps 2, 3, and 4
- Identify decision aid(s).
- Select measurement tools that will add value to the clinical encounter.
  - Clinical: SF 36v2®, health history, co-morbidities, health habits, etc.
  - Decision Support: Decisional Conflict Scale, Preparation for Decision Making Scale, Decision Self-Efficacy Scale, Decisional Regret Scale, etc.

**STEP 7: DESIGN FEED FORWARD AND FEEDBACK REPORTS**
- Feed forward (display useful data in real time): individual patient report for clinician at the episode of care
- Feedback: individual patient report for clinician after episode of care and aggregate report for clinicians, administrative staff
### GROUP TASK

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<th>TASK DETAILS</th>
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<td><strong>MANAGEMENT/ADMINISTRATIVE ISSUES</strong></td>
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<td>Steering Group</td>
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<td>Budget</td>
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<td>Sustainability</td>
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<td>Communications</td>
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<td><strong>DECISION SUPPORT MATERIALS</strong></td>
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<td>General - all materials</td>
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<td><strong>PILOT SITE TRAINING EVENTS/WORKSHOPS</strong></td>
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<td><strong>Interim UK attachment for US patient videos</strong></td>
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<td><strong>Autotutorial</strong></td>
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<td><strong>Patient Information sheets</strong></td>
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<td><strong>Personal Decision Forms PDFs)</strong></td>
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Appendix H: NHS Institute for Innovation and Improvement’s Sustainability Model (90)
Appendix I: Glossary of Terms

**Decision Aids:** Tools used to help people become involved in decision making by providing information about treatment options and outcomes for a specific health issue, and also by helping to clarify patient values. They help to compliment counseling from the health care provider, not replace it (62).

**Decisional Conflict:** is uncertainty about what course of action to take when there isn’t one best choice available (63).

**Decision Support:** Informational and value clarification counseling provided to patients via decision aids and decision coaching from health coaches to help patients make realistic choices (45).

**Evidence-Based Medicine:** Movement aimed at helping health care providers make the best decisions based on the best and most current evidence available (34).

**Health Coach:** Typically a health care provider trained specifically in shared decision making competencies whose role is to support the patient in being involved in their health care decisions. The coach can help the patient understand health issue information as well as help the patient to clarify their values (52).

**Quality Decision:** The extent to which the choice best matches the informed patient’s values and preferences (48).

**Informed Choice:** Practice of providing information about treatment choices to patients so that decisions are based on a combination of the best evidence and patient values (36).

**Informed Patient Choice:** A form of patient engagement where the physician shares the scientific information with the patient, and then the patient becomes the sole decision-maker about their treatment choice (36).

**Patient-Centredness:** One dimension of quality health care that defines care as respectful and responsive to patient preferences, needs, and values and also ensures that patient values guide all clinical decisions (1,2).

**Preference-Sensitive Decisions:** Decisions that rely on the patient’s judgments of the associated harms and benefits of treatment choices because there is no single best treatment choice (47,48).

**Practice Pattern Variation:** The study of unwarranted variation in health care delivery as a means of studying health care quality with respect to clinical appropriateness, medical necessity and supply-sensitive care (24).

**Risk Communication:** Portion of shared decision making where information about the benefits, harms, and uncertainties about the treatment choices is shared with the patient (1,8,41,42).

**Shared Decision Making:** The collaboration between patients and their health care provider to come to an agreement about a health care decision. It is a two-way information exchange and deliberation process (38).
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