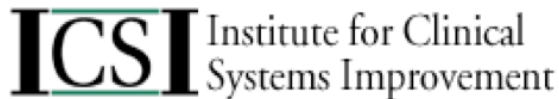# A Lexicon for Shared Decision-Making
(A Consensus Operational Definition)

A joint product of the Minnesota Shared Decision Making Collaborative (MSDMC), Institute for Clinical Systems Improvement (ICSI), and The University of Minnesota (UMN)

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The Minnesota Shared Decision Making Collaborative

ICSI Institute for Clinical Systems Improvement

UNIVERSITY OF MINNESOTA

"Shared decision-making operates under the premise that, armed with good information, consumers can and will participate in the medical decision-making process by asking informed questions and expressing personal values and opinions about their conditions and treatment options.

Although patients are more informed than they were 20 or 30 years ago, some express frustration and dissatisfaction because they do not feel they have adequate (if any) input into the decisions that clinicians are making about their health and their lives. . .

Patients often do not know enough about their treatment options to make informed decisions. . . they may not understand the [scientific] evidence base underlying the decisions being offered. . . Providers are not always supportive of patient involvement in the decision-making process. . . [or] are supportive of the concept but do not know how to make it happen. . .

Decisions. . . are often driven by physicians' preferences. . . rather than scientific evidence [and patient values and preferences]. The resulting variations in care across the country are tremendous and well-documented".

Excerpts from Agency for Health Care Research and Quality (2012)

https://www.cahps.ahrq.gov/Quality-Improvement/Improvement-Guide/Browse-Interventions/Communication/Shared-Decision-Making.aspx

C o n t e n t s

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Core group was drawn from the Steering Committee of the Minnesota Shared Decision Making Collaborative at the time of this work. Thanks to Jan Schuerman MBA of ICSI for project assistance during the later phases of this work.

B. Members of the Minnesota Shared Decision-Making Collaborative.

Thanks to the many members of the MSDMC Steering Committee who contributed suggestions along the way in the many meetings and conversations about this lexicon and its application.

In particular, thanks goes to Larry Morrissey MD (Chair of the Collaborative), Tom Marr MD, J. Daniel Nelson MD, Terry Corbin, and Leif Solberg MD for their detailed critiques.

Steering Committee members and their affiliations as of February 2012 are listed on page 14.

Aim, background, problem—Why create an operational definition for shared decision-making?

Aim: To hasten the widespread implementation and consistent understanding of shared decision-making among clinicians, purchasers, health plans and all the other people of Minnesota through the development and widespread use of a consensus-based operational definition of shared decision-making in practice.

Background: Hopes are high that SDM will improve patient-centeredness, patient experience, and clinical quality when implemented on a meaningful scale. But the field (and this includes patients) has little *widespread and agreed-upon* detailed functional definition to guide widespread implementation or performance measurement. Different, but entirely compatible, short definitions created by leading researchers, practitioners and system implementers are in place, but there remains confusion or ambiguity across clinicians, care systems, policymakers and patients as to just what shared decision making needs to look like in practice.

The problem: How would I recognize genuine shared decision-making if I saw it? What counts as the genuine article? Shared decision-making can be considered an *emerging* field because 1) interest in implementation and its scope of application has increased, and 2) significant challenges remain for implementation on a meaningful scale in U.S. care systems. Implementation here in Minnesota was accompanied by these ambiguities typical of emerging fields:

1. The customary definitions emphasize values, principles, and goals much more than functional or operational specifics.

Our Minnesota community is moving forward, but could use an operationally focused definition to guide widespread implementation and performance measurement. Different, but compatible, short definitions created by leading researchers, practitioners, and advocates are in place, but there has remained confusion or ambiguity as to just what shared decision-making needs to look like in practice (Moumjid et al, 2007).

- *For patients and families:* "What should I expect to encounter in shared decision-making? How would I recognize genuine article if I saw it—the difference between the real thing and an advertising claim? How would I know whether the care my family received was up to standard?

- *For purchasers:* "What exactly am I buying if I add shared decision-making to the package? What do I tell my employees (or other constituents) they can expect to encounter from this benefit?

- *For health plans:* "What specifically do I require provider systems to provide to health plan members—and what will I specifically look at to see if they are providing it or not?"

- *For clinicians and provider groups:* "What exactly do I need to implement if it is to count as shared decision-making—and to advertise myself as doing SDM? What are core functions, and what is up to me to decide?"

- *For policymakers and measurement experts:* "If I am being asked to change the rules or business models to support SDM, exactly what functions need to be supported? What core functions will I measure?"

2. Implementation requires fidelity to a definition AND an acceptable range of local adaptation.

A generally understood operational definition was needed to enable our community to agree on what functions are to be in place in "the genuine article"—and how to assess and improve our own practices and compare notes using such a shared template.

But such a definition could not become a cookie-cutter prescription. A definition of SDM in action must include a set of defining uniformities AND a set of permissible local adaptations—a map of both the uniformities and acceptable differences ("you can drop X or modify Y and it still counts as SDM"). Otherwise, the definition would not be flexible enough across the many contexts for implementation. This is the challenge of balancing "fidelity and local adaptation" (Callahan, 2010).

How to read this document:

This is source document containing all the detail that the creators and contributors found necessary to answer: "what do you mean by that?" It is a formal description, densely packed with numbered clauses, sub-clauses and fine-print annotations. It contains defining information that can be used to create customized summaries, tools, and derivative documents for specific applications.

This document is not itself a handy summary (except for the facing page—"at a glance"). It does not include task-specific or audience-specific summaries or derivative tools, although these will be important to generate while applying this lexicon to specific practical problems.

Organization

Summary (facing page) starts with a general definition ("what"), followed by defining clauses ("how" and "supported by") and named parameters.

- The *defining clauses* are declarative statements of what genuine SDM looks like in action—an extended definition—uniformities to be expected. *Read these numbered clauses as if one long run-on sentence.*

- The *parameters* are a vocabulary for how one instance of how one instance of SDM might legitimately differ from another one. *Read these as a typology of differences.*

Part I spells out the "how" and "supported by" defining clauses

- Sub-clauses are specified, often with bullet points.

- Fine-print annotations define terms, refer to literature, or clarify concepts and balances

- Some defining clauses also include "transformations"—legitimate variations on the defining clause, e.g., "you can delete X, modify Y, or substitute Z and it's still a genuine case of SDM".
  See appendix 3 for description of the method.

Defining clauses are a set of required functions, not specific ways of carrying them out. They represent fidelity to the definition of SDM in action, but leave room (and require) a great deal of local adaptation such as specific workflows. *Read this as a pattern, not a "cookie cutter".*

Part II spells out the "how" and "supported by" parameters—a vocabulary for legitimate differences.

- Each parameter has a set of categories (in boxes) that represent possible types, levels, or methods that might legitimately differ between instances of SDM in action.

- Some parameters articulate *types*—different legitimate approaches. Other parameters outline *levels* that might be regarded as developmental stages toward full aspiration.

- But there is no presumption that one of these variations is empirically proven best.

At a glance: Shared decision-making lexicon or operational definition

What: Patients and providers collaborate to clarify all acceptable options, ensure that the patient is well-informed (as well as the provider), and choose a course of care consistent with patient values and preferences and the best available medical evidence.

Defining clauses or functions for SDM (What you must see in action)	Parameters (Permissible differences between instances of SDM)
How: *Setting up for decision-making* 1. A situation presents itself and is recognized as suited to shared decision making (SDM)	1. Kind of situation or condition for SDM 2. Time available for decision-making
2. SDM is initiated by any involved party	3. Who will be participating in making the decision 4. Presence (or not) of a decision coach or facilitator
3. While a balanced relationship is maintained between the parties making the decision	5. Symmetry of the decision-making process
Making the decision 4. Creating a shared understanding of all the information needed to make the decision	
5. Using developed resources, methods and tools.	6. Elaborateness of decision-aid media
6. With clinician and patient seeking a mutually satisfying decision in which they have confidence	7. Approach used to identify decisional conflict in ongoing decision-making process
Following up on the decision 7. Following up with next steps once the decision is made, including ongoing decision-making needs	8. Level of ongoing support for moving forward with decisions and identifying new ones
Supported by: *Organizational processes* 8. Systematic and reliable organizational processes and supportive culture for doing SDM in a patient-centered way.	9. Level of coordination across providers & venues 10. Choice of target population or type of condition 11. Level of system support & office process reliability for SDM in the practice 12. Level that practice-based data is used to improve quality & effectiveness
Patient, provider, community demand for SDM 9. A community or population with the expectation that participation in shared decision-making will lead to better care and health.	13. Level of community or individual expectation for SDM

Auxiliary parameters are available if needed for specific uses

In detail: An Operational Definition of Shared Decision Making

Part I: Defining clauses with acceptable variations

Transformations (T) broaden what counts as SDM by specifying acceptable variations—what can be dropped, changed or substituted

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What: Patients and providers collaborate to clarify all acceptable options, ensure that the patient is well-informed (as well as the provider), and choose a course of care consistent with patient values and preferences and the best available medical evidence.

How:

Setting up for decision-making

1. A situation presents itself and is recognized as suited to shared decision-making—in context of a clinical relationship.

    A. A clinician, patient or family member may recognize a situation that needs SDM and processes ensure the creation or maintenance of a mutually respectful clinical relationship focused on a well-informed patient's best interest as defined by mutual agreement of patient and clinician.

        Annotation: Beginning steps to initiate a new relationship might include introducing yourself, making eye contact, describing roles & relationships among team members, asking questions, active listening, speaking directly to patients & family.

    B. Any involved party sees the need to weigh at least two options—including "doing nothing",

    C. Signs of decisional conflict are evident—a state of uncertainty about the course of action.

        Annotation: Signs of decisional conflict may include verbalized uncertainty about choices or the undesired consequences of alternatives, vacillation between choices, delayed decision-making, distress while attempting decision making, questioning personal values and beliefs while attempting to make a decision. (O'Connor 1995; Ottawa Health Decision Centre; Leblanc et all (2009))

    D. The patient, family, or patient's representative can participate

T1	Delete clause 1C. (Shared decision-making may be initiated even without evident signs of decisional conflict on the part of the patient)

2. SDM is initiated by any involved party, and tailored to the situation at hand.

    A. Includes determining the kind of decision, e.g., a one-time procedure, a longer-term chronic condition, or use of screening procedures.

    B. Assessing mutual readiness for participation for shared decision-making, with the clinician responsible for offering the SDM opportunity if no one else does it first.

        Annotation: Signs of mutual readiness may include willingness to explore respective responsibilities, presence of a constructive patient-clinician relationship, openness to negotiation, seeking mutual agreement, and establishing a plan; taking time to follow a process to reach those ends and absence of distrust and that the expectations for the shared decision-making fits the practical situation at hand (neither underdone nor overdone).

    C. Tailored to the level of complexity of the decision issues (not over or under-doing SDM for the situation at hand).

T2	Delete 2A.
	(Explicit conversation about the kind of decision to be made may not be necessary, at least at the outset, because it is already obvious, involves a mixture of decisions, or is not a patient-centered starting point for conversation)

3. Maintaining a balanced relationship between the parties that are making the decision.

> *Annotation*: Signs of a balanced relationship may include recognition that provider and patient each bring different expertise to the table, both listen to understand as well as talk to be understood, neither attempts to trump the other but are willing to go to lengths to ensure that they hear and understand each other, and can not only agree, but agree to disagree. (Inspired by Charles, Gafni & Whelan, 1997))

A. Clarification of roles in making the decision—clinician or team, patient, family or other decision makers—including who is responsible in the end for making the decision.

B. Demonstrating beliefs and attitudes such as:
- Mutual respect for the legitimacy of each other's roles, expertise, and points of view, including that physicians and patients bring different kinds of expertise or knowledge to the table regarding the patient's conditions and options.
- Awareness of limits to one's perspective such as knowledge base or prior investments in particular courses of action that are in effect conflicts of interest. For example a clinician who has built a career around a particular procedure or treatment may not be the most objective person for an SDM discussion and may want to involve someone else.
- Both parties work together actively to get a good decision
- Beliefs such as "patients knows *themselves* best" or "what works for me isn't necessarily going to be the right thing for anyone else" (Foundation for Informed Medical Decision Making—FIMDM)
- They can take whatever time is necessary (within reality constraints of the situation) to make the decision and loop back, revisit and reconsider as needed (not necessarily a linear process)
- Physicians or other clinicians don't know a specific patient's preferences until they ask.

	No transformations. (Establishing a balanced relationship with respect for the different expertise or conflicts of interest everyone brings to the table is required for genuine shared decision-making)

Making the decision

4. Creating a shared understanding of all the information needed to make the decision

A. Clarification of the decision that needs to be made, including
- What is the decision in front of us
- Explicit discussion about *when* the decision should be made—and the time available to do it
- Who is and is not to provide support and advice on the decision—the social context, e.g., spouse, family, anyone applying pressure who may be part of leading to decisional conflict

B. Adequate & accurate patient and clinician knowledge of condition, diagnosis, likely course

C. A shared understanding of what is important to the patient—preferences and values

D. Clarifying the options—exploring the universe of all viable options, including
- Delineating the options: a) the benefits and risks b) in a way that the patient can understand c) done in different ways for different patients with different capabilities and ways of taking in information d) done with cultural sensitivity such as language & cultural beliefs

  > *Annotations—options*: All the options means not filtered by physician preference, bias, or "wish to stay on schedule". All viable options means "all the options the physician or patient feels are viable"

  > *Annotation—risks and benefits:* Alternative terminology for "risks and benefits" is sometimes used, e.g., "benefits and harms" or "pros and cons". Probability assessment applies to both benefits and harms. Some people may use the word "burden" for "risk".

- Describing risks & benefits associated with each option—using best practices for risk communication and including financial costs such as co-payments, insurance coverage, out of pocket costs.

  > *Annotation*: Best practices for communicating risks & benefits may include information in "digestible amounts", pausing to check understanding, delaying discussions if distress escalates, engaging family members as appropriate,

anticipating critical unasked questions, balancing limitations of what is known with confidence that this is best medical knowledge (Epstein et al, 2004); use of absolute rather than relative risk measures and number needed to treat.

E. Concordance or values matching—the relationship of the risks and benefits to the values and preferences—which risks and benefits matter most to the patient.

	No transformations. (Clauses A-E are all necessary for genuine shared decision making)

5. Using developed resources, methods and tools

A. Listening to what the patient has to say—"where they are at"—using active listening that includes
   - Conversation and facilitation skills to guide conversations in impartial fashion
     Annotation: Impartial facilitation means leading the patient through a process of understanding and decision-making rather than "having a thumb on the scale" promoting a particular set of information or answer.
   - Conversation tailored to the patient's level of health literacy and health numeracy
     Annotation: Health numeracy (ability to use numeric information in the context of healthcare) is considered one of the key domains of health literacy in a model put forth by the Institute of Medicine. Sensitivity to health literacy and numeracy is parallel to cultural sensitivity when it comes to being able to participate in SDM and involves use of best practices for making comparisons such as use of natural frequencies (Institute of Medicine Comm. on health literacy).
   - A decision coach (a person) or a function or tool to effectively guide such conversation

B. Using cultural sensitivity best practices

C. Using developed / proven tools
   - Decision guide—tool that facilitates a systematic discussion process for making decisions
   - Decision aids—tools to provide comprehensive, current, comprehensible, balanced, evidence-based information
     Annotation: A "decision aid" is to 1) frame the decision and options available in a balanced, unbiased way, using graphic illustrations; 2) explain what is known and not known about the potential risks & benefits of the reasonable options based on the best available clinical literature; 3) use interview material from patients who have faced a similar choice to communicate both the common alternative ways of thinking about the decision that might lead to different decisions and to share with patients what the experience of the various choices might be like, including what it would be like to experience some of the most frequent side effects or complications of the options (excerpt from FMDM).
   - Tools for assessing patient activation, readiness for SDM and role preferences

D. Done in a way that offers self-correction, either through an automated function of the decision aid or via conversation with the patient to identify deficiencies in information or decision-making rather than finding out at the very end about some early misunderstanding.
     Annotation: Key areas to assess are accuracy of knowledge, especially not believing falsehoods (fibroids aren't cancer) as opposed to knowing the exact right answer (fibroids are smooth muscle tumors); assessing values concordance (which choice is best for you); realistic expectations; satisfaction with decision-making role and process

T3	5A: Delete " a decision coach. . ." (A separate decision coach does not always have to be involved if the conversations are facilitated effectively by others)
	5B & 5D: No transformations
T4	5C: Delete 5C if there is a different systematic process in place to facilitate making decisions and providing balanced evidence based information.

6. With clinician & patient seeking a mutually satisfying decision in which all have confidence
   Annotation: In different situations, a physician or other clinician or provider function as responsible medical decision-makers

A. Leaving space for the patient to change his/her mind, reconsider, have second thoughts, "loop back" (assuming time permits before action must be taken), reconsider whether the decision is right for them, identifying any remaining decisional conflict;

B. Asking whether the patient and clinician are both satisfied with the decision process—concordant for both.

> *Annotation:* "Mutually satisfying" is a goal for SDM, but in the end it is the patient's decision and the patient's satisfaction and confidence in it.

C. With a way to deal with the possibility that the clinician doesn't agree with the patient decision

> *Annotation*: Professional pathways exist for physicians to decide whether to work with the patient, documenting such decisions, handling any ethical concerns regarding a decision not to work together vs. patient abandonment, and use of second opinions in helping resolve physician discomfort with patient decisions.

	No transformations

7. Support in taking next steps for care plan once the decision is made—with continuity, coordination, and identification of new decision-making needs as they may arise

A. Roles, goals and next steps are included in a care plan available to patient and clinician

B. With continuing attention to re-emerging decisional conflict, adjustment of the decision and plan along the way, "conditional" decisions (if X happens, then do Y) or the emergence of new decision-making needs (new diagnoses, complications, episodes of care, options for care).

> *Annotation*: New decision-making situations and needs may well arise over time. These are identified and as much as possible are addressed with a consistency of process across clinicians and venues—with a patient experience of continuity and coordination over: 1) whatever calendar time is needed for the situation or conditions, 2) across different circumstances or diagnoses that come into the picture for that situation, 3) across episodes of care for whatever conditions are the focus of SDM, 4) across venues/sites of care for conditions about which SDM is a focus

	No transformations

Supported by:
Organizational processes

8. With systematic and reliable organizational processes and supportive culture for doing SDM in a patient-centered way

> *Annotation:* This clause speaks at the level of care system action rather than at the level of an particular act of SDM.

A. Sufficient clinician awareness and competence in SDM such as through training in SDM—formal or on-the-job.

B. Doing reliably and consistently all the clauses 1-7 above, and

C. Routine practice-based data collected and used for QI on core SDM processes and outcomes

	A: No transformations
T5	B: Delete "reliably and consistently" but with a plan to become more reliable and consistent
T6	C: Delete "routine" but with a plan to become more routine

Patient, provider, community demand for SDM

9. A community, population or individual with awareness and expectation that patient participation in shared decision-making (SDM) will lead to better care and health.

Expectation by patients and clinicians that situations will arise when engaging in shared decision making will lead to better care and health.

> *Annotation:* Shared decision-making involves weighing alternative courses of action with generally similar risks and benefits (or that appear viable to patients or clinicians), and where choice requires exploration of those risks and benefits in view of individual patient values and preferences.

	No transformations. (It takes at least one patient and provider aware, open to, and expecting SDM for it to be supported)

Part II: Parameters of Shared Decision-Making (SDM)
How instances of SDM or its organizational supports might differ from one another

Annotations:
1. **Any genuine instance of SDM (or SDM practice) can be described using a category for each parameter**. If the particular practice is not developed enough to fit any of the categories for any one parameter, it does not count as genuine shared decision-making.
2. **These parameter values are descriptive, not evaluative.** There is no data or presumption that any one of the values for the parameters is better than another one—even though several of these could be read as developmental sequences. ***Do not read these as "good-better-best" categories.***
3. These are separate parameters with descriptive categories. Don't read this as a table with columns

Parameter	Descriptive categories for that parameter				

Setting up for decision-making
A situation presents itself and is recognized as suited to shared decision-making (clause 1)
SDM is initiated by any involved party—in context of a new or existing relationship (clause 2)
While a balanced relationship is maintained between parties making the decision (clause 3)

1. **Kind of situation or condition for SDM**	One-time treatment decision *Example:* breast CA initial treat.	Potentially serial treatment decisions *Example:* low back pain	Preventive care / screening decisions *Example:* PSA testing	Lifestyle decisions *Example:* Smoking cessation, exercise	Chronic care treatment decisions *Example:* diabetes treatment	Life-stage decisions *Examples:* move in with family, assisted living, hospice

2. **Time available for decision-making**	Elective — Can take as much time as necessary—no deadline, can decide to "do nothing", e.g. knee replacement	Pressing but not emergency — Have to make a decision, but have weeks to months, e.g. CA treatment	Emergency — Need to make a decision very quickly—minutes to hours to days, e.g. ruptured abdominal aortic aneurysm

3. **Who will be participating in making the decision** (beyond patient & clinician)	No one else: only the patient and clinician	The patient, clinician + 1 other person — Examples: spouse, parents, child, family member, non-family representative	The patient, clinician, and more than one other person — Examples: Additional family or community agents

4. **Presence (or not) of a decision coach or facilitator** (to aid those making the decision)	None: Treating clinician and patient only — Treating clinician and patient without separate coach / facilitator	Coach without clinical training — A (lay) person trained to do SDM coaching, but without clinical training	Coach with clinical training — Nurse, health educator or other with clinical training

5. **Symmetry of the decision-making process** — From Charles, Gafni & Whelan	Provider as agent — Provider informs patient and collects information about patient preferences; then makes decision based on informed understanding of patient's values and preferences.	Balanced provider & patient agency — Provider and patient have equal influence and status / power in the process, although not at every moment. Both share in the decision-making.	Patient as agent (aka "informed choice") — Patient discusses decision with provider but makes the decision as the dominant agent in the interaction

Making the decision

Creating the shared base of information needed to make an informed decision (clause 4)
Using developed resources, methods and tools (clause 5)
With clinician & patient seeking to reach a mutually satisfying decision in which they have confidence (clause 6)

6. **Elaborateness of decision-aid media** (Adapted from International Patient Decision Aid Standards--IPDAS)	Oral; no tangible decision aids A systematic process is in place to help without tangible decision aids	Essential elements of decision aids: • Unbiased source, current • Low-literacy compatible • Culturally sensitive • All major options included • Risks, benefits, preferences addressed • Encouraging a deliberative discussion process • Systematic development process documented	Essential elements plus some or all of: • Patient stories included; • Risk presented with pictographs; • Structured guidance for how to make the decision (a "deliberative process") • Proven tool effectiveness • If web-based, best practices are used
7. **Approach used to identify decisional conflict in an ongoing decision-making process** (From Sepucha & Mulley)	Informal / non-systematic Elements 1-4 may or may not be checked or are checked at random times during the ongoing process 1. Sufficient understanding—knowledge? 2. Consistent w values, culture, health literacy & numeracy? 3. Confidence that decision is best for me? 4. Satisfied with decision process?	Partially systematic Some elements are checked routinely or are checked only some of the time during the ongoing process	Systematic All four elements are checked routinely all along the ongoing process

Following up on the decision

Support in taking next steps once the decision is made; with continuity, coordination, and identification and support of new decision-making needs as they may arise (clause 7)

8. **Level of ongoing support for moving forward with decisions & identifying new ones**	Reactive & informal Problems dealt with as they occur as brought to attention by patient / family	Partially structured and sometimes proactive Some but not all problems proactively identified and addressed systematically	Proactive & structured Systematic process for identifying roles, goals, steps, with a plan for follow up

Supported by

Organizational processes
With systematic and reliable organizational processes and supportive culture for doing SDM (clause 8)

9. **Level of coordination across providers & venues for care**	Provider-patient only Depends on provider / patient memory & chart, carries over from visit to visit, decision to decision or venue to venue just for that provider and patient	Within the entire practice Everyone in the practice is expected to know about and act according to the decision and patient preferences, across the venues they work in.	Beyond the practice Providers in at least one other practice or venue know about and act according to the decision and patient preferences
10. **Target population, type of condition** (scope of application to situations)	Circumscribed / pilot SDM for a small number of conditions / situations, e.g. 3 or fewer	Spreading SDM for many conditions / situations, e.g., greater than 3	Generalized SDM for all major conditions / situations presenting at that practice

11. **Level of system support & office process reliability for SDM in the practice** (Adapted from Lean and reliability science)	Informal / individual Most processes for SDM vary substantially by clinician and are not especially reliable or consistent	Partially routinized Some standards set for some SDM processes but variability and random clinician preference still operate	Standard Work A standardized, consistent, reliable system for SDM that is error-proofed
12. **Level of use of practice-based data—to improve quality & effectiveness**	Starting Commitment and the beginnings of a system for collecting and using practice data for QI and effectiveness	Partially complete Partial but useable system for using practice-based data for decision-making and reporting results at system or unit level	Complete & routine Routine collection and use of practice-based data with internal performance reporting for decision-making and improvement

Patient, provider, community demand for SDM
A community, population, or individual that is expecting shared decision-making   *(clause 9)*

13. **Level of community or individual expectation for SDM**	Limited but sufficient Sufficient reach of readiness and expectation to enable SDM programming to function in this community or practice	Partial Wide but substantially incomplete readiness and expectation for SDM need for continuing education, consciousness-raising, clarification	Widely accepted & understood Almost universal community expectation for SDM as a standard function in healthcare

Orientation to The Minnesota Shared Decision-Making Collaborative
www.msdmc.org

The Minnesota
Shared Decision
Making Collaborative

What is shared decision-making?
"Shared Decision Making (SDM) is a process in which patients and providers collaborate to clarify all acceptable options, ensure that the patient is well-informed, and choose a course of care consistent with patient values and preferences and the best available medical evidence".

(Minnesota shared decision-making collaborative, 3/11)

The concept of shared decision-making emerged more than 30 years ago after John Wennberg, M.D., former director of the Dartmouth Institute for Health Policy and Clinical Practice, identified wide variations in surgical treatment for common conditions and suggested that some unnecessary treatments could be eliminated if patients were better informed about the benefits and drawbacks.

Since then, physicians (primarily in academic centers) have been testing and refining the shared decision-making model. This has resulted in a growing body of literature from pilot and demonstration projects across the country that have found patients benefit from a more formal process for making decisions about their treatment options.

The need for SDM has increased as patients face increasingly complex treatment choices for conditions where no one treatment is clearly superior and when the best choice often depends on their preferences and values—including financial costs to the patient.

Some policymakers and health plans have embraced SDM in the belief that it will result in cost savings and reduce

> **"…Physicians have a tendency to downplay negative side effects** of treatments and make unwarranted assumptions about what patients want.
>
> - A University of Michigan survey of 375 patients who had discussed prostate-specific antigen (PSA) testing with a health care provider found that the providers emphasized the pros of testing in 71 % of discussions but addressed the cons only 32 % of the time.
>
> - An Archives of Internal Medicine article (9/09) reported that patients did not have discussions about the downsides of testing, had limited knowledge about what the test would tell them and of the mortality risk associated with prostate cancer, and were not routinely asked about their preferences regarding testing..."

unnecessary medical procedures. Evidence does not indicate that shared decision-making necessarily reduces utilization but does show it limits unwanted care.

National health reform discussions include SDM and the state of Minnesota is studying SDM in context of public insurance programs and health care homes. The state's provider groups and payer organizations formed a **Minnesota Shared Decision Making**

> **"Minnesota's elective surgery rates all over the map. Reasons unclear for variations—studied in light of doctor-patient collaboration.**
> Minnesota has sharp variations in elective surgery rates. . .with patients in Detroit Lakes twice as likely as others to have arterial bypasses and men in Bemidji three times as likely to have enlarged prostates removed. . .The researchers chose Minnesota for their first state-focused report because it's a leader in the use of informed medical decision-making [shared decision-making]. . ."   (Star & Tribune front page article 2/24/11)

Collaborative to identify best practices for implementing shared decision-making in clinical practice.

(Foregoing text adapted from *Minnesota Medicine* Jan, 2010)

A sample of commonly occurring situations in which shared decision-making tools are developed:

PSA testing and prostate CA tx	Low back pain	End of life care
Breast cancer treatment	Genetic testing	Depression and ADHD treatments
Breast cancer surgery type	Childbirth choices	Diabetes medications
Angina / CAD treatment	Statins for high cholesterol	Knee surgeries
Osteoporosis medications	Uterine fibroid treatments	Menopause and HRT

More at http://shareddecisions.mayoclinic.org/

Purpose of Minnesota Shared Decision Making Collaborative (MSDMC):

1. To enhance effective shared medical decision-making between patients and their clinicians by studying and implementing methods to assure that medical decisions are well-informed by best available evidence and consistent with patient preferences.

2. Work with government entities, policy makers, payers and purchasers, health professionals, educators, and the media to provide support for, and remove barriers to the adoption of SDM best practices.

The collaborative consists of a standing **Steering Committee** and task-oriented **Workgroups**. The collaborative was originally sponsored by HealthPartners Health Plan and is now facilitated by ICSI. Workgroups seek to include interested participants from the community who are not members of the Steering Committee.

Workgroups: Minnesota Shared Decision-Making Collaborative

1. **Policy:** Develop recommendations and advice health plans, employers, state agencies like DHS and MDH, legislators, and other policy makers regarding policies that will best promote widespread adoption of high quality shared decision making in clinical practices.

2. **Lexicon:** Support the development of (and applications for) a shared understanding amongst Collaborative members and in our community about Shared Decision Making (SDM) by developing and promoting the use of operational definition and a key SDM terms grounded in published work on SDM.

3. **Measurement:** Define, implement, and study a community wide decision quality measurement approach that can be used: In practice (for QI and self assessment), for accountability measures and public reporting and for research.

4. **Implementation:** Develop a template that can be used as a guide for starting and moving forward with SDM implementation in various settings. Create an organized collection of resources and references that may be helpful for SDM implementation. Provide advice, based on personal and practical experience, about the use of methods, tools, and resources for SDM implementation in various settings

5. **Education**: Provide education on shared decision making to targeted audiences.

6. **Patient Engagement:** Develop and share information promoting patient and community common understanding of key concepts and language of SDM.

No longer meeting, a time-limited Media Workgroup met to work collaboratively with media organizations and journalists in Minnesota to improve the quality of medical reporting and promote shared making. In addition, an Education Workgroup focused on education on SDM for targeted audiences.

Steering Committee: Minnesota Shared Decision Making Collaborative (as of February 2012)

Donna Anderson, MPH	Patient Advocate	Tom Marr, MD	HealthPartners health plan
Steve Bergeson, MD	Allina Hospitals and Clinics	Ruth Mickelson JD, MPH, MA	
Kristina Bloomquist, MEd	Medica health plan	Lawrence Morrissey, MD	Stillwater Medical Group
Janny Brust, MPH		Gary Oftedahl, MD	Institute for Clinical Systems Impr.
Eric Bundgaard	AARP	David Pautz, MD FACP	Blue Cross Blue Shield of MN
Craig Christiansen, MD	UCare	C.J. Peek, PhD	U of MN Dept. of Family Medicine
Terry Clark, MD	Essentia Health, East Region	Janet Schuerman, MBA	Institute for Clinical Systems Impr.
Terry Corbin,	Patient Advocate; Corbin & Co	Gary Schwitzer, PhD	U of MN School of Journalism
Terry Crowson, MD	HealthPartners Health Plan	Kris Soegaard	Buyers Healthcare Action Group
Paul Huddleston, MD	Mayo Clinic	Leif Solberg, MD	HealthPartners Research Foundation
Ken Joslyn, MD	Hennepin County	Gretchen Taylor, MPH, RD	MN Department of Health)
Mary Ann Kish, MD	HealthPartners Medical Group	Cally Vinz, RN	Institute for Clinical Systems Impr.
Karen Kraemer, RN	HealthPartners Health Plan	Mark Wilkowske, MD	Park Nicollet Health Services
Annie LeBlanc, PhD	Mayo Clinic	Roxanne Wilson	CentraCare
Jennifer Lundblad, PhD	Stratis Health	Pam Zoeller	HealthPartners Medical Group
Marie Maes-Voreis, RN	MN Department of Health		

Appendix 2
Auxiliary parameters

Auxiliary parameters are not a standard part of this lexicon but may have specialized applications and hence are retained in this appendix rather than completely discarded. For example "type of relationship" or "who identified the situation or need" may be useful in research or descriptive studies of the kinds of SDM taking place across the country. Auxiliary parameters were created in earlier versions of this lexicon but are not felt to be central to it.

Setting up for decision-making

Type of relationship in which SDM is taking place	New New clinician or setting previously unknown. No prior patient-clinician relationship	New, but with known team New clinician but within a familiar practice or partner of the clinician normally seen	Well-established Clinician and setting are familiar; well-established patient-clinician relationship

Who identified the situation or need	Provider-identified	Identified by other clinical care team member e.g. health plan case manager, health coach, public health nurse, nurse navigator	Patient- or family-identified

Making the decision

Kind of decision aid media	Oral; no tangible decision aids (A systematic process is in place to help without tangible decision aids)	Visual: text, or text with graphics Can be web or print.	Audio visual: video or animation with graphics. Can be web or video.

Shared decision making organizational processes

Level of participation in provider group (Scope of provider involvement)	Early adopters only Only one or a few providers in the group or department are doing SDM	Spreading Expectation and evidence that all providers in a group or department are adopting and implementing SDM in their practices	Standard Work All providers in a group have adopted and are doing SDM routinely

Reliability of process to identify patients & situations for SDM (Adapted from Lean and reliability science)	Informal Depends on physician, staff, or patient awareness—someone who happens to know & notice. Some situations identified, many not	Partially routinized Physician, staff, and patient awareness augmented by some system reminders. Many situations identified, some not.	Standard work Physician, staff, and patient awareness backed up by routine, reliable system reminders. Almost all situations identified

Level of leadership / administrative alignment (Adapted from Schein & Collins)	Not aligned SDM on the list of strategic priorities, but conflicts with other priorities or incentives are apparent. SDM is espoused but not yet "designed in".	Partially aligned Some alignment achieved but ongoing work on unresolved tensions between priorities, incentives, standards	Fully aligned Constructive balance achieved between priorities, incentives, standards. SDM fully designed into priorities & incentives

Appendix 3

About the method for creating an archetype or operational definition:
Paradigm case formulation and parametric analysis

Many different but entirely compatible definitions for SDM—accompanied by values and principles guide the general development of the field. But the field (and this includes patients) has little widespread and agreed-upon *detailed functional definition* to guide widespread *implementation* and performance measurement.

A consensus operational definition with standing in the field must serve practical purposes across a broad range of people interested in SDM. It needs to combine the perspectives of a broad range of people and perspectives—using a method capable of generating consensus on defining clauses for "what is the genuine article". An articulation of such defining functions is a *paradigm case* that we can all agree is the functional essence of SDM. This guides specific implementation.

Fortunately, methods for defining such complex subject matters that meet the requirements (box at the right) exist in the published literature (Ossorio, 2006). A "paradigm case formulation" is a vehicle for creating a definition that maps both similarities and differences. A "parametric analysis" builds on the paradigm case to create a specific vocabulary for how one instance of a genuine health care home might differ from another instance across town.

The paradigm case and parameters amount to a set of interrelated concepts (like an extended definition) used in comparing practices, setting standards and measures, or asking research questions using a common vocabulary.

Current applications of this methodology in emerging fields of healthcare include palliative care, health care home, shared decision-making and integration of behavioral health in primary care.

CJ Peek PhD of the University of Minnesota Department of Family Medicine and Community Health devised the work process and conducted the facilitation for these intensive lexicon projects.

Methodology adapted from:
- Ossorio (2006) "Conceptual-Notational Devices", a chapter in *The Behavior of Persons*, The Collected Works of Peter G. Ossorio, Vol 5., Descriptive Psychology Press, Ann Arbor MI.
- Peek (2011). A collaborative care lexicon for asking practice and research development questions. One of three papers in: *A National Agenda for Research in Collaborative Care: Papers From the Collaborative Care Research Network Research Development Conference*. AHRQ Publication No. 11-0067. Rockville, MD. http://www.ahrq.gov/research/collaborativecare/

Requirements: A method for creating an operational definition with standing in the field would. . .

- Be consensual but analytic (a disciplined transparent process—not a political campaign)
- Involve actual implementers and users ("native speakers" of the health care home language)
- Focus on what functionalities look like in practice (not just on principles, values, or visible 'anatomical features')
- Specify acceptable variations around the required archetype—so it is not a rigid prescription.
- Be amenable to gathering around it an expanding circle of "owners" and contributors (not just an elite group coming up with a declaration)

Method: Paradigm case formulation and parametric analysis

1. **First comes a *paradigm case of SDM in action*:** An incontrovertible case of SDM is described in clauses. "If that's not SDM in action, I don't know what is!"

   - All clauses are required for a practice to count as a genuine SDM. It is not a menu from which to pick and choose. All these are required to be the "genuine article".
   - But the clauses also contain "transformations" that specify acceptable variations that are necessary for local adaption of the core functions.

2. **Then come *parameters of SDM in practice*:** Building on the paradigm case clauses, fundamental dimensions (parameters) articulate how particular instances of SDM (or SDM programs) might legitimately differ from one another.

   The categories along these dimensions are intended to be descriptive and are not "value judgments"

Appendix 4
About the need for consistent concepts, lexicons and "archetypes" in new fields

Why include lexicon / conceptual development as part of forming practice development or research agendas? Questions about terms often come early in conversations intended to create research or practice-development agendas for emerging healthcare fields. For example--

"Do we have a good enough *shared* vocabulary (set of concepts and distinctions) for asking research questions together across many practices? Do we mean similar enough things by the words we use or how we distinguish one form of practice from another for purposes of investigating their effects? Do we have a shared view of the edges of the concept we are investigating—the boundaries of the genuine article or the scope of our subject matter? If we don't share enough of that vocabulary, we will *think* we are asking the same research questions, using the same distinctions, doing the same interventions, or measuring the same things—but we *won't* be—and will confuse our practices, patients, and our funding organizations. . ." (from Peek, 2010; also see Stenger & Devoe, 2010)

In general, clearer and more consistent concepts and definition for a field are needed when:

1. Enough people are stumbling over language and what things mean— especially as encountered *in practice*, not only *in theory* or at the level of principles and values.

2. Enough people need clearer boundaries for an area X—what counts as "this is a genuine example of it" for describing to the public, setting expectations, assigning insurance benefits, certifications, or saying how something is different than "usual".

3. People are asking, "What components are necessary for a given practice to really be X? What are the dimensions and milestones for practice improvement within these components?"

> "**. . . All mature scientific or technical fields have lexicons** (systems of terms and concepts) developed well enough to allow collaborative and geographically distributed scientific, engineering, or applications work to take place. These lexicons are developed for practical reasons of communication among professionals doing the real work of science and practice.
>
> Systematically related concepts have an esteemed place in the history of mature fields that we now take for granted, e.g., electrical engineering, physics, and software development. Conceptual development in these fields has enabled them to become mature sciences or technologies with associated empirical triumphs. In many cases the conceptual or pre-empirical development of these fields was done so long ago that we take it for granted and now see only the concrete empirical achievements.
>
> But it takes a generally understood system of concepts and distinctions to do good science. . ."
>
> From Peek (2009) and inspired by Bergner. R. (2006) An Open Letter from Isaac Newton to the Field of Psychology. *Advances in Descriptive Psychology,* Vol. 8., Descriptive Psychology Press, Ann Arbor MI.

4. Researchers want to ask quality or research questions more consistently and clearly—especially in geographically distributed research or QI networks

5. There is a felt need to improve the consistency or reputation of an area with "outsiders", e.g., policy-shapers, legislators, funders and others who are not living the experience as "insiders".

6. When your field is being distorted or misunderstood by the public or subset—when practitioners themselves are inconsistent in the way they present the field to the outside world.

Lexicon / conceptual development aimed at creating consistently understood research or practice development questions has been used in emerging healthcare fields such as collaborative care (behavioral health / primary care collaboration), palliative care, shared decision-making, and patient-centered medical home. The methodology employed by this author has been paradigm case formulation and parametric analysis (Ossorio, 2006)

Ossorio (2006)."Conceptual-Notational Devices", a chapter in *The Behavior of Persons*, The Collected Works of Peter G. Ossorio, Vol 5., Descriptive Psychology Press, Ann Arbor MI.

References

Callahan, C. Coustanie, M., Weiner M., Beck, R., Livin, L., Kellams J., Willis D., & Hendrie, H. (2011). Implementing dementia care models in primary care settings: The aging brain care medical home. *Aging Mental Health*, January 2011; Vol 15(1) pp. 5-12.

Charles, C., Gafni, A., and Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science & Medicine*, 44, 681-692

Epstein, R., Alper B., & Quill, T., (2004). Communicating evidence for participatory decision making. *JAMA* Vol 291, No. 19, pp. 2359-2366.

Foundation for Informed Medical Decision Making: http://informedmedicaldecisions.org/

Institute of Medicine Committee on Health Literacy: http://www.iom.edu/Activities/PublicHealth/RtblHealthLiteracy.aspx

International Patient Decision Aid Standards (IPDAS): http://ipdas.ohri.ca/

Johnson B. (1992). *Polarity Management: Identifying and Managing Unsolvable Problems.* HRD Press. See also www.polaritymanagement.com

LeBlanc A, Kenny DA, O'Connor AM, Legar F. (2009). Decisional Conflict in Patients and Their Physicians: A Dyadic Approach to Shared Decision Making. *Med Decis Making OnlineFirst,* February 4, 2009, doi:10.1177/0272989X08327067.

Moumjid, N., Gafni, A., Bremond A., Carrere M. (2007). Shared decision making in the medical encounter: Are we all talking about the same thing? *Med Decis Making* 2007; 27; 539-546.

O'Connor, A.M. (1995) Validation of a decisional conflict scale. *Med Decis Making* 15(1): 25-30

Ottawa Health Decision Centre: URL for evaluation measures: http://decisionaid.ohri.ca/eval.html

Ossorio, P.G. (2006). *The Behavior of Persons.* Descriptive Psychology Press, Ann Arbor

Peek, C.J. (2011). A collaborative care lexicon for asking practice and research development questions. One of three papers in: *A National Agenda for Research in Collaborative Care: Papers From the Collaborative Care Research Network Research* Development Conference. AHRQ Publication No. 11-0067. Rockville, MD. http://www.ahrq.gov/research/collaborativecare/

Peek and Oftedahl (2010). A consensus operational definition of patient-centered medical home. A joint product of the University of Minnesota and the Institute for Clinical Systems Improvement. http://www.icsi.org/health_care_home_operational_definition/health_care_home_operational_definition__.html

Sepucha K.R., Flowlder, F.J., Mulley, A.G. (2004). Policy support for patient-centered care: The need for measureable improvements in decision quality. *Health Affairs web exclusive,* October 7, 2004.

Stenger & Devoe (2010). Policy challenges in building the medical home: Do we have a shared blueprint? *JABFM, May-June 2010, Vol 23, No. 3.*

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