Shared Decision Making Process Scale General User Guide

I. Purpose:

To measure the extent to which patients are involved in the decision-making process.

II. Versions:

Shared Decision Making Process Scale v.2.0: 4 item version of the shared decision making process survey (see Table). Users can fill in the condition, treatment and alternative treatment to customize to the clinical situation. The items were written assuming that there are broadly two options (e.g., surgery or non surgical approaches).

Shared Decision Making Process Caregiver version: 4-item version to be used with adult caregiver for pediatric situations (see Table).

III. Timing

The SDM Process Scale survey should be administered <u>after</u> a consult with a health care provider where a specific decision was discussed. In one analysis, scores obtained shortly after a visit (~1 month) did not differ significantly from those obtained 12 months after the visit) [1]. While closer to the actual discussion is preferred, studies have used up to a 2 year look back.

IV. Items and Scoring:

The survey has been used across a range of conditions including breast, colorectal, prostate or lung cancer screening; high cholesterol, high blood pressure, and depression, and ADHD (Caregiver version); stable coronary artery disease, cataracts, breast cancer treatment, prostate cancer treatment, hip osteoarthritis, knee osteoarthritis, spinal stenosis, and herniated disc. The Table illustrates the items for three different clinical contexts, including the Caregiver version.

In 2020, the scoring for the SDM Process scale was revised to provide partial credit for responses of 'some' = 0.5. The scoring is detailed in the Table. Participants receive 1 point for a response of "yes" or "a lot", 0.5 point for "some", and 0 point for all other responses. The total points are summed and result in total scores from 0-4, with higher scores indicating more shared decision making.

For missing data, we recommend using a mean replacement for those items for those individuals who have missing data on 1 item. Surveys with more than 1 missing item do not get a total score.

Table: Shared Decision Making Process Scale Items and Scoring for Different Decisions

SDM Element	SDM Process Items*			Responses and Scoring
	Surgical decision	Cancer screening decision	Medication decision (Caregiver version)	
Options	Did any of your healthcare providers talk about non-surgical treatments as an option for you?	Did any of your healthcare providers talk about stool-based tests as an option for you?	Did your <i>child's</i> healthcare providers talk about ways other than medicine <i>to treat their ADHD?</i>	1 = Yes 0 = No
Pros	How much did you and your healthcare providers talk about the reasons you might want to have hip replacement surgery?	How much did you and your health care providers talk about the reasons you might want to have a colonoscopy to screen for colorectal cancer?	How much did you and your <i>child's</i> healthcare providers talk about the reasons you might want <i>your child</i> to take medicine to <i>treat their ADHD</i> ?	1 = A lot 0.5 = Some 0 = A little 0 = Not at all
Cons	How much did you and your healthcare providers talk about the reasons you might not want to have hip replacement surgery?	How much did you and your healthcare providers talk about the reasons you might not want to have a colonoscopy to screen for colorectal cancer?	How much did you and your child's healthcare providers talk about the reasons you might not want your child to take medicine to treat their ADHD?	1 = A lot 0.5 = Some 0 = A little 0 = Not at all
Preferences	Did any of your healthcare providers ask you what you wanted to do to treat your hip pain?	Did any of your healthcare providers ask you what you wanted to do to screen for colorectal cancer?	Did your child's healthcare providers ask you whether or not you wanted your child to take medicine to treat their ADHD?	1 = Yes 0 = No

^{*}Italicized items can be customized for the specific clinical context

V. Partnership for Quality Measure #2962 Shared Decision Making Process:

The SDM Process Scale is also used as the basis for a patient-reported performance measure for selected surgical decisions. For those who are interested in the PQM endorsed measure, please refer to the PQM document for more details on sampling, administration and scoring: https://p4qm.org/measures?combine=2962

VI. Development Process:

In 2007, a team of researchers at the University of Michigan developed several items to be used in the DECISIONS survey, the first national survey of how common medical decisions were being made in the United States [2,3]. One key goal was to develop items that would assess the extent to which shared decision making happened across 10 different medical decisions. The SDM Process Scale is based on four questions from that survey.

The survey items were derived from the shared decision making model (SDM), a conceptual framework that was first outlined by Mulley in the late 1980s [4] and extended by Mulley and Sepucha [5,6]. The model takes a systems approach to understanding and improving clinical decision making that focuses on two key participants: patients (and family) and clinicians. The model emphasizes the fundamentally social nature of the decision making task, and the fact that it cannot be completed by the clinicians or patients alone, but rather requires interactions between them. The guiding principles behind the items included: 1) patients should have adequate knowledge and experience to answer; 2) minimize need for judgment or evaluation; 3) cover the key elements necessary for a shared decision process; 4) be short and easy to adapt to a variety of settings. Although the items do not cover all possible SDM behaviors, these four elements (discussion of options, pros, cons and preferences) are foundational components in widely accepted definitions [6–8].

In 2020, the investigators conducted a meta-analysis of the scores across a range of surgical decisions [9]. The findings suggested that a slight modification to the scoring would result in better performance for the scale. The new scoring was updated in the 2022 User Guide.

The survey items were adapted for a pediatric decision (medications for attention deficit hyperactivity disorder) to be completed by adult caregivers [10].

VII. Psychometric Properties:

Two papers, Valentine et al 2021 [9] and Vo et al 2022 [11], summarize psychometrics of the survey. A few highlights are included here:

<u>Floor and ceiling effects</u>: Generally, the SDM Process Scale distributions are typically normal without significant floor or ceiling effects. In a few studies, there have been quite low scores but that is likely an accurate reflection of lack of shared decision making for that clinical context (e.g., cardiology decisions regarding stents and bypass surgery) [9]. In studies where respondents scored videotaped conversations with varying amounts of SDM, the distributions tended to be normal and did not exhibit floor or ceiling effects [12].

<u>Scores</u>: While there are not clear benchmarks, the scores for cancer screening topics are typically low (ranged from 1.2 to 1.9); scores for medication decisions are a bit higher (ranged from 1.4 to 2.7) [11]; as are scores for surgery decisions (ranged from 0.9 to 2.7) [9].

<u>Clinical topics</u>: tested in many different clinical topics including:

- 1. Breast [11], prostate [11], colorectal [11], lung cancer screening [13],
- 2. Medications for depression [14], high cholesterol [11], high blood pressure [11], ADHD [10],
- 3. And surgery for hip/knee osteoarthritis, lumbar herniated disc, lumbar spinal stenosis, cataracts, coronary artery disease, and breast and prostate cancer [11]

Reliability:

- Internal consistency: the score is technically a composite and as a result, Cronbach's alpha may not be an appropriate measure of reliability, however we have calculated it for some samples and found Cronbach alphas of 0.77 for breast cancer surgery [15], 0.78 for hip and knee osteoarthritis [16], 0.54 for spine [17], 0.87 for hip and knee osteoarthritis [17].
- Retest reliability: short term (~4 week) retest reliability is generally adequate with the majority (7/8) internal correlation coefficients > 0.7 [11].

Validity

- Content validity was confirmed through the extensive feedback from patients and providers in the development process as well as in the field tests.
- Construct validity: Those who had higher SDMP scores reported:
 - o better decision quality [9,16,18],
 - higher decision confidence as measure by SURE scale [9,11],
 - higher satisfaction [18],
 - lower decision regret [9,11,18],
 - o were less likely to think they made the wrong decision [15], and
 - reported less dissonance (conflict between what was important to them and the decision that was made) [19]
 - o clinical sites that made an effort to implement SDM (with patient decision aids and/or coaching) had higher scores than usual care sites [17,20,21]

VIII. Sample size considerations

The standard deviations are typically around 1 for the measure, though do vary by topic and sample (ranging from 0.82-1.23) [9,11]. We have observed a 0.41SD - 0.84SD difference between sites that do and do not make an effort to do shared decision making [21]. A sample size of about 50-60 would be needed to detect differences in proportions of 0.5 SD for the measure with 80% power assuming standard deviation of about 1.

IX. Copyright:

The SDM Process Scale is protected by copyright. It is available to use at no cost, provided that you:

- Cite the reference in any questionnaires or publications
- Do not charge for or profit from it
- Do not alter items except for customization for a specific condition/interventions and reformatting

X: FAQ and Adaptations

Please contact <u>decisions@mgb.org</u> with any questions about adapting the survey to different clinical contexts. The following have been asked by prior users and we briefly summarize frequently asked questions and responses here.

Q: Is it ok to replace healthcare providers with 'surgeon' or 'primary care physician' or another clinician label?

Response: Yes, it is fine to replace the general term with a specific clinician.

Q: The clinical situation has more than two main options, can I still use the scale? Response: Yes, in this situation, users are able to either add items to cover the option, reasons to have and reasons not to have it for each core option. As a result, the survey will have more than four items. The scoring is scaled so that each element (option, pro, con, preference) still gets one point and total scores range from 0-4 points. We do not recommend including more than 3 options.

Q: How long is too long for the time frame?

Response: Studies have used up to a 2 year look back with adequate performance. We do recommend adding a time frame to the items (e.g., "In the past 12 months, how much did you and your healthcare providers...") if there is a long look-back period.

XI. User Guide References:

- 1. Sepucha KR, Langford AT, Belkora JK, Chang Y, Moy B, Partridge AH, et al. Impact of Timing on Measurement of Decision Quality and Shared Decision Making: Longitudinal Cohort Study of Breast Cancer Patients. Med Decis Mak Int J Soc Med Decis Mak. 2019 Aug;39(6):642–50.
- Zikmund-Fisher BJ, Couper MP, Singer E, Levin CA, Fowler FJJ, Ziniel S, et al. The DECISIONS study: a nationwide survey of United States adults regarding 9 common medical decisions. Med Decis Mak Int J Soc Med Decis Mak. 2010 Oct;30(5 Suppl):20S-34S.
- 3. Zikmund-Fisher BJ, Couper MP, Singer E, Ubel PA, Ziniel S, Fowler FJJ, et al. Deficits and variations in patients' experience with making 9 common medical decisions: the DECISIONS survey. Med Decis Mak Int J Soc Med Decis Mak. 2010 Oct;30(5 Suppl):85S-95S.
- 4. Mulley AG. Methodological issues in the application of effectiveness and outcomes research to clinical practice. In Washington D.C.: National Academy Press; 1990.
- 5. Sepucha KR, Mulley AG. Extending decision support: preparation and implementation. Patient Educ Couns. 2003 Jul;50(3):269–71.
- 6. Sepucha K, Mulley AGJ. A perspective on the patient's role in treatment decisions. Med Care Res Rev MCRR. 2009 Feb;66(1 Suppl):53S-74S.
- 7. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med 1982. 1999 Sep;49(5):651–61.
- 8. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Educ Couns. 2006 Mar;60(3):301–12.
- 9. Valentine KD, Vo H, Fowler FJJ, Brodney S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. Med Decis Mak Int J Soc Med Decis Mak. 2021 Feb;41(2):108–19.
- Valentine KD, Lipstein EA, Vo H, Cosenza C, Barry MJ, Sepucha K. Pediatric Caregiver Version of the Shared Decision Making Process Scale: Validity and Reliability for ADHD Treatment Decisions. Acad Pediatr. 2022 Dec;22(8):1503–9.
- 11. Vo H, Valentine KD, Barry MJ, Sepucha KR. Evaluation of the shared decision-making process scale in cancer screening and medication decisions. Patient Educ Couns. 2023 Mar;108:107617.
- 12. Valentine KD, Mancini B, Vo H, Brodney S, Cosenza C, Barry MJ, et al. Using Standardized Videos to Examine the Validity of the Shared Decision Making

- Process Scale: Results of a Randomized Online Experiment. Med Decis Mak Int J Soc Med Decis Mak. 2022 Jan;42(1):105–13.
- 13. Tan NQP, Nishi SPE, Lowenstein LM, Mendoza TR, Lopez-Olivo MA, Crocker LC, et al. Impact of the shared decision-making process on lung cancer screening decisions. Cancer Med. 2022 Feb;11(3):790–7.
- 14. Brodney S, Valentine KD, Vo HA, Cosenza C, Barry MJ, Sepucha KR. Measuring shared decision-making in younger and older adults with depression. Int J Qual Health Care J Int Soc Qual Health Care. 2022 Oct 12;34(4):mzac076.
- 15. Sepucha K, Feibelmann S, Chang Y, Hewitt S, Ziogas A. Measuring the quality of surgical decisions for Latina breast cancer patients. Health Expect Int J Public Particip Health Care Health Policy. 2015 Dec;18(6):2389–400.
- Sepucha K, Feibelmann S, Chang Y, Clay CF, Kearing SA, Tomek I, et al. Factors associated with the quality of patients' surgical decisions for treatment of hip and knee osteoarthritis. J Am Coll Surg. 2013 Oct;217(4):694–701.
- 17. Sepucha K, Atlas SJ, Chang Y, Dorrwachter J, Freiberg A, Mangla M, et al. Patient Decision Aids Improve Decision Quality and Patient Experience and Reduce Surgical Rates in Routine Orthopaedic Care: A Prospective Cohort Study. J Bone Joint Surg Am. 2017 Aug 2;99(15):1253–60.
- 18. Brodney S, Fowler FJJ, Barry MJ, Chang Y, Sepucha K. Comparison of Three Measures of Shared Decision Making: SDM Process_4, CollaboRATE, and SURE Scales. Med Decis Mak Int J Soc Med Decis Mak. 2019 Aug;39(6):673–80.
- 19. Fowler FJJ, Gallagher PM, Drake KM, Sepucha KR. Decision dissonance: evaluating an approach to measuring the quality of surgical decision making. Jt Comm J Qual Patient Saf. 2013 Mar;39(3):136–44.
- 20. Fowler FJJ, Sepucha KR. National Quality Forum Measure Testing Attachment for Measure 2962. Available from https://p4qm.org/measures using the Measure Database [Internet]. Available from: https://p4qm.org/measures/
- 21. Fowler FJJ, Sepucha KR, Stringfellow V, Valentine KD. Validation of the SDM Process Scale to Evaluate Shared Decision-Making at Clinical Sites. J Patient Exp. 2021;8:23743735211060812.