



Support Tools for Preference-Sensitive Decisions in Healthcare: Where Are We? Where Do We Go? How Do We Get There?

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Published online: 29 June 2019
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“Understanding and respecting patients’ values, preferences and expressed needs are the foundation of patient-centered care.” Harvey Picker [1]

In *Crossing the Quality Chasm: A New Health System for the 21st Century*, the Institute of Medicine described patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” [2]. The operationalization of patient-centered care requires shared decision-making (SDM), a process in which “patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them” [3].

SDM is on the continuum between paternalistic and informed decision-making [4]. The extremes of the continuum are characterized by unilateral decisions. In

paternalistic decision-making, the patient complies with a healthcare provider’s deliberation and decision, while in informed decision-making, the healthcare provider offers expertise and information to the patient, but deliberation and decision-making are done by the patient. In situations with limited options or room for varying preferences, e.g., in situations of high acuity and little time, patients may be content with having a healthcare provider make decisions on their behalf. However, the majority of care decisions are potentially preference sensitive, i.e., they are characterized by situations where the evidence for the superiority of one treatment over another is either not available or does not allow differentiation, and where the best choice between two or more valid approaches depends on how individuals value their respective risks and benefits [5, 6].

To date, diverse methodological and implementation challenges have limited the large-scale, systemic integration of SDM into routine clinical decision-making. For

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system-level shifts toward SDM and patient-centered care, it is critical to identify efficient means of discerning clinically relevant treatment options, characterizing them with respect to preference-relevant characteristics, eliciting valid preferences from an individual patient, and facilitating their integration into clinical decisions. SDM is deeply rooted in interpersonal relationships and interdependence [7, 8]. In this era of machine learning, development of complex algorithms and automated decision support, and an increasing focus on precision medicine, building a stronger case for interpersonal relationships and interdependence between individuals has never been more crucial.

Owing to a convergence of administrative [9] and research [10, 11] support for system-level shifts toward patient-centered care, rapid advances in health preference research (HPR) [12], and an increasing focus on the practicalities of implementing SDM and patient-centered care [13, 14], the routine elicitation and integration of patient preferences into clinical decisions is becoming a viable option. To inform research, policy, and practice aimed at providing patient-centered care, the International Academy of Health Preference Research (IAHPR), at their 2018 meeting in Montreal, Quebec, Canada, on 14 October 2018, held a symposium and panel discussion entitled “Support Tools for Preference-Sensitive Decisions”. This paper, which is one of a series of articles reflecting on key issues discussed at IAHPR meetings [15–17], summarizes the presentations and discussion.

The symposium started with panelists’ presentations in which they shared their experiences with the development and/or fielding of support tools for preference-sensitive decisions:

Dr. Deborah Marshall (DM) presented on an ongoing pragmatic randomized trial of a patient-reported outcome measures (PROMs)-based decision aid and surgeon report for total knee arthroplasty (TKA) [18]. In the context of the large (approximately 45,000 per year) and increasing numbers of knee replacements in Canada, long wait times (70% of patients receive care within the benchmark of 182 days) [19], and up to 30% of recipients being dissatisfied with the results, the goal of the aid is to improve decision quality and satisfaction by setting realistic, individual-specific expectations based on the experiences of similar individuals.

The decision aid presents patients with information on how they compare (pre-surgery) on the five dimensions of EQ-5D-5L health-related quality of life (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) relative to similar patients (matched on age, sex, body mass index), and the 3-month post-surgical outcomes of similar patients (individualized to each patient based on the aforementioned characteristics and baseline EQ-5D-5L). The aid uses a database of over 6000 TKAs in Alberta with PROMs to provide individualized information regarding the

likely outcomes of TKA. The decision aid generates a summary report that is available for review and discussion by the patient and surgeon during consultation along with an appropriateness checklist that is completed by the surgeon [20]. The appropriateness checklist was developed to assess the appropriateness of joint replacement in patients with osteoarthritis and has been used in clinical settings as part of the BEST-Knee (Best Evidence for Surgical Treatment for Total Knee Arthroplasty) prospective research study in Alberta [21].

In order to fully integrate the decision aid into routine TKA decision-making, several lessons were learned and challenges were identified: (1) embed it within the existing infrastructure; (2) leverage existing relationships at the clinic; (3) sufficient volumes of PROMs data are needed to provide individualized outcomes; (4) the need to ensure that patients complete the online decision aid before the surgeon consult visit, with adequate time for reflection; and (5) the need to collect PROMs data for patients who do not proceed to surgery for comparison.

Dr. France Légaré (FL) described the development, use, and evaluation of a decision guide to facilitate informed, value congruent decision-making related to housing decisions of the elderly in Quebec, Canada. The tool allowed for the qualitative and quantitative elicitation of patients’ priorities: individual priorities were identified qualitatively in the form of pros and cons for alternative care arrangements; their value was described using quantitative importance ratings. The training of care teams in the use of the tool resulted in increasing confidence levels among providers, and facilitated the capture and use of relevant information in a large-scale, ongoing trial. Evidence suggests positive ratings by home care teams, improved participation in decision-making by caregivers of cognitively impaired older adults, and a greater match between caregivers’ preferred and actual participation in decision-making; the evidence also highlights limitations due to cognitive abilities among impaired seniors and complicated decision-making situations [22–24].

Dr. Janine van Til (JT) presented the results of a systematic review of value clarification methods (VCMs)—strategies intended to help patients evaluate the desirability of diverse feasible options to determine which option they prefer [25]. After describing various VCM approaches (e.g., option grids, rating scales, pros and cons) and highlighting the diversity of underlying theories (e.g., expected utility theory, conjoint analysis, multi-attribute utility theory), Dr. van Til characterized VCMs for patients with prostate cancer with respect to the characteristics and prioritization of attributes, the design and implementation of survey instruments (generally implemented using adaptive conjoint analysis), and the presentation of results. The summary was followed by a case study that described how personalized attribute selection and preference elicitation using an analytical

hierarchy process (AHP) can be incorporated into a decision aid that is prospectively being evaluated in clinical practice.

Dr. Jan Ostermann (JO) presented on challenges faced in the development of a decision support tool for the preference-concordant selection of antiretroviral regimens (ARVs) for the treatment of HIV. He highlighted methodological challenges related to the large number of available treatment options, a similarly large number of preference-relevant characteristics of ARVs [26], and substantial preference heterogeneity in the patient population. Additional challenges related to incomplete, inconsistent, and/or changing clinical trials evidence, scientific and statistical uncertainty surrounding estimates of preference-relevant characteristics of ARVs, such as risks of adverse effects and long-term complications, and frequently non-definitive treatment guidelines, all of which complicate the translation of treatment options into patient-relevant information, decision rules, and/or weights in a decision support tool.

Dr. Nick Bansback (NB) presented a framework for pathways or policy options aimed at improving the uptake of information on patient preferences in clinical practice. Eight options, along a push–pull continuum, were mentioned as potential means of increasing the value attributable to patient preference information and facilitating its widespread use:

- demonstrate that clinicians’ consideration of patient preferences improves outcomes;
- help clinicians feel like they are doing a better job;
- provide better and more accessible tools;
- help clinicians save time;
- provide protection against litigation;
- have patients demand it;
- have payors require it; or even
- pay clinicians to do it.

Dr. Bansback further described experiences with and lessons learned from the development and use of a versatile decision support platform.

1 Where Are We?

With rapid technological advances, artificial intelligence, machine learning, and the robotization of decision support and decision-making activities, ever more preventive, curative, and palliative care decisions are becoming potentially preference sensitive. Never have we as a society been exposed to a more urgent need in delineating what is ‘optimal’ preference elicitation and decision-making support, as this is at the core of an ethical approach to decision-making. There is a growing body of evidence that preference-concordant care can improve patient satisfaction [27] and health outcomes [28]. The SDM process with its two-way

information exchange—healthcare providers provide information based on their expertise, and patients inform their providers about their concerns, values, and preferences—is the key to optimizing healthcare decision-making.

The presentations and subsequent discussion highlighted the fact that there are no standardized or generalizable ways of conducting SDM. On the one hand, this leaves us with perhaps more variation in clinical practice than may be optimal. It is unclear if practice varies due to SDM approaches or actual differences in patient and provider preferences. On the other hand, a single, idealized approach to SDM does not exist, and the innovations to improve SDM covered in the symposium should be viewed as a progression toward better integration of patient perspectives with the evidence base, leading to informed value-congruent decisions.

2 Where Do We Want To Go?

SDM’s defining characteristic, the concerted selection of the best course of action by patients and providers, requires a shared understanding of patient preferences and clinically relevant treatment options, and a joint decision-making process. The systemic integration of SDM into clinical practice requires the availability, accessibility, and use of tools that facilitate the communication of patient preferences to providers, the communication of the characteristics of potential courses of action and their consequences to patients, and systematic deliberation and joint decision-making. It also requires the skills needed by clinical teams to operationalize SDM [29]. The standardization of these processes will ensure that variation in clinical decision-making across patients is the result of heterogeneity in treatment preferences and clinical indications, and not the result of limited information flow, or heterogeneity in SDM participation preferences by either patients or providers.

3 How Do We Get There?

The symposium discussion highlighted the oft-made observation that SDM can bridge the paternalistic versus informed decision-making divide. Yet, the ideal implementation of SDM is elusive. One clinician’s or researcher’s perspective may clash with another’s or with that of his or her own patients, returning us back to the origin, or to one view at the expense of another. HPR can potentially solve this dilemma by reminding us all that SDM relies on information flow based on optimal interpersonal relationships, and by providing support tools for effectively and efficiently carrying out SDM.

To accomplish this, clinical guidelines should include patient perspectives informed by HPR, and clinical teams

require relevant training. This serves as a conduit between the patient population and clinical practice. Rather than a naive one-size-fits-all approach, modern HPR must take into account heterogeneity in preferences and nuances of the populations and clinical domains when building a decision aid. The presentations by DM, FL, and JT provided examples of this. In practice, this might be as simple as a conversation between the provider and the patient, using HPR-informed SDM support tools as a starting point. The dialog helps the clinician (and the patient) to understand the individual patient's preferences and tailor the healthcare experience. The presentation by JO covered challenges of actually carrying this out, while NB's talk covered eight options and considerations during this process.

Symposium discussions on the next steps toward the development and integration of support tools in preference-sensitive decisions centered on three 'A's: Accountability, Accessibility, and Adaptability.

Accountability requires the development and implementation of a legal, regulatory, and administrative framework for the use of preference-oriented decision support tools. Critical to this framework is the involvement of regulators and payers, and appropriate institutional oversight, e.g., by institutional review boards. Litigation is also a concern as it is closely associated with decision regret [30].

Accessibility is critical to the large-scale adoption of support tools, and to achieving buy-in from patients and clinicians. This requires a systematic identification of decision points, the characterization of preference-relevant aspects of these decisions, and their effective communication to patients. Costs for development, implementation, and maintenance of the technological and human resource infrastructure to support preference-relevant decisions were mentioned as a major potential barrier. An open-source mandate from funders, and contributions from payers, patients and providers, were discussed as potential funding options for development and fielding of support tools. The increasing connectivity of patients and providers was discussed as providing new opportunities for communication outside of the traditional in-person encounter between patients and providers. It also requires additional training of clinical teams.

Adaptability was a common theme in the discussion, as support tools must be flexible enough to accommodate changes in preferences, technologies, and evidence over time. This area seems particularly challenging and will need to be considered by future researchers and clinicians. Key points include the adaptation of SDM to reflect dynamic clinical trials evidence and a changing evidence base, changing technologies, and the potential role of electronic medical records. As daunting as some of these may feel, this is not new or unique to HPR and SDM. Science must always adapt, and clinical guidelines are revisited regularly by professional associations, panels, and advisory boards.

4 Conclusion

The need for SDM can be viewed as a consequence of the advancement of modern medicine. Historically, not only was medicine paternalistic in nature, but there were few (legitimate) options available for treatment. Early cancer treatment was limited to surgery only; and not until 1903 did radiation therapy become an option [31]. Decades later, however, we have an amazing array of potential alternatives for many chronic and acute conditions, which can be overwhelming for clinicians without guidelines, and overwhelming for patients without SDM. HPR holds the potential to provide the critical tools required for the advancement of SDM and to fully utilize clinical advancements. By facilitating the communication of preferences between patients and providers, and assisting with valuations, we are positioned to move into the era of patient-centered care and precision medicine with greater confidence and, potentially, economic efficiency.

Compliance with Ethical Standards

Conflict of interest All authors declare that they have no conflict of interest.

References

1. Picker Institute. Patient-centered care: the road ahead. Picker Institute; 2013. <http://ipfcc.org/resources/Patient-Centered-Care-The-Road-Ahead.pdf>. Accessed 21 Jun 2019.
2. Institute of Medicine (US) Committee on Quality of Health Care in America. In: Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academies Press (US); 2001.
3. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. *BMJ*. 2010;341:c5146.
4. Friesen-Storms JH, Bours GJ, van der Weijden T, Beurskens AJ. Shared decision making in chronic care in the context of evidence based practice in nursing. *Int J Nurs Stud*. 2015;52(1):393–402.
5. Wennberg JE. Unwarranted variations in healthcare delivery: implications for academic medical centres. *BMJ*. 2002;325(7370):961–4.
6. Elwyn G, Frosch D, Rollnick S. Dual equipoise shared decision making: definitions for decision and behaviour support interventions. *Implement Sci*. 2009;4:75.
7. Légaré F, Moumjid-Ferdjaoui N, Drolet R, et al. Core competencies for shared decision making training programs: insights from an international, interdisciplinary working group. *J Contin Educ Health Prof*. 2013;33(4):267–73.
8. Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff (Millwood)*. 2013;32(2):276–84.
9. Frampton S, Guastello S, Brady C, et al. Patient-centered care improvement guide. Derby: Planetree; 2008.
10. PCORI. Patient-Centered Outcomes Research Institute. 2019. <https://www.pcori.org/about-us>. Accessed 26 June 2019.

11. National Institutes of Health. All of Us Research Program. 2019. <https://allofus.nih.gov/>. Accessed 26 June 2019.
12. Craig B, Lancsar E, Mühlbacher A, Brown D, Ostermann J. Health preference research: an overview. *The Patient*. 2017;. <https://doi.org/10.1007/s40271-017-0253-9>.
13. Robert Wood Johnson Foundation, AcademyHealth. Moving patient-centered care forward: how do we get there? 2018. https://www.academyhealth.org/sites/default/files/movingpatientcentercareforward_october2018.pdf. Accessed 21 Jun 2019.
14. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361–7.
15. Groothuis-Oudshoorn CGM, Flynn TN, Yoo HI, Magidson J, Oppe M. Key issues and potential solutions for understanding healthcare preference heterogeneity free from patient-level scale confounds. *Patient*. 2018;11(5):463–6.
16. Gonzalez JM, Johnson FR, Levitan B, Noel R, Peay H. Symposium title: preference evidence for regulatory decisions. *Patient*. 2018;11(5):467–73.
17. Norman R, Craig BM, Hansen P, et al. Issues in the design of discrete choice experiments. *Patient*. 2019;12(3):281–5.
18. Bansback N, Trenaman L, MacDonald KV, et al. An individualized patient-reported outcome measure (PROM) based patient decision aid and surgeon report for patients considering total knee arthroplasty: protocol for a pragmatic randomized controlled trial. *BMC Musculoskelet Disord*. 2019;20(1):89.
19. Canadian Institute for Health Information. Wait times for priority procedures in Canada. 2019. <https://www.cihi.ca/en/wait-times-for-priority-procedures-in-canada>. Accessed 26 June 2019.
20. Hawker G, Bohm ER, Conner-Spady B, et al. Perspectives of Canadian stakeholders on criteria for appropriateness for total joint arthroplasty in patients with hip and knee osteoarthritis. *Arthritis Rheumatol*. 2015;67(7):1806–15.
21. Marshall D, Faris P, Jones A, et al. Relationship between appropriateness and arthroplasty recommendation. *Int J Technol Assess Health Care*. 2019;34(S1):58–9.
22. Adekpedjou R, Stacey D, Briere N, et al. Engaging caregivers in health-related housing decisions for older adults with cognitive impairment: a cluster randomized trial. *Gerontologist*. 2019. <https://doi.org/10.1093/geront/gnz045> (Epub 2019 May 16).
23. Adekpedjou R, Stacey D, Briere N, et al. “Please listen to me”: a cross-sectional study of experiences of seniors and their caregivers making housing decisions. *PLoS One*. 2018;13(8):e0202975.
24. Haesebaert J, Adekpedjou R, Croteau J, Robitaille H, Legare F. Shared decision-making experienced by Canadians facing health care decisions: a web-based survey. *CMAJ Open*. 2019;7(2):E210–6.
25. Fagerlin A, Pignone M, Abhyankar P, et al. Clarifying values: an updated review. *BMC Med Inform Decis Mak*. 2013;13(Suppl 2):S8.
26. Yelverton V, Ostermann J, Hobbie A, Madut D, Thielman N. A mixed methods approach to understanding antiretroviral treatment preferences: what do patients really want? *AIDS Patient Care STDS*. 2018;32(9):340–8.
27. O’Connor AM, Rostom A, Fiset V, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. *BMJ*. 1999;319(7212):731–4.
28. Preference Collaborative Review Group. Patients’ preferences within randomised trials: systematic review and patient level meta-analysis. *BMJ*. 2008;337:a1864.
29. Legare F, Adekpedjou R, Stacey D, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev*. 2018;7:CD006732.
30. Durand MA, Moulton B, Cockle E, Mann M, Elwyn G. Can shared decision-making reduce medical malpractice litigation? A systematic review. *BMC Health Serv Res*. 2015;15:167.
31. American Society of Clinical Oncology. Cancer progress timeline. 2019. <https://www.asco.org/research-progress/cancer-progress-timeline>. Accessed 26 June 2019.