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## How should decision aids be developed and which patient outcomes should be assessed? Comments on Tilburt et al

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We have read with great interest the recent article by Tilburt et al, published in *Cancer*<sup>1</sup>. The article describes the results of a small multicenter cluster randomized controlled trial during which 21 urology practices which are affiliated with NCORP sites were randomized to implement two different types of decision aids either prior to the clinical visit (i.e., previsit DA), during the clinical visit (within-visit DA), during both times (i.e., pre and within), or usual care.

Results showed that the investigators succeeded in recruiting a large proportion of minority men into the study from urological practices. This is an important achievement, as prostate cancer is usually diagnosed in community settings, but most research is being conducted in regional cancer centers. Thus, the ability to conduct a trial successfully in the community setting is an important contribution. We are not surprised of the null result of prostate cancer knowledge. Tilburt et al., note that in past research, knowledge has not been notably associated with the use of decision aids; hence the decision to focus on knowledge as the primary outcome is puzzling. Knowledge has played an outsized role in the judgement and decision-making literature, driven by the common belief that a patient needs to be informed to make a medical decision. We are not arguing with this core assumption, however, we ask investigators to think about what “being informed” really means for individual patients. It has been well-established that patients’ approach to decision-making does not necessarily follow a rational model.<sup>2</sup> Instead, patients’ understanding and decisions are influenced by beliefs and expectations, swayed by affect, and guided by opinions from experts and non-experts alike.<sup>3,4</sup> When asked, patients generally agree that they feel informed. However, given these myriads of influences, knowledge as a measure of decision making is clearly suboptimal.

Which outcome measures should then be used? Before we answer this question, we suggest that the design and format of decision aids be reconceptualized, followed by the development of appropriate assessment tools. We recommend that the clinical encounter should primarily focus on patients’ treatment preferences. Rather than starting

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the consultation process with detailed information about all available options, our team has developed an approach that focuses on assessing patients' initial thoughts about their prostate treatment options. These initial "leanings" are a perfect transition to discussing options that are relevant to the patient, to educate about alternative options, and to derive a shared decision. Most importantly, the patient becomes an active participant in the decision-making process. To standardize this elicitation process, we have developed a web-based software that leads the patient through a series of basic questions about their preferences for treatment options (e.g., do you prefer to be treated now or to be actively monitored by your physician?). Physicians use the results of this process to shape their consultation with the patient. The preference elicitation process can be done prior to or during the clinical encounter. Another important component is to provide communication training to physicians to allow providers to take advantage of this shared-decision making approach. Finally, returning to the questions of outcome measures, we suggest that assessments of preference-congruent decisions and decisional regret be used within days or weeks of the decision.

### References:

1. Tilburt JC, Zahrieh D, Pacyna JE, et al., Decision aids for localized prostate cancer in diverse minority men: Primary outcome results from a multicenter cancer care delivery trial (Alliance A 191402D). *Cancer*, published online Month 00, 2021 in Wiley Online Library
2. Slovic P, Finucane ML, Peters E, & MacGregor DG (2004). Risk as analysis and risk as feelings: Some thoughts about affect, reason, risk, and rationality. *Risk Analysis*, 24(2), 311–322. 10.1111/j.0272-4332.2004.00433.x [PubMed: 15078302]
3. Shen MJ, Nelson CJ, Peters E, Slovin SF, Hall SJ, Hall M, Herrera PC, Leventhal EA, Leventhal H, Diefenbach MA (2015) Decision-making Processes among Prostate Cancer Survivors with Rising PSA Levels: Results from a Qualitative Analysis. *Med Decis Making*. 35(4):477–86. 10.1177/0272989X14558424.x [PubMed: 25385751]
4. Peters E, Lipkus I, & Diefenbach MA (2006). The functions of affect in health communications and in the construction of health preferences. *Journal of Communication*, 56(Suppl 1), S140–S162. 10.1111/j.1460-2466.2006.00287.x