Integrated Citizen Centered Digital Health and Social Care
A. Värri et al. (Eds.)

doi:10.3233/SHTI200693

Measures of Decision Aid Quality Are Preference-Sensitive and Interest-Conflicted - 2: Empirical Measures

Jack DOWIE[a][b][1], Mette Kjer KALTOFT[b] and Vije Kumar RAJPUT[c]
[a]*London School of Hygiene and Tropical Medicine*
[b]*University of Southern Denmark*
[c]*Stonydelph Health Centre, Tamworth, UK*

Abstract. Empirical measures of 'decision aid quality', like normative ones, are of a formative construct and therefore embody interest-conflicted preferences in their criteria selection and weighting. The preferences of the International Patient Decision Aid Standards consortium distinguish the quality of the decision-making process and the quality of the choice that is made '(i.e., decision quality)'. The Decision Conflict Scale features heavily in their profile measure of the former and Decision Quality Instruments (DQIs), have been developed by members of the consortium to measure the latter. We confirm that both of these, and other components, like the higher-level measures, are preference-sensitive and interest-conflicted. Non-financial interest-conflicted preferences are endemic in healthcare research, policy-making, and practice. That they are inevitable means the main problem lies in the denial of this and attitude to and behaviour towards alternatives, equally interest-conflicted.

Keywords: Decision aid, empirical evaluation, IPDAS, Decision Conflict Scale, Decision Quality Instrument, conflict of interest

1. Introduction

In the companion paper [1] it was established that quality is a formative construct and measures of it are therefore preference-sensitive. They are sensitive to the preferences involved in the selection of the component scales (items) and to the weights used to aggregate those scales into an index measure. The measurement of the quality of a decision aid is no exception. The popular International Patient Decision Aid Standards measure, with its proposed 'certification' standard, reflects the preferences emerging from the consortium responsible for its development and maintenance. It was also established that, given the expanded definition of 'interest' relevant in healthcare research and provision, which include commitments to particular theoretical, methodological and ethical frameworks, institutional practices and schools of thought [2], the IPDASi measure is interest-conflicted. However, it was emphasised that this applies to all related measures, so the only possible objections can be to failure to

---

[1] Corresponding author, Jack Dowie, LSHTM, 15-17 Tavistock Place, London, UK WC1H 9SH; email: jack.dowie@lshtm.ac.uk

acknowledge the formative ontology of the measure, to attempts to establish the measure as a 'gold standard', and to criticism of alternatives on the ground that they reflect interest-conflicted preferences.

In this paper we focus on the empirical measurement of the quality of decision aids *as implemented*. We make clear from the outset here that our overriding preference is to avoid all normative measures, whether IPDASi or ones based on alternative interest-based preferences. Normative considerations should exert influence, but only via empirical outcome quality constructs, not independently or *a priori*. Notwithstanding, empirical measures, like normative measures, are of some formative construct of decision aid quality, so the task is again to demonstrate that they embody interest-conflicted preferences through their criteria selection and weighting. Conceptually, these alternatives will be measures of *different constructs* of decision aid quality rather than *different measures* of decision aid quality, which does not exist until it is formed.

While we again focus on the IPDAS position [3] it is appropriate to start with the conclusion from the latest Cochrane review, which was framed within it. “When people use decision aids, they improve their knowledge of the options (high-quality evidence) and feel better informed and more clear about what matters most to them (high-quality evidence). They probably have more accurate expectations of benefits and harms of options (moderate-quality evidence) and probably participate more in decision making (moderate-quality evidence). People who use decision aids may achieve decisions that are consistent with their informed values (evidence is not as strong; more research could change results). People and their clinicians were more likely to talk about the decision when using an aid. Decision aids have a variable effect on the option chosen, depending on the choice being considered. Decision aids do not worsen health outcomes, and people using them are not less satisfied. More research is needed to assess if people continue with the option they chose and also to assess what impact decision aids have on healthcare systems.“ [4] (p3).

While of some interest, both these overall conclusions and the underlying meta-analyses are of questionable benefit. It is hard to imagine any decision maker deciding whether or not to use '*a* decision aid', any more than they would be deciding whether or not to prescribe '*a* drug' or perform '*an* operation'. The meaningful decision is whether to use *this or that or no* decision aid - this or that type of drug or none, this or that type of surgery or none. So, it is the reports and assessments of the individual studies they review that are of real value. As implied in the overall conclusions, a wide range of 'outcome' criteria are reported in these and the way these are brought (or not brought) into the evaluation of a decision aid is preference-sensitive and interest-conflicted.

2. IPDAS on Decision Aid 'Effectiveness'

Apart from developing its normative instrument, the International Patient Decision Aid Standards consortium has also published its preferences in relation to the empirical measurement of individual decision aid quality [3]. An umbrella concept is introduced – effectiveness – under which two separate constructs and measures are advanced. As before the purpose of quoting at length is to establish that preferences are clearly embedded in making this split, as well as in the selection of items and metrics. This is not made explicit in the presentation, which includes several 'shoulds'.

“To establish the effectiveness of a PtDA [Patient Decision Aid], it is critical to provide evidence that the PtDA improves two constructs: i) the quality of the decision-making process and ii) the quality of the choice that is made (i.e., ‘decision quality’)… For the *quality of the decision-making process*, the core attributes that *should* be measured include the extent to which PtDAs help patients to: • Recognize that a decision needs to be made (e.g., as measured by items in the Preparation for Decision Making Scale. • Feel informed about the options and about the risks, benefits, and consequences of the options (e.g. as measured by the “Feeling Uninformed” subscale of the Decisional Conflict Scale). • Be clear about what matters most to them for this decision (e.g. as measured by the “Unclear Values” subscale of the Decisional Conflict Scale. • Discuss goals, concerns, and preferences with their health care providers (e.g. as measured by items in the Perceived Involvement in Care Scale. • Be involved in decision making (e.g., as measured by the Control Preferences Scale and adaptations of it)… *The quality of the choice that is made, or decision quality*, is defined as the extent to which patients are informed and receive treatments that reflect their goals and treatment preferences. It follows from this construct definition that two core attributes *should* be measured: • Informed patient: This attribute is measured by assessing a patient’s knowledge of the options and outcomes. It is not assessed in terms of patient perceptions of their knowledge level; instead, factual items are used to assess objectively a patient’s understanding of the information. This may, when applicable, include an assessment of whether or not the patient holds realistic expectations of risks and benefits. • Concordance between what matters most to the patient and the chosen option: Most approaches to measuring this attribute require (1) the elicitation of a patient’s goals and/or treatment preferences; (2) the identification of the patient’s chosen or implemented option; and (3) a calculation of the extent to which the option best meets the patient’s stated goals or treatment preferences.” [4] (p2) (italics supplied).

3. Two Decision Quality Measures

In the space available here we focus on the Decision Quality Instruments (DQIs), developed by members of the IPDAS consortium to measure ‘the quality of the choice that is made, or decision quality’, and on the Decision Conflict Scale which features heavily in their profile measure of the ‘quality of the decision making process’.

As a *profile* measure, a DQI produces two scores. The *DQI-Knowledge Score* is the percentage of correct responses to a set of questions. A threshold for considering a patient to be ‘well-informed’ is set, using (if available) the mean knowledge score for a group of patients who have viewed a decision aid. The *DQI-Concordance Score* measures ‘the extent to which patients received treatments that reflected what is most important to them’. A binary *Decision Quality Composite Score* is created with a score of 1 for patients who were well-informed *and* received treatments matching their preferences, 0 for all others. The DQI composite score is only at the group level, available only after follow-up months after the decision, and being binary does not provide a scalar index measure. So DQIs are essentially research tools, not ones to be used in real time within clinical practice. They are not preference-sensitive index measures, assessed and available immediately after the point of decision, and before any deliberation occurs, any decision is taken, any actions engaged in, or outcomes known. In all these respects they reflect interest-conflicted preferences orthogonal to ours.

While the Decisional Conflict Scale may be a valid measure for the eponymous construct (i.e. decision *conflict*) - it lacks content validity for this task because of the 3 items which make up its Uncertainty subscale. ('This decision is easy for me to make', 'I feel sure about what to choose' and 'I am clear about what choice is best for me'.) These penalize an aid that correctly reports the situation as one of decisional equipoise or near equipoise, a 'false clarity' bias being rewarded. In 20 of the Cochrane studies reporting all subscales, the Uncertainty score was 46% higher than the average of the other four in the decision aid arm, thereby reducing the effect of the decision aid relative to usual care. The 4-item SURE version of DCS is even more prone to this bias [5].

4. Discussion

It is time to summarise our interest-conflicted preferences, scattered throughout the above, or only hinted at. Our preferred decision support tool displays a Decision Opinion as the expected value of each option, produced by applying the criterion weights of the decision owner to the performance ratings of each option on each criterion. Our (interest-conflicted) preference is for the quality of the tool to be measured at each use, empirically (not normatively) and comparatively, with genuine usual care as the mandatory comparator in order to avoid interest-conflicted Partial Or Non-Comparative Evaluation (PONCE) [6]. This measurement is to occur in the decision making setting immediately after engagement with the tool, in order that the tool's Decision Opinion Quality is minimally confounded by any subsequent discussion or decision. The Decision Opinion Quality of the 'usual care' comparator is to be measured separately and independently, in maximal ignorance of the contents or Opinion of the tool, to further avoid bias from PONCE. Our (interest-conflicted) preferences for this quality assessment exclude, in agreement with Elwyn and Miron-Shatz [7], any objective assessment of the knowledge of any party to the decision. (Apart from its unknown relevance in the decision, such a 'knowledge'- assessing instrument is of a formative construct and therefore preference-sensitive and interest-conflicted.) They also exclude, again in agreement with Elwyn and Miron-Shatz, all 'downstream' outcomes of any sort, whether they relate to the health consequences of actions taken as a result of the eventual decision, or any later psychological/affective effects such as experienced regret. (*Anticipated* regret is assumed to be a key input into criterion weighting). Finally, they exclude any concern with the extent to which any elicited intention, or subsequent behaviour 'matches' the values expressed by the user during engagement with the tool.

Historically, there was passing interest in PtDAs based on Decision Analysis - Dolan 2002 [8], Montgomery 2003 [9], Bekker 2004 [10] - which came close to meeting the above preferences. These Cochrane-included trials had positive outcomes, but the reported 'obstacles' in delivery and clinician acceptance undoubtedly contributed to their demise, along with paternalistic projection on to patients: '… there are concerns that encouraging individuals to adopt this more systematic approach to making choices places an additional burden on the decision process that may lead to greater distress, decisional conflict and post-choice regret.' [10] (p266). As seen above, our preferences rule out decision conflict and post-choice regret as relevant criteria.

Potential 'distress' becomes a criterion for the decision owner to weight in deciding whether or not to engage with 'a systematic process'.

5. Conclusion

Non-financial interest-conflicted preferences are endemic in healthcare research, policy-making and practice. The fact that they are essential, as well as inevitable, means that the problem lies in their denial or disguise. Paradoxically, much high-quality research into decision support is undertaken by researchers hostile to positivist methodologies. But implying that a formative construct is reflective, or can be treated as such, because it embodies widely-supported preferences in line with current practices, is essentially positivistic. This needs to be explicitly acknowledged. Spelling out our preferred measure for evaluating decision aids, or introducing other non-IPDAS measures, has not been the aim. It is limited to establishing that a 'level playing field' must acknowledge that all quality measures are preference-sensitive and interest-aligned, if not interest-conflicted. The preservation of existing structures and practices in healthcare research and provision may not be an interest embedded in some alternative constructs and measures of decision aid quality.

References

[1] Dowie J, Kaltoft MK. Measures of decision aid quality are preference-sensitive and interest-conflicted - 1: normative measures. Stud Health Technol Inform. 2020.
[2] Wiersma M, Kerridge I, Lipworth W, Rodwin M. Should we try to manage non-financial interests? BMJ. 2018 361:k1240.
[3] Sepucha KR, Borkhoff CM, Lally J, Levin CA, Matlock DD, Ng CJ, et al. Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. BMC Med Inform Decis Mak. 2013 13:S12.
[4] Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Syst Rev. 2017:4.
[5] Kaltoft MK, Nielsen JB, Dowie J. The evaluation of decision support tools requires a measure of decision quality that has content and construct validity in person-centred care. Stud Health Technol Inform. 2018 247:331–335.
[6] Dowie J. The danger of partial evaluation. Health Care Anal. 1995 3:232–4
[7] Elwyn G, Miron-Shatz T. Deliberation before determination: The definition and evaluation of good decision making. Health Expect. 2010 13(2):139–47.
[8] Dolan JG, Frisina S. Randomized controlled trial of a patient decision aid for colorectal cancer screening, Med Decis Making. 2002 22(2):125–39.
[9] Montgomery AA, Fahey T, Peters TJ. A factorial randomised controlled trial of decision analysis and an information video plus leaflet for newly diagnosed hypertensive patients. Br J Gen Pract. 2003 53 (491):446–53.
[10] Bekker HL, Hewison J, Thornton JG. Applying decision analysis to facilitate informed decision making about prenatal diagnosis for Down syndrome: A randomised controlled trial. Prenat Diagn. 2004 24(4): 265–75.