

The Evaluation of Decision Support Tools Needs to Be Preference Context-Sensitive

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Abstract. Individuals have different preferences in how they wish to relate to healthcare professionals such as doctors. Given choice, they also have preferences in relation to the type and location of support they want for their health and healthcare decisions. We argue that preference-based clusters within this heterogeneity constitute different contexts and that evaluations of decision aids should be context-sensitive in this respect. We draw attention to two distinct preference-based clusters: individuals with a preference for ‘intermediative’ decision support as a patient, implemented in a largely qualitative deliberative model, on the one hand, and for ‘apomediative’ decision support as a person, implemented in a largely quantitative multi-criteria decision analytic model, on the other. For convenience, we refer to the latter as Person Decision Support Tools (PDSTs), leaving Patient Decision Aids (PDAs) for its former, conventional use. Seeking to establish proof of method, we present an online PDST that can help individuals establish which of these two types of decision support they would find optimal. It is based on nine key attributes on which PDAs and PDSTs can be contrasted. Within population heterogeneity, preference clusters should be identified, and acknowledged and respected as contexts relevant to the evaluation of decision support tools.

Keywords. Patient decision aid, person decision support tool, decision quality, apomediation, intermediation, shared decision making, preferences

1. Introduction

In a much-needed reminder that shared decision making is a means to an end, not an end in itself, Barry and co-authors argue that the ultimate product of a shared decision making process - indeed of any decision making process - is the *decision* [1]. The primary outcome in the evaluation of any decision-making process, perhaps especially a decision-aided one, should therefore be the *quality* of that decision. It is somewhat surprising, then, that the latest systematic review concluded that, while patient decision aids used in clinical encounters significantly increased patients’ knowledge, lowered decisional conflict, increased observation-based assessment of shared decision making, and satisfaction with the decision-making process, decision quality was not mentioned as an outcome anywhere in the research covered [2]. Among the possible explanations, we suggest here that it is because *decision quality*, as a formative construct, requires measurement which is both context- and preference-sensitive. It follows that both types of sensitivity are needed in evaluating any decision making process (including shared

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decision making), in evaluating any decision aids designed to support decision making (whether ‘shared’ or not), and in evaluating any instrument proposed to evaluate either.

The vast majority of health decisions taken by individuals are *preference-sensitive*. Multiple considerations – various benefits and harms - are relevant and decisions require the relative importance of each to be established, indicating the trade-offs they are willing to make among them. Any decision aid needs to recognise and reflect the multi-criterial and preference-sensitive nature of health decisions. In the context of person-centred health decisions the relevant preferences are those of the individual person (patient-as-person, not as patient) elicited at the point of care [3]. The individual’s preferences cannot be treated as just further epidemiological characteristics, to be added to their age, sex, location, or literacy level [4]. This ontological transgression is committed in any clinical or clinical guideline context when the person’s preferences are regarded as adequately captured by the dependent variable in a group-based regression equation which employs their epidemiological characteristics as the independent variables.

This offence can, however, only occur in the clinical setting. Elicitation and use of average group preferences is valid and necessary in policy development and decision making. Here the key issue becomes the appropriate level of aggregation and hence the appropriate context for analysis and evaluation. It is clear from clustering studies that preference-based sub-groups exist in most populations in relation to many, if not most, health-related conditions. As just one example, in the case of PSA screening for Prostate Cancer, preference-based sub-groups are constituted by the different relative importance attached to avoiding prostate cancer on the one hand and experiencing the impotence and incontinence side effects of treatment on the other [5]. In this paper we argue that a preference cluster constitutes a context and that evaluations of decision aids and decision quality should be sensitive to preference-defined contexts.

Preferences may relate to states, as in the PSA screening case, or to processes. Here we pursue the notion of preference-based contextualisation in the provision of decision support processes that can potentially enhance decision quality. If there is surprise that *cognition-based contexts* are being proposed, it is worth pointing out that contextualisation on the basis of *cognitive pathology* is well accepted in mental health. And, beyond health, segmentation on the basis of the preferences of consumers – in most cases assumed to be in ‘normal’ health – is the accepted basis of marketing success.

2. Preference-Based Contexts for Decision Support

As stated at the outset, a vital contribution made by the Barry piece is in pointing to the context-sensitivity of the definition and measurement of shared decision making. They note that the National Quality Forum definition does not specify how or where it might take place and that patients and clinicians interact in many ways - phone conversations, virtual visits, email, and web portals are all ways of communicating about a decision.

Furthermore, they acknowledge that personal preferences will affect not only the type and location of shared decision making, but whether it occurs. Crucially for this paper they draw attention to their earlier study [6] in which it was found that 38% of men given a decision aid on PSA screening for prostate cancer outside a visit wanted to make the decision themselves *before* viewing it. This figure rose to 43% *after* viewing the aid. ‘In the face of such strong data, should we still require these men to come in for an additional face-to-face visit to say that shared decision-making happened?’ ask the authors. Finally, they note that the Cochrane review showed that the use of patient

decision aids is linked to improvements in ‘decision quality’ in the domains we have discussed, including knowledge, involvement, and match between values and choices, without apparent harms [7]. ‘These benefits were seen regardless of whether the patient decision aids were used within or outside of clinician visits.’

It is clear from this, and many other studies (including on internet searching), that individuals have heterogeneous preferences in relation to the way they wish to relate to health professionals (especially doctors); also, that given choice, they have preferences in relation to the type and location of support they prefer for their health decisions. At the moment they have limited choice, especially where only licenced practitioners can perform some actions (diagnose conditions, prescribe many medications). But the scope for autonomous choice is expanding rapidly as the digital paradigm envisaged by futurists such as Eric Topol [8], Robin Farmfarmanian [9], and Bertalan Mesko and Dave deBronkart [10], encroaches on the status quo. In the not too distant future *self-production* of health is supplemented by its *co-creation* undertaken in collaboration with a healthcare professional; a process akin to ‘shared decision making’ but only when the empowered person is the driver [11].

The mainstream orthodoxy in relation to decision support for individual’s health decisions focuses on just one context, that of Shared Decision Making (SDM) between clinician (or clinical team) and patient. This SDM can be facilitated by Patient Decision Aids such as Option Grids [12], assessed normatively by IPDASi standards [13]. The extent to which the SDM occurs in deliberative consultations is to be measured by instruments such as OPTION [14]. Empirical implementations of the PDAs are to be evaluated by DQIs [15]. (We cite only Dartmouth-Boston examples; others exist.)

To make clear the existence of at least one other major context, we draw attention to two distinct preference-based clusters in the population: individuals with a preference for *intermediative* decision support as a patient, implemented in a largely qualitative *deliberative* model on the one hand, and for *apomediative* decision support as a person, implemented in a largely quantitative *multi-criteria decision analytic* model on the other. For convenience we will refer to the latter as *Person* Decision Support Tools (PDSTs), leaving *Patient* Decision Aids (PDAs) for its former, conventional, use.

Following Eysenbach [16] decision support is ‘apomediative,’ when the resources involved are produced independently of the provider of the good or service in question (apo = away from) and are delivered publicly accessible ‘direct to *person*’ in the community. Familiar examples of apomediative decision support resources, based on largely quantitative multi-criteria decision analytic models, are the proliferating product and service comparison websites, such as ‘Which’ in the UK, ‘Consumer Reports’ in the US, and ‘Taenk’ in Denmark. Apomediation is distinguished from ‘intermediation,’ where the provider develops a decision support resource on the basis of their perceptions and decisions as to what the *patient* can benefit from, as well as their in/ability to deliver options that could potentially be covered in the resource. Intermediation is not provider-independent and options present in an apomediative aid may be censored or filtered on the basis of the beliefs, values, and interests of providers – and any other stakeholders involved in intermediative aid development. Public access PDSTs which constitute the main type of apomediative resource, eschew such option censoring or filtering, seeking to supply high quality independent guidance without conflicts of interest of any sort.

Apomediation is to be distinguished from ‘dis-intermediation,’ where the individual (sometimes a dissatisfied patient) attempts to find what they want without help from healthcare providers, for example by doing anonymous internet searches. Apomediation can therefore be seen as acknowledging some of the motivations underlying dis-

intermediation but seeking to supply a better alternative to Dr Google - one which will be superior, or inferior, to intermediation *depending on the preferences of the person*.

If engagement with an apomediative aid results in a decision to contact a healthcare professional, we have the possibility of blended ‘apo-intermediation’. However, in this case the clinician will engage with the person in a way that is different from that which characterises the pure intermediative mode. For example, they will need to be prepared to discuss options in the apomediative PDST that may not have appeared in an intermediative PDA for the same decision.

Even if an intermediative aid is made available online at home as preparation for an encounter - as in the Barry PSA study - it remains an intermediative PDA. It will be recalled that 43% of their participants decided to treat it as apomediative support, so the issue is whether those who prefer to decide for themselves would not be better served by a genuine apomediative aid, one which will have different characteristics and require different standards and evaluation.

3. Establishing Preference-Based Contexts

Information support is only a component of decision support. Decision support requires showing how any information can be incorporated into a decision framework that also introduces the preference component and makes the impact of each component observable and explorable. It is characteristic of intermediative decision aids that they are not based on any analytic model and aim to help the patient ‘make up their mind’ during shared encounter deliberation, without producing a preliminary opinion to be discussed. In contrast, to be effective in their community setting, apomediative resources must include decision support, not just information support.

Seeking to establish proof of method, we present an online PDST that can help individuals establish which of the two types of decision support they would find optimal, based on their preferences over the key distinguishing attributes. Nine attributes which distinguish PDAs from PDSTs (as defined) were derived from surveying a large number of the PDAs in the Ottawa Directory (<https://decisionaid.ohri.ca/AZlist.html>), as well as the IPDASi checklist for PDAs [13] and a tabular comparison of the latter with the contents of an MCDA-based PDST. [17] (Table 2, p.6). These attributes exclude those associated with development processes, or supplementary information presentation concerning condition or options, where both types are assumed to meet equally well. Full definitions are in the online tool at <https://ale.rsyd.dk> (enter 1498 as survey ID).

Shorthand versions of the nine criteria are:

- Home vs clinic engagement.
- No option filtering vs option filtering.
- Do nothing option included vs only action options.
- Numerical vs verbal chances.
- Absolute vs relative risks.
- Overall vs only condition-specific mortality/morbidity.
- Functional vs clinical outcomes.
- Numerical vs verbal preference weights.
- Calculated option scores vs no opinion.

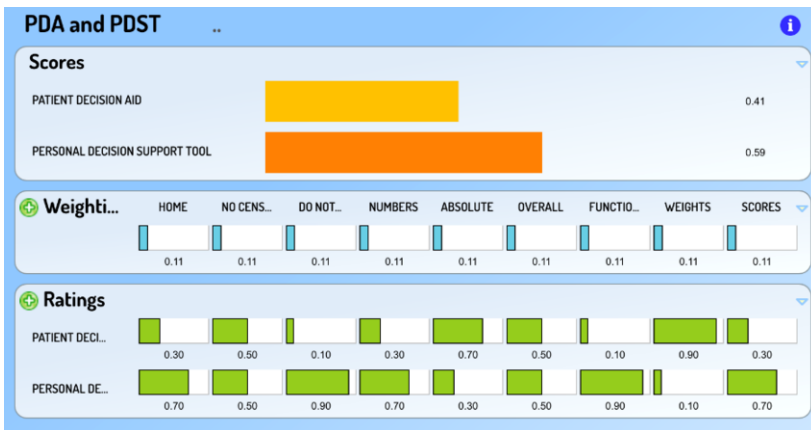


Figure 1. Screen capture from online tool with purely illustrative responses.

Slight stereotyping of PDAs is involved as a few will not match all these characteristics.

Results from this survey will establish the number and strength of the emergent preference clusters, but their existence is not in serious doubt. Even a small number preferring PDSTs will justify their production and delivery, subject to cost-effectiveness considerations. In this respect, any relevant cost-effectiveness analysis must cover the production and delivery processes for both types, as well as their service consequences. In many cases, especially screening, PDSTs are likely to be cost-effective, possibly even cost saving, as a result of reducing preference-based over-diagnosis and over-treatment.

4. Conclusion

The preferences of individuals in relation to health and healthcare decision making processes are heterogeneous. Within this heterogeneity preference clusters should be identified and acknowledged and respected as contexts relevant to the evaluation of decision support tools. The task of developing normative and empirical evaluation tools for the full range of preference-based contexts, including apomediation, remains.

Funding

The software used was installed at <https://ale.rsyd.dk> as part of a nationally funded project to develop decision support tools. SATS J.nr. 1-1010/116/27

Conflict of Interest

Jack Dowie has a financial interest in the Annalisa software when used commercially.

References

- [1] M.J. Barry, S. Edgman-Levitan, and K. Sepucha, Shared Decision-Making: staying focused on the ultimate goal, *NEJM Catalyst* (2018).
- [2] P. Scalia, M-A. Durand, J.L. Berkowitz, N.P.Ramesh, M.J. Faber, J.A.M. Kremer, et al., The impact and utility of encounter patient decision aids: systematic review, meta-analysis and narrative synthesis, *Patient Education and Counseling* **102** (2018), 817-841.
- [3] J. H. Eklund, I.K. Holmström, T. Kumlin, E. Kaminsky, K. Skoglund, J. Högländer, et al. "Same same or different?" A review of reviews of person-centered and patient-centered care, *Patient Education and Counseling* **102** (2019), 3–11.
- [4] M.K. Kaltoft, J.B. Nielsen, G. Salkeld, and J. Dowie, Preferences cannot be treated as epidemiological characteristics in person-centred care: a riposte, *European Journal for Person Centered Healthcare* **4** (2016), 6–9.
- [5] M.K. Kaltoft, R. Turner, M. Cunich, G. Salkeld, J.B. Nielsen, and J. Dowie, Addressing preference heterogeneity in public health policy by combining Cluster Analysis and Multi-Criteria Decision Analysis: Proof of Method, *Health Economics Review* **5** (2015), 1-11.
- [6] M.J. Barry, R.M. Wexler, C.D. Brackett, K.R. Sepucha, L.H. Simmons, B.S. Gerstein, et al., Responses to a Decision Aid on Prostate Cancer Screening in Primary Care Practices, *American Journal of Preventive Medicine* **49** (2015), 520–525.
- [7] D. Stacey, F. Légaré, K. Lewis, M.J. Barry, C.L Bennett, K.B. Eden, et al., Decision aids for people facing health treatment or screening decisions, *Cochrane Database Systematic Reviews* (2017).
- [8] E. Topol, *The Patient will See You Now: the future of medicine is in your hands*, Basic Books, New York, 2015.
- [9] R. Farmanfarmanian. *The Patient as CEO: How technology empowers the healthcare consumer*, Lioncrest Publishing, United States, 2015.
- [10] D. deBronkart and B. Meskó. The Digital Health Manifesto, *The Medical Futurist* (2018). Available from: <http://medicalfuturist.com/digital-health-manifesto/> (accessed Jun 3, 2019).
- [11] J. Dowie and M.K. Kaltoft, The future of health is self-production and co-creation based on apomediative decision support, *Medical Sciences* **6** (2018), 66.
- [12] P. Scalia, M-A. Durand, J. Kremer, M. Faber, and G. Elwyn, Online, Interactive Option Grid Patient Decision Aids and their Effect on User Preferences, *Medical Decision Making* **38** (2017), 56-68.
- [13] G. Elwyn, A.M. O'Connor, C. Bennett, R.G. Newcombe, M. Politi, M-A. Durand, et al., Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi), *PLoS One* **4** (2009), e4705.
- [14] G. Elwyn, A. Edwards, M. Wensing, K. Hood, C. Atwell, and R. Grol, Shared decision making: developing the OPTION scale for measuring patient involvement, *Quality & Safety in Health Care* **12** (2003), 93-99.
- [15] K.R. Sepucha, J.K. Belkora, Y. Chang, C. Cosenza, C.A. Levin, B. Moy, et al., Measuring decision quality: psychometric evaluation of a new instrument for breast cancer surgery, *BMC Medical Informatics and Decision Making* **12** (2012), 51.
- [16] G. Eysenbach, From intermediation to disintermediation and apomediative: new models for consumers to access and assess the credibility of health information in the age of Web2.0, *Stud Health Technol Inform* **129** (2007), 162–166.
- [17] Ø. Eiring, K. Nytrøen, S. Kienlin, S. Khodambashi, M. Nylenna, The development and feasibility of a personal health-optimization system for people with bipolar disorder, *BMC Medical Informatics and Decision Making* **17** (2017), 1–11.