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When Do We Deliberate About Our Health?

An investigation into the decision aid as a service system inflection point

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Patients' medical decision-making represents a critical inflection point within healthcare systems. To help contextualise this deliberative process, clinicians, medical centres, and other researchers produce material artefacts — known as decision aids — that serve to shape outcomes in the system. This presentation will summarise findings from an analysis of the Cochrane Inventory and Mayo Clinic archive of decision aids and extrapolates two models: a model of the complexity of systems that surround clinician and patient at various points in the medical system and a model of the clinician<>patient conversation, as depicted in the decision aids themselves.

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RSD TOPIC(S): Health & Well-Being

Decisions within medical systems

When a patient enters the medical system making decisions emerges as a key activity. In many medical encounters, the problem is mundane; the path forward is obvious – indisputable to the treating clinician. Does a patient have a bacterial infection? Antibiotics. A deep cut? Sutures. A broken bone? Set and cast. Beyond these more transactional experiences, many significant health issues in contemporary practice occur in a space where decisions are not so clear-cut. Deliberation occurs when there is decisional conflict, or a state of uncertainty, about a plan of action. Specifically, the kinds of decisions where clinicians and patients need to engage in deliberative conversation about treatment options are "when no single option has clear superiority, or all carry risks, and a trade-off needs to be made between them." (Jardine & Robinson, 2013). Stacey et al. (2008) identify two paradigms that may cause decisional conflict within a clinical setting – major life transitions and health threats. Major transitions include pregnancy, childbirth, retirement, and old age. Both health threats and major life transitions can indicate a current or anticipated change in the current health state.

A key leverage point for intervention in the medical decision-making process is the authoring, designing, and development of clinical decision aids. These aids are structured physical or digital/interactive documents that can serve one or more of several functions:

- communicative, helping a patient understand the diagnosis and prognosis;
- to contextualise a clinician's conditional recommendations by presenting a range of treatment options, accompanied by lay explanations of risk in various contexts;
- to help the patient surface their values in the face of risk and potential side effects of different treatment options. (Elwyn et al. 2010)

Although decision aids are developed explicitly to support decision-making, research suggests that there is little evidence that decision-aid developers incorporate theories of decision-making into their design. (Durand et al., 2008, Elwyn et al., 2010b). Additionally, Elwyn et al. (2011) observe that when decision-making theory is included in the design of decision aids, developers focus on how people make decisions rather than how

design can support decision-making. Literature suggests there is a critical gap in the understanding of the logic that supports the clinician<>patient conversation and how design can be used to aid that logic. When we refer to logic, we refer to the principles underlying the arrangements of elements in a designed interaction. This logic needs to be understood and considered to develop effective decision aids. (Elwyn et al., 2010a, Hargreaves & Montori, 2014)

Most clinical decision aids proceed from one of several assumptions:

- Information is the problem — if patients had proper information about their health situation and/or this set of treatment protocols, they would feel the necessary agency to rationally choose a course of action from the menu of existing approaches.
- Understanding is the problem — if patients understood the implications (usually risk) of the different treatment options, they would be able to select an option that matches their level of tolerance of the different implications.
- Values are the problem — if patients were able to surface their values in a clinical conversation in the face of this liminal choice, they would understand the dimensions of their choice as it relates to their lived experience and mindset.
- Communication is the problem — if patients could express their preferences and values in a way that a clinician could more effectively parse, the clinician could guide the patient to the most effective treatment path.

While all of these approaches have a degree of accuracy, shared-decision making (SDM) and the decision-aid construction processes unduly pathologise the patient's decision-making approach and neglect the complementary role the clinician plays in decision-making. These underlying assumptions — that it is principally the patient's process that needs to be redesigned — need further examination. The perspective needs to move away from designing to improve the patient's situation and towards designing for the clinician<>patient couplet.

Further, it is difficult to imagine this project as successful without some accounting for the systems that surround both patients and clinicians. For the patient, these systems might include family, social and work life. For the clinician, the context of their role as a

professional in the complex network of medical service-provisioning represents an important influence on the process. Awareness of and accounting for these aspects in a model of SDM is more authentic than representing decisions as socially isolated and may be key to engagement with a more holistic perspective towards medical consultation.

A number of models have been advanced to support decision-making, both in clinical contexts and beyond. The SEIPS model of human-centred design for the patient journey has been iteratively developed over the past decade (Carayon et al., 2006, 2020; Holden et al., 2013; Holden & Carayon, 2021) depicts the complex network of socio-technical relations between patients and the many systems that comprise healthcare. Human-centred design can open healthcare systems to patients, yet these systems remain the domain of healthcare professionals. Patients navigating these systems may find them to be disorienting and alienating. Gary Klein's empirical research on decision-making in expert systems (Klein & Moon, 2006, 2006a; Klein 2017) contradicts many commonly held beliefs about decision-making. Klein's work especially focuses on contexts where the decision-makers have domain expertise. Compelling possibilities exist for reframing medical shared decision-making processes to domains where all participants' expertise can be applied, rather than just the clinician's. Deliberative approaches (Shapiro, 2006; Fishkin, 2008; Arnold Mages, 2018) to decision-making encompass a dialectical approach to developing understanding and surfacing people's values in the face of complex civic decisions. Further,

Review of decision aids

The Cochrane Inventory

The Cochrane Inventory, maintained by the Ottawa Hospital Research Institute (OHRI), is the largest and most comprehensive collection of publically available decision aids. The inventory contains 295 decision aids pertaining to a diverse set (n=136) of health states that vary from life-threatening illnesses such as cancer, temporary health states such as pregnancy, and behavioural health choices such as contraception. Decision aids represented in the Cochrane Inventory were developed primarily by Healthwise (56%).

Researchers analysed the Cochrane Inventory across multiple dimensions, including the type of decisional conflict (major life transition or health threat), deliberation point (preventative treatment, screening, treatment), disease classification, condition severity, and audience. The goals of the analysis are two-fold — to validate a proposed model of when deliberation occurs in the healthcare service system and identify service points where expanded use of decision aids could aid deliberation.

Researchers observed that the vast majority, 80%, of Cochrane Inventory decision aids supported deliberation when a patient encounters a health threat, and only 20% supported a patient during a major life transition. Additionally, the majority of decision aids were designed to be used during the treatment deliberation point of the healthcare service model (74%), in contrast to screening (16%) and preventative treatment (10%). The targeted patient was assumed to be an adult unless otherwise specified; few decision aids deviated from this model. Decision aids designed to support the deliberation of a teenage or adolescent patient were infrequent (8%), and even fewer addressed deliberation over potential courses of action with an elderly or senior patient (3%).

Mayo Clinic: Knowledge and Evaluation Unit — Care that Fits

Researchers also collected data on decision aids developed by the Mayo Clinic's Knowledge and Evaluation Unit. Although the Mayo Clinic's repository of decision aids is much smaller (13 decision aids supporting ten unique health states) than the repository maintained by OHRI, researchers observed similar trends.

Project goals

This project comprises an artefact review of decision aids offered in the Cochrane Inventory and the Mayo Clinic's library tools developed by the Knowledge and Evaluation Unit. This research theorises at what point in the medical service model decision aids are intended to be used and identifies which audiences, deliberation points, and conditions decision aids are meant to support. The results of this project include a service map showing when decision aids are intended to be used and a visualisation showing where the decision aids are intended to function with respect to the phase of the life course, the imminence of health condition, potential severity of

disease condition, and expected age of the patient. The project takes a systemic approach, creating an abstracted diagram of the patient journey through the healthcare service system and notes when decision aids could facilitate potential clinician<>patient decision inflection points. Extrapolating from a textual analysis of the decision aids, the research will attempt to represent the complexity of social and medical systems that surround patient and clinician and enables the development of a key model to understand the clinician<>patient conversation.

References

1. Arnold Mages, Michael (2018) Designing Civic Conversations: Things and facilitation in high-stakes and difficult conversations (Unpublished doctoral dissertation). Carnegie Mellon University, Pittsburgh, PA

2. Carayon, P., Schoofs Hundt, A., Karsh, B.-T., Gurses, A. P., Alvarado, C. J., Smith, M., & Flatley Brennan, P. (2006). Work system design for patient safety: The SEIPS model. Quality in Health Care, 15(suppl 1), i50–i58. https://doi.org/10.1136/qshc.2005.015842

3. Carayon, P., Wooldridge, A., Hoonakker, P., Hundt, A. S., & Kelly, M. M. (2020). SEIPS 3.0: Human-centered design of the patient journey for patient safety. Applied Ergonomics, 84, 103033. https://doi.org/10.1016/j.apergo.2019.103033

4. Elwyn, G., Frosch, D., Volandes, A. E., Edwards, A., & Montori, V. M. (2010). Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. Medical Decision Making : An International Journal of the Society for Medical Decision Making, 30, 701–711. https://doi.org/10.1177/0272989X10386231

5. Elwyn, G., Stiel, M., Durand, A., Boivin, J. (2010). The design of patient decision support interventions: addressing the theory-practice gap. Journal of Evaluation in Clinical Practice, 17: 565 –574. https://doi:10.1111/j.1365-2753.2010.01517.x.

6. Elwyn, G., Kreuwel, I., Durand, M. A., Sivell, S., Joseph-Williams, N., Evans, R., Edwards, A. (2011). How to develop web-based decision support interventions for patients: A process map. Patient Education and Counseling, 82: 260 - 265.

7. Fishkin, J. S. (2008). Deliberative Democracy. In The Blackwell Guide to Social and Political Philosophy (pp. 221–238). Oxford, UK: Blackwell Publishers Ltd. https://doi.org/10.1002/9780470756621.ch10

8. Hargraves, I., & Montori, V. M. (2014). Decision aids, empowerment, and shared decision making: Each works or fails to work in patient-clinician conversations. BMJ (Online), 349(September), 1–2. https://doi.org/10.1136/bmj.g5811

9. Holden, R. J., & Carayon, P. (2021). SEIPS 101 and seven simple SEIPS tools. BMJ Quality & Safety, 30(11), 901–910. https://doi.org/10.1136/bmjqs-2020-012538

10. Holden, R. J., Carayon, P., Gurses, A. P., Hoonakker, P., Hundt, A. S., Ozok, A. A., & Rivera-Rodriguez, A. J. (2013). SEIPS 2.0: A human factors framework for studying and improving the work of healthcare professionals and patients. Ergonomics, 56(11), 1669–1686. https://doi.org/10.1080/00140139.2013.838643

11. Jardine, O., & Robinson, L. (2013). Patient decision aids - a tool for shared decision-making. InnovAiT: The RCGP Journal for Associates in Training, 6(4), 248–254. https://doi.org/10.1177/1755738012469357

12. Klein, G., & Moon, B. (2006). Making sense of sensemaking 1: Alternative perspectives. IEEE Intelligent Systems, 21(4), 70–73. https://doi.org/10.1109/MIS.2006.75

13. Klein, G., & Moon, B. (2006a). Making sense of sensemaking 2: A macrocognitive model. IEEE Intelligent Systems, 21(5), 88–92. https://doi.org/10.1109/MIS.2006.100

14. Klein, G. (2017). Sources of power: how people make decisions (20th anniversary ed.). Cambridge, MA: MIT Press.

15. Shapiro, I. (2003). Optimal Deliberation? In J. S. Fishkin & P. Laslett (Eds.), Debating Deliberative Democracy (pp. 121–137). https://doi.org/10.1002/9780470690734.ch6

16. Stacey, D., Murray, M. A., Légaré, F., Dunn, S., Menard, P., O'Connor, A. (2008). Decision Coaching to Support Shared Decision Making: A Framework, Evidence, and Implications for Nursing Practice, Education, and Policy. Worldviews on Evidence-Based Nursing. 5(1):25–35.