



A Universal Decision Support System

Addressing the Decision-Making Needs of Patients, Families, and Clinicians in the Setting of Critical Illness

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Abstract

In the setting of a complex critical illness, preference-sensitive decision making—choosing between two or more reasonable treatment options—can be difficult for patients, families, and clinicians alike. A common challenge to making high-quality decisions in this setting is a lack of critical information access and sharing among participants. Decision aids—brochures, web applications, and videos—are a major focus of current research because mounting evidence suggests they can improve decision-making quality and enhance collaborative shared decision making. However, many decision aids have important limitations, including a relatively narrow capacity for personalization, an inability to gather and generate clinical data, a focus on only a single disease or treatment, and high developmental costs. To address these issues and

to help guide future research, we propose a model of “universal” electronic decision support that can be easily adapted by clinicians and patients/families for whatever decision is at hand. In this scalable web-based platform, a general shared decision-making core structure would accommodate simple, interchangeable disease and treatment information modules. The format and content of the system could be adapted to decisional participants’ unique characteristics, abilities, and needs. Universal decision support can better standardize a decisional approach and also allow a unique degree of personalization within a framework of shared decision making. We also discuss potential criticisms of this approach as well as strategies that can overcome them in a critical illness setting.

Keywords: critical illness; decision support; shared decision making; patient-centeredness; surrogate decision making

The purpose of this article is to discuss the current state of decision-making quality in the setting of critical illness, the role that decision aids can best serve in supporting decision making, the benefits and limitations of different decision aid formats, and a novel web-based “universal” decision support system as a proposed unifying model for future decision aid research. Although this new approach focuses on critical illness managed in intensive care units (ICUs), its principles could be applied to any situation

involving a preference-sensitive decision—that is, a decision in which two or more reasonable options exist or when users might value the risks and benefits associated with options differently (1, 2).

The Clinical Tasks of Decision Making—and How to Measure Their Quality

In critical illness, as in all fields of medicine, there is often no single best treatment for

a specific condition or situation. Therefore, a good decision is one that best aligns a patient’s values and preferences with the treatment that is most likely to result in an outcome that they want (3). This alignment of values and choice requires decision makers to acquire adequate knowledge about the nature of problem and decision at hand, to consider the outcomes that they value the most, to make the treatment choice, and to take action—all clinical tasks that involve exchanging information (4, 5).

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As shown in Figure 1, the quality of decision making is quantified by measuring attributes of both the decision-making process (e.g., presence of conflict, active participation, knowledge level, clarifying values) as well as the faithfulness of the decisional outcome (i.e., “choice made”) to patient values (e.g., accuracy of risk/benefit perception, certainty about choice, alignment of choice and values) (6).

There Is a Significant Quality Gap in Preference-Sensitive Decision Making, Especially in an ICU Setting

Decision-making quality in ICUs is often suboptimal because of deficiencies in shared decision making—the preferred decisional process of information exchange, deliberation, and supportive consensus building—between clinicians and patients/families (3, 7). Without this collaborative support, it may be hard to address patients’ and families’ low health literacy, poor facility with risk estimates, imperfect language skills, or stress related to being a substitute decision maker (4, 8–12). And without effective collaborative information exchange, many family members cannot overcome common deficits in medical

comprehension about the diagnosis, prognosis, and the nature of the decision at hand (13, 14). Although families often lack a sophisticated sense of long-term health outcomes, clinicians are commonly reluctant to prognosticate about even short-term survival, often fail to clarify patients’ values (7, 13), and frequently display inadequate communication skills (15). The sum total of such inadequately supported (i.e., low quality) shared decision making can be choices that are misaligned with values, internal decisional conflict, strained therapeutic alliance between families and clinicians, unreasonable expectations for outcomes, and long-term psychological distress (3, 7, 11, 14, 16–20).

Decision Aids Can Improve Decision-Making Quality by Addressing Clinically Relevant and Responsive Targets, but Also Possess Notable Limitations

Decision aids (also known as decision support tools) are evidence-based written brochures, web- or computer-based applications, or videos designed to assist people who are making preference-sensitive

decisions (1, 2). Decision aids may be directed toward patients, clinicians, or both and can be used in both inpatient and outpatient settings. Methodologically rigorous, theory-driven decision aids can facilitate the collaborative alignment of choice and values among patient/family and clinician participants, thereby enhancing the patient-centeredness of the process (2, 21). Examples of clinically tested decision aids in different formats are shown in Table 1. Most decision aids address relatively straightforward topics such as screening, medications, and surgeries. Few exist that are relevant to complex critical illnesses aside from decision aids designed to elicit values, resuscitation preferences, or goals of care (19, 22). Clinical decision support tools, not a focus of this review, may also be familiar to clinicians as guideline adherence assistants embedded within electronic health systems or even as components of medical devices such as mechanical ventilators (23). Patient-focused decision aids are generally not subject to enforcement of medical device regulation by the United States Food and Drug Administration provided they aim to “self-manage [a] disease or condition without providing specific treatment or treatment suggestions” (24).

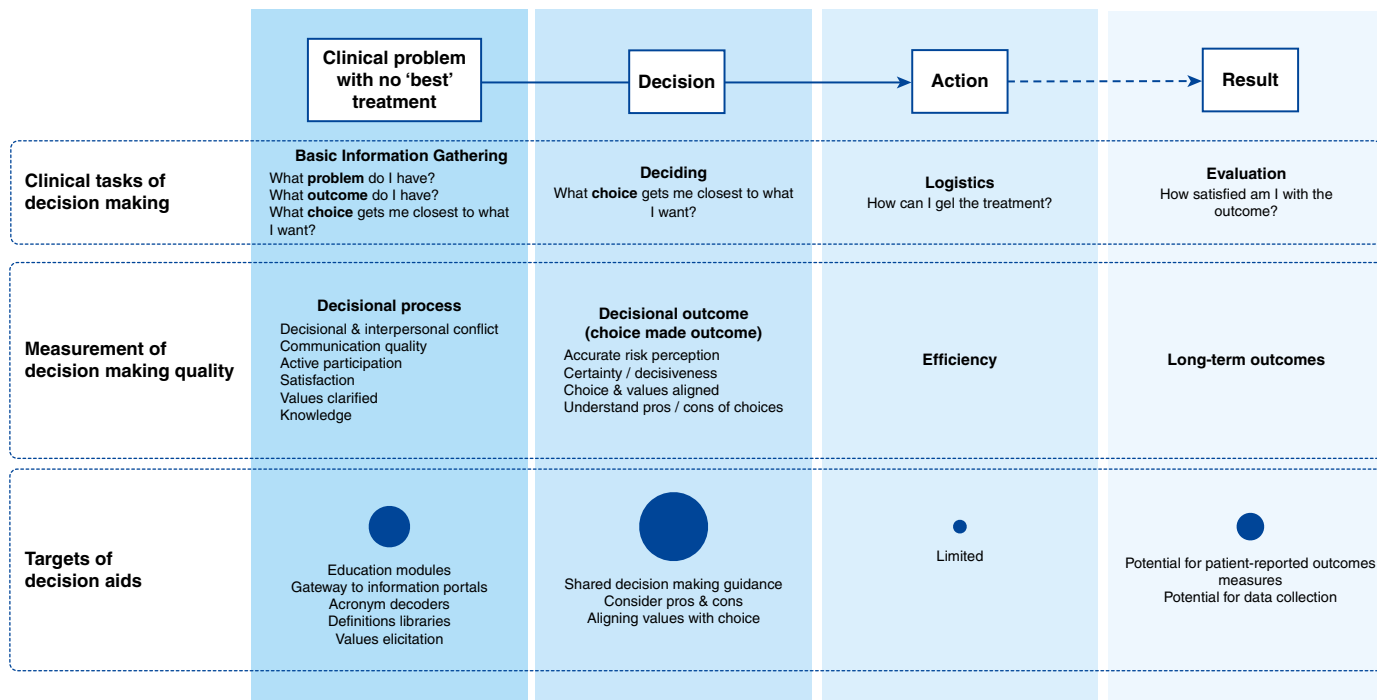


Figure 1. Decision-making performance, quality, and targets for decision aids.

Table 1. Comparison of Decision Aid Formats and Characteristics

	Pamphlets and Brochures	Computer- or Web-based	Video or DVD
Examples	Intubation in COPD (43) Feeding tube placement in dementia (44) Colon cancer screening in the elderly (45)	Statin/aspirin choice (46) Genetic testing for breast cancer susceptibility (47) Lung transplantation for cystic fibrosis (48)	Cardiac arrest in cancer (22) Advanced care planning in dementia (49) Surgery for back pain (50)
Inexpensive	+++	+	+
Ease of technological development	+++	+	++
Easily updated	++	++	+
Adaptable to individual users	+	+++	+
Interactive	+	+++	++
Capability of gathering or exporting user data	–	+++	+
Can involve patient and provider	+	++	+
Individualizable	+	++	+
User experience and engagement	+	++	++
Multimedia experience	+	++	+++

Definition of abbreviation: COPD = chronic obstructive pulmonary disease.
–, none; +, low level; ++, moderate level; +++, high level.

Decision aids target educational and supportive factors that are potentially more responsive to change than more difficult to address issues common in health-care settings such as social stresses, financial toxicity, emotional distress, and hospital environment factors (Figure 1) (25–27). There is strong evidence that decision aids can improve both the decision-making process and decisional (“choice made”) outcomes across a variety of medical conditions. For example, a recent Cochrane review of studies including more than 34,000 patients found that decision aids reduced uncertainty about choice as well as both interpersonal and decisional conflict (1). Decision aids also improved patient–provider communication and prognostic concordance, satisfaction, active participation in decision making, medical knowledge, and the alignment of values with choice (1). A recent study in the setting of chronic critical illness demonstrated that a written decision aid compared with usual care improved physician–family concordance for prognosis, the quality of communication, and medical comprehension (19).

What Are the Limitations in the Current Approach to Developing Decision Aids?

Decision aids and their current general developmental approach have some

shortcomings worth considering that are related to cost, technological demands, personalization, user interaction and engagement, and adaptability to user needs and preferences.

Many of these limitations are related to specific tradeoffs in features among the different formats of decision aids as shown in Table 1. For example, although pamphlets and brochures are the most inexpensive type of decision aids to develop, they are also less interactive, engaging, and individualizable for complex decisions. Users find videos highly engaging and convenient. However, these are not typically interactive or generally individualizable, require at least basic expertise in filming and editing to produce, and are substantially more expensive to develop than brochures. Computer- or web-based decision aids have perhaps the greatest capacity for user adaptation and data exportation. Yet they require programming expertise that few researchers or clinicians possess and can be extremely costly to develop (as we have found firsthand). Also, web-based aids are generally built on a wide variety of technological platforms, which limits dissemination and adaptation to different populations and slows the implementation of subsequent technological improvements—increasing costs further.

Decision aids also share limitations across formats. Most primarily address

highly specific, low-acuity clinical questions and lack the functionality of direct collaborative participation of patients, families, and providers. Many are poorly personalizable to the range of user abilities (e.g., reading and health literacy level, language capabilities) and may make overly optimistic assumptions about the users’ understanding of even basic information (5). They are often difficult to update based on cumulative patient experiences or new research findings and are “disconnected” from the actual outcomes that users experience after making the decision at hand. Importantly, ClinicalTrials.gov currently lists nearly 1,100 active or recently completed trials involving different decision aids. However, both the economic sustainability and the logistical feasibility of continuing to develop a separate decision aid for each of the thousands of diseases and treatments is questionable. But what is a potential solution to address these problems with decision aids?

A “Universal” Decision Support System Could Enhance the Known Benefits of Decision Aids While Also Addressing Their Limitations

We propose a “universal” systems-based approach to complex decisions both to build on the strengths of current decision

aids and to address their developmental limitations outlined above. Rather than focusing development around single, specific diseases using one-off designs and a variety of information technology infrastructures, the goal is to build a decision aid that accommodates nearly any preference-sensitive decision. This novel decision support system would include (1) a capability to adapt to the unique needs and abilities (i.e., “profiles”) of the decision makers themselves, (2) an ability to incorporate different electronic disease- and treatment-specific “plug-in” information modules, and (3) a core shared decision-making structural template that would accommodate the information modules in a format that matches their profile-based needs and abilities (Figure 2). This system is based on concepts drawn from the medical decision-making literature (1, 2), information technology (28), marketing (29), learning health-care systems (30), and our experience in developing web-based decision aids (31).

Decision-Maker User Profiling

User profiling adaptive capability would be the first and more innovative element of the

proposed personalized decision support system, providing users with what they both want (individualization) and need (targeted information content and user ability-appropriate formatting). To perform user profiling, patient responses to brief questions completed within the digital decision system’s user interface could be matched to a defined user profile—a meaningful collection of attributes, characteristics, and values. The profile in turn would be used to adapt the decision aid interface, or “view,” to the unique user. Examples of possible user profiles are shown in Figure 3. This is similar to the concept of “preference diagnosis,” in which physician recommendations are adapted to individual values (32). User profiling has been performed successfully for decades in marketing and advertisement using a developmental process similar to what is more familiar to medical researchers as qualitative methodology (29). It is, in fact, a pervasive element of our daily interaction with technology such as our purchasing behaviors and internet searches. The potential value of such profiles is that they could serve to personalize the user

experience of decision support, economize the programmatic approach to the number of different possible user “views” and target users who may need specific informational resources or support systems. One profile could even specify those who may want clinicians to give recommendations or even make the decision for them in a parallel process to decision aid viewing (33). Last, selected and patient-approved data elements gathered longitudinally could be matched to profiles and cataloged in a “medical social networking” function that could help to answer users’ basic contextual questions like, “What did other people like me choose in this situation—and what happened next?” This capability is much desired by patients because it reflects our most common decisional behavior—informing our decisions with the greater universe of others’ decisional experiences (34).

Disease and Treatment Plug-in Modules

The second element of a universal support system would be a portfolio of brief,

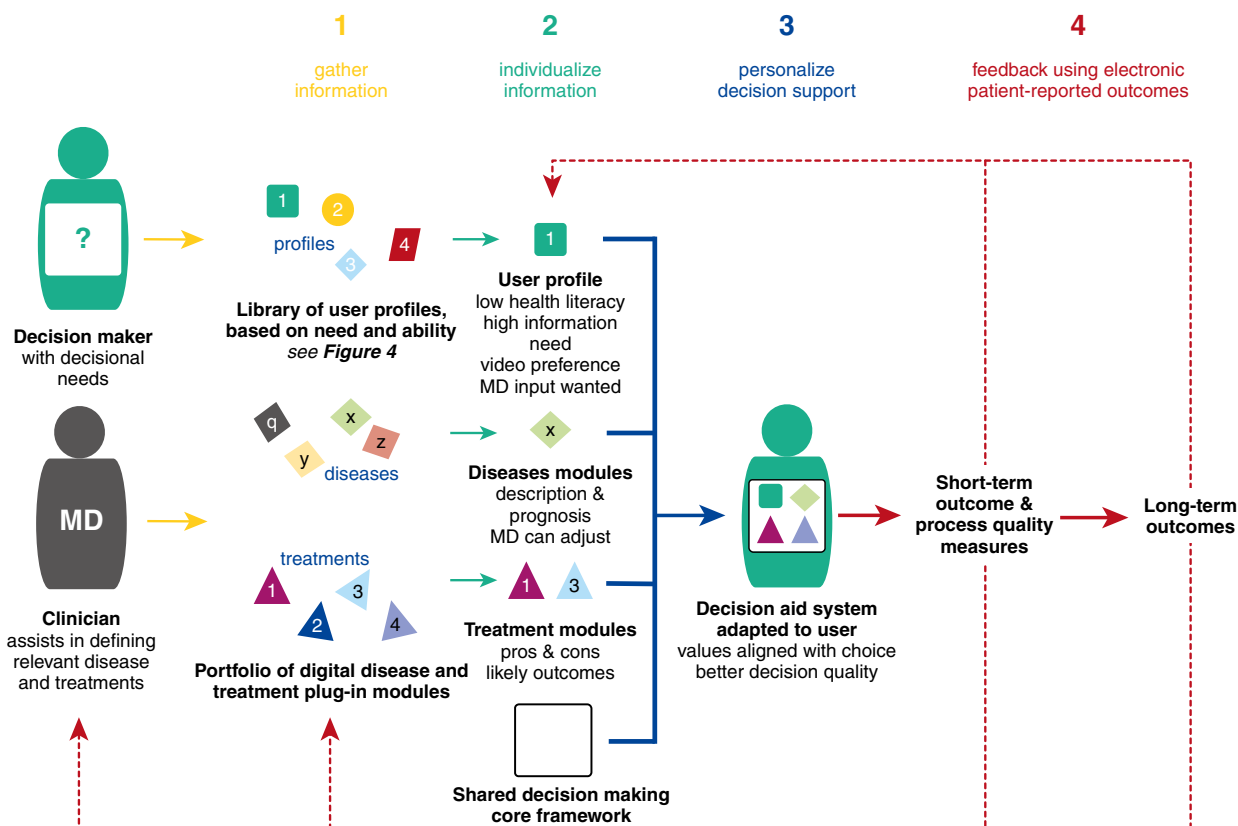


Figure 2. Example of a universal decision aid system for complex critical illnesses.

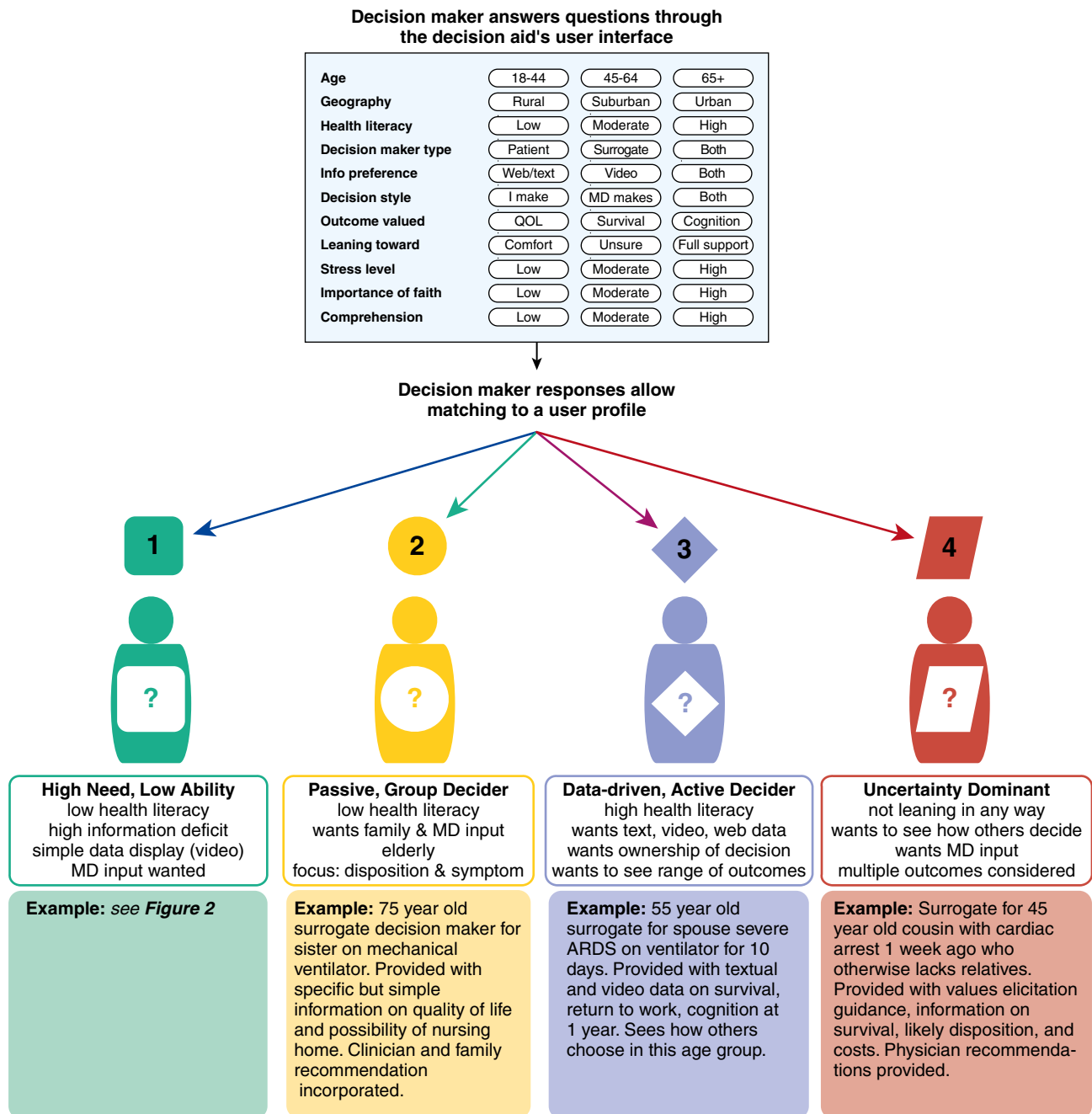


Figure 3. Examples of user profiling to meet decision makers' needs. ARDS = acute respiratory distress syndrome; QOL = quality of life.

standardized, modular web-based information plug-ins for each disease or treatment. These plug-ins could be text, video, or a combination of formats, ideally linked to information about associated health trajectories. A unified open-sourced module system would allow multiple users to develop, update, and share modules widely and inexpensively across different populations and in various

languages. Potential parallels include user-authored programs and services such as GitHub, Wikipedia, and UpToDate. Clinicians could assist users by identifying appropriate disease modules, even adjusting uncertainty bounds around prognostic model estimates, and simplifying the often overwhelming number of treatment choices for patients/families.

Core Shared Decision-Making Structure

The third structural element of the novel decision support platform would be a general shared decision making core template that would incorporate the unique user content, preferences, and modules in the context of the decisional quality concepts shown in Figure 1. This foundational element could guide users

stepwise through key elements of the shared decision-making process, such as identifying the actual decision at hand, describing the problem and treatment alternatives, eliciting patient values, clarifying the family's preferred decision-making role, and prompting a check of understanding among others (7, 35). Such a conceptual framing has been incorporated successfully into past written general aids (36) and is being applied currently in a web-based adaptation of a written decision aid for families, physicians, and nurses of chronically critically ill patients (19).

Putting It All Together: A Practical Example

A practical example of how such a universal decision support system could be applied clinically is shown in Figures 2 and 3 (*see* online supplement for more detailed description). Step 1 is information gathering, in which the user answers a few simple questions (e.g., age, outcome preference) that get to the heart of what makes their experience unique, and the clinician searches the portfolio of diseases and treatments for those most relevant. Step 2 is the individualization of information by the decision system. The user profile is ascertained and the disease and treatment modules are incorporated into the core shared decision-making structure. Figure 3 shows other examples of how users might be matched to a few of the multiple possible profiles, resulting in different decision support user experiences. In the example shown in Figure 2, the profile would be "low health literacy, high information need, preference for video-based information display, and desire for a clinician's recommendation." Step 3 is the personalization of the decision. The decision support system interface is adapted to address informational content needs (e.g., sepsis information module, goals of treatment module), items for further thought (values elicitation), barriers (e.g., textual display appropriate for low health literacy and reading level), and information format preferences (e.g., video preferred to text). Through decisional interface queries, the user indicates current needs, their emotions about the decision, and the way in which they are leaning—information that can be shared among participants, including the

clinician. Finally, in Step 4, the users themselves provide feedback about their post-decisional experience process and outcome information (e.g., satisfaction ratings, depression symptoms) periodically using web-based patient-reported outcomes measures (28). These short- and long-term measures could be incorporated into the continuously aggregating pool of data from which the profiles are generated to improve them and the predictive ability of prognostic estimates in a learning health-care model (30). Not only could this allow future users to see how others decided, it could inexpensively expedite the provision of long-term outcomes data for the development of predictive symptom trajectory models. In sum total, universal decision support aims to be temporally aligned with the evolution of "P4 medicine": promoting *participatory* medicine by engaging both patients/families and clinicians, enhancing the proactive *preventative* mitigation of unwanted long-term outcomes, *personalization* to individual abilities and needs, and informing *predictive* decisional processes (37).

Defining Developmental Challenges—and Mapping Out the Next Steps

Developing a successful universal decision support system will require that a number of challenges be addressed.

First, the concept itself may sound like an oversimplification of a process that is perhaps the most complex element of a clinician's daily practice. However, this system is conceptualized as accommodating infinitely more detailed specification and refinement based on future user input. Also, we have developed collaborative, patient- and provider-facing decision platforms with electronic reporting features in the setting of critical illness (31); others already use sophisticated translational ICU databases for multiple tasks (38, 39).

Second, such a system would require expertise beyond that of a standard research or industry team, and will demand the novel process of navigating the rapidly accumulating amounts of web- and cloud-based health data that patients and providers increasingly value in decision making (34). Although logistically

challenging, we think that interaction among decisional participants and relevant content experts will enable this much-needed platform using novel strategies, cycles of iterative prototyping, and the application of technologies in both medical and nonmedical use (34).

Third, the development of such a system requires a funding source. Although the Affordable Care Act does not fund the decision aids it champions, it does set up the presence of future interoperable data environments—an important national incentive. It will be critical to develop a practical, visible "minimal viable product" (here, a handful of key disease and treatment modules) using modest federal or small business funding, or through a health information technology accelerator. Once this usable prototype is generated, federal, commercial, or mixed partners can facilitate the platform's scaling to broader groups of users. This lean approach will be most likely to ensure that a clinically relevant solution and truly scalable platform is developed—one aimed to get early buy-in from clinicians and patients. We believe that nonprofit stakeholders would want to be involved to help drive the vision of meeting the needs of a deserving patient community. Additionally, the financial value proposition on a population basis may be enormous given the unique efficiencies gained in clinical care and research from an established digital infrastructure, a unified approach to addressing marked practice variation across health systems, and a focus on reducing low value care (32, 40, 41).

Fourth, to avoid information biased toward economic gains to specific groups, the data included in decision aid modules need to be reviewed, vetted rigorously, and approved by groups without conflicts of interest.

Fifth, we do not believe that a software program can substitute for the emotional and informational support that a collaborative patient/family-clinician relationship can provide during a serious illness. However, it is likely that the commonly inadequate patient-clinician communication that is so widely reported may only worsen over time because of increasing patient loads, use of nonphysician providers in ICUs, and shiftwork-driven hospital care. A decision support system could possibly improve efficiency and collaboration by

allowing patients/families to perform tasks that could be done before, rather than during, ICU family meetings, such as prioritizing concerns, gathering questions, and reflecting on personal values (42).

The next steps will include identifying consensus groups to define easily understandable templates for diseases and treatments, finding partner providers/patients/organizations to provide collaborative assistance, developing decision aid information technology infrastructure, and piloting early versions of the platform's usability in select populations. In fact, the "ICU laboratory" may be the highest-yield general plan for working out problems and defining

efficient solutions before transporting this platform to other health-care venues.

Conclusions

Decision aids have great promise to improve decision making in complex illnesses by bringing informational equality to patient/family-clinician interactions. However, they possess important conceptual, technological, and logistical limitations. As a potential solution to the developmental limitations of many current decision aids, we propose a scalable web-based universal decision support platform that includes user

individualization, interchangeable disease and treatment modules, and a general shared decision-making core structure. Such an open-access, widely accessible system would have great potential to increase decisional quality, improve the therapeutic alliance between patients and providers, and enhance the patient centeredness of care in critical illness as well as other preference-sensitive decisions. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

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