

# An Ethical Framework for Incorporating Digital Technology into Advance Directives: Promoting Informed Advance Decision Making in Healthcare

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Despite the presumed value of advance directives, research to demonstrate impact has shown mixed results. For advance directives to serve their role promoting patient autonomy, it is important that patients be informed decision makers. The capacity to make decisions depends upon understanding, appreciation, reasoning, and communication. Advance directives are in part faulty because these elements are often limited. The present paper explores how the application of digital technology could be organized around a framework promoting these four elements. Given the state of digital advancements, there is great potential for advance directives to be meaningfully enhanced. The beneficial effects of incorporating digital technology would be maximized if they were organized around the aim of making advance directives not only documents for declaring preferences but also ethics-driven tools with decision aid functionality. Such advance directives would aid users in making decisions that involve complex factors with potentially far-reaching impact and would also elucidate the users' thought processes to aid those tasked with interpreting and implementing decisions based on an advance directive. Such advance directives might have embedded interactive features for learning; access to content that furthers one's ability to project oneself into possible, future scenarios; review of the logical consistency of stated preferences; and modes for effective electronic sharing. Important considerations include mitigating the introduction of bias depending on the presentation of information; optimizing interfacing with surrogate decision makers and treating clinicians; and prioritizing essential components to respect time constraints.

## INTRODUCTION

As the pervasiveness of COVID-19 has made the possibility of serious illness and death more immediate for many, there is increasing recognition of the importance of considering and declaring care preferences in the

event of future incapacitating illness or injury [1,2]. At the same time, these circumstances have freshly brought to light the shortcomings in current methods to do so. Advance directives are one important means to prepare for future healthcare scenarios. An advance directive is a document through which users leave written instructions

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outlining care preferences in the event that they are incapable of consenting to, refusing, or requesting services for themselves. Despite the potential utility and presumed value of advance directives, research to demonstrate impact has shown mixed results [1,3]. While some of this inconsistency may be due to lack of a standardized method of evaluation [4], it also likely suggests that there are shortcomings in the current configuration of advance directives.

As digital technology becomes increasingly embedded in healthcare, there have been efforts to improve advance directives by incorporating online and electronic features, particularly towards the end of increasing completion rates and availability of the document. Advance directives, though, are founded on a respect for patient autonomy and informed consent; their existence is not an end in itself. The primary aim of an advance directive is to increase the likelihood that patients' received care matches their preferred care [5]. The present paper posits that, given this priority and the state of digital advancements, there is great potential for advance directives to be meaningfully enriched with digital technology and the beneficial effect of such efforts would be maximized if they were organized around the aim of making advance directives not only documents for declaring preferences but also tools with decision aid functionality. We suggest that such a framework would usefully guide how technology is applied, facilitating the realization of advance directives as tools that promote goal concordant care. These instruments would aid users in making decisions that involve complex factors with potentially far-reaching impact and would also make the users' thought processes more transparent for those tasked with interpreting and implementing decisions based on an advance directive. The present paper probes the need for such a framework and provides an exploration of how it might be realized, which is largely missing from the current literature.

### **INCORPORATING DIGITAL TECHNOLOGY IN ADVANCE DIRECTIVES TO SUPPORT INFORMED DECISION MAKING**

Discussions around enhancing advance directives with digital technology should center on upholding patient rights [6]. In order for advance directives to serve their role in promoting patient autonomy, it is important for patients to be informed decision makers. The capacity to make decisions depends upon *understanding*: the ability to comprehend the components of the decision being made; *appreciation*: the ability to apply the information to oneself and one's situation; *reasoning*: the ability to negotiate the relevant factors coherently; and *communication*: the ability to share and express one's choices [7]. Advance directives are in part faulty because these

elements are often limited (Table 1). When it comes to understanding, health literacy is recognized as a barrier to engaging with advance directives; many do not know the meaning of the decisions they are being asked to consider [8-10]. When it comes to appreciation, individuals have a limited ability to project themselves into the future and anticipate the care they would want as their health status changes [11,12]. When it comes to reasoning, patients often construct advance directives with internal inconsistencies, leaving clinicians at a loss for how to apply conflicting statements [13]. In terms of communication, advance directives are often not readily available or accessible when needed [1,14]. Well-applied digital enhancement of advance directives could help address these concerns.

As of yet, digital technology has been applied in a limited way to enrich advance directives. Often, the extent is to bring online or put in electronic form the static document itself. This is sometimes complimented with related text such as educational booklets or cursory definitions of the terminology used [14]. Efforts to increase completion rates and availability of documents have used computer generated reminders. There are limited examples of more involved "e-planning" where designers have included graphics, audio or video recordings, and links with answers to frequently asked questions or other relevant online information [14,15]. There is much unrealized potential in the enrichment of advance directives with digital technology, which should be incorporated with a refined sense of purpose. The remainder of this paper explores how the application of digital technology could be organized around the framework of promoting informed decision making, which is presented in Table 1.

#### *Understanding*

Given the importance of health literacy for completing an advance directive, advance directives can themselves be designed to improve health literacy. Multilingual text, audio, graphics, and video can teach users about the core terminology and concepts necessary to meaningfully consider the questions presented. The array of ways that technology can embed and present information means that users can self-select preferred formats and self-drive the level of depth. Algorithms can also be used to increase the likelihood that users encounter what is pertinent to them through personalized recommendations. Through such a tool, users can not only engage in multi-faceted and individualized ways, but comprehension can be verified and further learning encouraged when gaps are identified. There are many guiding examples in similar fields of well-embedded informing functions; for example, the Apple iOS 15 Health App has the capacity to aid the user in interpreting lab results received from

**Table 1. A Framework for Digitally Enhancing Advance Directives to Support Decision Making Capacity**

	<b>Understanding</b>	<b>Appreciation</b>	<b>Reasoning</b>	<b>Communication</b>
<b>Definition</b>	The ability to comprehend the components of the decision being made	The ability to apply the information to oneself and one's situation	The ability to negotiate the relevant factors coherently	The ability to share and express one's choices
<b>Challenge for advance directives</b>	Low health literacy	Poor affective forecasting	Conflicting stated preferences	Inaccessible or unavailable documentation
<b>Possible application of digital technology to address the challenge</b>	Text, audio, graphics, and video clarifying core terminology and concepts with multilingual support	Video accounts from other's lived experiences; links to forums for peer exchange; interactive thought exercises; immersive simulations	Artificial intelligence algorithms that detect and flag inconsistencies; interactive vignettes with empathetic chatbots; multiuser activities	Secure, electronic repositories for storing and sharing; "keyholder" functionality to grant access; reminders for completion, updating, and sharing

a doctor, providing information on what the labs commonly assess, what the results might mean, and how they compare to the user's previous lab results [16]. Digital technology is a powerful tool for education and can be applied to improve understanding of the content relevant for completing an advance directive.

### *Appreciation*

Advance directives can link users to tools that support efforts to draw connections back to oneself and more richly consider hypothetical situations, both of which are necessary to address a limited ability to project oneself vividly and realistically into the future. Using digital technology, advance directives can guide users towards video accounts from others' lived experiences, forums for peer exchange, and interactive thought exercises, all of which would familiarize users not only with what future scenarios might entail but also help them to gain insight into how they themselves might adapt and respond to changing circumstances in ways previously not considered. One example of a rich repository of material comes from the collaborative project DIPEX, through which a large volume of semi-structured audio- and video-recorded narrative interviews has been gathered from diverse participants describing their personal experiences with specific health conditions [17]. Affective forecasting, the ability to predict one's future feelings, is essential for anticipating future values, goals, and preferences as one's circumstances change. Aiding users in deepening this type of appreciation is important if respecting the autonomy of the future self-hinges on fidelity to the declared preferences of the present self, who is an imperfect surrogate.

### *Reasoning*

Advance directives can draw on digital technology

to support reasoning in the face of complex, real-life scenarios by assisting efforts to weigh multiple variables. Interactive vignettes can introduce realistic scenarios that engage users in the exercise of considering relevant factors, and chat rooms with empathetic chatbots can guide someone in reasoning through their preferences. Such empathetic chatbots have been explored in other contexts [18]. Algorithms can detect and flag inconsistencies to then prompt the user to further consider responses, suggest personalized content for clarification, and perhaps even offer recommendations. Moreover, multi-user activities involving, for example, a patient and surrogate or patient and doctor, can explore in real-time the decision-making based on the content of the advance directive. These multi-user exercises would be a way to review whether conclusions drawn from the advance directive are in accordance with the patient's true preferences as a way of validating the logical clarity of the advance directive and others' reasoning based on it. Such "serious games" have been explored elsewhere, for example, in training medical students around moral decision making [19]. Digital technology can help guide users towards improved overall coherence or to gain better insight into significant contradictions.

### *Communication*

Advance directives that are designed using digital technology have the potential to be saved, distributed, and accessed more easily. Enhancements in this arena include secure, electronic repositories through which users can store and send documents anytime, anywhere and "keyholder" functionality that can grant access to advance directives by those authorized if the individual becomes incapacitated or dies [14]. Digital technology can also be used to generate reminders for completion, updating, or sharing. All these features would support the aspect of advance directives that depends on communication.

### *Transparency: An Additional Factor in Consideration of Clinicians and Surrogates*

An advance directive designed to support informed decision making could offer the additional benefit of illuminating the user's thought process, providing valuable insight to those tasked with interpreting the document. Standard advance directives are opaque, offering little that indicates how and why the person arrived at his or her declared position. One important concern when applying advance directives in clinical settings is that the statements regarding preferred care often do not map directly onto the situation at hand, and so surrogates and clinicians must extrapolate to make treatment decisions. Even in cases where a standard advance directive is available, surrogate decision makers and healthcare professionals are limited in their ability to reliably identify the patient's preferred care based on the available content. Advance directives with the aforementioned features, in contrast, could have the added benefit of illuminating the user's decision-making process by using digital technology to potentially capture information such as how empirical evidence influenced the user's position, how factors were weighed, and even what values and goals underlay the choices. This information would complement the statements contained in an advance directive in a way that would be valuable when it came time to apply the advance directive to clinical decision making in practice, possibly leading to treatment decisions that more closely resemble the patient's true preferences. See Box 1, which presents an illustrative use case.

## CONCLUSIONS AND OUTLOOK

In summary, an advance directive enriched with digital technology that is driven by the purpose of creating decision aids might have embedded interactive features for learning; links to optional external exercises to enhance one's ability to project oneself into possible, future scenarios; an embedded review of the logical consistency of stated preferences; and modes for effective electronic sharing. Such enhanced advance directives would have the added benefit of potentially capturing information to improve transparency around the user's decision-making process, guiding surrogates and clinicians in the process of determining which treatments best align with the patient's wishes. Important considerations in the actual design include mitigating the possible introduction of bias depending on the presentation of information and prioritizing essential components in efficient versions that are compatible with time constraints. It should be emphasized that such a tool would serve as a complement to discussion with and guidance from a clinician or an advance care planning professional.

The above suggestion for incorporating technology presents many options for enhancing advance directives, but developers and researchers should explore which elements make the most meaningful difference keeping in mind the goal of supporting decision-making capacity. Best practice standards should be used in the process of evaluation to measure whether changes lead to increased incidences of goal concordant care [4]. Moreover, further research would be needed to determine user experience, including the experience of clinicians and surrogates alongside the experience of the person completing the advance directive, in a process of co-design. A rich fur-

#### **Box 1. Digitally Enhanced Advance Directives – A Use Case**

Subarachnoid hemorrhage is a complex neurological incident associated with burdensome treatment and a high risk of poor outcome. Typically caused by a ruptured aneurysm of a cerebral artery, it tends to affect adults between 40 and 60 years with a frequency of 10:100,000 [20]. There are many complications that occur unpredictably within 3 to 14 days after the first bleeding event, and how to respond to these incidences must be determined quickly as the interventions are highly time sensitive. The patient is often incapacitated while a number of fine-grained decisions are made about whether to intervene or provide palliative measures. It would not be feasible for someone to have considered and declared preferences for every possible scenario, requiring surrogates and clinicians to extrapolate from known wishes to determine treatment that is most likely to reflect the patient's preferences. Moreover, since subarachnoid hemorrhage often affects relatively healthy adults, a completed advance directive may not have been informed by any comparable life events. A well-considered advance directive generated with supportive digital technologies would be valuable in such a scenario to promote respect for the patient's preferences. An enhanced advance directive could assist users in determining preferences that are likely to reflect their goals and values as their healthcare status changes by offering insight ahead of time into what critical care may entail and how cognitive or physical disability might be experienced: addressing a lack of personal experience to aid decision making, the tool might present a descriptive animation of a common intensive care intervention, such as mechanical ventilation, or connect users to accounts of others experience of a common disability, such as one-sided paralysis. The tool could also collect users' responses in a way that captures their underlying reasoning in favor of or against certain interventions to make clinician and surrogate efforts of interpretation and extrapolation more robust.

ther area for research would be to explore whether game theory, mechanism design, and artificial intelligence methods could draw on aggregate data from such enhanced advance directive to make predictions regarding individuals' care preferences [21].

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