ACCSCIENCE PUBLISHING

Design+

ARTICLE

Toward meaningful and compassionate privacy notices: An exploratory value-sensitive design study

Nelson Shen[1,2†*], Prathiga Suthanthirarajan[2†], Raha Moradhasel[1], Hwayeon Danielle Shin[1,2], and Kate Sellen[3]

[1]Krembil Centre for Neuroinformatics, Centre for Addiction and Mental Health, Toronto, Ontario, Canada

[2]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

[3]Faculty of Design, Ontario College for Arts and Design, Toronto, Ontario, Canada

Abstract

The rapid evolution of digital health tools and artificial intelligence has a transformative potential to improve mental health care access and delivery, yet people are often uninformed about their data. Privacy notices (or simply, "notices") often fail to inform readers due to their length, complexity, and lack of accessibility. This study employs a value-sensitive design (VSD) approach to conceptually, empirically, and technically investigate how digital mental health notices can meaningfully inform their readers. Through a conceptual investigation, a conceptual model from prior VSD works was adapted to explicitly include the concept of meaningful consent. Honesty, helpfulness, universal usability, and privacy were the human values that were mapped to the different domains of the conceptual model for meaningful consent. Using these values as a framework, an empirical investigation and technical investigations were conducted to identify the values people associate with meaningful consent (empirical) and the tensions that exist between values in more innovative notice designs (technical). To identify the values and value tensions, 19 interviews were conducted with a diverse sample of past, present, and potential users of the Hope by Centre for Addiction and Mental Health suicide safety planning app to explore their views on meaningful consent. The findings from the empirical investigations added depth to the value definitions, where participants described honesty as "transparency," emphasizing being upfront, straightforward, and candid. Helpfulness centered on simplifying notices and enhancing user experience and interfaces for better comprehension. Universal usability stressed equitable, compassionate design, while privacy required clear, formal choices (e.g., "yes" or "no") in notices. The technical investigation identified tensions predominantly between honesty and helpfulness, where over-simple or over-complex designs can be received with skepticism. Based on these findings, this study provides recommendations for adjustments to existing guidelines for meaningful consent.

Keywords: Value-sensitive design; Privacy notices; Meaningful consent; Digital mental health

†*These authors contributed equally to this work.*

***Corresponding author:**
Nelson Shen
(nelson.shen@camh.ca)

Citation: Shen N, Suthanthirarajan P, Moradhasel R, Shin HD, Sellen K. Toward meaningful and compassionate privacy notices: An exploratory value-sensitive design study. *Design+*. 2025;2(2):8158. doi: 10.36922/dp.8158

Received: December 24, 2024

Revised: February 27, 2025

Accepted: April 14, 2025

Published online: April 24, 2025

1. Introduction

The ongoing digitalization of mental health care is changing how it is accessed and delivered.[1] Despite the transformative potential of digital mental health tools and artificial intelligence (AI), there are many challenges to patient acceptance of their use to support mental health care. A common barrier to acceptance is patient perceptions of privacy risks and their understanding of data practices (e.g., data collection, use, and disclosure).[2-5]

Privacy notices (herein referred to as "notices") are the typical mechanism for informing digital health users about the data practices of an organization. The digital health marketplace operates on a "notice and choice" paradigm, which assumes users can make an informed choice based on the available notice, implying consent.[6] An express consent approach requires users to opt into the terms outlined in the notice (i.e., "click to accept"). These models fail to achieve informed consent as notices are often long, jargon-heavy, and written at a college level, if available.[7] "Notice and consent" creates a problematic dynamic, where consent is uninformed and provides app vendors with legitimate power over data uses. This is particularly concerning with digital mental health tools due to the sensitive nature of the data they collect.[8,9] The opacity of data practices contributes to a growing sense of mistrust among users and raises critical questions about the ethical use of data in digital mental health.[10,11]

The concept of meaningful consent was intended to address the opacity by emphasizing the need for organizations to enable comprehension of the notices, where consent is only valid "if it is reasonable to expect that your customers will understand the nature, purpose, and consequences of the collection, use or disclosure of their personal information."[12] Guidance on implementing meaningful consent suggests that literacy gaps need to be bridged, and patient preferences should be included in its development.[13]

A recent review found mixed evidence on how to implement notices and consent forms, where some studies supported brevity, and others supported more detailed information.[13,14] This finding suggests that notice design preferences are highly context-dependent, shaped not only by the user experience and interface (UX/UI) but also by broader social factors (e.g., literacy, expectations, relationships, and norms).[15] This context-dependency creates a challenge in designing notices and requires further guidance to support meaningful consent. Without nuanced and specific recommendations for designing meaningful consent, organizations may struggle to ensure that individuals fully understand the implications of data collection and use, potentially undermining informed decision-making. This study uses a value-sensitive design (VSD) approach to identify how socio-technological factors may be incorporated into notice design.

2. Theoretical approach and conceptual framework

While human-centered design is an increasingly adopted approach in developing digital health tools, it primarily focuses on the needs, preferences, and experiences of individual users. It has been argued that VSD may better capture the ethical, societal, and political aspects of design.[16] VSD offers a theoretically grounded and holistic approach that fills the gap by "frontloading" ethical and socio-technical considerations early in the design process by designing for values. Within this context, values are defined as a set of guiding principles of what people consider to be most important in life, focusing on ethics and morality.[17] Given that the concept of informed consent is deeply rooted in philosophy and ethics,[17,18] this study will use a VSD approach in exploring the design of digital mental health privacy notices. VSD consists of a "tripartite methodology" to inform design: conceptual, empirical, and technological investigations.[17]

2.1. Conceptual investigation

Conceptual investigations comprise analytically, theoretically, or philosophically informed explorations of values relevant to stakeholders and technology. This process explores how these values are defined, prioritized, and potentially come into tension with one another. This phase often involves philosophical analysis and ethical reasoning to ensure a comprehensive understanding of the values at stake.[17]

This investigation explores meaningful consent through two perspectives: the user and the privacy notice. The user is a direct stakeholder since they will be engaging with the privacy notices to decide whether they want to use the app and share their data. They will also be experiencing any privacy implications. Drawing on actor-network theory (ANT),[19] notices are treated as direct stakeholders as they are active "actors" that mediate relationships, negotiate power, and translate values, laws, and user agreements. Notices also embody the legal/regulatory requirements and interests of the other direct and indirect stakeholders. Much like in-person interactions, a privacy notice provides cues for people to interpret, act upon, and reinforce or challenge power dynamics between individuals.[20] This conceptual investigation explores the interaction between a potential digital mental health user and the notice of a hospital-based application, which is based on the insights derived from workshops with digital health privacy regulators and decision-makers.[13]

Rooted in the principles of the Belmont Report and the Fadden and Beauchamp bioethics texts, Friedman *et al.*'s[21] seminal VSD work defines informed consent as a value, consisting of a six-dimension process of "informing" (disclosure, comprehension) and "consenting" (voluntariness, competence, agreement, and minimal distraction).[22,23] The concept of "informed" encompasses *disclosure* and *comprehension*. *Disclosure* refers to the provision of accurate, explicit information about the benefits and harms of a service and the data management practices of the vendor. *Comprehension* refers to how an individual interprets the information. This conceptual investigation expands the original definition to include how the information is presented in the notice or to the individual. This expansion is based on Friedman *et al.*'s[20] discussion of the role of cues in in-person interaction as an aspect of interpretation and the ANT-based assumption that the notice is a direct stakeholder.

The concept of "consent" encompasses *voluntariness*, *competence*, and *agreement*. *Voluntariness* refers to the ability to make a choice without coercion or manipulation, while *competence* requires the individual to have the physical, mental, and emotional capabilities to make the choice. *Agreement* refers to the need for there to be a clear choice. A sixth dimension of *minimal distraction* was added in a later conceptualization, where the first five dimensions should be met without diverting the user from the task of being informed or consenting.[24]

Meaningful consent is an essential element of the Personal Information Protection and Electronic Documentations Act (PIPEDA)—the federal privacy legislation for private-sector organizations in Canada. PIPEDA serves as the foundation for provincial health privacy legislation, where applicable (e.g., if deemed substantially similar). Meaningful consent focuses on the comprehension aspect, where people must understand what they are consenting to. The Office of the Privacy Commissioner of Canada's Meaningful Consent Guidelines (OPC guidelines)[25,26] were used to expand upon the six informed consent dimensions by adding values. The guidelines are:

(i) Be accountable and stand ready to demonstrate compliance; Organizations should be in a position to demonstrate compliance with the consent obligations by ensuring meaningful consent (e.g., not buried in the notice).
(ii) Emphasize key elements: Organizations must allow individuals to quickly review key elements impacting their privacy decisions upfront by placing additional emphasis on what information is collected; who has access to the information; for what purposes is the information collected, used, or disclosed; risk of harm and other consequences.
(iii) Allow individuals to control the level of detail they get and when: Information must be provided to individuals in manageable and easily accessible ways (potentially including layers), and individuals should be able to control how much more detail they wish to obtain and when.
(iv) Be innovative and creative: Organizations should design and adopt innovative processes that leverage the interactive and innovative user experience and user interface approaches.
(v) Consider the consumer's perspective: Organizations must take the consumer's perspective into account to ensure that it is user-friendly and that the information is generally understandable and customized to their target audience, including vulnerable populations.
(vi) Make consent a dynamic and ongoing process: Informed consent is an ongoing process that changes as circumstances change; organizations should not rely on a static moment in time but rather treat consent as a dynamic and interactive process.
(vii) Provide individuals with clear options to say "yes" or "no": Provide clear options of "yes" or "no." Choices must be explained clearly and be accessible regardless of an opt-in/opt-out approach; otherwise, it is a condition of service.

The OPC guidelines were used as a framework to identify four values for the conceptual investigation: honesty, helpfulness, universal usability, and privacy (Figure 1). These values complement the six dimensions of informed consent to conceptualize meaningful consent, where there should be honest disclosure, helpful comprehension, universal usability considerations with competence, and enablement of privacy through voluntary agreement.

Honesty has been described as "orientation toward the truth (authentic) and honest self-representation (absence of manipulation)."[27(p153)] This value was selected to represent the disclosure and minimal distraction dimensions, where information should be communicated in an authentic and non-manipulative way. The OPC guidelines suggest that organizations should emphasize key elements and be accountable.

Helpfulness can be defined as "extending a hand to someone devoid of expectancy in return, utilizing available power and resources for the welfare of others, helping individuals with their adversities, to shoulder their burden sharing responsibilities, and heartily smoothing out one's problems without causing a sense of discomfort."[28(p107)] The OPC guidelines focus on helping people comprehend by improving interactions between users and privacy notices. This should occur by emphasizing key elements and allowing for control of details through innovative

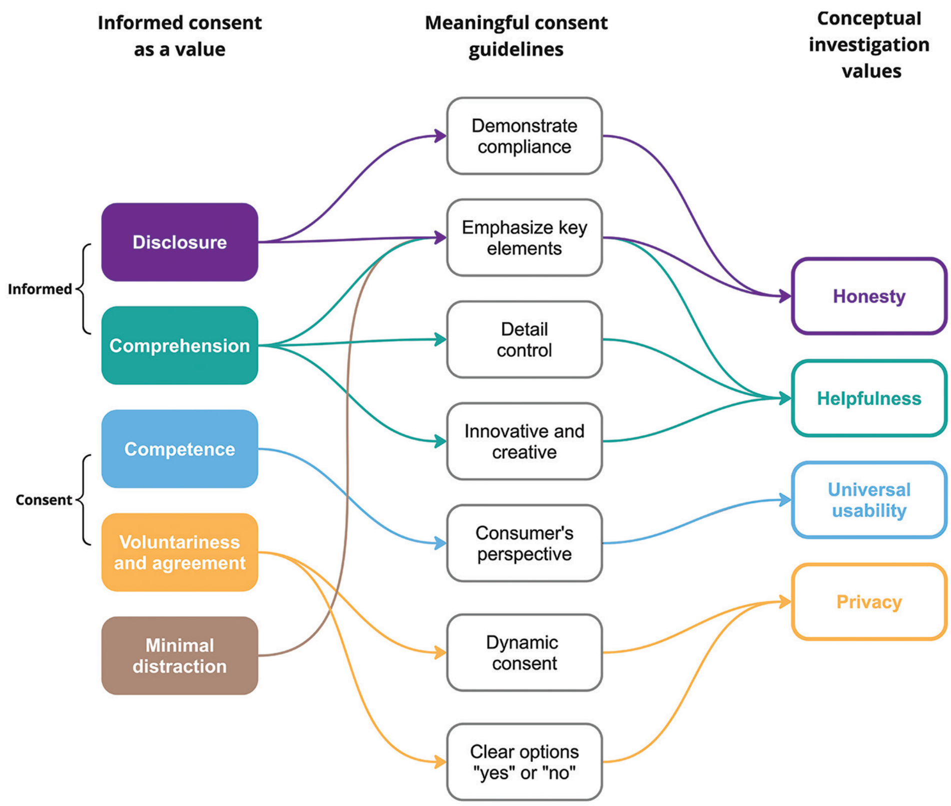

Figure 1. Conceptual investigation: Framework for identifying values that conceptualize meaningful consent

and creative digital processes. Moreover, the guidelines ask organizations to consider the consumer's perspective, calling for a human-centered design approach to align notices to user needs.

Considering the consumer's perspective also speaks to the value of universal usability, defined by Friedman and Hendry as "making all people successful users of information technology."[17(p28)] This definition implies both equality and equity. In terms of comprehension, this means that everyone should understand the material the same way (equality). However, this value also aligns this concept with competence. This means that equity considerations should be made for any physical, mental, and/or emotional limitations of the individual.

The last value is privacy (informational) and is based on Westin's definition as the "claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others."[29(p7)] This value is at the heart of consent, where there is a voluntary agreement to share data with another party. The OPC calls for clear "yes" or "no" options and dynamic consent.

The dimension of minimal distraction cross-cuts all values. Information should be absent from manipulation, designed to help understand rather than distract. Consent should not be coerced in the process of making a choice nor by an individual's abilities.

This paper reports on the empirical and technical investigations to provide a greater understanding of these values. An empirical investigation examined the experiences, perceptions, and behaviors of individuals and groups affected by the technology (e.g., notice). The technical investigation focused on how technology supports or undermines identified values, exploring the affordances and limitations of specific technical designs. Using this approach, this study asks the following research questions:

(i) What values are most important to consider when designing privacy notices? (Empirical)
(ii) What are the values and value tensions in innovative privacy notice designs? (Technical).

3. Methods

This VSD study is part of a broader study at the Centre for Addiction and Mental Health (CAMH) and was applied in the context of the Hope by CAMH app. The Hope app supports suicide safety planning for individuals in the community who are at risk, providing them with a plan for when they are in crisis. At present, all data in the Hope app are stored on the phone.[30] However, there is growing interest in exploring how the data might be used to improve suicide risk detection, prevention, and care services.[30] As such, this study will inform the development of a meaningful consent process as the app and other AI initiatives at CAMH evolve.[1] This study received ethics approval at CAMH (CAMH REB#82_2020).

3.1. Subject recruitment

In this study, we conducted semi-structured interviews with Hope app users (past, present, and potential users). Participants were recruited through electronic posting on the CAMH online research registry and the EENet Community of Practice, and flyers posted in waiting areas at CAMH. Interested participants contacted the research team. To be eligible, participants had to be English-speaking, at least 18 years old, Hope app users, and provide informed consent to participate in the study. Recruitment occurred between October 2023 and August 2024.

A maximum variation strategy was used to recruit a diverse range of perspectives so as to identify cross-cutting themes. Maximum variation was sought based on user type, digital health use, history with CAMH, trusting disposition, privacy knowledge, and privacy protection behaviors. These characteristics were selected based on the eHealth Trust Model – a theory-grounded, evidence-based patient privacy research framework.[31] The model constructs were also validated in follow-up studies on privacy and consent.[5,32] Race, age, and gender were also monitored for socio-demographic diversity, as there are equity and digital divide implications across different population groups.[5] Variation was determined through responses to an 11-item pre-interview survey through REDCap.[33]

3.2. Data collection

One-on-one interviews were conducted virtually through Webex video conferencing software, each lasting approximately 90 min. A semi-structured interview format was selected to allow the interviewer (NS) to pursue ideas in greater depth, when necessary. Key aspects related to the use of the research data, the voluntary nature of participation, and assurance of confidentiality were emphasized before starting the interview. Participants were given the opportunity to ask questions before electronically signing the consent form (via REDCap). The research team developed and piloted the interview guide to explore participant values (empirical investigation) and thoughts on innovative privacy notice designs, such as the nutrition label approach (iOS/Android app store), table of contents (Slack), emphasized key points (Twitter/X), frequently asked questions (FAQs; Strava), and key point summary (Canva and Coursera).

Interviews were recorded and transcribed verbatim. Transcripts were analyzed using rapid qualitative analysis, a pragmatic implementation science method suited for time-sensitive research.[34,35] A template of key domains from the interview guide was used to summarize transcripts, with notable quotations integrated where relevant. The research team independently summarized three transcripts to ensure consistency, and discrepancies were resolved by the lead author (NS). Transcripts were divided among the team for paired summarization, with all summaries reviewed for accuracy. The summaries were exported into Microsoft Excel for matrix analysis, identifying common themes across key domains. Themes were reviewed and finalized through team discussions. Participant characteristics from pre-interview surveys were summarized using descriptive statistics.

4. Results

4.1. Participant characteristics

Nineteen participants were included in the diverse sample, capturing maximum variation across gender, age, race/ethnicity, history with CAMH, trust, privacy knowledge, and confidence in protecting privacy (Table A1). Three-quarters of the participants identified as men (42.1%) and women (31.5%), with the remaining individuals identifying as either non-binary (21.1%) or transgender (5.3%). More than half of the participants were less than 29 years old (52.6%). There was a diversity of ethnic identities, with 36.8% of participants identifying as White individuals. While most participants use digital tools and services routinely (68.4%), approximately one-quarter of the participants have used the Hope app at some point (26.3%). Less than half of the participants have received care at CAMH (47.3%). Most of the participants self-reported as being trust (47.3%) and knowledgeable about privacy rights (47.3%). Their trust levels varied, with 47.3% of participants leaning toward trust (rating of 5+ out of 7), 31.5% leaning toward distrust (rating of 5+ out of 7), and 21.1% being neutral. There were mixed levels of knowledge of privacy rights and risks, with more participants reporting good or very good (47.3% and 42.1%, respectively). There was also a mix in levels of confidence in protecting privacy rights; however, 52.6% of participants reported being confident (42.1%) or completely confident (10.5%).

Overall, most participants described their experiences with privacy notices as negative due to the length and complexity of the notices. Engagement with privacy notices varied, with most skim reading the full text or skim reading for key points on the apps' data practices and looking for cues to determine the trustworthiness of the app provider (e.g., familiarity, reputation, history, professional standards, app reviews, and size). Several participants regard reading notices as a waste of time or pointless, thus not engaging with them. There was a small group of participants who read notices as they felt responsible for understanding what they were getting into. Moreover, some felt anxious about their data and wanted to make sure they knew everything before they started using the app. Participants were divided on why notices are designed this way. Some believed organizations were meeting legal requirements, while a few mentioned that designing notices is not an organization's priority. Others saw it as an intentional effort to obscure information and create confusion. The full description of the privacy experiences, which were navigated as part of the interview, will be reported elsewhere.

4.2. Empirical investigation: Characterizing values

The most shared values were related to honesty and helpfulness. Honesty, often described as *transparency*, emphasizes clarity in how data are collected and used, providing breadth and depth of information. Participants highlighted the importance of writing notices in *clear language* to avoid *confusion or uncertainty*. Many stressed the need to be *upfront*, making notices readily available to avoid *gatekeeping information*. *Respect*, *responsibility*, and *accountability* were also noted, including addressing privacy breaches with actionable steps. One participant shared their experience:

> I've had like data breaches on certain accounts, [and] I've had some of the companies throw it under the rug and [not] actually address it. So, I guess if something like that did happen, they [should] make sure customers are aware and do things to protect themselves, like changing passwords and stuff like that. (Interviewee 11)

> Helpfulness was also emphasized, with participants advocating for accessible and user-friendly notices, formatted in *chunks* or short summaries of one to three pages. Suggestions included highlighting key points, standardizing formats for better comparisons, and making notices more approachable through conversational language, colors, and even humor. One participant suggested a playful approach, "I know this is a bummer, but you guys, you should really read this." (Interviewee 17)

Universal usability was also a key theme in most interviews, with the most common word being *accessible*. Participants believed notices should be inclusive and *user-friendly across varying populations*, such as *immigrants*, *people with English as a second language*, or *people with intellectual disabilities*. The attention-deficit disorder was also mentioned a few times. Empathy and equity were recurring ideas, with one participant stressing proactive design to *do the least harm and the most good*. Participants emphasized the need to be *compassionate* by being proactive in the design:

> Understanding that there may be people from multiple walks of life using this app, and it being presented in a way that, you know, if you have questions, just click here… to open an email box or send off your question before you agree. You can have a Contact Us button right there so that if people don't quite understand that, you're giving them a very easy ability to then get their questions answered, even if it's not immediate, but so that it just makes it more user-accessible. (Interviewee 16)

The privacy value was mentioned by some participants, often referred to as autonomy. For some, this meant *freedom and choice,* or having the *ability to say yes or no to data collecting*. A couple of people mentioned privacy notifications as a mechanism. Others defined it as *letting users know if they have control*, asking notices to be clear about privacy-related information such as anonymity, risks, privacy and security safeguards, and responsibilities.

4.3. Technical investigation: Innovative privacy notices

Overall, participants preferred privacy notices with innovative designs but found overly simple approaches insufficient. While the table of contents approach (Slack) helped organize and navigate information, participants still found it overwhelming. Similarly, summaries of key points (Coursera) and paragraph summary statements (Canva) were seen as incomplete and lacking depth.

> Even though it's better than a plain block of text, it's not engaging enough for most users. (Interviewee 5)

> It doesn't feel comprehensive – if I wanted to learn more, I'd have to work too hard to find it. (Interviewee 6)

Across these approaches, participants criticized summaries as being too vague, oversimplified, and untrustworthy. Simplified notices were also seen to obscure transparency, as participants shared:

> The key points are so vague that I'm left wondering what's being hidden. (Interviewee 15)

> The summaries don't add much – they're too vague and miss important details. (Interviewee 11)

The nutritional label approach (iOS and Google Play app stores) received initial praise for its straightforward design and clarity. Participants appreciated its digestibility, with one stating, "This approach is great for people who want to read the full details, but in an organized way" (Interviewee 6).

Despite having a progressive disclosure through links, concerns arose over its oversimplification, which could lead to key details being omitted or overlooked. Some participants questioned its transparency, suggesting the format should include easily accessible definitions or explanations for users seeking more information.

> I'd prefer if they explained more why they need certain data types instead of just listing them. (Interviewee 8)

> This format feels a bit like it's trying to gloss over important details. (Interviewee 9)

Strava's notice, combining an FAQ (frequently asked questions) and nutritional label approach, received praise for balancing simplicity and depth. Participants appreciated the clear, upfront answers and clickable links for more details, with one participant stating, "The yes/no answers make it quick to understand and the detailed links are there for those who care" (Interviewee 18).

This format allowed users to grasp essential information quickly while offering transparency for those seeking deeper insights. However, some participants raised concerns that the simplicity of yes/no responses might deter users from exploring critical details, such as data-sharing practices. Some also felt that there was too much volume of information at once.

> It's nice that they make it simple, but it ends up raising more questions than it answers. I want more detail upfront, not hidden under another click. (Interviewee 19)

> It's easy, but it's almost too easy that it becomes overwhelming. There are so many colors, links, and options that I just feel like there's too much going on. I don't know where to start. (Interviewee 21)

The Twitter/X FAQ format was generally well-received for its approachable tone and conversational language, which made the information feel more accessible and less intimidating. Features, such as large subheadings, clickable links, and relatable phrasing, such as "Seriously, what happens with my data?" appealed to some users. One participant noted that the lighthearted tone "sort of humanizes a big organization" (Interviewee 8). However, many participants criticized the tone as unnecessary or disingenuous, with summaries being overly vague and lacking meaningful insights. As one participant remarked, "Of course, 'you give some data, we get some data'; like, it doesn't teach me anything" (Interviewee 22).

There was also broad agreement that this format is unsuitable for certain contexts, particularly in industries like healthcare. One participant shared, "If I went to the [redacted] Hospital page and I saw this, I'd be like, I don't think I'm gonna go to the [redacted] Hospital actually" (Interviewee 14).

Google's approach, featuring icons, bold subheadings, videos, and ample whitespace, received mixed feedback. Participants appreciated the accessible language, intuitive navigation through the sidebar, and visual elements, such as icons and bold text, which improved readability. One participant noted, "This approach combines visuals and text in a way that makes it easy to digest" (Interviewee 7).

However, some found the whitespace and icons inefficient, requiring excessive scrolling to access information. The use of videos drew divided opinions. While some participants appreciated the effort to *meet users where they're at*, most felt videos were inefficient and less practical than reading:

> I personally wouldn't watch the video. I don't have the patience to sit through it and wait for them to explain something I could probably find faster by just reading. If they're going to include videos, they need to make sure they're very short – like under a minute – otherwise, people will just skip them. (Interviewee 12)

4.3.1. Value tensions

This technical investigation revealed key value tensions reflecting challenges in balancing transparency, user engagement, and accessibility. These tensions are related to the OPC guidelines emphasizing key information, control of detail, innovative approaches, and consumer perspectives.

The most prominent tension was between transparency (honesty) and simplicity (helpfulness). Participants appreciated clear, concise summaries and emphasized key points, but oversimplified information was criticized for being vague.

> I love how quick it is to understand, but I'm not sure if I'm missing something important by not reading everything. (Interviewee 4)

> It's too simplified. I'm worried they're glossing over important stuff. (Interviewee 15)

Similarly, there was a trade-off between comprehensiveness (honesty) and cognitive load (helpfulness), where providing detailed information could overwhelm users. While Strava's notice was praised for letting users control how much they read, it was also criticized as overwhelming and difficult to navigate.

> I appreciate the effort to simplify it, but when there's so much text and so many clickable sections, it gets a little exhausting to figure out where to focus. (Interviewee 12)

Participants discussed alternatives, such as using dropdowns or hover-over text for key details but expressed concern about usability.

> If you had to click on it, and it opened up a new tab or link or it rearranged the format of the whole page, it might be a little bit weird. (Interviewee 5)

The tension between professionalism and approachability further complicated the balance between honesty and helpfulness. Interactive, conversational tones like those used by Twitter/X and Google appealed to some participants but were deemed inappropriate by others, particularly for serious topics like privacy or healthcare. Participants questioned the credibility of such approaches. This tension also intersected with Universal Usability, as efforts to appeal to different audiences risked undermining the gravity of privacy issues while maintaining the status quo in tone has not effectively engaged most users.

> Similar to a hospital, X is acknowledging that they have users that have a variety of literacy and understanding of tech savviness. But because this is a social media platform, I'm a little bit more accepting of the lightheartedness than I wouldn't be in a hospital setting. Because in a hospital setting, if I saw too much informal language, I would get worried and call into question how much I trust this information. (Interviewee 18)

There was also a tension between accessibility (universal usability) and cognitive load (helpfulness), which highlighted the challenges of making notices inclusive without compromising usability. Multimedia elements, such as icons, images, and videos were seen as helpful for some audiences but detracted from clarity for others. For example, Google's use of icons and spacing was praised for enhancing accessibility, but criticized for creating inefficiencies:

> In terms of like the content itself, it seems a little too heavy, like there's just so much in there that doesn't really make you interested in one click [or] scroll down. I see all these like different things. Like even with font size, for example, it seems like it's not proportionate to the page that it's on. It's like pretty small, and [I don't] understand the use of like little images like that. It's just making that page way longer than it should be. (Interviewee 10)

5. Discussion

This VSD study identified honesty, helpfulness, universality, and privacy as core values of meaningful consent for privacy notice readers, skimmers, and non-readers. Honesty was characterized as being "transparent," requiring organizations to make privacy notices "upfront" and easy to find. The term "upfront" was also used to describe the language used in the notice, where it is clear, straightforward, and candid about points of concern (e.g., past privacy breaches and data uses). For these participants, "upfront" demonstrates integrity and respect for the reader. Helpfulness referred to the UX/UI of the notice. There was a clear desire for organizations to approach notices differently, simplifying what needs to be understood in different ways. Universal usability was a value many participants brought up as a need to be equitable. They emphasized that, for disadvantaged or vulnerable populations in particular, notices need to be more compassionate. This meant exploring how design can empower individuals by providing clear channels for support. These supports can vary from embedding quick access to definitions to a clear display of contact information to clarify privacy implications, to chatbots to have a conversation about privacy. Furthermore, there is a need to reflect on the potential unintended consequences of design decisions and implement measures to mitigate those that may cause harm. Some believed that privacy, as a core value, can be operationalized through expressed consent. They should be able to respond with "yes" or "no" before proceeding.

The empirical investigation supported the recommendations stipulated in the OPC guidelines, especially the guidelines around design, where notices should emphasize key elements, allow for control of detail, and be innovative and creative, as well as take the consumer's perspective into account. These guidelines predominantly reflect the value of helpfulness – elements that will bridge the data literacy gaps through information and UX/UI design. Based on these values, this study adds the following recommendations to the OPC guidelines:

(i) Make privacy notices easy to find;
(ii) Be upfront about past privacy and security incidents;
(iii) Support individuals who are concerned by providing clear and discoverable communication channels and recommendations;
(iv) Make the language in privacy notices personable and professional; and
(v) Be compassionate; provide other options to accommodate marginalized and vulnerable populations, including considerations for neurodivergence.

Most of the values identified in the empirical investigation focused on the concept of meaningfulness rather than consent, which provides little insight into designing the consenting process. This conflicts with a recent finding that two-thirds of Canadians also believe opt-in consent mechanisms should be a requirement for sharing data[36] and the common sentiment that patients want granular control of their data.[33,37] The growing evidence suggests consent type may have a limited impact on consent decisions as the volume of consent requests is increasing, leading to consent fatigue and discordant privacy behaviors (e.g., privacy paradoxes).[38] As seen here, digital health privacy decisions are commonly based on trust heuristics (e.g., the other party's reputation, familiarity, and legitimacy).[33,37]

Design decisions should be implemented judiciously, balancing values to create notices that are both informative and trustworthy. The technical investigation highlighted the complexity of meaningful consent and will require more than "short and simple language."[13] Notices employing multiple strategies (e.g., simplified content, approachable language, control of detail, accessibility) were better received. However, overly simplified or vague designs risk appearing unprofessional or deceptive, fostering skepticism. That is, there is a threshold where these strategies become perceived as oversimplified, vague, unprofessional, or cumbersome – all of which would introduce skepticism toward the notice and the organization. Given the contextual nature of privacy and consent, there is no standard approach. Designers should focus on the quality of information and consider how transparency and UX elements shape perceptions and actions, which can be unintentionally misleading.[39,40]

While this VSD study presents the conceptual, empirical, and technical investigations on meaningful consent in digital mental health, the insights are preliminary, as there are limitations to consider. The exploratory nature of this qualitative study limits applicability beyond the context of the Hope app and the digital mental health context. In addition, the study relied on self-identification of Hope app usage and self-reports rather than actual behaviors. As such, the findings may not fully reflect the views of the Hope app and digital mental health users and potential user or their consent choices. However, maximum variation was achieved, allowing for the identification of cross-cutting themes across a diverse group of participants based on demographics and theory. Finally, the technical investigation of notices from well-known organizations may introduce participant biases toward the notice. The perspectives shared may also be related to the data type implied by the nature of the organization, which is distinct from mental health data and healthcare organizations. Future technical investigations will present notice prototypes for mental health, specifically to better understand the values and tensions discussed above.

The investigations also focused on the value perspectives of two stakeholders – the reader and the notice – operating under the assumption that the notice was provided by CAMH, whose values emphasize patient-centeredness (e.g., "respecting patients' values, preferences, and expressed needs").[41] This study acknowledges that other social, cultural, political, and bureaucratic factors may impact the feasibility of implementing these values.[42] This power differential is a common limitation of VSD.[43,44] Future phases of work include participatory and co-design research with a spectrum of direct and indirect stakeholders, where establishing a trauma-informed and anti-oppressive collaborative environment(s) will be a priority.[45,46]

6. Conclusion

This study explored meaningful consent in a digital mental health context through the Hope by CAMH app. With growing interest in implementing AI initiatives to support clinical care and patient recovery, in this case, for suicide support, there is a corresponding need to engage and empower patients in decision-making. Notably, the few participants who read through privacy notices shared that their behaviors were driven by feelings of personal responsibility or anxiety. As such, there is an imperative for healthcare organizations to adopt more innovative, systemic, and equitable approaches to moving this existing burden from end users to providers of digital mental health tools.[47] Present "notice and consent" mechanisms have generally been ineffective at informing and consenting. Future studies will need to push beyond document or interface design and explore how a more meaningful, holistic, and compassionate experience can be achieved, especially for those seeking digital mental health support.

Acknowledgments

We would like to recognize and thank Dr. Lydia Sequeira, Iman Kassam, Ryan Chan, and James Sunwoo for their invaluable support in getting this project running. We would also like to thank all the participants for sharing their perspectives and their ongoing engagement in this work.

Funding

We would like to acknowledge AMS Healthcare for funding this work through the Fellowship in Compassion and Artificial Intelligence.

Conflict of interest

The authors declare they have no competing interests.

Author contributions

Conceptualization: Nelson Shen, Kate Sellen
Formal analysis: Nelson Shen, Prathiga Suthanthirarajan, Raha Moradhasel, Hwayeon Danielle Shin
Investigation: Nelson Shen
Methodology: Nelson Shen, Kate Sellen
Writing – original draft: Nelson Shen, Prathiga Suthanthirarajan
Writing – review & editing: All authors

Ethics approval and consent to participate

This study received ethics approval at the CAMH, Canada's largest academic mental health hospital (CAMH

REB#82_2020). The informed consent process follows the standard operating procedures at CAMH. Potential participants were required to provide informed consent to participate. They were provided with the consent form and time to review. The consent form was reviewed with the participant, and questions about the study were answered. Participants digitally signed the consent form through the REDCap platform and were attested by the interviewer before the interview began.

Consent for publication

The informed consent was obtained online through a digital signature from each participant before the study. The informed consent form contained a section outlining the use of the research results for dissemination and publication (Section XI), where the interview data will be de-identified before data analysis. In addition, the informed consent highlights that confidentiality will be maintained (Section VIII), where all quotes used will be presented anonymously so that no identifying information will be included in publications.

Availability of data

Data are available from the corresponding author upon reasonable request.

References

1. Yu J, Shen N, Conway S, *et al*. A holistic approach to integrating patient, family, and lived experience voices in the development of the BrainHealth Databank: A digital learning health system to enable artificial intelligence in the clinic. *Front Health Serv*. 2023;3:1198195.

   doi: 10.3389/frhs.2023.1198195

2. Shen N, Kassam I, Chen S, *et al*. Canadian perspectives of digital mental health supports: Findings from a national survey conducted during the COVID-19 pandemic. *Digit Health*. 2022;8:205520762211022.

   doi: 10.1177/20552076221102253

3. Williamson SM, Prybutok V. Balancing privacy and progress: A review of privacy challenges, systemic oversight, and patient perceptions in AI-driven healthcare. *Appl Sci*. 2024;14(2):675.

   doi: 10.3390/app14020675

4. Pietrzykowski T, Smilowska K. The reality of informed consent: Empirical studies on patient comprehension-systematic review. *Trials*. 2021;22(1):57.

   doi: 10.1186/s13063-020-04969-w

5. Shen N, Kassam I, Kemp J, *et al*. Canadians and digital health data: Privacy experiences and perspectives. In: Strudwick G, Keshavjee K, Zavar A, Ahmed Gurey T, Jahin N, editors. *Studies in Health Technology and Informatics*. Amsterdam: IOS Press; 2025.

   doi: 10.3233/SHTI250009

6. Kim NS. *Consentability: Consent and Its Limits*. United Kingdom: Cambridge University Press; 2019. Available from: https://papers.ssrn.com/abstract=3367917 [Last accessed on 2024 Oct 13].

7. Jilka S, Simblett S, Odoi CM, *et al*. Terms and conditions apply: Critical issues for readability and jargon in mental health depression apps. *Internet Interv*. 2021;25:100433.

   doi: 10.1016/j.invent.2021.100433

8. Torous J, Bucci S, Bell IH, *et al*. The growing field of digital psychiatry: Current evidence and the future of apps, social media, chatbots, and virtual reality. *World Psychiatry*. 2021;20(3):318-335.

   doi: 10.1002/wps.20883

9. Smith KA, Blease C, Faurholt-Jepsen M, *et al*. Digital mental health: Challenges and next steps. *BMJ Ment Health*. 2023;26(1):e300670.

   doi: 10.1136/bmjment-2023-300670

10. Andreotta AJ, Kirkham N, Rizzi M. AI, big data, and the future of consent. *AI Soc*. 2022;37(4):1715-1728.

    doi: 10.1007/s00146-021-01262-5

11. Pendse SR, Stapleton L, Kumar N, De Choudhury M, Chancellor S. Advancing a consent-forward paradigm for digital mental health data. *Nat Mental Health*. 2024;2(11):1298-307.

    doi: 10.1038/s44220-024-00330-1

12. Office of the Privacy Commissioner of Canada. *PIPEDA Fair Information Principle 3 - Consent*; 2018. Available from: https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/p_principle/principles/p_consent [Last accessed on 2024 Dec 02].

13. Shen N, Kassam I, Ilkina D, Wickham S, Carter-Langford A. Meaningful digital consent in Canada: Recommendations from pan-Canadian consent management workshops. *HCQ*. 2022;24(4):40-47.

    doi: 10.12927/hcq.2022.26712

14. Kassam I, Ilkina D, Kemp J, Roble H, Carter-Langford A, Shen N. Patient perspectives and preferences for consent in the digital health context: State-of-the-art literature review. *J Med Internet Res*. 2023;25(1):e42507.

    doi: 10.2196/42507

15. Knijnenburg BP, Page X, Wisniewski P, Lipford HR, Proferes N, Romano J, editors. *Modern Socio-Technical Perspectives on Privacy.* Berlin: Springer International Publishing; 2022.

doi: 10.1007/978-3-030-82786-1

16. Van Velsen L, Ludden G, Grünloh C. The limitations of user- and human-centered design in an eHealth context and how to move beyond them. *J Med Internet Res*. 2022;24(10):e37341.

doi: 10.2196/37341

17. Friedman B, Hendry D. *Value Sensitive Design: Shaping Technology with Moral Imagination*. United States: MIT Press; 2019.

18. Goldstein MM. Health information technology and the idea of informed consent. J *Law Med Ethics*. 2010;38(1):27-35.

doi: 10.1111/j.1748-720X.2010.00463.x

19. Latour B. On actor-network theory: A few clarifications. *Soziale Welt*. 1996;47(4):369-381.

20. Friedman B, Felten E, Millett LI. Informed consent online: A conceptual model and design principles. In: *University of Washington Computer Science and Engineering Technical Report* 00-12-2; 2000. p. 8.

21. Friedman B, Kahn PH, Borning A. Value Sensitive Design and Information Systems. In: Himma KE, Tavani HT, editors. *The Handbook of Information and Computer Ethics*. 1st ed. United States: Wiley; 2008. p. 69-101.

doi: 10.1002/9780470281819.ch4

22. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. US Department of Health, Education, and Welfare; 1979. Avaialble from: https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_final.pdf [Last accessed on 2024 Nov 29].

23. Faden RR, Beauchamp TL. *A History and Theory of Informed Consent*. Oxford: Oxford University Press; 1986.

24. Friedman B, Howe DC, Felten E. Informed consent in the Mozilla browser: implementing value-sensitive design. In: *Proceedings of the 35th Annual Hawaii International Conference on System Sciences*. IEEE Computer Society; 2002. p. 10.

doi: 10.1109/HICSS.2002.994366

25. Office of the Privacy Commissioner of Canada. *Consultation on consent under PIPEDA*; 2017. Available from: https://www.priv.gc.ca/en/about-the-opc/what-we-do/consultations/completed-consultations/consultation-on-consent-under-pipeda [Last accessed on 2024 Dec 02].

26. Office of the Privacy Commissioner of Canada. *Consent and Privacy - A Discussion Paper Exploring Potential Enhancements to consent under the Personal Information Protection and Electronic Documents Act*; 2016. Available from: https://www.priv.gc.ca/en/opc-actions-and-decisions/research/explore-privacy-research/2016/consent_201605 [Last accessed on 2023 Oct 03].

27. Autora G. *Current Challenges in Psychological Science*. Serbia: Filozofski fakultet u Nišu; 2023.

doi: 10.46630/dpp.2023

28. Aslan S, Aybek B. The value of helpfulness: An analysis of the 4th grade primary school students' views and their drawings. *Int Online J Educ Sci*. 2019;11(5):106-118.

doi: 10.15345/iojes.2019.05.007

29. Westin AF. *Privacy and Freedom*. New York: Athenum; 1967.

30. Shin HD, Zaheer J, Torous J, Strudwick G. Designing implementation strategies for a digital suicide safety planning intervention in a psychiatric emergency department: Protocol for a multimethod research project. *JMIR Res Protoc*. 2023;12(1):e50643.

doi: 10.2196/50643

31. Shen N, Strauss J, Silver M, Carter-Langford A, Wiljer D. The eHealth trust model: A patient privacy research framework. *Stud Health Technol Inform*. 2019;257:382-387.

doi: 10.3233/978-1-61499-951-5-382

32. Shen N, Kassam I, Zhao H, *et al*. Foundations for meaningful consent in Canada's digital health ecosystem: Retrospective study. *JMIR Med Inform*. 2022;10(3):e30986.

doi: 10.2196/30986

33. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)-a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Informat*. 2009;42(2):377-381.

doi: 10.1016/j.jbi.2008.08.010

34. Kowalski CP, Nevedal AL, Finley EP, *et al*. Planning for and assessing rigor in rapid qualitative analysis (PARRQA): A consensus-based framework for designing, conducting, and reporting. *Implement Sci*. 2024;19(1):71.

doi: 10.1186/s13012-024-01397-1

35. Hamilton AB, Finley EP. Qualitative methods in implementation research: An introduction. *Psychiatry Res*. 2019;280:112516.

doi: 10.1016/j.psychres.2019.112516

36. Canada Health Infoway. *What Canadians Think 2022 - Privacy Edition Survey: Canadians' Perspectives on Digital Health Privacy*. Canada Health Infoway; 2022. https://www.infoway-inforoute.ca/en/component/edocman/resources/reports/privacy/6403-what-canadians-think-2022-privacy-edition-survey-canadians-perspectives-on-digital-health-privacy [Last accessed on 2023 Feb 08].

37. Bernaerdt J, Moerenhout T, Devisch I. Vulnerable patients' attitudes towards sharing medical data and granular control in patient portal systems: An interview study. *J Eval Clin Pract*. 2021;27(2):429-37.

doi: 10.1111/jep.13465

38. Van der Schyff K, Foster G, Renaud K, Flowerday S. Online

privacy fatigue: A scoping review and research agenda. *Future Internet*. 2023;15(5):164.

doi: 10.3390/fi15050164

39. Anhalt-Depies C, Stenglein JL, Zuckerberg B, Townsend PA, Rissman AR. Tradeoffs and tools for data quality, privacy, transparency, and trust in citizen science. *Biol Conserv*. 2019;238:108195.

    doi: 10.1016/j.biocon.2019.108195

40. Wong RY, Mulligan DK, Van Wyk E, Pierce J, Chuang J. Eliciting values reflections by engaging privacy futures using design workbooks. *Proc ACM Hum Comput Interact*. 2017;1:1-26.

    doi: 10.1145/3134746

41. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. United States: John Wiley and Sons; 2002.

42. Desai MU, Paranamana N, Dovidio JF, Davidson L, Stanhope V. System-Centered Care: How bureaucracy and racialization decenter attempts at person-centered mental health care. *Clin Psychol Sci*. 2023;11(3):476-489.

    doi: 10.1177/21677026221133053

43. Zaman B, Jafari Naimi N. A Value Sensitive Design Case Study: Why Values do (not) Design. In: *Workshop Charting the Next Decade for Value Sensitive Design, Critical Alternatives Conference* 2015.

44. Borning A, Muller M. Next Steps for Value Sensitive Design. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM; 2012. p. 1125-1134.

    doi: 10.1145/2207676.2208560

45. Dietkus R. The call for trauma-informed design research and practice. *Des Manag Rev*. 2022;33(2):26-31.

    doi: 10.1111/drev.12295

46. Carey H. Anti-oppression mindsets for collaborative design. In: *Synergy - DRS International Conference 2020*; 2020.

    doi: 10.21606/drs.2020.277

47. World Economic Forum. R*eimagining Notice and Consent for Human- Technology Interaction.* Switzerland: World Economic Forum; 2020.

Appendix

Table A1. Participant demographics and characteristics

Participant characteristics (n=19)	Count, n (%)
Gender identity	
Man	8 (42.1)
Woman	6 (31.6)
Non-binary (genderqueer, gender fluid)	4 (21.1)
Transgender man	1 (5.3)
Age	
20 – 29	10 (52.6)
30 – 39	6 (31.6)
40 – 49	2 (10.5)
n/a	1 (5.3)
Racial or ethnic identity	
Black (e.g., African, African Canadian, Afro-Caribbean descent)	2 (10.5)
East Asian (e.g., Chinese, Japanese, Korean, Taiwanese descent)	2 (10.5)
Middle Eastern (e.g., Arab, Persian)	1 (5.3)
South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)	1 (5.3)
Southeast Asian (e.g., Cambodian, Filipino, Indonesian, Thai, Vietnamese)	2 (11.8)
White (e.g., European descent)	7 (36.8)
Other	3 (15.8)
Prefer not to answer	1 (5.3)
Have you used the Hope by CAMHa app?	
No, but I am aware of the app	7 (41.2)
No, but I have considered using the app	7 (41.2)
Yes, I have used it in the past	2 (10.5)
Yes, I currently use it	3 (15.8)
In the past year, how often do you use digital tools and services to support self-management of your health conditions (e.g., health apps, online programs)?	
I do not use digital tools and services to support my health	2 (10.5)
I used digital tools and services before, but have stopped	3 (15.8)
Less than once a month	1 (5.3)
1 – 2 times a month	4 (21.1)
3 – 4 times a month	2 (10.5)
Weekly	2 (10.5)
Daily	5 (26.3)
Have you ever received care at CAMH[a]?	
No, I have not received care from CAMH	10 (58.8)
Yes, I have received care in the past	5 (26.3)
Yes, currently receiving care	4 (21.1)
On a scale of 1 – 7, how much do you trust most people?	
1 - Distrust	0 (0.0)
2	2 (10.5)
3	4 (21.1)
4 - Neither distrust nor trust	4 (21.1)
5	7 (36.8)
6	2 (10.5)
7 - Trust	0 (0.0)
How would you rate your knowledge of how to protect your privacy rights?	
Very poor	1 (5.3)
Poor	3 (15.8)
Neutral	6 (31.6)
Good	4 (21.1)
Very good	5 (26.3)
How would you rate your knowledge of the privacy risks of new technologies?	
Very poor	1 (5.3)
Poor	4 (21.1)
Neutral	6 (31.6)
Good	6 (31.6)
Very good	2 (11.8)
How confident are you in your ability to protect your privacy online?	
Not at all confident	3 (15.8)
Slightly confident	2 (10.5)
Somewhat confident	4 (21.1)
Confident	8 (42.1)
Completely confident	2 (10.5)

(Cont'd...)

Table A1. *(Continued)*

Note: [a]CAMH: Centre for Addiction and Mental Health.