What Patients Want from Clinicians and Health Systems as AI Enters Clinical Care

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INTRODUCTION

Most explorations of artificial intelligence (AI) in healthcare focus on the perspectives and experiences of clinicians.[1,2] Little attention has been paid to patients as stakeholders in the sweeping change currently underway.[3,4] Herein, we report results from a co-design exercise designed to understand what patients want from clinicians and healthcare organizations as AI becomes embedded in care.

METHODS

Patients were recruited from the OpenNotes Lab Insight Panel (LIP), a panel of patients, care partners, and clinicians. As part of a larger project focused on developing a patient-centric framework for evaluating the development and use of AI tools in healthcare, patients completed four 90-min focus groups conducted virtually, recorded, and transcribed. The groups were designed to assess priorities for different use cases of AI in healthcare.[5] Group transcripts were analyzed using rapid assessment procedures.[6] In RAP, groups are summarized and coded as soon as they are completed, and each analysis influences the subsequent group. The first transcript, meeting chat, and participant notes were reviewed, coded and mapped to the project research questions, and comprehensively summarized by two team members. New codes were added to the codebook as necessary, and all coding discrepancies were resolved through discussion. This final codebook was used to code all remaining groups. In this paper, we describe findings related to patients' expectations of their clinicians and healthcare organizations around the use of AI in healthcare. The study was reviewed by the Beth Israel Deaconess Medical Center Institutional Review Board and was determined to not be human subjects research.

RESULTS

Ten patients participated. Participants were primarily female ($n=8$ female). Fifty percent identified as white/Caucasian ($n=5$), 30% as black ($n=3$), and 10% Asian ($n=1$) with one preferring not to answer. Participants resided in the US southern states ($n=4$), Midwest ($n=3$), West ($n=2$), and Northeast ($n=1$). Education levels ranged from some college to graduate degree (some college ($n=3$), college degree ($n=2$), graduate degree ($n=4$)).

First, patients wanted clinicians to be transparent about the use of AI in their care, including the employment of ambient scribes for documentation, diagnostic tools, and AI-generated responses to portal messages (Table 1). However, they preferred not to discuss AI during time-limited clinical visits. Instead, participants offered solutions such as providing patient AI education, disclosures, and resources as pre-visit work, and developing dedicated page on the organization's website with more information about the tools being used in care. They stressed the need for educational resources and felt healthcare organizations should play a large role in creating them. They suggested that organizations should also provide education for clinicians, helping ensure that patients and clinicians share a common understanding of the tools.

Second, patients expressed concerns about data privacy when AI tools are used. Specific to ambient scribes, participants were concerned about who would have access to the recordings and transcripts from visits, where they would be stored, and how their privacy would be protected. Third, they wanted the option to clearly opt out of the use of individual AI tools at the point of care. Finally, participants wanted their clinicians to use these tools as aids to clinical judgment rather than as decision-makers and specifically noted that over-reliance would place the onus of accurate, high-quality care on the tool rather than on the clinician.

DISCUSSION

As AI tools are increasingly used in care, our findings suggest that patients want their clinicians and organizations to prioritize patient-centric implementation strategies that balance innovation with trust. Participants in our groups held a nuanced view of AI. Rather than outright rejection or total acceptance, participants wanted meaningful transparency, robust privacy protections, and genuine clinician and patient autonomy in decision-making. Critically, they wanted healthcare organizations to foster a culture in which AI-powered tools augment, rather than replace, clinical judgment, ensuring accountability remains with clinicians. It is important to note that participants in the groups were generally well-educated and may be more interested in health IT than the general public. However,

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Table 1 What Patients Want from Clinicians and Healthcare Organizations Around the Use of AI in Their Care

Domain	Representative quotes
Transparency around use of AI tools	"Patients should know that the (AI) tool is being used."
	"The doctor should ask – is this okay with you if we use this?"
	"I put a note in my portal about a situation and I thought I got a really great answer because I got it very quickly. And I was going to go think about that answer and then was told that there was no Jennifer—my answer had been generated by AI and nobody told me that it was being generated by AI…I don't trust that organization like I did before this happened to me."
	"It should be a preview that says this is an AI generated report. Patients need to see that every single time. Yes, this was a conversation that you and I had, but this is still an AI generated report. That has to be there every single time."
	"It doesn't say on here that these notes were generated by ChatGPT and/or edited by Chat…Disclosure, definitely."
	"It's almost like they need to check off the box saying yes, it's OK…I need a signature…You really need to give them a five-minute crash course in what will be happening almost every time they visit."
Education about AI	"Something the system could do is put out education in whatever format patients prefer."
	"I had an AI generated note from a recent doctor's visit and I wouldn't have looked for it if I hadn't been a part of this…I had no idea it was being used at all."
	"Something we mentioned over and over was…the fact that this is AI generated at the beginning of it…I think that's really important at the beginning and a reminder, because…it's shocking to me how many people are very fearful of it."
	"Are the patients informed not only about the AI being used, but about their ability to not engage with it, if they choose not to[?]"
	"I would love patient facing materials to explicitly say they are generated with AI so if they are shared with caregivers everyone understands where the information is coming from."
	"Might be something to educate physicians on with [the] Abridge roll out (they need to vocalize observations)."
	"The doctors have to take the time to explain how AI supports this care. He has to emphasize that I'm still the doctor…Patients have to really, really understand…You really need to give them a five-minute crash course in what will be happening almost every time they visit."
Data privacy	"Once my information is used by the (AI) tool, who has access to it?"
	"Where does it go? Are they then selling my information?"
	"Where I'm feeling uncomfortable with the AI is the AI interpreting things…What I said is what I said and what the doctor said is what the doctor said. Can it just be exactly what was said?"
	"A lot of times I'll ask the doctor, is it OK if I record? Because a lot of times there are things that they break down that I don't remember when I get home…If that audio is something that's just a thing that happens, there's accountability there for both the patient and the doctor's protection measure."
	"The next time I put something in my portal and I got an answer…the prescription was not filled correctly. AI did misread my chart…I just felt it wasn't—it was—I don't trust that organization like I did before this happened to me."
Clinician over-reliance on AI for decision-making	"What resources do patients have when clinicians over rely on the (AI) tool?"
	"My concern is that physicians will lean on it a lot, a lot more than maybe they should as far as proofreading and stuff like that…It's going to be easier for them not to. And not saying that I'm not trusting the physicians to do this, but it just seems like it's going to be kind of, lean on this. I can do this, I can just use this."
	"I don't think these AI generated notes should go out without somebody looking at them first…I wouldn't expect a note to go out to a patient without a clinician looking at it first."
	"The doctors have to take the time to explain how AI supports this care. He has to emphasize that I'm still the doctor. I'm still in charge of all of the decision making. We're just using this tool."
	"We're pressed for time. If a note is good enough, we might just leave it…AI cannot get into the head of a clinician, so I'm not quite sure how to address that."
	"My physicians, they've been with me for ten years plus. They know how I look versus when I'm really sick or whatever…The feeling part, I think, is what's kind of missing in there."

their concerns around AI are reflective of national surveys, mirroring concerns around trust and accountability.

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Data Availability *The qualitative data generated for this study are not publicly available due to the small number of participants across the groups, which increases the risk that individuals could be re-identified from transcript content, including through combinations of role, clinical details, or speech patterns even after de-identification.*

Declarations

Ethics Approval and Consent to Participate *This project was determined to not be human subjects research by the Beth Isreal Deaconess Committee on Clinical Investigations (IRB).*

Conflict of interest *All authors report receiving salary support from Abridge AI, Inc. and Google LLC through contracts with Beth Israel Deaconess Medical Center.*

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REFERENCES

1. **Tierney AA, Gayre G, Hoberman B, et al.** Ambient Artificial Intelligence Scribes to Alleviate the Burden of Clinical Documentation. NEJM Catal. 2024;5(3). https://doi.org/10.1056/cat.23.0404.
2. **Olson KD, Meeker D, Troup M, et al.** Use of Ambient AI Scribes to Reduce Administrative Burden and Professional Burnout. JAMA Netw Open. 2025;8(10):e2534976-e2534976. https://doi.org/10.1001/jamanetworkopen.2025.34976.
3. **Campos HO, Salmi L.** Critical AI Health Literacy as Liberation Technology: A New Skill for Patient Empowerment. NAM Perspectives. Published online December 8, 2025. https://doi.org/10.31478/202512a.
4. **Salmi L, Lewis DM, Clarke JL, et al.** A proof-of-concept study for patient use of open notes with large language models. JAMIA Open. 2025;8(2). https://doi.org/10.1093/jamiaopen/ooaf021.
5. **Scerpella DL, Salmi L, Hurwitz I, et al.** Solutions for Increased Adoption of Patient Portal Shared Access: A Human-Centered Design Approach Using the Double Diamond Model. Appl Clin Inform. 2025;16(05):1728-1737.https://doi.org/10.1055/a-2710-4288.
6. **Renfro CP, Rome Z, Gatwood J, Hohmeier KC.** Use of Rapid Assessment Procedures when analyzing qualitative data in pharmacy research. Res Soc Adm Pharm. 2022;18(1):2249-2253.https://doi.org/10.1016/J.SAPHARM.2021.05.013.

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