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Patient Perspective on Artificial Intelligence in Healthcare: Insights for Diagnostic Communication and Tool Implementation

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Preprint
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Patient Perspective on Artificial Intelligence in Healthcare: Insights for Diagnostic Communication and Tool Implementation

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Abstract

Background: Artificial intelligence (AI) Is rapidly transforming healthcare, offering potential benefits in diagnosis, treatment, and workflow efficiency. However, limited research explores patient perspectives on AI, especially in its role in diagnosis and communication. This study examines patient perceptions of various AI applications, focusing on the diagnostic process and communication.

Objective: To examine patient perspectives on AI use in healthcare, particularly in diagnostic processes and communication, identifying key concerns, expectations, and opportunities to guide the development and implementation of AI tools.

Methods: A co-design focus group workshop was conducted with 17 participants (patients and family members) aged 18-80. The session included interactive activities, discussions, and guideline development exploring five AI scenarios: (1) Patient Portal Messaging, (2) Radiological Imaging, (3) Ambient Digital Scribe, (4) Virtual Human Telehealth Call, (5) Clinical Decision Support for HIV Testing. Thematic analysis was used to analyze transcripts and facilitator notes

Results: Participants reported varying comfort levels with AI applications, with higher comfort for AI tools with less direct patient interaction, such as ambient digital scribes and radiology image readers, and lower comfort for those with more direct interaction, such as virtual human telehealth calls. Five key themes regarding patient perspectives of AI emerged: (1) Concerns Around Model Development and Validation, (2) Concerns Around AI Systems for Patients and Providers, (3) Expectations Around Disclosure of AI Usage, (4) Excitement and Opportunities for AI to Better Address Patient Needs, (5) Patient Concerns Around Data Protection, Privacy, and Security. Participants emphasized the importance of transparency in AI development validation, preferred AI as a supplementary tool rather than a replacement for human clinicians and stressed the need for clear communication about AI's role in their care. They also highlighted the potential for AI to enhance patient understanding and engagement while expressing concerns about data security and privacy.

Conclusions: This study highlights the importance of incorporating patient perspectives in the design and implementation of AI tools in healthcare. Transparency, human oversight, clear communication, and data privacy are crucial for patient trust and acceptance of AI in diagnostic processes. These findings inform strategies for individual clinicians, healthcare organizations, and policymakers to ensure responsible and patient-centered AI deployment in healthcare.

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Introduction

Artificial intelligence (AI) has been widely adopted in numerous social and scientific areas, including integration into various healthcare applications[1,2]. AI offers great potential for improving patient care, especially in enhancing the early detection of diseases, automating routine works/tasks to manage patients and resources, and improving and streamlining workflow processes[3]. Through its ability to accommodate complex data, AI has shown great promise in enhancing diagnostic opportunities in a variety of clinical processes of the electronic health record (EHR) including diagnostic imaging, clinical decision support systems (CDSS), and patient monitoring tools[4-8]. As AI continues to be rapidly deployed in various aspects of clinical practice, there are diagnostic safety implications given diagnostic errors remain the leading cause of adverse outcomes in healthcare[9].

Existing research highlights the potential of AI to enhance diagnostic safety by identifying patterns in clinical data, improving early detection of diseases, and supporting decision-making[10-12]. For example, AI-based radiology tools have demonstrated the ability to detect pathologies like fractures or cancers with accuracy comparable to human radiologists[13,14]. Similarly, CDSS tools use patient data to recommend diagnoses or tests, potentially mitigating diagnostic errors[15]. These AI tools designed to support the diagnostic process have the potential to reduce diagnostic errors by providing additional diagnostic information but can only do so through effective communication to ensure that patients are informed, engaged, and empowered in their care. As the adoption of these novel AI technologies will directly impact diagnosis, and subsequently patient health outcomes, incorporating patient viewpoints into the design and implementation processes is critical to their widespread acceptance[16].

Few studies explore patient perspectives on AI's role, particularly in diagnosis and diagnostic communication[17]. Much of the recent literature around patient perspectives on AI focus on AI more broadly, with research focused solely on understanding patient attitudes toward, or acceptance of, AI as a diagnostic tool rather than their perspectives on the role AI should play in diagnosis and its communication across a variety of theoretical and practical applications[18-21]. Research that has prioritized AI in the context of diagnosis and communication have focused on applications in specific contexts, such as two recent studies that analyzed patient attitudes towards an AI-based diagnosis and communication of radiology image reading[22,23]. Our study seeks to address this gap by using focus groups and co-design workshops to examine patient perceptions of various AI applications, with a specific focus on the diagnostic process and communication.

Methods

Study Design and Setting

This study employed a focus group methodology using co-design principles to explore patient and family member perspectives on AI in clinical practice. A single two-hour session was conducted in a centrally located research office which included a larger conference room and additional smaller rooms for breakout discussions. The session included interactive activities, facilitated discussions, and collaborative guideline development to gather insights and recommendations on AI integration in healthcare.

Participants

Adult patients and family members aged 18-80 years old were recruited through email outreach, word of mouth, and networks such as our Patient and Family Advisory Council for Quality and Safety (PFACQS) and Georgetown University network. Participants were required to be English-speaking and willing to participate in the session.

Procedures

The session was facilitated by a team of researchers with expertise in human factors engineering, diagnostic safety, and patient engagement. Lead facilitators were trained in qualitative research methods. Activities included (1) introduction and icebreaker (a brief overview of the session's objectives, followed by an icebreaker to create a comfortable and engaging atmosphere), (2) "what is AI?" activity (participants discussed examples of AI in everyday life to build foundational understanding, (3) breakout sessions (participants were divided into smaller groups for five specific AI scenarios, (4) guideline/recommendation development, (5) reflection and feedback (the session concluded with a debrief where participants shared insights and reflections). Materials provided to participants included an agenda, activity materials, and data collection for demographics and session evaluation.

Breakout sessions included small group (2-4 participants) discussions of AI scenarios, individually presented by a dedicated facilitator who rotated across groups. Five scenarios were presented: (1) **PPM** (Use of AI for patient portal messaging), (2) **RIR** (Use of AI in Radiological Imaging Review), (3) **ADS** (Ambient Digital Scribe), (4) **VHT** (Virtual Human Telehealth), (5) **CDS** (Use of AI for Clinical Decision Support – HIV Testing). The specific scenarios can be found in Appendix 1. For every scenario, participants were first asked to share their comfort levels with the application of AI on a scale of 1 to 5 (1 being least comfortable and 5 being most comfortable). Then structured discussion was led by the facilitator through a series of questions about information of interest, trust, benefits, concerns, and communication strategies about the use of AI for this specific scenario.

Data Collection

The session was recorded and transcribed verbatim, with facilitator notes collected to supplement the transcripts. Participants completed a demographic questionnaire to capture relevant characteristics such as age, gender, and background. Following the session, participants were asked to complete an evaluation form to provide feedback on the session's content, structure, and overall experience. Participants were provided gift cards as compensation for their time.

Data Analysis

The research team conducted thematic analysis using an inductive approach, developing a codebook of themes that emerged during focus-group discussions and reflected patients' perceptions around applications of AI in healthcare. All focus group transcripts were independently reviewed and assigned codes by two different members of the research team. Discrepancies were identified and discussed until a consensus was reached.

Ethical Considerations

This study received IRB approval by the MedStar Health Research Institute and participation was

voluntary. Informed consent was waived under the approved protocol.

Results

Participant Demographics

A total of 17 participants attended the AI focus group session, representing a diverse range of perspective and varied experiences with healthcare (Table 1).

Table 1. AI co-design workshop participant demographics (n=17).

	Patients (n=17)
Age	
18-24	4, 23.5%
25-34	4, 23.5%
35-44	2, 11.8%
45-54	2, 11.8%
55-64	2, 11.8%
65-74	3, 17.6%
75 and older	0
Prefer not to answer	0
Gender	
Male	4 (27%)
Female	11 (73%)
Non-binary	0
Prefer not to say	0
Race	
White (non-Hispanic)	5, 29.4%
White (Hispanic)	0
African American/Black	4, 23.5%
Asian	6, 35.3%
American Indian or Alaska Native	0
Native Hawaiian or Other Pacific Islander	0
More than one race	1, 5.9%
Prefer not to answer	1, 5.9%
Highest Level of Education	
Some high school	0
High school graduate	0
Some college/ Associates degree	2, 11.8%
Bachelors degree	3, 17.6%
Masters degree	10, 58.8%
Doctoral or professional degree	1, 11.8%

Participants reported a variety of medical conditions, reflecting a diverse range of health experiences. These included chronic conditions such as polycystic ovary syndrome, generalized anxiety and depression, hypertension, ulcerative colitis, arthritis, and diabetes. More complex conditions were also represented, such as avascular necrosis, stroke, kidney transplant, heart transplant, cancer, and post-traumatic stress disorder. This range of conditions provided valuable perspectives on the integration of AI in addressing diverse healthcare needs.

Patient Comfort Across Scenarios

Participants expressed overall comfort with AI being integrated into the diagnostic process, given

that implementation involved key themes that addressed their concerns and expectations. However, participants' comfort levels varied significantly depending on the level of human interaction involved in the process (Table 2, Figure 1). The results showed that comfort level drastically decreased with the amount of human interaction involved in the replaced process. For example, the scenario participants were least comfortable with was the virtual human telehealth visit in which an AI-generated human would replace the physician when communicating a new diagnosis. Similarly, participants also appeared less comfortable with an AI chatbot sharing details about lab results. In contrast, participants were most comfortable with the ambient digital scribe scenario, in which an AI scribe documents clinical notes during a patient visit.

Table 2. Participants' comfort levels (average and range) with each AI scenario on a scale of 1 to 5 (1 being the least comfortable and 5 being the most comfortable).

Scenario	Average Comfort Level	Range
ADS: Ambient Digital Scribe	4.24	2-5
RIR: Radiology Image Reader	4.00	2-5
CDS: Clinical Decision Support Tool	3.94	1-5
PPM: Patient Portal Messaging	3.68	2-5
VHT: Virtual Human Telehealth	1.68	1-4

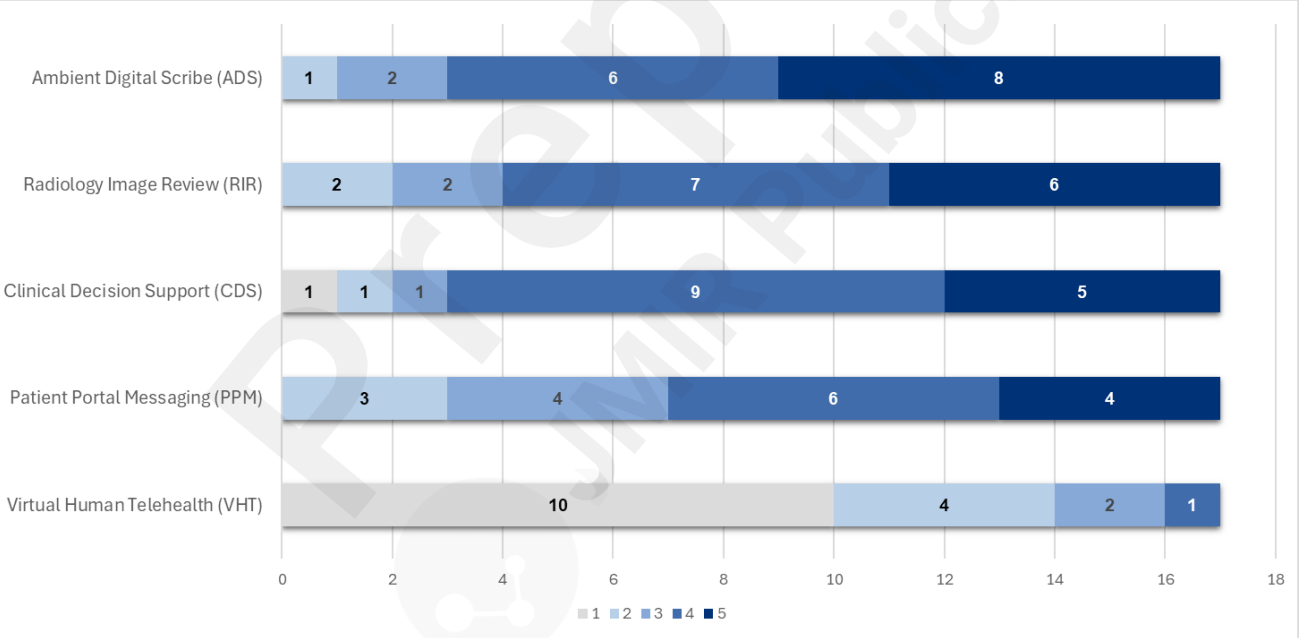

Figure 1. Frequency of participants' comfort levels with each AI scenario on a scale of 1 to 5 (1 being the least comfortable and 5 being the most comfortable).

Analysis of the co-design session discussions revealed five key themes that highlighted participants' concerns, expectations, and opportunities for AI integration into clinical workflows: Validation, Usability, Opportunities, Transparency, and Privacy (Figure 2). These themes provide critical insights into how patients perceive and evaluate AI technologies, which were further reflected in their comfort levels across different AI implementation scenarios.

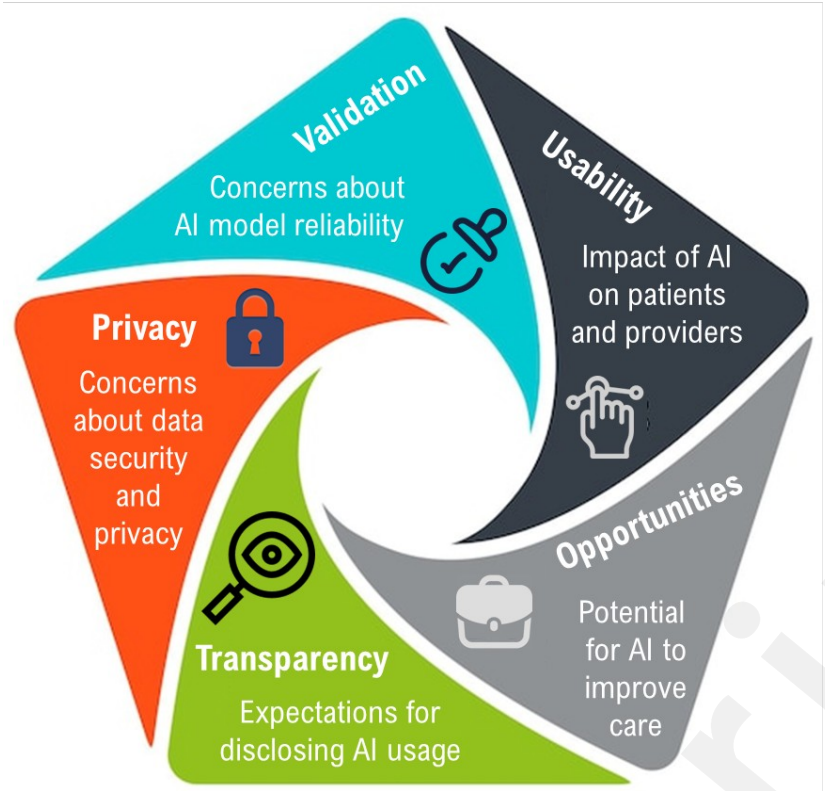

Figure 2. Key themes identified from participant discussions, highlighting concerns, expectations, and opportunities related to the integration of AI into healthcare.

Theme 1: Validation - Concerns Around Model Development and Validation

Participants generally posed questions around the development of AI algorithms and models, particularly around the design, training, and evaluation processes that ensure the tools meet clinical needs while maintaining safety, accuracy, and reliability. Participants expressed that transparency in how AI models are created—such as the sources of their knowledge, the models' ability to adapt to diverse cases, and its overall reliability—is essential for trust. Participants expressed concerns about how AI learns, its capacity to account for complexity in healthcare, and the ethical considerations inherent in its creation particularly regarding marginalized or vulnerable populations.

Data Input and Validation

Participants were interested in learning about the types of data used to train AI systems, emphasizing that clarity regarding the accuracy and currentness of the data was a top priority. In the CDS scenario, one participant asked, *"Where does this data come from that its following algorithms? What features is it using?"* Similarly, in the ADS scenario, a participant questioned, *"How does it translate what's being said? What's its database? And where's it pulling its information from the make the translations as a scribe?".* These comments underscore a strong desire for transparency about the sources and validation of training data.

AI Guidelines, Evidence, and Algorithms

Participants shared that AI systems should adhere to clinical guidelines and be validated through

robust, evidence-based processes. They expressed skepticism about the reliability of algorithms if their development was not clearly linked to established medical practices. In the CDS scenario, one participant remarked, *"I'd want to know if it's based on current standards of care."* In the VHT scenario, a participant asked, *"What are the diagnoses it's forecasted?"*

Accuracy and Reliability

The performance and reliability of AI systems were significant concerns, with participants expressing the need for transparency about error rates and diagnostic limitations. Many viewed accuracy as a cornerstone of trust in AI tools, with some participants expressing skepticism about the accuracy and reliability of AI broadly saying, *"In an imaging informatics course, we're actually building AI models, and the highest accuracy I got is 45%. It's very tough for an AI model to predict the actual problem."* Similar quotes also highlighted participants' concerns regarding the accuracy of current AI tools, which were mediated by transparency regarding metrics and figures. In the RIR scenario, a participant noted, *"I think I would like to know the failure rate and the defective rate. Because I'm sure I can find research says AI is effective and correct…as long as you're providing me some something. I want specificity on how accurate it has been.'"*

Personalization and Adaptability

Participants questioned whether AI tools could account for individual patient factors, such as age, ethnicity, and medical history to provide tailored care. Many worried that AI systems might rely on overly general recommendations, neglecting the nuances of personal health. In the PPM scenario, one participant said, *"If we all use the same algorithm, but we have different diet habits or lifestyles, how does it account for those differences?"* Similarly, in the ADS scenario, a participant remarked, *"Does the AI know my specific conditions or is it just applying general rules?"* These comments underscore the need for AI systems to integrate personalized information to ensure their recommendations are both accurate and relevant.

Concerns regarding personalization were primarily discussed in the VHT and PPM scenarios, with many of the discussions surrounding live feedback. Patients were uneasy at the prospect of communicating directly with AI, believing that AI would not have the capability to adjust interpretations of health-related problems with the addition of new information such as personal lifestyle choices like diet and exercise. This sentiment is exemplified by a participant who said, *"My next question would be, well, why is my lab value out of range? The AI wouldn't know my lifestyle. It wouldn't know the things that I do on a daily basis. But I can explain to my provider, these are things that I eat every day, or this is my sleep schedule, or this is how much water I'm in taking. So that provider would be able to give me more specific information on the human factors aspect and things that actually change, versus an AI would probably skew something that's a little bit more general.*"

Perceived Risks and Benefits

Participants across all scenarios acknowledged AI in healthcare would likely provide meaningful benefits such as increases to diagnostic processes or improved accessibility of patient data. Despite these potential benefits, participants were cautious about the limitations and of AI, expressing that the risks of implementation may outweigh the benefits. Many participants shared that AI would likely be beneficial to providers specifically, with one suggesting that AI is likely to be "*more convenient for*

the provider than it is for the patient." In the VHT scenario, a participant noted, *"...AI can free them up to do something beneficial to their patient load."* Participants believed that these improvements to the provider workflow would have downstream impacts on their care with one saying, *"...the doctor has a lot more time with the patient."* These benefits though, should not come at a cost to the patient. For example, one participant shared that increases to efficiency could be possible, but the current state of AI reflects "*too many checks that have to go into the balance in order to make it a time saver*".

Marginalized and Vulnerable Populations

Across all five scenarios, participants questioned whether AI systems were adequately designed to serve historically underserved groups, such as individuals from racial and ethnic minorities or lower socioeconomic backgrounds. Concerns often focused on whether the datasets used to train AI tools included sufficient representation of these populations, as well as the potential for biases in algorithm design to exacerbate existing inequities. In the CDS scenario, one participant remarked, *"I think about just ensuring that it is, where the data came from, make sure that I'm not being biased because of X, Y, and Z in my medical record for my gender, race, whatever it is like."* This sentiment reflects a common skepticism about the inclusiveness of AI training data. Similarly, in the RIR scenario, a participant asked, *"I would be worried about the biases of selecting the populations for these different diagnoses. Because like I said, what may look like something normal for some people could be something else for others just based on presentation. I don't know how much data this has accumulated to be that specific to find out?"*. Broadly participants were concerned that AI models may be developed using biased data and urged that data sets should be trained using diverse populations in order to prevent the inequities.

Theme 2: Usability - Concerns Around AI Systems for Patients and Providers

Patients expressed concerns around the adaptability of AI and the workflow around AI-patient-provider systems for addressing patients' unique clinical needs. Clinical use explores how AI systems are utilized in healthcare settings to enhance patient care and decision-making. This theme emphasizes the importance of defining AI's role as a supportive tool that complements, rather than replaces, clinicians while ensuring that human oversight is maintained in order to build trust with patients.

AI as a Secondary or Assistive Tool

Participants across all scenarios except ADS expressed a preference for AI to act as a supplementary tool that supports human providers rather than a replacement. They appreciated the potential of AI to provide additional insights or handle routine tasks but emphasized that providers should ultimately be making the final decisions that relate to their care. An example of this is shown in the VHT scenario, one participant remarked, *"I think it would be good to use as a supplement or a good reference point... but I don't think it should be used in any case as the primary source of education for any diagnosis."* Similarly, another participant in the RIR scenario noted, *"If it's used as a tool by a physician, and the physician is still very much involved, I'm okay with it."*

Contextual Use of AI

Patient comfort with AI varied significantly depending on the task or clinical context. Participants shared that they were generally more open to interacting with AI if the diagnosis had less severe outcomes but expressed greater hesitancy about its use in the context of diagnoses with poorer outcomes. This variability of comfort based on diagnosis is exemplified by the following quote from a participant in the VHT scenario: *"I think it depends on the diagnosis...if you're telling me, 'You're allergic to dogs'... that's okay. If they're saying you have a brain tumor, I don't want AI telling me that."* A participant in the RIR scenario echoed a similar sentiment regarding how diagnosis may alter their comfort level saying, *"I would say the severity of the diagnosis would play a huge role"*.

Discussions in the CDS scenario also highlighted the need for AI tools to adapt their involvement based on the complexity of the situation. Similar to the diagnostic concerns, participants felt that AI was more equipped to handle routine or low-stakes tasks such as summarizing medical records or flagging potential issues. One participant remarked, *"...routine testing I would feel comfortable for, like diabetes or things like that, like blood pressure."* Another participant also shared that they would feel more comfortable with AI assisting in tasks such as *"blood work, urinalysis, and even radiology results"*.

Clinical Workflow

Exclusively in the RIR scenario, participants raised questions about how AI tools would be integrated into their care, curious about whether AI would enhance existing workflows or create new care pathways. One participant shared, *"I would want to know before and kind of what the workflow of it is like, what's the policy? Are you looking at it before the AI software?".* Another participant was curious how AI would be integrated into the clinical workflow asking, *"Are they going to connect it to the machine that's doing the scans or the MRIs?"*. These comments highlight a desire for clarity on how AI tools are incorporated into care processes.

Efficiency Gains

Across all scenarios participants valued AI's potential to handle repetitive or administrative tasks, freeing up clinicians to spend more time on patient care. One participant in the ADS scenario shared, *"maybe AI would actually do better"* when discussing the scribe's ability to document notes when compared to their provider.

While patients expressed some excitement around efficiency gains, there was still an undercurrent of apprehension with participants highlighting that such benefits should not compromise quality of care. For example, a patient in the RIR discussed concerns about AI supplementing the low staffing of the healthcare system at the expense of human touch, describing a system where *"AI becomes primary, and human becomes secondary. That's scary."*

Impact on Clinical Decision-Making

The use of AI in clinical decision-making sparked mixed reactions, particularly in the PPM, CDS, and RIR scenarios. While participants appreciated AI's potential to provide additional data or insights, they were uncomfortable with the idea of AI functioning autonomously in the decision-making process. They emphasized the importance of provider oversight when making final decisions regarding their care, highlighting the potential for AI to serve as a tool to enhance the provider's understanding of a patient's care. A participant in the RIR scenario expressed the importance of

provider involvement saying, *“So I'm understanding that it's an added layer, and I think for me, I still understand that there's a physician involved. It's not only AI.”*

Although decision-making was discussed broadly, many conversations included specific concerns regarding AI generating a diagnosis for a patient without provider insight. This hesitance regarding the potential for AI make a diagnosis is shared by a participant in the CDS scenario who noted, *“I don't want the AI to be the final say for my diagnosis. I think the doctor should have that final say in... whatever the diagnosis is.”* These concerns reflect a preference for AI tools to serve a supporting role in the diagnostic process rather than decision-makers.

Theme 3: Transparency - Expectations Around Disclosure of AI Usage

Communication is central to patients’ acceptance of AI in healthcare. This theme revolves around how AI’s role is explained to patients, including the depth of information provided and the level of transparency about its involvement. Participants emphasized the need for clear, respectful, and comprehensive communication to foster trust.

Patient Communication Preferences

Although not discussed in the VHT or CDS Scenarios, a large portion of the quotes centered around participants’ preferences for how information about AI’s role in their care should be communicated. Some patients wanted high-level summaries that did not overwhelm them with technical details such as participants who shared in the PPM scenario that they’d like *“general information, nothing too in-depth"* or *“general information of how it works”*. Others, though, preferred to receive detailed explanations of AI’s capabilities, limitations, and data inputs used for development as expressed by a participant in the RIR scenario who said, *“For me, I want to know some statistics. I want numbers. Percentages in terms of its accuracy and frequency use in that nature. So that kind of gives me a little more confidence that I could be okay with what had been told me beforehand, before I decide to accept this.”*

Preferences surrounding timing of communication was also an important consideration for participants. Most participants requested that the use of AI tools be disclosed *“ahead of time”*, ensuring that, at minimum, they are informed of AIs presence and purpose prior to interacting with it. This sentiment was shared by a participant in the ADS scenario who said, *“I want to know about it [the AI digital scribe] before I get to the doctor... I would rather have the opportunity to know about it, think about it, review, know what the process is, then decide.”*

Healthcare Provider’s Role in AI Communication

Participants in the PPM, ADS, and RIR scenarios emphasized the critical role of healthcare providers in explaining and endorsing AI tools sharing that *“how a doctor wants to introduce that [AI] is critically important, because you’re [the patient] going to have to acclimate”*. Many participants expressed that they were more likely to trust and accept AI if their provider confidently explained its purpose and benefits. In the ADS scenario, one participant *stated they would ask their provider “How much do you trust this AI? Or how often do you use this? Do you actually review it?”*.

Transparency about AI Usage

Participants, outside of the CDS scenario, consistently stressed the importance of being informed when AI is involved in their care. They wanted clear explanations of what contributions AI made have such as distinguishing *“what the doctors have said themselves, and what AI put together”*. Another participant in the RIR scenario echoed a similar sentiment sharing, *“If the AI found something, I would want to know if it was found by the AI.”* Beyond AI contribution level, some participants also appreciated having the capabilities and limitations of the AI tools communicated to them. For example, a participant in the ADS scenario stated they would ask *"How is this being processed and what is the accuracy?”* especially if the tool were to affect clinical decision-making. Transparency for patients is not just about disclosing the use of AI, but also informing them about specific details regarding its level of involvement and role in the diagnostic process. Clarifying these details for patients will increase their trust and comfort with the use of AI in their care.

AI’s Intended Use

A dominating theme in the VHT, PPM, and RIR scenarios, patients expressed varying levels of comfort depending on how AI was used in their care. Many were more comfortable with AI handling routine or supplemental tasks, such as providing documentation, sending appointment reminders, or offering additional information about a diagnosis, but were hesitant about AI making critical decisions. In the VHT scenario, many of the participants agreed that a virtual AI provider would be more beneficial for follow-up or clarification questions relating to nutrition or medications after receiving a new diagnosis. One participant noted *“I think it would be a good use as a supplement to... or a good reference point. If you have that face-to-face interaction and you forget something you can go back and use the AI for that purpose. But I don't think it should be used in any case as the primary source of education for any diagnosis.”* Similarly, participants in the PPM scenario preferred that AI simply summarize laboratory findings rather than interpret them and make a diagnosis or recommendations with one participant saying, *“If the AI is just helping with notes or summarizing conversations, that’s fine”*, while another said, *“I still don't know if I would be comfortable with interpretation.”*

Informed Consent for AI Use

Occasionally in the VHT, ADS, and RIR scenarios, participants emphasized the importance of informed consent when AI tools were used in their care. Not only do they want to be fully aware of AI’s role, but they also want to be given the opportunity to consent to its implementation. For example, in the VHT scenario, one participant believed that patients should not be *“forced to use the robot”* and instead be given an option to speak with a human instead. Similarly, a participant from the RIR scenario discussed the importance of receiving relevant data and statistics from the model as part of the consent process, suggesting that it would give them *“a little more confidence that [they] could be okay”* with the use of AI.

The Importance of Human Empathy

Despite acknowledging the benefits of AI, participants consistently emphasized the irreplaceable value of empathy and human connection in healthcare settings. Many expressed concerns that increasing reliance on AI could detract from the emotional connection and understanding offered by human providers. One participant in the CDS scenario suggested that the human connection plays a pivotal role in the building of trust between patient and provider which plays a pivotal role in

patient care saying, *"...the personal trust and relationship [patients] should have with [their] primary care physician should be the same almost as a partner or spouse, because [their] life, in part, is in their hands."*

Participants were also concerned about the ability to communicate with AI, especially depending on the type of news being delivered. In the VHT scenario, participants were uncomfortable with AI communicating a diagnosis, suggesting that empathy is a critical component to understanding and accepting such life-altering information. For example, one participant said, *"Something like a diagnosis of diabetes is a major lifestyle issue. And I would rather hear personally from him to get some empathy, some understanding."*

Theme 4: Opportunities - Excitement and Opportunities for AI to Better Address Patient Needs

Participants discussed ways AI can improve patient engagement, understanding, and comfort. AI's potential to provide additional information, clarify medical concepts, or answer follow-up questions was highlighted as valuable. However, patients expressed that its utility depends on their ability to control its involvement and whether it is used in a supportive capacity. Participants also considered barriers to engagement, such as digital literacy gaps, and emphasizes the importance of making AI tools accessible and non-intrusive.

Enhancing Patient Understanding

Participants in the VHT and PPM scenarios frequently discussed how AI could be used to provide supplemental information, answer follow-up questions, and clarify medical concepts. In the VHT scenario, one participant stated they would appreciate if the scenario was an optional feature available "*because [the participant] also comes up with questions*" after they leave an appointment where they received a diagnosis. AI providing accessible information outside of appointments was also important to a participant from the PPM scenario who said, *"I would say I like the idea of having the supplemental information and having being able to access that outside of appointments..."*

Similarly, participants suggested that AI could also serve to enhance comprehension and reduce gaps in understanding, particularly for patients with limited health literacy. This theme can be observed in a statement made by a participant from the PPM scenario who recounted, *"My parents, when they read their medical history and the doctor's notes, have no clue what any of it means. They have to put it in ChatGPT so it could be easier to understand."*

Patient Comfort with AI Use

Participants discussed various scenarios in which patients may intentionally or unintentionally withhold information from AI tools. Some participants raised concerns that patients may withhold information from AI tools out of discomfort, such as the suggestion made by a participant from the ADS scenario who said, *"I think when it comes to sexually transmitted infections or anything like that is definitely sensitive information and wouldn't be comfortable."* Similarly, a participant from the same scenario mentioned that a reluctance to share information with AI may come from fear of data misuse saying, *"If that recording is sent somewhere else, what would this situation be?"*. In such scenarios, patients who feel uncomfortable with AI use may be unwilling to share specific information with the tool due to a lack of trust or understanding.

According to participants, information can also be withheld by patients in situations where patients have a lack of literacy (digital or otherwise). Participants were concerned that these patients may have a more difficult time interacting or engaging with AI, reducing the effectiveness of information exchange between AI and patients. For example, a participant in the PPM scenario mentioned that their older adult parents would *"need extra help"* with navigating the AI messaging software. Similarly, a participant in the VHT scenario expressed concern for patients who *"[don't] even speak the language that the AI is presenting"*.

Patient Control over AI Involvement

Patients expressed a strong preference for having control over whether and how AI is incorporated into their care. Many participants emphasized the importance of being informed about AI's role and having the ability to opt out of its use if desired, particularly for sensitive or high-stakes situations. For example, a participant from the VHT felt uncomfortable with meeting one on one with a virtual AI provider saying, *"Don't put me with an AI by myself."* Similarly, a participant wanted clarity on how the ADS tool would be integrated into the clinical workflow asking, *"I would like to review it before it gets uploaded, and does it get uploaded into my chart? And at what point in time does it get uploaded into my EHR?"* These questions reflect a broader desire to have clarity and insight into how AI operates and integrates into patient care while reserving the right to opt out if desired.

Theme 5: Privacy - Patient Concerns Around Data Protection, Privacy, and Security

Protection of data reflects patients' concerns about the security and privacy of sensitive health information in AI systems. This theme captures the desire for robust safeguards to prevent misuse or unauthorized access. Trust in AI systems hinges on assurances that personal information is handled responsibly, kept secure, and used exclusively for intended healthcare purposes.

Data Security and Privacy Concerns

Participants expressed apprehension about the safety of their data and whether it could be accessed, shared, or misused without their consent. These concerns were particularly pronounced in scenarios involving ADS and CDS scenarios, where participants envisioned a higher likelihood of sensitive information being stored or transmitted electronically. Issues pertaining to data security and privacy were not addressed by any participants in the RIR scenario. One participant in the ADS scenario questioned the way that the tool would store and transfer data asking questions like, *"Is it transferable? Is it something that would stay within my own healthcare unit? Or is information [that] other providers, other healthcare professionals, would be able to access as well?"* Such questions not only underscore the importance of data storage and transfer for patients, but also a desire to remain informed and aware of how those processes might look with the implementation of AI in healthcare. Similarly, another participant from the same scenario asked *"How is it [data/the recording] stored? Is it going to be posted on the patient portal? Do we go back ourselves? Are we able to access it? Are you storing it in our file?*", once again outlining the potential concerns patients have regarding handling of their data.

Privacy was also a common concern for participants with many expressing fears of their data being used without their knowledge or consent. In the VHT scenario, a participant wanted to know if the AI

tool would utilize their data for model development asking, *"Would it be a gain from me, like if it was mining my data?"*. Similarly, a participant from the PPM scenario question *"How much the ChatBot knows"* with regards to their data. Both quotes showcase the need for transparency regarding what data is collected and if and how it is being used to further train models. Additionally, participants requested that AI implement *"privacy protocols"*, as mentioned by a participant in the ADS scenario, that serve to protect patient data and privacy.

Participants also raised concerns about potential misuse of their data, particularly for non-care-related purposes. In the ADS scenario, one participant remarked, *"How does this coincide with insurance companies as well? Like if insurance companies get a hold of this information could they decline to take me on?"* Participants were concerned that their data could be used for purposes not directly related to patient care without their consent which can have negative impacts on the ability of patients to receive care/treatment. Overall, these concerns illustrate a broader mistrust of data handling practices and a need for systems to prioritize patient consent.

Participant Evaluation

Participants provided largely positive evaluations of the co-design session (Table 3).

Table 3. Participant evaluation of the AI co-design workshop (n=17).

Overall Experience	1 Poor	2	3	4	5 Excellent
How would you rate the meeting overall?				2 (11.8%)	15 (88.2%)
	1 Not Useful	2	3	4	5 Very Useful
In general, how useful was the meeting?				4 (23.5%)	13 (76.5%)
What did you think about the materials presented and discussed during the meeting?				5 (29.4%)	12 (70.6%)
What did you think about the guideline/ recommendation discussion?			1 (6.7%)	5 (33.3%)	9 (60%)
	1 Almost Nothing	2	3	4	5 A lot
How much did the meeting contribute to a shared awareness of AI and diagnostic safety?			3 (5.9%)	8 (47.1%)	8 (47.1%)
	1 Not at all	2	3	4	5 Very Much
How much say did you feel you had in the discussion?			2 (11.8%)		15 (88.2%)
Do you think that the opinion of the different stakeholders that were present at the meeting were all taken into consideration?		1 (5.9%)	3 (17.6%)	6 (35.3%)	7 (41.2%)

Participants highlighted several aspects of the workshop that they liked best. They appreciated the open and nonjudgmental environment, which allowed for free sharing of opinions and thoughts without bias or pressure. Many valued the interactive nature of the session, particularly the small

group discussions, which facilitated deeper engagement, diverse perspectives, and meaningful participation. The diverse backgrounds of participants, including patients from different races and professions, enriched the discussions and provided new insights. Participants also found the materials well-prepared, appreciated the brief AI introduction, and enjoyed the opportunity to learn more about AI in relation to their healthcare. Overall, the combination of open dialogue, group interaction, and thoughtful organization was highly praised.

Participants shared a few areas for improvement in the workshop. The most common concern was the limited time available, with several noting the need for more time to discuss topics in greater depth and brainstorm ideas. Some also suggested dedicating additional time for group discussions and addressing specific examples of AI currently in use or relevant case studies. Suggestions included incorporating more complex cases or scenarios, discussing AI bias in greater detail, and diversifying both the researcher backgrounds and participant groups to include more primary care providers, individuals from different socioeconomic groups, and a broader generational representation. While some recommended separating patients based on their AI knowledge for tailored discussions, others emphasized maintaining a mix of diverse perspectives within groups. Overall, participants highlighted opportunities to enhance inclusivity, depth of discussion, and time for meaningful engagement.

Discussion

Principle Results

AI, while previously a technology of the future, has become a technology of the present. AI-driven technologies, including machine learning-driven CDS algorithms, deep-learning radiology scan classifiers, and large language model (LLM)-driven ADS, have already been implemented in hundreds of hospitals nationwide. This work, in examining patient perceptions of five different scenarios describing current and future AI technologies in healthcare, provides a contemporary view of the multifaceted patient perspectives on AI's role in providing diagnostic information, facilitating communication, and supporting decision-making. Many patient perceptions held true across all scenarios:

1. The importance of transparency in how AI models are developed, validated, and their ability to address diverse needs reliably.
2. Preference for AI to complement rather than replace human providers and stressed the importance of maintaining human oversight in clinical decision-making.
3. Clear and respectful communication about AI's role in care, along with patient consent, was seen as essential to build trust.
4. AI's potential to enhance patient engagement, understanding, and access to information, provided it is implemented as a supportive tool that respects patient autonomy.
5. Concerns about the security and privacy of their data, emphasizing the need for transparency and robust safeguards to prevent misuse or unauthorized access.

Outlook on AI implementation into the diagnostic process was generally positive with participants consistently highlighting AI's ability to identify patterns and provide supplemental diagnostic information that might otherwise be overlooked by human providers. However, they emphasized that AI tools must integrate seamlessly into clinical workflows and preserve the essential human connection in patient-provider communication as seen in the results regarding patient comfort levels across scenarios. Comfort level drastically decreased with AI applications aimed at supplementing communication. For example, the scenario participants were least comfortable with was the VHT scenario in which an AI-generated human would replace the physician when communicating a new

diagnosis. Similarly, participants also appeared less comfortable with an AI chatbot sharing details about lab results. In contrast, participants were most comfortable with the ADS scenario, in which the application of AI was intended to enhance patient-provider communication by removing the need for providers to focus on documentation during clinic visits.

Comparison with Prior Work

The findings of our work that held true across all scenarios are expectedly consistent with prior work – patients' concerns with privacy, data security, and bias have been well documented[24,25]. Specifically, our findings align well with the findings that patients have a generally positive outlook on AI's implementation into their care given that there are adequate guardrails to protect against a variety of potential harms[26]. Our work was unique in its focus on how such concerns are explicitly perceived in the context of AI applied to diagnosis and its communication. Few qualitative studies have explored patient perceptions of AI in the context of diagnosis and communication, but our results appear to be in alignment with prior findings. Patients considered AI to be a helpful supplementary tool that should not serve as a replacement to human clinicians, a sentiment already documented for applications of AI in radiology[23].

While there is prior work identifying patient perceptions on in the implementation of AI in healthcare broadly, there has been limited work identifying patient perceptions of AI's role in reducing diagnostic errors through the enhancement of patient-provider communication. As a recent scoping review identified that patient's attitudes towards AI (which may impact their experiences when they interacting with these tools in practice) are influenced by various factors including familiarity with function, previous exposure to similar tools, supervision during use, simplicity of tools, evidence in support of the tools, cost of the tools, and more, it is imperative that we continue to update our understanding of patient perceptions on AI applied to clinical workflows related to diagnosis[17]. As AI becomes ubiquitous both inside and outside of healthcare, patients' familiarity (and thus their attitudes towards AI) will continue to evolve. It is critical that we continue to assess patient perceptions for AI tools used to enhance the diagnostic process and communication so both their design and integration into healthcare organizations can be adjusted to maximize patient benefit.

Implications at the Individual Clinician, Organizational, and Policy/Regulatory Levels

Our findings have clear implications for clinical practice, finding that patients consistently stressed the importance of clinicians playing a central role in facilitating their experience with AI tools. Patients emphasized that their trust in AI would be built through transparent communication and clinician endorsement. Patients valued clinician involvement in contextualizing AI's outputs, interpreting its recommendations, and providing assurances about its accuracy and reliability. Patients additionally expressed concerns that AI could disrupt workflows or reduce human interaction, particularly in scenarios where key diagnostic information was to be communicated. To address this, organizations should prioritize implementation of AI tools that enhance human connection in care such as those that reduce administrative burdens. These tools should be designed such that they complement, rather than overshadow, the clinician's role in communicating diagnoses.

From a policy perspective, our findings reinforce the urgency of addressing gaps in regulations

governing AI in healthcare, particularly concerning equity[27]. Patients expressed concern that biased data inputs which could undermine the diagnostic accuracy of AI tools and have harmful effects on historically underserved populations. Policies should ensure that tools are trained on diverse datasets and validated across varied populations to alleviate the concerns of patients and subsequently build trust and acceptance.

Importance of Involving Patients in AI Deployment

Our findings underscore the critical role patients play in the acceptance and success of AI tools designed to enhance the diagnostic process, emphasizing the need to involve them in the development and implementation of these technologies. As primary stakeholders most directly impacted by changes to diagnostic workflows, patients have invaluable insights, as demonstrated in our results, that can guide the design of tools to align with their expectations and foster trust[27]. Participants in this study expressed a dynamic view of AI tool implementation, with key insights into concerns that should be addressed during design and implementation such as the importance of human connection and interaction, concerns regarding equity, personalization, and data security, and the pivotal role clinicians have in their understanding and comfort with new technology. By involving patients in the development of these tools, the healthcare system can better anticipate risks, communicate with patients more effectively, and deploy tools that not only improve that diagnostic process but also enhance trust and adoptions, ensuring alignment with patient values and priorities.

Limitations

There are several limitations of this work. First, focus groups were guided through each scenario by a different team member, so discussions between scenarios may have altered in content and digression based on the team member. Additionally, due to time constraints, each focus group had a limited amount of time to discuss each scenario, so saturation may not have been reached. To reduce the abstractness of AI and provide more structure to our conversations, we chose to discuss specific case studies of diagnostic-related AI applications; however, this approach limits the generalization of our findings to other clinical scenarios and problems. This work is not a comprehensive report on all patient concerns.

Conclusions

This study underscores the importance of understanding patient perspectives on AI in healthcare, particularly in the context of diagnostic communication. Patients demonstrated a sophisticated understanding of AI's potential to enhance diagnostic safety, improve efficiency, and address inequities. However, patients also highlighted significant concerns about transparency, trust, and the preservation of human connection. These findings emphasize the need for thoughtful design and integration of AI tools that balance technological innovation with human-centered care across individual, organizational, and policy levels to ensure it supports meaningful, transparent, and equitable patient-provider interaction. As AI becomes increasingly ubiquitous, it is critical to iteratively assess and address evolving patient perceptions to ensure these tools not only demonstrate diagnostic accuracy, but also aligned with the values and expectations of the patients they serve.

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References

- 1. Hajkowicz S, Sanderson C, Karimi S, Bratanova A, Naughtin C. Artificial intelligence adoption in the physical sciences, natural sciences, life sciences, social sciences and the arts and humanities: A bibliometric analysis of research publications from 1960-2021. *Technology in Society*. 2023;74:102260.
- 2. Du-Harpur X, Watt F, Luscombe N, Lynch M. What is AI? Applications of artificial intelligence to dermatology. *British Journal of Dermatology*. 2020;183(3):423-430.
- 3. Sunarti S, Rahman FF, Naufal M, Risky M, Febriyanto K, Masnina R. Artificial intelligence in healthcare: opportunities and risk for future. *Gaceta sanitaria*. 2021;35:S67-S70.
- 4. Hardy M, Harvey H. Artificial intelligence in diagnostic imaging: impact on the radiography profession. *The British journal of radiology*. 2020;93(1108):20190840.
- 5. Wang L, Chen X, Zhang L, et al. Artificial intelligence in clinical decision support systems for oncology. *International Journal of Medical Sciences*. 2023;20(1):79.
- 6. Shaik T, Tao X, Higgins N, et al. Remote patient monitoring using artificial intelligence: Current state, applications, and challenges. *Wiley Interdisciplinary Reviews: Data Mining and Knowledge Discovery*. 2023;13(2):e1485.
- 7. Juhn Y, Liu H. Artificial intelligence approaches using natural language processing to advance EHR-based clinical research. *Journal of Allergy and Clinical Immunology*. 2020;145(2):463-469.
- 8. Auerbach AD. Laying a Foundation for the Use of Artificial Intelligence in Diagnosis. *JAMA Network Open*. 2024;7(9):e2431907-e2431907.
- 9. Newman-Toker DE, Nassery N, Schaffer AC, et al. Burden of serious harms from diagnostic error in the USA. *BMJ Quality & Safety*. 2024;33(2):109-120.
- 10. Pushadapu N. AI-Enhanced Techniques for Pattern Recognition in Radiology Imaging: Applications, Models, and Case Studies. *Journal of Bioinformatics and Artificial Intelligence*. 2022;2(1):153-190.
- 11. Reddy A, Reddy RP, Roghani AK, et al. Artificial Intelligence in Parkinson's Disease: Early Detection and Diagnostic Advancements. *Ageing Research Reviews*. 2024:102410.
- 12. Giordano C, Brennan M, Mohamed B, Rashidi P, Modave F, Tighe P. Accessing artificial intelligence for clinical decision-making. *Frontiers in digital health*. 2021;3:645232.
- 13. Cohen M, Puntonet J, Sanchez J, et al. Artificial intelligence vs.

radiologist: accuracy of wrist fracture detection on radiographs. *European radiology*. 2023;33(6):3974-3983.

- 14. Zheng Q, Yang L, Zeng B, et al. Artificial intelligence performance in detecting tumor metastasis from medical radiology imaging: A systematic review and meta-analysis. *EClinicalMedicine*. 2021;31
- 15. Ouanes K, Farhah N. Effectiveness of Artificial Intelligence (AI) in Clinical Decision Support Systems and Care Delivery. *Journal of Medical Systems*. 2024;48(1):74.
- 16. Hoseini M. Patient Experiences with AI in Healthcare Settings. *AI and Tech in Behavioral and Social Sciences*. 2023;1(3):12-18.
- 17. Moy S, Irannejad M, Manning SJ, et al. Patient Perspectives on the Use of Artificial Intelligence in Health Care: A Scoping Review. *Journal of Patient-Centered Research and Reviews*. 2024;11(1):51.
- 18. Haggenmüller S, Krieghoff-Henning E, Jutzi T, et al. Digital natives' preferences on mobile artificial intelligence apps for skin cancer diagnostics: survey study. *JMIR mHealth and uHealth*. 2021;9(8):e22909.
- 19. Jutzi TB, Krieghoff-Henning EI, Holland-Letz T, et al. Artificial intelligence in skin cancer diagnostics: the patients' perspective. *Frontiers in medicine*. 2020;7:233.
- 20. Lennox-Chhugani N, Chen Y, Pearson V, Trzcinski B, James J. Women's attitudes to the use of AI image readers: a case study from a national breast screening programme. *BMJ Health & Care Informatics*. 2021;28(1)
- 21. Ongena YP, Yakar D, Haan M, Kwee TC. Artificial intelligence in screening mammography: a population survey of women's preferences. *Journal of the American College of Radiology*. 2021;18(1):79-86.
- 22. Kosan E, Krois J, Wingenfeld K, Deuter CE, Gaudin R, Schwendicke F. Patients' perspectives on artificial intelligence in dentistry: a controlled study. *Journal of Clinical Medicine*. 2022;11(8):2143.
- 23. Zhang Z, Citardi D, Wang D, Genc Y, Shan J, Fan X. Patients' perceptions of using artificial intelligence (AI)-based technology to comprehend radiology imaging data. *Health informatics journal*. 2021;27(2):14604582211011215.
- 24. Williamson SM, Prybutok V. Balancing privacy and progress: a review of privacy challenges, systemic oversight, and patient perceptions in AI-driven healthcare. *Applied Sciences*. 2024;14(2):675.
- 25. Beets B, Newman TP, Howell EL, Bao L, Yang S. Surveying public perceptions of artificial intelligence in health care in the United States: systematic review. *Journal of Medical Internet Research*. 2023;25:e40337.
- 26. Richardson JP, Smith C, Curtis S, et al. Patient apprehensions about the use of artificial intelligence in healthcare. *NPJ digital medicine*. 2021;4(1):140.
- 27. Ratwani RM, Sutton K, Galarraga JE. Addressing AI algorithmic bias in health care. *JAMA*. 2024;332(13):1051-1052.

28. Miller K, Biro J, Gold JA, Hose B-Z, Singh H, Ratwani R. Documenting Diagnosis: Exploring the Impact of Electronic Health Records on Diagnostic Safety. *Agency for Healthcare Research and Quality*. 2024;24-0010-3-EF.

Supplementary Files

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Multimedia Appendixes

AI Scenarios for Breakout Discussion.
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