

Designing participatory AI for pregnancy information seeking across personal networks and social media

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CCS Concepts

• **Human-centered computing** → **Empirical studies in HCI**.

1 Introduction

Pregnancy creates evolving, stage-specific information needs related to both physical and mental health, with each trimester introducing distinct demands [7–9, 14]. The information needs, physical and emotional self-care practices, and social relationships that shape pregnancy experiences are interconnected during pregnancy [15]. Pregnant people turn to a variety of information sources to address their needs. For example, to address physical needs, many women use tracking tools to support their well-being by monitoring weight, diet, blood pressure, glucose levels, mood, and symptoms [6, 16, 17], and to follow fetal development through milestones [1, 13]. To address emotional needs, people often use social platforms to connect with others who have had similar experiences. For instance, women experiencing pregnancy complications or loss often turn to pregnancy forums, such as Reddit, BabyCenter, and What to Expect, to seek reassurance [2, 5, 12]. Pregnancy information-seeking can be a social activity, where people draw on the experiential knowledge of their family and close networks. For example, mothers and mothers-in-law often share guidance from their own pregnancy experiences, including advice about bodily changes, food practices, and managing physical symptoms [3, 4]. Additionally, people engage with information sources for social purposes. For instance, pregnancy tracking apps can support connection and bonding by enabling partners, family members, and friends to participate in and share aspects of the pregnancy journey [10, 11].

Pregnancy requires ongoing engagement with information rather than a single episode of information seeking, a process that existing models of health information seeking do not fully capture. Moreover, the pregnancy information ecosystem continues to evolve, with new information sources emerging (e.g., AI) and new health-related challenges shaping information needs (e.g., COVID-19 vaccination during pregnancy). To understand how pregnant people in the United States navigate this evolving landscape, including their mental models of information sources and strategies for using them, we conducted an interview study with 14 participants who were either currently pregnant or had been pregnant within the previous six months. Drawing on our findings, we present two design scenarios.

2 Scenario 1: A participatory AI system for the close social circle

2.1 Empirical findings

Our empirical findings indicate that people value offloading the cognitive effort of information seeking, obtaining personalized information, and being directed to relevant sources for further

investigation. To support these needs, participants relied on both their social circles and AI.

2.1.1 Social circle. People frequently turned to their social circles for support in seeking, evaluating, and verifying information. For instance, several participants highlighted the important role their partners played in researching pregnancy-related questions. One participant explained, *"Where I have lacked in doing research, he's been really diligent on. (I ask) I'm feeling this, have you read this in your book? and he can usually help me."* Participants deliberately turned to members of their close social circles with relevant expertise to help interpret and evaluate pregnancy information. This expertise ranged from professional training to research experience and lived experience. For example, one participant relied on their partner's scientific background, explaining, *"He's a biologist, and his mother is a physician, so I would turn to them first, because they can guide me where to look for."* Others relied on family members with research expertise to help interpret scientific evidence. As one participant noted, *"If I ever had to actually look at a study, my husband has a PhD, and so he knows how to read abstracts, or interpret them."* Participants also valued practical expertise: *"I do have some family friends who have doula experience, or along the lines of that, [who] have been a really good resource for me."*

Friends, family, and peers with pregnancy experience were valuable sources of context-specific advice, although participants weighed that advice based on how recent and relevant the experiences were: *"I would ask my mom and my stepmom and my friends that were pregnant or had kids questions... But then I don't always take that advice or trust it, because if I ask my mom something, that was 30 years ago and things have changed."* Participants especially valued advice from people with similar experiences, particularly when authoritative resources were limited. As one participant explained, *"There's not many resources out there for pregnant athletes...there are four moms on my team who have gone through this before, I mainly talk to them about what they did, and follow the same thing."* Participants also valued advice grounded in shared local and social contexts, viewing it as more relevant than information *"from strangers online"*. As one participant explained, *"I was part of a local mom's group, and when I was giving birth, I was trying to be like, oh, what hospital do I go to? For that, I relied more on peer online groups of local moms."*

2.1.2 AI. Participants used AI to obtain personalized information and identifying relevant sources. People valued AI's conversational style and its ability to tailor responses to their circumstances. As one participant explained, *"At the beginning, when I was more nervous about rates of miscarriage and symptoms, I would ask, I'm this far along, these are the symptoms I'm having, do you think I'm okay? ChatGPT frames it in a human way. It's not just the cold hard data."*

Participants appreciated receiving immediate responses during moments of uncertainty. For example, after an intense workout and concerns about its potential effects on the baby, one participant said, *"I think I did ask ChatGPT or Gemini to get an immediate answer that maybe I trusted like 60–70%, and it was not to give me the verdict...I was trying to understand more of how that works."* Beyond answering questions, participants used AI to reduce the effort of finding information by identifying other sources that they could verify themselves. As one participant explained, *"When I'm lazy, I go to ChatGPT, and I'm like if there are any research on this, when were they done? Give me the name of them, so I can go and check them."*

2.2 Design suggestion

Building on this insight, we propose an AI-mediated information-seeking system that coordinates a pregnant person's trusted social network by using each member's expertise and lived experience. The pregnant person begins by inviting members of her social circle, each of whom creates a profile describing the expertise they bring relative to pregnancy and to her specifically. The areas of expertise may include lived experience (e.g., having experienced a twin pregnancy within the past two years), professional expertise with a clearly defined scope of practice (e.g., a pediatric nurse without obstetric specialization), local knowledge (e.g., familiarity with healthcare resources in the same neighborhood or city), or personal knowledge of the pregnant person's preferences and circumstances (e.g., a spouse or close family member). When the pregnant person submits a question, the AI first evaluates whether it involves potential emergency symptoms, displaying a warning for red-flag symptoms such as bleeding; otherwise, it notifies the members of the support network she assembled when setting up the system.

Participants respond by locating relevant information, attaching supporting sources, sharing relevant personal experiences, and adding multimodal evidence and notes. Before assembling the final view, the AI returns to each contributor a synthesis of their own material. Contributors can flag where the system has mischaracterized what they offered, collapsed a distinction they consider important, or ranked their evidence in a way they would dispute, and they can mark which parts of their contribution they most want the pregnant person to see. This correction stage is limited to each participant's own contributions: contributors see their own history, not others' submissions or how their input was evaluated. This preserves independent contributions and reduces social pressure.

The pregnant person then receives a single integrated view that has passed through a round of correction by the people whose knowledge it summarizes. This view is organized in five layers: 1) source typing, which tags each piece of information by kind (clinical guideline, social media post, lived experience, and so on); 2) attribution, which identifies who contributed it and their declared expertise; 3) a summary of what was found across all contributions; 4) conflict, which makes disagreements between contributions explicit and visualizes them; and 5) comparison, which checks claims against current authoritative guidance and flags advice that may reflect outdated recommendations. If substantial disagreement remains, the pregnant person can delegate a follow-up investigation

to trusted individuals, such as an experienced friend. The system incorporates the resulting findings into an updated synthesis.

3 Scenario 2: Participatory evidence synthesis for social media health information

3.1 Empirical findings

Our findings show that social media, particularly TikTok, is a major source of pregnancy information. People use TikTok as an accessible starting point for pregnancy information, where they can learn from others' experiences, understand community perspectives, discover personalized content, and identify topics or sources for further investigation.

Participants described using TikTok to identify common experiences and discover topics for further exploration. As one participant explained, *"(TikTok) For me, it's a place where I go and it's the beginning of, I have this question, let me see what's the overall consensus around this question... and then through there I find other resources, other questions that help me narrow down what I'm looking for."* Participants also valued TikTok's personalized recommendations and accessible format. One participant shared, *"I found a lot of pregnant women fitness channels on TikTok. I would say my algorithm leans more towards wellness, like health and beauty regimens. It's been really cool because that information feels a little vain to ask about."* Others appreciated that social media content was often more engaging than traditional health materials: *"It's not the most exciting read every time to go through government agency websites, or even your doctor office. They give you tons of pamphlets and brochures...on TikToks and Instagram, you can learn some fun things from those. Doesn't necessarily have to be NIH-approved or anything like that."* Participants also used TikTok to search for practical advice when experiencing symptoms. One participant explained, *"TikTok was the easiest to search for specific things I was looking for...I watch so many videos and stuff on social media about morning sickness, tips and tricks, and stuff like that. I guess at that point, I was kind of desperate to try anything that people had."*

Participants described consistently cross-referencing what they encountered on TikTok against other sources. TikTok currently offers a fact-checking feature that allows the community to add notes to videos and vote on those notes. However, this mechanism frames verification as a binary judgment of whether content is accurate.

3.2 Design suggestion

We propose a design that help people understand how claims are supported, contested, and situated within a broader evidence landscape. The system surfaces disagreement in the context where it occurs: alongside a video's claims, viewers can attach other TikTok videos that present conflicting perspectives, creating a navigable collection of related viewpoints. These counterpoints are presented as additional contributions that can be examined. Personalized feeds may repeatedly expose viewers to one perspective while filtering out competing viewpoints. Hence, community-identified counterpoints can help restore visibility to alternative interpretations that exist on the platform.

Conflicting videos do not represent equally credible perspectives. Counterpoint videos are treated as evidence contributions within

the same framework as other sources, rather than presented as a neutral "other side." Each video is labeled as social media content, linked to supporting evidence where available, and accompanied by provenance information and contributor disclosures. Since this mechanism can be exploited for self-promotion (e.g., creators attaching their own content as a counterpoint to popular videos) transparency about contributor history, incentives, and potential commercial interests becomes essential.

How should viewers evaluate competing claims when multiple videos appear credible? The system provides a pathway for unresolved or highly contested questions to be escalated to relevant institutional expertise. When a claim generates sustained disagreement and significant community attention, it can be submitted as a question to participating healthcare organizations. Experts provide relevant guidance, explain its evidentiary basis, and describe areas of uncertainty or ongoing debate. The system adapts these responses into the platform's format and attaches them to all videos addressing the same claim, rather than only the video that initiated the escalation. In this model, the community identifies which questions require deeper investigation, experts contribute contextualized reasoning, and viewers make informed decisions based on a broader understanding of what is known, contested, and uncertain.

4 Discussion

These scenarios raise questions we hope to explore with workshop participants. Pregnancy is a domain where embodied knowledge and lived experience can provide important insights that complement clinical guidance. When lived experience contradicts clinical recommendations, how should such tensions be interpreted by AI, and which should be treated as the anomaly? How can systems help people appropriately evaluate conflicting contributions from individuals with different expertise, experiences, and personal connections to the situation? We are also interested in the opportunities and challenges of designing systems that can distinguish substantive differences in perspectives from those driven by misinformation, personal beliefs, or commercial interests. Finally, as AI and social media become increasingly used for health information seeking, it is important to consider the risks of mis/disinformation, particularly in high-stakes contexts like pregnancy. This raises questions about the role of healthcare professionals and institutions in online information ecosystems and how they can contribute to providing trustworthy and accessible information.

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