Outlining the Borders for LLM Applications in Patient Education: Developing an Expert-in-the-Loop LLM-Powered Chatbot for Prostate Cancer Patient Education

YUEXING HAO, Cornell University, USA
JASON HOLMES, Mayo Clinic Arizona, USA
MARK WADDLE, Mayo Clinic Rochester, USA
NATHAN YU, Mayo Clinic Arizona, USA
KIRSTIN VICKERS, Mayo Clinic Rochester, USA
HEATHER PRESTON, Mayo Clinic Rochester, USA
DREW MARGOLIN, Cornell University, USA
CORINNA E. LÖCKENHOFF, Cornell University, USA
ADITYA VASHISTHA, Cornell University, USA
MARZYEH GHASSEMI, Massachusetts Institute of Technology, USA
SALEH KALANTARI, Cornell University, USA
WEI LIU, Mayo Clinic Arizona, USA

Cancer patients often struggle to transition swiftly to treatment due to limited institutional resources, lack of sophisticated professional guidance, and low health literacy. The emergence of Large Language Models (LLMs) offers new opportunities for such patients to access the wealth of existing patient education materials. The current paper presents the development process for an LLM-based chatbot focused on prostate cancer education, including needs assessment, co-design, and usability studies. The resulting application, MedEduChat, integrates with patients' electronic health record data and features a closed-domain, semi-structured, patient-centered approach to address real-world needs. This paper contributes to the growing field of patient-LLM interaction by demonstrating the potential of LLM-based chatbots to enhance prostate cancer patient education and by offering co-design guidelines for future LLM-based healthcare downstream applications.

CCS Concepts: • **Human-centered computing → Empirical studies in interaction design**; *Accessibility systems and tools*; • **Social and professional topics → Seniors**; • **Applied computing →** *Consumer health.*

Additional Key Words and Phrases: Patient Education; Large Language Model; Prostate Cancer; Accessibility.

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1 INTRODUCTION

Cancer patients are vulnerable and face high uncertainty, and they are in need of information and social support to help them maintain agency and make informed decisions about their treatment [8, 22, 62]. In addition to learning about the specific details of potential biomedical treatments, they may also need assistance with psychological and social concerns [72]. However, current cancer treatment regimens often lack a comprehensive and timely educational component, leaving patients without the support they urgently need during these challenging and stressful times [7, 29]. Because of the need to understand and the burdens of dealing with cancer, patients would like to consult with clinical professionals regarding these issues [86, 93]. However, in current medical systems, clinical professionals have limited time and capacity to engage in this kind of dialogue [32], and understanding the evolving personal and cognitive needs of patients is often the first thing that is cut when healthcare resources are strained [83].

Large language models (LLMs) offer the capability of acting as chatbot companions for cancer patients by providing both medical information and emotional support [25, 90]. Leveraging LLMs' capabilities for information summarization, explanation, and real-time interactions in natural language processing tasks, a chatbot built on strong LLM features that are tailored to a particular cancer domain can offer unique personalized interactions that respond to patient inquiries [27, 75]. Unlike conventional chatbots, LLM-based chatbots have the potential for more nuanced and individualized engagement [70], providing real-time interactions and clinical education enhancement for patient users. By providing timely and useful information, these chatbots can help patients understand what to expect physically and emotionally after a diagnosis or at the start of treatment [104]. Among various LLMs, Chat Generative Pre-Trained Transformer 4 (ChatGPT-4) stands out for its lower error rates [41, 42, 58, 87, 97], making it the current preferred choice for such data processing and interactions. Structured peer support can bridge gaps in patients' needs and alleviate negative emotions [44]. As patients navigate different stages of their cancer journey, an interactive chatbot can empower them with essential information and educational support [73, 80]. Additionally, internet health information resources play a supportive, stimulating, and interactive role in the patient's treatment journey [20, 34, 77].

In this paper, we evaluated three research questions regarding the usefulness of educational LLMs for patients: **(RQ1) What are the current challenges in prostate cancer patient education? (RQ2) How can we enact a successful co-design and co-development process with patients, AI practitioners, and medical experts for an LLM-based educational tool? (RQ3) Can the resulting LLM-based chatbot enhance prostate cancer patients' educational experience?** To answer RQ1 we conducted a needs-assessment survey with prostate cancer patients currently using electronic learning (e-learning) modules. The e-learning module is a web-based patient education intervention that is mediated electronically via the Internet asynchronously [81]. For RQ2, we engaged in a co-design study with clinicians, AI researchers, and patient advocates to develop guidelines for the LLM-based chatbot, MedEduChat. To address RQ3, we assessed MedEduChat's effectiveness through a usability study with seven patients and gathered feedback from three clinicians on the chatbot's responses.

To conduct the study in the clinical setting, we partnered with a clinic's radiation oncology department in the western United States to develop and evaluate the patient-centered chatbot[1]. This department provides services including radiation therapy (both proton and photon therapy), imaging, and consultations. Partnership with the clinic eliminates barriers to gaining comprehensive insights into real-world prostate cancer cases. Rather than simply presenting a new LLM-based chatbot product, our goal is to offer a nuanced, practical, and reflective perspective on defining and developing LLM-based applications in healthcare. This process, which we refer to as *outlining the borders*, seeks to

[1]The clinic's name will remain anonymous until publication.

illuminate the structural conditions that influence researchers' and practitioners' approaches to achieving meaningful and sustainable impact within healthcare systems. The full study was approved by the Ethical Review Board of the clinic where the study took place.

This research made three main contributions to the field of patient-LLM interaction. First, it made strides in identifying the current challenges and scenarios that patients face during prostate cancer education. Second, we encompassed a collaborative process between researchers, clinical professionals, artificial intelligence (AI) researchers, and prostate cancer patient advocates to co-design MedEduChat, a patient-centered, closed-domain, semi-structured cancer education chatbot. We recruited clinical professionals who offered guidance on providing accurate information, AI researchers contributed insights on feasibility and technical capabilities, and patient advocates shared perspectives on which information is most important for patients and the best ways to deliver and understand it. Third, we evaluated the resulting chatbot's effectiveness in patient education through feedback from real-world prostate cancer patients and clinical professionals. This study, therefore, presented a comprehensive design paradigm for LLM-based healthcare technologies in the high-stakes setting of cancer patient education and addressed the personalized educational needs of different patient users in an empirical fashion. Future research will focus on assessing and validating the chatbot's performance and large-scale interaction experiences with broader patient populations.

2 RELATED WORK

2.1 Prostate Cancer Patients' Educational Demands

Prostate cancer is the most common cancer and the second leading cause of cancer death among men in the United States [84]. The survival rate for five years or more after a prostate cancer diagnosis is 97.5% [46]. Approximately 1 in 8 men will be diagnosed with prostate cancer at some point in their lives. Despite limited research on prostate cancer patient education, patients are actively seeking various methods to meet their educational needs.

Patients' health information-seeking behavior from online sources about their diseases has significantly increased [40, 47, 56]. Cancer patients and survivors have many information needs that are not covered by the written documents they typically receive, as McRoy et al. suggest that current materials address at most 33% of their questions [63]. DeWalt et al.'s systematic review highlights that low literacy is linked to various negative health outcomes [26]. By 2020, 54% of Americans had reading proficiency below the sixth-grade level [67], which can adversely impact patients' health-related behaviors [52].

Online platforms like social media and forums have potential to serve as sustainable, lay-language tools for enhancing patient education and potentially improving health outcomes [22, 92]. These platforms are particularly valuable for addressing the sensitive nature of cancer, as online cancer communities allow patients to discuss potentially embarrassing or taboo topics while maintaining privacy [30, 96]. Additionally, online cancer offers a welcoming space for patients without clinical backgrounds to share their experiences in simple language, facilitating narrative medicine [47]. Narrative-based medicine emphasizes a patient-centered perspective in diagnosis and encourages self-reflection on the treatment journey, offering valuable support to both clinicians and patients navigating through the uncertain time [66, 85, 99].

Multiple online resources currently exist to help with patient education, such as virtual support group communities (which may include social media and online forums) and websites recommended by search engines. Although they generally lack visual and aural cues and other features of face-to-face interactions, such sites can make it easier for patients to connect with their target populations and overcome communication challenges [96]. There is also considerable support for the potential of virtual environments to provide patients with a sense of empowerment, control, and knowledge [19]. For example, a study on online prostate cancer communities indicated that sharing information helped the patients to feel more positive about their diagnosis and treatment side effects and that patients also gained a sense of friendship with others who shared similar experiences [74].

However, these online resources are also sometimes associated with drawbacks, such as inaccurate information, skepticism toward medical providers, and clinical inefficacy due to the need to counter those effects. Patients may develop a dependence on online resources that leads them to distance. They may be exposed to unpleasant or aggressive experiences typical of social engagement in cyberspace [14]. Clinical professionals have a great deal of concern about maintaining the integrity of medical information and about the erosion of trust in expertise that has been driven at least in part by the growth of online information-seeking [19]. Relying on information from questionable online sources is sometimes associated with refusing or discontinuing effective treatments or making unadvised modifications to treatments, which can negatively affect a patient's prognosis [89].

2.2 AI-Based Chatbots for Patient Education

Perceiving the need for an efficient means of patient education, multiple research studies have focused on developing AI or LLM-based medical chatbots, particularly in the contest of distance and online learning [9, 50, 54, 79]. Chatbots offer an interactive approach that can engage patients in a flexible, open-ended manner, enabling researchers to observe intuitive behaviors and thought processes [12]. There is hope that such chatbots, if firmly grounded in high-quality information sources, could serve as valuable resources for patients, while alleviating the burden on expert clinicians [6, 98]. Prior to the ChatGPT era, the IBM Watson Assistant platform was capable of interacting with patients to share therapy information and provide additional details upon request [24]. Additionally, PROSCA in Germany had success in automating repetitive tasks of patient education, allowing physicians to focus on the more personalized and empathetic aspects of care [36]. Multiple other virtual assistants and interactive communication technologies have gained popularity for providing health information [71].

Various types of machine learning (ML) models have been used to extract cancer-related information from text, examples include Latent Dirichlet Allocation and Bidirectional long-short-term memory models [13, 65]. Established LLMs, such as Flan-PaLM, have tended to be strongest in the medical context, achieving top-tier accuracy across multiple-choice datasets such as MultiMedQA and MedQA [82, 101]. Several new LLMs have shown improved performance on modifying cancer-related terminologies and clinical terms, including RadOnc-GPT [60, 61], Radiology-LLaMa2[59], ClinicalRadioBERT[76], CancerBert [102], SMART*health* GPT [3], BiomedGPT[100], or CancerGPT [57]. Studies have found these LLMs to be successful at explaining and summarizing cancer-related knowledge [2].

Although AI or LLM shows its strong promise in the medical domain, there are some concerns about output coherence and accuracy, as well as "AI hesitancy" among patients (that is, resistance against or suspicion of these tools) [68]. Wei and colleagues compared patients' use of standard Google search vs. ChatGPT for cancer-related questions, and found out that ChatGPT had poorer reliability and accuracy [95]. ChatGPT's answers also demonstrate high accuracy in dispelling common cancer myths [49]. However, Ayers and colleagues found that the patients regarded an AI-based chatbot as being a better communicator than physicians' responses to queries, and suggested that clinical professionals could improve their communication skills by reviewing and modifying AI-written drafts [10].

Despite the usefulness of these systems, it is important to remember that auto-generated summaries may introduce misinterpretations, fabrications, attribution errors, and incomprehensiveness [4, 69, 87]. A cautionary note emerges from a study that found as many as one-third of treatments recommended by GPT-3, did not have full concordance with the National Comprehensive Cancer Network guidelines [23]. The effectiveness of current LLMs is also influenced by users' prompts, meaning that the output generated by skilled researchers who are familiar with LLMs may not be the same as that received by a patient [1]. Even when LLMs are trained specifically on medical data and health information, accurate responses cannot be guaranteed [38, 43, 55, 103].

3 STUDY 1: NEEDS ASSESSMENT STUDY

3.1 Needs Assessment Study on Patient Education

The existing e-learning module was created by the clinic's care team; they are accessible via a web page, tailored for an audience of eighth-grade level and above and recommended for patients after diagnosis but before beginning treatment. The information presented includes videos, data visualizations, and other engaging content, all developed and fact-checked by board-certified clinical professionals. Access is restricted, requiring a passcode or clinician supervision. The education module takes about 20 minutes to complete and is divided into six categories: 1) "A message from your care team"; 2) "How serious is prostate cancer?" 3) "What are your treatment options?" 4) "What about side effects?" 5) "How do you decide on treatment?" 6) "A final word from your care team." The e-learning module is designed for all types of prostate cancer patients, and the information provide is static and the same for all viewers.

To evaluate the clinic's current patient education experience, we administered an optional, anonymous, seven-item feedback survey to 204 prostate cancer patients who had completed the clinic's e-learning modules. The survey was collected from September 2023 until June 2024. Due to the clinic's protocol, every question was optional, resulting in a slightly varying number of responses for each question. The survey questions focused on users' experience with the e-learning modules. The survey questions are presented in full in Appendix A.1.

Regarding the total time that the respondents had spent researching prostate cancer diagnosis and treatment options: 54% of respondents reported spending three or more hours, 32% reported spending between one and three hours, 13% reported spending less than one hour, and 1% reported spending no time at all. In regard to the many times they accessed the e-learning content, 75% of respondents reported accessing it only once, 24% had accessed it between two and four times, and 1% had accessed it five or more times.

3.2 Survey Result

From the survey result, we conducted a quantitative analysis to interpret and evaluate the prostate cancer e-learning module. The average age for all the users who answered any part of the survey was 70.02 years old (SD 6.53, n = 204).

The respondents generally gave a high evaluation of the existing e-learning module. A strong majority (90.2%) agreed that the e-learning module better prepared them for discussing their prostate cancer diagnosis with the healthcare team, with 19.8% feeling neutral and no respondents disagreeing. In terms of understanding their prostate cancer diagnosis, 71% found the information helpful helpful, 26% felt neutral, and 3% disagreed. Large majorities of respondents also agreed that the module's length and level of detail were about right, and they would recommend the e-learning module to other patients. (The full quantitative outcomes are shown in Figure 1.) It is important to be aware that these numbers could be somewhat skewed toward positive responses, since patients who did not like the e-learning modules may have been less likely to complete them and then answer the survey questions.

Three of the survey questions allowed for short answer feedback. In regard to their favorite parts of the learning experience, 65 participants responded, and the most commonly mentioned themes were, "*comparison between treatment options*," "*explanations of what to expect*," "*during treatment, treatment option details*," and "*simple vocabulary/ease of understanding*." When asked about their least favorite part, three main feedback themes from 58 respondents were

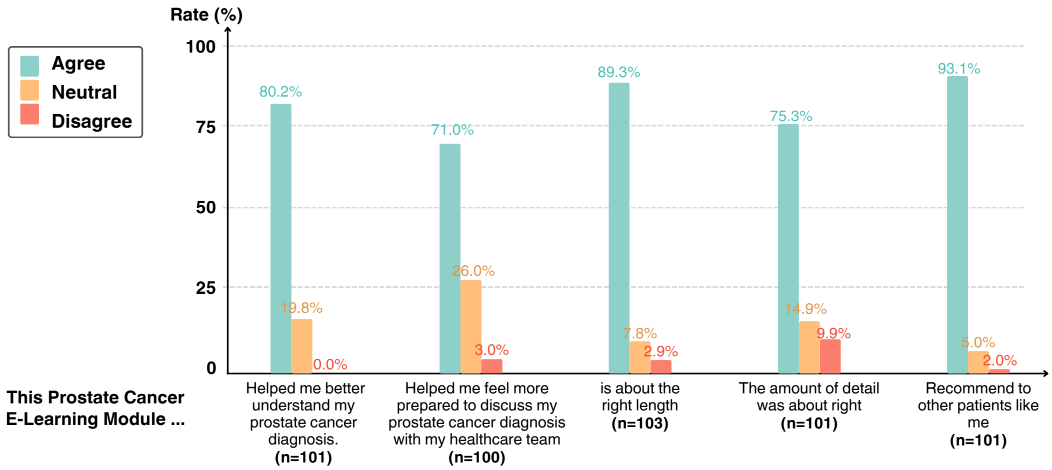

Fig. 1. Needs assessment survey quantitative results.

"*didn't mention different machines for radiation delivery*," "*looking for possible additional options*," and "*maybe more depth of details would have been helpful*."

In the open-ended "Other Comments" section, 32 participants responded with diverse feedback on the e-learning module. Positive feedback included the e-learning module saves time in searching: "*After millions of web pages, this e-learning module centered me. I wish I would have been to see this before my appointments.*" "*Definitely informing. Made me feel more confident about types of treatments.*" Comments included: "*Would it be nice to have a conversation so I could get certain questions answered instead of simply deal with a material that's statically presented?*" and "*I have SBRT [stereotactic body radiation therapy] questions that are unanswered.*" Several participants also raised questions about the dating of statistics used in the material, noting that it appeared to have not been updated in many years.

Overall, respondents were happy with the e-learning modules. They found the modules were good for reliable and trustworthy information, an overview of the upcoming treatment process, layman's terms, and patient-friendly treatment explanations. However, there were several areas where the e-learning modules were not sufficient. The survey feedback indicated that while patients appreciated having a dedicated online resource direct from their provider, they were unhappy with the static one-module-fits-all approach, which left some of their specific questions unanswered. Some respondents felt significantly slighted that they were not getting this information directly from their physicians, but most understood it as a useful way to gain basic information so that they could then have more focused in-person conversations. From a design standpoint, the needs assessment survey highlighted three key areas of interest: the need for greater personalization and customization, the need for more detailed information-delivery options, and the need to account for diverse learning methods.

4 STUDY 2: CO-DESIGN STUDY

To address the limitations of e-learning module, we next **(RQ2) co-designed a patient-centered LLM-based chatbot**. Based on the collective mode of patient-healthcare expert-AI interaction [51, 105], our diverse team consisted of design researchers, clinical professionals, and specialists in human-computer interaction, patient education, clinical settings, psychology, and AI. Following the needs assessment survey to understand prostate cancer patients' education demand, we then recruited three board-certified clinical professionals, three AI practitioners specializing in cancer or the general healthcare domain, and three experienced cancer patient advocates from the local community to co-design the chatbot. All participants (except the patient advocates) have received the highest degree in their own field (Ph.D. or M.D.). They have rich experience working or observing in the healthcare field and possess knowledge of each other's areas of expertise. The study participants' details are displayed in Table 1.

AI Practitioners	**Affiliation**	**Use AI For...**	**Experience**	**Clinical Professionals**	**Clinical Domain**	**Experience**
A1	Hospital	Radiation Oncology	10-30 yrs	C1	Oncology/ Hematology	39 yrs
A2	Academia	Clinical Notes	5-10 yrs	C2	Oncology	21 yrs
A3	Hospital	System Management	10-30 yrs	C3	Urology	4 yrs

Patient Advocate	**Cancer Domain**	**Active years since diagnosis**
PA1	Prostate & Breast Cancer	13 yrs
PA2	Prostate Cancer	4 yrs
PA3	Prostate Cancer	2 yrs

Table 1. Co-Design study participants.

To better understand these experts' outlook on patient education needs, we conducted semi-structured one-on-one interviews, each lasting around 60 minutes. During the first half of each interview, we sought to (1) understand the participants' daily practices regarding patient education, (2) learn about current solutions and resources for patient education, and (3) identify existing challenges and gaps in AI integration in healthcare settings. In the second half of the interview, we proposed the LLM-based chatbot as a potential solution and gathered the participants' feedback on this approach and on chatbot design. For the clinical professionals, we focused on the tasks they would like the chatbot to address and their concerns about its capabilities. We discussed the technical capabilities of the LLM with AI researchers. For patient advocates, we emphasized their insights on how to conduct effective interactions with patients and useful approaches to patient education. All of the interviews were conducted through Zoom and were audio-recorded and transcribed for further analysis. Each of the participant was rewarded with $50 after the interview in compensation for their time and contributions. The first author conducted the thematic analysis [18, 91], with ongoing discussions among the research team to refine the emerging themes and coding framework.

4.1 Experts' Design Recommendations

All of the 9 participants in the co-design process (3 clinical professionals, 3 AI researchers, and 3 patient advocates), expressed interests in a patient-centered educational chatbot and believed that it could be useful for enhancing health outcomes. There are ten main themes emerged from these qualitative interviews, which are "need for patient education," "chatbot design," "patients' trust," "communication," "chatbot's efficacy," "AI integrations," "AI evaluations," "patient education resources," "expert involvements," and "diversity." One of the most common advantages mentioned by these experts was that such an application could alleviate the time pressure on clinical professionals by explaining basic concepts and preparing patients to ask more targeted questions during in-person consultations. (Of course, given the self-selection bias of study participation, this process omitted experts who might be completely skeptical of such approaches.) Several specific themes regarding design considerations for the chatbot are discussed in the following sections.

4.1.1 *Reliability of LLM-Generated Information.*

The expert participants largely ignored concerns about the reliability/accuracy of LLM-generated information and instead focused on patients' tendency to turn to even-more-questionable information sources. These participants did not perceive an increase in human-based patient education within the medical system as a feasible goal. According to our interviews, patients have limited options for asking questions, and they frequently turn to Internet searches since clinicians do not have sufficient time allotted to address their needs. Although clinicians do their best to respond to patient queries, doing so in an effective fashion is not realistic within current institutional structures; thus patients often endure long waiting times for consultation appointments or online responses, from their physicians and when they do receive such response they are likely to be rushed and unsatisfactory. As one advocate noted, "*Sometimes the patient needs a chance to ask questions on an ongoing basis. Questions keep popping up*" (PA1, Advocate). Frustrated with the inability of the existing medical system to meet their needs, patients typically turn to online public searches, where they may encounter a vast amount of conflicting and unverified information, leading to misunderstandings and confusion. Even when such public online resources are well-intentioned and grounded in evidence-based medical practice, they may not be personalized to the patient's specific health conditions or individual situation, resulting in perspectives that conflict with sound clinical advice. The ideal health education chatbot, according to these experts, would be one that can answer patents' questions accurately and in a way that is tailored to their overall medical status.

4.1.2 *Chatbot Tone.*

The contributing experts were also concerned with the prevalence of negative or discouraging perspectives in online spaces. They indicated that effective chatbots should maintain an optimistic and encouraging tone, avoiding pessimistic opinions and assumptions. The chatbot should recognize inquiries with a pessimistic outlook and respond supportively, and if it detects concerning phenomena such as suicidal thoughts, then it should refer the user to appropriate in-person clinical support. Given the significant mental health challenges associated with cancer, chatbots need to be sensitive to these issues. Fortunately, good information sources can help to alleviate mental stress. As one of the expert patient advocates stated: "*Each treatment is filled with uncertainty. As a patient, without proper education, I feel like I'm shooting in the dark. Educating cancer patients with easily understandable evidence can improve mental health and alleviate stress*" (PA3, Advocate).

4.1.3 *Chatbot's Capability and Liability.*

Clinician participants pointed out that medical experts are liable for responsible and ethical professional practice, and expressed concerns that a chatbot might not be held to the standards. For example, one clinical professional noted that "*Clinicians usually take responsibility, but can LLM take it? Probably not. We cannot blindly trust LLM*" (C1, Oncologist). This same participant went on to say that, "*We do not accept some online resources or evidence because their references are often not provided, and they lack the precision needed to translate absolute risks and risk reductions. We highly value clinical practice guidelines, which typically involve a thorough review of the literature*" (C1). Another clinician emphasized that "*Cancer patients want to be very focused and set clear boundaries on the information they receive because every aspect of their lives has been completely transformed*" (C2, Oncologist). The concern in these outlooks is that chatbots may be developed with a profit-seeking motive that is not grounded in care and professional ethical responsibility. However, the respondents were also aware that current institutional practices made it difficult for clinicians to enact such ethical ideals. They perceived that chatbots could potentially offer hope for better solutions, while also remaining skeptical about their implementation. This highlights the importance of clearly defining the limits and scope of chatbot use for patient education, and the vital issue of addressing the technology's shortcomings in delivering precise and trustworthy information.

4.1.4 Design Guidelines for LLM-Based Chatbot in Cancer. After analyzing the qualitative co-design study results, we summarized seven co-design features for developing the MedEduChat, as summarized in Table 2.

Co-Design Features	Explanation	Quotes
Closed Domain	Reduce misinformation or bias in the chatbot's output, it should provide information only after fact-checking from trustworthy organizations [94]	[Advocate, PA1] *"A lot of what I did in the community was to direct them to good sites. Drawing the borderline and extracting the correct information is very important [for cancer education]."*
Semi-Structured	Provide guidance and instructions in a clear and understandable format	[Oncology, C2] *"Patient participation in these educational resources is very spotty, and their ability to comprehend the information is also often lacking... There should be some guidance to help direct patients."*
Patient-Centered	Offer personalized, individualized information tailored to the health literacy level of each patient user [22, 45], rather than a one-size-fits-all approach	[Oncology/Hematology, C1] *"Getting patients to go to these authoritative [prostate cancer] websites and to receive education there is challenging. A very big reason is that it's not individualized."*
No Harm	Avoid any harmful responses from the chatbot	[Oncology, C2] *"LLM-generated responses must not contain harmful information. The chatbot should avoid causing harm even if it isn't always helpful."*
Data Privacy	Since MedEduChat connects with patients' health data, it needs to strictly comply with HIPAA guidelines for data protection [1]	[AI Practitioner, A1] *"Handling clinical patient data requires extreme sensitivity and caution."*
Education Model	Provide an effective learning experience based on well-tested educational practices	[Advocate, PA1] *"... beginning with a theoretical or instructional model can lead to more effective educational outcomes."*
Diverse & Iterative Feedback	Routinely collect user feedback from diverse patients and incorporate it to enhance the chatbot's functionality	[Oncology, C2] *"It's crucial to study and test tools within diverse populations. Effective solutions involve designing tools and understanding how they can be implemented and adopted in practice."* [AI Practitioner, A3] *"LLM can continuously improve by learning from patient users' evaluations."*

[1] HIPAA: Health Insurance Portability and Accountability Act

Table 2. Recommended features from co-design study participants for LLM-Based chatbots in cancer patient education

It is critical that the materials provided by the chatbot adhere to up-to-date information and professional guidelines [5, 78], and that they are grounded in a user's current medical information via integration with their clinic's internal database. This is regard as a "closed domain" since the chatbot does not draw from random external information sources (2a: Closed Domain). Accordingly, we designed MedEduChat to connect with our partnered clinic's patient EHR databases and library, incorporating information such as family and medical history, lab results, diagnosis details, treatment details, and clinical notes. From the EHR system, we also retrieved patient self-reported educationdetails, such as the clinical learner assessments in Appendix A.2.1 and/or co-learner assessments in Appendix A.2.2, and in-basket messages. This closed-domain, comprehensive, and personalized medical information enables patients to begin exploring and educating themselves about their own prostate cancer. Since patients may struggle to interpret health data, provided in standard medical formats, MedEduChat was designed to analyze existing health profiles and generate relevant patient-centered learning materials. This approach allows patients to focus on disease-specific and treatment-related information relevant to their individual conditions.

Defining MedEduChat's borders helps prevent the dissemination of misguided medical advice, misinformation, or harmful inaccuracies. It ensures that MedEduChat provides sufficient information support without replacing the importance of clinician-patient consultations. Public search engines are not effective educational tools for the prostate cancer domain. While search engines can collect data from diverse sources, they often yield misinformation, lack rigorous evidence or references, and bias. Therefore, for cancer consultation and education, it's important to carefully select the materials for the closed-domain chatbot.

Clinicians are concerned about the lack of guidance in LLM-based chatbots compared to the existing e-learning modules. To make sure patient users receive sufficient education, MedEduChat follows the education model and asks patient users to experience the full education cycles (Figure 2b: Semi-Structured). Unlike static e-learning modules that lack flexibility and personalization, MedEduChat also offers a semi-structured approach: it partially guides patients to ask the right questions and responds to their requested level of detail.

Additionally, the chatbot was designed to improve during the educational session, as more patient-specific context is gained, making it more aligned with specific users' needs, such as literacy level, response length and tone, and educational interests (Figure 2c: Patient-Centered).

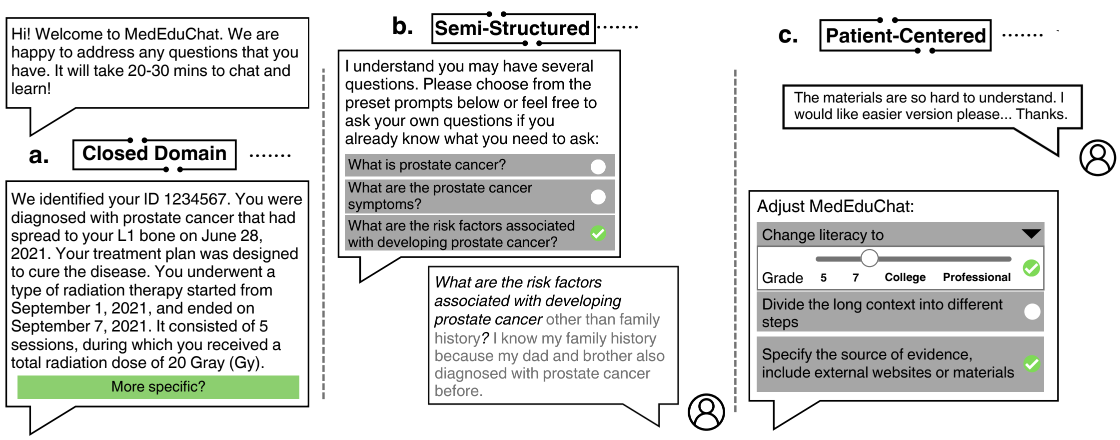

Fig. 2. Features incorporated in the LLM-based chatbot design.

4.2 MedEduChat Development Details

The educational model that we adopted is known as "5E," including the steps of Engage, Explore, Explain, Elaborate, and Evaluate [21, 28, 88]. To apply this model to the chatbot prostate cancer education context, we synthesized the five steps into three main stages: **health outcome explanation, learning enhancement, and engagement**. The health outcome explanation component offers lay-language information to help users understand their diagnosis and treatment options. Users can further explore the details of treatments through the learning enhancement options, depending on their level of interest and literacy. Ultimately, the goal is to help them engage in their treatment in a knowledgeable and intentional fashion promoting agency and understanding (Figure 3).

Our research team designed the chatbot, using the code-free conversational AI platform Generative Studio X (GSX) from OneReach.ai[2]. OneReach.ai is a conversational AI platform designed to create and deploy interactive conversational experiences. GSX allows users to create and deploy conversational LLM experiences, as well as deliver surveys, share information, and collect data from users. This platform can be integrated and powered by GPT-4 or Turbo models to develop an LLM-based chatbot. We then integrated MedEduChat with OpenAI's GPT-4o through the clinic's Azure-hosted endpoint, which is HIPAA compliant. This setup allows for the sharing of the patient's aforementioned health information with GPT-4o without the concern of patient privacy and patient data security.

MedEduChat used a retrieval augmented generation (RAG) technique to retrieve information from the clinic's backend database. The clinical data were recorded and stored using the clinic-wide Electrical Medical Record (EMR) system, Epic (Epic Systems, Verona, WI)[3], and the radiation oncology-specific oncology information system, Aria ver. 16 (Varian Medical System, Palo Alto, CA). MedEduChat followed specific instructions defined in its system prompt on how to retrieve data for a patient, given the patient ID. Four data retrieval functions were defined for this work: get_patient_details(), get_patient_treatment_details(), get_patient_diagnosis_details(), get_patient_clinical_notes(), and get_patient_treatment_details(). When MedEduChat initiated the call to process these functions, based on the context of the conversation with the patient, a data server uses SQL to query the specific information that was requested by the patient. The returned data was then added to the conversation history so that MedEduChat can use it as context.

4.3 Sample MedEduChat Scenarios

MedEduChat incorporated details of a particular user's case, including the cancer type, stage, lab results, treatment history, symptoms, medication history, family medical background, and demographic data. If the patient already received treatment, then MedEduChat also incorporated relevant treatment details. After compiling an overview of the patient's health conditions, MedEduChat offered pre-set prompts to guide the patient toward asking questions that are most relevant to their interests. (These semi-structured pre-set prompts are listed in full in Appendix A.3).

Using these prompts and the patient's clinical profile, MedEduChat was able to incorporate the retrieved patient data as part of the educational session. The chatbot then generated answers using partnered clinic's fine-tuned LLM tailored to the patient's requests. Upon reviewing the answers, patients can choose to explore more in-depth details or modify their prompts if desired. The goal of these step-by-step interactions was to help patients gain a clearer understanding of their cancer diagnosis, treatment options, treatment history (if any), and potential side effects (Figure 3, Stage I).

During the "Learning Enhancement" stage, patients can learn about their treatment experience or weigh trade-offs in treatment burdens and statistical health outcomes (Figure 3, Stage II). For example, if a shorter distance to the treatment location is a priority for the patient, then they can assess this factor in relation to treatment efficacy. This iterative assessment process enhanced the learning experience and improved patients' comprehension of clinical decisions.

The final "Engagement" stage encouraged patient users to continue taking the initiative in their treatment process and provides an opportunity to evaluate MedEduChat's performance, including any suggestions to help developers fine-tune the chatbot (Figure 3, Stage III). Users also had the option to save or print their conversation history for future reference, and they can receive LLM-generated summaries that highlight key learning points and outcomes.

We anticipate that patients may return to the chatbot for more information and ask questions as their treatment journey continues. They can continue interacting with MedEduChat after their follow-up visits or at any time during

[3]https://www.epic.com/
[3]https://onereach.ai/

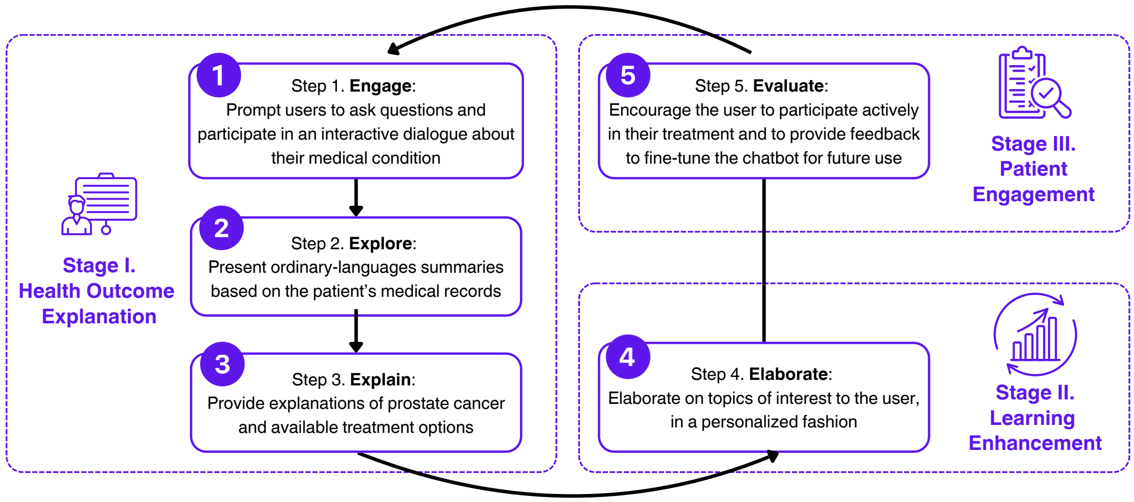

Fig. 3. Stages and steps of the LLM-based chatbot design.

their treatments. A demo video and a sample chat history in the supplementary material show a full typical scenario of how a prostate cancer patient user may interact with MedEduChat.

5 STUDY 3: USABILITY EVALUATION

5.1 Methodology

To evaluate the usability, feasibility, and acceptance of MedEduChat, we conducted a study involving seven prostate cancer patients (mean age 74.57 yrs; SD 7.55) (Table 3). The inclusion criteria were that participants had a formal diagnosis of prostate cancer (any stage), that their cancer was non-metastatic, that they had a basic level of computer literacy, and that they were willing to engage with an experimental educational chatbot. Participants were asked to sign a consent form before the study, which explained that they would be asked to share their chat history and survey results. The sessions were conducted individually for each participant and took approximately 45-60 minutes to complete. Participants who completed their session received a $30 compensation for their time and contributions. Figure 4 shows an overview of the usability study design.

The participants were first asked to fill out a pre-intervention survey, which took approximately 6 to 10 minutes. They were then asked to engage in interactions with MedEduChat for approximately 20 to 30 minutes. Finally, they were asked to complete a post-intervention survey and provide feedback about the chatbot, which took around 15 to 20 minutes. Since MedEduChat is still a developing prototype and may generate errors, users accessed it through screens shared by the researchers, allowing us to monitor the interactions and intervene if necessary. However, the patients were allowed to interact freely with MedEduChat without external instructions, and interruptions occurred only if a usability problem, misinformation, or bug was encountered.

The pre-intervention survey included demographic information, a 4-item health confidence score scale (HCS) [16, 17] and a 5-item patient health engagement scale (PHE) [37]. The post-intervention survey repeated the HCS scale and also presented the 4-item Usability Metric for User Experience (UMUX) [31], and 5 questions regarding participants' interaction experience with MedEduChat. These 5 questions were adapted from the e-learning Needs Assessment

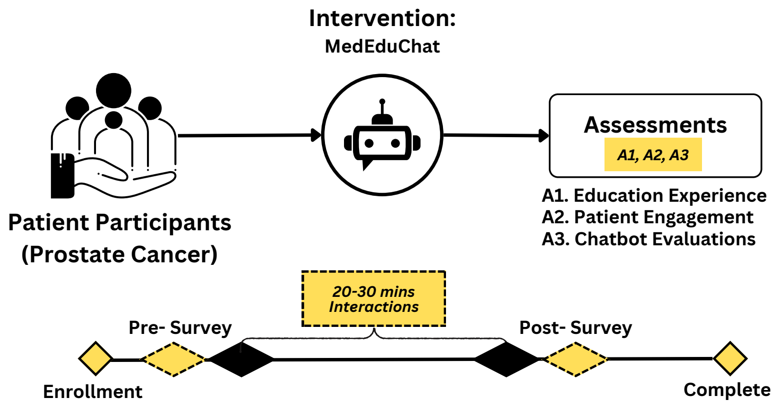

Fig. 4. Usability study design.

Survey (questions 2, 3, 4, 5, and 7) by replacing references to "online learning course" with "MedEduChat" (for details, see Appendix A.1). All these items were adapted to the prostate cancer setting. We substituted some general survey items, such as "my *health*" or "my *illness*," with "my *prostate cancer*," and phrases like "*This system* is easy to use" were changed to "*MedEduChat* is easy to use." The pre- and post-intervention survey items were displayed in the supplementary materials.

The survey results and chat histories produced during this study were used to address **RQ3: Can MedEduChat enhance patients' educational experience?** We analyzed the data across three dimensions: *patient education experience*, *patient engagement*, and *chatbot efficacy*. Three clinicians were recruited to assist in quantitatively reviewing the chat histories from a patient-education perspective and to evaluate them for instances of factual inaccuracy MedEduChat's protocols for instances of factual inaccuracies (Table 4). The commentary provided by these experts was audio-recorded, transcribed, and summarized, and each clinician received $70 in compensation for their assistance.

Patient Participant ID	Age	Education Level	Race/Ethnicity	Prostate Cancer Stage
P1	84	Ph.D.	White	IIB stage
P2	80	M.S.	White	III stage
P3	67	M.S.	White	II stage
P4	68	Ph.D.	White	III stage
P5	71	M.S.	Asian	III stage
P6	76	Ph.D.	White	II stage
P7	68	D.D.S.	White	IV stage

Table 3. Demographic profiles of patient participants in the MedEduChat's usability study.

5.2 Descriptive Survey Results

Prior to participating in this study, five out of the seven patient participants had spent more than three hours learning about their prostate cancer diagnosis and treatment options. One participant spent less than one hour, and another

Clinical Professionals	Clinical Domain	Experience
C4	Medical Physics	18 yrs
C5	Radiation Oncology	4 yrs
C6	Prostate Cancer Education (i.e. anxiety disorder, depression)	12 yrs

Table 4. Demographic profiles of clinical professionals who were asked to analyze the MedEduChat interaction data during the usability study

spent between one and three hours. The 5-item PHE score was 8.71 out of 15 (SD = 2.50), showing a moderate level of patient engagement across the participant sample prior to the use of MedEduChat.

We compared the HCS score, indicating patient confidence, from before to after the use of MedEduChat. The mean pre-interaction HCS was 9.57 (SD 1.38), while the mean post-interaction HCS score increased to 10.71 (SD 1.40). While the participant sample was too small to establish statistical significance, this increase in a scoring range from 0 to 12 indicated a notable improvement in patients' health confidence.

We also administered the same 5-item clinic survey shown in Figure 1. In regard to the interaction-experience questions, all 7 patient participants gave MedEduChat a 100% on every item, except for "*the amount of detail in MedEduChat was about right*," where one participant (P2) expressed a neutral response.

The average score for the UMUX was 92.86 out of 100 (SD 6.23), indicating a high degree of perceived usability. The most variable responses were in regard to the UMUX survey item "*Using MedEduChat is a frustrating experience*." In the follow-up short answers, some patients commentedon design elements, for example ny mentioning that the presentation"*Need more visuals*" (P3). The most common concerns however, were about the impact of the information and its mental health implications. Some participants felt that using the MedEduChat left them feeling isolated and lacking support for handling the weighty information that they received. One comment indicated, for example: "*Some suggestions are pretty radical, like preventive surgery. Although greater awareness never hurts, I can end up becoming an emotional wreck by getting that information*" (P6). Another participant noted that "*Some words sound scary, especially when 'death' is mentioned in the sentences*" (P7).

5.3 MedEduChat Impacts on Patient Education

5.3.1 Education Scope and Borders. We observed that some users did not adhere to the intended scope and structure of MedEduChat for prostate cancer education. Since MedEduChat is semi-structured and allows for open-ended questions, some patients skipped the prescribed steps and stages, posing inquiries like, "*What is my survival rate*" (P7)? "*What are the risk factors of polycythemia*" (P6)? "*Should I stop drinking whole milk? I heard dairy products affect prostate cancer*" (P3). These types of questions, especially those lacking rigorous research confirmation or stemming from unresolved and inconclusive studies, were challenging to address and fell beyond MedEduChat's capabilities. Given that MedEduChat provided information only after thorough fact-checking, it responded with, "*As an AI model, I am trained on all of the established facts in medical science about prostate cancer. I am not able to answer your question on ... It's best to discuss with your healthcare provider, who can give you personalized advice based on your specific situation.*" If robust information is available for an unexpected inquiry, MedEduChat will provide those reliable resources, such as the clinic's internal materials, PubMed literature, and information from external cancer society websites (i.e., National Cancer Institute, American Cancer Society), but then it also prompted the user to return to the original structured educational goals.

This process appeared to be effective in our usability study; patients who initially sought to ask questions outside of the intended scope soon returned to the original intended educational content and subsequently more closely followed the structured model. This left users with unanswered questions, but they seemed to largely accept the limitations of the chatbot and of scientific knowledge in a positive manner. For example, after receiving feedback from MedEduChat suggesting the need to consult a healthcare provider for further information, one participant commented: "*MedEduChat is like a gatekeeper for my questions, which helps ease the anxiety of waiting for answers. It's even good to know that it is unresolved yet*" (P6).

5.3.2 Iterative Learning Process. Although the usability study provided patient participants with only a single 20-30 minute interaction session with the chatbot, some participants commented on the value of engaging with the learning process in an ongoing or iterative fashion: "*I would encourage someone to use the chatbot several times rather than just once... [Patient users] might get different, more thorough, or more focused answers each time*" (C4). The memory function of MedEduChat, which saves previous chat history, supported this process and allowed for more personalized interactions over time. Users may also learn over time to improve the phrasing of their queries to elicit more relevant and comprehensive responses. As one patient participant explained, "*The nature of AI, in my experience, isn't a one-stop shot. It's beneficial to go through it once, and then maybe a second time, to get more comprehensive responses. The answers might not necessarily be better, but they could be different and provide a better description*" (P1). Through this iterative learning process, MedEduChat became more personalized and better adapted to the specific educational needs of diverse individual patients. The clinicians who helped to review the chatbot output also emphasized the need for iterative information delivery and pointed out the repetition with variation can be valuable in the learning process while also improving trust in the reliability of the answers received.

5.3.3 Unlearning and relearning processes. Three of the patient participants (P3, P6, P7) described a process that can be summarized as "*unlearning*," in which their misconceptions and false assumptions about prostate cancer and treatments were challenged by the information MedEduChat provided. For example, one participant stated: "*My question is about the medication Zanubrutinib, which is used for non-lymphoma cancers and is reported to destroy lymphoma cells. Can it also be effective in destroying prostate cancer?*" and he commented, "*I know I cannot get a 'yes' or 'no' answer from this esoteric question. This drug (Zanubrutinib) is very rarely used [in prostate cancer]. But it explains not only what the drug was but also how it differed from what caused prostate cancer*" (P3). This interaction showed how the chatbot can assist patients in "*unlearning*" questionable assumptions and *relearning*" more accurate perspectives relevant to their treatment. While the *unlearning*" process helps adjust patients' expectations to become more realistic, it can also offer a sense of emotional relief, agency, and competency by connecting patients to reliable and relevant information.

5.4 Clinical Efficacy and Accuracy

The clinicians who participated in reviewing the chatbot histories reaffirmed our findings in co-design study regarding the difficulties of patient education, even without being asked. One clinician, for example, noted that delivering patient education during consultations was "*repetitive and time-consuming*" (C4), and indicated that such activities were not an optimal use of their time. Simultaneously however, the clinicians also recognized that patients need to be informed about their coniditions, maintaining agency and engagement during the diagnosis and treatment process, and feel confident about making decisions in consultation with their medical providers. As one clinician stated, "*The level of data and level of depth determines patient health outcomes. Patient education helps patients become familiar with concepts and engage in complex discussions*" (C6). The clinicians agreed that robust patient-education technology could enhance clinical efficacy by empowering patients to better prepare for face-to-face consultations, so they could focus on decision-making, treatment details, and other specific health concerns.

The clinicians further suggested that collaborations among patients, technological resources, and clinical experts may lead to better outcomes and experiences compared to either patient autonomous self-learning (which may create more confusing and misinformation than actual learning) or traditional patient-clinician consultations (as they may lack sufficient time or communication abilities to effectively assist in patients' learning). They were optimistic that technologies such as MedEduChat could act as a bridge connecting patients and clinicians outside of regular hours and allow clinicians to set borders within which patients can freely explore: "*If we deploy MedEduChat, I can forsee that we don't need to answer 100% of all patient inquiries but 30% questions that MedEduChat couldn't answer or doesn't answer well*" (C6). While individual clinical professional or patient situations are influenced by various factors, MedEduChat can serve as a responsive companion, offering empathy, personalized feedback, and timely responses. Although MedEduChat's understanding of language and medical domain knowledge remained uncertain, and there were many tasks that cannot rely solely on LLM, MedEduChat's closed domain data pool can still "*offer valuable after-hours patient education support*" (C5). Patient education, without providing clinical advice or decisions, represented an ideal area for patient-LLM-clinician collaboration.

We also evaluated the reading level of information presented by MedEduChat using the Flesch Reading Ease (FRE) score and the Flesch–Kincaid Grade Level score (FKGL) [33, 48, 53]. In regard to reading level, MedEduChat's responses had an average FRE score of 49.90 (SD 8.41) and a mean FKGL score of 8.9 (SD 1.71), both of which indicate a reading level of 10th to 12th grade. On average, MedEduChat generated 283 sentences (SD 91.21) per response, with a mean total word count of 2,622.71 (SD 827.14) during the user sessions. The average number of words per sentence was 9.97 (SD 3.60).

5.5 Information Delivery

At the same time, the clinicians had concerns about MedEduChat's ability to provide accurate medical information, and pointed out that there were many tasks that cannot rely solely on LLMs. One issue that emerged is that MedEduChat relied on extracting information from medical record systems that were often chaotically organized, unstructured, and/or incompleted. The information added to these systems by harried clinicians is often poorly structured and may require clinical expertise to interpret; in some cases it may even be inaccurate or misleading. Each clinician had their own way of presenting patient health results, especially in clinical notes and in-basket message communications. Pathology reports, imaging annotations, and lab results often needed extra interpretation as well. Because of this variation, our data retrieval methods might not work equally well for all patients. Even with accurate original data, LLMs can still make false claims, affecting the accuracy of the information delivered. "*Closed domain data doesn't guarantee it's 100% correct. There are some manual errors, confusing abbreviations, or missing data in EHR profiles*" (C5). If the EHR contained mistakes, the accuracy of LLM-generated responses were also at risk. Given the complexity of clinical content-created by different professionals at different times, summarizing it accurately for non-expert patients can be a real challenge.

6 DISCUSSION

6.1 Integration of LLMs in Prostate Cancer Education

6.1.1 Suitability of LLMs for Cancer Domain Design Context. Given the sensitivity and complexity of the prostate cancer domain, implementing downstream designs with LLMs was inherently challenging and requires heightened monitoring. Our co-design and usability studies for MedEduChat revealed the prevalence of concerns about information accuracy, as well as a great deal of hope that such technologies may eventually serve to relieve burdens on clinicians by providing clear, layman-language answers to patients' questions. Although MedEduChat was restricted from offering medical treatment advice or making treatment decisions, it was designed to deliver relevant medical information and explanations.

However, LLMs still face challenges in processing multimedia materials, which are crucial in prostate cancer care. While LLMs can interpret text and statistics effectively, their performance with images, audio, and videos is less reliable. Despite MedEduChat's integration with comprehensive patient health profiles, important information from patient-clinical team interactions—such as in-person consultations and telehealth sessions—often remains untranslatable into text suitable for LLM fine-tuning. Establishing clear borders for what LLMs can and cannot do is essential for their effective adaptation to the prostate cancer domain.

6.1.2 Concerns on LLMs' Technical Ability. The LLMs may present misinformation because cancer experiences and treatments vary widely from case to case. While online misinformation can be quickly updated and spread, fact-checking information often takes longer to become available. Therefore, deploying MedEduChat in a clinical setting requires careful consideration. Additionally, some users may express negative views about their treatments or medications, which can affect the responses generated by MedEduChat, especially if they deviate from the semi-structured instructions.

The variability in patient inquiries and even minor differences in prompts can result in diverse outputs. The lack of standardization in patient inquiries challenges the LLM's ability to generate accurate responses from existing data. Misinterpretation of these inquiries can result in misinformation and increase patient anxiety. To mitigate these issues, the backend design should incorporate features for prompt autocorrection and response tone adjustment to reduce any passive tone in conversations.

6.1.3 Establish clear expectations for what LLMs can and cannot do within the medical domain. Where can non-expert prostate cancer patients be involved in the LLM-based chatbot? Instead of designing a perfect MedEduChat, we focus on defining the chatbot's borders and developing guidelines to help future researchers and practitioners develop LLM-based downstream tasks in the patient education domain.

Ideally, we can seek to find a sweet spot of patient-LLM clinician collaboration in which the strengths of the technology are combined with the strengths of human expertise and oversight. Doing so will require an ongoing dialogue between technology developers and medical practitioners. With our needs assessment, co-design, and usability studies, we can draw a borderline that optimizes the patient-LLM-clinician collaboration performance and improve the outcome of prostate cancer patient education.

6.2 How AI/LLMs Complement Human Patient Educators?

One of the most common concerns among our participants was that AI/LLM chatbots might come to be seen as a substitute for information provided by human clinical professionals. While the clinical process is logical and rigorous, it is not simply algorithmic, and often it is based on wide-varying information about the patient that is hard to distill into a digital format. Even if AI makes accurate information summaries (which it will not always do), there are some nuances that clinicians may capture in regard to patients' conditions or communication needs that AI does not have the capacity to notice. Thus, AI cannot hold authority and replace the importance of human clinicians. It is important to understand the role and scope of the tool—and to treat it skeptically as a touchstone and starting point rather than as a an authoritative expert. The twin risks are that patients may not be aware of these concerns and thus accept the chatbot's pronouncements too naively, or that patients may feel slighted and frustrated by being diverted to a chatbot and thus refuse to use it altogether, losing faith in the medical system in the process.

The best way to understand AI's role in clinical practice is that it can potentially help reduce the burden of repetitive explanatory tasks and thus freeing human clinicians to focus on higher-level questions and concerns. One of our participants noted that: "*Radiology would come first with the AI integration since it's more diagnostic. So AI could assist in accurate observing and aids in recognition to identify things*" (C3). While AI views each clinical case as a data point, expert cancer clinicians see it as a complex canvas of puzzles. AI excels at tasks within fixed-scope contexts, efficiently responding to well-defined queries in a predictable fashion based on its information sources. In contrast, expert clinicians offer a comprehensive perspective, providing flexible evaluations and making decisions based on a nuanced understanding of each patient's case and a broader grasp of relevant scientific knowledge. By teaming up, AI and clinical professionals can combine their strengths, with AI handling precise, data-driven tasks and clinicians providing nuanced observation and guidance from the overview standpoint.

6.3 Human-Computer Interaction Research for LLM Integration in Healthcare

Without access to real-world clinical data, human-computer interaction (HCI) research on AI in healthcare is often based on researchers' assumptions, studies with small sample sizes, specific participant roles, and subjective self-reported information rather than standardized reports. This can introduce biases due to the busy and sensitive nature of healthcare settings. While there are many innovative HCI designs for healthcare systems or tools, there is still a significant gap between hypothetical patient cases and real-world clinical applications.

To effectively integrate LLM-based technologies into healthcare, future HCI researchers need to address several key questions before designing or evaluating these systems: What are the *borders* of AI/LLM-based applications in healthcare? Who are the primary and secondary users in these settings? How can HCI research better guide LLM integration by considering human factors, beyond just efficiency and accuracy? What are the biases or errors that can be mitigated in healthcare information delivery [35, 64]?

Defining HCI's role in LLM integration is crucial as we tackle this emerging problem in the interdisciplinary field of Health and AI. We need to understand the future steps necessary for successful implementation, ensuring that LLM applications are user-centered and incorporate inputs from all stakeholders.

6.4 Limitation and Future Work

Our usability study involved a very small sample of prostate cancer patients and clinicians, which may be unrepresentative of the broader prostate cancer patient community. It is particularly notable that the overwhelming majority of the patient participants are identified as White and that all of the participants were highly educated, which limits the usability study's diverse feedback. Due to the nature of our recruitment and the participating clinic, we did not have the opportunity to include more diverse patients, but future research should seek to better address this issue, as demographic characteristics may be highly salient to chatbot use. In particular, non-English speaking patients, those with lower education levels, and those of different ethnic and geographic backgrounds should be studied in regard to the usability of health education technologies.

Because patients experience numerous barriers to learning (e.g., stress, anxiety, fatigue, pain, low health literacy, medical jargon, complexity of information, and time pressure, among others), it is important for patient education to be as accessible as possible and minimize the burden of learning [15, 39]. Beyond the general qualitative feedback, the current study did not evaluate cognitive stress metrics or other potential difficulties that might be associated with chatbot usel these should be carefully examined in future research. Developers may be able to draw from specific established techniques to minimize cognitive demands and barriers to learning when creating patient education technologies [11].

Our study was specifically focused on the use of an LLM-based educational chatbot by non-metastatic prostate cancer patients, and the results may not be generalizable to other types of illness. Some of the topics and concerns that emerged during our research and some of the co-design outcomes may potentially be useful for broader healthcare technology development, but caution should be used in overgeneralizing the results. Future researchers should consider the unique characteristics of different illnesses before extending our approach to other medical contexts.

7 CONCLUSION

In this paper, we presented the development and usability evaluation of MedEduchat, an LLM-based chatbot for prostate cancer patient education. The chatbot is able to securely link with users' electronic health records and provide responses to their medical questions via semi-structured interactions and personalized explanations. We envision MedEduChat as an initial effort to curate personalized educational content and harness the technical capabilities of LLMs to improve patient educational experiences. Our work contributes to the field of patient-LLM interaction by emphasizing co-design features and in-depth collaborations between patients, medical experts, and technology experts. This approach and the insights gathered can contribute to the development of future LLM-based applications in healthcare and help improve the patient experience. With MedEduChat, prostate cancer patients of varying educational needs can engage with personalized education more easily and accessibly, making the learning process more enjoyable.

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A APPENDIX

A.1 Survey Items

Survey Introduction: This brief, anonymous survey will take just a few minutes to complete. Your feedback is important and will help us improve this online learning course. Thank you.

(1) **[Short Answer]**What is your age?
(2) **[Multiple Choice]** Prior to viewing this online learning course, about how much time did you spend learning about your prostate cancer diagnosis and treatment options?
(3) **[Likert Scale]** Please answer the following:
    (a) This online learning course helped me feel more prepared to discuss my prostate cancer diagnosis with my healthcare team
    (b) This online learning course helped me better understand my prostate cancer diagnosis
    (c) The online learning course was about the right length
    (d) The amount of detail in this online learning course was about right
    (e) I would recommend this online learning course to other patients like me
(4) **[Short Answer]** What did you like most about this online learning course?
(5) **[Short Answer]** What did you like least about this online learning course?
(6) **[Multiple Choice]**How many times did you open and use this online learning course?
(7) **[Short Answer]**Other comments?

A.2 Learning Assessment

A.2.1 Primary Learner.

(1) Primary Learner Name
(2) Relationship to Primary Learner
    - Patient
    - Family
    - Significant Other
    - Caregiver
    - Mother
    - Father
    - Guardian
    - Foster Parent
    - Other (Comment)
(3) Does the patient express the desire and motivation to learn?
    - Yes
    - No
    - Unable to assess
    - Other (Comment)
(4) What is the preferred language of the primary learner for medical teaching?
(5) Is an interpreter required?
(6) How does the primary learner prefer to learn new concepts?

- Listening
- Reading
- Demonstrating / Seeing
- Doing
- Pictures / Videos
- Other (Comment)

A.2.2 [Optional] Co-Learner(s). Every item is the same as A.2.1 with changing primary learner to co-learner.

A.3 MedEduChat Chatbot Structure

Category	Contents
Introduction	Hi, my name is MedEduChat. I have been designed to help you with answering questions about your prostate cancer diagnosis and treatment. If at anytime you would like me to clarify, use less medical jargon, be more concise, or discuss a different question, please let me know. Before we begin, will you please enter you patient ID?
Patient ID	• Patient Details – Name, Date of Birth, Sex, Race, Language, Ethnicity Group, Learner/Co-Learner Assessment Outcomes, Attending Physician(s) • Diagnosis Details – Primary Diagnosis, Primary Diagnosis Onset Date, Stage, Secondary Diagnosis, Secondary Diagnosis Onset Date, Stage, Gleason Score, prostate-specific antigen (PSA) test result • Treatment Details (if available) • Clinical Notes Summary – Follow-Up Visits, Symptoms, Imaging Results • In-Basket Message Takeaway (if available)
Pre-Set Instructions	I understand that you may have several questions. Please choose from the pre-set prompts below, and we will personalize this educational journey for you: • Pre-Set Prompt 1 • Pre-Set Prompt 2 • Pre-Set Prompt 3 Which question would you like to start with, or do you have any specific concerns or questions about your diagnosis and treatment so far?

Pre-Set Prompt 1	What is prostate cancer and how serious is prostate cancer? • What is the PSA level? • What is Gleason's score? – How is a Gleason score determined? – What is a typical Gleason score? – What's the difference between a Gleason score and a grade? • Is your cancer low-risk or high-risk?
Pre-Set Prompt 2	Is my cancer low-risk or high-risk? • What are my treatment options? • What are active surveillance, surgery, external beam radiation, and brachytherapy?
Pre-Set Prompt 3	What are the risk factors associated with developing prostate cancer? • Erectile dysfunction. • Leaking urine. • Frequent urination. • Loose stools.
If not cover all materials	Are you interested in exploring the other questions? For example, question prompts 2.1, 3.1, 3.3?
Ending	If you would like to learn more, please visit this prostate cancer education module website: XXX. Thank you for participating in the MedEduChat journey! We hope you enjoy this educational experience. Please complete this evaluation form to receive your participation incentive: XXXXX.

Table 5. MedEduChat workflow structure and the pre-set prompts.

B MEDEDUCHAT SAMPLE CHAT HISTORY

B.1 Introduction

The following chat history has been carefully reviewed and edited to remove all identifiable patient health information (PHI) in compliance with study IRB and the clinic's privacy regulations. The de-identified content retains the original context and intent of the conversation ensuring that the key insights and exchanges remain intact while fully protecting patient confidentiality.

In this sample chat history, **blue** annotations represent patient participant responses, **underlined** annotations denote pre-set prompts, and **'XXX'** indicates where PHI has been removed.

B.2 Sample Chat Content

MedEduChat: Hi, my name is MedEduChat. I have been designed to help you with answering questions about your prostate cancer diagnosis and treatment. If at any time you would like me to clarify, use less medical jargon, be more concise, or discuss a different question, please let me know. Before we begin, will you please enter your patient ID?

Me: XXXXXXXX

MedEduChat: Thank you. I will now retrieve your patient details, diagnosis details, treatment planning details, and clinical notes. This will help us have a more informed discussion.

Diagnosis and Treatment Details

Patient Details:

- Name: XXXXXXX
- Date of Birth: XXX XX XXXX
- Sex: Male
- Race: XXX
- Language: XXXX
- Ethnicity: XXXXX
- Attending Physician: Dr. XXXX

Diagnosis Details:

- Primary Diagnosis: Malignant neoplasm of prostate (ICD-XX: XX)
- Onset Date: XXX XX XXXX
- Stage: Not specified
- Secondary Diagnosis: Right upper lobe nodule radiographic NSCLC (ICD-10-CM: XXXX)
- Onset Date: XXX XX XXXX
- Stage: Stage IA3 (T1c N0 M0)

Clinical Notes:

- Follow-up Visits: Regular follow-ups with no significant issues reported. The most recent follow-up on XXX XX XXXX indicated a stable condition without evidence of recurrence.
- Symptoms: No significant symptoms reported. Good appetite, stable weight, no pain, and no respiratory issues.
- Imaging Results: Stable findings with no evidence of metastatic disease.

MedEduChat: Now let's discuss the three main questions we want to cover in this session:

- What is prostate cancer and how serious is it?
- How is prostate cancer typically treated?
- What are the risk factors associated with developing prostate cancer?

Which question would you like to start with, or do you have any specific concerns or questions about your diagnosis and treatment so far?

Me: Sure, let's do the first one: What is prostate cancer and how serious is it?

MedEduChat: Great! Let's start with *What is prostate cancer and how serious is it?*

What is Prostate Cancer? Prostate cancer is a type of cancer that occurs in the prostate, a small walnut-shaped gland in men that produces seminal fluid which nourishes and transports sperm. It is one of the most common types of cancer in men.

How Serious is Prostate Cancer? The seriousness of prostate cancer can vary widely. Some types of prostate cancer grow slowly and may need minimal or even no treatment, while other types are aggressive and can spread quickly. The seriousness is often determined by several factors including:

- **Stage of Cancer:** This indicates how far the cancer has spread. Early-stage prostate cancer (confined to the prostate) is generally less serious and more treatable than advanced-stage cancer (spread to other parts of the body).
- **Gleason Score:** This score helps to evaluate the aggressiveness of the cancer. A higher Gleason score indicates a more aggressive cancer.
- **PSA Levels:** Prostate-specific antigen (PSA) levels in the blood can help to detect prostate cancer early and monitor its progression.

Additional Information:

- **Symptoms:** Early prostate cancer usually causes no symptoms. Advanced prostate cancer can cause symptoms such as difficulty urinating, blood in the urine, bone pain, and erectile dysfunction.
- **Prognosis:** The prognosis for prostate cancer is generally good, especially when detected early. The 5-year survival rate for localized prostate cancer is nearly 100

Would you like to delve deeper into any specific aspect of prostate cancer, such as PSA levels, Gleason score, or whether your cancer is considered low-risk or high-risk? Or shall we move on to the next main question?

Me: Yes, I am interested in knowing more about my PSA level please.

MedEduChat: Sure, let's discuss PSA levels.

What is PSA? PSA stands for Prostate-Specific Antigen, a protein produced by both normal and malignant cells of the prostate gland. The PSA test measures the level of PSA in a man's blood and is used as a screening tool for prostate cancer.

Understanding PSA Levels:

- **Normal PSA Levels:** Generally, a PSA level below 4.0 ng/mL is considered normal. However, this can vary based on age and other factors.
- **Elevated PSA Levels:** Higher levels of PSA can indicate the presence of prostate cancer, but they can also be caused by other conditions such as benign prostatic hyperplasia (BPH) or prostatitis (inflammation of the prostate).

Your PSA Levels: From your clinical notes, here is a summary of your PSA levels over time:

- XXX 20XX: PSA X.X (initial diagnosis)
- XXX 20XX: PSA nadir 0.XX (after initial treatment)
- XXX 20XX: PSA rise to X.X
- XXX 20XX: PSA up to X.X

Importance of PSA Levels:

- **Monitoring:** PSA levels are used to monitor the effectiveness of treatment and to check for recurrence of cancer.
- **Trend:** The trend in PSA levels over time is more important than a single measurement. A rising PSA level may indicate the need for further investigation or treatment.

Would you like to know more about how PSA levels are used in your specific treatment plan, or shall we move on to the next main question?

Me: Good to know. Sure, next main question.

MedEduChat: Great! Let's move on to the second main question: *How is prostate cancer typically treated?*

How is Prostate Cancer Typically Treated?

The treatment for prostate cancer depends on several factors, including the stage of the cancer, the Gleason score, PSA levels, the patient's age, overall health, and personal preferences. Here are some common treatment options:

Active Surveillance:

- Suitable for low-risk, slow-growing prostate cancer.
- Involves regular monitoring with PSA tests, digital rectal exams (DRE), and possibly biopsies.
- Treatment is initiated if the cancer shows signs of progression.

Surgery:

- **Radical Prostatectomy**: Removal of the entire prostate gland and some surrounding tissue. This can be done through open surgery or minimally invasive techniques like laparoscopic or robotic surgery.
- **Transurethral Resection of the Prostate (TURP)**: Used to relieve symptoms in advanced cases by removing part of the prostate.

Radiation Therapy:

- **External Beam Radiation Therapy (EBRT)**: Uses high-energy beams to target and kill cancer cells.
- **Brachytherapy**: Involves placing radioactive seeds directly into the prostate.

Hormone Therapy (Androgen Deprivation Therapy - ADT):

- Reduces levels of male hormones (androgens) that can stimulate the growth of prostate cancer cells.
- Can be used in combination with other treatments or for advanced cancer.

Chemotherapy:

Uses drugs to kill rapidly growing cancer cells. Typically used for advanced prostate cancer that has spread to other parts of the body.

Immunotherapy:

Uses the body's immune system to fight cancer.

- **Sipuleucel-T (Provenge)**: A type of immunotherapy specifically for prostate cancer.

Targeted Therapy:

Uses drugs that target specific molecules involved in cancer growth and spread.

- **PARP Inhibitors**: Used for prostate cancers with specific genetic mutations.

Your Treatment Plan:

Based on your records, you have not undergone any therapy yet. Would you like to know more about any specific treatment option, such as active surveillance, surgery, or other treatments available? Or shall we move on to the next main question?

Me: I don't know, I heard surgery + radiation therapy could be a good combination for my prostate cancer treatment, right?

MedEduChat:

Combining surgery and radiation therapy can indeed be an effective treatment strategy for prostate cancer, especially in certain cases. Here's a bit more detail on how these treatments can work together:

Surgery (Radical Prostatectomy):

- **Purpose**: To remove the entire prostate gland and some surrounding tissue.
- **When Used**: Often used for localized prostate cancer that has not spread beyond the prostate gland.
- **Benefits**: Can be curative if the cancer is confined to the prostate. Provides a clear pathology report to guide further treatment.

Radiation Therapy:

- **Purpose**: To kill any remaining cancer cells in the prostate area or surrounding tissues.
- **When Used**: Can be used as an adjuvant therapy (after surgery) to reduce the risk of recurrence, or as a salvage therapy if the cancer returns after surgery.
- **Types**:
  - **External Beam Radiation Therapy (EBRT)**: High-energy beams target the prostate area.
  - **Brachytherapy**: Radioactive seeds are implanted directly into the prostate.

Combination Benefits:

- **Higher Efficacy**: Combining surgery and radiation can be more effective in eliminating cancer cells and reducing the risk of recurrence.
- **Targeted Approach**: Surgery removes the primary tumor, while radiation targets any remaining cancer cells.
- **Personalized Treatment**: The combination can be tailored based on the stage, Gleason score, and other individual factors.

Considerations:

- **Side Effects**: Both treatments have potential side effects, such as urinary incontinence, erectile dysfunction, and bowel issues. Combining treatments may increase the risk of these side effects.
- **Recovery Time**: Surgery requires a recovery period, and radiation therapy may extend the overall treatment time.

Prostate Cancer Side Effects:

- **Surgery (Radical Prostatectomy)**: Urinary incontinence, erectile dysfunction, infection, bleeding, bowel dysfunction.
- **Radiation Therapy**: Urinary problems, bowel issues, erectile dysfunction, fatigue, skin reactions.
- **Hormone Therapy**: Hot flashes, loss of libido, erectile dysfunction, bone thinning, weight gain, mood changes, fatigue.
- **Chemotherapy**: Nausea, hair loss, fatigue, increased infection risk, mouth sores.
- **Immunotherapy/Targeted Therapy**: Immune-related side effects, skin reactions, fatigue, diarrhea.

Managing Side Effects:

Medications, lifestyle changes, and supportive care can help manage symptoms like nausea, pain, or erectile dysfunction. Physical therapy, counseling, and support groups provide additional support.

Would you like to explore more about any specific risk factor, or do you have any other questions or concerns about your prostate cancer diagnosis and treatment?

Me: No, I am all good. Thank you!

MedEduChat: You're welcome! Thank you for participating in the MedEduChat journey! We hope you enjoy this educational experience. Please complete this evaluation form: XXXXX.