

Exploring Potential Roles for Artificial Intelligence in Patient Advocacy

Andrew Simkus and Kristen Holtz

Background

In November of 2022, OpenAI previewed one of the most advanced large language models (LLMs) available to the public, Chat Generative Pre-trained Transformer (better known as ChatGPT).¹ LLMs like OpenAI's ChatGPT and Google's Bard are a breakthrough in artificial intelligence (AI) allowing automatic learning and communication through natural language interactions with human users, information from the world wide web, and even other LLMs.² The capabilities of LLMs have been expanding exponentially over a very short time.

What began as an interactive chat that could help identify, sort through, and uniquely communicate vast amounts of textual information by comprehending and generating natural language, is now being incorporated into audio, photographic, videographic, and even virtual reality mediums. While there are still concerns regarding accuracy, privacy, and barriers to adoption, AI generated-content (AIGC) is entering an exciting new era of abilities and potential applications.³

While the ability of AI to instantly synthesize huge swaths of natural written, verbal, and visual information will undoubtedly benefit many fields of life, perhaps the most valuable platform for its use is in public health. AI technology has already been used to develop apps that can scan and diagnose photographs of potential skin cancers⁴ and has been found capable of instantly identifying early signs of disease from professional imaging.⁵⁻⁷ It has been adapted to assist with interpersonal communications within virtual reality experiences^{8,9} and even talk

therapy for helping treat issues like social anxiety.¹⁰

The potential for AI as a tool for health equity is outstanding as it can deliver quality clinical expertise, screenings, outreach, and in some cases even treatment to individuals in any location, in any language, in real time, and free of charge. There is also hope that the utilization of AI may help mitigate implicit bias that compromises care for many minority patients.^{11,12} With these capabilities, AI may be an excellent technology to assist with patient advocacy - helping empower patients to address certain barriers to receiving care.

Patient advocacy occurs when someone is brought into a healthcare team to help educate and empower patients to navigate healthcare systems and make informed decisions about their health.¹³

At KDH Research & Communication, we have designed and tested a series of interventions that use patient advocacy to increase minority representation in lupus clinical trials (CTs). While we have found that patient advocacy is effective in enhancing patient cognitive outcomes (increasing knowledge about and intentions) related to CT participation,¹⁴ there are limitations of using individuals as patient advocates that may be circumvented with added support from a clinically trained AI LLM platform.

In this brief, we brainstorm potential supportive roles for AI LLMs in providing patient advocacy that addresses CT representation among historically underrepresented groups.

Patient advocacy and clinical trial representation

Systemic lupus erythematosus is an inflammatory autoimmune disease that varies largely by race and ethnicity in its prevalence and severity. Disproportionately affecting racial/ethnic minorities¹⁵ who are underrepresented in CTs.^{15,16} Such underrepresentation in lupus CTs can make it difficult for the FDA to approve efficacious treatments among these patient groups at higher risk of detrimental outcomes.¹⁷ Because racial and ethnic minorities have the greatest risk of developing lupus and often experience more severe manifestations of the disease, it is imperative that diverse populations are well represented in CTs.

Disparities in CT representation occur when certain groups of the population hold shared reasons for not participating in CTs. These reasons, commonly referred to as barriers to care; include accessibility issues like access to transportation,¹⁸ understandable information materials,¹⁹ or child-care.²⁰ Patients may be unaware of CT opportunities²¹ or that CTs may provide services at reduced-cost or even for free.²² There may be trust issues among minority patients who have been historically discriminated against by medical systems,^{18,21,23} or worries about potential deportation among patients who are undocumented migrants.¹⁹ There are also health literacy issues where patients may not understand their disease²⁴ or how they may benefit from participating in CTs.^{19,25}

Patient advocacy can help patients address barriers to care in hopes of enhancing the likelihood that these patient groups seek information about and ultimately participate in CTs. Health equity interventions have used various types of patient advocates to conduct outreach with minority lupus patients and have proven beneficial in increasing patient knowledge about and intentions towards participating in various CTs.^{14,26,27} In regard to lupus CT participation, patient advocacy aims to educate patients about lupus and available treatment options, increase awareness around clinical research, and explain how ensuring diverse representation in CTs is important for identifying efficacious treatments. AI LLMs may be particularly efficacious with providing personally tailored logistic/educational forms of support.

Limitations of using individuals as patient advocates

Nurses have long served as patient advocates, helping educate patients about a wide variety of conditions and

treatment options; however, due to the potential for time limitations, cultural mismatching, and concerns of power dynamics among medical professionals,^{28,29} community health workers, and even patient peers have often been selected to provide patient advocacy.^{30,31} While there are undoubtedly many aspects of patient advocacy which necessitate human connection, there are logistical and educational forms of support that humans may be limited in providing. For example, there are limitations on personal availability, concerns about accuracy of information, and limitations in the amount of dense medical information patient advocates can remember and accurately translate to other languages or literacy levels. AI LLMs can be used to address each of these limitations.

Current strengths of AI LLMs in patient advocacy, according to ChatGPT

While we explored the scientific literature on ways that AI LLMs are being used to support patients with engaging their healthcare, we have not seen any studies exploring the ability of AI LLMs to directly provide advocacy directly to patients, and thus the potential uses are still speculative at this stage. We decided to ask the publicly available ChatGPT 3.5 itself what barriers to care its capabilities would be most efficient at helping patients address. Specifically, we asked, “How do you think ChatGPT could be used to help patients who are underrepresented in clinical trials overcome barriers to care?” Here is the response received from ChatGPT, version 3.5:

“ChatGPT could help by creating accessible, easy-to-understand resources about clinical trials, breaking down complex medical information, and offering guidance on how to navigate the healthcare system. It could also provide information in various languages, increasing accessibility for a broader range of individuals. Additionally, it could address specific concerns or barriers that underrepresented patients may face, such as a lack of information, mistrust, or logistical issues, thereby supporting their participation in clinical trials.”

Sounds willing and ready!

Roles for AI in patient advocacy

As LLMs improve and expand in their reliability and capability, AI patient advocacy (AIPA) will likely assist with a wide array of patient needs. For instance, AIPA could facilitate clinical-related triage and documentation,

and even assist patients in obtaining pre-authorizations from insurance companies. With the ability to conduct lightning fast, exhaustive literature reviews, and synthesize relevant findings from research papers, AIPA could effectively educate patients about their illness and the best practices for managing their disease. By learning and communicating via natural language, AIPA may interact with patients and care providers as an expert chatbot, answering questions for nurses, doctors, social workers, patients, and their family members.³² AIPA may be used to provide up to date lists of local providers, services, and clinical trials. AIPA may be used to remind patients about appointments, procedures, and concerns related to clinical protocols. Moreover, LLMs are capable of communicating with patients through both text and speech, allowing blind and visually impaired patients around the world to access vital information at their fingertips that otherwise would have required personal assistance and access to extensive resources. AIPA can do all of this, while tailoring the language it uses with each individual patient user to match both language and literacy levels.

Ethical concerns of AI for patient advocacy

While both the reliability and trust in LLMs has been increasing in short time, there are serious concerns related to breaches to privacy, LLMs ability to protect private health information, the ability of LLMs to generate false or wrong information, and to learn bias from the content it processes.³³ Patients' ability to trust the information given by LLMs is an important concern regarding moving towards AIPA. Research on patient trust in LLM support is promising, with ChatGPT health-related responses being considered by patients as trustworthy, valuable, and not dangerous.³⁴ Any LLM being used for AIPA purposes would at a minimum necessitate guaranteed reliability, privacy, and a lack of bias based on patient characteristics. AIPA would require compliance with data protection laws like the health insurance portability and accountability act (HIPAA).

Discussion

The ChatGPT software was released to the public in 2022 as a research preview to gather feedback from users on its abilities and exactitude, as of November 2023, the software has been updated several times to enhance its accuracy, security, and overall capabilities.³⁵ While there are still concerns about LLMs ability to generate false information and/or bias, and whether LLMs have the security in place to protect sensitive personal information; the speed at which these technologies are learning, adapting, and advancing suggests that such concerns could be resolved in short time

with careful consideration of the specific needs related to AIPA. Once these concerns are acceptably addressed, AIPA may be the most impactful tool for achieving health equity that the world has seen.

With the ability to instantly search and sort relevant and credible local resources, synthesize and convey complex medical information in any language, through written or spoken platforms, at any time anywhere -- AIPA could be easily accessible to all types of patients, across all areas with Internet access. AIPA specifically targeting CT inclusion will likely be most beneficial in logistical and educational roles: helping patients easily comprehend relevant resources, translating complicated medical information, and assisting patients in navigating the health systems in their area. AIPA could also educate patient groups about the importance of CTs, the protective policies and levels of care provided in CTs and help identify services to help overcome physical barriers to care such as transportation.

While the capabilities of newly developed LLMs and the wide range of potential applications for their use are still being considered, it is undoubtable that AI will find new exciting roles in healthcare which can help improve patient health, engagement, and inclusion. The concept of AIPA is promising for being able to reach and inform a larger audience of patients than has ever been plausible. As such, AIPA may have tremendous impacts on diverse patient representation in CTs, and in turn in identifying effective treatments for underrepresented patient groups.

References

- ¹ Kashyap R, OpenAI C. A First Chat with ChatGPT: The First Step in the Road-Map for AI (Artificial Intelligence). Available at SSRN 2023;
- ² Singh SK, Kumar S, Mehra PS. Chat GPT & Google Bard AI: A Review. IEEE: 2023.
- ³ Zhang C, Zhang C, Zheng S, et al. A complete survey on generative ai (aigc): Is chatgpt from gpt-4 to gpt-5 all you need? arXiv preprint arXiv:230311717 2023;
- ⁴ Das K, Cockerell CJ, Patil A, et al. Machine learning and its application in skin cancer. International Journal of Environmental Research and Public Health 2021;18(24):13409
- ⁵ Hunter B, Hindocha S, Lee RW. The role of artificial intelligence in early cancer diagnosis. Cancers 2022;14(6):1524
- ⁶ Janarthanan S, Rajendran M, Biju TS, et al. Artificial intelligence (AI) combined with medical imaging enables rapid diagnosis for Covid-19. Applications of Artificial Intelligence in COVID-19 2021;55-72

- ⁷ Dilsizian SE, Siegel EL. Artificial intelligence in medicine and cardiac imaging: harnessing big data and advanced computing to provide personalized medical diagnosis and treatment. *Current cardiology reports* 2014;16(1-8)
- ⁸ Olsen A, Follow P. Adolescent Trauma Therapy using storytelling, music, artificial intelligence (AI) and virtual reality (VR).
- ⁹ Holohan M, Fiske A. “Like I’m Talking to a Real Person”: Exploring the Meaning of Transference for the Use and Design of AI-Based Applications in Psychotherapy. *Frontiers in Psychology* 2021;12(720476)
- ¹⁰ Dewi M, Fahmi H. Implementation of AI Chatbot Application for Social Anxiety Problem. *IT for Society* 2023;8(1):
- ¹¹ Lin Y-T, Hung T-W, Huang LT-L. Engineering equity: How AI can help reduce the harm of implicit bias. *Philosophy & Technology* 2021;34(Suppl 1):65-90
- ¹² Thomasian NM, Eickhoff C, Adashi EY. Advancing health equity with artificial intelligence. *Journal of public health policy* 2021;42(602-611)
- ¹³ Gilkey MB, Earp JAL, French EA. What is patient advocacy? *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care: Strategies for Achieving Patient-Centered Care* 2007;1(
- ¹⁴ Sheikh SZ, Donovan C, Menezes C, et al. Feasibility and Utility of a Pilot Peer Education Program to Improve Patient Engagement in Lupus Clinical Trials: Implementation and Evaluation in a Multisite Model Within a Lupus Clinical Trials Network. *ACR Open Rheumatology* 2023;
- ¹⁵ Izmirly PM, Parton H, Wang L, et al. Prevalence of Systemic Lupus Erythematosus in the United States: Estimates From a Meta-Analysis of the Centers for Disease Control and Prevention National Lupus Registries. *Arthritis & Rheumatology* 2021;73(6):991-6, doi:10.1002/art.41632
- ¹⁶ Falasinnu T, Chaichian Y, Bass MB, Simard JF. The Representation of Gender and Race/Ethnic Groups in Randomized Clinical Trials of Individuals with Systemic Lupus Erythematosus. *Current rheumatology reports* 2018;20(4):20, doi:https://doi.org/10.1007/s11926-018-0728-2
- ¹⁷ Sheikh SZ, Englund TR, Burriss SW, et al. EMBRACE: One Small Story in Lupus—One Giant Challenge in Clinical Trials. *ACR Open Rheumatology* 2022, doi:https://doi.org/10.1002/acr2.11477
- ¹⁸ Mills EJ, Seely D, Rachlis B, et al. Barriers to participation in clinical trials of cancer: a meta-analysis and systematic review of patient-reported factors. *The lancet oncology* 2006;7(2):141-148
- ¹⁹ George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American journal of public health* 2014;104(2):e16-e31
- ²⁰ Guadagnolo BA, Petereit DG, Helbig P, et al. Involving American Indians and medically underserved rural populations in cancer clinical trials. *Clinical Trials* 2009;6(6):610-617
- ²¹ Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer* 2008;112(2):228-242
- ²² National Cancer Institute. Results from Quarterly Omnibus Survey: Clinical Trials Questions-April 22, 1997. National Institute of Health: Bethesda, MD; 1997.
- ²³ Harris Y, Gorelick PB, Samuels P, Bempong I. Why African Americans may not be participating in clinical trials. *Journal of the National Medical Association* 1996;88(10):630
- ²⁴ The Society for Women’s Health Research. Dialogues on diversifying clinical trials: successful strategies for engaging women and minorities in clinical trials. Food and Drug Administration, Office of Women’s Health: Washington, DC; 2011.
- ²⁵ Evans KR, Lewis MJ, Hudson SV. The role of health literacy on African American and Hispanic/Latino perspectives on cancer clinical trials. *Journal of Cancer Education* 2012;27(2):299-305
- ²⁶ Fouad MN, Acemgil A, Bae S, et al. Patient navigation as a model to increase participation of African American in cancer clinical trials. *J Oncol Pract* 2016;12(6):556-563
- ²⁷ Fouad MN, Johnson R, Nagy C, et al. Adherence and retention in clinical trials: a community-based approach. *Cancer* 2014;120(Suppl 7):1106-1112
- ²⁸ Water T, Ford K, Spence D, Rasmussen S. Patient advocacy by nurses - past, present and future. *Contemp Nurse* 2016;52(6):696-709, doi:10.1080/10376178.2016.1235981
- ²⁹ Allmark P, Klarzynski R. The case against nurse advocacy. *Br J Nurs* 1992;1(12):33-6, doi:10.12968/bjon.1992.1.12.33
- ³⁰ Nemcek MA, Sabatier R. State of evaluation: Community health workers. *Public Health Nursing* 2003;20(4):260-270
- ³¹ Mongan D, Long J, Farragher L. Models of patient advocacy: evidence brief. Dublin; 2016. Available from: <https://assets.gov.ie/11430/6d56e960e4ef45cda1fa0b1d2fababb8.pdf>.

Acknowledgements

This research was self-funded.



KDH RESEARCH &
COMMUNICATION

145 15th Street NE,
Suite 831
Atlanta, GA 30309

www.kdhrc.com
publicaffairs@kdhrc.com



ANDREW SIMKUS
is an Analyst at KDH
Research &
Communication.



KRISTEN D. HOLTZ is
the Founder and
President at KDH
Research &
Communication.

KDH RESEARCH & COMMUNICATION is a non-partisan, public health, research and communications agency. The goal of the “Informing Public Health” brief series is to disseminate innovative, objective, and timely information to solve public health and other social issues. KDHRC actively contributes to a future when all people can find, understand, and act on information to safeguard the health of themselves, their families, and their communities.

The views expressed here are those of the authors and do not necessarily reflect those of KDH Research & Communication, its board, or funders. Permission is granted for reproduction of this document with attribution to KDH Research & Communication.
