UNITED STATES of CARE

THE PEOPLE'S PERSPECTIVE ON ARTIFICIAL INTELLIGENCE IN HEALTH CARE:

Insights from Our Early Listening Work

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Overview

Artificial intelligence (AI) is rapidly growing and becoming increasingly prevalent in every aspect of today's society. People often interact with AI systems when they purchase tickets, book appointments, or communicate with an online chatbot instead of a customer service representative. Currently, AI is a major area of focus for stakeholders across the health care ecosystem – including patient groups and advocates, tech companies and innovators, large health systems and corporations, pharmaceutical and device companies, and state and federal policymakers. While the technology itself continues to evolve and integrate into everyday people's health care experiences, so too does the surrounding policy landscape.

United States of Care (USofCare) sits at the intersection of policy, politics, and people. Our work is predicated on listening to people and what they want out of the health care system at a foundational level. Such deep listening informs policy solutions to drive advocacy at the state and federal levels. USofCare observes that the end users of AI – everyday people – are absent from the critical conversations that legislators, regulators and innovators are having, resulting in AI policy in health care without people at the center. As a result, USofCare undertook preliminary interviews to better understand the perceptions, beliefs, and attitudes that people hold regarding AI in health care to further inform ongoing policy conversations. This research brief summarizes the findings from those targeted interviews and contextualizes them within the broader federal regulatory landscape.

Key Themes from Our Research

1 | MIXED LEVELS OF TRUST AND COMFORT WITH AI IN HEALTH CARE

Participants' feelings on AI integration in health care ranged from cautious optimism to skepticism, valuing trust, transparency, and human involvement in diagnosis and treatment decisions.

2 | INTEREST AND ENGAGEMENT WITH AI IN HEALTH CARE

Participants were keenly interested in learning more about AI and its applications in health care, while raising concerns about how AI affects data security, job displacement, and the connection between patients and providers.

3 | EQUITY AND ETHICS FOR AI IN HEALTH CARE

While some participants were optimistic about AI's potential to address disparities and increase access, others stressed the importance of thoughtful design and implementation to ensure equity.

4 | FUTURE OUTLOOK AND EXPECTATIONS

Participants indicated that USofCare and consumers and patients could play a pivotal role in shaping AI implementation by informing policy change, emphasizing the importance of community engagement incorporating diverse perspectives into advocacy and initiatives.

Background

Catalyzed by the global pandemic, the convergence of health care and technology is paving the way for the transformative application of AI in health care delivery. The deployment of AI in health care has the potential to address supply-and-demand workforce challenges and reduce operational burdens that have hampered the health sector for decades. However, the increasing reliance on automated systems has also sparked debates on issues ranging from algorithmic bias in hiring to the ethical use of AI in patient care. Human interaction in medicine is crucial, and technology should be leveraged to enhance it. Maintaining this delicate balance ensures that technology serves as a valuable ally that empowers providers to deliver more personalized, timely, and compassionate care while enabling patients to benefit fully from the promise of AI.

The federal government is starting to take action on the growing use of AI in health care settings. As indicated by the October 2022 Executive Blueprint for an AI Bill of Rights, much of the existing regulatory framework seeks to harness AI tools to improve health care outcomes and innovations while establishing clear equity standards and patient protections. Because of this growing policy conversation, USofCare undertook research to gain further insights about what this technology means to everyday patients and consumers.

USofCare's Approach

In March 2024, we engaged in individual in-depth conversations with members of our Voices of Real Life Members to learn about the role and implications of AI in health care from the people's perspective. Members of the Voices of Real Life council come from a variety of backgrounds and help advise USofCare's work identifying health care policies that better serve all individuals, including those who are more likely to be affected by policies and practices that keep health care out of reach for vulnerable populations. The aim of these interviews was to identify insights that could inform future public opinion and listening research on this topic.

As such, USofCare approached these initial conversations by asking a series of questions based on four topic areas:

- Trust and Comfort with AI in Health Care
- Interest and Engagement with AI in Health Care
- Equity and Ethical Implications of AI in Health Care
- Future Outlook and Expectations

Key Themes from Our Listening Work

From these interviews, USofCare identified key themes and perspectives that revealed how the Voices of Real Live participants feel about AI in health care.

1

Mixed Levels of Trust and Comfort with AI in Health Care

Participants' feelings on AI integration in health care ranged from cautious optimism to skepticism, while emphasizing the importance of trust, transparency, and human involvement in diagnosis and treatment decisions. While some participants were open to the use of AI in treatment recommendations, others stressed the significance of human and professional input, especially when prescribing medications. Participants universally value transparency regarding AI's role in health care visits, appreciating the empowerment that comes with being informed about their care.

> **I have a lot of trust in [AI]. I think that there are so many blocks put in place legally around health care that AI health care is safer in terms of protecting my data and my identity than many other AI utilizations.**

> **Speaking as a patient and a woman of color, I'm extremely weary of transitioning to AI platforms for diagnostics and treatments primarily because I don't know if it would make any aspect of managing our care improved.**

> **I'm definitely someone to really want to actually connect to a human being and a doctor who wants to listen holistically to how I conduct my care.**

> **I think [AI in health care] removes a central human element from a specialty that requires human connection.**

[1]**Methods and limitations to our research:** All five interview participants identified as women, ranging in age from 24 to 47 years old. All interviews lasted no more than 60 minutes in length and were conducted virtually. With only five interview participants, USofCare recognizes that the ability to extrapolate these themes and findings for broader interpretation is extremely limited. We acknowledge there is not enough diversity in backgrounds, experiences, and viewpoints to fully capture the breadth of human experiences and perspectives regarding AI in health care, and that additional research is needed. Insights drawn from such a small group may not be representative of larger populations or applicable to a broader context.

2 Interest and Engagement with AI in Health Care

Voices of Real Life members were keenly interested in learning more about AI and its applications in health care, but raised concerns about how AI affects data security, job displacement, and the connection between patients and providers. Despite this, participants were intrigued by AI's ability to improve precision medicine, promote inclusivity for individuals with disabilities, and streamline health care processes.

> **I'm curious about how AI will deal with the uniqueness of people with disabilities or people who might not have 'straightforward health care' life... I certainly know the challenge of trying to find a doctor that can provide a holistic type of care.**

> **I think that AI can create more opportunities to access care in a way that's less demanding on the bandwidth of already extremely busy and burdened people. And can make it easier for them even from a billing perspective.**

> **I'm very fascinated with how we can use AI to empower patients as partners in their own care.**

> **I am definitely interested in [using AI for] mental health and finding out whether it can train a robot, chat bot, or whatever to do an escalation mental health crisis deflation.**

3

Equity and Ethics for AI in Health Care

In navigating the equity and ethical implications of AI in health care, participants highlighted the crucial role of community involvement. While some were optimistic about AI's potential to address disparities and increase access, others stressed the importance of thoughtful design and implementation to ensure equity. Challenges like trust issues, cultural sensitivity, and ethical concerns highlight the need for proactive engagement with communities and diverse stakeholders. Lastly, clear regulations and guidelines were seen as critical for the responsible integration of AI in health care.

[Equity and ethical implications are] 100 percent important not just in writing the models but in having people who are experienced in these communities who aren't AI experts sitting next to them and saying, You're missing this... it's the same on the policy level.

You should have to sign an oath or you take an ethical course on providing health care. AI should follow those ethics whether it be the health care code of ethics or whatever it needs to follow in order to assure that it is adhering to the rules.

Make sure that you have all the stakeholders involved at the table including patients including nonprofits that are involved with patients and those people are two separate entities.

4 Future Outlook and Expectations

Participants indicated that USofCare and advocacy organizations could play a pivotal role in shaping AI implementation by informing policy change. They emphasized the importance of community engagement, and suggested incorporating diverse perspectives into advocacy initiatives. Moreover, by leveraging listening work and community engagement, participants envision a bridge between policymakers and communities. Additionally, they advocated for inclusive, ethical AI development to propel its potential to improve health care outcomes and reduce costs, especially for underserved populations.

> **I think the listening work is key especially if we're talking about developing ethical and inclusive AI continuing that listening work and doing very specific outreach in who you're bringing to the table.**

> **USofCare can influence and step in assuring that AI developments are not abandoning the idea of holistic health care and hearing the voices first.**

> **Through listening work, USofCare has access to pathways to reach consumers and stakeholders in health care which translates to being able to really pull in the voice of consumers in a way that's meaningful.**

Connecting Our Initial Insights to the Current Regulatory Landscape

As they take steps towards regulating how AI is used in health care settings, federal policymakers are starting to explore the concerns shared by our interview participants. The Biden Administration, through its October 2022 Executive Blueprint for an AI Bill of Rights and its March 2024 Office of Management and Budget (OMB) Policy Memorandum, outlined its vision for the design and deployment of AI across a variety of sectors, with a particular emphasis on using AI to lead to innovation while instituting consumer protections and safeguards.

Much of the federal action on the use of AI in health care is entrusted to the Department of Health & Human Services (HHS) and its various sub-agencies. HHS sub-agencies are investigating not only how AI and machine learning can lead to public health innovation through data collection and analysis, but also how AI tools can affect protocol. For example, the Food & Drug Administration (FDA) published a discussion paper in May 2023 seeking guidance and feedback about the implications of AI to the review process for new medical drugs and products.

Our research participants expressed the importance of ethical and equity standards for the use of AI in health care, which federal policymakers are starting to consider. Many HHS sub-agencies have undertaken research and designed conceptual frameworks to examine how AI algorithms perpetuate systemic racial biases and further inequitable health outcomes. The Biden Administration has also finalized rules related to how AI algorithms make decisions within health care contexts. The Office of the National Coordinator for Health Information Technology (ONC) established transparency requirements for AI used in certified health information technology, while the rule adopted by the Center for Medicare & Medicaid Services (CMS) requires medical necessity determinations within Medicare Advantage programs to be based on an individual's circumstances, rather than relying on algorithmic judgment. Additionally, an April 2024 final rule from CMS and the HHS Office for Civil Rights (OCR) explicitly states that certain entities must take action to mitigate the risk of discrimination from the usage of AI tools in clinical decision making.

Through its AI Task Force, HHS is convening several sub-agency heads to develop a comprehensive federal strategy around key considerations for the use of AI in health care, including public health, research and discovery, and ethics and responsibility. Congress is also following suit and exploring AI through the launch of their own task forces and caucuses, including the House Bipartisan Task Force on Artificial Intelligence, Senate Bipartisan AI Working Group, and the House Digital Health Caucus. As Congress and state legislatures start to engage in legislative action, it is critical that policies that regulate the use of AI in health care are centered around the concerns, needs, and experiences of its end users: people and communities.

Conclusion

The critical need to understand people's opinions about the present and future usage of AI in health care is highlighted by this preliminary listening research. The participants, despite their lack of experience with AI, showed interest in and willingness to interact with AI in health care, despite having prevalent worries about privacy, trust, and the moral ramifications of AI. However, the limited sample size restricted the applicability of the results to broader communities.

In order to capture a wider range of perspectives and experiences, future research should place a higher priority on inclusivity and strive for larger and more diverse participant pools. Furthermore, longitudinal studies may provide insightful information about how attitudes and perceptions of AI in health care change over time. Researchers, medical professionals, and technology developers should work together with patient and consumer advocacy groups, which would encourage multidisciplinary discussion and the co-creation of AI solutions that are morally sound, socially conscious, and focused on improving patient outcomes. Future research can help advance AI in health care while maintaining human-centricity and alignment with societal values by taking the critical steps to bring everyday people's perspectives into consideration at every possible opportunity.