Using Health AI Tools:
A Listening Session with Patient Advocacy Organizations

AdvaMed
Advanced Medical Technology Association

CTA™

Maverick Health Policy

On September 13, 2024, AdvaMed and the Consumer Technology Association (CTA)® co-hosted a listening session with several patient advocacy organizations to:

- Understand current perspectives on health AI
- Identify need for education
- Identify action items for AdvaMed and CTA

This is a report on the takeaways.

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PARTICIPANTS

AdvaMed
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Health AI Listening Session Participant List

<table>
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• American Cancer Society Cancer Action Network
• Breakthrough T1D
• National Health Council
• National Minority Health Association</td><td>Participants
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• Asian & Pacific Islander American Health Forum
• Epilepsy Foundation of America
• HealthyWomen
• Mental Health America
• National Psoriasis Foundation</td></tr>
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Landscape Scan: Key Takeaways

There is variation in patient advocacy groups' existing activity on health AI

- **Despite variation, most organizations contributed to the listening session discussions:**
  - Many expressed interest in learning more about health AI generally (including the different processing systems) and specific applications in healthcare
  - Many expressed interest in participating in more conversations bringing together advocacy groups, associations, and innovators to streamline communication and build relationships across the industry

- **Most organizations have at least acknowledged the use of health AI:** While varied in the level of detail and specificity, most organizations have some form of content regarding health AI on their websites. Oftentimes, content references applications of AI rather than policy positions on health AI.

- **Many have funded research projects:** Many organizations have funded research on AI and machine learning for their respective populations / disease focus areas.

- **Two organizations have more public-facing AI messaging than others:** National Health Council and The Light Collective have the most advanced materials and resources for health AI.

Landscape Scan Highlight: National Health Council

NHC hosts monthly AI Affinity Groups to explore how AI is impacting patients:

Speakers so far include:

- Google's Senior Medical Lead: Dr. Kapil Parakh
- National Academy of Medicine's Senior Advisory: Laura Adams

NHC statement on health AI for a U.S. Senate Finance Committee hearing in February 2024:

Primary theme: wants patients to be a collaborative part of the development and planned use of health AI. Patients must have input into the effect of algorithms, devices, and other aspects of AI creation, use, and analysis.

Concerns: data bias, minimizing potential risks of the unintended consequences of use, adverse events, overriding patient and provider expertise, inadvertent reinforcement of implicit and explicit biases and inequities, inaccuracies in training data that lead to hard-to-detect and misleading results, and the weakening of patient privacy protections.

Recommendations:

- Expert human oversight of many AI uses is critical to maintaining safety and accuracy and ensuring continuous improvements to retrain as conditions change.
- Pre-deployment testing should be conducted in a diverse range of real-world clinical settings.
- Robust and continuous feedback loops should be created, leveraged, and optimized to identify and mitigate the risk of harms.

Landscape Scan Highlight: National Health Council

NHC has several resources for patient engagement that AI developers can use

Patient Compensation Tools: NHC has several tools - including best practices and a fair-market value calculator - that help healthcare companies fairly compensate patients, caregivers, and patient representatives for patient engagement activities

NHC Patient Engagement Fair-Market Value Calculator

+ User Guide
+ Interpreting Your Results
+ FMV Houlry Rate Methodology
+ Glossary

Other Resources:

- **Blueprint for Developing Patient-Centered Core Impact Sets:** A tool that helps researchers create patient-centered data sets, that help them understand the issues and experiences patients care about – not just what typical research might say
- **Patient Experience Map:** Resources that help researchers understand patients' experiences, both before and after diagnosis

Landscape Scan Highlight: The Light Collective*

In partnership with the National Academy of Medicine, the patient-led cohort published the Patient AI Rights Initiative in 2024:

Primary Goal: establish foundational expectations for patient partnership with national initiatives on AI rights and governance

**The Light Collective was unable to attend the September 13 listening session. However, they are an outspoken patient advocacy organization in the health AI space and their positions are relevant to review.*

AI Rights for Patients outlines seven collective rights for patients in health AI:

- Patient-led Governance
- Independent Duty to Patients
- Transparency
- Self-Determination
- Identity Security and Privacy
- Right of Action
- Shared Benefit

Listening Session

DISCUSSION SUMMARY

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Notable Quotes

“AI in patient care is like an iceberg – patients only see the ChatGPT-like tools, but not the majority of applications of AI in healthcare”

”When you get in a car, you don’t care how the seat belt works, just that it does. Do patients feel that way about AI in healthcare?”

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Listening Session: Key Takeaways

Health AI education is needed so patients and patient advocates can meaningfully contribute to policy conversations and tech development

- **Patients are not aware of the extend health AI is used:** Patients need meaningful education on health AI so they can articulate their excitement and concerns for AI.

- **Patient advocates are excited about AI:** The group discussed several concrete ways AI can improve patients' health journeys including care coordination and patient empowerment.

- **Prior auth and UM is the biggest concern:** AI may scale existing, systemic problems with prior auth and UM. Other concerns included transparency and data privacy.

- **Interest in collaboration:** The group agreed that an education effort is needed; however, many do not have the time, resources, or expertise to dedicate to it. There are opportunities to work together to create materials, amplify existing work, and streamline education efforts.

Generally, how do patient groups feel about health AI?

Patients and patient advocacy organizations should be involved in health AI discussions, but there is a wide variation in comfort levels.

- Some organizations are still learning about different types of AI systems.
- Other organizations do not have the time or resources to dedicate to AI.
- Some organizations do not feel like they have buy-in from leaders in their organization to dedicate additional time and resources to AI.

Patients often only see the "tip of the iceberg" when it comes to the use of AI in their health journeys.

- Most patients do not think about AI until they interact with ChatGPT-type tools.
- Lack of understanding can lead to mistrust and stop patients from fully consenting.

Patient advocacy groups are concerned about misinformation related to AI.

- On the patient level – concern about misinformation from AI tools or being overwhelmed with the amount of information AI provides them access to.
- On the provider level – those who don't understand AI tools might tell patients to "not use the internet" to prevent the spread of misinformation, causing potential trust issues between providers and patients and towards AI adoption.

Biggest Concern for AI: Prior Authorization & Utilization Management (UM)

Worried about health plans using AI to deny claims:

- Mass or accelerated denials of claims may decrease patients' access to needed care
- Prior auth denials and UM practices might harm patient-provider relationships

AI is not the only problem with prior auth:

- Underlying problem is not just the use of AI, but AI scaling existing problems in UM and prior auth
- Want both AI oversight and systemic reforms to UM (e.g., prohibiting/limiting step therapy requirements)

What else are patient advocacy groups concerned about with AI?

1 **Transparency and consent:** Patients want to understand how AI is used in their care; should have the ability to opt-out when appropriate; should be empowered to make informed decisions not overwhelmed by the volume/detail of information.

2 **Data Privacy:** Patients do not trust their data will be used responsibly – especially patients with rare diseases; patients are unable to decipher confusing data privacy policies. Few negative experiences dominate the AI narrative because of their severity, so needs to be discussed.

3 **Data Representation:** Worried that the data AI models are trained on is not representative of certain patient populations, which could reinforce disparities or outdated assumptions.

4 **Overlooking populations:** Tech developers may choose to not create AI tools for certain populations if they feel that they are too complex – even if those populations could benefit.

What are patient advocacy groups most excited for with health AI?

1

Improving Patient-Provider Relationships

Tools that alleviate clinicians' burden and strengthen relationships with patients

2

Access to Care

AI tools can help bolster the workforce or screen/ triage patients – in many cases, AI tools are enabling care in areas that lacked services before

3

Language Accessibility

Generative AI tools can help with translation of medical information for patients with limited English proficiency

4

Care Coordination

AI tools can help patients keep track and understand their medical records better; can also help with coordination between clinicians and care settings

5

Patient Empowerment

AI tools could empower patients in certain processes like prior auth/ UM, asking questions to their clinicians, comparing costs, etc.

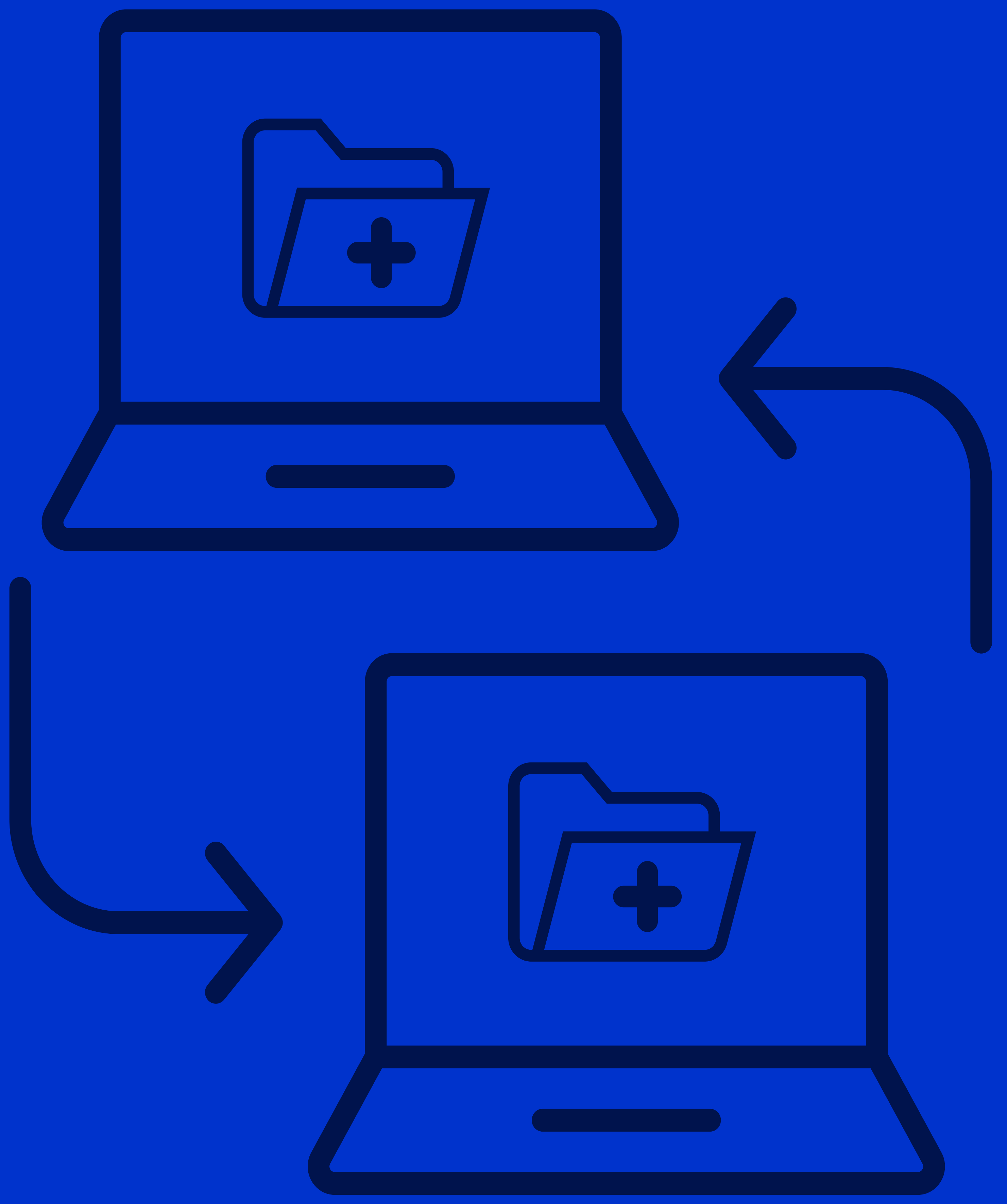
Cautionary Tale: EHR Rollout for Providers

EHR deployment did not go as smoothly as advertised:

- Providers were not considered in the rollout of EHRs – what was promised as a “modernization” solution led to additional burden and reporting without additional support
- Some providers were also left out of EHR deployment – mental health providers still often do not use EHRs, fragmenting care coordination
- Worries that consolidated data can cause issues for patients if misused (i.e., background checks)

Health AI implementation must be different:

- AI tool developers and implementers need to consider how AI tools fit into clinician workflows and other stakeholder processes
- Need to ask “who is left out” and make sure these gaps are addressed



Everyone needs more education on health AI

Patient advocacy organizations asked for more education for themselves to be well-equipped to educate the following audiences on health AI

PATIENTS

- Patients do not yet have a grasp on how health AI impacts theirm care to articulate their opinions
- Patients need education in understandable language – and specific to their needs – to meaningfully participate in conversations

POLICYMAKERS

- Policymakers are attempting to regulate health AI without understanding it
- Policymakers need a better understanding of what health AI is and to learn what areas matter most to patients — to prioritize issues when developing policy

INNOVATORS

- Innovators are creating new tools without understanding how or if patients will use them
- Tech companies need education on patient perspectives and concerns – but without overwhelming any one advocacy group

What should a patient-led health AI education campaign look like?

- **Easy to understand –** Provides baseline definitions and information in common language.
- **Gives examples –** Illustrate the number of ways AI impacts patients' health journeys – beyond "ChatGPT" – and identifies specific areas of opportunity in care delivery or treatments.
- **Positive –** Highlights where health AI operates in favorable ways and benefits patients without letting fear dominate the narrative.
- **Realistic –** After explaining how AI can help, be realistic and specific in concerns about AI on issues like privacy and security.
- **Judicious –** Selective in the information it includes to not overwhelm audiences with information. Prioritizes only what is most important.
- **Adaptable –** Beyond baseline education, patient advocacy organizations can tweak the language to adapt it to their member populations' needs.
- **Local –** Education materials should be delivered to patients and providers on a local level, by organizations who have trusted connections.
- **Timely –** Regulatory conversations are happening now, and patient advocacy organizations need to act quickly so patient voices are not left out.

What specific action items / resources did the group identify to support their activity on health AI?

1 **Education / Health AI 101:** A jointly-led education campaign that begins with creating a “Health AI 101” resource that organizations can all use and adapt.

2 **Consolidation of Resources:** A shared library of different organizations’ work / resources to date – will help with amplifying work that is already done, avoiding duplicative materials, and identifying gaps in information.

3 **Open Forums:** Opportunities for more frequent, streamlined, and targeted conversations with each other, CTA and AdvaMed, and innovators.

4 **Good Housekeeping Seals:** A simple benchmark that can help patient organizations and providers understand tech companies adhere to good practices. It MUST incorporate patient voices in development.