MEETING SUMMARY

PRESIDENT'S CANCER PANEL

REDUCING CANCER CARE INEQUITIES: LEVERAGING TECHNOLOGY OPPORTUNITIES TO ENHANCE PATIENT NAVIGATION:

TECHNOLOGY OPPORTUNITIES FOR PATIENT NAVIGATION

November 2 and 3, 2023
Virtual Meeting

This meeting was the second in the President's Cancer Panel's (the Panel's) 2023 series on patient navigation and technology. The meeting brought together stakeholders from many sectors, including the technology industry, health systems, and research. Participants discussed the current state of patient navigation and technology, barriers, and opportunities for the future. The meeting was available to the public via live feed, and members of the public were invited to submit written comments and questions during and afterward. Participants were encouraged to continue the conversation on social media using the hashtags #Tech4CancerNavigation, #PatientNavigation, and #NationalCancerPlan.

This meeting summary was prepared to satisfy requirements established by the Federal Advisory Committee Act. The summary provides an overview of presentations and discussions occurring as part of the workshop and does not necessarily reflect the views of Panel members.

President's Cancer Panel

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WELCOME AND INTRODUCTIONS

Dr. Elizabeth Jaffee welcomed attendees. She invited Panel members, speakers, working group members, and other attendees to introduce themselves. Dr. Jaffee then reviewed the history of the President's Cancer Panel, which was established by the National Cancer Act of 1971 and charged with monitoring the activities of the National Cancer Program and reporting to the President of the United States on barriers to progress in reducing the burden of cancer.

In April 2023, with leadership from National Cancer institute (NCI) Director Monica Bertagnolli, the U.S. Department of Health and Human Services (HHS) released the National Cancer Plan, a long-term initiative to meet the goals of President Biden's Cancer Moonshot.

Two of the eight goals of the National Cancer Plan are to Eliminate Inequities and Deliver Optimal Care. Through this meeting series, the Panel will prospectively assess the needs related to these goals, focusing on gaps and opportunities related to the use of technology to support cancer patient navigation. To assist with the meeting series planning, the Panel created the Working Group on Addressing Inequities in Cancer Care through Innovative Navigation Models.

There are many definitions of the term "patient navigation." Dr. Jaffee shared the definition that the Panel would be using for the day's meeting.

Patient navigation is a person-centered healthcare service delivery model that aims to overcome individual and systemic barriers to accessing timely and quality cancer care. It is an evidence-based intervention demonstrated to reduce disparities in cancer care.

Navigation may be carried out by various members of the healthcare team, including, but not limited to, patient navigators, community health workers, social workers, physicians, and nurses.

Navigation may also be achieved through systems and resources that are not directly managed or delivered by a member of the healthcare team.

For this series, discussion is focused on navigation to improve access to care for patients from the time of suspected or confirmed cancer diagnosis through the end of active treatment.

The first meeting of this series was held October 17, 2023. Themes that emerged during that meeting's discussions included the importance of trust between communities, health systems, and technology; navigation and technology considerations that account for age, geography, and culture; and how to develop and implement best practices for navigation technologies.

The third meeting in this series, focused on policy, is scheduled for December 7, 2023. More information about that meeting is available on the Panel website.

Dr. Jaffee introduced meeting facilitator Mr. Scott Wheeler, who reviewed guidelines for the day's discussion.

NAVIGATION TECHNOLOGY REACH AND ACCESS

Amila Patel, PharmD, BCOP, Chief Clinical and Strategy Officer, Navigating Cancer

Dr. Patel was an oncology pharmacist before she transitioned to the healthcare technology sector. She saw an opportunity to help enable better cancer care delivery and patient outcomes through technology.

Navigating the cancer care journey is burdensome for patients due to a complex and costly healthcare system that leaves patients behind. Major issues include delays in care, unmet social support needs, financial toxicity, reactive symptom management, high acute care utilization, and misaligned end-of-life care. Modern cancer care delivery is fragmented, and, despite advances in cancer diagnosis and management, access to patient-centered, high-quality care in the United States is challenging.

Many technology companies are attempting to address pain points in the cancer care continuum, from prediagnosis to survivorship and end-of-life care. Digital solutions for care navigation are effective at enhancing quality and often support value-based oncology care initiatives. Analysis of technology's influence on care through large multi-center studies has found many benefits, including increased health-related quality of life, fewer emergency department visits, reduced length of hospital stays, and reduced treatment-related toxicities.

Despite these significant benefits, broad implementation of digital solutions remains a challenge. Significant barriers exist for all stakeholder groups, including patients, providers, payers, and technology systems.

Dr. Patel and her colleagues conducted a hybrid implementation-effectiveness evaluation over the course of three years to assess improvements in care delivery and better patient outcomes. They concluded that successful implementation and use will depend on driving adoption and engagement, improving operational efficiency for care teams, shifting to more proactive symptom management, addressing demographic barriers to technology adoption and use, and consistently evaluating the effectiveness of solutions to drive lower costs and better outcomes. To achieve successful adoption of the technology, they leveraged both “quick wins,” like a simplified registration process for patients, and long-term investments, like deeper electronic health record (EHR) integrations and data analytics.

Key takeaways from the process include:

- **Clinician buy-in:** Implementation plans should incorporate providers into the training process, with introduction of the digital health solution as part of routine patient care.
- **Design for patient diversity:** Tools must be designed to meet patients where they are and account for diverse patient populations.
- **Collaboration:** Partnership between technology vendors and clinicians is necessary for transformation of care delivery.
- **Data insights:** Health systems should gather both quantitative and qualitative feedback to continuously optimize the digital health solution.

QUESTIONS AND COMMENTS FOR PRESENTER

- The value-based payment model, as opposed to existing fee-for-service models, reimburses providers for providing care that results in positive outcomes and better patient support. There is a clear role in this framework for patient navigation.
- Patient needs regarding technology are diverse and individualized. Technology vendors should focus on ensuring that the tools they create remove as many barriers as possible.
- Interoperability is key to ensuring that technology tools work across health systems and teams and help preserve continuity of care.
- Dr. Patel and her colleagues at Navigating Cancer incorporate caregiver perspectives into the technology development process. Their tools are designed to ensure that caregivers have the same level of access that patients do.
- Introducing new technology immediately after a cancer diagnosis is challenging, as a patient may already be overwhelmed. Developers should consider the context in which a technology will be used to ensure that it does not create additional burden for patients and caregivers or clinicians.

DISCUSSION

Existing and Emerging Technologies for Patient Navigation

- In addition to any technologies introduced by their providers, many patients use direct-to-consumer products like mobile health applications that they download outside of a care setting.
- Some health systems use technological solutions quite early in the care continuum, concurrently with screenings. The tools are integrated with patients’ EHRs and enable more targeted outreach to those who are eligible, as well as more integrated documentation of treatment decisions and patient needs.
- Existing platforms for patient use are often focused on logistical concerns like appointment scheduling and test results. Some patient advocacy organizations have created tools for shared decision-making; broader use of these could help patients feel more informed and empowered in their care.
- There is an opportunity for technological solutions to integrate with EHRs and scheduling platforms. These tools could automatically analyze incoming data from clinic notes, prescriptions,

and treatment plans to match patients with the financial resources they may need to help prevent financial toxicity.

- Tools are emerging to automatically match patients with clinical trials, which will not only benefit those individual patients for whom standard-of-care treatment has failed, but also improve trial accrual. Currently, many trials are closed due to insufficient enrollment. The tools can also help patients understand trial eligibility criteria and connect them with resources to support travel, where needed.
- Some organizations are developing platforms to give patients more control over their own health records and care journey, connect them with the resources they need, and help them make more informed decisions.
- Kaiser Permanente is developing a tool called prospective navigation to partially automate the process of connecting patients with navigation and other resources and to reduce the number of unnecessary tests, treatments, appointments, and procedures. Both patients and their care teams can view and access the tool. The platform interfaces with a clinical library as well as patients' EHRs.
- An opportunity exists to create a patient-facing tool to capture family history. Systematically integrating these data into a patient's EHR and automatically evaluating them could help predict future cancer risk and other outcomes.
- Another area of opportunity is to create software to improve the informed consent process for clinical trial enrollment to make the process more transparent and accessible to participants.
- Not all patients have medical homes and up-to-date EHRs; this is a complicating factor that should be taken into consideration when developing tools.
- After-visit summaries may already be integrated into patient portals, but there are opportunities to improve the utility of this feature so that patients feel informed and empowered about their visit and next steps.
- Challenges and considerations include payment models for navigation technologies, how to capture relevant information from multiple sources (e.g., social determinants of health [SDOH] measures, EHRs, and wearables), and ensuring that a given tool has direct value to the patient. Developers should also take care to consider the entire oncology ecosystem and situate their products in the context of other existing processes and technologies.

Lessons Learned from Existing Technologies

- Current tools are most effective when they create a hub through which navigators can collaborate with one another and the entire care team. Linkage with patient health records is also an important feature.
- Technology should be usable by patient navigators in addition to providers and patients.
- Tools that provide opportunities for patients to state their needs are quite useful. A patient's needs and condition are in constant flux, including outside of visits to their provider, and it is helpful for them to get support addressing issues between appointments. Patients are more likely to use these platforms when they resemble other tools the patients already know and have used.
- To reduce burden, tools should be designed to be easily maintained and updated over time without creating disruptions in service or introducing errors. For example, chatbots must be continually retrained with up-to-date and accurate information.

- Systems should be codesigned with patients, in accordance with how they use technology. Many patients are already relying on unvetted artificial intelligence (AI) like ChatGPT to answer urgent or on-the-spot health questions. It is important to present them with alternatives that they can use and that will meet their practical needs.
- To reduce burden and administrative load for health systems and staff, as well as patients, technology companies should prioritize the development of tools that automatically mine and curate healthcare data.
- Providing patients with predictive analytics and education around those data can help them feel empowered to self-navigate.
- Technologies need an accountability pathway (e.g., an individual who can oversee the tool and mitigate risk).
- Platforms should be accessible not only to patients but also to their caregivers.
- Tools should save patients and navigators time. Any interface or function that creates friction will lead to a drop-off in use, but tools that improve efficiency and ease will naturally encourage adoption and uptake.
- A system-wide approach is required for widespread success. The same tools must be adopted and used across a health system, not just within a single team.
- The distress screening tool is an example of successful integration of navigation and technology within a patient's care experience. In some clinic settings and health systems, patients have become accustomed to completing the screener as part of their routine care.
- Practices and tools from other medical specialties should be considered, adapted, and adopted to get the best services to the patient.

Barriers to Technology Adoption and Use

- A major barrier to innovation is resource limitation, including within information technology departments. These professionals are typically supporting many programs and applications already and may be hesitant to add more.
- There are not yet business and payment models in place to support, adopt, and sustain new navigation technology.
- Physicians are experiencing administrative burden and technology fatigue. They may feel resistant to learning new tools.
- End users, whether providers, patients, or navigators, need context and understanding regarding a tool's purpose, function, and benefit to them. It is important not to lump new technologies together but to make a clear case for each.
- Digital and health literacy and language barriers can present significant obstacles, as can patient concerns about how their data will be used and whether their privacy will be protected.
- Large gaps remain regarding patient access to clinical data.
- New technologies must be interoperable with existing systems, especially health records.
- Trust is a significant barrier; end users need to be able to believe that a platform will provide benefit and not increase burden or cause harm. Developers can increase trust by evaluating and validating their platforms with patient-centered metrics before launch.
- A health equity perspective must be integrated into the development process.

- Many patients, particularly those in under-resourced communities, lack access to computing devices beyond smartphones.
- Existing tools do not provide sufficient context for the patient experience. Users may wonder why they are receiving specific messages or prompts, and this lack of clarity damages trust and willingness to continue using a platform. It is important to convey to patients that technological solutions are there to improve their experience.

Early Adopters: Patients, Navigators, and Providers

- When considering early adopters, it is important to focus on populations that have been historically underrepresented in care and health research. This can be achieved in part by partnering with those communities to develop technologies.
- Technology vendors should incorporate insights from early adopters all along the continuum of care and throughout the healthcare ecosystem.
- Cohorts of early adopters and testers should include those who will be using the tools in their regular workflows, particularly in late- and early-stage settings and in local and community clinics that may have fewer resources overall.
- The question of which early adopter groups to consider will vary by the type of technology being developed.
- Early adopters should be offered training and support, and developers should be intentional in integrating insights from these users.
- Academic institutions can also help validate new technologies.
- Technologically literate and savvy patients are another important group to consult. Their insights as regular technology users can be quite meaningful.
- “Early adopter” may not be the right term to use in this context if what is meant is focusing on the overall end user experience through beta testing. An optimal approach will include both beta testing and the incorporation of post-launch feedback from true early adopters.
- Technologies should reflect the population the technology is designed to support. An equity-first approach will help ensure that all communities have equal access and benefit from new tools.
- Clinicians can help increase the trust and uptake of new technologies with their patients; however, some technologies will be adopted outside of a clinical home. Those patients must still be able to access support and information about the tool’s role in their care.
- An important consideration is how new technologies will be adapted for or used by patients who are non-native speakers of English. Dr. Patel and her colleagues have found that many patients who are non-native English speakers will still use English-first or English-only tools; however, to support true equity, patients must be able to access health information and tools in their preferred language. It is often challenging to get funding support to translate existing tools.
- Developers and technology companies should identify how they intend to evaluate their technology and what kinds of metrics and feedback will be useful in refining and improving their tools.

DEVELOPING AND CURATING TRUSTED TECHNOLOGIES AND CONTENT

Irene Chen, PhD, Assistant Professor, University of California, Berkeley

AI is a rapidly growing component of healthcare. Unfortunately, algorithms are as vulnerable to bias as the humans who create and train them, and these biases are already increasing pre-existing health disparities and widening gaps in equity and access to care. Audits of these algorithms show that classifiers produced using state-of-the-art computer vision techniques consistently and selectively underdiagnosed under-served patient populations with lung and skin cancers. Yet awareness of this limitation is low; surveys have found that many people believe that incorporating AI and other technological tools will reduce bias and increase equity.

Dr. Chen's research focuses on questions of equity and fairness in the healthcare system. Creating equitable healthcare is challenging for many reasons, including significant existing disparities (e.g., maternal mortality for Black women in the United States), uneven sample sizes in datasets, differing distributions of data across subpopulations, and biased systems and datasets resulting in algorithmic bias.

Bias audits of algorithms are only one segment of the model development pipeline. Mitigating inequity will require incorporating an ethical lens into every segment:

- **Problem selection:** One of the largest disparities today in precision medicine is the focus on the health needs of a narrow subset of health conditions that primarily affect a select number of advantaged groups. Dr. Chen's work in intimate partner violence is already demonstrating the benefit that can be derived when the pool of research questions expands to include previously neglected populations and conditions.
- **Data collection:** Once a problem is identified and funded, the method of data collection and the populations included must be carefully considered. For example, 96 percent of existing genome-wide association study (GWAS) data has been collected from individuals of European descent. Data from these individuals is not generalizable to the entire global population, yet it is often treated as though it is.
- **Outcome definition:** The choice of label in machine learning problems can have large effects on the problem formulation. Diagnosis labels can have their own noise and bias.
- **Algorithm development:** Equity-aware algorithm development remains a large area of interest for the machine learning community. It is important for algorithm developers to account for differing levels of access to healthcare that can result in differing levels of data capture. Accommodating these differences will require modeling access to care as a latent variable, designing deep generative models to infer disease subtyping and alignment, and carefully integrating and comparing subtypes.
- **Post-deployment:** Bias audits will continue to be important as the role of technology in healthcare continues to expand. Although algorithms are often inscrutable, Dr. Chen and her colleagues are gaining insight into the ways algorithmic bias can manifest. These results can often be detected by studying the impact on different patient populations. Dr. Chen developed estimation techniques to determine which components are the strongest contributors to

discrimination. Understanding these underpinnings can help inform strategic resource allocation to address algorithmic biases.

Strategies for reducing algorithmic bias include carefully selecting which stage of the machine learning pipeline to address, framing equity problems as computational challenges, and keeping the end user in mind.

Large Language Model (LLM)-based chatbots are an increasingly common interface between patients and medical algorithms. Outstanding questions regarding the use of LLMs for equitable healthcare include:

- How can researchers audit black-box models?
- Can LLMs increase empathy in the clinical process? What do patients want from their providers and clinical LLMs?
- Can increased access to healthcare improve equity?

QUESTIONS AND COMMENTS FOR PRESENTER

- Analysis by Dr. Chen and her colleagues has found that the accuracy of chest X-ray scans differs across self-reported race groups and genders. The cause of this disparity is yet unknown. It may be related to reduced levels of access to care and imaging among under-resourced populations, or an artifact of the analytic process and the metrics selected.
- An anti-bias framework will require accurate metrics and a clear assessment of existing interventions, but it also requires a flexible and responsive view of fairness and equity. In some contexts, an equitable approach means providing additional support to specific populations experiencing health disparities. The science of equity assessment in healthcare is still relatively young, and new developments are continually emerging.

DISCUSSION

Promoting Equity in Early Engagement to Mitigate Harm

- Equity in technology design begins at the earliest stages of development, including problem formulation. Marginalized communities should be consulted as early as possible, and their input must be taken seriously. The needs of end users may not align with the intentions of designers, but incorporating the lived experience, needs, and preferences of these users is essential to avoid tokenism or superficial gestures toward equity.
- Conducting an ethnographic survey of a tool’s anticipated user base can provide developers with a great deal of important information and enable a collaborative, and thus more equitable, approach.
- Family organizations, community groups, local and national patient advocacy organizations, and community advisory boards also provide vital insight into the end user population and improve technology adoption. Broad engagement beyond these groups is also important. Investigators and research institutions can provide a different perspective as well.
- Regulation and funding requirements are the most effective levers to pull. Requiring and incentivizing an inclusive approach will get results.
- Structuring the feedback process to allow for rapid input and the integration of those insights will help accelerate the development process.

- Community engagement strategies should be tailored to the purpose of the engagement and how the tool will be used. Community members should feel empowered and as though their input is helping shape the process and inform important decisions.
- Grassroots input is a crucial source of data that has been historically overlooked. Patients, end users, and their communities can offer vital insights regarding medical terminology and their experiences of human and technological bias.
- Investing in data collection and analysis by humans and AI can help uncover human decisions that could taint downstream models if left unchecked.

How to Prevent, Detect, and Overcome Algorithmic Bias

- To help prevent and overcome algorithmic bias in U.S.-based technologies, data from immigrant populations should be compared with data from their home countries.
- Instead of attempting to prove that an algorithm is biased, investigators could work backward by identifying a disparity and tracing it to its source.
- Using observational data introduces confounding factors that are less of a concern with clinical data, but incorporating real-world data is important, as many patients do not have access to or the ability to participate in and contribute data to clinical trials. Without observational data, these patients and their experience may be overlooked.
- Creating more inclusive, more accessible clinical trials can help generate evidence that is relevant to the population being served.
- It is important to remember that data are filtered through human beings, who have the capacity for bias.

Challenges to the Inclusive Development and Evaluation of Trusted Technology

- Resources, particularly time and money, are limited, and limit inclusive technology development and evaluation. With funding, the *All of Us* Research Program was able to conduct thorough testing to ensure that its communications and user interfaces were truly accessible and usable to participants.
- Cancer-related stigmas differ by cancer type and by culture. More trust may be required to disclose certain cancer diagnoses.
- Technology must be accessible to people with disabilities, including those with low or no vision, hearing impairments, and limited mobility.
- New tools should be able to function on older device models and at lower bandwidths. They should work across multiple operating systems.
- Users who submit feedback should be notified that their input has been received and will be addressed.
- The accuracy and responsiveness of tools should be evaluated outside of the development environment, in the real world, with beta testing by the populations who will actually use the tools. This will help ensure that the group for whom each tool was developed will use and benefit from it.
- AI should be explainable and interpretable, with its accuracy rate and other metrics made clear to users. Like human providers, algorithms are not infallible, and transparency about this reality is key to maintaining trust.

- Investigators and technology designers should work to identify settings in which patients do not have access to tools and how this will limit the adoption, use, and effectiveness of new technologies.
- Technology developers should be trained on topics like medical ethics and stigma.
- Frontline care providers know their populations well and are an important resource. Engaging these individuals will build trust among patients as well as engagement among the providers themselves.

Strategies to Overcome Misinformation

- New patient-facing platforms should incorporate evidence-based health information for easy access.
- Providers should preempt a patient's turn toward misinformation by offering evidence-based, accessible communication up front wherever possible.
- Patients may seek information for which there is not yet an evidence base. Capturing data regarding these searches could help investigators create trusted communications that acknowledge these gaps and provide at least some accurate information in the interim.
- Providers, navigators, and developers should recognize and accept that many patients have already consulted the internet by the time they speak with a provider. It is important to implement standards and practices for addressing misinformation and to create an atmosphere of understanding so that patients feel comfortable sharing and discussing what they've found.
- Patients trust and will consult other patients regarding their experience with illness, treatments, technologies, and providers. Efforts to connect the patient community with accurate and up-to-date information will ripple outward.
- Providing patients with curated and trusted information will reduce their need to look elsewhere.
- Patient-led advocacy groups should receive funding to validate new technologies and information.
- Patients may turn to outside sources because they do not like what they hear from the medical community. Providers should provide sensitive information with care and humility.
- Many health system platforms can create a summary of a patient visit. Providing a patient with the information they need immediately after an appointment can reduce their chance of seeking that information from unvetted sources.

TECHNOLOGY POTENTIAL ACROSS THE CARE CONTINUUM

Kingsley Ndoh, MD, MPH, Founder and Chief Strategist, Hurone AI, Clinical Assistant Professor of Global Health, University of Washington

Dr. Ndoh reviewed the journey of a cancer patient, from diagnosis through survivorship and end-of-life care, then summarized the breadth of existing navigation-related technologies. The current landscape is broad and includes EHRs, patient portals, mobile health (mHealth) applications, telemedicine, AI-assisted care platforms, remote patient monitoring, and wearable devices like smartwatches.

Technology should reduce administrative and other burdens for both providers and patients, not create additional work. Tools like wearable devices, remote patient monitoring tools, predictive analytics, and chatbots and virtual assistants have the potential to automate tasks and relieve burden, but it is important that these and other technological tools support and not replace human interaction.

Today, AI tools can create personalized care paths for each patient based on their medical history, current health status, and specific type and stage of cancer. They can send out automated alerts and reminders for scheduled treatments, medication times, and follow-up appointments, reducing missed appointments. They can monitor patient health in real time and alert healthcare providers if any abnormalities or signs of health deterioration are detected. In the future, care delivery may be enhanced by augmented and virtual reality, advanced data analytics, and the integration of Internet of Things devices.

Technological tools have the potential to enhance the patient experience, improve data management and analysis, streamline treatment planning and management, and reduce errors and increase safety. Challenges to the adoption of new technologies include ethical concerns and algorithmic bias, data privacy and security, a lack of standardization across platforms and health systems, complex payment systems, gaps in technological literacy, and limitations in infrastructure like broadband internet.

On October 30, 2023, the White House released an Executive Order on the Safe, Secure, and Trustworthy Development and Use of Artificial Intelligence. The order addresses many of the topics under discussion in this meeting series, particularly bias and discrimination, algorithm sharing by industry, data privacy, and safety standards, as well as the responsible use of AI in healthcare.

Mitigating algorithmic bias in healthcare must begin with creating more diverse training sets. There is a significant discrepancy between the demographics of the United States population and the demographics of individuals whose data is used to train health-related algorithms. This mismatch results in biased algorithms that provide substandard care and poorer outcomes to populations that are already experiencing significant health disparities.

To address these limitations, Dr. Ndoh recommends international and inter-hospital collaborations and partnerships; explainable AI, in which human stewards maintain intellectual oversight of the tool; a multidisciplinary, user-centered development approach; patient and provider education; and unstructured supplementary service data text-message integration. Areas of opportunity include user-centered design, genetic counseling, the integration of oncology-specific generative AI, low-cost technologies like text messaging, and integration with genomic data to enable personalized medicine.

QUESTIONS AND COMMENTS FOR PRESENTER

- Dr. Ndoh emphasized the importance and urgency of implementing regulations, guidelines, and safety standards for AI. Failures of privacy or safety would damage public trust in technology and could jeopardize national security.
- Virtual reality technology could be used to provide patients with a more immersive experience when interacting with avatars and other AI supports.
- Mitigating bias is a complex challenge. Potential approaches include international collaborations, using synthetic data, and incorporating ethical and social factors into the technology development process. When evaluating the effectiveness of emerging tools, researchers should assess patient outcomes in addition to assessing how well the tools perform compared to existing solutions or processes.
- Research has shown that users prefer AI assistants that do not pretend to be human. Confusion about whether a user is addressing a person or a chatbot can reduce trust. Some studies have found that users rate an AI interface as more empathetic than a human provider, but only until they learn they are not interacting with another person. The user interface and language an AI

assistant uses must be curated very carefully in order to provide empathetic and effective support without misleading patients.

- In the digital age, users have come to expect that interactions through their mobile device will be with another human being. Survey respondents, for example, anticipate that a person will be reading and potentially responding to what they type in a free-text field.
- Synthetic data has its own limitations and should supplement but not supplant the intentional collection of primary data from a larger, more diverse population.

DISCUSSION

Opportunities to Leverage Technology to Enhance Patient Navigation

- Technological tools could be helpful in reducing financial uncertainty for patients, especially in the period directly after diagnosis. An automated system could match patients with the information and resources they need.
- Other solutions could help patients understand their treatment options and the evidence base for them.
- While not in scope for this meeting, participants noted that there are opportunities to use technology to:
    - Increase access to and uptake of screenings, including among family members of those recently diagnosed, and to guide patients through next steps following an adverse screening.
    - Help patients transition from active care to survivorship by providing detailed and accessible information about this next phase.
- There is an opportunity to integrate real-time, automated clinical trial matching into existing systems, particularly patients' EHRs, to connect patients with trials at earlier stages in their cancer journey.
- In addition to new tools, technological solutions could help integrate existing platforms and systems, streamlining workflows and connecting meaningful data points from clinic notes, information and resources, and EHRs.
- Potential solutions could provide targeted support during moments of transition for patients, such as leaving a particular care setting.
- Platforms could provide vetted information, context, and reassurance for patients during moments of vulnerability, such as high suspicion in a diagnostic phase.
- Platforms could help bridge delays in access to care by connecting patients with the providers they need. This is especially important for patients outside of health systems and those who have no clinical homes.
- Follow-ups after tests and scans are another area of opportunity. Automated notifications and appointment scheduling could help reduce administrative burden for team members.
- Technological tools could help navigators gain greater insights into patient burdens and needs and enable faster connection between patients and resources or support.
- Machine learning could be used to help assess navigators' workloads and assign cases.

- Technological solutions should help patients, navigators, and providers bridge different platforms and health systems to access records quickly.
- Current platforms to match patients with clinical trials include Deep 6 AI, Microsoft's tools, OncoLens, and Outcomes4Me.

Using Technology to Facilitate Smooth Transitions During the Patient Journey

- Technology could help bridge different health system platforms and consolidate patient records. This is especially important in multidisciplinary care; at present, important information may be lost in the transition between providers or specialties. These tools could also help support interoperability between the clinic and pharmacy, reducing administrative burden, delays in medication access due to insurance issues, and the risk of medical errors.
- Creating standardized resources for providers would ensure that a patient's entire care team is using consistent language and communicating effectively.
- Expanding the federal government's Health Information Exchange is another area of opportunity.
- Technological solutions could support an integrated tumor review board that crosses facilities. This strategy would require a navigator with access to all relevant data who could serve as an advocate and information broker for the patient.
- Other community points of coordination that could be better supported by technology include:
    - Social workers
    - Movement and rehabilitation
    - Education
    - Meal support programs
    - Transportation
    - Social support, including support groups for patients and families
- Patients entering the cancer care continuum must become researchers, gathering and synthesizing information from many sources, some of which may not be up to date or accurate. There is an opportunity for tools to deliver a consolidated body of knowledge tailored to the patient. The information in this repository would need to be vetted and continually updated.
- If support systems are not carefully designed, they could introduce errors, fail to connect patients with the resources and answers they need, and reduce trust.
- Current examples of tools to support transitions include the Personal Health Network Project; the CareApp program in Howard County, Maryland; and the Aunt Bertha platform.

Providing Consistent Access to Patients in All Settings

- Remote patient monitoring via wearable devices can help keep patients connected and their providers and navigators informed. Medicare and Medicaid currently provide wearable devices to certain patient subpopulations.
- The ability to provide consistent access and care is predicated on an evidence-based awareness of which strategies are effective.

- The optimal approach will merge in-person and technology-enabled care like telemedicine and automated appointment scheduling. Care can be delivered locally, with expertise accessed remotely.
- It is quite challenging, but vital, to democratize care between major cancer centers and under-resourced practices. Technology could help connect individuals in lower-resource settings with navigators and providers at larger health systems, but infrastructure remains a significant bottleneck.
- A better business model is needed to support clinical trials in under-resourced settings. Technological solutions could also support patients in these areas in enrolling and participating in clinical trials. The inclusion criteria for some trials may unnecessarily bar participation by these patients; gathering and analyzing data on this point may help identify meaningful ways to expand inclusion criteria and thus enroll more patients, including those with the greatest need and least access. Global information system mapping could help identify areas of greater need.
- The United States Department of Veteran Affairs (VA) has an integrated digital system that allows for a decentralized model of care. The system includes components like tumor boards, genetic counseling, and infusion sites. This model is made possible by the VA's self-contained system of care and might be challenging to translate to other payer models and health systems.
- Technology tools could help utilize and digitize access to state cancer registries that have "Rapid Case Ascertainment" programs, find cases in under-resourced areas, and target resources to those patients and communities.
- Remote patient monitoring can help care teams track blood pressure, blood glucose, weight, and activity. These tools have already been implemented successfully in local settings and rely on cellular data to circumvent the need for broadband internet access. Widespread implementation of this technology will require thoughtful consideration of the diverse needs and realities of different communities and settings.
- Technology solutions could help shift some of the workload from navigators to patients, empowering them to take a more active role in their treatment and care.

How Technology Evolves to Help Digital Health

- The Kaiser Permanente consortium has developed algorithms to extract complex cases and share them with a panel of offsite experts. The algorithm can match patients to specialists outside of their local clinical home.
- Some patient navigators use consumer communication platforms like WhatsApp as a pathway to reaching under-resourced populations. Once the patients have been engaged, the navigators transition them to a more secure system to protect their private health information.
- The Vanderbilt-Ingram Cancer Center has developed and validated a tool to support patient education. Resources from the tool can be deployed to patients who are awaiting an appointment or testing.

Strategies for Reducing Patient Concerns About Monitoring

- Patients are less likely to be concerned or feel "tracked" by new technologies that are introduced by trusted messengers.
- Providers and navigators can assuage or preempt patients' concerns by ensuring, and emphasizing, that any new tool is optional to use.

- Barriers to remote patient monitoring include the requirement for devices to be continually synced to the network, which can require effort by the patient. Patients will be more likely to invest this time and energy if they understand how the data will be used to inform their care.
- Activity trackers can be useful in helping reduce adverse outcomes associated with inactivity. Some devices are non-continuous, which gives the patient some sense of control over when their data are shared. These devices are already on the market and in use but have proven challenging to implement in lower-resource settings, as there are no payment models in place to support them.
- Remote symptom management can be quite challenging in oncology. Patients undergoing treatment are likely to have a significant number of side effects and symptoms, some of which may be emergent and others that may be addressed through interaction with a provider.
- The quantity of data and information provided to patients must be carefully titrated to ensure that patients feel informed and empowered, not overwhelmed. Mobile information should be integrated with evidence-based care.
- Algorithms to analyze data from wearable and mobile devices could help identify trends in an individual patient's status and suggest any relevant next steps.

Examples of Technology Tools in Rural and Community Settings

- Advancing Synergy developed a platform to support low-income breast cancer patients who receive care in community clinic settings. The platform was developed collaboratively with patients and was both patient- and provider-facing. It provided patients with netbooks that connected them with community-based navigation support, oncology expertise, and social workers. The platform has three levels: high touch, medium touch, and low touch. Patients identified as high touch, whether for reasons of medical or social need, have the most frequent communication with their care team. Data from this study showed that increased technological literacy led to increased engagement and better symptom management. Patients viewed the device provided as an important connection to their care team and a support in itself.

Wearable Technology in Low-Resource Settings

- There may be a role for wearable technology in these settings and an opportunity for discovery via capturing real-world data. In general, technological innovation is less of a barrier than funding and support. To advance this work and related innovation, the government could incentivize research in this area.
- Some existing treatments and care approaches require access to specific devices and are therefore not an option in lower-resource settings. Expanding access to devices and infrastructure and adapting these treatment approaches can help increase equitable care and outcomes.

EMERGING TECHNOLOGIES

DISCUSSION

Creating New Technologies That Can Be Easily Maintained and Updated

- Dr. Zhang and her colleagues in China have created a "living" knowledge base that can be continually updated with new information for patient navigators. The platform provides support for clinical decision-making and interfaces with patients' EHRs.

- Technology developers should be responsible for, and oriented toward, creating tools that can be easily updated. Collaboration between the technology sector, providers, and researchers can help ensure that needs like this are understood and met.
- An alternative approach could involve shifting the burden of oversight and updating from developers to users. This process would create additional work for health systems but would also empower them to feel confident that their tools and information are current and aligned with the most recent research. Organizations like the National Comprehensive Cancer Network license the content of their clinical practice guidelines, which are continually updated and an important resource for this kind of platform. However, these guidelines may not have been developed with sufficient data from under-resourced populations and should be applied with caution to patients from these groups.
- The field of oncology is progressing rapidly, and technology tools should be evaluated regularly to ensure that they are able to keep up with new developments in the field. Dr. Kolevska and her colleagues are testing an automated system that prompts users to review information every three months to ensure that clinical decisions are based on the most recent data. Real-world data are also important to incorporate, as these may better reflect a local patient population.
- Some health systems have created digital oversight committees to ensure that their tools are up to date, accurate, and not contributing to medical errors or bias.
- LLMs are adept at coding and could help identify where updates are needed.
- Platforms must also stay up to date with user hardware and operating systems.
- Chatbots may help patients gather enough information to formulate clear and meaningful questions to their providers.

AI to Enhance Patient Education

- Generative AI can populate information into navigation systems. Researchers could work with providers and gather data from patients with similar diagnoses to build and validate a dataset.
- Patients should feel empowered to raise questions with their providers, but they should also be informed. The sheer amount of information and misinformation on the internet can overwhelm providers when patients present it. Training patients to use validated AI chatbots could help them find and curate more reliable, relevant, and up-to-date information.
- It is important to remember that biomedical literature is, itself, historically quite biased, and that even scientific publications may have an agenda. Developers and clinicians should keep this context in mind when referring patients to, or drawing on, the literature to support patient education.
- Using augmented reality (AR) can improve users' understanding and retention of information. AR tools could be used not only for patient education but also to train navigators and providers. As this solution is not accessible for those with low or no vision, alternatives would be needed.
- Mobile technology is extremely effective at reaching broad audiences. There are many opportunities to use this technology to reach patients and providers.

Reducing Cost and Improving the Translation of Navigation Information with AI

- Machine translation was one of the first applications for AI and has progressed significantly over the last few decades. However, this progress is not universal; higher-resourced languages like English have received more attention and effort and have therefore benefited more from these advancements. Equity will depend on developing algorithms to support lower-resourced languages as well, and this effort, in turn, will depend on funding support.

- Digital navigation services also benefit providers. Some newer solutions help streamline the clinical workflow by simplifying the user interface from open-text fields to dropdown menus and decision trees. These efforts save time and money and reduce medical errors.
- The utility of health technology tools can be complicated by privacy concerns. Patients want information that is customized to their needs, but Health Insurance Portability and Accountability Act (HIPAA) regulations limit how, and how much, their personal health data can be used.
- AI could be very helpful in translating raw data from wearable devices like smart watches and fitness trackers into clinically relevant information. These tools could even provide automated alerts to patients regarding emergent symptoms and could help reduce the number of preventable emergency department visits, adverse events, and hospital readmissions. This would be especially beneficial in rural and remote areas in which care can be difficult to access quickly.

CLOSING COMMENTS

- Mobile applications have great potential for providing health education to patients.
- Many patients may have difficulty getting time off from work or finding the childcare necessary to attend frequent appointments with their physician or as part of a clinical trial. These logistical concerns may be an area in which technology can help, whether by reducing the number of unnecessary appointments or connecting patients with childcare support.
- Technological tools may also help fill a gap in helping patients and caregivers understand and navigate their insurance coverage and in helping them build financial literacy and competency.
- Another opportunity for technological tools is identifying which patients need navigation and how to help them, then connecting the patients to the appropriate local resources.
- When a patient transitions from a health system to hospice at home or in the community, the continuity of care may be disrupted, and the patient’s records and preferences may be lost. Technological supports could help provide continuity and ensure that a patient’s needs and preferences are understood.
- Technological tools can be used to improve uptake of annual screenings in high-risk populations, particularly for lung cancer, through reminders and directing patients to affordable screenings and follow-ups. It can also automate follow-up reminders for patients who need long-term surveillance following cancer treatment.
- AI could be used to detect precancerous lesions on scans before the lesions are visible to pathologists. However, the tools must be further refined. The use of AI in imaging and diagnostics is already resulting in an increase in incidental findings. Patients are learning their results without context. It will be important to improve both the sensitivity and accuracy of the AI tools and to provide clearer communication to patients to avoid creating undue concern.
- The utility of technological tools is limited not only for the end user but also for health systems. Incentivizing interoperability and cooperation among technology vendors and developers could help resolve friction and lead to better patient navigation and care.

CLOSING REMARKS

Panel members thanked presenters and participants for their productive input and discussion. The Panel and Working Group will consider the information provided during this meeting and others in the series as they develop recommendations to be included in the Panel's report to the President. Additional written testimony and comments can be submitted at any time to the President's Cancer Panel via email (PresCancerPanel@mail.nih.gov).

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *Reducing Cancer Care Inequities: Leveraging Technology Opportunities to Enhance Patient Navigation: Technology Opportunities for Patient Navigation,* held on November 2 and 3, 2023, is accurate and complete.

Certified by: ____ Date: January 21, 2024

Elizabeth M. Jaffee, MD, FACR, FAACP

Chair

President's Cancer Panel