MEETING SUMMARY
PRESIDENT'S CANCER PANEL
REDUCING CANCER CARE INEQUITIES: LEVERAGING TECHNOLOGY OPPORTUNITIES TO ENHANCE PATIENT NAVIGATION: OPPORTUNITIES FOR ENHANCING PATIENT NAVIGATION

October 17, 2023
New Orleans, Louisiana

This meeting was the first in the President's Cancer Panel's (the Panel's) 2023 series on opportunities related to the use of technology to support patient navigation. The meeting brought together stakeholders from many sectors, including clinical care, healthcare systems, health technology, and advocacy. Participants discussed barriers and opportunities related to patient navigation and technology. 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 after the workshop. 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

Elizabeth M. Jaffee, MD, FACR, FAACP, Chair
Mitchel S. Berger, MD, FACS, FAANS
Carol A. Brown, MD, FACOG, FACS

National Cancer Institute, National Institutes of Health

Maureen Johnson, PhD, Executive Secretary, President's Cancer Panel

Working Group on Addressing Inequities in Cancer Care Through Innovative Navigation Models

Tracy Battaglia, MD, MPH, Professor of Medicine and Community Health Sciences, Boston University Schools of Medicine and Public Health, Boston Medical Center
Ricki Fairley, MBA, CEO and Co-Founder, TOUCH, The Black Breast Cancer Alliance
Michelle Mollica, PhD, MPH, RN, OCN, Deputy Director, Office of Cancer Survivorship, National Cancer Institute
Kingsley Ndoh, MD, MPH, Founder and Chief Strategist, Hurone AI, Clinical Assistant Professor of Global Health, University of Washington

Participants

Valerie D. Bouldin, MEd, Acting Director of Boards and Commissions, City of New Orleans
Elizabeth Calhoun, PhD, MEd, Professor, University of Illinois at Chicago
Heather Ciccarelli, MSW, Director, Patient Navigation Initiative, American Cancer Society
Mary Cosper, LCSW-BACS, MPH, Patient Services Director, Cancer Association of Greater New Orleans/Cancer Association of Louisiana

Monica Dean, Director of Patient Navigation Program Development, Academy of Oncology Nurse & Patient Navigators

Andrea Dwyer, MPH, Director, Colorado Cancer Screening Program, University of Colorado

Bilikisu Elewonibi, PhD, MPH, Assistant Professor, Department of Epidemiology and Population Health, Louisiana State University Health Science Center New Orleans

Linda Fleisher, PhD, MPH, Research Professor, Cancer Prevention & Control, Fox Chase Cancer Center

Paul Friedlander, MD, Professor, Department of Otolaryngology, Tulane University School of Medicine, Chief of Otolaryngology, Southeast Louisiana Veterans Healthcare System

Sharon Gentry, MSN, RN, HON-ONN-CG, AOCN, CBCN, Program Director, Academy of Oncology Nurse and Patient Navigators

Darcie Green, Executive Director, Latinas Contra Cancer

Angela Hammett, MSN, RN, Director of Patient Navigation and Support Services, Mary Bird Perkins Cancer Centers

Eugene Lengerich, VMD, Professor of Public Health Sciences and Family & Community Medicine, Penn State University, Associate Director for Health Disparities and Engagement and Director of the Office for Cancer Health Equity, Penn State Cancer Institute

Gina McWhirter, RN, MSN, MBA, Director, VA National TeleOncology, Department of Veterans Affairs

Samyukta Mullangi, MD, Medical Director, Thyme Care

Phyllis Pettit Nassi, MSW, Associate Director, Office of Community Outreach & Engagement, Huntsman Cancer Institute, University of Utah

Augusto Ochoa, MD, Deputy Director, LSU-LCMC Cancer Center, LSU Health New Orleans

Steven R. Patierno, PhD, Deputy Director, Duke Cancer Institute, Charles D. Watts Distinguished Professor of Medicine, Professor of Pharmacology and Cancer Biology, and Professor of Family Medicine and Community Health, Duke University School of Medicine

Gabrielle Rocque, MD, MSPH, Associate Professor, Divisions of Hematology & Oncology and Gerontology, Geriatrics, & Palliative Care, University of Alabama at Birmingham

Elizabeth A. Rohan, PhD, MSW, Health Scientist, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention

Shinobu Watanabe-Galloway, PhD, MA, Professor and Dr. Tim Hawks Chair in Cancer Prevention and Population Science, Department of Epidemiology, College of Public Health, University of Nebraska Medical Center

Stephanie Wheeler, PhD, MPH, Michael S. O'Malley Distinguished Professor, Department of Health Policy and Management, Associate Director of Community Outreach and Engagement, UNC Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill

Valarie Worthy, MSN, RN, Nurse Navigator, TOUCH BBCA

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 of 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 would focus 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 second and third meeting in this series, focused on patient navigation technology and policy, respectively, are scheduled for November 2–3 and December 7, 2023. More information about those meetings is available on the Panel website.

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

PATIENT NAVIGATION NEEDS

Ricki Fairley, MBA, CEO and Co-Founder, TOUCH, The Black Breast Cancer Alliance (BBCA)
Valarie Worthy, MSN, RN, Nurse Navigator, TOUCH BBCA

Ms. Fairley and Ms. Worthy are long-time survivors of breast cancer who became patient advocates. Their dual experience as survivors and experts in community engagement provides an important lens on cancer patient navigation.

Patient navigation is necessary to improve cancer outcomes by reducing the barriers that would prevent patients from following and completing their treatment plans. Needs may include:

- Coordination of care, providing support with appointments, referrals, tests, procedures, and other consultations

- Health education around diagnosis, treatment, side effects, clinical trials, and shared decision-making

- Financial resources for patients and caregivers, including navigator care

- Psychosocial and emotional support for patients and their families

- Advocacy to ensure a patient is heard

Navigators are experts in their fields, but patients are experts on their own lives and experiences. A navigator's first action should be to ask a patient three questions: "How do you feel about this diagnosis?" "What do you know about cancer?" and "What are your support systems?" These indicators can immediately help a navigator guide a patient toward the resources, information, and support they need.

Patient navigation is a vital component of cancer care, but not every patient will require the same level of navigation support. With limited resources, navigators should triage their patients in order to direct their efforts toward the patients who need them most. Navigators must also be keenly aware of the resources available in their community, especially those like advocacy organizations and peer groups that can be accessed after hours. Ms. Fairley and Ms. Worthy's organization, TOUCH BBCA, offers a support group with virtual weekly meetings and a nurse navigator program that includes an all-hours help line for urgent questions.

In conclusion, Ms. Fairley and Ms. Worthy emphasized the vital role navigators play in a patient's cancer journey.

Questions for Presenters

- Many TOUCH BBCA referrals come from social media, where the organization hosts a weekly series called The Doctor Is In. Each episode of the series reaches between 5,000 and 10,000 viewers. Other people find the organization through search engines and word of mouth.

- TOUCH BBCA offers support across the United States, with greater concentration near urban areas. Patients who work with the organization often go on to create TOUCH BBCA chapters in their communities.

DISCUSSION

Navigation Across the Care Continuum

- Participants agreed that navigation is a vital resource at every stage of a patient's cancer journey, from diagnosis to survivorship or end-of-life care. While the focus of this meeting was limited to the portion of the journey that begins at diagnosis, navigation support could also be extremely meaningful in the earliest stages, when a patient has begun to suspect that something is wrong with their health but may not yet have a medical home, or during the challenging period before undergoing screening and follow-up or receiving a diagnosis.

- Community navigators and health workers are trusted experts and thus have a fundamental role in bringing patients into cancer care systems.

- The approach to care should be bidirectional, not only meeting patients where they are but also helping them get where they need to go. This may include fostering connections between small local clinics and larger cancer centers.

- Technology should be easy to use and reduce the burden for patients. At present, navigation of the healthcare system requires a great deal of health literacy, technological literacy, and administrative labor. Obstructions like long wait times on phone lines, limited office hours, or difficult-to-navigate patient portals make it even more difficult for patients to access the care they need.

Diverse Patient Needs

- Patient needs are highly variable and are influenced by many socioeconomic and demographic factors. Specific considerations identified include:
    - Some patients change geographic locations and lose continuity of care, and others must travel long distances to see a provider.
    - The levels of funding and other resources, including navigators, available to each community are inconsistent.
    - In some locations, more resources may need to be allocated to transportation or housing support; navigators must be able to prioritize the communities in greatest need.
    - Patients and communities have differing levels of access to technology and supportive infrastructure.
    - LGBTQIA patients experience significant health disparities and often lack access to safe, respectful care. These patients may be more likely than average to be diagnosed in an emergency department setting and may not have a trusted primary care provider.
    - Economic awareness and need are significant concerns, not only at baseline but also in the context of cancer-related financial toxicity.
    - Navigators need access to a patient's health system and its technological platforms.
    - Carers and family members must understand how to support the patient. Navigators and systems should ensure that family members or caregivers are allowed to act as notetakers, translators, or technological support.
    - Care must be culturally competent, and patients should be addressed in the language they speak, not only in person but in all communications. This can be helped by building a more diverse and representative workforce that mirrors the local community.
    - Not all patients will have caregivers or family support.
    - There is significant cultural stigma around illness, particularly cancer, which intensifies the need to communicate sensitively and respect patients' privacy and wishes.

Needs and Questions Navigation Can Address

- One of a navigator's primary roles is to remove barriers between patients and the care and support they need, whether that means understanding a treatment plan or finding housing assistance.

- Patient needs change over time. Effective navigation is a longitudinal process. Navigators must continue to ask patients questions to ensure they are providing appropriate and meaningful support in the areas of a patient's greatest need.

- Navigators can act as a bridge between patients and providers who may not share the patient's background or experience. They can act as advocates for their patients when needed.

- Education is an important aspect of navigators' work. They can offer clarity, demystify medical language, assuage fears, address myths or misunderstandings, and help patients understand their condition and treatment options in order to make more informed decisions.

- Some navigators offer support for clinical as well as nonclinical issues. Navigators should be both proactive and reactive in their work.

- Navigators may also be able to help support patients with lower technological literacy in accessing the information and tools they need.

- Some areas of navigation, like interfacing with insurance companies or billing departments, require specialized skills, experience, and relationships.

- Navigators also act as care coordinators.

Variable Needs by Cancer Type and Treatment Plan

- Each cancer type presents unique challenges to patients and requires tailored support from navigators. Each patient subpopulation, including younger patients and those with head and neck cancers, has different needs, concerns, and life circumstances.

- Patients with rare cancers may need more highly specialized support and more hands-on assistance connecting to care and clinical trials, particularly outside of urban areas and large cancer centers.

- Some cancer treatments and their consequences (e.g., ostomies) may create new medical challenges that require a great deal of adaptation and support.

- Much of the existing research literature on cancer patient navigation pertains to breast cancer; there is significantly less information about navigating other cancers.

- Healthcare in the United States is highly specialized and fragmented; just as oncologists may specialize in one cancer type, so too may navigators need to—or choose to—focus on one particular cancer type or patient subpopulation.

- However, a well-trained navigator should have the core competencies to support patients with any cancer type.

- The most effective navigators are those who can connect with their patients, often through shared background or experience, regardless of cancer type or treatment plan.

OPPORTUNITIES FOR IMPROVING PROVIDER- AND SYSTEM-BASED NAVIGATION

Tracy Battaglia, MD, MPH, Professor of Medicine and Community Health Sciences, Boston University Schools of Medicine and Public Health, Boston Medical Center

Dr. Battaglia presented an implementation science framework for identifying gaps and opportunities in patient navigation.

In 2014, Boston was named among the worst cities for breast cancer disparities between Black and White women. Dr. Battaglia and her counterparts at organizations around the city came together to understand the local causes of this issue and find solutions. They determined that although evidence-based strategies for patient navigation existed, those strategies were not being implemented consistently in health systems across the city. They found inconsistent approaches even within individual hospitals.

Dr. Battaglia and her colleagues received a collaborative innovation award from the National Center for Advancing Translational Sciences (NCATS) to investigate further with a Type 1 effectiveness

October 17, 2023

intervention trial. The trial identified three general barriers: lack of reliable systems to identify eligible patients in need of navigation, lack of communication across cancer departments and navigation teams, and capacity of navigators. Study data indicated that 50 percent of breast cancer patients did not receive navigation support, and only 35 percent received navigation that included screening for social needs. The team used mixed-methods analysis to build a comprehensive model of obstacles to the implementation of evidence-based navigation. The data identified specific barriers at each point in the navigation continuum.

- **Patients** lacked awareness of navigation resources and assistance identifying unmet social needs.

- **Providers and teams** lacked defined roles in the navigation process and communication between navigators and providers.

- **Organizations** lacked systems to identify which patients needed navigation, electronic health record (EHR) systems to support documentation and reporting, and policy or central oversight regarding navigation; they also experienced fragmentation of their oncology services.

- **Community resources** lacked coordination with healthcare systems.

- **The workforce** lacked funding, policy support, training, and recruitment resources.

These findings are supported in the scientific literature. A systematic review published in June 2023 identified similar barriers at the individual, provider, and system levels. The review also importantly identified facilitators, or factors that improve access to and effectiveness of cancer patient navigation. Facilitators included culturally competent and bilingual navigators; training for staff; effective communication within and across teams; and the use of technology to reduce administrative burden.

The Colorado Cancer Screening Program and the National Navigation Roundtable created a framework for considering the complexities of implementing patient navigation in real-world settings. The model, called the Patient Navigation Sustainability Assessment Tool, incorporates funding, workforce development, integration with clinical workflows, and more.

In conclusion, Dr. Battaglia highlighted the many opportunities for technology to enhance patient navigation at all levels of the cancer care continuum, from individual patient experiences to systems and policies.

Questions for Presenter

- To increase awareness among and relationships with healthcare providers, it will be important to implement internal systems to ensure awareness of staffing, roles, and responsibilities. She emphasized that navigation occurs as part of a team, and that it's important for providers to understand what their navigator colleagues do and how they can help.

DISCUSSION

Navigator and Navigation Needs for Optimal Cancer Patient Support

- Participants supported the idea of a centralized navigation portal or database to connect navigators with detailed information about local resources, opportunities for training and professional development, other navigators, and information about clinical trials. The database would need to be continually updated to ensure the information remains accurate and useful.

- Navigators need providers to be aware of navigation and of their navigator colleagues, and to understand how, why, and when to call for their support.

- Navigators need a sustainable source of funding for their work. Philanthropic support can be inconsistent. There is ample evidence that patient navigation decreases costs for hospital systems and payers. These organizations would benefit from investing in navigation.

- Navigators need standardized metrics of success in order to continue to demonstrate the value and importance of their work. Standards exist and have been published but need to be more widely adopted. Ensuring that data collection systems are easy to implement and use will increase uptake.

- Navigators need champions within health system leadership who will support their funding and promote their work.

- Patients being treated at specialized cancer centers may need local navigation support when they return home. It is important for navigators to be able to connect to one another to ensure a patient does not slip through the cracks.

Most Important Outcomes Patient Navigation Can Support

- Outcomes supported by patient navigation include

  - Decreased hospital readmissions

  - Adherence to treatment protocols

  - Decreased no-show rates

  - Synchronized insurance approvals with appointments

  - Fewer emergency department visits

  - Patients feeling supported and heard

  - Increased trust between patients and their communities and the healthcare system

  - Patient education and empowerment

  - Increased patient satisfaction

  - Referrals to mental health providers

  - Referrals to specialists and for follow-up visits

  - Increased navigator connection to local communities and awareness of the resources available

  - Reducing burden on other members of the healthcare team so they can prioritize their tasks

  - Greater enrollment in clinical trials

  - Reducing clinician burnout

  - Demonstrating the business case for patient navigation

Critical Engagement Touchpoints for Patient Navigation

- Critical engagement touchpoints include those patients who have not yet been diagnosed and those who have lost access to care. Identifying these patients early on allows navigators to

provide support before conditions—medical, financial, or otherwise—worsen. Technology could help identify these patients and others at points of greatest need.

- Navigation-related metrics should be built into existing data collection. Distress screenings could be as routinized as recording a patient's height and weight.

- It is not enough to capture data; those data must be actionable, useful, and of high quality. The data should be accessible to health systems and to patients.

- Patients need access to technology in order to access care. Navigators could partner with agencies and organizations that connect individuals with resources like broadband internet and mobile devices.

- No single solution will work for all patients, or even for the same patient over time. Navigators and their teams must be adaptive.

Additional Navigator and Navigation Needs

- Navigators need professional supervision and support.

- Navigators need professional development and training. This will require additional sustainable funding for navigation. Navigators should be able to bill for and accredit navigation services in order to move the professional community forward.

- Navigators need on-the-job experience and interaction with peers.

- The patient navigator profession needs national general navigation standards that will not detract from existing specializations or pull navigators away from the specialized subpopulations (e.g., Spanish-speaking communities) they serve.

- The process of developing models for payment should include payers. This framework creates its own challenges and opportunities but will allow navigators to bridge many different care settings.

- Navigators need to be looped in to care outside of hospital settings, including at-home palliative care.

- As telehealth continues to grow, navigators should be included in the development of policies and best practices. Navigators can help patients connect to and access telehealth appointments and other technological supports.

- Navigators need to ensure that patients are not being left behind by technological advancement or other changes in medical practice. Grassroots efforts and peer education can support this goal.

- Navigators should partner with community organizations like churches and health centers to create trusted spaces for patients to interact.

BARRIERS TO TECHNOLOGY USE

Andrea Dwyer, MPH, Director, Colorado Cancer Screening Program, University of Colorado

Dr. Dwyer and her colleagues work to quantitatively assess issues related to technology in patient navigation. In their research, they have found that:

- Patients' medical information is spread across different provider platforms. Patients need to manage logins to multiple portals, which causes confusion and makes it difficult to track the continuum of care.

- One of patients' primary frustrations is communication with office staff. Working patients have difficulty calling into the appointment line during business hours and may need to make several phone calls. Appointment reminders and other automated systems could be refined to provide more efficient support.

- Many technologies, including patient portals, are not patient friendly and do not seem to have been designed with the end user in mind.

Barriers to the use of technology vary widely depending on demographics and other factors. Technological accessibility and literacy, cultural differences, and health literacy all impact many aspects of care, from making appointments to accessing portals for results and important materials.

Navigators and providers experience additional barriers to implementing and using technology with patients. Cancer centers and providers in remote, rural, and under-resourced areas may not have the funding to implement high-tech solutions and the newest platforms. Tracking patients across platforms is complex and may have privacy implications. Artificial intelligence (AI) and business intelligence (BI) could help solve this issue, but these tools are not consistently accessible. Another barrier is variability in metrics for patient navigation implementation. Definitions of patient navigation vary widely, and data are collected from many different sources. Information sharing can be complicated, as each provider or system may have its own platform, and navigators need to be able to quickly contact providers.

There are downsides to technology-augmented navigation. Communication and information sharing are complex and require access to many different systems. Providing information to patients via web links requires navigators to put in work to ensure that their sources are accurate, credible, accessible, and up to date; in addition, patients have their own preferences regarding how they want to receive information. Incorporating AI could also create additional work, as navigators would need to confirm that the tool was providing accurate, useful information in order to prevent negative impacts on patient care and outcomes. Technological literacy remains a significant limitation on technological tools' potential.

The human side of patient navigation, particularly building relationships with patients, is central to navigation's effectiveness. Technological tools must not disrupt, block, or break this trust. Many navigators also note that tools for navigation do not seem to have been developed with end users like themselves in mind.

DISCUSSION

Barriers Patients Face to Using Technology

- There is a significant difference between the many technologies that exist and those that are actually used. The implementation of technology does not ensure its utility or uptake by patients. Many factors contribute to this divide:

    o Education and training; people cannot use technologies if they don't know how

    o Infrastructure challenges, including disruptions created by extreme weather events

    o The quantity and quality of information, which may be overwhelming and difficult to understand

- Information may be disseminated through technological platforms like patient portals without context, leading to further confusion, such as when a patient receives lab results without any explanation of what those results mean.

- Even for users comfortable with technology, it can be difficult to navigate systems to get information and answers.

- Assumptions are made about "easy" technologies like Zoom. Users still need training to understand how the tools work.

- Much of the power of interactions with providers comes from human connection and nonverbal communication. It is unclear how technological tools could reproduce that aspect of care.

- Introducing technology may diminish trust between a patient and provider. It is important for navigators to introduce any new technology to patients in context and to explain that the tool will not replace human interaction. Insufficient explanations could damage trust and understanding between patients and navigators. Patients are also concerned about the privacy and security of their data. When introducing a new tool, navigators should be prepared to answer related questions and assuage concerns.

- Technology is often not accessible to users with disabilities. Closed captions, braille, and other adaptations should be built into tool design.

- Economic need is a very significant barrier. Even patients who are technologically fluent and want to use new tools will be unable to do so without the funds to buy and maintain devices. Additionally, patients in need may still not quality for services.

- Each person has their own preferences regarding how they learn and communicate. Video calls may be optimal for some patients but challenging for others. Patients who experience obstacles with literacy, numeracy, health literacy, and financial literacy may feel too embarrassed to admit that a tool does not work for their skills, abilities, and needs.

- The barriers a patient encounters are specific to their background, experience, and demographics. Older patients and younger patients, for example, have unique challenges and concerns.

- Caregivers are not often considered part of the end user group, but they often need access to the same information patients do.

- Another barrier to accessing navigation and other care is privacy. In many communities, large households are common. Sharing a home may make it difficult to keep telehealth appointments and make phone calls. Household members may also share devices, making it challenging for a patient to consistently use a device to access care.

- Programs to provide broadband internet, devices, and other technology supports are only helpful if they are sustainable. Patients and their families need continuous, reliable internet access and devices in order to use technological tools.

- Technology cannot provide a solution for every patient. Some patients have had bad experiences with technology in the past, while others find the tools inaccessible. Historically, these patients have been labeled non-compliant, which affects their access to quality care in the future. Navigators must be prepared to adapt and find alternative means to ensure no patient is left behind.

Opportunities and Next Steps

- An area in which technology could be especially helpful is in making and rescheduling appointments. Current systems are not working for patients or providers. There is an opportunity to improve the experience and thus decrease canceled or missed appointments and loss to follow-up. The same is true for asking medical questions and completing and uploading documents, neither of which are easy for patients to accomplish in their portals now.

- Meaningful next steps could include encouraging journals to put out a call for publications regarding effective navigation technologies, as well as organizing conversations and opportunities to share best practices.

Barriers Navigators and Providers Face to Using Technology

- Clinicians are overburdened already and may not have time or capacity to integrate new technologies into their workflows. Even simple mobile applications have ethical, IT, and legal considerations; and the applications themselves take time to learn and incorporate.

- As technological tools become more widespread and patients receive more information, providers and their teams must be staffed and prepared to field more patient questions and communication, some of which may be urgent. Creating multiple channels creates multiple paths to accessing providers, who do not have capacity to respond to all inquiries.

- AI is increasingly being used for diagnosis but can sometimes yield inaccurate results and alarming false positives. Clinicians using these tools may have to do additional work to ensure the technology's findings are accurate.

- Interoperability creates additional barriers, as a patient's data may not translate between platforms or providers.

- Health systems and centers are willing to try new tools, but when those tools have not been thoughtfully designed, implemented, or launched, they fail, and the organization may become frustrated or disenchanted and default to using spreadsheets and other older solutions. Smaller organizations need the funding and information on the front end to select tools that are interoperable, effective, and will work in their setting.

- Providers and navigators may have different levels of access to platforms, which could lead to discrepancies or gaps in information within a patient's care team.

Downsides of Using Technology to Augment Navigation Services

- Patients can sense when navigators and providers are uncomfortable with technology, and this influences the patient's trust of the tool.

- There is a risk that technology, if not implemented thoughtfully, could minimize the human connection between patients and their navigators.

- Current technologies are not sophisticated enough to adapt to community-specific challenges and may reinforce bias and health disparities.

- Successful implementation of technology would improve relationships between patients and navigators, but only if the tool is truly the right solution for the situation.

- Local infrastructure in many communities cannot support a transition to further reliance on technology. If new tools are implemented without greater investment in infrastructure, health disparities—especially race-based disparities—will increase.

- Caregivers may have different preferences and skills than the patients they support. These important members of a patient's care team should have a seat at the table as new technologies are developed and tested.

- An area in which technology can be useful is resource management. Each navigator holds institutional knowledge that is often lost when they leave a position. Providing a repository for this information will help ensure continuity and reduce additional labor amid workforce turnover. This would also be helpful in onboarding new navigators who are recent arrivals to the community.

- Technology could be used to monitor and manage the volume of communications sent to patients. Excessive contact can frustrate patients and cause them to withdraw. It could also be used to connect patients to support outside of business hours.

CURRENT USE AND CHALLENGES TO ADOPTING NEW TECHNOLOGIES

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.

In a hypothetical use case for AI-assisted navigation, technology could help prevent missed appointments, reduce miscommunication and language barriers, avert adverse events by ensuring accurate reporting of side effects, and provide culturally appropriate support. Any navigation technology must be developed in consultation and collaboration with end users, including navigators and patients.

The benefits of adopting new technologies may include enhanced patient experience, improved data management and analysis, better treatment planning and management, and reduced medical errors and improved safety. Challenges include ethical concerns and algorithmic bias, data privacy and security, lack of standardization, payer systems, technological literacy, and limitations in infrastructure (e.g., internet access). Algorithmic bias is of special concern, as the majority of cancer data currently being used to train these platforms is heavily biased toward White patients and could exacerbate disparities if not equalized.

To address these limitations, Dr. Ndoh recommends international and inter-hospital collaborations and partnerships; explainable AI, or XAI, 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 (USSD) 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.

The U.S. government can support this important work by offering funding for technology and AI initiatives, regulating algorithmic transparency, incentivizing the collection of more diverse patient data, implementing standard guidelines for the ethical use of AI in cancer care, and supporting education and training programs.

Questions for Presenter

- Panel members asked Dr. Ndoh to explain USSD. The concept is similar to short messaging service (SMS) technology, which allows individuals to send and receive text messages without an internet connection.

- Dr. Berger asked Dr. Ndoh to identify how current AI technologies can be easily integrated into patient care and communication. Dr. Ndoh said that one immediate use for AI is targeting patients and understanding their needs based on demographic information like Z codes, which are factors influencing health status or reasons for contact with health services that are not classifiable elsewhere as diseases, injuries, or external causes.

- Dr. Brown asked for examples of successfully training AI on more diverse datasets. Dr. Ndoh mentioned the MIT Jameel Clinic, which is working to increase diversity in training sets and the accuracy of the resulting algorithms. Inter-center and international collaboration is an important path toward creating more diverse training sets, which result in more equitable and accurate algorithms.

- A participant noted that Z codes may present a deceptive or incomplete picture of a patient's circumstances. Dr. Ndoh agreed and added that Z scores can be combined with other data to create a more accurate profile.

- Dr. Ndoh noted that just as patients' needs are evolving, so, too, are the resources to support them.

- Although incorporating international data into training sets may increase diversity, it will not necessarily produce an algorithm that reflects the diversity of communities in the United States. The pathway to ensuring equitable and diverse algorithms is to build a diverse workforce that reflects and represents many different communities. Dr. Ndoh added that technology companies are working to increase staff diversity and now include ethicists in their AI development teams.

DISCUSSION

Organizational Challenges Associated with Adopting New Technologies

- Many of the technologies in use now and under development were created with patients and providers, not navigators, in mind and may not offer a path for navigators to access the system and find information they need. Mobile health applications often do not interface with EHRs—or, when they do, they may not be accessible to navigators, especially those working outside of hospital systems.

- Patients and navigators may be reluctant to use new applications, which require effort and time to learn. Users need to be trained, but many technologies do not include end-user trainings in their rollout.

- Data ownership is a complicated issue, particularly when health systems and providers are using multiple platforms.

- Launching new systems requires a great deal of time, effort, and staffing. Technology experts within the healthcare system are already overburdened.

- Different groups within healthcare systems compete for limited resources, including resources for technology. Navigators are typically not prioritized.

- Privacy and protecting patient's health data is a significant concern with programs created by for-profit third-party vendors. Health systems must ensure that these companies are not selling or compromising patient data. There may be a role in this space for nonprofit organizations and associations that are already trusted participants in the medical community.

- The proliferation of new technologies has saturated the market, making it challenging to identify which tools will be useful and effective for a given setting.

- Some hospital systems have cobbled together their own platforms to ensure they retain control of the data. This approach is inefficient and creates additional administrative burden.

- When developing, selecting, and implementing new tools, it is useful to distinguish between tasks that navigators may have taken on (like appointment reminders) and navigators' actual purview and work. Technology may be able to address one or both of these facets.

- Existing platforms are often not interoperable within and across care teams. When one provider makes a patient handoff to another provider or a navigator, their data may not follow.

Current Navigator Use of Technology and Benefits

- Some health systems have integrated their patient navigation portal with patient-reported outcomes and EHRs. Incoming patients undergo multiple psychosocial screenings, the results of which are entered into their EHR. Navigators and other team members use these data to assess patient needs and connect them with resources.

- A well-designed platform should not only help a navigator document their work but also help navigators provide more effective care and facilitate achievement of quality standards.

- Navigation technologies are new enough that there is not yet a large body of evidence from which to draw firm conclusions.

- Existing technologies are useful for supporting financial navigation and insurance questions. Platforms include real-time dashboards that allow document and application tracking.

- Duke Primary Care created a screening algorithm to identify patients at high risk for prostate cancer. The algorithm screened 59,000 patients and identified more than 500 young men with elevated PSA scores and aggressive disease. Screening data is shared with navigators, who then connect with patients to guide them to treatment. That program was presented to the North Carolina legislature and has since been adopted as the state screening guideline. Eleven other states are now following suit. This project required a significant upfront investment but has proven a cost-effective and life-saving measure.

- The ACCURE intervention trial aimed to address disparities in treatment completion between Black and White patients with breast or lung cancer. This multicomponent intervention included navigation, EHR-derived data, and implicit bias training for providers.

- TOUCH BBCA uses a database to track side effects as well as social and emotional trends among patients. This information is shared back to clinical trial investigators.

Navigation Needs for Technology Selection and Implementation

- Patient data should be kept in a central location that is easy for navigators to access.

- A centralized database should include shareable resources. This function would need to be approached carefully to ensure that patient privacy is protected and that Tribal sovereignty and data rights are upheld.

- Any new technology should save navigators and patients time and energy, not require more work or create additional steps.

- A useful resource would provide additional entry points into the health system for patients, who are often frustrated and feel locked out of care by the challenges of navigating office phone lines and portals.

- It would be especially useful for a tool to take over certain administrative tasks so that navigators and providers can use their time with patients for more specialized tasks. The tool would not decrease the amount of time a patient spends with their provider, but rather increase the efficiency of that time.

- A great deal of information, including navigation data, is entered into patients' medical records, but it is challenging to extract data in order to analyze it and demonstrate return on investment. Streamlining the data workflow to facilitate access by approved users would support research and allow navigators to make a stronger case for their work.

- Standardization of input fields is an essential component of interoperability. To be optimally useful, data must be comparable across platforms.

- Navigators and providers have different needs; both should be consulted in the development of future technological tools. The optimal platform would be configurable for use by all members of a care team.

- Tools should be developed with the explicit aim of reducing health disparities by increasing navigators' ability to care for all their patients equally.

- To make technologies more useful for patients, portals could include links to up-to-date, reliable health information from trusted sources, as well as functions to enable secure text and video messaging. This would also ensure navigators have the most recent health information.

- Technology could be used to assess navigators' caseload and triage patients based on risk.

- Videoconferencing applications like Zoom can be used for navigator training and professional development.

Translating Best Practices Across Organizations

- Organizations like the Academy of Oncology Nurse & Patient Navigators and the National Navigation Roundtable are working to create and implement tools to streamline data access, support professional development, and reduce the burden for navigators. To avoid reproducing effort and to enable consistency in the field, organizations should collaborate and exchange ideas and solutions. An important next step will be disseminating this work and creating sustainable partnerships and infrastructure to support it.

- The *Journal of Oncology Navigation & Survivorship* publishes information about this work and the field in general, as well as conference proceedings and other research articles.

- The National Navigation Roundtable recently created and published standardized job descriptions and competencies for beginner, intermediate, and advanced navigators. Health systems should draw on resources like this for consistency and efficiency.

- The American College of Surgeons Commission on Cancer provides accreditation standards for cancer centers that include standards for navigation and provides a forum for sharing best practices.

- Navigators should be integrated into support groups to better understand patients' challenges and to learn from their lived experience.

- The North Carolina Oncology Navigators Association represents more than 300 navigators and offers an annual conference, trainings, and continuing education programs.

- Technology vendors like Epic should be included in conversations about the future of navigation technology. These conversations should also intentionally include community health workers; navigators from frontier and rural areas, under-resourced communities; and others working outside of major cancer centers.

- Health systems and institutions are working in silos, with each organization's technology specialist focusing on their small piece of the puzzle. Communication and collaboration will be key to making progress.

CLOSING COMMENTS

- Federal programs to connect patients with resources already exist; two examples are the National Comprehensive Cancer Control Program and the Federal Communications Commission's Affordable Connectivity Program, which provides eligible households with a discount on broadband service and connected devices. Solutions like this may need wider implementation, to be better publicized, or both.

- State-level government offices are exploring ways to use federal funds to reach under-resourced communities, particularly those in rural areas. These offices are important links in the chain of patient navigation and should be included in conversations about improving access to care.

- Technology can be utilized not only to connect individuals with resources but also to connect navigators to their peers and community. A navigator database would enable partnerships and greater coverage of issues within the navigation field.

- Caregiver access is an important component of effective technology solutions. Portals and platforms may not support separate access by individuals other than the patient.

- An area of future exploration could be disparities in navigation access by gender.

- Navigators have a major role in connecting patients to clinical trials, both at large cancer centers and in community clinical settings. To equitably integrate advances in cancer care, navigators should be trained and educated in this vital aspect of their work. That lack of centralized clinical trial information is a major barrier.

- Patient navigation began as an intervention to address health disparities. An area of significant opportunity is in the uptake of genomic testing, where stark disparities exist.

It is important to build an evidence base to better support policy, funding, further research, and implementation of patient navigation technologies. More data on the effectiveness and suitability of existing technologies are needed.

Although *promotoras de salud,* or community health workers, have been proven to be extremely effective in connecting patients with the care they need, there are few pathways for their professional development and few opportunities for them to grow in these roles. Additional training would support their continued participation and important work.

Expanding broadband internet access could be a major component of improving equitable access to care.

It is important to name the specific populations that are being left behind by new technologies and tailor strategies accordingly. A one-size-fits-all approach to equity could intensify rather than reduce gaps. Inclusion must be incorporated into every stage of the technology development and testing process.

Barriers to progress are unique to each region and health system, but thoughtful, large-scale solutions may support many different communities. There is a wide variety of obstacles, including geographic distance from a cancer center or clinic and the implementation of up-to-date technology.

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 series *Reducing Cancer Care Inequities: Leveraging Technology to Enhance Patient Navigation* meeting *Opportunities for Enhancing Patient Navigation*, held on October 17, 2023, is accurate and complete.

Certified by: _____ Date: January 4, 2024

      Elizabeth M. Jaffee, MD, FACR, FAACP
      Chair
      President's Cancer Panel