MEETING SUMMARY

PRESIDENT'S CANCER PANEL

IMPROVING RESILIENCE AND EQUITY IN CANCER SCREENING: INNOVATION TO INCREASE SCREENING

Thursday, February 11, 2021
Virtual Meeting

This workshop was the fifth in the President's Cancer Panel's (the Panel) 2020–2021 series on cancer screening. Previous workshops in the series focused on barriers and opportunities related to screening for lung, colorectal, cervical, and breast cancer, including those relevant to the healthcare system disruptions caused by the coronavirus disease (COVID-19) pandemic. The current workshop brought together stakeholders from various sectors to discuss innovations in the areas of public health and community engagement, data sharing and professional training, and remote care and insurance that could contribute to development and implementation of resilient and equitable cancer screening programs. The workshop 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 live-Tweet at #ImprovingCancerScreening.

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

John P. Williams, MD, FACS, Chair

Edith P. Mitchell, MD, MACP, FCPP

Robert A. Ingram

National Cancer Institute, National Institutes of Health

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

Meeting Participants

Tracy A. Battaglia, MD, Associate Professor of Medicine, General Internal Medicine, Boston University School of Medicine/Boston Medical Center

Jay Bhatt, DO, MPH, MPA, Principal and Founder, JDB Strategies, Faculty Member, University of Illinois at Chicago School of Public Health

Kathleen Biesecker, Director, Communications, Clinical Product, CVS Health

David Chambers, PhD, Deputy Director for Implementation Science, National Cancer Institute, National Institutes of Health

Peter W. Chauncey, MSPH, Principal, PWC Solutions, LLC

Doug Clarke, MD, MBA, Medical Officer, Center for Medicare and Medicaid Innovation, Centers for Medicare & Medicaid Services

Katherine Crew, MD, Associate Professor of Medicine and Epidemiology, Irving Medical Center, Director, Clinical Breast Cancer Prevention Program, Herbert Irving Comprehensive Cancer Center, Columbia University

Roslyn Y. Daniels, President, Black Health Matters

L. Allen Dobson, Jr., MD, CEO (Retired), Community Care of NC, Inc.

Ann M. Geiger, PhD, MPH, Scientific Director, NCORP Cancer Care Delivery Research, Division of Cancer Control and Population Sciences, National Cancer Institute

Venus Ginés, MPH, President, Dia de la Mujer Latina

Daniel F. Harris, MD, Regional Quality Advisor, Mid-Atlantic Permanente Medical Group

Todd G. Hartley, CEO, WireBuzz

Judd Hollander, MD, Senior Vice President, Healthcare Delivery Innovation, Associate Dean, Strategic Health Initiatives, Thomas Jefferson University

Louis Jacques, MD, Senior Vice President, Chief Clinical Officer, ADVI

John Kairys, MD, Chief Medical Information Officer, Jefferson Health

Gregory C. Kane, MD, MACP, Professor and Chairman, Department of Medicine, Thomas Jefferson University Hospital

Warren A. Kibbe, PhD, Vice Chair and Professor of Biostatistics and Bioinformatics, Duke University

Daniel Knecht, MD, MBA, Vice President, Transformation Clinical Product, CVS Health

Gary L. Kreps, PhD, University Distinguished Professor, Director, Center for Health and Risk Communication, George Mason University

Alex H. Krist, MD, MPH, Professor, Family Medicine and Population Health, Virginia Commonwealth University

Earnestine Yvonne Lewis, Founding Director, National Center for African American Health Consciousness

Sara Lomax-Reese, President and CEO, WURD Radio, LLC

Ana Maria Lopez, MD, Professor and Vice Chair, Sidney Kimmel Cancer Center, Thomas Jefferson University

Jennifer Malin, MD, PhD, Senior Medical Director, Oncology and Genetics, UnitedHealthcare

Abner A. Mason, Founder and CEO, ConsejoSano

Shivan J. Mehta, MD, Assistant Professor of Medicine and Health Policy, University of Pennsylvania Perelman School of Medicine

Ryan M. Moog, MBA, Director and Solution Executive of Research, Cerner Corporation

Phuong Khanh (P.K.) Morrow, MD, Vice President, Global Development, Therapeutic Area Head, Hematology, Amgen

Martin J. Murphy, PhD, Chief Executive Officer, Shanghai TuoXin Health Promotion Center

Heidi D. Nelson, MD, Professor, Health Systems Science, Kaiser Permanente Bernard J. Tyson School of Medicine

Andrea Noel, MD, Clinical Informatics Team, Epic Systems Corporation

Jayant Parthasarathy, PhD, CEO, Astrin Biosciences

Shez Partovi, MD, Worldwide Lead, Healthcare, Life Sciences, and Genomics, Amazon Web Services

Rakesh Patel, MD, Chair, High-Risk Breast Program, Medical Director, Radiation Oncology, Good Samaritan Hospital

Wyatt Pickner, MPH, Research Manager, American Indian Cancer Foundation

Joseph Ravenell, MD, Associate Professor of Population Health and Medicine, New York University Grossman School of Medicine

Mary Reid, PhD, Distinguished Professor of Oncology, Chief and Director, Cancer Screening, Survivorship, and Faculty Mentoring, Department of Medicine, Roswell Park Comprehensive Cancer Center

Thomas J. Schuch, MD, MPH, Chief Information Officer, South Boston Community Health Center

Bimal Shah, MD, MBA, Chief Medical Officer, Product and Analytics, Teledoc Health

Shravya Shetty, MS, Engineering Director, Google Health

Melissa A. Simon, MD, George H. Gardner Professor of Clinical Gynecology, Vice Chair of Research, Departmetof Obstetrics and Gynecology, Northwestern University Feinberg School of Medicine

Prentiss Taylor, MD, Vice President for Medical Affairs, Doctor On Demand Telemedicine

Reginald Ware, CEO, BlackDoctor.org

Armenta L. Washington, Senior Research Coordinator, Office of Diversity and Outreach, Abramson Cancer Center, University of Pennsylvania Perelman School of Medicine

Kevin B. Weiss, MD, Chief Officer, Sponsoring Institutions and Clinical Learning Environments, Accreditation Council for Graduate Medical Education

Karen Wernli, PhD, Associate Investigator, Kaiser Permanente Washington Health Research Institute

Cheryl L. Willman, MD, Director and CEO, University of New Mexico Comprehensive Cancer Center

James B. Wilson, JD, MA, CEO Emeritus, BlueCross BlueShield of NC

Susan Woods, MD, Physician, Southern Maine Health Care

WELCOME AND INTRODUCTIONS

Dr. John Williams welcomed invited participants and other attendees, introduced the Panel members, described the history and purpose of the Panel, and provided an overview of the current series of Panel meetings. He also introduced meeting facilitator Mr. Scott Wheeler. Dr. Edith Mitchell noted that previous meetings in the series have discussed barriers to optimal screening for cancers of the lung, colorectum, cervix, and breast. Mr. Robert Ingram explained that the goal of the current meeting is to think about innovative ways to improve cancer screening, including opportunities created by the disruption of the healthcare system by the COVID-19 pandemic.

The meeting was organized into three sessions, each including a group of experts selected to address specific topics related to cancer screening.

SESSION 1: INNOVATIONS IN PUBLIC HEALTH AND COMMUNITY ENGAGEMENT

Mr. Wheeler presented the following priorities related to public health and community engagement that were identified during previous meetings in the series.

- Build an infrastructure to support public health campaigns that educate about cancer risk factors and screening tests and encourage people to be screened.
- Reach, train, and empower community leaders and organizations to reach into underscreened communities (e.g., racial/ethnic underrepresented, rural, low socioeconomic status).
- Develop and deliver culturally appropriate messaging and community outreach to educate about and encourage screening in underserved/underrepresented communities.
- Create networks of community navigators and technology tools (high touch/high tech) to support community members in screening decisions and address logistical challenges, particularly those faced by underserved/underrepresented communities.
- Increase clinical access to address disparities faced by those who may not be able to take much time away during traditional business hours (e.g., hourly workers, caregivers).

Participants were asked to discuss how these priorities could be achieved more quickly and efficiently. A mind map was used to visually organize key points of discussion in real time.

KEY POINTS OF DISCUSSION

Build Infrastructure to Support Public Health Campaigns

- Healthcare infrastructure needs to be more representative of the communities being served. Community representatives should be involved in development of systems for delivery of care, navigation, and clinical trials.
- A recent National Cancer Institute (NCI) publication estimates there will be 10,000 excess deaths from cancer due to declines in breast and colorectal cancer screening during the pandemic. This presents a substantial challenge to the cancer control community.
- The Eliminating Disparities in Clinical Trials (EDICT) initiative established several years ago included 300 diverse representatives from different disciplines, age groups, and racial/ethnic backgrounds. Recommendations developed by the group focused on overcoming misinformation and miscommunication, which lead to mistrust. These issues have been exacerbated during the COVID-19 pandemic.
- The Centers for Disease Control and Prevention (CDC) Empower Health program is working to empower patients, caregivers, and others with knowledge of the value of screening and the benefits of early detection.
- The same messages and communication channels may not be effective across different communities. Strategies must be developed based on the needs of specific communities. It also is important to remember that communities are not homogenous; there are communities within communities that have different cultures and communication preferences.
- Information on cancer screening should be provided in multiple settings. Outreach should be done in trusted spaces (e.g., libraries).
- Cross-collaborations among agencies to engage community members are critically important.
- Providing information is not sufficient. It is important to pique the public's interest and communicate why screening is so important. Messaging about staying safe during the COVID-19 pandemic and receiving the COVID-19 vaccine should be expanded to promote other preventive services, including cancer screening. The U.S. Preventive Services Task Force (USPSTF) has an app that provides a list of preventive services an individual may be eligible for based on age and gender assigned at birth. This approach could be expanded for cancer screening.
- Abramson Cancer Center partnered with Enon Tabernacle Baptist Church to engage over 1,400 individuals in various ways during the pandemic. The American Cancer Society (ACS) FluFIT model was used to plan a drive-by event for fecal immunochemical test (FIT) distribution. Physicians were available to answer questions and provide instructions for how to use the kit.
- Communication efforts must be based on evidence and carefully tailored to the needs of target audiences. Ideas must be communicated in the right way with the right examples and right images through the audience's desired communication channels. Communications should not be generalized across all channels and populations.
- The main goal of communication is to promote adoption. When it comes to getting people to act, complexity is the enemy of execution. Messages should be concise and clearly define the next step people should take. There also must be opportunities for people to easily take the recommended actions. Options could include bringing screening services to patients or combining screening with other healthcare activities.
- Blackdoctor.org is a health and wellness destination for African Americans that focuses on a variety of health conditions and concerns. The platform highlights authentic African American leaders and reaches more than 20 million people per month. The organization has successfully addressed

COVID-19 vaccine hesitancy within the African American community over the past several months through this trusted platform.

- Many African Americans do not feel they are treated fairly by the healthcare system. In addition to educating patients about screening, steps must be taken to ensure patients receive all the care they need in a timely manner. Patients must be treated well when they interact with the healthcare system. This will help build trust. WURD radio in Philadelphia sponsored a glaucoma screening project for African Americans. In addition to using trusted messengers and tailored messages, patients were provided with transportation and lunch and were treated with respect and compassion. This was critical to the success of the program.
- Many people do not know lung cancer screening is available because it is relatively new. In addition to raising awareness, people need to understand that screening is an ongoing process. Most people cannot absorb all the necessary information at one time, which is why it is important to have multiple communication channels and recurring messages. For example, radio campaigns should be done every year to reinforce messages and reach people who may be newly eligible for screening.
- Messages about screening should be linked to healthcare systems whenever possible. Messages could be delivered through electronic health records (EHRs), text message, or letters. Many patients want to hear about screening directly from their doctors.
- Healthcare systems should leverage the wisdom and linkages within communities. Existing communication infrastructure should be used whenever possible.
- Widely available technologies, such as smartphones, should be used. Many people without smartphones likely have a family member with a smartphone.
- Research has demonstrated the value of incorporating community health workers (CHW) and promotoras into health and wellness systems. CHWs/promotoras understand system and cultural barriers and can help improve the health literacy of the populations they serve. CHWs/promotoras can make valuable contributions to planning and implementation of efforts to promote cancer screening.
- Día de la Mujer Latina developed CHW/promotora training modules on COVID-19 and telehealth community navigation. Many CHWs/promotoras communicate with clients using WhatsApp, which is popular within the Latino community.
- Community-academic partnerships can be effective for health promotion. A webinar series for CHWs and others in Flint, Michigan, proved to be an effective way to coordinate messaging and share resources during the COVID-19 pandemic.
- Abramson Cancer Center has developed the Cancer Clinical Trials Community Ambassador Training Program that provides training on clinical trials for community members who then help inform their communities about the importance of trial participation.
- ConsejoSano is a patient engagement and patient navigation company focused on connecting low-income, multicultural, undocumented patients with low health literacy to healthcare. The group works with Medicaid plans to reach these populations and encourage them to be screened for cancer.
- Health plans should collect information on race, ethnicity, and language to allow measurement of baseline screening rates and the impact of efforts to increase screening. Health plans should be incentivized to measure and address health disparities. The Medicare Advantage Star Rating program creates incentives for plans to measure quality and address gaps; a similar quality program should be developed for Medicaid, which serves millions of low-income Americans. Financial incentives encourage plans to innovate and improve.
- Health communications should be developed based on marketing principles. Spaced repetition of exposure helps people absorb and become comfortable with information. Continual dialogue from multiple organizations and programs could help get people more comfortable with screening.

Reach, Train, and Empower Community Leaders and Organizations

- Developing a diverse workforce that includes trusted messengers is critical. CHWs, promotoras, and other types of health workers who serve as a bridge between healthcare systems and communities often are unpaid. When they are paid, they are often underpaid and funded with short-term grants or philanthropic funds.
- There is strong evidence that CHWs and others who fulfill similar navigation functions are effective. The next challenge is to replicate and scale-up. Innovation, including policy change, is needed to ensure that navigators—whether they have a clinical or lay background—become trusted members of the workforce and are reimbursed accordingly. The National Navigation Roundtable is working on this issue. The COVID-19 pandemic has created opportunity for these types of policy changes.
- Workforce investments should be driven by the needs and assets of the community being served. It is important to build on what is there and develop areas of highest need.
- Efforts must be made to not only develop culturally appropriate messages but also to have culturally appropriate conversations. Conversations with and among community members help build trust and demystify complex healthcare system processes; this in turn encourages people to take action based on the health messages they hear. These crucial conversations can happen at trusted community sites such as barber shops and libraries.
- Mobile units should go out in the community to reach people where they are. In the current environment, people may have a hard time traveling long distances or be hesitant to use public transportation.
- Improved cultural competence training is needed for healthcare providers and researchers who will be communicating with underserved communities. Medical schools, community hospitals, federally qualified health centers (FQHCs), and others must commit to this; cultural competency will not be achieved with 2-hour webinars. Baylor College of Medicine has implemented successful cultural competency training for its medical students.
- It is important to help communities understand the data that support screening recommendations. People need to understand how statements about risk apply to them and relate to their real-world experiences. Patient storytelling, including digital storytelling, that draws on the experiences of community members can be effective. Children also can help raise awareness about health issues among their parents and grandparents.
- Each community has its own values and knowledge systems; these vary across communities, even communities of the same racial/ethnic background. Communities have the knowledge to identify solutions to the health challenges they face, but they need capacity and resources to implement these solutions. Decision-making power must be at the community level; too often, people from outside a community make decisions without meaningful community involvement. Successful community decision-making has occurred with distribution of COVID-19 vaccines to tribal communities.
- Many American Indian/Alaska Native (AI/AN) populations live in urban areas and receive health services from programs funded by the Indian Health Service. People may be hesitant to be screened for cancer because there are few options within their health system for treatment if they are diagnosed with cancer. Mainstream healthcare systems often are not accessible to indigenous populations due to distance and/or cultural differences.
- Communities would benefit from having resources and messaging that can be tailored to their needs.
- The United States could use the Emergency Broadcast System or a similar system to update individuals on health and screening recommendations that are relevant to them. For example, women could receive a text message when they reach the age at which the USPSTF recommends they begin screening mammography. Messages could be tailored based on race/ethnicity and location (e.g., instructions on where to go to be screened).

- Existing resources—such as NCI-designated cancer centers, the National Clinical Trials Network, and CDC programs—should be leveraged to serve communities across the United States. NCI-designated cancer centers are required to demonstrate substantial commitment to their catchment areas, which could include a focus on cancer screening. NCI also has provided supplements to cancer centers for community outreach and engagement, which has encouraged partnerships with community organizations.
- Guidance and training are needed to promote better delivery of prevention and screening services during virtual visits, which have increased substantially during the pandemic. This may be an opportunity for collaboration between NCI-funded centers and community partners.
- Flexible funding mechanisms are needed to allow researchers to build long-term, ongoing relationships with communities. Community relationships should transcend a single research project and should not be abandoned when a project ends.

Develop and Deliver Culturally Appropriate Messaging

- It is not sufficient to translate messaging into different languages. Messages also must be reviewed for cultural appropriateness and context. Literal translations may lack important nuance or even be offensive. CHWs and promotoras may be able to help with culturally appropriate translations.
- It is difficult to develop clear messages when there are differences among screening guidelines. Alignment of guidelines would be helpful for messaging, which would improve community trust and facilitate provider implementation.

Create Networks of Community Navigators and Technology Tools

- CHWs can be an important part of value-based care models and can perform many roles. Among other things, CHWs can facilitate upfront conversations about goals of care and patient/family preferences. CHW job descriptions should be considered broadly so their talents can be fully utilized.
- CHWs have helped with shared decision-making for prostate cancer screening. They likely could help with shared decision-making for lung cancer screening as well, but current policy does not allow for reimbursement of shared decision-making done by CHWs. Policy barriers such as this should be explored. Allowing other members of the healthcare team to help with shared decision-making for lung cancer screening would relieve the burden on primary care providers.
- Policies related to CHWs differ among states. In Texas, legislation is being considered that would categorize CHW/promotora activities as care coordination rather than administration. This change would allow CHWs/promotoras to be reimbursed through Medicaid. This bill is the result of strong policy advocacy by CHWs. Many legislators were unaware of the value of CHWs and promotoras in their communities before being informed by advocates.
- Texas was the first U.S. state to manage CHW training programs through its Department of State Health Services. Dia de la Mujer Latina was the first organization in Texas to offer bilingual (English and Spanish) training. The training focuses on eight core competencies that cover communication, interpersonal, and advocacy skills. This training gives providers confidence in the abilities of CHWs.
- CHWs and promotoras should be invited to the table when decisions are being made. Former President Obama created a National Promotoras Steering Committee to help communities understand available health plans when the Affordable Care Act (ACA) marketplace was launched.
- It is important to consider unintended consequences when creating policies that allow reimbursement for services provided by CHWs. For example, these policies could create opportunities for health systems to classify employees within their system as CHWs to access these funds.

- Education is necessary but insufficient to increase screening. It must be easy for people to follow the steps to be screened. Each additional step that requires individual effort has potential to reduce participation. Automated systems can help make things easier for people to be screened.
- Communication modality is an important consideration. Many healthcare systems rely on electronic patient portals because they are low cost; however, using these portals can be challenging for many people. Mailed letters and text messaging may be more effective ways of reaching some patients, particularly minority populations. Text messages are far more likely to be read than emails.
- ConsejoSano is hired by health plans, including many Medicaid plans, to engage plan members. The organization has found that text messaging is the preferred mode of communication for most people; however, the 1991 Telephone Consumer Protection Act prohibits plans from sending text messages to members unless they have advance permission. This legislative barrier should be addressed to facilitate communication between health plans and their members.

Increase Clinical Access to Address Disparities

- The benefits of telehealth have been illustrated during the COVID-19 pandemic. Engagement of patients through telehealth should continue after the pandemic.
- Clinical trials have shipped materials to patients during the pandemic. This approach could be used beyond the pandemic to address access challenges.
- Offering all recommended cancer screenings on a single day may help people optimize time away from work.
- Family-focused approaches should be used to promote cancer screening and prevention. For example, when a woman is screened for cervical cancer, she can be informed about opportunities for her children to receive the human papillomavirus (HPV) vaccine. Women who undergo breast cancer screening should be encouraged to talk to family members about mammography; it may be helpful to allow family members to coordinate their appointments. Family-focused approaches can be particularly effective for Asian, Latinx, and AI/AN populations.
- Cancer screening could be paired with other public health efforts such as flu or COVID-19 vaccination.
- Childcare or elder care responsibilities can be a barrier to screening.
- Cancer screening may not be the highest priority for many people. ConsejoSano attempts to identify and address social determinants of health (e.g., food insecurity) before discussing cancer screening. This approach can help build trust.
- Traditional healthcare organizations should partner with alternative medicine providers or holistic healers, who are trusted sources in some communities.
- Employers should provide paid time off for cancer screening.
- Support should be provided for patients who receive a positive screening result to ensure they receive appropriate follow-up care. Quality metrics related to timeliness of follow-up could be considered.
- CHWs can help identify and address mental health issues, including those that arise through the cancer screening and diagnosis process.

Wrap-Up

- Analyses should be done to identify the needs of each community to inform development and implementation of the best possible strategies to improve cancer screening. Infrastructure for ongoing evaluation should be created so that messages and strategies can be refined over time.

- Racial misclassification in EHRs and other data systems should be addressed. This could include training of health professionals on how to collect and document this information.

SESSION 2: INNOVATIONS IN EHRs, DATA SHARING, AND PROFESSIONAL TRAINING

Mr. Wheeler presented priorities highlighted below related to EHRs, data sharing, and professional training that were identified during previous meetings in the series.

- Develop interactive tools to allow patients to assess cancer risk based on family history and other factors. Enable those tools to interface with EHRs so information can be shared with providers.
- Develop a screening workflow within healthcare systems that educates patients about cancer screening and collects appropriate medical and family history before visits with their clinicians.
- Ensure access to usable information on longitudinal screening and family history in EHRs.
- Share patient screening and family history (including genetic indications of risk) across different EHR systems to support screening discussions as patients move between provider networks.
- Accelerate the rollout of programs to train clinicians and other healthcare providers on frequently changing cancer screening guidelines.
- Incorporate training on understanding the concepts of cancer risk, risk reduction, early detection, and current screening guidelines into all medical education programs.
- Develop a standard taxonomy and utilize it to communicate about screening and tests.
- Create a set of tools to help health systems envision a population health approach to cancer screening.

Participants were asked to discuss how these priorities could be achieved more quickly and efficiently. A mind map was used to visually organize key points of discussion in real time.

KEY POINTS OF DISCUSSION

Data Standards and Interoperability

- Many challenges—including data structure and implementation—need to be addressed simultaneously to build better systems.
- Data relevant to screening—including screening results—often are not in shareable formats. This precludes sharing between EHR systems and deters follow-up of abnormal screening results.
- Fast Healthcare Interoperability Resources (FHIR) does include standards for information exchange, but these standards are not widely used. In general, laboratory data are more structured than other types of clinical data.
- Family history variables are different across systems and tools, which precludes data sharing and creates inefficiencies.
- Incidental findings must be captured in structured formats to ensure that patients receive recommended follow-up care.
- Efforts to align terminology within an institution can help with data standardization.
- EHR interoperability is particularly important for people who receive care at multiple healthcare systems over time. This is the case for many members of vulnerable populations.
- Creation of learning health systems that partner with other stakeholders (e.g., public health) and utilize common, interoperable technologies will help drive progress.

- EHR vendors need input from specialists to create effective tools for providers. These tools also depend on the availability of structured clinical data. Sharing among healthcare systems, particularly those that use different EHR platforms, requires collaboration and interoperability.
- Health maintenance tools—including family history—come standard with all Epic systems. However, many institutions modify the standard questions and fields; in some cases, modifications are different within different departments in the same institution (e.g., pulmonology vs primary care). These modifications can create challenges for interoperability within and between systems. Ideally, there would be a standard core set of questions based on best practices. It may be beneficial for healthcare systems to hire clinical informaticists to inform tools built, as well as implementation and training.
- The United States Core Data for Interoperability guidelines include standards for family history and various tests.
- Meaningful use standards attempted to create structured family history data but were unable to capture the nuance of family history information. Most providers continued to use free text to document family history information. Efforts should be made to use similar formats across platforms and structured data whenever possible, but it may not be possible for all family history data to be in structured formats.
- It would be helpful to have a common repository of patient data that could be accessed through different EHRs and health systems. The current system is fragmented, which makes it difficult to obtain accurate information about a patient's medical history.
- A health information ecosystem that includes data and captures information on the source of those data is needed. Better integration is needed between healthcare systems and health departments.
- The U.S. Food and Drug Administration (FDA) Oncology Center of Excellence launched the Informed Exchange and Data Transformation (INFORMED) Initiative to explore use of real-world data for regulatory review. Dr. Sean Khozin spearheaded this initiative and is now CEO of CancerLinQ.

Patient Tools

- The Agency for Healthcare Research and Quality has provided funds to redevelop web-based tools as SMART [Substitutable Medical Apps, Reusable Technologies] on FHIR applications to facilitate import of patient data from third-party platforms into EHRs.
- Patients will be more likely to provide information through electronic portals if they benefit from using the portals (e.g., able to email providers). Consideration must be given to how to reach patients who are unable or unwilling to use electronic portals (e.g., physical letters).
- Patient-provided data—such as family history—may be captured through multiple interfaces at different times. All this information should be integrated and available in a convenient place for providers to view and use.
- Technology is not sufficient to ensure screening reaches all populations. Many patients are not comfortable using electronic patient portals. Several studies have shown that personalized services, such as patient navigation, have a greater impact on screening. The best approach may be to use technology to identify patients and high-touch strategies to ensure they are screened.

EHR Design and Provider Workflows

- EHRs can prompt providers to collect important data. There is opportunity to use artificial intelligence to create EHR prompts and ensure that information entered is meaningful and appropriate (i.e., quality assurance). Ideally, prompts will be actionable without requiring a lot of work.
- EHR systems must be thoughtfully constructed to be easy for providers to use. Systems that require additional user effort will not be as effective. The right information must be provided at the right

time. Sifting through large amounts of information to find the “right” information creates significant cognitive load for providers.

- Recommendations for follow-up or next steps should be clearly stated in formats that can be used for automated algorithms. This will make it easier for primary care providers who are reviewing findings and communicating with patients. Follow-up recommendations need to include both the action (e.g., screening modality) and interval/target date.
- Requiring providers to enter data with discrete element requirements (e.g., check boxes, drop-down menus) can create friction in systems, making them less usable. Natural language processing (NLP) has potential to extract structured data from narrative text in health records. Use of NLP may help avoid clinician cognitive burnout.
- Clearly defined roles and responsibilities within systems are important for ensuring continuity of care; people need to ensure that gaps in EHRs and other systems are filled.
- Healthcare systems should take steps to ensure that all of the pieces necessary for effective cancer screening are in place and working together. This may be accomplished through creation of a strategic plan or a committee that oversees screening. For example, Kaiser Permanente has a group charged with implementing the cancer screening strategy for the organization.
- It is not sufficient to create EHR-based tools. Enabling technologies must be implemented in ways that make them useful to end users. Effective implementation requires coordination among people with different expertise and roles within an institution.
- EHR vendors need to work with health plans and the Centers for Medicare & Medicaid Services (CMS) to ensure that quality and value metrics are captured within EHRs. Consideration should be given to how to incentivize plans to identify and address the needs of high-risk populations.
- EHRs should be structured to allow systematic stratification of primary care patients based on cancer risk (e.g., family history, smoking history) so that personalized screening recommendations can be provided. This likely will require changes in both data collection and functionality. Incorporation of patient-entered data (e.g., through SMART on FHIR apps) for things like family history may be helpful.
- It is relatively simple to identify people who are eligible for screening; however, it is more complicated to create algorithms to provide guidance on what to do for patients who receive an abnormal screening test result. For example, if a polyp is found, when does a patient return for routine screening? Basic screening guidelines do not cover these types of scenarios, and patients with previous abnormal results often get lost within systems. EHRs currently do not provide support for these types of situations. In many cases, next steps cannot be clearly determined using algorithms. Good clinical decision-making is needed as well.
- One health system is working to combine surveillance and screening within its EHR so providers can easily access all relevant information at the same time. There are some tools available through Epic. The challenge is to make sure there are high-quality, structured data and develop an implementation plan to ensure data are entered.
- Systems should flag patients who have not yet received recommended follow-up care. Patients and providers should be notified.
- Making guidelines machine readable would hasten their implementation and facilitate individualization of screening recommendations.
- Machine learning and NLP have potential to help guide screening recommendations and implementation in the short term while standard taxonomies are being developed and implemented. It may take several years for data standards to be deployed.
- Federal resources may help speed development and adoption of stronger EHR systems.

- All providers—not only primary care providers—should see screening prompts and encourage patients to talk to the appropriate provider about screening. However, this is complicated if a patient has providers in multiple healthcare systems.
- There is a digital divide within the healthcare community. Some providers view information technology (IT) as a tool, while many early-career providers view IT as more of an integral part of how they deliver care.
- Family and medical history data must be accurate to be useful. Policies that allow longer appointment times may facilitate collection of more complete and accurate information.
- Systems must be scalable and adaptable. Rural providers and communities do not have the same resources or capacity as other communities.
- Healthcare personnel should track technology access and preferences for their patients to optimize communication.

Community Outreach

- Many healthcare systems have been successful in increasing cancer screening within their patient populations. However, many people fall through the cracks because they do not have a regular healthcare provider or source of care.
- It is important to understand local barriers—including local beliefs and resources—and develop appropriate solutions. In many rural areas, it may be helpful to promote FIT rather than colonoscopy since the latter likely would require travel to a distant medical facility.
- Barriers may be different across cancer types. Lung cancer screening rates have remained far lower than screening rates for other cancers.
- It is challenging to convey individual-level risk information to people. It is important to help people who are at higher-than-average risk of cancer understand that it is particularly critical to go for screening.
- Outreach to vulnerable communities is critical to ensure that all people have access to the benefits of cancer screening.
- Healthcare systems need to engage their primary care providers in systems-level efforts to promote cancer screening. Directly communicating with patients without involving primary care providers will not be as effective.

Incentives to Improve Data Collection and Screening

- Financial incentives have driven healthcare institutions to adopt technology. Consideration should be given to how to structure incentives to promote cancer screening. Most value-based care models are driven by actuarial models that are relatively short (e.g., 12 months), but the benefits of screening will not be realized within that timeframe. The Center for Medicare & Medicaid Innovation (CMMI) or others should construct longer term models (e.g., 60 months) so that systems are incentivized to promote screening.
- NCI or the Department of Health and Human Services (HHS) should convene health plans, EHR vendors, and cancer screening programs to discuss performance metrics and data elements needed to incentivize cancer screening.
- Organizations often are resistant to change unless there are incentives or mandates. Accreditation requirements may help drive change. The meaningful use incentives of the HITECH [Health Information Technology for Economic and Clinical Health] Act helped drive EHR use.
- The pieces of strong cancer screening programs are largely there, but more must be done to bring various players together to make sure systems are effective and efficient.

Challenges with Guidelines

- A single set of recommendations for each cancer type would reduce confusion for both patients and providers. Organizations use different methods to generate guidelines, which is not necessarily a bad thing; however, it would be useful for the various groups to agree on some common themes.
- More needs to be done to ensure appropriate screening of high-risk individuals to whom existing guidelines may not apply.
- Differences between guidelines often occur because people and organizations value different things and, thus, weigh potential harms and outcomes differently. Technology may be able to help people understand the reasons underlying differences in guidelines so they can choose the guidelines that are most aligned with their values and preferences.

SESSION 3: INNOVATIONS IN TELEHEALTH, REMOTE CARE, AND INSURANCE

Mr. Wheeler presented priorities highlighted below related to telehealth, remote care, and insurance that were identified during previous meetings in the series.

- Include diagnostic tests following positive screening in screening guidelines and provide insurance coverage of those tests without cost-sharing.
- Create seamless links between healthcare facilities serving rural communities and large health centers with full-service screening capabilities.
- Integrate telehealth into screening programs to reach underrepresented communities.
- Leverage telehealth to support patients in screening preparations and provide initial guidance and education that limits time demands during patient and provider engagement.
- Enable providers (need to define which providers) to offer genetic testing with informed consent rather than requiring a pretest appointment with a genetic counselor.
- Ensure patient/community and provider access to broadband and other infrastructure needed for telehealth (address the digital divide).
- Leverage wellness programs to help individuals understand cancer risk and encourage screening practices aligned with current guidelines.

Participants were asked to discuss how these priorities could be achieved more quickly and efficiently. A mind map was used to visually organize key points of discussion in real time.

KEY POINTS OF DISCUSSION

Diagnostic Tests After Positive Screen

- Stakeholders—including payors, employers, patients, and healthcare professionals—should come together to develop strategies to increase cancer screening. Strategies should be evidence based. Payors are open to considering coverage for services that improve care quality. Creation of unfunded mandates based on insufficient evidence is not an effective way to build relationships.
- Value-based care models that include patient incentives and rewards for healthy lifestyle choices and compliance with evidence-based recommendations can be embedded within insurance plans.
- Systems should be designed to make it easy for patients to take the next step if they receive a positive screening test result. Patient navigators and community health workers may be helpful in this regard.
- Organizations should be incentivized to create systems that relieve physician burden and reduce unnecessary visits.
- User-friendly patient portals that facilitate information access and sharing are needed.

- Team-based care approaches are needed to ensure that preventive care is promoted every time a patient interacts with the healthcare system. This should include interactions with pharmacists, care managers, etc.
- Under the Affordable Care Act, preventive services recommended by USPSTF must be covered without copay or coinsurance. USPSTF guidelines generally are focused on average-risk individuals. Requirements for coverage of preventive services for high-risk individuals are less clear. For example, it may be appropriate for an individual with Lynch syndrome to receive a colonoscopy every 2 years beginning at age 40; however, some insurance companies may view these tests as diagnostic rather than screening since they are not aligned with USPSTF recommendations. This makes it difficult for providers and patients to understand potential out-of-pocket expenses for screening tests.
- Coordination among insurance companies, facilities, and providers could help increase uptake of lung cancer screening.
- It is important to ensure patients who receive a positive screening test result have access to appropriate follow-up care. Furthermore, those who are diagnosed with cancer need access to appropriate treatment.
- Based on current law, Medicare coinsurance waivers (e.g., for diagnostic tests) require congressional action. CMMI demonstrations have some flexibility in this regard.
- Private health insurance plan use of deductibles, copays, and coinsurance are based on the idea that consumers will make better choices if they bear some of the cost of their care. The ACA created a special situation for preventive services. Extending this to cancer treatment would represent a significant shift in the basic insurance benefit structure. A stronger argument could be made to extend no-cost coverage to tests that currently are considered diagnostic but could be considered part of the screening process (e.g., colonoscopy after positive FIT).
- Seamless connections between screening, follow-up care, and treatment would benefit patients and providers.

Telehealth and Broadband Access

- There is potential to use telehealth to deliver preventive services to individuals who have trouble getting to an office visit. Some patients—such as those in remote areas and inner cities—lack access to technology. Many state coalitions are working to improve broadband access in underserved areas; however, more can be done to address this challenge.
- There is opportunity for innovative partnerships between health plans, healthcare systems, and cell phone carriers. For example, health plans could offer subsidies for cell phone data or carriers could agree not to count data used for telehealth as part of a customer's data use.
- All of the sectors that would benefit from universal broadband access—including education, medicine, employer groups, and others—should come together to identify the statutory, regulatory, and economic barriers to achieving this goal to create the political will to address them. Potential federal convening bodies include the Health Resources and Services Administration, U.S. Department of Housing and Urban Development, American Telehealth Association, and Federal Communications Commission (FCC). There also is a Senate broadband caucus. State gubernatorial leadership also will be critical as there are many unique issues across the states. There are laws in some states that make it difficult for local jurisdictions to address broadband access.
- NCI and FCC are working together on a telehealth initiative.
- State Medicaid plans can use their managed care Requests for Proposals to promote innovation with respect to broadband and telehealth access.

- FCC data on broadband access are based on information from telecommunications companies and are an overestimate. Some organizations have been crowdsourcing to generate more accurate data. These data should be used to inform FCC policies.
- Digital inclusion issues are based largely on economic rather than demographic factors. There are community organizations in many areas that provide digital devices and promote digital literacy.
- Healthcare systems should ensure their tools are mobile optimized since many people exclusively use mobile devices. Support should be provided for both synchronous and asynchronous virtual care, and proxy users should be enabled whenever helpful to the patient.
- Not every telehealth interaction requires broadband. Lower bandwidth (e.g., no video) is likely sufficient for many conversations. Telehealth solutions should allow flexibility in this regard.

Linkages Among Health Centers

- Linkages between rural communities and large health centers are important, but there also are health centers in nonrural areas that would benefit from partnerships with large, full-service medical institutions.
- Telemedicine can play a role in partnerships between health centers. Patients can access technologies (e.g., mammography) in their local clinics, and results can be interpreted by an expert at another facility.
- Through Project ECHO [Extension for Community Healthcare Outcomes], the University of New Mexico Cancer Center partners with practitioners in rural communities and tribal nations. The program involves training, assisting with test interpretation, and assisting with navigation. The scope of the program includes cancer screening as well as some cancer care.
- Due to the way reimbursement is structured, cancer centers have a financial incentive to have patients travel long distances to physically visit the cancer center. Reimbursement for helping to guide or manage care of patients at remote locations is minimal or nonexistent, even if this arrangement is better for the patient. Systems should be created to pay for expertise that contributes to high-quality care rather than only visits.
- Several programs around the country use mobile units to conduct cancer screening, particularly for underserved populations. These programs can partner with NCI-designated cancer centers or other centers to ensure that patients receive any necessary follow-up tests and treatment. During the pandemic, the University of New Mexico used mobile units to deliver cancer care, including chemotherapy, to tribal communities.
- Providing increased reimbursement for services provided to patients in certain zip codes could incentivize cancer centers and other healthcare centers to use mobile units or other models to deliver care to those patients.
- State licensing laws are a barrier to remote care provided across state lines or by qualified providers in other countries.
- One model for providing remote care is to use providers in the same health system or a company that provides comprehensive primary and specialty care services.
- Remote care programs can include training local personnel to conduct screening (e.g., perform ultrasound, take pictures of skin lesions) and having providers at a remote site interpret the results. Treatment and management plans can be developed through conversations between the remote and local providers.
- Technology is not sufficient to develop remote care programs; effective workflows, operations, expertise, and reimbursement policies also are critical.

- Providers have been forced to use telemedicine during the pandemic, and many may continue using it. Virtual interactions are different than in-person interactions. Provider training at all levels (e.g., graduate medical education, continuing medical education) is needed to help providers be as effective as possible in delivering care via telemedicine. This would help them gain skills and confidence.
- Patients may benefit from telehealth training or tips as well. Some patients may be uncomfortable interacting with providers virtually, although a trusting relationship with the provider helps to overcome this discomfort in many cases.
- Immersive technologies and virtual reality may have roles in provider training in the future.
- Screening should be discussed with patients at multiple points of contact (e.g., pharmacies, churches, primary care providers).
- Collaboration among providers is critical to ensure that patients are screened and receive all necessary follow-up care in a timely manner. Interoperability among EHRs and other data sources could support this collaboration and should be a high-priority goal.
- Patients should be empowered to access and control their own medical data so they can share data with providers as they desire.

Genetic Testing, Genetic Counseling, and Informed Consent

- Genetic testing is a great application for telemedicine. Sample collection kits can be mailed to patients' homes and mailed back for processing, and communication can be done virtually.
- Some but not all insurance companies require pretest genetic counseling from a genetic counselor before covering a genetic test.
- Medicare covers genetic testing in the context of a cancer diagnosis, but, because it has not been defined by Congress as a necessary preventive service, it is not covered in the context of screening.
- Genetic counselors are important for interpreting results of genetic tests. There was disagreement about whether patients should be required to meet with a genetic counselor before undergoing genetic testing. Some participants felt that genetic counselors should meet with the patient, do an assessment, order the appropriate test, and have a follow-up conversation with the patient. Other participants noted that there are not enough genetic counselors to do this for all patients who undergo genetic testing. Requirements for pretest counseling by a genetic counselor result in delays.
- Some societies have recommended that physicians be able to order the test and provide pretest counseling; genetic counselor time would be reserved for discussion of results, with a focus on complex results.
- Genetic counseling is not reimbursed in some states, which affects how health systems use counselors.
- It is important that patients understand what information they may get from a genetic test before agreeing to get one. Genetic counselors are best able to have this conversation with patients.
- It is important to distinguish between people undergoing genetic testing as part of cancer treatment from asymptomatic people undergoing genetic testing to assess risk of cancer or to inform screening. Many oncologists have the knowledge and expertise to interpret genetic test results. Not all clinicians have the same level of knowledge.
- Failure to provide genetic testing to high-risk individuals can lead to harm.
- Informed consent before any test or procedure—including genetic testing—is very important. Patients must understand the implications of potential findings of a genetic test before agreeing to the test. The question is whether all physicians should be able to conduct informed consent for genetic testing; they do informed consent for many other types of services and tests.

- Fewer people undergo genetic testing based on risk of hereditary colorectal cancer compared with breast or ovarian cancer. More effort should be made to identify people who should be tested for colorectal cancer risk.

Wellness Programs

- An assessment should be done of how well cancer screening is addressed at annual wellness visits. As a next step, it is important to understand who is not participating in annual wellness visits.
- Time spent on asynchronous communication with patients (e.g., using patient portals) should be reimbursed. Team members other than physicians should be able to do this and be reimbursed.
- Many younger people with commercial health insurance have the same insurance for only a few years at a time. Plans are unlikely to reap the benefits of health and wellness behaviors in this relatively short timeframe. Different payment models that provide incentives for plans to support lifetime health and wellness should be considered. If all plans promote health and wellness, all plans will benefit in the long term.
- Creation of a single-payor healthcare system would address the problem of short-term versus long-term risk.
- One model proposed is to hold payors accountable for later care if patients did not receive recommended preventive or screening services. Another model would be shared accountability among payors, providers, and patients.
- CVS Aetna uses advanced analytics to identify members who have not received recommended cancer screenings. They conduct outreach to patients and send letters to providers and pharmacists to encourage screening of these patients.
- UnitedHealthcare sends FIT kits to members who have not received recommended colorectal cancer screening.
- A program like the Medicare Advantage Star Rating program could incentivize health plans to cover and promote health and wellness activities.
- Metrics for health and wellness could be used to incentivize employers to promote cancer screening.

Wrap-Up

- Payment should focus on ensuring quality of care, not healthcare delivery mechanisms.
- Single-payor health insurance should be adopted in the United States.
- Cancer screening should be including in a prepaid bundle to align incentives with quality of care.
- It should be made as easy as possible for patients to get the care they need and for physicians to provide the right care at the right time.
- Broadband access should be considered a utility. Investments in broadband access should be made in rural areas.
- Incentives should be increased for major healthcare systems to serve patients in underserved areas (e.g., using zip codes).
- Medical teams and patients need to be educated about the optimum use of telemedicine.
- Barriers related to lack of cross-state licensing of healthcare providers should be addressed.
- There needs to be a focus on technologies that empower patients to better understand risk and self-administer low-tech surveys.

PUBLIC COMMENT

Members of the public were encouraged to submit ideas and comments using the question-and-answer feature of the viewing platform. They also were invited to submit written testimony to the President's Cancer Panel via email (PresCancerPanel@mail.nih.gov) or the Panel website (https://prescancerpanel.cancer.gov).

CLOSING REMARKS

Panel members thanked the participant panels for their productive input and discussion. The Panel will consider the information provided during this workshop and others in the series as they develop recommendations to be included in the Panel's report to the President.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, Improving Resilience and Equity in Cancer Screening: Innovation to Increase Screening, held on February 11, 2021, is accurate and complete.

Certified by: ______________________ Date: May 3, 2021

John P. Williams, MD, FACS
Chair
President's Cancer Panel