MEETING SUMMARY

PRESIDENT'S CANCER PANEL

IMPROVING RESILIENCE AND EQUITY IN BREAST CANCER SCREENING: LESSONS FROM COVID-19 AND BEYOND

November 16 and 18, 2020
Virtual Meeting

This workshop was the fourth in the President's Cancer Panel's (the Panel) 2020–2021 series on cancer screening. The workshop brought together stakeholders from several sectors, including clinical care, healthcare systems, insurance companies, government agencies, research, and advocacy. Participants discussed barriers and opportunities related to breast cancer screening, including those relevant to the healthcare system disruptions caused by the coronavirus disease (COVID-19) pandemic. 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

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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 Panel series of meetings. The Panel is concerned about the long-term consequences of cancer screenings missed and delayed due to massive disruptions of the healthcare system during the COVID-19 pandemic. The pandemic has created new barriers to screening and exacerbated those that already existed. The current Panel series will explore practices and barriers present before the pandemic, implications of the pandemic for screening, and opportunities to improve the equity and resilience of cancer screening in the United States.

To assist with series planning, the Panel created the Working Group on Cancer Screening During the COVID-19 Era. Cancer type-specific planning subgroups for lung, colorectal, cervical, and breast cancers were established. These subgroups—comprising clinicians, researchers, and patient advocates—helped identify barriers, opportunities, and potential solutions in their respective areas. Several cross-cutting themes were identified across cancer types, including disparities, equity, and inclusion; telemedicine; and access and uptake issues.

Dr. Edith Mitchell introduced meeting facilitator Mr. Scott Wheeler and the Co-Chairs of the Breast Cancer Planning Subgroup, Drs. Kevin Hughes and Worta McCaskill-Stevens. Drs. Hughes and McCaskill-Stevens introduced subgroup members, as well as members of the breast cancer stakeholder panel invited to participate in the meeting. Input received at all series meetings will be considered and inform development of recommendations to be presented in the Panel's report to the President of the United States.

BREAST CANCER WORKING GROUP PRESENTATION

Drs. Hughes and McCaskill-Stevens provided an overview of the opportunities to improve breast cancer screening that were rated most highly by subcommittee and stakeholder panel members before the meeting. A noncomprehensive list of barriers and solutions related to each opportunity also was presented. Many barriers and solutions are relevant to multiple opportunities.

OPPORTUNITY 1: RISK-BASED SCREENING

Improved identification of people at high and low risk of breast cancer and application of risk-based screening would help reduce the burden of breast cancer.

Barriers

- Difficulty using risk models in clinical settings
- Risk model limitations (e.g., insufficient discrimination, lack of nonmutation risk factors)
- Lack of, or lack of access to, models that predict risk of adverse screening outcomes and aggressive cancers in European and non-European populations
- Lack of clinically actionable thresholds and effective screening strategies for risk groups
- Patient and provider confusion due to variation in screening mammogram guidelines and early detection recommendations by numerous societies and organizations
- Lack of communication and education that low-risk women need less or less-intensive screening
- Lack of annotated datasets and funding to support the development of new risk models, exacerbated by lag time between discovery and implementation
- Backlog of patients needing screening that cannot be addressed by an overloaded system that is further slowed by necessary COVID-19 preventive measures

- Lifetime risk estimates to guide screening decisions that may inadvertently suggest that risk is constant over time when it may change based on age and other factors

Solutions

- Develop apps or electronic tools to communicate risk levels to patients and families.
- Identify patients with risk factors and confirm appropriate screening.
- Communicate with patients via text message.
- Use polygenic risk scores.
- Incorporate breast density into risk models.
- Develop new risk models based on artificial intelligence (AI) and image analysis.
- Correlate mammograms with tissue collection for molecular characterization and/or AI.
- Standardize clinical annotation.
- Create innovative funding models to translate research findings into practice (e.g., commercial partnering).
- Concentrate on the highest risk women to maximize screening impact.

OPPORTUNITY 2: GENETIC TESTING EXPANSION

Expansion of genetic testing would help identify people at high risk of breast cancer or other cancers and enable enhanced screening and/or other risk reduction strategies.

Barriers

- Difficulty in assessing, managing, and explaining risk levels based on test results
- Logistical barriers (e.g., time, cost, lack of tools and organizational pathways) that discourage providers from ordering tests and impede genetic counseling
- Mandates from insurers and major professional organizations for pretest genetic counseling and use of genetic counselors that impede access
- Difficulty identifying patients eligible for testing
- Lack of understanding and fear of genetic testing among healthcare providers
- Limited reimbursement of cascade testing (identification of relatives of mutation carriers)

Solutions

- Develop tools to assist in interpretation of genetic testing results.
- Simplify management guidelines.
- Simplify testing processes.
- Use telehealth to increase efficiency of genetic testing.
- Educate providers in genetics.
- Eliminate requirements related to whether and how pretest counseling before genetic testing is done.
- Create a quality measure for number of genetic tests done.
- Reimburse providers for identifying and testing at-risk relatives.
- Provide patients incentives to find at-risk relatives.
- Develop tools and guidance to help patients inform their relatives of the need for testing.

OPPORTUNITY 3: WORK TO ELIMINATE DISPARITIES IN SCREENING

Address racial, cultural, geographic, and economic disparities and systemic racism.

Barriers

- Lack of educational campaigns to support screening and research in underrepresented groups (e.g., racial/ethnic, LGBTQ, physically impaired).
- Requirement that at-risk women under 40, particularly black women, undergo risk assessment and be found to be at high risk before getting breast imaging
- Inequitable distribution of screening resources and facility capacity (e.g., geographical [rural], socioeconomic [inner city])
- Patient challenges navigating the healthcare system and obtaining screening at early enough age

Solutions

- Engage experts in integrating social determinants of health to improve health equity.
- Engage in collaborative efforts to secure resources to attain equity in screening.
- Support research using new technology and social determinants to improve knowledge and inform development of tools to identify and screen high-risk women when the at-risk threshold is unmet.
- Educate physicians about risks among women under 40, particularly black women.

OPPORTUNITY 4: ALIGNMENT OF MULTIPLE SCREENING GUIDELINES

Lessen breast screening confusion to improve participation and compliance.

Barriers

- Lack of clarity across professional and society screening guidelines with respect to defining high-risk patients who need earlier mammography or other breast imaging
- Lack of consistency across professional and society screening guidelines regarding age of initiation and screening interval
- Lack of established approaches for primary care-radiology partnerships to maximize screening

Solutions

- Educate women and providers about the guidelines that are consistent across professional societies (e.g., 50–74 age range).
- Conduct a massive education campaign for primary care providers.
- Improve screening education of patients and providers.

OPPORTUNITY 5: PERCEPTION

Change the perception of breast cancer screening from an instance of care to an episode of care that includes management of the results.

Barriers

- Lack of a holistic approach to management of findings due to the perception that screening is an isolated activity
- Inconsistent and unclear requirements and costs imposed by insurance companies
- Requirements by some practices and insurers for prescriptions prior to mammograms

- Challenges communicating results and follow-up recommendations when patients obtain imaging without a physician order
- Lack of consideration of comorbidities when deciding when to stop screening

Solutions

- Educate patients and providers.
- Identify processes and most effective stakeholder to negotiate with insurance companies.
- Test use of smartphones and establish a network for women without primary care providers.

BREAST CANCER SCREENING IMPROVEMENT OPPORTUNITIES

A mind map was used to visually organize and present barriers and potential solutions identified prior to the meeting. Mr. Wheeler facilitated discussion on each of the five opportunity areas. Stakeholders elaborated on previously identified barriers and solutions and offered new suggestions for ways to improve breast cancer screening. Input was recorded in real time through updates to the mind map. Participants were urged to think about what screening barriers have been exacerbated during the COVID-19 pandemic and how changes created by the pandemic may provide opportunities to enhance cancer screening in the long term. They also were asked to consider four factors to help identify recommendations that may be most important and practical—feasibility, impact, responsible party, and resilience.

RISK-BASED SCREENING AND GENETIC TESTING EXPANSION

Two opportunities—risk-based screening and genetic testing expansion—were discussed together due to the high level of overlap between the topics.

COVID-19 Considerations

- Risk assessments and risk-based guidance should inform decisions about how to address screening backlogs caused by the COVID-19 pandemic. Underlying risk factors and screening history should be taken into account when prioritizing women for screening.
- Cancer screening should not be characterized as nonessential or elective.

Risk-Based Guidelines

- Women at average risk of breast cancer should begin screening at age 40, 45, or 50 and be screened annually or biennially, depending on the screening guidelines used. Only a small proportion of women should start screening early due to being at high risk.
- More individualized approaches for risk assessment and screening guidelines are needed. Risk assessments should include genetic and nongenetic factors.
- Patients and providers may be unaware that the screening guidelines they are familiar with are for average-risk women.
- Differences between screening guidelines are confusing to providers and patients. The American College of Obstetricians and Gynecologists (ACOG) convened guideline makers in an attempt to generate consensus on guidelines, but the effort failed. There may be potential to align guidelines for high-risk women.

Risk Assessment and Risk Models

- The goal of risk assessment and risk modeling is to identify patients who will benefit most from early and/or more frequent screening or screening with different modalities.

- Current screening guidelines are risk based, but consideration is needed to determine how best to implement and/or improve these. Risk assessment may also help reduce the risk of cancer as preventive interventions are developed.
- Primary care providers often do not have time to do a full risk assessment. Risk assessments could be done when a woman goes to her first screening mammogram. Mechanisms for follow-up would be needed to ensure that women identified as high risk receive appropriate screening and care. One participant's institution attempted to implement this approach, but it failed due to time and cost requirements. Another participant's institution was able to implement it with collaboration between the radiology and information technology (IT) departments.
- Most women receive their mammograms at general radiology facilities, not at specialty breast imaging facilities. If risk assessment is done at the time of screening, efforts must be made to ensure that it is implemented at all facilities that perform mammograms.
- Ideally, risk assessment would be done well before the first screening mammogram so that women who need genetic testing or other services can be identified as early as possible. However, it is challenging to systematically identify and assess women within the U.S. healthcare system. The other challenge is being prepared to offer supplemental screening to women who need it.
- *BRCA* mutation carriers should be identified by age 30 so they can begin thinking about interventions. There may be opportunities for obstetricians/gynecologists to recommend genetic screening when women receive a Pap smear or prenatal care. The American College of Obstetricians and Gynecologists should be engaged on this topic so it can revisit guidelines related to genetic testing if warranted.
- Kaiser has tried to systematically assess risk of women every five years starting at age 25, but it has proven to be challenging to implement. There were licensing issues with integrating the Tyrer-Cuzick model into Epic. There also is not a systematic family history assessment within the Kaiser Epic platform. Ideally, a systematic family history relevant to multiple diseases would be done. If this type of population-based health management is difficult within an integrated health system like Kaiser, it will be even more challenging in other health systems.
- Aside from the recommendations for women with a lifetime risk over 20 percent, there are not clear guidelines on how risk assessment or genetic testing results should be used to guide screening. There is disagreement among guideline groups about how high-risk women should be screened. There is resistance to covering additional imaging tests (e.g., ultrasound, magnetic resonance imaging [MRI]) because these are expensive. The U.S. Preventive Services Task Force (USPSTF) has not issued clear recommendations for screening of high-risk women. This means patients who receive screening beyond a mammogram often incur out-of-pocket expenses, which creates disparities. The lack of a USPSTF recommendation is likely due to the fact that there is not sufficient evidence to support specific recommendations for various populations. Conducting randomized clinical trials to generate those data would be exceedingly, and likely prohibitively, expensive.
- Risk assessment should not be based only on genetic factors. The complexity of breast tissue may be informative.
- Risk-based management guidelines should be simplified.
- More complicated tools require more provider and patient time, and it is unclear if they would add benefit. There has been ongoing discussion for 15 years on whether and how to integrate mammographic density into risk assessment, but consensus has not been reached.
- It is unclear whether quantitative risk estimates will drive women's screening behaviors. One study found no correlation between anxiety about breast cancer and probability of death within 10 years. The Study of Tamoxifen and Raloxifene (STAR) trial—which offered tamoxifen and raloxifene to women at increased risk of breast cancer—used multiple quantitative risk models (i.e., National

Surgical Adjuvant Breast and Bowel Project [NSABP], National Cancer Institute [NCI]/Gail Model, Tyrer-Cuzick). Of the 200,000 women for whom risk was assessed, only half were at increased risk, which suggested that perceived risk did not correlate with actual risk. Among those determined to be at high risk, only 20 percent enrolled in the trial. Quantitative risk modeling is not as personal as genetic testing; the two approaches to risk assessment may have different effects on screening behavior.

- The responsibility of healthcare providers is to inform patients, not convince them to make a specific decision.
- One barrier to risk assessment is that risk models are difficult to use. The Breast Cancer Surveillance Consortium (BCSC) risk model is simpler than some other models. Risk factors in the model are collected at the time of screening. When done at the time of a baseline mammogram, the model can inform decisions about when to schedule the next mammogram.
- Existing risk models are not perfect, but they are useful when applied to large groups. Models are becoming more efficient as additional risk factors, including genetic factors, are integrated. These factors must be integrated into electronic health records (EHRs) so they can be used easily in risk modeling.
- Some EHR vendors are building risk models into their systems. If the variables of the model can be entered into the EHR, information on risk and recommended next screening date could be included in patient letters.
- Risk models and tools are needed to identify women at increased risk of being diagnosed with advanced breast cancer even when receiving recommended screening. These women may benefit from being screened more aggressively (e.g., more often, additional imaging modalities).
- Increased funding is needed for large longitudinal databases, such as BCSC, so data can be collected to build risk models for rare outcomes like advanced breast cancer, particularly in minority subgroups. It is important that screening results and risk be monitored over time. Additional research then will be needed to determine whether these women would benefit from supplemental imaging.
- Efforts should be made to use clinical data in EHRs to inform research on risk models and thresholds. The National Patient-Centered Clinical Research Network (PCORnet) has a model for extracting data from EHRs. While extracting data from EHRs is challenging and requires careful curation, it should be doable. Use of standardized terminology in breast imaging across the country will be helpful, although there is less consistency in pathology records.
- Epic and Cerner have anonymized patient records available for research purposes.
- AI may be helpful for developing risk models. Annotated images and clinical data are needed as inputs for AI algorithms. Large, annotated image datasets are not available at this time and should be generated.
- Cancer registries need to capture information when women go outside their home healthcare system to get supplemental imaging. Interoperability between EHR systems is critical for enabling this.
- Identifying high-risk women is not sufficient. Longitudinal follow-up systems are needed to increase the likelihood that women receive recommended screening. Many systems do not have automated systems for reminder/recall of women who should be receiving additional screening, and women may be hesitant to receive additional screening if they incur significant out-of-pocket cost.
- Reimbursement tied to quality metrics could be used to incentivize use of recommended risk models and provision of appropriate genetic counseling.

Risk Thresholds

- Expert groups should be convened to establish risk thresholds to identify women who should be screened earlier and/or receive supplemental screening. Patient benefit, age, cost, and imaging capacity may play a role in setting these thresholds. Careful consideration must be given to the balance of benefits and harms for different groups of women.
- Decisions also must be made on the outcomes to be used for risk thresholds. Lifetime risk is not very useful as a threshold measure because it covers such a large span of time; 5- or 10-year risk estimates may be more useful.
- Different thresholds are needed to identify young women at high risk of early-onset breast cancer and to characterize age-related risk among average-risk women.
- Thought must be given to how risk thresholds will be communicated to different types of patients.
- Research is needed to determine the best screening test for young women.

Age to Stop Screening

- Mandatory stop ages within screening guidelines are a point of frustration for many. There is not a set age at which screening should stop. Chronological age does not necessarily correspond to health and performance status. For otherwise healthy women, it would be better for the patient to identify and treat a cancer earlier rather than later.
- USPSTF guidelines state that there are not clinical trial data to support screening of women older than 75 years of age; however, the guidelines do not explicitly call for screening to stop at this age. Decisions on screening of older women should be individualized.
- Life expectancy is sometimes used to inform decisions about the age at which to stop screening. One perspective is that if a patient is healthy enough to be treated for cancer, she should continue to be screened. However, potential risk of overdiagnosis and overtreatment also must be considered. A patient should not be treated for a cancer that would not progress enough to impact her quality of life during her lifetime. Evidence suggests that women should have a life expectancy of at least 10 years to benefit from screening. There are tools to assess longevity, but these are not widely used.

EHRs, Technology, and Provider Workflow

- Cerner is interested in linking its EHR systems to consumer technologies (e.g., apps) able to use patient data to calculate risk. This type of approach could be used to determine if patients should undergo genetic testing. EHRs integrated with external tools could help guide patients through the genetic testing process.
- Genetic testing results often are not stored within the EHR, or, if they are, they are not in a usable format. Standard ontologies and data dictionaries are needed so that results can be integrated into EHRs and clinical decision support tools. To be useful to providers, information needs to be quickly accessible and in a usable format. An example of data standardization is the adoption of the Digital Imaging and Communications in Medicine (DICOM) standard for images.
- Fast Healthcare Interoperability Resources (FHIR) standards for genetic data—which have been developed only in the past year or so—allow integration of data into EHRs. Leading-edge hospitals and companies are utilizing consumer apps to integrate genetic data, social history data, and clinical data from Cerner EHRs to inform clinical decision support tools. Only a small percentage of hospitals are using this type of technology right now, but the foundation is being laid for more widespread use.
- The 21st Century Cures Act was intended to promote interoperability, though it is not being accomplished quickly enough. The Act also required direct release of medical test results to patients, which underscores the need for patient education.

- Lack of standardization across EHRs at different institutions is a barrier to development of clinical decision supports.
- It is not realistic to expect providers to screen all patients to identify those who may qualify for genetic testing. Primary care providers have too many demands on their time. Other systems-based tools are needed; for example, chatbots or EHR-based surveys could be used to assess risk. Ideally, patients could complete risk assessments prior to visits to reduce the time spent on this issue during appointments. These types of tools do exist and are being used more often.
- A high-level screen that covers all cancers likely would be the best approach, with follow-up as needed if risk is identified in a particular area.
- Rather than creating a system to identify people who would benefit most from genetic testing, it may be more efficient to provide all patients with the opportunity. At the very least, patients should be able to pay for their own testing.
- EHR systems are working to streamline systems and processes to make it easier for institutions to identify and meet payor requirements related to genetic testing.
- Leaders often are needed to promote change and implement new processes. Efforts must be made to ensure that progress is made at all institutions, not just those that are well resourced.
- Technology and innovation—including AI—have potential to transform healthcare.
- Health systems should build a culture that prioritizes the well-being of the community. They should take into account social determinants of health and disparities experienced in the communities they serve. It is somewhat easier to build this culture in integrated healthcare systems. Performance measurements and strategic plans can be developed with community well-being in mind and implemented at scale. Community benefit funds can help address challenges faced in communities served by federally qualified health centers (FQHCs) and rural health clinics.
- Risk assessment tools that are user friendly and easily accessible to patients and providers are needed. These should be interoperable with different EHR systems and adaptable to future guideline changes.

Genetic Testing

- Consideration should be given to the harms done by failing to identify individuals at high risk for cancer through genetic testing. Additional cancers would be identified earlier or prevented if testing were expanded. The cost of genetic testing has fallen dramatically, so large-scale testing is more feasible than in the past.
- Geisinger Health System has created the My Code program through which all patients—not just those identified as high risk for a given disease—are given the opportunity to have genetic testing done using clinical laboratory specimens collected for other purposes. A panel of 75 genes is tested, including genes relevant to cancer, heart disease, dementia, and other illnesses. About 90 percent of patients who have clinical specimens collected agree to genetic testing. Testing is done on a contractual basis with a large commercial genetics firm, and the cost of testing is covered through multiple grants. Results are sent to the patient and primary care provider. Patients are offered the opportunity to contact the genetic counseling service; they are offered a telephone counseling visit and, if they wish to pursue it, an in-person counseling visit. This model removes some burden from the primary care provider. It does depend on having adequate genetic counseling resources, though the uptake of genetic counseling for people with identified mutations has been lower than expected. Over 100,000 individuals have been tested to date.
- In Canada, patients who qualify for genetic testing are tested for free through their provincial health program. Patients who do not qualify or want to be tested more quickly can be tested through Women's College Hospital for $250. Testing is done through a contract with Invitae. About 2,000 patients have been tested to date. Of these, about 2.4 percent have had mutations identified, which is

higher than would be expected for population-based screening; patients with strong family history or other risk factors are likely overrepresented in the sample. The program has found that only a small percentage of patients accept pretest counseling when it is offered. Posttest counseling is offered to everyone with positive results. Barriers of the program include the cost to patients, limited marketing, and lack of acceptance by genetic counselors. Despite the fact that there are long waiting lists to be tested through provincial programs, genetic counselors do not want to refer patients to the Women's College Hospital program because they do not want to support a program that does not require pretest counseling.

- Systems that provide free genetic testing and require pretest genetic counseling will always need to triage patients based on risk to manage resource allocation. However, studies have shown that the majority of mutation carriers would not qualify for testing because they would not meet the criteria of being at high risk using current models. This supports the idea that genetic testing should be implemented more broadly, which would allow creation of a universal personalized risk score.
- Genetic testing programs should track whether patients in whom mutations are identified undergo genetic counseling and, if not, determine what follow-up services or care they receive.
- Genetic testing is different than other laboratory tests because the results are relevant not just to the patient but to family members as well.
- Clinicians want to make sure their patients have everything needed to inform treatment planning. It is becoming clear that determining whether a patient has *BRCA* mutations is important for treatment, particularly for PARP (poly ADP ribose polymerase) inhibitors. Providers may be more likely to advise *BRCA* testing if they know the results may drive future treatment decisions.
- Risk assessment and genetic counseling are recommended by USPSTF, so they should be fully covered by insurance. Advocacy may be needed to ensure that these services are being recommended and used in the clinic.
- Worldwide, 26 million people have had direct-to-consumer genetic testing done through commercial services (e.g., 23andMe) and agreed to share their genetic information with the companies that conducted the testing. High-risk individuals who have done this may believe they have been tested, even though many commercial platforms do not include all variants relevant to cancer risk. Some direct-to-consumer services, such as Invitae, do offer a comprehensive genetic testing platform. Direct-to-consumer platforms have raised awareness of genetics and genetic factors associated with disease, which likely has driven many patients to better understand their own risk through testing.
- In 1997, the American Society of Clinical Oncology (ASCO) pronounced that taking a family history and offering genetic testing are in the purview of practice for oncologists. This led to a concerted effort to provide oncologists with cancer genetics education and ensure they are comfortable communicating with patients about genetics. Genetics is now included on oncology board exams.
- The considerations surrounding genetic testing and counseling are very different for patients who have been diagnosed with cancer and those who are being seen in the primary care setting. Oncologists likely are better equipped to oversee genetic testing and related counseling than are primary care providers.
- The number of genetic tests performed would not be an informative quality metric; it would be better to create a metric that reflects the percentage of tests performed among patients for whom testing is appropriate.
- It would be simpler if genetic testing were limited to genes for which risks are understood and for which clear guidelines exist. However, the field has moved toward including more genes, including variants of unknown significance.
- Healthcare systems have a responsibility to contact patients if the patients are found to have a variant of unknown significance that later is determined to be pathogenic.

Genetic Counseling

- Some insurance companies require patients to receive genetic counseling from a certified genetic counselor before undergoing genetic testing. The rationale for this is that it ensures that informed consent is obtained and that limitations, risks, and benefits for both patients and their family members are explained. The requirement can be waived in some cases (e.g., test results may impact a pending surgery). The American College of Medical Genetics and the National Comprehensive Cancer Network, among other organizations, advocate for both pre- and posttest counseling.
- Hereditary cancer panels are becoming larger and more complex. They now include low-penetrance genes and investigational genes that may not have associated management guidelines. This means the results are increasingly difficult to interpret, and patients have a high likelihood of learning they have a variant of unknown significance. Genetic counselors are well equipped to help patients understand the complexities of these results and allay anxiety associated with an unclear result. Most patients who receive genetic counseling report high satisfaction with the experience.
- Many people believe that requiring pretest counseling from a genetic counselor is unnecessarily restrictive and creates a barrier to genetic testing.
- Most genetic counselors recognize that creative thinking is needed to bypass long wait times for genetic testing in some parts of the United States.
- Group genetic counseling sessions may be one way to deal with the shortage of genetic counselors.
- Virtual and telephonic genetic counseling can help overcome limited availability of genetic counselors in many areas. Genetic counselors must be licensed in the state in which the patient is in order to provide care, either in-person or via telemedicine. There are at least two large national genetic counseling providers that employ genetic counselors licensed throughout the country and can provide same-day or next-day appointments for most patients in the United States.
- Technology should be leveraged to ensure that all patients receive the genetic counseling they need. Invitae has a chatbot that can perform many pretest functions and administer Tyrer-Cuzick. Videos also can be useful. These types of tools should be made available in a range of settings (e.g., primary care, OB/GYN, breast imaging centers).
- Genetic counselors should be practicing at the top of their scope and spending most of their time on complex patients. Most patients do not need pretest counseling, and many patients do not need posttest counseling. It is important to identify the patients who do need counseling. The need for counseling is not driven solely by family history of cancer; factors such as level of anxiety, family dynamics, and tolerance for being diagnosed with variants of uncertain significance should be taken into account. These factors should be considered when implementing genetic testing programs.
- A National Society of Genetic Counselors work group is developing a tool to identify patients who would benefit from pretest counseling with a genetic counselor. The tool assesses things such as anxiety about genetic testing and complexity of family dynamics.
- The burden of temporary disutility following a positive screen was found to be higher among African American women and women with higher levels of cancer concern. This suggests it may be a good idea to prescreen for patients at higher risk for downstream consequences.
- A web-based educational intervention for patients participating in the Molecular Analysis for Therapy Choice (MATCH) trial found that risk communication increased knowledge and reduced concern.
- Posttest genetic counseling is more important than pretest counseling. The risk of not doing pretest counseling is much lower than the risk of not testing.

Patient Barriers/Cost

- Higher patient cost for a service or drug results in lower utilization. Cost is a significant barrier for many underserved and underrepresented populations, who are unlikely to be able to afford $250 for genetic testing.
- Any cost to patients is a barrier, no matter how low. Preventive services should be made available for free to patients so they are more accessible. A shifting cost scale based on resources was proposed as an alternative to making preventive care available to everyone for free; however, patients can easily fall through the cracks of such a system.
- Screening tests are free, but patients who receive a positive test may bear the cost of follow-up tests and treatments depending on their health plan. Many patients cannot afford the recommended care and are forced to choose between competing priorities.
- Not all patients need genetic testing. Screening mechanisms are needed to identify those who do.
- Systems should be designed to minimize the number of times patients need to attend appointments since that necessitates time off work and other logistical challenges.

Provider Education

- Primary care providers need access to information and education so they can interpret genetic testing results and communicate about them with patients. Even when patients meet with a genetic counselor, they often want to discuss findings and implications with their primary care providers.
- Technology should be used to provide support regarding genetic testing to primary care providers, particularly those in rural areas. The increase in telemedicine use in the post-COVID-19 era should help.
- When prenatal genetic testing was emerging, many thought obstetricians/gynecologists were not qualified to address genetics with patients. However, obstetricians/gynecologists now are trained in prenatal genetics and routinely provide testing for high-risk women. In many communities, there are not enough genetic counselors to fulfill this role. Patients with complicated genetic issues are referred to genetic counselors and physicians with degrees in genetic medicine. The model of including non-genetic counselors could be extended to cancer.
- Medical trainees now are required to have extensive knowledge of genetics, and providers will be increasingly qualified to provide information on genetic testing to patients. However, physicians trained earlier may not be comfortable discussing genetic testing or genetic testing results with patients. Creative solutions are needed to ensure patients of these providers have access to services; telehealth could help address access issues for patients in both rural and urban settings.
- Primary care providers need clear guidance on which patients should be offered genetic testing.

Patient Education and Communication

- Educating patients about screening and genetic testing will be most effective if it is done in multiple ways and through multiple sources (e.g., via television, at a mammogram appointment, through primary care providers).
- Risk assessment should be presented to patients as a way to help them stay healthy. It is important to communicate to patients that interventions reduce the risk of cancer, not necessarily prevent it in all patients.
- Clear communication is needed to ensure that patients understand that lifetime risk estimates do not mean breast cancer risk is constant over time.
- Tools are needed to better communicate to patients when they should be screened less or stop screening.

WORK TO ELIMINATE DISPARITIES IN SCREENING

Factors Contributing to Disparities

- Many women do not know they are at high risk until after they are diagnosed with cancer.
- Some populations, including some immigrant populations, are unfamiliar with cancer screening.
- Racial/ethnic groups are not monolithic populations. Office of Management and Budget race/ethnicity categories are broad and do not capture heterogeneity within groups.
- Neighborhoods may be better predictors of disparities than race. Women in low-resource communities may have inadequate access to care independent of race. The American Medical Association (AMA) recently recommended that zip codes or ancestry be used instead of race. The Agency for Healthcare Research and Quality (AHRQ) and the University of Wisconsin have developed a neighborhood deprivation index.
- Studies have found that African American race remains a negative predictor of breast cancer outcomes even when access to care is equal. Both systems- and biology-based disparities should be addressed.
- The Centers for Disease Control and Prevention (CDC) Agency for Toxic Substances and Disease Registry has developed a social vulnerability index. The index was initially created for emergency preparedness, but many chronic disease groups now are using it as well.
- The United Kingdom National Health System has published an analysis of UK Biobank data using an index of social deprivation.
- Structural inequities can impact health outcomes, and it is challenging to accomplish the societal-level changes needed to address these inequities.

Community Outreach and Engagement

- Educational campaigns should align with consensus screening guidelines.
- It is not sufficient to provide access to or insurance coverage for screening services; education also is needed. Community-based outreach must be tailored to the community. Messaging must be clear, culturally competent, and carried to the community through trusted sources. Several examples were given. Outreach to male household leaders in Barcelona was effective in increasing screening among Muslim women. A study in rural North Carolina found that education through trusted community sources (e.g., church leaders, hair salons) was effective for increasing cancer screening among African Americans. Indian Health Service community-based navigators helped increase breast cancer screening and reduced advanced breast cancer diagnoses in the community served by one Navajo Nation clinic.
- NCI-designated cancer centers and National Institutes of Health (NIH) Clinical and Translational Science Awards have a mandate to engage their communities.
- Community outreach is expensive, but it may be cost-effective when savings from earlier detection of cancer are taken into account.
- Many people harbor distrust of science, particularly vaccines and genetics. Providers must be able to communicate with their patients about the science that supports screening in ways that patients can understand. Community advocates also should be trained to communicate scientific information.
- The diversity and cultural competency of the healthcare workforce are important considerations when working to build trust in communities, particularly African American communities. Humility also is needed to promote understanding of and communication with communities.
- Health systems-level solutions should address disparities across all diseases, not only breast cancer. Structural inequities and racism impact many diseases. The *Community Guide* framework of

multilevel interventions to increase community demand and care delivery should be applied to provide multidisease support.

- Many black women will decline risk assessment or genetic testing even when cost is not a factor. Communication is needed to ensure patients are making informed decisions.
- Education about risk and screening should take place in community settings, not only in healthcare settings. Prior exposure to these messages will make it easier for patients to have discussions with their providers.

Insurance and Cost

- Some women—including those with high-deductible health plans—may choose not to be screened because they think they would be unable to pay for follow-up diagnostic tests or treatments. Insurance plans should be structured to incentivize appropriate care. Treatment of an abnormal screening finding should be considered part of the same episode of care and should be covered.
- Insurance companies should have a role in education about screening. It is in payors' best interests for cancers to be diagnosed in the earliest possible stage; however, it was acknowledged that commercial payors are primarily motivated by short-term savings because many people frequently change health plans.
- Creation of out-of-pocket cost bundles for cancer screening and treatment were discussed. This may be more feasible for screening since the services are more defined. It would be more difficult for treatment because patients may receive care from different facilities (e.g., radiology, oncology), and there is a broad range of treatment options with very different costs.
- Consideration should be given to ways to structure insurance design to ensure free access to high-value care. The Medicare Payment Advisory Commission (MedPAC) has addressed this issue in recent documents.
- Patients should be provided with information on out-of-pocket costs associated with all aspects of care. Navigators often do not have this type of information. Care must be taken to ensure that cost information does not deter patients from receiving high-value care. Patients should be linked to resources that can help defray costs if needed.
- Rural Health Clinics receive cost-based reimbursement. Services such as navigation would be paid for if they were shown to be clinically justified. Nonprofit hospitals must demonstrate community benefit, including spending on community benefit initiatives. It may be possible to cover navigation or other support services as a community benefit.
- Partnerships with patient groups should be established to advocate for coverage of services that would support delivery of care related to screening.
- Demonstration projects through Medicare or commercial payors could be used to explore value-based reimbursement for specific services related to screening.

Access to Screening Facilities

- There is inequitable access to screening resources based on geography and socioeconomic factors.
- Screening capacity at various locations across the country is poorly understood. Past studies have looked at the ratio of facilities or units to women age-eligible for mammography, but this approach does not take into account operational hours. There has been a steady decline in mammography facilities over the past several years and a concomitant increase in the number of mammography units. This may be due to consolidation of services in fewer facilities in high-population areas, which would result in decreased access in low-population areas.

- Quality of imaging and quality of care are important considerations. The Susan G. Komen African American Health Equity Initiative has found that quality of imaging and quality of care often are different in black communities.
- In the United States, practitioners must read 480 mammograms per year to qualify to read mammography. About half of mammograms are read by people who read below 1,000 scans per year; at this rate, a person would be expected to see only a few cases of breast cancer per year, which may not be sufficient to maintain expertise. Europe has higher minimum thresholds for reading screening mammographs (~2,500 per year). The United States could consider increasing minimum requirements for reading mammography to try to increase quality.
- The pipeline of breast imagers is inadequate. In the near future, there will be too few imagers to fill open positions.
- AI technologies capable of reading 3D imaging (e.g., 3DQuorum) will be increasingly available to support radiologists who may not read large numbers of screening mammograms.
- EHR data may help identify gaps in breast cancer screening and related care.
- Digital mammography makes it possible for images to be read remotely by breast imaging specialists. Some community radiology practices have breast specialists. For those that do not, a Project ECHO (Extension for Community Healthcare Outcomes) model could be adopted wherein screening facilities could partner with larger centers to assist with interpretation of scans.
- People living in rural communities have less access to clinical trials than those in more populated communities. Although about 18 percent of U.S. women live in rural communities, only about 1 percent of participants in the Tomosynthesis Mammographic Imaging Screening Trial (TMIST) are from rural areas, despite concerted efforts to recruit them. Recruitment is being done through the NCI Community Oncology Research Program. On the other hand, TMIST has been relatively successful in recruiting African Americans, who make up about 20 percent of enrollment.
- The cost of screening has increased for healthcare systems as screening technologies have improved. The cost can be burdensome for freestanding rural hospitals, particularly those in states that did not expand Medicaid.
- Adventist Health—which primarily serves California, Oregon, and Hawaii—has increased access for rural communities by leveraging scale and aligning providers across the network; optimizing government-based programming (e.g., Rural Health Clinics); and using risk-based arrangements that incentivize preventive care.
- Smaller hospitals should create linkages with larger systems to allow them to access resources and expertise. Healthcare systems also should partner with academic institutions, including NCI-designated cancer centers, when possible. Linkages with academic medical centers can help improve quality of care in community-based facilities.
- NCI-designated cancer centers have a mandate to address the health needs of the people in their catchment areas. Huntsman Cancer Institute is working to make genetic testing services available to everyone in Utah.

Follow-Up Care

- Many women who have BI-RADS 4 or 5 lesions identified through screening do not return for follow-up care. Women often need navigation support to receive biopsy following an abnormal screen since it can be a complex process, especially if not all services are provided in one location. Different models of care delivery should be developed to ensure that care is effectively delivered to all populations. For example, mobile vans may be useful for follow-up diagnostic care in addition to screening.

ALIGNMENT OF MULTIPLE SCREENING GUIDELINES

Guideline Development

- Organizations often develop different guidelines even when they review the same evidence because they make different decisions about the balance of harms and benefits. USPSTF and American Cancer Society (ACS) guidelines have more similarities than differences, but they differ with respect to the recommended age of screening initiation. ACS recommends annual screening starting at age 45. USPSTF recommends biennial screening starting at age 50, with allowances for screening before age 50 based on the patient's preference. Specialty societies—such as the Society of Breast Imaging (SBI) and American College of Radiology (ACR)—recommend annual screening beginning at age 40.
- Screening facilities often recommend annual screening because they use specialty society guidelines. Primary care providers may follow USPSTF guidelines. This results in patients getting mixed messages from the healthcare system. It may be helpful to engage radiologists to discuss this issue. To date, radiologists as a group have been resistant to changing their guidelines.
- Organizations should consider using a living guideline model that allows for updates whenever important data become available. Many organizations currently update guidelines on a set schedule.
- Different organizations use different processes to weigh different types of evidence (e.g., randomized clinical trials, epidemiological data, modeling data). USPSTF reviews evidence on an ongoing basis as it becomes available and makes recommendations based on that evidence.

Data

- ACS analyses found that biennial versus annual screening results in increased risk of advanced cancer diagnosis among premenopausal women but not among postmenopausal women. However, some high-risk postmenopausal women (e.g., with dense breasts, taking estrogen replacement therapy, with a family history) would continue to benefit from annual screening.
- Education may be needed to increase awareness among guideline makers and others in the field about relevant studies and publications.
- Modeling shows that annual screening leads to projected reductions in mortality; however, the overall benefit of annual screening throughout the lifetime is unclear because it is accompanied by the high cost of more procedures and recalls. The benefit may be clearer if a risk-based approach were used to distinguish postmenopausal who would benefit most from annual screening from those who should be screened biennially.
- Endpoints beyond mortality should be considered when evaluating screening. The need for patients to receive chemotherapy and/or radiotherapy due to later-stage diagnosis is associated with financial, physical, and emotional cost.
- High risk for breast cancer is not clearly defined, nor are clinical guidelines based on risk. Various factors influence risk, and it is not always clear how women with various combinations of risk factors should be screened.

Insurance Coverage and Cost

- The Affordable Care Act (ACA) requires coverage with no cost-sharing for preventive services recommended by USPSTF. This requirement should be expanded to include science-based guidelines from organizations such as ACS.
- Most insurance companies will pay for annual screening despite the USPSTF recommendation for biennial screening. However, payors often will not pay for mammograms or other annual screening tests done even one day less than a year from the previous mammogram. This inflexibility requires

some patients to reschedule their mammograms, which results in lower compliance. Insurance companies should be encouraged to adopt more flexible policies.

- Technologies for screening and genetic testing have gotten better and less expensive over the past several years, which changes cost-effectiveness considerations.

Patient Perspective

- It is easier for patients to adhere to annual screening than biennial screening. With a recommendation for biennial screening, there is a risk that the interval will extend beyond two years, which will increase risk of interval cancers for some women.
- Differences in screening guidelines undermine patient trust and may also impact payor decisions about coverage.
- Changes in recommendations may undermine patients' trust in their providers and the healthcare system.

Guideline Implementation

- The age of screening initiation has not changed substantially since the 2009 change in USPSTF guidelines; most women still receive their first mammogram between ages 40 and 42. Annual utilization has dropped across all groups except African Americans. Most women continue to be guideline adherent based on the two-year interval. Most studies allow a 1- to 2-month buffer when measuring screening intervals (e.g., 13-month interval would be considered adherent to annual screening).
- The healthcare system should reflect on its success in implementing risk-based screening guidelines. Complex messages often are missed by both patients and providers, and consideration must be given to how to improve implementation of evidence-based guidelines. It may be best to work toward simpler and more consistent messaging.
- Adherence to any of the existing guidelines would help realize the benefit of breast cancer screening. The most important goal should be for women to regularly undergo high-quality screening.

Providers

- Primary care providers need to be educated so they understand the rationale behind guidelines and guideline changes. It also would be helpful to explain to providers why guidelines differ among organizations. Providers also may need help to understand concepts such as breast density and how it relates to risk and screening.
- It is likely too much to expect primary care providers to have nuanced conversations with every patient and conduct shared decision-making, as is required for lung cancer screening. These discussions could be conducted by nonphysicians (e.g., nurses, nurse practitioners, patient navigators). There are tools available to facilitate these discussions, and tools may be needed to help patients directly access the information they need to make decisions.
- Provider recommendations are very important for driving health behaviors. However, healthcare providers and systems need to respect patients' informed decisions about screening. Some patients choose not to be screened for various reasons. If providers are too forceful with their recommendations to screen hesitant patients, those patients may become even more resistant to screening. It is important to respect patients' decisions and provide room for them to change their minds.

Systems

- Kaiser Permanente has pursued risk-based breast cancer screening for the past 25 years. Initially, risk assessments were done at the systems level to identify those at high risk and recommend screening based on patient risk factors. More recently, the organization has moved away from a systems approach, which has resulted in high-risk women being less likely to be screened frequently while lower risk women are more likely to be screened frequently.
- Healthcare systems should be incentivized to screen patients and provide continuity of care. Fine-tuning processes to ensure that patients receive recommended follow-up care can earn money for systems by preventing so-called leakage.
- Consideration should be given to the role of government in population screening. Other countries, such as the United Kingdom, do population-based screening. Screening studies generally are not done in the United States. The United States learns from studies done in other countries and tries to apply lessons to the heterogeneous U.S. healthcare system and population.
- Alignment of guidelines would make it easier to design and implement clinical decision support within EHRs. AI also may be able to help with decision support for information that cannot be standardized.

PERCEPTION

- Support was expressed for the idea of encouraging guideline makers to view breast cancer screening as an episode of care that encompasses all steps required for diagnostic resolution rather than an instance of care. This likely would facilitate more comprehensive coverage of care provided after the initial screening test. This may be a topic on which guideline makers would agree.
- Ensuring that women have access to recommended care following an abnormal screening test has significant potential to improve equity and increase screening uptake.
- Value-based insurance designs that align incentives with desired outcomes should be pursued. Consideration should be given to payment models that will ensure equity in outcomes. The Panel could consider recommending that Medicare or a large commercial payor conduct a demonstration project to explore insurance designs that promote equity. The Balanced Budget Act limits the ability of Medicare to waive cost-sharing for certain types of care, and policy changes may be needed to address this. Bills related to this have recently been introduced in Congress.
- Coverage of follow-up and diagnostic services with no cost-sharing for patients would lead to an increase in premiums; however, the increase likely would be very small.
- The United States has worse outcomes than other countries for many health metrics (e.g., infant mortality, maternal morbidity and mortality). In general, cancer outcomes are better in the United States than in many other countries; however, many cancer patients experience financial toxicity due to the cost of cancer treatment. The continuum of cancer care in the United States must be reconsidered. There should be increased investment in risk assessment, prevention, and early detection.
- The requirement for patients to have a prescription before receiving follow-up screening is a potential barrier, although this does not seem to be a common problem.
- Many women are hesitant to be screened or undergo follow-up imaging because of concerns about their copays. It is difficult for providers to keep track of copays for different plans and patients, which makes it challenging to be transparent about costs. There are proprietary services that will provide patient-level cost information, but these require a subscription, which necessitates a commitment on the part of the healthcare system.

- Women who receive an abnormal screening result should return to normal screening after six months to a few years of surveillance. Women who have been treated for breast cancer could potentially return to normal screening after five years.

PUBLIC COMMENT AND QUESTIONS

Members of the public submitted written comments and questions, which were read and discussed by the Panel, Working Group members, and the stakeholder panel near the end of each workshop day.

- A member of the public asked whether there are healthcare systems or primary care providers offering genetic testing and counseling without genetic counselors. Many providers and healthcare systems are doing this, albeit in different ways. For the Geisinger program discussed previously, patients are provided with printed information when they agree to participate. Genetic counseling is provided to those with positive test results, but not those with negative results. In other settings, management of results and provision of genetic counseling sometimes are provided through the company that supplies the tests.
- A member of the public noted that breast cancer screening and risk reduction involve more than imaging and genetics. Other areas of prevention education are needed (e.g., exercise, alcohol consumption, ideal body weight), and pharmacological interventions may be appropriate for some high-risk patients. It was agreed that lifestyle factors should be promoted and incorporated into patient management.
- A member of the public suggested treating all African American women as high risk and focusing efforts on expanding genetic testing in this population. More work is needed to refine risk prediction models so they can distinguish risk within the heterogeneous African American population. Excessive mammograms can lead to excessive diagnosis, which is harmful to patients. Current risk-based screening is age based, but this has disadvantaged African American women, who are at higher risk for aggressive interval cancers. More information is needed to enable identification of high-risk women and improve risk-based guidelines for these individuals. One option may be to offer genetic testing to all black women.
- A member of the public noted that the National Accreditation Program for Breast Centers (NAPBC) is concerned about reaching rural areas and areas that are underserved with limited access to NAPBC centers. New options for these programs—such as mentoring or aligning with accredited programs—are being explored; this illustrates the value and cross-pollination ability of accreditation programs. Accreditation programs can play an important role in ensuring evidence-based interventions are implemented in different types of communities. Consideration should be given to how partnerships between accredited and nonaccredited programs would be funded. It is hoped that some of the infrastructure created to deal with the challenges of the COVID-19 pandemic will be repurposed to address other healthcare needs in underserved communities.
- A member of the public commented that African American women do not receive the same information or the same responses to questions from their primary care providers. There are medical societies working on this, particularly in African American communities. It is important to make providers aware of this issue.
- A member of the public commented that community outreach is key to education of African American communities. There is opportunity to leverage the wide range of social, civic, and religious networks that have been in existence for decades in these communities.
- A member of the public noted that African American women have not been informed about genetic testing or risk assessment and asked whether this reflects a deficit in outreach. Many people harbor distrust of genetics, but most will agree to undergo genetic testing if they believe it will help them or their families. It is important to strive for equity in communication about and access to genetic

testing. Racism and unequal treatment have deprived many patients of the information they need to save their lives. Increasing diversity of the medical workforce can help address some of these issues. Providers also need adequate time to discuss genetics with their patients.

CLOSING REMARKS

Panel members and Breast Cancer Planning Subgroup Co-Chairs and members thanked the stakeholder panel for its productive input and discussion. The Panel and Working Group 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. Additional written testimony and comments can be submitted at any time to the President's Cancer Panel via email (PresCancerPanel@mail.nih.gov) or the Panel website (https://prescancerpanel.cancer.gov).

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *Improving Resilience and Equity in Breast Cancer Screening: Lessons from COVID-19 and Beyond*, held on November 16 and 18, 2020, is accurate and complete.

Certified by: _____ Date: March 10, 2021

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