

# Delaware Cancer Consortium 2022 Annual Retreat Question and Answer Document

*Keynote Address: Closing Gaps Along the Cancer Control Continuum to Advance Health Equity Among the Nation's Vulnerable Low-Income Populations*

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- 1. COVID-19 impacted various stages of cancer prevention and treatment, causing reduced or delayed access to care, later diagnoses, and delayed or modified treatments. Common barriers map to these issues, so conditions related to COVID-19 exacerbate the existing system of barriers. Do you see this as mostly a short- to intermediate-term effect or a more systemic issue that will affect cancer incidence and mortality for a longer period?**

This issue could potentially be systemic and affect cancer incidence and mortality rates for a longer period of time. This is especially true for populations with lower socioeconomic status characteristics and low-income or low-resourced communities comprised of populations considered "high risk" for cancer incidence, morbidity, and mortality.

Some of the same vulnerable populations (e.g., those with lower levels of income or education, those that have inadequate health insurance, residents of medically underserved areas, and those who experience an absence of routine medical care) that are disproportionately impacted by COVID-19 incidence, morbidity, and mortality share common factors with populations disproportionately impacted by higher rates of cancer incidence, prevalence, morbidity (including hospitalizations), late-stage or advanced cancers, and associated mortality, especially among preventable cancers.

- 2. What can you share with us about the increased burden of cancer due to COVID-19 as a longer-term issue on systems of care, research, and individuals?**

Due to the increased burden of cancer that has occurred during the COVID-19 pandemic, several long-term issues on systems of care include:

- **Cancer recurrence surveillance:** There will be a great need for care coordination and extensive recurrence surveillance to monitor, track (long-term), and – where possible – prevent cancer recurrence, especially among the uninsured, underinsured, and newly unemployed. Some American families may have experienced a loss in comprehensive health care coverage if the primary income-earner became newly unemployed during the COVID-19 pandemic. As a result, they may have deferred routine cancer care.
- **Survivorship care:** There will be an urgent need to immediately re-engage and provide patient-centered and follow-up care to cancer survivors diagnosed with other co-morbid conditions; these include diabetes, heart disease, hypertension, stroke, and Alzheimer's disease. Competing medical conditions may have warranted more immediate medical attention, thereby delaying cancer survivors' decisions about self-reporting cancer-related complications or causing survivors to be unaware of symptoms associated with metastatic cancer. In some instances, out-of-pocket medical expenses associated with managing other co-morbid conditions can be costly. As a result, minimal financial resources were available to successfully manage cancer conditions appropriately throughout the COVID-19 pandemic.
- **Early detection/treatment:** In the absence of participating in routine or recommended cancer screening for the past two years, a larger number of adults will be diagnosed with late-stage or advanced cancers. This includes populations who were already considered "high risk" for

cancer, including low-income adults with a family history of cancer, who use tobacco products, or who do not have a routine source of medical care (for various reasons) but participated in a cancer screening yielding abnormal results prior to the onset of the COVID-19 pandemic. This also includes low-income, underinsured adults who were screened for cancer prior to the COVID-19 pandemic and received abnormal test results, but did not receive follow-up care or delayed care because they could not afford to pay the associated out-of-pocket costs that are not covered by their health insurance.

Due to the increased burden of cancer that has occurred during the COVID-19 pandemic, a range of research will be needed on topics such as:

- Long-term effects of COVID-19 (long-haulers) on cancer survivors, with data stratified by cancer types and stages, gender, age group, number of co-morbidities, geography-zip code, census tract, or county level.
- Monitoring and tracking cancer recurrence rates, occurrence of metastatic cancer, survivorship rates, hospital readmission rates (long-term monitoring), and mortality rates of COVID-19 long-haulers who are also cancer survivors.
- Monitoring and tracking cancer survivorship rates and hospital readmission rates (long-term monitoring) of COVID-19 long-haulers who are also cancer survivors and diagnosed with co-morbidities such as hypertension, heart disease, stroke, diabetes, Alzheimer's disease, and kidney disease.
- Monitoring and tracking disability rates, including both short- and long-term disabilities, on COVID-19 long-haulers who are also cancer survivors, to account for long-haulers that became physically disabled after acquiring COVID-19.

**3. Let's look at the goal of quality, accessible, equitable cancer care across the continuum. At this moment, many locales in the U.S. face a shortage of care providers at many levels. Workforce shortages is a vital issue in cancer health care, among physicians, nurses and nurse practitioners, and diagnosticians. What are the first things we might do to accelerate the redevelopment of skilled providers, especially in the cancer continuum?**

- Now more than ever, we are reminded of the significance of multi-disciplinary teams. It will be important for hospitals (including critical access hospitals), federally qualified health centers (FQHCs), rural health clinics, and free clinics to establish, maintain, or strengthen long-term internships with Schools of Medicine, Schools of Nursing, Schools of Pharmacy, Schools of Allied Health (to reach registered dietitians) and Schools of Public Health (to include health educators, and community health educators).
- A long-term financial investment in recruiting primary care physicians, oncologists, radiologists, and other physicians to work and build practices located within medically underserved areas (both rural and metropolitan), health professional shortage areas (HPSAs), critical access hospitals (CAHs), and FQHCs remains critical.
- Develop credentialing and certification programs for Community Health Workers (CHWs). It will be important for hospitals (including CAHs), FQHCs, rural health clinics, free clinics, and community colleges with an Allied Health area of concentration to establish long-term internships with agencies, organizations, and health systems that train and certify CHWs or patient navigators, including CHWs who are also certified medical assistants (CMAs) and certified nursing assistants (CNAs). In some instances, CHWs may have two jobs at the same time.

- Invest in long-term sustainable models, such as CHW models. Consider partnering with the state Medicaid agency and health plans to seek opportunities for reimbursement of services provided by certified CHWs to patients diagnosed with expensive chronic diseases or medical conditions such as cancer, diabetes (Type 1 and Type 2), heart disease, hypertension, kidney disease, chronic obstructive pulmonary disease (COPD), Alzheimer’s disease, and stroke.

**4. At the upstream level, CHWs have become a critical asset in efforts related to cancer detection and cancer health promotion. What are some of the key roles that CHWs play that would support individuals and get them into screening and treatment opportunities sooner?**

CHWs can play a pivotal role in helping individuals access care, such as:

- Providing general information about the importance of routine medical care and screening (such as preventive cancer screening) and navigating populations to cancer screening sites. This is especially true within communities comprised of inadequate health systems, pharmacy deserts, and food deserts.
- Ensuring that populations are aware of and educated about free support services provided to address their needs/barriers related to transportation (such as to and from cancer screening sites, primary care physician offices, and health systems providing cancer test results).
- Ensuring that populations are aware of and educated about patient navigators to assist them with navigating health systems throughout the cancer care continuum, including during the cancer recurrence phase.
- Ensuring that populations are aware of and educated about nurse navigators to assist them with navigating health systems and treatment/medication-related issues throughout the cancer care continuum, including during the cancer recurrence phase.
- Ensuring that populations are aware of and educated about registered dietitians to assist them with navigating health systems and nutrition issues throughout the cancer care continuum, including during the cancer recurrence phase.
- Identifying community terms that resonate more with cancer survivors, populations at “high risk” for cancer, and vulnerable populations (such as populations with lower levels of literacy, health literacy, or digital literacy), as well as identifying and communicating cancer myths and misinformation to the members of the multi-disciplinary team. This will help care teams develop care plans that address some of these barriers, challenges, or issues.

CHWs can also utilize some best practices and lessons learned during the COVID-19 pandemic and apply them to cancer screening, early detection, and treatment. These valuable lessons learned in primary and secondary prevention during the COVID-19 pandemic can be applied to low-income or low-resourced communities, as well as populations with low socioeconomic status characteristics overall. For example, it may be helpful to replicate some of the COVID-19 lessons learned and apply them to cancer screening and early detection approaches, such as lessons arounds community education, engagement, and vaccination and increasing access to care within “hard to reach” communities or amongst neighboring communities.

It may be helpful to maximize use of some COVID-19 vaccination sites (new sites established within the community for the first time) as long-term sites for community screening and wellness with a focus on cancer, hypertension, and diabetes. This will provide stability rather than episodic approaches to communities. It may also be helpful to feature public service ads (PSAs) with CHWs working alone or alongside nurses to reach populations that historically don’t seek health care or don’t have a routine

source of care but trust CHWs. Placing PSAs for cancer screening, early detection, and treatment in the same areas where COVID-19 vaccination sites were newly established or remain established within low-income communities with high rates of cancer incidence, prevalence, and/or mortality rates may also be helpful.

**5. Concerning your previous comments about Cancer Moonshot’s Goal 2: the strong suggestion seems to be to work intensively in communities to educate, support, and empower people to know and deal with barriers, to get access to resources, and to build a community system to reduce cancer burden. What are the main ingredients of a successful, sustainable promotion, education, and support system in communities where inequities block positive change?**

The main ingredients include:

- Invest in long-term sustainable models, such as the use of CHWs. The expansion of a CHW model throughout the state would serve as a “springboard” for increasing awareness about how to access care – including routine preventive services (free cancer screenings), navigating more vulnerable populations along the cancer care continuum, and building or expanding community trust about the health care system.
- Develop and maintain credentialing and certification programs for CHWs and create PSAs highlighting CHW roles. PSAs can be aired via radio, social media, and television in low-income communities and areas with high rates of cancer incidence, prevalence, morbidity, and mortality.
- Secure partnerships with Medicaid and health plans to identify health services (such as navigation) that can be rendered reimbursable if provided by a certified CHW to patients with chronic medical conditions such as cancer, diabetes, heart disease, stroke, kidney disease, and COPD.
- Establish and maintain partnerships with schools that provide CMA, CNA, CHW, or patient navigation trainings or certification/credentialing courses. This would create an opportunity for some professionals to be certified as both a CMA and CHW, thereby expanding the CHW workforce within communities, as well as increasing the salary for some professionals.
- Identify and apply to funding opportunities from the federal government or private foundations that address social determinants of health with community engagement. Incorporate a CHW model in the proposal with feedback obtained from CHWs as experts.

*Panel Discussion: Prioritizing Cancer Health Equity at the Legislative Level*

Representative Kendra Johnson, Delaware House of Representatives

**1. The African American Task Force is charged with recommending legislative action on the factors in the social system that disadvantage African Americans systematically, including education, housing, economic development, community empowerment, and environmental justice, among others. When we think about tackling the inequitable burden of cancer, how do you think health equity and particularly equity in cancer health could support improvement in any of these other parts of the system?**

Health equity and equity in cancer health could support improvements in other parts of the systems by first recognizing that all systems are interconnected. If one system is out of sync, it will and does impact all other parts of that system. When we think about the inequitable burden of cancer, a holistic approach must be utilized to ensure better outcomes and that approach will span education, housing, economics, and environmental justice.

**2. How do you see the provider community being involved in supporting improvement in cancer health equity?**

The provider community would be partners in improving health equity. Without their buy-in and participation, improvements will not occur.

**3. Raising up the voices of people in the communities is crucial to understanding what is needed for better cancer prevention and high-quality treatment. How do you think partnerships can be built and activated to create strong programs for equity in all aspects of the cancer prevention to survivor continuum?**

Connection—Buy-in—Education—Needs assessment—Implementation—Follow-up

To reach communities, the first step must be connecting with community leaders and activists, faith-based institutions, and other partners. These initial connections ensure that we will reach at-risk individuals and that trusted entities within the communities are the bridge and will assist with creating trust within the community.

The creation of the Racial Equity Consortium will continue the work that was started by the Delaware Legislative Black Caucus's Justice For All Agenda. This act would establish the Racial Equity Consortium for the purposes of studying and making recommendations to address the disparities and inequities faced by persons of color in this State. Once the legislation is passed, it will continue the work of the task force and operationalize the recommendations that have been passed by the body.

*Panel Discussion: Building on Past Successes: Targeting Racial Disparities in Breast and Lung Cancer*

Scott Siegel, Ph.D.

**1. Are there observable trends at this point about the effects of COVID-19 on screening rates for breast cancer and lung cancer in Delaware?**

At this point, we don't have strong enough data to understand the longer-term impact of COVID-19 on screening rates. Screening rates dropped during 2020 but have since rebounded. However, certain racial/ethnic groups and other sub-populations have not seen the same level of rebound, so it will be important to strengthen outreach.

**2. Are there estimates that researchers are making about more advanced stages and deaths over time, as the impacts of COVID are better understood and considered?**

Yes, the National Cancer Institute has made some estimates about excess mortality (see [here](#)). However, it remains to be seen whether there will be long-term effects beyond the cohort of individuals who were late to receive screening or missed screening entirely during the early days of the pandemic.

**3. For breast cancer and lung cancer, access to information and screening is a first line of defense. What do you think are best or promising practices for outreach to inform and support women to act early, in regard to lowering breast cancer risk? What are the best ways to reach people to promote lung cancer screening?**

The research on health communications clearly shows that disseminating educational and informational messages through multiple channels and at multiple times is more likely to influence screening behavior. In addition, when messengers are trusted members of the community who are deemed to have expertise/authority to speak about a subject, the messages are more impactful.

**4. Structural interventions at the neighborhood level include reducing tobacco access in the hot spots. What similar structural interventions might reduce the elevated risk related to breast cancer and alcohol use?**

We know that communities with a higher density of off-site alcohol retailers (i.e., liquor stores) also have higher rates of unhealthy alcohol use and secondary negative consequences (such as more domestic violence and pedestrian accidents). Some communities, like Baltimore, have begun to experiment with policies that would limit the number of retailers, particularly in high-risk communities. My understanding of the evidence strongly suggests we should consider a similar approach in Delaware, particularly since we are ranked first in the nation for alcohol-attributable breast cancer.

**5. Are there any hot spots or cold spots in Sussex County?**

We have not yet had the opportunity to evaluate whether hot or cold spots exist statewide. However, we're currently working with the State on this very question.

**6. Are you aware of the survival rates of triple-negative breast cancer in Delaware?**

We believe the survival rates for triple-negative breast cancer in Delaware are comparable to what's seen nationally.

**7. If you had state funds, how would you use the funds for a nicotine metabolism program/trial?**

We have very good evidence from highly controlled trials to show that personalizing medication-based treatment for smoking cessation based on individuals' rate of nicotine metabolism can maximize quit rates while minimizing side-effects. We would love to evaluate whether this could be translated to community settings and high-risk populations. One possibility would be to align Medicaid policy with this approach to cover the cost of nicotine metabolism testing and cover varenicline as a first-line treatment for individuals with faster nicotine metabolism. There is the potential to significantly increase quit rates in a cost-effective manner.

*Panel Discussion: Services in the Era of COVID-19*

Nicole Pickles, Cancer Support Community Delaware (CSCDE)

**1. What would you say are the most challenging things that those in treatment or those who are concentrating on positive survivorship face personally, and how have these challenges been affected by COVID?**

Many of those in treatment or focused on positive survivorship can struggle with loss of hope, loss of control, and feelings of isolation. All of these feelings have been multiplied during COVID-19 because the pandemic has also caused the same thoughts. Additionally, COVID-19 has impacted those in treatment financially. For many, cancer treatment can be expensive, and the loss of work time or loss of a job due to the pandemic makes financially navigating cancer even more stressful. As we now move into a "post" pandemic world, things are more expensive and assistance is even harder to find.

**2. What encouragement would you give people who are caring for a person coping with cancer in the age of pandemic?**

Those caring for a person coping with cancer should remember to take care of themselves too. This could include going to a support group, exercising, eating well, or taking a stress reduction class. Caretakers should still be social, as those connections are important, but they need to be safe and smart when around others to keep themselves and their loved one healthy. If the caretaker is not healthy, it will be harder to take care of the loved one who needs them.

**3. What do you think are the most effective social media approaches to helping people manage the emotional and personal aspects of cancer, and for whom would certain social media approaches be better than others?**

CSCDE's approach for social media is to provide education, inspiration, and information. We know the younger generations are utilizing social media more, and these platforms can be a great way to connect with people going through the same journey as you, both globally and locally. Social media has also become a way to locate and find support that is relevant to attend. In some cases, these supports may not have been something they had considered engaging in, such as Health Coaching or a sound meditation class.