National Summit on Health Equity

November 9-10, 2015 │ St. Louis, Missouri

Meeting Highlights

On November 10, 2015, the American Cancer Society Cancer Action Network (ACS CAN) hosted the first National Summit on Health Equity in St. Louis, Missouri. The summit brought together over 150 innovative thinkers in public policy, business, technology, academia, patient care, community health, and patient advocacy to examine public policy solutions for assuring greater health equity for cancer patients in the evolving health care system.

Summit speakers included 17 leading experts from across the health care spectrum who explored enhancing clinical trial enrollment; using technology to improve health literacy; expanding access to care; tobacco use in diverse communities; and the importance of transitions of care for cancer survivors in medically underserved communities. Breakout sessions offered experts and attendees the opportunity to examine potential policy solutions to the problems identified in each plenary session. The summit culminated in a unique "Action Institute" where participants identified specific solutions they intend to put into use in their own communities.

Key Conference Takeaways

The Promise of Health Equity

Not all Americans have benefited equally from advances in cancer prevention, early detection, and treatment. There continue to be adverse differences in cancer incidence, prevalence, survivorship, and mortality among specific populations in the US.[1] Individuals of lower socioeconomic status (SES), the medically underserved, and those without health insurance often suffer disproportionately from cancer and other disease burdens compared to the general population.[1] Research shows that ethnic minorities and other medically underserved groups still have higher cancer rates and are less likely to be diagnosed early or receive optimal treatment.[2] The promise of health equity is that all Americans will receive access to quality care, no matter their race, ethnicity, sexual orientation, income level, or ZIP code.

Challenges

1. Research shows that inequalities exist in cancer survivorship based on socioeconomic status and geographic location.[1] The lack of coordinated care transitions for cancer patients, coupled with the cost of cancer care, continue to perpetuate a significantly lower rate of survival for many cancer patients.[3]
2. Technology provides significant opportunities to address existing gaps in America's health care system, such as access to care problems for rural and/or low-income populations. However, many Americans are unable to get or do not know how to use these new tools due to economic and/or technological barriers.[4]
3. Clinical trials are considered essential for the discovery and development of better drugs and treatments for cancer. Despite Congressional mandates to include female and racial/ethnic minorities in publicly funded research, women and minorities remain underrepresented.[5]

4. Even with overall decreases in the use of tobacco, populations targeted by the tobacco industry, such as communities of color; those of low socioeconomic status; the Lesbian, Gay, Bisexual, and Transgender (LGBT) community; and individuals with mental illness and addictions, still have significant rates of tobacco usage.[6]
5. The Affordable Care Act (ACA) has provided access to coverage to millions of Americans. But millions of lower-income, underserved Americans in Medicaid non-expansion states still face problems finding affording coverage.

Action Steps
1. Develop partnerships and collaborate with health care and community stakeholders to effectively reach hard to reach, at-risk populations.
2. Develop and use targeted, evidence-based strategies to reach hard to reach, at-risk populations.
3. Close insurance gaps to solve access issues.
4. Stress the importance of preventive services to health care and community sectors to improve access to disparate populations.
5. Provide access to peer support, patient navigation, and other case management services to harbor trust and ensure greater coordination of care.

Opening Session

Dr. Alonzo Plough, Vice President of Research-Evaluation-Learning and Chief Science Officer at the Robert Wood Johnson Foundation (RWJF) opened the conference by framing the challenges of achieving health equity for cancer patients. Dr. Plough discussed RWJF's "Culture of Health" program (cultureofhealth.org), where community residents and stakeholders from multiple sectors come together to create a culture of health in areas where people live,

eat, work and play.[7] RWJF's *Building a Culture of Health Action Model* will set tangible goals and measure the progress for four interconnected action areas, with equity and opportunity being the overarching themes:
1. Making Health a Shared Value
2. Fostering Cross-Sector Collaboration to Improve Well-Being
3. Creating Healthier, More Equitable Communities
4. Strengthening Integration of Health Services and Systems[7]

The goal of the *Culture of Health Action Model* – which mirrored the goal of the conference - is intended to "spark a productive national conversation about the physical, social, economic and emotional conditions that influence health," and to encourage different community sectors to partner together to improve health outcomes among *ALL* Americans.[7]

Break Out Discussion Highlights

Bridging the Digital Divide and Improving Health Literacy (Gary Doolittle, MD, University of Kansas Medical Center (Moderator); Kelly Brittain, PhD, RN, Michigan State University College of Nursing; McCrae Parker, ZeroDivide**)**

America's health care system is increasingly leveraging new technologies aimed at improving the quality, delivery, and patient experience of care.[8] These technologies present opportunities to address existing gaps in America's health care system, such as the lack of access to care for rural and/or low-income populations.[9] Despite this promise, current economic and/or technological barriers prevent many Americans from reaping the benefits.[4] Additionally, more Americans are turning to electronic and online sources for health information, rather than to their medical

providers.[10] It is important to harness these emerging resources to ensure that patients not only have access to this information, but are also able to participate in the production of it. Otherwise, the technology may simply widen the digital divide by generating further health inequities rather than leveraging the technology to narrow the gap.

The primary barrier preventing the use of eHealth technologies is the lack of broadband connectivity across the U.S. According to a 2015 FCC report, 53 percent of rural Americans and 17 percent of all Americans are without broadband access.[4] For low income, minority residents in urban areas, many eHealth tools are not personalized or made culturally relevant for different populations, such as ensuring the tool(s) is made available in the preferred language of the end user. Additional barriers include lack of technological "know-how" to operate these tools, poor functionality and usability, and privacy concerns over easily accessible personal health information.

Numerous solutions exist to overcome these barriers. Providing equitable broadband access across the U.S. is a first step. In addition, eHealth technologies must be created with a user-centered design to encourage adoption. Even further, technological "how-to" trainings can increase uptake among individuals that lack adequate levels of technological proficiency. Finally, both vendors and providers should make better efforts at educating their health care population regarding the availability of these tools,

as well as offer additional technological educational trainings to ensure the digital divide narrows and health literacy improves.[11]

Recommendations:
- Provide equitable broadband connectivity across the U.S.;
- Ensure that eHealth tools are personalized, in the preferred language, and culturally relevant to the end user;
- Have vendors create "how-to" trainings for greater technological proficiency; and
- Have vendors and providers educate their health care populations on the availability of these tools and educational trainings.

Clinical Trials Enrollment (Sharon Halon, MSN, Bristol-Myers Squibb (Moderator); Luther Clark, MD, FACC, FACP, Merck & Co., Inc.; Lannis Hall, MD, MPH, Siteman Cancer Center; Luckson Mathieu, MD, Food and Drug Administration)

Over twenty years after Congress mandated that research funded by the NIH include women and racial/ethnic minorities, female representation has increased, but still remains low.[5] Additionally, less than five percent of trial participants are non-white ethnic or racial groups.[12] Clinical trials are considered essential for the discovery and development of better drugs and treatments for cancer, and participation in trials has been shown to lower cancer mortality in patients with some types of tumors. As the demographics of the U.S. continue to diversify, it is imperative that trials reflect the greater population and include underrepresented groups as part of the trial design and development stage.

Multiple barriers exist to achieving a diverse participation in clinical trials, including mistrust of clinical trials (e.g. Tuskegee study),[13] geographical underrepresentation (e.g. reduced presence of academic centers in rural areas), transportations issues, and issues with the timing and length of clinical trials.[14,15] Additionally, many trials, particularly clinical

genetics research, use tumor registries to establish what mutations they use for their study population. This can often be disproportionately skewed towards whites, as disparate populations are less likely to consent to participate in tumor registries.[16] Finally, exclusion criteria for trials often include individuals with comorbidities, which disproportionately exclude minority populations, as they often have higher rates of comorbidities.[17]

Many solutions exist to overcome these barriers. Providing targeted education about clinical trials and their potential benefits and ethical requirements could aid in recruitment of underrepresented groups, along with providing an opportunity for researchers to understand and address negative perceptions associated with clinical research. In addition, engaging and educating providers in the importance and use of clinical trials could be beneficial because many individuals trust their provider's opinion. The use of patient navigators, recruitment specialists, and other ancillary providers as a gateway to clinical trial participation could also be a potential solution - helping to explain the benefits and any possible harms of the clinical trial to these populations in a more effective manner. Finally, many researchers are attempting to address logistical hurdles that patients face by helping with transportation and timing issues tied to clinic visits; unfortunately, these can be rather expensive and time consuming for researchers.[14]

Recommendations:
- Provide underrepresented populations with targeted education about the positive attributes/benefits of clinical trials;
- Address negative perceptions associated with clinical research through education;
- Engage and educate providers in the importance and use of clinical trials;
- Use patient navigators, recruitment specialists, and other ancillary providers as a gateway to clinical trial participation; and
- Bring the trial to the participant.

Access to Care, Prevention, and the Affordable Care Act (JudyAnn Bigby, MD, Mathematica Policy Research (Moderator); Peggy Payne, MA, Cigna; Michael Trujillo, MD, MPH, ABQ Health Partners)

Cancer prevention and early detection saves lives and reduces health care costs.[18] Preventive services also help reduce insurance gaps by detecting cancers early when treatment is more effective and less costly. Yet, many Americans still do not have access to preventive services that could literally save their lives. The implementation of the ACA has facilitated increased access to health care; however, because of the Supreme Court's ruling that essentially made Medicaid expansion optional, many states have failed to expand Medicaid. This has left millions of Americans without access to cancer prevention and early detection services.

Barriers to health care access and preventive services are countless, including lack of a usual source of care, financial barriers, and language barriers. New populations using insurance for the first time are often unfamiliar with their coverage and require assistance in navigating the health care system.

Sustainable navigation programs, peer support, community partnerships, and other support systems must be established and sustained over time. Insurers can play a role in helping the newly insured understand the benefits of their coverage by providing information that is culturally sensitive and appropriate. Moreover, by reiterating the business case for cancer prevention and showing the savings of real dollars over time, insurers will be incentivized to play an active role in educating their newly insured. The combination of offering culturally and linguistically appropriate products, as well as bringing the information to 'where the people are,' insurers and community groups can help increase utilization of early detection and prevention programs.

Recommendations:
- Develop/use targeted cancer prevention approaches in diverse communities that can be sustained in the long-term;
- Use peer support, patient navigation, and community partnerships to assist newly insured populations in their insurance coverage benefits, particularly preventive services; and
- Provide information to patients that are culturally sensitive and linguistically appropriate.

Tobacco Use and Health Disparities (Rosie Henson, MSSW, MPH, American Cancer Society, Inc. (Moderator); Delmonte Jefferson, National African American Tobacco Prevention Network; Catherine Saucedo, Smoking Cessation Leadership Center University of California, San Francisco; Dr. Scout, LGBT HealthLink at CenterLink)

Despite substantial reductions in U.S. tobacco consumption rates in the United States over the past 50 years, higher consumption rates among most racial minorities; those of low socioeconomic status; the LGBT community; and those with mental health and substance abuse challenges remain. The tobacco industry targets these communities with tailored marketing strategies. For example, in the substance addiction community, tobacco is often marketed as a stress reliever to help people deal with their substance abuse.

A broader commitment across every level of government, the public health community, and the medical community is required to reduce tobacco consumption in these communities. Prevention and cessation strategies need credible targeted actions to counter the tobacco industry, including engagement with organizations, utilizing leaders and allies trusted by these communities, engaging the medical community, and ensuring that tobacco screening, assessment, referral, and the full complement of cessation treatments and services are available. Often, for many individuals and service providers, tobacco use is often not addressed. Therefore, it is essential to know how to talk with the communities, know who should do the talking, and to establish credibility to be able to achieve results.

Recommendations:
- Have credible leadership in the communities (e.g. champions of change) to help build communities of change, through trusted engagement of organizations, leaders, and allies within the communities;
- Use affirmative, targeted prevention and cessation strategies to counter the tobacco industry's marketing strategies; and
- Get tobacco cessation on the agenda of the medical community for screening, assessment, referral, and the full complement of cessation treatments.

Transitioning to Survivorship (Cardinale Smith, MD, PhD, Icahn School of Medicine at Mount Sinai (Moderator); Reginald Tucker-Seeley, PhD, Dana-Farber Cancer Institute and Harvard T.H. Chan School of Public Health; Tina Shropshire, Truman Medical Center)

Cancer patients face multiple challenges throughout the course of their treatment - accessing care, out of pocket costs, finding the right providers, and a myriad of treatment decisions. For minority cancer patients, studies have shown that cancers are diagnosed later, and survival rates are lower.[1] Equally daunting are the challenges facing cancer survivors, including equity issues for access to post-cancer care. For many survivors the transition from oncology care back to primary care – following the end of cancer treatment – is disjointed. Many of these patients do not have a survivor care plan and are not fully clear about their next steps. These patients face a "new normal" and must figure out how to deal with the on-going challenges of post-cancer care.

Two distinct tools can help both cancer patients and survivors - patient navigation and palliative care. Patient navigation programs provide one-on-one guidance to help cancer patients, cancer survivors, and their families deal with the physical, financial, and emotional challenges that come with a cancer diagnosis.[19] For survivors – navigators can help ensure access to appropriate follow-up services, help with medication questions, and help survivors seek treatment for any lingering or new health issues related to their treatment. These services are critical to survivors across all income levels.

Palliative care can help improve the quality of life for cancer survivors. Cancer patients often struggle with pain throughout the cancer care continuum, and often times into survivorship. Having access to palliative care allows cancer patients and survivors to keep their pain under control and live more productive lives.

Patient access to services such as palliative care and patient navigation provide an extra layer of support for patients and families who are navigating the health care system, and provide patients with access to symptom management, supportive services to coordinate patient care, and psychosocial services to assist the patient and the patient's family.[20]

Recommendations:
- Improve access to palliative care and patient navigation to provide an extra layer of support for patients and families navigating the health care system;
- Ensure that providers and hospital systems do a better job of addressing the individual concerns of patients and their families throughout the care continuum; and
- Provide patients and their families with resources regarding the costs, treatment options, and treatment decision making process cancer care to allow them to be better informed.
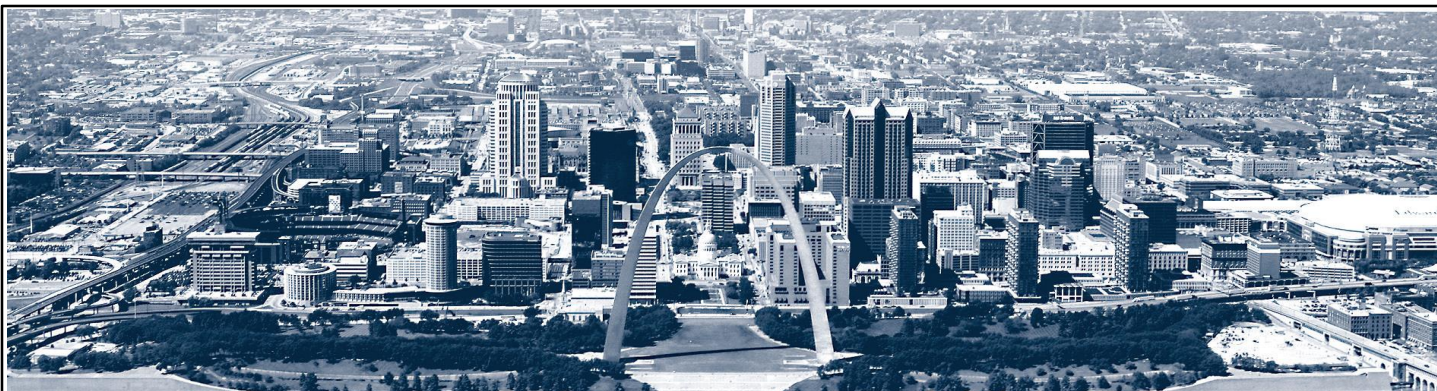
Action Institute

Dr. Brian Smedley, Co-founder and Executive Director of the National Collaborative for Health Equity (NCHE), set the stage for the Action Institute panel by highlighting the social, economic, and environmental factors that shape health inequities among racial and ethnic populations. Dr. Smedley discussed the NCHE's "Place Matters" initiative and their goal to build healthier and more equitable communities through partnerships with multiple stakeholders, and through policy initiatives NCHE has underway.[21]

Participants in the Action Institute identified five overarching policy solutions/considerations to help advance health equity:

Action Steps

1. **Develop partnerships and collaborate with health care and community stakeholders to effectively reach hard to reach, at-risk populations.** Partnerships and collaboration among health care industry sectors and community organizations are needed to increase access to care and to acknowledge cultural differences within communities.

2. **Develop and use targeted, evidence-based strategies to reach hard to reach, at-risk populations.** Targeted policy approaches and evidence-based prevention strategies that are community and culturally appropriate are needed to address disparities.

3. **Close insurance gaps to solve access issues.** Insurance gaps need to be filled to solve the access issue, particularly for those states who have not expanded their Medicaid programs.

4. **Stress the importance of preventive services to health care and community sectors to improve access to disparate populations.** Insurance does not guarantee use, so the importance of preventive services should be stressed amongst providers and throughout communities.

5. **Provide access to peer support, patient navigation, and other case management services to harbor trust and ensure greater coordination of care.** Sustainability, trust, and coordination of care are all vital to increasing access to care among disparate populations. In particular, providing access to peer support, patient navigation, and other case management services will harbor trust and ensure better coordination and follow-up of care.

Conclusion

The robust discussions and exchanges at the National Summit on Health Equity helped to shed new light on key policy issues surrounding health equity and cancer, as well as possible solutions to improve the health disparity gaps among populations. This summary report highlights the barriers and identifies the policy solutions discussed at the Summit on November 10th. It is clear, however, that partnerships, collaboration, and education are all vitally important to the health equity cause. Public- and private-sector leaders and policymakers must continue to foster and engage in the health equity discussion in order to move the nation forward to make high-quality health care accessible to all Americans regardless of race, ethnicity, sexual orientation, income level, or ZIP code.

Panelists

Health Equity Landscape
Alonzo Plough, PhD, MPH, Robert Wood Johnson Foundation (Moderator)
JudyAnn Bigby, MD, Mathematica Policy Research
Gary Doolittle, MD, University of Kansas Medical Center
Cardinale Smith, MD, PhD, Icahn School of Medicine at Mount Sinai

Bridging the Digital Divide and Improving Health Literacy
Gary Doolittle, MD, University of Kansas Medical Center (Moderator)
Kelly Brittain, PhD, RN, Michigan State University College of Nursing
McCrae Parker, ZeroDivide

Clinical Trials Enrollment
Sharon Halon, MSN, Bristol-Myers Squibb (Moderator)
Luther Clark, MD, FACC, FACP, Merck & Co., Inc.
Lannis Hall, MD, MPH, Siteman Cancer Center
Luckson Mathieu, MD, Food and Drug Administration

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Transitioning to Survivorship
Cardinale Smith, MD, PhD, Icahn School of Medicine at Mount Sinai (Moderator)
Reginald Tucker-Seeley, PhD, Dana-Farber Cancer Institute and Harvard T.H. Chan School of Public Health
Tina Shropshire, Truman Medical Center

About ACS CAN

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. ACS CAN gives ordinary people extraordinary power to fight cancer with the training and tools they need to make their voices heard.

For more information, visit acscan.org

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References

[1] American Cancer Society. Cancer Facts & Figures, 2015. Atlanta: American Cancer Society, 2015.

[2] National Cancer Institute. Cancer health disparities. Published March 11, 2008. http://www.cancer.gov/about-nci/organization/crchd/cancer-health-disparities-fact-sheet#q1.

[3] Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population; Board on Health Care Services; Institute of Medicine; Levit L, Balogh E, Nass S, et al., editors. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Washington (DC): National Academies Press (US); 2013 Dec 27. 8, Accessible and Affordable Cancer Care. Available from: http://www.ncbi.nlm.nih.gov/books/NBK202155/.

[4] Federal Communications Commission. *2015 Broadband Progress Report*. https://www.fcc.gov/reports-research/reports/broadband-progress-reports/2015-broadband-progress-report.

[5] National Institutes of Health. Inclusion of women and minorities in clinical research. Updated December 1, 2015. http://orwh.od.nih.gov/research/inclusion/.

[6] Centers for Disease Control and Prevention. Cigarette smoking in the United States. Updated December 14, 2015. http://www.cdc.gov/tobacco/campaign/tips/resources/data/cigarette-smoking-in-united-states.html.

[7] Robert Wood Johnson Foundation. Building a culture of health. Accessed January 13, 2016. http://www.cultureofhealth.org/.

[8] Berwick DM, Nolan TW, Whittington J. The Triple Aim: Care, Health, and Cost. *Health Affairs*. 2008; 27, (3): 759-69. doi: 10.1377/hlthaff.27.3.759

[9] Key Facts about the Uninsured Population. *Kaiser Family Foundation*. Accessed January 13, 2016. http://kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/.

[10] Pew Research Center. *The Smartphone Difference*. Published April 2015. Accessed January 13, 2016. http://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/

[11] The "O-Bar" at Ocshner Health Systems is a recent example of providers making efforts to improve health literacy and bridge the digital divide. Accessed January 13, 2016. http://www.wwltv.com/story/news/health/2015/02/11/ochsner-bar-app/23262855/.

[12] Chen MS, Lara PN, Dang JHT, Paterniti DA, Kelly K. Twenty years post-NIH revitalization act: enhancing minority participation in clinical trials (EMPaCT): laying the groundwork for improving minority clinical trial accrual. Cancer. 2014; 120(7 suppl): 1091-6.

[13] Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved*. 2010; 21(3): 879–897. doi:10.1353/hpu.0.0323.

[14] Raghavan D. Predicting low trial accrual mathematically: is that the right emphasis? *JNCI J Natl Cancer Inst.* 2016; 108(2): djv379. doi: 10.1093/jnci/djv379.

[15] Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health Soc Care Commun*. 2004; 12:382-388.

[16] White DB, Koehly LM, Omogbehin A, McBride CM. African Americans' responses to genetic explanations of lung cancer disparities and their willingness to participate in clinical genetics research. *Genetics in Medicine*. 2010; 12: 496-502. doi: 10.1097/GIM.0b013e3181e5e513.

[17] Pemberthy L, Brown R, Wilson-Genderson M, Dahman B, Ginder G, Siminoff LA. Barriers to therapeutic clinical trials enrollment: differences between African-American and white cancer patients identified at the time of eligibility assessment. *Clin Trials*. 2012; 9:788-797.

[18] American Cancer Society. Cancer prevention & early detection: Facts & figures 2015-2016. Atlanta: American Cancer Society; 2015.

[19] Simon S. Navigators help cancer patients manage their care. American Cancer Society. Published December 6, 2013. Accessed January 13, 2016. http://www.cancer.org/cancer/news/news/navigators-help-cancer-patients-manage-their-care.

[20] American Cancer Society. *A guide to palliative or supportive care*. Updated September 23, 2014. Accessed January 13, 2016. http://www.cancer.org/treatment/treatmentsandsideeffects/palliativecare/supportive-care.

[21] National Collaborative for Health Equity. Place Matters. 2014. Accessed January 13, 2016. http://nationalcollaborative.org/?q=node/37.