



# Executive Summary

ACORI Call to Action Summit





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# Summit Overview

On September 13 and 14, 2021, the Association of Community Cancer Centers (ACCC), in collaboration with Stand Up to Cancer, hosted the ACORI (ACCC Community Oncology Research Institute) Call to Action Summit: Activating Equity in Community Oncology Research, a virtual event bringing together oncology programs and practices, research team members, patient advocates, trial sponsors, industry representatives, research networks, and regulatory agencies. The goal of the Summit was to highlight the importance of diversifying clinical trials and to identify concrete strategies for engaging patients, caregivers, and their communities to strengthen oncology research across the United States.

Day 1 of the Summit featured four panel discussions among experts from a range of backgrounds and experiences across the oncology research spectrum. Day 2 was structured around three topical discussions followed by breakout sessions with Summit participants to identify action items for ACCC, oncology programs and practices, industry sponsors, and stakeholders involved in research. 120 people from more than 60 organizations participated and, overall, the Summit generated 200+ ideas for action items to make cancer care research more diverse, equitable, and accessible.

## Why a Call to Action?

The purpose of creating a Call to Action is to move beyond the discussion and recognition of common challenges to leverage the vast experience and expertise of attendees to generate actionable ideas that advance equity. The Summit sought first to start a conversation on health equity in cancer care research, the role of oncology programs and practices in carrying out equitable and accessible research, and the need to bring the patient and community perspectives into all aspects of the research process. Using the rich insights generated on Day 1 as framing, participants engaged in small group conversations that moved those discussions forward to identify concrete steps that ACCC, oncology programs and practices, and other stakeholders (e.g., patient advocates and industry partners) can take to intentionally activate equity in cancer research. Taken together, these action items provide a foundation for a comprehensive plan to create systemic change in community oncology research.

## Overview of Action Items

An overview of the action items co-developed by the Summit participants for ACCC and oncology programs and practices, as well as other stakeholders, is included below. The full list of prioritized items can be found on pages 8 to 15. The action items identified for ACCC are

intended to serve as foundational resources in support of the additional action items for other stakeholders in their work to improve equity and inclusion in research and diversify clinical trials.

## Action Items for ACCC

- 1 Ensure that patient experiences and perspectives are embedded in all phases of research** at oncology programs and practices, by collecting and sharing patient experiences and identified needs. Hardwire the inclusion of patients into ACORI and ACCC's work through formalized roles within the organizations' structure.
- 2 Strengthen connections between oncology programs and practices and relevant stakeholder organizations** by convening all pertinent parties, creating mentorship and networking opportunities, and hosting working sessions to share best practices, in order to build capacity and formalize the process of incorporating patient and caregiver feedback into research. Advocate to other stakeholders on the needs of oncology programs and practices doing research.
- 3 Engage oncology programs and practices, community organizations, academic institutions, patient advocacy organizations, and industry sponsors on the importance of patient and community involvement in research.** Strategies might include clarifying the process, timing, and

roles of each stakeholder; creating online platforms for collaboration for patient and community engagement; building matching programs between researchers and community cancer programs and research staff; and maintaining or contributing to repositories of community organizations for partnership and oncology programs and practices that are ready to conduct research.

- 4 Develop and actively share—in partnership with stakeholders—tools and resources that oncology programs and practices can use to more effectively incorporate the patient and community perspectives into their work.** High-value resources include tools for patient and community engagement, conducting high-quality needs assessments, finding and implementing research opportunities, case studies of best practices for community-based cancer research studies, and making the case to their own leadership on the importance of research in the community cancer setting.

- 5 Advocate for more diversity and representation in clinical trials consistent with the burden of cancer,** through engagement with state and federal governments on topics like funding for implementation of research in community oncology, prioritization of research projects, and the need for flexible telehealth for research, and with industry sponsors to co-develop targets and support partnerships with diversity in mind.

## Action Items for Oncology Programs and Practices

- 1 Engage the community and intentionally understand their needs, barriers to participation in research, and community assets that can be leveraged to improve trial enrollment and retention,** beginning with a community needs assessment that focuses on equity and inclusion, using multiple methods of engagement with community leaders and organizations, and partnering with other stakeholders to more effectively support the patient and community experience.
- 2 Engage directly with patients and caregivers to ensure that their experiences and perspectives are embedded in the entire research process,** from enhancing research awareness to involving patients and patient advocacy groups in the entire research

process—including designing the study question, protocols, and implementation plan (if applicable) and effective methods to propose that all eligible patients participate in clinical trials. This could also mean soliciting patient feedback throughout the entire trial, including patients as co-investigators or creating a patient-centered research dissemination plan. Implementing cancer programs and practices could also connect trial participants with other current or prospective trial participants, and train all providers on inclusive patient engagement.

- 3 Build capacity to conduct equitable and patient-centered research by focusing on long-term sustainability,** including ensuring that providers have the financial resources and schedule flexibility to engage in research, advocating to industry for more equitable research methods, and investing in additional resources, like technology, to support diverse enrollment and retention.

## Action Items for Other Stakeholders

*Note: Action items in this section target industry sponsors, large academic centers, and any organization involved in trial design, implementation, and dissemination.*

- 1 Target and partner with underrepresented clinical trial sites, such as oncology programs and practices serving understudied and underserved patients,** by sharing decision-making tools and processes; identifying priority sites and targeted populations and/or geographies; and developing additional resources to help sites plan for inclusive research practices and increase diverse patient participation and retention.
- 2 Identify and work with historically underrepresented communities to support their engagement with research and ability to participate in clinical trials,** by creating tailored resources for clinical trial participants, their caregivers, and patient advocates and increasing resources that cover trial volunteers' out-of-pocket costs.
- 3 Engage patients to better understand and embed their perspectives into trial design and implementation,** from gathering their input on protocols, diversity plans, and clinical research programs and designing with inclusive principles.



# ACORI Call to Action Summit Agenda

The Summit opened with a powerful patient story from a cancer survivor and clinical trial participant. Her testimony grounded the Summit in the importance of centering the patient perspective and highlighted the impact of clinical trials and the barriers that many patients face, especially in historically underserved and underrepresented communities.

Before convening panel discussions, ACCC presented the results from a recent member survey (variable n of 31), including many Summit participants. Forty-five percent of responding organizations do not engage patients in research design and conduct. Of those that do, only 21% engage patients through community partnerships. The survey also found that community cancer programs, which comprised 71% of respondents, reported limited diversity among enrolled trial participants, limited access to information about which trials could be opened at their site, and difficulty recruiting patients. These results underline the importance of supporting oncology programs and practices in their efforts to engage the community and of identifying the most promising strategies for improving diversity in research participation.

## DAY 1



Day 1 included four panel discussions focused on advancing health equity, centering the patient perspective in community cancer research, fostering research readiness, and promoting the inclusion of underrepresented groups in cancer drug development. Across the four panels, several cross-cutting themes emerged:

- Research activities, across all phases, should be grounded in patients' lived experiences.
- Clinical trials should be an accepted standard of care treatment option for all patients and, as such, should be equitable and accessible.
- All stakeholders, especially oncology programs and practices, should demonstrate to patients and their communities that they are valued and welcomed in the decision-making process.
- Challenges remain, including defining accountability for recruitment and retention, addressing common barriers to clinical trial participation, and understanding the readiness of oncology programs and practices to conduct cancer clinical research.

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<sup>1</sup> See Appendix for the full two-day Summit agenda.

## PANEL 1: Advancing Health Equity through Community Cancer Research

This panel was moderated by Sybil Green, JD, RPh, MHA (Diversity and Inclusion Officer, ASCO) and included Ysabel Duron (President/Executive Director, *The Latino Cancer Initiative*), Linda Burhansstipanov, MSPH, DrPH (President, *Native American Cancer Initiatives*), and Karen Winkfield, MD, PhD (Executive Director, *Meharry-Vanderbilt Alliance*). The panel focused on the evolving context around health equity in cancer research and the potential role for oncology programs and practices to play in advancing health equity through research. Key takeaways include:

- **The importance of understanding the patient and community context.** Historical injustice and bias play a significant role in inequity of cancer care and research. An understanding of the historical, cultural, and political context of the community is vital to productive patient engagement.
- **The need to invite understudied populations, in particular historically marginalized communities, to participate.** Although historically marginalized communities want to be involved in research, stakeholders in the research field need to systematically ask them to participate and go a step further and address the barriers to participation that these communities may face.
- **The value of trust.** Among others, building trust with patients and the community requires deep engagement, a willingness to identify and work with existing needs and assets in the community, and a commitment to compensating community partners for their work in support of research.

## PANEL 2: Centering the Patient Perspective in Community Cancer Research

This panel was moderated by Jeanne Regnante (Chief Health Equity and Diversity Officer, *LUNGeVity Foundation*) and included Shonta Chambers, MSW (Executive Vice President of Health Equity and Community Engagement, *Patient Advocate Foundation*), Venus Ginés, MA, P/CHWI (CEO/Founder, *Día de la Mujer Latina*), and Rodney Haring, PhD, MSW (Director, Center for Indigenous Research, *Roswell Park Comprehensive Cancer Center*). This discussion focused on the importance of bringing research to the community and of centering the patient and their experience throughout the research process. Key takeaways include:

- **The need for patient and community input.** Nothing regarding patients or communities should be done without their input. This input belongs in every step of the research process from designing protocols to disseminating results.
- **The connection between the patient and the community.** In many cases, to understand the patient is to understand the community, so a deep investment in both is necessary.
- **The importance of understanding the social determinants of health and how they shape trial participation.** It is vital to consider the costs of participation that patients face, including transportation and childcare. Failing to acknowledge these costs will make it more difficult to engage a diverse population.

### PANEL 3: Fostering Readiness for Community Cancer Research

This panel was moderated by Nadine J. Barrett, PhD, MA, MS (Assistant Professor, *Family Medicine and Community Health*; Co-Director, Clinical and Translational Science Institute (CTSI); Director, Center for Equity in Research; Associate Director, Equity, Community and Stakeholder Strategy, *Duke Cancer Institute*) and included Nina Bickell, MD, MPH (Co-Lead, Cancer Prevention and Control, *Tisch Cancer Institute*), Randall A. Oyer, MD (Medical Director, *Ann B. Barshinger Cancer Institute, Penn Medicine Lancaster General Health*), and Robert Winn, MD (Director and Lipman Chair in Oncology, *VCU Massey Cancer Center*). Discussion centered on the potential of oncology programs and practices to conduct research and reach underserved communities and the common needs that they face in building institutional capacity to undertake such research. Key takeaways included:

- **The difference between readiness and capacity.** For oncology programs and practices, moving from research readiness to research capacity requires intentional investments in time and resources across all levels of their institutions.
- **The need to make available resources for providers.** To create a sustainable shift towards research, providers need resources to create the time and capacity necessary for undertaking research without disrupting ongoing patient care.
- **The role that industry needs to play in improving access.** Important shifts in trial sponsorship are needed for the industry to play its part in truly diversifying research. For example, industry could expand the categories of out-of-pocket costs that it covers to support more trial participation from diverse cancer programs and practices and patients.

### PANEL 4: Promoting Inclusion of Members of Racial and Ethnic Minority Groups in Cancer Drug Development.

The panel was moderated by Lola A. Fashoyin-Aje, MD, MPH (Associate Director, *FDA Oncology Center of Excellence*) and included Jennie R. Crews, MD, MMM, FACP (Medical Director, *SCCA Network & Community Sites, Seattle Cancer Care Alliance*), Erin Williams, MBA (Associate Director, Clinical Research Operations, *University of Texas Southwestern Medical Center, Simmons Comprehensive Cancer Center*), and Racquel Racadio, MPH (Senior Manager, Diversity and Representation in Clinical Research, *Amgen*). Conversation focused on inclusive drug development and a discussion of Dr. Fashoyin-Aje's recent article, *Promoting Inclusion of Members of Racial and Ethnic Minority Groups in Cancer Drug Development*. Key takeaways include:

- **The need for a diversity plan.** A clinical trial recruitment and retention strategy that does not include a thoughtful diversity plan will not achieve inclusion.
- **The importance of considering the entire trial timeline.** Diversity should be a consideration throughout the research process. Taking the time to consider diversity during trial design and site selection is critical.
- **The value of building a relationship between industry and community.** Industry and sponsors need to more actively engage the communities in which they are working.



## DAY 2

Day 2 began with a presentation from Stand Up to Cancer highlighting a new research initiative to advance health equity in colorectal cancer screening, and a collaborative campaign with Hip Hop Public Health to spread awareness about the importance of colorectal cancer screening, specifically in Black and Hispanic/Latinx communities. Their presentation highlighted the importance of creating inclusive and culturally relevant materials to better reach diverse audiences.

Attendees then participated in three breakout discussions focused on generating action items to address the issues articulated on Day 1. Each session included time for participants to brainstorm ideas, discuss and refine those ideas as a group, and finally prioritize ideas. The sessions focused on:

### SESSION 1

Harnessing the Power of Community Partnerships to Improve Patient Accrual

### SESSION 2

Building Research Capacity to Strengthen Cancer Trials in the Community

### SESSION 3

Incorporating the Patient Perspective into Research: From Design to Dissemination

The action items generated and prioritized in these small group discussions are provided below, organized by the type of organization to which they apply.

- 1 Action Items for ACCC
- 2 Action Items for Oncology Programs and Practices
- 3 Action Items for Other Stakeholders

# Full List of Action Items

## Action Items for ACCC

1

*Ensure that patient experiences and perspectives are embedded in all phases of research in oncology programs and practices, and hardwire patient engagement into ACORI and ACCC's work.*

- **Amplify patient perspectives and input in research for ACCC members.** Collect and amplify patient experiences in clinical trials in oncology programs and practices, including convening panels, forming a group of survivors willing to speak on their experience, and facilitating conversations between former trial participants and current study volunteers and research staff as needed.
- **Embed patient and community perspectives within ACORI and ACCC's work.** Include the patient perspective in the ACORI Task Force and ensure that these patients represent the diversity of cancer patients. Establish a patient partners' advisory group (i.e., patients and patient advocacy organizations) to inform ACCC members in their efforts to improve community engagement in research, identify local organizations and partners, and integrate the community voice in future ACORI processes.

2

*Strengthen connections between oncology programs and practices and relevant organizations to build capacity, improve research readiness, and formalize the process of incorporating patient feedback into research.*

- **Continue developing a community platform for oncology programs and practices** doing research through ACORI to facilitate the sharing of best practices, identify potential mentorship opportunities, and create space for collaboration.
- **Organize dedicated working sessions for oncology programs and practices** engaged in research to reflect on their experiences and share learnings, best practices, and resources to build capacity for conducting clinical trials, increasing patient accrual, and ensuring community involvement.
- **Connect sites for research collaborations and create pathways for researchers from different oncology programs and practices to network with each other,** including connecting oncology programs and practices with less research experience to those with more research experience for networking and mentoring. Advocate to other stakeholders on the needs of oncology programs and practices doing research.

3

*Engage oncology programs and practices, community organizations, large academic centers, patient advocates, industry, and other stakeholders on the importance of patient and community involvement in research.*

- **Bring stakeholders together for collaboration and exchange on patient and community engagement** through an online platform, clarifying the process, timing, and roles of each stakeholder.
- **Connect oncology programs and practices with larger academic centers through “matching programs” to help set up trials** and with potential community partners through a database of community organizations.
- **Maintain or contribute to a repository of “oncology programs and practices ready to conduct research”** help assess members’ research program demographics and consider how to align oncology program and practice needs with interests of investigators and industry partners.

4

*Develop and actively share—in partnership with stakeholders—tools and resources that oncology programs and practices can use to more effectively incorporate the patient and community perspective on research into their work, including tools to help communicate with patients and the community, start their journey as research sites, and carry out meaningful community and program needs assessments.*

- **Collaborate with patient advocacy groups to develop culturally-relevant materials that oncology programs and practices can use to more effectively engage patients and communities on the basics of research and clinical trials:**
  - Adapt standards for “Universal Patient Language.”
  - Build accessible campaigns about clinical trials that use easily understood language, including animated videos on why clinical trials are important, commercials that raise awareness of clinical trials, or other resources that explain how trials work.
  - Create case studies of best practices for community-based cancer research studies.
  - Supplement existing materials, including translating materials into different languages and tailoring resources to different communities and patient populations.
  - Provide suggestions for dissemination and communication plans to assist oncology programs and practices in getting materials into the community.
- **Create templates for conducting and utilizing community needs assessments for use by oncology programs and practices, including building on existing templates and resources:**
  - Provide templates with a standardized methodology for oncology programs and practices to conduct and use a needs assessment with material on how to map community assets and the social determinants of health (SDOH), and to understand the local context.
  - Provide guidance for oncology programs and practices to help address SDOH barriers and aggregate nationally available resources.

- **Create a repository of materials and learning modules for oncology programs and practices related to planning for, finding, and implementing research opportunities:**
  - Create a tool to assess capacity and institutional readiness, especially for understanding readiness to conduct research in community settings.
  - Develop a “Community Oncology Research Blueprint” to serve as a handbook for oncology practices and programs to get started with research, including:
    - Sample budgets, business plans, organizational charts, and advisory board membership guidelines.
    - Research protocol-specific recommendations to make protocols more inclusive.
    - Use of technological tools, such as telehealth, to conduct clinical trials, data collection and management, and devices for patients to report problems to providers and monitors.
  - Share guidelines for oncology programs and practices related to hiring, onboarding, and training research staff with a focus on community engagement and diversity:
    - Hire a diverse workforce, including interview questions and process recommendations.
    - Create effective navigator programs to support research.
    - Develop training and resources for clinicians on health equity, the value of community engagement, and the importance of establishing clinical research as a standard of care.
  
- **Help oncology programs and practices make the case for clinical research to build buy-in among clinician and administrative leaders:**
  - Quantify ROI on research to help gain buy-in from oncology program and practice leaders.
  - Create materials on the business case for hiring staff to carry out research-specific roles and how that hiring practice helps sites retain patients in trials.

5

*Advocate for more diversity and representation in clinical trials consistent with the burden of cancer, speaking to state and federal government and industry sponsors.*

- **Advocate to state governments to ensure that communities and oncology programs and practices are represented in research (e.g., funding, prioritization).**
- **Advocate to state and federal government for legislation to address compliance barriers** to funding non-medical research needs (e.g., non-drug/treatment-related, costs of participation in clinical trials) and for continued expansion of telehealth in the context of research.
- **Collaborate with industry sponsors to help meet their objectives of diversity and inclusion in clinical trials**, including working with industry to co-develop targets and connect and support partnerships with oncology programs and practices to conduct research.

## Action Items for Oncology Programs and Practices

1

*Engage directly with patients to ensure that their experiences and perspectives are embedded in the entire trial process.*

- **Involve trial volunteers in protocol design, throughout all stages of research and dissemination:**
  - Mandate that research teams include patient advocates and solicit feedback from patients who have participated in previous trials.
  - Involve patients in the institution's leadership more permanently, for example, adding a patient representative seat on the hospital board to systematically offer the patient perspective.
- **Offer all eligible patients the option to participate in clinical trials:**
  - Systematically ask patients if they would be interested in participating in future trials if they are not currently eligible for a trial.
  - When discussing trial participation with patients, or when enrolling them, inquire about what they will need in order to participate. Follow up on their answer(s).
- **Use available resources or create curriculum related to clinical research and trials (videos, reading materials, etc.) that can be provided during each clinic visit.**
- **Connect patients, families, and caregivers who are participating in clinical trials; connect interested patients with current or former participants.** Ask for feedback from patients, families, and caregivers throughout the trial. If possible, create a "patient liaison" role that can collect patient feedback and share that input with the clinical trial team.
- **Train staff, researchers, faculty, and all other providers with specific onboarding related to the community, bias, effective communication, and cultural humility.** Set rules of engagement: ensure that all staff are listening with intention and prioritizing transparency and accountability towards goals.

2

*Engage the community and intentionally understand their needs, barriers to participation in research, and community assets that can be utilized to improve participation.*

- **Conduct community needs assessments focused on developing a local understanding of community needs, specific barriers, and health inequity drivers:**
  - Engage a community advisory council to co-create and help conduct community needs assessments and identify specific structural drivers of health inequities in the community.

- Expand the scope of community needs assessment to highlight and identify potential community partners, leaders, and the most important community assets.
  - Consider conducting an Equity Audit (such as the one by Beloved Community) and using the [ASCO-ACCC Clinical Trial Site Assessment Tool for Ensuring Racial and Ethnic Diversity in Clinical Trials](#). Adapt research and care and internal management practices based on results.
  - Assign a specific staff member to screen for SDOH and follow-up as needed.
- **To reduce burden on community partners and avoid duplicative effort, coordinate with other organizations that might be interested in working with those community partners, such as other oncology programs and practices or medical providers in different fields:**
  - Potential partners: community centers, faith-based organizations, social service organizations, schools, barber shops, cultural centers, etc.
  - Recommendations on finding partners: Engage interested staff—and patients—to help brainstorm potential partners.
- **Use multiple channels and methods of engagement with the community:**
  - Facilitate town halls, hold information opportunities, and conduct learning sessions where community members are asked explicitly what would help build trust in clinical research.
  - Collect patient stories and use lived experiences to create materials like videos, social media posts, or other resources to share with community organizations.
  - Empower a “patient influencer” in the community who can talk about the importance of research and experiences on clinical trials.
  - *Important considerations:* When engaging with community partners, is vital to compensate partners for their time and to assess the availability of local funding opportunities; it is also important to start building trust, understand the social context, and serve the community prior to looking for help with trials.
- **Form partnerships beyond your community with other oncology programs and practices, larger academic centers, and advocacy groups:**
  - Collaborate with advocacy groups that provide patient support, navigation, and financial assistance.
  - Collaborate on learning opportunities with cancer centers that have more research experience or with larger academic centers; bring your learnings and community’s perspective to larger centers to ensure that their voice is heard there as well.
  - Partner with businesses and nonprofits to directly address barriers to, for example, ride share apps, food delivery providers, hotels, and local charities.

## 3

*Intentionally build capacity to conduct equitable and patient-centered research.*

- **Build capacity to conduct equitable and patient-centered research and ensure that culture shifts towards patient-centered research are sustainable in the long term:**
  - Give staff the financial resources, time, space, and organizational support that they need to fully engage with research (i.e., ensure that staff have time for trainings), while ensuring organizational and leadership buy-in and long-term support.
  - Make research goals and metrics part of the organization's yearly goals and demonstrate accountability by reporting progress publicly.
  - Make space for staff to seek support or to check-in regarding questions about trials or the research process.
  - Integrate research and clinical teams in building dedicated workflows that allow providers and research teams to discuss new and ongoing trials.
  - Designate a "physician champion" who is invested in implementing clinical trials and works to build a cultural understanding that clinical trials should be the standard of care.
- **Ask sponsors directly for the funding that is needed to implement trials in an equitable way and set accrual targets that represent the population affected.**
- **Invest in additional resources like technology that will support diverse enrollment and retention.** This could include providing IT support for remote visits, as well as training and resources to understand and address social determinants of health that might impact ability to participate virtually.

## Action Items for Other Stakeholders

Note: Action items in this section target industry sponsors, large academic centers, and any organization involved in trial design, implementation, and dissemination. Patient advocacy groups can also play an important role to help accomplish these goals.

1

*Target and partner with underrepresented clinical trial sites such as oncology programs and practices serving understudied and underserved populations.*

- **Share decision-making tools and processes and identify priority geographies, sites, and communities historically underrepresented in research to conduct trials that foster participation and accrual from a diverse set of patients.**
- **Invest in long-term relationships with research sites at oncology programs and practices and provide additional resources to sites newer to clinical research to help them plan for inclusive research practices and increase diverse patient participation and retention.**

2

*Identify and work with historically underrepresented communities to support their engagement with research and ability to participate in clinical trials.*

- **Create tailored resources for clinical trial participants, their caregivers, and patient advocates (as well as materials for oncology programs and practices to engage these groups) to increase engagement in clinical research.**
- **Seek to engage and support the underserved communities in which trials are currently occurring:**
  - Establish an advisory committee with community leaders, patients, and researchers and engage the committee in every part of the trial design process, to review protocols and consents.
  - Create pathways for ongoing engagement throughout trials. Pay special attention to communities that are not typically participating and invite them to join this process.



- **Identify patients who are more likely to incur out-of-pocket costs related to clinical trial participation including lodging, childcare, and transportation; partner with organizations that can support patients:**
  - Increase flexibility across organizations for shared collaborative care under the research protocol design.

3

*Engage patients to better understand and embed their perspectives into trial design and implementation.*

- **Incorporate the patient perspective in all phases of trial design and implementation:**
  - Integrate these perspectives from protocol design and continuing past the end of a trial to understand and address patient feedback, including individual protocols.
  - Engage underserved patients specifically in creating diversity and inclusion plans for recruitment and retention.
  - Engage patients across your organization's entire clinical research program. This could include a patient panel for each study.
- **Design trials with inclusivity in mind and create additional pathways to avoid exclusion:**
  - Set up a phone line for patients to provide feedback about what worked well for them or what did not work well; intentionally address health literacy barriers, for example, when designing consent forms.
  - Encourage scientists, researchers, clinicians, and allied staff to have small-group conversations (not lectures) with advocates and patients where feedback and questions can come from either side.

## Agenda

### DAY 1: Monday, September 13

12:00 PM Welcoming Remarks

12:55 PM **Advancing Health Equity through Community Cancer Research**

- Sybil Green, JD, RPh, MHA, Diversity and Inclusion Officer, *ASCO* (Moderator)
- Linda Burhansstipanov, MSPH, DrPH, President, *Native American Cancer Initiatives*
- Ysabel Duron, President/Executive Director, *The Latino Cancer Institute*
- Karen Winkfield, MD, PhD, Executive Director, *Meharry-Vanderbilt Alliance*

1:40 PM **Centering the Patient Perspective in Community Cancer Research**

- Jeanne Regnante, Chief Health Equity and Diversity Officer, *LUNGevity Foundation* (Moderator)
- Shonta Chambers, MSW, Executive Vice President of Health Equity and Community Engagement, *Patient Advocate Foundation*
- Venus Ginés, MA, P/CHWI, CEO and Founder, *Día de la Mujer Latina*
- Rodney Haring, PhD, MSW, Director, *Center for Indigenous Cancer Research, Roswell Park Comprehensive Cancer Center*

2:40 PM **Fostering Readiness for Community Cancer Research**

- Nadine J. Barrett, PhD, MA, MS, Assistant Professor, *Family Medicine and Community Health*; Co-Director, *Clinical and Translational Science Institute (CTSI)*; Director, *Center for Equity in Research*; Associate Director, Equity, Community and Stakeholder Strategy, *Duke Cancer Institute* (Moderator)
- Nina Bickell, MD, MPH, Co-Lead, Cancer Prevention and Control, *Tisch Cancer Institute*
- Randall A. Oyer, MD, Medical Director, *Ann B. Barshinger Cancer Institute, Penn Medicine Lancaster General Health*; ACORI Chair
- Robert Winn, MD, Director and Lipman Chair in Oncology, *VCU Massey Cancer Center*

3:30 PM **Promoting Inclusion of Members of Racial and Ethnic Minority Groups in Cancer Drug Development**

- Lola A. Fashoyin-Aje, MD, MPH, Associate Director, *FDA Oncology Center of Excellence* (Moderator)
- Jennie R. Crews, MD, MMM, FACP, Medical Director, *SCCA Network & Community Sites, Seattle Cancer Care Alliance*
- Racquel Racadio, MPH, Senior Manager, Diversity and Representation in Clinical Research, *Amgen*
- Erin Williams MBA, Associate Director, *SCCC Clinical Research Operations, University of Texas Southwestern Medical Center, Simmons Comprehensive Cancer Center*

4:30 PM

Closing Remarks

- Randall A. Oyer, MD, Medical Director, *Ann B. Barshinger Cancer Institute, Penn Medicine Lancaster General Health*; ACORI Chair

5:00 PM

Adjourn

**DAY 2: Tuesday, September 14**

12:00 PM

Welcome Remarks

12:30 PM

Stand Up to Cancer Special Session

- Olajide Williams, MD, Founder and President, *Hip Hop Public Health*
- Sung Poblete, PhD, RN, Chief Executive Officer, *Stand Up to Cancer*

1:00 PM

**Breakout Session 1: Harnessing the Power of Community Partnerships to Improve Patient Accrual**

- Karen Winkfield, MD, PhD, Executive Director, *Meharry-Vanderbilt Alliance* (Moderator)

2:05 PM

**Breakout Session 2: Building Research Capacity to Strengthen Cancer Trials in the Community**

- Lola A. Fashoyin-Aje, MD, MPH, Associate Director, *FDA Oncology Center of Excellence* (Moderator)

3:25 PM

**Breakout Session 3: Incorporating the Patient Perspective into Research—From Design to Dissemination**

- Carla Strom, MLA, Assistant Director, Operations, *Wake Forest Baptist Health Comprehensive Cancer Center* (Moderator)

4:30 PM

Closing Remarks & Call to Action

5:00 PM

Adjourn

## List of Summit Participants, Faculty, and Planning Committee

### Faculty

FIRST NAME	LAST NAME	ORGANIZATION NAME
Racquel	Racadio	Amgen
Venus	Gines	Dia de la Mujer Latina
Nadine	Barrett	Duke Cancer Institute
Karen	Winkfield	Meharry-Vanderbilt Alliance
Linda	Burhansstipanov	Native American Cancer Initiatives
Michaela	Marchi	Patient Advocate
Shonta	Chambers	Patient Advocate Foundation
Rodney	Haring	Roswell Park Comprehensive Cancer Center
Ysabel	Duron	The Latino Cancer Institute
Nina	Bickell	Tisch Cancer Institute
Erin	Williams	UT Southwestern Medical Center
Robert	Winn	VCU Massey Cancer Center
Carla	Strom	Wake Forest Baptist Health Comprehensive Cancer Center

### Participants

FIRST NAME	LAST NAME	ORGANIZATION NAME
Tara	Perloff	Abramson Cancer Center, Penn Medicine
Maria	Hendricks	Abramson Cancer Center, Penn Medicine
Tina	Schmitz	Altru Health System
Mark	Fleury	American Cancer Society Cancer Action Network (ACS CAN)
Dorothy	Butler	American Cancer Society Cancer Action Network (ACS CAN)
Gina	Borden	American Health Network - New Albany Oncology/Hematology
Misha	Loeffler	American Indian Cancer Foundation
Suanna	Bruinooge	American Society of Clinical Oncology
Maricarmen	Planas-Silva	Angelmira's Center for Women with Advanced Cancer
Jodie	Davis	Anita Stewart Oncology Center
Samantha	Carter	AnMed Health
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## Resource Library Links

### Day 1

- #InclusionPledge for Black Women, Tigerlily Foundation, <https://www.tigerlilyfoundation.org/inclusionpledgeforblackwomen/>
- #KnowMoreDisparities and #PullUpASeat Bi-Directional Conversation Series, Tigerlily Foundation. <https://www.tigerlilyfoundation.org/programs/advocacy/knowmoredisparities-and-pullupaseat-bi-directional-conversation-series/>
- Carrying Equity in COVID-19 Vaccination Forward: Guidance Informed by Communities of Color. Brunson EK, Schoch-Spana M, Carnes M, Hosangadi D, Long R, Ravi S, Taylor M, Trotochaud M, Veenema TG, on behalf of the CommuniVax Coalition. <https://www.centerforhealthsecurity.org/our-work/publications/carrying-equity-in-covid-19-vaccination-forward-guidance-informed-by-communities-of-color>
- National Black Family Cancer Awareness Week #BlackFamCan; Social Media Toolkit for Oncology Center of Excellence Project Community Initiative, FDA. <https://www.fda.gov/about-fda/oncology-center-excellence/national-black-family-cancer-awareness-week-blackfamcan>
- US Cancer Centers of Excellence Strategies for Increased Inclusion of Racial and Ethnic Minorities in Clinical Trials, Regnante, et. al. <https://ascopubs.org/doi/10.1200/JOP.18.00638>
- Promoting Inclusion of Members of Racial and Ethnic Minority Groups in Cancer Drug Development Lola Fashoyin-Aje, MD, MPH; Julia A. Beaver, MD; Richard Pazdur, MD. <https://jamanetwork.com/journals/jamaoncology/article-abstract/2781888>
- Let's Tackle The Hidden Real-World Reasons For Poor Clinical Trial Diversity. <https://www.clinicalleader.com/doc/let-s-tackle-the-hidden-real-world-reasons-for-poor-clinical-trial-diversity-0001>
- Congress Passes Sprawling Year-End Legislative Package that Impacts Cancer Research and Delivery. <https://www.asco.org/practice-policy/policy-issues-statements/asco-in-action/congress-passes-sprawling-year-end#:~:text=CLINICAL TREATMENT Act %E2%80%93 As part of the,life-threatening conditions who are enrolled in clinical trials.>
- Enhancing the Diversity of Clinical Trial Populations – Eligibility Criteria, Enrollment Practices, and Trial Designs Guidance for Industry. <https://www.fda.gov/regulatory-information/search-fda-guidance-documents/enhancing-diversity-clinical-trial-populations-eligibility-criteria-enrollment-practices-and-trial>
- All Together Now for Inclusive Cancer Trials (Stand up to Cancer, LUNgevity Foundation, Moffitt Cancer Center and Platform Q). [https://www.cancercoachlive.com/app/signup/partnerregistration?\\_loc=/app/directToPresentation/080921\\_CAN\\_OML\\_CME\\_clinicalTrials&\\_dg=MD&\\_em=Demo@email.com&\\_fn=Demo&\\_ln=Demo&\\_ref=PQH\\_Supporter\\_Link](https://www.cancercoachlive.com/app/signup/partnerregistration?_loc=/app/directToPresentation/080921_CAN_OML_CME_clinicalTrials&_dg=MD&_em=Demo@email.com&_fn=Demo&_ln=Demo&_ref=PQH_Supporter_Link)

### Day 2

- Stand Up to Cancer Resources Toolkit. <https://standuptocancer.org/toolkit-advocacy/>
- FasterCures, Engaging Patients in Research. <https://milkeninstitute.org/programs/engaging-patients-in-research>
- A Virtual Summit to Define the Role of Oncology Advanced Practitioners in Equitable Cancer Care Delivery: Executive Summary. ACCC. <https://www.accc-cancer.org/docs/projects/health-equity/oncology-advanced-practitioner-summit-executive-summary-07-23-21.pdf>
- The SCRS Diversity Site Assessment Tool© (DSAT). <https://myscrs.org/learning-campus/diversity-in-clinical-trials/>
- Critical Aspects of a Sustainable Clinical Research Program in the Community-Based Oncology Practice, Jennifer L. Ersek, PhD, MSPH; Stephanie L. Graff, MD, FACP; Francis P. Arena, MD, FACP; Neelima Denduluri, MD; and Edward S. Kim, MD. [https://ascopubs.org/doi/10.1200/EDBK\\_238485](https://ascopubs.org/doi/10.1200/EDBK_238485)
- Elevating Cancer Equity: Recommendations to Reduce Racial Disparities in Access to Guideline Adherent Cancer Care, NCCN. [https://www.nccn.org/docs/default-source/oncology-policy-program/2021\\_recommendations\\_for\\_elevating\\_cancer\\_equity.pdf?sfvrsn=5d2c0d84\\_2](https://www.nccn.org/docs/default-source/oncology-policy-program/2021_recommendations_for_elevating_cancer_equity.pdf?sfvrsn=5d2c0d84_2)





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