![Comprehensive Cancer Control — Collaborating to Conquer Cancer](logo)

COMPREHENSIVE CANCER CONTROL COALITIONS

CONSIDERATIONS TO ASSESS REPRESENTATION AND ENGAGEMENT

The Comprehensive Cancer Control National Partnership (CCCNP) is a 20+ year collaboration of diverse national organizations working together to build and strengthen Comprehensive Cancer Control (CCC) efforts across the nation. This Tip Sheet seeks to help coalitions assess whether they are inclusive and representative of the communities they serve when working to improve cancer outcomes in their state, tribal nation or territory.

Why It Is Important

Nothing about us without us

Health inequities are rooted in our history. Our society was built on a foundation that was unjust to many people, leading to structural bias in systems and policies that perpetuate health inequities.

CCC coalitions can improve cancer outcomes for all persons when they engage with communities and work with organizations across all sectors. CCC coalitions are uniquely able to address social determinants of health (SDOH) to advance health equity in cancer control work, but only when partners and resources across many types of work and sectors[1] are incorporated. Communities that experience these inequities must also be represented, and their voices be uplifted, listened to and incorporated into decision making.

Coalitions should use different tools to build relationships between traditional and non-traditional partners that work with different communities. Factors such as social class, race, gender, disability and sexual identity overlap, leading to increased discrimination and power imbalances. To achieve health equity, CCC coalitions and their member organizations must routinely review how they understand, operate and implement activities to equitably include and engage many different perspectives.

How to Use this Resource to Improve Inclusivity and Representation

Use this resource as a "checklist" to assess your coalition's effectiveness in creating an inclusive environment and to develop an approach for coalition-wide improvements. Not all CCC coalitions are alike. A coalition should work together to choose the considerations most helpful to the specific context, priorities and needs of the coalition and the communities it serves. Remember that achieving equity is a cyclical and iterative process dependent on the context and readiness of all involved partners.[2] Inclusivity and equity-focused considerations provided below were adapted from Melody Goodman's engagement principles.[3]

A **companion assessment tool** is also available to apply Tip Sheet considerations into coalition work and help a coalition measure their effectiveness in creating an inclusive and representative environment for coalition members. A coalition should work together to adapt this assessment to their specific needs. Use the questions as they appear or transfer these questions into a survey instrument (ex. SurveyMonkey, Qualtrics).

Acknowledgements

CONSIDERATION 1

Reinforce shared purpose and mutual benefit by fostering trust and community, as well as partner input, co-learning and co-benefits between all members.

QUESTIONS FOR YOUR COALITION

- Does your coalition provide a space to foster mutual interests and provide mutual benefit to all partners?

OPPORTUNITIES FOR IMPROVEMENT

Include skill-building and leadership opportunities for coalition members representing the population(s) of focus. For example, encourage coalition members to form and/or join steering committees to provide guidance on the steps and strategies to achieve long-term goals.

Allow members to take on different activities that support and strengthen each other's contributions towards a common goal.[4] Propose activities that align the coalition's objectives to those of its members' organizations. For example, a coalition-dedicated newsletter can highlight its members' resources and initiatives as part of an overall communications strategy.

Encourage connections between fellow coalition members and their communities. Examples include attending each other's events and learning more about the specific issues facing fellow coalition members' organizations and communities.

CONSIDERATION 2

Engage with different community members, coalition members, and/or partners within your community by sharing resources and strengths to increase coalition sustainability[5] and resiliency.[6]

QUESTIONS FOR YOUR COALITION

- Do your activities aim to achieve change across multiple sectors and multiple disciplines?
- What measures are in place to assess members' readiness and motivation to achieve coalition-wide change?
- What processes are in place to determine and leverage strengths and resources of individual coalition members?

OPPORTUNITIES FOR IMPROVEMENT

Periodically rotate coalition leadership. Refer to the **9 Habits of Successful CCC Coalitions** to help with succession planning and cultivating new leaders.

Engage with new traditional and non-traditional partners who bring different strengths and perspectives to the table.

Engage community members with personal cancer experiences, including survivors and caregivers.

Use the **Community Tool Box for Identifying Community Assets and Resources** to discover new working partners.

Use **Power Mapping** as another way to identify new partners.

Engage with partners working to address social determinants of health, such as organizations focused on housing and food security. Examples include **DC Greens**, **Feeding America** and the **National Low Income Housing Coalition.**

CONSIDERATION 3

Strive for action-oriented partnerships to help the coalition assign and share responsibility for community-driven systems change.[7]

QUESTIONS FOR YOUR COALITION

- Are coalition action plans built for multiple sectors to engage with one another?
- Do action plans allow for shared decision-making and co-creation of objectives and activities?

OPPORTUNITIES FOR IMPROVEMENT

In your strategic and/or operations plan, include opportunities for co-learning and capacity building for partners.

Establish planning processes that integrate methods and time for shared decision-making and co-creation. Shared decision-making is one of the **9 Habits of Successful CCC Coalitions**.

CONSIDERATION 4

Center health equity in your evaluation approaches to better assess community changes, community capacity outcomes and evaluate specific intervention strategies.[8]

QUESTIONS FOR YOUR COALITION

- What evaluation measures are in place to measure change across multiple sectors and because of collective work?
- Is the evaluation approach based on an equity-focused framework?
- How does the coalition facilitate relationship-building and collaboration between coalition members and community partners?
- Are protections in place to ensure researchers use community-driven research practices when engaging with fellow coalition members?
- How are resources, activities and populations prioritized?
- How does your coalition ensure that data is shared, available and accessible to all?

OPPORTUNITIES FOR IMPROVEMENT

Take **Implementation Science Base Camp** and **Action for Policy, Systems, and Environmental Change** trainings**.**

Involve all partners in research design, implementation and dissemination processes.

Co-develop evaluation approaches with community members.

Include a systems perspective in coalition evaluation to think about how multi-sectoral community change leads to population level outcomes.[9] Check out **CDC's Thinking in Systems Overview** for more context and consider using **social network analysis** to document your coalition's relationship characteristics.

Incorporate internal and external factors, such as policy, systems and environmental (PSE) change and health equity[10], into your evaluation design.

Include equity principles[11] in your evaluation framework, such as those shared by the **American Cancer Society** and **CDC's Health Equity Guiding Principles for Communication**.

CONSIDERATION 5

For maximum impact, **select and refine strategies that use socioecological approaches** to address root causes of social problems.

QUESTIONS FOR YOUR COALITION

- Are your cancer plans built to address root causes and are coalition members participating in activities?
- Are there opportunities for community partners and trained facilitators to bridge respectful, safe and inclusive discussions and interventions?

OPPORTUNITIES FOR IMPROVEMENT

Work with coalition members to request and incorporate community perspectives when developing objectives and strategies for a cancer plan.

When working with community partners to determine health needs and focus areas, prioritize strategies to address root causes.

Engage social needs sector partners, such as social workers, to provide culturally-appropriate discussions on SDOH.[12]

Adopt a socioecological framework to help communicate, inform and support action plans. Read how **Kentucky** used this model to identify different intervention approaches to address cancer disparities in their state.

CONSIDERATION 6

Focus on PSE change activity to reduce disease burden in a population of focus via long-term solutions.[13]

QUESTIONS FOR YOUR COALITION

- Does the overall cancer plan implementation strategy and/or action plans include PSE strategies?
- Are financial institutions and/or economic development partners at the table?

OPPORTUNITIES FOR IMPROVEMENT

When selecting promising practices or evidence-based interventions with community partners, consider its reach and the resources needed to be effective.

Explore CCC-specific PSE resources: **Action4PSEChange** and **ACS's Guide for PSE Change for CCC Programs**.

Ensure all activities included in the coalition's policy efforts are inclusive and equity-focused. Include community partners in the coalition's policy efforts.

Explore how entities such as technology and financial institutions can support activities addressing SDOH and PSE change. In addition to resources, these entities can lead community education activities.[14]

CONSIDERATION 7

Diversify leadership to build capacity[15] and sustainability, which in turn, increases a coalition's relevance and effectiveness.

QUESTIONS FOR YOUR COALITION

- Are strategies in place to ensure leadership is diverse and balances power and privilege?
- What strategies are in place to ensure that coalition members work towards cultural humility?
- Does the action plan ensure representation across all levels and areas of work?
- What evaluation measures are in place to monitor this?
- Are coalition leaders and members supported and encouraged to share their lived experiences and how it impacts their perspectives?

OPPORTUNITIES FOR IMPROVEMENT

Work with coalition members to establish a system, such as a tracking document or spreadsheet, to ensure a spread of perspectives across leadership positions.

Create a brave coalition space by encouraging coalition leaders to share their lived experiences and social identities, and how these influence their perspectives and access in society.

Establish and follow schedules to routinely rotate and share leadership roles amongst partners and populations of focus.

Adapt this **diversity audit resource** to assess your coalition's current leadership practices and develop metrics that align with the group's vision and strategies. This **assessment** provided under Habit 1: Empowering Leadership may also be helpful.

CONSIDERATION 8

Confront historical and current distribution of power and privilege that contribute to health inequities. Encourage autonomy of other coalition members to build and maintain trust within the coalition.

QUESTIONS FOR YOUR COALITION

- Does your coalition member engagement strategy address power through relationship building, open communication, as well as shared and transparent decision making?
- Does your action plan address root causes of inequity?
- Does the coalition work to deepen member understanding of the influence power, privilege and status quo perspectives have on health programs, policies and outcomes?[16]
- Does the coalition understand how collective action and impact can be used to diffuse power and privilege?
- Does the coalition appropriately compensate community partners for their contributions, time and efforts?

OPPORTUNITIES FOR IMPROVEMENT

Facilitate opportunities with your coalition members to discuss how to better collaborate for equity and justice.[17] Conversations can be structured around the following topics:

- **Focusing on power imbalance as a root cause of health inequities.** Ask coalition members to think about shifting from individual behavior change to addressing organizational, systems-level and structural change.
- **Shifting power through relationship and trust-building among coalition members**. Practice recognizing assumptions/biases, active listening, positionality and empathy.
- **Storytelling to shift narrative.** Create a safe place for coalition members to communicate authentically from lived experiences and a place of vulnerability.
- **Establishing mechanisms to hold coalitions accountable for applying and sustaining learned skills.** Support and maintain changes in coalition practice by providing toolkits and resources, such as the **Health Equity Toolbox** and the **Together, Equitable, Accessible, Meaningful (TEAM) training**, to help coalition members apply what they have learned. Build action plans that increase coalition transparency, consistency and openness to constructive feedback regarding these practices.

CONSIDERATION 9

Think about **sustainable approaches** to meet and maintain goals and objectives of the coalition.

QUESTIONS FOR YOUR COALITION

- What are the predictors of sustainability within your coalition?

  Example Predictors: Effective leadership, member diversity, history of past collaborations, structure, sustainability plans, community buy-in; system transformation[18]

- What are the barriers of sustainability within your coalition?

  Example Barriers: Governance challenges, structural issues, lack of funding, staff turnover, shifting priorities[18]

OPPORTUNITIES FOR IMPROVEMENT

Identify sustainability predictors and barriers by using this **Program Sustainability Assessment Tool (PSAT)**.

Use the Sustainability Report generated by the PSAT tool to build your sustainability plan by focusing on the existing strengths and processes within your coalition. For example, you can focus on fundraising and/or resource development.

Use the **Wilder Collaboration Factors Inventory** to assess the success of your collaborations.

CONSIDERATION 10

Build community ownership through a participatory process that encourages partners at all levels to provide input on coalition activities and build trust with populations of focus.

QUESTIONS FOR YOUR COALITION

- Is your coalition effective in generating partnerships built on action?
- Do the partners feel like owners of the work? Do they feel like their voices have been heard and incorporated?

OPPORTUNITIES FOR IMPROVEMENT

Conduct a **participatory planning process** that identifies relevant partners and encourages their participation using tailored communication.

Assign an individual or team to convene and maintain this process. Use this **Participatory Methods resource** to generate ideas and action for inclusive development and social change.

Use this **facilitation guide** to incorporate Community-Based Participatory Research methods into your partner practices.

Disseminate research findings back to the community.

Direct financial power back to communities via **participatory budgeting**, allowing them to collectively decide how to allocate resources.

CONSIDERATION 11

Incorporate accountability and transparency into your coalition activities to help achieve goals and practice sustainability. "Social accountability" requires systems and their leadership to take responsibility for demanding equitable outcomes.[19]

QUESTIONS FOR YOUR COALITION

- What are group contingencies to ensure individual and collective members' accountability for their contributions? Are reports shared for greater transparency?
- What systems are in place to gather and incorporate feedback from partners?

OPPORTUNITIES FOR IMPROVEMENT

Establish and use coalition guiding principles and/or bylaws to keep the coalition accountable and collectively engaged. Use this living document as a checklist to see if a coalition is building leadership and power with and for those who experience marginalization.[20] Refer to **Habit 7: Clear Roles and Accountability** for more information.

Use this **charter template** from the CDC if your coalition does not have an existing guiding principles document.

Comprehensive Approaches and Frameworks to Consider

A coalition should routinely revisit the considerations above to maintain and enhance coalition wide improvements. The below frameworks and approaches provide greater context for these considerations. Note that these resources are not included in the text above. Please reference the considerations table for resources pertaining to each topic discussed.

Assessing Community Engagement Conceptual Model from the National Academy of Medicine identifies concepts and indicators to best measure the extent, process and impact of meaningful community engagement related to health programs, policies, and outcomes.

Comprehensive Participatory Planning and Evaluation (CPPE) is a five-step action-oriented approach to guide project planning and evaluation, with emphasis on community participation.

Advancing Health Equity in Ohio's CCC Program Checklist is an example tool created and used by Ohio to generate ideas that integrate, operationalize and evaluate equity concepts in the CCC program, cancer plan and partnerships.

Equity and Inclusion Guiding Engagement Principles (PCORI) are principles used to strengthen research team activity and team development, as well as study development, conduct and the dissemination of findings.

Comprehensive Cancer Control Plan Health Equity Tip Sheet provides CCC program staff, coalition staff and volunteers ways to help address health equity when revising the CCC cancer plan.

Transforming the Narrative: Health Equity and The Community Toolkit provides insight from project partners that built and amplified transformative narratives in their communities to achieve health equity.

The 9 Habits of Successful CCC Coalitions is a resource for coalitions and other cancer-related organizations to build habits that empower members and sustain successful coalitions.

Resources for Specific Populations

- **National LGBT Cancer Network Best and Promising Practices** provides seven ways organizations can practice inclusivity by integrating LGBTQI+ populations in activities surrounding policy, evaluation, finance, research dissemination and more.
- **Asian American, Native Hawaiian and Pacific Islander (AANHPI) Racial Equity Framework** provides context, strategies and outcomes community partners can implement to achieve equitable outcomes for AANHPI persons.
- The **Black Health Equity Working Group** developed a governance framework for health data collected from Black communities in Ontario. This framework outlines equitable approaches for Black communities to achieve data sovereignty, including data collection, management, analysis and use.
- The **Salud America! Health Equity Report Card** generates local housing, transit, healthcare and other data to drive equitable outcomes for Hispanic/Latin(x/a/o) communities.
- This **infographic** from the National Institute for Health Care Management Foundation addresses what is needed to move towards health equity for Hispanic/Latin(x/a/o) persons.
- Another **infographic** from the National Institute for Health Care Management Foundation addresses health equity for American Indian communities.
- This **Urban Indian Health Institute report** provides insight on indigenous health equity for American Indian/Alaska Native persons as well as emphasizes approaches that are grounded in cultural and traditional knowledge systems.

Additional Resources

Health Equity in Cancer (CDC)

Comprehensive Cancer Control National Partnership (CCCNP) Health Equity Resources

A Practitioner's Guide for Advancing Health Equity-Community Strategies for Preventing Chronic Disease

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