

# COMPREHENSIVE CANCER CONTROL PLAN

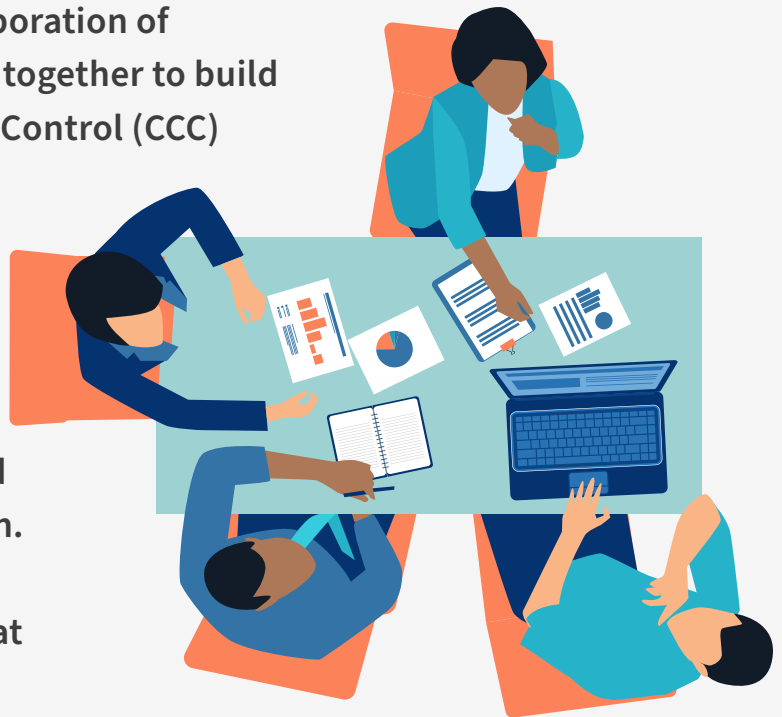


## TIP SHEET

# CHILDHOOD CANCER

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 is part of a series offered through the CCCNP to assist CCC programs charged with developing, implementing, and evaluating cancer control plans tailored to their state/tribe/territory/jurisdiction. CCC Plans focus coalition efforts on evidence-based interventions (EBIs) that impact cancer prevention and control across the cancer continuum.





## How to Use This Tip Sheet

### Use When Updating Your CCC Plans

Tip Sheets can be used to help CCC program staff, coalition staff, and volunteers update CCC plans. Each tip sheet focuses on a specific topic (e.g., colorectal cancer screening, tobacco control, risk factors for cancer survivors). Follow the steps throughout the Tip Sheet to help guide your process in updating your cancer plan for that specific topic area. Some ideas:

- Incorporate the Tip Sheet into your plan update process – share it with your coalition workgroups and use it to help guide your decisions.
- Identify a lead person to ensure that the Tip Sheet is used by the workgroup or team assigned to update the plan section that addresses each Tip Sheet topic.
- Use the Tip Sheet to check that the topic is appropriately addressed in your plan and that the elements outlined on the next page are covered (objective, data, strategies).
- Use the **worksheet** at the end of this document with your partners to ask and answer critical questions related to the topic as you update your plan.

### Use When Implementing Your CCC Plan

Tip Sheets can be used while you are implementing the priorities in your plan. The partners and resources listed in each sheet can help ensure your coalition work stays on track and is of high quality. Some ideas:

- Use with coalition leadership and workgroups as they implement the plan, to find resources, data, and to think about partners that could be engaged in implementing specific strategies from the plan.
- Engage coalition members and reactivate workgroups that have been inactive or need a renewed sense of direction.
- Orient new CCC program staff and coalition members or leaders, to help them better understand the importance of the Tip Sheet topics to CCC efforts, and to provide access to relevant information and resources
- Use the Tip Sheets to help with decision making when identifying priorities from the CCC plan.
- Help a priority workgroup who is just forming to help find an area to focus in on, especially by using the questions at the end of the Tip Sheets.
- Use as a tool to check progress in implementing the plan's priorities, especially focusing on data being collected, EBI's being used and the engagement of key implementation partners.
- Share them with partners (community organizations, FQHCs, Primary Care Associations, etc.) as a resource about a specific topic including sources of information, data, and evidence-based interventions.

## Definitions

- **SMART Objective** – is an objective in the cancer plan that is Specific, Measurable, Achievable, Relevant, and Time-bound.
- **Evidence-Based Strategy** – is a specific activity that is designed to achieve the objective and is based on evidence that the strategy is expected to work in your situation, i.e., it has been evaluated and shown to work.
- **Crude vs. Age-adjusted Rates** – Crude rates are influenced by the age distribution of the state’s population. Even if two states have the same age-adjusted rates, the state with the relatively older population will generally have higher crude rates because incidence or death rates for most cancers increase with age. Age-adjusting the rates ensures that differences in incidence or deaths from one year to another, or between one geographic area and another, are not due to differences in the age distribution of the populations being compared. Find out more [here](#).
- **Populations of Focus** – are those groups experiencing the greatest cancer disparities in your region. Disparities might include higher cancer incidence or mortality; greater challenges accessing cancer screening, treatment, and/or survivorship care services; or populations experiencing bias in society and the healthcare system.
- **Health Equity** – occurs when every person has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances.
- **Health Disparity** – is a type of difference in health that is closely linked with social or economic disadvantage. Health disparities negatively affect groups of people who have systemically experienced greater social or economic obstacles to health. These obstacles stem from discrimination or exclusion that is historically linked to characteristics such as race or ethnicity, socioeconomic status, disability, sexual orientation, and many other factors.<sup>1</sup>
- **Social Determinants of Health (SDoH)** – are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.<sup>2</sup>

<sup>1</sup> U.S. Department of Health and Human Services. The Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase I report: Recommendations for the framework and format of Healthy People 2020 [Internet]. Section IV: Advisory Committee findings and recommendations [cited 2010 January 6]. Available from: [http://www.healthypeople.gov/sites/default/files/PhaseI\\_0.pdf](http://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf).

<sup>2</sup> Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved 12/04/2020, from <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>.



## Tips for Updating Your CCC Plan

- **Use your current cancer plan as a starting point:** Think of this process as updating the current plan instead of starting a new plan from scratch.
- **Be systematic:** Assign workgroups to review and update certain sections of the plan. Create a process that is common across all workgroups tasked with updating the plan, which should include a standard set of criteria for the inclusion of plan goals, objectives, and strategies.
- **Focus workgroups on assessing and updating the core aspects of the plan:** the goals, objectives, and strategies.
- **Identify someone to take the lead** on writing the introduction, connecting text, and putting the document together for publication.
- **Use data to determine the focus of the plan:** Which cancers are most prevalent in the population? What subpopulations experience the most disparities?
- **View through a health equity lens:** Be intentional and proactive in keeping health equity issues at the forefront in every step of the cancer plan process – when engaging partners, collecting data, and setting goals. Include representatives from your population of focus in the writing of your cancer plan.

Use these resources to explore more cancer control planning tips and examples:

- **Nine Habits of Successful CCC Coalitions**
- **CCC Implementation Building Blocks** (see page 7 of the Appendices for more tips on updating your plan)

Additional resources you can use:

- Search other CCC plans to get ideas – **CDC's CCC Plan Map and Search Tool**
- **CDC Cancer Plan Self-Assessment Tool**
- **GW State Cancer Plans Priority Alignment Resource Guide and Tool**
- **A Practitioner's Guide for Advancing Health Equity: Community Strategies for Preventing Chronic Disease**

### Checklist for Updating Your CCC Plan

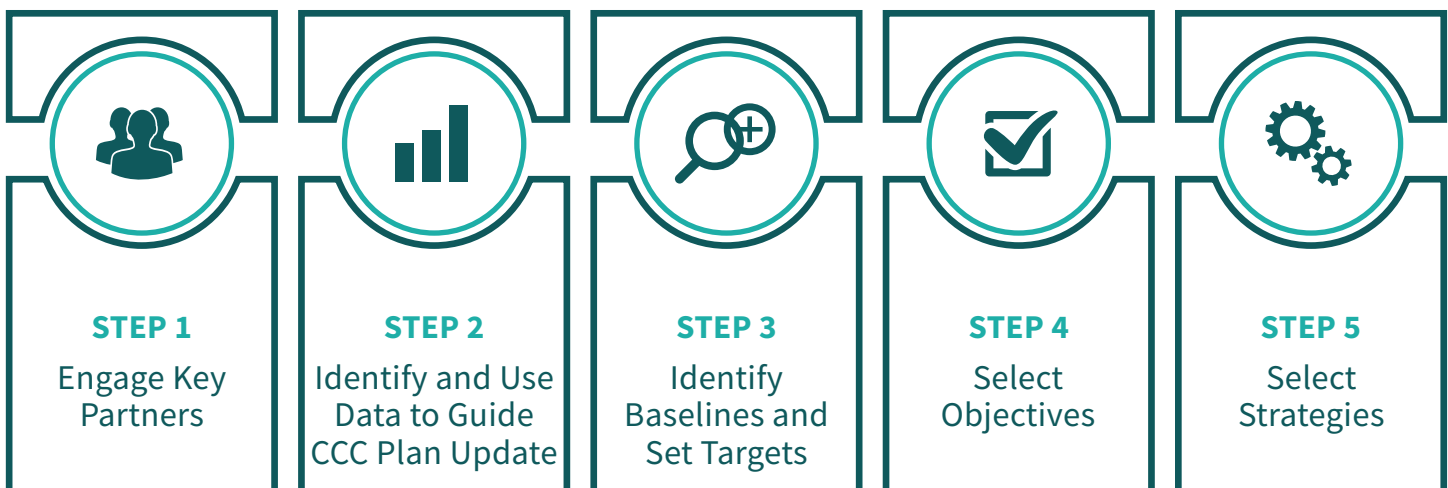
- Ensure that your workgroup is familiar with your current cancer plan.**
- Create a systematic process for the workgroup to follow that is intentional about addressing health equity.**
- Use data to focus on the populations with the highest cancer burdens.**
- Focus workgroups on assessing and updating goals, objectives, and strategies.**
- Identify someone to write the introduction and assemble the final document.**

# COMPREHENSIVE CANCER CONTROL PLAN UPDATE TIP SHEET

## Childhood Cancer

### Why a Childhood Cancer Focus is an Important Part of Your CCC Plan

- Childhood cancer is the number one cause of death by disease in children.<sup>1</sup>
- Through dedicated workgroups and/or sections of their cancer plans, CCC coalitions are in a unique position to educate their partners and communities about the needs of childhood cancer survivors and their families, including:
  - Survivorship needs are substantial and differ from those of adults. The need for support includes not only the patient but also parents and siblings.<sup>2</sup>
  - Survivors of childhood cancer require lifelong surveillance<sup>3</sup> because late effects contribute to significant morbidity among adults who were treated for cancer during childhood: 60% to more than 90% develop one or more chronic health conditions, and 20% to 80% experience severe or life-threatening complications during adulthood.<sup>4</sup>





## STEP 1 Engage Key Partners

- Engage experts in the area of childhood cancer (including at least one childhood cancer survivor or caregiver as a coalition member). Partner with organizations and agencies who have access to the data you need and partners who will be critical to implementing your childhood cancer strategies:
- Academic researchers studying childhood cancer
- **ACS Cancer Action Network (ACS-CAN)**
- **American Cancer Society (ACS)**
- **American Childhood Cancer Organization**
- Cancer centers and survivorship clinics/ programs
- **Cancer Support Community**
- Cancer Registries (find registries at the **National Program of Cancer Registries site**) (**NCI SEER**)
- **Children's Oncology Group**
- Community organizations and churches that can partner on reaching underserved patients/ caregivers (Promotores de Salud, etc.)
- Current coalition workgroup or advisory group members focused on childhood cancer education
- Health plans, insurance providers
- **The Leukemia & Lymphoma Society (LLS)**
- Local medical associations that include the following practice areas: radiation oncology, medical oncology, primary care, nurses, and navigators
- Medical coders/billers – they are a link between patients, providers, and insurers
- **North American Association of Central Cancer Registries**
- Organizations and individuals with a focus on childhood cancer
- Parents, children, and families living with childhood cancer, survivors of childhood cancer
- Provider champions
- School nurses and social workers
- State health insurance commissioner's office
- State Medicaid and Medicare offices





## STEP 2

# Identify and Use Data to Guide CCC Plan Update

**NOTE:** For this tip sheet, *childhood cancer* refers to cancer patients from birth to 19 years old, in accordance with the World Health Organization (WHO) definition.<sup>5</sup> Because no standard definition is recognized in the United States, we suggest that coalitions adopt the WHO definition to facilitate data collection and comparison.

Data is essential to your cancer plan in several ways, including:

- Identifying the following:
  - Populations that have higher incidence and mortality rates of childhood cancer. It is helpful to examine this at a minimum by gender, race/ethnicity, health insurance status, and geographic area.
  - Childhood cancer rates, progress, and trends over time to identify specific areas for focus
  - Location(s) (i.e., state/tribe/territory) where a childhood cancer patient is diagnosed and treated to understand potential issues related to access to services in your jurisdiction
  - Percentage of children in the jurisdiction with and without health insurance, specifying private vs. state-based coverage
  - Availability and type of providers, services, and ancillary support (survivor programs, etc.) in different geographic areas and population groups to inform the selection of objectives and strategies
- Comparing local data with national data and/or neighboring state data to highlight key areas of need or lagging progress
- Laying a foundation to measure progress over the life of the plan (e.g., baselines and targets)
- CCC coalitions can
  - Provide data in easy-to-understand formats to communicate the importance of childhood cancer strategies.
  - Collect and share information about where childhood cancer diagnosis and/or treatment is available in the state, tribe, or territory.
  - Analyze healthcare provider survey data on knowledge, attitudes, and practices about childhood cancer diagnosis and treatment.
  - Provide support for the complete collection of childhood cancer data regardless of the rarity of diagnoses.

It is best to use data from your own state, tribe, or territory, but national data can help you set targets, letting you compare your data with other locations and the nation.

### Local data sources:

Your central cancer registry (**National Program of Cancer Registries [NPCR]** and the **National Health Interview Survey** (NOTE: The CDC Childhood STAR Project is developing a new data collection system in the NPCR to enable rapid case reporting and contribute to understanding cancer and the best treatment options. Follow the progress of the initiative [here](#)).

### National data sources:

- **American Cancer Society Cancer in Children**
- **Cancer in North America**
- **Cancer Stat Facts**
- **Health Information National Trends Survey (HINTS)**
- **LLS Facts and Statistics**
- **National Cancer Institute (NCI) Cancer Trends Progress Report**
- **SEER Cancer Statistics Review**
- **State Cancer Profiles**
- **The Cancer Atlas**
- **US Cancer Statistics**
- **CDC Tracking Pediatric and Young Adult Cancer Cases**
- **NCI Childhood Cancer Data Initiative**
- **NCI National Childhood Cancer Registry**
- **NCI National Childhood Cancer Registry Explorer**



### STEP 3 Identify Baselines and Set Targets

The questions in the worksheet at the end of this document can guide you through the data gathering, decision-making, and priority setting processes. Think about the following as you work through the questions:

- Set goals to help measure your progress in decreasing the burden of childhood cancer based on your data, stakeholder input, and local/national targets.
- Set goals to increase access to diagnosis and treatment for all children.
- Set goals to help measure your progress in decreasing the number of uninsured children in your jurisdiction.
- Review health department chronic disease plans to see what survivorship baselines and targets are already being used by your partners that can be incorporated into the cancer plan.
- Set goals related to the enhancement of survivorship care and quality of life for residents surviving childhood cancer.
- Remember to cite your data sources.





## STEP 4 Select Objectives

Use the data collected in Step 2 to create SMART (Specific, Measurable, Attainable, Realistic, Time-limited) objectives that support specific needs within your communities, including a special focus on subpopulations that experience health disparities.

### EXAMPLE OBJECTIVES



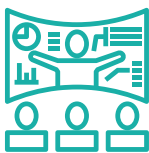
Increase the 5-year survival rate of childhood cancer survivors from 84% to 87% by 2025.



Increase the percentage of childhood cancer survivors who are diagnosed and/or treated at a pediatric cancer center from 81% to 90% by 2025.



Increase the percentage of childhood cancer survivors and families who receive comprehensive written information at diagnosis.



By 2025, hold two or more annual events to increase awareness for pediatric cancer with a greater emphasis on research, clinical trials, and effective treatment options.



By 2025, decrease the percentage of children without health insurance from 7.6% (Baseline, 2018 US Census Bureau's American Community Survey) to 5.2% (national average) or lower.



## STEP 5 Select Strategies

When choosing strategies that can help address the needs you have identified, think about existing networks, programs, and services you can leverage, enhance, or expand. Also, consider if the strategy is realistic and feasible given current support for addressing this issue, as well as available resources to implement the strategy. Often, using a combination of these strategies is more effective than implementing a single strategy.

### **Access to Care**

- Promote increased access to integrated palliative care services for children facing any stage of cancer.
- Use community health workers, patient navigators, churches, and community support programs, especially in underserved communities, to assist with reducing structural barriers. This includes assisting with scheduling appointments, providing transportation, providing language translation, and providing childcare.
- Increase support for state transportation assistance programs, including transportation options for children and their families who live in rural and underserved areas.
- Help parents of children without health insurance to apply for insurance.
- Identify and address patient and family care and cancer-related educational needs such as diagnosis, treatment, fertility, late effects, psychosocial support programs, sibling support, and respite care.
- Increase access to all phases of pediatric oncology clinical trials.

### **Education**

- Increase public awareness of the incidence and impact of pediatric cancer on America's children.
- Educate patients, parents, K-12 educators, and school counselors on the physical, emotional, and cognitive impacts of childhood cancer and on the support that should be available through the school system (IEP, educational consultants, etc.).
- Educate human resource professionals as to the full extent of resources available to pediatric cancer caregivers through the Family Medical Leave Act.
- Identify and address the need for consumer-friendly explanations of pediatric clinical trials, informed consent, and referral patterns.
- Educate the public about how to access government-sponsored health insurance programs.
- Regularly update state pediatric primary care providers and adult primary care providers about evidence-based, personalized care and screening for childhood cancer survivors through free, accredited CME programs.
- Support programs that teach self-advocacy to survivors of childhood cancer before they transition to an adult health system.

- Support programs that facilitate job training for childhood cancer survivors.
- Celebrate Cancer Survivor Day (June 1) and include childhood cancer survivors.
- Work with stakeholders to create and maintain a comprehensive list of childhood cancer resources for pediatric cancer patients and their families, to be distributed at all treatment locations.
- Work with public health economists to calculate the financial impacts of childhood cancer in the state such as loss of income by parents, out-of-pocket costs for care, data on financial hardships/medical bankruptcy, and long-term financial impacts on pediatric cancer survivors such as employability and insurability.
- Work with state and national partners to support funding for pediatric cancer research.
- Ensure that treatment locations provide pediatric cancer patients and their families with
  - A list of local resources
  - An annual reminder and patient assessment
- Promote utilization of recommendations/standards for follow-up care (e.g., **COG Passport for Care; Psychosocial Standards of Care Project for Childhood Cancer**), including baselines for neuro-cognitive status and follow-up screening.
- Support the relevant state agencies by increasing staff support for processing and facilitating new and renewal health insurance applications.
- Incentivize the creation and maintenance of pediatric cancer survivor clinics by publicizing them and creating grant opportunities for them.
- Support the development and implementation of systems changes that establish a seamless continuum of care between pediatric and adult primary care for childhood cancer survivors, including electronic health record tools that help providers identify patients for transitioning, referral with records to adult primary care providers, and personalized recommendations for survivorship screening in adulthood.

### Health System Changes

- Encourage hospitals to identify and enroll in national research/clinical trials such as Children’s Oncology Group research, NCI research, and **LLS’s Dare to Dream Project**, as well as clinical trial navigation from **LLS’s Clinical Trial Support Center**.
- Reduce structural barriers to healthcare access by supporting patient navigation programs and the employment of social workers to provide childhood cancer care.
- Expand workforce training in pediatric palliative care and pediatric oncology nursing.
- Regularly assess and streamline the new and renewal health insurance application forms to ensure simplicity and resistance to errors by including past and prospective applicants in the review processes.
- Work with health insurance providers to examine their claims data and identify providers with high childhood cancer incidence. This will help guide provider and community education and outreach.

For health systems changes, establishing relationships and shared outcomes with systems is important to consider upfront. It is also helpful to have a clinical champion who can energize clinic staff and keep everyone focused on improving childhood cancer rates and survivorship needs. Periodically monitoring clinic-level childhood cancer rates is an important activity when implementing health system interventions so that approaches can be adjusted as needed (see the data section above).

## References

1. Centers for Disease Control and Prevention, National Center for Health Statistics, FastStats, Child Health, <https://www.cdc.gov/nchs/fastats/child-health.htm>, retrieved 2-15-23.
2. A review of psychosocial interventions targeting families of children with cancer, <https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/review-of-psychosocial-interventions-targeting-families-of-children-with-cancer/E9850222B14DEEBE9285C218BDDCCC13>; Psychosocial Impact of Cancer Patients on Their Family Members, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3804735/>; The Forgotten Children, <https://www.intechopen.com/chapters/53759>.
3. Children's Oncology Group, **Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers**, Version 5.0 (October 2018).
4. National Cancer Institute, Late Effects of Treatment for Childhood Cancer (PDQ®)–Health Professional Version, <https://www.cancer.gov/types/childhood-cancers/late-effects-hp-pdq#>, retrieved 12-8-22.
5. World Health Organization, Childhood Cancer, <https://www.who.int/news-room/fact-sheets/detail/cancer-in-children>, retrieved 12-8-22.

## Resources

- The **Cancer Support Community (CSC)** offers a **location finder** for support groups in some geographic areas designed for parents of children with cancer; a **Cancer Support Community Helpline** that can provide information and navigation in pediatric oncology; and **Frankly Speaking about Cancer: What Do I Tell the Kids** booklet, for people who are concerned about children and teens who are part of a family living with cancer. A new tool through Patient Planning Services (PPS), a social enterprise of CSC, is called Checking IN. This is an evidence-based digital pediatric distress screener with EMR integration (licensing fee required). More information on Checking IN can be found here.
- The **Leukemia & Lymphoma Society** resources include **The Trish Greene Back to School Program For Children With Cancer**, which offers free information and materials to parents and educators, and the **Survivorship Workbook for Children and Adolescents** and the **Survivorship Workbook for Young Adults**, which help individuals collect important information needed throughout diagnosis, treatment, follow-up care and long-term management of blood cancer.

### Mental Health Resources

- **Cancer.Net Counseling**
- **Children's Oncology Group**
- **St. Jude Children's Research Hospital Psychology and Mental Health Services**
- **Healthy People 2030**

# Worksheet: Questions to Ask and Answer

---

**Use this worksheet to help you and your cancer coalition partners to identify childhood cancer gaps, challenges, and opportunities. Record your answers and use the information to help inform your selection of objectives and strategies for your updated plan.**

1. Overall, how are we doing in childhood cancer rates compared to the national rates, our neighboring states, and our own rates in previous years?

What objectives do we want to set, given our analysis of this data?

2. There are disparities in every type of cancer, including childhood cancers. Are access to care, communication, and/or education about disease, treatment, resources, or services lacking in specific geographic areas or sub-populations?

Do we know why? If we do not know why, how do we find out? Examples:

- Treatment, resources, education, support, etc., are lacking due to language barriers.
- There are not enough social workers in hospitals to provide equitable care for patient families.
- Social workers are not aware of available resources.
- Limited accessibility to diagnosis and treatment services that are either too far away, not culturally appropriate, or restrictive based on insurance status.

---

What strategies should we select, given the answers to these questions?

3. Children’s hospitals have a requisite standard of care that can help to implement policy and system changes to support childhood cancer objectives. Build partnerships with children’s hospitals to promote cancer plan goals. Do we have existing connections with partners? How can we engage partners? Why will they want to be involved? What is the value proposition for them?

What strategies should we select, given the answers to these questions?

4. What existing services, networks, or programs could we leverage to increase childhood cancer awareness and education? Example: Promote nationwide childhood cancer nonprofits, childhood cancer hospitals, research facilities and programs, and comprehensive cancer control plans/CCC coalitions.

What strategies should we select, given the answers to this question? Example: Hold annual meetings with stakeholders in the childhood cancer community.

---

5. What childhood cancer policies do we want to advocate for or promote?

What strategies should we select, given the answers to this question?

6. What gets measured is what gets done.

- How can we best track childhood cancer awareness and education outcomes?
- How do we know we are making progress along the way?
- How do we track where children, adolescents, and young adults live versus where they are being treated?
- How do we communicate these data to the public and policymakers, along with making “one voice” recommendations?

What strategies should we select, given the answers to these questions?

# Acknowledgments

---

A special thank you to the following individuals who contributed to the development of this document.

## **American Cancer Society, Inc.**

- Gayle Bagley, Director, Comprehensive Cancer Control

## **American Childhood Cancer Organization**

- Jessica Beckstrand, “What About Kids?®” State Director
- Ruth I. Hoffman, MPH, CEO

## **George Washington University Cancer Center**

- Liza A. Fues, J.D., Technical Assistance Coordinator
- Ruta Rangel, M.S., Program Associate

## **Leukemia & Lymphoma Society**

- Tricia Hernandez, M.S., Senior Manager, Community Engagement