Handbook For Community Change

May 2019











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PREFACE

Welcome!

The Fred Hutch/University of Washington Cancer Consortium (the Consortium) welcomes you to the Community Action Coalition. As a Comprehensive Cancer Center, the Consortium is indebted to the communities we serve for their support of, commitment to, and use of our Cancer Center Consortium. Comprising four distinguished institutions, Fred Hutchinson Cancer Research Center, the University of Washington, Seattle Children's, and the Seattle Cancer Care Alliance, the Consortium aims to serve the larger community in which we exist. As researchers, clinicians, and staff, we focus on cancer and cancer-related behaviors and the impact they have on individuals, families, and communities in our region. Our region is called our "catchment area" and it includes the 13 counties of western Washington State (see Figure 1 below). While we also have a presence in other parts of the state, and even to other states in the Northwest, these 13 counties are where the majority of our patients come from.



Figure 1 The Consortium's Catchment Area

As with many areas throughout this country, cancer is a critical problem in our catchment area. In the catchment area, there were more than 30,000 cases of cancer in the past year. Each case involves not only the patient with cancer, but also the family members of that patient, as well as community groups such as employers who are affected when patients need to take time off from work.

In 2017, we conducted a needs assessment of the catchment area. This needs assessment indicated that there were many barriers as well as facilitators for cancer prevention and control in our catchment area. Almost all of us know individuals who have had cancer. We have seen their struggles with this deadly disease. Thus, cancer affects all of us. We may also know individuals who have been successfully treated for cancer. This gives us hope.

We are eager to work with you, the Community Action Coalition, to bring the community voice to our Consortium. As a member of the Community Action Coalition, your contribution to the prevention and control of this disease is tremendously important. The Consortium will focus its research and service to the entire catchment area and try to address some of the inequities that exist in the catchment area. In this way, we can reduce the burden of cancer and reduce the cancer inequities in our catchment area.

This Handbook will acquaint you with cancer in the catchment area. It can be considered as a planning guide for implementing community change around cancer prevention and control. We encourage you to refer to this Handbook often.

Once again, welcome. We are confident that our partnership will make this a successful effort to reduce cancer in our communities.

Thank you for your participation!

Jason Mendoza, MD, MPH

Associate Director

Katherine Briant, MPH, CHES Program Administrator

Katherine g. Briant



Section 1: Needs Assessment Summary

Section 1: Needs Assessment

Our "Report to the Community" is the result of a needs assessment that we conducted in 2017 and 2018. It summarizes the cancer and cancer-related burdens in our catchment area. It also identifies the barriers and facilitators to reducing the cancer burden. Please take time to familiarize yourself with this report as it helps form the basis for our understanding of cancer and cancer-related behaviors in the catchment area.

Section 2: The Big Picture

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Fred Hutch/University of Washington Cancer Consortium

As you saw in the "Report to the Community", cancer is a significant burden in our catchment area. We also noted that the burden is not shared equally among all people in the catchment area. Fortunately, the Fred Hutch/University of Washington Cancer Consortium (the Consortium) exists to reduce this burden.

The Consortium is a partnership between four institutions. These institutions are Fred Hutchinson Cancer Research Center (Fred Hutch), the University of Washington (UW), Seattle Children's (SC), and the Seattle Cancer Care Alliance (SCCA). In this way, the Consortium partnership covers the myriad aspects of cancer prevention, treatment, and survivorship. The Consortium is one of only 70 National Cancer Institute-designated Cancer Centers throughout the United States and the only one in Washington State. The Consortium develops and translates scientific knowledge from promising laboratory discoveries into new treatments for cancer patients. The Consortium not only disseminates evidence-based findings into communities that can benefit from these findings, but also, through the experience of working with patients, helps inform national research and treatment priorities. Together, the Consortium's four

Fred Hutch



University of Washington



Seattle Children's



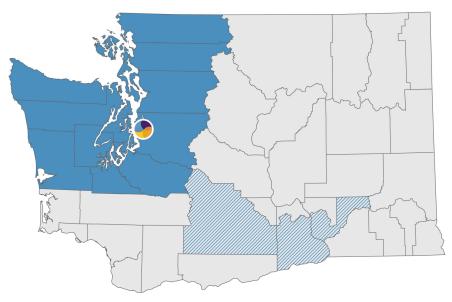
Seattle Cancer Care Alliance



institutions unify their commitment in the prevention, diagnosis, and treatment of cancer.

The Consortium has long been concerned with the burden of cancer and the inequities in cancer prevention and treatment among the people it serves. In 2010, the Consortium established the Health Disparities Research Center (HDRC) to begin to take a look at these issues. After five years of developmental work, the HDRC became an official part of the Consortium and expanded its efforts to reduce cancer inequities. In 2017, the HDRC was renamed the Office of Community Outreach and Engagement (OCOE). The OCOE expanded the mission of the HDRC to encompass the entire catchment area and identify strategic ways to address the cancer burden identified in a needs assessment. Dr. Beti Thompson, Dr. Jay Mendoza, and Ms. Kathy Briant reformulated the new office. Currently the office is supported by the Consortium which has committed over \$1.4M annually to work in the catchment area.

The Catchment Area



The catchment area, as described earlier in Figure 1, incorporates the 13 counties of western Washington State (see above). The 13 counties include

Clallam, Jefferson, Grays Harbor, Mason, Kitsap, Thurston, Pierce, King, Snohomish, Skagit, Island, San Juan, and Whatcom. The catchment area is bounded by the Cascade mountain range on the east and the Pacific Ocean on the west. It extends northward to the Canadian border. As can be seen from the map, the Consortium also conducts work in a part of eastern Washington. Although it is not part of the catchment area, the Consortium has many prevention and control activities in that region.

The catchment area has a population of over 5 million people, of whom 32.3% are of racial/ethnic minority status. Last year, the area had over 30,000 cancer cases. Approximately 83% of Consortium cancer patients come from the catchment area. The area is identical to the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registry which allows the Consortium to have regular and accurate information on cancers in the catchment area.

A Community Engagement Approach

The OCOE uses a unique approach when exploring the cancer burden in the catchment area. This approach is called Community-Based Participatory Research (CBPR) which is a community engagement approach. It is based on the idea that problems are more likely to be solved if individuals who are affected by the problem are involved in its solution. This is especially true for communities experiencing health disparities.

The intention of the OCOE is to work with the communities in our catchment area to reduce the cancer burden. As you will remember from the "Report to the Community", our needs assessment summary report, we interviewed a number of community stakeholders to better understand the issues related to the cancer burden. Now we have created this Community Action Coalition. You, the members, are the voices of the community and we count

on you to help us in the effort to reduce the cancer burden for all and to focus on eliminating cancer disparities.

The cancer burden and cancer inequities are a community problem that the Consortium would like to focus on. The causes of disparities in communities can arise from socioeconomic factors, lack of health insurance, inadequate education, and cultural differences. We believe that the answers to addressing these multifaceted community issues can be found in the communities themselves.

The Community Action Coalition is designed with the notion that "community problems need community solutions." The goal of reducing the burden of cancer can only be achieved through public health work at the community level. This means that the Coalition, in partnership with the Consortium, will should use collective resources to coordinate prevention and educational activities and implement strategies that focus on community engagement and participation.



Section 3: The Community Action Coalition

Section 3: The Community Action Coalition

The Community Action Coalition (the Coalition) consists of a group of individuals who represent the 13 different counties within the catchment area. The Coalition works in partnership with the Consortium to support community change and positive health outcomes. It does this by providing input into and making decisions on interventions, advocacy, and programs that reduce the cancer burden within the catchment area.



Effectiveness of Coalitions

Community coalitions can be a very effective means of achieving a coordinated approach to reducing the cancer burden and cancer inequities in the catchment area. The Coalition will guide work with communities and

underserved populations to provide meaningful activities around the cancer problem. In summary, the Coalition will allow us all to:

- Create a structure for organizations and individuals to share ownership of common goals around cancer prevention and control;
- Share and conserve resources;
- Enlarge our base of support, networks, and other connections;
- Have greater credibility than would individual organizations;
- Achieve widespread reach within catchment area communities; and
- Foster cooperation between grassroots organizations, community members, and diverse sectors of large organizations.



What the Coalition Does for You

The Community Action Coalition is a dynamic body. It is important to remember that coalitions serve many purposes to its membership and to the wider community. Some of these factors include:

- Creating the opportunity to have an open space to share knowledge and expertise, brainstorm ideas, and develop strategies among likeminded individuals with a specific mission.
- Sharing risks and responsibilities among members. All activities and opinions are decided among the group, and thus, no sole representative will be held accountable.
- Building community concern for a cancer issue by acknowledging and actively reviewing current issues and solutions.
- Bringing awareness to communities about important cancer topics and issues.
- Fostering connections between community sectors, increasing networks among counties and addressing intersectional factors.
- Serving as a community advocate, partaking in local decisionmaking and increasing sustainability of successful interventions to decrease the cancer burden at the local and state-levels.



The Role of the Community Action Coalition

- The Community Action Coalition can be thought of as a bridge and therefore plays a dual role by representing the community and its needs to the Consortium and sharing information about the Consortium with the community. The Coalition helps the Consortium understand what the barriers and facilitators to cancer prevention and control are within their communities.
- One charge of the Coalition is to help the Consortium understand the most effective use of available resources to the catchment area.
 Other roles may include advising and/or collaborating on implementing appropriate and relevant cancer prevention and control activities. In addition, the Coalition will provide project legitimacy.
- Moving forward, we hope to see more benefits and triumphs along the way that can build strong working relationships.
- Overwhelmingly, we believe that the community, the Coalition, and the Consortium will benefit from these efforts.



Coalition Members Out in the Community

As Coalition members engage in catchment area communities, it is important to let community groups, organizations, their membership, and individuals know about the partnership between the Coalition and the Consortium. Coalition members may also gather information about catchment area communities to share with the Coalition. Below are a few examples of requests that can be made of community members:

- Input. Ideas and reactions to the partnership; suggestions for supplemental activities, and names of others who may be important to invite to the Coalition.
- Stakeholders. Identifying individuals who are stakeholders in the community and identifying trusted media outlets or networks in the community.
- Participation. Distribution of materials for Coalition organizations and/or activities, presence on a speakers' bureau, or suggestions on other activities the community would like to be involved in.
- Resources. Contributions of things like meeting space and media time.

Section 4: Structure And Governance

Section 4: Structure/Governance

Successful collaboration between the Coalition and the Consortium requires:

- Early and continuing communication of roles and responsibilities;
- Early and continuing clarification of goals and activities;
- Commitment to mutual consultation and maximization of local ownership; and
- A general process for resolving disagreements.

The remainder of this section addresses some of the common areas Coalitions need to think about when establishing procedures.

General Membership Roles & Responsibilities

A successful partnership requires that individuals in the collaboration are cognizant of their roles and responsibilities. The roles of Coalition members are as follows:

- Engage in both short and long-term planning to address the problem of cancer in the catchment area;
- Contribute to discussions on planning and implementation activities;
- Plan, execute, review, and assess the Consortium's and the Coalition's performance; and

Inform the community about the cancer burden, focusing on short and long-term solutions. Coalition members also have certain responsibilities. These are necessary to keep the partnership going from both Coalition members and Consortium members. They are to:

 Attend at least 2 out of 4 meetings per year which can be done either in-person or virtually. If a member cannot attend a meeting, please notify Hallie Pritchett at hpritche@fredhutch.org;

- Listen actively to the ideas and opinions expressed by Coalition members;
- Engage in constructive discussion;
- Be open to alternative plans;
- Review and respond to any cancer-related information;
- Represent constituencies, acknowledging and drawing on the diversity of opinions represented;
- Inform community members about the process and the decisions that are being made;
- Active members are required to participate in voting and the decision-making processes (see section: "<u>The Decision-Making</u> <u>Process</u>");
- Address dissension or concerns in the community and bring them back to the meeting;

 Commit to working together as a successful plan depends on a good faith effort from all Coalition members.



Steering Committee Roles & Responsibilities

The Community Action Coalition includes an elected Steering Committee. This steering committee is a subgroup of coalition members who make decisions when the entire body cannot be convened. Steering Committee members meet four times per year to handle matters related to operations of the coalition. Members are elected by self-volunteering or through an internal nomination form process. The pilot group will serve on the committee for one or two year terms, with subsequent members all filling 2

year terms. This staggered process allows for mentorship of new committee members. Steering Committee members are expected to:

- Attend quarterly meetings for both the Steering Committee and full membership meetings
- Support preparation of materials and agendas for coalition meetings
- Provide guidance towards the strategic plan by prioritizing goals and objectives
- Serve as a liaison between CAC members and staff
- Make executive decisions for the CAC to keep momentum moving forward
- Share coalition updates during full membership meetings
- Invest the CAC in equitable, bidirectional cancer prevention projects
- Support coalition members to execute tasks and activities as needed
- Evaluate the contributions of the coalition to related outcomes
- Assist with recommending and/or recruiting new members
- Review nominations for the Beti Thompson Trailblazer Award
- Inspire coalition members to create and engage in future projects



2020 Pilot Steering Committee Members:

- Ardis Schmiege, Stilly Valley Connections (1 year term)
- Ben Young, Communities of Color Coalition (1 year term)
- Joyce Jefferson, Korean Women's Association (2 year term)
- **Sharmane Joseph**, Seattle Cancer Care Alliance (2 year term)
- Giselle Zapata-Garcia, Latinos Promoting Good Health / King County Elections (1 year term)
- **Sandra Huber**, Verdant Health (2 year term)
- Jenna Bowman, United Healthcare Community Plan (1 year term)

Adding New Members

Since the Coalition is a dynamic body, we recognize that individuals may experience new situations that no longer give them the time or flexibility to participate. In addition, as new issues or priorities develop, it will be necessary to recruit new members who have expertise in those areas. As vacancies arise, OCOE staff will work with Steering Committee and Coalition at large to identify new members.

Communication

It is important for the partnership to maintain open and strong communication. This will become an invaluable tool. It is vital that each member of the partnership have an opportunity to express ideas and concerns.

Open communication has many benefits, including the following:

Learn and listen to others.

- Accept and appreciate the individual differences and values.
- Give proper credit/recognition when it is due.
- Establish lines of communication with others and take the time to talk with others.
- Anticipate any potential conflicts.
- Give and receive feedback on important information, messages, or directives.
- Learn to attack the problem, not the people.
- Admit your mistakes.
- Explain your actions to others.

This list is just a small sample of open-communication advantages and techniques that provide a road map for the partnership.

Conflict Resolution

Effective conflict resolution requires good communication procedures. The approach to conflict resolution comes from the level of openness and level of trust among partnership members. While members of the Coalition will share common goals, conflicts can arise based on differences in strategy and opinion. With any potential conflicts, there are at least two effective approaches to resolving issues: 1) Negotiation and 2) Problem-solving.

<u>Negotiating</u> Negotiations will involve compromise, as each side tries to give up as little as possible, while giving concessions to the other members. Both sides involved should benefit in some meaningful way. It is important to remember and communicate any common goals.

<u>Problem-solving</u> This is perhaps the most important and useful tool in communication and Coalition building. Problem-solving should meet the needs of all members without sacrifice on the part of any other members. Communication for problem solving should go outside the boundaries of one's own interest ("think outside the box"). As a partnership, we should expect different points of view from different members, and a problem-solving approach is the most effective means of conflict resolution.

Decision-making

All Coalition members are part of the decision-making process. The process will include consideration of all aspects that can affect the potential audience and provide responses to the goals. When discussing a project that requires a decision, the following steps are encouraged:

- Define the problem
- Gather and share information about the problem
- Make a list of possible solutions to the problem
- List the pros and cons of each potential solution
- Choose a solution to pursue
- Carry out strategies to solve the problem



 Evaluate the decision that was made. For this partnership, it will be important to have decisions made by consensus, which means that the entire group agrees on the decision. If members cannot agree, the group must vote on a decision or defer the decision to a later time.

The Decision-Making Process

Coalition members will participate in matters or pressing issues that require attention through a voting process. This requires active members in the decision-making process to be part of what will be considered the **quorum** or the "minimum number of active coalition members necessary to conduct a vote."

Voting Rights Among Active Members

- Votes are counted as <u>"1 vote per participating organization"</u>. Organizations that have more than one representative should designate one member as a designee for voting.
- Which individual is serving as an organization's designee may change from vote to vote at the discretion of the organization.,



- The official quorum for our Community Action Coalition is designated as 60% of full membership. If a vote is necessary, applicable information will be sent in advance of the meeting at which the vote would be conducted.
- Voting may take place during Coalition meetings (either inperson or remote) or via email communication, if necessary.

The **Steering Committee** and emergency voting procedures:

 If an issue requires an emergency vote or more immediate action, it will be the role of the Coalition Steering Committee to convene (in-person or remotely) to cast their votes on behalf of the coalition members

The Steering Committee may choose to exercise the option to defer an official vote based on a "case by case" basis. The Steering Committee may also request to have the voting done remotely with as many coalition members participating as possible, should they feel the need

Compensation

The Consortium will provide a modest stipend for Coalition members. At each meeting, attendees will be given a form to complete that signifies they received the stipend. To award stipends, members are required to complete a W-9 form, which will be done at the first meeting.

Depending on the time of day and length of the meeting, refreshments and/or a meal will be provided at all coalition meetings.

The First Meeting of the Coalition

The initial meeting of the Coalition and the Consortium will include both new and returning members from the Health Disparities Research Center Community Advisory Board and will be held on the Fred Hutch campus on Thursday, May 2, 2019. Subsequent meetings will then be rotated



among the various counties within the catchment area. These locations will be determined by the Coalition at each meeting.

Section 5:

Getting Started

Section 5: Getting Started

Just as a building begins with a blueprint, the activities of the Community Action Coalition need an overall plan for its undertakings. After establishing a governance system, the first order of the Coalition is to conduct a SWOT analysis (see below), and then to develop a strategic plan. The strategic plan involves setting goals, determining actions to achieve the goals, and identifying and mobilizing resources to execute the actions.



The SWOT Analysis

In order to create objectives around the broad goals, we will conduct a SWOT analysis. SWOT stands for <u>Strengths</u>, <u>Weaknesses</u>, <u>Opportunities</u>,

and <u>Threats</u>. A facilitator will guide the group into identifying these factors around each of the goals.

Strengths

- What do the Coalition and Consortium do well?
- O What are their unique skills?
- What expert or specialized knowledge does the Coalition have?
- What critical experiences do the Coalition and the Consortium have?

Weaknesses

- In what areas does the partnership need to improve?
- Where do the Coalition and the Consortium need further education and/or experience?
- What resources are lacking to accomplish the goals?

Opportunities

- What are the goals Coalition members are currently working towards?
- How can you do more with existing participants?
- How can you use technology to enhance the goals?
- Are there new target audiences that can be reached?

Threats

- What obstacles does the partnership face?
- What is going on in the economy that may affect the goals?
- What barriers prevent education and outreach?
- o How does geography affect the goals?

The following is an example of some things that may come up in a SWOT analysis.

Strengths	Extensive knowledge of the area Good communication with partners in the area Bicultural staff available Knowledge of community resources
WEAKNESSES	Limited funding Transportation issues Lack of culturally relevant programs Limited staff
Opportunities	Availability of social media Interest in health among faith-based organizations Community centers as Combining education with access to screening
THREATS	Limited access to care in rural areas Increasing demand for services Fear of cancer diagnosis from screening Decreased funding for programs

The Strategic Plan

A comprehensive strategic plan begins with a set of goals. As you will see from the "Report to the Community", in our catchment area, the top five major cancer sites for incidence (new cases) and mortality (death) rates are lung, breast, colorectal, prostate, and hematologic (blood) cancers. You may wish to think of goals around those cancers. In terms of cancer-related behaviors, obesity, smoking, and lack of physical activity are behaviors that contribute to cancer. Lack of screening for early detection of cancer leads to increased mortality as cancers are discovered later when they are not as curable. As part of the strategic plan, we will identify the goals the Coalition would like to work on over the next three to five years.

Setting Goals

Once the SWOT analysis is done, goals can be selected and then objectives can be established. For example, using the SWOT analysis example, a three to five-year objective might be, "To partner with tribes in the catchment area to implement smoking cessation programs." Other goals might be around early detection, such as "To increase colorectal cancer screening among rural residents."

By the end of strategic planning, the Community Action Coalition will have a blueprint for the next three to five years. This "Community Outreach and Engagement Strategic Plan" will be shared with the Consortium's leadership. This ongoing connection between the Coalition and the Consortium leadership will ensure that the needs in our catchment area are addressed on an ongoing basis, as the Consortium leadership will help the Office of Community Outreach and Engagement identify resources for implementation of the "Community Outreach and Engagement Strategic Plan".

Section 6: Annual Action Planning

Section 6: Annual Action Planning

Once the strategic plan is finished and approved by the Community Action Coalition, it is time to put the plan to work. Annually, the Coalition will develop an Annual Action Plan that summarizes the objectives and activities that will be done in each year. Objectives will need to be SMART, that is Specific, Measurable, Actionable or Attainable, Realistic, and Time-bound in order to be results oriented over the three to five years of the plan.

For example, using the goal of "partnering with tribes in the catchment area to implement smoking cessation programs for tribal members in their communities", an annual plan for the first year might be "To partner with two tribes in the catchment area to conduct a series of "Quit & Win" contests over one year." Similarly, the early detection objective might be "To partner with the Breast, Cervical and Colon Health Program and two federally qualified health centers to conduct eight colorectal education and screening events in rural areas of the catchment area over one year." The annual action plan is the specific implementation of the objectives.

It is wise to think of the annual action plan in terms of the following:

- What will be done?
- When will it be done?
- Where will it be done?
- Who will do it?
- What resources can be used?

The final annual action will be a list of activities that are desired in that specific year. The Coalition will receive information from the OCOE staff regarding past activities and the impact such activities have had on the overall goals and objectives.

Using the example of smoking cessation among Native Americans:

What will be done?	A "Quit & Win" contest where smokers are instructed in how to quit smoking and receive entries to a cash prize if they successfully quit for 30 days.
When will it be done?	The first one will start on New Year's Day because many smokers attempt to quit then.
Where will it be done?	It will be done with two tribes in the catchment area.
Who will do it?	The CHE for American Indian/Alaska Native communities and the tribal representative(s) will partner to implement this activity.
What resources can be used?	Quit kits available through the Consortium; will attempt to raise funds for a cash prize; staff time and effort; staff mileage.

Using the example of colorectal cancer screening in rural areas, a plan might look like this:

What will be done?	CHEs will staff the inflatable walk-through colon and partner with BCCHP and FQHCs to distribute FIT kits to age-eligible people who go through the colon.
When will it be done?	Spring, summer and early fall when the weather is pleasant and the colon can be hosted outdoors if needed.
Where will it be done?	In Whatcom, Skagit, and Clallam Counties.
Who will do it?	The CHE for Rural Populations will partner with BCCHP and FQHCs to plan and host events.
What resources can be used?	FIT kits, analysis of kits, staff time and effort, staff mileage.

Section 7:
The
Strategic
Plan

Section 8: The Annual Action Plan

Appendices