

Summary Report: 2016-2020 Cancer Plan Survey Comprehensive Cancer Control Program (CCCP)

Background

Like all US states, Colorado has a statewide cancer plan—developed by cancer community members and supported by the Centers for Disease Control and Prevention (CDC)—that sets forth measurable 5-year objectives with the potential to positively impact a state's cancer burden. Colorado's comprehensive 2016-2020 plan covers topics from prevention, screening, treatment and survivorship, in addition to policy and health equity. The Colorado Cancer Plan goals and objectives are intended to be a framework for collaborative efforts across the state that can empower individuals and organizations in Colorado's fight against cancer.

The Colorado Department of Public Health and Environment (CDPHE), through its Comprehensive Cancer Control Program (CCCP), initially funded the Colorado Cancer Coalition (CCC) to coordinate the process for developing and implementing the statewide cancer plan. But, due to <u>organizational changes at the Colorado Cancer Coalition</u>, CCCP assumed responsibility for leading the development of the 2016-2020 Colorado Cancer Plan in April 2015. To ensure ongoing momentum in collaborative efforts that reduce the state's cancer burden, CDPHE sought feedback from stakeholders across the state.

The purpose of the survey was to assess the needs, gaps and direction of the 2016-2020 Colorado Cancer Plan by identifying:

- the cancer community's knowledge and understanding of the plan's purpose and use.
- stakeholder priorities for the plan and their motivations for involvement.
- possible gap areas in the plan and its implementation.
- key partners and motivations for involvement.

Methods

An online survey was administered April 22 - May 15, 2015 to statewide cancer prevention and control stakeholders who were identified through existing networks at CDPHE and throughout the state. Data collection occurred via Survey Monkey, a web-based survey tool. To ensure the largest and most representative sample, the survey link was emailed by the CCCP team to several individuals, mailing lists and published in the COPrevent newsletter. The survey included a combination of 16 multiple choice, scaled and open-ended questions that addressed stakeholders' experience and understanding of the plan, and provided the opportunity to offer guidance and suggestions. A total of 191 anonymous respondents completed the survey.

Limitations. This data collection and analysis provides a point-in-time snapshot of perceptions among Colorado Cancer Plan stakeholders who self-selected into the survey through convenience and snowball sampling. Thus, the results presented here may not fully represent the target population. The survey was also implemented during the shift from one organizing body (CCC) to another (CDPHE) during the planning stages of the Cancer Plan. This timing may have contributed to some confusion about the role and expectations of the State and should be considered when reviewing respondent feedback. Nonetheless, these data provide valuable insight for strategic planning.

Sample

Geographic Representation. Slightly more than one-third of respondents (34%, n=65) reported that they represented statewide interests related to cancer. The remaining two-thirds of respondents (66%, n=126) indicated that they represented single (n=72) or multiple (n=54) counties, mostly urban. Denver (29%), Arapahoe (18%) and Jefferson (14%) were most frequently selected. Only two counties were not represented in this sample: Jackson and Routt.

Affiliation/Role. Respondents reported widely distributed affiliations. Nonprofits (29%, n=56), hospitals/clinics (24%, n=46) and college/university (19%, n=37) were most frequently selected. Only 11% of respondents (n=21) were affiliated with CDPHE. Respondents most frequently reported their roles as current employees/professionals in the field of cancer (38%, n=72). Fifteen percent of respondents (n=29) were cancer survivors. Very few retired professional (2%, n=4) and students (1%, n=2) participated.

Interests. Twenty-nine percent of respondents (n=55) reported interest in all cancers, with the remainder (71%, n=136) interested in specific cancer types. Respondents most frequently reported interest in breast (35%, n=66), colorectal (28%, n=54) and lung (24%, n=45) cancers. Respondents also reported most interest in the early stages of the continuum of care, including prevention (72%, n=137), screening and early detection (59%, n=112) diagnosis and treatment (51%, n=98) and post-treatment survivorship (36%, n=69).

Community Involvement. Sixty-one percent of respondents (n=117) reported involvement with the cancer community for five or more years, with a handful noting involvement spanning two decades or more. Seven percent of respondents (n=13) reported no involvement in the cancer community. Sixty three percent of respondents (n=121) indicated that they collaborate with CDPHE in some capacity, with the Cancer, Cardiovascular Disease and Pulmonary Disease (CCPD) Grants Program (31%, n=59), the Women's Wellness Connection (28%, n=53) and Tobacco Programs (23%, n=48) most frequently reported. Only 35% of respondents (n=66) reported current or previous involvement in the Colorado Cancer Plan, though 18% (n=35) were not sure.

Key Findings

Key findings are reported below for primary areas of interest examined in the survey.

CDPHE should facilitate the implementation of the statewide cancer plan.

Most respondents (62%, n=119) identified CDPHE as the preferred organization to facilitate the implementation of the cancer plan, with the remaining 38% divided between universities (16%, n=13), nonprofits (10%, n=19) and other (12%, n=22).

The State Health Department should be able to convene the organizations that should be involved and also understand the nuances for getting the plan to the point of implementation. At that point have the community actually implement it.

The state department of health has a mandate to promote and protect the health of all Coloradans. While working with everyone is necessary, the state should not defer leadership roles to other organizations. They should make this a priority.

Respondents recognized the complexity of this process and noted the value and need for actively engaged stakeholders at all stages.

I believe this is a multi-level task with many branches of support needed. Due to funding and support this should be split between State and Non-Profit in an effort to work on promoting effective team collaboration to reach the highest impact.

Even respondents who selected an alternate organization to lead the implementation still valued the role of CDPHE as an "active partner" and "oversight body" with the resources and structure to administer the process.

[CDPHE should] Lead the effort in getting a solid, committed team on board to finalize the Plan and have them ensure that there is STATEWIDE buy in.

Ultimately [CDPHE should be in] the leadership role, but with other types of organizations on the leadership committee.

<u>Stakeholders' motivation and involvement may depend on their understanding of the cancer</u> plan and how relevant it is to their professional and personal interests.

Better alignment with stakeholder interests and increased understanding (via improved communication) about the plan is needed. Respondents repeatedly reported the need to understand the cancer plan's relevancy to their daily work. Buy-in depends on how well the plan meets individual's professional needs.

To make it more useful to me in my work than it has been in the past and to better understand how to incorporate it into the work I would like to be doing. Also because I think I [would] be a positive influence on the plan for the consumer sector.

Knowing that it has value or relevance to what I and our clinical team already do at our Cancer Center. Few of my colleagues even know it exists; none have ever found it necessary to review.

Respondents without previous involvement in the Cancer Plan were less likely than their previously involved peers to indicate interest in involvement, although several respondents new to the cancer plan did express interest in involvement.

Partners should also represent a wide array of interests and regions.

Respondents commented about the need for non-urban/non-Denver regions to have a voice at the table though some suggested that passion and motivation was equally important. A diversity of expertise across multiple sectors is also essential. Respondents suggested numerous individuals and organizations as candidates for leadership.

I think you need cancer leaders throughout the state not just Denver.

We also need to identify people from other parts of the state, but I'm unfamiliar with those folks. Specifically, Colorado Springs, Grand Junction, and Durango. If possible, engage folks from other areas as well: SE Colorado, San Luis Valley, Vail and/or Glenwood, Pueblo.

Education, communication and outreach about the Cancer Plan are needed.

Perceptions were generally positive about the usefulness of the Cancer Plan; however, increased and consistent communication is desired and needed, both to educate the cancer community and encourage alignment and, ultimately, ensure its impact.

The who, what, when, where, why and how of the cancer plan needs to be better marketed.

Confidence in the impact of the plan can be established through better communication.

Knowing that it will help move cancer related activities forward in Colorado. Seeing and learning about...where impacts have been made through the use of the cancer plan in the past and intended actions and participants moving forward.

All members of the cancer community need to feel welcome at the table.

Being invited to meetings or included in emails to know what is taking place regarding the Colorado Cancer Plan.

Workgroups should be flexible and may need to be organized in multiple ways.

While slightly more than half of respondents (54%, n=103) indicated that workgroups should be organized along the cancer continuum, there were noted concerns about potentially losing buy-in from cancer-type experts.

I think organizing work around the continuum of care makes sense, however, we need to ensure that the "body part" special interest groups do not become disenfranchised. It must be made clear how they fit and how they will contribute while still maintaining their passion around specific cancer types.

It is nice to align all cancer types by the phases listed, but there are areas specific to each disease type that will impact these areas (ie: screening has been shown to be less than effective in certain disease types. Prevention (areas like diet and exercise) can be important for all disease types, but prevention of colorectal cancer (by colonoscopy) is unique to that disease. At the university level, oncologists are often specialized by disease type (though some disciplines overlap, ie: surgery/palliative care.)

I'm torn. I think you will get better buy in from npos/community organizations if it's organized by cancer type, but I think organizing by continuum of care will bring better collaboration and just makes more sense now that it's organized that way.

Several respondents commented that a hybrid of the continuum and cancer type structures may be necessary to ensure involvement of cancer-type experts and successful collaborations.

Both - work groups along the cancer continuum of care should address all-cancer objectives while work groups for cancer types should implement disease-specific nuances in implementation.

If organized by continuum of care, it seems there will also be a need for subgroups organized by diagnosis.

Conclusion

The Colorado cancer community comprises individuals who are passionate about their work and highly value collaborative efforts to address cancer. The Cancer Plan can be a key tool for stakeholder engagement and can fuel collaborative efforts, but there is a need for clarity about its purpose and significance. Including the broader community in conversations about the plan to ensure it remains relevant to individual practice may be needed for widespread support. Increased communication and education—and having the right partners at the table—can help bridge this divide.

CDPHE is in a natural position to guide the development of an organizational structure and continue in an administrative capacity to move the Cancer Plan forward. In that capacity, CDPHE should ensure that the leadership and direction of the plan is a collaborative effort among individuals and organizations across the state with the expertise and capacity to ensure the plan's success.

CDPHE has engaged Strategic Health Concepts (SHC) to help facilitate the next steps. SHC's lengthy experience working with national and state cancer organizations and state cancer plan implementation efforts puts them in a good position to utilize these findings to guide upcoming conversations with stakeholders.