



# ***SURVEY OF MEMBERS AND PARTNERS***

**August 2007**

## **Introduction**

C-Change is the only national organization that regularly convenes leaders from the private, not-for-profit, and government sectors to address the burden of cancer on the people of the United States. This unique constellation of leaders comes together to collaboratively address important cancer issues that are either not being addressed at all or where there is an opportunity to significantly accelerate progress through collaborative action.

C-Change was originally founded as the National Dialogue on Cancer in 1998 under the leadership of President and Mrs. George H. W. Bush. The membership consists of CEOs and other senior leaders from within the traditional cancer community and those outside that community whose work has the potential for significantly impacting on the cancer burden.

In 2003, C-Change was incorporated in order to more effectively move from dialogue among its members to action. The mission of C-Change is to leverage the expertise and resources of its members to eliminate cancer as a major public health problem at the earliest possible time.

C-Change's members come from 130+ organizations whose interests span the three sectors and the full continuum of cancer: research, primary prevention, early detection, treatment and quality cancer care, and survivorship. Typically, the senior individual from an organization is a voting member of C-Change. Other individuals from the same organization are recognized as 'partners'.

The work of C-Change includes ongoing initiatives derived through member-driven teams from both the time of the National Dialogue on Cancer and when it became C-Change. In addition, in 2005, C-Change announced an initial focus on primary prevention and early detection which had resulted in a number of member-driven strategic initiatives.

As 2008 approaches, it has become clear that there is a need to review the current portfolio of C-Change initiatives to determine how best to build upon the accomplishments to date and to identify potential new areas for three-sector collaborative work. As a member-driven organization, the Board of Directors determined that a survey of the membership would be useful in setting the organization's future course.

## **Survey Overview**

A three-question, electronic survey was developed to seek input on C-Change's future direction. The survey questions asked the membership to carefully consider the unique nature of C-Change's membership and the opportunity to significantly impact the burden of cancer when asked:

- Which of the current strategic initiatives should be continued?
- What new strategic initiatives should C-Change consider that are uniquely suited to three-sector, collaborative action?
- Is your organization willing to contribute resources to future collaborative action?

The survey was sent by email to the official list of C-Change members and partners. In addition, a number of selected individuals who are leaders of key organizations not yet included in the membership of C-Change were sent the survey.

The survey was first sent on August 7, 2007. Reminder emails were sent on August 10, 13, and 15. The survey closed after 10 days on August 17. Seventy-nine (79) responses were received. Respondent consisted of those representing:

|                                     |          |
|-------------------------------------|----------|
| Government (including academia)     | 16 (20%) |
| Private companies                   | 19 (24%) |
| Not-for-Profit organizations        | 27 (34%) |
| Cancer centers (from the 3 sectors) | 8 (10%)  |
| Other and anonymous                 | 9 (11%)  |

It should be noted that seven of the cancer center responses came from the Directors of NCI-designated cancer centers. Of the 27 responses from not-for-profit organizations, 17 came from their CEOs.

## Results and Analysis: Current Initiatives

### *Results*

The survey asked members, partners, and friends to review a list of 22 current initiatives and to determine which should be continued given C-Change's unique membership and the opportunity for impact. Seventy-seven (77) of the 79 respondents (97%) provided input on this question. The initiatives are listed in the table below in descending order based on the percentage of respondents indicating the initiative should be continued.

| <b><i>C-Change Strategic Initiative</i></b>                               | <b><i>Percentage</i></b> |
|---|--------------------------|
| Making the Business Case for Cancer Prevention & Early Detection          | 83%                      |
| Summer Internship Program   | 79%                      |
| Equal Access to Quality Cancer Care Forum                                 | 70%                      |
| Comprehensive Cancer Control (CCC) Leadership Summit                      | 67%                      |
| Raising Public Awareness of Cancer Prevention & Early Detection           | 66%                      |
| Promoting Resource Development for Comprehensive Cancer & Tobacco Control | 64%                      |
| Clinical Trials Policy Guidance   | 61%                      |
| CCC Leadership Institutes States and Tribes                               | 61%                      |
| Cancer Chemoprevention Research   | 59%                      |
| Cancer Surveillance Summit II   | 55%                      |
| Careers in Cancer Speaker's Kit   | 54%                      |
| Access to Quality Cancer Care Guidance                                    | 53%                      |
| Clinical Trails Practice Guidance   | 49%                      |
| Behavioral Research Forum   | 49%                      |
| Cancer Patient Navigation Promotion                                       | 47%                      |
| Cancer Core Competencies  | 39%                      |
| Summer Internship Web Portal  | 38%                      |
| American Indian/Alaskan Native Dialogue on Colorectal Cancer              | 32%                      |
| Excellence in Comprehensive Cancer Control Awards                         | 32%                      |
| Pacific Island Jurisdictions Leadership Institutes                        | 24%                      |
| <b><i>Cancer: Caring and Conquering</i></b> MedSurg Column                | 22%                      |
| Pacific Island Jurisdiction CCC Plan Implementation                       | 20%                      |

## **Results and Analysis: Current Initiatives (continued)**

### ***Analysis***

Three factors which should be kept in mind as these results are interpreted:

- The eclectic nature of the C-Change membership (three-sectors and across the full cancer continuum) suggests that respondents would likely have greater awareness and understanding of some initiatives more than others;
- Some respondents may not have been fully familiar with the actual content of some of the current initiatives. For example, several members proposed future initiatives that address the use of biomarkers and clinical trials design, especially for personalized therapeutics and chemopreventive agents while failing to vote for continuation of the current chemoprevention research initiative which includes these very issues;
- Some respondents may not have been aware of the underlying strategy behind some of the initiatives. For example, the low level of support for the Pacific Island jurisdiction initiatives represents C-Change contributing to the needs of people not well supported as part of the population disparity efforts of other cancer organizations; and
- The level of support indicated for each initiative is independent of the investment costs of continuing the initiative. For example, the high level of support for continuing the internship program does not account for the very high staff and monetary investment by C-Change and low member organization participation during each year's internship effort.

More than 50% of the respondents support continuing twelve of the 22 current, C-Change strategic initiatives. This would seem to validate the importance of those initiatives going forward. Indeed, considering the eclectic nature of the C-Change membership, this result could be interpreted as a relatively high level of support. Of the remaining ten initiatives, seven have continuation support of at least 25% of the membership; and the remaining three are just below that level of support. For some of the reasons noted above, a low percentage of support cannot be interpreted entirely as meaning the initiative is not an important investment.

## **Results and Analysis – Future Potential Initiatives**

### ***Result***

Question 2 asked respondents to suggest future strategic initiatives given C-Change's unique membership and the potential for a major impact on the cancer burden. Respondents could make up to three separate suggestions. Fifty-five (55) respondents (70%) made at least one such suggestion; 38 (49%) made at least two suggestions; and 23 (29%) made three suggestions.

The suggestions made came in a variety of categories and are summarized in Attachment 1 without any regard to potential priority and in the words largely used by respondents. Within each category, respondent ideas are presented in sub-categories: problem statements; policy interventions; other interventions. None of the categories are mutually exclusive. Many members provided suggestions that were variations on ideas presented by others. Thus, no attempt has been made to tie a number of responses to any one idea in Attachment 1. It should also be noted that a number of suggestions were made which represent 'operational advice' and these too are summarized in Attachment 1.

Question 3 on the survey asked respondents if their organization would be willing to invest resources in the initiatives they suggested should they be selected. Sixty-seven (67) respondents (85%) replied to the question as follows:

|       |     |
|-------|-----|
| Yes   | 42% |
| No    | 4%  |
| Maybe | 54% |

### ***Analysis***

Respondent's suggestions for new strategic initiatives included a mix of variations on existing initiatives, initiatives already being planned for early 2008, and initiatives not previously in the portfolio. In the latter category, it is clear that the respondents see a potential for C-Change becoming much more active in its communications activities to the public and in cancer policy and advocacy, particularly around research and access to care.

It is also clear that C-Change's members want to assure that the organization is not simply duplicating the work of others and has a unique and synergistic role in all that it does.

Many of the suggestions for future initiatives came in the form of problem statements or broad suggestions for C-Change interventions and not in the form of specific strategic initiatives. For those that represent high impact opportunities, additional work will be required to refine and frame these in the context of specific strategies that capitalize on C-Change's unique, three-sector membership.

It is gratifying to note the proportion of members willing to invest in the work of C-Change on initiatives they deem as important. In all 96% of respondents indicated they would or might commit organizations resources to C-Change's strategic initiatives. Among the 4% who said they would not, were several respondents whose organizations do not have the capacity or legal charter to do so.

## ATTACHMENT 1

### Strategic Initiatives Suggested by C-Change 2007 Survey Respondents

#### ***Cancer Health Disparities***

Problem statements:

- Address the enormous disproportionate burden of cancer among African Americans;
- There is no strategy for addressing cancer disparities across the full continuum of cancer.

Other interventions:

- Compile what is know about addressing disparities and develop optional leveraging strategies for focusing efforts;
- Encourage a concentration of education and screening resources on segments of the population and geographic areas of greatest needs.
- Better connect cancer screening programs to the access needs of underrepresented populations.

#### ***Access to Care and Services***

Problem statements:

- Address the reimbursement-insurance challenge;
- Specialists have not bought in to patient navigation;
- No one addresses identifying and quantifying inefficiency in cancer care.

Policy interventions:

- Advocate for consistent reimbursement for patient care, including standard costs while on clinical trials;
- Define a position on access to non-approved cancer therapeutics for patients with late stage cancers;
- Increase information dissemination and advocacy for universal access to health care;
- Advocate with FDA and Congress to assure that cutting-edge treatments are available;
- Regulatory reform to expedite the development and approval of new treatment modalities;
- Advocate for adequate and fair reimbursement policies for various treatment modalities (the current system favors over-prescription of high-margin, injectible drugs);
- Advocate for adequate funding for FDA that does not require reliance on the current user-fee arrangement.

## ***Access to Care and Services*** (continued)

Other interventions:

- Address lung cancer screening and research;
- Conduct a forum on access to cancer pain management services;
- Identify rationale mechanisms for 3<sup>rd</sup> party reimbursement;
- Develop a strategy for faster dissemination of research advances;
- Provide leadership and bring cancer to the table in the health care reform discussion, including access to cancer screening and treatment;
- Conduct more Capitol Hill briefings;
- Increase access to primary prevention and early detection services;
- Convene members to develop 'one-voice' on policies related to primary prevention, education and access to cancer care;
- Develop a consensus statement on assuring access to quality medical care and psychosocial support for all who have cancer;
- Develop new ideas for hospice care where continuing therapeutic care now blends into palliative care (i.e., good palliative care should not depend on a decision that further therapy is futile);
- Forecast how Medicare, Medicaid, and systems of cancer care will have to adapt if major changes in coverage and reimbursement occur;
- Bring together the stakeholders interested in quality care issues (e.g., ASCO, government).

## ***Information Dissemination***

Problem statements:

- There is a need to focus attention on the overall cancer burden across society.

Other interventions:

- Conduct a C-Change national and local campaign on a high priority topic (e.g. colorectal cancer);
- Provide a messaging campaign across all members;
- Strongly make the business case for prevention and early detection;
- Convene the three sectors to act synergistically in their communications efforts;
- Capitalize on C-Changes leaders and develop a public relations strategy on key cancer issues;
- Develop a cancer professional eCommunity for networking purposes;
- Market C-Change as a powerful voice for cancer issues;
- Focus on issues of young adults with cancer by increasing public and provider awareness;
- Focus on tobacco education and follow-up among 3<sup>rd</sup> graders;
- Make cancer statistics more understandable to the public.

## ***Research***

Problem statements:

- Federal agencies are working at cross purposes: specifically, NCI and FDA/CMS.

Policy interventions:

- Reverse the downturn in Federal funding for cancer research;
- Increase support for cancer research;
- Advocate for more applied research;
- Address the reimbursement of biomarkers;
- Encourage biomarker validation for advancing research and clinical trials.

Other interventions:

- Promote clinical trial enrollment/participation;
- Facilitate the utilization of biomarkers, lab-based and in vivo imaging to help select candidates for therapeutic clinical trials;
- Increase the importance of and resources for population and public health research relative to basic and clinical sciences;
- Expand training in and support for including scientific evidence in public health, primary care and specialty practice;
- Translate behavioral research into evidence-based behavioral interventions;
- Develop strategies for faster sharing of evidence based interventions;
- Address the role, quality and oversight of clinical trials at non-USA sites for USA market approval by FDA;
- Address the stem cell research issue;
- Develop a business case for chemoprevention and vaccine drug development;
- Review the applicability of current NCI funding mechanisms to future cancer research needs.

## ***Primary Prevention***

Problem statements:

- Address translational issues.

Policy interventions:

- Double the Federal budget focused on cancer prevention;
- Reach out to Capitol Hill on tobacco use here and globally;
- Advocate for better use of tobacco taxes for cancer control.

Other interventions:

- Develop a multi-sector strategy for addressing the obesity epidemic;
- Increase the level of work focusing on prevention;
- Maintain a C-Change focus on primary prevention and early detection.

## ***Capacity Building for Comprehensive Cancer Control***

Policy interventions:

- Focus on both national and state policy changes that impact on the cancer burden;
- Create a government fund to support interagency collaborations for comprehensive cancer control.

Other interventions:

- Develop strategies for tapping into the leadership of state consortia for comprehensive cancer control;
- Develop a leadership 'module' on cancer patient navigation;
- Identify mechanisms to integrate private sector support into state comprehensive cancer control efforts;
- Provide research findings to state comprehensive cancer control programs;
- Publish state cancer plans success, failures, and future directions;
- Establish a strategy for coordinating Federal and state cancer control efforts;
- Increase collaboration between the NCI Cancer Centers Program and CDC's Comprehensive Cancer Control Program.

## ***Other Suggested Interventions***

Problem statements:

- There is no national voice on cancer rehabilitation.

Policy interventions:

- Conduct a televised, presidential debate on issues impacting on cancer care;
- Advocate for more public-private partnerships;
- Cultivate the next administration to make cancer a more prominent part of the national agenda.

Other interventions:

- Develop a compendium of resource needs for personalized medicine in all sectors (across research, commercialization and delivery);
- Develop innovative models for addressing the cancer workforce crisis
- Increase efforts to improve quality of life for cancer survivors;
- Provide for better sharing of data for evidence based cancer planning;
- Convene a national conference on cancer;
- Conduct a national effort to make career opportunities in cancer more attractive economically (e.g., post-doctoral support);
- Develop a 'top 10' list of action steps all C-Change organizations can take vis-à-vis prevention;
- Develop a consensus national cancer goal and timeline.

### ***Operational Advice***

- Do not duplicate the work of others (an implied suggestion that we are);
- There is too much on the plate; reduce the list of initiatives and do not add others until the current ones are done;
- Partner more effectively with others working on current initiatives (e.g., messaging work);
- Identify areas not being worked on by others;
- We are not yet living up to our potential in primary prevention;
- Remain a driving force for collaboration;
- Develop much stronger ties to the CEO Roundtable and visibly demonstrate this.