STRATEGIC INITIATIVES

PROGRESS REPORT

JANUARY – AUGUST 2012

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PREPARED AUGUST 31, 2012

2012 Strategic Initiatives Overview

Accelerating Research

#1 Increasing Privacy Protection and Reducing Research Impediments

Challenge: In 2009, an Institute of Medicine (IOM) report concluded that the HIPAA Privacy Rule does not adequately protect patient privacy and that it significantly impedes research.

Goal: Change the HIPAA Privacy Rule and related research and health data policies to strengthen patient privacy protection and accelerate cancer research through advocacy and education efforts.

Transforming the Health System

#2 Promoting a National Shift to Cancer Risk Reduction (Prevention and Early Detection)

Challenge: The acute care centered health care delivery system does not have the resources or incentives to foster the optimal utilization of evidence based cancer prevention and early detection services. Despite the fact that *about half of all cancer deaths are preventable* by changes in tobacco use, nutrition, exercise, and screening, the country's energy and attention remains focused largely on the treatment of disease rather than a more balanced focus that includes adherence to well proven prevention and early detection measures.

Goal: Cut cancer deaths in half by implementing a long term and sustained national strategy that motivates U.S leaders and the public to take the steps necessary to prioritize and implement cancer prevention.

#3 Implementing a National Cancer Health Disparities Strategy

Challenge: Cancer health disparities remain a persistent and challenging issue that has not resonated with policymakers and the general public to inspire action for change.

Goal: As part of a long term, collaborative strategy to eliminate cancer health disparities, 1) Develop messages that describe the societal and economic cost of cancer health disparities that will resonate with the public and policymakers and stimulate action, 2) Intervene in communities experiencing a significant cancer burden using a multi-sector approach.

#4 Sustaining a Strong National Cancer Workforce

Challenge: The demand for cancer services is projected to exceed the supply of cancer health professionals threatening access and quality across the continuum of research and care.

Goal: Define and pursue a coordinated national strategy for ensuring the capacity and skills of the cancer workforce.

#5 Assuring Value in Cancer Care

Challenge: A 2009 IOM National Cancer Policy Forum workshop defined challenges and opportunities for improving value in cancer care. Persistent economic pressure in the health sector, debate regarding health reform, and differing opinions about defining 'value' and means for achieving it add to the challenge.

Goal: Improve the quality of life of cancer patients through fully informed, patient/family decisions resulting in significantly increased use of palliative care services and increased length of stay in which patients are enrolled in hospice care.

Supporting State, Tribe, and Territory Comprehensive Cancer Control Efforts

#6 Comprehensive Cancer Control (CCC)

Challenge: To continually support progress and improvement in the implementation of state, tribe, and territory comprehensive cancer control plans.

Goal: (1) Actively engage coalitions in the local implementation of C-Change strategies related to research and health system transformation, (2) Facilitate the engagement of C-Change members in CCC Coalitions, and (3) Support the collaborative efforts of the CCC National Partners in providing training and technical assistance to coalitions.

Ongoing Dissemination and Advocacy To fulfill the potential impact of completed work initiatives by leveraging our collective messaging power through advocacy efforts and by promoting dissemination and adoption by the membership and other relevant stakeholders.

#1 Increasing Privacy Protection and Reducing Research Impediments

Challenge: In 2009, an Institute of Medicine (IOM) report concluded that the HIPAA Privacy Rule does not adequately protect patient privacy and that it significantly impedes research, making critical information more difficult, more costly, and, in some cases, impossible to obtain.

Goal: Change the HIPAA Privacy Rule and related research and health data policies to strengthen patient privacy protection and accelerate cancer research through advocacy and education efforts.

Unique C-Change Approach

1. **Reframe / contribute to a better understanding of the problem**
    A. Illustrate the cost of HIPAA to the health system and research enterprise in terms of time, dollars, and opportunity cost
    B. Illustrate the impact of HIPAA to patients in terms of access, cost, and timely discovery
2. **Define a feasible solution**
    A. Engage with legal and research experts in cancer and other disease communities to explore solutions
    B. Engage expertise from Hogan Lovells
3. **Advocate for change**
    A. Prevent current legislation and regulations from worsening by submitting public comments on relevant regulations and strategies
    B. Promote the adoption and implementation of a solution (legislation and/or regulation)

2012 Milestones through August 2012

- Completed the white paper, "The Costs of HIPAA to Patients, to Progress, and to the Nation's Health." Available on the C-Change website for future reference in advocacy efforts
- Participate in the final meeting of the Indiana University (IU) NIH ARRA Grant Panel to define a detailed solution to research barriers imposed by the HIPAA Privacy Rule in collaboration with leaders and experts from law, ethics, research, healthcare, and patient advocacy including cancer and other disease communities
- Hosted 2 HIPAA Policy Sub-committee meeting to review the preliminary and revised recommendations of the IU panel
- Secured a commitment from Hogan Lovells to draft a legislative model and political strategy
- Presented a poster based upon the cost study at the CDC /NCCC Conference

2012 Plans for September – December 2012

- Engage broader C-Change membership in discussion of upcoming legislative effort to strengthen their understanding and support of this patient privacy and research issue
- Collaborate with Hogan Lovells to develop a legislative model and political strategy
- Review the proposal and strategy with the HIPAA Policy Sub-Committee and Advisory Committee
- Begin identifying political champions and select research and patient advocates for a 'grass tops' approach
- Consult the Board Policy Committee for guidance

2013 Priorities

- Secure support and resources to pursue political strategy
- Implement the strategy in pursuit of legislative change
- Continue to comment on related research, privacy, and health information technology regulations

#2 Promoting a National Shift to Risk Reduction (Prevention and Early Detection)

Challenge: The acute care centered health care delivery system does not have the resources or incentives to foster the optimal utilization of evidence based cancer prevention and early detection services. Despite the fact that *about half of all cancer deaths are preventable* by changes in tobacco use, nutrition, exercise, and screening, the country's energy and attention remains focused largely on the treatment of disease rather than a more balanced focus that includes adherence to well proven prevention and early detection measures.

Goal: Cut cancer deaths in half by implementing a long term and sustained national strategy that motivates U.S leaders and the public to take the steps necessary to prioritize and implement cancer prevention.

Unique C-Change Actions

Focusing on the key fact that *one-half or more of cancer deaths can be prevented* through evidence-based actions, C-Change will leverage its unique multi-sector leadership to increase public awareness and to motivate the public and policy makers to make prevention a priority.

1) **Develop a campaign to effectively communicate the core message -** Develop core message language that is simple and communicates to leaders, policy makers, and the general public and develop a communications plan for leaders in each sector to promote the core message
2) **Start with ourselves –** Engage members to make meaningful commitments to assure their own organizational messages, policies and agendas are consistent with the above objectives.
3) **Recruit other leaders -** Engage non-traditional, influential leaders who are willing to lead by example and communicate the core message.
4) **Convince the American population -** Execute a non-traditional earned media campaign to convince the American public of the possibility and importance of cancer prevention.
5) **Advocate –** Execute a coordinated advocacy strategy toward specified policy objectives

2012 Milestones through August 2012

- Developed unique strategy (summarized above)
- Developed platform of cross-cutting and risk factor-specific issues based on evidence and member survey
- Formed sub-committees: Steering and Policy, Communications, Leadership Outreach
- Surveyed and analyzed existing cancer prevention related messages and communications research
- Created a messaging framework to guide cancer prevention messengers and conducted focus group testing to further refine on cancer prevention messages for C-Change messengers
- Identified an initial policy objective, substantial federal investments in prevention that should be no less than the current amount, drafted a communications plan to guide C-Change coordinated actions toward this objective
- Developed a fact sheet to educate the C-Change membership on this topic
- Presented risk reduction messaging at the NCI meeting, Uniting Systems Through Communication Science
- Presented a poster on cancer prevention messaging at the CDC /NCCC Conference

2012 Plans for September – December 2012

- Engage a communications consultant to implement strategies for coordinated advocacy toward C-Change's priority objectives, develop an advocacy strategy, and recruit C-Change members and other leaders to participate
- Identify a second priority objective
- Continue to identify, recruit, and motivate leaders from all sectors to act toward cancer prevention objectives at the federal, state, and community level issues
- Further refine cancer prevention messages
- Develop an evaluation plan

2013 Priorities

- Implement advocacy, communications and evaluation plans
- Monitor landscape for opportunities to advance cancer risk reduction policies and programs and coordinate action where appropriate

#3 Implementing a National Cancer Health Disparities Strategy

Challenge: Cancer health disparities remain a persistent and challenging issue that has not resonated with policymakers and the general public to inspire action for change.

Goal: As part of a long term, collaborative strategy to eliminate cancer health disparities, 1) Develop messages that describe the societal and economic cost of cancer health disparities that will resonate with the public and policymakers and stimulate action, 2) Intervene in communities experiencing a significant cancer burden using a multi-sector approach.

Unique C-Change Approach

1. **Reframe the problem and promote action**
   A. Commission a Case Statement illustrating the economic toll of disparities on society in terms of premature death, lost productivity, and medical care costs
   B. Develop Position Statement based upon the Case Statement and other disparities evidence including a call to action for members/stakeholders
   C. Develop messaging tools and a dissemination plan based upon the Case and Position Statements that will resonate with the public and policymakers to inspire societal action
2. **Engage a disparate community in a multi-sector intervention project**
   A. Establish a model for identifying disparate communities using traditional and non-traditional data sources
   B. Engage national and local stakeholders to support a community-specific intervention
   C. Engage a community who is willing and ready to partner with stakeholders
   D. Support a community in creating a sustainable plan for eliminating cancer health disparities in their community
   E. Implement the plan in collaboration with a community and other local and national stakeholders
   F. Share the assessment, planning, and implementation efforts to inspire translation in other communities
3. **Collaborate and promote HHS's *National Partnership for Action to End Health Disparities* -** Engage in a partnership by increasing awareness of the national disparities agenda

2012 Milestones through August 2012

For Goal 1) Messaging

- Formed a Messaging Workgroup
- Engaged a public affairs firm to develop messages based upon the Case and Position Statements, other disparities reports, and focus group testing
- Developed, tested, and revised message frames based upon focus group feedback from participants at the ASCO Annual Meeting and the ICC Biennial Symposium
- Developed survey for C-Change members regarding potential calls to action to accompany the message frame
- Presented aspects of all C-Change initiatives that address aspects of disparities at the ICC Biennial Symposium
- Presented a poster on the health disparities case statement and initiatives at the CDC /NCCC Conference

For Goal 2) Geographic Intervention Project

- Formed a Steering Committee and Data Workgroup
- Developed strategic approach for assessment, planning, and intervention
- Developed a methodology and completed an initial analysis of cancer disparities for 50 states
- Developed criteria for narrowing targeted community list and engaging in a successful partnership
- Began community level analysis in Mississippi and in Detroit to explore potential rural/urban, southern/northern sites
- Initiated a survey of membership on local presence, coalition involvement, and data sources

2012 Plans for September – December 2012

For Goal 1) Messaging

- Finalize the message frame and priority calls to action
- Develop a communication and evaluation plan
- Begin implementation

For Goal 2) Geographic Intervention Project

- Complete community-level analysis for Mississippi and Detroit
- Form Community Engagement Workgroup
- Engage community consultant to gather additional information about community assets and challenges
- Assess all available data and determine initial communities to approach

2013 Priorities

For Goal 1) Messaging

- Continue implementation, evaluate, and adapt plan as needed

For Goal 2) Geographic Intervention Project

- Publish Assessment phase findings for use by other organizations, CCC coalitions, and policymakers
- Approach target communities to share findings and assess interest in partnership
- Engage C-Change and local leaders in partnership for community intervention
- Award planning grant(s) for communities to develop a plan with assistance of relevant experts
- Secure national and local partners and other resources to support plan
- Begin plan implementation

#4 Sustaining a Strong National Cancer Workforce

Challenge: The demand for cancer services is projected to exceed the supply of cancer health professionals threatening access and quality across the continuum of research and care.

Goal: Define and pursue a coordinated national strategy for ensuring the capacity and skills of the cancer workforce.

Unique C-Change Approach

1. **Define a National Strategy** - Convene leaders across all disciplines to develop a cohesive and coordinated strategy for the cancer workforce to meet current and future demands for care
    A. Develop a strategy, position statement, and call to action to increase the quantity, quality, and value of the cancer workforce
    B. Seek endorsements from C-Change member organizations
    C. Publish in a professional journal
2. **Pursue Action** - Engage leaders to pursue aspects of the national strategy that they can uniquely affect
    A. Promote adoption of strategy actions by C-Change members and others
    B. Pursue strategy actions uniquely suited to C-Change's capacity
        i. Promote careers in cancer in all disciplines key to comprehensive care
        ii. Leverage role of non-traditional caregivers, "the Careforce"
3. **Advocate** – Support policies benefiting cancer professional education, training, retention, and practice

2012 Milestones through August 2012

- Completed National Strategy and Position Statement
- Hosted webinar to seek endorsements for the National Strategy (26 to date) and promote adoption
- Presented the National Strategy at the CDC /NCCC Conference
- Formed sub-committees to pursue actions: Cancer Career Grant, Careforce Summit
- Released RFP for Cancer Career Promotion Grants , received 30 applications, awarded 3 grants
- Developed initial Careforce Summit plan
- Conducted key informant interviews in preparation for the Summit
- Developed plans to conduct 3 focus groups with members of the Careforce
- Published a manuscript regarding the Pain and Palliative Care Core Competency initiative in the journal of the American Association of Cancer Education
- Presented the Pain and Palliative Care Core Competency initiative at the CDC /NCCC Conference

2012 Plans for September – December 2012

- Secure additional endorsements and submit National Strategy and Position Statement for publication
- Assess the initial progress of Career Promotion grantees
- Host 3 Careforce focus groups (in Washington, DC; Chicago, IL; and a location TBD)

2013 Priorities

- Opportunistically promote the National Strategy
- Host "Careforce" Summit
- Summarize the summit findings and identify unique actions for C-Change and others to take
- Complete Career Promotion Grant implementation and evaluation and disseminate findings to inspire action by others

#5 Assuring Value in Cancer Care

Challenge: A 2009 IOM National Cancer Policy Forum workshop defined challenges and opportunities for improving value in cancer care. Persistent economic pressure in the health sector, debate regarding health reform, differing opinions and definitions for 'value' and means for achieving it add to the challenge

Goal: Improve the quality of life of cancer patients through fully informed, patient/family decisions resulting in significantly increased use of palliative care services and increased length of stay in which patients are enrolled in hospice care.

Current focus:

- **Change practice** to embrace palliative care and hospice care services at appropriate points
- **Create capacity** (personnel, policies, and resources) to support the appropriate delivery of palliative care and hospice care
- **Create demand** for palliative care and hospice care by informing the public about the nature, importance, and benefits of these services

Unique C-Change Approach

1. **Advocacy -** Develop an advocacy agenda to increase the use of palliative care and increase the average length of hospice care
    A. Advocate for the use of palliative care and hospice care services at appropriate points
    B. Advocate for the use of active treatment, if desired, throughout hospice
    C. Advocate for reimbursement for conversations around advanced care planning
    D. Advocate for a national research agenda for palliative care and hospice care

2. **National Conversation -** Change the way the public thinks about and acts regarding palliative care and hospice care
    A. Research the knowledge, values, and beliefs about palliative care and hospice care of underrepresented populations and those with cancer disparities
    B. Create demand for palliative care and hospice care
    C. Work toward common language and definitions for palliative and hospice care
3. **Guidance -** Provide guidance that improves access to and delivery of palliative and hospice care
    A. Promote essential elements of specialized palliative care and hospice care
    B. Develop playbook/call to action that C-Change members organizations can adopt and/or act
4. **Cross-Cutting Efforts**
    A. Scan and map the palliative care and hospice care environments to avoid duplication, inconsistencies, and differences in philosophies, optimize resources, and expand the reach of joint efforts
    B. Engage in the development and execution of other organizations' agendas with regard to palliative care and hospice care
    C. Provide linkages among organizations with similar agendas
    D. Continually assess capacity for palliative care and hospice care services

2012 Milestones through August 2012

- Completed platform and plan development jointly with ASCO and the Advisory Committee
- Created a plan for providing community guidance with consultative support of The Grant Group
- Formed 3 sub-committees: Advocacy, National Conversation, and Guidance
- Presented a poster regarding the case statement and platform for palliative and hospice care at the CDC /NCCC Conference

2012 Plans for September – December 2012

- Develop and pursue initial sub-committee agendas
- The Advocacy sub-committee will:
    - Summarize existing research and data in support of concurrent use of hospice care and active treatment
    - Define specific weaknesses in current policy
    - Begin to define policy solutions based upon new or existing proposals and data
    - Develop a public communication and political strategy to make concurrent use of palliative and hospice with active treatment possible.
- The National Conversation sub-committee will:
    - Engage a consultant to design and administer a public opinion survey regarding the knowledge, values, and beliefs about palliative care and hospice care of underrepresented populations and those with cancer disparities
- The Guidance sub-committee will:
    - Endorse the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines)
    - Promote endorsement and adoption of NCP guidelines by C-Change members
    - Assess opportunities to create incentives/ mandates to implement NCP Guidelines (through JCAHO Certification for hospital-based care and other incentives for community-based care)
    - Recognize C-Change members who adopt and implement NCP Guidelines
    - Finalize community guidance document and adapt for use by CCC coalitions
- The staff will work in collaboration with the Advisory Committee and LiveSTRONG to complete an environmental scan. The scan will help to identify opportunities to avoid duplication, inconsistencies, and differences in philosophies, optimize resources, and expand the reach of joint efforts

2013 Priorities

- Complete planning and pursue implementation of sub-committee plans
- Disseminate community guidance document to CCC Coalitions
- Review Third Edition of the NCP Guidelines

#6 **Comprehensive Cancer Control (CCC)**

Challenge: To continually support progress and improvement in the implementation of state, tribe/tribal organization, and territory comprehensive cancer control plans.

Goal: (1) Actively engage coalitions in the local implementation of C-Change strategies related to research and health system transformation, and (2) Support the collaborative efforts of the CCC National Partners in providing training and technical assistance to coalitions.

Unique C-Change Approach

1. **Strengthen the leadership, knowledge, skills, membership, and resources of coalitions** to achieve their CCC plan goals
   A. Provide technical assistance (TA), tools, and training for low performing coalitions
   B. Provide coalitions with tools from existing and new C-Change initiatives through a series of webinars
   C. Leverage C-Change members' leadership, knowledge, skills, and resources by engaging them to provide on-site technical assistance, lead webinars, and engage C-Change members' local affiliates and chapters in CCC coalitions
2. **Recognize and promote excellence among coalitions and policymakers** by annually awarding an Exemplary Elected Official and CCC Champion for their efforts in progressing CCC Coalition plan priorities and CCC Coalitions (State, Tribe, and Territory coalition), for making a measurable impact in a CCC plan priority
3. **Support activities of the Comprehensive Cancer Control National Partnership** by pursuing collaborative actions and participating in the strategic and operational activities of the partnership

2012 Milestones - Q1

- Developed plan to support coalitions in need of technical assistance (TA)
- Partnered with the American College of Surgeons Commission on Cancer to co-fund TA for 4 coalitions and engaged SHC to provide consulting support
- Approached the Virginia and Mississippi CCC coalitions and secured their interest and commitment to the TA process. Conducted initial conference call with coalition leadership teams to plan initial site visit
- Developed an initial schedule for a webinar series featuring C-Change initiatives
- Hosted a webinar featuring the 2011 CCC Awardees and promoted the 2012 Award Call for Nominations
- Initiated survey of membership presence at the state and local level through chapters, affiliates, and resources
- Presented a poster regarding the Making the Business Case Initiative, the CEO Cancer Gold Standard, and the Toolkit for Engaging Business in CCC Coalitions at the CDC /NCCC Conference
- As part of the National Partnership for CCC, helped plan and implement a workshop for coalitions, which included speakers featuring several C-Change priorities*. The agenda included:
  - Impacting Cancer Survivor's Quality of Life: Pain and Palliative Care Policy Opportunities*
  - Impacting Cancer Disparities: Using Data to Understand Disparities and Shape Local Initiatives*

- Innovative Partners for Change: Systems Change through Businesses as CCC Partner*
- Opportunities to Impact Population Health: Linkages with Primary Care
- Chronic Disease Coordination: A Vision for Now and the Future
- Local Implementation of CCC: Leveraging Community Support to Sustain Coalition Efforts

- As part of the National Partnership for CCC, helping to plan a policy workshop for the PIJ coalitions in 2013

2012 Plans for September – December 2012

- Conduct initial on-site visits with Virginia and Mississippi coalitions and develop action plans
- Approach 2 more CCC coalitions (TBD) regarding TA support to begin planning process
- Host webinar featuring CCC Coalition Business Engagement toolkit for CCC coalition leaders
- Host additional webinars featuring other C-Change initiatives such as the disparities and prevention messaging and messaging tools
- Seek additional member survey responses
- Continue planning efforts for PIJ coalition workshop

Next Steps 2013 Priorities

- Complete TA support for Virginia and Mississippi
- Provide TA support for at least 2 more coalitions
- Host webinar featuring 2012 CCC Award winners and release 2013 Call for CCC Award Nominations
- Co-host PIJ coalition workshop
- Promote C-Change member engagement in CCC coalitions

APPENDIX A – HIPAA DOCUMENTS

THE COSTS OF HIPAA

TO PATIENTS, TO PROGRESS, AND TO THE NATION'S HEALTH

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Abstract

Recent studies including a 2009 Institute of Medicine report have highlighted how the HIPAA Privacy Rule fails to protect privacy and has created significant barriers to research. The purpose of this article is to outline the impact of the HIPAA Privacy Rule on patients and its cost to the research enterprise in terms of time, dollars, and lost opportunities. During this review, we found that HIPAA burdens the research process by deterring patients from participating in research, creating an enrollment bias and translating into research that is not applicable to all populations, perpetuating treatment disparities. Biospecimen data is difficult to re-use, limiting personalized medicine, which directly impacts cancer patients' and their ability to quickly find a treatment that will benefit them and minimize side effects. The limited utility of de-identified data and perceived restrictions on data mining also limit other forms of research including comparative effectiveness research. Further, the protocols required to meet HIPAA privacy standards have subjected clinical trial enrollees to burdensome paperwork and added thousands of hours and hundreds of thousands of dollars to the time and costs of individual studies, taking limited resources away from clinical cancer research. In some trials, insufficient resources to manage these protocols have led to the abandonment of studies all together, undermining the trust that clinical researchers have worked to establish with clinical trial participants. We conclude that actions must be taken to exempt research from the HIPAA Privacy Rule to improve patient privacy protection and improve the economy and efficiency of lifesaving research.

See www.c-changetogether.org/hipaa for full text

HIPAA Issue Summary

Problem Summary The HIPAA Privacy Rule:	**Solution Summary** Create and implement new legislation where:
▪ Burdens patients with additional contacts and paperwork ▪ Perpetuates health disparities through selection bias ▪ Creates barriers to the involvement of children in research ▪ Does little to protect privacy ▪ Slows the research and discovery process ▪ Increases costs and wastes resources ▪ Discourages reuse of information through records based research ▪ Undermines the national investments in Health Information Technology (HIT) ▪ Creates conflicting and duplicative federal regulations ▪ Allows for conflicting states regulations	The use of personally identifiable information (PII) for health research would be permitted outside the constraints of the HIPAA Privacy Rule using data from patients participating in research who actively choose not to opt-out of having their data used for future information-based research purposes if: ▪ PII is deidentified to the extent consistent with the research need ▪ PII is kept in place (rather than duplicated or transferred) to the extent consistent with the research need ▪ PII is subject to best practice security safeguards appropriate to the type of data involved ▪ Standards are enforced by an agency(s) with resources and capabilities in research and security practices ▪ Federal law preempts state regulation of the use of PII for health research Health researchers otherwise complying with these requirements would be free to use PII for information-based health research without a federal requirement for IRB approval if no new data is collected from individuals.

Patient Perspectives

Previous public opinion polls have revealed mixed views on expectations for privacy in information-based health research. The National Health Council recently conducted focus group testing to explore patient and caregiver views on the HIPAA Privacy Rule and its ramifications for medical research. The focus groups involved 59 participants from across country including adult patients, family caregivers of children with severe chronic physical conditions, and family caregivers of adults with chronic mental conditions. Participants were:

- Unaware of the HIPAA privacy rule before the focus groups
- Considered medical research essential to discovery of better treatments and cures
- Saw particular value in records-based research
- Viewed research interests as more important than their own concern over privacy
    - Did not want their name or contact information shared, but wanted their data widely used to advance research
- Saw no need for continual re-authorization
- Expressed anger about the Privacy Rule's effect on research
- Wanted to "fix" the Privacy Rule

National Health Council. The HIPAA Privacy Rule: Exploration of Patients and Caregiver Perspectives. 2012. Funded through NIH RC1 CA146501-01.

HIPAA Advisory Committee – As of 8/24/2012

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David Pugach, JD	American Cancer Society Cancer Action Network
Mary Lee Watts, MPH, RD	American Association for Cancer Research
Robert C. Young, MD	RCY Medicine

C-Change Campaign to Cut Cancer in Half (Working Title)

Key Facts: One half or more of cancer deaths can be prevented by changes in tobacco use, nutrition, physical fitness and affordable early detection; we know from science how to make these changes

Goal: Reduce deaths from cancer by 50% with what we already know will work

C-Change believes that the Nation needs a strong coordinated effort by private businesses, non-for-profit organizations, and government to reduce the risk of cancer through aggressive action at the national, state, and local levels

Overall Strategy: Marshal a concerted new effort on the risk reduction front of the war on cancer

We will use proven ways to change six risks associated with getting cancer. We will:

1. Reduce tobacco consumption
2. Increase physical activity
3. Improve nutrition habits
4. Increase evidence-based screening and early detection
5. Increase proven cancer-preventive vaccinations
6. Increase protection against excessive UV light exposure

Key Approaches:

1. Build a bold new, powerful, sustained, and consistent education and advocacy campaign to reach the public and policy makers for the purpose of driving science based changes that will reduce the risk of cancer in the Nation
2. Engage the Nation's public opinion leaders to support and advocate for policies and programs leading to major national improvements in reducing the risk of cancer

Getty Images North America

C-Change Platform

Evidence-based policies, interventions, and outcomes supported by C-Change

Risk-specific

Reduce tobacco consumption

- Increase the price of all tobacco products, state tobacco taxes, and federal excise taxes on tobacco products
- Use a portion of tobacco tax revenues to provide meaningful support for tobacco control programs
- Support laws prohibiting smoking in public places
- Implement mass media campaigns to raise awareness at national, state, and/or local about tobacco use
- Promote U.S. ratification of the Framework Convention for Tobacco Control (FCTC)
- Build and sustain comprehensive tobacco control programs at the state and local levels
- Strengthen the national infrastructure for tobacco cessation services including support for quit lines
- Promote risk identification and counseling for patients who use tobacco products
- Support strong FDA actions to reduce the death toll from tobacco use

Reduce physical inactivity, poor diet, overweight and obesity

- Implement campaigns promoting physical activity
- Promote community interventions to increase physical activity
- Increase availability of nutritional information in restaurants
- Increase availability in schools of physical activity and healthy foods and eliminate excessive availability of unhealthy foods
- Reduce marketing of unhealthy foods targeting children, adolescents, and youth
- Promote risk identification and counseling for obese and overweight patients

Promote evidence-based screening and early detection

- Promote United States Preventive Services Task Force (USPSTF) recommendations on cancer screening related to breast, cervical, and colorectal cancers
- Educate and inform on the benefits of breast, cervical, and colorectal cancer screening as per USPSTF guidelines
- Educate patients to make fully informed decisions about prostate cancer screening in consult with their physicians

Increase vaccination against viruses that cause cancer

- Make Hepatitis B (HBV) vaccine available for everyone to prevent liver cancer
- Make human papillomavirus (HPV) vaccine available for adolescent girls to prevent cervical cancers
- Increase education on the benefits, risks, and myths associated with the HPV and HBV vaccines

Protect against excessive ultraviolet light exposure

- Promote proven sun-safety behaviors
- Eliminate promotion for tanning beds, particularly toward children and adolescents
- Inspect and regulate tanning beds and services

Cross-cutting

C-Change supports the following changes that cut across multiple risks:

- Promote full utilization of preventive health benefits through employers, private health insurance, Medicaid, and Medicare
- Promote accreditation by businesses under the CEO Cancer Gold Standard ™
- Promote implementation of the U.S Department of Health and Human Services National Prevention Strategy including healthy communities, preventive clinical and community services, empowered individuals, and eliminating health disparities
- Advocate for the federal government to dedicate sufficient funds to key primary prevention and early detection strategies, such as the Prevention Fund and Centers for Disease Control and Prevention (CDC) funding
- Support research to develop more and better ways to reduce the risk of cancer

Preamble

Neither the public, nor policymakers know or base their actions on two key facts: a) one half or more of cancer deaths can be prevented by changes in tobacco use, diet, physical fitness and affordable early detection; and b) we already have the capacity to make these changes given what we know now from science.

It is unacceptable for the Nation to continue to ignore the opportunity to prevent so many new cases of cancer given the large amount of lives and quality of life at stake.

Objectives

C-Change and its members are uniquely situated to take a series of actions to increase public awareness that over one half of all cancer deaths can be prevented and to motivate the public and policy makers to take the steps necessary to give cancer prevention the priority it deserves. To do so, C-Change will develop a campaign and recruit leaders in all three sectors to:

- Have American businesses of all sizes take a leadership role in stimulating action to make cancer risk reduction a priority in their communities broadly, including leading by example with their own workforces.
- Catalyze America's not-for-profit organizations to examine and enhance their advocacy, outreach, and granting agendas to place a priority on and provide leadership in cancer risk reduction.
- Concretely support the position that America's federal government must annually invest substantially in cancer risk reduction efforts and, at a minimum, this amount should not be any less than the current level, used to replace existing risk reduction efforts, or delayed in their commitment and implementation.
- Motivate all leaders, regardless of their sector, to fully support all three of the above objectives to assure a strong, multi-sector approach to change.

Actions

1) Develop a campaign to effectively communicate the core message that over 50% of all cancer deaths can be prevented by taking advantage of what we already know works

a. C-Change staff will work with members and partners to develop core message language that is simple and communicates to the general public that over half of all cancer deaths are preventable.

b. C-Change staff will develop a communications plan *where it will ask* leaders in each of the three sectors (public, businesses, non-profit) to make the commitments *to promote awareness and actions to maximize the potential of cancer prevention.*

2) Start with ourselves

C-Change affiliated leaders will make meaningful commitments to assure their own organizational messages, policies and agendas are consistent with the above objectives.

3) Recruit other leaders

C-Change will work through contacts to develop non-traditional, influential leaders who are willing to lead by example through 1) prioritizing prevention through their own organization and 2) communicating this message to others.

4) Convince the American population

C-Change will execute a non-traditional earned media campaign to convince the American public of the possibility and importance of cancer prevention. Leaders will work through multiple venues to communicate the core message to raise awareness that cancer is preventable and that they can and should do something about it. C-Change staff will serve as a catalyst to create, search for, and connect leaders to communication opportunities.

5) Advocate

At appropriate times, C-Change leaders will aggressively promote messages targeting a specific policy objective that is consistent with the C-Change risk reduction strategy objectives.

a) C-Change and its members will advocate that the federal government dedicate sufficient funds to key primary prevention and early detection strategies, including a commitment not to reduce the size of the current financial commitment to such strategies.
b) C-Change will support federal efforts that promote community based prevention and will reach out to community leaders to promote these policies and programs at both the community and state level.
c) C-Change will work with the private sector to 1) promote the adoption of these policies and programs in the workplace and 2) ask more business leaders to serve as spokespersons, emphasizing the power and importance of primary prevention and early detection and supporting the adoption of these policies and programs in their communities and states.

C-Change Risk Reduction Communications Subcommittee report to the Steering and Policy Subcommittee

The initial goal of this subcommittee is to find a way to communicate the fact that [at least or up to] 50% of cancer deaths can be prevented through six behavior changes, and we already know from science how to make these changes, for the purpose of inspiring American leaders and the entire population to promote evidence-based policies and programs that encourage these behavior changes.

Task 1:
Using current messaging research on these topics and identify specific language to accomplish the above.

Subcommittee conclusions: No research to our knowledge has been done on communicating the above messages to the specific audiences of business, policy maker, non-profit leaders or the general public for the purpose stated above. Using available data, the Subcommittee identified messaging "tips" and relevant messaging language. To be sure the identified language is strong and motivating, minimal message testing will be required (note that this testing will be and not nearly as extensive as previous Ad Council/C-Change work).

Task 2: Come up with a communications plan that will provide platforms for leaders identified by the Leadership Outreach Subcommittee to communicate our messages and tailor the messages for different audiences. The Subcommittee will meet in-person in early July to create a communications plan, and identify the types of resources necessary to execute this plan.

Cancer prevention message TIPS:

Create a sense of urgency

People tune out without a problem/urgency set-up
Consider providing a call to action

Make a connection

1. Messages that empower people are more effective
2. Examples of real people, including kids are most effective, and personalizing to their *own* kids is even better
3. Personal messages are better than abstract ones; personal stories can be effective especially with policy makers
4. Get to know (through background research) the audience to whom you will be communicating

Show the path

1. Provide concrete specific examples to promote local, community health
2. Provide a first step
3. Make the first step an easy one

Dos and Don'ts

Messaging "do"	*Messaging "don't"*
Communicate the importance of personal responsibility (policy makers and public)	Use the word "intervention". Alternatives: Programs, policies, and strategies are easier to understand (policy makers and public)
Use language: "Making healthy choices easier choices" (policy makers and public)	Talk about "Prevention." Assume the general population believes you cannot "prevent" cancer, try "reduce the risk" instead (public)
Challenge conventional wisdom with unexpected facts (public, business and public health leaders across the political spectrum)	Use words: Social determinants of health, health in all policies, disparities, etc. or anything that takes away choice, makes people feel powerless/not empowered in their health (policy makers and public)
Use language: "Prevention is about healthcare vs. sick care" (policy makers and public)	Start with "tax", unpopular and takes away from the empowering frame when communicating with the general population (policy makers and public)
Cite credible organizations like the American Cancer Society when referring to data (public)	Talk about the abstract groups i.e. "healthy communities" (policy makers and public)
Talk about individuals, i.e. healthy "Americans" (policy makers and public)	Talk about short term economic benefits of prevention—in this climate the health argument is stronger (policy makers and public)
Tie the problem to a realistic policy solution (policy makers)	
Use language: "Improving health for ALL Americans" (policy makers and public)	

General:
People believe there are too many recommendations about how to prevent cancer and it is therefore difficult to know which ones to follow

Cancer Prevention Communications Language

Expected knowledge and action

Below are some language ideas broken into "set-up", "message", and "ask". Keep in mind the goal of each in terms of what we want them to "know" and "do" as stated here:

	What we want them to know	What we want them to do
Set-up	This is relevant to their goals and we need them	Keep listening
Message	If we work together we can prevent cancer deaths	Want to work with us; keep listening
Ask	By partnering with C-Change, it will be easy for them to contribute to this important movement	Agree to meet with us; agree to support a specific policy (policy makers)

Language ideas

Set-up	• Your leadership is critical now to prevent this from being the first generation of American kids who live shorter, sicker lives than their parents (concepts: kids, set-up urgency, personal, for everyone) • What is more important – care or caring? Link care to treatment and caring to prevention (concepts: Message Works, for cancer center leader) • Would you like to hear about a unique way to increase your profits? (for business leader) • Did you know that about half of your workforce is at a heightened risk of cancer that will ultimately be treated under your healthcare dollars? (for business leader) • Do you want to learn how to help your constituents have more opportunities that make healthier choices easier choices (for policy makers)
Message delivery	• We can cut cancer deaths in half by using what we already know from science will work to make the healthy choice the easy choice (concepts: unexpected facts, healthy choice is the easy choice, for business and policy and non-profit leaders) • Would you give up two minutes if someone you trusted told you to simply listen to how you could reduce cancer risk for you and your family?(concepts: Message Works, for cancer center leader) • We can support CDC efforts to provide cancer prevention kits for schools and small businesses (for policy maker) • Prevention will encourage employees to be responsible for their own health instead of depending on the employer, and is good for business (for business leader) • You can play a leadership role in your community (name community), improve your workforce, and your bottom line (for business leaders) • It's within our power to create a better prevention and early detection infrastructure, and government and policy leaders should take a leading role in activating these initiatives (for cancer center leaders) • Cancer prevention is a great example of how we can shift to a new emphasis on health outcomes rather than the debate on controlling health treatment/costs.(for policy maker) • All Americans should have the tools and opportunities to make the best possible choices about their health. Yet, over half of deaths from cancer can be traced back to preventable factors.
ASK	• Let's work together to advocate for funds for programs that promote tobacco cessation, provide healthy food options, and increase access to safe, inexpensive physical activity opportunities for ALL American (concepts: specifics, ALL Americans) • Test yourself. Take our quiz and maybe find out some surprising things most people don't know about cancer prevention. Create top ten things people don't know about cancer prevention. • Let's meet to discuss how your voice can make a difference in activating cancer prevention initiatives (cancer center leaders) • Let's discuss how your organization can advocate for prevention as it relates to your mission, while also preserving your priorities (for not-for-profit and cancer center leaders) • Support HR xxx and other legislation that preserves and grows funding for healthy choices that can reduce their risk of cancer (concept: be specific; for policy makers)

Support for Federal Funding for Prevention (June 2012)

Federal funding for prevention: A C-Change priority

Federal funding for prevention has saved lives through programs such as breast and cervical cancer screening and tobacco control. Today, at least half of all cancer deaths are preventable through change in tobacco use, physical activity, nutrition, and screening. C-Change is applying a unique three sector collaborative approach to promote a national shift to cancer risk reduction. As one of the three sectors, C-Change believes that the federal government must make substantial annual investments in cancer risk reduction efforts, and these investment amounts should be no less than the current level, new funds should not be used to replace existing risk reduction efforts, and funds should not be delayed in their commitment and implementation.

FACTS

- *It is within our power to prevent about 50 percent of all cancer deaths* by changes in tobacco use, diet, exercise and screening. [1]
- *Preventable, non-communicable chronic conditions including cancer consume 75% of the total U.S. spending on medical care.* [2] U.S. Health expenditures are about 18% of GDP[3].
- *Current investments in prevention are low*: Only 0.12 percent of the total 2013 HHS President's budget request ($941 billion) is for CDC's Chronic Disease Program ($1.1 billion), [4] the leading U.S. government program to prevent chronic diseases; only 3.1% of the 2.5 trillion health expenditures by government are for public health agencies, [ii] a primary function of which is disease prevention[5]
- A 2011 Institute of Medicine consensus report "For the Public's Health, investing in America's Future", recommends that congress double the current federal appropriation for public health….[6]

Investing in prevention works

- A recent Health Affairs article reports that Cancer deaths fell by 1.1 percent for each 10 percent increase in local public health spending between 1993 and 2005. Infant mortality and deaths from cardiovascular disease and diabetes also declined.[7]

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[1] American Cancer Society. Cancer Facts &Figures 2012. Atlanta: American Cancer Society; 2012.
[2] Center for Disease Control and Prevention. Rising Health Care Costs are Unsustainable. Accessed from: http://www.cdc.gov/workplacehealthpromotion/businesscase/reasons/rising.html on June 21, 2012.
[3] Martin, A.B. et al. January 2012. Growth in US health spending remained slow in 2010; Health share of gross domestic product was unchanged from 2009. *Health Affairs* 31(1): 208-219.
[4] Department of Health and Human Services. Fiscal Year 2013 Budget in Brief: Strengthening Health and Opportunity for all Americans. Accessed from: http://www.hhs.gov/budget/budget-brief-fy2013.pdf on June 21, 2012.
[5] National Association of County and City Health Officials. Public Health Communications Toolkit. Accessed from: http://www.naccho.org/advocacy/marketing/toolkit/factsheets.cfm on June 21, 2012.
[6] Institute of Medicine. 2011. Accessed from: http://www.iom.edu/~/media/Files/Report%20Files/2012/For-the-Publics-Health/phfunding_slides.pdf on May 18, 2012.

- Other research demonstrates that prevention through better behavioral and economic conditions will save 4.5 million lives and save almost $600 billion over the next 25 years. [8]

Sources of federal funding for cancer prevention

Several U.S. agencies such as the National Cancer Institute, the Food and Drug Administration, and the Health Resources and Services Administration invest in cancer prevention efforts. The largest and most direct sources of federal funding for cancer prevention, however, are the CDC and the Prevention Fund.

Centers for Disease Control and Prevention (CDC)

Federal discretionary funds to the CDC are a primary source of funding for prevention. CDC supports state and local health departments, health promotion efforts in schools and workplaces, community programs, research, and more. More than 70 percent of the CDC's budget supports state and local health organizations, agencies, and academic institutions.[9] Specific CDC programs for cancer and chronic disease prevention include:

- Assistance for state/tribe/territory Comprehensive Cancer Control Coalitions
- Communications campaigns such as *Screen for Life*, which informs those age 50 and older about the importance of regular colorectal cancer screening tests
- Tracking cancer trends and improving surveillance
- The National Breast and Cervical Cancer Early Detection Program, which provides access to screening for underserved women throughout the country, territories, and tribes provided over 500,000 screens in 2010[10]
- Tobacco control efforts including resources to coordinate tobacco prevention and cessation activities including the 2012 *TIPS from Former Smokers* campaign which led to a 130% increase in national quit line calls in the first week it aired.
- Promoting improved nutrition, physical activity, and obesity through resources for state programs, surveillance, applied research, and partnership development

Prevention and Public Health Fund

The Prevention and Public Health Fund (PPHF) is the first mandatory funding stream dedicated to disease prevention and early detection. During the Patient Protection and Affordable Care Act (ACA) discussions this piece had bipartisan support. Whatever happens to the ACA now we need to make sure that these historic funding levels are at least sustained.

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[7] Glen P. Mays and Sharla A. Smith. Evidence Links Increases in Public Health Spending to Declines in Preventable Deaths. Health Affairs 30, no8 (2011).

[8] Bobby Milstein, Jack Homer, Peter Briss, Deron Burton and Terry Pechacek. Why Behavioral and Environmental Conditions are Needed to Improve Health at Lower Costs. Health Affairs, 30, no5, (2011): 823-832.

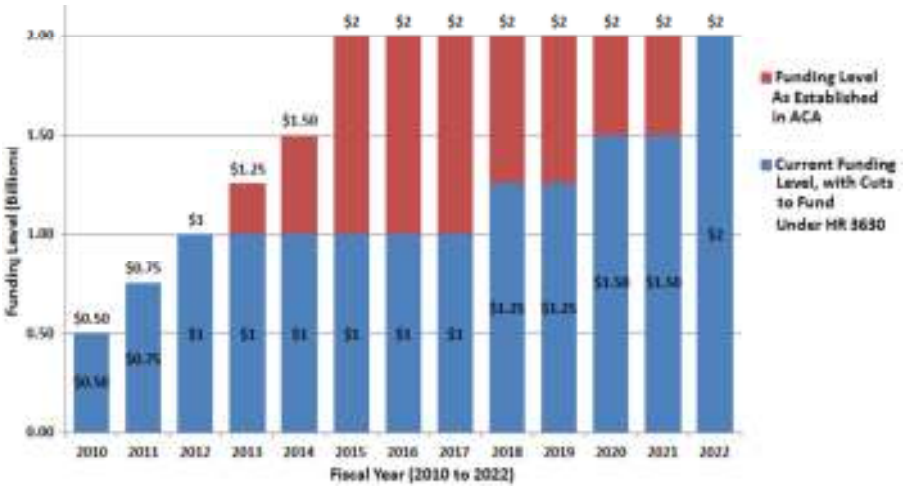
[9] American Public Health Association. Get the Facts: Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). Accessed from http://www.apha.org/NR/rdonlyres/57C7B13D-F88C-453B-807A-8655C5106E2D/0/CDCHRSA.pdf 5/16/2012 on May 18, 2012

[v] Department of Health and Human Services Fiscal Year 2013. Accessed from: http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations_budget_form_pdf/FY2013_CDC_CJ_Final.pdf on June 21, 2012.

[10] Center for Disease Control and Prevention. National Breast and Cervical Cancer Early Detection Program (NBCCEDP). National Aggregate. Accessed from: http://www.cdc.gov/cancer/nbccedp/data/summaries/national_aggregate.htm on June 21, 2012.

- By law the PPHF is required to "provide for expanded and sustained national investment in prevention and public health programs to improve health and help restrain the rate of growth in private and public health care costs"
- In 2011, almost 20 percent of the $750 million PPHF allotted went to Community Transformation Grants, for "promoting healthy lifestyles, especially among population groups experiencing the greatest burden of chronic disease." 2011 Community Transformation Grants were awarded to 29 Large Counties, 10 States (to serve the entire state), 14 States minus their Large Counties, 7 Tribes, and 1 Territory. These grants support cancer prevention through strategies promoting tobacco-free living, active living and healthy eating, quality clinical and other preventive services, and healthy and safe physical environments
- Other 2011 PPHF allocations include State Chronic Disease Prevention grants, tobacco media campaigns and cessation services, and workplace wellness programs
- In 2013 the PPHF is expected to support hundreds of thousands of breast and cervical cancer screenings[v]

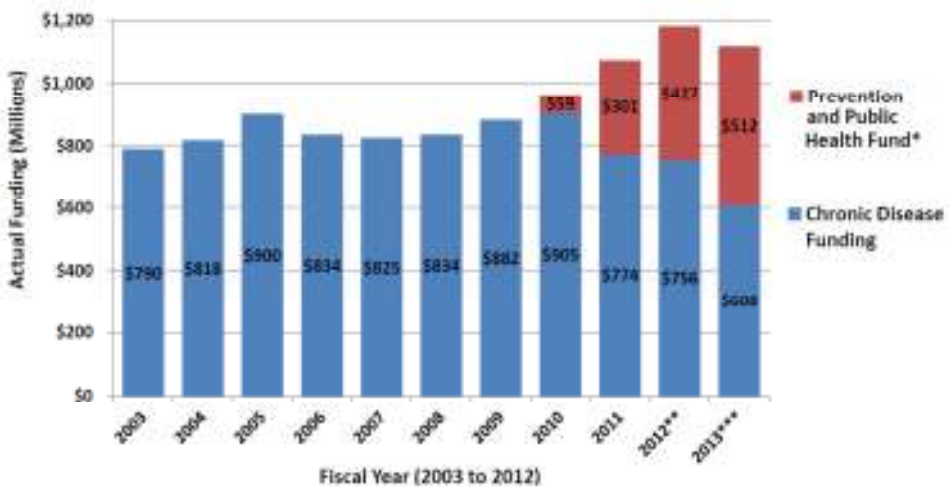
Prevention and Public Health Fund Allocation FY (2010-2022): Current funding under P.L 112-96 vs. established under the Affordable Care Act[viii]



PROBLEM: Prevention funds are decreasing

Because CDC's budget is allocated by Congress every year, available amounts may vary year to year. The ACA's historic provision for mandatory prevention funding through the PPHF has the potential to mitigate this problem by providing a guaranteed funding stream for prevention that allows for long-term strategic execution of prevention programs. However, controversy about the Affordable Care Act and the current economic environment has contributed to frequent threats to investments in disease prevention. 2012 threats include:

CDC Chronic Disease Funding FY 2003-



*FY 2010-2012 CDC values are supplemented by the Prevention and Public Health Fund
** FY2012 value represents the HHS spending plan numbers for FY2012
*** FY2013 is based on the President's Budget Request
Updated 3/12/2012

- The "Sequester Replacement Reconciliation Act" (HR 5652) voted by the house, threatened to eliminate the PPHF (May 2012)
- The House "Interest Rate Reduction Act" (HR4628) threatened to eliminate the PPHF to pay for student loans (April 2012), but was ultimately rejected
- The Middle Class Tax Relief and Job Creation Act of 2012 (HR 3630), signed into law (February 2012), reduced the Prevention and Public Health Fund by $6.25 billion over 10 years to temporarily extend unemployment benefits and avert a planned Medicare payment cut to physicians through Dec. 31 2012
- The 2013 President's budget request represents an 19.6 percent decrease in CDC Chronic Disease funding compared to planned spending in 2012[11]

WHAT CAN C-CHANGE MEMBERS DO?

- Advocate that the federal government dedicate sufficient funds to proven primary prevention and early detection strategies
- Ask your constituents to advocate that the federal government dedicate sufficient funds to proven primary prevention and early detection strategies
- Ask your legislators to support the full amount of the Prevention Fund to be used for its stated purpose
- Support the federal government in promoting community based prevention and reach out to community leaders to promote these policies and programs at both the community and state level

[11] Trust for America's Health. CDC Chronic Disease Funding Chart. Accessed at http://healthyamericans.org/health-issues/wp-content/uploads/2012/03/Funding-Charts-PPHF-CDC-Chronic-3-12-121.pdf on May 18, 2012

Risk Reduction Advisory Committee – As of 8/24/2012

Leader and/or Designee	Organization
Matthew L. Myers, JD, Chair	Campaign for Tobacco-Free Kids
Carolyn "Bo" R. Aldige	Prevent Cancer Foundation
Carolyn Angeleri Ricci	Avon Foundation for Women
John E. Arradondo, MD, MPH	Volunteer State Medical Association
Dileep G. Bal, MD, MPH	Department of Health, State of Hawaii
Alan J. Balch	Preventive Health Partnership
Anna D. Barker, PhD	Arizona State University
Georges Benjamin, MD, MPH	American Public Health Association
Jimmy Boyd	Men's Health Network
Tim Byers, MD, MPH	University of Colorado Cancer Center
Larry Cohen, MSW	Prevention Institute
Peggy Conlon	Advertising Council, Inc.
Robert T. Croyle, PhD	National Cancer Institute
Dennis M. Deapen, DrPH	Keck School of Medicine, University of Southern California
John N. Dornan, Jr.	CEO Roundtable on Cancer, Inc.
Lloyd K. Everson, MD	US Oncology-McKesson
Leslie S. Given, MPA	Strategic Health Concepts
Robert J. Gould, PhD	Brodeur Worldwide
Cheryl G. Healton, DrPh, MPA	LEGACY | For Longer Healthier Lives
Philip Huang, MD, MPH	Austin/Travis County Health and Human Services Department
Elmer E. Huerta, MD, MPH	Prevencion, Inc.
Marc Hurlbert, PhD	Avon Foundation
Judith Salmon Kaur, MD	Mayo Clinic Comprehensive Cancer Center
Stephen Kindred, MD, MPH	State Farm Insurance Companies
Sara Koka, MPH, MS	Association of State and Territorial Health Officials
Charles E. Kupchella, PhD	University of North Dakota
Jeffrey Levi, PhD	Trust for America's Health
Jerold Mande	U.S. Department of Agriculture
Keith Mason	American Heart Association
Peter Melnyk	
Andy Miller, MHSE, MCHES	LIVESTRONG
Martin J. Murphy, Jr., PhD, DMedSc	CEO Roundtable on Cancer, Inc.
Marcus G. Plescia, MD, MPH	Centers for Disease Control and Prevention
Scott Ratzan, MPA, MD	Johnson & Johnson
Sheila Ross	Lung Cancer Alliance
Josh Schafer	Astellas
Anthony Signorelli	Advertising Council, Inc.
Robert Smith, PhD	American Cancer Society
Cathy Trzaskawka	Endo Pharmaceuticals
Richard Wender, MD	Thomas Jefferson University [AAP]
Faye Wong, RD, MPH	Centers for Disease Control and Prevention
Matthew Zachary	I'm Too Young For This! Cancer Foundation
David A. Zauche	Partnership for Prevention

Risk Reduction Steering and Policy Subcommittee

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Robert J. Gould, PhD	Brodeur Worldwide
Cheryl G. Healton, DrPh, MPA	LEGACY | For Longer Healthier Lives
Jeffrey Levi, PhD	Trust for America's Health
Marcus G. Plescia, MD, MPH	Centers for Disease Control and Prevention
Scott Ratzan, MPA, MD	Johnson & Johnson
Anthony Signorelli	Advertising Council, Inc.

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Sana Chehimi, MPH	Prevention Institute
Galen Cole, PhD, MPH	Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion
Robert J. Gould, PhD	Brodeur Worldwide
Lynn Hanessian	Edelman
Bradford W. Hesse, PhD	National Cancer Institute
Wendi Klevan	American Cancer Society
Laura Segal	Trust for America's Health
Anthony Signorelli	Advertising Council, Inc.

Risk Reduction Leadership Outreach Subcommittee

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Carolyn "Bo" R. Aldige	Prevent Cancer Foundation
Dileep G. Bal, MD, MPH	Department of Health, State of Hawaii
Jimmy Boyd	Men's Health Network
Julia Cartwright	LEGACY | For Longer Healthier Lives
John N. Dornan, Jr.	CEO Roundtable on Cancer, Inc.
Paul Handel, MD	Health Care Service Corporation
Cheryl G. Healton, DrPh, MPA	LEGACY | For Longer Healthier Lives
Marc Hurlbert, PhD	Avon Foundation
Judith Salmon Kaur, MD	Mayo Clinic Comprehensive Cancer Center
Stephen Kindred, MD, MPH	State Farm Insurance Companies
Charles E. Kupchella, PhD	University of North Dakota
James Marks, MD, MPH	Robert Wood Johnson Foundation
Keith Mason	American Heart Association
Electra Paskett	Ohio State University
Susan L. Polan, PhD	American Public Health Association
Josh Schafer	Astellas
William J. Todd	Georgia Tech- College of Management
Cathy Trzaskawka	Endo Pharmaceuticals

APPENDIX C – DISPARITIES DOCUMENTS

Messages & Messaging Tools

Encourage decision makers to promote health by creating and supporting policies that benefit all constituents, especially disparate populations.

UNIQUE C-CHANGE ACTION: Develop audience-specific messages to advance the notion that cancer health disparities affect everyone and exact a substantial toll on society in terms of:

- Premature death ($193B)
- Lost productivity ($471M)
- Medical care costs ($2.3B)

C-Change's Societal and Economic Impact of Cancer Health Disparities Case Statement, Disparities Position Statement, Robert Wood Johnson Foundation's guidance document, *A New Way to Talk about the Social Determinants of Health,* other national research are being used to develop messages.

See http://c-changetogether.org/disparities and ttp://www.rwjf.org/files/research/vpmessageguide20101029.pdf

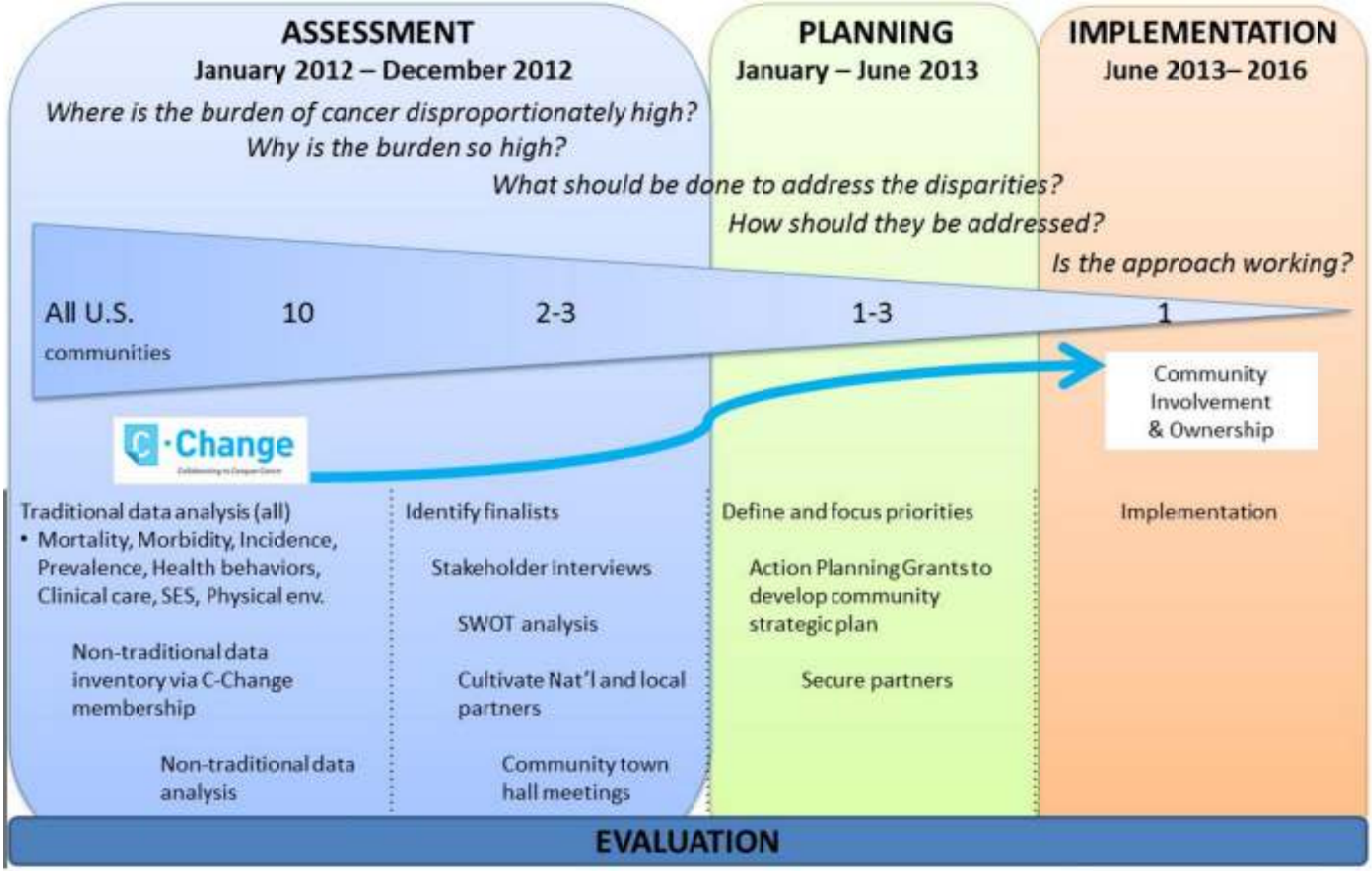
Message Frames under Consideration

Health starts long before illness. What happens in our homes, schools, jobs and communities has a strong impact on how likely it is for a person to suffer from a preventable cancer.

All Americans should have the tools and opportunities to make the best possible choices about their own health. Yet, more than half of deaths from cancer can be traced back to preventable factors.

Americans who are a part of the medically underserved, low income or minority populations bear an unequal burden of suffering from cancer, far beyond what genetics would explain. Better access to care is part of the solution, but other factors matter.

It is within our power to create better research, prevention, screening, and treatment infrastructure to tackle this problem. Leaders in business, government, and our communities must take a leading role in activating these initiatives.


ASSESSMENT
January 2012 – December 2012
PLANNING
January – June 2013
IMPLEMENTATION
June 2013– 2016
Where is the burden of cancer disproportionately high?
Why is the burden so high?
What should be done to address the disparities?
How should they be addressed?
Is the approach working?
All U.S. communities
10
2-3
1-3
1
C-Change
Community Involvement & Ownership
Traditional data analysis (all)
• Mortality, Morbidity, Incidence, Prevalence, Health behaviors, Clinical care, SES, Physical env.
Non-traditional data inventory via C-Change membership
Non-traditional data analysis
Identify finalists
Stakeholder interviews
SWOT analysis
Cultivate Nat'l and local partners
Community town hall meetings
Define and focus priorities
Action Planning Grants to develop community strategic plan
Secure partners
Implementation
EVALUATION

Implementing a National Cancer Health Disparities Strategy
Geographic Intervention Demonstration Project

Approach for Community Selection & Intervention

C-Change will demonstrate the impact of a multi-sector effort in communities experiencing a higher cancer burden by leveraging the combined strengths of C-Change's unique membership. C-Change will engage key community leaders, stakeholders and advocates to intervene in select U.S. communities with disparities in an effort to address several key questions:

1. *Where is the burden of cancer disproportionately high?*
2. *Why is the burden so high?*
3. *What should be done to address the disparities?*
4. *How should they be addressed?*

The resulting assessment, planning, intervention, and evaluation efforts will be documented in detail to promote translation into other communities and sustainability of the overall effort.

Project Goal:
Create a multi-sector model for intervention in a defined geographic area to reduce cancer disparities that can be translated into other communities. This Geographic Intervention Project will:

- Translate C-Change's position statement on health disparities into action.
- Demonstrate that a multi-sector intervention is possible and effective.
- Be based upon data and evidence-based actions, but not be portrayed as a research project.
- Contribute to national disparity-reducing efforts by leveraging C-Change's unique multi-sector membership.
- Recognize limited resources in the context of great need.
- Engage ready and willing community partners.
- Require a commitment to sustainability (5-10 years) from all parties (community, C-Change and members' organizations).
- Maintain transparency.
- Be documented for future distribution and promotion within and beyond the C-Change membership to encourage translation in other communities.

Approach:
Initially, C-Change will engage with one community. This investment decision will be guided by the following questions and vetting process

1. **Where is the greatest need? [12].**
    a. Use traditional data sources to perform an analysis of all states to identify *the greatest cancer burden* at the state level.
        - Demographic data (Census)

[12] The Steering Committee originally defined need as "communities experiencing premature death from cancer." Since this data is not readily available, an alternative model was developed using data that was readily available and stable across geography that incorporates demographic characteristics, risk factors, disease incidence, stage of diagnosis, and mortality.

- Risk factor data (BRFSS)
- Incidence data (State Cancer Registry)
- Mortality data (State Vital Records)

b. With a narrowed list of states (5-10), perform an analysis to identify the greatest cancer burden at the county / county –cluster level using proprietary data obtained from C-Change members, non-traditional data, and publically available data sources such as:
   - Community Commons - http://www.communitycommons.org
   - RWJ County Health Rankings - www.countyhealthrankings.org, United
   - Health Care's Health in Number - http://www.healthinnumbers.com)

2. Can C-Change leverage its multi-sector membership in this community?

a. Survey members to assess the presence of their members, chapters, and affiliates near the targeted communities
   - Assess interest of C-Change members' organizations
   - Leverage member contacts with community leaders/advocates

b. Link with NCI funded projects geared towards addressing cancer health disparities in communities

c. Link with State CCC Coalition to assess interest and alignment of CCC plan priorities with community needs

d. Secure commitment to sustain the effort (5-10 years) to realize positive outcomes

3. Is the community able and willing to work together?

a. Obtain additional insights about the community needs and assets through site visits, focus groups, and town hall meetings.

b. Assess presence of active community advocates/ leaders

c. Determine community willingness to collaborate with C-Change and lead partners

4. Will this effort be successful in a manner that will translate to other communities?

a. Consider the community's relative chances for successful outcomes (are the problems and potential solutions of this community so unique that the model can't be translated?)

b. Assess likelihood of C-Change members identifying with the community/demonstration and being willing to translate leadership into other communities

c. Assess community's commitment to continuously and thoroughly document lessons learned for translation of the process in other communities

Highlights of 50 State Analysis

Defining the Burden of Cancer
The C-Change Project

Prepared by:

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Cancer Prevention and Control Program
March 13, 2012
(This project is supported by NAACCR)

Methodology (Data continued)

- Five year risk factor rates (2005-2009) were obtained from the CDC BRFSS.
- The risk factor variables obtained from the CDC BRFSS include:
  - **smoking** (the % of the population in each state that currently smoke)
  - **mammography screening** (the % of women in each state age 50+ who have had a mammogram in the past two years)
  - **colorectal cancer screening** (the % of the population in each state age 50+ who have ever had a colonoscopy or sigmoidoscopy)
  - **PAP test screening** (the % of women in each state age 18+ who have had a PAP test in the last 3 years)
  - **Obesity** (the average BMI for each state)
  - **Exercise** (the % of the population in each state who exercise at least once a week)
  - **Diet** (the % of the population in each state that eat 5 fruits and/or vegetables daily)
- **Two year incidence rates** (2008-2009) for lung, breast, colorectal and cervical cancer and the **proportion of cases with late stage diagnosis** for colorectal and breast cancer were calculated using data from the NAACCR CINA data file.
- Data from Kansas and Vermont were excluded.
- **Five year mortality rates** (2005-2009) were also calculated from data supplied by NAACCR.
- **Five year** (2006-2010) **poverty rates** (the proportion of people in each state living below the federal poverty index) and **literacy rates** (the proportion of the population in each state with a college degree) were obtained from the U.S. Census Quick Facts website.

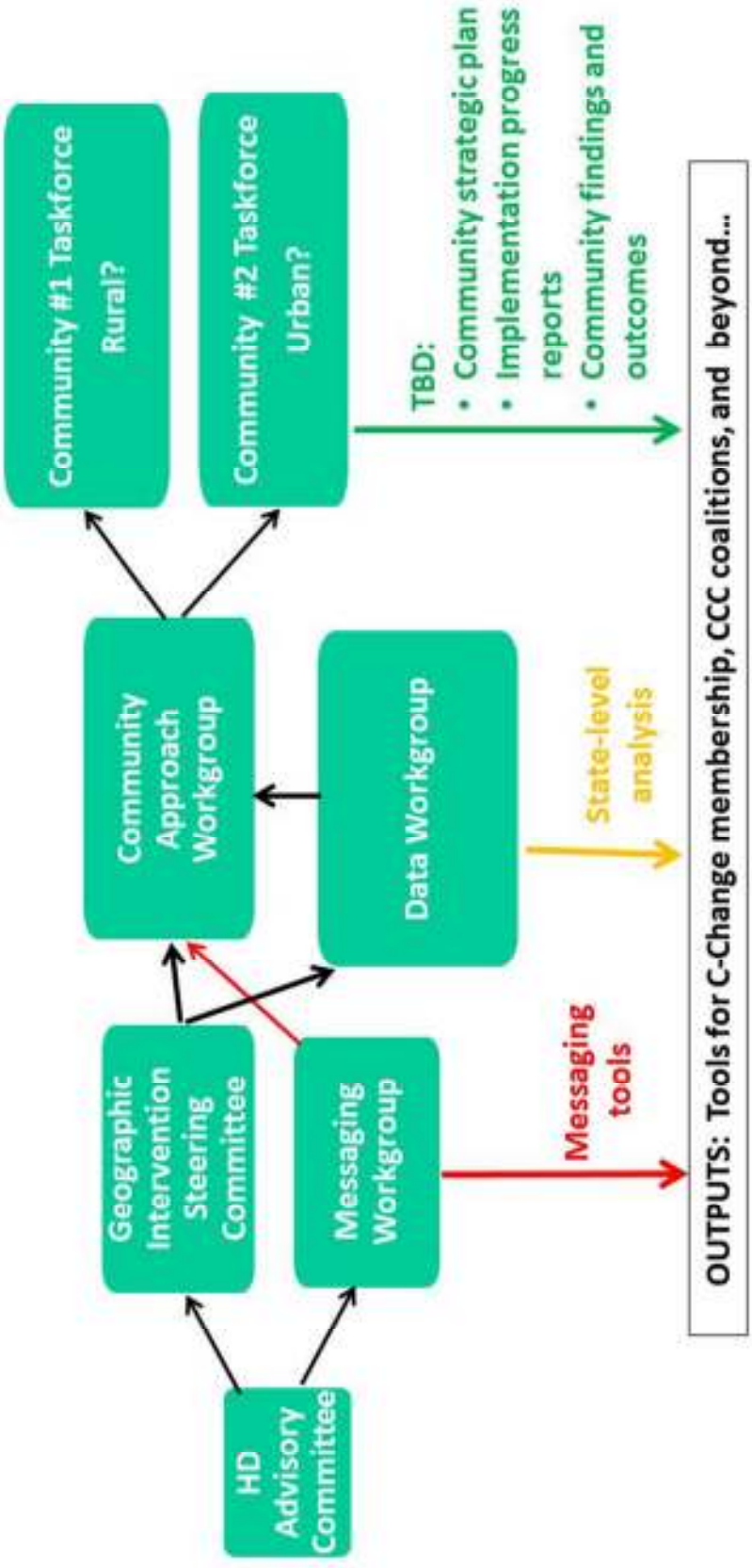
Colorectal Cancer Rank for States 2008-09

State	Smoking		Exercise		College Ed+		Colonoscopy		Incidence		Mortality		Overall
	%	Rank	%	Rank	%	Rank	%	Rank	Rate	Rank	Rate	Rank	Index
Mississippi	23.7	6	68.0	1	19.5	3	53.5	2	53.8	2	24.7	1	8
Louisiana	22.2	11	69.5	4	20.9	5	51.2	1	53.6	3	23.7	3	14
West Virginia	26.3	2	70.7	8	17.3	1	54.1	5	52.4	6	22.4	5	20
Oklahoma	25.2	3	69.4	3	22.6	9	53.5	3	48.0	16	21.6	13	37
Kentucky	27.2	1	69.5	5	20.3	4	61.4	30	57.1	1	23.5	4	38
Alabama	23.0	8	70.2	6	21.7	6	57.1	14	52.1	8	21.5	15	44
Arkansas	22.7	9	70.6	7	19.1	2	54.0	4	45.4	26	22.0	8	44
Indiana	24.9	4	73.7	11	22.4	8	57.9	18	49.1	14	21.8	10	50
Illinois	20.1	19	75.5	22	30.3	37	57.4	17	52.6	5	22.0	7	55
Nebraska	19.0	29	76.8	27	27.7	31	55.1	10	50.7	12	22.2	6	57
Nevada	22.2	12	73.9	12	21.8	7	55.5	11	45.1	27	21.5	14	62
Tennessee	23.7	7	69.4	2	22.7	10	57.9	19	47.3	21	21.0	17	63
Pennsylvania	21.5	15	75.3	20	26.4	26	60.7	29	53.2	4	21.7	12	65
Ohio	21.7	14	74.6	17	24.1	13	59.0	22	47.6	18	21.8	11	66
Alaska	22.6	10	78.1	34	27.0	28	56.6	13	52.3	7	20.1	24	68
Missouri	23.8	5	74.3	15	25.0	17	59.6	24	49.1	15	20.8	18	69
New Jersey	16.7	42	72.9	10	34.6	44	58.5	21	49.4	13	21.9	9	75
North Dakota	19.5	25	76.0	24	26.3	25	57.2	16	51.5	10	19.7	26	77
Iowa	19.5	23	76.3	25	24.5	15	59.8	27	51.2	11	20.6	19	78
South Dakota	19.0	28	75.9	23	25.3	18	59.3	23	47.0	22	20.2	23	91
Wyoming	20.9	18	77.5	32	23.6	11	54.4	6	41.9	40	19.5	27	93
Texas	18.7	31	72.0	9	25.8	20	56.2	12	43.5	36	19.2	31	99
Montana	18.6	32	78.7	38	27.9	32	54.8	8	45.5	25	18.3	37	104
South Carolina	21.4	16	74.2	14	24.0	12	62.6	32	41.9	41	20.2	22	109
Georgia	19.7	22	75.3	19	27.2	29	59.7	26	44.6	33	19.5	29	111
New York	18.5	33	74.0	13	32.1	41	64.8	35	47.6	19	19.4	30	113
Hawaii	16.5	45	80.8	44	29.4	34	57.2	15	51.9	9	16.0	48	113
Maine	19.5	24	78.5	37	26.5	27	68.5	43	47.5	20	20.3	21	113
North Carolina	21.7	13	75.0	18	26.1	23	64.3	34	44.9	30	18.9	32	114
Washington DC	17.3	41	78.7	39	49.2	49	66.7	39	44.8	31	24.3	2	115
Michigan	21.1	17	77.0	29	25.0	16	67.4	40	43.6	35	20.3	20	116
New Mexico	19.9	21	77.2	30	25.5	19	54.4	7	38.9	47	17.9	40	117
Florida	19.3	27	74.4	16	25.9	22	61.6	31	43.4	37	18.6	34	124
California	14.3	48	76.9	28	30.1	36	58.5	20	44.6	32	17.7	42	131
Idaho	17.4	40	79.2	41	24.3	14	54.9	9	40.6	45	16.9	46	132
Delaware	19.5	26	77.4	31	27.7	30	71.4	49	45.0	29	19.9	25	132
Maryland	16.7	43	76.7	26	35.7	46	69.1	45	43.2	38	21.2	16	137
New Hampshire	18.2	34	79.4	42	32.9	42	67.9	42	46.3	23	18.5	36	140
Massachusetts	16.7	44	78.3	36	38.3	48	68.9	44	46.1	24	18.8	33	144
Virginia	18.8	30	78.0	33	33.8	43	67.6	41	41.9	42	19.5	28	146
Rhode Island	17.7	38	75.4	21	30.3	38	69.3	47	44.6	34	18.5	35	148
Wisconsin	19.9	20	79.7	43	25.8	21	65.7	38	40.7	44	18.2	39	149
Oregon	17.6	39	82.2	47	28.6	33	63.8	33	42.2	39	18.3	38	150
Arizona	18.0	36	78.2	35	26.3	24	60.4	28	36.0	48	17.1	44	152
Connecticut	16.1	47	79.0	40	35.2	45	69.1	46	47.9	17	17.0	45	152
Colorado	18.2	35	82.3	48	35.9	47	59.6	25	40.0	46	17.5	43	157
Minnesota	17.8	37	83.8	49	31.4	40	69.6	48	45.1	28	17.8	41	159
Washington	16.4	46	81.8	46	31.0	39	65.0	36	41.8	43	16.6	47	170
Utah	10.4	49	81.1	45	29.4	35	65.1	37	34.2	49	14.5	49	178

Summery of top ten states with the highest burden for each type of cancer

Lung	Breast	Colorectal	Cervical
Kentucky	Mississippi	Mississippi	Arkansas
West Virginia	Arkansas	Louisiana	Louisiana
Mississippi	Oklahoma	West Virginia	Oklahoma
Tennessee	Louisiana	Oklahoma	West Virginia
Oklahoma	West Virginia	Kentucky	Mississippi
Arkansas	Alabama	Alabama	Texas
Indiana	Texas	Arkansas	Alabama
Alabama	Kentucky	Indiana	Kentucky
Louisiana	Nevada	Illinois	Nevada
Missouri	Tennessee	Nebraska	Wyoming

Geographic Intervention Demonstration Project – Committee and Outputs



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APPENDIX D – WORKFORCE DOCUMENTS

A National Strategy to Strengthen the Cancer Workforce: Position Statement and Call to Action

Executive Summary

No national strategy for strengthening the cancer workforce exists to address the growing demand for cancer services and growing shortages of cancer professionals. Patients with cancer are increasingly experiencing delays in diagnosis, treatment, and coordinated follow up as a result of the strained workforce. C-Change developed a national strategy that summarizes the challenge, outlines solutions, and calls for needed action by policymakers, educators, institutional leaders, and the public. The quantity, quality, and organization of the cancer workforce must be addressed in a coordinated approach to prevent, diagnose, and halt disease as early as possible to have maximal benefit to patients.

About C-Change

C-Change is the only organization that assembles the Nation's cancer leaders from the private, public, and not-for-profit sectors and from across the cancer continuum— from prevention, early detection, treatment, to palliative care and survivorship. The mission of C-Change is to eliminate cancer at the earliest time possible by leveraging the expertise and resources of its members. The cancer workforce shortage is one challenge that C-Change's members identified as an important priority for collaborative action by its diverse membership.

CHALLENGE

The demand for cancer services is projected to exceed the supply of cancer professionals threatening access to care for people at risk for and living with cancer.

Definition of the Cancer Workforce

Broader than just oncologists and other oncology specialists, the cancer workforce includes an extensive team of health professionals, reflecting the complexity of the disease and the life-long duration of treatment and surveillance that can last from weeks to decades. This team includes many professional disciplines (e.g. physicians, nurses, social workers, pharmacists, researchers, public health workers, cancer registrars) who are oncology specialists, as well as other specialists, and primary care providers. The team also includes non-traditional caregivers (e.g. lay patient navigators, family caregivers, volunteers). Together, they all play a role in cancer through research, prevention, early detection, treatment, survivorship, surveillance, and end of life care.

Cancer Workforce Shortages

Because the cancer workforce is broader than a single discipline or specialty, no single statistic defines the challenge – a gap in the supply of professionals to meet the demand for care. However, viewed in aggregate, the statistics below illustrate a significant and worsening challenge driven by an aging population and increased access to care.

- The current physician shortage is approximately 8% and is projected to be greater than 20% in 2025[13]
- The supply of oncologists is predicted to increase by only 14% by 2020, creating a shortage of 2,500 to 4,080 oncologists[14]
- More than 20% of the U.S. population lives in areas deemed by the federal government as health professional shortage areas without access to adequate medical care[15]
- One-third of critical access hospitals lack a surgeon living in the county[16]
- Currently, the U.S. has approximately 4,400 hospice and palliative medicine physicians, but 6,000 to 18,000 are needed to meet the gap between supply and demand[17]
- By 2020, the shortage of registered nurses will be greater than 1 million[18]
- Only 33,000[19] of 120,000 registered nurses who specialize in oncology[20] are certified
- The social work labor force is older than most professions, with nearly 30% of licensed social workers over the age of 55[21]
- Eighty-five percent of all healthcare practice social workers work in metropolitan areas, while only two percent practice in rural areas[22]
- 250,000 more public health workers will be needed by 2020[23]
- By 2015, 81,000 additional clinical laboratory technologists will be needed to replace retiring staff and another 68,000 to fill newly created positions[24]
- While 25% of the U.S. population is comprised of African Americans, Hispanics, and Native Americans, medical training programs are comprised of fewer than 7% of underrepresented minorities[25], and only 16.8% of registered nurses identify as Non-White or Hispanic[26]

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Impact of Cancer Workforce Shortages

With existing and projected shortages, the current and worsening impact to individuals at risk for and living with cancer is significant:

- Delays in diagnosis, possibly at later stages of disease
- Longer wait times to be seen by a professional
- Delays in treatment
- Care provided by less experienced professionals
- Fragmentation of services
- Less frequent interaction of clinical and supportive services
- Delays in the evaluation and management of symptoms
- Worsening health disparities
- Decreased clinical trial enrollment

The cumulative effect of limited access and delays erodes the quality of coordinated, transdisicplinary care, making it an infrequent luxury rather than the standard of care.

SOLUTIONS

C-Change's vision of the solution to the cancer workforce challenge is multi-faceted. The cancer workforce "pipeline" for recruiting, educating, training, and retaining professionals across disciplines, the continuum of care, and geography, has many points of influence and control. Therefore, the leadership and resources required to improve it are diffuse. The guiding principles transcend the pipeline and encourage coordinated effort.

Guiding Principles

C-Change believes the following guiding principles should drive a coordinated national strategy to expand the capacity, strengthen the skills, and optimize the system to support patients, families, and teams of cancer professionals.

Increase Quantity – *Recruit, retain, and support re-entry of cancer professionals to expand the capacity of the workforce*

1) Cancer professions need to be aggressively promoted as rewarding, stable, and important careers.
2) Students and professionals need to be retained by supporting their success and satisfaction.

Increase Quality - *Train and retrain cancer professionals to strengthen their knowledge and skills*

3) Cancer professionals must be better prepared with the needed knowledge and skills to meet the health, cultural, and informational needs of the populations they serve.
4) Cancer professionals must maintain competency and be prepared to lead within the team, organization, community, and system in which they work.

Improve Value - *Optimize the role and organization of cancer professionals to realize the full value of the workforce*

5) Cancer professionals should be individually supported to apply their entire scope of practice.
6) Cancer professionals should be organizationally supported to leverage their time, talent, and distribution.

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Needed Actions

Keeping in mind the numerous points of influence and control in the cancer workforce "pipeline," C-Change believes that the following complementary actions need to be taken in accordance with the guiding principles.

Increase Quantity - *Recruit and retain cancer professionals to expand the capacity of the workforce*

- Promote health/cancer careers from elementary through high school
- Provide internships for high school and college students
- Include general cancer education as part of health literacy into elementary and high school level curricula to educate consumers at an early age
- Expand scholarship and loan forgiveness programs
- Mentor college students in research and health careers to consider specialization in oncology
- Provide accessible training and career opportunities for individuals re-entering the workforce or changing careers (e.g. empty nesters, discharged military personnel)
- Establish career retention programs (e.g. clinical ladders, flexible work arrangements)
- Create more incentives to encourage practice in underserved areas
- Streamline visa requirements for foreign-trained health professionals
- Recruit and retain ethnically and culturally diverse professionals
- Develop minority mentoring programs (e.g. with minority student and health professional associations)
- Recruit and retain multi-lingual professionals
- Leverage technology to provide distance learning programs and provide remote care support

Increase Quality - *Train and retrain cancer professionals to strengthen their knowledge and skills*

- Promote cancer specialty certification among all health professionals
- Improve the competency of non-oncology health professionals by infusing cancer-focused coursework into curricula for all health disciplines
    - Emphasize cancer prevention and early detection
    - Emphasize pain management, palliative care, and end-of-life care
- Create incentives for organizations to create and sustain a culturally relevant workforce
- Prepare healthcare professionals with needed skills in technology, team practice, and lifelong learning
- Maximize health information technology to support patient safety, care coordination, and best practices
- Improve the competency in cancer care for non-traditional healthcare providers (e.g. community health workers, volunteers)
- Improve patient and caregiver education, including teaching self-advocacy skills, to help patients navigate the care process and participate as informed consumers

Improve Value - *Optimize the role and organization of cancer professionals to realize the full value of the workforce*

- Establish national licensing reciprocity agreements to support practice in underserved areas
- Standardize scope of practice in state practice acts
- Promote professional practice to the maximum scope as defined by the license
- Streamline visa and licensure requirements for foreign-trained and military-trained health professionals
- Develop and promote transdisciplinary standards for cancer professional training and practice in all care settings
- Explore new models of care through demonstration programs

- Leverage the role of volunteers and non-traditional caregivers (e.g. lay patient navigators, community health workers, clergy)
- Leverage the role of licensed, non-oncology health professionals in support of cancer specialists
    - Emphasize coordination between primary and specialty caregivers
    - Emphasize cancer prevention and early detection
    - Emphasize pain, palliative care, and end-of-life care
- Promote programs that improve system efficiency and value to patients and their support system
    - Patient navigation programs
    - Survivorship programs
    - Palliative care programs
    - Hospice care

CALL TO ACTION

Since the quantity, quality, and value of the cancer workforce are controlled and influenced by numerous entities, leadership is needed from federal and state policymakers, educators from all levels and disciplines, healthcare and research institutions, as well as the general public to strengthen the workforce:

Federal Policymakers

- Appropriate funds to begin and sustain the National Health Workforce Commission and its related research and practice programs
- Promote job creation in the health sector through mechanisms that expand federally-funded training program capacity and healthcare institution reimbursement (Medicare)
- Facilitate a national approach to licensing across state lines to assist underserved communities
- Streamline visa requirements for foreign-trained and military-trained health professionals

State Policymakers

- Promote job creation in the health sector through mechanisms that expand state-funded training program capacity and healthcare institution reimbursement (Medicaid)
- Collaborate with other state policymakers to establish licensing reciprocity agreements
- Standardize scope of practice in state practice acts
- Streamline licensure requirements for foreign-trained and military-trained health professionals

Educators / Schools of Training

Primary/ Secondary / Undergraduate

- Educate students to be informed health consumers
- Promote health/cancer careers by creating internships and scholarships
- Promote diversity

Specialists / Generalists

- Promote careers in cancer by creating internships and scholarships
- Expand program capacity and throughput
- Promote diversity

Health / Healthcare Institutions

- Retain health professionals
- Maximize professional autonomy within license and scope of practice
- Promote and reward transdisciplinary care
- Create programs to maximize patient benefit and system efficiency
- Nominate leaders to the National Health Workforce Commission

General Public / Volunteers (voters)

- Support job creation in the health sector
- Volunteer to promote health and healing
- Consider a career in cancer

ACKNOWLEDGEMENT AND ENDORSEMENT

The principles and recommended actions were created by a multi-sector, multidisciplinary team of leaders convened by C-Change:

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Paula Rieger, RN, MSN, AOCN, FAAN	Oncology Nursing Society
Shannon Vann, CTR	North American Association of Central Cancer Registries
Mary C. White	Centers for Disease Control and Prevention
Armin D Weinberg, PhD	Life Beyond Cancer Foundation
Kristen A. Cox, MS	C-Change
Alison P. Smith, BA, BSN, RN	C-Change

This position statement has been endorsed by: *(updated 8/30/12)*

1. American Cancer Society, Inc.
2. American Cancer Society Cancer Action Network
3. American College of Surgeons Commission on Cancer
4. American Society of Clinical Oncology
5. Association of American Cancer Institutes
6. Association of Community Cancer Centers
7. Association of Oncology Social Work
8. California Health Collaborative
9. Cancer Registries of Central and Northern California
10. Central Brain Tumor Registry of the US
11. Centers for Disease Control and Prevention
12. Chao Family Comprehensive Cancer Center
13. Colon Cancer Alliance
14. Dana-Farber Cancer Institute
15. INTEGRIS Health
16. Intercultural Cancer Council
17. Life Beyond Cancer Foundation
18. LIVE**STRONG**
19. Men's Health Network
20. National Association of Social Workers
21. North American Association of Central Cancer Registries
22. Oncology Nursing Society
23. Susan G. Komen for the Cure
24. The GW Cancer Institute
25. The US Oncology Network
26. The Warren Alpert Medical School of Brown University

Promoting Careers in Cancer

In February 2012, C-Change released a Request for Proposal for programs to recruit, retain, and support re-entry of individuals in cancer careers. Starting as early as grade school, cancer professions need to be aggressively promoted as rewarding, stable, important, and attractive career choices. The C-Change Cancer Career Promotion Grants were designed to help develop new, unique programs that draw individuals into careers in cancer. Programs were invited to focus on areas such as oncology specialization among any/all disciplines, engagement of underrepresented students, patient navigation, cancer prevention, cancer surveillance, palliative care, and end of life care. Funding was not intended to sustain existing programs. C-Change will work with grantees to disseminate tools, findings, and best practices to inspire broader career promotion efforts. Grant applications were invited from academic, health care, and professional institutions, comprehensive cancer control coalitions, community organizations, trade organizations, and other associations interested in promoting careers in cancer

By March 2012, thirty applications were received from a wide variety of organizations across the country including associations, community groups, comprehensive cancer coalitions, academic institutions, and healthcare organizations. The program proposals targeted a wide range of disciplines, geographies, points on the continuum of care, and stages of the workforce development pipeline.

In April 2012, the Cancer Career Promotion Grant Review Sub-Committee met to review the applications and recommended program funding awards. Three sites were selected based upon the merits of their application and the diverse mix of opportunities that they represented as a group of model programs. Each site is addressing a unique aspect of the workforce challenge, early career promotion, specialization, and care of disparate communities. Grantees included:

- **Gulfcoast South Area Health Education Center –** This program will engage high school students from underserved communities to pursue cancer careers through a multi-pronged initiative including internships, workshops, and informational presentations. Students will be encouraged to train and remain in their communities, which are designated as Health Professional Shortage Area by HHS.

- **Texas Christian University College of Nursing** – This program will develop and implement a model oncology nurse extern program designed to provide undergraduate nurses with an intensive clinical experience in oncology, spanning the continuum of research, prevention, care, survivorship, and end of life. Few baccalaureate nursing programs offer significant exposure to oncology nursing during undergraduate training, so this program will be design as a national model for adoption by other schools of nursing.

- **Alaska Native Tribal Consortium** – This program will develop and implement a training module for Behavioral Health Aides in survivorship support. Behavioral Health Aides are often the only health care provider serving remote, native communities, so equipping scarce health professionals with better cancer support skills and resources will improve access and awareness to care needs.

The "Careforce"

Careforce Concept

Beyond traditionally trained cancer professionals, many individuals play an important role in cancer care such as family members, volunteers, lay navigators, community health workers, and clergy. However, the literature documenting the size, roles, training, support, supervision, compensation, impact, barriers, and opportunities for the careforce is sparse. A systematic assessment of barriers and opportunities and subsequent actions to better engage and support the careforce would be a unique and valuable contribution to the cancer community.

Careforce Goal

As part of a National Strategy to Strengthen the Cancer Workforce, C-Change aims to better understand, support, and leverage the roles of the "careforce," as caregivers, volunteers, and advocates.

Summit Objectives

C-Change is planning a Careforce Summit to launch this initiative with the following objectives:

- Define the scope of roles currently and potentially served by non-traditional caregivers in cancer
- Define key challenges to engage and better integrate non-traditional caregivers (e.g. licensing, employee benefits, immigration, professional workforce training)
- Define strategies for promoting research and translation of effective models of training and care

C-Change has outlined the following process and timeline to achieve the stated goal and objectives:

2012

1. Convene summit planning committee (February)
2. Develop data gather plan (April-May)
3. Conduct key informant phone interviews with leaders from national organizations who engage or depend upon the careforce to gather their perspectives, data, and access to careforce members (June-July)
4. Conduct careforce phone interviews with individuals serving in caregiving roles to gather their perspective (June-July)
5. Based upon the key informant and careforce phone interviews, conduct focus groups among members of the careforce to explore issues and opportunities more deeply (August-October)
6. Based upon the phone interview and focus group findings, conduct surveys of national organizations and careforce members to gather a broader sample of information and opinions (October-November)
7. Utilized the findings of the interviews, focus groups, and surveys to inform the design of the summit (ongoing)

2013

8. Host the summit (Q1-2)
9. Develop and publish recommendations from the summit (Q2)
10. Identify C-Change specific actions (Q3)
11. Convene appropriate leadership and support to develop a detailed action plan (Q3-4)
    Potential actions stemming from the summit include, but are not limited to defining core competency standards for the careforce, developing a training methods and tools based upon the standards

Cancer Workforce Advisory Committee – As of 8/30/2012

Leader and/or Designee	Organization
Edward J. Benz, Jr., MD, FACS, Co-Chair	Dana Farber Cancer Institute
Elizabeth J. Clark, PhD, ACSW, MPH, Co-Chair	National Association of Social Workers
Bruce Behringer, MPH	Tennessee Department of Health
Jabbar Bennett, PhD	Brown University Graduate School
Jimmy Boyd	Men's Health Network
Gretchen Brown, MSW	National Hospital and Palliative Care Organization
Suanna S. Bruinooge	American Society of Clinical Oncology
Stacy Collins, MSW	National Association of Social Workers
Tina Devry, MHA	Iowa Cancer Consortium
Christian Downs, MHA, JD	Association of Community Cancer Centers
Mignon Dryden, CTR	Cancer Registries of Central and Northern California
Elizabeth M. Duke, PhD	University of Maryland, School of Public Policy
Clese Erickson	American Association of Medical Colleges
Angelina Esparza, MPH, BSN, BA	American Cancer Society
Matthew Farber, MA	Association of Community Cancer Centers
Annette L. Galassi, RN, MA	National Cancer Institute
Kristi C. Guillory, MS, JD	American Cancer Society Cancer Action Network, Inc.
Amy Hanley	American Society of Clinical Oncology
Joyce Hendershott, MSW, LISW-S, ACSW	OSU James Cancer Hospital & Solove Research Institute
Roger C. Herdman, MD	Institute of Medicine/National Academy of Sciences
Janie Hofacker	Association of American Cancer Institutes
Linda S. House, RN, BSN, MSM	Cancer Support Community
Betsy A. Kohler, MPH, CTR	North American Association of Central Cancer Registries
Charles E. Kupchella, PhD	University of North Dakota
Cheri Lattimer, RN, BSN	Case Management Society of America / National Transitions of Care Coalition
Laura Levit, JD	Institute of Medicine
Allen S. Lichter, MD	American Society of Clinical Oncology
Maureen Y. Lichtveld, MD, MPH	Tulane University School of Public Health and Tropical Medicine
Kelsey Mace	American Society of Clinical Oncology
Norma Martinez Rodgers, PhD, RN, FAAN	National Association of Hispanic Nurses
Kathi Mooney, PhD, FAAN, RN	University of Utah
Patricia Mullan, PhD	American Association of Cancer Education
John E. Niederhuber, MD	INOVA Health System
Asua Ofosu	National Association of Social Workers
Chandini Portteus	Susan G. Komen for the Cure
Paula Rieger, RN, MSN, CAE, FAAN	Oncology Nursing Society
Katherine Roland, MPH	Centers for Disease Control and Prevention
Kimberly A. Sabelko, PhD	Susan G. Komen for the Cure
Edward Salsberg	Health Resources and Services Administration
Sharon Sharpe, BSAM	Comprehensive Cancer Control Board, DCPC
Sharon Stack, PhD	Harper Cancer Research Institute, University of Notre Dame
Barbara Duffy Stewart, MPH	Association of American Cancer Institutes
Alec Stone, MA, MPA	Oncology Nursing Society
Shannon Vann, CTR	North American Association of Central Cancer Registries

continued

Armin D. Weinberg, PhD	Life Beyond Cancer Foundation
Mary C. White, ScD, MPH	Centers for Disease Control and Prevention
David P. Winchester, MD	American College of Surgeons/Commission on Cancer
Governor Bob Wise	Alliance for Excellent Education
Christopher Zurawsky	Association of American Cancer Institutes

Workforce Advisory Committee – Non-Traditional Caregivers Summit Planning Committee

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Jabbar Bennett, PhD	Brown University Graduate School
Angelina Esparza, MPH, BSN, BA	American Cancer Society
Annette L. Galassi, RN, MA	National Cancer Institute
Kristi C. Guillory, MS, JD	American Cancer Society Cancer Action Network, Inc.
Amy Hanley	American Society of Clinical Oncology
Janie Hofacker	Association of American Cancer Institutes
Charles E. Kupchella, PhD	University of North Dakota
Katherine Roland, MPH	Centers for Disease Control and Prevention

Workforce Advisory Committee – Cancer Career Promotion Grant Review Committee

Leader and/or Designee	Organization
Edward J. Benz, Jr., MD, FACS, Chair	Dana Farber Cancer Institute
Jabbar Bennett, PhD	Brown University Graduate School
Angelina Esparza, MPH, BSN, BA	American Cancer Society
Annette L. Galassi, RN, MA	National Cancer Institute
Kristi C. Guillory, MS, JD	American Cancer Society Cancer Action Network, Inc.
Amy Hanley	American Society of Clinical Oncology
Janie Hofacker	Association of American Cancer Institutes
Charles E. Kupchella, PhD	University of North Dakota

APPENDIX E – VALUE IN CANCER CARE DOCUMENTS

Palliative Care and Hospice Care

Quality of Life at Every Stage

No one wants to suffer. No one should have to.

Palliative care and hospice care can greatly increase quality of life for cancer patients.

Less Suffering, Greater Quality of Life.

Initiative Goals:

- *Increase the use of palliative care throughout cancer treatment*

- *Increase the number of patients and families accessing hospice care, and increase the length of hospice care*

C-Change's Approach:

- **Change practice** to embrace palliative care and hospice care services at appropriate points
- **Create capacity** (personnel, policies, and resources) to support the appropriate delivery of palliative care and hospice care
- **Create demand** for palliative care and hospice care by informing the public about the nature, importance, and benefits of these services

Assuring Value in Cancer Care Initiative Platform

Advocacy Develop an advocacy agenda to increase the use of palliative care, and Increase the number of patients and families accessing hospice care, and increase the length of hospice care	***National Conversation*** Change the way the public thinks about and acts regarding palliative care and hospice care	***Guidance*** Provide guidance that improves access to and delivery of palliative care and hospice care

• **Advocate for the use of palliative care and hospice care services at appropriate points**
• **Advocate for the use of active treatment, if desired, throughout hospice (concurrent care)**
  ○ Identify regulatory and other barriers to concurrent use
  ○ Identify a package of services that can be utilized and reimbursed without overly burdensome regulations
  ○ Design an advocacy strategy to remove barriers to concurrent use
  ○ Develop metrics for success
• **Advocate for reimbursement for conversations around advanced care planning**
  ○ Identify the regulations that need to be changed
  ○ Develop advocacy strategy
  ○ Advocate for change
• **Advocate for a national research agenda for palliative care and hospice care**
  ○ Identify gaps in the research
  ○ Define national research agenda building from previous work by National Palliative Care Research Center, IOM, NIH, ACS, ASCO, and leading professional organizations
  ○ Reach consensus on national research agenda
  ○ Advocate for national research agenda
	• **Research the knowledge, values, and beliefs about palliative care and hospice care of underrepresented populations and those with cancer disparities**
	
	Other:
	• **Create demand for palliative care and hospice care**
	
	• **Educate on the importance of increasing the capacity of the palliative care and hospice care workforces**
	
	• **Work towards common language and agreed upon definitions for palliative care and hospice care**
		• **Promote common standards of palliative care and hospice care**
		  ○ Identify common standards
		  ○ Disseminate guidance and tools for communities to assess and improve their capacity, competency, and services
		  ○ Develop incentives to adopt common standards
		
		• **Develop playbook/ call to action**
		  ○ Create menu of items that C-Change member organizations and others can adopt and/or act upon

Cross-Cutting Efforts

- **Environmental Scan/ Mapping Project**- Inventory the priorities of other organizations that are related to palliative care and hospice care to avoid duplication, inconsistencies, and differences in philosophies, optimize resources, and expand the reach of joint efforts
- **Actively engage in the development and execution of other organizations' agendas with regard to palliative care and hospice care**
- **Provide linkages among organizations with similar agendas**
- **Continually assess capacity and workforce needs for palliative care and hospice care services**

Value in Cancer Care Advisory Committee – As of 8/30/2012

Leader and/or Designee	Organization
Tom Kean, MPH, Co-Chair	C-Change
Allen S. Lichter, MD, Co-Chair	American Society of Clinical Oncology
Amy Abernethy, MD	Duke University
Joel W. Beetsch, PhD	Sanofi
Pamela Bennett, RN, BSN	Purdue Pharma, L.P.
Roy Beveridge	US Oncology
Jimmy Boyd	Men's Health Network
Otis W. Brawley, MD, FACP	American Cancer Society
Matt Brow	US Oncology-McKesson
John Broyles, M.Sc. (Philosophy)	Coalition to Transform Advanced Care (C-TAC)
Greg Brozeit	International Myeloma Foundation
Brooke Bumpers, JD	Hogan Lovells, LLC
Nancy Davenport-Ennis, RN	National Patient Advocate Foundation
John N. Dornan, Jr.	CEO Roundtable on Cancer, Inc.
Eric Dube, PhD	GlaxoSmithKline
Geoffrey Dunn, MD, FACS	Hamot Medical Center
Lynn Erdman	Susan G. Komen for the Cure
Lloyd K. Everson, MD	US Oncology-McKesson
Laura Fennimore, RN, DNP	UPMC Health Plan
Patricia Ganz, MD	University of California Los Angeles School of Public Health
Willis Goldbeck	Institute for Alternative Futures
Gary Gordon, MD, PhD	Abbott Laboratories, Inc.
S. Orlene Grant, RN, BSN, MSN	The Grant Group, LLC
Ralph Hauke, MD, FACP	Nebraska Cancer Specialists
Daniel Hayes, MD	Maine Center for Cancer Medicine
Chris Herman, MSW, LICSW	National Association of Social Workers
Ruth I. Hoffman, MPH	American Childhood Cancer Organization
Linda S. House, RN, BSN, MSM	Cancer Support Community
Patti Fine Jewell, MPA	Pfizer Inc.
Deborah Y. Kamin, PhD	American Society of Clinical Oncology
Judith Salmon Kaur, MD	Mayo Clinic Comprehensive Cancer Center
Johnathan Keyserling, JD	National Hospice and Palliative Care Organization
Rebecca A. Kirch, JD	American Cancer Society
Ira Klein, MD, MBA, FACP	Aetna| Aetna Oncology Solutions
Tom Koutsoumpas	Mintz Levin-Center for Health Law & Policy
Randall Krakauer, MD, FACP, FACR	Aetna
Kurt Kresge, MBA	Merck Vaccines
Jeremy Leffler	Sanofi
Laura Livingston	American Society of Clinical Oncology
William J. Mayer, MD, MPH	Bronson Healthcare Group
Diane E. Meier, MD	Mount Sinai School of Medicine
Andy Miller, MHSE, MCHES	LIVESTRONG
Kathi Mooney, PhD, FAAN, RN	University of Utah

continued

Sean Morrison, MD	Mount Sinai School of Medicine
Martin J. Murphy, Jr., PhD, DMedSc	CEO Roundtable on Cancer, Inc.
Sharyl J. Nass, PhD	National Cancer Policy Forum, Institute of Medicine
Lee N. Newcomer, MD	United Healthcare
William Novelli	Georgetown University
Carol S. Palackhdarry, MD, MS	Active Health Management/ Aetna-Hartford, CT.
Richard Payne, MD	Duke University
Janet A. Phoenix, MD, MPH	The Grant Group, LLC
Scott Ramsey, MD, PhD	Fred Hutchinson Cancer Research Center
Wayne Rawlins, MD, MBA	Aetna
Gary M. Reedy	Johnson & Johnson
Lonny Reisman, MD	Aetna
Lisa Richardson, MD, MPH	Centers for Disease Control and Prevention
Paula Rieger, RN, MSN, CAE, FAAN	Oncology Nursing Society
Mace Rothenberg, MD	Pfizer Oncology
Michael H. Samuelson, MA	Samuelson and Associates
Selma Schimmel	Vital Options International
Julian C. Schink, MD	Robert H. Lurie Comp. Cancer Ctr of Northwestern University
Lowell E. Schnipper, MD	Harvard Medical School
Thomas P. Sellers, MPA	Millennium: The Takeda Oncology Company
Robert Siegel, MD	George Washington University Medical Center-
Thomas J. Smith, MD, FACP	Johns Hopkins School of Medicine
Ira B. Steinberg, MD	Aveo Oncology
Benjamin Steinmetz, MS	GlaxoSmithKline
Cathy Trzaskawka	Endo Pharmaceuticals
Mollie Williams, MPH	
David P. Winchester, MD	American College of Surgeons/Commission on Cancer
Katherine Winfree, PhD, MPH	Eli Lilly and Company
William Winkenwerder, Jr., MD, MBA	Highmark Inc.
Dana Wollins, MGC	American Society of Clinical Oncology
Amy Wotring, MPP	National Patient Advocacy Foundation

Value in Cancer Care – Steering Committee

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Ralph Hauke, MD, FACP	Nebraska Cancer Specialists
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Allen S. Lichter, MD	American Society of Clinical Oncology
Andy Miller, MHSE, MCHES	LIVESTRONG

Value in Cancer Care – Advocacy Subcommittee

Amy Abernethy, MD	Duke University
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Pamela Bennett, RN, BSN	Purdue Pharma, L.P.
Keysha Brooks-Coley	American Cancer Society
Matt Brow	US Oncology-McKesson
Brooke Bumpers, JD	Hogan Lovells, LLC
Stephen D'Amato, PharmD, MSc	Pfizer, Inc.
Lloyd K. Everson, MD	US Oncology-McKesson
Laura Fennimore, RN, DNP	UPMC Health Plan
Willis Goldbeck	Institute for Alternative Futures
Patti Fine Jewell, MPA	Pfizer Inc.
Kevin Kappel	Coalition to Transform Advanced Care (C-TAC)
Johnathan Keyserling, JD	National Hospice and Palliative Care Organization
William J. Mayer, MD, MPH	Bronson Healthcare Group
Gwen Mayes	National Patient Advocate Foundation
Kathi Mooney, PhD, FAAN, RN	University of Utah
Sean Morrison, MD	Mount Sinai School of Medicine
Lee N. Newcomer, MD	United Healthcare
Thomas J. Smith, MD, FACP	Johns Hopkins School of Medicine

Value in Cancer Care – National Conversation Subcommittee

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Greg Brozeit	International Myeloma Foundation
S. Orlene Grant, RN, BSN, MSN	The Grant Group, LLC
Chris Herman, MSW, LICSW	National Association of Social Workers
Judith Salmon Kaur, MD	Mayo Clinic Comprehensive Cancer Center
Richard Payne, MD	Duke University
Wayne Rawlins, MD, MBA	Aetna
Michael H. Samuelson, MA	Samuelson and Associates
Selma Schimmel	Vital Options International
Ira B. Steinberg, MD	Aveo Oncology
Katherine Winfree, PhD, MPH	Eli Lilly and Company

Value in Cancer Care – Guidance Subcommittee

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Nancy Davenport-Ennis, RN	National Patient Advocate Foundation
Geoffrey Dunn, MD, FACS	Hamot Medical Center
Patricia Ganz, MD	University of California Los Angeles School of Public Health
Chris Herman, MSW, LICSW	National Association of Social Workers
Linda S. House, RN, BSN, MSM	Cancer Support Community
Randall Krakauer, MD, FACP, FACR	Aetna
Larry Lanier	National Patient Advocate Foundation
Diane E. Meier, MD	Mount Sinai School of Medicine
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Julian C. Schink, MD	Robert H. Lurie Comp. Cancer Ctr of Northwestern University
Brad Stuart, MD	Sutter Health

APPENDIX F – CCC DOCUMENTS

Technical Assistance Scope of Work for Selected CCC Coalitions

Overall Purpose of Technical Assistance

To provide customized technical assistance to select CCC coalitions who have struggled to make significant progress on the implementation of priorities within their CCC plan and/or who have known issues with coalition functioning and/or operations.

Selected Coalitions

A list of coalitions will be developed incorporating the input of CDC CCC program staff. Coalition selection criteria include:

- The coalition has shown a significant lack of progress on implementation of priorities from their cancer plan over the past 12-24 months.
- There are known issues with coalition functioning and/or operations over the past 12-24 months.

Upon selection, the CCC Coalition leadership (CCC Program Director and CCC Coalition Chair(s)) will be contacted via telephone/email and provided an overview of the assistance being offered. They will be asked to agree to following requirements:

- Willingness and commitment to participate and follow through with identified actions in a technical assistance process where coalition leadership engages in shared decision-making and focuses on agreed upon solutions, priorities and actions.
- Agreement to engage in direct and honest communications about coalition issues, with a focus on solutions to those issues.
- Agreement to participate in and arrange the logistics for at least two on-site visits with technical assistance consultants (Strategic Health Concepts) and coalition leadership (individuals to be determined) and at least monthly conference calls over a 6-month period.
- Agreement to make measurable progress of the action plan in between TA contacts

Overall Coalition TA Approach Once a Coalition Is Selected

The approach described below is intended to occur over approximately six months. Each coalition's needs may suggest a slightly different frequency or duration of visit or phone contact. The approach will be modified based upon the initial assessment and achievement of progress.

- **Initial Assessment**: An initial assessment will be done to identify coalition issues, desired outcomes and areas for change and planning. This assessment will be done through a variety of modalities including via telephone interviews, materials review, and a coalition leadership self-assessment. This information will help shape an agenda for the first on-site technical assistance visit.
- **First On-Site Visit**: This will likely be a one-day on-site meeting with coalition leadership. The meeting will include major agenda items such as a review and discussion of the initial assessment findings, agreement on the areas for change, discussions regarding potential solutions in those areas, and a selection of priority implementation actions. Priority implementation actions will likely include coalition operational actions such as infrastructure adjustments, communication improvement, and

role delineation and actions will be focused on implementing priority objectives/strategies from the coalition's CCC plan. The first visit will culminate with consensus on a specific action plan with action items, responsibilities and a timeline. The action plan will guide the coalition leadership and help them stay on track with being accountable for the actions they identified. The action plan will also include suggested resources/opportunities for the coalition to link to external resources, such as experts, materials, organizations, etc. that may help them be successful in carrying out their identified activities in the action plan. When appropriate, coalitions will be connected with ACoS and C-Change resources or other relevant tools from National Partnership organizations. The action plan will be written and provided to the coalition leadership by Strategic Health Concepts (SHC) within 1 week of the meeting. A follow-up call will be held with coalition leadership shortly after the site visit to review the action plan and make any adjustments needed.

- **Ongoing Technical Assistance**: Monthly technical assistance "check-in" calls and ongoing electronic communication will help to assure accountability, follow through, and problem solving around the action plan including the use of suggested resources and materials. It is anticipated that the calls will be a combination of individual and conference calls with coalition leadership.
- **Second On-Site Visit:** The second visit will also be a one-day on-site meeting with coalition leadership. The meeting will include major agenda items such as continuing the discussions held in the first visit, follow up on progress and challenges encountered while implementing the action plan, and if appropriate selecting new actions or continuing on with selected priority actions. A revised action plan will be written and provided to coalition leadership by SHC within 1 week of the meeting.

Project Roles and Responsibilities

ACoS-CoC and C-Change aim to secure funding for four coalitions to have customized technical assistance over the course of 2012 and early 2013. It is anticipated that assistance with two coalitions at a time will occur within the first six months of the project and the remaining two coalitions will receive assistance in the final six months of the project. ACoS-CoC and C-Change will report jointly to the CCC National Partnership regarding the plans, progress, and outcomes of this joint endeavor in accordance with the Comprehensive Cancer Control National Partnership Member-Led Initiative Implementation Guidelines.

Strategic Health Concepts (SHC) will work with ACoS-CoC and C-Change throughout the course of the contract period and will take a lead responsibility for delivering the technical assistance to the coalitions. All deliverables such as contact with coalitions, calls, emails, on-site visits and written action plans will be carried out by SHC as described in this scope of work. Frequent communication with ACoS-CoC and C-Change via emails and conference calls corresponding with the major milestones of each coalition's visit plan during the contract period. These initial tasks include coalition selection with CDC input and contacting coalitions to secure their participation. SHC will work with ACoS-CoC and C-Change to identify opportunities to utilize the expertise of constituents from each organization and other CCC National Partners in the technical assistance process. Ongoing communication and emails on the progress of the project, issues encountered, etc. will be frequent and timely. SHC welcomes any level of involvement from the ACoS-CoC and C-Change throughout the technical assistance process.

SHC will ensure compliance with the Comprehensive Cancer Control National Partnership Member-Led Initiative Implementation Guidelines.

Comprehensive Cancer Control (CCC) Awards
Information & Nomination Process

Since its founding in 1998, C-Change has made the development and effective implementation of state, tribe/tribal organization, territory and Pacific island jurisdiction (PIJ) CCC plans a strategic priority. To further encourage the effective implementation of quality CCC plans and sustainment of CCC coalitions, in 2012 C-Change will present awards in each of the following categories:

(1.) **CCC Coalition Impact Award** will recognizes one (1) state, one (1) tribe/tribal organization and one (1) PIJ CCC coalition that have successfully achieved evidenced-based and measurable impact in projects and/or interventions consistent with priorities in their respective CCC plan.

(2.) **CCC Champion Award** recognizes a volunteer CCC coalition member and/or partner that has gone above and beyond the call of duty to advance projects and/or interventions consistent with priorities in their respective CCC plan.

(3.) **Exemplary CCC Leadership by an Elected Official Award** recognizes an elected official that has been instrumental in advancing projects and/or interventions consistent with priorities in their respective state, tribe/tribal organization, territory or PIJ CCC plan or their active leadership and/or engagement in the CCC coalition.

In May 2012, C-Change solicited nominations from State, Tribe/Tribal Organization, Territory and Pacific Island Jurisdiction CCC Coalitions. A panel of CCC experts representing C-Change member organizations reviewed and competitively scored the nominations and selected the following winners:

- CCC State Coalition Impact Award
  Utah Cancer Action Network

- CCC PIJ Coalition Impact Award
  Kosrae Comprehensive Cancer Control Partnership

- CCC Champion Award
  Keith Howard

- Exemplary CCC Leadership by an Elected Official Award –
  Representative Reverend Joseph H. Neal

PAST C-CHANGE CCC AWARD WINNERS			
	Exemplary CCC Planning Award		
2006	Washington State CCC Partnership		
	Exemplary CCC Implementation Award	**Exemplary CCC Leadership by an Elected Official Award**	
2006	▪ Michigan Cancer Control Consortium		
2007	▪ Iowa Consortium for CCC ▪ Pennsylvania CCC	▪ Senator Donald E. Williams, Jr. (CT) ▪ Councilman David Catania (DC) ▪ Senator Rosalyn H. Baker (HI)	
2008	▪ Arkansas Cancer Coalition ▪ Cherokee Nation Cancer Control Coalition ▪ American Samoa Community Cancer Coalition	▪ Governor Ruth Ann Minner (DE) ▪ Dutchess County Executive William Steinhaus (NY)	
2009	▪ Wyoming CCC Consortium ▪ Delaware Cancer Consortium ▪ Alaska Native Tribal Health Consortium ▪ Guam CCC Coalition	▪ Rep. Ken Esquibel (WY) ▪ Lt. Gov. Michael Cruz, MD (Guam)	
2010	▪ Arkansas Cancer Coalition ▪ Northern Plains CCC Coalition ▪ Guam CCC Coalition	▪ Senator Bob H. Skilling (State of Kosrae, FSM)	
	CCC Impact Award	**Exemplary CCC Leadership by an Elected Official Award**	**CCC Champion Award**
2011	▪ Partnership to Reduce Cancer in Rhode Island ▪ Fond du Lac Wiidookaage Cancer Team	▪ Senator Rosalyn H. Baker (HI)	▪ Patricia Davis, Mountains of Hope Cancer Coalition
2012	▪ Utah Cancer Action Network ▪ Kosrae Comprehensive Cancer Control Partnership	▪ Representative Reverend Joseph H. Neal	▪ Keith Howard, Wyoming Comprehensive Cancer Control Consortium

CCC Advisory Committee – As of 8/30/2012

Leader and/or Designee	Organization
William J. Todd, Chair	Georgia Tech- College of Management
Brandie S. Adams, MPH	National Association of County & City Health Officials
Lori Belle-Isle, MPH	American Cancer Society
Jimmy Boyd	Men's Health Network
Kym Cravatt, MPH, CHES	Cherokee Nation Health Services
John N. Dornan, Jr.	CEO Roundtable on Cancer, Inc.
Leslie S. Given, MPA	Strategic Health Concepts
Ronald B. Herberman, MD	Intrexon Corporation
Bradford W. Hesse, PhD	National Cancer Institute
Ruth I. Hoffman, MPH	American Childhood Cancer Organization
Karin Hohman, RN, MBA	Strategic Health Concepts
Philip Huang, MD, MPH	Austin/Travis County Health and Human Services Department
Charles E. Kupchella, PhD	University of North Dakota
Nancy E. Lins	N. E. Lins & Associates
Janet H. Matope, MS	Men's Health Network
Devon McGoldrick, MPH	LIVESTRONG
Marion Morra	Morra Communications
Neal A. Palafox, MD, MPH	University of Hawaii-John A. Burns School of Medicine
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Laura Seeff, MD	Centers for Disease Control & Prevention
Latoya L. Stewart, MPH	Susan G. Komen for the Cure
Cathy Trzaskawka	Endo Pharmaceuticals
Armin D. Weinberg, PhD	Life Beyond Cancer Foundation

CCC Awards Subcommittee

Leader and/or Designee	Organization
Brandie Adams, MPH	National Association of County and City Health Officials
Leslie Given, MPA	Strategic Health Concepts
Brandon Leonard	Men’s Health Network
William Todd	Georgia Tech College of Management