

2011 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. In addition, the public's energy and attention is focused largely on the treatment of disease and injuries rather than a more balanced focus that includes adherence to well proven prevention and early detection measures.

Goal: Develop and implement a long term and sustained national strategy that integrates cancer prevention and early detection policy and practice recommendations from related national guidance and other C-Change initiatives.

#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: Develop a case statement and messages that describe the societal and economic cost of cancer health disparities that will resonate with the public and policymakers for use by stakeholders in their advocacy efforts and develop a long term, collaborative strategy to eliminate cancer health disparities.

#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, and (2) 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.

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, 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.

Leadership:

- Robert C. Young, MD (RCY Medicine), Chair and Cost Paper Workgroup Chair
- Tom Burish, PhD (University of Notre Dame), Position Paper Workgroup Chair
- Victor Vogel, MD, MHS (Geisinger Medical Center), Advocacy Workgroup Chair

Focus of Effort:

- Illustrate the barriers and burdens
- Offer concrete suggestions for changes
- Prepare for strong opposition by privacy advocates
- Present the perspectives of health/disease researchers
- Align support of patient advocates
- Engage legislators / caucuses and regulators

Recent Progress:

- *Cost Study:* This sub-committee of researchers and economists determined that existing studies sufficiently illustrate the time, cost burden, and opportunity costs of HIPAA. Rather than commission new research, the group has engaged a science writer to summarize existing research from the IOM report and other literature for use in the position statement. The statement will be geared toward policymakers and regulators. The subcommittee will review the draft report in January 2011.
- Indiana University (IU) received an NIH ARRA Grant to propose a detailed framework for exempting research from HIPAA in accordance with the primary IOM recommendation. Alison Smith was appointed as a panel member representing C-Change to provide access to the broader cancer research and patient advocacy communities. Position Paper Sub-Group Chair Tom Burish, committee member Dennis Deapen, Donna Boswell (Hogan Lovells), and representatives from other advocacy and disease organizations participated in the first forum on behalf of C-Change. Forum 2 of 3 was held in Washington, DC in December 2010.
- *Position Paper:* The IU Grant team is authoring a series of brief position papers. C-Change reviewed and provided comment on the draft IU paper. C-Change will develop additional position statements as necessary.
- *Communication and Advocacy:* C-Change is working collaboratively with the American Society of Clinical Oncology (ASCO), American Association of Cancer Research (AACR), and Infectious Disease Society of America (ISDA) on advocacy efforts. Relationships with other disease research communities such as the HIV, mental health, and gastrointestinal disease groups are being pursued. Each organization is gathering vignettes illustrating the barriers imposed by HIPAA to the research process. These vignettes will be used to develop a speaker's kit for use in raising awareness and support among researchers and clinicians as well as policymakers and regulators. The vignettes will also be provided to the IU grant team for possible integration in their position papers or final recommendations. Coalition members are considering the possibility of holding hill briefings and visits to sensitize policymakers to the challenge, cultivate an issue champion, and prepare for more specific advocacy efforts.

- Submitted public comments in September 2010 regarding Modification to the HIPAA Privacy, Security, and Enforcement Rules under the Health Information and Technology for Economic and Clinical Health Act (“HITECH”).
- Hosted a special session at the C-Change Annual Meeting in November 2010 for the membership to meet with the Indiana University NIH ARRA Grant Primary Investigator to ensure cancer community input into their recommendations.
- Submitted public comments in January 2011 to the Office of the National Coordinator for Health Information Technology regarding the President’s Council of Advisors on Science and Technology (PCAST) report, “Realizing the Full Potential of Health Information Technology To Improve Healthcare for Americans: The Path Forward.”

Next Steps for 2011

- Continue to gather vignettes regarding HIPAA barriers from the cancer community.
- Continue to engage additional organizations through the review of public comments in response to recent HIPAA modifications related to research.
- Complete and disseminate the HIPAA Cost Study Report.
- Develop a position statement for exempting research from HIPAA and/or modifying existing regulations and guidance.
- Develop speaker’s kit of HIPAA issues including cost study highlights and anecdotes to raise awareness among research and clinical communities of the broadly felt impact of HIPAA across research types (clinical trials, information-based research, etc.) and diseases.
- Host hill briefings with coalition members.
- Define and pursue a communication and advocacy plan that utilizes the findings of the cost study, position paper, and Indiana University recommendations.

Workgroups

Cost Study Paper: Robert C. Young, MD, Chair, Martin Brown, PhD, Stan Crosley, JD, Dennis Deapen, DrPH, David Meltzer, MD, PhD, Sharyl Nass, PhD, Roberta Ness, MD, MPH, Scott Ramsey, MD, PhD, , Deborah Schrag, MD, MPH

Position Paper: Tom Burish, PhD, Chair, Melissa Bianchi, JD, Donna Boswell, JD Suanna Bruinooge, Stan Crosley, JD, Dennis Deapen, DrPH, Sandra Horning, MD, Mace Rothenberg, MD

Communication and Advocacy plan: Victor Vogel, MD, MHS, Chair, Marianne Alciati, PhD, Melissa Bianchi, JD, Donna Boswell, JD, Jeff Allen, PhD, Pam Bradley, PhD, Adam Clark, PhD, Candi Wolff, JD Barbara Wood, Esq.

Advisory Committee

Leader and/or Designee	Organization
Robert C. Young, MD, Chair	RCY Medicine
Marianne H. Alciati, PhD	
Jeff Allen, PhD	Friends of Cancer Research
Anna Barker, PhD	National Cancer Institute
Edward J. Benz, Jr., MD	Dana Farber Cancer Institute
Melissa Bianchi, JD	Hogan Lovells
Donna Boswell, JD	Hogan Lovells
Pam Bradley, PhD	American Association of Cancer Research
Martin Brown, PhD	National Cancer Institute

Tom Burish, PhD	University of Notre Dame
Fred Cate	Indiana University
Adam M. Clark, PhD	FasterCures
Stan Crosely, JD	Indiana University
Gregory A. Curt, MD	AstraZeneca Pharmaceuticals
Robert Daum, MD	Infectious Disease Society of America
Dennis Deapen, DrPH	USC Keck School of Medicine / NAACCR
Lloyd Everson, MD	Life Beyond Cancer Foundation
Greer Gay, PhD	American College of Surgeons Commission on Cancer
Ronald B. Herberman, MD	Intrexon
Ruth Hoffman, MPH	American Childhood Cancer Organization
John Hohneker, MD	Novartis Pharmaceuticals Corporation
Sandra Horning, MD	Genentech
Allen Lichter, MD	American Society of Clinical Oncology
Kim Linthicum	
David Meltzer, MD, PhD	University of Chicago
Andy Miller, MHSE, CHES	Lance Armstrong Foundation
Sharyl J. Nass, PhD	Institute of Medicine
Shelley Fuld Nasso	Susan G. Komen for the Cure
Roberta Ness, MD, MPH	The University of Texas School of Public Health
John Niederhuber, MD	Inova Health System
Chandini Portteus	Susan G. Komen for the Cure
Scott Ramsey, MD, PhD	Fred Hutchinson Cancer Research Center
Lisa Richardson, MD, MPH	Center for Disease Control and Prevention
Mace Rothenberg, MD	Pfizer Oncology
Deborah Schrag, MD, MPH	Dana Farber Cancer Institute
Ellen V. Sigal, PhD	Friends of Cancer Research
Suanna Steeby Bruinooge	American Society of Clinical Oncology
Cathy Trzaskawka	Endo Pharmaceuticals
Victor Vogel, MD, MHS	American Cancer Society
Mary Lee Watts	AACR
Candi Wolff, JD	Hogan Lovells
Barbara A. Wood, Esq.	

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. In addition, the public's energy and attention is focused largely on the treatment of disease and injuries rather than a more balanced focus that includes adherence to well proven prevention and early detection measures.

Goal: Develop and implement a long term and sustained national strategy that integrates cancer prevention and early detection policy and practice recommendations from related national guidance and other C-Change initiatives.

Leadership:

- Matt Myers, JD (Campaign for Tobacco-Free Kids)

Focus of Effort:

- Develop and implement a sustained national cancer risk reduction strategy that mobilizes senior thought leaders from within and beyond the cancer and health communities to provide advocacy for needed policy and practice changes.
- Link the national strategy with efforts of other stakeholder organizations that address similar risk factors (e.g. American Heart Association, etc.) and with the National Prevention and Health Promotion Strategy that is part of health reform.

Scope of Work:

- Mobilize a high-level leadership team to serve as advocates for cancer risk policy and practice issues.
- Continue to implement a national "Call to Action" for cancer risk reduction.
- Contribute to the development of cancer goals for Healthy People 2020.

Recent Progress:

- Analyzed key provisions of the health care reform legislation that impact cancer risk reduction efforts and disseminated to the Advisory Committee to help guide future C-Change policy actions.
- Conducted a survey of committee members, to help determine specific risk reduction provisions of the health care reform legislation in which C-Change is uniquely positioned to engage (e.g. making nominations to the national committees such as the National Prevention, Health Promotion and Public Health Council's Advisory Workgroup, submitting public comments on the National Prevention and Health Promotion Strategy, providing input on the community transformation grant process).
- Submitted a nomination in October 2010 for the U.S. Preventive Services Task Force.
- Submitted comments in December 2010 and January 2011 on the National Prevention and Health Promotion Strategy.
- Hosted a conference call with a select group of thought leaders to strategize around the question of how best C-Change can make a bold commitment to ensure prevention elements of health care reform are implemented.

Proposed Actions for 2011:

- Engage a team of high-level leaders from within and beyond the health community to serve as advocates for cancer risk reduction policy and practice issues to translate rhetorical commitment into sustained action and tangible support.
- Develop an advocacy strategy to protect the Public Health and Prevention Fund.

- Engage C-Change membership and other stakeholders, within and beyond the health community, to carry out an advocacy strategy.
- Develop a broader cancer risk reduction advocacy strategy to ensure that cancer risk reduction elements of health reform and other legislation are successfully implemented and sustained.
- Pursue implementation of an advocacy strategy.

Advisory Committee

Leader and/or Designee	Organization
Matt Myers, JD, Chair	Campaign for Tobacco Free Kids
Carolyn (Bo) Aldige	Prevent Cancer Foundation
John Arrandondo, MD, MPH	Volunteer State Medical Association
Dileep Bal, MD, MPH	State of Hawaii Department of Health - Kauai District
Alan Balch, PhD	Partnership for Prevention
Anna Barker, PhD	National Cancer Institute
Georges Benjamin, MD, MPH	American Public Health Association
Tim Byers, MD, MPH	University of Colorado – Health Sciences Center
Peggy Conlon	The Advertising Council
Dennis Deapen, DrPH	USC Keck School of Medicine / NAACCR
John Dornan Jr.	CEO Roundtable on Cancer
Lloyd Everson, MD	U.S. Oncology
Leslie Given, MPA	Strategic Health Concepts
Rob Gould	Partnership for Prevention
Peggy Harrington	CEO Roundtable on Cancer
Cheryl Heaton, DrPH, MPA	Legacy – For Longer Healthier Lives
Phil Huang, MD, MPH	Austin-Travis County Health Department
Elmer Huerta, MD, MPH	Cancer Preventorium, Washington Cancer Institute
Marc Hurlbert, PhD	Avon Foundation for Women
Rebecca Johnson	National Association of City & County Health Officials
Sara Koka, MPH, MS	Association of State and Territorial Health Officials
Charles Kupchella, PhD	University of North Dakota
Keith Mason	National Forum for Heart Disease & Stroke Prevention
Peter Melnyk	Astellas
Andy Miller, MHSE, CHES	Lance Armstrong Foundation
Marty Murphy, PhD	CEO Roundtable on Cancer
Marcus Plescia, MD, MPH	Centers for Disease Control & Prevention
Carolyn Angeleri Ricci	Avon Foundation for Women
Anthony Signorelli	The Advertising Council
Cathy Trzaskawka	Endo Pharmaceuticals
Richard Wender, MD	Thomas Jefferson University
Drew Saelens	Men’s Health Network
Robert Smith, PhD	American Cancer Society
Faye Wong, MPH	Centers for Disease Control & Prevention
Matt Zachary	I’m Too Young For This! Cancer Foundation

#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: Develop a case statement and messages that describe the societal and economic cost of cancer health disparities that will resonate with the public and policymakers for use by stakeholders in their advocacy efforts and develop a long term, collaborative strategy to eliminate cancer health disparities.

Leadership:

- Armin Weinberg, PhD (Intercultural Cancer Council, Baylor College of Medicine), Co-Chair
- Harold Freeman, MD (Ralph Lauren Cancer Center), Co-Chair

Focus of Effort:

- As part of an evolving long-term strategy, develop and disseminate the “Societal and Economic Impact of Cancer Health Disparities Case Statement” and associated advocacy messages.

Scope of Work:

- Develop and disseminate the “Societal and Economic Impact of Cancer Health Disparities Case Statement.”
- Convene briefings with policymakers and stakeholders on the case statement.
- Develop and implement a plan that assures support from the C-Change membership to address cancer health disparities as one of their programmatic and/or policy priorities.
- Coordinate and integrate C-Change’s efforts with the U.S. Department of Health and Human Services (HHS) multi-sector driven “National Partnership to End Health Disparities.”

Recent Progress:

- Commissioned and completed the “Societal and Economic Impact of Cancer Health Disparities Case Statement.”
- Convened Advisory Committee to develop a strategy for an advocacy and messaging campaign based upon the Case Statement for target audiences which will include policy makers and the general public.
- Analyzed key provisions of the health care reform legislation that impact cancer health disparity efforts and disseminated to the Advisory Committee to identify unique opportunities for C-Change action.

Next Steps for 2011:

- Publish and disseminate the “Societal and Economic Impact of Cancer Health Disparities Case Statement.”
- Develop advocacy messages for use by the C-Change membership and other stakeholders.
- Engage C-Change membership to use advocacy messages and address cancer health disparities as one of their programmatic and/or policy priorities.
- Convene briefings with policymakers on the “Societal and Economic Impact of Cancer Health Disparities Case Statement.”
- Prioritize opportunities for policy involvement stemming from health reform provisions.
- Continue to coordinate and integrate C-Change’s cancer health disparities strategy into the efforts of the U.S. Department of Health and Human Services (HHS) multi-sector driven “National Partnership to End Cancer Health Disparities.”

Advisory Committee

<u>Leader and/or Designee</u>	<u>Organization</u>
Armin Weinberg, PhD, Co-Chair	Intercultural Cancer Council/ Baylor College of Medicine
Harold Freeman, MD, Co-Chair	Ralph Lauren Center for Cancer Care & Prevention
John Arrandondo, MD, MPH	Volunteer State Medical Association
Joel Beetsch, PhD	Sanofi-Aventis US
Clement Bezold, PhD	Institute for Alternative Futures
Linda Blount, MPH	American Cancer Society
Sharon Brigner, MS, RN	PHRMA
Ahmed Calvo, MD, MPH	Health Services Resources Administration
Allicia Girvan, PhD	Eli Lilly & Company
S. Orlene Grant, MSN	The Grant Group, LLC
Deborah Guadalupe Duran, PhD	National Cancer Institute
Nikki Hayes, MPH	Centers for Disease Control and Prevention
Cheryl Heaton, DrPH, MPA	Legacy – For Longer Healthier Lives
Nina Hill, PhD	Pfizer, Inc.
Marc Hurlbert, PhD	Avon Foundation for Women
Lovell Jones, PhD	Intercultural Cancer Council
Rebecca Johnson	National Association of City and County Health Officials
Judith Salmon Kaur, MD	Mayo Clinic
Gerard Kenealley, MD, MA	Cephalon, Inc.
Gabriel Leung, PharmD	
Maureen Lichtveld, MD, MPH	Tulane Univ. School of Public Health & Tropical Medicine
Kimberly Linthicum	
Andy Miller, MHSE, CHES	Lance Armstrong Foundation
Neal Palafox, MD, MPH	University of Hawaii/JABSOM
Janet Pheonix, MD, MPH	The Grant Group, LLC
Marcus Plescia, MD, MPH	Centers for Disease Control & Prevention
Amelie Ramirez, DrPH	University of Texas Health Science Center at San Antonio
Wayne Rawlins, MD	Aetna
Carolyn Angeleri Ricci	Avon Foundation for Women
Rochelle Rollins, PhD, MPH	HHS/Office of Minority Health
Drew Saelens	Men’s Health Network
Anthony Signorelli	The Advertising Council
Elizabeth Thompson	Susan G. Komen for the Cure
Shaun Trotter	Robert H. Lurie CCC at Northwestern University
Donald Warne, MD, MPH	Aberdeen Area Tribal Chairman’s Health Board
Erica Childs Warner, MPH	Prevent Cancer Foundation

TRANSFORMING THE HEALTH SYSTEM

#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.

Leadership:

- Edward Benz, MD (Dana Farber Cancer Institute), Co-Chair
- Elizabeth “Betsy” Clark, PhD, ACSW, MPH (National Association of Social Workers), Co-Chair

Themes Guiding the Advisory Committee:

- Workforce development remains a central concern and priority
- A collaborative effort is necessary
- A national workforce development strategy should span the pipeline of workforce development (recruitment, training, licensing, retention), primary and specialty care, the full continuum of cancer care, innovative models of care, and key drivers of research, policy, and practice
- A complex, comprehensive strategy and prioritized areas for collective efforts are needed to balance short-term and longer-term efforts

Recent Progress:

- Nominated two C-Change members and endorsed four candidates that were nominated by other C-Change members for the National Health Care Workforce Commission created by Patient Protection and Affordable Care Act. C-Change has extended congratulatory notes to the commission appointees and extended our willingness to provide a cancer perspective to commission priorities. Of note, Peter Buerhaus and Fitzhugh Mullan were appointed to the commission, both having direct experience working with the cancer community.
- Convened the Advisory Committee in July to discuss overall approach and formed two workgroups, the Framework Workgroup focused on developing a comprehensive framework for sustaining the cancer workforce and the Policy Workgroup focused on unique opportunities for C-Change to act on policy opportunities stemming from the implementation of health reform.
- Convened the Framework Workgroup to define the main pillars for a strategic framework: maximize efficiency of the pipeline for developing oncology-specialized health professionals from recruitment into health professions through training, licensing and retention; better leverage skills and coordination with non-oncology health professionals; and strengthen ability of consumers—including patients, advocates, and policy makers. The group plans to review best practices from other disciplines and industries.
- Convened the Policy Workgroup to evaluate potential policy priorities that are uniquely suited for C-Change action. With guidance from Hogan Lovells, C-Change will explore more specific opportunities for impacting the regulatory implementation of four key provisions.

Next Steps for 2011:

- Framework Workgroup: Articulate a comprehensive framework for sustaining a strong national cancer workforce with specific strategies for action, and develop recommendations for unique C-Change actions stemming from the framework for consideration by the Advisory Committee.
- Policy Workgroup: Evaluate and act upon workforce policy opportunities stemming from health reform where C-Change is uniquely positioned to act.

- Disseminate guiding framework recommendations.
- Pursue specific, unique efforts stemming from the framework.
- Focus on specific policy opportunities stemming from reform.
- Pursue selected recommendations through C-Change and engaging other organizations as appropriate.
- Develop and pursue a collaborative advocacy strategy regarding short- and longer-term priorities.

Workgroups

Policy: Elizabeth Clark, PhD, ACSW, MPH, Chair; Gretchen Brown, MSW; Stacy Collins, MSW; Matt Farber, MA; Maureen Lichtveld, MD, PhD; Paula Rieger, RN, MSN, AOCN, FAAN; Alec Stone, MPA; Chris Zurawsky; Asua Ofosu, JD; Shannon Vann, CTR

Framework: Edward Benz, MD, Chair; Jabbar R. Bennett, PhD; Stacy Collins, MSW; Clese Erikson, MP Aff; Angelina Esparza, RN, MPH; Amy Hanley; Annette Galassi, RN, MA; Joyce Hendershott, MSW, LISW-S, ACSW; Janie Hofacker, RN, BSN, MS; Charles Kupchella, PhD; Shannon Vann, CTR

Advisory Committee

Leader and/or Designee	Organization
Edward Benz, MD, Co-Chair	Dana Farber Cancer Institute
Betsy Clark, PhD, ACSW, MPH, Co-Chair	National Association of Social Workers
Bruce Behringer, MPH	East Tennessee State University
Jabbar R. Bennett, PhD	Brown University
Gretchen M. Brown, MSW	National Hospice and Palliative Care Organization
Tina Devry, MHA	Iowa Cancer Consortium
Christian Downs, MHA/ Matt Farber, MA	Association of Community Cancer Centers
Elizabeth Duke, PhD	University of Maryland
Clese Erikson, MP Aff	American Association of Medical Colleges
Annette Galassi, RN, MA	National Cancer Institute
Angelina Esparza, RN, MPH	American Cancer Society
Joyce Hendershott, MSW, LISW-S, ACSW	Association of Oncology Social Workers
Linda House, RN, BSN, MSM	St. Vincents Indianapolis
Betsy Kohler, MPH, CTR/ Mignon Dryden, CTR / Shannon Vann, CTR	North Amer. Assoc. of Central Cancer Registries
Charles Kupchella, PhD	University of North Dakota, emeritus
Cheri Lattimer, RN, BSN	Case Mgmt Socy of America / National Transitions of Care Coalition
Maureen Lichtveld, MD, MPH	Tulane University School of Medicine
Allen Lichter, MD/ Suanna Bruinooge	American Society for Clinical Oncology
Roger Herdman, MD / Laura Levit, JD	Institute of Medicine
Norma Martinez Rogers, PhD, RN, FAAN	National Association of Hispanic Nurses
Pearl Moore, RN, MN, FAAN	Oncology Nursing Society, formerly
Patricia B. Mullan, PhD	American Association of Cancer Education
John Niederhuber, MD	Inova Health System
Chandini Portteus	Susan G. Komen for the Cure
Paula Rieger, RN, MSN, AOCN, FAAN	Oncology Nursing Society

Ed Salsberg, MPA
Sharon Sharpe
Barbara Duffy Stewart, MPH
/ Chris Zurawsky
Saira Sultan / Denis O'Hara
Armin Weinberg, PhD
Mary White, ScD, MPH
David Winchester, MD
Governor Bob Wise

Health Services Research Administration
Center for Disease Control and Prevention
Association of American Cancer Institutes

Sanofi-Aventis
Intercultural Cancer Council / Baylor
Center for Disease Control and Prevention
American College of Surgeons
Alliance for Excellent Education

TRANSFORMING THE HEALTH SYSTEM

#5 Assuring Value in Cancer Care

Challenge: A 2009 IOM National Cancer Policy Forum workshop focused on a wide range of issues related to achieving optimal value in cancer care. It is clear from the workshop that this issue is timely and of great relevance given the current focus on health reform and persistent economic pressures. It is also clear that there remains a wide range of opinions about what ‘value’ means in the cancer context and means for achieving it through collaborative actions.

Goal: Reach consensus on the scope of what defines value in oncology care and identify strategies to optimize those outcomes that can be economically sustained.

Leadership

- Allen Lichter, MD (ASCO), Co-Chair
- Tom Kean, MPH (C-Change), Co-Chair

Guiding Principles

- Perspectives on the meaning of “value” differ
- “Value” is a function of more than cost
- Expectations for quality cancer care are high and growing
- A ‘rescue’ mentality prevails and contributes to cost
- Tension exists between societal costs and individual outcomes
- ‘Rationing’ occurs at this time
- The rising cost of cancer care is economically unsustainable
- Paying for emerging new therapies will be challenging
- The health care system does not provide adequate incentives for some practices that constitute high value cancer care
- The health care system does not provide adequate disincentives for some practices that constitute low value cancer care
- Reaching consensus on some high and low value cancer care practices is the starting place for taking action

Recent Progress:

2010 served as the initial developmental year for the C-Change/ASCO joint initiative on Assuring Value in Cancer Care. Throughout the course of the year the Advisory Committee focused on defining the problem and developing a feasible approach that appealed to the multi-sector committee members and would ultimately improve the care that individuals with cancer receive. The committee eventually agreed on an initial goal for high value care, and two initial, specific outcomes.

Primary Goal:

The primary goal is to improve the quality of care and quality of life for cancer patients through fostering fully-informed patient/family decisions.

Initial Outcomes:

The initial focus for this initiative is directed specifically at achieving two major outcomes:

- Increased use of palliative care services

- Increased average length of stay in hospice care

2011 Scope of Work:

To reach the goals and achieve the outcomes of the initiative, the committee leadership met in January 2011 to finalize a strategy and timeline for 2011, which includes:

- Case Statement
- Goal Statement
- Communications & Public Affairs Strategy
- Strategic Planning
- Market Research—Patient Perspectives
- Research Agenda
- Social Marketing--Change language and cultural norms
- Develop Tools (patient tools, provider tools, system tools & policies, etc.)
- Hill Briefing

Advisory Committee

Leader and/or Designee	Organization
Tom Kean, MPH, Co-Chair	C-Change
Allen Lichter, MD, Co-Chair	American Society for Clinical Oncology
Kirsten Anderson, MD	Aetna
Pamela Bennett, RN, BSN	Purdue Pharma, LP
Roy Beveridge, MD	US Oncology
Diane Blum, MSW	Cancer Care, Inc.
Otis Brawley, MD	American Cancer Society
Matt Brow	US Oncology
Carl Brown, PhD, AOCN	Oncology Nursing Society
Greg Brozeit	International Myeloma Foundation
Tim Cook	Eli Lilly
Nancy Davenport-Ennis	National Patient Advocate Foundation
John Dornan	CEO Roundtable on Cancer, Inc.
Eric Dube, PhD	GlaxoSmithKline
Geoffrey Dunn, MD	Hamot Medical Center
Lloyd Everson, MD	US Oncology
Patricia Ganz, MD	UCLA, Jonsson Comprehensive Cancer Center
Willis Goldbeck	Institute for Alternative Futures
Gary Gordon, MD, PhD	Abbott Laboratories, Inc.
S. Orlene Grant, RN, BSN, MSN	The Grant Group, LLC
Steve Hahn	ASCO
Daniel Hayes, MD	Maine Center for Cancer Medicine
Ruth Hoffman, MPH	American Childhood Cancer Organization
Linda House, RN, BSN, MSM	St. Vincent Indianapolis
Patti Fine Jewell	Pfizer, Inc
Deborah Kamin, PhD	American Society for Clinical Oncology
Judith Kaur, MD	Mayo Clinic Comprehensive Cancer Center
Gerarad Kennealey, MD	Cephalon
Rebecca Kirch	American Cancer Society
Fran Kochman	GlaxoSmithKline
Kurt Kresge	Merck
Gabe Leung, MS, PharmD	
Laura Livingston	American Society for Clinical Oncology
Craig Lustig, MPA	
William Mayer, MD, MPH	Bronson Healthcare Group

Diane Meier, MD	Center to Advance Palliative Care
Andy Miller, MHSE, CHES	Lance Armstrong Foundation
Sean Morrison, MD	American Academy of Hospice and Palliative Medicine
Marty Murphy, PhD	CEO Roundtable on Cancer, Inc.
Shelley Fuld Nasso	Susan G. Komen for the Cure
Sharyl Nass, PhD	Institute of Medicine
Lee Newcomer, MD	United Healthcare
Janet Phoenix, MD, MPH	The Grant Group, LLC
Scott Ramsey, MD, PhD	Fred Hutchinson Cancer Research Center
Wayne Rawlins, MD	Aetna
Gary Reedy	Johnson & Johnson
Paula Rieger, RN, MSN, CAE, FAAN	Oncology Nursing Society
Lonny Reisman, MD	Aetna
Lisa Richardson, MD, MPH	Center for Disease Control and Prevention
Mace Rothenberg, MD	Pfizer, Inc
Michael Samuleson	The Health & Wellness Institute
Selma Schimmel	Vital Options International
Julian Schink, MD	Robert H. Lurie Comp. Cancer Center of Northwestern Univ.
Lowell Schnipper, MD	Beth Israel Deaconess Medical Center
Tom Sellers	National Coalition for Cancer Survivorship
Robert Siegel, MD	George Washington University Med. Center
Thomas Smith, MD	Virginia Commonwealth University
Ira Steinberg, MD	Sanofi-Aventis
Benjamin Steinmetz, MS	GlaxoSmithKline
Cathy Trzaskawka	Endo Pharmaceuticals
Marian Wentworth	Merck Vaccines
Mollie Williams, MPH	Susan G. Komen for the Cure
David Winchester, MD	American College of Surgeons
Katherine Winfree	Eli Lilly
William Winkenwerder, MD, MBA	The Winkenwerder Company
Dana Wollins, MGC	American Society for Clinical Oncology
Amy Wotring	National Patient Advocacy Foundation

SUPPORTING STATE, TRIBE, AND TERRITORY CCC EFFORTS

#6 Comprehensive Cancer Control (CCC)

Challenge: To continually support progress and improvement in the implementation of state, tribe, territory, and Pacific Island Jurisdiction (PIJ) comprehensive cancer control plans.

Goal(s):

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

C-Change-Driven CCC Effort

Leadership: William (Bill) Todd, (Georgia Cancer Coalition), Chair

Focus of Effort:

- Develop and implement a strategy for advancing CCC efforts in States, Tribes, Territories and PIJ's that extends beyond C-Change's current contribution to the National Partners for CCC and is linked to C-Change's strategic initiatives and other member-driven interests.

Scope of Work:

- Convene an Advisory Committee to provide guidance on the development of a national strategy for advancing CCC that is consistent with C-Change's strategic priorities.
- Provide annual awards to State, Tribe, Territory and PIJ CCC Coalitions for exemplary cancer plan implementation.
- Promote resource development for the implementation of targeted State Comprehensive Cancer and State Tobacco Control Plans in conjunction with the Campaign for Tobacco Free Kids.

Recent Progress:

- Analyzed key provisions of the health care reform legislation that impact CCC efforts and disseminated them at the CCC Leadership Institute in June 2010, to help guide future coalition efforts.
- In accordance with the National Partnership for CCC's 2008-2013 Strategic Plan, collaborated to address selected policy recommendations generated through the 2008-09 Policy and Practice Summits to assure selected coalitions are provided needed technical assistance to aid in their CCC plan implementation efforts.
- Identified the opportunity to develop a value proposition for use by coalitions to engage community leaders in coalition efforts with an initial emphasis on increasing the engagement of the business community.
- Drafted a CCC Value Proposition toolkit which is currently being refined by the Advisory Committee.
- Presented annual awards to State, Tribe, Territory and PIJ CCC Coalitions and an elected official for exemplary CCC plan implementation at the C-Change Annual Meeting in November 2010.
- In conjunction with the Campaign for Tobacco Free Kids, provided a grant to help support a successful campaign for a tobacco tax increase of 50 cents in South Carolina that will be partially utilized to fund tobacco and cancer control efforts within the state. Two more grants, currently in progress, were given to support similar efforts in California and Massachusetts.

Next Steps for 2011:

- Finalize and disseminate the CCC Value Proposition toolkit to CCC Coalitions.
- Continue to foster state tobacco and cancer control resource development efforts in conjunction with the Campaign for Tobacco Free Kids.
- Continue to provide annual awards to State, Tribe, Territory and PIJ CCC Coalitions for exemplary cancer plan implementation.

Advisory Committee

Leader and/or Designee	Organization
William Todd, Chair	Georgia Cancer Coalition
Lori Belle-Isle, MPH	American Cancer Society
Kym Cravatt, MPH, CHES	Cherokee Nation Cancer Programs
John Dornan Jr.	CEO Roundtable on Cancer
Leslie Given, MPA	Strategic Health Concepts
Ronald B. Herberman, MD	Intexron Corporation
Brad Hesse, PhD	National Cancer Institute
Karin Hohman, RN, MBA	Strategic Health Concepts
Phil Huang, MD, MPH	Austin-Travis County Health Department
Rebecca Johnson	National Association of City and County Health Officials
Charles Kupchella, PhD	University of North Dakota
Nancy Lins	N. E. Lins & Associates
Andy Miller, MHSE, CHES	Lance Armstrong Foundation
Marion Morra, MA, ScD	Morra Communications
Shelley Fuld Nasso	Susan G. Komen for the Cure
Neal Palafox, MD, MPH	University of Hawaii / JABSOM
Marcus Plescia, MD, MPH	Centers for Disease Control & Prevention
Drew Saelens	Men's Health Network
Laura Seeff, MD	Centers for Disease Control & Prevention
Cathy Trzaskawka	Endo Pharmaceuticals
Armin Weinberg, PhD	Baylor College of Medicine
Geoff Werth	US Oncology-McKesson

National Partners-Driven CCC Effort

Focus of Effort:

- Continue to actively participate in and support the efforts of the CCC National Partnership.

2010 Scope of Work:

- Presented relevant C-Change initiatives to the 2010 CCC Leadership Institute participants through plenary session presentations and workshop modules.

Recent Progress:

- In conjunction with the CCC National Partnership, convened a leadership institute for 487 leaders of State, Tribe, Territory and Pacific Island Jurisdiction CCC Coalitions. Plenary and workshop sessions focused on policy and practice issues designed to advance CCC efforts. Workshops spearheaded by C-Change included:
 - Risk Reduction and Early Detection Public Messaging (Gary Gurian and Anthony Signorelli)
 - Promoting the CEO Cancer Gold Standard (Gary Gurian, Phil Huang, John Dornan, Andy Miller, and Judy Jonas)
 - Patient Navigation Programs (Tasha Tilghman-Bryant)
 - Competency-based Workforce Development for Non-oncology Health Professionals (Alison Smith and Maureen Lichtveld)
 - Pain and Palliative Care Competency for Non-oncology Health Professionals (Alison Smith, Maureen Lichtveld, and Pam Bennett)
 - South Puget Intertribal Planning Agency's (SPIPA) CCC C-Change Pain and Palliative Care Competency Grant results were presented in a plenary session (John Simmons)
- Participated in the Strategic Planning meeting with the National Partners to determine priorities for 2011.

Next Steps for 2011

- Support development of CCC National Partnership plans to provide technical assistance and training for sustaining coalition membership, supporting policy change related to health reform, and building coalition resources.
- Provide two coalitions with technical assistance visits to address significant membership and resource concerns in conjunction with Susan G. Komen for the Cure.

CCC National Partnership Organizations:

American Cancer Society
American Cancer Society – Cancer Action Network
American College of Surgeons
Association of State and Territorial Health Officials
C-Change
Centers for Disease Control and Prevention
Health Resources and Services Administration
Intercultural Cancer Council
Lance Armstrong Foundation
Leukemia and Lymphoma Society
National Association of Chronic Disease Directors
National Association of County and City Health Officials
National Cancer Institute
North American Association of Central Cancer Registries
Susan G. Komen for the Cure

Goal:

- 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.

Document & Toolkit Dissemination – through conferences and response to inquiries via website

- Access to Quality Cancer Care Guidance Document
- Cancer Patient Navigation Toolkit
- Cancer Surveillance and Information Summit Proceedings
- Clinical Trials Policy and Practice Guidance Documents
- Making the Business Case for Cancer Risk Reduction Materials
- Core Competency Toolkit

Prevention and Early Detection Messages

- Presented the background research and messaging playbook at the June 2010 State, Tribe, Territory and PIJ CCC Leadership Institute and respond to inquiries regarding the messages and related materials found on the C-Change website.

Promotion the CEO Gold Standard – The Austin Model

- In conjunction with the Lance Armstrong Foundation, American Cancer Society-Great Plains Division, Austin-Travis County Health Department and the CEO Roundtable on Cancer, a roll-out of the initiative will encourage business leaders in Austin to become a CEO Cancer Gold Standard™ Accredited employer (Fall 2010). The following Austin-based companies are currently in process for becoming Gold Standard Accredited and will serve as models to be highlighted during the roll-out event: Seton Health Systems, Dell, and Cancer Prevention and Research Institute of Texas.

Removing barriers to a larger national investment in chemoprevention drug development

Goal: C-Change will disseminate the publications stemming from the Cancer Chemoprevention Research initiative and advocate for resolution of the barriers posed by patent and intellectual property law, reimbursement, clinical trial design, and regulatory approval to enable an increased national investment in chemoprevention and vaccine research.

- Responded to Senator Feinstein’s staff inquiry about our request to add “chemoprevention and immunoprevention” to the research categories eligible for funding within the Peer Reviewed Medical Research Program (PRMRP) in the FY 2011 Department of Defense (DOD) appropriations bill.
- Submitted comments and presented recommendations at the 6/2 National Institutes of Health and the Food and Drug Administration Joint Leadership Council: Stakeholders Meeting (Ron Herberman). The newly formed council aims to “more effectively collaborate to advance the translation of biomedical research discoveries into approved diagnostics and therapies as well as promote science to enhance the evaluation tools used for regulatory review.”
- Continuing efforts to develop a request to the FDA for additional preventive vaccine guidance for researchers (Ron Herberman, Samir Khleif, Olja Finn).
- Continuing to advocate for the inclusion of chemoprevention provisions in preliminary efforts to reintroduce the Cancer Act though efforts lead by FOCCR, AACR, and ASCO.

Cancer Core Competency Initiative - Grant Site Findings

- **University of Florida / UF-Shands Cancer Center / Rural Health Partnership of North Central Florida** - MDs, RNs, and MSWs practicing in rural primary care clinics (mostly FQHCs)
 - 102 participants, 90% reported gaining new knowledge and skills to provide better patient care
- **South Puget Intertribal Planning Agency's (SPIPA) CCC** - Native community members/lay health workers and tribal healthcare providers serving the five tribes
 - 102 participants, 120% improvement in confidence, 7% increase in knowledge
- **Iowa Cancer Coalition** - RNs and MAs practicing in rural long term care facilities
 - 40 participants, 12% increase in knowledge from pre- to post-test scores; possible addition to Iowa nursing school curriculum
- **Virginia Commonwealth University** - Pediatric-focused interns, PCPs, and RNs
 - 310 participants to date, 32% increase in knowledge

Pain and Palliative Care Program impact to date:

- 554 individuals participated in pain and palliative care training programs held at four different grant sites, each demonstrating improvement in their target population
- Enduring materials – continue to be disseminated through follow-on programs, presentations, publications, and web resources. Materials include curriculum resources; video teaching tools; on-line courses; clinical practice tools; and patient pain assessment and reporting tools.
- Presentations and publications will continue to reach audiences across the country
 - Oncology Nursing Society 35th Annual Congress, May 2010, San Diego, CA – podium presentation to 50 participants
 - Comprehensive Cancer Control Leadership Institute, June 2010, Los Angeles, CA - 487 leaders of State, Tribe, Territory and Pacific Island Jurisdiction Comprehensive Cancer Control Coalitions (CCC) during a plenary session; and 45 CCC leaders during 2 workshop sessions
 - Florida Society of Oncology Social Workers, October 22, 2010, Orlando, FL – workshop presentation on The Role of The Oncology Social Worker in Strengthening the Non-Oncology Workforce through a Competency-based Approach
 - Five pending publications in peer-reviewed journals including a publication by each grant site and a summary article by C-Change
 - Four pending presentations by each grant site at relevant professional conferences
- Web Resources - www.cancercorecompetency.org has been updated with all of the tools and findings from each grant site, freely available to all users. In October, an email announcement regarding these new resources will reach 800+ recipients including the C-Change membership, all CCC coalition leaders, and previous subscribers to C-Change workforce materials

Next Steps for 2011

- Author a manuscript for publication describing the overall grant process and outcomes
- Continue to engage the Advisory Committee in additional dissemination efforts.
- Continued dissemination through presentations at relevant, national conferences, dissemination of toolkits, and updating the website with new resources from the grant sites
- Present the values of the Cancer Core Competency Initiative in addressing workforce shortages at the Tennessee Cancer Coalition Summit, June 16-17, 2011, Nashville, TN