

Communicating about Cancer Health Disparities

Introduction

Disparities in cancer health are prevalent in the United States, and exact a substantial toll on society in terms of premature death, lower productivity, and the costs of medical care. To examine the true cost disparities impart on the nation and our communities, C-Change commissioned a case statement entitled *The Societal and Economic Impact of Cancer Health Disparities*.

The case statement is distilled in this messaging guide to help C-Change members, partners and all cancer advocates to communicate effectively in their efforts to eliminate disparities. To further inform our efforts, we relied upon extensive messaging research performed by the Robert Wood Johnson Foundation (RWJF) in its document, *A New Way to Talk About the Social Determinants of Health*. We also performed message research and focus group testing among participants at two cancer conferences – the 2012 annual meeting of the American Society of Clinical Oncologists and the 2012 biennial symposium of the Intercultural Cancer Council, in addition to a number of in depth interviews with experts.

When communicating with policymakers, it is important to be specific about the desired course of action and consistent in your messages. These goals informed our subsequent research and led us to develop a specific and targeted list of calls to action for policymakers to help combat cancer health disparities. This list of actions was informed by research among cancer leaders, conference attendees and through a survey of C-Change’s membership.

A final word about the key and supplementary messages from the excellent RWJF report:

“It turns out that trying to figure out how to say something simply can be a complicated process. Each of us has developed our own set of beliefs and values. As we listen and learn new concepts, we try to fit what we hear into these existing frames. And because many of our beliefs are so deeply held, it means even the most seemingly innocuous terms can be laden with meaning.”ⁱ

We took this counsel seriously in the development of the key messages found on the following pages. The way we think about and talk about cancer health disparities – particularly within the cancer advocacy and health communities – is not necessarily how participants in the broader public or the political sphere think about health. And within the political sphere, political ideologies provide the lens through which agents of change view problems and solutions. It is with this insight in mind that we developed the following messages. We hope you will find them useful, and we look forward to your feedback and input as we continue to push for an end to the problem of disparities in cancer health.

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Key Messages

The following key messages were developed to help advocates foster a dialogue on cancer health disparities with individuals who are not familiar with the concept. These messages create a frame around health based on research into what policymakers and the public respond to best, describe the problem, and serve as priming language to help messengers move to a more nuanced discussion of disparities and the calls to action we seek. Explanation for the inclusion of certain phrases is found in the section on the right.

Key Messages:

Where health starts

Good health starts long before a visit to the doctor's office. What happens in our homes, schools, and jobs has a strong impact on how likely it is for a person to suffer from a preventable disease, including cancer.

Educated choices

In fact, more than half of all cancer deaths can be prevented. We believe all Americans should have the tools and opportunities to make the best possible choices about their own health, regardless of the where they live or the job they work.

Fixing health care where it starts

However, some Americans share an unequal burden of suffering from cancer, far beyond what genetics would explain. This is known as disparities in cancer health. Factors like the accessibility of cancer screening resources, access to quality education, and the availability of healthy food choices have an enormous impact on health. Ensuring all Americans have opportunities for good health means fixing health care where health starts, not just where it ends.

Within our power

It is within our power to create better screening programs, and research, prevention and treatment programs to tackle the problem of disparities in cancer health. And while better access to care is part of the solution, these other factors matter.

Leaders in business, government and our communities have the power to improve these factors. They can do so by taking the following actions...

Why messages were included:

Where health starts - The framing statement "Good health starts..." was the highest performing statement among elite audiences, and scored among the top frames to swing voters in the RWJF report. This frame is a proxy for the concept of social determinants of health, and uses colloquial, values-driven language, focuses on the solution versus the problem, and implicitly acknowledges the notion of personal responsibility. Starting with frames that appeal right of center and moving to the left is important in getting diverse audiences on-board with our message.

Educated choices - It is important to not overwhelm a new audience with statistics when introducing the concept of disparities. Central to the idea of health disparities is the idea that certain factors contributing to cancer can be prevented. This statistic – that half of all cancer deaths can be traced back to preventable factors – serves this role.

Fixing health care - In the previous statement, we acknowledge the role of personal responsibility and then subsequently raised the issue of an unequal burden based on factors outside of that population's control. We did not use racial terms, because disparities exist across socioeconomic as well as racial/ethnic boundaries, and because of RWJF research that indicated leading with explicit talk about race caused some participants to be less open to subsequent messaging.ⁱⁱ

We then give reasons for the prevalence of disparities – including some of the contributing factors. This information was important in the RWJF report to prime skeptical audiences to accept why disparities exist and understand the problem's origin.

We end this paragraph with a high-performing frame from the RWJF research – that good health means fixing health care where it starts, not just where it ends.

Within our power - Across all groups we tested, empowerment language performed well and was motivating for our potential messengers. This statement is a bridge to calls to action language found in a later section of this guide.

Supplementary Messages

The following messages support and supplement our key messages about cancer health disparities. They add context and further information about the problem at hand and what must be done. Because these messages are full of statistics, we do not recommend beginning a discussion about disparities with someone unfamiliar with the issue with these messages, rather, they are best employed as material to support our case and more fully describe the reality of disparities in cancer health.

The Economic Impact of Disparities in Cancer

- By eliminating disparities in cancer health, we would prevent the loss of a tremendous number of lives and economic resources.
- Racial and ethnic disparities in cancer health exact an enormous toll on our economy – nearly **\$197 billion** annually, which includes:ⁱⁱⁱ
 - **\$193 billion** due to premature death
 - **\$2.3 billion** in direct medical costs
 - **\$471.5 million** in lost productivity
- That so many Americans die from preventable cancers is a national tragedy. Americans who earn less, who live in areas without accessible medical care, or who come from traditionally disadvantaged groups needlessly die from cancer at a higher rate than other Americans.^{iv}
- We believe all Americans should be given an opportunity to live a long, healthy life, regardless of their income, education ethnic background, or their zip code.^v
- Unequal suffering from cancer is socially unacceptable, economically unsustainable, and within our power to change.
- If we as a society could end racial disparities in cancer mortality, a C-Change analysis estimates there would be over **240,000 fewer cancer deaths** each year, and a savings in total economic costs as a result of premature death of between **\$193 billion** to over to **\$1 trillion** per year.^{vi}

The Business and Workplace Impact of Cancer Disparities

- A healthy workforce is key to a productive economy. Yet, disparities in cancer health result in significant costs to productivity. This is due to more disability days taken by those with cancer, and fewer hours worked.^{vii}
- C-Change estimates the costs of losses in productivity to the economy because of racial/ethnic disparities in cancer to be **\$471.5 million** annually.^{viii}

Community and Personal Health Issues

- Cancer is a physical, emotional and economic burden. It is the **2nd most common** cause of adult death in the US and the leading cause of disease in children.
- Cancer impacts some groups more severely.

- For example, a study showed black women with breast cancer were 48 percent more likely to die within three years of diagnosis than white women with the disease.^{ix}
- Cancer causes personal bankruptcy at nearly twice the rate of the general public within a year of diagnosis, and the median time to bankruptcy is just **2.5 years after diagnosis**.^x
- **About 50% of all cancer deaths** are preventable by changes in tobacco, exercise, diet, and screening.^{xi}
- Cancer disparities are costly to our workforce, health care system, economy and society.

Workforce Issues and Disparities in Cancer

- The demand of cancer services is growing, but no national strategy for strengthening the cancer workforce exists. By 2020, **250,000** more public health workers will be needed.
- Cancer health disparities issues could be exacerbated by this challenge.
- 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.
- Eighty-five percent of all health care practice social workers work in metropolitan areas, while only two percent practice in rural areas.
- Patients with cancer are increasingly experiencing delays in diagnosis, treatment, and coordinated follow-up as a result of the strained workforce.
- 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, and only **16.8%** of registered nurses identify as Non-White or Hispanic.
- With these existing and projected shortages, the current and worsening impact to individuals at risk for, and living with cancer, is significant.^{xii}

Prevention Issues and Disparities in Cancer

- Every American deserves to live a long, healthy life. But we're falling short of that goal.
- Preventing disease is the most effective, common-sense way to improve health and reduce healthcare costs.
- About **50%** of cancer cases can be prevented by changes in tobacco use, nutrition, and physical activity, and many more lives can be saved through screening.
- Programs designed to lower individual risk of cancer can yield substantial economic value to the nation and would save lives. If cancer mortality for persons with low socioeconomic status could be lowered to mortality rates experienced by more affluent and better-educated persons, substantial costs due to premature death could be avoided.

Disparities Defined

- Cancer health disparities are the differences in the prevalence of cancers, their treatment and treatment outcomes across some of the population far beyond what their genetics would explain.
- People who are poor, lack health insurance, and are medically underserved (have limited or no access to effective health care)—regardless of ethnic and racial background—often bear a greater burden of disease than the general population.
- Race disparities in cancer incidence and mortality are due in part to differences in:^{xiii}
 - Exposure to cancer causing agents
 - Access to screening and cancer care after the onset of symptoms
 - Access to appropriate cancer treatment
 - Contextual and environmental factors that affect cancer survival, and
 - Genetic factors.
- The data on the relationship between cancer burden and socioeconomic status are not as rich as the data for racial and ethnic differences, primarily because cancer registries do not include socioeconomic measures. This presents a significant impediment to effective surveillance of cancer health disparities. However, it is clear that socioeconomic status has a significant impact on disparities in cancer health.
- Socioeconomic status influences the cancer burden through:^{xiv}
 - Increased exposure to cancer risk factors such as higher rates of smoking, heavy drinking, obesity, physical inactivity, and exposure to environmental carcinogens.
 - Reducing the likelihood of cancer screening and early detection
 - Reducing the likelihood of timely treatment, and
 - A decreased likelihood of effective contextual support for cancer patients and greater contextual stress for cancer survivors.
- Traditionally disadvantaged groups have a lower documented prevalence of cancer, likely due to the fact they are screened for cancer less frequently and survival rates are lower—so fewer people are living with cancer for the long term.
- African Americans/Blacks, Asian Americans, Hispanic/Latinos, American Indians, Alaska Natives, and underserved Whites are more likely than the general population to have higher incidence and death statistics for certain types of cancer.

Calls to Action to Address Cancer Health Disparities

The following list of calls to action are primarily targeted at lawmakers, but are intended to be broad enough to be supported by the range of sectors who have a stake in seeking the elimination of cancer and cancer disparities. Supplementary information, such as titles of legislation or specific government initiatives, should be added when available.

Risk Reduction

- Increase access to cancer screening
- Protect funding and implementation of federal prevention, diagnosis, and treatment programs
- Promote multi-sector implementation of the HHS National Prevention Strategy

Treatment

- Expand and promote the use of professional and lay patient navigation programs
- Increase access to care through development of new service delivery sites in geographically underserved areas
- Promote access to and utilization of medical homes for vulnerable populations

Research and Overarching Issues

- Support programs related to social determinants of health including literacy, access to healthy foods, safe and affordable housing, and public transit
- Increase patient-centered outcomes research specific to reducing cancer health disparities with better data collection standards
- Increase diversity recruitment requirements for clinical trials-focusing on approaches for recruiting and retaining minority participants

Workforce

- Expand training opportunities for professional and lay patient navigators in community and care settings
- Facilitate a national approach to state reciprocity for licensing of cancer health care professionals to assist underserved communities
- Support programs for recruiting providers from underserved communities to train and return to practice in their communities

Communicating about Cancer Health Disparities - Methods

It can be helpful to think about messaging as a three-step process: “set-up,” “core message,” and “ask”. The purpose of each step is to advance the conversation and move your audience to a decision and/or action. The column on the right details what we want to accomplish with each step, and best practices for success. Key and supplementary messages included in this document flow from the “set-up” into the “core message” step of this process.

	What we want them to know	Purpose and Best Practice
1. Set-up	<ul style="list-style-type: none"> Our message about cancer health disparities is relevant to the audience’s goals as an organization We share similar values about health care This is an urgent issue 	<p>The set-up must lead your audience to understand and agree with your general message frame about cancer health disparities and be open to continued dialogue.</p> <p><i>Creating a sense of urgency is important in your set-up. Additionally, your frame for talking about disparities should align with your audience’s goals – e.g., business leaders need to think about the bottom line; many policymakers believe personal responsibility is an important part of health care.</i></p>
2. Core Message	<ul style="list-style-type: none"> Cancer health disparities reductions are within our power, achievable and have concrete benefits If we work together we can reduce cancer deaths through addressing cancer health disparities 	<p>The core message helps your audience to better understand cancer health disparities issues, believe you have the right solutions to the challenge, and believe that collaborating on cancer prevention aligns with their own goals.</p> <p><i>Messages that empower people and show they can make a difference are more effective. This is also the right step for adding personal experiences. Personal stories tend to be effective particularly with policymakers because it helps them connect both rationally and emotionally. Also, ask questions! This step, in particular, is a dialogue. It is important to connect at a personal level with your audience. Get their thoughts on disparities.</i></p>
3. Ask	<ul style="list-style-type: none"> By partnering with C-Change, it will be easy for you to contribute to this important movement There is a specific action you can take to bring about change 	<p>We want the audience to agree to work with us, and if there is a more specific call to action, we want the audience to agree to support that specific policy or business action.</p> <p><i>Provide specific examples for promoting reductions in cancer disparities. Provide a “first step” to continue the dialogue and/or take action. Making this first step easy is important – the first conversation is not an ideal time for a large request.</i></p>

Conversing on Cancer Health Disparities – Tips

The following chart lays out tips for engaging in conversations about cancer health disparities. Several tips are based on best practice suggestions in the Robert Wood Johnson Foundation’s paper, *A New Way to Talk about the Social Determinants of Health*, pg. 5.

Do:

- Use a statistic that will grab the audience’s attention and challenge conventional wisdom.
- Use colloquial, values-driven and emotionally compelling language. Academic language, such as “interventions” do not resonate with some audiences the way talking about family, healthy choices, and saving lives can.
- Identify the problem and potential solutions. The “ask” step of messaging responds to an audience’s desire for concrete direction – either an example of the kind of action that would address the problem, or a set of principles that can guide us to where we need to go.
- Communicate the importance of personal responsibility. This idea resonates with audiences across the political spectrum, and makes people more receptive to the idea that society has a role to play in ensuring healthy choices are universally available.
- Use language with policymakers and the public to reframe how they think about health, such as “Disparities in cancer health go beyond genetics – and it’s within our power to reduce disparities in cancer.”
- When referring to data, cite credible organizations such as the American Cancer Society to credential your statement.
- Gather information about whom you’ll communicate with through background research so you can tailor your messaging.

Don’t:

- Use too many statistics that can confuse the audience and lessen the impact. Focus on the single most important statistic and the audience’s ability to create change.
- Use technical terms such as “intervention” with policymakers, business leaders and the public. Good alternatives include programs, policies, initiatives, and strategies. In general, simpler language is more effective.
- Use phrases and words that take away choice and/or could make people feel powerless in their health, e.g., social determinants of health, genetics, etc.
- Use the word “prevention” with the general public when possible. The general population believes you cannot “prevent” cancer. Instead, talk about “reducing the risk of cancer.”
- Lead off policy discussions by talking about taxes as a way to fund programs. Taxation as a policy option is unpopular and takes away from the empowerment frame when communicating with the general population.
- Talk about abstract groups, e.g., “healthy communities.” Particularly when speaking with business leaders or policymakers, refer to the communities in which they do business and serve.
- Over-emphasize the short-term economic benefits of disparities reductions—while the economic case is important, remember that saving lives is also a strong argument.

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- ⁱ Robert Wood Johnson Foundation (RWJF) Vulnerable Populations Portfolio, "A New Way to Talk About the Social Determinants of Health." Last modified January 1, 2010. Accessed September 10, 2012. <http://www.rwjf.org/content/rwjf/en/research-publications/find-rwjf-research/2010/07/a-new-way-to-talk-about-the-social-determinants-of-health.html>. PDF available at the included hyperlink.
- ⁱⁱ RWJF, pgs. 5, 24, 31
- ⁱⁱⁱ Gaskin, Darrell J., LaVeist, Thomas A., Richard, Patrick, Ford, Jean G. C-Change, "The Societal and Economic Impact of Cancer Health Disparities." Accessed September 14, 2012, pg. 2.
- ^{iv} Gaskin et al., pg. 19
- ^v Gaskin et al., pgs. 19, 21
- ^{vi} Gaskin et al., pg. 40
- ^{vii} Gaskin et al., pg. 9
- ^{viii} Gaskin et al., pg. 46
- ^{ix} Health Day, "Black Breast Cancer Patients May Have Higher Death Risk in First 3 Years." Accessed Nov 10, 2012. <http://consumer.healthday.com/Article.asp?AID=670218>
- ^x American Society of Clinical Oncology (ASCO) 2011 Annual Meeting: Abstract 6007. Presented June 6, 2011.
- ^{xi} Gaskin et al., pg. 48
- ^{xii} C-Change, "A National Strategy to Strengthen the Cancer Workforce: Position Statement and Call to Action." Accessed October 2, 2012. http://c-changetogether.org/Websites/cchange/images/Documents/c-change_workforkce_position_statement-_february_2012v1.pdf
- ^{xiii} Gaskin et al., pg. 12
- ^{xiv} Gaskin et al., pg. 14