



Stop Cancer Before It Starts!

The Prevent Cancer Foundation

# ADVOCACY ACADEMY

Prevention in the 114th Congress

## FINAL REPORT

Wednesday, December 3, 2014

Washington, DC



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# agenda

prevent



Cancer  
FOUNDATION

On December 3, 2014, the Prevent Cancer Foundation held a one-day Advocacy Academy: Prevention in the 114th Congress. The event brought together dozens of advocates from cancer organizations as well as stakeholders from other chronic disease and health advocacy organizations to prepare for the 114th Congress.

Led by professional facilitator and scientific strategist Robert Mittman, participants worked together in an effort to strategically and comprehensively address the most pressing policy and advocacy challenges facing cancer prevention and early detection efforts. Throughout the day, participants discussed the current state of cancer prevention policy and what a shared vision of success would look like if effective cancer prevention policies were in place. Attendees brainstormed the most important policy needed to realize this vision and the obstacles that could derail those changes. Finally, small groups determined the most important strategies for overcoming these barriers and outlined specific actions that could be taken in order to achieve sustainable and meaningful policy changes.

The advocacy work of the Prevent Cancer Foundation is driven by the following policy priorities. Each is accomplished through work with the U.S. Congress and executive branch (including federal agencies) as well as colleague organizations, state legislatures, and relevant stakeholders including grassroots advocates.



## PREVENTION

Support and work towards policies and education efforts that will reduce cancer diagnoses and preventable deaths.



## ACCESS

Increase access to necessary health care services including cancer prevention and early detection screening and resources.



## DISPARITIES

Reduce the barriers for all individuals (particularly those who are underserved) to achieve optimal health and wellness including, but not limited to access, affordability, and equity.



## FUNDING

Ensure adequate funding for cancer research, prevention, and early detection efforts at federal and state levels.



## HEALTH CARE

Promote patient-centered, accessible, integrated, high-quality health care for all.

# Prevent Cancer Foundation Advocacy Academy: Prevention in the 114th Congress

## GOAL

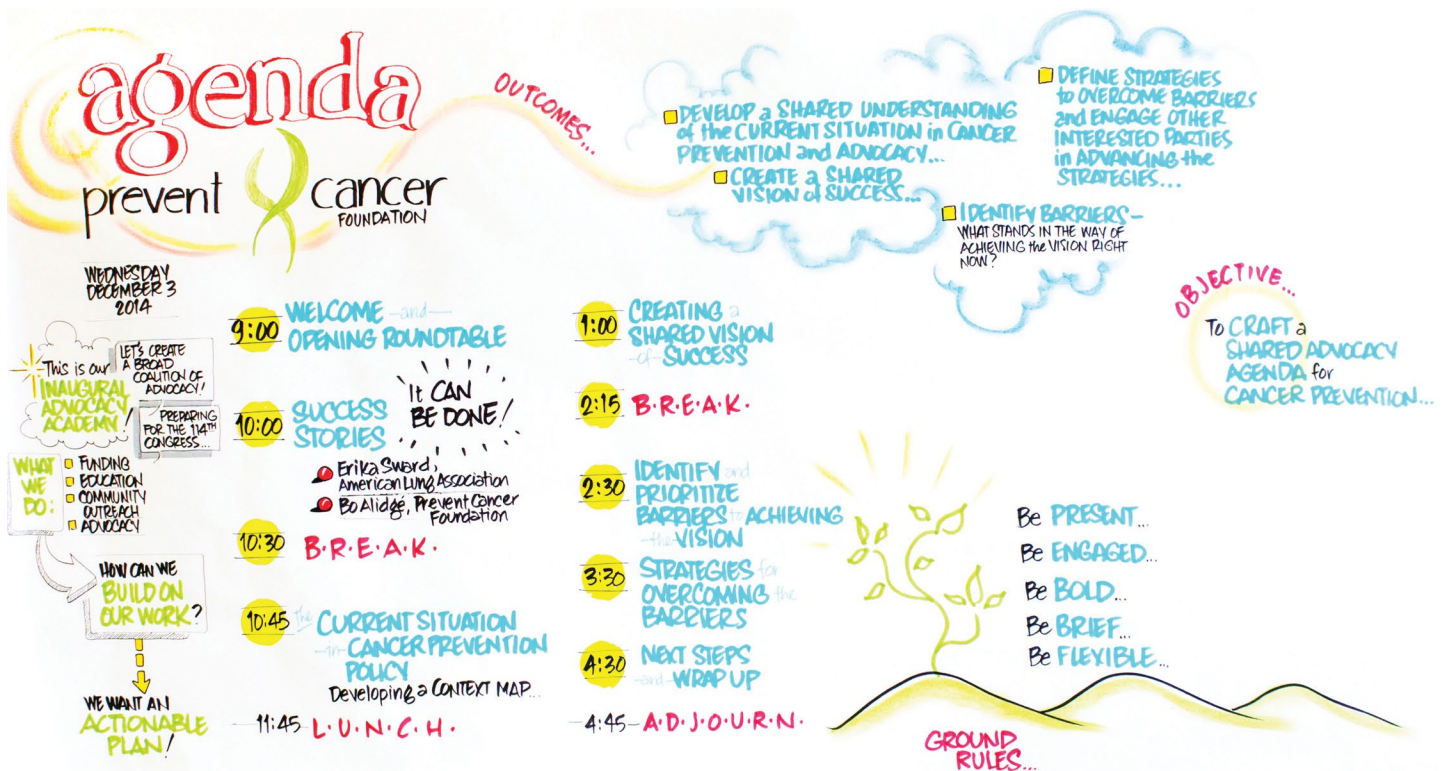
Craft a shared advocacy agenda for cancer prevention

## OBJECTIVES

- Work with experienced health advocacy organizations to strengthen their networks and effectively impact policy from prevention through survivorship and help guarantee patient access to quality care and therapies
- Empower organizations with the ability to collaborate in order to make an impact on prevention legislation, policies, and regulations
- Develop a shared understanding of the current situation in cancer prevention and advocacy
- Create a shared vision of success with all participant organizations and stakeholders
- Identify barriers to success and develop strategies to overcome those barriers and advance cancer prevention and early detection in the 114th Congress

## ADVOCACY ACADEMY AGENDA

- I. Welcome and Opening Remarks
- II. Success Stories
- III. The Current Situation in Cancer Prevention Policy
- IV. Create a Shared Vision of Success
- V. Identify and Prioritize Barriers to Achieving the Vision
- VI. Develop strategies to Overcome the Barriers
- VII. Determine next Steps and Wrap-Up



The Advocacy Academy was captured by graphic facilitator Anthony Weeks and his illustrations are included throughout this report.

# Welcome and Opening Remarks

Prevent Cancer Foundation President and Founder Carolyn (Bo) Aldigé welcomed attendees to the Advocacy Academy. She noted that the Foundation is dedicated to saving lives through cancer prevention and early detection. Over the past 30 years, the Foundation has invested over \$138 million in support of the following:

**FUNDING** early-career researchers who focus on live-saving cancer prevention and detection science

**EDUCATIONAL PROGRAMS** that help individuals across the country understand the importance of healthy lifestyle choices

**COMMUNITY OUTREACH** efforts to help vulnerable populations adhere to recommendations leading to lifesaving cancer prevention and early detection

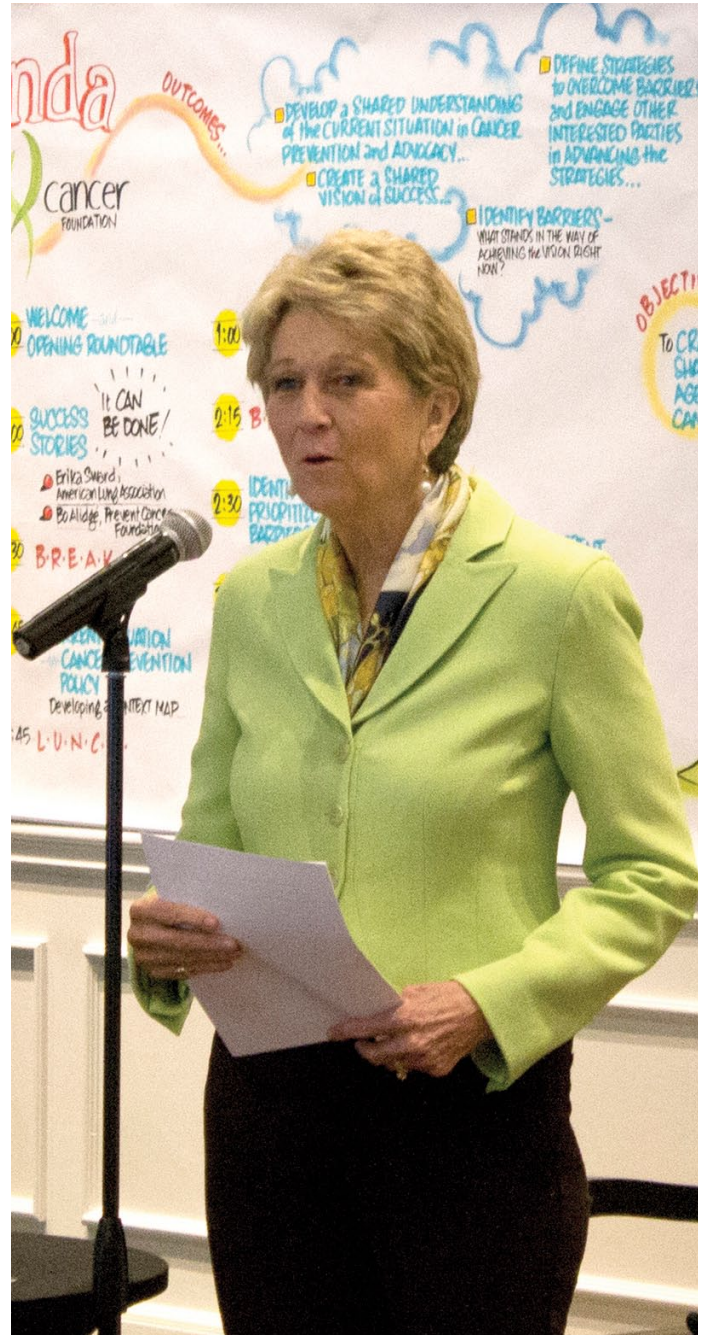
**ADVOCACY** to engage law and policy makers to support legislation, regulations, and policy to support cancer research, prevention, and early detection

Through each of these elements, the Prevent Cancer Foundation is working to create a world where we can decrease the number of people and families who suffer from life-limiting and devastating diseases.

Ms. Aldigé noted that the group gathered together for the Advocacy Academy because as the Prevent Cancer Foundation sets its policy agenda for the 114th Congress, it will be much stronger if health and patient advocacy organizations work together. She encouraged participants to function as a broad coalition of advocates who can speak on behalf of tens of millions of individuals and families, and virtually every community across this nation who are at risk for, or will experience, cancer, diabetes, arthritis, heart disease, and many other chronic diseases that are largely preventable.

Ms. Aldigé noted the importance of the Advocacy Academy as a working meeting, to which participants were invited because of the expertise and experience they could tap into and inform the conversation.

Additionally, the Advocacy Academy was timed in anticipation of the sweeping changes the midterm elections would bring. Regardless of political affiliation, there are many new dynamics at play on Capitol Hill and in state legislatures across the country. What's more, the next two years will be spent in the run-up to



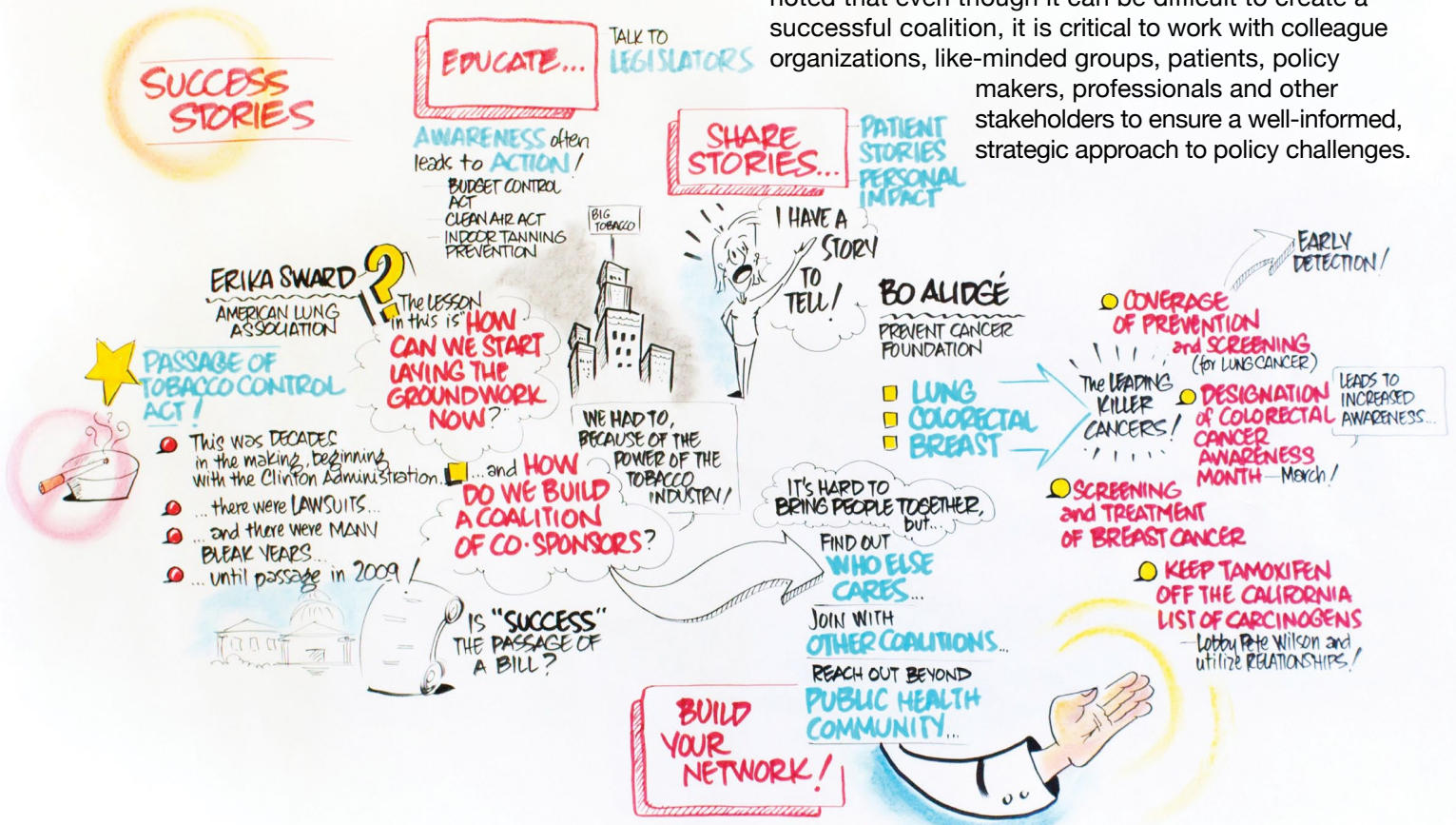
a Presidential election, ongoing budget and financing debates, and competing demands for funding, attention, and priority. As such, the Advocacy Academy focused on how organizations can build on their work together - and support one another - in a fiercely competitive environment. The Advocacy Academy would be a starting point for an increasingly important conversation.

# Success Stories

Carolyn (Bo) Aldigé (Prevent Cancer Foundation) and Erika Sward (American Lung Association) spoke to the Advocacy Academy participants about previous successes in cancer prevention and early detection policy. Ms. Sward focused on passage of the Family Smoking Prevention and Tobacco Control Act as a major legislative milestone in the fight against cancer and the vital importance of a cohesive coalition poised to take action on areas of common interest. She also remarked that advocates must not only focus on passing legislation and working towards new prevention policies, but also building on past successes and protecting the progress that has already been made.

Ms. Aldigé discussed the tremendous progress that has been made over the past several decades in cancer prevention and early detection. She noted that through the relentless work of advocates and coalitions, successes included coverage for lung cancer screening, federal designation of National Colorectal Cancer Awareness Month, enhanced screening and treatment measures for breast cancer, and advocacy to keep the breast cancer drug tamoxifen off California's list of carcinogens.

Both speakers wove in the importance of relationships and perseverance in the face of seemingly-insurmountable odds and daunting opponents. They noted that even though it can be difficult to create a successful coalition, it is critical to work with colleague organizations, like-minded groups, patients, policy makers, professionals and other stakeholders to ensure a well-informed, strategic approach to policy challenges.



# The Current Situation in Cancer Prevention Policy: Looking at the Context



Outcomes from group discussions were captured and are outlined throughout this report.

## CANCER CARE PAYMENT ISSUES

- Inadequate insurance and cost sharing
- Lack of insurance portability
- High specialty drug costs
- Stepped therapies that restrict access to beneficial treatments
- Narrow insurance coverage networks
- Inadequate physician reimbursement
- Cost-driven clinical pathways
- Lack transparency in assessing cost vs. benefit
- Lack of dialogue between insurance companies and pharmaceutical companies
- High transportation costs and barriers

## COMMUNICATIONS ISSUES AND TRENDS

- Significant challenges exist in reaching underserved populations
- Strong communications messages are needed for different segments of the population as well as policymakers
- Health advocates are competing against multi-million dollar advertising campaigns
- Messaging is needed regarding the social and structural issues that contribute to chronic illness

- Cancer prevention messaging that is positive and avoids blaming is key
- Lessons can be learned from pharmaceutical companies regarding prevention advertising/marketing
- Individuals need reputable information on health behaviors e.g., smoking cessation and eating well
- Prevention messages must be integrated as early as possible
- Cancer prevention must be made “sexy” on multiple levels
- Millennials should be a target demographic for education about cancer prevention and early detection
- Outreach across social media channels/ platforms is necessary
- Behavioral health messaging is critical for communities most in need

## HEALTH CARE ACCESS ISSUES AND TRENDS

- Screening modalities are sometimes unreliable
- Challenges exist in accessing specialists
- Primary care providers often lack cancer prevention training
- Low-income and underserved populations still have rationed health care
- Recommendations for prevention are not clearly understood by the general population
- Consolidation of health care services has resulted in

# The Current Situation in Cancer Prevention Policy: Looking at the Context (continued)

- a lack of providers in underserved areas such as rural communities
- A lack of oncology health care providers in the pipeline will be a challenge
- Millions of people are still uninsured or underinsured and there is a lack of access to screening
- The Affordable Care Act (ACA) has resulted in some unintended policy consequences, such as changes in the Centers for Disease Control and Prevention (CDC) changes to screening programs
- Many healthcare providers work normal business hours and some people cannot fit appointments into their schedules

## POLICY ISSUES AND TRENDS

- Deep negative repercussions exist due to the Budget Control Act and sequestration
- Prevention efforts are damaged by a lack of dynamic scoring
- Sharing of information about symptoms could lead to earlier detection
- Continual reductions in funding for basic discovery research are devastating
- “No new money” exists to fund cancer prevention and early detection research and initiatives
- Labeling food and calorie counts has been critical to cancer prevention
- States can inform federal prevention policy

## RESEARCH ISSUES AND TRENDS

- A bigger evidence base is yet to be built, although there is not a paucity of prevention evidence
- The research bureaucracy is big and systems do not talk to one another
- Our country values short-term priorities and there is a lack of investment in long-term research
- Methods for collecting evidence are archaic (e.g. slow clinical trials)
- Primary and secondary prevention are both important
- Research is done nationally, not internationally, although many solutions would benefit global populations
- A need exists for a government, academic, and private research partnership—“There is something wrong with asking for pennies and dimes at grocery checkout lines to fund cancer research.”
- Prevention research cannot be divorced from future preparation
- The research base on prevention must grow
- Big data is important to research but the prevention and early detection fields are behind in utilizing it

- Stakeholders do not properly communicate with one another
- Translational research is critical, yet underutilized
- A need for research on behavioral interventions is key, particularly those that are tailored to specific populations
- Successes in past research are ignored in favor of new research

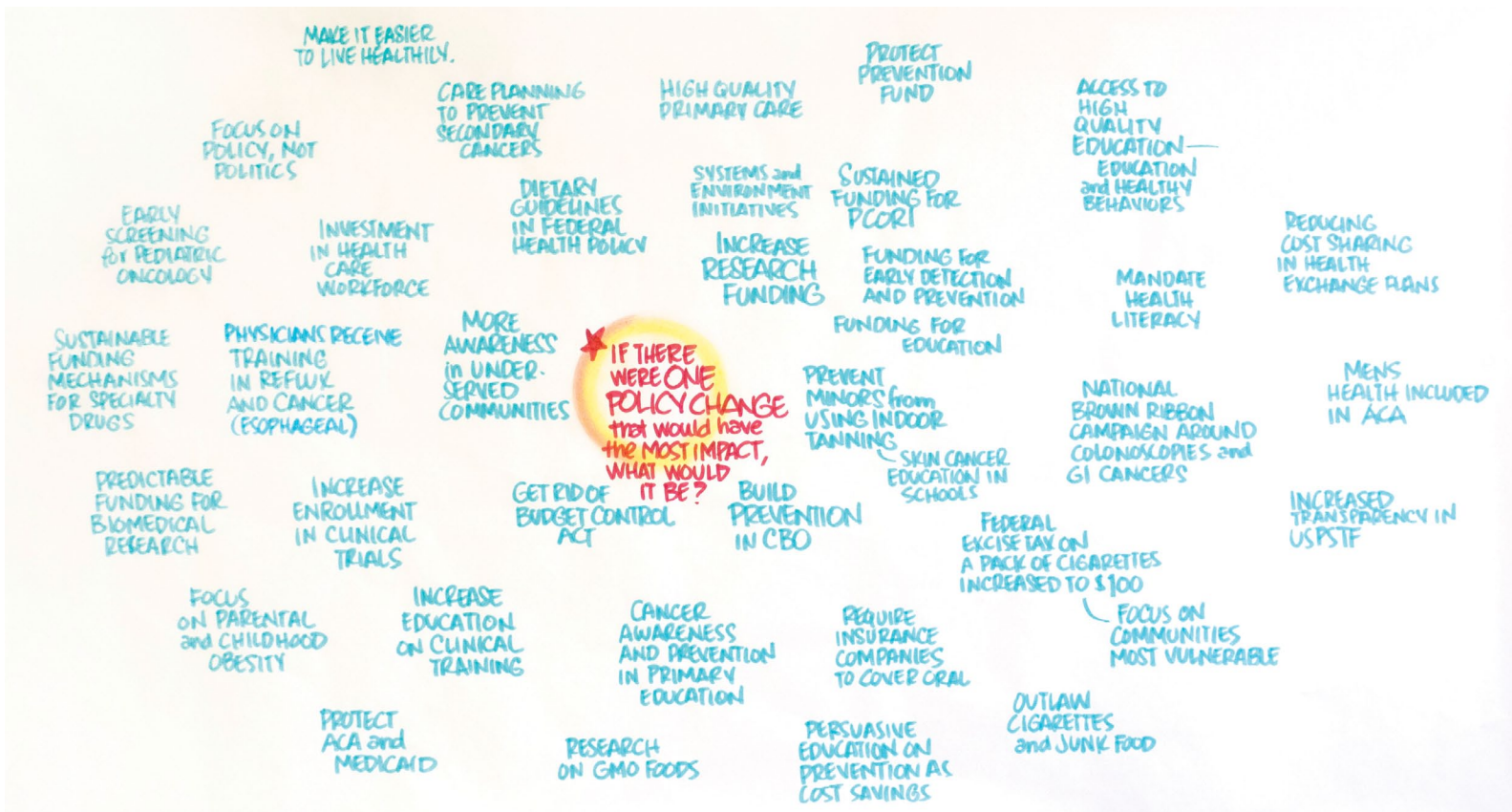
## KEY UNCERTAINTIES

- How do we reach and motivate all populations so that they can make healthy lifestyle choices?
- Why prevention? There are still things that are lower on the hierarchy of needs and prevention is often seen as a luxury.
- How can we convince politicians to invest in long-term prevention strategies?
- What is the return on investment for prevention strategies?
- How do we know when we are successful?
- What is the future of the Affordable Care Act?
- What is the impact of dynamic scoring?
- What’s going to happen in the next two years in federal and state government?





# If there were one policy change that would have the most impact, what would it be?



## EDUCATIONAL

- Enhance access to, and funding for, high quality education regarding healthy behaviors
- Include cancer awareness and prevention information in primary education
- Increase education on clinical training
- Mandate health literacy
- Create a national “brown ribbon campaign” around GI cancer and screening

## ENVIRONMENTAL AND BEHAVIORAL

- Make it easier to live healthily
- Implement systems and environment initiatives that promote prevention
- Increase the federal excise tax on cigarettes to \$100
- Outlaw cigarettes and junk food
- Focus on obesity
- Conduct research on genetically modified foods
- Promote dietary guidelines in federal health policy
- Prevent minors from using indoor tanning beds
- Implement skin cancer education in schools



## If there were one policy change that would have the most impact, what would it be? (continued)

### FEDERAL INITIATIVES

- Protect the Prevention and Public Health Fund
- Ensure sustainable funding for the Patient Centered Outcomes Research Institute (PCORI)
- Increase the transparency of the United States Preventive Services Task Force (USPSTF)
- Focus on policy, not politics

### FOCUS ON UNDERSERVED COMMUNITIES

- Enhance awareness of prevention and early detection in underserved communities
- Focus on most vulnerable communities

### FUNDING AND FINANCE

- Work to increase and ensure predictable funding for biomedical research
- Build prevention into Congressional Budget Office (CBO) scoring

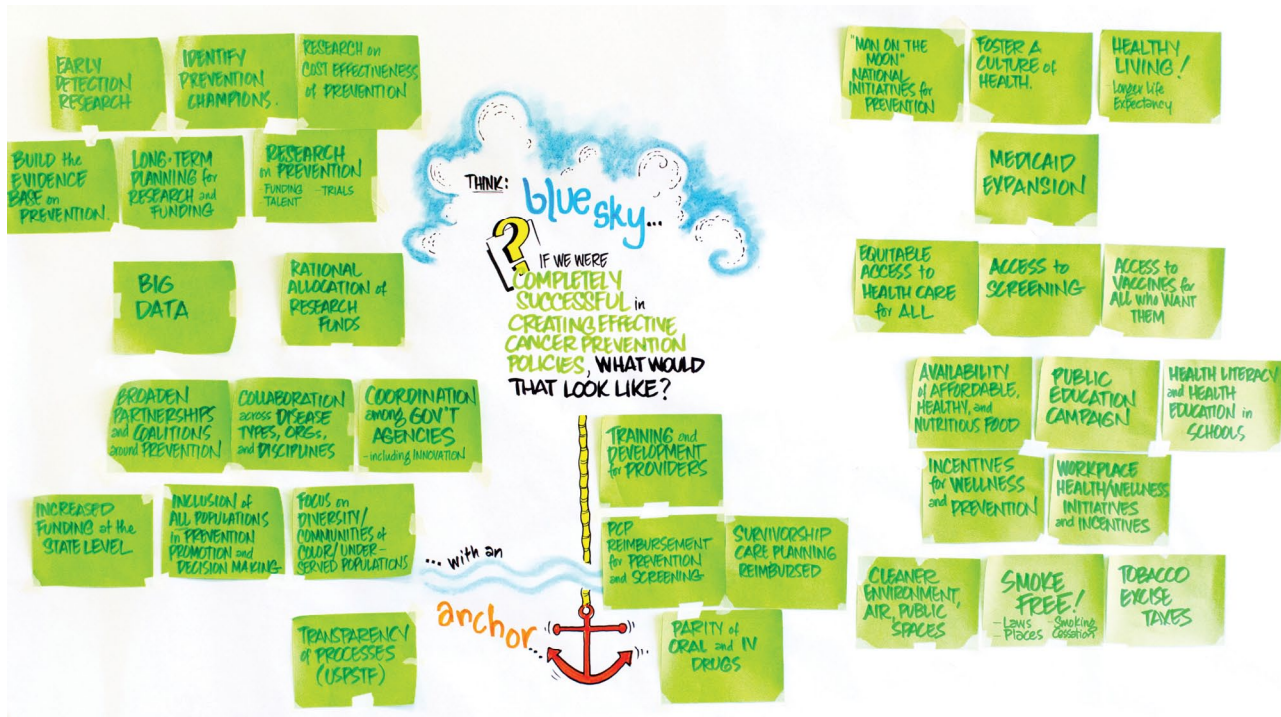
- Eliminate the Budget Control Act
- Promote sustainable funding mechanisms for specialty drugs
- Require insurance companies to cover oral chemotherapy drugs
- Reduce cost sharing in health insurance plans
- Educate decision makers about prevention as a cost saving measure
- Encourage funding for prevention and early detection

### MEDICAL, HEALTH, AND WORKFORCE

- Ensure care planning to prevent secondary cancers
- Ensure high quality primary care
- Invest in the healthcare workforce
- Increase enrollment in clinical trials



# If we were completely successful in creating effective cancer prevention policies, what would that look like?



## COLLABORATION AND COORDINATION

- Broad partnerships and coalitions around prevention are needed
- Collaboration across disease types, organizations, and disciplines is critical
- Coordination amongst government agencies is vital

## EDUCATIONAL

- A cancer prevention and early detection public education campaign should be created
- Health literacy and education courses should be available in schools

## ENVIRONMENTAL AND BEHAVIORAL

- A culture of health should permeate the nation
- Healthy and nutritious foods should be available across the country
- Incentives should exist for health and wellness
- A cleaner environment should be a priority
- The nation should be tobacco-free
- Tobacco excise taxes should be increased



## If we were completely successful in creating effective cancer prevention policies, what would that look like? (continued)

### FEDERAL INITIATIVES

- The U.S. Preventive Services Task Force (USPSTF) should be more transparent
- Cancer prevention champions should be identified

### FUNDING

- Increased funding for cancer prevention and early detection should be a priority

### HEALTH CARE AND EQUITY

- Medicaid should be expanded in all 50 states
- All populations should be included in prevention promotion and decision making
- Communities of color and underserved populations should be a focus
- Equitable access to health care for all should exist
- Equitable access to cancer screenings for all should exist
- Equitable access to vaccines for all should exist
- Parity for oral and intravenous chemotherapy drugs should be in place

### MEDICAL, HEALTH, AND WORKFORCE

- Providers should receive training and development in cancer prevention and early detection
- Reimbursement should exist for primary care physicians for prevention and screening

### RESEARCH

- Ample prevention and early detection research should be a priority



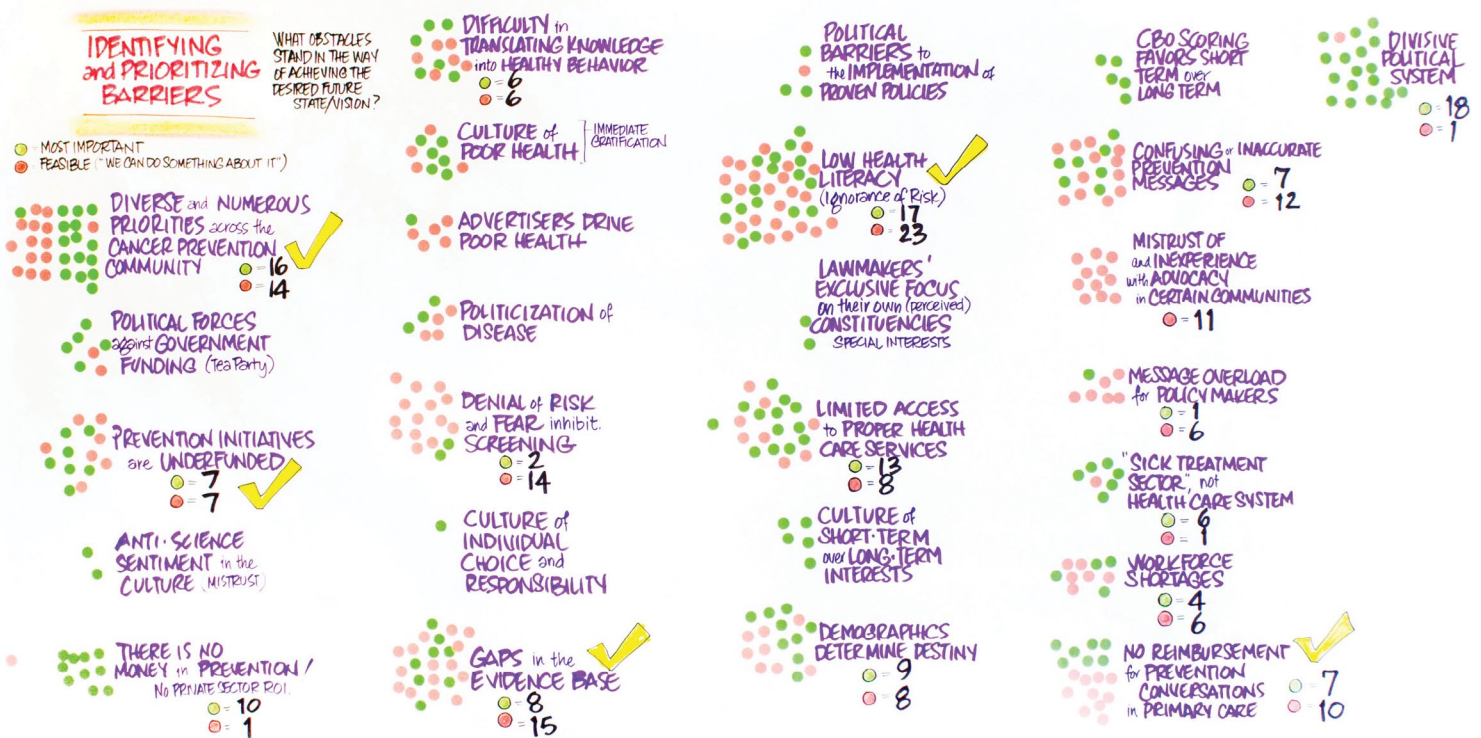
- Cost-effectiveness research on cancer prevention and early detection should be a priority
- A strong evidence base for prevention should exist
- A long-term plan for research and funding should be in place

### OTHER

- A major goal should be national cancer prevention and early detection “moonshot”



# Identifying and Prioritizing Barriers: What are the barriers to the desired future vision?



## COLLABORATION AND COORDINATION

- Diverse and numerous priorities exist across the cancer prevention community

## EDUCATIONAL

- Health literacy is too low
- Denial of risk and fear of screening are prevalent
- Prevention messages can be confusing and inaccurate
- Translating knowledge into healthy behaviors is difficult

## ENVIRONMENTAL AND BEHAVIORAL

- The United States has an anti-science sentiment in the culture (mistrust)
- A culture of poor health, immediate gratification, individual choice, and responsibility exists in the U.S.
- Advertisers drive poor health



## Identifying and Prioritizing Barriers: What are the barriers to the desired future vision? (continued)

### FINANCE AND FUNDING

- Reimbursement does not exist for prevention conversations in primary care
- Prevention initiatives are underfunded
- There is no money in prevention and no private sector return on investment
- There are political forces against government funding

### HEALTHCARE AND ACCESS

- Limited access to proper health care services is a major challenge
- Demographics determine destiny and drive health disparities
- The United States has a “sick treatment sector” instead of health care system

### MEDICAL, HEALTH, AND WORKFORCE

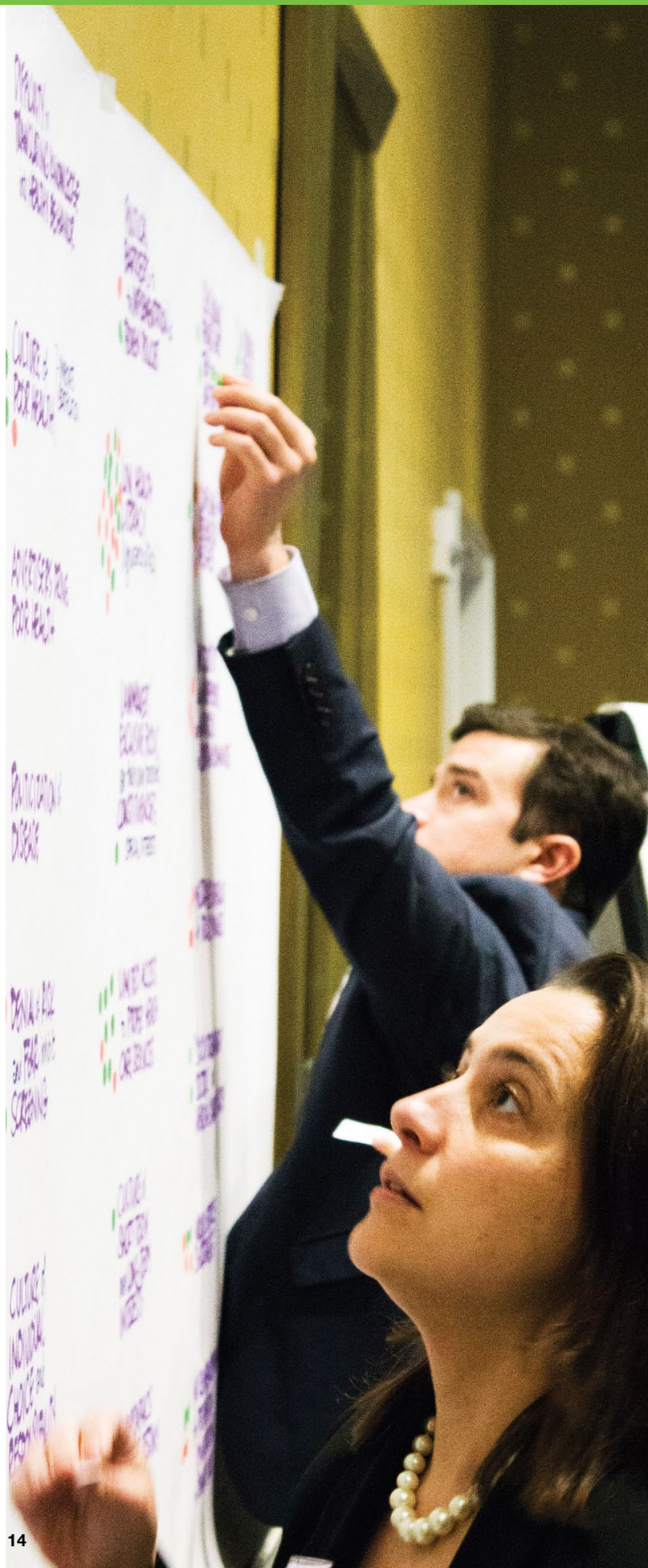
- Significant healthcare workforce shortages exist

### POLITICAL SYSTEM

- The United States has a divisive political system that makes it difficult to accomplish meaningful change
- Significant political barriers pose a threat to the implementation of proven policies
- A general mistrust of, and inexperience with, advocacy in certain communities is a barrier to action
- Policy makers are overloaded with different issues and competing priorities
- The politicization of different diseases is a challenge
- Lawmakers exclusively focus on their own (perceived) constituencies and special interests
- A culture of short-term over long-term interests has negative repercussions
- The Congressional Budget Office (CBO) scoring favors short-term over long-term solutions

### RESEARCH

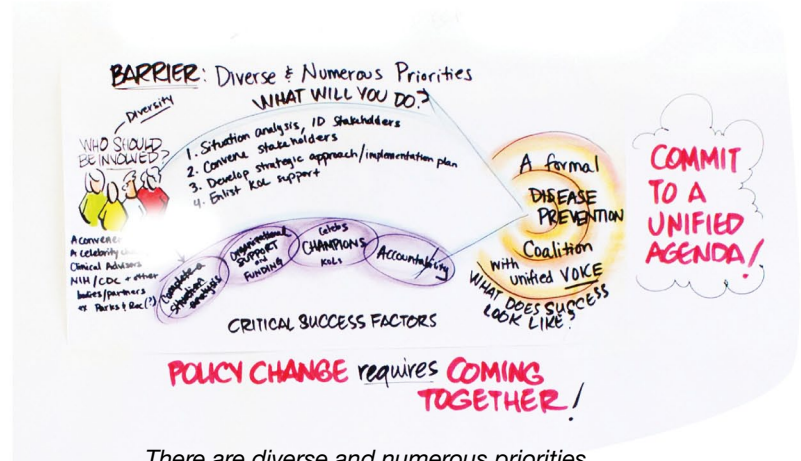
- Gaps in the evidence base exist and pose challenges



# Strategies to Overcome the Barriers



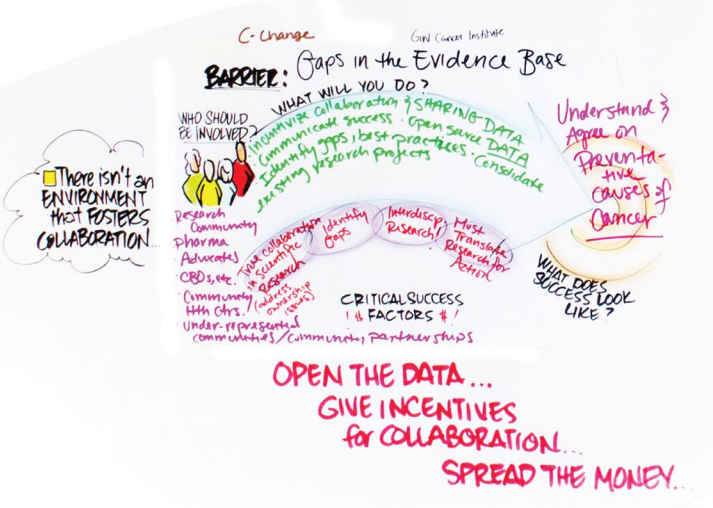
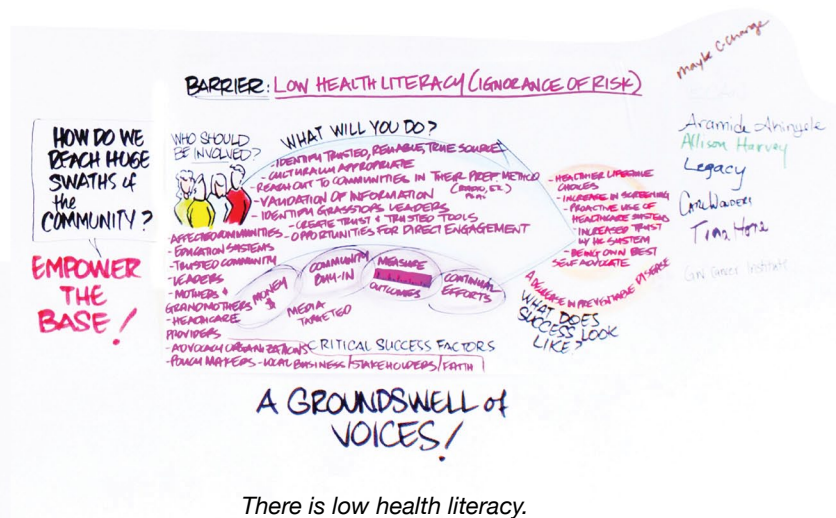
Prevention initiatives are under funded.



There are diverse and numerous priorities.



There is no reimbursement for prevention conversations in primary care.



There are gaps in the evidence base.

## Strategies to Overcome the Barriers (continued)



### 1. BARRIER: PREVENTION INITIATIVES ARE UNDERFUNDED.

#### Who should be involved?

- Government
- Industry
- Community leaders
- Elected officials
- Payers
- Medical professionals
- Patients and advocates

#### What does success look like?

- A diverse coalition would be formed to develop a funding plan for evidence-based prevention initiatives.

#### What are the critical success factors?

- Relationships
- Urgency
- Parameters
- Commitment to plan

#### What will you do?

- Convince all players to join a coalition based on individual interests.

### 2. BARRIER: THERE ARE DIVERSE AND NUMEROUS PRIORITIES.

#### Who should be involved?

- A convener
- A celebrity champion
- Clinical advisors
- National Institutes of Health
- Centers for Disease Control and Prevention
- Other relevant bodies/partners such as Departments of Parks and Recreation

#### What does success look like?

- A formal disease prevention coalition with a unified voice

#### What are the critical success factors?

- Organizational support and funding
- Champions—celebrities and key opinion leaders
- Accountability

#### What will you do?

- Situation analysis
- Convene stakeholders
- Develop strategic approach/implementation plan
- Enlist key opinion leader support



## Strategies to Overcome the Barriers (continued)

### 3. BARRIER: THERE IS NO REIMBURSEMENT FOR PREVENTION CONVERSATIONS IN PRIMARY CARE.

#### Who should be involved?

- Payers—private and CMS
- Physician groups
- Advocacy and public health groups

#### What does success look like?

- Replace fee for service model with individual patient outcomes

#### What are the critical success factors?

- Behavioral change
- Change of financial incentives for physicians and providers
- Electronic medical record integration
- Consistent guidelines
- Focus on guidelines for care

#### What will you do?

- Implement models
- Proven success stories
- Report and develop supporting evidence
- Collect personal stories
- Identify physician champions
- Build a coalition

### 4. BARRIER: THERE ARE GAPS IN THE EVIDENCE BASE.

#### Who should be involved?

- Research community
- Pharmaceutical companies
- Advocates
- Congressional Budget Office
- Community health centers
- Underrepresented communities

#### What does success look like?

- Understand and agree on preventable causes of cancer

#### What are the critical success factors?

- True collaboration in scientific research (address ownership issues)
- Identify gaps
- Interdisciplinary research
- Must translate research for action
- Resources and funding

#### What will you do?

- Incentivize collaboration and sharing of data
- Communicate success
- Promote open source data
- Identify gaps and best practices
- Consolidate existing research projects



### 5. BARRIER: THERE IS LOW HEALTH LITERACY.

#### Who should be involved?

- Affected communities
- Educational systems
- Trusted community leaders
- Families
- Healthcare providers
- Advocacy organizations
- Policy makers
- Local businesses
- Faith community leaders
- Other stakeholders

#### What does success look like?

- Healthier lifestyle choices
- Increase in screening
- Proactive use of healthcare systems
- Increased trust in healthcare systems
- Being own best self-advocate
- A decrease in preventable disease

#### What are the critical success factors?

- Money and resources
- Community buy-in
- Measurement of outcomes
- Continual efforts
- Targeted media

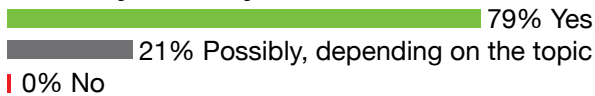
#### What will you do?

- Identify trusted and reliable sources
- Create culturally appropriate health literacy materials
- Reach out to communities through their preferred methods of communication
- Validate health literacy information
- Identify grassroots leaders
- Create trust and trusted tools
- Create opportunities for direct engagement

# 2014 Advocacy Academy Participant Feedback

Following the Advocacy Academy, participants were surveyed regarding their experience and ideas for future events.

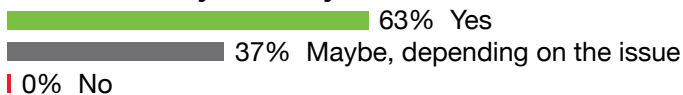
## Would you attend another Prevent Cancer Foundation Advocacy Academy Event in the future?



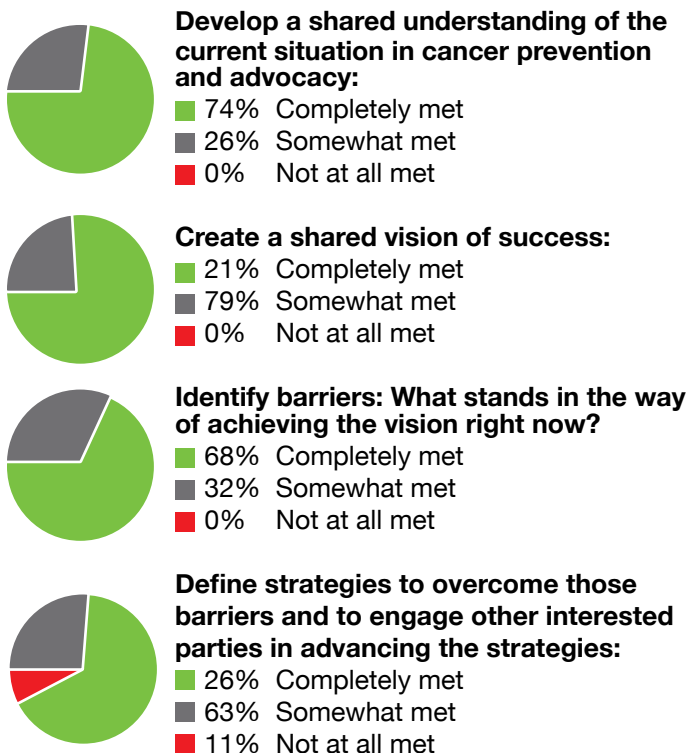
## Did the Advocacy Academy keep you engaged throughout the day?



## Are you interested in working with the Prevent Cancer Foundation on furthering the ideas outlined at the Advocacy Academy event?



## How well do you believe that the following outcomes of the Advocacy Academy were met?



## What was your favorite component of the Advocacy Academy?

*I would say a tie between the participants, facilitator, and artist, all of which were critical*

*It is hard to choose only one.*

## How can future Advocacy Academy events be improved upon?

*Drill down into specific policy areas such as funding, research, and disparities.*

*Identify potentially feasible strategies for achieving goals and ways to prepare our organizations to participate.*

*I would do round 2 of this and actually end with a bill we can all get behind*

***I loved the graphic artist!  
 As I am a visual learner, it was nice to have everything pulled together through that medium as opposed to written notes.***

***The facilitator and agenda were excellent and the outcomes were impressive.***



*Stop Cancer Before It Starts!*

**The Prevent Cancer Foundation's mission is saving lives through cancer prevention and early detection. Since 1985, the foundation, a 501(c)3 nonprofit organization, has invested over \$138 million in support of cancer prevention research, education, outreach, and advocacy programs nationwide and has played a pivotal role in developing a body of knowledge that is the basis for important prevention and early detection strategies.**



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