



**Empowering patients and caregivers through a national patient education program.**

**Background:** In 2013, 1.6 million people in the US will be newly diagnosed with cancer. Countless more will be affected by a loved one's cancer diagnosis. For many, an essential part of coping is to search for information on treatments, side effects, and maintaining a good quality of life. New developments in the diagnosis and treatment of cancer are happening constantly. Yet, this information is not always easy to obtain in one place. Therefore, it is imperative that individuals have access to unbiased resources that explain advances in cancer research, provide effective communication tools, and empower them throughout their care.

**Purpose/Objectives:** To meet this need the Cancer Support Community (CSC) created the national patient education program *Frankly Speaking About Cancer: New Discoveries*. The program consists of a comprehensive patient education booklet, professionally-led workshops and online content that combine the most current clinical and psychosocial information on cancer and novel therapies. The purpose of the current analyses is to evaluate how this program is meeting its goals, namely, providing meaningful information and tools to empower patients to take an active role in their healthcare management.

**Methods/Approach:** In 2012, CSC delivered 22 *Frankly Speaking About Cancer: New Discoveries* workshops to 432 patients and their loved ones through its affiliate network across the US. Attendees completed a post-workshop evaluation assessing demographics, knowledge gained from attending the workshop, patient-provider communication, and overall workshop satisfaction. Of the 432 attendees, 331 completed evaluations (76% response rate).

**Results:** The majority of respondents (66.7%) were people diagnosed with cancer, and the remainder were spouses/partners and family members. 72.7% of respondents were female, and 85.9% were Caucasian. Most respondents (77.6%) reported a 'high' or 'very high' level of knowledge about cancer treatments after attending the workshop, significantly higher than pre-workshop knowledge levels. In addition, a majority reported feeling better equipped to ask questions to their healthcare team (81.1%), and discuss the possibility of clinical trials with their healthcare team (68.6%) after attending the workshop. Nearly all (95%) recommend the workshop to others impacted by a cancer diagnosis.

**Conclusions:** Workshop results suggest the program is successful in improving access to comprehensive information about the treatment of cancer. Results also indicate a strong need to continue to provide clear and relevant information and support to people impacted by cancer, through this interactive, comprehensive program format.



# Empowering patients and caregivers through a national patient education program

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# Cancer Support Community Mission

To ensure that all people impacted by cancer are:

- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community



# Frankly Speaking About Cancer Series

- Provide easy to understand in-depth coverage of topics of relevance to those affected by cancer
- Guided by Patient Empowerment Approach
- Topics are tumor type-specific or more general
- Up-to-date content reflecting new advances in cancer, delivered via:
  - Web-based materials
  - Print materials
  - Professionally-led workshops
  - Online radio series



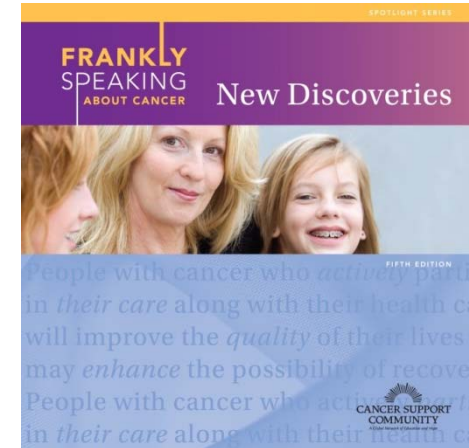
# Background

- 1.6 million people diagnosed with cancer this year (+ family and loved ones)
- For many, essential component of coping is having access to information, especially on the most recent developments in cancer



# Program Overview

- CSC created a national education program, *Frankly Speaking About Cancer: New Discoveries*
- Discusses current clinical and psychosocial information on cancer, including:
  - cancer and genetics
  - biomarkers
  - clinical trials
  - research on benefits of social and emotional support
- Program delivery (print, online, workshops)
  - In 2012, 22 workshops with 432 attendees



# Purpose & Methods

- Goal is to evaluate how program is meeting its goals of:
  - providing meaningful information and
  - providing tools to empower participants
- After workshop, attendees completed paper & pencil evaluation



# Respondent Characteristics

- N=331 (response rate = 76%)
- Avg age= 61.4 years (s.d. = 12.5 yrs)
- Most were:
  - Female (72.7%)
  - Caucasian (85.9%)
- Attendee Breakdown:
  - people diagnosed with cancer (66.7%)
  - spouses/partners (11.2%)
  - other family members (10.3%)
  - health care professionals (5.8%)
- For 51.4%, this was their first CSC workshop





# Respondents with Cancer

- 45.1% had been diagnosed with breast cancer
- 27.5% diagnosed with metastatic disease
- 28.5% diagnosed in past year
- 32.4% diagnosed 5+ years ago
- Treatments respondents have had:
  - Surgery (64.9%)
  - Chemotherapy (62.5%)
  - Radiation therapy (42.8%)
  - Clinical trial (9.4%)
  - Targeted therapy (9.0%)

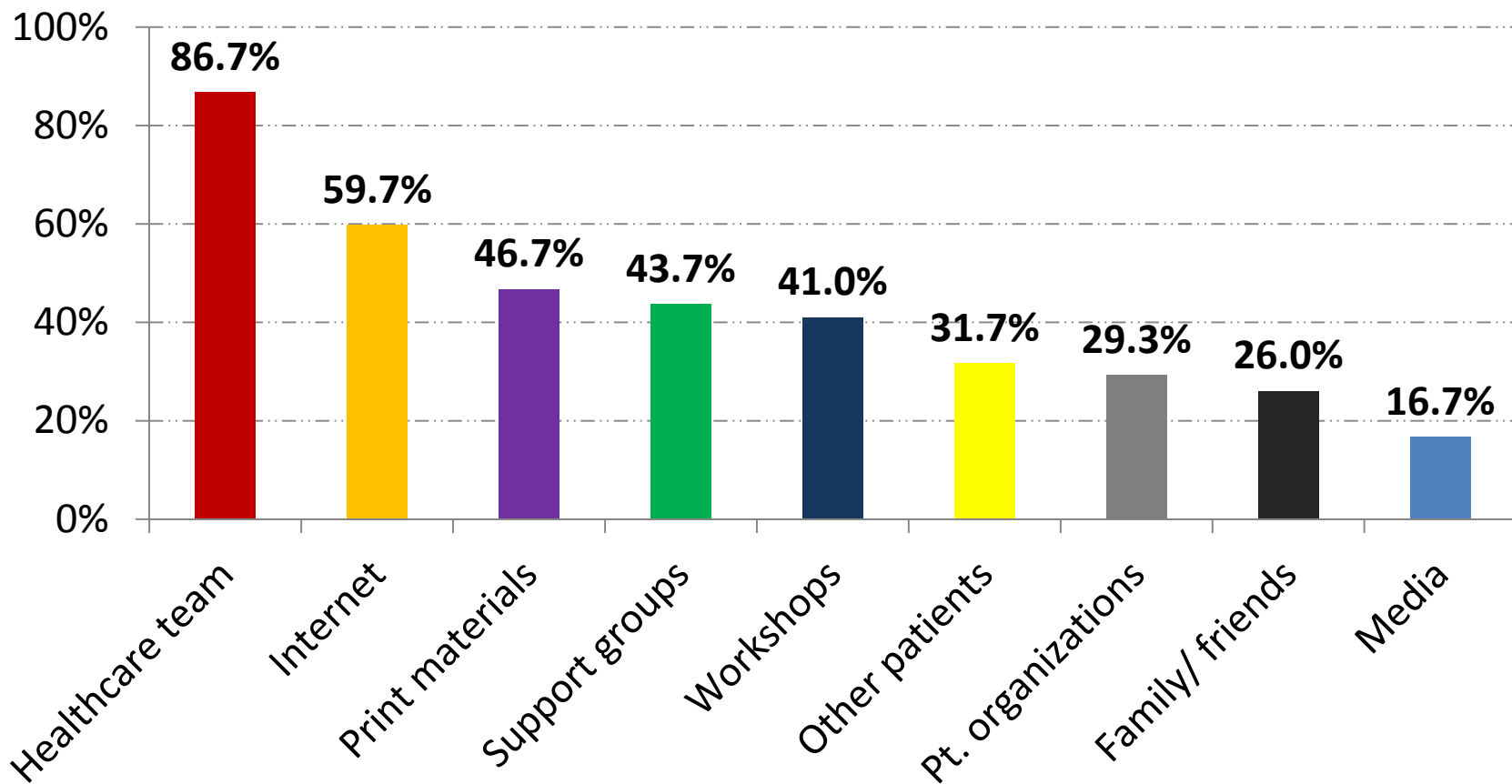
# Treatment Decision-Making

- 47.8% received multiple treatment options at diagnosis
- Decision-making was influenced by:
  - Physician recommendation (64.0%)
  - Best chances of survival (46.0%)
  - Aggressiveness of treatment (41.0%)
  - Treatment side effects (14.4%)
  - Convenience (7.9%)
- Cost was not indicated as a factor even though it was an option

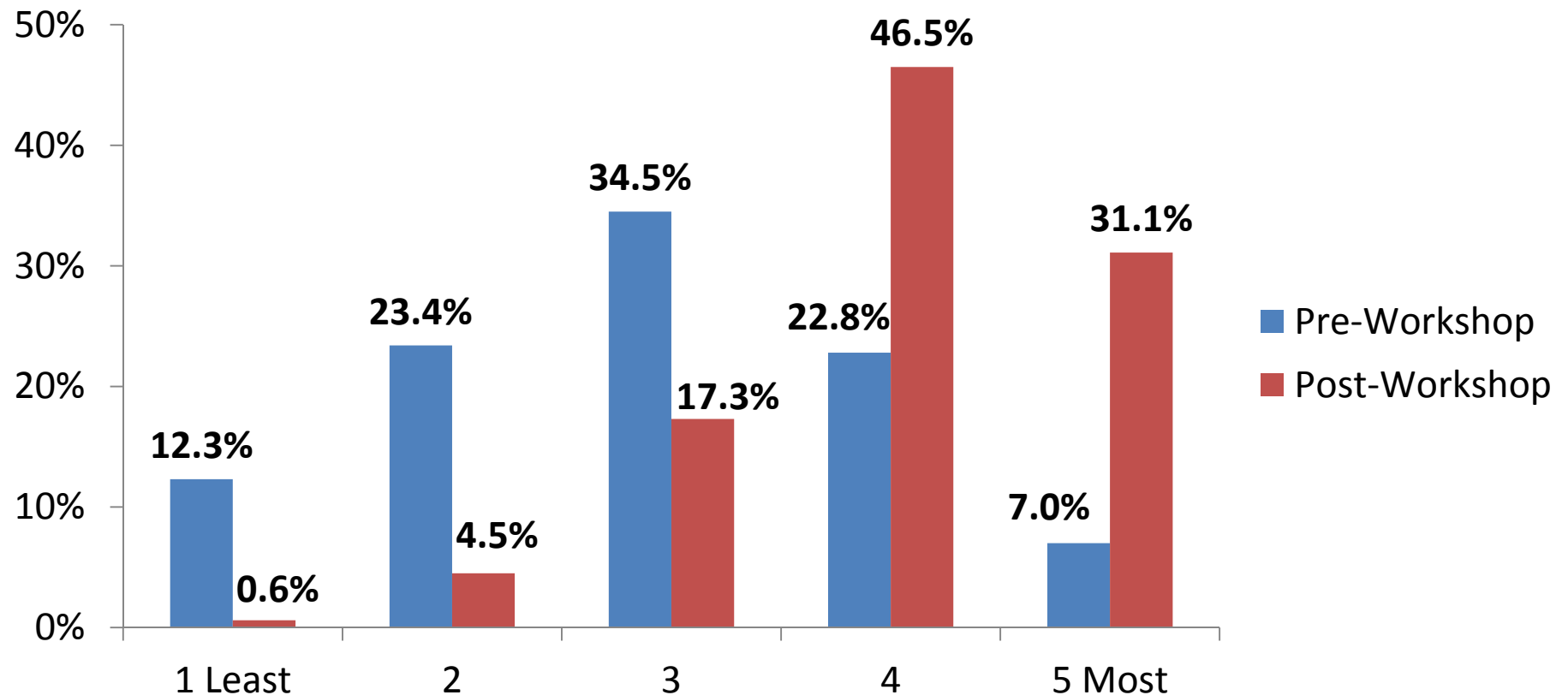


# Information Seeking

## Sources of Cancer Treatment Information



# Results: Increase in Knowledge



- Participants reported significant gains in knowledge after attending the workshop ( $p < .01$ ).

# Results: Other Outcomes

- Majority (81.1%) reported feeling better equipped to ask questions to their health care team
- 68.6% reported intent to discuss the possibility of clinical trials with their health care team
- Nearly all recommend ('4' or '5' on 5-pt scale) the workshop (95.0%)
- 89.2% indicated the expertise of the speaker was the most valuable aspect



# Conclusions

- This program proves to be effective in:
  - Increasing knowledge about cancer treatment and testing options
  - Empowering the participant to speak to their healthcare team
- Survey results point to continued need and desire for patient and caregiver education materials and services
- CSC will continue to offer program

# For More Information



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