

A new model for training patient advocates to advance the adoption of research results in community oncology practices.

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ABSTRACT

BACKGROUND

The advocate community has been identified as an influential component in disseminating the results of research reported at ASCO. A pilot program offered by Research Advocacy Network represents a new model of training for advocates. It prepared advocates to better understand the common concepts in oncology, improve statistical skills to interpret the presentations and identify the influencers and barriers to adoption of research results in clinical practice.

PARTICIPANTS

Advocates were selected based on their ability to disseminate results reported at ASCO to a patient constituency. The program involved 15 advocates with representation from six cancer sites, six of which attended ASCO for the first time.

- Breast – 7 advocates
- Lymphoma – 2 advocates
- Sarcoma – 1 advocate
- Pancreatic – 2 advocates
- Brain – 2 advocates
- Colon – 1 advocate

"I was new to patient advocacy and it was important to learn about the field – the similarities, differences and overlaps."

ACTIVITIES/METHODS

- Background packets were sent to the participants prior to all teleconferences.
- Pre-ASCO teleconferences emphasized some of the "common concepts" in oncology:
 - Targeted Therapies
 - Drug Safety and Approval Process
 - Statistics for Advocates
 - Understanding Treatment Guidelines
 - Managing the Logistical Aspects of the ASCO Meeting

- Post-ASCO teleconferences concentrated on disseminating research results:
 - A panel discussed changes to clinical practice from the evidence presented at ASCO.
 - "Tell Your Story": participants shared their individual accomplishments.
- Participants were responsible for reporting their efforts in disseminating the results that could change clinical practice in their disease site.
- All teleconferences in the course are digitally archived and available for synchronized audio and video playback with web access.

"Everything about the web casts was valuable. They extended my knowledge and understanding, especially about targeted therapies and antiangiogenesis."

RESULTS

Participants reported an increased:

- understanding of scientific concepts and language
- increased confidence in dialoguing with researchers
- improved ability to translate research results for their constituencies

Participants provided the research results:

- through educational programs for
 - staff and volunteers
 - new member organizations
 - the public and other advocates including those performing grant review
- to newly diagnosed patients and caregivers on a one-on-one basis, through teleconferences and online patient support groups
- to survivor hotlines
- through articles in newsletters that reached close to 125,000 readers
 - Young Survival Coalition
 - Y-ME National Breast Cancer Organization
 - National Brain Tumor Foundation
 - PanCAN
 - Breast Cancer Research Program

- through reports to their member organizations
 - Komen's network of over 100 affiliates
 - PanCAN Team Hopes
- on their Web sites, listservs
- to the GI SPORE and Interspire clinical trial committees
- to Cooperative Group Advocate Committees
- to advocates serving on the Cancer Survivorship Advisory Council at the USC/Norris Cancer Center
- to the media
- to their Board of Directors
- to other organizations they work with including
 - The Wellness Community
 - American Cancer Society
 - Beatitudes Health Ministry

CONCLUSION

- Preparatory lectures help advocates maximize the experience of interpreting and translating the results from the ASCO meeting.
- More prepared advocates
 - help to advance the dissemination of research results through their formal and informal distribution channels.
 - are able to translate the information more rapidly to their constituencies.

"I was very thankful to have had the opportunity to participate in the program and would recommend it to others in years to come!"

Background

The advocate community has been identified as an influential component in disseminating the results of research reported at ASCO. A pilot program was offered by Research Advocacy Network to prepare advocates to better understand the common concepts in oncology, improve statistical skills to interpret the presentations and identify the influencers and barriers to adoption of research results to clinical practice.

Methods

Advocates were selected based on their ability to disseminate results reported at ASCO to a patient constituency. Pre-ASCO webconferences lecture topics included: Targeted Therapies, Drug Safety and Approval Process, Statistics for Advocates. Post ASCO sessions explored evidence-based medicine principles a webconference that included case presentations and discussions. Participants were responsible for reporting their efforts in disseminating the results that could change clinical practice in their disease site.

Results

Fifteen advocates representing six cancer sites participated in the program. Six of the participants were first time attendees. Participants reported a high level of understanding of the concepts and confidence increase resulting in improved dialogue with researchers. Participants placed articles in newsletters with a combined circulation of over 125,000 readers. Research results were provided to staff and volunteers, via teleconferences, web sites and individually to newly diagnosed patients, caregivers, patient support groups and survivor hotlines.

Conclusions

Preparatory lectures help advocates maximize the experience of attending and interpreting the results from the ASCO annual meeting. More prepared advocates help to advance the dissemination of research results through their formal and informal distribution channels and are able to translate the information more rapidly to their constituencies.

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