

ABSTRACT

Background

The patient advocacy movement has changed the face of research. Patient advocates have provided invaluable input into medical research. As the involvement of advocates in research grows, there is a need to educate more advocates and integrate them more fully into the research community. The Research Advocacy Network has identified three impact points on the research continuum (design, conduct and reporting results) and has developed programs to increase the influence of advocates in these activities.

Materials and Methods

The Research Advocacy Network (RAN) develops relevant materials to advance patient focused research. RAN works to equip advocates for more purposeful and effective advocacy and collapse the amount of time it takes for research results to reach community practice.

Results

Fact Sheets, which are part of the *What it Means to Me* series, were created to explain the results of the MA17 and the exemestane studies to patients. Two newsletters were distributed to physicians (UpDate) and patients (Options) to provide research results that change the standard of care. The delivery of companion pieces to two audiences fosters more rapid implementation of research results into community practice. *Network News*, an e-newsletter, is published monthly and covers a variety of topics including research results and tools for advocates. Tactics to equip advocates for more purposeful and effective advocacy included trainings and workshops held at Siteman Cancer Center and at Cooperative Groups meetings. A communication simulation, housed on the RAN web site, was developed to improve advocate skills. Curriculum was developed to explain trial design and how study design affects the interpretation of results, early stopping rules, endpoints, surrogate endpoints and the regulatory and approval processes. Patient education materials were developed on the importance and use of tissue in research. A web site for research advocates was developed which includes advocate opportunities in research advocacy, the Fact Sheets and other advocate tools/resources. RAN worked to build network capacity through numerous targeted collaborations with advocate organizations, government, industry and others in the research community.

Discussion

Researchers and advocates can make a difference in moving patient focused research into patient care by expanding and increasing their collaborations. The Research Advocacy Network seeks to identify opportunities for meaningful collaborations and provide advocates with tools and education that will enhance their role in influencing patient focused research. There is also a need to evaluate patient advocate interventions and collaborations. Evaluations of successes and lessons learned can improve and expand successful collaborations.



The Research Advocacy Network (RAN) has identified three points along the research continuum where advocates can make a difference by bringing the patient perspective to the research process. RAN has accomplished a number of initiatives that correspond to these three points on the research continuum.

STUDY DESIGN

Training

RAN conducted trainings for advocates in advocate organizations including

- St. Louis Affiliate of the Susan G. Komen Breast Cancer Foundation – Research in Action: What is Research Advocacy? March and September 2004
- National Lymphedema Network – Lymph Science Advocacy Program (LSAP): November 2004 Program consisted of a workshop that covered basic research (cancer and lymphatic system), the clinical trials system and patient protections.

RAN trained advocates in the Cooperative Groups under a contract with the Coalition of National Cancer Cooperative Groups.

Communications Module

Knowledge and the ability to communicate are the advocate's best tools. RAN developed an online course to help improve advocates efforts in communicating with researchers and physicians.

- Verbal and nonverbal communication, tips for communicating with the research community, a theory of communication
- Offers a typical committee simulation showing constructive advocate involvement in the research process.

Knowledge Management Research

RAN is evaluating its online communications module for research advocates. "Knowledge Management 'Best Practice': Improving Knowledge Transfer in a Virtual Organization" is the subject of a doctoral dissertation. The purpose of the research is to:

- test a model of Knowledge Transfer
- identify barriers that can prevent transfer of knowledge in a "virtual" organization

Consulting/Grant Review

RAN has offered their expertise to the research community by:

- making formal presentations about research advocacy to professional organizations and advocates
- offering observations and recommendations about trial design and patient education materials
- serving on advisory committees to pharmaceutical and biotech companies
- working with the NCI's CARRA Program.

RESEARCH CONDUCTED

St. Louis Susan G. Komen Breast Cancer Affiliate Model
Collaboration with the Komen St. Louis Affiliate, the Siteman Cancer Center and RAN developed an educational model for attracting and training research advocates. The model uses a two-step process.

- Step 1: half day seminar to increase awareness and understanding of medical research and research advocacy activities.
- Step 2: in-depth training to understand the cancer research system, patient protections, possible roles (IRB, grant reviewer) for research advocates, and a laboratory tour. Participants developed an action plan.

Patient Educational Materials

RAN was awarded a competitive grant from Genentech, Inc. Tissue Collection Grant program to develop educational tools to increase tissue research awareness.

- Developed content materials on the importance of the study of human tissue in the development of new treatments for cancer.

- Educational tools cover topics including:
 - What is Tissue and Why Is It Important?
 - Cancer Therapy Development: The Role of Tissue in this Process
 - Why Should I Consider Donating Tissue?

IRB Pilot Program

RAN conducted a pilot program to better understand the barriers to using advocates as community members of local IRBs.

- Conducted a focus group with four major research institutions focused on, attracting, training, and retaining, community members.
- Findings: IRBs need an organized way to prescreen and train potential community members.
- Focus group findings were validated at workshop conducted at 2004 Annual IRB Conference.

RESULTS REPORTED

Fast Facts: *What It Means To Me*
RAN has developed information for patients about recently released research results called *What It Means to Me*.

- One-page fact sheets contain the latest research and its relevance to a potential patient.
- Clinicians have provided them to their patients to save time in the clinic and provide patients with a shared decision-making aid.

Newsletters: *Options* and *UpDate*
RAN developed companion newsletters discussing research results that could change clinical practice.

- *Options*: for advocates, patients and their families and friends
- *UpDate*: for healthcare professionals, especially community oncologists
- Both cover the same information
- First issue focused on the treatment of adjuvant breast cancer
- Mailed to almost 18,000 researchers and advocates.

eNewsletter: *Network News*

RAN publishes an eNewsletter ten times a year for advocates and researchers. A selection of topics covered in 2004 include: Advocates in Action, Events for Advocates, Issues in Research, Research Results and Tools for Advocates (SkillBuilders).