Module 1: Who are advocates?

Technical Assistance Materials for Investigators California Breast Cancer Research Program

Research Advocacy

- Research advocacy began in 1930's in U.S.
- Cancer survivors doubled in number in the twenty years between 1990 - 2010 (6 million to 12 million)
 - Cancer advocacy has grown at faster rates in this time period
- Focus: awareness; education;
 - fundraising; research

Advocates

Represents a Community

 Perspective beyond personal

Affiliation/Connection
 Link to community

Experience – Knowledge & Skills

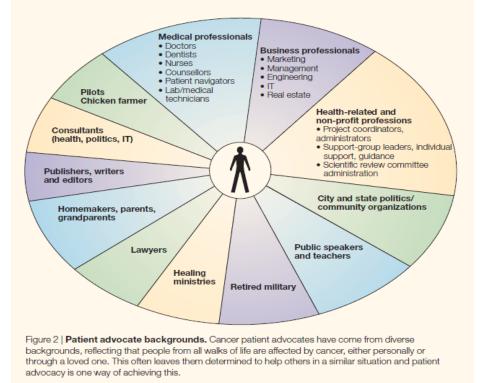


Advocates in CBCRP-Funded Research

Three criteria

- California residency
- Active involvement in an appropriate organization or community
- Ability to represent the priorities, concerns, needs and views of the community (or organization) and not only her/his personal perspective

Patient Advocate Backgrounds Are Varied



www.nature.com/reviews/cancer

Reach out to CBCRP

• 1-888-313-2277

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Module 2: Why is advocacy involvement important?

Technical Assistance Materials for Investigators California Breast Cancer Research Program

Advocacy Involvement Strengthens Breast Cancer Research

- Focuses research on questions of greatest relevance
- Provides encouragement to researchers and emphasizes the urgency of finding solutions
- Improves the quality of the research (e.g., increases validity of survey instruments, improves recruitment and retention of participants, encourages culturally sensitive interpretation of findings)
- Encourages practical application of research findings

- Facilitates more effective dissemination of research findings to affected communities, health care providers, and policymakers
- Increases funding for research
- Informs lay people about the research that affects their lives, families and communities
- Empowers advocates to guide the breast cancer research agenda to answer their questions

Multiple Organizations and Funders Concur

- American Association for Cancer Research
 American Cancer Society
 Food and Drug Administration (FDA)
 Komen
 National Cancer Institute
 Patient Centered Outcomes and Research Institute (PCORI)
 US Department of Defense (DOD) Congression
- US Department of Defense (DOD) Congressionally Directed Medical Research Programs

Impact on Projects & Science

Purpose of research

Relevance

- O Application of results
- Accountability

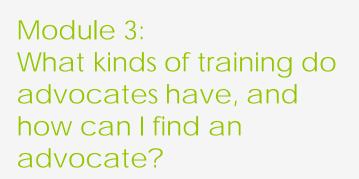


Community engaged research is increasingly important to funding agencies and universities.

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Technical Assistance Materials for Investigators California Breast Cancer Research Program

Many Ways Advocates Receive Training

- National Breast Cancer Coalition Fund Project LEAD®
- The San Antonio Breast Cancer Symposium (SABCS)
- The American Society of Clinical Oncology (ASCO)
- The American Association for Cancer Research (AACR)
- Susan G. Komen for the Cure[®], Advocates in Science
- Research Advocacy Network (RAN)
- US Cochrane Center for Evidence Based Medicine
- Patient-Centered Outcomes Research Institute (PCORI)
- Numerous websites, newsletters, and publications
- During participation in research projects such as yours

Start Early

The earlier you start looking for an advocate to work with, the better
At least six weeks before the letter of intent (LOI) is due

Multiple Resources for Finding an Advocate

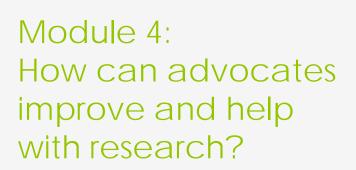
• Colleagues who have worked with advocates

- Recommendations on advocates that they have worked with
- Tips for meaningful engagement
- Internet Search: organizations in your geographic area
- CBCRP Staff: have gathered lists of advocates across California who are interested in being contacted

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Technical Assistance Materials for Investigators California Breast Cancer Research Program

What do Investigators Say?

"I cannot say enough good things about the support provided to our clinical trials research by the advocates involved with our research. Preparing to present our plans to these advocates and subsequently our findings helped us to focus on making our presentations logical, clear and understandable. They made critical suggestions relevant to how our presentation would be perceived by both scientists and lay people. Their input helped us to focus our research on the important issues and led to changes of a variety of things including the title of our trial to be more sensitive and considerate of the women in our trial. The advocates also made our involvement in breast cancer research more poignant and consequential adding some urgency to get things done."

-David Feldman, M.D., Stanford School of Medicine

"I have worked with advocates for several years and their patient perspective has helped shaped the goals of our breast research program. Our collaborations have enriched the lab and I look forward to continued interaction."

-Rob West, M.D., Stanford University Medical Center

"Working with advocates has brought a whole new dimension to our research. The advocates provide a unique perspective and critical feedback that helped strengthen our research proposals and projects. We are grateful for their involvement and participation as part of the research team"

-Sharon Pitteri, Ph.D., Stanford Cancer Institute

Roles Advocates Play in Your CBCRP Research Project

LOI & Application Preparation and Submission:

- Offer feedback on specific areas
 - Impact on patients
 - Critical path
 - Translational potential
- Develop and Review sections of proposal
 - Project Summary
 - O Translational Goal
 - Impact on Breast Cancer
- Through these steps, help communicate the importance of project to BC patients and families
- Collaborate in defining their role during the project's implementation and dissemination of the results
- Work with your team to make public abstract accessible to nonscientific audience

Research Project:

- Participate in team meetings
- Help with crafting plain language summaries for talking with public about project and results
- Talk with community about projects, research, and importance
- Help with creating materials (educational and outreach)
- Impact translational potential of research

-19

Roles Advocates Play in Research

Table 1. Examples of advocate involvement in cancer research

Strata/examples	Activities	Contributions
 Allocating research funding DOD CDMRP NCI and NCI-funded programs; cooperative groups Nonprofit organizations 	 Establishing research priorities Writing research funding announcements Peer review Programmatic review 	 Ensure cancer relevance Focus on impact rather than elegance Increase attention to areas of importance to public (e.g., environmental causes of cancer, health disparities, palliative care) Encourage collaboration across disciplines and among stakeholders
Participating in research teams Funded research programs University research groups NCI-funded SPORE 	 Writing and providing feedback on grant applications Participating in research group meetings Bridging gaps among stakeholders 	 Maintain focus on helping patients Stimulate discussion and collaboration Bring outsider perspective to the research Add a personal face and sense of urgency Increase public understanding of science
 Planning and implementing clinical trials NCI and NCI-funded clinical research like cooperative groups Academic cancer centers and consortia Drug company trials 	 Designing trials Reviewing informed consents Developing patient support materials Providing patient navigation and peer support Focusing recruitment and retention plans Membership on Protocol and Scientific Review Boards Membership on Institutional Review Boards (IRB) Membership on Data Safety Monitoring Boards (DSMB) Writing patient-friendly research 	 Sensitize researchers to issues that will have an impact on patient recruitment, retention, and satisfaction Provide consumer perspective on ethical issues Focus on toxicities as well as benefits Encourage quality-of-life add-ons Encourage collaboration across disciplines and among stakeholders Add a personal face and sense of urgency Increase public understanding of science
 Translating and disseminating research Professional societies, such as the American Association for Cancer Research (AACR) and the American Society of Clinical Oncology (ASCO) Nonprofit organizations 	 summaries Presentations at advocacy and scientific meetings Planning and attendance at advocacy and scientific meetings and training Publication in advocacy and scientific journals, websites, listservs, and blogs Public outreach through national, regional and local organizations, and media 	 Develop future advocates Sensitize researchers to issues that are important to public stakeholders Help public understand the importance of cancer research Increase awareness of cancer research progress
Research and public policy oversight Government Academia Foundations 	 Clinical practice guideline committees Working groups, study groups, and think tanks Protocol and science review boards IRBs and DSMBs 	 Increase transparency Provide patient/consumer focus Provide outsider perspective Help disseminate results

Table from Perlmutter, J., Bell, S.K., and Darien, G., Cancer Research Advocacy: Past, Present, and Future, Cancer Res; 73(15) August 1, 2013

Resource: Reading List on Advocacy Involvement

Samson et al. EPJ Nonlinear Biomedical Physics 2013, 1:1 http://www.epjnonlinearbiomedphys.com/content/1/1/1 EPJ Nonlinear Biomedical Physics a SpringerOpen Journal

EPJ.org

COMMENTARY

Open Access

Advocacy spurs innovation: promoting synergy between physical and biomedical sciences

Susan Samson^{1,2,3,9*}, Irene Acerbi^{1,4,5,10}, Carole Baas^{6,11}, Valerie Weaver^{1,4,5,7,12} and Hope Rugo^{3,8,13}

Perspective

Cancer Research

Cancer Research Advocacy: Past, Present, and Future

Jane Perlmutter¹, Shannon K. Bell², and Gwen Darien³

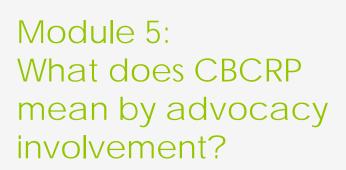
Abstract

In this article, we present a brief history of cancer advocacy and discuss the variety of ways advocates have become involved in cancer research and subsequently present principles that establish a framework for successful research advocacy based on a review of many early initiatives coupled with our knowledge as long-time cancer advocates. Challenges to effective advocacy are described, and recommendations for increasing meaningful contributions by research advocates are proposed. The purpose of this article is to discuss the exciting field of research advocacy and to help shape a more productive future for advocates and their scientific collaborators. *Cancer Res* 73(15): 1–5. ©2013 AACR.

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Advocates in CBCRP-Funded Research

Three criteria

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Award Types & Phases

 Award Types
 Innovative, Developmental, and Exploratory Awards (IDEA)
 Translational Awards

Translational Awards

Phases

- Letter of Intent (LOI)
- O Application
- Funded Project

Example Advocate Activities

LOI & Application Preparation and Submission:

- Offer feedback on specific areas
 - Impact on patients
 - O Critical path
 - Translational potential
- Develop and Review sections of proposal
 - Project Summary
 - O Translational Goal
 - Impact on Breast Cancer
- Through these steps, help communicate the importance of project to BC patients and families
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Research Project:

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Module 6: What are expectations for advocacy involvement in CBCRP letters of intent (LOIs)?

Technical Assistance Materials for Investigators California Breast Cancer Research Program

A complete LOI includes:

IDEA Awards

- Title Page (1 page maximum)
 - Project Title
 - Priority Issue
- Project summary (2 pages maximum)
 - Project Title
 - Project Summary
 - Innovative Elements
 - O Critical Path
 - Investigative Team
 - O Involvement of advocates
- Advocate Documentation (1 page maximum)
- Pl Biosketch (4 pages maximum)

Translational Awards

- Title Page (1 page maximum)
 - Project Title
 - Priority Issue
- Project summary (2 pages maximum)
 - Project Title
 - Translational Goal
 - Impact on Breast Cancer
 - Background and PI Qualifications
 - Specific Aims
 - Human Subjects Involvement
 - O Involvement of advocates
- Advocate Documentation (1 page maximum)
- PI Biosketch (4 pages maximum)

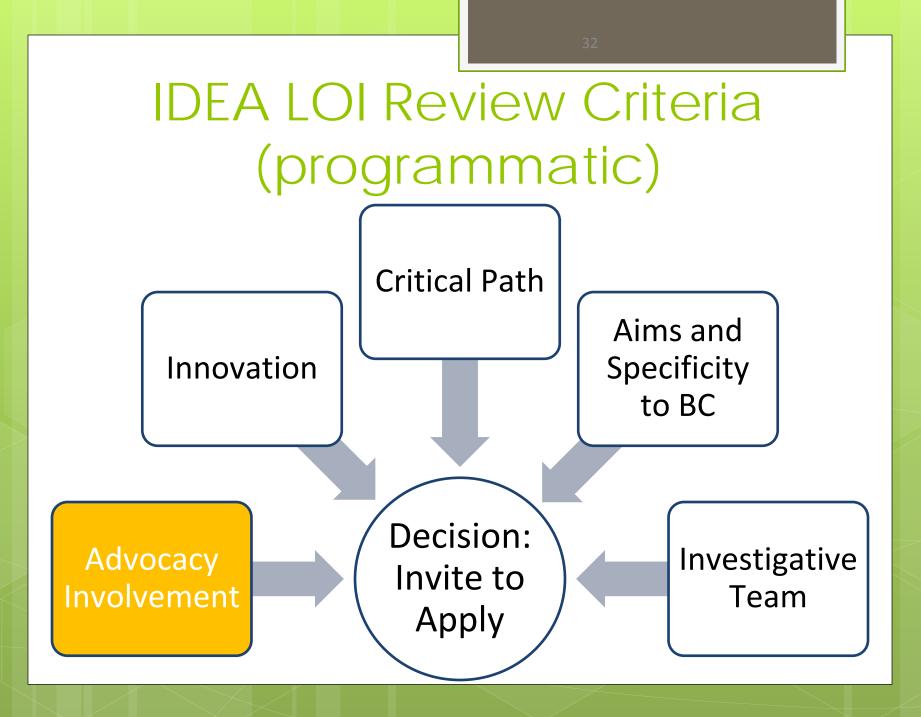
Involvement of advocates

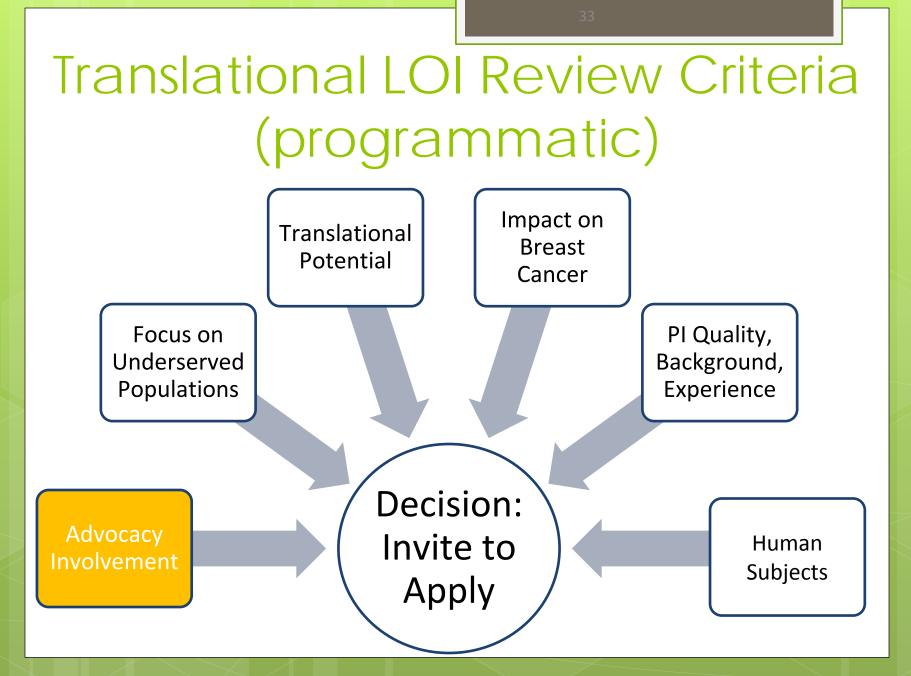
- 4-6 sentences
- Name the advocacy organization.
- Why is the organization appropriate for your project?
- With whom have you communicated at the organization?
- What is the role of the advocate in the project
 - O Design
 - Implementation
 - Interpretation
 - O Dissemination

Advocate Documentation

Email or letter

- From advocate or representative from the advocacy organization
- Documents their willingness to explore participation in the research application





Steps for a Successful LOI Submission:

Investigator identifies advocate. Contacts CBCRP if needed to help find an advocate.

Research Idea

1

Input/Feedback

2

Investigator contacts advocate 6 weeks ahead of submission date and they agree to work togther. They discuss the research idea and the advocate provides input and feedback. Advocate reads LOI draft and provides feedback and suggestions. Advocate writes brief letter of collaboration.

Collaboration

3

LOI Submission

4

LOI submitted to the CBCRP. Investigator notifies advocate if asked to submit a full proposal.

Suggested Timeline

- For the LOI we recommend a minimum of a 6-week timeline
 - Week 1: Investigator identifies Advocate. They discuss the research idea and the Advocate provides input and feedback.
 - Week 2-3: Investigator sends the Advocate the LOI draft. The Advocate provides feedback and suggestions.
 - Week 4-6: Investigator and Advocate work on final proposal and writes the letter of commitment (or email).
 - Week 6: Investigator sends advocate final LOI and submits to the CBCRP.
 - Follow-up: Investigators informs Advocate if invited to submit an application.

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Module 7: What are expectations for advocacy involvement in CBCRP applications and projects?

A complete Application Includes: IDEA Awards & Translational Awards

- Budget Summary
- Budget Justification & Facilities
- Key Personnel
- Other Key Personnel Biographical Sketch & Other Support (use NIH Biosketch)
- Research Plan
- Human Subjects
- Vertebrate Animals
- O Appendix List
- O Appendix uploads

- Lay Abstract
- Scientific Abstract
- O Program Responsiveness
- Critical Path & Underserved
- Advocacy Involvement
- Letter of Commitment
- Distinction from Other Funding
- PI Biographical Sketch & Other Support (use NIH Biosketch)

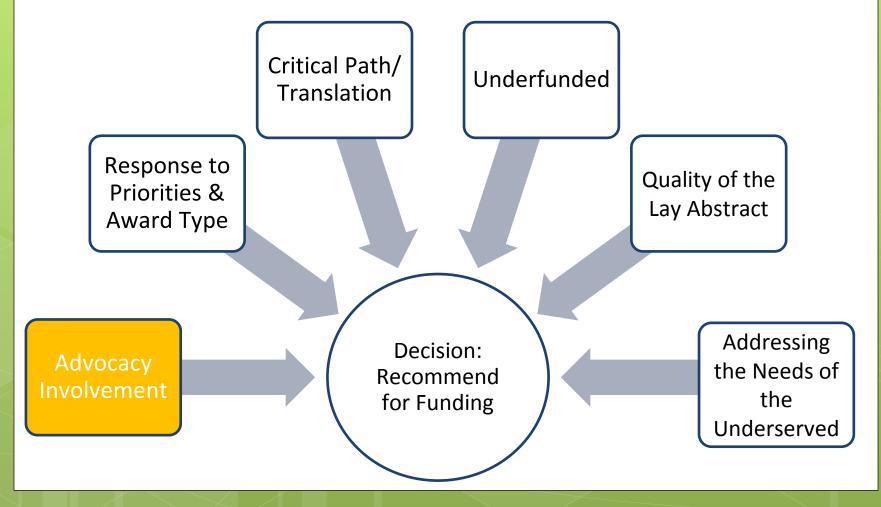
Advocacy Involvement

1 page limit; three sections
Advocacy Organization/Advocates(s) Selection and Engagement to Date
Advocate(s) Role in Proposed Research
Meetings and Compensation

Letter of Commitment

- Brief summary of project
- Why organization is interested in supporting project
- Any history of working with the PI or academic institution
- Describe how project is relevant to community that the advocate and/or their organization represents
- Describe what the expectations, roles and duties are for advocate and investigator
- O Template available in application forms

IDEA & Translational Application Review Criteria (programmatic)



Advocacy Involvement in Funded Projects

Implement plans as noted in your application

Regular meetings

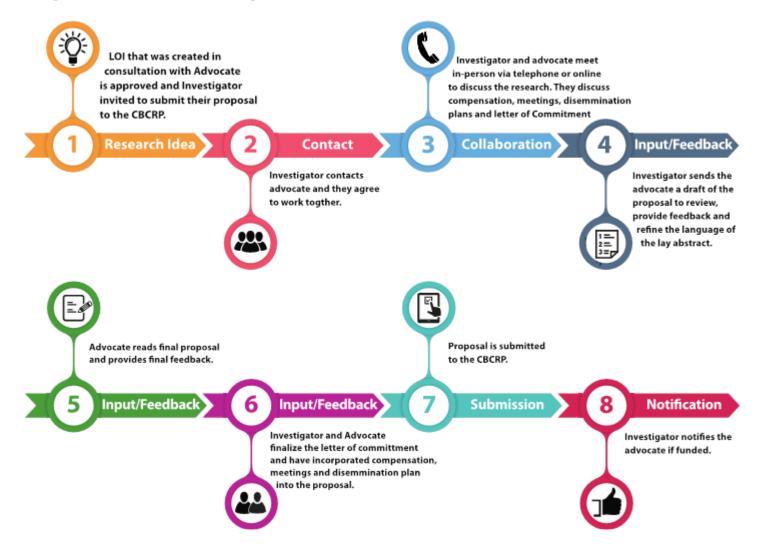
• Report out in yearly report (2-page limit)

- Written by investigator and advocate
- List of planned activities (described in proposal)
- Any new activities
- Account of progress

University of California Office of th California Breast Cancer Res		Progress or ADVOCACY II Fo		
AWARD NUMBER:	PROJECT	YEAR (Check one): 1st 2nd	3rd	Final
PRINCIPAL INVESTIGATOR(S):				
ADVOCATES(S):				
PROJECT TITLE:				
INSTITUTION:				
Instructions:				
Provide a detailed account of the progress that v activities described in the research proposal and			planned advo	cacy involvement
The summary must include:				
 The list of planned activities described in th involvement reports labeled with the status A description of any new advocacy involver After each planned activity, an account of p rationale for any new activities. The summa The signature of the advocate(s) involved w 	of "completed", "on going" or ment activities that were not or rogress made towards each any of progress must be writte	"discontinued" covered in the application or previous of these activities. Include the reasor in from both the scientist and advoca	report ns for disconti	nued activities and the
The text should focus on the research support pr exceed 2 pages.	ovided by this grant, and not	include results obtained from funding	g by other gra	ants or agencies. Do not
Please note: The investigator should take the los	ad in writing responses to iter	ms 1 and 2. Together, the investigate	r and advoca	to should write

Please note: The investigator should take the lead in writing responses to items 1 and 2. Together, the investigator and advocate should write response to item 3. If opinions are diverging on account of progress made, both investigator and advocate provide separate responses to item 3.

Steps for a Successful Proposal Submission:



Suggested Timeline: December - March

- **December/January:** Investigator informs Advocate that their LOI was approved and Investigator was invited to submit proposal. Investigator provides an early draft of the research plan to advocate.
- January: Investigator presents the research idea and plan to the Advocate (in-person, telephone or online). Advocate asks questions and provides input on the research. They begin work on letter of commitment, compensation, meetings and dissemination plan.
- February: Investigator sends full in-progress proposal for Advocate to review, ask questions and provide feedback on the proposal and to refine the language of the proposal. Investigator and advocate continue working on and refining letter of commitment.
- February/March: Investigator and Advocate finalize the letter of commitment, compensation, meetings and dissemination plan.
- Follow-up: Investigators sends a copy of the full proposal to Advocate and informs them if the proposal was funded.

Additional Tips

- Establish relationship early
- Send materials prior to meeting on phone or in person
- Stay open to questions from advocates
- Offer lab tour
- Clarify roles
- Cover advocate compensation
- Provide opportunities for advocates to learn more
- Mutual respect for each others time
- Set a schedule of check-ins
- Name advocates in papers, posters, presentations

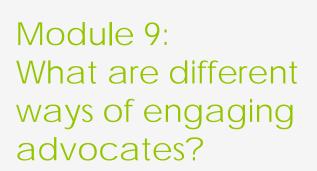
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Compensation

- Compensation must be agreed upon before work commences; described in application; included in project budget
- Compensate out-of-pocket expenses to undertake activities as described in proposal
- Compensate advocate time and expertise
 - Project honoraria or consulting fees
 - Hourly basis or fixed fee
- Funding for conference attendance (e.g. CBCRP Symposiums, SABCS, ASCO, AACR)

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Roles Advocates Play in Research

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Example Advocate Activities

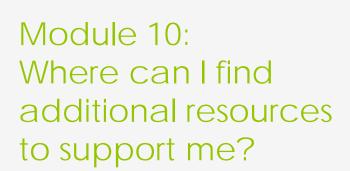
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CBCRP Technical Assistance

- O TA Modules
- O Webinars
- Additional materials/ handouts
- Staff Consultations



ABOUT | SUPPORTUS | CONTACT

Q

PRIORITIES | APPROACH | FUNDING OPPORTUNITIES | FUNDED RESEARCH |

* ADVOCACY INVOLVEMENT

- UNDERSTANDING ADVOCACY
- RESOURCES FOR ADVOCATES
 RESOURCES FOR INVESTIGATORS
- ADVOCACY INVOLVEMENT REQUIREMENTS

PROGRAMMATIC STRATEGIES

ADDITIONAL MATERIALS FOR INVESTIGATORS

The following handouts can be useful for investigators seeking additional information on successfully involving advocates in projects:

Strong Application Responses on Advocacy Involvement

- IDEA Sample 1
- IDEA Sample 2
- IDEA Sample 3

RESOURCES FOR INVESTIGATORS

Technical Assistance for Involving Advocates in CBCRP Projects

Because we require applicants and funded researchers to engage breast cancer or community advocates in their projects, and this may be a requirement that is new to applicants or investigators, we have created a suite of technical assistance (TA) tools designed to answer questions and provide support. The following technical assistance tools are available to you:

- TA modules: Brief, narrated power point presentations that walk through essential content. You can access them by clicking on any of the 10 modules below.
- Webinars: 90-minute live web- and phone-based presentations presented by CBCRP staff. Webinars are provided for the letter of intent (LOI) and application stage, and walk applicants through CBCRP expectations for advocacy involvement and provide tips to give materials the competitive edge. You can sign up for webinars by clicking on the "sign up" buttons below.
- Additional materials: Applicants and investigators can access handouts by clicking links that are grouped on the left side of this page. These handouts include samples of strong advocacy involvement responses, reading lists, example timelines of collaboration, and other content that is likely to be of interest to applicants and investigators.
- Staff consultations: You are always welcome to contact CBCRP Staff. Staff are knowledgable and prepared to help answer questions you may have.

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