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

Figure 2 | Patient advocate backgrounds. Cancer patient advocates have come from diverse backgrounds, reflecting that people from all walks of life are affected by cancer, either personally or through a loved one. This often leaves them determined to help others in a similar situation and patient advocacy is one way of achieving this.

Reach out to CBCRP

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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) Congressionally Directed Medical Research Programs
Community engaged research is increasingly important to funding agencies and universities.
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Module 3: What kinds of training do advocates have, and how can I find an advocate?

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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Module 4: How can advocates improve and help with research?

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
  - 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 non-scientific 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
### Roles Advocates Play in Research

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<th>Table 1. Examples of advocate involvement in cancer research</th>
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<td><strong>Strata/examples</strong></td>
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| Allocating research funding                              | • 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                           | • 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                 | • 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 summaries             | • 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                    | • 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                      | • 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

Advocacy spurs innovation: promoting synergy between physical and biomedical sciences

Susan Samson1,2,3,*, Irene Acerbi1,4,5,10, Carole Baas6,11, Valerie Weaver1,4,5,7,12 and Hope Rugo3,8,13

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.

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Module 5: What does CBCRP mean by advocacy involvement?

Technical Assistance Materials for Investigators
California Breast Cancer Research Program
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
Award Types & Phases

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

Phases
- Letter of Intent (LOI)
- Application
- Funded Project
Example Advocate Activities

**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
  - 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
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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
  - Critical Path
  - Investigative Team
  - Involvement of advocates
- Advocate Documentation (1 page maximum)
- PI 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
  - 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
  - Design
  - Implementation
  - Interpretation
  - Dissemination
Advocate Documentation

- Email or letter
- From advocate or representative from the advocacy organization
- Documents their willingness to explore participation in the research application
IDEA LOI Review Criteria (programmatic)

- Innovation
- Advocacy Involvement
- Critical Path
- Aims and Specificity to BC
- Investigative Team

Decision: Invite to Apply
Translational LOI Review Criteria (programmatic)

- Translational Potential
- Impact on Breast Cancer
- Focus on Underserved Populations
- PI Quality, Background, Experience
- Advocacy Involvement
- Human Subjects

Decision: Invite to Apply
Steps for a Successful LOI Submission:

1. **Research Idea**
   - Investigator identifies advocate. Contacts CBCRP if needed to help find an advocate.

2. **Input/Feedback**
   - Investigator contacts advocate 6 weeks ahead of submission date and they agree to work together. They discuss the research idea and the advocate provides input and feedback.

3. **Collaboration**
   - Advocate reads LOI draft and provides feedback and suggestions. Advocate writes brief letter of collaboration.

4. **LOI Submission**
   - 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.
Reach out to CBC RP

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

Technical Assistance Materials for Investigators
California Breast Cancer Research Program
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
- Appendix List
- Appendix uploads

- Lay Abstract
- Scientific Abstract
- 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
- Template available in application forms
IDEA & Translational Application Review Criteria (programmatic)

- Critical Path/Translation
- Underfunded
- Response to Priorities & Award Type
- Quality of the Lay Abstract
- Advocacy Involvement
- Addressing the Needs of the Underserved

Decision: Recommend for Funding
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

---

[Form]

University of California Office of the President
California Breast Cancer Research Program

Progress or Final Report
ADVOCACY INVOLVEMENT Form

**Award Number:** [Field]

**Project Year:** [Field] 1st 2nd 3rd Final

**Principal Investigator(s):** [Field]

**Advocate(s):** [Field]

**Project Title:** [Field]

**Institution:** [Field]

Instructions:

Provide a detailed account of the progress that was made during the reporting period towards achievement of the planned advocacy involvement activities described in the research proposal and the advocate-researcher letter of commitment. The summary must include:

1. The list of planned activities described in the research proposal and the advocate-researcher letter of commitment and previous advocacy involvement reports labeled with the status of "completed," "on-going," or "discontinued."
2. A description of any new advocacy involvement activities that were not covered in the application or previous reports.
3. After each planned activity, an account of progress made towards each of these activities, include the reasons for discontinued activities and the rationale for any new activities. The summary of progress must be written from both the scientist and advocate perspective.
4. The signature of the advocate(s) involved with the project, and the investigator.

The text should focus on the research support provided by this grant, and not include results obtained from funding by other grants or agencies. Do not exceed 2 pages.

Please note: The investigator should take the lead in writing responses to Items 1 and 2. Together, the investigator and advocate should write responses 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:

1. **Research Idea**
   - LOI that was created in consultation with Advocate is approved and Investigator invited to submit their proposal to the CBCRP.

2. **Contact**
   - Investigator contacts advocate and they agree to work together.

3. **Collaboration**
   - Investigator and advocate meet in-person via telephone or online to discuss the research. They discuss compensation, meetings, dissemination plans and letter of Commitment.

4. **Input/Feedback**
   - Investigator sends the advocate a draft of the proposal to review, provide feedback and refine the language of the lay abstract.

5. **Input/Feedback**
   - Advocate reads final proposal and provides final feedback.

6. **Input/Feedback**
   - Investigator and Advocate finalize the letter of commitment and have incorporated compensation, meetings and dissemination plan into the proposal.

7. **Submission**
   - Proposal is submitted to the CBCRP.

8. **Notification**
   - Investigator notifies the advocate if funded.
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 other's time
- Set a schedule of check-ins
- Name advocates in papers, posters, presentations
Reach out to CBCRP

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Module 8: How do I compensate advocates?

Technical Assistance Materials for Investigators
California Breast Cancer Research Program
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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Module 9: What are different ways of engaging advocates?

Technical Assistance Materials for Investigators
California Breast Cancer Research Program
## Roles Advocates Play in Research

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Module 10: Where can I find additional resources to support me?

Technical Assistance Materials for Investigators
California Breast Cancer Research Program
CBCRP Technical Assistance

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