



## Module 9: What are different ways of engaging advocates?

Technical Assistance  
Materials for Investigators

California Breast Cancer Research  
Program

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# Roles Advocates Play in Research

Table 1. Examples of advocate involvement in cancer research

<b>Strata/examples</b>	<b>Activities</b>	<b>Contributions</b>
<b>Allocating research funding</b> <ul style="list-style-type: none"> <li>• DOD CDMRP</li> <li>• NCI and NCI-funded programs; cooperative groups</li> <li>• Nonprofit organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Establishing research priorities</li> <li>• Writing research funding announcements</li> <li>• Peer review</li> <li>• Programmatic review</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure cancer relevance</li> <li>• Focus on impact rather than elegance</li> <li>• Increase attention to areas of importance to public (e.g., environmental causes of cancer, health disparities, palliative care)</li> <li>• Encourage collaboration across disciplines and among stakeholders</li> </ul>
<b>Participating in research teams</b> <ul style="list-style-type: none"> <li>• Funded research programs</li> <li>• University research groups</li> <li>• NCI-funded SPORE</li> </ul>	<ul style="list-style-type: none"> <li>• Writing and providing feedback on grant applications</li> <li>• Participating in research group meetings</li> <li>• Bridging gaps among stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>• Maintain focus on helping patients</li> <li>• Stimulate discussion and collaboration</li> <li>• Bring outsider perspective to the research</li> <li>• Add a personal face and sense of urgency</li> <li>• Increase public understanding of science</li> </ul>
<b>Planning and implementing clinical trials</b> <ul style="list-style-type: none"> <li>• NCI and NCI-funded clinical research like cooperative groups</li> <li>• Academic cancer centers and consortia</li> <li>• Drug company trials</li> </ul>	<ul style="list-style-type: none"> <li>• Designing trials</li> <li>• Reviewing informed consents</li> <li>• Developing patient support materials</li> <li>• Providing patient navigation and peer support</li> <li>• Focusing recruitment and retention plans</li> <li>• Membership on Protocol and Scientific Review Boards</li> <li>• Membership on Institutional Review Boards (IRB)</li> <li>• Membership on Data Safety Monitoring Boards (DSMB)</li> <li>• Writing patient-friendly research summaries</li> </ul>	<ul style="list-style-type: none"> <li>• Sensitize researchers to issues that will have an impact on patient recruitment, retention, and satisfaction</li> <li>• Provide consumer perspective on ethical issues</li> <li>• Focus on toxicities as well as benefits</li> <li>• Encourage quality-of-life add-ons</li> <li>• Encourage collaboration across disciplines and among stakeholders</li> <li>• Add a personal face and sense of urgency</li> <li>• Increase public understanding of science</li> </ul>
<b>Translating and disseminating research</b> <ul style="list-style-type: none"> <li>• Professional societies, such as the American Association for Cancer Research (AACR) and the American Society of Clinical Oncology (ASCO)</li> <li>• Nonprofit organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Presentations at advocacy and scientific meetings</li> <li>• Planning and attendance at advocacy and scientific meetings and training</li> <li>• Publication in advocacy and scientific journals, websites, listservs, and blogs</li> <li>• Public outreach through national, regional and local organizations, and media</li> </ul>	<ul style="list-style-type: none"> <li>• Develop future advocates</li> <li>• Sensitize researchers to issues that are important to public stakeholders</li> <li>• Help public understand the importance of cancer research</li> <li>• Increase awareness of cancer research progress</li> </ul>
<b>Research and public policy oversight</b> <ul style="list-style-type: none"> <li>• Government</li> <li>• Academia</li> <li>• Foundations</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical practice guideline committees</li> <li>• Working groups, study groups, and think tanks</li> <li>• Protocol and science review boards</li> <li>• IRBs and DSMBs</li> </ul>	<ul style="list-style-type: none"> <li>• Increase transparency</li> <li>• Provide patient/consumer focus</li> <li>• Provide outsider perspective</li> <li>• Help disseminate results</li> </ul>

# 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
- 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

# Reach out to CBCRP

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