



# Advocacy Involvement

IDEA & Translational Grant  
Applications to CBCRP

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What is  
advocacy  
involvement  
in research  
and who are  
advocates?



# 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 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



# Advocates

- Represents a Community
  - Perspective beyond personal
- Affiliation/Connection
  - Link to community
- Experience
  - Knowledge & Skills





# Patient Advocate Backgrounds Are Varied

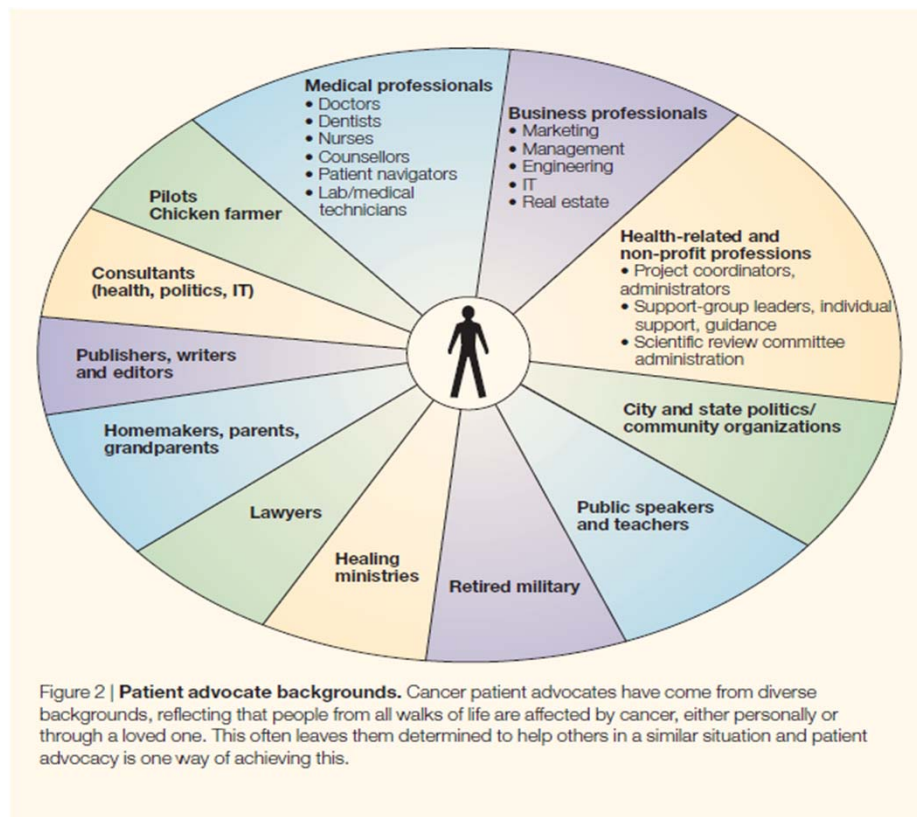


Figure 2 | **Patient advocate backgrounds.** Cancer patient advocates have come from diverse backgrounds, reflecting that people from all walks of life are affected by cancer, either personally or through a loved one. This often leaves them determined to help others in a similar situation and patient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

[www.nature.com/reviews/cancer](http://www.nature.com/reviews/cancer)



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Why is  
advocacy  
involvement  
important?



# 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



# 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



# Impact on Projects & Science

- Purpose of research
- Relevance
- Application of results
- Accountability



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





How can  
advocates  
help with  
research?



# 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

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>

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



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What do we  
mean by  
'advocacy  
involvement?'



- Advocacy involvement is a component in two specific award types
  - Innovative, Developmental, and Exploratory Awards (IDEA)
  - Translational Awards
- There are three main areas where engagement occurs:
  - Letter of Intent (LOI)
  - Application
  - Funded project

# 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

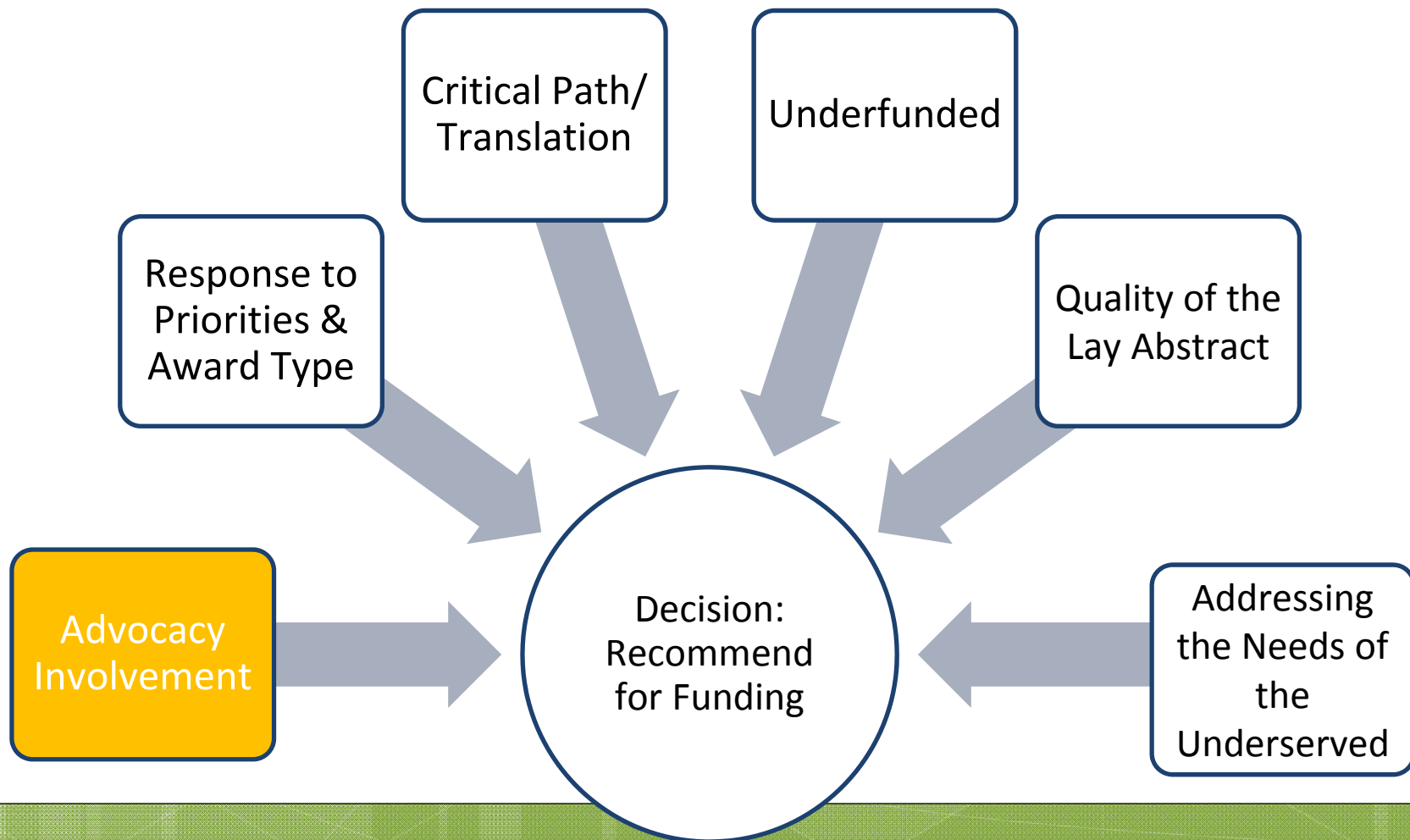
- 1 page limit; three sections
- Advocacy Organization/Advocates(s) Selection and Engagement to Date
- Advocate(s) Role in Proposed Research
- Meetings and Compensation

# 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)




# 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 the President California Breast Cancer Research Program		Progress or Final Report ADVOCACY INVOLVEMENT Form	
AWARD NUMBER:	<input type="text"/>	PROJECT YEAR (Check one):	<input type="checkbox"/> 1st <input type="checkbox"/> 2nd <input type="checkbox"/> 3rd <input type="checkbox"/> Final
PRINCIPAL INVESTIGATOR(S):	<input type="text"/>		
ADVOCATES(S):	<input type="text"/>		
PROJECT TITLE:	<input type="text"/>		
INSTITUTION:	<input type="text"/>		
<b>Instructions:</b> 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 <u>must include</u> : <ol style="list-style-type: none"><li>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"</li><li>2. A description of any new advocacy involvement activities that were not covered in the application or previous report</li><li>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.</li><li>4. The signature of the advocate(s) involved with the project, and the investigator</li></ol> 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 response to item 3. If opinions are diverging on account of progress made, both investigator and advocate provide separate responses to item 3.			





Successful  
Collaboration:  
Proposal  
Submission



## 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.





# Advocate compensation



# 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)





Additional  
Help?



# 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

# Reach out to CBCCRP

- 1-888-313-2277
- Program Officers
  - Katie McKenzie, Ph.D. [katherine.mckenzie@ucop.edu](mailto:katherine.mckenzie@ucop.edu)
  - Senaida Poole, Ph.D. [senaida.poole@ucop.edu](mailto:senaida.poole@ucop.edu)
  - Carmela Lomonaco, Ph.D. [carmela.lomonaco@ucop.edu](mailto:carmela.lomonaco@ucop.edu)
  - General Email: [getinfo@CABreastCancer.org](mailto:getinfo@CABreastCancer.org)



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Questions?