

CBCRP's New Advocacy Involvement Requirements

FAQ For Scientists

General

Is advocate involvement required in all CBCRP grants?

Yes, starting in 2012. Requirements vary depending on the award type so be sure to read the instructions carefully.

Why is the CBCRP requiring advocacy involvement in basic science investigator-initiated (IDEA and Translational) awards?

The CBCRP was established through the vision and efforts of breast cancer advocates and we are deeply committed to advocate involvement in all aspects of our program. Also a growing body of data show that health and medical research projects greatly benefit from being directly informed by the experiences and knowledge of those affected: namely, those who have or had the disease, those who care for people with the disease, or those who represent a specific community impacted by the disease.

While we recognize that substantively involving advocates in investigator-initiated research projects is new to many scientists, we have heard from basic to social scientists that it is not only possible but beneficial to do so. The CBCRP provides guidance to researchers and advocates. As this effort matures, we will refine our process and technical assistance to make this requirement as easy and successful as possible.

What is the role of advocates in CBCRP-funded research?

There are many roles that advocates can undertake and tasks that they can engage in to enhance research projects. Researchers and advocates report that meaningful community engagement can improve the research process, as well as the results. Advocates can help to:

- Identify or develop research questions of concern to the community
- Improve study approach and instrument design through community input for user friendly, culturally sensitive, accurate and valid practices and measures
- Review and edit the Lay Abstract
- Encourage scientists and impart the urgency of solving breast cancer questions
- Help recruit participants with appropriate messages and protocols
- Provide an important local, patient or other perspective during analysis and interpretation which may lead to more robust findings
- Identify additional resources and funding opportunities
- Frame questions and results for better dissemination of findings for both lay and scientific audiences

How can I find an advocate to work with?

A good way to start is by contacting colleagues who have been funded by CBCRP (you can search by institution or PI name on our [website](#)); ask them what organization/s they have

worked with and for contact name/s. You can look for breast cancer or other appropriate organizations in your geographic area. We are creating a database of people interested and experienced in working with researchers; contact us for assistance at 1-888-313-2277 or getinfo@CaBreastCancer.org.

May I have more than one advocate involved with my project?

Yes, some advocates work together in teams and prefer this approach although you are only required to name one advocate.

When should I involve an advocate in my project?

Involve advocates as early as possible in your project. Research projects can benefit greatly from the perspective of those who are affected by the disease. Advocates can help inform research questions, connect scientists with resources, and help shape the application. Do not wait until just before the application is due to work with advocates—this is usually evident in the application and results in a lower programmatic review score.

What qualifications should I look for when recruiting an advocate to participate?

CBCRP has some criteria for advocates to work on funded projects. Experienced advocates have an understanding of breast cancer and of the research process that is helpful for the more basic science projects. Generally they are affiliated with a breast cancer or other community organization interested in the research topic. It is most important that advocates represent a larger group, and are able to communicate information to others in their organization and other relevant audiences. A list of suggested qualifications is posted under [Advocate Resources](#). If you or a potential advocate has questions about qualifications, please contact a Program Officer at 1-888-313-2277 or email us at getinfo@CaBreastCancer.org.

Scientists who have extensive experience working with advocates say that selecting an advocate can be as important as selecting a collaborator on a project. It is important to talk with them to be sure they are interested in your work; have the right training and broad perspective to participate; and are connected to a relevant organization and other people who may also be interested in your work.

LOI and Full Application Requirements

What happens if I don't have an advocate or advocacy group listed in my LOI or application?

For both the LOI and the full application, you must name a breast cancer or other relevant group. Failure to have contacted an appropriate organization and describe the role of the advocate/s in the proposed project is grounds for rejecting an LOI.

A full application must include the name/s of advocate/s and a detailed description of how you will work together in both an application form and in the Letter of Commitment. This is a critical part of the programmatic score and failure to include this information is grounds for rejecting an application.

What is a letter of commitment? How is it different from a letter of support?

In the past, the CBCRP asked scientists to include a *letter of support* from an advocate or advocacy organization. A *letter of commitment* demonstrates a more active role in a project than a letter of support and spells out specific agreements that should be made prior to beginning a research project. Beginning with Cycle 19 (2013), we require a letter of commitment written and signed by both the applying scientist and the advocate/s involved in the project.

The letter of commitment should include agreements about expectations, communication, meetings, roles, and responsibilities for both the advocate(s) and the scientist(s.) The letter of commitment should include specific agreements about how the advocate will be compensated.

How can the advocate/s help with the application?

Advocates have a unique perspective that may help to focus or refine research questions to make them more meaningful to women with breast cancer and reflect their urgency in better understanding breast cancer. They may offer a different perspective on research approaches and provide ideas about how to recruit participants or make information available to lay communities. At a minimum, advocates may provide a non-scientific review and editing of the lay abstract. The lay abstract is very important to the CBCRP and is scored by scientists, clinicians and advocates who may have little understanding of your specific field.

Do I have to compensate the advocate? If so, how much?

CBCRP has a budget line item and a corresponding budget justification section for advocate compensation. While each project and situation is different, at a minimum the grant should reimburse any expenses that an advocate incurs participating in the research project, such as mileage and parking to attend meetings and travel to the CBCRP Symposium or other appropriate training opportunities.

Beyond that, compensation should be agreed upon ahead of time by all parties, be fair, and reflect the time and other contributions the advocate(s) bring(s) to the project. An advocate or their organization may be designated to receive the financial compensation. We also encourage grantees to sponsor the advocate to attend a relevant conference and/or to provide additional training. Include details about your compensation agreement in the application. If you have any questions about compensating advocates, don't hesitate to contact CBCRP Program Officers at 1-888-313-2277 or getinfo@CaBreastCancer.org.

Working with Advocates in Research Implementation

How can I effectively involve an advocate in my research project?

Be sure to communicate clearly and listen well; make sure roles and responsibilities are clear; remain organized and follow-through with the agreements you made; and address

any conflicts or misunderstandings directly. Mutual respect for each other's different knowledge and perspective goes a long way towards a beneficial relationship between scientists and advocates.

What is the best way to communicate with advocates?

From experience, we've seen that the best way for researcher-advocate teams to communicate is in person. For this reason, it is best to work with an advocate that is geographically close. When teams have worked together for more than five years and on at least two research projects, phone meetings or conference calls may suffice. In-person meetings are essential in the beginning to minimize misunderstandings and improve the quality of the discussion and dialogue.

It is important to choose a meeting site and time that is convenient for the advocate/s. This could be the advocacy organization or a community center between your institution and the advocate's home or place of work. You may choose to alternate sites. While we don't require that the entire research team attend, we do recommend encouraging junior researchers to take part to help train future scientists to work with advocates.

How often should I/we meet with the advocate/s listed on my grant?

At least quarterly. You should work with your team and the advocate/s to develop the meeting schedule that works best for both, but you must meet approximately every 3 months at a mutually agreed upon location.

What are common pitfalls when involving advocates?

The most common issues we've heard from scientists and advocates are:

- waiting until the last week to find an advocate to involve in their project;
- not holding regular meetings;
- not communicating clearly;
- involving someone merely as a token and not truly listening to or valuing their input;
- unclear roles and responsibilities; and
- involving someone as an advocate who is not associated with an organization or one that is not relevant to the research project.

For links to resources on working with Advocates, go to [CBCRP's Advocacy website](#).