



**Continuing to Improve the Odds Together:
Next Steps for Engaging Researchers and Advocates**
Findings from the 2022 Metastatic Breast Cancer Research Conference

Background

Basic cancer research improves when research scientists engage with patient advocates, including better research paradigms that are more translational and providing both groups with a better sense of purpose. Growing work over the past decade has generated anecdotal evidence demonstrating the value of advocates and researchers working together. To encourage engagement with advocates, Theresa’s Research Foundation has hosted an annual Metastatic Breast Cancer Research Conference (MBCRC) for nine years with scientific presentations about current trends in metastatic breast cancer research and advocate presentations about their experiences engaging with scientists. Over the past few years, the group established best practices and opportunities for researchers and advocates to build relationships.

In June 2021, Theresa’s Research Foundation coordinated a group of researchers and advocates to discuss the barriers to researchers working with patient advocates, which was then presented and refined during the 2021 MBCRC. The findings and next steps were presented as a poster at AACR in April 2022 and published in *npj Breast Cancer* in June 2022. This work identified four main barriers to researchers initiating and establishing relationships with advocates then provided short- and long-term goals to overcome them (Table 1).¹

Table 1. Challenges and opportunities for establishing relationships between advocates and researchers.		
Barrier	Short-term goal	Long-term goal
It is not always clear why patient advocates should be included in research	Encourage granting agencies to require including patient advocates in grant applications and provide a statement about the value of these partnerships such as the American Cancer Society (ACS), the DOD, and Susan G. Komen	Perform a quantitative research project to demonstrate the value of patient advocates and researchers working together
Researchers are worried about saying the wrong thing	Support spaces where open communication is encouraged	Create training programs for research scientists to learn how to work with patient advocates and communicate effectively
Researchers do not know how to begin working with patient advocates	Connect with patient advocates through Twitter, consider following social media chats such as #BCSM, #LCSM, and others; Attend conferences that patient advocates attend and engage through programs like GRASP	Develop a platform that would connect researchers and patient advocates nationwide
Researchers do not know how to include patient advocates in research	- Review existing programs from peer institutions that support patient advocate inclusion in research to determine the potential value at your institution; Consider activities that support longstanding relationships within the time commitment both parties are available such as journal clubs, practicing elevator pitches, writing lay abstracts, and inviting patient advocates to laboratory meetings	Request that groups who require patient advocate involvement provide compensation rubrics; Ask that NCI update grant and comprehensive cancer center designation rubrics to incorporate working with patient advocates

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¹ Stires, H., Bado, I., Brown, T. *et al.* Improving the odds together: a framework for breast cancer research scientists to include patient advocates in their research. *npj Breast Cancer* **8**, 75 (2022). <https://doi.org/10.1038/s41523-022-00440-y>

Key outstanding questions for each of the barriers are:

- Barrier 1: It is not always clear why patient advocates should be included in research. Question: How can we demonstrate and define success?
- Barrier 2: Researchers are worried about saying the wrong thing. Question: What types of programs exist or can be created to support open communication between researchers and advocates?
- Barrier 3: Researchers do not know how to begin working with patient advocates. Question: How do researchers and advocates meet and how can we improve on these meeting opportunities?
- Barrier 4: Researchers do not know how to include advocates in research. Question: How can we encourage advocates to participate in research and how can we ensure they receive adequate remuneration for their time?

Approach

During the 2022 MBCRC, in person attendees self-selected into four groups to discuss next steps to overcome each of the four barriers described in the npj Breast Cancer manuscript (Table 2). Patient advocates, basic-science researchers, and clinicians were all included in the group discussions. Group leaders collated the findings and shared them with the broad conference (in person and virtual attendees) the next day. In this white paper, we highlight key findings and next steps. It will be important to provide a clear and quantitative overview of WHY researchers should work with advocates to encourage new groups to do so, then provide a framework for ensuring advocates are compensated for their time. There was also important discussion on best practices for creating training programs and initiating relationships.

Group	Goal	Questions discussed
Quantitative analysis (Overcoming Barrier 1)	To demonstrate advocate-researcher relationships are beneficial, we want to perform a quantitative analysis demonstrating the value of these relationships.	<ul style="list-style-type: none"> • How would we perform an analysis to demonstrate the value? • Should we survey those who work together? What about those who do not? • What questions should we ask? • What endpoints are appropriate to measure?
Training programs (Overcoming Barrier 2)	To prepare and encourage researchers to work with advocates from early stages of their career, establish programs at universities that facilitate relationship development between researchers and advocates.	<ul style="list-style-type: none"> • We know there are a lot of models of this approach, but how can we encourage programs to be developed? • What are barriers to developing these types of programs? • What are best practices? • How can we encourage NCI to update grant and comprehensive cancer center designation rubrics to incorporate working with patient advocates
Marking Connections (Overcoming Barrier 3)	To help advocates and researchers find one another, discuss current forums and future opportunities for engagement.	<ul style="list-style-type: none"> • Besides a match.com-like forum, what are practical ways for researchers and advocates to connect? • In creating a match.com-like platform, what types of information would be most valuable for advocates to include? For researchers?
Advocate remuneration (Overcoming Barrier 4)	To ensure patient advocates receive adequate remuneration for their time, discuss best practices for remuneration. Rather than providing strict guidelines with specific financial values, <i>the goal is to identify key considerations when determining how to provide remuneration for advocates.</i>	<ul style="list-style-type: none"> • Industry has discussed this before. What are challenges/opportunities for academia that differ from industry's experience? • What are best practices when it comes to remuneration? • What are opportunities to provide remuneration beyond financial payment? • What external considerations should be taken into account (e.g., university protocols, grant requirements, etc)? • What should be included in a rubric for remuneration decisions?

Table 2. Breakout group goals and discussion questions from the conference

Findings

Quantitative Assessments

One of the key barriers identified in the manuscript is that it is not always clear why patient advocates should be included in research. Anecdotal stories from researchers who work with advocates highlight the value of improved science communication, more translatable science leading to more grants and publications, and improved drive from a sense of urgency provided by people living with the disease. Working with advocates provides an experience for young trainees who frequently have not yet had personal experience with breast cancer. However, anecdotal stories may be perceived as biased or not representative of the overall impact. To overcome this, the group discussed opportunities for quantitative assessments. It is critically important to use quantitative approaches (i.e., numbers, charts, figures, or graphs) to help more scientists and advocates understand the need, funding agencies realize the problem, and the whole society see that working together will be the most effective approach to tackling metastatic breast cancer.

We agreed that it would be challenging to perform a prospective, controlled trial and instead believe a survey would provide a broad assessment of the perceived impacts of patient advocate involvement. The target audience of the survey would be researchers, both those who work with advocates and those who do not. Questions should be focused on perceptions of working with advocates and decisions related to begin to determine potential impacts of working together.

Engagement and Remuneration

As it becomes more widely accepted that advocates' contribution has a great impact on the quality and outcome of research, advocates are more and more viewed as collaborators whose roles should be defined and compensated for their work. Additionally, we need to define the different opportunities that exist for working together. There are a lot of things to consider when it comes to remuneration, from the activity to the amount of time invested to the advocates' personal views. The group agreed that advocates should receive remuneration based on their level of involvement, but there are no guidelines for fair and reasonable compensation for advocates.

In recent years, Industry has worked to develop a framework for compensation for patient engagement. The National Health Council developed [a toolkit on compensation](#) for patient engagement activities to support compensation and reimbursement decisions. The goal was to create a toolkit to guide compensation of patients and patient groups involved in patient engagement activities, mostly related to medical product development. While this is a great starting point adjustments would need to be made to accommodate the unique needs of academic research. Similarly, the Patient Focused Medicines Development [established a toolkit](#) that created "Global Principles for remunerating the patient community for interactions with the pharmaceutical industry in an efficient and effective way."

To establish best practices for academics, we suggest working with grant professionals at academic institutions and granting organizations to understand what is feasible within the permitted guidelines. In addition to financial compensation, remuneration can include acknowledgement/ authorship, and covering travel expenses to conferences and training programs. At the very least, advocates should not have to pay out of pocket to engage with a researcher, which can include covering the advocates' cost of attending conferences. It would be helpful to have a rubric/table with roles and responsibilities with suggestions for remuneration based on level of involvement. Once written, this guide could be shared with Academic institutions

to help initiate discussions with advocates on potential research collaborations. Additionally, the guide could be shared with organizations who include advocates in research proposals (e.g., Komen, Department of Defense) to provide a foundation for how to compensate advocates and encourage them to include advocate remuneration as a line item in grants. Eventually, sharing this information with the NIH to encourage them to do the same will be critical for more widespread adoption.

Training Programs

To establish longer-term relationships with advocates, the group discussed training opportunities for researchers with a focus on trainees (i.e., the next generation of breast cancer researchers). They focused on opportunities to learn best practices from already established groups and some best practices agreed upon by the advocates and researchers.

At Cornell University, a Community Cancer Partnership Program started with a recognition that advocates and researchers were often intimidated of one another when initially working together in grant reviews panels. An effort was made to overcome the intimidation by developing researcher-advocate relationships while the researchers were still in training. Starting a program that facilitates relationships between trainees and advocates is not resource intensive, but can use already established frameworks (e.g., invite advocates to internal scientific presentations, host advocate panels, include advocates as speakers during classes). Bob Riter has written about the program and their [website](#) includes a plethora of resources for advocates and researchers interested in engaging.

The groups identified some best practices/ considerations when working together:

- *Establish ground rules:* We know that many (both researchers AND advocates) can feel intimidated and/or are worried about saying the wrong thing. Before beginning sessions that introduce advocates and researchers, remind the group of the goal of learning together and from one another, suggesting a need for humility and openness.
- *Improve science communication:* One of the biggest benefits to researchers working with advocates is a chance to improve science communication, both with peers and with the public. The manuscript highlights some ideas such as practicing elevator pitches and writing lay abstracts. Consider asking advocates to score the researchers/ provide feedback in some way so the trainees understand areas for improvement.
- *Think simply:* Many training programs have opportunities for trainees to learn outside of the lab, including in classes, during retreats, and in symposium. Rather than starting an entirely new program to introduce advocates, consider ways of incorporating advocates into already established programs.
- *Create frameworks and succession plans:* When introducing advocates into training programs, leaders who oversee the relationship building should have succession plans in place. Many graduate students and post docs enjoy having leadership positions, and providing opportunities for them to lead, then pass the program to the next set of trainees for program consistency.
- *Use virtual spaces:* The COVID-19 pandemic taught us that connections can be made virtually. Researchers should consider opportunities to connect with both local and distant advocates via Zoom.
- *Consider where these relationships could be fostered:* Including patient advocates in seminars or journal clubs both trains them on how science is discussed but also provides

a forum for relationship building. It would also be helpful to establish training programs for patient advocates, including how to be a research advocate as well as scientific background.

- *Provide a user space for advocates to create and share templates:* Many trainees and advocates have not submitted grants before, and both groups could benefit from a training and/or shared documents about grant components like lay abstracts, personal statements, and biosketches. Advocates would also benefit from shared templates for letters of support and scoring sheets.

Making Connections

Many researchers (and advocates) are unsure of how to begin relationships and where to find each other. Researchers on medical campuses may have an easier time connecting with patients who are advocates, as well as just seeing patients daily at work, even in the cafeteria at lunch. This can allow researchers to recognize that their research has a human factor/effect, while those in non-medical center affiliated labs may have a harder time finding local advocates. It would be helpful to share opportunities for advocates to learn more (see Bob's link), and to find ways (training, programs) to help researchers feel more comfortable about working with advocates.

Both groups may feel intimidated – researchers are worried about not knowing what it feels like to deal with cancer at every moment as a patient, and about imposing on advocates, while advocates may feel embarrassed for not understanding the science, and about disappointing researchers when they struggle with their health. Communication is key and clearly establishing expectations up front may help prevent these feelings.

The group discussed practical ways to connect. Consider creating programs (see above) to engage the community and bring advocates into laboratories.

- *Connect at conferences*
 - *Create special sessions at meetings:* Promote intermingling between senior researchers, trainees, and advocates, rather than isolated tables. Consider having different colored name tags for each category (patient advocate, researchers, clinicians), so when the groups form, they will know that they have a representative from each category for discussions.
 - *Advertise a meet up location:* At bigger conferences, organizations such as GRASP could advertise a meet up location for researchers, trainees, clinicians, and advocates to connect. Along with the meet up location, they could have a one pager to share with new researchers about the value of connecting to try to bridge the gap from patients to the bench.
 - *Host a researcher/advocate mixer:* Develop a formal meeting area for advocates and researchers to mingle. Consider bringing a list of questions to ask about each other's experiences to get conversations started.
- *Reach out to established advocacy groups*
 - This could include: listing of advocacy groups, and HOW to reach out to them – for example, how would researchers identify the appropriate advocacy group, how do they know who is contact person, when is the best time to reach out, should they contact local or national groups etc.
- *Create an electronic tool (e.g., an app, a website) that both advocates and researchers could use*

- *Meetings*: A section to indicate what meetings they will be attending.
- *Openness for connecting*: A way indicate their level of comfort on being contacted/open for discussion later.
- *Cancer type*: For researchers, area of study. For advocates, cancer subtype and metastasis of interest.
- *Time commitment*: Frequency of meeting, availability for engaging.
- *Location*: Where they are located and (for advocates) willingness to travel.

Overall, many who attended the conference agreed that there is great value in researchers working with patient advocates. These practical next steps will continue to encourage others to develop these relationships.