

AHRQ's Community Forum
Supporting Patient and Consumer Involvement in
Patient-Centered Outcomes Webinar
Moderator: Danielle Lavallee
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2:30 p.m. EDT

[START]

Introduction

DANIELLE LAVALLEE: Good afternoon. We'll go ahead and get started. I'd like to thank everyone for taking time out of their busy schedules to attend today's webinar. My name is Danielle Lavallee. I am part of the Community Forum Team and will be moderating this session. As you know, we are recording this webinar and have the intent to post it for viewing at a later date. We'll certainly provide that information to attendees at that time.

As an overview for today, I'm going to start by providing a brief background to the Agency for Healthcare Research and Quality's Community Forum project highlighting some of our efforts and activities to date. I will then turn things over to our wonderful presenters to discuss today's topic on supporting patient and consumer involvement in research. We have reserved time at the end of the webinar for a question and answer period. Please feel free to submit your questions to me throughout and we will address them at the end of the presentation as time permits.

To meet our goals today, our presenters will be providing insights on approaches to identifying patient and consumer representatives, approaches and considerations to support their involvement throughout the research process, and strategies for partnering with patients and consumers in the translation and dissemination of research products. The Community Forum initiative is funded under the American Recovery and Reinvestment Act of 2009. Its purpose is to improve and expand public and stakeholder engagement in patients centered outcomes research reported by AHRQ.

The initiative, led by American Institutes for Research, is separated into two parts. The first, which I'll simply touch on today, is focused on assessing alternative methods of public deliberation to obtain feedback from lay members of the public to inform healthcare research and policy. The goals of the experiment are threefold: first, to evaluate public deliberation as an effective method for soliciting public input on ethical and value-laden issues in healthcare such as those that are involved in comparative effectiveness research; second, to see which methods are most effective; and, third, to obtain public input that will inform AHRQ's Effective Healthcare Program.

The second part of the initiative seeks to expand stakeholder input and involvement in all aspects of the research activities in the effective healthcare program. The American Institutes for Research has partnered with the Center for Medical Technology Policy, Consumers Union and AcademyHealth to conduct the various activities within this portion of the project. Today's webinar is one example of work being conducted as part of this focus.

. Involving patient and consumer representatives throughout the research process is a new and evolving practice within healthcare research. As such, the focus in much of our Community Forum work in the first year centered on understanding the best approach to support and expand collaboration with these stakeholders in the EHC program research activities.

To this effort, the Community Forum team convened the individuals listed here as a Technical Expert Panel for a day-long discussion on supporting patient and consumer involvement in Patient Centered Outcomes Research. The panel consisted of patients and consumers who have had the experience of representing the patient perspective on research projects, as well as people who have worked with existing training programs to facilitate patient and consumer collaboration in research activities.

The discussion provided insight on techniques and resources to effectively and efficiently identify patient and consumer representatives; mechanisms to provide support and training to facilitate their involvement throughout the process; and strategies for partnering with patients and consumers in the translation and dissemination of research products. They have been a dynamic group of individuals to work with and learn from! So I'm excited that a few of them

have joined us today.

Today, we are very fortunate to have three of our "experts" join us to share the insights from the July 13th panel discussion. Each presenter will utilize their experience and work in patient engagement and research advocacy to provide examples and context. To start us off, Carolyn Branson, Consumer Reviewer Administration Manager at SRA International, will be discussing approaches to outreach and identification of patient and consumer representatives for involvement in research.

Following Carolyn's presentation, Amy Bonoff, Graduate of and mentor for the National Breast Cancer Coalition's Project LEAD Institute will discuss approaches to providing support and training for Patient and Consumer Representatives.

And finally to wrap up, Lawrence Sadwin, 25 year advocate for the American Heart Association and current president of the Friends of the World Heart Federation will discuss strategies for partnering with Patients to Disseminate Research. With that, I am going to turn things over to Carolyn to start us off with our first presentation.

[pause]

MS. LAVALLEE: So, Carolyn, are you on with us?

CAROLYN BRANSON: I am.

MS. LAVALLEE: Excellent. So prior to you starting, I do want to give a more formal introduction of Carolyn. We're very fortunate to have her with us today. As the Consumer Reviewer Administration Manager at SRA International, Carolyn leads the efforts to promote and facilitate the participation of consumer advocates who are survivors of cancer and other diseases, illnesses, and injuries in the Department of Defense Congressionally Directed Medical Research Program.

As part of SRA's Peer Review and Science Management Center, Carolyn manages a team of professionals to recruit, assess, train, and support volunteer consumer advocates to ensure the inclusion of the survivor's community perspectives in the scientific peer review process. Carolyn works with hundreds of leading consumer advocates in support organizations to identify and nominate qualified candidates; she interviews and assesses each nominee to determine those most likely to be successful members of

scientific peer review panels. She oversees a mentoring and training program that carefully guides those consumer/advocates with minimal scientific or medical backgrounds into the scientific research and peer review process.

So with that, Carolyn, I will send the presentation over to you.

Outreach to Identify Patient and Consumer Representatives

MS. BRANSON: Okay. And I would like to start with to saying what an honor it is to be with you and to lead off the discussion today on the value and the importance of involving consumer advocates in research activity. So over the next few minutes, we'll talk a little bit about who are these consumer advocate representatives and what characteristics they share, how you can identify, and that's in quotes, the right person for your needs, what selection techniques are effective, and then what's worked for us at SRA International.

If we talk about the patient representatives and who they are, we've all heard the importance of making a first good impression. And not the least of those is when you're working with patient representatives, you need to call them by the name that they're comfortable with. So what you see here is who those are. They may be patients. They may be survivors. They may be what they call themselves thrivers. And it depends on when you meet them as to whether they consider themselves patients in a lot of cases.

Also you might check a few organization websites as a hint to figure out what title is the best one to use. Consumer representatives and patient representatives are members of advocacy groups for patients as well as other kinds of community advocacy groups. And they may be family members or caregivers or they may actually be healthcare providers.

However you refer to them, patient representatives should be recognized as having a specific expertise. And that is a personal experience with a condition. And that is a valuable contribution to the research team. They're no different than other experts like statisticians that bring a specific expertise to the team. Characteristics then of patient representatives are that they have personal

experience with this disease or illness or injury or condition. The researchers must be cognizant of where the patient is in his or her journey with that condition and depending on your needs and the tasks you're asking of them.

A possible rule of thumb is to look at someone at least a year out from their diagnosis. Early on, their focus is inward and it takes time for them to be able to move beyond their own personal experience and represent others. Also in that year's time or more, they're likely expanding their knowledge about treatment options and/or the science of their disease and science in general.

And they're also more likely to be able to speak extemporaneously in public. And this is a really vital function for them to have. You'll hear a lot more about that from our second speaker.

In addition, the consumer advocate review representatives, we all agree that they must participate in some organization that it's a very helpful thing for them to do that. Avoiding conflicts of interest is another important characteristic of patient representatives. And that's sometimes a challenge to enforce and make sure that you pull that out of this individual. But it must be met.

Guidelines as to what determines a conflict may vary slightly for consumer advocates versus scientists. But those guidelines must be clearly defined, reinforced often, and a new conflict of interest statement signed each time their path [phonetic] changes or they serve at a different time.

To identify the right consumer, it's critical that you allow adequate time for recruitment. So even before that, you should establish the objectives you have, the roles that the consumer representative will play, and what expectations you have of them before you even start recruiting. Once you start, utilize a known organization wherever possible. They can provide basic training and they have the existing infrastructure that's needed for transparent and fair recruitment practices.

Use a [phonetic] centralized or a national patient advocate group such as Patient Advocates in Research (PAIR) or CUE and certain government agencies like the FDA and the CDMRP, which is the Department of Defense and their contractors and consultants, and then certainly disease-specific

organizations like the National Breast Cancer Coalition's Project Lead and the Ovarian Cancer National Alliance. They're all valuable sources for recommending and identifying trained patient/consumer representatives.

Even so, identifying patient and consumer representatives requires dedicated resources. A number of such organizations like the FDA Patient Representative Program, Project Lead, and my own company SRA International have dedicated staff to identify and maintain continued relationships with patient and consumer representatives.

In addition, including patient and consumer representatives on your selection committee to help recruit and retain representatives is important. Consumer advocates who have worked with you and better understand your needs are the best ambassadors for sharing their experience with others one on one or through their organization. And they do this in many ways and we talked about this with the expert panel. They may blog to others. They may use Twitter. They may use Facebook. Or they may use their organization newsletter.

They're your best salespeople to get others interesting in working with you and to spread the word about research products and outcomes to the communities that you want to reach. Again, you'll hear more about this from our third speaker.

We provide sample press releases for example including short versions for sharing in blogs so that individuals and organizations can know about the work that's being done. So if you contact organizations, have your materials developed to describe who you're looking for and how you hope to use them.

In addition in selecting, you can use multiple recruitment methods in order to identify a broader demographic, older patients, minorities, and the underserved. And these may range from letters to organizations to contact via email to going into churches and barbershops. And never undervalue the power of AARP. Sorry, I couldn't resist that one.

As we said about determining techniques for selection, you need to determine what specific information you need as part of your recruitment plan. So you're looking for patients' caregiver experience. What have they done before in the advocacy community and in the support community? What have they done? What experience do they have?

Advocacy experience, this may help you determine their comfort for example in working with scientists and researchers. They must have the ability to represent other patients and survivors' point of view and not just their own personal one. What knowledge and skills do they have related to the disease area for which you're recruiting?

And then also disease experience; some of the consumer advocates I work with have several cancers for example. And they can induce their different organizations that use consumer advocates wearing their different hats. And I use that term with quotes.

And the work experience that individual has, for example, an individual who's an attorney or a teacher may be more likely to have the skills to speak extemporaneously for example. Education, it's not always necessary that the consumer representative have advanced degrees, but you might need that extra level of knowledge and experience for the work you need them to do.

A big part of this, and we had a lot of discussion about this in July with the Expert Panel, is the importance of interviewing the person that you want to come on board to work with you. We all came to this conclusion that that interview is critical for many reasons. For the interview to be effective, you develop your questions early on that will provide the information you need to make a decision on whom you will select.

This interview, of course, should be part of a larger recruitment process and may be done by a telephone or in person. It may be done by an individual, but it should be someone who can put the advocate at ease, who can ask the tough questions, and know when to delve more deeply while not asking the wrong questions, in quotes. Or it may be done by one or more individuals, so you may actually have a panel of individuals. But if you can have that initial contact with one person and then lead them into that group, it will be helpful.

In selecting patient representatives, it's very helpful to include more than one patient or consumer representative in any activity. That gives you a chance for a broader perspective of the individual experience. It provides a patient representative with a colleague in the experience. And mentoring is an essential part of many of the successful efforts that involve consumer representatives.

I'd like to move into a little bit to give you a little more information about SRA and give you more information on how we work with consumer advocates for some of our clients. SRA was founded in 1978 and we remain dedicated to solving complex problems of global significance for clients in national security, civil government and global health. Within SRA, the vision of the Center for Peer Review Science Management (PRSM) is enhancing human health around the world through innovative science, knowledge, and technology solutions.

My group within (PRSM) supports clients including as you've heard the DOD Congressionally Directed Medical Research Programs, which is under the U.S. Army Medical Research and Materiel Command and the Cancer Prevention and Research Institute of Texas Research Program. And for them, we recruit, train, and support consumer advocates and scientists for a scientific peer reviews of applications submitted for funding to these two organizations. We've overseen over the years the scientific peer review of nearly 70,000 research applications.

Training and working with consumer advocates and having them be an integral part of the review of the research applications has been going on with PRSM since the mid 1990s. So we've been doing this a long time. We have a lot of systems in place to make things happen. You will find the FDA for example and their patient representative program has also been working with patient advocates since the '90s.

A big part of why we are so successful is that we develop real partnerships with both our clients and with our consumer advocates and their organizations. We do that by basing all interactions on respect and acknowledged values, the value of the consumer advocates to the process. We do that by maintaining regular contact with organizations and advocates. We clearly define the needs and involve their advocates and their organizations in helping determine who we need. This is client-centered for us. But early on, the definition of who can serve as a consumer advocate reviewer is developed.

Then we ask the organizations to nominate advocates they would like to represent them and the community of others with their same illness or disease. We follow up with them regularly with a thank-you letter and give them kudos for nominating a successful person in the process.

In downtimes or when you don't need help, you can email your point of contact just to let them know that things are still moving forward. And we haven't had to use anyone yet, but it's coming up. And making that contact is really critical. And as one of the panel of experts said, sometimes you just have to put on your high heels and go to lunch.

Offer them a unique opportunity. That's what we do. We do a flyer for each of our programs and we start out with Unique Opportunity in bold capital letters with a picture that's appropriate to go with the particular program. If you can find a way to make the experience you're offering unique or provide some sort of catchy hook, something that will make people say, oh; maybe I want to read what they're asking about, read whatever this document is.

Set your standards high. You'll hear that a lot from our second speaker especially. Know what you want, what training or background of the consumer representative will lead to them being most effective, and be realistic on who can do the job. All of these things require that you have successful processes developed and that you follow them rigorously.

So we'll move now to talking a little bit about recruitment, support, and evaluation. Recruitment includes providing the client or us providing the client with a program consumer outreach plan each year that describes timelines for the recruitment of each of 15 programs; what organizations will be contacted, how consumer advocates will be selected, how many advocates are in the pool, and how many will be able to serve as mentors versus new advocates needed et cetera. And once this plan has been accepted by the client, we begin taking advantage of those partnerships we've developed with more than 400 organizations. We send out emails and/or call the representatives in those organizations who have nominated successful candidates in the past. And even if they didn't, we still contact them and hope for better the next time around.

We're constantly on the lookout for new organizations. So we're searching with them. Many of our advocates get in touch with us about new organizations they've either joined or learned about. We provide the organization with an electronic nomination form for the DOD programs. That's also available on the CDMRP website. That form is a real

key piece in this process because it describes the minimum qualifications of consumer advocates and describes what they should include in that organization in their letter of nomination.

We send them an attachment letter that describes the process for recruitment and for the peer review session. We've also developed flyers for each program and the CDMRP has developed a consumer advocate brochure. We share all of those things electronically. We try to do everything electronically where we can in this day and age because we need to be sure that people can work in a database and that they can follow through with electronic submission of packets. It's kind of a mini test to just see if the organization and the individual people will be comfortable working electronically.

When I started in 2005 with the program that I do for the CDMRP, we were sending every single application in banker boxes to the reviewers. And they were working at the peer review meeting with a Palm Pilot. We've come a long way. We try to do everything electronically.

Each nominee then completes an essay as well in addition to the letter of nomination and the nomination form that the nominee and the organization complete. The essay content is described in that nomination form. And again, that's why it's such a critical piece. It describes their advocacy—they should describe their advocacy support in the community they will be representing. And they answer a few questions to help us to determine their ability to represent others, not just their personal views, and to try and determine how they deal with controversy; also how well they keep up with developments in the science and treatment of their disease.

Requiring an essay helps us determine their ability to write well and determine their ability to think objectively. They also submit a resume that helps with some of the issues mentioned before, years in advocacy, type of work, and educational background. The package is then evaluated and scored by two SRA senior scientists who look for level of work in advocacy, written and verbal communication skills as evidenced by their writing, but also by the letter of nomination, and the way and level of effort they put in to keeping abreast of the science and treatment of their illness.

Finally, if they scored well, we do a half hour telephone

interview with scripted questions with them. If they're successful in that interview and we are actively recruiting at the time for upcoming peer reviews, we tell them more about the process and ascertain their ability to serve.

So this is the process of just getting things started and getting people into the pipeline to serve for us. We have nearly 1,400 consumer reviewers in our pool for the 18 programs that we've served over the years at the DOD. And we can't contact everyone all the time. However, we do send thank-yous for their service. And they keep in touch with us as well to let us know how they're doing and also because they wanted to be considered for a future opportunity.

For most of our programs for the DOD and those programs range from the breast cancer program and the lung cancer program to the neurofibromatosis program and so forth and then two military programs and health programs as well. And for most of our programs, consumer advocates can serve for up to three peer review terms. For others, it can be more. But even if they're serving more than three terms, we do require a new letter of support from their organization stating that they continue to be involved in advocacy or support.

We provide training including a variety of webinars, videos, manuals, on site orientations, and trained mentors. An important part of the training we provide is to the scientific review officers who are our panel managers. We want to ensure that they understand who their consumers are and how they should include them and how they should be recognized at all times. And as an aside, training your researchers will be invaluable. And I put training in quotes there, but it's educating your researchers about who your consumer representatives are.

We have three consumer reviewer administrators whose sole purpose is the recruitment, support, training, and evaluation of the consumers. The three of us are a nurse, a social worker, and a health educator by training. But we have all experience working with volunteers and with persons dealing with illness and injury. Amy will be discussing training and support momentarily. But it's important to note that providing training is also a key part of successful recruitment.

In terms of evaluation, we obtain feedback throughout the process both written and verbal from a variety of sources.

We obtain that feedback in a timely manner. We debrief with all participants involved. And we modify and improve the process as we move along.

So to continue [phonetic] with successful support, we developed and provide easily accessible and appropriate training. We provide time immediately after their contribution for one on one or small group debriefing.

So for peer reviews, we usually have multiple panels going on. And as the consumer advocates who are a part of those peer review panels complete their work, they meet with us, whichever consumer reviewer administrator they work with and with the rest of the panel members who are consumer advocates. And that may be one other person or it may three other people. And they get to talk about their experience immediately so that they can let us know what worked and what didn't work.

Provide time immediately after for this one on one debriefing. Take all suggestions seriously to show that you're paying attention. Make suggested changes as soon as you can. The military talks about turning on a dime where feasible. There's nothing better than hearing a consumer advocate say to you, you know at that least meeting I told you such and such and you fixed [phonetic] it. That's really nice. So know that we're being listened to.

Provide a written evaluation tool for your consumer advocates to provide input. That's a critical part of our work as well. We do it in a variety of ways over the years. We are currently doing it via a survey monkey [phonetic]. I'm not pushing that particular organization company, but that's just how we do it so that everybody can have access to it readily. We provide compassionate, passionate, and knowledgeable points of contact.

And finally, to summarize, really these are three very, very important things. You need dedicated resources for recruitment. You need to develop partnerships for recruitment with national and local advocacy organizations and with patient and consumer representatives themselves. And provide clear descriptions of the activity and expectations of involvement.

Recruitment is an important process and requires dedicated staff support. To facilitate recruitment, develop partnerships with organizations who can help identify patient consumer reps. Also recognize that patients and

consumers themselves can be an integral part of the recruitment process. Be clear on the main [phonetic] expectations of involvement upfront so consumers understand what is expected. Thank you so much.

MS. LAVALLEE: Excellent. Thanks, Carolyn. I appreciate the presentation. I am now going to switch over to Amy's presentation for today. And while I switch over her slides, I'd also like introduce Amy as well. Amy, can you hear us? Are you on?

AMY BONOFF: I'm on.

MS. LAVALLEE: Excellent. So Amy is our next presenter. And she's a 14 year breast cancer survivor and an active and experienced National Breast Cancer Coalition advocate. Amy is a graduate of the ProjectLEAD Institute, Quality Care LEAD, and Clinical Trials LEAD. She is also a current member of the Agency for Healthcare Research and Quality's Effective Healthcare Program stakeholder group as well as a mentor for the Project LEAD Institute.

Among Amy's many activities, she is cochair of the National Breast Care Coalition Quality Care Advocate Advisory Committee. She has participated in the Department of Defense Breast Cancer Research Program Programmatic Review, and is a member of the Scientific Advisory Committee of the Susan Love/Avon Army of Women. Amy is a recipient of the San Antonio Cancer Symposium Scholarship, 2007, and is a sought-after speaker on breast cancer advocacy in research, access, and quality care.

So we are thrilled she is with us today to discuss important training for patient and consumer representations involved in research. And with that, Amy, I will turn it over to you.

Supporting Patient and Consumer Representatives throughout the Research Process

MS. BONOFF: Thank you very much. And thank you, Carolyn. That was an excellent presentation. You've set the bar very high and let me say that.

What I am going to do today really following up on Carolyn's excellent presentation is really to talk about the training and support. And one of the key issues that frequently arises is how best to support and train patient

and consumer representatives to fulfill the needs that are involved in the research activities.

So during the panel discussion, we each shared our thoughts and insights on this topic given our experiences. And I'm going to start by presenting the insights from that expert panel and then frame them in the context of my work with ProjectLEAD.

So many organizations have recognized the valuable input of patients and consumers contribute and, thus, have worked to develop programs to train and support their involvement. You've certainly heard an excellent one with Carolyn's organization. We've listed some of them today. We'll talk about LEAD and certainly FDA Patient Representative is one that we all are familiar with.

I just wanted to center on Consumers United for Evidence-based Healthcare because I think their goal—they're a coalition of consumer advocacy groups. And what they are trying to do is forge a partnership with health groups and strengthen the voice of consumers in healthcare research. And that's exactly what we're trying to accomplish today and I just like that.

I also wanted to give another example not listed on the slide of a different kind of training. And that is the Alamo Breast Cancer Foundation, which provides ongoing education for trained breast cancer advocates during the largest scientific breast cancer symposium, which occurs in San Antonio every year. What they do is they have hot topics every night trying to educate and discuss some of the important issues that were mentioned during this very complicated symposium during the day and so to continue the education of advocates. And it's another interesting way of approaching learning.

So principles for training programs, I think these are the most important points to be made of all. It's really important to set appropriate goals. And I think what you have to say is right at the outset what is the goal of the training? And what do you want your trainees to be able to do at the end of the training? You have to be able to set those goals for what you want participants to know.

The approach to supporting patient and consumer involvement should be tailored towards, the intent or the role of their participation, and certainly the FDA is a very good example of training on regulatory processes as is specific to the

activity they are asking for. You have to ensure the appropriate resources are available given the intent of involving patients and consumers in the process.

And, therefore, you have take into account the level of knowledge and experience, understand the motivations of learners, which Carolyn spoke about, and also provide ongoing and mixed training methods. And I will talk a little about this. It's called adult education. And it really has to do with giving different kinds of learning and we'll discuss it, and problem solving so as to reach out and get the most meaningful lessons for the researchers and for the patients.

If we talk about adults and principles for adult learning and I have to keep a straight face here, repetition is certainly one of them. And use of plain language is another. You have to also identify skilled faculty members for training courses. And you have to ensure that training is evaluated and continuously updated.

The most important point is this is not abstract or theoretical. It is actually the application. In other words, how are you going to use what you are teaching? You have to craft that so that that goal and that understanding are constantly in evidence and providing information to support that goal.

The contents should be relevant to the context at hand. But what is also important is that training includes not only technical content. We're always talking about scientific research and peer review. But there is also training on other skills such as public speaking, skills in negotiation, understanding and providing support on how to work in multidisciplinary groups and that's also important. And what is important here in training and critical thinking, what's really important is to realize this is not just for the patient and consumer representative. But it is true for all stakeholders who might be involved in collaborative research activities.

In addition to training, there are other opportunities for support. And I think the most important one is establishing mentorship programs. Carolyn described beautifully how she tried to recruit. And what is important there is that for the Department of Defense, there actually is a mentorship process where new consumer reviewers are assigned to mentors who explain the ins and the outs of pre-meeting work as well as the meeting

processes and procedures.

Networking is also important for patients and consumers involved in research advocacy. This allows them to learn from others' experiences and also find out about other programs and opportunities for involvement in research advocacy.

And finally, anything that helps to reduce barriers for participation such as travel expenses per diem to offset lost days at work and daycare expenses are all for further valued approaches for support. That is really the summary of what we were discussing in terms of training and support in our technical panel.

And so what I'm going to do now is turn to the National Breast Cancer Coalition ProjectLEAD story where you'll see a lot of the things that we were talking are framed in our program for education and training. What is ProjectLEAD? What I want to say right at the outset is that ProjectLEAD is an intensive five day course on the biology and epidemiology of breast cancer. And as you will see, it is a huge investment both in cost and in time, and may, therefore, not be the perfect model for general consumer education. But the principles apply to all training programs no matter how simple or complex the training design.

And so if you look at this slide, you can see all the key context that both Carolyn and I have been talking about; learning the concepts and language of science, working with a mentor and not only during the teaching but also as a guide in the advocacy career that you're trying to create for yourself, collaboration, choosing of participants so carefully as Carolyn described, good faculty, adult learning, again repetition, small study sessions, case studies, role playing.

And note here personal action plan; so a mentor and a student work together to decide not only what they've learn-to help with the teaching and the learning process, but also what are they going to do with that learning? Where are they going to take it and to support that continuing education? Webinars, LEAD casts [phonetic], many different ways of using education before large meetings; all of this is support. Like the Alamo supported continued education.

And so ProjectLEAD is done [phonetic]. And I will now

continue the description of how we built this program and how it's continuing to change. Why it's important is because it not only teaches the concepts and language of science, but it enables advocates to take a seat at the table and to engage as an active participant from the beginning.

We as advocates are given tools to critically appraise research proposals and scientific reporting. And in so doing, we build bridges between consumer advocacy and the scientific community. And also we build credibility for the consumer advocacy community. All this is so necessary and it is based in teaching and learning.

NBCC advocacy training was started in 1995 with ProjectLEAD. Clearly we're a little bit younger than some of the other ones mentioned, but we've had over 2,000 graduates. And we have continually changed and upgraded the training. In 2008, we created the Center for NBCC Advocacy Training in order to consolidate, expand and enhance the range of NBCC research advocacy and public training.

And what's important is you're constantly evaluating and improving for the next group. And you're trying to answer the needs and add additional courses if necessary such as emerging leaders training for younger people or continuing education. And just recently in the last couple of weeks for the first time, we held a half a day course for journalists because they need to be educated.

Here are some of the types of projects reported [phonetic]. I mentioned the basic ProjectLEAD 5 Day institute the Intensive Science and Research Methodology course. And then we added clinical trials. Once you've taken ProjectLEAD, it's an advanced course in proof design and implementation in clinical trials quality care, which is certainly important to the people working towards system-wide improvements in quality of breast cancer care; and also taking note of the global need for education with International ProjectLEAD, which brings science and clinical trial training to the international advocacy community.

So these things are all built out of the original ProjectLEAD course. And here is one that's interesting and it's probably maybe the best model for a general consumer education in terms of time commitment. ProjectLEAD workshop is two day course. But again, one of the limitations you have limited goals. With limited time, you

have limited goals. But it is an introductory level course on basic sciences and context and language.

And what it does, it really teaches a basic understanding of statistics so that students can read the newspaper and research articles and understand not only what has been said, but what has been left unsaid and how the numbers can be manipulated to make a small story a big headline. So it's really skill building and understanding of science. And interestingly enough, it really is a feeder [phonetic] for ProjectLEAD because a lot of people take the two day workshop and then are very excited to sign up for ProjectLEAD.

We've talked a lot about the Department of Defense Breast Cancer Research program. NBCC worked on designing that program. And what their vision was is that educated consumers work as peers with the scientists from the start. And that is very important because I always say I have been thrilled to work on that program.

And it is very exciting and very real—I want to say this right. It's a real honor to know that your vote counts every much as equal to each scientific vote so that you as a peer are just as responsible. Your voice is heard. You are a co-chair. You can be a co-chair. You can be a reviewer. But in every sense you are an equal member sitting at that table. And so you really need to be well educated in order to take that responsible position.

NBCC principles align with ProjectLEAD in the sense that we support evidence-based healthcare. And we care about developing a consumer perspective to shape the research agenda always at the beginning to take a seat at the table and help shape that research agenda. And we also obviously keep the efforts focused on the mission to end breast cancer.

We have believed in the universal healthcare reform and we were instrumental in assuring the language educated consumer involvement on committees. That language was added to the bill and we had to fight to keep it in the bill. But it is a very important forum for the future of advocacy.

And the principles of ProjectLEAD clearly set the bar high for student selection and for curriculum. But underlying everything is a belief in the adult ability to learn complex scientific context in critical appraisal skills.

You ground the program in adult learning principles. As we've said in a few different places, repetition is always good; to repeat small study groups to support and make sure that people understand what was said in the larger lectures all the safe learning environments so that the weakest who are the least knowledgeable can catch up with the rest.

And then something called Risk Zone Theory, which means if you imagine three to six circles, there is a comfort level right in the center where we're all comfortable and we really know the information. So the content we're very comfortable with it. But if you stretch out a little bit more, you're in the risk zone where you actually learn something you haven't learned before and you would risk. But if you go too far, you're in a panic zone and you can't absorb anything. So if you're trying to do as adult learning, you have to try to make sure all your students are in a risk zone where they're learning, but not where it's beyond their ability to comprehend.

And then finally a graduate action plan, again it's very important that you have not only the learning, but you make sure that learning becomes an actuality that you walk away with a plan on what each student is going to do with that learning to support their advocacy career and offer continuing education and mentoring throughout. I've been a mentor. Mentoring is very important because I often get calls to say who can I talk to if I'm interested in this? Who can help? And if I can't do it, I can get someone else to help. In other words, what we're trying to do is build this advocacy community and make it stronger and make it more effective.

Faculty, it's absolutely key. It is outstanding teaching skills. It's just a key requirement. Also faculty has to believe that students can learn complex science. And they also have to be willing to accept the continuing commitment to refine and improve the course. The faculty is committed and they are inspired. And if they don't work out, they're just not asked back. It's a continuing and an impressive faculty commitment.

The curriculum, as I said, was basic science, epidemiology, clinical medicine, and advocacy development. And I want to take a moment on that last point because advocacy development isn't just about providing technical training. Advocacy development talks about the skills for appraisal of evidence, communication skills, and the critical

appraisal skills. These are all part of development and training. And it's outside of the technical training.

It's important and it talks about the centrality of evidence-based healthcare. It talks about how you're able to influence strategies, role playing to be able to feel what it's like to be at the table and make your voice heard, what the opportunities are there in front of you, and again the graduate action plan. So just recognize that training and support doesn't just focus on scientific training for ProjectLEAD advocates. And this is true for everyone who needs to work on the advocacy community.

And in summary, research advocacy continues to grow with a focus on patient-centered outcomes research. And patient advocacy groups are becoming more interested in supporting research advocacy. Developing and maintaining training programs is resource and time-consuming. Thus, it's important to learn and utilize and draw from existing programs where available.

We have examples of organizations with training programs in place and you can use those. Not one program is going to be perfect. But to be able to take and borrow from each one of them will be a valuable resource for researchers looking to identify patients and consumers to involve in the research projects.

And this is a resource page. And again, we stressed in our expert panel over and over again it is important to know there is no reason to reinvent the wheel with respect to training. Time and effort have been put in to developing great resources. And these resources are available for researchers and research advocates and may assist with initiatives to provide support and training.

I just want to highlight the Consumers United for Evidence-based Healthcare. There is an online course, Understanding Evidence-based Healthcare, a Foundation for Action that is absolutely excellent. It's six hours. You can take it whenever you want to and it is a very good course on evidence-based healthcare.

And it is a prerequisite for anybody who is going to take ProjectLEAD. They need to have finished that course before they come to the program. It's narrated by an advocate Musa Mayer and an epidemiologist, Kay Dickerson. And I would just suggest it for everyone.

We've also listed others and tried to use wherever possible the web addresses. The Food and Drug was too long for me to put in there and fit it on the page. But I hope everybody does use these. And with that, I'm going to thank you all for listening and hand it over to our last presenter.

MS. LAVALLEE: Amy, thanks. That was wonderful. So our last presenter, I'm just going to bring up his slides, is Larry Sadwin.

LAWRENCE SADWIN: Hi there.

MS. LAVALLEE: Larry has been a tireless advocate for the American Heart Association for more than 25 years, after being diagnosed with heart disease and also losing his father to the disease. He has served in nearly every volunteer capacity for the association, culminating with the prestigious national post of Chairman of the Board in 2001 to 2002, and as chief volunteer executive officer position is responsible for the overall administration of the association's business affairs, public relations and development.

In addition to his work with the American Heart Association, Larry currently serves as the President for the Friends of the World Heart Federation. He also serves as a consumer stakeholder on AHRQs DEcIDE Cardiovascular Consortium, and has previously served as a member on the Council of Public Representatives to the Director of the NIH.

So with that, I'm going to—Larry, are you there?

MR. SADWIN: I am.

MS. LAVALLEE: Excellent. All right, so I'm going to pull up the slides and turn things over to you.

Partnering with Patients to Disseminate Research Projects

MR. SADWIN: Thank you, Danielle.

MS. LAVALLEE: You're welcome, and it's all yours.

MR. SADWIN: Great. It always feels like a - - stress test having to follow people like Carolyn and Amy. And I'm also clearly aware that I am the only thing between the audience

and the rest of their lives. So some of the things I'm going to talk about today will be an emphasis of things that Carolyn and Amy have already presented. But I am also honored to be able to participate.

And I appreciate the audience's willingness to listen as I hope I am able to provide you with enough valid reason that you will agree that patient and consumer representatives are a key resource for disseminating research findings. Not only do they understand what type of information is needed to inform decisions, but they understand how best to deliver message so they resonate with patients and consumers.

For this the organizations they are affiliated with often reach a broader audience including clinicians providing outreach to other key stakeholders for research products. So I'm going to cite [phonetic] the insights gleaned from the panel discussion. And then I will also hopefully put them into context for you with the work I have done with the American Heart Association to demonstrate how partnering with patient and consumer groups assist [phonetic] with effective dissemination of evidence to key audiences.

So two overreaching points for partnering with patients to disseminate research products are listed here. The key to partnering effectively with patients and consumers is to identify organizations early in the research process that would make good partners in dissemination and then develop relationships within those organizations. Researchers must be willing to put in the time and effort to build these relationships. As one colleague stated, make it personal. This includes taking the time to meet in person and fostering [phonetic] ongoing communication.

So these are some of the suggestions contributed by the technical expert panel regarding effective dissemination. Dissemination should not be an afterthought, but a critical component of the research process. One of the frustrations for advocacy organizations is when they are contacted at the end to disseminate research findings without any prior consultation on what is needed and in what manner about the constituency that they serve.

There is a need to establish early on who the audience is for the research findings and why the information is important for them. This should be done in collaboration with consumer organizations. And then finally, the

messages need to be direct and easy to remember. If this does not work, this can hurt you.

Information should be made accessible to consumers by using plain language and visual presentations. Organizations are more likely to disseminate information if it is made as easy as possible for them. I think Carolyn mentioned earlier writing a short blurb about the findings that organizations can easily paste into their newsletter. And people are more likely to pay attention to information if it comes from an organization they already know and trust such as the American Heart Association. It makes sense to partner with such organization whenever possible.

So all of you already know this, but it is worth repeating that the Heart Association works to disseminate important information to patients and consumers, caregivers, clinicians, and educators on cardiovascular disease and stroke. The information is disseminated in a multitude of ways; print, website, television, Utube, and now Twitter, Facebook, and, of course, conference and scientific sessions, and in multiple languages. It is a trusted organization for accessing important information.

So in case some of you are having difficulty reading this slide, it reads: Caution, this sign has sharp edges. Do not touch the edges of this sign. Also the bridge is out ahead. As we all know, research often results in important information and evidence that patients and consumers can use to inform their decision making. So an important risk and that all dissemination has risks is to get the message right. This sign is obviously a very bad test at messaging.

Messaging is critical. As seen here, the focus is a picture of a woman with a bypass scar. You don't really think of it, do you? But a patient does. The message makes it resonate emotionally with the audience as well as communicate the important information. We want this to bring people to our website where tools are available. Also you will agree, it's a good powerful effective test at messaging.

The American Heart Association has been active in disseminating information on a range of topics from prevention to treatment options for patients. This information disseminated is based on research providing critical information for patients and consumers interested in preventing or making treatment decisions about heart

disease and stroke. Affecting decisions in change can be challenging unless you can connect with the audience in a manner that resonates with their needs.

The AHA website is one of the greatest sources of traffic for patients and consumers. And I'll briefly focus on three places that one can go on the Heart Association's website. Choose to Move is a 12-week physical activity program for women. It offers concrete information that people can put into action.

The Heart Profiler site offers treatment decision tools for patients diagnosed with heart disease. This website allows patients to compare treatment options to inform treatment decisions and access published medical trials relating to their age.

And finally, the Small Steps to Big Changes is part of My Life Check. It combines many little changes that have big impacts on cardiovascular health. Hopefully you will agree that it provides a simple actionable message.

The Heart Association has also used a variety of dissemination approaches in the area of emergency cardiac care. One approach is to use teaching messages to essentially teach and help people remember important information for CPR. Now the first message, 15-2, was what we started to try to get across to people about to do CPR to remember that it was 15 compressions to two breaths.

The next thing, it turns out that the proper rhythm for quality compression happens to be the same as the Bee Gee's song Stayin' Alive, which I will refrain from singing or humming. But my guess is it's going to be some part of your memory during this presentation.

And finally, push hard and fast in the center. When it became obvious to the Heart Association that even though people exposed to a cardiac event were trained in CPR, they were not responding and they were reluctant to perform because of the press [phonetic] component. And so now our message is simply push hard and fast in the center.

This interactive website this time [phonetic] from the Heart Association are hands only CPR talking [phonetic] to an audience obviously some of the people, although it seems to me this would be a good site for all of us practice on for our CPR training. For people who might not otherwise pay attention to the message, it presents the information

in an engaging way.

My final example is in the area of stroke here. I highlight this as it gets to the point that our dissemination capabilities reach a broader audience, in this case medical professionals. The first step to promoting this was to disseminate information to healthcare and to teaching medical professionals in guiding [phonetic] the necessary systems that needed to be in place. Much of this was accomplished in part so that the American Stroke Association - - with the guidelines program.

Appropriate systems have been implemented at the four stages of stroke response. And that's in pre-hospital [phonetic], acute care, secondary intervention, and rehabilitation. The next step was to get information on stroke response out to the public through a variety of means. In addition to the usual channels such as this website, important messages were disseminated by involving community leaders. And in one case, Mike Reed [phonetic] was kind enough to prepare a video to target messages for us in the African American community. And it's as mentioned in one of the earlier presentations, using a faith based approach has been extremely effective.

Our dissemination efforts are working. The American Heart Association evaluates on progress and reductions in coronary heart disease and stroke by monitoring death rates. We have seen a 25.8% reduction in death rate for coronary heart disease and 24.4% reduction in death rate for strokes since our baseline data from 1999. Although I'm very fond of statistics, I'm also acutely aware that I think I am part of the statistics and frankly believe that through research and the efforts of the American Heart Association, I got to see the four beautiful faces of my grandchildren I might not ever have seen if it weren't for the efforts of organizations that you are probably all involved in.

So in two clicks, you have available to you the opportunity to explore the American Heart Association's statements and guidelines, clinical updates, a one page newsletter which monthly alerts applicants, awardees, and related professionals to upcoming funding activities, and informs readers about related Heart Association opportunities. This site also provides membership opportunity to over 27,000 professionals to researchers and interact with 16 scientific councils that comprise AHA's multidisciplinary

membership. Another click on research will take you to the grants available throughout the AHA funding sources. I recommend to all of you that you visit our site.

Finally in summary, the key takeaways are to develop sincere relationships with the organizations who serve the end users of your product. They are wonderful resources to help throughout the research process from topic identification through dissemination of research products. Involving patient and consumer organizations upfront will make dissemination efforts easier and it will ensure that the evidence being generated is in line with the needs of the patients and consumers needs.

And that concludes my presentation, Danielle.

Q&A

MS. LAVALLEE: Wonderful. Thank you, Larry. I really appreciate it. So we have some time left now to address any questions individuals might have. I have received a couple of questions regarding the availability of Power Point slides from the presenters today. Those will be made available on the Effective Healthcare website. I will send a follow-up email to all participants today with the specific date and address of the webcast.

So if you have questions for our panelists today and would like to submit them, please feel free to use the Question and Answer forum at the bottom right hand corner of the Web-X format and I will be happy to facilitate addressing your questions to the panelists.

[long pause]

I'm not seeing any questions that have been displayed. We'll give the folks a few moments to address any questions that they might have.

[pause]

Well, since there don't seem to be any questions for our panelists, we'll go ahead and—oh, actually, you know what? We just had a couple of questions pop up. Here we go.

So I'm going to start with one for Carolyn. So, Carolyn, this question is for you. The question is could you describe your training for grant peer review?

MS. BRANSON: Okay. Can you hear me now?

MS. LAVALLEE: I can.

MS. BRANSON: Okay. I just turned it up really loud. Well, okay, we do a variety of training. Early on, we do a panel member webinar. So all of the members of the panel get a chance to hear that. And that talks about the different types of applications that will be submitted for funding. So that's in the form of a webinar.

We do a novice webinar and a mentor webinar. So for our new consumer reviewers, we do a webinar that helps explain the process and what their rights and responsibilities are as a consumer advocate reviewer. We do a mentor webinar to explain to the mentor what their job is as a mentor. This is pretty new for us. We've just started those two. And so we're hoping to have good results as a result of that training.

We provide a handbook, which is online which is extensive and goes into all aspects of the process of peer review as well as information about conflicts of interest and confidentiality and some of those key issues that our consumers especially need to understand and also how to use our database. We provide on-site consumer orientation that includes information about what they need to know now that they are in the place where we have the peer review.

But also we have a presentation by one of the consumer advocates who has done this before. And that presentation helps the new consumers and those who have been there before to hear about what the experience is like from their perspective to give them some guidance on what they can expect as a consumer advocate. We also go over scoring and some of the other key information that they need to know.

And we don't want to overwhelm them pre-meeting because when we give them the webinar we do for a new nominee, the new consumer reviewer is an hour. So we don't want to overtax them at that time. So we have things we save for just before the actual peer review meeting begins.

We also do a plenary session at the peer review, which again breaks down more information they need to have just before they go into their panel rooms. We kind of over-orient them. We also give them further information that's specific to their particular panel that they're sitting on when they go into the panel rooms. So it's a constant

provision of the information of various sorts.

I don't know that I can get into much more detail than that though. Do you think that will answer the question?

MS. LAVALLEE: I think that provides a great overview. We had another question that I'm actually going to open up to all three panelists. It is question just do you know of any advances or any progress to develop one source for all the different organizations to recruit patient advocates? So I know this is something that's been discussed about before. So I'm not sure if any of the panelists have other thoughts about that. Go ahead.

MS. BONOFF: I was just going to say it's very hard to think of one universal patient advocacy because I really think that there are many needs and many different programs. And I don't see it as one universal source. And I really think that you have to draw from some of these different—and I know it's difficult to draw from different groups and different resources.

But I think given the fact that the needs are different, you really have to draw accordingly to fit the needs that you are looking at and the goals that you have set for your program.

MS. BRANSON: And certainly some of the organizations' training focus is very specific to what that organization in hoping their advocates will do. So I totally agree with Amy. You have to pull together the course that you need for your particular group.

She mentioned the one course that is more on evidence-based medicine. And I think that gives you a course that a lot of people can take. And I've actually started looking at that particular course and thought it looked really good.

So there are various ways that you may be able to pull from those existing resources of training and not have to start from the beginning. But you do need to tailor it to the work that you want the advocates to do so that they have enough information to be successful.

MR. SADWIN: So some of these national organizations collaborate together on certain initiatives. I can think of the Cancer Society, the Lung Association, the Heart Association, and their tobacco efforts. But at a grassroots level, I know the Heart Association honors those folks to a great degree and spends an awful lot of time training them in a specific

- - society [phonetic] as I assume most of the other organizations do.

So I am not familiar at this point where any organization that is trying to do this at that level.

MS. LAVALLEE: Okay, I have another question that's come up. And, Amy, I believe this is going to be targeted towards you. A number of presenters focused on the level of intensity required to both recruit and provide training and support for patients and consumers to engage in various parts of the research enterprise.

Has anyone done any cost studies to inform future grant makers about what proportion of funds should be allocated to ensure adequate engagement of these important stakeholders?

MS. BRANSON: Oh, what a great question.

MS. BONOFF: I was just going to say the same. The answer is no. But, Carolyn, you're first.

MS. BRANSON: No, no. I mean I totally agree. As far as I know, there has not been such a thing done. Now certainly the DOD Congressionally Directed Medical Research Programs do have grant applications submitted that use consumer advocates in their work.

But in terms of what it costs and how to figure that, no, not that I'm aware of. There could be something that's been funded in that direction, but I'd have to look that up on the CDMRP, do a search on the CDMRP website to see if such work any has been done. But it's an excellent question and something we should consider doing, Amy.

MS. BONOFF: Well, no, I appreciate it [phonetic]. I thought the question was so good because I did try to stress in my presentation that this educating and training comes at a cost of time, commitment, and dollars to run these programs. And you hit it. Has anybody funded those? We funded to various different philanthropic organizations. But it's a good point and one that should be followed up on.

MS. LAVALLEE: And another question that fits [phonetic] right into that issue specifically and I think you both touched on this, Amy and Carolyn, is how are your programs currently funded? So ProjectLEAD for example, how do you have the funding for supporting and training patients and

consumers for their involvement?

MS. BONOFF: For ProjectLEAD, it's funded by several organizations, most notably Avon, who has been behind the ProjectLEAD course for many years since its inception if I'm not mistaken. And there are other philanthropic funders as well. Carolyn?

MS. BRANSON: Well, SRA is actually under contract to the Department of Defense Congressionally Directed Medical Research Program. And so our training is part of that contract. So we are funded to do whatever training and recruitment and support as needed. That's including the funding of the three of us who do most of the work.

MS. BONOFF: Now, Carolyn, that's interesting. You could almost think that your contract or the cost of your contract is or could represent a cost of training.

MS. BRANSON: Yeah, certainly a portion of it; yeah, a portion of the contract.

MS. BONOFF: It just came to me as you were speaking.

MS. BRANSON: Mm-hmm. No, it's an excellent point. I think the problem with it is that what we do crosses a lot of different areas of funding of the contract. But, yeah, that's a thought. We could certainly look at that as—but I don't know. I think it misses something if we do it that way. But, yes, that's a possibility certainly.

MS. LAVALLEE: And here we have another question. Carolyn, this one is directed to you as well. Could you provide information on how you evaluate the consumer input into the grant peer review, so what your evaluation processes are?

MS. BRANSON: Okay. We do several things. We start with the consumer advocates are assigned to particular applications that they review. And so as part of that, they are assigned to a panel. That panel has the leader in the form of a scientific review officer. So we ask the scientific review officer, who is a scientist, to assess how the consumer did. So that's number one.

And we have a form and we ask them to complete certain questions that range from as simple as do they get their reviews in on time to do they influence a panel. And that's important for our consumer advocates because they need to feel as though they've had impact. And if they feel so somebody listened to them and actually changed

their vote, they are so rewarded. They feel so valued.

So part of that is the SRO then, the Scientific Review Officer, will do an assessment written for us to let us know how the consumers on their panel did. We as the consumer reviewer administrators also observe them during the period process and make notes on how they're doing.

So we're looking at are they contributing? Do they speak up? Do they ask questions? Do they seem to have an effect on the panel? Do they speak with an unbiased approach and not just from their own personal story and so forth? So there are multiple things that we're looking at from them as well.

The CDMRP staff will give us feedback on how they felt the consumers did. And then we ask the consumers as the reverse of that to let us know how they thought we did in the process and what we could do to improve.

So the evaluation tools are for the scientific review officer who manages the panel. And then we have our own tools that we use to assess them. A lot of it is feeling as though that person was well received, was able to hold their own with the scientists, and provided good written reviews as well as their verbal participation in the panel.

I don't know if that gives you enough for what you're looking for.

MS. LAVALLEE: You gave a pretty comprehensive answer. It doesn't look like we have any other questions. And we have reached close to the end of our hour.

So I would just like to take a few minutes to thank, one, our panelists for presenting today. It certainly is always great to have the opportunity to interact with you and certainly I've learned a lot in my work from working with you. And I also thank everyone who's taken time out of their day to listen in on the webinar.

I will certainly send a follow-up email to the participants today, the attendees with additional information on the webinar. And so the panel can read some of the feedback that I've been seeing, certainly accolades to you all for your presentations from many of the attendees who attended today.

So thanks to all and I hope everyone has a great rest of their week.

MS. BONOFF: Thank you.

MS. BRANSON: Bye-bye, Amy.

[END]