
Research Advocacy Network

Advancing Patient-Focused Research

**Advocacy Program
Research Awareness Event Tool Kit
for
Community Cancer Centers**

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Background

There are very few people who have not been touched by cancer. Most of us have either had cancer or our family and friends have been diagnosed with the disease. The numbers reported by the American Cancer Society may explain the reason - in the United States, men have a 1 in 2 lifetime risk of developing cancer and women have a 1 in 3 lifetime risk of developing the disease. The longer we live, the more likely we will be touched by cancer. Those who have been touched by cancer want to give back and help make a difference in the lives of current and future patients. Many see research as the answer to finding a cure for cancer or changing cancer into a chronic disease. Those touched by cancer in your community may or may not know about the research going on in your community or how to actively support that research. You can invite them to be part of your cancer center and provide their time and talents to advancing the research you are conducting.

Introduction

Advocates and advocate organizations bring the patient and community perspective to research, gain a greater understanding of the importance of that research and communicate information about research efforts to patients and the public. There are a number of ways to find people supportive of cancer research in your community and invite their participation. The two most common approaches are 1) invite people you already know, your former patients and their family members or 2) offer an open invitation to the community by conducting a symposium to introduce them to your work and to becoming research advocates. This guide is directed at helping you plan a successful symposium.

Research Advocacy Group Planning Meeting

Who should attend? The planning meeting should include staff, who have expressed interest in involving the community in the work of your cancer center. A Principal Investigator(s) must be involved. Someone should be chosen as a liaison to coordinate the efforts of your volunteers. If you already have a volunteer coordinator, that individual would be the most appropriate. If you do not, then that would be an agenda item for the meeting. Other nurses, research coordinators, administrators who have either expressed interest or could gain from the volunteer activities may also be included in the discussion.

“Consumer advocates are playing such an important role with the support of cancer research. They are providing critical analyses and insights that help ensure that research advances are more quickly and carefully translated to the patient and public health settings.”

Christopher L. Hatch PhD,
Health Scientist Administrator,
National Cancer Institute web site

Agenda for Research Advocacy Group Planning Meeting:

The agenda for the planning meeting might include:

- Discussion of Advocate Program and how it could fit into the mission of your organization
- Review of Research Advocacy Activities
- Review of other community volunteer opportunities
- Discussion of how these activities and opportunities fit with your cancer center mission
- Answer the following questions:
 - Do we want to engage the community in this way?
 - Are we ready to give commitment of time and money?
 - Who would serve as the liaison for the advocate volunteers?
- Develop goals and objectives for your program, e.g., engage the community in our research activities, develop an advocate program for our cancer center
- Have proposed activities for the advocates in the program. (A list of potential advocate activities is included in the appendices.)

Inviting Patients and Family Members to Join Your Advocate Program

One way to begin is to personally invite a small group of patients and family members to be the Steering Committee for your advocate program. Twelve to 15 people would be a good recruitment goal for this effort. These people should fit the following criteria:

- expressed interest in helping other cancer patients and/or the work of your cancer center
- involved in the community
- positive, energetic personality
- supportive of cancer research
- good communicator

The invitation can be either by phone or in writing (See Appendix for a sample letter). In either case you want to provide enough information to interest them without overwhelming them.

The information should include:

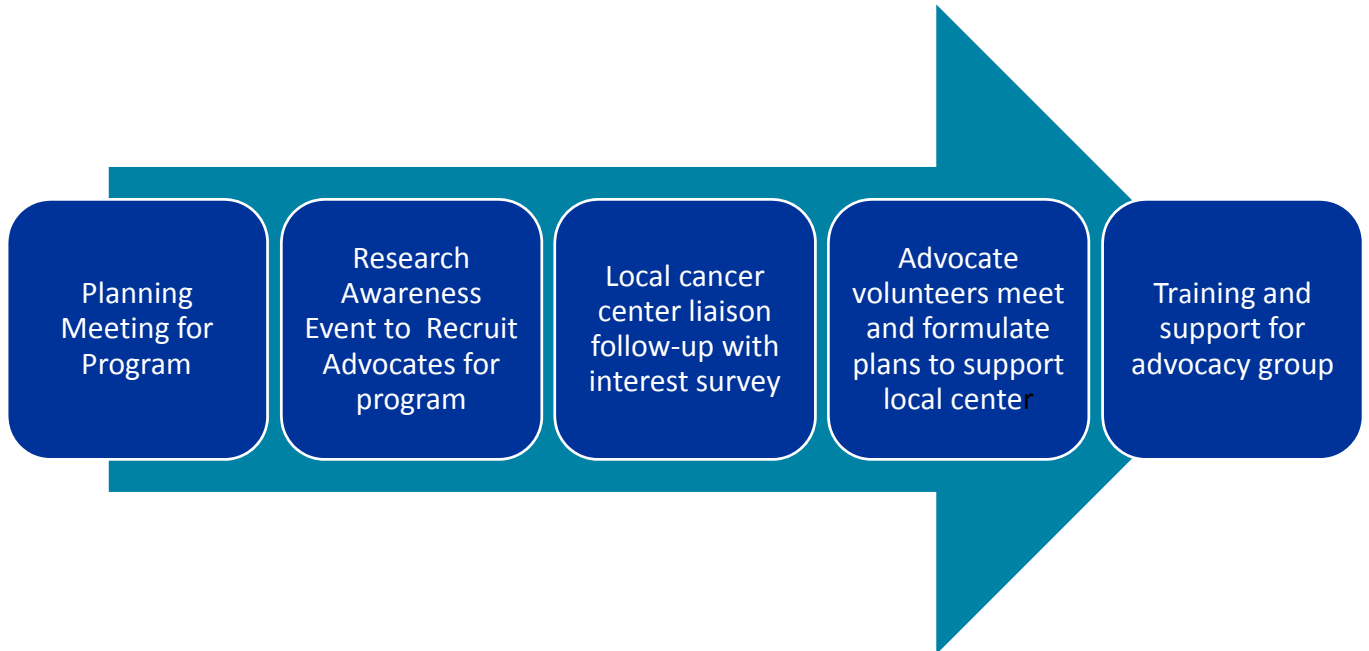
- how you know them – patient, family member of patient
- why you chose them – you seemed so interested in our cancer center, you were so helpful to other patients, you said you wanted to help other cancer patients

- what you plan to do – develop an advocate program
- how they can help you do that – provide the patient perspective to our research
- provide specific day and time to meet or ask them to provide their preferences – we want to bring everyone together to brainstorm what the program will look like.
 - Please join us on _____
 - Please provide the best days of the week and times of the day that are good for you

Advocate organizations from your community could be an appropriate partner for you in developing your advocate program.

- Advocate organizations communicate with patients and their families and friends through:
 - newsletters,
 - web sites,
 - call centers with follow-up mailings,
 - events such as conferences, health fairs and fund-raisers and
 - support groups in the community.
- Advocate organizations and their members are active in the following activities:
 - research advocacy - providing the patient perspective to research,
 - political advocacy - lobbying Congress and state legislators for increased funding for cancer research and policies that support the cancer patient in receiving better treatment and increased quality of life,
 - service or support advocacy - providing information and educational materials to offer support to patients and their families, and
 - fund-raising advocacy which seeks private funding for cancer research and services.
- As partners you can:
 - share volunteers who may want to be involved in the advocate organizations activities and in the research advocacy activities at your cancer center.
 - jointly conduct research awareness and fund raising programs in your community
 - support each other's projects and activities by informing your volunteers about these opportunities

Your local hospitals may already have established contacts with these organizations and would be willing to share their list with you. You can also access them by searching the web or going to the American Cancer Society web site and putting in the name of your city or zip codes in your area.



Advocate Recruitment

Hosting a Research Awareness Event

A research awareness event has two potential outcomes 1) introduces the community to the research you are conducting and 2) invites members of the community to become actively involved in supporting that research. An event can reach a larger audience with the messages of 1) the importance of cancer research to advancing better patient care and 2) the value of having that research available and accessible to their community

To encourage the widest participation the event should be held at the time most convenient for a wide range of community members, which usually means either evenings or weekends. You need a large number of attendees to recruit enough people for your advocate program. Many people may be interested in hearing about cancer research but may not be willing or able to volunteer to be part of your program.

TIPS FOR A SUCCESSFUL EVENT



Select a site that is in a central location and has adequate parking. If there is a charge for parking, it would be helpful if you absorbed that cost.



The site should be one well-known in the community and easy to access by car and public transportation.



The room itself should be comfortable and spacious enough to accommodate 25 – 50 people seated at tables.



Having tables available provides space for coffee cups or writing pads to take notes. You may have such a space available in your clinic or cancer center.

TIPS

The event does not have to be an expensive undertaking but should include some form of refreshments. If held on a weekday evening, dessert and coffee could be served. If held on a weekend, a continental breakfast around 10 am or coffee and cookies or cupcakes around 2 pm would be appropriate. We have included a sample budget in the appendices.

We have provided a timeline to help you plan and manage the activities leading up to a successful event. See appendix for a sample timeline.

Getting the word out

The more widely you market the event, the more likely you will have a good turnout. It is important to have a simple marketing plan to provide different methods to advertise the event.

- Develop a marketing plan that includes:
 - advocate and service organizations

- hospitals and contact people in your community – they can hang posters in their public areas, put flyers in their waiting rooms
 - advocate organizations, e.g., American Cancer Society. local Komen for the Cure Affiliate – they can invite their staff and members and distribute flyers by email or at their events
 - service organizations, e.g., support groups, Red Cross – they can invite their staff and volunteers and distribute flyers at their offices or meetings
 - media
 - newspapers can be asked to write an article about the event or list in community events section of their paper
 - TV and radio usually provide public service announcements (PSA) about events in their area free of charge
 - social media and web
 - develop a page for your website to create awareness of the group and sign up for the event
 - develop a Facebook page for the event or if your organization has a Facebook page post about the event on a regular basis leading up to the event date
 - if your organization has a Twitter handle, use a specific #hashtag for the event/campaign
- distribution methods
 - email lists to send invitations electronically – you can ask your advocate organization partners if they would be willing to send invitations to their constituents
 - post to web page, Facebook, Twitter
 - newsletters – you can ask your advocate organization partners if they would put an announcement or article about the event in their newsletters
 - posters to hang in your clinic and give to advocate and service organizations for their locations
 - flyers for your waiting room and to give to advocate and service organizations for their offices and meetings
 - ads – if you want to pay for advertisements in newspapers and church and community bulletins
- what printed materials and template you need to provide
 - save the date card (see appendix for sample)
 - invitation (see appendix for sample)

- flyer/poster (see appendix for sample)
- announcement/ad (see appendix for sample)

The Event Program

The program for the event should center on the research and how members of the community can be involved in research. It is important that a researcher/clinician be the featured speaker and an advocate who has supported research in their community end the program. (See appendix for a sample event program)

The Event

Someone from your cancer center should be at the location early to check to make sure everything is ready, including the food, the registration table, podium, screen and tables are set-up as your directed, and the audio visual (AV) and sound system are working correctly. Another staff person or volunteer should be there to greet the people as they arrive. You should have a registration table where they can sign in with their name, email address, and mailing address. You do not need to have name badges but if you want to include name badges be sure and supply markers for them to use to print their names and enough space to allow people to sign in while others are filling in their names on the badges.

It is important to provide evaluation forms to collect their input on the event. You can also use this same form for them to sign-up for inclusion in your advocate program. (See appendix ___ for a sample evaluation and sign-up form). These forms can be left on the tables or included in any hand-outs you may want to distribute. In either case, be sure and collect them at the end of the event.



Follow-up

Once the event is over, it is important to contact those who volunteered to be part of your advocate program within two weeks. Thank them for their willingness to support your efforts and let them know how you will involve them at your cancer center. You may decide to have a special meeting for all the volunteers. You may choose to have a training session before they begin or you may assign them to a staff person who will mentor them. The activities you have chosen and the number of volunteers may dictate whether a meeting, training session or mentoring approach is best.

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Sample Letter to Join Advocate Program

[Insert logo for local center]

[Date]

[Addressee]

Dear [Name],

As a [enter how you know them – patient, family member of patient] you seemed interested in supporting the work of our cancer center and helping cancer patients served by our center. You were very helpful to other patients, and we would like to invite you to join us to take the next steps with us as we develop an advocate program for ____ center. The purpose of the advocate program is to (supply goal developed at planning meeting).

We would like for you to join us on [provide specific day and time to meet or ask them to provide their preferences]. We want to bring everyone together to brainstorm what the program will look like.

Sincerely,

Sample Event Budget

Item		Range
Printing, copying-	Print flyers Invitations Programs	.10-.25 ea for black/white copies up to \$2.50 for color copies
Refreshments		\$0 (if donated) up to \$10-\$20/person dependent on what is served, cookies, coffee
Location	Charges for rent meeting room	\$0 (if donated by cancer center or local business) to \$150 if held at a hotel
Parking for speakers and attendees		\$0 (if free parking at meeting location) to \$10-\$25 per person
AV		\$0 (if av is available at center) up to \$600 if rented (depending on venue rental policy)
Gift Bags		Contents can be donated by local merchants

Event Timeline

Task	Date	Assigned to:	Notes:
Set event date	Minimum two months before event		
Develop budget			
Determine location			
Send invitations	4-6 weeks before event		
Ask speakers	Immediately after setting date (may need to adjust event date to get the desired speaker)		
Print and distribute flyers	4-6 weeks before event		
Contact media	4-6 weeks before event		
Order refreshments	At least 3 weeks before event		
Order materials for handout and gift bags	At least 3 weeks before event		
<ul style="list-style-type: none"> • Confirm AV • Confirm refreshment order • Confirm speakers • Gift Bags and handouts 	2-3 days prior to event		
Event			
Follow-up with volunteers who signed up at event	Within 2 weeks post event		
Meeting with volunteers			

Potential Advocate Activities

- Talking with potential clinical trial participants
- Representing the community by serving on Institutional Review Board or Ethics Committee
- Reviewing informed consents, protocols (study plans) for clinical trials
- Reviewing educational materials for patients interested in participating in clinical trials
- Conducting support groups for patients participating in clinical trials and their family members
- Acting as an advisor to their local hospital or clinic about accessibility and support for clinical trial participants
- Working to raise dollars for cancer research and to offset costs for people participating in clinical trials
- Be available in the clinic to talk to patients about their experience participating in a clinical trial
- Talk to patients and the public about clinical trials
- Work with state legislators to enact laws and regulations that support patients' participation in cancer research
- Be a Volunteer Peer-to-Peer "Treatment Buddy"
- Be a Volunteer Shopper "Shopping Angel" - groceries, meals, and supplements for both patients and families
- Volunteer for "Healing Wheels" transportation to and from treatment
- Volunteer for Delivery Drivers - location and provision of durable medical equipment
- Serve as a Host or Hostess for events, e.g. support groups and information events
- Volunteer for cosmetic assistance for wigs, makeup, and other appearance articles
- Be a Volunteer "Handy Skills" - low-cost free home repairs and upgrades for the disabled

Save the Date!!!
Cancer Research Awareness
Event
[Date]
[Time]

Dessert and coffee will be served

[Insert Location]

[Insert Address]

Free parking available

No charge to attend, please reserve your seat by
calling [insert info]

Speakers:

[insert speakers name]

Medical Oncologist

[insert speakers name]

Patient Advocate / Cancer Survivor

Insert logo of local
center

Event Invitation - Sample

(Letter size paper)

**YOU ARE INVITED!!!
Cancer Research Awareness**

Event

[Date]

[Time]

Dessert and coffee will be served

Insert logo of local
center

[Insert Location]

[Insert Address]

Free parking available

No charge to attend, please reserve your seat by
calling [insert info]

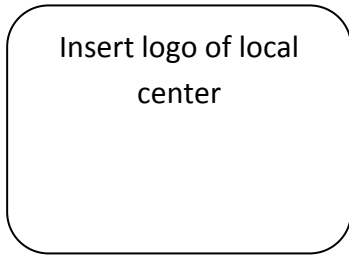
Speakers:

[insert speakers name]

Medical Oncologist

[insert speakers name]

Patient Advocate / Cancer Survivor



Cancer Research Awareness Event

[Date]

[Time]

Dessert and coffee will be served

[Insert Location]

[Insert Address]

Free parking available

No charge to attend, please reserve your seat by calling [insert info]

Speakers:

[Insert speaker's name]

Medical Oncologist

[insert speakers name]

Cancer Survivor and Patient Advocate

Event Announcement/ Ad -Sample

(Small ad)

Cancer Research Awareness Event

[Date] [Time]

[Insert Location]

[Insert Address]

Dessert and coffee will be served. Free parking available

No charge to attend, please reserve your seat by calling
[insert info]

Speakers:

[insert speakers name]

Medical Oncologist

[insert speakers name]

Patient Advocate / Cancer Survivor

SPONSORED BY: ___CANCER CENTER

Event Evaluation and Sign-up form – Sample

Insert logo of local center

Event Name, Date

Evaluation Form

Thank you so much for participating in this event! Your opinion counts! Please tell us how you feel about the presentation by completing this evaluation form. Your input will help us know how to design programs that will best match your needs. Please feel free to add suggestions / comments on the back of the page.

	1= Strongly agree	2= Agree	3= No Opinion	4= Disagree	5= Strongly disagree
The content of the session will be valuable to me.	1	2	3	4	5
The length of the session was adequate for the material.	1	2	3	4	5
Speakers:					
[insert speaker name] Comments:	1	2	3	4	5
[insert speaker name] Comments:	1	2	3	4	5
The facilities for this session were satisfactory.	1	2	3	4	5
Room arrangement was conducive to an informative session.	1	2	3	4	5
Comments: (please continue on the back if needed)					

Volunteer Sign-Up Form Sample

**[Event Name, Date]
Volunteer Sign-Up Form**

Name:	
Address:	
City, State Zip	
Phone:	
Email:	

<i>Please check to indicate you would be interested in learning more about:</i>	<input checked="" type="checkbox"/>
Talking with potential clinical trial participants	<input type="checkbox"/>
Representing the community by serving on Institutional Review Board or Ethics Committee	<input type="checkbox"/>
Reviewing informed consents, protocols (study plans) for clinical trials	<input type="checkbox"/>
Reviewing educational materials for patients interested in participating in clinical trials	<input type="checkbox"/>
Conducting support groups for patients participating in clinical trials and their family members	<input type="checkbox"/>
Acting as an advisor to their local hospital or clinic about accessibility and support for clinical trial participants	<input type="checkbox"/>
Working to raise dollars for cancer research and to offset costs for people participating in clinical trials	<input type="checkbox"/>
Be available in the clinic to talk to patients about their experience participating in a clinical trial	<input type="checkbox"/>
Talking to patients and the public about clinical trials	<input type="checkbox"/>
Working with state legislators to enact laws and regulations that support patients' participation in cancer research	<input type="checkbox"/>
[insert your cancer center activities that you would like to recruit volunteers]	<input type="checkbox"/>
[insert your cancer center activities that you would like to recruit volunteers]	<input type="checkbox"/>
[insert your cancer center activities that you would like to recruit volunteers]	<input type="checkbox"/>