



Cancer Research

Cancer Research Advocacy: Past, Present, Future

Jane Perlmutter, Shannon K. Bell and Gwen Darien

Cancer Res Published OnlineFirst May 29, 2013.

Updated version	Access the most recent version of this article at: doi:10.1158/0008-5472.CAN-12-4553-T
Author Manuscript	Author manuscripts have been peer reviewed and accepted for publication but have not yet been edited.

E-mail alerts	Sign up to receive free email-alerts related to this article or journal.
Reprints and Subscriptions	To order reprints of this article or to subscribe to the journal, contact the AACR Publications Department at pubs@aacr.org .
Permissions	To request permission to re-use all or part of this article, contact the AACR Publications Department at permissions@aacr.org .

Title: Cancer Research Advocacy: Past, Present, and Future

Authors and affiliations: Jane Perlmutter¹, Shannon K. Bell², and Gwen Darien³

¹Gemini Group, Ann Arbor, MI; ²NCI, Bethesda, MD; ³Pathways Project, Montclair, NJ.

Running Title: Cancer Research Advocacy

Keywords: Cancer, Research, Advocacy

Financial Support: None

Corresponding Author: Jane Perlmutter

507 N. 5th Ave.

Ann Arbor, MI 48104

734-604-5263

janep@gemini-grp.com

Conflict of Interest: None

Word Count: 2,663

Table and Figures: One table; no Figures

ABSTRACT

In this paper we present a brief history of cancer advocacy, and discuss the variety of ways advocates have become involved in cancer research, and subsequently present principles that establish a framework for successful research advocacy, based on a review of many early initiatives coupled with our knowledge as long-time cancer advocates. Challenges to effective advocacy are described, and recommendations for increasing meaningful contributions by research advocates are proposed. The purpose of this paper is to discuss the exciting field of research advocacy and to help shape a more productive future for advocates and their scientific collaborators.

1. Introduction

Between 1990 and 2010 the number of cancer survivors in the United States increased from about six million to more than 12 million [1]. During the same time, the number of cancer survivors who participated in cancer research advocacy increased even more rapidly. Within the past 15 years, advocates have become involved in the research process by playing a part in determining what and how research is done and often, by securing or providing funding for cancer research.

In spite of the growth of cancer research advocacy, there is meager literature about its practice and contributions. Previously published works have introduced research advocacy [2-4], begun to clarify the various types of advocacy [5, 6], discussed the moral/ethical imperative of engaging patients/consumers in the research process [7] and provided anecdotal accounts regarding the benefits of engaging advocates or non-scientific consumers in the research process [7-9]. This field is evolving, but extensive ambiguity, and some ambivalence, exists about the role and impact of advocates.

While many individuals define themselves as cancer advocates, only a subset of them are interested in research. Like other cancer advocates who may focus on peer support, increasing public awareness about cancer or public health policy, a majority of cancer research advocates have themselves faced cancer diagnoses. Transitioning from a survivor (including family member or caregiver) to a patient advocate requires development of new skills such as information seeking, communication, problem-solving and negotiation [10]. Advocates who become involved in research often have a strong belief and/or interest in science and are committed to expanding their understanding of cancer. They work to become skilled at negotiating the various research organizations and processes with the goal of

becoming a vital voice in the cancer research community.

2. The History of Research Advocacy

To some extent the journey from cancer patient, or caregiver, to advocate may be a natural response to cancer. However, strong leadership and organization are required to leverage this common instinct into successful systemic change, which is a primary goal of organized cancer advocacy. The field of health advocacy may be traced to the founding of organizations focused on raising awareness of specific diseases. Among the first such health advocacy organizations was the American Society for the Control of Cancer, the predecessor of the American Cancer Society (ACS), which was founded in 1913. This was followed by the Prevention and Relief of Heart Disease, the predecessor of the American Heart Association in 1915 and other similar organizations.

The focus of health advocacy expanded beyond education and awareness to fundraising for research in the 1930s. In 1936, ACS' Women's Field Army began raising money for cancer research, and this was rapidly followed by other health advocacy organizations (e.g., the March of Dimes founded in 1938 to raise funds for research to eradicate polio). ACS was also a leader in expanding health advocacy to peer support, in which cancer survivors counseled and supported other people diagnosed with cancer. In particular, they started the Reach to Recovery program in 1952 to provide peer support to breast cancer patients. Almost twenty-five years later, a plethora of more local, grassroots organizations followed suit (e.g., SHARE was founded in 1977 in New York City to support women with ovarian and breast cancer, while Y-ME was founded in 1978 in Chicago to support women with breast cancer). Many other non-profits were founded in the second half of the twentieth century; they focused on education and awareness, fundraising for research and/or peer support of other cancers. In addition to the increasing presence of non-profit organizations focused on cancer advocacy, other forces were bringing cancer into public attention. In 1971 Richard Nixon, spurred on by advocates, most notably Mary Lasker, who raised funds for medical research as early as the 1940's, and clinicians, especially Dr. Sidney Farber, declared a "war on cancer."

Influenced by a number of social, environmental/workplace and rights-based movements, health advocacy in general and cancer advocacy in particular, became more action oriented beginning in the 1980s. As Chong [11] points out in *Collective Action and the Civil Rights Movement* many recent social rights movements developed "riding on the coattails of the civil rights movement." As a society, the civil rights movement of the 1960s taught us

that there is power in numbers, that a collection of individuals with a singular goal can change a system. So, it is not surprising that HIV/AIDS activists came together in the early 1980s as dissatisfaction with the care they were receiving grew [12]. This new research advocacy movement gathered momentum as HIV/AIDS activism transitioned from an exclusive focus on support advocacy. They organized, educated themselves about science and research and challenged the system, arguing that as ultimate consumers of the science, their perspective was valuable. For the first time, the activist/expert held a distinct role in what was funded and how research was done. Also, AIDS activists were especially concerned about the slowness of drug approval and access to investigational therapies. In the late 1980s and early 1990s, influenced by AIDS activists, the Food and Drug Administration (FDA) modified its policies to provide investigational therapies to patients with life-threatening illnesses for whom no other treatment is available. The new policies, referred to as compassionate use or expanded access, continue to be debated and refined today. Nevertheless, they are generally viewed as public policy wins for the AIDS community, and have led to successful partnerships that are being modeled by cancer advocates.

The National Coalition of Cancer Survivorship (NCCS), founded in 1986 may be the first cancer advocacy organization to adopt a more activist approach to ensure that public policy is consistent with the needs of their growing constituency of people living with a cancer diagnosis. The National Breast Cancer Coalition (NBCC), which was founded in 1991, had deep roots in the Women's health movement and consciously adopted many of the tactics of AIDS activists. In particular, NBCC educated their leaders and grassroots members about science and research, and demanded a "seat at the table" where decisions were being made about breast cancer research. Their initial focus was on increasing governmental spending on breast cancer. In 1993, under the leadership of the NBCC and its many member organizations, advocates successfully lobbied congress to earmark \$210 million for peer reviewed breast cancer research as part of the Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP). Further, rather than adding these funds to traditional governmental research programs (i.e., National Cancer Institute—NCI), advocates fought to establish a new research program managed by the DOD. Most important, advocates were to play a key decision-making role in managing these funds. Since the establishment of this new program in 1993, breast cancer advocates have successfully lobbied to maintain and increase CDMRP funds, and continue to play key roles in defining research priorities, reviewing proposals and allocating funding. Moreover, breast cancer advocates are increasingly involved in the research projects, as required by some of the CDMRP research award mechanisms. Following the success in breast cancer, advocates for an

increasing number of other cancers (including ovarian, prostate, leukemia, and lung) and other diseases (for example, neurofibroma, autism, genetic diseases, and post traumatic stress syndrome) have successfully lobbied for CDMRP funding.

In the early 1990s, the National Cancer Institute (NCI) began to involve research advocates in some of their internal groups and later in projects funded by NCI such as the Specialized Program in Research Excellence (SPORE) grants and cooperative groups.⁵ In 1996, NCI's interest in actively involving advocates became formalized with the formation of the Office of Liaison Activities (currently the Office of Advocacy Relations). This was followed by the NCI Director's Consumer Liaison Group (DCLG) in late 1997, and creation of the Consumer Advocates in Research and Related Activities (CARRA) program, in 2001. These activities have continued to grow and gain visibility within and outside NCI.

3. Current Practices in Cancer Research Advocacy

3.1. Where Advocates Contribute

While few advocates are involved in the day-to-day work of conducting cancer research, many are involved in activities that influence the direction of that work, such as: 1) allocating research funding; 2) participating on research teams; 3) planning and implementing clinical trials; 4) translating and disseminating research, and 5) research policy and oversight. While there is significant overlap among these activities and the skills needed to effectively participate in them, many individuals begin their research advocate journey through review of research grant applications. This sometimes leads to opportunities for deeper involvement with individual research teams or clinical trials. As these advocates become more competent and recognized for their contributions, they may be invited to participate in a wide variety of activities, as illustrated in Table 1.

3.2. What Advocates Contribute

The trend of increasing collaboration between researchers and advocates has been significantly influenced by the early successes of these partnerships. Both researchers and advocates often point to the following key benefits of including advocates in the research process:

Add a Human Face and Sense of Urgency to Cancer Research: *Most advocates have been personally affected by cancer. They not only share scientists' sense of urgency, but they also provide a face – an immediate reminder – of why the science matters.*

Ensure Patient Focuses: *Researchers and advocates ultimately want the same thing — to eradicate the burden of cancer. Having an advocate at the table helps participants maintain their patient focus when elegant or perfect science or scientific ambition threatens pragmatic outcomes. Advocates also help focus research on issues that are important to patients.*

Provide a Diverse Perspective: *In addition to a collective patient perspective, advocates bring an experiential knowledge of the disease as well as a breadth of life and work experience that can change the very nature of the conversation.*

Stimulate Discussion: *One of the most effective ways advocates contribute to research is by asking questions. Well-articulated, naïve or simple questions often bring to light issues not previously considered by the researcher resulting in robust discussions. Advocates are also well positioned to ask questions that may be more difficult for professional colleagues to raise.*

Expand Public Understanding of Science: *As advocates become better acquainted with the research process and the highly complex nature of the diseases we call cancer, they often more fully appreciate and convey its potential to their constituents. This in turn increases support for funding, participation in clinical trials and tissue donation.*

Spur Innovation: *Numerous partnerships between advocates and researchers have led to innovations in clinical trials (e.g., I-SPY), tumor banks (e.g., Komen/IU Simmon Cancer Center normal and inflammatory breast cancer tissue bank), and other innovative research partnerships (e.g., Stand Up To Cancer, the Learning Collaborative).*

4. The Future of Research Advocacy

To a large extent, the development of research advocacy has been opportunistic. In the early years, success could often be attributed to dynamic individuals, both advocates and researchers, who were open to exploring uncharted territory and defining new roles. Advocates are currently engaged in many areas of cancer research and their

contributions are widely recognized, albeit not quantified. Yet, there have been few guiding principles for establishing successful collaboration, or analysis of challenges that would help the field of research advocacy mature. Dialogue about such principles has recently begun [13]. We provide a summary of our views here.

4.1. Preparing Cancer Research Advocates

Becoming a research advocate requires more than just a personal cancer experience, an interest in science and the desire to give back. While these factors are important, they are simply the foundation for advocacy. Individual advocates have a responsibility to understand their role and become knowledgeable about the work in which they are engaged. We propose the following guidelines for successful engagement and participation.

Understand Science and Research: A basic understanding of science and research concepts is necessary to develop the knowledge and credibility to engage in discussions with researchers and effectively contribute to the research process. Advocacy organizations as well as professional societies such as AACR and ASCO currently provide training opportunities that support survivors in learning about science and the research process.

Stay Abreast of Science and Research: Advocates must be comfortable reviewing scientific literature, even in the absence of full understanding. While advocates do not need to be scientists – and should avoid falling into the trap of trying to be – they must be willing to stay abreast of this dynamic field.

Represent Collective Patient Experience: Research advocates must represent a larger perspective than their own. Prior to pursuing opportunities, advocates should gain exposure to numerous other patients, survivors and family members in order to broaden their perspective into a more well-rounded robust patient perspective. Advocates should also actively seek exposure to and understanding of the experiences of those most different from themselves, such as other cultures, socio-economic situations, etc. Investigators and organizations who match advocates with investigators, such as the NCI Office of Advocacy Relations, should be very diligent in ensuring advocates both represent diverse experiences and receive training to become more culturally competent. Ultimately, research advocates should be capable of conveying many different perspectives, including minority and underrepresented populations.

Unique Ethical Issues Facing Research Advocates: Research advocates are not immune to conflicts of interest that exist in medical research and practice. It is important for advocates to be sensitive to the ethical issues surrounding their involvement in research. If an advocate feels they cannot remain independent, they should resign their position. Advocates must never forget that their primary responsibility is to represent the interests of current and future patients.

Professional Engagement: One of the most fundamental issues facing advocates is understanding that although advocates may be volunteering their time, energy and knowledge, it is imperative that they always behave as if it is a job.

Creating a Pipeline of Advocates: Successfully preparing advocates to engage in the research process must be a collaborative activity shared by current seasoned research advocates and the organizations that engage them. This is particularly challenging since the number of seasoned advocates is limited, and understanding of the role and contributions of research advocates is limited.

4.2. Sound Practices for Maximizing Advocate Contributions

There is a need to create a culture of involvement. This entails a shift away from whether or not to engage advocates in the research process towards a culture of acceptance, and therefore, a focus on how to effectively include advocates.

Create Formal Opportunities to Engage Advocates: Requests for applications for research should increasingly mandate advocate involvement. It is important that organizations requiring advocate involvement provide the necessary guidance to do so successfully. This could include:

- A “matching service” to help researchers identify qualified advocates
- Defining expectations about the role of the research advocate
- Suggestions for establishing a budget to support advocate training, meeting attendance and compensation as appropriate

Meaningful Participation: When advocates' involvement is superficial or last minute, their contributions are likely to be minimal. Since advocates are capable of contributing to all aspects of the cancer research endeavor, they should be viewed as valued colleagues and involved from the earliest conceptualization and throughout the project. Advocates should be included in presentations and publications related to their work on a project.

Clear Expectations: Prior to establishing a collaboration, researchers and advocates should clarify the roles and expectations of all participants.

Assessment: It is important to establish a mechanism for researchers to provide feedback to advocates, and vice versa, when they collaborate. The results of these assessments should be used to improve future engagements and should be shared with the broader community.

5. Conclusions

Despite our overall enthusiasm for including advocates in cancer research, we recognize doing so can be challenging. Frank discussion of both the benefits and costs of actively including research advocates in the research process is meant to encourage self reflection and to bring more attention to this important field of practice. We believe that open dialogue can only strengthen the role and potential of engaging advocates in the research process. All involved should identify, adopt and disseminate promising practices when possible. By regularly assessing advocacy engagements, we will be able to systematically improve the discipline.

ACKNOWLEDGEMENTS

We would like to thank Daniel F. Hayes, and Marion Perlmutter, both of the University of Michigan and Clifford Hudis of Memorial Sloan-Kettering Cancer Center for thoughtful comments on previous drafts.

REFERENCES

1. Cancer Survivors --- United States, 2007. MMWR Morb Mortal Wkly Rep 2011; 60:269-272.
2. Haran C: Three's company: The Army, women with cancer and the medical community have joined forces. MAMM 3:38-43,57, 2001. <http://cdmrp.army.mil/pubs/articles/threescompany.htm>.
3. Hewlett S, De Wit M., Richards P, Quest E, Hughes R, Heiberg T, Kirwan J: Patients and professionals as research partners: challenges, practicalities, and benefits. Arthritis Rheum 2006; 55:676-680.

4. Platner J, Bennett LM, Millikan R, Bark MD: The partnership between breast cancer advocates and scientists. *Environ Mol Mutagen* 2002; 39:102-107.
5. Collyar D: How have patient advocates in the United States benefited cancer research? *Nat Rev Cancer* 2005; 5:73-78.
6. Nilsen E, Myrhaug H, Johansen M, Oliver S, Oxman AD: Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review). *Cochrane Database Syst* 2009; Rev 3.
7. Andersson E, Tritter J, Wilson R (eds): *Health Democracy: The Future of Involvement in Health and Social Care*. London, UK, Involved and NHS National Centre for Involvement.
<http://www.involve.org.uk/assets/Uploads/Healthy-Democracy.pdf>.
8. Brenner B: Sister support: Women create a breast cancer movement, in Kasper A, Ferguson SJ (eds): *Breast Cancer: Society Shapes an Epidemic*. New York, NY, St. Martin's Press, 2000; 235-254.
9. Wright D, Corner J, Hopkinson J, Foster C: Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. *Health Expert* 2005; 9:3-12.
10. Clark EJ, Stovall EL: Advocacy: The cornerstone of cancer survivorship. *Cancer Pract* 1996; 4:239-244.
11. Chong D: *Collective Action and the Civil Rights Movement*. Chicago, IL, University of Chicago Press, 1991.
12. Dresser, R: *When Science Offers Salvation: Patient Advocacy and Research Ethics*. New York, NY, Oxford University Press, 2001.
13. Advocates in Research Working Group. Recommendations. Bethesda, MD, National Cancer Institute 2011; NIH Publication No. 11-7687.

Table 1. Examples of Advocate Involvement in Cancer Research

Strata/Examples	Activities	Contributions
Allocating Research Funding <ul style="list-style-type: none"> • Department of Defense (DOD) Congressionally Directed Medical Research Programs (CDMRP) • NCI and NCI Funded programs; Cooperative Groups • Non-Profit Organizations 	<ul style="list-style-type: none"> • Establishing research priorities • Writing RFAs • Peer review • Programmatic review 	<ul style="list-style-type: none"> • Ensure cancer relevance • Focus on impact rather than elegance • Increase attention to areas of importance to public (e.g., environmental causes of cancer, health disparities, palliative care) • Encourage collaboration across disciplines and among stakeholders
Participating in Research Teams <ul style="list-style-type: none"> • Funded Research Programs • University Research Groups • NCI funded Specialized Programs of Research Excellence (SPORE) 	<ul style="list-style-type: none"> • Writing and providing feedback on grant applications • Participating in research group meetings • Bridging gaps among stakeholders 	<ul style="list-style-type: none"> • Maintain focus on helping patients • Stimulate discussion and collaboration • Bring outsider perspective to the research • Add a personal face and sense of urgency • Increase public understanding of science
Planning & Implementing Clinical Trials <ul style="list-style-type: none"> • NCI and NCI Funded Clinical Research like Cooperative groups • Academic Cancer Centers and Consortia • Drug Company Trials 	<ul style="list-style-type: none"> • Designing trials • Reviewing informed consents • Developing patient support materials • Providing patient navigation and peer support • Focusing recruitment & retention plans • Membership on Protocol and Scientific Review Boards (SRBs and PRBs) • Membership on Institutional Review Boards (IRBs) • Membership on Data Safety Monitoring Boards (DSMBs) • Writing patient friendly research summaries 	<ul style="list-style-type: none"> • Sensitize researchers to issues that will impact patient recruitment, retention and satisfaction • Provide consumer perspective on ethical issues • Focus on toxicities as well as benefits • Encourage Quality of Life (QOL) add-ons • Encourage collaboration across disciplines and among stakeholders • Add a personal face and sense of urgency • Increase public understanding of science
Translating & Disseminating Research <ul style="list-style-type: none"> • Professional Societies such as the American Association for Cancer Research (AACR) and American Society of Clinical Oncology (ASCO) • Non-profit organizations 	<ul style="list-style-type: none"> • Presentations at advocacy and scientific meetings • Planning and attendance at advocacy and scientific meetings and training • Publication in advocacy and scientific journals, websites, listservs and blogs • Public outreach through national, regional, and local organizations and media 	<ul style="list-style-type: none"> • Develop future advocates • Sensitize researchers to issues that are important to public stakeholders • Help public understand the importance of cancer research • Increase awareness of cancer research progress
Research & Public Policy Oversight <ul style="list-style-type: none"> • Government • Academia • Foundations 	<ul style="list-style-type: none"> • Clinical Practice Guideline Committees • Working Groups, Study Groups and Think Tanks • Protocol and Science Review Boards • IRBs and DSMBs 	<ul style="list-style-type: none"> • Increase transparency • Provide patient/consumer focus • Provide outsider perspective • Help disseminate results