

Patient engagement in cancer research from the patient's perspective

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Patient engagement in cancer research involves the inclusion of patient voices into research to ensure knowledge generated will improve the lives of all cancer patients. Patients involved in research have an interest in science, an experience with cancer and want to work directly with researchers to ensure patient concerns are heard. There are many opportunities for patient engagement in laboratory and clinical research, throughout the lifecycle of the project from conception to completion. Researchers and patient advocates can take practical steps to ensure their engagement is effective and meaningful. Adding the patient voice in research honors those who have died, so future cancer patients have access to new therapies to live longer and better lives.

Tweetable abstract: Adding the patient voice in research honors those who have died so that future cancer patients have access to new therapies to live longer and better lives.

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Cancer patient advocacy has been around for many years, and there were key inflection points in the trajectory of patient advocacy that shaped the current landscape of research advocacy and patient engagement in cancer research [1]. One early influencer was Terese Lasser, who was instrumental in initiating Reach-to-Recovery in 1952, a patient-centered program through the American Cancer Society. In the 1970s, First Lady Betty Ford and others raised public awareness about breast cancer, which spurred the formation of several grassroots cancer advocacy organizations. In the 1980s and 1990s, two prominent breast cancer advocacy organizations emerged and are still leaders today, Susan G. Komen [2,3] and the National Breast Cancer Coalition [4–6]. These organizations set expectations for patient engagement in cancer research, including scientific research grant review. Today many cancer-related organizations advocate for various cancers. One relatively new phenomenon has been the emergence of cancer advocacy organizations focusing on a subset of common cancers or specific patient populations [7–11]. An important program supporting consumer advocate involvement is the US Department of Defense's Congressionally Directed Medical Research Program (CDMRP), establishing the Breast Cancer Research Program in 1993. Currently, there are multiple CDMRP programs covering at least seven cancers. The involvement of consumer advocates has been required from the beginning and led other programs to do the same, including the California Breast Cancer Research Program, which involves patients from strategic planning to their inclusion on every funded project [5,12]. By 1996, a patient advocate was nominated for a National Institutes of Health, National Cancer Institute (NCI) Intramural Council. After considerable discussion, the patient advocate position was approved in 1998, which has resulted in the continuation of inclusion of patients on key committees and boards at the NCI today. Currently, the NCI supports patient advocate involvement through the Office of Advocacy Relations [13,14], and many more institutions value and encourage patient involvement in cancer research.

Although progress has been made in the inclusion of patient advocates in research over the past 30 years, there are still challenges to ensure consistent and meaningful patient engagement in research. This narrative review article is a patient's perspective on what researchers and patient advocates can do to enhance their ability to work together

to ensure meaningful engagement adds urgency and purpose to cancer research with the goal of improving the lives of all cancer patients.

Research patient advocates

Patient advocates are people who have had a diagnosis of cancer, been a caregiver of someone with cancer or affected by someone with cancer and patients can advocate for different causes in different ways. For example, patients can advocate for public policy by talking to government officials and encouraging them to pass legislation to improve the lives of cancer patients. Other patient advocates focus on fundraising for patient programs or research. Still others may be more interested in providing direct support to patients in a variety of ways. The type of patient advocacy addressed in this article is research patient advocacy. Research patient advocates focus on research, have a willingness to become educated in the science of cancer and want to make a broader impact in cancer and its treatments.

In 2011 the NCI published the recommendations of the Advocates in Research Working Group, which was convened in 2007 “to consider how to most effectively and consistently engage individual advocates in the research process to accelerate progress and benefit patients” [15]. The working group defined a research advocate as someone “who brings a nonscientific viewpoint to the research process and communicates a collective patient perspective. A collective patient perspective is created when a person has knowledge of multiple disease experiences and conveys this collective perspective rather than his or her own exclusive experience” [15,16].

Patients who engage in research are not all the same. Different types of patients can be involved in research in various ways [16]. For example, some projects benefit from learning about the experiences of patients. Engaging individual patients who have the specific disease can inform the project about their experiences; however, most patients do not have basic knowledge about research methods or the scientific process. Other projects may benefit from the engagement of research patient advocates. They not only have personal experience with the disease, they also have learned about research and scientific methods. Research patient advocates bring a broad perspective versus a singular personal experience to the discussions. Research patient advocates can be involved and provide relevant patient perspective throughout the entire research project from conception to completion. They can provide valuable contributions in both laboratory and clinical research projects.

As with many areas in science, diversity is beneficial among research patient advocates. This is even more important in cancer advocacy because patients differ from each other in many ways; their only ‘common bond’ is a diagnosis of cancer. Their backgrounds and life experiences vary widely, in addition to their cancer experience. Different life experiences can influence a patient’s perceptions and guide their feedback on projects. For example, opinions and experiences differ by cancer types, stages of cancer, geographic areas, socioeconomic situations and race/ethnicity. For a true representation of the patient perspective, involving multiple patients can enhance engagement to be more meaningful and effective.

Patient advocacy in cancer research

Many articles have been written about patient advocacy in cancer research. One of the earliest in 1998 addressing the different types of advocacy as well as several areas of research advocacy [17]. Interestingly, the difference in perception between patients and researchers was highlighted, especially noting that research advocacy was a relatively new concept. Their perceptions were different, and at that time sometimes confrontational. However, patients did challenge some areas of research and changed the interest of some funding organizations, specifically regarding environmental causes of cancer. These activities set the stage for including patients in cancer research.

Early in the inclusion of patient advocates in cancer research, there was an obvious need for structure around engagement, a strong framework for research patient engagement communicated to all participants that fits the specific purpose of the engagement. In one analysis of 65 frameworks, five categories were identified [18]. This study concluded that a single, off-the-shelf framework may not be useful; however, a menu of resources to design a framework may make more sense [18]. Developing a strong framework based on a clear agreed-on purpose and goal is key to keeping patient engagement in a research project focused, effective and meaningful. People have a tendency to try to fit everything in one box – a one-size-fits-all approach – but patient engagement is diverse and specific needs can vary, so identifying the purpose for engagement should be the first step for any project. In general, one often-used purpose of patient engagement is to enhance research by improving and accelerating new treatments for cancer patients [1]. Another common purpose for involving patients is to put a human face on cancer, which will add urgency to research [19]. Patients can also ensure research maintains a patient focus, add diverse perspectives,

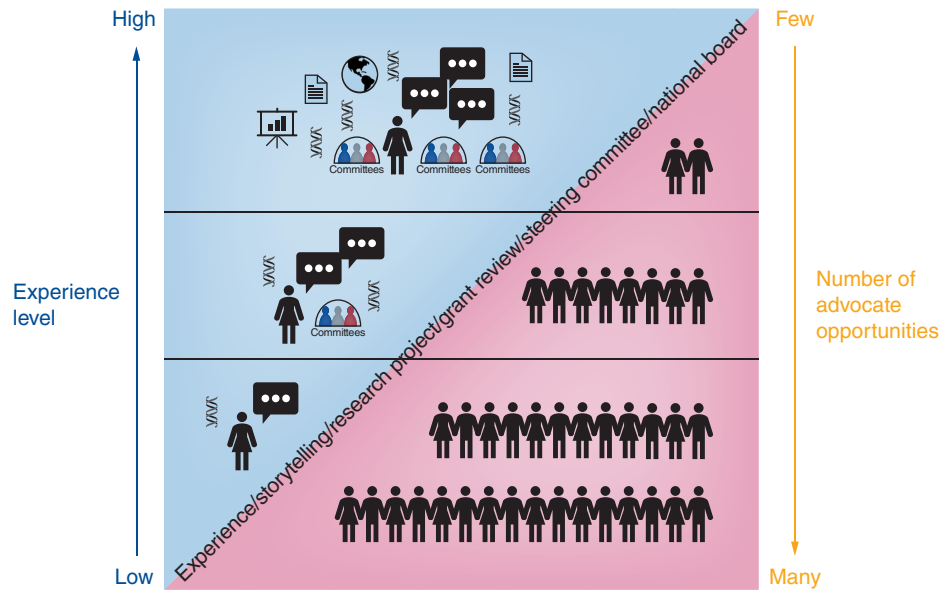


Figure 1. Numbers of opportunities and experience level needed for patient engagement in cancer research.

encourage discussion and spur innovation [19]. However, these purposes are broad and hard to quantify or measure their effectiveness. Putting some effort into developing a framework of patient engagement can make a meaningful measurable difference and will enhance the overall engagement experience for both the researcher and the patient.

There are many opportunities for patient advocate involvement; however, there are differences in the types of engagement and the experiences of the patient advocate needed (Figure 1). For example, some opportunities do not require patients with high levels of research advocacy experience. These low-experience opportunities provide a majority of engagement opportunities for patient advocates. For example, many patients are engaged in storytelling and providing individual experience knowledge. Other opportunities require patients to have a higher and broader level of experience. However, not as many of these opportunities are available for patient advocates. These include participating in research grant review, involvement on research teams, speaking at meetings and participating as panelists in workshops. There are also rare opportunities (e.g., on national advisory boards) that require a patient advocate with a higher level of experience.

The experiences of research patient advocates are multifaceted. A research patient advocate, like all patient advocates, brings the experience of a cancer diagnosis to the discussion. However, as research patient advocates gain more awareness and understanding of the field, they do not focus solely on their own experiences and instead consider a broader perspective, representing all patients. They also build an understanding of the research process and scientific methods: they do not study a specific topic, but learn the basics so they can learn more about specific projects and be able to understand the way the project will affect patients. It is easier for patients to be involved in research if they have a basic understanding of not only research, science and cancer but also of the research environment. Many patient advocates have never been in a research laboratory and are unfamiliar with the academic hierarchy and regulations. Learning these basics helps the patient advocate understand the entire project and increases their ability to make a meaningful contribution in the context of this knowledge. On the other hand, some patient advocates focus on one area of research, topic or cancer type and become very knowledgeable in that specific area. However, even the most knowledgeable patient advocates will always be looking at research through the lens of the patients; they are not going to provide input on experimental details. They will always bring a nonscientific viewpoint to the research and a broad patient perspective.

There have been several articles written about the areas of research where patient advocates are engaged [15,19–25]. Although there are multiple areas of research for engagement, following are examples of engagement in clinical research, laboratory research and in advisory roles. In general, clinical research refers to involvement in clinical trials compared with laboratory research, which refers to research done in a laboratory. Laboratory research is a broad category spanning very ‘basic’ or foundational studies conducted in test tubes to translational research, which may involve research in mice or human tissue. Each area is broad and can include many ways advocates can be involved.

Clinical research

Research patient advocates are involved in various areas of clinical trials [19,25], including drug development [20,21]. The US government-funded National Clinical Trials Network (NCTN) has been engaging patient advocates in clinical trials for more than 25 years as of this writing [26]. Each network group involves patients in different ways. In 2012, Katz *et al.* [27] published a survey to learn about the role of patient advocates in an NCTN group, CALGB (now the Alliance for Clinical Trials in Oncology), from the patient and investigator perspectives. Interestingly, they found that a majority of both patient advocates and investigators thought there was benefit from engaging patients. As expected, patients had a higher value of their role than investigators, and investigators pointed out areas for improvement, including training, communication and clarifying the role of the patient advocate [27]. A recent project from another NCTN group, SWOG Cancer Research Network, mapped a novel framework for patient engagement [28,29]. This includes a roadmap to involve patients throughout the development of clinical trials and addresses two unmet needs, training and assessment. It will be interesting to evaluate the implementation of this framework to determine whether it can enhance engagement of patients in SWOG clinical trials in a meaningful way. Another example from SWOG was the development of an external stakeholder advisory group of patient advisors to work with the research team on the TrACER study (S1415CD) [30]. They published best practices and co-presented a poster on stakeholder influence on the trial. This is a good example of how patient involvement within the NCTN can be structured and successful. Currently many patient advocates are fully integrated in NCTN activities and specific studies.

Opportunities for patient advocate engagement exist in the pharmaceutical industry and even some smaller biotechnology companies. These opportunities vary in extent and purpose and can include working on specific trials or on overarching topics such as patient-reported outcome measures, implemented across many trials. Patient advocate involvement is increasing in some, but not all, pharmaceutical companies. Unfortunately, there is no easy way to find out about potential opportunities at companies. In addition, there is a lack of transparency around current practices in patient advocate engagement within companies. Few publications or presentations acknowledge the inclusion of patient advocates. It is important to remember that there are differences between patients involved in government-funded compared with pharmaceutical-company-sponsored clinical trials. One key difference is in compensation. Pharmaceutical companies always compensate patients engaged in their clinical trials. Another difference is in the overall goals. Many government trials are to improve patient care and gain more knowledge, whereas pharmaceutical trials are to gain drug approval. Patient advocates interested in engaging with companies need to be proactive, attend meetings and network with patient advocacy directors at pharmaceutical companies. Pharmaceutical companies approve most new drugs, so patient involvement is important.

Patients can be involved throughout the lifecycle of the clinical research from concept to completion (Figure 2). For example, during conception patients can give guidance on study design relating to patient burden, endpoints important to patients and which patient-reported outcome measurements are appropriate. During the conduct of the study, patients can help with ongoing barriers to accrual and additional patient information and educational materials. Upon completion of the study, patients can help communicate study results to the community and patients. Involving patients in clinical trial development will ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient-relevant endpoints.

Within clinical research, patients are interested in a variety of topics. One of these is biospecimen collection [31–33]. There are programs where patients are treated as partners in research not merely tissue donors [33]. They have a voice and collaborate in running the biobanks. In one program at the UK Institute of Cancer Research Clinical Trials Statistical Unit patients are engaged in biospecimen collection. For example, in two breast cancer clinical trials requiring multiple mandatory biopsies the influence of patient advocates was documented [32]. Patient advocates were involved in trial design, consent review and clinical site training. They learned along the way and had an impact. One of the key components was to educate site staff that patients will be willing to participate in trials with multiple mandatory biopsies if fully informed about what to expect and shown the rationale for the multiple biopsies. Clinical trials are becoming more complicated and biospecimen collection more common. Engaging patient advocates to review the acceptability of biopsies and other biospecimen collection protocols and processes can facilitate patient acceptability of the trial and enhance accrual.

Laboratory research

Patient advocates engaged in laboratory research projects is a considerable area of involvement and can be viewed from many angles. For example, some advocates concentrate on increasing funding for research by educating the

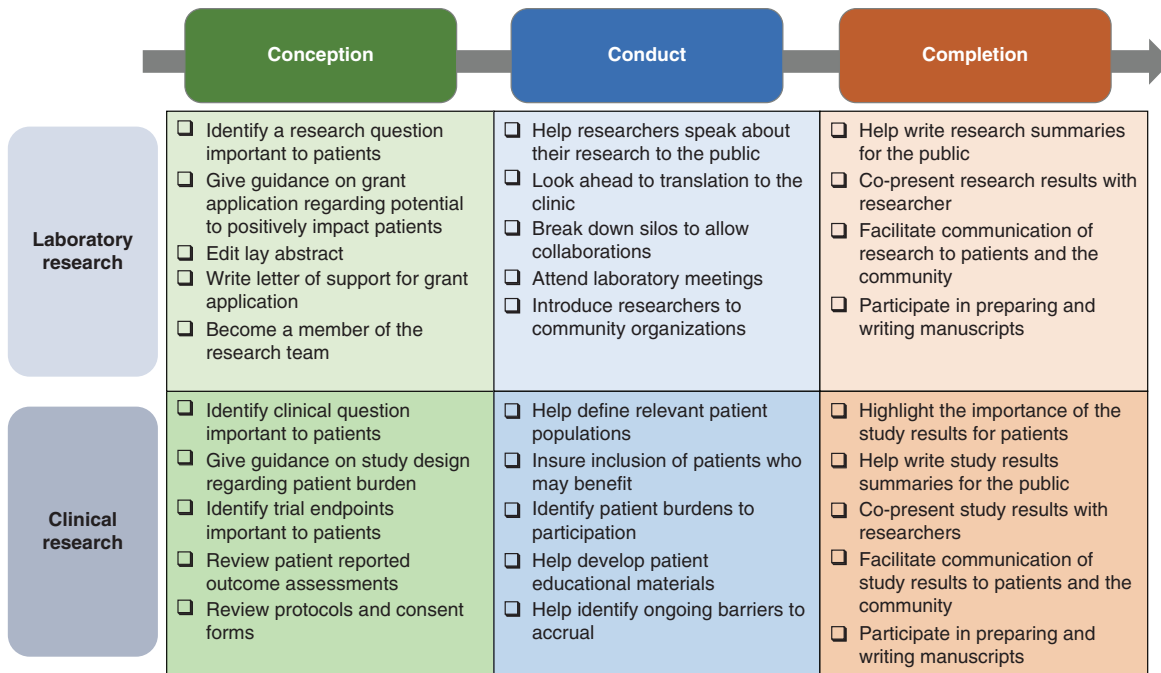


Figure 2. Patient advocate engagement through the lifecycle of laboratory and clinical research.

public and lobbying for support [19,23,25]. This effort is important for many reasons, including to increase public trust in research by communicating the importance of research in plain language [15,19,22]. Research patient advocates can be a liaison between researchers and the community [23]. Patient advocates are interested and usually very good at communicating with the public. Being a member of a research team allows them to know the research and be able to translate it into plain language for the public to understand. This is demonstrated in a unique program in science communication at Cornell University, where scientists connect with local advocates and community members while learning to communicate science to the public [24]. This puts a human face on cancer and exposes scientists to patients.

Patient advocates can be involved directly in research projects as a member of the research team [19,22]. It is always important to remember that although a goal is to be a valued and equal member of the research team, the patient advocate needs to be able to maintain independence so that they can truly advocate for patients during discussions. Although patient advocates will have general knowledge about research, they will appreciate learning more about the specific research project as they engage with researchers over the conduct of the project. They are not there to become a research scientist; however, they will learn concepts and ideas that can help identify how research may influence patients. Research patient advocates can be involved along the entire research continuum from conception to completion (Figure 2). Patients can add value in identification of the research question and giving guidance during grant application submission. Patients can help write a lay/public abstract and help convey the importance of the research to patients. At the completion of the project, patients can facilitate communication of the results to patients and the community. Their involvement can enhance research to be more patient centered and can instill a sense of urgency in research throughout the conduct of the research project.

Advisory

In addition to being involved in clinical and laboratory research projects as part of research teams, patients are often involved in oversight and are members of advisory committees and boards [23]. In these roles, patients can influence policy and strategies [19,22,23]. There are opportunities for advocate involvement in advisory committees and boards at several organizations and institutions, including the NCI, US FDA, American Society of Clinical Oncology and American Association for Cancer Research. Many large cancer centers have opportunities for advocate involvement on Institutional Review Board (IRB) and various scientific review committees. These opportunities give patients a voice where decisions about new directions in research are made. Another area where key decisions are made is

in deciding funding of research grants [5,13]. Many organizations engage patient advocates in scientific grant peer review. One popular program that involves many consumer advocate reviewers is the CDMRP [5]. It not only has consumer reviewers but also requires consumer advocate inclusion on the research team, and this must be identified before grant submission. Some funding mechanisms require more than one consumer advocate, realizing that larger granting mechanisms require more participation. Other organizations also require patient advocate involvement (e.g., Susan G. Komen, Stand Up to Cancer) and have patient advocate reviewers (e.g., Susan G. Komen, American Society of Clinical Oncology, Metavivor, Patient-Centered Outcomes Research Institute). Most cancer organizations are interested in funding translational projects – that is, research that will make a difference in the treatment and survival of patients. Patient reviewers focus on potential patient impact and evaluate whether the applicant has a clear understanding about how their research may benefit patients, even if the benefit is many years away.

How to engage patient advocates in research

The role of patient advocates can vary as widely as each project varies. In general, their role can include advisory, designing the project or clinical trial, reviewing projects and disseminating research [15]. However, each project and each engagement should be assessed individually to maximize appropriate and meaningful engagement.

Key factors to enhance patient–researcher engagement include assembling a good team of advocates, building a foundation with common mission and goals and establishing clear roles and responsibilities [34]. Having a purpose and opportunities to engage early in the research process is also an important aspect of a good patient engagement program [19,35]. One part of patient engagement often forgotten is to assess the impact of patient involvement. Unfortunately, there are few examples, and measurements vary depending on the project [28,36]. Ideally, assessments should measure whether expectations were met by both the researcher and the patient [19].

Having an environment of respect, equitable power and trust is also important [35]. This is developed through establishing clear communication from the beginning and throughout engagement [1,15,35,37]. Clear communication is essential for setting common goals and expectations, meeting frequency and defining the role of the advocate in each phase of the project. Patients must be willing to be objective and bring a broad cancer patient perspective to the conversation [1,19]. It is also important to value the patient's time and expertise to the project, which can be done by offering compensation [35]. This can be in honorarium for participation or to provide travel expenses for advocates to attend scientific meetings, which will increase their knowledge about the project. It is important to have this conversation when the engagement begins.

The process of patient engagement in research is unique to the setting and the specific research project. However, there are a few overarching steps that can be taken to ensure good patient advocate engagement in research based on prior literature and personal experience. What follows provides a road map for researchers and advocates outlining what to consider when participating in research projects together. This is a unique relationship, so a few key steps will ensure a meaningful contribution.

For researchers

Researchers can take a few practical steps to ensure effective and meaningful engagement of patients into their research projects (Figure 3). The inclusion of patients in research projects begins with the researcher deciding, or sometimes being required, to include patients in their research. It is the responsibility of researchers to contact patients and invite them to participate. To do this, researchers should have a clear idea about why they want to include patients in their research. This is an important first step, often overlooked in the process of patient engagement.

Once researchers decide to engage a patient advocate, they need to find a patient to include in their research project. This is not an easy task, but there are some practical steps to take to begin the process. On the basis of research needs, determine what type of patient or research patient advocate would be best for the project. It is not only important to match the need with the appropriate patient, but also to match the expertise and experience of the patient with the project. For example, if the research project focuses on metastatic breast cancer, it is a good idea to engage a patient with metastatic breast cancer to join the research team. Some projects may benefit from the engagement of several patients because the collective view of many allows for multiple opinions and mentorship opportunities for new advocates. Identifying patients for a specific research project can be challenging. Asking mentors or colleagues is a good starting point. Researchers can make an effort to meet patient advocates at scientific meetings like American Society of Clinical Oncology or American Association for Cancer Research

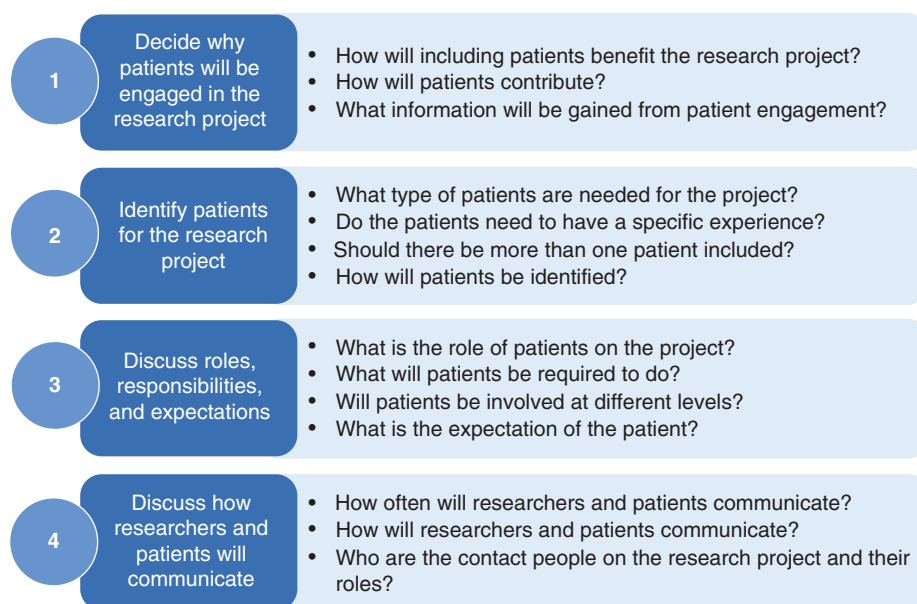


Figure 3. Steps researchers can take to ensure effective and meaningful engagement of patients into research projects.

Annual Meetings. Taking advantage of community events, including speaking for local cancer organizations, will increase access to patient advocates. If the grant funder is requiring patient advocate involvement, ask them for recommendations. As researchers commit to always engaging patients in their research, it becomes easier as working relationships develop.

Once a patient advocate is identified and accepts the invitation to participate, the real work begins. The first thing to do is to discuss roles, responsibilities and expectations. This is the most important discussion to have at the beginning of the project. Many items should be discussed; however, items will vary depending on the specific project, the specific need and level of engagement expected. This is also a great time to get to know each other and begin building a working relationship.

Communication is key to a successful engagement of advocates in research. At the beginning of the project, the researcher and patient advocate should agree on how often and in what way communication will be maintained throughout the conduct of the project. This will ensure fewer misunderstandings and reinforce expectations of both researcher and patient.

For patients

Patient advocates can follow the following advice to ensure effective engagement in research. Being an effective patient advocate on a research project requires some effort and motivation.

Represent a collective viewpoint

An experienced patient advocate learns from each experience, talks to other patients, facilitates support groups and can represent a collective patient perspective. Research patient advocates do not represent their personal individual experiences; they represent the broader patient population. Therefore, although the patient story and experience is important in some situations, in research meetings, it is not appropriate to ask personal questions about your cancer and rarely appropriate to start a comment with a personal cancer story.

Learn listening & effective communication skills

Two main skills all patient advocates need to learn are how to be a good listener and how to communicate effectively. Keeping up with scientific conversations can be challenging, so it is important to develop skills to help follow the conversations. One option is to avoid distractions so that you can listen and to take notes. Then previous conversations can easily be referred to. Communication is a skill that will develop over time. One helpful hint is to be aware of time constraints and try not to monopolize the conversation and to stay on topic and be succinct.

This should not discourage patients from speaking up; it is just a reminder to be respectful of the situation. In addition, many times agreeing with previous comments or complementing a speaker is a good way to engage and acknowledge the researchers. There is an art to disagreeing without being disagreeable, well worth the effort to learn.

Participate in conversations

Many times advocates are hesitant to speak up in a scientific meeting because they are afraid they will be 'wrong.' Patients provide their perspective and opinion, so they are never 'wrong.' It is a perception, not a test. Their opinion may change after facts they were unaware of are revealed; however, their initial opinion is important for researcher to hear. The patient is not there to evaluate the science but to speak on a broader patient perspective, so it is not necessary to speak in scientific jargon; plain language is appropriate. For patients to feel more comfortable speaking up, having one-on-one conversations with researchers can boost confidence. This skill improves over time and after many opportunities to engage with researchers.

Network

Effective patient advocates network with researchers and among other patient advocates. Patient advocates should make an effort to meet researchers studying a topic that interests them. Join patient advocacy communities to learn and meet other patients. One very active advocacy community network is the Patient Advocates in Research email list, founded by Deborah Collyar. Scientific meetings offer exceptional opportunities to network and taking advantage of the collaborative environment will enhance a patient advocate's experience.

Set realistic expectations

Patient advocates should set realistic expectations about their contribution and time they are able to commit to a project. Being able to discuss these issues with researchers is important. Do not expect to make a huge difference on every project. Sometimes it is small or may even seem underwhelming. Other times it will be substantial and very satisfying. Knowing that all engagements are different will help set realistic expectations.

Keep learning

Each patient advocate, regardless of previous experience, should never stop learning. Newer patient advocates should seek out learning opportunities, in-person or online [4,38]. Being prepared to participate on a research project, can take time and discipline. The alternative is being unprepared and not being able to contribute to a project. Advocates can ask a researcher to help them learn more about their specific project. Seeking out a mentor can also be helpful if one-on-one interactions are preferred. Several on-line training resources [39–43], trainings during scientific meeting [44–46] and comprehensive training programs [47–50] are available to patient advocates. One long standing breast cancer training is Project Lead[®] Institute conducted by the National Breast Cancer Coalition [4]. Project Lead is an intensive, multiday training [47]. Keeping up-to-date with new research can be overwhelming; however, learning will always be a part of participating in research. Accepting challenging opportunities may add to their knowledge, even if they feel uncertain at the beginning.

Conclusion

Including patient advocates in research is important. They can make valuable contributions in both laboratory-based and clinical research projects. It is highly recommended to involve advocates from conception to completion so that patients can help form the research questions and identify patient concerns early in development. Researchers should put concerted thought into how to involve advocates specific to their project and needs in a meaningful way. This may mean engaging more than one patient advocate or finding someone with appropriate experience for the project. Giving concerted effort and thought into specific ways patients can be involved to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient. Patient involvement in laboratory research can enhance research to be more patient centered and can instill a sense of urgency throughout the course of the research project. Patient involvement in clinical trial development will ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.

There are some practical steps researchers can take to engage patient advocates. This article proposed the following suggestions to ensure meaningful engagement: decide why patients will be involved in the research project; identify patients; discuss roles, responsibilities and expectations; and discuss how researchers and patients will communicate.

Patient advocates can also follow some practical suggestions to ensure effective engagement: represent a collective viewpoint, learn listening and communication skills, participate in conversations, network with researchers and patient advocates, set realistic expectations and keep learning.

Effective patient engagement requires effort of both the researcher and the patient advocate; both must be committed to the process and communicate throughout the engagement. Patient engagement must not be about checking off a box on a form, with minimal contact after funding is secured. It is about making a difference to the way science is conducted, with urgency and value of the patient perspective and experience.

Future perspective

Engaging patients in cancer research is both challenging and rewarding. However, the goal “to generate knowledge and insight that will improve the lives of all cancer patients” should always drive the engagement of patients as partners in all areas of cancer research [51]. It is important to acknowledge the significance of early patient advocacy in cancer that has led to the current landscape of patient engagement in cancer research. Without their efforts, the patient voice in research would be much less if present at all. Although patient advocacy has come a long way, there is still work to be done to ensure the inclusion of patients in cancer research is universal and leads to the improvement of the lives of all cancer patients.

One major concern is a lack of diverse representation of patients involved in research. The opportunities to engage in research, although increasing, are not expansive. For example, there are more opportunities to be involved in research at academic institutions in large cities and fewer opportunities for those who live in rural communities. This limits opportunities for many patients who may be interested and can add an important community patient voice to clinical and laboratory research. Although some research patient engagement opportunities are not location based, it is harder for rural and underrepresented patients to be identified and asked to participate. The lack of opportunity is not the only barrier; there is also the dogma that patient advocacy as a purely volunteer activity. To ensure representation this is a huge barrier to overcome. Many times incidental costs (e.g., travel, parking, time off from work, childcare) are not reimbursed. Acknowledging the importance of the patient voice in research through compensation for their expertise and time can begin to overcome this barrier. There are likely more reasons for the lack of diverse patient representation in research, beyond the obvious ones mentioned here. More research is needed to evaluate the barriers to patient participation in research and to determine how to overcome these barriers to improve diverse representation of all patients in research.

Matching patient advocates to research engagement opportunities is still a challenge. It is sometimes hard for new advocates to find out about opportunities, and it is hard for researchers to find patient advocates interested in research. It is not clear what the solution will be; however, it is difficult to envision broad coordination across all cancers, so matching may be more effective when facilitated by cancer type. It is not only important to match patients with opportunities; it is also important to train advocates and have a path for new patient advocates as opportunities increase.

Training of research patient advocates has been an ongoing challenge. Most trainings are offered by individual cancer organizations by cancer type and are hard for patients to navigate. This creates a barrier, specifically for patients who advocate for rare tumors. Currently there is a lot of competition for in-person trainings, highlighting limited training opportunities and the increase in number of patients seeking training.

Assessing the impact of patient engagement in cancer research needs to be addressed. Having information and evidence on the impact of engaging patients in research will help patients and researchers understand their roles and clearly define ways patients can influence research.

Even though there are challenges, it is important to engage patients in research. Patients bring urgency to research. Too many patient advocates have died from cancer, and others are currently waiting for the next treatment to be discovered to give them more time. This adds an urgency to research that is hard to quantify. The loss of patient advocates is devastating; those of us left behind have an obligation to make sure their life and death are remembered and can motivate researchers to find new therapies and cures quickly. Keeping the voice of patients in research is one way to honor those who have died so that future cancer patients have access to new therapies to live longer and better lives.

Executive summary

Research patient advocates

- Patient advocates can provide valuable contributions in both laboratory and clinical research projects from concept to completion.
- Involving more than one patient can provide diverse representation of patient perspectives and enhance engagement to be more meaningful and effective.

Patient engagement in cancer research

- Putting some effort into specific ways patients can be involved to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient.
- Patient involvement in clinical trial development will ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.
- Patient involvement in laboratory research can enhance research to be more patient centered and can instill a sense of urgency in research throughout the course of the research project.

How to engage patients in cancer research

- Researchers can follow the following steps: decide why patients will be engaged in the research project; identify patients; discuss roles, responsibilities and expectations; and discuss how researchers and patients will communicate.
- Patient advocates can ensure effective engagement by representing a collective viewpoint, learning listening and communication skills, participating in conversations, networking with researchers and patient advocates, setting realistic expectations and continuing to learn.

Future challenges and opportunities

- There is a lack of representation of diverse patients engaged in research.
- Matching patient advocates to research engagement opportunities is still a challenge.
- Keeping the voice of patients in research is one way to honor those who have died so that future cancer patients have access to new therapies to live longer and better lives.

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