National Cancer Institute

Advocates in Research
WORKING GROUP

A National Data Grid Infrastructure for Sharing Biospecimens in Early Cancer Detection

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Recommendations

Foreword

The cancer research enterprise is vast and complex, with many individuals and organizations involved in myriad ways. Patients, and the advocates who represent them, are among the largest group of stakeholders in cancer research. For many who become advocates, a personal experience with cancer triggers a strong desire to become intimately involved in the research process as a way to give back and make a difference. Through research advocacy, advocates partner with researchers to bring a distinct, diverse, and critical perspective to the scientific process.

Highly effective engagements between researchers and advocates currently result from the commitment of individuals who understand the potential value that an informed advocate can bring to the research process. These individuals are willing to invest the time and energy necessary to actualize that vision—they are the innovators paving the way. But, in the absence of evidence or a system that defines, informs, and supports those who want to contribute, these individuals will continue to be the outliers rather than the standard.

We believe that the efforts of the Advocates in Research Working Group (ARWG) and the resulting recommendations will help advance research advocacy and build consensus and shared meaning around its practice. We anticipate that rigorous evaluation and documentation of research advocacy will lead to a better understanding of its benefits, ultimately enabling advocate involvement to become a standard practice in cancer research. The ARWG's report is intended to help guide the National Cancer Institute (NCI) as it seeks to strengthen the process for engaging advocates in research in an effective, transparent way.

Finally, although the ARWG's recommendations are tailored to the distinct needs of NCI, it is our hope—and one shared by NCI and the full ARWG membership—that this work can serve as a foundation for successful advocate engagement throughout the cancer research enterprise, acting as a blueprint for organizations across the nation.

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Recommendations

Since the late 1990s, the National Cancer Institute (NCI) has facilitated the engagement of individual advocates in its research. In 1993, the National Cancer Advisory Board (NCAB) conducted a survey of advocacy groups and found they had a strong interest in fostering relationships with NCI to increase communication and collaboration. In 1996, NCI created the Office of Liaison Activities, now the Office of Advocacy Relations (OAR), to develop and cultivate these relationships. In 1997, the Institute broke new ground by launching the NCI Director's Consumer Liaison Group (DCLG), a federal advisory board consisting solely of consumer advocates.

In September 2007, NCI Director Dr. John E. Niederhuber asked the DCLG to consider how to most effectively and consistently engage individual advocates in the research process to accelerate progress and benefit patients. As a result of this request, the DCLG established the Advocates in Research Working Group (ARWG). The ARWG was active throughout 2008 and 2009, approving its final recommendations in summer 2010. The ARWG comprised an array of stakeholders in the cancer research process, including research advocates, a broad range of NCI staff, and extramural researchers.

The ARWG considered the engagement of advocates throughout NCI and the NCI-funded research community, such as NCI-designated Cancer Centers, Specialized Programs of Research Excellence (SPOREs), and NCI Clinical Trial Cooperative Groups. However, because implementation must occur within a particular environment, the ARWG focused specifically on NCI when discussing the implementation of its recommendations, which are based on the culture, practice, and structure of NCI and are intended to meet the specific needs of the Institute. Although some of the recommendations are limited in scope to NCI, the ARWG hopes its report will be applicable across multiple research environments, thus serving as a guide for developing promising approaches that the broader research community can use to engage research advocates.

Early on the term *research advocate* was defined and provided context for the work of the ARWG:

■ A **research advocate** 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.

The ARWG analyzed information about current advocate engagement practices and identified four primary ways advocates engage in the research process. These roles included advising, designing, reviewing, and disseminating. The group defined the scope of each role and identified examples to clarify each one further:

1. Advocates engaged in **advisory roles** help develop recommendations or advise on strategic directions or broad policy issues. Advisory activities include participation on a formal advisory board or providing a critical perspective as part of a panel discussion at a scientific meeting.

2. Advocates engaged in **design roles** develop new or enhance existing programs or activities. Design activities include serving on a committee or panel involved in development of a new program or oversight of an existing program to provide the patient perspective or to identify patient barriers to implementation.

3. Advocates engaged in **review roles** evaluate and analyze research proposals and ongoing research activities. Review activities include participating in peer or concept review panels.

4. Advocates engaged in **dissemination roles** interpret and communicate scientific information for nonscientific audiences. Dissemination activities include using scientific content to develop, edit, and/or distribute research findings to such audiences.

The ARWG identified outcomes associated with engaging advocates in research. These outcomes fit into two broad areas: enhanced research and increased public understanding and support of research.

1. **Enhancing research**

   a. Advocate involvement improves clinical research feasibility by providing experiential knowledge of protocols' impacts on patients.

   b. Advocate involvement provides a perspective that can stimulate innovation and expand the scope of inquiry.

   c. Advocate involvement serves as an immediate reminder of the need for research focused on patient benefit and outcomes.

2. **Increasing public understanding and support of research**

   a. Advocate involvement increases public trust through enhanced transparency and accountability.

b. Advocate involvement helps break down barriers between the public and researchers.

c. Advocate involvement establishes a conduit for regular communication between the public and researchers.

d. Advocate involvement assists in disseminating research findings in clear and understandable ways.

e. Advocate involvement helps other advocates understand and effectively communicate about science and research institutions.

Recognizing the need for a systematic yet adaptable, centralized, and transparent process for advocate engagement, the ARWG identified seven broad themes around which its specific recommendations were developed. The ARWG understood that the needs and interests of investigators across NCI and the broader research enterprise may vary significantly. Therefore, the recommendations are intended to provide support, clarity, and guidance but not necessarily to restrict or limit current effective practices.

1. **Recruit:** Proactively recruit experienced and diverse research advocates and encourage NCI investigators and staff* to engage advocates.

2. **Assess:** Develop a robust application process that generates a cadre of highly qualified research advocates who can meet the scientific needs of NCI.

3. **Match:** Develop a matching process that identifies program needs and effectively engages the right advocate in the right activity at the right time.

4. **Train:** Provide training, coaching, and informational resources to advocates and NCI staff to ensure all participants have the knowledge and tools they need to be effective.

5. **Facilitate:** Leverage NCI's centralized resources and expertise to better inform and support the advocate engagement process.

6. **Monitor:** Track and evaluate the advocate engagement process to implement continuous improvements and develop an evidence base around engaging advocates in research.

7. **Promote:** Develop a process to retain and recognize advocates and staff who successfully work together and communicate these successes across the community.

Each of the recommendations presented in the report addresses a critical component in the comprehensive process of successfully involving advocates in research. The ARWG developed a rationale that serves as the foundation for each recommendation. The process for implementation represents a balance between a vision of seamless integration of advocates into NCI's work and the realities and constraints of the current structural, functional, economic, and

* The term *NCI staff* will be used throughout this document to refer to the collective group of professionals employed by NCI, including investigators, program staff, and administrators.

political environments. The ARWG recommends engaging advocates in advisory and design roles as NCI implements these recommendations. Doing so will create a process that not only meets the needs of NCI but also is transparent and feasible for external stakeholders.

Recommendation 1

Recruit

Proactively Recruit Experienced and Diverse Research Advocates and Encourage NCI Investigators and Staff to Engage Advocates

Due to natural attrition and the continually evolving scientific and programmatic needs of NCI, recruitment of research advocates should occur on an ongoing basis. Recruiting a diverse group of advocates who have experience with the research system is critical to maximizing the benefits that advocates bring to the research process.

Engaging qualified advocates in a wide array of activities allows NCI to take full advantage of the experiential perspective advocates inherently bring as well as benefit from their diverse experiences and backgrounds.

In 2001 and 2004, NCI sought out community advocates to participate in the peer-review process. Upon selection, these advocates became part of the NCI Consumer Advocates in Research and Related Activities (CARRA) program. Since that time, there has been no subsequent formal opportunity for advocates to apply to participate in NCI activities. Advocates lost through natural attrition have not been replaced, nor have advocates with specific skill sets that align with NCI's scientific needs been purposefully included. Accordingly, NCI commonly reaches out beyond the current pool of advocates to identify individuals who meet the specific and continually evolving scientific needs of the Institute.

As a whole, the current cadre of CARRA advocates does not adequately reflect the diversity of the United States or the populations affected by cancer—nor does it does collectively portray the broad range of viewpoints and experiences that exist within the patient perspective. At times, NCI staff identify the need to engage individuals from a particular culture or background. Given the lack of demographic diversity within the current CARRA membership, the same individuals are repeatedly tapped to fill these specific needs. Thus, a limited number of individuals repeatedly represent a large group perspective, limiting the wealth of within-group perspectives. Additionally, this situation may limit when and how these advocates are engaged, consigning them to the more traditional role of representing a particular subgroup of patients. Establishing an ongoing recruitment process will allow NCI to engage a larger number of diverse and experienced advocates.

Outreach into the various Divisions, Offices, and Centers across NCI will help Institute staff learn about the benefits of and process for engaging advocates in their work. NCI staff should be encouraged to use OAR expertise and resources as they engage advocates. Whenever reasonable, advocates should be asked to complete the NCI application process (see Recommendation 2), which will allow them

to engage more fully with NCI and take advantage of the training and facilitation provided by OAR. Doing so also will allow OAR to monitor the engagement of research advocates across NCI and apply best practices, identify training and information needs, implement process improvements, and begin to develop a comprehensive and accurate evidence base related to engaging advocates in research.

Recruit Experienced Research Advocates

NCI should pursue opportunities to collaborate with other organizations that involve advocates in their work. This could include traditional advocacy organizations; professional societies; foundations; other federal agencies; and NCI-funded organizations, such as Cancer Centers and NCI Clinical Trials Cooperative Groups. Partnering with these organizations should allow for new connections between NCI and advocates engaged in the research process within other venues. Additionally, NCI should create opportunities to network with research advocates by having a presence at scientific and advocacy meetings. Finally, social media tools, such as Facebook and Twitter, can provide opportunities to reach additional experienced research advocates.

Develop Strategies to Recruit Diverse Advocates to Engage with NCI

NCI research advocates should reflect the broad array of Americans affected by cancer and meet the needs of NCI's specific research interests. The ARWG recommends defining desired dimensions of diversity, setting specific recruitment goals, and designing recruitment strategies to meet these goals.

NCI should identify recruitment strategies that target underrepresented groups and individuals. These may include identifying community liaisons and key places of information dissemination and developing targeted recruitment messages. NCI should use its existing resources, such as the Center to Reduce Cancer Health Disparities and the Office of Communications and Education; community resources, such as the Intercultural Cancer Council; and the expertise of community leaders. Recruiting individuals affected by cancer who have not had training or experience as research advocates may enhance NCI's ability to diversify its cadre of advocates. However, this tactic cannot be undertaken until NCI has identified and/or developed the tools and resources necessary to train unprepared advocates to engage in the research process.

Although not traditional dimensions of diversity, professional experience and specific scientific areas of interest are unique attributes that differentiate advocates and the skills and perspectives they can offer. As NCI opportunities for engagement expand and increase, the Institute will need advocates with diverse knowledge and skill sets to appropriately pair advocates with specific activities.

Encourage NCI Staff to Engage Advocates

Interest in and understanding of when, where, and how to involve advocates in the research process vary dramatically across NCI. Although a portion of NCI staff understands not only the benefit of engaging advocates but also how to do so effectively, this understanding is not consistent throughout the Institute. Many staff members have an interest in engaging advocates but may not understand exactly when doing so would add benefit or how to do so effectively. Educating NCI staff in key leadership and communication positions about the benefits of engaging research advocates and the value of doing so through a centralized resource, such as OAR, is essential.

To implement this guidance and monitor outcomes, NCI staff must engage advocates effectively and communicate with OAR about these engagements. Doing so will allow OAR to identify and promote promising approaches as well as track and evaluate these activities. Such a culture of inclusion and collaboration is necessary for success and should be facilitated through the development of a robust outreach program (see Recommendation 7).

The ARWG discussed the merits of mandating advocate involvement in NCI research activities but determined that such a requirement is neither pragmatic nor beneficial, given its inconsistency with the independent research culture of NCI. The ARWG believes that creating an effective and supportive process for engaging advocates, combined with appropriate outreach activities, will encourage NCI investigators and staff to engage advocates in their research efforts through OAR.

Recommendation 2
Assess
Develop a Robust Application Process that Generates a Cadre of Highly Qualified Research Advocates who Can Meet the Scientific Needs of NCI

No current application process exists for advocates at NCI. When advocates express interest in working with NCI, there is no systematic method for evaluating their level of preparedness or informing NCI of their availability. When a need cannot be met through the current CARRA membership, OAR staff work with established advocacy organizations to identify an advocate and assess him or her through an ad hoc review of prior advocacy experience. This process takes time, and results vary.

Proactively identifying the knowledge, skills, and characteristics that enable research advocates to contribute to the research process and building a system that assesses potential research advocates against these benchmarks will lead to more consistent and successful collaborations between research advocates and the research community. Additionally, assessing specific skills in an ongoing and standardized manner will allow NCI to regularly identify new and diverse advocates and training needs.

Identify the Knowledge, Skills, and Characteristics that Enable Advocates to Contribute

Like the journey from patient to survivor, the evolution from cancer survivor to advocate to research advocate is layered and complex. Basic advocacy eligibility criteria include proficiency in the English language, basic use of and access to technology, firsthand knowledge of the patient perspective through a personal or specialized experience, and the ability to represent a collective patient perspective developed through an enduring experience with a variety of cancer patients and advocacy organizations.

However, the baseline criterion for engaging as a research advocate in the scientific process is much more stringent. To be regarded as highly qualified or fully prepared to engage in the research process, an advocate must demonstrate a basic understanding of the cancer disease process, the research process, and familiarity with how the scientific community works and communicates. In addition to having these knowledge bases, a research advocate must have the ability to effectively engage in the research process, work as a nonscientific member of a scientific team, and communicate effectively with researchers.

Develop a Process to Assess Advocate Readiness

NCI should use the knowledge and skills identified as critical to an advocate's success to develop eligibility criteria and an online application process that effectively assesses advocate readiness. The assessment should be valid and reliable, but not overly burdensome to applicants. The entire process should be constructed and implemented with as much transparency as possible. The application process should enable NCI to review an advocate's resume, answers to standard questions, and responses to hypothetical scenarios to evaluate relevant experience; references; interpersonal and communication skills; teamwork and problem-solving abilities; and understanding of the disease process, research process, and cancer community. To create a successful application process that will support the selection and training of a robust cadre of research advocates, NCI should engage human resource professionals to identify the specific knowledge, skills, and characteristics an individual must possess to contribute successfully to the research process.

The ARWG was fully aware that access to technology as a basic eligibility criterion and an online application process may limit some individuals' access and opportunity to engage with NCI. This issue was discussed at length as it conflicts with the ARWG's goal to expand and diversify the number and types of individuals who engage in the research process. However, because a vast majority of the research process and communication about that process is conducted with the use of technology, it was determined to be an unavoidable requirement for engagement. As such, the need to augment individuals' access to, understanding of, and use of basic technology such as email should be considered and integrated into

whatever strategies are identified to recruit diverse advocates into the research process.

Communication is pivotal to the success of the entire engagement process, and there are several points at which communication is paramount, including during the assessment process. When an applicant is accepted, he or she should receive a timely notification of acceptance, a basic "introduction to NCI" package of materials, and an invitation to participate in an orientation teleconference. This teleconference should orient the advocate to the NCI mission and organizational structure, how research advocates are engaged in the research process at NCI, and specifically how advocates are matched with and selected for individual NCI activities and research activities occurring in organizations outside NCI, such as Clinical Trial Cooperative Groups, cancer centers, and academic institutions. Communication with individuals who are not fully prepared to engage in NCI research activities is important and should include what experiences and/or skills were missing as well as ideas for how that individual may be able to enhance his or her qualifications as a research advocate. NCI should consider preparing current NCI advocates with extensive experience to participate in this conversation.

To ensure that this cadre of NCI advocates can meet the scientific needs of the Institute, a process should be developed to remove individuals from the advocate pool if they no longer seem suitable. Final criteria should be determined by a work group of internal and external stakeholders. Potential indicators that an individual is no longer suitable are likely to include an extended period of non-engagement or negative feedback (of an egregious nature or from multiple sources).

Recommendation 3
Match
Develop a Matching Process that Identifies Program Needs and Effectively Engages the Right Advocate in the Right Activity at the Right Time

The current process for matching an advocate with an NCI activity includes evaluating the activity's logistical requirements and the advocate's demographic information, prior experience, and self-reported areas of interest. Currently, the most rigorous selection criterion is an advocate's self-reported knowledge or experience in a particular topic area (e.g., biospecimens), disease site (e.g., pancreatic or colon cancer), or population (e.g., children or older adults).

Though many advocates and NCI staff have found success with the current system, it is based on limited and self-reported criteria that may be insufficient to support a good match between the activity and the research advocate. To maximize the value of engaging advocates in research and to aid in the retention of both advocates and NCI staff, a more rigorous approach should be undertaken.

Develop a Process that Identifies the Critical Requirements for a Specific NCI Activity

To effectively define the requirements of an NCI activity, OAR should develop a process or set of questions that can support NCI staff in determining the role they would like an advocate to play and the knowledge or skill sets the advocate needs to effectively contribute to the activity. NCI should continue to consider logistical

details, such as when the activity takes place, whether the advocate will need to participate by phone or in person, and expected time commitment for participation. NCI staff also should consider how to facilitate the advocate's participation, which can include such topics as advocate orientation, training or mentoring, travel costs, and honoraria.

Develop a Process that Identifies the Right Research Advocate for Each NCI Activity

The ARWG anticipates that the robust assessment process previously outlined will result in a diverse cadre of highly qualified research advocates. Information about these advocates will be housed in a searchable database that OAR staff can use to match the right advocate to the right activity, based on the information provided by the requesting office. OAR currently maintains a database of advocates through the CARRA program. This database should be evaluated for its ability to support the newly identified requirements and process of advocate engagement and be modified accordingly. The matching process should take into account the requirements of the identified activity, the prior experiences of the research advocate, and any additional professional skills he or she possesses.

At times, it may be necessary to reach beyond the cadre of NCI advocates to fill unique or highly technical activity requirements. When necessary, OAR staff will consult with the broader cancer community to identify appropriate participants. This consultation should be done in conjunction with NCI advocates who are well respected and have significant connections to the cancer community and advocacy organizations.

During the matching process, two critical communication steps will be notification each time an advocate is being considered for an activity and notification each time an advocate is not selected. In some cases, communication between NCI staff and the advocates under consideration will be part of the matching process. The requirements of each activity should be clearly and fully communicated to all potential participants so that they can determine whether they are prepared and able to participate effectively.

Access to relevant training and information supports research advocates in developing and maintaining the knowledge and skills necessary to effectively contribute to the research process. To provide an informed opinion on how scientific discovery affects the patient community, advocates must have access to up-to-date information and training, which should include an understanding of cutting-edge science.

Research advocates have different information needs at different times in their work as advocates. These needs include baseline information prior to participation in an activity, activity-specific information, and continuously updated information related to the continually evolving cancer research process.

Recommendation 4
Train
Provide Training, Coaching, and Informational Resources to Advocates and NCI Staff to Ensure all Participants Have the Knowledge and Tools They Need to Be Effective

Many organizations have developed trainings and resources for advocates. These resources come from a wide range of sources, including government agencies, professional societies, advocacy organizations, and pharmaceutical companies. This information also comes in a wide variety of formats, including formal in-person training, online training modules, tutorials, magazines, fact sheets, reports, websites, journals, and peer mentoring.

Barriers to accessing and evaluating resources are just as prevalent and varied as the resources themselves. Journal articles are generally unavailable to the public until 12 months after publication. Trainings are often in person and inaccessible to individuals in large numbers. Many resources are developed on an ad hoc basis with little quality control, and mentoring relationships lack a formal process and predetermined outcomes. Finally, resources are spread throughout a large, highly complex community and, even when available, can be difficult to locate.

Having the appropriate training and resources available is essential to the successful participation of research advocates in the research process. Development of these resources will support effective engagements, increase advocates' desire to remain engaged with NCI, and encourage NCI staff to further engage advocates.

Develop and Maintain an Online Repository of Trainings and Resources

A public, online repository of training resources will provide advocates with easy access to the materials they need to prepare for and effectively engage in the research process. NCI, in conjunction with key stakeholders, should develop a process to identify and solicit trainings and resources currently in the community, then organize those resources into a searchable database that will be publicly available online. This process should include a scan of the cancer advocacy environment to identify existing resources that meet the needs of research advocates. The repository must be maintained to ensure the content remains relevant to the work of NCI and meets the needs of advocates. A work group that includes internal and external members—advocates as well as scientific experts—should develop criteria for what resources should be included, such as a resource's ability to provide current, accurate, and evidence-based information free from commercial bias. The work group also should determine a process for adding new content and eliminating unneeded or outdated content on an ongoing basis. If possible, the repository should be interactive, allowing NCI advocates to rate resources and/or comment on how they were able to apply the information. A process for ongoing maintenance of resources and user feedback is essential.

Once a comprehensive environmental scan is conducted and those resources are made available, the work group should engage in

a gap analysis to identify unmet information and training needs within the research advocacy community. Once identified, the work group should engage the broad cancer community in an effort to collectively develop materials that meet the resource needs of the research advocacy community.

Develop Resources that Enable Advocates to Develop Professionally

NCI should consider creating resources to support research advocates in becoming highly skilled. These resources could include information about the skill sets and knowledge bases important to success, information on how to attain the knowledge and skills, and a template that would enable advocates to plan their developmental process. Participation in training could be encouraged by coupling opportunities for engagement with demonstrated knowledge and skills or training course completion. For example, a minimum number of educational activities per year could be a requirement for continued consideration for NCI activities.

Expand Opportunities for Formally and Informally Mentoring Advocates

Mentoring is a highly effective method for enhancing knowledge and skill sets. Pairing new advocates with experienced research advocates provides opportunities for growth for all participants and is an excellent training mechanism. Research advocates who have extensive and varied experience and an in-depth understanding of NCI and the research process should be considered as mentors. Individuals being asked to mentor others should be provided with training and guidance about how to be an effective mentor. Engaging seasoned and highly effective research advocates as mentors will expand the cadre of highly qualified advocates available to NCI and the wider community. Additionally, this mechanism may be particularly useful in helping train and prepare a more diverse cadre of NCI advocates.

Develop Resources to Support NCI Staff in Engaging Advocates

Many NCI staff members show an interest in engaging advocates but are unsure about how to do so effectively. As such, support for NCI staff is vital for continued and expanded engagement of research advocates across the spectrum of NCI activities. NCI should provide training, resources, and tools to support staff in identifying when advocates can play a positive role and how to effectively engage them. These resources could include one-page fact sheets, check-lists, online training modules, and case studies demonstrating how others have successfully partnered with advocates. These resources will complement the personal facilitation process discussed in Recommendation 5.

Recommendation 5
Facilitate
Leverage NCI's Centralized Resources and Expertise to Better Inform and Support the Engagement Process

To maximize the benefit of engaging advocates in the research process, support is essential throughout an advocate's involvement in an activity. As nonscientists, advocates bring a diverse perspective to the research process, and although this diversity is part of the inherent value of their involvement, it can increase the likelihood of miscommunication.

Currently many DOCs seek OAR support in the selection and engagement of advocates in their work; however, NCI does not have a systematic facilitation process or established policies to guide decision-making around a number of issues, such as compensation or conflict of interest. The ARWG recommends that OAR act as a clearinghouse to facilitate the effective engagement of advocates throughout the research process. This centralized role will allow OAR to increase the quality and consistency of advocate engagement within NCI and reduce the administrative burden of doing so. A comprehensive advocate involvement process facilitated by a centralized office with expertise in advocacy will maximize the benefits of engaging advocates in the research process. Likewise, such a centralized resource would be well positioned to track, evaluate, and maintain an effective process.

Develop Guidelines and Promising Approaches that Facilitate the Engagement Process

OAR should build upon the guidelines provided in the ARWG's report and create a portfolio of promising approaches to provide an overall framework for advocate engagement at NCI. To ensure its usability, guidance should be developed in conjunction with seasoned advocates and researchers with experience engaging advocates. Such guidance should address numerous topics, such as advocate selection, role definition, orientation and harmonization into existing projects, term limits, compensation, and conflict of interest. This guidance will enhance role clarity, provide a point of reference, and promote consistency across the constantly evolving scientific landscape. All such guidance should be widely distributed within NCI and across the cancer advocacy community and be integrated into training materials and resources as they are developed.

Facilitate Engagement to Support Effective Relationships

Communication is imperative to success. OAR should support both NCI staff and advocates throughout the engagement process as needed. OAR should use the above-mentioned guidance to support NCI staff members in further developing promising approaches for how they engage advocates. OAR should facilitate communication, helping all parties come to agreement about the wide array of areas where miscommunication can create potential problems. These areas include participant roles, responsibilities, and expectations; knowledge and skills necessary for full participation; orientation and harmonization into existing projects; potential confidentiality

and conflict-of-interest issues; training needs and mentoring opportunities; desired outcomes; and more.

Specific opportunities for feedback should be provided during the early part of the engagement process and throughout the activity. This feedback should specify the elements of the engagement that work well and those that need improvement. Private conversations between the researcher, the advocate, and OAR staff should be encouraged as an effective way to clarify and address areas of confusion or concern as early as possible.

NCI staff should consider advocate engagement at the beginning of all projects and seek advocate involvement as early as is appropriate as well as throughout the life cycle of the project. This process enables advocates to be fully engaged and maximizes their contributions. Projects frequently include multiple opportunities across various roles for advocate partners.

To make evidence-based decisions about the best ways to engage advocates, NCI must track and evaluate its research advocate engagement process. Such an evidence base will allow NCI to continue as a leader in identifying best practices and innovations in how advocates are engaged in research. NCI does not currently track and evaluate all advocate engagements because many advocates are engaged through processes independent of OAR.

No formal feedback system exists to provide advocates or staff with timely guidance that would allow them to engage more effectively and learn from mistakes or miscommunications. Evaluation has been inconsistent and, when it has occurred, has been informal and retrospective, centered on participant satisfaction alone. Such evaluation has not included process improvement or the identification of outcomes related to engaging advocates in the research process. Without the in-depth understanding that comes from compiling and evaluating a comprehensive set of data, not only are decisions about how, when, and where to engage advocates not fully informed, but it is difficult to define a clear model of success for advocate engagement.

NCI should consider several common issues when designing an approach to tracking and evaluating advocate engagement. First, evaluation data must be either qualitative or quantitative. Anecdotes are not independently sufficient to inform programs. Data should be collected prospectively and longitudinally to evaluate long-term trends in research advocacy as well as individual engagements. Finally, because there will be a dearth of data available in the beginning of this effort, a broad set of baseline data should be collected.

Common technical systems should be identified and employed throughout the engagement process to allow for comprehensive information tracking. Because evaluation needs will change over

Recommendation 6
Monitor
Track and Evaluate the Advocate Engagement Process to Implement Continuous Improvements and Develop an Evidence Base around Engaging Advocates in Research

time and data sets will grow with continual evaluation, NCI will need to be flexible in its approach to evaluation.

Evaluate Each Individual Activity for Quality Control and Feedback

Assessing each advocate activity provides a mechanism for immediate quality control and participant feedback, allowing the system and participants to identify and address successes and problems immediately and adjust as new developments and insights arise. NCI staff and advocates should complete formal, but not burdensome, evaluations of their experiences at the end of each engagement. OAR may consider additional opportunities for evaluation, such as annual reviews, for activities in which advocates are engaged on a longer-term basis.

Evaluate the Effectiveness of the Advocate Engagement Process

Tracking and evaluation should monitor how effectively each component of the process is working and promote efficiency in the advocate engagement process. For example, how well prepared was the advocate to successfully engage in the activity, as judged by the advocate and NCI staff? Efforts should be made to track data related to cost, time, utilization rates, attrition, participant satisfaction, success rates, and other metrics related to each function of the process. Additional monitoring needs could include effectiveness of and advocate satisfaction with available training and resources; NCI staff satisfaction with availability of advocates who have the desired qualifications; and status of the NCI advocate pool, including diversity, recruitment success, and other issues.

Evaluate the Outcomes of Engaging Advocates

Throughout its work, the ARWG uncovered a need for improved understanding of the impact of engaging advocates in scientific activities. Accordingly, NCI should collect data on advocate activities to improve understanding of the spectrum of outcomes associated with advocate engagement and develop an evidence base. These data also will allow the Institute to understand what roles advocates play at NCI and determine how these roles can be maximized and may change over time. NCI should use data collection mechanisms that avoid favoring previously identified outcomes and demonstrate what effect an advocate had on the outcome of an activity. Such data would be able to answer such questions as: Which results would not have occurred if the advocate were not present? How did the advocate change the group dynamic or group conversation? What were the advocate's independent contributions?

Explore Correlations between Advocate Skill Sets and Activity Outcomes

Each advocate brings a unique set of skills and experiences to the research process. Understanding how these skills and experiences promote success within different activities is important for engaging

the right advocate at the right time. NCI should collect data to identify potential correlations between the knowledge and skills an advocate exhibits and the reported outcomes of the advocate's involvement. Understanding the most successful advocate-activity matches would allow NCI to enhance advocate training and develop the skill sets shown to lead to positive outcomes most often. For each advocate, NCI might consider collecting data on profession, professional skill sets, formal education, scientific training, advocacy training, involvement with advocacy organizations, primary advocacy activities, experience in NCI activities, and volunteer experience.

A comprehensive tracking and evaluation process will allow NCI to see that advocates are being engaged and enable OAR to anticipate the types of skill sets and knowledge that will add value to NCI activities. Collecting longitudinal data on specific skill sets requested by NCI staff also will inform NCI's outreach plan and enable OAR to recruit advocates who meet specific NCI research needs.

NCI is uniquely positioned to identify models and concepts that set the standard for effective advocate involvement in the research process and to distinguish individuals and organizations who exemplify this standard. Recognizing and promoting successful advocate-researcher collaborations support retention efforts by highlighting the benefits of engaging advocates in the research process as well as best practices for doing so. It also shows appreciation for those involved in the process.

Although some advocates have been individually recognized by NCI staff members, there has been no systematic effort to recognize advocates or NCI staff. Efforts related to other recommendations, such as effective assessment and matching of advocates, also are likely to increase the retention rate of both NCI staff and advocates. Promoting successful involvement of advocates in NCI programs will enhance understanding, transparency, and trust of NCI in the advocacy community.

Retain Highly Qualified Advocates

Best practices to retain advocates should be infused throughout the engagement process. Advocate retention must be balanced with the needs to recruit more diverse advocates and to consistently recruit advocates new to NCI. Some of the best practices that are likely to retain advocates include timely and effective communication with advocates before, during, and after engaging them; providing advocates with more opportunities to be involved; increasing transparency about where and how advocates are engaged across NCI; providing external incentives, such as access to journals, formal training opportunities, teleconferences, or webinars, which not only allow advocates to stay connected to NCI and other advocates but also increase advocates' skills even when they are not working on a specific project; and recognizing the contributions made by advocates and, specifically, how their involvement benefits the research process and the patients it serves.

Recommendation 7
Promote
Develop a Process to Retain and Recognize Advocates and NCI Staff who Successfully Work Together and Communicate These Successes across the Research Community

Encourage the Use of Promising Approaches for Advocate Engagement among NCI Staff

The ARWG identified strategies to encourage NCI to effectively engage research advocates, many of which will occur as the recommendations are implemented. For example, identifying highly qualified advocates and effectively preparing them for each project can help encourage participation—as can providing support and guidance to staff and researchers and acknowledging and addressing barriers.

Promote Advocate-Researcher Collaborations

Stories of successful engagements should be developed and disseminated to the advocacy community through such mechanisms as the OAR website, *NCI Nealon Digest,* and conferences. Advocates should be encouraged to share their own stories with OAR. Communicating where and how advocates have been engaged at NCI will help promote the Institute's engagement of advocates and may address concerns that advocates are not being engaged. NCI should develop a new OAR webpage that highlights past advocate involvement, features current and upcoming opportunities, and details recent projects in which advocates participated. This information would help advocates better understand how NCI engages advocates and the types of individuals being engaged.

NCI can increase the knowledge and utilization of advocates by developing such materials as case studies about successful engagements and using them to inform NCI staff about the process for and benefits of engaging advocates. These success stories can be shared through presentations at brown bag sessions and in NCI and NIH media, such as the *NCI Cancer Bulletin,* the *NIH Catalyst,* the *NIH Record,* the *NIH Health Beat,* and NIH podcasts. An award for successful staff-advocate collaborations presented during the NIH or NCI award ceremonies would not only recognize individuals who have set a standard for effective engagement but also promote the idea of involving advocates in research in a venue supported by leadership. Recognizing staff and researchers for the time and effort spent involving an advocate is important and should be formalized whenever possible.

I n summary, promoting effective advocate involvement in the cancer research process allows for the collective experience of scientists and advocates working together to help enhance research outcomes. NCI's long history of support of cancer research advocacy has made it a leader in this field.

The ARWG's recommendations build on the prior success of NCI and identify new opportunities to enhance that success. A number of the elements contained in the recommendations are innovative in their approach. Of note are:

■ Evaluation tools developed alongside each component of the system,

- Ongoing consultation with external collaborators and stakeholders on the specifics of each recommendation area, and

- The ability to regularly report on advocate engagement in NCI activities through tracking and evaluation efforts.

Implementation of the ARWG's recommendations will occur in a phased approach, based on available resources. Because advocacy engagement is not a new enterprise for NCI, these recommendations will be implemented as enhancements to the existing advocacy engagement infrastructure.

OAR will coordinate and manage this implementation. Advocates currently engaged in NCI activities will be asked to participate in the testing of enhancements put in place as a result of these recommendations. The ARWG is encouraged that OAR can begin to implement these recommendations immediately. The ARWG noted that without a centralized system of implementation and process of evaluation, these recommendations are likely to be less effective.

Although the ARWG recommendations are primarily intended to meet the specific needs of NCI, the ARWG hopes that its report will be applicable across multiple research environments. In this way, it can serve as a guide for how the broader research community can engage research advocates in their efforts to further scientific discovery and, ultimately, reduce the burden of disease and improve lives.