Advocate⇔Researcher Working Together Toolkit

Updated July 2017

Tools developed to assist researchers and advocates seeking to work together on research grant projects. These tools were created and are regularly updated by Susan G. Komen 's Advocates in Science (AIS):

- ARMs (Advocates, Researchers, Mentors) Initiative Taskforce
- AIS – Steering Committee

This **Toolkit** includes:

- Building advocate⇔researcher relationships to strengthen research
- Timeline for Full Application Development
- Guidelines for Advocate Involvement in Komen-Funded Research *(Also available at:* Guidelines for Advocates)
- Patient Advocate Involvement Plan – Suggestions for Researchers
- Writing a Lay Abstract
- Komen Scholar Testimonials *(available separately upon request)*
    - *Clinical*—Bryan Schneider, MD; Director, IU Health Precision Genomics Program. Indiana University Melvin and Bren Simon Cancer Center
    - *Basic/Translational*—Geoff Wahl, Ph.D.; Daniel & Marina Lewis Chair & Professor Gene Expression Laboratory, Salk Institute, CA
    - *Basic/Translational*—Danny R. Welch, Ph.D., Professor & Chair, Dept. of Cancer Biology, The University of Kansas Cancer Center
    - *Community Health*--Anna Maria Napoles, Ph.D., MPH; Professor, Dept. of Medicine & Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco, CA
    - *Community Health*—Amelie G. Ramirez, D.Ph.; Professor & interim Chair, Dept. of Epidemiology & Biostatistics, The University of Texas Health Science Center, San Antonio, TX
- Resources for advocates *(Please refer to: http://sgk.mn/2lBg8vC)*
    - Patient Advocate Letter of Support/Commitment
    - Patient Advocate Bio Template & Examples

Last fall's "The Call to ARMs: Advocates, Researchers, Mentors" webinar can be view at*: https://youtu.be/wUEi-RN2kwc* This webinar focuses on the Grant Implementation and Completion phases of the grant project.

Building advocate⇔researcher relationships to strengthen research

Intent: Komen seeks to encourage researchers to develop *productive, lasting* relationships with patient advocates

Why: All Komen-funded grant mechanisms require at least one advocate to be *actively* involved to (1) ensure patients' perspectives are integrated into the research decision-making process, and (2) energize science to find cures. It also facilitates advocates becoming well-versed in the science of breast cancer and complexities of research. This empowers them to be more effective community ambassadors for research and contributors to the research enterprise.

How: Advocates are a critical part of the research/mentor team. They should be involved in every step of the research project, including the planning, implementation and public dissemination of the research.

Who: Advocates, involved as mentors or as a part of the research team, should:

- Have a strong personal connection to breast cancer (i.e., breast cancer survivors or "co-survivors," such as a close family member or personal caregiver.) Their experience better informs the research decision-making process by providing the unique and valuable perspectives on what it's like in "real life" to be a cancer survivor or co-survivor.
- Be broadly connected to other breast cancer survivors/co-survivors, to assure a **knowledgeable, *collective* perspective** (vs. an individual perspective) is integrated into the scientific dialogue and decisions most impactful and important to patients/survivors. A broad, collective perspective helps advocates more effectively share and identify what's meaningful to patients, and what will resonate (or not) with patients.

Key Points:

- **Outcome:** The goal of including an advocate(s) is to **build a long-term, mutually beneficial, and productive relationship to enable both a better understanding of the research by the advocate, and a better understanding of how the research can and should impact patients for the researcher**. The purpose of requiring an advocate goes far beyond just including a person's name on a grant to meet this requirement. They must be actively involved.
    - Key to building an effective relationship is treating all parties with mutual respect and professionalism; seeking to first understand the perspectives of the other team members; and assuring consistent communications and timely follow-through.
    - *Side note:* In training grants, although the Grantee/Principal Investigator and the Advocate Mentor are the key players in this relationship, the Lead Mentor's visible support and guidance in securing and developing this relationship definitely impacts its success.

- **Co-Learning:** The goal is to help advocates understand the research process and outcomes; AND the PI and research team to learn more about what really matters to patients/survivors and the urgency of finding answers for patients. *(Taken from PCORI Patient Engagement Rubric)*

- **Budget:** Reasonable compensation of advocates is allowed for most grant mechanisms when advocates perform services that would otherwise be a contracted expense. Compensation may be in the form of salary, per-hour compensation, or honoraria. Advocates may be compensated for their out-of-pocket expenses, i.e., travel, parking, printing, registration fees, etc. If possible, advocates should be provided access to relevant literature or articles.

1. Developing the Grant Proposal		
Applicant/PI	**Advocate Mentor**	**Lead Mentor***
Responsibilities: • As you begin your grant proposal (at least 4-6 weeks prior to due date), personally call and/or email a "qualified advocate" (3rd bullet in opening comments) to invite them to work with you in your project. • If you don't know an advocate: 1) visit with your Lead Mentor to identify who might be a good match for your project; 2) if your institution has an advocate group, get in touch with that group's leadership; and/or 3) contact *(advocatesinscience@komen.org)* to request a list and bios of Advocates in Science (AIS), who have expressed an interest in working with researchers. • When you invite an advocate to work with you, describe your research and the particular project you are seeking funding for. Offer to send any drafts that have been started. Ask the advocate what they are interested in learning. • Facilitate at least one meeting (preferably several) involving the advocate and you as the grant is being developed. The first meeting should occur as early as possible in the process (preferably shortly after the RFA is release and prior to any substantive work on the design or narrative). • If you are in close physical proximity, try to arrange for an in-person meeting. If not, by phone or skype will work. • During the first meeting, come to a mutual agreement with all key players regarding: (1) the roles and responsibilities of each of the parties; and (2) a timeline for review and feedback on the proposal at several stages of development. Invite your Lead Mentor to participate in this foundational meeting. *(See Guidelines for Advocate*	**Responsibilities:** • Become familiar with the project by reading the project proposal, work with PI to define expectations, and be honest about your ability to commit the time and attention needed before committing to being involved. • Review project goals with PI, ask questions, and discuss project meetings and expectations. Discuss ideas for how to contribute as a team member. This should include setting adequate timeframes for you to be able to thoughtfully review the proposal and share your input with the PI. • Share with your PI, your experience in research advocacy and connection to other survivors/co-survivors and/or patient advocacy organizations (e.g., Komen & others). • Try to make the PI aware of generally held concerns and hopes among survivors/co-survivors/advocates regarding the topic at hand or the field in general. This helps the PI better understand what patients' believe have greatest relevance and impact. • Learn the jargon *(while you help teach the PI how to avoid it when communicating to people not in the research/medical fields)*. • Timely and thoughtfully review the grant proposal before it is submitted. Pay particular attention to the Lay Abstract and Impact sections to assure they are easily understood and convey why this research is important to patients. *(See "Writing a Lay Abstract" see pages 13-14)* • Also review and sign off on the	**Responsibilities:** • Encourage and facilitate the PI's connection with a patient advocate(s). • Be a role model for developing mutually respectful, mutually beneficial and lasting advocate⇔researcher relationships. If needed, coach the PI on working effectively with the advocate. Assure the proposal has included or addressed the advocate's key concerns and comments. • Work with PI in selecting, recruiting & effectively involving an appropriate advocate(s) to work with him/her as a mentor/research team member. • Welcome the advocate to the team. Express and demonstrate your appreciation for their involvement. • Share your background. Discuss your goals, role and expectations related to your mentee, his/her career, and this grant.

Involvement (pages 9-10), Patient Advocate Involvement Plan (pages 11-12), & PI Timeline for Full Application development (page 8). Komen Scholars testimonials available upon request LGraves@komen.org) • Optimally, go over your ideas for the proposal before writing it, and see if the advocate has input, especially about patient impact and the plan for their involvement. • Assure the advocate(s) has at <u>least 2 weeks</u> to review and comment on the draft proposal, especially the Lay Abstract and Impact sections to assure they are understandable and compelling to the broader survivor/co-survivor community. *(See "Writing a Lay Abstract" document; see pages 13-14)* • Co-develop and have the Advocate Mentor sign off on the plan for their role. (*Ideas for advocate involvement, see page 11-12)* • If a clinical trial is involved, be sure to solicit the advocate for ideas on tissue donation issues, sampling frequency, etc. • Encourage the advocate(s) to always ask you questions if he/she doesn't understand something or would like more information. ***<u>Post-submission communications</u>*** • Let the Advocate Mentor & Lead Mentor know when the grant is submitted. Offer to share the final proposal. • Share the outcome of the review with the Advocate Mentor & Lead Mentor. Share the comments received for everyone's improvement. If invited to submit a full app or if funded, mutually discuss ideas for improving. • Thank the Advocate Mentor for their support and involvement.	described plan for your advocate role. • Discuss and provide comments and suggestions as needed. • Where possible, your input should reflect positions likely to be held by a wide variety of patients and advocates. When presenting highly personal perspectives, identify them as such. • Supply your bio, and if requested, a letter of support. *(Letter of Support guide, see page 15-16)* • Discuss what you can do to help plan and then disseminate information about the research and its results to the breast cancer survivor/co-survivor /advocacy community. *(See Guidelines for Advocate Involvement (pages 9-10), Patient Advocate Involvement Plan (pages 11-12), & PI Timeline for Full Application development (page 8). Komen Scholars testimonials available upon request LGraves@komen.org)* • Where possible, identify activities where the PI can visit with breast cancer patients, caregivers and advocates. ***<u>Post-submission communications</u>*** • After the grant is reviewed, arrange to meet with the PI. Discuss how it did, what the comments were, and how to improve it. Participate in a revision, if that is required. • If revised, read the revision and discuss again to be sure your suggestions were considered/included.	

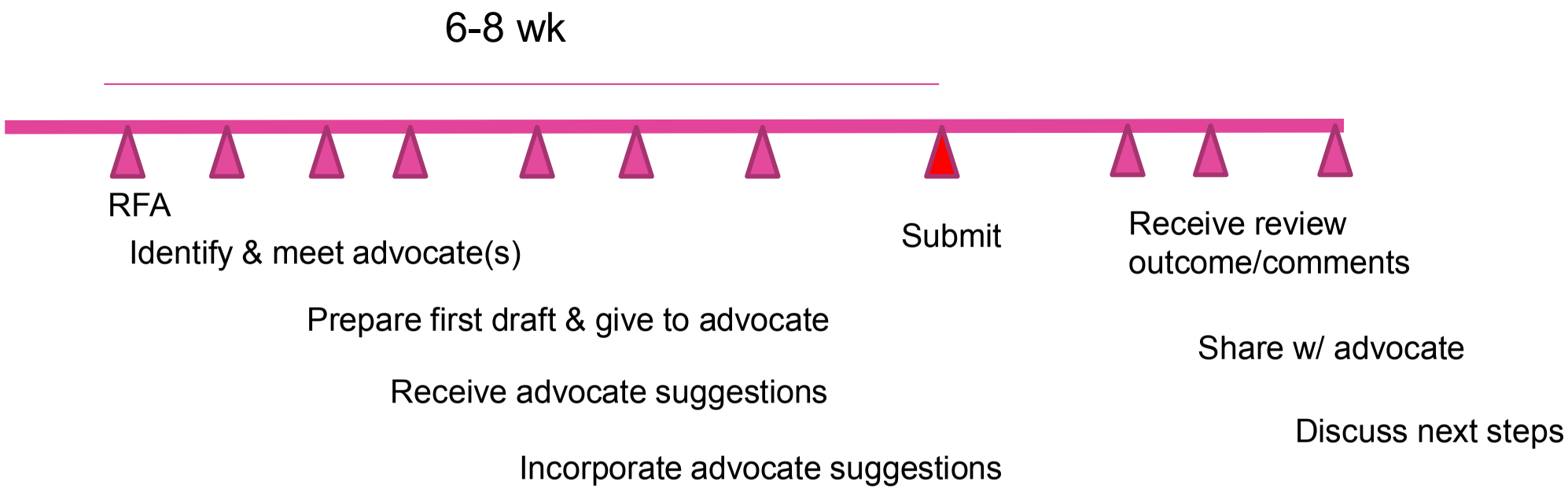
2. Project Implementation		
Grantee/PI	**Advocate Mentor**	**Lead Mentor***
Responsibilities: • Conduct a post-award meeting with the research/mentor team, including the advocate. Discuss, update and agree upon roles, responsibilities and timelines. *(See Guidelines for Advocate Involvement (pages 9-10), Patient Advocate Involvement Plan (pages 11-12), & PI Timeline for Full Application development (page 8). Komen Scholars testimonials available upon request LGraves@komen.org)* • Recommend and assist the advocate in accessing relevant background reading, websites or other information that would be helpful to them in better understanding your research or field of research, and are suitable to their level of understanding. • Introduce the advocate(s) to your research team/other mentors. • Invite the advocate to tour your lab/clinic. • Ensure the advocate is included in email communications with the team or mentor committee. • Conduct periodic meetings over the course of the project, perhaps monthly for the first 1-2 quarters then quarterly after that. Keep everyone in the loop on the project's progress and need for revisions. • Include the advocate in writing the annual project reports to Komen, especially, the portions related to their involvement. • Invite the advocate to project and/or related meetings. You may also wish to include the advocate in social gatherings of the scientific team. • Invite advocates to educational events they might be interested in. • "Having Coffee is a great idea!" or getting together outside of lab/clinic meetings is a great	**Responsibilities:** • Become informed about the science. But do not expect to be an expert—i.e., read recommended background materials; ask the PI for assistance if you have difficulty understanding the basics. • Never be afraid to ask if you don't understand. The only stupid question is the one you don't ask. Because then you don't learn...and they won't learn how to communicate in ways people can understand. • Manage your expectations: ➢ The role of the advocate can and will vary even within the life of a grant. ➢ In Basic/Foundational research, what you can add probably won't be obvious. ➢ You won't always be able to offer something. ➢ What's important is to better understand and gain an appreciation of the research process .and how slow and difficult progress can be. It's REsearch. You search and then you re-search What is learned in the process can be as important as whether or not it actually proves out as expected. ➢ Seek to understand the importance of the research being done and how it might be able to ultimately impact patients. ➢ *(See Guidelines for Advocate Involvement (pages 9-10),Patient Advocate Involvement Plan (pages 11-12), & PI Timeline for Full Application development (page 8). Komen Scholars testimonials available upon request LGraves@komen.org)* • Actively participate, as feasible (in person or by teleconference), in meetings & discussions, especially	**Responsibilities:** • Participate in the initial meeting with the advocate where roles, responsibilities and timelines are updated and agreed to. • At least quarterly, check-in with the advocate and PI to see how they are working together. • Review the annual project reports to Komen. • Mutually discuss what you believe is working well and what could work more effectively. What could all the parties do to enhance the relationship?

venue for discussing questions and complex issues. • Actively engage the advocate, soliciting their input and requesting them to follow-up on aspects of the project/research where they may have questions or feel they can contribute. • Ensure the advocate is involved in planning for all project-related clinical trials; including but not limited to determining the schema, eligibility requirements, on trial requirements, and out-of-pocket costs; and reviewing recruitment plans, Informed Consent, patient-related documents/processes, and any other patient education or information materials. • Mutually discuss with the advocate what you both believe is working well and what could work more effectively. What could you each do to enhance the relationship?	those focusing on matters important to patients. • Pick your battles—i.e., distinguish between issues you feel are extremely important versus those about which you might have an opinion but not a strong one. • Be flexible and work to understand the other person's perspective when you disagree. • Participate in writing the annual project reports to Komen, especially those sections related to your involvement with the project. • Offer to review grants, abstracts, presentations, posters and articles being developed by investigators involved in the project. • Actively participate in the planning for all project-related clinical trials. This could include determining the schema, eligibility requirements, on trial requirements, and out-of-pocket costs; and reviewing recruitment plans, Informed Consent documents/processes, and any other patient education or information materials. • Proactively volunteer for activities you think would be useful (i.e., informally surveying other advocates about a difficult issue). • If possible, offer to connect the PI with the broader patient/survivor/co-survivor community. Invite him/her to join you for events or to possibly present at a meeting. • Provide timely feedback on any documents you are asked to review. Be sure you know and adhere to deadlines. • Provide to and solicit feedback from the PI and other advocates to assist you in improving your effectiveness and impact. • Mutually discuss what you believe is working well and what could work more effectively. What could you each do to enhance the relationship?	

3. Project Completion		
Grantee/PI	**Advocate Mentor**	**Lead Mentor***
Responsibilities: • Involve the advocate in analyzing the results what was learned, how does/may it ultimately impact patients. Discuss future RFAs that might build on the study's work. • Involve the advocate in the final project report to Komen. • Involve the advocate in writing a plain language summary of the study results. • Involve the advocate in planning and disseminating the results especially in sharing the results with the public, the patient/survivor/co-survivor community; and, if there is one, the local Komen affiliate community. This can also take the form of working with the advocate to contact local newspapers to participate in and be recognized in press releases. • Consider (if resources exist for travel) inviting advocate to co-present posters/presentations with you. • Consider involving the advocate in writing publications (contributing author). • Meet with the advocate and Lead Mentor to debrief on the mentorship experience to determine what worked well, what was learned, and how to improve future advocate⇔researcher relationships. • Participate in Komen's process to review and enhance advocate⇔researcher relationships.	**Responsibilities:** • Assist in analyzing the results what was learned, how does/may it impact patients, and how will the research's work be moved forward or used in future grant applications. • Assist in developing the final project report to Komen. • Assist in planning for and disseminating the results. • Focus on communications to the broader community and providing information that helps people better understand the research process and this research's ultimate impact on patients' ability to feel, function and survive. • Be an ambassador for research. Share information that helps people better understand the research process and this research's ultimate impact on patients. • Meet with the PI and Lead Mentor to debrief on the mentorship experience to determine what worked well, what was learned, and how to improve future advocate⇔researcher relationships. • Participate in Komen's process to review and enhance advocate⇔researcher relationships.	**Responsibilities:** • Participate in the discussions with the advocate regarding the analysis of the study; manuscript development, authorship and acknowledgments; disseminating the results; and how to identify and consider future RFAs that might build on the study's work. • Meet with the advocate and PI to debrief on the mentorship experience to determine what worked well, what was learned, and how to improve future advocate⇔researcher relationships. • Participate in Komen's process to review and enhance advocate⇔researcher relationships.

**** Lead Mentor** - The Applicant/PI must propose ONE Lead Mentor. The primary purpose of the Lead Mentor is to provide the research, scientific, clinical, management, and leadership guidance necessary to foster the Applicant/PI's career advancement and the successful development of the proposed research project. The Lead Mentor should be committed both to the research training of the Applicant/PI and the proposed research project.*

Advocate⇔Researcher Working Together
Timeline for Full Application



Guidelines for Advocate Involvement in Komen Funded Research

Komen is strongly committed to including breast cancer research advocates in the design and implementation of Komen-funded research projects. Advocates provide essential patient perspectives and are real life experts on living with breast cancer 24/7.

This guide, developed by Susan G. Komen® Advocates in Science (AIS), suggests ways to effectively involve advocates in Komen-funded research. For more assistance in identifying trained advocates or questions about involving advocates in a research project, please contact advocatesinscience@komen.org.

Who can serve as a research advocate?

- Advocates who have been diagnosed with breast cancer; have a known genetic mutation; or have a strong personal connection or experience with breast cancer (i.e., family, friend, caregiver).
- Advocates must represent a collective breast cancer patient/survivor perspective (i.e., insights and experiences of other breast cancer survivors).
- Advocates should be actively involved in the broader breast cancer research advocacy community.
- Advocates should have a basic understanding of the science of breast cancer and the peer review research process.
- Advocates are not required to be an AIS member. Information about AIS and joining AIS is at http://sgk.mn/2lBg8vC

Identifying a research advocate

- The AIS program has advocate members across the US and in other countries. For help in finding an advocate, contact our program staff at advocatesinscience@komen.org.
- Ask for recommendations from collaborators, who have worked with research advocates.

How research advocates can be effectively involved in research

- Research advocates should be involved early (and often) in developing a research project.
- Researchers and advocates should develop a mutually beneficial relationship. For example: researchers educate advocates about their project; advocates educate researchers about patients' concerns and experiences. For a copy of the "Building advocate⇔researcher relationships to strengthen research" toolkit, contact advocatesinscience@komen.org.
- Advocates can review early drafts of applications to identify possible patient concerns. Do not wait until the last minute to work with an advocate. Be respectful of her/his time, commitment and expertise.
- Advocates can provide regular input about the project. As advocates learn more about a research project, they may identify additional ways to assist. Their collective patient perspectives help focus the research on what matters to patients.
- Researchers and advocates should communicate regularly to keep informed about the project's progress. Use email, phone calls, and team meetings – whatever works best for the researcher and the advocate.
- Advocates work closely with researchers to ensure terminology used is clear for all audiences. For a copy of "Writing a Lay Abstract," contact advocatesinscience@komen.org.
- Tax dollars, donors and investors fund research. Effectively sharing results with the general public benefits the breast cancer research field. Patients and funders want to know how your research may ultimately improve patients' care and survival.
- Advocates and researchers should work together to determine the advocate's role and responsibilities.
- For testimonials from Komen Scholars about how they have involved advocates, contact advocatesinscience@komen.org.

What roles can a research advocate fill on a research project?

Advocates have a wide range of skills, experience and knowledge to enhance a research team's work. Advocates may have specific suggestions on how they can contribute to a project. Some possibilities are described below. For a copy of the "Patient Advocate Involvement Plan – Suggestions for Researchers," contact advocatesinscience@komen.org.

Possible Advocate Roles in the Application's Development

- Provide feedback on a project's impact on patients by identifying the research's translation potential (i.e., how meaningful or important the outcome(s) could be to patients).
- Work with researchers to develop and review the application's Innovation and Significance section. Advocates can help assure this section highlights the project's importance to breast cancer patients and their families.
- Work with the research team to develop and review the lay abstract and other portions of the application to assure terminology is understandable to a general, non-scientific audience; and conveys the project's potential overall impact on breast cancer research and patient care.
- Help define their role during the project's implementation, annual reporting, and articulating the impact of the research findings.

Possible Roles of Advocates in Research Project Implementation

- Work with researchers to develop plain language summaries highlighting the project's potential impact on patients.
- Be a community ambassador speaking about the research and its potential significance to patients. Public speaking engagements are an excellent opportunity for advocates and researchers to co-present. Refer to Komen Scholar Testimonials for further guidance. Contact advocatesinscience@komen.org for these testimonials.
- Assist researchers in connecting with their local Komen Affiliate and the broader breast cancer community.
- Work with researchers to create educational materials, events, webinars and teleconferences for local, regional, and national groups and organizations to inform them about the research and its importance to breast cancer patients.
- Participate in research project team's update/planning meetings, seminars and other events essential to the project's success.

Possible Roles of Advocates in a Clinical Project (involving clinical trials)

- Work with the project team to design and develop the clinical trial to identify potential barriers to accrual and/or retention.
- Help develop patient-focused education materials. For instance: co-author study brochures to give a short, easy-to-understand description of the clinical trial.
- Review the clinical trial's proposed design. Provide a breast cancer patient point-of-view regarding eligibility criteria, frequency of invasive testing, costs, logistical requirements, and patient feelings when deciding whether to participate.
- Help define how the patient experience will be monitored. For example, developing patient reported outcomes (PROs) or questionnaires; or identifying topics for personal interviews. As appropriate, provide assistance and support throughout the study accrual period, including ways to address recruitment or retention issues.
- Help develop and review the language used in Informed Consent forms, questionnaires, and other documents for patients. Advocates help maximize readability and sensitivity to patient concerns and needs.
- Review the Informed Consent process to assure patients have ample opportunities to discuss and truly understand the nature of the research, what they are expected to do, the risks/benefits, their costs, and what information they will receive on the clinical trial's progress, completion, and results.

Possible Roles of Advocates in a Training Project for Junior Faculty, Postdoctoral Researchers, and Graduate Students

- Advocates can help make a research project more patient-focused and likely to positively impact the lives of breast cancer patients. Researchers can learn more about what is critical to patients.
- Provide a patient point-of-view in mentoring committees and project presentations. Advocates add a different, more poignant perspective to your project and its relevance to patients.
- Review publications and communications. Advocates help clarify why the research is critical and relevant to patients and the community.

How often should the research team meet with the research advocate(s) listed in the application?

- Frequency of meetings should be driven by the project plan and the schedules of the people involved.
- The application should include mutually agreed upon details on how often the research team will meet with the advocate(s) and the type(s) of meetings that will occur.

Should research advocates be compensated?

Compensation will vary depending on the extent and nature of the advocate's involvement.

- Reasonable compensation is allowed when advocates perform services that would otherwise be a contracted expense. Compensation may be a salary, per-hour compensation, or honoraria.
- Offer to cover out-of-pocket expenses incurred to attend meetings and conferences identified in the project application (e.g., travel expenses, conference fees, mileage, parking, etc.). All meetings and conferences must be directly related to the proposed training or research plan.
- Researchers and advocates should agree on compensation and expenses to be reimbursed. These should be identified and supported in the budget justification section of the application, especially project and/or consulting fees.

Advocates must provide a Letter of Support and Biosketch

- A biosketch (no more than 5 pages in an NIH or other acceptable format) should be submitted for advocates listed as key members of the research team. Examples are provided on the Komen website at http://sgk.mn/2lBg8vC.
- All advocates, listed on your project, must submit a Letter of Support. Their letter should identify their level of commitment to and role(s) in the project. An example is provided on the Komen website at http://sgk.mn/2lBg8vC.

Patient Advocate Involvement Plan -Suggestions for Researchers

OVERVIEW

Komen has a strong commitment to including breast cancer research advocates to provide the patient perspective in the design and implementation of research projects funded through the Komen Research Grant Program. A Patient Advocate Involvement Plan section must be completed in the Application Narrative. For assistance in identifying trained advocates or to discuss including advocates in the proposed research project, contact advocatesinscience@komen.org.

Below are some ideas and suggestions to consider as you develop your Patient Advocate Involvement plan. It is not necessary to include every item below, just the items that are relevant to your project. Refer to the "Guidelines for Advocate Involvement in Komen Funded Research" document for additional information.

Research Involvement

- Describe how an advocate provided input while you were writing your application. For example, mention if they reviewed and edited sections of the application. Discuss whether it was valuable and how it helped you strengthen the application especially with regard to the potential impact your research will have on patients.
- Describe the advocate's role as a member of your Mentor Committee (if applicable), and whether the advocate will be invited to attend all Mentor Committee meetings.
- Describe if the advocate will be invited to attend any meetings/seminars where research described in your proposal will be presented. Discuss how often these will occur.
- If your research project includes a clinical trial, describe how the advocate will assist you in developing the trial design. Discuss how the advocate may assist you in identifying patient-focused benefits and/or risks for participants, and potential challenges or barriers to accrual.
- Describe how you will update the advocate on progress of your research. It is suggested that updates occur at least annually (or more often) to seek input about how the work that has been completed so far is relevant to patients. Also you can ask the advocate for feedback about what is planned for the next year.

Community Involvement

- If the advocate is involved with the local Susan G. Komen Affiliate, they could assist you in making a connection with the Affiliate and offer opportunities to participate in community events, like presenting your research as a poster or talk to convey the significance of your work for the patient community.
- Describe how the advocate could assist you in developing and presenting your research in plain language.

Experience of Patient Advocate Mentor

- Describe the strengths the advocate will bring to your research. You can find information about their previous experiences in their biosketch.
- If you have prior experience working with the advocate, describe your experience and what was gained during collaboration.

Personal Impact on your Career Development

- Add a personal statement on why involving a patient advocate in your research and training will impact your individual understanding of breast cancer.
- Describe how working with a patient advocate may impact your future work.
- Describe how you will continue involving patient advocates even after Komen funding has ended. Describe how your experience with an advocate may influence your future career in breast cancer research.
- In what way will having an advocate mentor influence your career decisions about continuing to conduct breast cancer research?

Writing a Lay Abstract…

A **patient-focused summary** about your research

- ***What do you hope to prove?***
- ***Why is it important to patients?***
- ***Why do you think it will work/be successful?***
- ***How may it ultimately impact how people feel, function, or survive?***

*Writing an abstract in plain, everyday language is **not easy**.*

Especially, when you regularly use scientific or medical language.

Key things to consider:

Think about your audience.

Use language they can easily understand and relate to. *How would you explain your research to your mom in a way she can understand what it is and why it is important?*

- ***Chose common, everyday words***. Avoid research or medical jargon and acronyms. When you use these terms everyday, you take them for granted. You forget others many not understand or relate to what they mean. If you use jargon, define it in plain language and provide a "real life" example, analogy, or visual aid.

- ***Keep it short and to the point!*** Try to keep sentences to 15 words or less, paragraphs brief, and overall text concise. If a sentence has conjunctions (i.e., but, however, and) or semicolons, break it into two sentences. And it's okay to start a sentence with these words.

Organize and filter content with your reader's needs in mind. Try to see it from their perspective. *How would you explain it to a patient in a respectful way that gains their understanding?*

Use clear and descriptive headings.

- Start with a title or ***short paragraph highlighting what your research is intended to discover.*** It should be in clear, everyday terms. The reader shouldn't have to go on a scavenger hunt to figure out what this abstract is about.

- Use ***meaningful headings*** to describe the content of different sections or paragraphs. This gives your readers "road signs" to help them easily navigate through your abstract. "Road signs" can walk the reader logically through:
  - ✓ *What are you proposing to do?*
  - ✓ *Why are you doing it?*
  - ✓ *Why do you think it will work?*
  - ✓ *What patient-focused difference do you hope it will make?*

Include only the information your audience really needs to know. *What is essential to helping them understand what I am doing and why?*

Put long lists of items into bulleted lists where practical. Use numerical lists when the items need to be understood or completed in order.

Use complete sentences. Every sentence should have a noun and a verb.

Use appropriate punctuation & grammar to enable the reader to easily read and comprehend what you are trying to explain.

Spell check!

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When describing your ***intended outcome or impact, avoid using conclusive, unqualified terms.***

- Stating your research "will/would/could" is misleading. It suggests that if you do this research it will be so. If you know what the outcome will be, the research is not necessary.

- Use qualifiers "If this research is successful", "It may", "This research seeks to determine whether or not," etc.

When you think you have the final document

- ***Use fresh eyes when you edit or proofread it.*** Set the document aside and proofread it again after taking a break.

- ***Read it aloud***. This is one of the best ways to discover errors, incomplete thoughts, or incorrect grammar.

- ***Take it for a test drive!***

    - Ask someone unfamiliar with the research who is not from the medical or research field, to read your abstract. This is one of the quickest ways to discover what you have not made clear.

    - Ask them: *Please describe in your own words, what you think this research is about. And why it is important.*

Additional Tools/Resources

Much of this information has been taken from:

The PRISM Readability Toolkit.

- *http://bit.ly/2qDMLGu*
- This is a free resource of the ***Program for Readability In Science and Medicine (PRISM)***. The purpose of the initiative is to improve the quality of print materials provided to research participants. However, it is also an excellent resource for those wishing to write readable, patient-centered research documents, such as "lay abstracts."

Transcend Readability Tools

- *http://bit.ly/2sUVcmU*

Readability Formulas

- *http://bit.ly/1hDLqZ4*

Checking grammar

- ***GrammarCheck***
    - *http://www.grammarcheck.net*
- ***Grammarly***
    - *https://www.grammarly.com*

Susan G. Komen offers some excellent guidance and links on:

- Grant writing - *http://sgk.mn/2sUVuKz*

Example

Original Text (12th grade)
This brochure includes tips that can help you prevent errors in your surgery and make sure that you have the correct procedure performed at the correct place, or site, on your body.

Plain Language (6th Grade)
Mistakes sometimes happen during surgery. Doctors may do the wrong surgery or operate on the wrong part of your body. Or they operate on the wrong person.

From ***Plain Language = Better Health Care***, Transcend website *http://bit.ly/2rSmqcC*

Patient Advocate Letter of Support

OVERVIEW

As a part of the researcher's application, your letter of support will demonstrate your enthusiasm and support for the proposed research project. Your letter can help strengthen the application by providing the advocate perspective on why the research is important to patients. It is an important piece of the application package that researcher and advocate peer review panelists find very helpful.

Below are some ideas and suggestions to consider as you develop your letter of support. Be sure that the content of your letter is tailored to the project. It is not necessary to include every item below, just the items that are relevant to the project you are supporting. Some additional idea generators are contained in the "Guidelines for Advocate Involvement in Komen Funded Research" document.

Format

- Use personal letterhead if you have it. If not, include your name, address, phone # and email address.
- Maximum of two pages, include page number if more than one page
- Date the letter
- Address the letter to Susan G. Komen, Dallas, TX
- Salutation: Dear Komen Reviewers
- Sign the letter and either fax it or submit a scanned copy to the researcher; your signature is needed in the submission

Introductory Paragraph

- Include the name of the researcher and the title of the application
- Indicate your commitment to serving as an advocate on the project

Body of Letter (2-4 paragraphs)

- Research
    - Give a short one- or two-sentence summary of the research
    - Describe why you believe the research is important to patients
- Your Advocacy Experience
    - Survivorship
    - Advocate involvement (organization, your title if you have one, areas of focus)
    - Involvement with the local Susan G. Komen Affiliate, including any community events
    - Reasons why you are interested in supporting breast cancer research
    - Experience that you have in collaborating with researchers
    - Experience that you have in serving as an advocate or consumer reviewer in the peer review process (Komen, DoD, other)
- The Researcher
    - Describe how you have worked with the researcher to-date on this project
    - If you have worked with the researcher before, briefly describe your experience
    - Comment on the strengths of the applicant that you have observed, and indicate confidence in their ability to conduct the research
- Your Role if Project is Funded
    - Discuss how you will continue to provide input on patient perspective throughout the project, and in

what way(s)
  - Describe the nature of your role and the frequency of your meetings as a member of the researcher's Mentor Committee.
  - Describe if you will attend and/or co-present with the researcher at any meetings/seminars where research results will be shared. Include comments regarding where the presentations or meetings would occur, and how often they might happen.
  - Discuss how you will keep current on progress of the research, including nature and frequency of meetings.
  - Discuss how you will assist the researcher in connecting with Komen and the breast cancer community.

Closing Paragraph

- Discuss your perception of the impact the research will have on patients, short- and long-term
- Describe why you believe that the research should be conducted and why is should be funded
- Restate your commitment to support and collaborate with the researcher on the project
- Thank Komen for their consideration of the application