



Advocate ↔ Researcher

Working Together

Toolkit

THE UNIVERSITY OF KANSAS

CANCER CENTER

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Introduction

This toolkit was created by Susan G. Komen's Advocates in Science (AIS). With Komen's permission, Patient and Investigator Voices Organizing Together (PIVOT) have adapted the toolkit for use at The University of Kansas Cancer Center (KUCC). Additional content was also developed and added by The University of Kansas Medical Center (KUMC). The purpose of this toolkit is to assist researchers and advocates seeking to work together on research projects.

Building relationships between advocates and researchers is a primary key to strengthen research. KUCC Research guidelines to assist in this relationship are presented as well. Involvement plans and defined roles of advocates and researchers are important. Letters, abstracts, templates and more help with this successful relationship.

Other organizations have provided researchers and advocates helpful resources. These are indicated in the Additional Resources section at the end of the toolkit. Though not specific to PIVOT, they are included in this toolkit to promote cohesiveness.

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Building advocate↔researcher relationships to strengthen research

Intent: PIVOT seeks to encourage researchers to develop productive, lasting relationships with patient research advocates

Why: Advocates bring reality to research by offering a patient perspective on previously overlooked features of clinical trials, patient care and the complex burdens patients face. Researchers benefit by learning about patients' cancer experiences, which can inform their research priorities and studies. These partnerships empower advocates to be more effective community ambassadors for research and contributors to the research enterprise.

How: Advocates are a critical part of the research team. They should be involved in every step of the research project, including the planning, implementation and public dissemination of the research. Please refer to the chart on page 6 or the [PCORI Patient Engagement Rubric](#) for more details and examples of advocate roles along the research process.

Who: Advocates should...

- Have a lived experience of cancer as a survivor, co-survivor or pre-vivor. 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 cancer communities to assure they offer a **knowledgeable, collective perspective** (vs. an individual perspective) to the scientific dialogue. A broad, collective perspective helps advocates more effectively express what is 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. Partnering with an advocate goes far beyond just including a person's name on a grant to meet a requirement; the advocate must be actively involved in the research decision-making process. The 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.
- **Co-Learning:** The goal is to help advocates understand the research process and outcomes; AND the research team to learn more about what really matters to patients/survivors and the urgency of finding answers for patients. (*Excerpt 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 should be compensated for their out-of-pocket expenses, i.e., travel, parking, printing, registration fees, etc. If possible, advocates should be provided free access to relevant literature or articles.

Researcher Guidelines for Involving Advocates in KUCC Research

This guide suggests ways to effectively involve patient research advocates in KUCC research with support from PIVOT. For more assistance in identifying trained advocates or for help with involving advocates in a research project, please contact pivot@kumc.edu.

Who can serve as a patient research advocate?

- Advocates must have a lived cancer experience as a survivor, co-survivor or pre-vivor. The advocate's cancer experience should match the specific cancer type, cancer stage or population being studied. For example, a researcher studying metastatic cancer should seek an advocate with a lived experience of metastatic cancer as a patient or family/friend caregiver.
- Advocates must represent a collective patient perspective, i.e. the insights and experiences of other cancer survivors.
- PIVOT recommends patient partners complete the PIVOT Certification training prior to working as a patient research advocate on a research project. This training prepares advocates by building skills and providing a basic understanding of the science of cancer and the peer review research process.

Identifying a patient research advocate

- For help in finding an advocate, contact PIVOT at pivot@kumc.edu.
- Ask for recommendations from collaborators who have worked with patient research advocates..
- If you are already working with a patient advocate, PIVOT could still provide support. Contact PIVOT at pivot@kumc.edu.

How patient research advocates can be effectively involved in research

- Researchers and advocates should develop a mutually beneficial relationship. This allows researchers to educate advocates about their project while advocates educate researchers about patients' concerns and experiences.
- Advocates should be involved early (and often) in developing a research project This may include helping to hone the research question. Advocates can review early drafts of applications to identify possible patient concerns. Remember, do not wait until the last minute to work with an advocate. Be respectful of his/her 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.
- Researchers and advocates should communicate regularly 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.
- Tax dollars, donors and investors fund research. Effectively sharing results with the general public benefits the field of cancer research. Patients and funders want to know how your research may ultimately improve patients' care, quality of life and survival.
- Advocates and researchers should work together to determine the advocate's role and responsibilities.

How often should the research team meet with the 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.

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

Advocates have a wide range of skills, experience and knowledge to enhance a researcher's work. Advocates may have specific suggestions of how they can contribute to a project. Some possibilities are described below. See also Patient Advocate Involvement Plan – Suggestions for Researchers on page 5 of this toolkit.

Possible Advocate Roles in the Application's Development

- Provide feedback on a project's impact on patients by identifying the translation potential of the research, 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 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 cancer research and patient outcomes.
- Help define their role in the project's implementation, annual reporting, and in 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 provide an excellent opportunity for advocates and researchers to co-present.
- Assist researchers in connecting with their cancer advocacy organizations and the broader 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 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, including but not limited to eligibility criteria.
- 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 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 or evaluating 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 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 research and its relevance to patients.
- Review publications and communications. Advocates help clarify why the research is critical and relevant to patients and the community.

Advocates should provide a Letter of Support and Biosketch

- PIVOT advocates require interaction with the researcher prior to providing a letter of support. It is imperative to build these discussions into the timeline for the research proposal.
- Advocates are encouraged to submit a Letter of Support. Their letter should identify their level of commitment to and role(s) in the project. Instructions and examples are provided on page 11 of this toolkit.
- 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. See page 13 for tips on writing a biosketch.

Budget Template for Patient Advocate Participation

Should patient research advocates be compensated? Yes. Compensation demonstrates that all members of the research team being valued as contributors to the research project and expresses gratitude of the value, worth, fairness of treatment with others involved in the research project to. Fair compensation will vary depending on the extent and nature of the advocate’s involvement/contributions to the research.

- Fair financial compensation is allowed when advocates perform services that would otherwise be a contracted expense. Compensation may be a salary, per-hour payment, or honoraria and should reflect the advocate’s role in the research project, skills and capabilities.
- All out-of-pocket expenses incurred to attend meetings and conferences identified on the project application (e.g. travel expenses, conference fees, mileage, parking, etc.) should be covered. 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.
- Budgets should include payments for research advocates. In addition, although incentives are not required, they may help you in engaging a larger patient population.
- PIVOT can help with compensation during proposal development.

After a project is funded PIVOT recommends the following compensation for patient research advocates partnering on a study:

Payments	
Hourly payment	\$20-\$50
Per meeting	\$25-\$50
Per day (participation in all day or an event-related activity)	\$100-\$200
Per year (longer term advisory team patient partners/members)	\$2000
Travel expenses	Reimbursed according to guidance provided prior to incurring costs (bus/taxi, airfare, per diem, mileage, food receipts, permission to purchase alcohol, etc.)
Parking	Reimbursed according to guidance provided prior to incurring costs (valet fee, airport options, validation of ticket in specified lots, etc.)
Incentives	
Public recognition or certificate	No cost

Conference/meeting fee waiver	To encourage participation locally, regionally and nationally, offering conference and meeting opportunities for enrichment
Conference/meeting attendance as collaborator	Costs covered as would be the case for other attendees from the research team (travel, lodging, parking, food, per diem, etc.)
Meals	Meals appropriate to the hour of the meeting; offer healthy snacks and beverages regardless of hour
Include participant on listservs that provide information about educational opportunities (like lectures; Grand Rounds)	No cost
Small appreciation gifts and cards	~\$10 value or less

Patient Advocate Involvement Plan: Suggestions for Researchers

OVERVIEW

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 relevant to your project. Refer to the chart on the next page 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 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 a local cancer advocacy organization, the advocate could assist you in connecting with this organization. They may identify opportunities to participate in community events, like presenting your research as a poster or talk to convey the significance of your work to the patient community.
- Describe how the advocate could assist you in developing and presenting your research in non-technical language.

Researcher and Advocate Responsibilities Along Project Stages

1. Developing the Grant Proposal	
Researcher	Patient Advocate
<p>Responsibilities:</p> <ul style="list-style-type: none"> • <u>As you begin your grant proposal (at least 4-6 weeks prior to due date)</u>, personally call and/or email a qualified advocate to invite them to work with you in your project. • If you don't know an advocate, contact PIVOT at pivot@kumc.edu for help with identifying someone. • When you invite an advocate to work with you, describe your research and the particular project. 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) with the advocate as the grant is being developed. The first meeting should occur as early as possible in the process (preferably shortly after the Request for Application (RFA) is released 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, arrange video conference or phone meetings. • 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. • Optimally, go over your ideas for the proposal before finalizing 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. <i>(See Writing a Lay Abstract on page 14)</i> • Co-develop and have the advocate sign off on the plan for their role. • If a clinical trial is involved, be sure to solicit the advocate for ideas on tissue donation issues, eligibility criteria, sampling frequency, etc. • Encourage the advocate(s) to always ask you questions if he/she doesn't understand something or would like more information. • Contact PIVOT when additional support is needed. 	<p>Responsibilities:</p> <ul style="list-style-type: none"> • Become familiar with the project by reading the project proposal. Work with PI (Principal Investigator) 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 time frames for you to be able to thoughtfully review the proposal and share your input with the PI. • Share with the PI your experience in research advocacy and connection to other survivors/co-survivors and/or patient advocacy organizations • 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. Share with the PI when they are using jargon. This can help them to avoid it when communicating to people not in the research/medical field. • 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. <i>See Writing a Lay Abstract (page 14).</i> • Also review and sign off on the 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. <i>See Patient Advocate Biographical Sketch (page 13) and Letter of Support guide (page 11).</i> • Contact PIVOT when additional support is needed.

Researcher and Advocate Responsibilities Along Project Stages

- Discuss what you can do to help plan and then disseminate information about the research and its results to the cancer survivor/co-survivor /advocacy community. *See Guidelines for Advocate Involvement (page 3) and Patient Advocate Involvement Plan (pages 6).*
- Where possible, identify activities where the PI can visit with groups of cancer survivors and co-survivors with experience relevant to the research e.g. cancer type, pre-vivor to metastatic, rural/ urban, minority group etc.

Post-submission communications

- Let the Advocate & PIVOT know when the grant is submitted. Offer to share the final proposal.
- Share the outcome of the review with the advocate. Share the comments received for everyone's improvement. If invited to submit a full application or if funded, mutually discuss ideas for improving the proposal.
- Thank the advocate for their support and involvement.

Post-submission communications

- After the grant is reviewed, arrange to meet with the PI. Discuss how it did, what the comments were, and how to improve it.
- If a full application is submitted, work with the PI to assure patient concerns are addressed and patient impact is clear.

Researcher and Advocate Responsibilities Along Project Stages

2. Project Implementation	
Researcher	Patient Advocate
<p>Responsibilities:</p> <ul style="list-style-type: none"> • Conduct a post-award meeting with the research/mentor team, including the advocate. Discuss, update and agree upon roles, responsibilities and timelines. • Invite the advocate to tour your lab/clinic. • 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. • Ensure the advocate is included in email communications with the team. • 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 the funder, 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 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? 	<p>Responsibilities:</p> <ul style="list-style-type: none"> • Never be afraid to ask for clarification if you don't understand. The only stupid question is the one you don't ask. • Become informed about the science. But do not expect to be an expert— i.e., read recommended background materials and ask the PI for help if you have difficulty understanding the basics. • Manage your expectations: <ul style="list-style-type: none"> ➤ 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. Understand and gain an appreciation of the research process and how slow and difficult progress can be. It's "RE"search. You search and then you re-search again. 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. <i>See Guidelines for Advocate Involvement (pages 2-4) and Patient Advocate Involvement Plan (pages 5-6).</i> • Actively participate, as feasible (in person or by teleconference), in meetings and discussions, especially 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 the funder, 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.

Researcher and Advocate Responsibilities Along Project Stages

- Actively participate in the planning for all project-related clinical trials. This could include determining 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.
- Pro-actively volunteer for activities you think would be useful, e.g. 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?

Researcher and Advocate Responsibilities Along Project Stages

3. Project Completion	
Researcher	Patient Advocate
<p>Responsibilities:</p> <ul style="list-style-type: none"> • Involve the advocate in analyzing the results, what was learned, and how it may ultimately impact patients. Discuss future RFAs that might build on the study’s work. • Involve the advocate in the final project report. • 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 any relevant community/cancer advocacy organization, if applicable. 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 the advocate to co-present posters/presentations with you. • Consider involving the advocate in writing publications (contributing author). • Meet with the advocate and the PIVOT project manager to debrief on the partnership experience to determine what worked well, what was learned, and how to improve future advocate ↔ researcher relationships. You may want to use the Frontiers Principles of Partnership Self-Assessment Tool on page 16 to assist in guiding this discussion. 	<p>Responsibilities:</p> <ul style="list-style-type: none"> • 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 the funder. • 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 researcher and PIVOT project manager to debrief on the experience to determine what worked well, what was learned, and how to improve future advocate ↔ researcher relationships. You may want to use the Frontiers Principles of Partnership Self-Assessment Tool on page 16 to assist in guiding this discussion.

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 the content of your letter is tailored to the project. It is not necessary to include every item below, just the items relevant to the project you are supporting.

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 the funder. Ask your research partner for this information.
- Salutation: Dear (Funder) Reviewers
- Sign the letter and either fax it or submit a scanned copy to the researcher. Your actual signature is required in the letter.

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
 - Your story or lived experience with cancer
 - Advocate involvement (organization, your title if you have one, areas of focus)
 - Involvement with PIVOT or a cancer advocacy organization, including any community events
 - Reasons why you are interested in supporting cancer research
 - Your experience in collaborating with researchers
 - Your experience 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 a collective 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 any relevant cancer communities

Closing Paragraph

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

Example

An example Research Advocate Letter of Support can be found [here](#).

Patient Advocate Biographical Sketch (Biosketch)

Adapted from:

<https://ww5.komen.org/GetInvolved/Participate/BecomeanAdvocate/BecomeanAdvocateinScience.html>

OVERVIEW

A biographical sketch—also known as a biosketch—is an abbreviated resume or Curriculum Vitae summarizing your cancer advocacy, professional and educational accomplishments, publications and research advocacy experience. It highlights important aspects of your advocacy experience, training, skills and interests to help researchers determine if you are a good fit for a particular project.

Format

Advocate biosketches may be submitted in any format. You are encouraged to develop one that could be used more broadly. Many funders require biosketches to be in a National Institutes of Health (NIH) format and no more than 5 pages.

Examples

- A blank NIH Word Template, Instructions, and Samples can be found [here](#).
- A sample Biosketch with notes to help guide the completion of each section can be found [here](#).
- An Example of a New Advocate Biosketch can be found [here](#).
- An Example of an Experienced Advocate Biosketch can be found [here](#).

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 way that is respectful and 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 to give 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.

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

- Stating your research “will/would/could” is misleading and conveys to the reader 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://www.nhlbi.nih.gov/crg/pdf-docs/ghchs_readability_toolkit.pdf
- 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://www.transcend.net/library/tools.html>

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

- Grant writing - <http://ww5.komen.org/ResearchGrants/ReviewProcess.html>
- Involving advocates in your research - http://ww5.komen.org/uploadedFiles/Content/ResearchGrants/GrantPrograms/FY14AdvocateInvolvementGuidelines_FINAL.pdf

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://www.transcend.net/library/health/PL_BetterHealth.pdf



Additional Resources

- **Frontiers Principles of Partnership Self-Assessment Tool** (see next page)
This tool can be useful for researchers to self-assess their readiness to engage patient research advocates. Team members can also use it at the end of the project to evaluate their research partnership experience.
Available at <https://goo.gl/G5uvfV>
- **PCORI Engagement Rubric for Applicants**
The rubric gives examples of patient research advocate roles along project stages.
Available at <https://goo.gl/ij9MEC>
- **Komen's "The Call to ARMs: Advocates, Researchers, Mentors" Webinar**
This webinar focuses on partnership during the grant implementation and completion phases of a project.
Available at <https://goo.gl/xci2Ct>

THE UNIVERSITY OF KANSAS

CANCER CENTER

Frontiers: Heartland Institute for Clinical and Translational Research
Community Partnership for Health

Principles of Partnership Self-Assessment Tool

The purpose of this self-assessment is to determine the extent to which research affiliated with Frontiers has abided by the Community Partnership for Health’s guiding principles of partnership. For each principle stated below, please state the extent to which you believe it has been put in place or adhered to. If the item is under development or not yet started, the CPH staff and resources are available to assist you and your team, so please write in a comment that will help us point you to opportunities, partners and resources. You can also reach us through a direct request found at www.frontiers/kumc.edu/cph. Please specify the area (e.g., Community Impact or the numbered component) in your request for support services.

	Completely in place/Completely adhered to	Partially in place/Partially adhered to	Under development/In process	Not yet started/ Not adhered to
Community Impact				
1. Established shared values, vision and mission among all parties				
2. Balanced community and research needs for the mutual benefit of all partners				
3. Agreed on measurable objectives and outcomes				
COMMENTS:				
Trust and Respect				
4. Engaged in open communication; demonstrated willingness to listen to others				
5. Valued differences of partnership members				
6. Performed all activities with cultural sensitivity and humility				
7. Strived to develop a common language				
COMMENTS:				
Commitment and Responsibility				
8. Maintained ongoing participation in meetings and activities				
9. Have clear understanding of partners expertise, strengths and roles				
10. Adhered to timeline completion of designated tasks				
11. Developed processes to ensure that priority areas are revisited on an ongoing basis				
COMMENTS:				

Acknowledgement: This evaluation tool is a modification of a product of the UMass Worcester Prevention Research Center that was supported by Cooperative Agreement Number U48DP001933 from the Centers for Disease Control and Prevention. (KK/AW 3/14)

Equitable Decision-Making				
12. Established shared operating principles				
13. Developed processes for establishing priorities				
14. Established processes for conflict resolution				
COMMENTS:				
Information and Data Gathering and Sharing				
15. Included patient/ community-relevant objectives and maintained fidelity to associated evaluation plans				
16. Informed all partners of findings and accomplishments in relevant projects and initiatives				
17. Disseminated work in progress and accomplished to multiple stakeholders in meaningful language and venues				
COMMENTS:				
Co-Learning and Capacity Building				
18. Built upon identified strengths and assets				
19. Provided learning opportunities for partners in identified priority areas				
20. Developed opportunities for patients/ community members to participate and develop marketable knowledge and skills				
COMMENTS:				
Shared Recognition				
21. Shared public/community recognition of partnership's accomplishments				
22. Created opportunities for shared authorship in reports and presentations for scientific and community audiences				
COMMENTS:				
View Partnership as an Evolving Process				
23. Adhered to processes for identifying and inviting new partners				
24. Recognized that people's priorities and time availability change over time				
25. Included periodic feedback and evaluation processes from all partnership stakeholders				
COMMENTS:				

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