

Lineberger Researcher Resources

ASCO Young Investigator and Career Development Awards

Submitting your Grant

Know what the RFP is asking for regarding engagement of patient or community advocates.

[ASCO FY24 RFP](#) information

If you need an advocate for your grant fill out [THIS FORM](#)

- You will be asked to submit information about you, the project, what the advocate will need to do, how much time the advocate will need to commit, time-frame, compensation.
- After you submit the form, an email with the information you provided will be sent to the LEAP email list (over 40 advocates) asking for interested and available advocates.
- You will be sent contact information about the advocates who are interested.

If an advocate is involved, a Letter of Support from the advocate will need to be included.

- Review this [LOS Guidance](#) yourself
- Write a first draft of a “letter of support” about your project for the advocate
- Send the draft LOS and the LOS guidance to the patient advocate for them to edit. Include the guidance you used as a reference. Ask them to add their specific experience information, review the letter, add more information, etc. Then ask for a signed letter to submit for the grant.
- Note: Most advocates will not have ‘letterhead’, so don’t ask for an LOS on letterhead.

Other Resources on Patient engagement

[Working with a Patient Advocate](#) video cast on the ASCO resource website, by Patty Spears, UNC Lineberger Patient Advocate.

Review other resources on the [ASCO Grant Resources](#) website

[Patient Engagement in Cancer Research from a Patient Perspective](#) publication written by Patty Spears, UNC Patient Advocate

Attached to this document:

- Advocate LOS Guidance
- How to write a Lay Abstract Guidance
- ASCO Language of Respect
- Short patient engagement presentation for LCCC researchers (updated 7/28/23)
- COE Coaching Guide for Research Programs – 2020

Patient Advocate Letter of Support

OVERVIEW

A letter of support is often required as a part of the researcher's grant application. Your letter of support should 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 reviewers find very helpful.

Below are some ideas and suggestions to consider as you write 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.

NOTE: You can ask the researcher to provide a draft letter for you to edit and fill in your personal information.

FORMAT

- Use personal letterhead if you have it. If not, include your name, address, phone # and email address at the top right or bottom (under your signature) of your letter.
- Ask if there is a page limit. If there is no page limit, stay within 1-2 pages, include page number if it is more than one page.
- Date the letter
- Address the letter to the funder or to the researcher (depends on application instructions), but either is usually OK.
- Sign the letter.
 - Insert a 'picture' of your signature. (sign a piece of paper, take a photo of it with your smartphone, insert the photo (.jpg) as your signature. Send your signed letter back to the researcher (.doc or .pdf)
 - Print, sign and scan to send pdf back to the researcher

INTRODUCTORY PARAGRAPH

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

BODY OF LETTER (2-4 paragraphs)

Talk about your Advocacy Experience

- Experience with cancer
- Advocate involvement (organization, your title if you have one, areas of focus)
- Involvement with community organizations and outreach events
- Reasons why you are interested in supporting breast cancer research
- Experience that you have in collaborating with researchers
- Other advocacy experiences

Talk about the Research

- Give a short one- or two-sentence summary of the research
- Describe why you believe the research is important to patients
- Researcher can help with this section by providing a first draft for you to edit.

Your interaction with 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

- How will you continue to provide input on patient perspective throughout the project, and in what way(s)
- Note 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 how often you will meet with the researcher and their team.
- Discuss how you will assist the researcher in connecting with the 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 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

Writing a Lay/Public Abstract

A 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 improve how people feel, function, or survive?



What You Need to Know

Think about your audience

Use common, everyday words
Keep it short and to the point

Avoid medical jargon and acronyms

Keep sentences to less than 15 words and brief paragraphs.

Split 1 long sentence into 2 short sentences

Organize and filter content

Use clear descriptive headings
Include only what your audience needs to know
Use bulleted lists where practical

Start with a good title or short descriptive paragraph highlighting the importance of your research

Use meaningful headings

Logically walk the reader through your research

Other things to keep in mind

Use complete sentences
Use appropriate punctuation and grammar
Spell check

Every sentence should have a noun and a verb

Appropriate grammar makes it easier to read and understand

Misspellings are not good

Writing about impact

Be precise and specific
How will your research improve the lives of patients
If successful what will it lead to a solution for an overarching research challenge

Do not use vague words like impact and or affect

It may take more than one sentence to be more specific

Tell the reader why this research is important to this field of research

When you think you are done...

Proofread with fresh eyes
Read it aloud
Take it for a test drive – give it to a non-scientific person to read

Resources

[Hemingway](#) – check for readability

[Grammarly](#) – check for readability

[NCI Dictionary](#) – definitions of common cancer terms

ASCO[®]

The Language of Respect

Health care professionals working in the field of oncology have respect for patients, families, and colleagues as a core tenet of practice and research. Unfortunately, the language of oncology does not always convey or represent that level of respect. In language about patients, this is likely not a result of intent, but an issue of shorthand communication, phraseology that made its way into modern parlance many years ago, and a lack of awareness.

Evidence¹ has shown that there is inconsistency in demonstrating appropriate respect in the forms of address used to introduce faculty at the ASCO Annual Meeting. It is essential that all faculty are introduced and addressed in a professional manner; the form of address should not be different based on gender, race, ethnicity, or seniority.

The American Society of Clinical Oncology and its leadership are committed to developing new norms that reflect appropriate respect for patients, families, advocates, and health care providers. To that end, we are providing this summary guidance to our faculty with some critical points to keep in mind and put into practice – at our Meetings and in all communications. There is certainly more language that may be considered disrespectful and/or offensive. Our goal is to begin the journey and to continue to evolve.

Directive: Demonstrate Respect for Patients and Families

Do not Blame Patients

- Patients do not fail therapies; therapies fail patients.
 - *Avoid:* “Six patients failed to respond to [study drug].” **or** “Six patients failed treatment.”
Instead: “[Study drug] did not yield a response in six patients” **or** “Six patients had tumors that did not respond to [study drug].”
 - *Avoid:* “## number of patients were screen failures.”
Instead: “## number of patients were not eligible for the study.”

Respect the Role of the Patient

- Doctors do not manage patients; doctors manage disease/therapies.
 - Use the word “treat” when referring to patients, as in “the experimental drug was used to treat six patients.”
 - Only use the word “manage” when referring to the disease, as in “steroids were used to manage brain metastases.”

Do not Dehumanize Patients

- Do not use a disease or condition on its own to refer to a patient.
 - Do not use the adjective form of diseases or conditions alone to refer to a person, as in “12 diabetics were included.”
Instead: “12 patients with diabetes were included.”
- Do not use language that implies that the patient is the disease.
 - *Avoid:* “The study included 250 EGFR mutants...”
Instead: “The study included 250 patients whose tumors had EGFR mutations” **or** “The study included 250 patients with EGFR-mutated tumors.”
 - *Avoid:* “The patient progressed...”
Instead: “The cancer/tumor progressed...” **or** “The patient experienced disease progression...”

Use Accurate Language Throughout the Session

- “Risk reduction” is the appropriate term for strategies that lessen the risk of developing cancer but do not necessarily prevent it.

Directive: Demonstrate Respect for Colleagues

- All chairs, faculty, presenters, and panelists, including patients and advocates, who have a doctoral degree (e.g., MD, PhD, ScD, PharmD) should be introduced and addressed as Dr. Full Name or Dr. Last Name.
- All other chairs, faculty, presenters, and panelists (including patients and advocates) should be introduced and addressed as Mr./Ms. Full Name or Mr./Ms. Last Name.
- These forms of address should continue during Q&A and panel discussions, regardless of whether the faculty know one another. The key element is consistency of address among all panelists.
- We will ask all faculty to commit to use of a professional form of address when accepting their session invitations. Chairs will be asked to briefly reiterate this policy with all faculty in their session immediately prior to the start of the session.

¹ [Evaluating Unconscious Bias: Speaker Introductions at an International Oncology Conference](#)

Narjust Duma et al., Journal of Clinical Oncology 2019 37:36, 3538-3545



LINEBERGER COMPREHENSIVE
CANCER CENTER



UNC
CANCER CARE

Including patient advocates in research

Patty Spears

Research Patient Advocate

UNC Lineberger Comprehensive Cancer Center

UPDATED: July 28, 2023

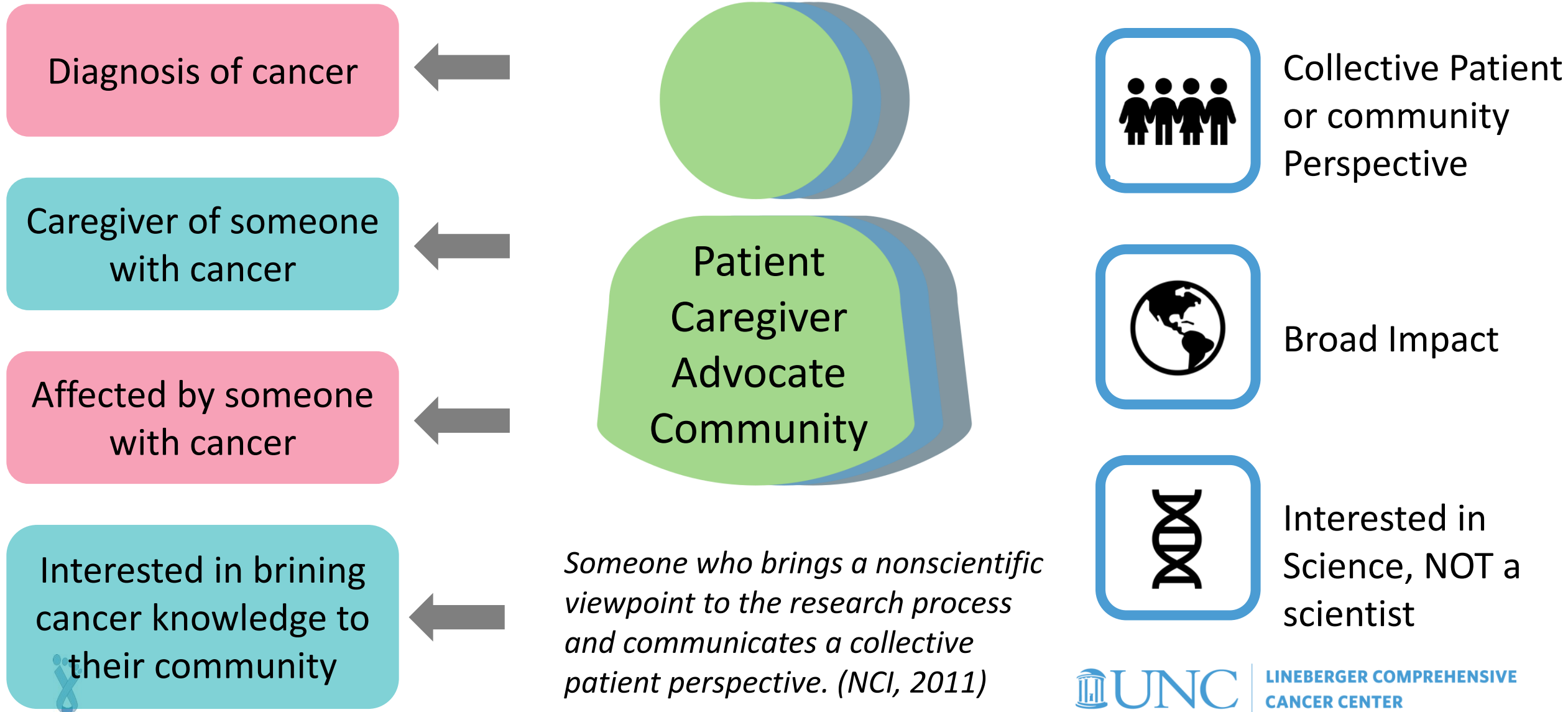
Contact me @

paspears@med.unc.edu

[@paspears88](https://twitter.com/paspears88) (twitter)



Who is a Research Patient Advocate?



Adding the patient voice to cancer research

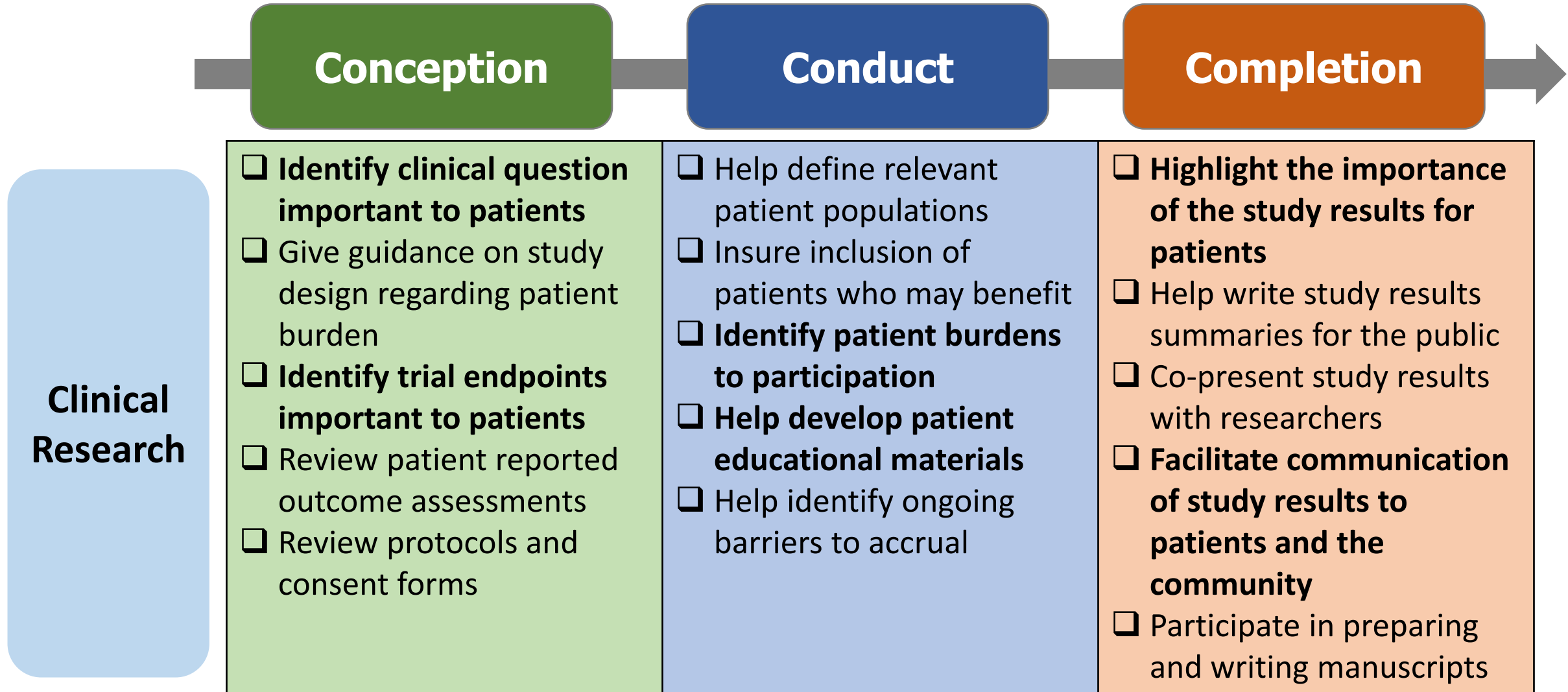
- **Putting some effort into specific ways advocates can be involved** to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient.

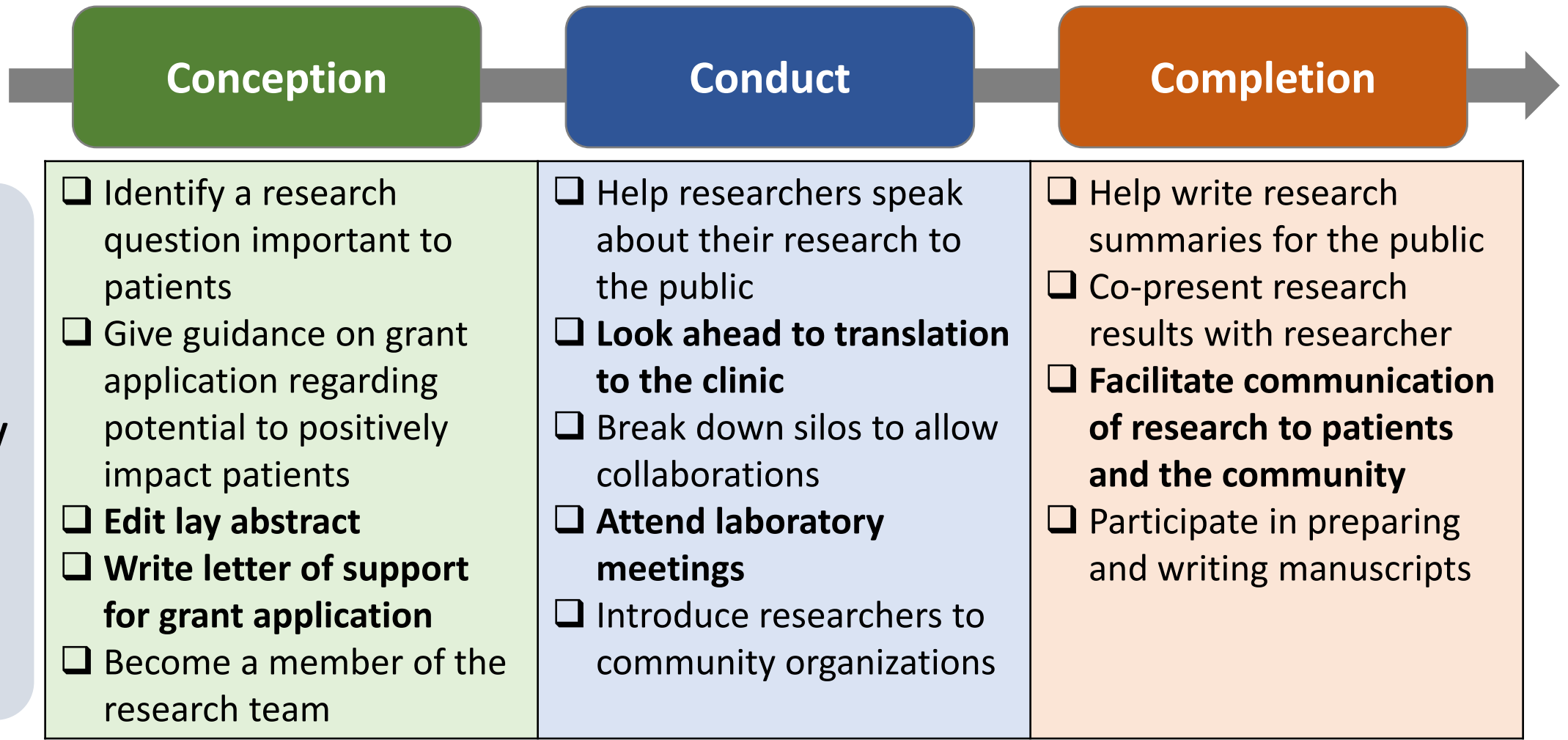
1 Clinical trial development: ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.

2 Laboratory research: enhance research to be more patient centered and community focused. Engagement can instill a sense of urgency in all research throughout the course of the research project.

3 Population science research: provide the patient and community perspective on implementation feasibility and to help communicate the importance of the research to the broader community.







Laboratory Research

Conception

Conduct

Completion

- Identify a research question important to patients
- Give guidance on grant application regarding potential to positively impact patients
- Edit lay abstract**
- Write letter of support for grant application**
- Become a member of the research team

- Help researchers speak about their research to the public
- Look ahead to translation to the clinic**
- Break down silos to allow collaborations
- Attend laboratory meetings**
- Introduce researchers to community organizations

- Help write research summaries for the public
- Co-present research results with researcher
- Facilitate communication of research to patients and the community**
- Participate in preparing and writing manuscripts



Population
Science
Research



Engaging patients adds urgency to **RESEARCH**

- **Early and often** – throughout the entire research process
- Patients understand the **burden** of their disease
- Patients know what is **important** to them – they know what is patient centric and what is not
- Patients can help you know more about the patient experience
- Patients can help you communicate your research to the public
- In clinical research
 - Patients can help design clinical trials that will **accrue and retain** participants
 - Patients can help identify **barriers** and potential accrual problems before trials open, saving time and money and ensuring the completion of trials



EXAMPLE #1 – APPLYING FOR A GRANT (GENERAL)

WHEN



You have an idea for a research project

You identified a funding opportunity!

Steps to engagement

The funder requires engagement of a patient or advocate!

Why?

Who?

What?

How?

Present your project to the advocate for general feedback.

Any requirements?
LOS or Biosketch

Review from patient perspective:

- Lay Abstract
- Impact Statement
- Personal Statement
- Etc...

Submit your proposal!

Let the advocate know and send them a copy of the final application

Notification of Funding

Let the advocate know the outcome



EXAMPLE #1 – APPLYING FOR A GRANT (LCCC)

WHEN



Request an Advocate
Fill out THIS FORM

Steps to
engagement

Why?

Who?

What?

How?

You have an idea for a research project

You identified a funding opportunity!

The funder requires engagement of a patient or advocate!

Even if not 'required' you can still boost your grant by adding an advocate!

Present your project to the advocate for general feedback.

Zoom!

Any requirements?
LOS or Biosketch

Review from patient perspective:

- Lay Abstract
- Impact Statement

Send to advocate with enough time to review!

Submit your proposal!

Let the advocate know and send them a copy of the final application

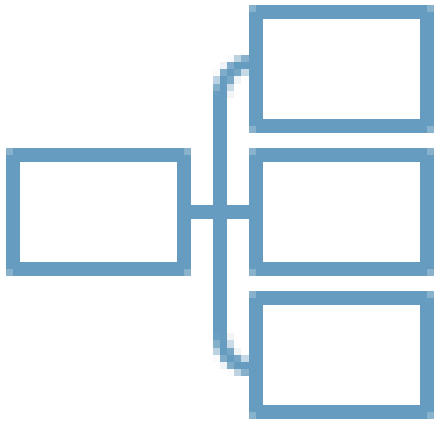
Notification of Funding

Let the advocate know the outcome

EXAMPLE #1A – PATIENT INVOLVEMENT IN CLINICAL RESEARCH



Meet with the advocate about the project and next steps



Review
Concept

Protocol & Consent Review
Intervention planning

Conduct of
the study

End of the
study

- ✓ Identify clinical question important to patients
- ✓ Give guidance on study design regarding patient burden
- ✓ Identify trial endpoints important to patients
- ✓ Review patient reported outcome assessments
- ✓ Review consent forms

- ✓ Facilitate communication of study results to patients and the community



EXAMPLE #1B – PATIENT INVOLVEMENT IN BASIC & TRANSLATIONAL RESEARCH



Meet with the advocate about the project and next steps



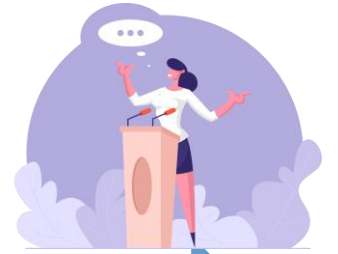
Invite to laboratory meetings

- ✓ Will learn more about your research
- ✓ Will meet your research team.
- ✓ A tour of the lab



Give to regular updates – written or via zoom.

- ✓ Can introduce you to community orgs
- ✓ Easier to learn in regular meetings.

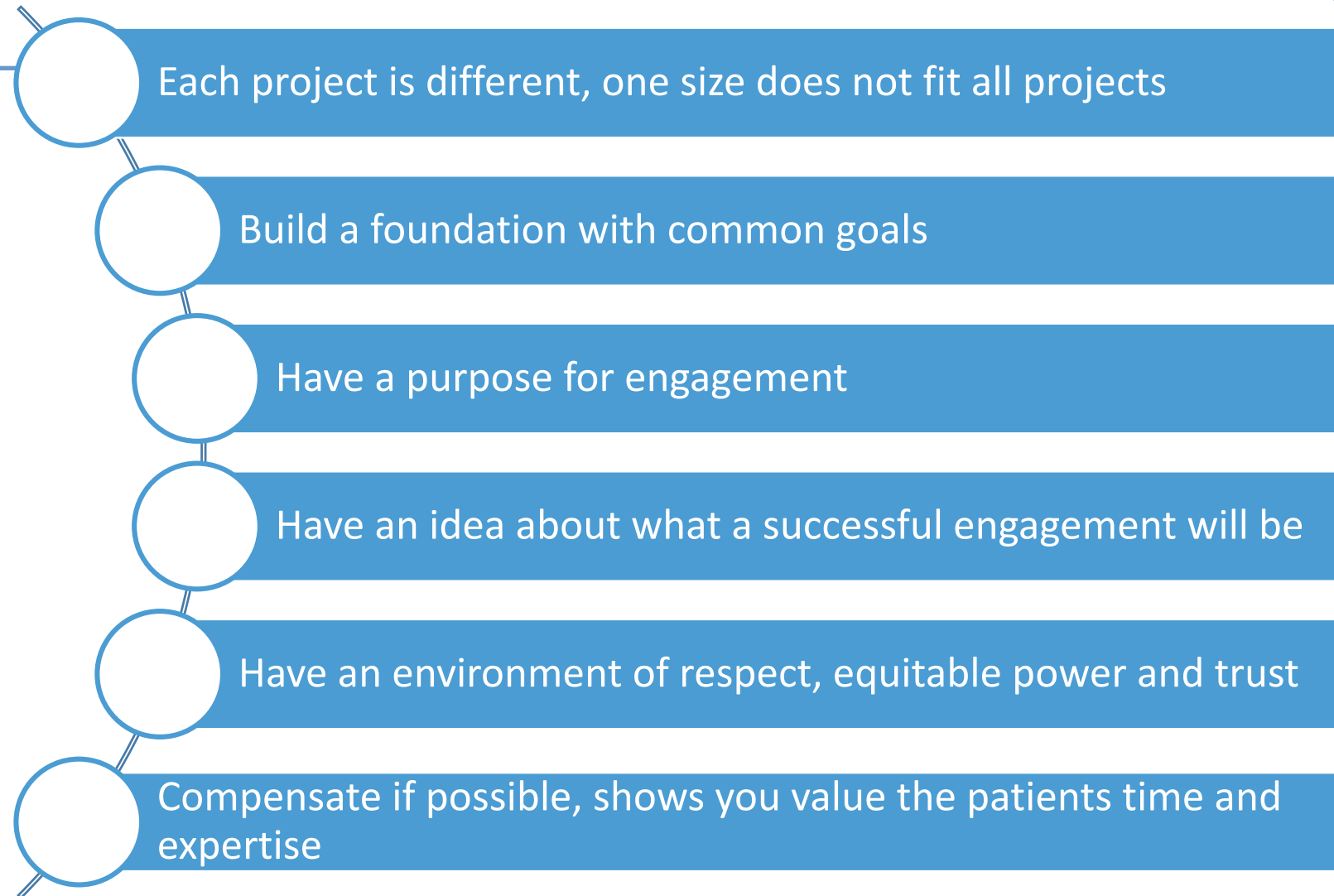


Communication of research results to patients and the community

- ✓ Public summaries
- ✓ Blogs
- ✓ Social Media
- ✓ The next grant!



How do you begin to engage an advocate in your research?



STEPS

to meaningful
engagement

1

Decide why patients will be engaged in the research project

- How will including patients benefit the research project?
- How will patients contribute?
- What information will be gained from patient engagement?

2

Identify patients for the research project

- What type of patients are needed for the project?
- Do the patients need to have a specific experience?
- Should there be more than one patient included?
- How will patients be identified?

3

Discuss roles, responsibilities, and expectations

- What is the role of patients on the project?
- What will patients be required to do?
- Will patients be involved at different levels?
- What is the expectation of the patient?

4

Discuss how researchers and patients will communicate

- How often will researchers and patients communicate?
- How will researchers and patients communicate?
- Who are the contact people on the research project and their roles?





Lineberger Excellence in Advocacy Program

Fill out [THIS FORM](#) If you need an advocate for your grant

Other Resources

[LOS Guidance](#) on how to write an advocate LOS

[ASCO Grant Resources](#) on the ASCO website

[Working with a Patient Advocate](#) video cast on the ASCO resource website

[Patient Engagement in Cancer Research from a Patient Perspective](#) publication



COE Coaching Guide:

How to infuse catchment priorities, community outreach & engagement over research lifespan

1) **Pre-Research:** Consider process for determining research focus that is catchment connected

- How can this research address a cancer burden / catchment priority?
 - Ex: Are there LCCC collaborators that can utilize the knowledge that will be gained by the research to address a cancer burden/catchment priority?
- How can this engage patients/community in developing the research question?
 - Ex: Are you engaging patient/community advisors (or CAB) in proposal?
 - Ex: Are you building off work that previously engaged community partners?

2) **During Research:** Consider how research itself can engage community members/organizations

- Ex: Does a patient/community member serve on research advisory committee?
- Ex: Do non-academic partners in NC help conduct research (e.g., recruitment assists)?
- Ex: Are students from high schools or historically Black college (HBCU) involved in lab?

3) **Post-Research:** Consider the policy or practice impact in catchment area

- What is the “So What?” of your research? Does it impact policy or practice in NC?
- Have you presented the findings of your research to non-academic audiences?
 - Ex: Researchers present findings to lay audiences (Impact = informing/educating)
 - Ex: Members speak at ACS scientific breakfasts and other community events
 - Ex: Lab participates in fundraisers (Impact = disseminating research and learning about community priorities, which could inform future research ideas)
- Strategize how your research could be more impactful across catchment area (NC)
 - Ex: Meet w/COE Office to develop dissemination plan for sharing results
 - Ex: Meet w/COE Office to identify community partners that could advise on how to translate your research results to create more impact

Examples from Lineberger Research Programs:

Population Science: (CPC)

- Colorectal cancer mortality hotspot found in catchment area using CIPHR data
- Identified predictors of CRC mortality hotspots
- Modeled statewide impact of, & piloted, CRC screening outreach programs in NC
- Engaged community partners to secure grants & conduct study
- Improved screening rates in NC
- Led to change in insurance policy coverage in BCBS

Basic Science: (MT)

- Registry/CIPHR analyses show that pancreatic cancer is prevalent in NC, especially among African American men (1.4X > whites)
- Studied KRAS gene mutations
- Identified new therapeutic approaches to treat pancreatic cancer
- Involves undergrads in Der lab
- Der Lab presented at Pancreatic Cancer Action Network and participated in their fundraisers

Clinical/Trans. Science: (BC)

- Black/white disparities in breast cancer mortality monitored using CIPHR data
- Carolina Breast Cancer Study identified biological and access-related root causes of black/white disparities
- Breast SPORE engaged patient advocates who advised studies
- Intervention studies funded
- Program members shared results at Komen Breakfast & ACS Community Advocacy Network; 100+ public, legislators attended