



LINEBERGER COMPREHENSIVE  
CANCER CENTER



UNC  
CANCER CARE

# Including patient advocates in research

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# Who is a Research Patient Advocate?

Diagnosis of cancer



Caregiver of someone with cancer



Affected by someone with cancer



Interested in bringing cancer knowledge to their community



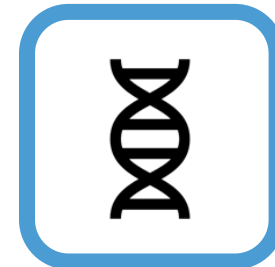
*Someone who brings a nonscientific viewpoint to the research process and communicates a collective patient perspective. (NCI, 2011)*



Collective Patient or community Perspective



Broad Impact



Interested in Science, NOT a scientist

# Adding the patient voice to cancer research

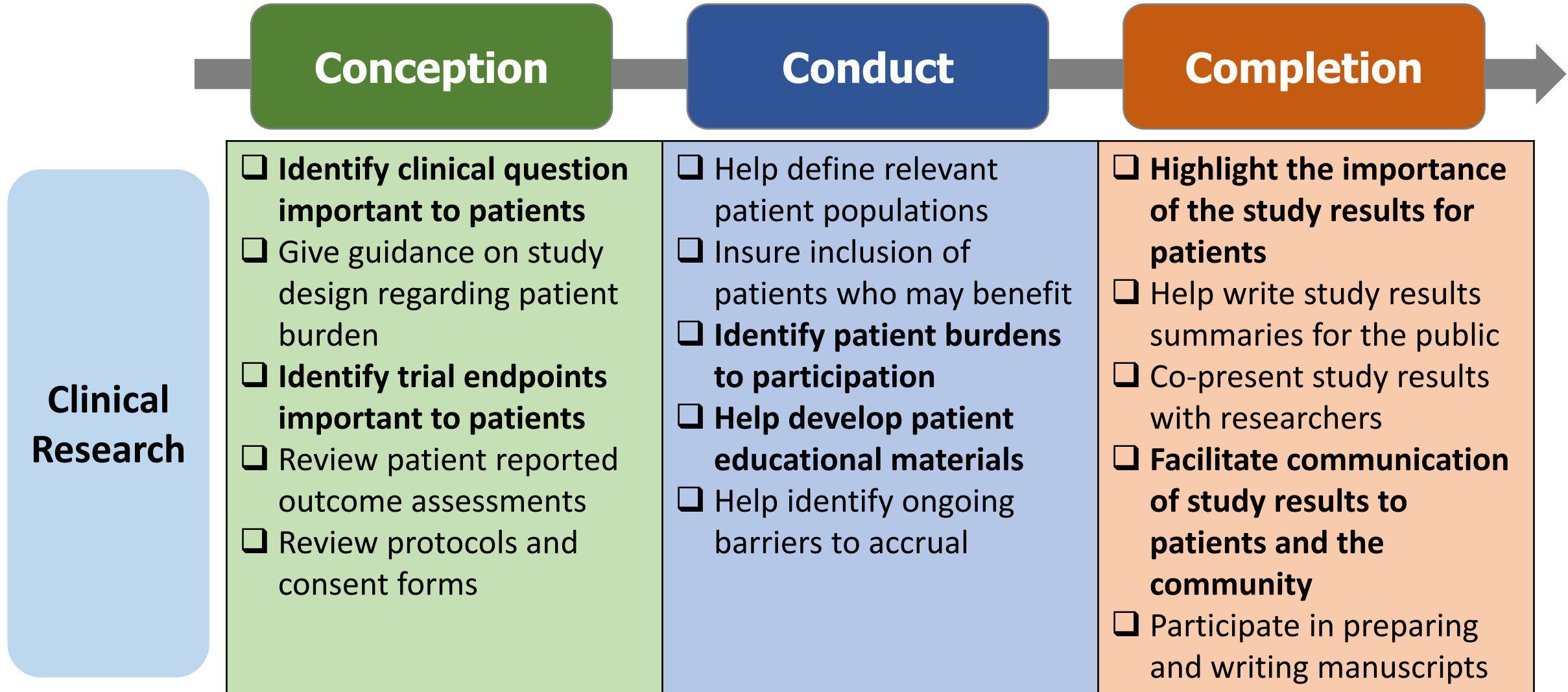
- **Putting some effort into specific ways advocates can be involved** to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient.

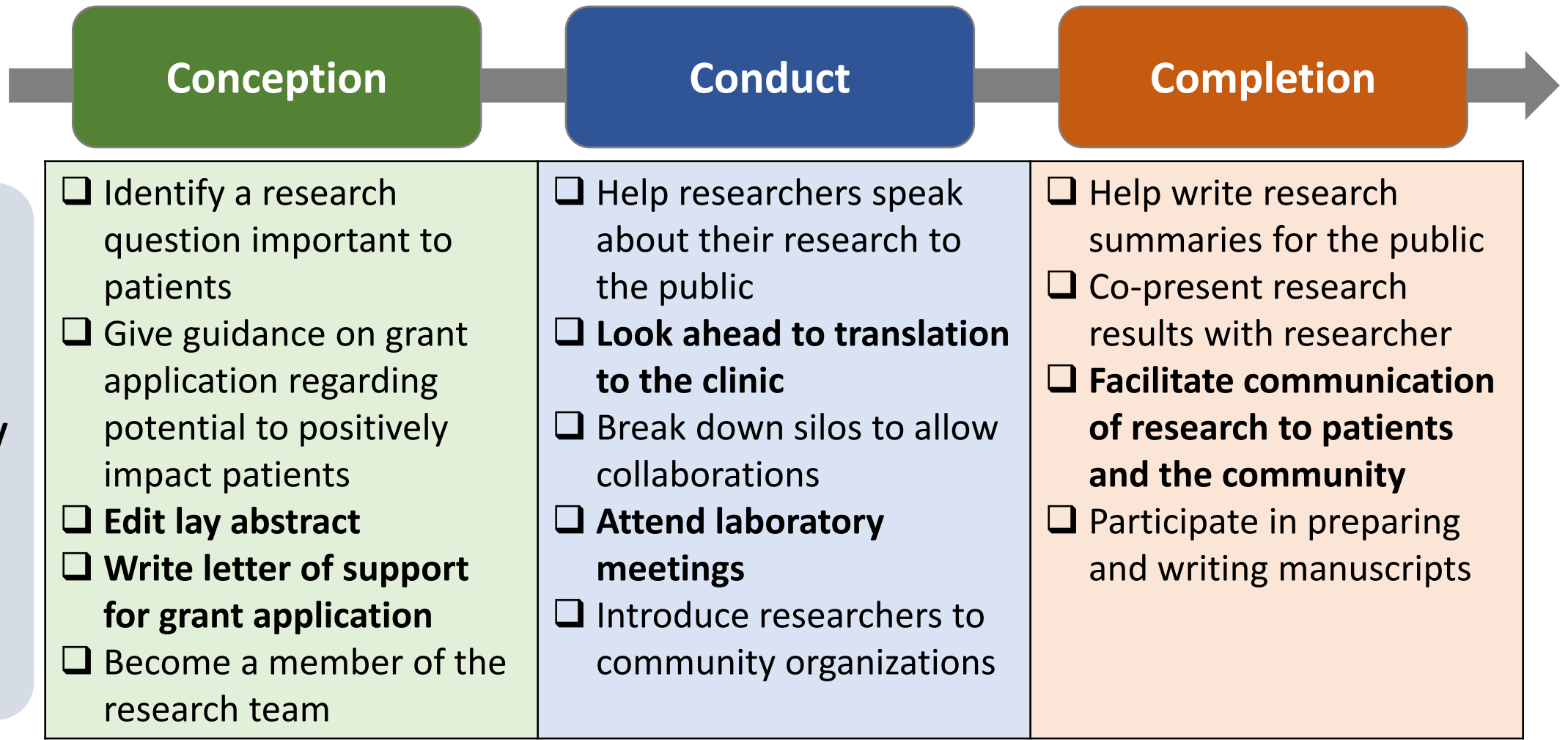
**1 Clinical trial development:** ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.

**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.

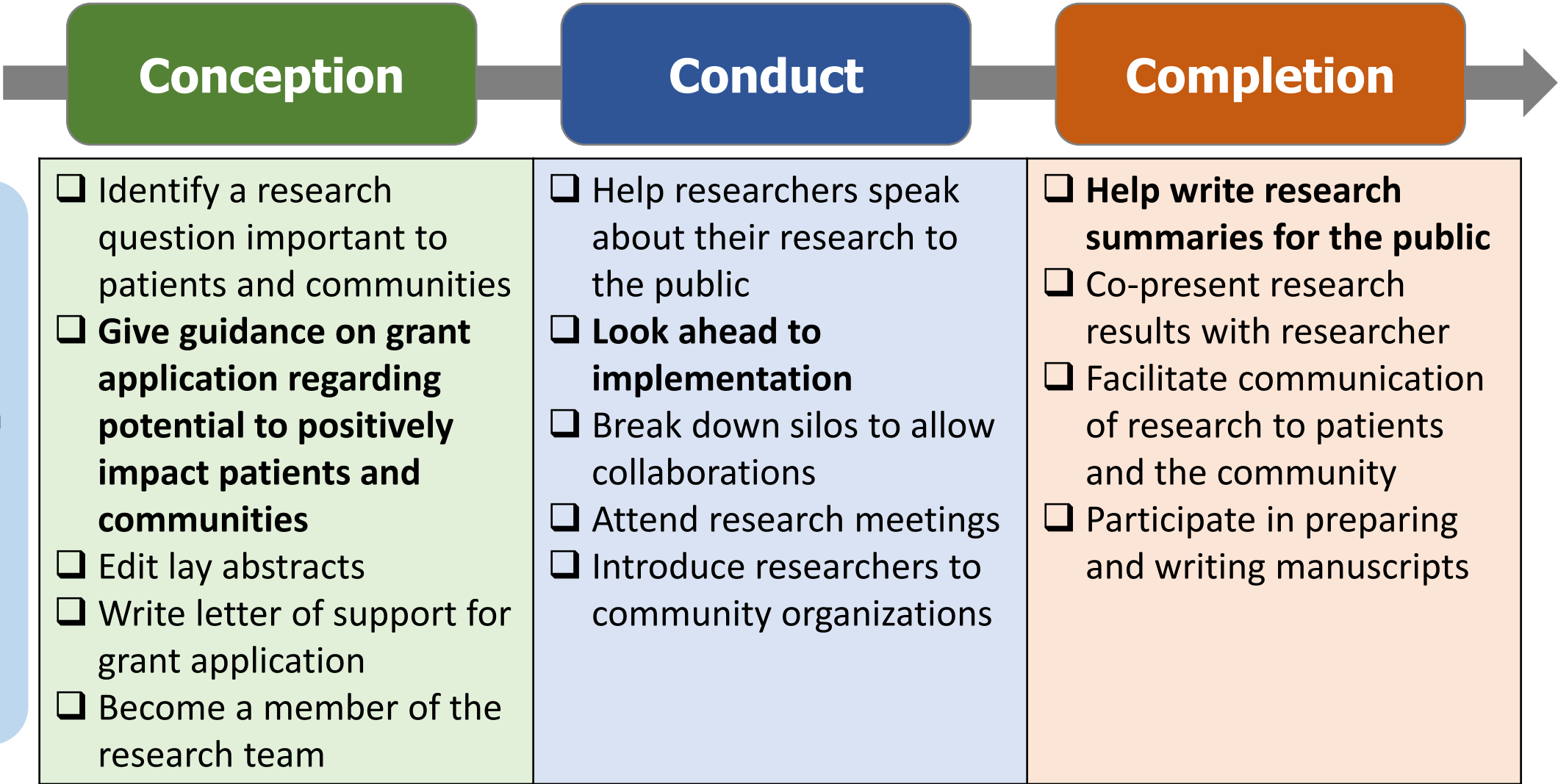
**3 Population science research:** provide the patient and community perspective on implementation feasibility and to help communicate the importance of the research to the broader community.







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

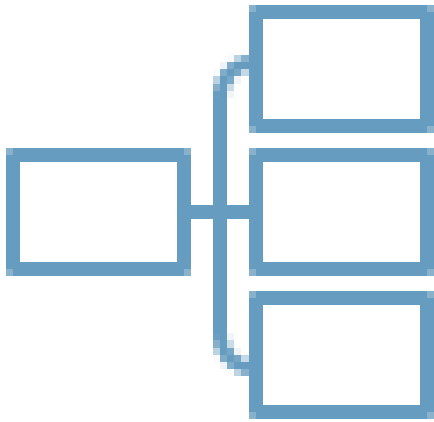
Notification of Funding

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

- ✓ 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



Protocol & Consent Review  
Intervention planning



Conduct of  
the study



End of the  
study

- ✓ 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



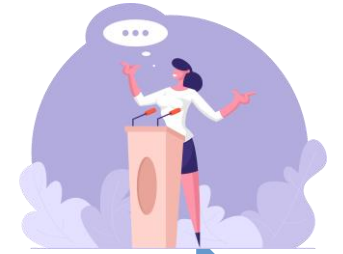
Invite to laboratory meetings

- ✓ 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.

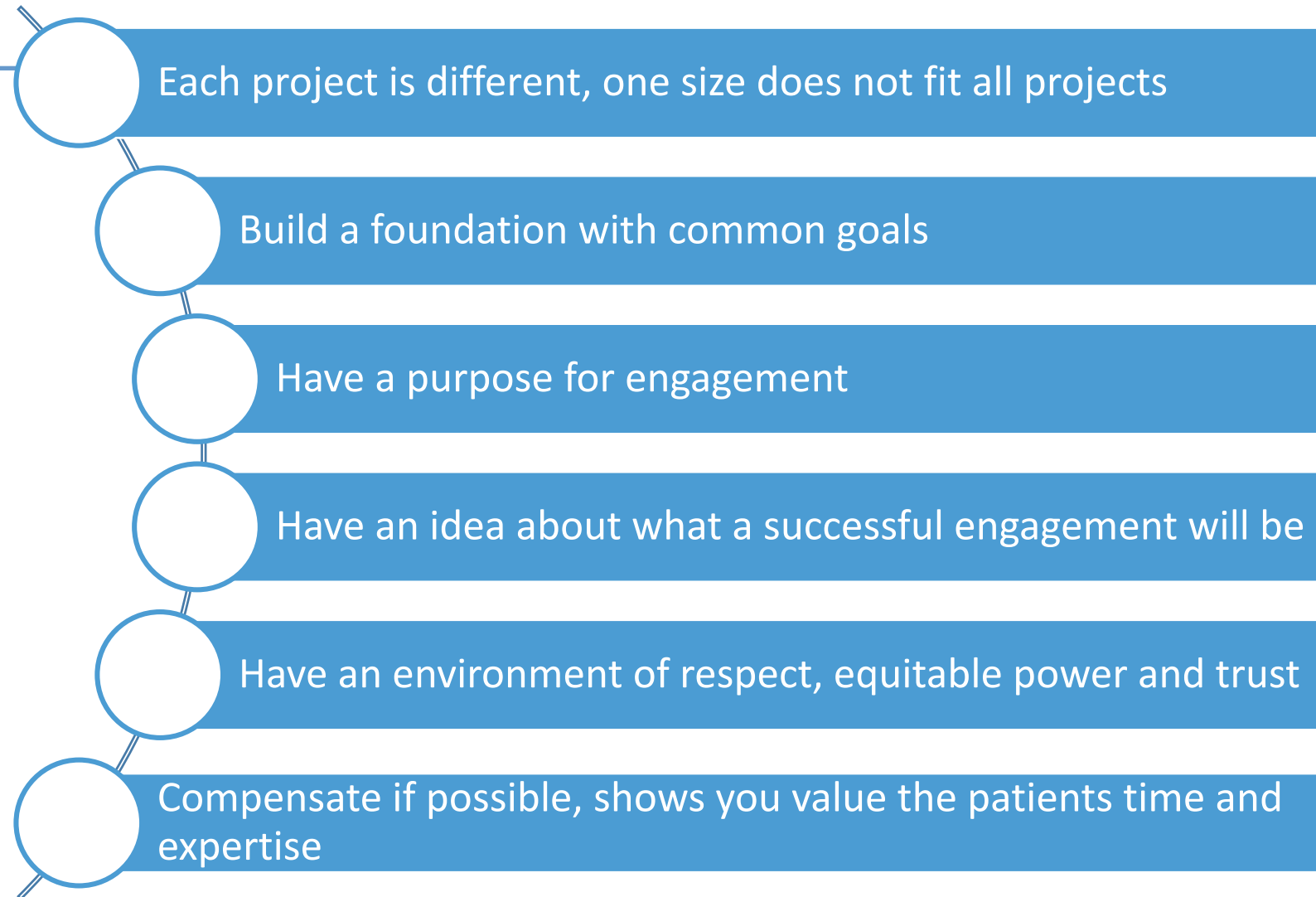


Communication of research results to patients and the community

- ✓ 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

