

A research advocate...



Brings the collective patient or community perspective to research



Makes a broad impact to the research process



Has an interest in science, even though they are NOT scientists

Different stakeholders have different perspectives

Doctor



Patient



“Oncologists most valued gains **in survival**, whereas patients assigned a higher monetary value to treatments that enhanced **QoL**.”
(Dilla 2016)

Adding advocate voices 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.

Laboratory

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.

Clinical Trials

Ensure the trials answer questions important to patients and have considered **patient burden, broad inclusion and patient relevant endpoints**.

Population

Provide the patient and community perspective on implementation feasibility and to help **communicate the importance of the research to the broader community**.



Engaging advocates adds urgency to cancer research

Early and Often

throughout the entire research process

Patients...

- understand the **burden** of their disease
- know what is **important** to them
- know what is **patient centric** and what is not
- know more about the patient **experience**
- help you **communicate** your research to the public

In Clinical Trials

- Patients can help design clinical trials that will **accrue and retain** participants
- Patients can help **identify barriers** and potential accrual problems



STEPS

to meaningful
engagement

1

Decide why advocates will be engaged in the research project

2

Identify advocates for the research project

3

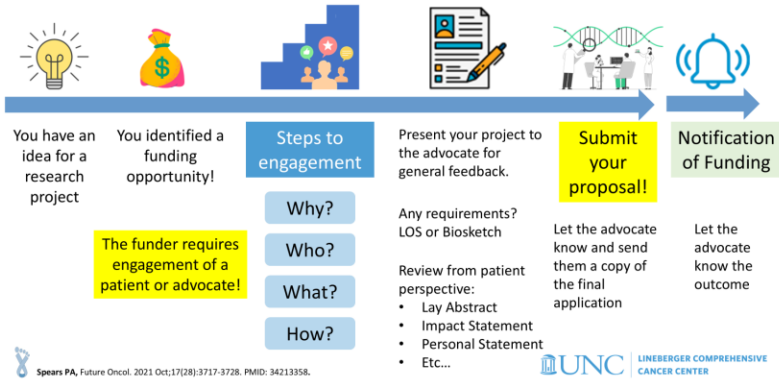
Discuss roles, responsibilities,
and expectations

4

Discuss how researchers and advocates will
communicate



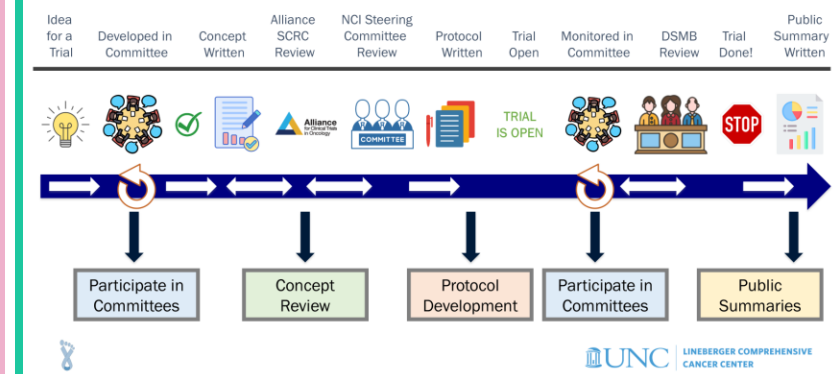
EXAMPLE: Applying for a Research Grant



EXAMPLE: Basic & Translational Research



EXAMPLE: PATIENT INVOLVEMENT IN CLINICAL TRIALS



Applying for Grants

- Require advocate involvement
- Reviewed by advocates
- Require impact on patients

Research

- Basic; Translational; Implementation
- Add patient perspective to your research

Clinical Trials

- Research Studies
- Add patient perspective to your clinical trial





Lineberger Excellence in Advocacy Program



Recruitment



Compensation



Training



Assessment



Engagement

92 advocates and growing!



14

Community
Advisory Board



8

Patient Advocates
for Research Council

Breast
Cancer
SPORE

8

Pancreatic
Cancer
SPORE

4

Endometrial
Cancer SPORE

5



25

Patient & Family
Advisory Council



SOUTHEASTERN
AMERICAN INDIAN
CANCER HEALTH EQUITY
PARTNERSHIP
(SAICEP)

A COLLABORATION BETWEEN
UNC CHS, UNMC, and DUKES CANCER INSTITUTE

SAICEP

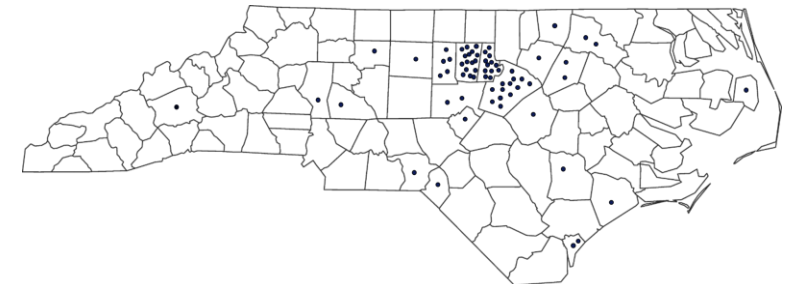
Advisory Board

9



32

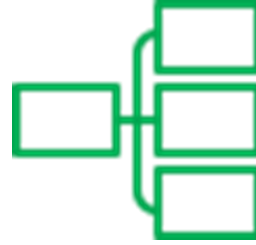
LCCC Advocates



Research Projects



Clinical Trials



Research Materials



Large Programs

- SPOREs
- P01s/U01s
- Stand Up 2 Cancer grants
- DoD grants

Individual Projects

- Individual investigator projects
 - Laboratory visits
- Patient and Community Advisory Boards for projects
 - Provide community connections/contacts
 - Support recruitment

Clinical Trials Office

- Protocol Review Committee
- Review new trials for accrual challenges
- Review ongoing trials for accrual enhancement

Feedback

- Advocate feedback on clinical trial design
- Provide patient and community perspective for trials
- Support recruitment

Patient Facing

- Review informed consents for clinical trials
- Review patient educational materials
- Review recruitment info

Public Facing

- Review website content
- Review public educational materials not associated with a clinical trial