

# A research advocate...



Brings the collective patient or community perspective to research

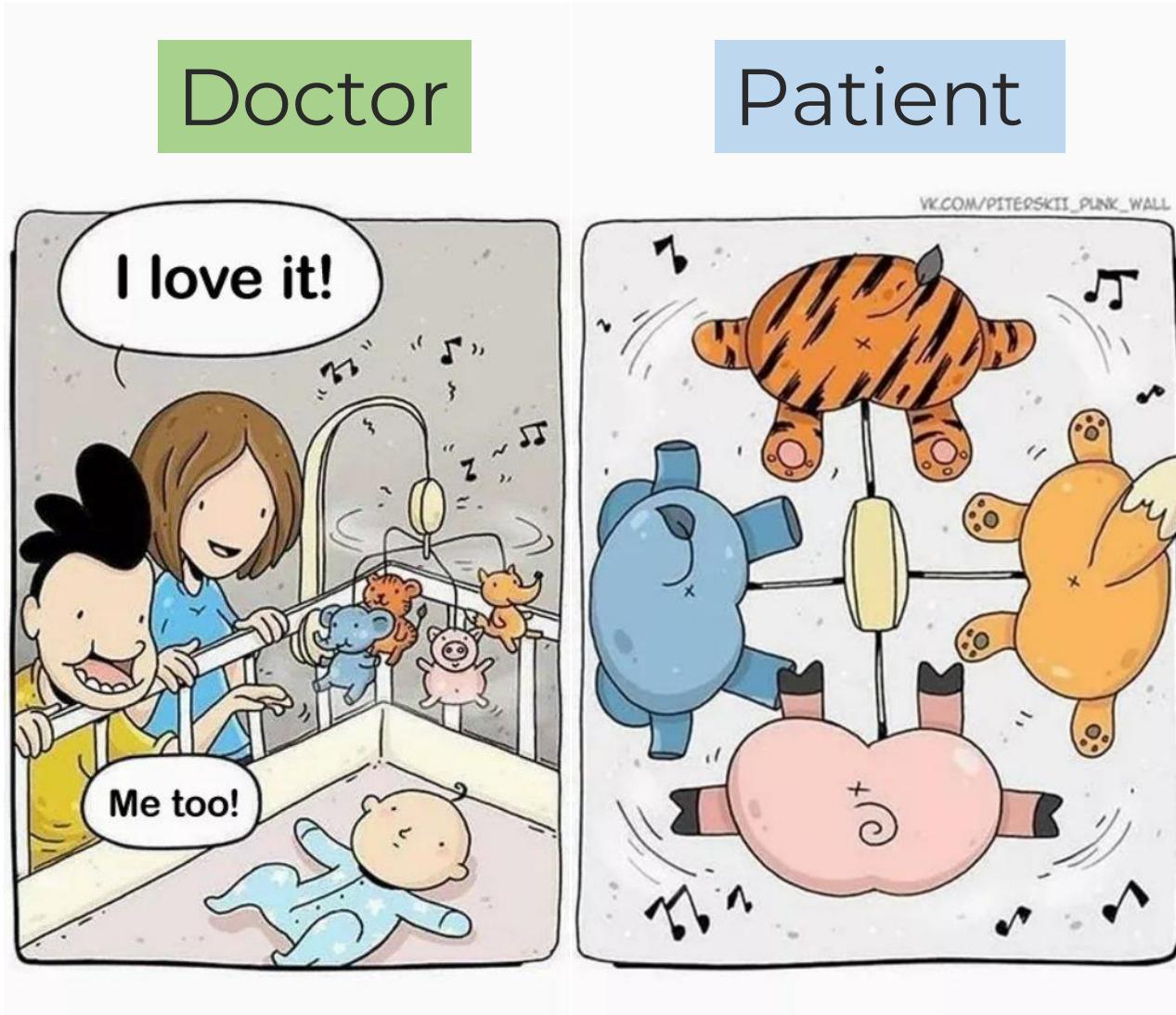


Makes a broad impact to the research process



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

# Different stakeholders have different perspectives



“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

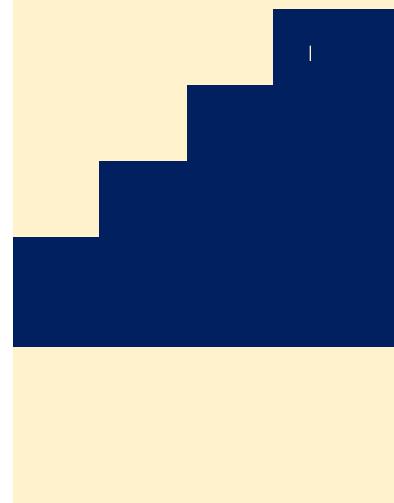
**In Clinical Trials**

- 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

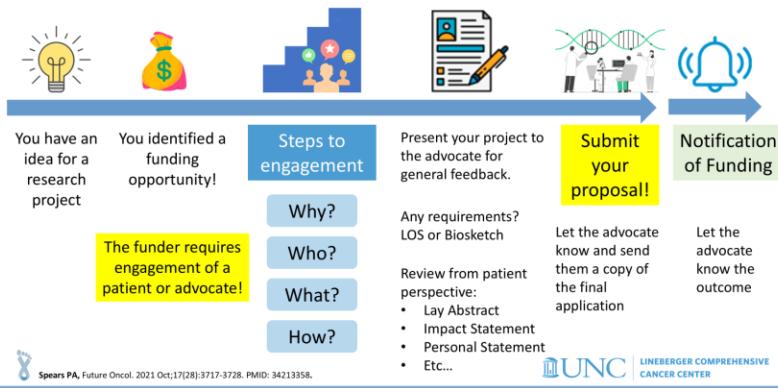
Discuss roles, responsibilities, and expectations

4

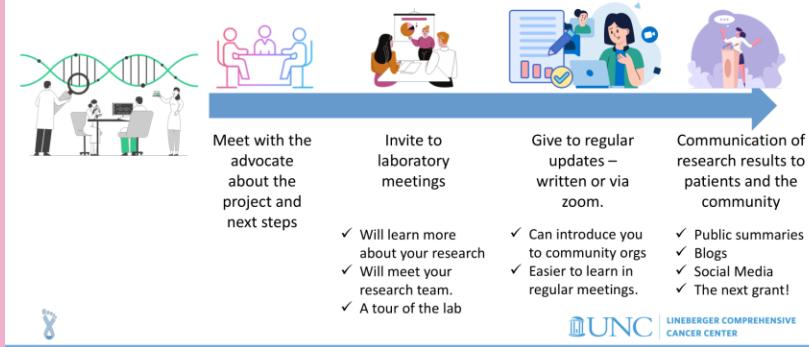
Discuss how researchers and advocates will communicate



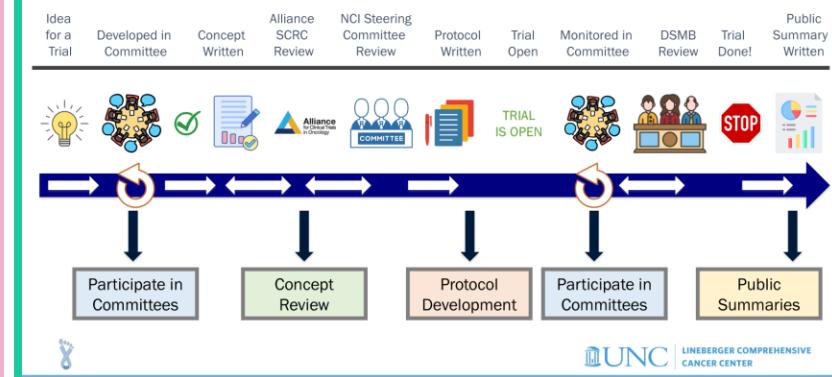
## EXAMPLE: Applying for a Research Grant



## 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





# LEAP

Lineberger Excellence in Advocacy Program



Recruitment



Compensation



Training



Assessment



Engagement

*92 advocates and growing!*



Community  
Advisory Board



Patient Advocates  
for Research Council

Breast  
Cancer  
SPORE

8

Pancreatic  
Cancer  
SPORE

4

Endometrial  
Cancer SPORE

5



Patient & Family  
Advisory Council

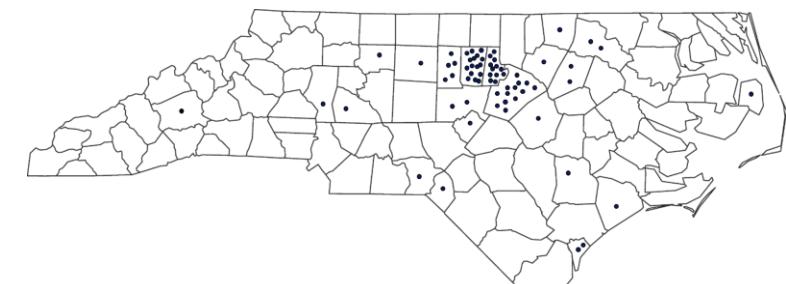


SOUTHEASTERN  
AMERICAN INDIAN  
CANCER HEALTH EQUITY  
PARTNERSHIP  
(SAICEP)

9



LCCC Advocates



SAICEP  
Advisory Board

## Research Projects



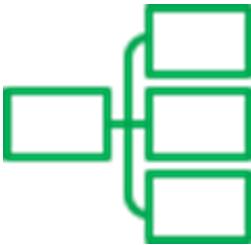
### Large Programs

- 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



### 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

## Research Materials



### 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