



# Including patient advocates in research

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## Who is a Research Patient Advocate?

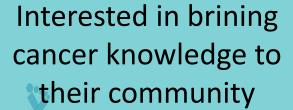
Diagnosis of cancer



Caregiver of someone with cancer



Affected by someone with cancer





Patient
Caregiver
Advocate
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.
- 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.
- 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.





#### Conception

#### **Conduct**

#### Completion

Clinical Research

- ☐ 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 protocols and consent forms

- ☐ Help define relevant patient populations
- ☐ Insure inclusion of patients who may benefit
- ☐ Identify patient burdens to participation
- Help develop patient educational materials
- ☐ Help identify ongoing barriers to accrual

- ☐ Highlight the importance of the study results for patients
- ☐ Help write study results summaries for the public
- ☐ Co-present study results with researchers
- ☐ Facilitate communication of study results to patients and the community
- ☐ Participate in preparing and writing manuscripts





#### Conception

#### **Conduct**

#### Completion

Laboratory Research

- ☐ 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





#### Conception

#### Conduct

#### Completion

Population Science Research

- ☐ Identify a research question important to patients and communities
- ☐ Give guidance on grant application regarding potential to positively impact patients and communities
- ☐ Edit lay abstracts
- ☐ 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 implementation
- ☐ Break down silos to allow collaborations
- ☐ Attend research 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





### 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

**WHEN** 



(GENERAL)











You have an idea for a research project

You identified a funding opportunity!

The funder requires

engagement of a

patient or advocate!

Steps to engagement

Who?

Why?

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!

Notification of Funding

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



## EXAMPLE #1 — APPLYING FOR A GRANT





(LCCC)





Request an Advocate
Fill out THIS FORM

You have an idea for a research project

You identified a funding opportunity!

The funder requires

engagement of a

patient or advocate!

Steps to engagement

Why?

Who?

What?

How?

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!



Notification of Funding

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

Let the advocate know the outcome

UNC

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CANCER CENTER

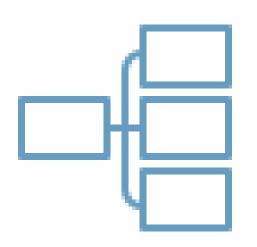
Even if not 'required' you can still boost your grant by adding an advocate!

Spears PA, Future Oncol. 2021 Oct;17(28):3717-3728. PMID: 34213358.

## 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

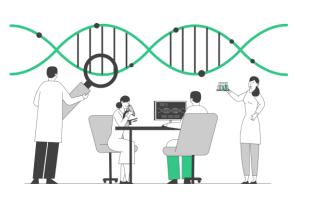
- ✓ Identify clinical question important to patients
- ✓ Give guidance on study design regarding patient burden
- ✓ Identify trial endpoints important to patients
- ✓ Review patient reported outcome assessments
- ✓ Review consent forms

✓ 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?

Each project is different, one size does not fit all projects

Build a foundation with common goals

Have a purpose for engagement

Have an idea about what a successful engagement will be

Have an environment of respect, equitable power and trust

Compensate if possible, shows you value the patients time and expertise





## **STEPS**

to meaningful engagement



- 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

Decide why

patients will be

engaged in 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?
- 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?

- 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?







### 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



