

# The importance of patient advocates in research: A scientist's perspective on value and implementation

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# Understand the disease you are investigating

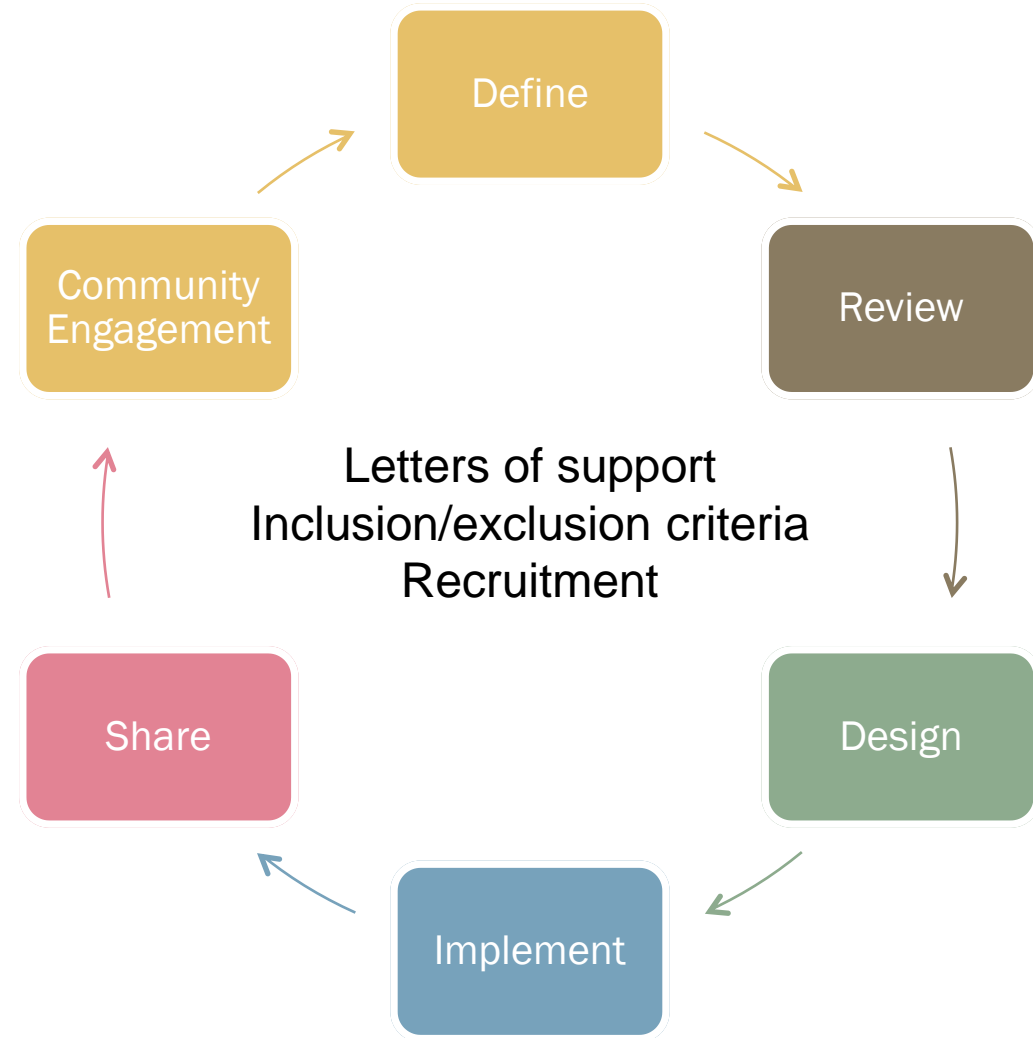
Remember:  
We do health  
sciences  
research for the  
benefit of current  
and future  
patients, and to  
prevent disease

- Even “basic scientists” should understand the clinical questions that are most important
- Resources: clinicians and patient advocates
- Educated patient advocates provide a voice of experience that goes beyond their own unique situation
- Ensures that scientific and medical advances are patient-centered and relevant
- Advocates ask the “hard” questions that scientists sometimes forget to address, e.g. “if this all works, what will it mean for patients?”
- Result: better projects, better grant applications, better outcomes



# The role of advocates is more common in clinical trials research but the same principles can, and should, be applied to discovery research

Advocates can support the entire research life cycle



# A practical example of how we got this started

HCI Women's  
Cancers Center  
Patient  
Advocate  
Committee  
(~ 3 years)

- 1. Advocate co-leader to launch the initiative with me**
  - Dr. Carla Lloyd, retired professor of communications and breast cancer survivor
- 2. Exploratory research**
  - Within HCI
  - Outside HCI (Georgetown)
- 3. Develop committee (with advocacy training and monthly meetings)**
- 4. Trial run**
  - DOD grant: presentation to PA committee, questions, letter of support. Funded!!!
- 5. Continued collaboration**
  - Other DOD grants, Komen grant
  - Very high funding rate
- 6. Educational activities**
  - Research on clinical trials participation
  - Progress on funded grants
- 7. Postdoc scientific liaison**
- 8. Expanding membership**



# Additional Resources



SURVIVORS & ADVOCATES PROGRAM,  
AMERICAN ASSOCIATION FOR CANCER RESEARCH

A website full of resources for advocates working with cancer researchers,  
from one of the premier cancer research advocacy programs in the U.S.

[https://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/Pages/educational-series-on-science-and-advocacy\\_\\_403E94.aspx#.W1DLq62-Lq1](https://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy/Pages/educational-series-on-science-and-advocacy__403E94.aspx#.W1DLq62-Lq1)



AMERICAN SOCIETY FOR CLINICAL ONCOLOGY

ASCO not only hosts the largest annual cancer meeting in the world,  
it also is a central hub for oncology research education and training,  
including ASCO University, a comprehensive e-learning center that  
supports lifelong learning for oncologists and all ASCO members  
including patient advocates at a discounted rate.

For ASCO: <https://www.asco.org/>

For ASCO University: <https://university.asco.org/>



DEPARTMENT OF DEFENSE CONGRESSIONALLY  
DIRECTED MEDICAL RESEARCH PROGRAM'S  
CONSUMER INVOLVEMENT PROGRAM

Consumers in this case meaning patients, survivors, caregivers, and those  
at particular risk for a disease. The program integrates consumers into  
the peer review process for awarding research grants.

<http://cdmrp.army.mil/cwg/>



NCI'S OFFICE OF ADVOCACY RELATIONS

This is the National Cancer Institute's advocacy program.

<http://advocacy.cancer.gov>



PATIENT ADVOCATES IN RESEARCH (PAIR) EMAIL LIST

Moderated by Deb Collyar, this is the primary discussion and  
distribution forum for patient advocates in cancer research, including  
cooperative group advocates.

contact Deb at [deborah@tumortime.com](mailto:deborah@tumortime.com) to be added to the list.

## Research Advocacy Network

RESEARCH ADVOCACY NETWORK

The mother lode. Membership gives you access to their Advocate Institute  
online educational materials for research advocates.

<http://www.researchadvocacy.org/>



National Breast Cancer Coalition

<http://www.stopbreastcancer.org/get-involved/training/>

