

PIVOT Educational Resources

PIVOT [YouTube Channel](#) – access webinars and testimonials

[Working Together Toolkit](#)– includes guidelines for advocate involvement in research, tips to strengthen advocate-researcher relationships, how to write a lay abstract and more

[KU Cancer Center Annual Research Highlights Report](#)

Cancer and Cancer Research Basics

[Cancer Information & Support Network \(CISN\)](#) - web-based training for patients, advocates and medical professionals who want to better understand cancer research.

ASCO's [Patient Information Site](#) – provides an introduction to cancer research and clinical trials.

Introduction to Cancer Biology [video](#) – an animated video teaching the basics of how cancer forms and spreads.

What is Research Advocacy?

National Cancer Institute [Research Advocacy 101](#) video series

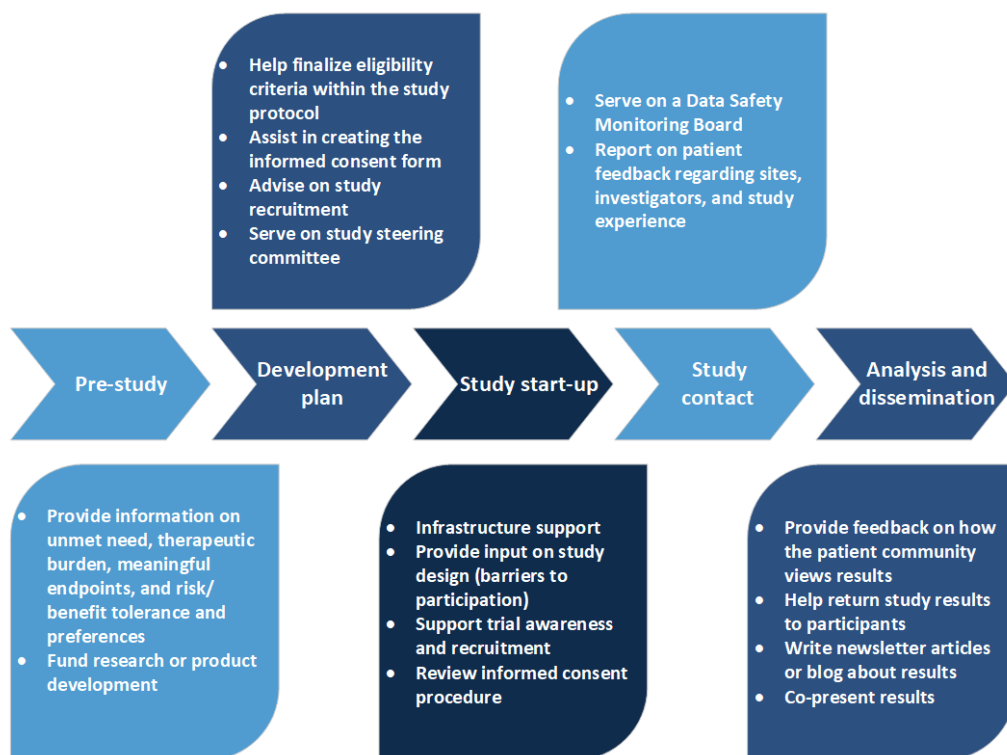
[Cancer Information & Support Network \(CISN\)](#) - brief discussions of key points about advocacy and research advocacy.

[Involving Advocates in Cancer Research](#) - challenges and successes of advocate engagement in the cancer research process.

Bench to Bedside Episode, [Research Advocacy Partnerships](#)

The role of a Patient Research Advocate in the Clinical Trials Continuum - how patient research advocates can contribute as a clinical trial is being developed, conducted and shared.

Research Advocacy Roles in the Clinical Trials Continuum



Adapted from materials from the Parkinson's Foundation and Fight Colorectal Cancer



Additional Tips and Guidance

[Susan G. Komen: Advocates in Science Clinical Trials Workshop PowerPoint](#)

[A Seat at the Table: A Research Advocate's Journey: Musa Mayer](#)

[Susan G. Komen: Impact Evaluation Tips for Research Applications](#)

[Toolkit for Journalists and Consumers](#)

[Clinical Trials Transformation Initiative: Patient Group Engagement Methods](#)

Stories and Testimonials

Videos and articles sharing patient advocates' and/or researchers' experiences in developing patient advocate and researcher relationships and collaborations.

[Developing Advocate-Researcher Relationships](#)

[Breakthroughs Save Lives: Two Lives. One breakthrough.](#) Brief video featuring six-time survivor Brittany Sullivan and her doctor, Conquer Cancer grantee, Breelyn Wilky, MD

[A Seat at the Table: A Research Advocate's Journey](#)

[Caught Off Guard](#) Article on the surprising insights and valuable relationship gained when a physician-scientist interviews a metastatic patient advocate.

Issues Important to Patient Research Advocates

[Health Equity: PLAN4Health](#) - resources to help users better understand health equity, health inequalities and the social determinants of health.

Financial Burden/Toxicities of Medical Treatment

- [Financial Toxicity Is a Clinically Relevant Patient-Centered Outcome](#)
- [Not Just Nausea and Vomiting: Cancer Docs Now Worry About 'Financial Toxicity'](#)
- [It's Not an Even Playing Field: How Financial Instability Takes A Toll On Cancer Patients](#)
- [The National Health Council Value Framework Get-Ready Checklist for Patient Organizations](#)
- [50 Health Issues That Count as a Pre-Existing Condition](#)

Health Data Basics

- [FasterCures](#) - video discussing what happens to your health information
- [HealthIT.gov - Patients & Families](#) - benefits of health information technology and how to take advantage of it to improve their lives
- [TheDataMap](#) - online portal for those curious about where their data goes and how the data are connected in a complicated system
- [Your Cells. Their Research. Your Permission?](#) - article by Rebecca Skloot
- Cancer Screening Video Series
 - [Part 1: Principles of Screening](#)
 - [Part 2: Validity - Sensitivity and Specificity](#)
 - [Part 3: Sensitivity/Specificity Tradeoff](#)

Recommended Books

[The Emperor of All Maladies: A Biography of Cancer](#), Siddhartha Mukherjee

[The Immortal Life of Henrietta Lacks](#), Rebecca Skloot

[The Developing Genome: An Introduction to Behavioral Epigenetics](#), David S. Moore

[Blind Spot: The Hidden Biases of Good People](#), Mahzarin R. Banaji and Anthony G. Greenwald

[How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS](#), David France