Conducting and Managing Cancer Clinical Trials
A Library of Resources

Chapter IX. Patient Resources

August 2020

ASCO® CENTRA
Center for Research & Analytics
This library of resources was compiled to centralize resources related to conducting and managing clinical trials. The resources are particularly helpful for physician investigators and research staff. A Task Force of the Research Community Forum, representing a range of community research stakeholder groups with a wealth of experience, compiled this list to help make it easier for research sites to find needed resources. Decisions to include resources were solely based on the Task Force’s own go-to resources, consultation with colleagues, and an environmental scan of available resources on these topics. Resources from commercial, for-profit entities are generally excluded from the library. The items listed are not necessarily endorsed by ASCO; they are listed based on the discretion and expertise of the Task Force.

This list is not exhaustive and will be updated periodically. Your feedback is welcomed! If you have ideas for content to add or edit, please email your suggestions to the ASCO Research Community Forum.

ACKNOWLEDGEMENTS
This document was developed with leadership from the ASCO Research Community Forum Resource Development Task Force. The following individuals made significant contributions to this document by providing insights, expertise, and resources, including Lora Black, RN, MPH (Chair of the Task Force); Andrea Buchmeier, MHA, CCRC, LSSGB; Mehmet Sitki Copur, MD, FACP; Peg Ford; Marge Good, RN, MPH; Stephanie Graff, MD, FACP; Keisha Humphries, BSN, OCN; Susan Leighton; Erika K. Radeke, MS; James A. Reeves, MD; Joel Saltzman, MD; Connie Szczepanek, RN, BSN, CCRP; Ramya Thota, MBBS; and ASCO staff leads Patricia Hurley, MSc CPHQ, and Courtney Davis.

Disclaimer: This library contains resources and templates that are provided as examples only for research programs to consider as they formulate their own resources. ASCO makes no warranties, expressed or implied, as to results obtained by individuals using the information and is not responsible for any action taken in reliance on the information contained herein.

When citing this Toolkit, or any of its components, please include the following content in the citation:

For more information contact researchcommunityforum@asco.org.
IX. Patient Resources

Cancer.Net provides timely, comprehensive, oncologist-approved information from ASCO that brings expertise and resources to people living with cancer and those who care for and about them, to help patients and families make informed health care decisions. These resources from Cancer.Net provide information, written with patients in mind, on varied topics related to cancer, healthcare and the medical field, and clinical research.

This section includes the following topics:
IX. Patient Resources
   A. Information for your Cancer Journey
      i. General Information
   B. Introduction to Cancer Research
   C. Research and Advocacy

A. Information for your Cancer Journey
The following resources provide helpful information for those beginning their cancer journey.

- Cancer Basics
- How is Cancer Treated
- Questions to Ask Your Health Care Team
- Learning About your Specific Cancer Type
- Financial Considerations

i. General Information
The following resources offer additional information to help learn about cancer.

- Medical News: 8 Ways to Separate Fact from Fiction
- Evaluating Cancer Information on the Internet
- Journals and Magazines. This listing covers leading oncology and general-medicine scientific journals and consumer magazines, which may be helpful in finding additional information, services, and support.

B. Introduction to Cancer Research
The following resources provide an overview of cancer research, including information on participating in clinical trials.

- Introduction to Cancer Research
- Drug Approval and Labeling
- Clinical Trials: ASCO's patient website, Cancer.Net, offers patient education materials regarding clinical trials. The website also includes patients' stories about their participation in clinical trials and a podcast. All of these resources are free to access.
• **Taking Part in Cancer Treatment Research Studies.** This resource provides information for people with cancer who are thinking about participating in a clinical trial.
• **Questions to Ask About Clinical Trials**
• **Clinicaltrials.gov** is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world.
• **Patient Safety and Informed Consent**
• **Health Insurance Coverage of Clinical Trials**

**C. Research and Advocacy**

• **Research and Advocacy**
• **PRE-ACT (Preparatory Education about Clinical Trials)**
• **What is the Patient's Role in Cancer Research?**
• **How Patient Advocates Help Cancer Research: An expert Q&A**
• **Understanding the Publication and Format of Cancer Research Studies**
• **Understanding Cancer Research Study Design and How to Evaluate Results**
• **Drug Discovery and Development**