

# How to Find Clinical Trials for Breast Cancer

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Understanding How to Find Clinical Trials for Breast Cancer

As a breast cancer patient, you have likely heard about clinical trials. You may be interested in volunteering for a clinical trial and would like more details about them, including finding clinical trials for breast cancer. How do you find the right one for your specific type of breast cancer?

In 2021, breast cancer patients have options when it comes to treatment. Clinical trials are one option for breast cancer patients. It's important to note that clinical trials are definitely [not a last resort](#). Years ago, they were viewed as a last option for end-stage cancer patients. Today, participation in clinical trials can be the first line of attack in applying the latest cutting-edge therapies to your cancer.

In the past 20 years, clinical trials have yielded the drugs and therapies utilized by today's breast cancer patients. Each drug approved by the U.S. Food and Drug Administration (FDA) began its journey to approval and use as the standard of care by going through rigorous clinical trials.

Once you have decided to approach clinical trials, we want to help you navigate the investigation process. We will outline:

- how to find clinical trials for breast cancer and where to access information about them
- the headaches and frustrations you may encounter during the process
- solutions to help support you in the clinical trial application process

Since each cancer journey is unique, deciding on the type of treatment to pursue is highly personal. Once you have had discussions with your oncologist and you are open to the idea of clinical trials, then it's time to begin your research on how to find clinical trials for breast cancer.

## Where do you find breast cancer clinical trials that apply to you?

Searching for a clinical trial is a process that has been made easier through the use of the internet. You can find many answers about clinical trials and how to access them on various websites, including those from the U.S. government, breast cancer research hospitals, private companies, and nonprofit organizations.

Finding, applying to, and being accepted into a clinical trial can be a very time-consuming process. It can also be confusing, overwhelming, and frustrating. You may encounter headaches along the way, but there are many resources to help you, both in finding a clinical trial that's right for you and supporting you during the application process.

## How do you approach finding the right clinical trial for you?

The first step is to ask your oncologist about clinical trials, specifically if they might be suitable for your stage and type of breast cancer. Speaking with your oncologist is a good place to begin the conversation, even if your oncologist is not aware of the latest clinical trials specifics.

Your oncologist may be aware of local clinical trials, though not necessarily all of the trials offered across the country or internationally. An oncologist's primary objective is to coordinate treatment with the current standard of care for their patients.

Many resources exist to help you find a clinical trial that may be right for you. The U.S. government has several websites that contain a complete list of all of the current breast cancer clinical trials. The top breast cancer research hospitals in the U.S. also conduct clinical trials. Their websites provide information about the ongoing and upcoming clinical trials available at their facilities.

Visiting the government public and private provider websites will be a helpful first step in understanding the clinical trials that exist for many types and stages of breast cancer. We will list their websites a bit later in this article. Let's first cover the basics of clinical trials before you begin your search.

## What should I know before beginning my search?

Before accessing these sites, it's essential to know a bit about clinical trials to help you in your search. There are four phases of clinical trials. Knowing what happens in each phase will help you understand which trials might appeal to you.

**Phase I** is a very small clinical trial enrolling 15 to 30 patients to test the safety and appropriate dosages in cancer patients. Researchers may try the drug in patients with different types of cancer. One of the main goals of a Phase I study is finding the appropriate, well-tolerated dose.

**Phase II** is more targeted than Phase I and tests the therapeutic effects of a drug for a specific type of cancer. Usually, this is a slightly larger group of 30 to 50 volunteers. This phase usually lasts for about two years.

**Phase III** tests whether the new therapy outperforms current conventional FDA-approved treatments. Phase III is a large study with hundreds to thousands of volunteers who participate at many sites across the country. Volunteers are split into different groups. All will receive either the best current conventional drugs and care, known as the standard of care, or receive the new experimental treatment.

The goal is for people of various ages and ethnic groups to join in this study so researchers can study its effects on different populations. This phase can take many years. Once the data is in and the therapy has performed well, the FDA will approve it for use in the general population. Now cancer patients with that specific type of cancer can access that FDA-approved therapy.

**Phase IV** happens after the new treatment has received FDA approval post-Phase III studies. Now the therapy can treat large numbers of cancer patients since it effectively combats that type of cancer. Phase IV studies the long-term effects of this therapy on multiple populations. Phase IV might also examine if the drug can be used in different doses or different types of disease.

Understanding the different phases of clinical trials makes it easier to understand what volunteering for a clinical trial involves. Now you can approach how to find clinical trials for breast cancer.

## Where do I find clinical trials for breast cancer?

Once you have discussed clinical trials with your doctor and you are ready to investigate clinical trials, where should you begin looking for information about specific clinical trials? Finding a study and learning the particulars and whether it might be suited to your type of breast cancer are your next steps. How do you find clinical trials for breast cancer specifically?

## Can websites help in my search?

There are two big websites connected to the U.S. government that are very helpful to people searching for clinical trials.

1. One leading resource provided by the U.S. National Library of Medicine at the National Institutes of Health is [Clinicaltrials.gov](https://clinicaltrials.gov), a database listing privately and publicly funded clinical studies in 50 states and 220 countries worldwide.

Clinicaltrials.gov is one of the most accessed databases for clinical trials, and it notes studies that are actively recruiting volunteers. You can enter specific search parameters to return studies for a particular type of cancer and other variables, including geographic location.

2. The National Cancer Institute (NCI) is the U.S. government's principal agency for cancer research. They have a website that will help you find NCI-supported clinical trials taking place across the U.S., Canada, and internationally. The website is [cancer.gov](http://cancer.gov).

[Cancer.gov](http://cancer.gov) allows you to search your type of cancer, input your age and your zip code to find trials close to you, though you can also do a search for all breast cancer trials. The NCI also has a toll-free phone number to call for help with finding clinical trials, 1-800-4CANCER.

3. [WCG CenterWatch](http://www.wcgcenterwatch.com) is an online resource for patients of all different diseases to find out about clinical trials. Their listings also include breast cancer clinical trials close to you. They have a free Patient Notification Service where they notify you via email if a hospital or another clinic within 100 miles of you is conducting a clinical trial in breast cancer.

## Where else can I find clinical trials?

Top breast cancer research hospitals also conduct clinical trials for breast cancer. They are well-known for their special treatment of breast cancer, and most offer their clinical trials in a hospital setting.

Some volunteers are willing to travel long distances to attend clinical trials, though some volunteers will not be able to travel as far. Each decision is personal as to how far you are willing to travel to participate.

Things to consider if you find a trial that may be some distance from your home are how often you will be at the site for treatment, testing, and medical visits. Also, financial considerations regarding housing during treatments and transportation costs should factor into a decision.

The following top cancer research hospitals all conduct breast cancer clinical trials. You can find a wealth of information about the clinical trials process and specifics about their trials on their websites.

1. [University of Texas](http://www.mdanderson.org), MD Anderson Cancer Center  
Located in Houston, Texas, and affiliated with the University of Texas, the MD Anderson Cancer Center is ranked number one in cancer care in the U.S. News & World Report's annual "Best Hospitals" survey. It has also been named one of the nation's top two cancer hospitals since 1990.
2. [Johns Hopkins University](http://www.jhu.edu), Kimmel Cancer Center  
Located in Baltimore, MD, Johns Hopkins offers many breast cancer clinical trials in Phases I through III. Their website explains how the clinical trial process works and includes details from some of their current breast cancer trials.

3. [Memorial Sloan Kettering Cancer Center](#)  
Located in various sites in New York City, Westchester, Long Island, and New Jersey, Memorial Sloan Kettering Cancer Center offers clinical trials they believe will improve some aspects of treatment and outcomes. Their website includes information about their clinical trials and a news section on the latest in breast cancer research.
4. [Cleveland Clinic](#)  
Located in and around Cleveland, OH, Cleveland Clinic comprises eleven hospitals and eighteen full-service health centers. They research breast cancer from standard approaches to cutting-edge genetically based, personalized medicine. Their site is searchable for current clinical trials as well as those where they are enrolling volunteers.
5. [Mayo Clinic](#)  
Located in Rochester, Minnesota, with campuses in Florida and Arizona, the Mayo Clinic has over 100 ongoing breast cancer clinical trials. It is recognized as a [Specialized Program of Research Excellence for breast cancer research](#), funded by the National Cancer Institute.

[Ciitizen](#) is a private company that offers patients with advanced and metastatic breast cancer a free clinical trial matching service through its partnership with IQVIA, the world's largest clinical research organization.

### How do I evaluate if the clinical trial is right for me?

Once you have found one or more clinical trials that might fit your type and stage of breast cancer, then it is time to dive into the information listed in the study details. Where will you receive treatment? What drugs or therapies will be studied? The key people to contact to learn more or apply to the clinical trial study are listed in the clinical trial posting.

When speaking with the appropriate clinical trial team members, they will likely ask you some questions to see if you are suitable for the trial. They will want to know about your type of cancer and its stage. Researchers may also ask what treatments you have already undergone. You can speak with a research coordinator to understand the study protocol and what you can expect to happen if you enroll in the study.

### What questions should I ask the clinical trial staff?

Because your oncologist cannot answer questions specific to a clinical trial, you must ask the clinical trial staff any questions about the clinical trial you are considering. Questions may have to do with timing, such as how long will the trial last and when it will begin enrolling volunteers?

Other questions may be related to the type of care you will receive during the clinical trial. What drug will you be taking, how often will you need to be seen by the trial's researchers or doctors,

and what types of scans or tests will be done to check progress? Who will monitor side effects and help you deal with them?

Yet other questions may have to do with financial responsibilities. Who will cover the cost of the clinical trial? Will your insurance cover all of the costs, and if not, who will be responsible for the remaining balance?

Some clinical trials offer to pay for the remaining costs after insurance, while others do not. It is essential to understand your financial responsibilities and what will be required of volunteers in a clinical trial before applying to it.

There will be many questions to answer before you ultimately decide whether or not to apply. Questions should be addressed to researchers from the study as well as your oncologist. Together, they can best assess your particular situation as it relates to the clinical study.

## Potential Headaches During the Application Process

Once you have found one or several trials that look promising, the next step is applying to the clinical trial. Application to the trial can be a challenging process for many reasons. Understanding the application criteria and completing the paperwork required can be confusing and stressful. You may also find collecting your medical records to be a very frustrating and time-consuming process.

Every potential clinical trial volunteer must submit their complete medical records to the clinical trial research team. The clinical trial team will pour over your records to determine whether your type and stage of cancer, as well as your health, qualify you for the study. If you are a fit, it means you have met the criteria to be included, called inclusion criteria. Unfortunately, sometimes you are not a fit because something in your records excludes your participation, known as exclusion criteria.

## How difficult is it to collect medical records?

One of the most daunting tasks is collecting and assembling your medical records. The last thing you wish to do while undergoing cancer treatment or applying to a breast cancer clinical trial is run around from provider to provider, collecting records and signing release forms, and then waiting for the records to arrive.

Many cancer patients collect their records along the way, sometimes immediately following each office visit, along with reports from tests and scans once they are complete. They may have it all assembled in one place.

However, many more cancer patients have not collected their records along the way and must backtrack to collect them and compile them once the documents are in their hands.

## Medical Records Ownership versus Access

Gathering and compiling your medical records can be a time-consuming chore. There are many issues to consider in trying to access and assemble your records.

Who owns medical records? Ownership of medical records is very complicated as there is no federal law that spells out who owns your medical records. Each state has different laws on who owns the medical records, though 29 states make no mention of medical records ownership.

The Health Insurance Portability and Accountability Act Privacy of 1996 (HIPAA) says that patients own the information inside their medical records. Patients must permit health care organizations to share their data with other health care organizations.

Regardless of who owns the records, access to the records is what is most important. By law, once you request a medical record, you have 30 days to receive it, though waiting 30 days is difficult if time is of the essence.

### Is there a uniform way to gather my records?

Unfortunately, there is also no consistent way to get your records. Each facility and provider may have different consent forms to fill out to access the records. Additionally, there is no incentive for each medical provider to get the records to you quickly. Some electronic health record (EHR) providers are legally allowed to withhold records if you have an outstanding balance or for other reasons.

Medical providers are only legally responsible for holding your records for seven to ten years, depending upon the state. If you were treated before that time and do not have your previous records, they may no longer exist. Sometimes medical practices close down, and if you don't have the records from your treatment there, you may no longer be able to access them.

Once you receive your medical records and have compiled them into one box or binder, you may have to scan them if they are all on paper, CD, and DVD format. Creating digital files makes for easy access and portability for submission to the clinical trial. Scanning and compiling records into one easily accessible file or folder takes time.

### Is there an easier way to assemble and manage records?

There are digital tools available that can help you [manage your breast cancer medical records](#). These include patient portals provided by clinical providers' practices, hospitals, mobile apps, and personal health records (PHRs).

[Ciitizen](#) is a private company offering a free online platform for breast cancer patients to manage their digital records. Ciitizen makes it easy to collect medical records by having you sign one consent form. They approach your caregivers and collect the records for you, sparing you the hassle of dealing with each provider. You sign one release form and focus on your health.



Once Ciitizen collects and compiles the information in one location, your records remain secure and protected digitally, and you control who gains access to them. You can share your history and records with doctors for second opinions, treatment options, and researchers for clinical trials all from one platform.

## What if I'm overwhelmed by the application process?

There is a lot of information to absorb about clinical trials, from investigating them, collecting your medical records, and applying them. You may have questions the clinical trial's research staff simply cannot answer for you. Your questions may relate to how it feels to go through a clinical trial and the decision-making process to apply to a clinical trial. There are groups that you can reach out to support you during your decision process.

You may want to speak to others who have been through a similar decision process about volunteering for a clinical trial or want more information in general about the impact it will have on your life.

Many nonprofit cancer support organizations can help you search for answers in understanding how clinical trials work and what it's like to be enrolled in one.

- [Breastcancer.org](https://www.breastcancer.org) is a leading patient-focused organization providing answers to questions specific to breast cancer for breast cancer patients. Breastcancer.org educates and empowers with expert information, and it includes a peer support community to help patients make educated decisions for themselves.

Its website contains a section about clinical trials that includes a discussion board for breast cancer patients entitled [Member Stories: Members Share Their Clinical Trial Experiences](#) pages.

- [Breastcancertrials.org](https://www.breastcancertrials.org) is a nonprofit service encouraging individuals with breast cancer to consider clinical trials as a routine option for care. You can browse their database for breast cancer clinical trials listings. Part of their website includes a guide of questions to ask researchers and doctors during the investigation process.

BreastCancerTrials.org recommends knowing as much as possible about the clinical trial process and understanding exactly what will happen to you during your participation in the clinical trial. They suggest you understand and be able to explain to others, including family members, precisely what the risks and benefits are when participating in a clinical trial.

- [Cancer Hope Network](https://www.cancerhope.org) (CHN) is a nonprofit organization providing one-on-one support to cancer patients. CHN provides connections across the U.S. to people just beginning their cancer journey with a volunteer who has completed treatment for the same or very similar cancer. Their volunteers include patients who have been in clinical trials and have firsthand knowledge about the clinical trials process.



Once a connection is made, the two people can have one or several phone calls to discuss their similar cancer experiences and the decision-making process that led the CHN volunteer to a clinical trial or other treatment.

- The [American Cancer Society's website](#) offers more information and support around clinical trials, including common questions and concerns patients may have. Their website also includes videos about answering questions you and your family members may have about volunteering for a clinical trial.
- [Survivingbreastcancer.org](#) is an online community whose mission is to empower those diagnosed with breast cancer and their families from day one and beyond. They develop programs and services for those diagnosed with breast cancer, living with metastatic breast cancer, and the spouses, family, and children of those who are diagnosed with breast cancer or have lost a loved one to the disease. They offer online support groups, education, and guides.
- The [National Breast Cancer Foundation, Inc](#) has an informational page about various support groups for breast cancer patients. Support groups are an effective way for breast cancer patients to relieve the stress and anxiety of going through diagnosis and treatment. They have listings of many free breast cancer resources to reach out to for support in addition to your friends and family.

## Understanding How to Find Clinical Trials for Breast Cancer

Hopefully, now you understand more about how to find clinical trials for breast cancer. Asking your oncologist about clinical trials is your first step. There are various online resources you can use to help find clinical trials that fit your specific type of breast cancer. Many of the websites listed above can help you narrow down the clinical trials near you that match your type of cancer and where you might want to volunteer.

Many organizations can help you navigate the process and guide you past any difficulties you may encounter, including accessing and obtaining your medical records. These private and nonprofit organizations, along with friends and family, can also help you understand, find, evaluate, and apply to a clinical trial while supporting you in your journey.