

## A WORKSHEET WITH QUESTIONS FOR YOU AND YOUR CARE TEAM

Clinical trials are research studies that help health care providers find the best cancer treatments. Clinical trials are not only for people with cancer who have tried other treatments. There are clinical trials for the newly diagnosed, for those who have had a recurrence, and for those who have had their cancer spread to other parts of their body. There also are trials for supportive care and symptom management. There are even clinical trials looking at improving mental and physical health.

This worksheet was created to help you talk to your health care team about whether a clinical trial is right for you. It is important to know if a clinical trial can be one of your treatment options.

## WHO SHOULD THINK OF PARTICIPATING IN A CLINICAL TRIAL?

Everyone facing a cancer diagnosis of any kind should be aware of clinical trials as a treatment option—but not everyone can or should be on a trial. A clinical trial can be a good option for people who are:

- Interested in getting access to the newest cancer treatments.
- Diagnosed at an advanced stage.
- Diagnosed with a rare, aggressive, or difficult to treat cancer.
- No longer responding to other treatments.
- At high risk for recurring or spreading after primary treatment.
- Interested in helping other cancer patients today and tomorrow by advancing cancer treatment.

The best way to know if you should consider being in a clinical trial is to talk to your health care provider and treatment team.

## TERMS YOU MAY HEAR

- **CLINICAL TRIAL:** A study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, symptom management, or treatment of a disease.
- **STANDARD OF CARE:** Treatment that is accepted by health care experts as a proper treatment for a certain type of cancer and that is widely used by health care professionals.
- **ELIGIBILITY CRITERIA:** Requirements that must be met for a person to participate in a clinical trial. These requirements help make sure that participants in a trial are like each other in terms of specific factors such as age, type and stage of cancer, general health, and previous treatment.
- **RANDOMIZATION:** Process by which participants in clinical trials are assigned by chance to separate groups that are given different treatments. This is done to ensure that every patient has an equal chance of getting either the standard of care or the new treatment being tested.
- **PLACEBO:** An inactive substance, sometimes called a “sugar pill.” Placebos are rarely used **by themselves** as a treatment in cancer clinical trials. Most clinical trials compare adding a new treatment vs. adding a placebo to the standard of care.
- **INFORMED CONSENT:** A process in which patients are given important information about the goals of the clinical trial, potential benefits, risks, side effects, and alternatives to participation. This is done to make sure patients understand the clinical trial and fully agree to participate.

## FINDING A CLINICAL TRIAL

Many people say they have never been told about clinical trials as treatment options. That's because not all providers who treat cancer offer clinical trials. And not all cancer centers offer clinical trials. If your provider does not talk to you about clinical trials, you should ask if they offer clinical trials or can refer you to one. If the answer is no, you may want to get a second

opinion from a specialist who does. A second opinion from a specialist who focuses on your specific type of cancer, even if it is over the phone or online, can help you learn more and feel confident about your treatment decisions. Advocacy groups that help people with your type of cancer can help you find a specialist.

### TIPS FOR FINDING A CLINICAL TRIAL

- Ask your provider what clinical trials are being offered at their site for your cancer type.
- Ask your provider if they know about a clinical trial they think would be right for you.
- If they don't know about any trials, ask for information about how to find a clinical trial.
- Ask an oncology nurse, social worker, or nurse navigator working with your doctor if they can help you find a clinical trial.
- Get a second opinion from a specialist at a cancer center that offers clinical trials, such as an NCI-designated cancer center. To find one visit: [www.cancer.gov/cancer-centers](http://www.cancer.gov/cancer-centers)
- Look at the website of a cancer center near you or call to see what trials they have open.
- Call the Cancer Support Community Helpline at 888-793-9355 or call a patient advocacy group for your type of cancer and ask about clinical trials.

### CONTACT THESE PROGRAMS OR USE THEIR WEBSITES TO SEARCH FOR CANCER CLINICAL TRIALS

- American Cancer Society Clinical Trial Matching Service: 800-303-569 or [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials)
- Centerwatch: 617-856-5900 or [www.centerwatch.com](http://www.centerwatch.com)
- Cancer Support Community: 800-814-8927 or [www.CancerSupportCommunity.org/ClinicalTrials](http://www.CancerSupportCommunity.org/ClinicalTrials)
- ClinicalTrials.gov provided by the U.S. National Library of Medicine: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- National Cancer Institute Clinical Trials Registry: 800-422-6237 or [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)
- National Cancer Institute's Designated Cancer Centers: [www.cancer.gov/cancer-centers](http://www.cancer.gov/cancer-centers)
- OncoLink Cancer Clinical Trials: [www.oncolink.org/cancer-treatment/clinical-trials](http://www.oncolink.org/cancer-treatment/clinical-trials)
- Triage Cancer Clinical Trials: [www.triagecancer.org/clinical-trials](http://www.triagecancer.org/clinical-trials)
- TrialCheck: [www.cancertrialshelp.org/cancer-trial-search](http://www.cancertrialshelp.org/cancer-trial-search)
- See the last page for a full list of resources.

## KEEP IN MIND

There are thousands of cancer clinical trials taking place throughout the U.S., but not all trials are offered in every city or state. You may be able to find a provider near you that is taking part in a trial for your type of cancer. But sometimes the only trials that are right for you may be in another city or state. You may have

to think about whether you are okay with changing doctors, traveling—and the cost of travel—to take part in a clinical trial that offers access to a new therapy for your specific type and stage of cancer. Some trials may offer financial help for your travel and lodging.

Even though there are lots of clinical trials taking place, it can take time to find one that is right for you. You will need to:

- Know as much as possible about the type of cancer you have. This includes the type, subtype, the stage, any treatments you have had, and any medical problems that could cause you to be ineligible for a trial. You will also need to have copies of test results for tumor biomarkers, hereditary cancer mutations, or scans.
- Keep all your medical records in one place. This will make it easier for you to provide the clinical trial team with the information they need to see if you are a good fit for the study.
- Discuss the possibility of any additional costs. While most trials cover the cost of the treatment being studied, they expect your health care plan to cover the cost of “standard” care. Check with your health care plan to see if they would cover such costs. Also see if any additional costs are covered—childcare, transportation, lost job time—that might result from additional doctor’s appointments, clinic visits or procedures.
- Review the clinical trial’s eligibility criteria (how they decide who they let in). These can be based on age, the cancer’s stage, treatments a patient already had, co-morbid conditions, and the cancer’s biomarkers. You may find a trial you are interested in but learn you don’t meet the criteria.

## TALK TO YOUR HEALTH CARE TEAM

You will want to think about your goals and values as you make treatment decisions. Your age, overall health, and treatments you have had can all influence your goals and values. Ask your health care provider all of your questions and then take time to think about the

answers. Take someone with you to your doctor’s visits to listen and take notes and then help you think about what you’ve learned. This will help you decide what is right for you.

## QUESTIONS FOR YOUR HEALTH CARE TEAM

These are some questions that can help you talk to your health care team about clinical trials. You can add more questions to the end of the list. Bring this with you to your provider's office.

### GENERAL QUESTIONS

- What type of cancer do I have?
- What stage of cancer do I have?
- Where can I get a second opinion?
- Are there any biomarkers I should be tested for? Could that help me qualify for a clinical trial or for other therapies?
- What trials are available for the type of cancer I have?

### QUESTIONS ABOUT SPECIFIC TRIALS

- Where are these trials offered?
- What are the possible benefits of this trial?
- What side effects might I experience?
- Are there extra biopsies, tests, or visits that are part of this trial?
- Have any other trials been done with this drug/treatment in people with the type of cancer that I have?

Other questions I have: \_\_\_\_\_

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## QUESTIONS FOR THE CLINICAL TRIAL TEAM

The clinical trial team will talk to you about why the study is being done. They will also tell you about the types of side effects that you may have and how they will be managed. The process of learning about the trial and the treatments you will be given is called informed consent.

It is important that you know why the clinical trial is taking place and how it will affect you. These are some questions you can ask the clinical trial team. You can add more questions to the end of the list. Bring this with you when you meet with the clinical trial team.

### HOW DOES THIS CLINICAL TRIAL WORK

- What treatments will I have as part of this trial?
- What phase is the trial in?
- What are their expected side effects? How much is known about the side effects of this treatment?
- What benefit might I get from participating in this trial?
- What tests will I need to have, and how often will I need to have them?
- Will these tests hurt? How much time do they take?
- Would I be getting these tests if I were not in the study?
- Does everyone in the study get the experimental therapy?
- Does the study compare a “standard of care” treatment to the experimental treatment?
- How many people in the study will get the experimental treatment?
- Will I know if I’m getting the experimental treatment?
- Are there placebos (sugar pills) used in this study?
- If I received a placebo and this is successful, will I get the drug at the end of the trial for compassionate distribution?

### QUESTIONS ABOUT SIDE EFFECTS, RISKS AND BENEFITS

- What are the possible risks, side effects, and benefits of the study treatment? How does that compare to the standard treatment I would get if I were not in the study?
- What are my alternative therapies if I do not participate on this trial?
- How will I know if the treatment is working?
- How will my medical records be shared?

- How will you protect my health while I am in the study?
- What happens if my health gets worse during the study?
- How will the study affect my everyday life?
- How will my family stay informed?

### **QUESTIONS ABOUT LOGISTICS AND COSTS**

- How long will I be in the study?
- Can I stop being in the study at any time?
- If I want to stop being in the study, what will happen?
- If I stop being in the study, will this affect my normal care?
- Where will the study take place?
- Will I will need to stay in the hospital?
- Will the clinical trial cover costs for getting to the trial site or for parking at your center?
- What costs will my health insurance cover?
- What costs will I have?
- Can I continue my treatment for other health problems?
- Who will be in charge of my care while I am in the study?
- Will I still see my own doctor?
- What will be my primary physician's role?
- Will my doctor know how I am doing on the study?
- What happens once the study ends?
- When will you be able to tell me the results of the study?
- Who do I call if I have more questions?
- What steps will you take to ensure my safety and privacy?

Other questions I have: \_\_\_\_\_  
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## THINK ABOUT YOUR TREATMENT GOALS AND VALUES

When you talk to your provider about clinical trials, you will also want to think about the goals that you have for your life. Possible goals may be to live as long and as well as possible, contribute to progress by taking part in research, make it to a special event or milestone, or find

cutting edge treatments. Let your health care team know about your treatment and personal goals.

Here are some questions to help you think through your goals:

Physical Health and Well-Being	<i>What is most important for you to be able to do? What are you worried about?</i>
Family and Social Relationships	<i>What's going on in the lives of others that is important to you? How can your family and friends help you during treatment?</i>
Work/School	<i>Do you want or need to continue working? Can you adjust your schedule or responsibilities?</i>
Community/ Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/ involved in your community? Are you able to participate in support groups?</i>
Other	<i>What else is important to you? Will the treatment affect your ability to travel?</i>
Top Treatment Goals	<i>What are your top goals for treatment?</i>
Clinical Trial	<i>Is this clinical trial the best treatment for me to meet these goals?</i>

Talk to your health care provider about your goals and ask if a clinical trial is the best treatment for you to meet your goals.

Take time to review the answers to all of your questions. Ask more questions if you need to.

Talk over your decision about whether or not to take part in the clinical trial with trusted family members or friends.

Taking the time to think about what is important to you will help you decide whether a clinical trial is right for you.

## Clinical Trials Resources

[American Cancer Society's Clinical Trial Matching Service](#) • 800-303-5691 • [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials)

[CenterWatch](#) • 617-856-5900 • [www.centerwatch.com](http://www.centerwatch.com)

[Cancer Support Community](#) • 800-814-8927 • [www.CancerSupportCommunity.org/ClinicalTrials](http://www.CancerSupportCommunity.org/ClinicalTrials)

[National Cancer Institute's Clinical Trials Registry](#) • 800-422-6237 • [www.cancer.gov/clinicaltrialsNational](http://www.cancer.gov/clinicaltrialsNational)

[National Cancer Institute's Designated Cancer Centers](#) • [www.cancer.gov/cancer-centers](http://www.cancer.gov/cancer-centers)

[OncoLink Cancer Clinical Trials](#) • [www.oncolink.org/cancer-treatment/clinical-trials](http://www.oncolink.org/cancer-treatment/clinical-trials)

[Library of Medicine's Clinical Trials Search](#) • [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

[Triage Cancer Clinical Trials](#) • 424-258-4628 • [www.triagecancer.org/clinical-trials](http://www.triagecancer.org/clinical-trials)

[TrialsCheck](#) • [www.cancertrialshelp.org/trialcheck](http://www.cancertrialshelp.org/trialcheck)

## Cancer Support Community Resources

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

**Open to Options®** — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs at [www.CancerSupportCommunity.org/FranklySpeakingAboutCancer](http://www.CancerSupportCommunity.org/FranklySpeakingAboutCancer).

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation)

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

**THIS PROGRAM WAS MADE POSSIBLE WITH FINANCIAL SUPPORT FROM:**



For more information and resources, please visit the CSC Cancer Clinical Trials page at [www.CancerSupportCommunity.org/ClinicalTrials](http://www.CancerSupportCommunity.org/ClinicalTrials). For print copies of this worksheet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org) or call 888-793-9355.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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