

If You Want To Find Ways To Prevent Cancer...

Learn About Prevention Clinical Trials



**“I decided to participate in a clinical trial to
help myself and my community.”**

U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

You may be reading this because...

You want to learn about ways to:

- Lower your chances of getting cancer
- Help doctors learn more about preventing cancer.

This brochure tells you about taking part in a study that may help find ways to prevent cancer.

A prevention trial is a research study.

A cancer prevention trial is a study of a large group of people. A prevention trial tries to find better ways to prevent people from getting cancer or lower the chances that people will get it.

A prevention trial is different from a treatment trial.

A treatment trial finds better ways to **treat** cancer in people who already have it.



“After my mother died from breast cancer, I wanted to do whatever I could to keep from getting cancer.”

Many people take part in prevention studies.

Men and women of all ages and backgrounds take part in these studies. Usually:

- They are healthy people.
- They are people who want to lower their chances for getting a certain cancer.

Each study has different rules about who can join.

For example:

- One study may have people of a certain age or sex.
- One study may have people with a certain family history.

There are prevention studies for men and women of all ages and backgrounds. You may know someone—a friend, relative, neighbor, or co-worker—in a study now.



People are asked to *take* or *do* something.

In some studies, people are asked to do something **to lower** cancer risk. For example:

- Exercise
- Follow a special diet.

In most studies, people are asked to take something **to lower** cancer risk. For example:

- Take a medicine
- Take a vitamin.

When people are asked to *take* something, it may be:

- **The standard agent:** A medicine or vitamin that is already used to prevent a certain cancer
- **The study agent:** A new medicine or vitamin that doctors hope will be better than what is already used to prevent a certain cancer
- **The placebo:** A pill that has no medicine at all. It helps doctors figure out whether or not the study agent really works to prevent cancer.



Most studies compare groups of people.

People who join a study are placed in different groups. Each group takes a different medicine or vitamin.

Each person has the same chance of being placed in any of the groups.

- No one can pick the group he or she is in.
- No one knows which group he or she is in—not even the doctors.
- This keeps the study fair, honest, and accurate.

Along the way, researchers will compare the groups to find out if there were any differences. Then they will be able to tell us which medicine or vitamin works the best to prevent cancer. When researchers can tell what works best, the study is over. If it is found to be unsafe, the study will be stopped right away.



If you are thinking about joining a study, you will get a lot of information.

Study staff will talk with you.

Before you join a study, a doctor, nurse, or another person who works on the study will tell you many things:

- Why the study is being done
- What will happen during the study
- What side effects you may have
- How the study may affect your daily life.

They will give you information in writing.

They will give you a **consent form** that tells you about the study. If you decide to take part in the study, you will be asked to sign the consent form. This means that you understand the benefits and risks and you choose to join.

You can and should ask questions.

You should ask questions about anything you do not understand.

You can change your mind and drop out.

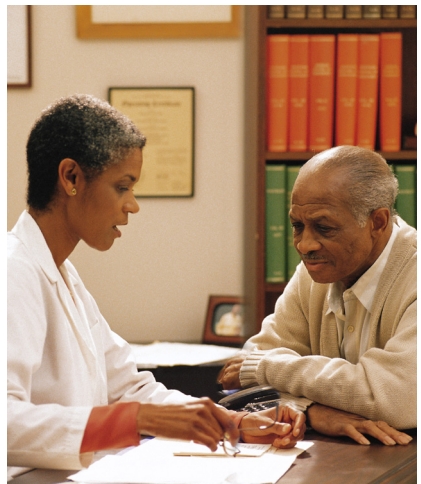
Even if you sign the consent form, you can still change your mind and stop at any time. Dropping out of a study will not affect your health care in the future.

You have rights. They will be protected.

Groups of experts at the national and local levels approve research studies before they begin.

- One of the most important groups is called an institutional review board (IRB).
- The IRB's job is to review research studies to make sure they are run safely and fairly.
- The IRB includes doctors, nurses, clergy, and people from the community.
- Researchers may collect a lot of information about you. But it will be kept as private and confidential as possible.

“I used to think that people in medical studies were just ‘guinea pigs.’ But I found out it wasn’t like that. I felt that my rights were protected.”



There are a lot of things to think about before you join a study.

Benefits

- You will see a health care provider during the study. But you should still see your own doctor for routine medical care.
- You take an active role in your own future health.
- You may lower your chance of getting cancer.
- You will have the chance to help your children and others who may get cancer in the future.

Risks

- The medicines or vitamins you take may have side effects.
- The medicines or vitamins you take may not work as well as proven ways to lower your chances of getting cancer.
- You may not lower your chances of getting cancer.

Costs and Time

- Research studies have costs. And health insurance does not always pay for all your costs in a study. So ask your doctor, nurse, or social worker about these costs before you decide to join.
- The study may take some of your time.

The decision to join is up to you.

- First, find out if there are studies that are right for you. Ask your doctor or nurse.
- Then, think about why you may want to take part in that study. Weigh this against why you may not want to join.
- Be aware that choosing to take part in a cancer prevention trial is just one way you can take care of your health.
- Talk with your family, friends, and doctor. But YOU are the one who should be happy with your final decision.

“I felt like what I was doing could make a difference in someone’s life someday.”



Here are some questions to ask your doctor or nurse.

About Cancer Prevention Studies

- Is there a prevention study that I can participate in?
- Why is the study being done?
- What is the difference between the two groups in the study?
- How long will the study last?
- How will I be told about the study results?

About Benefits and Risks

- How can this study help me?
- What are the side effects of the medicines or vitamins being used in the study?

About Protecting Your Rights

- How do I know this study is safe?
- How will my health be checked during the study?
- How will my health information be kept private?

About Deciding To Take Part

- What will I have to do if I take part?
- How could the study change what I do every day?
- Where will I have my medical exams?
- Will I be able to see my own doctor?
- What will I have to pay for if I take part in this trial?
- Will I be able to find out about the results?

You can find out more.

- If you have questions about cancer prevention trials, ask your doctor, nurse, or other health care provider.
- To find out more about cancer prevention trials in your area, ask your doctor.

or call:

National Cancer Institute

Cancer Information Service

1-800-4-CANCER (1-800-422-6237)

TTY (hearing impaired): 1-800-332-8615

or visit:

the Web at: www.cancer.gov

“I wanted to help myself and other people, and this study was right for me.”





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