

Participate in Observational Studies

Observational studies are research studies in which researchers collect information from participants or look at data that was already collected.

In observational studies, researchers follow groups of people over a period of time. Depending on the study, groups may include healthy people, people with cancer, or people who are at high risk for developing cancer, such as those with a family history.



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How observational studies help cancer research

Observational studies can help researchers learn more about cancer and suggest paths for future research that may lead to insights such as:

- how specific cancers form, grow, and spread
- genes that cause cancer to develop at a high rate within certain groups
- exposures or behaviors that may increase the risk of cancer
- clues to help prevent cancer
- clues that lead to new treatments
- patterns and trends of new cancer cases
- the experiences of people who have had cancer in the past

Types of observational studies

There are different types of observational studies. Two examples include natural history and longitudinal studies.

Natural history studies look at certain conditions in people with cancer or people who are at a high risk of developing cancer. Researchers often collect information about a person's and their family's medical history, as well as blood, saliva, and tumor samples that may be studied to learn more about how cancer develops or how it responds to treatment.

Longitudinal studies gather data on people over time, often to see whether those with different exposures have different cancer outcomes. Examples include those with different kinds of diets, smoking history, or other traits.

What to expect

What you do as part of an observational study depends on the study. In some studies, you may be asked to fill out surveys or questionnaires. Researchers may ask about your medical history and that of your family. They might ask you to provide tissue samples, such as blood, saliva, or—if you have cancer—your tumor. Some studies may require your medical records. For some studies you might be asked to come in for an in-person visit with the research team.



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Depending on the study, you might provide samples and information just once, or many times over the course of the study.

Possible risks and benefits

There are few risks to taking part in an observational research study. One possible risk is the accidental release of information from your health records. To prevent this from happening, there are security measures in place to protect your privacy.

A benefit of taking part in an observational study is knowing that you will help doctors learn more about cancer. These studies help create a foundation that can lead to further research that may help people with cancer in the future. Or they might help people in the future avoid cancer.

Your rights

Before you join a study, the research team will make sure you understand:

- why the study is being done
- what will happen during the study
- how it may affect your daily life

Once you understand the study and decide to take part, you will be asked to sign a consent form. But even after you sign the form, you can change your mind and leave the study at any time.

Costs and expenses

Most observational studies are free to those who take part. As you think about joining an observational study, be sure to ask the study team about costs.

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