



Ministry of Health, Welfare and Sport

# Medical research



## What is medical research on human subjects?

Medical research helps advance medical science. The purpose of medical research can be:

- to develop better treatments for diseases and conditions;
- to learn more about a disease or how the body works;
- to find better ways to detect and diagnose diseases.

Medical research is different from diagnostic examination, when a doctor examines you to find out what's causing your health problems.

The people who participate in medical research are often referred to as 'human subjects' or simply 'subjects'. Both sick people and healthy people can participate as subjects in medical research. Participation is always voluntary.

## What are the benefits for you?

Everyone who takes part in medical research has their own reasons for doing so. Perhaps you want to help advance scientific knowledge. Sometimes the research project will involve testing a new treatment that you hope to benefit from. Or that you hope others will benefit from, because research can increase our understanding of a disease process and lead to new methods of treatment. The researcher can tell you more about the possible benefits of participation.

## Things to bear in mind

Participating in medical research can be taxing and time-consuming. The treatment might have risks or side effects. If the treatment is experimental, researchers don't always know what the primary effects and side effects will be. The demands and the risks involved in participation will depend on the type of research, the type of treatment and possibly extra tests to measure the treatment's impact. The researcher will always give you this information.

## You decide

The decision to take part in a medical study is up to you. Even if your doctor asks you to take part, you can always refuse. You can also decide to stop taking part in a medical research project at any time – even after it has started – and you don't have to say why. Quitting a project will have no effect on the treatment you already received before the research project. Sometimes, though, leaving immediately would be harmful to your health. So if you want to leave, always tell the researcher first.

## Who is responsible for checking that the medical research is allowed?

In the Netherlands there are strict rules for medical research involving human subjects. A special committee looks at each research proposal in advance. The research cannot start until the committee has approved it. The committee assesses the research proposal to make sure:

- it is useful
- it is well designed
- the information given to participants is accurate
- the risks are not excessive
- it does not ask too much of participants.

The committee members know a great deal about research, but none of them have a personal interest in the research.

## Right to protection of personal data

During the course of the research, the researcher will collect data about you. This data is treated confidentially and is given a code, which will be used in any reports on the study. So your name will never appear in any report about the study.

## More information

If you decide to participate in a study, you will receive a letter containing detailed information about the study. You'll also be given the name of an independent expert you can contact if you have questions. And you can always put questions to the researcher, too.

For general information about participating in medical research, go to [www.government.nl/topics/medical-research](http://www.government.nl/topics/medical-research).