## Health for Participating in Clinical Trials: How do I decide?

Here is some info to help you make decisions about clinical trials. You can learn more about clinical trials at healthforallproject.org.

## **Basic Info**

#### What are clinical trials?

Clinical trials are studies that test the effects of medical treatments and procedures. Researchers need people to volunteer so we can improve health care.

#### How do clinical trials make a difference?

Clinical trials help find better ways to treat, prevent, and detect disease.

#### Who takes part in clinical trials?

A lot of people take part in clinical trials. It's important for clinical trials to include people from all walks of life. This way, new tools and new treatments can work better for all people.

#### What questions should I ask about a clinical trial?

Researchers will explain the clinical trial to you through an "informed consent" process. During the informed consent process, make sure you understand:

- What is the purpose of the research study?
- Who approved the study?
- Who is funding the study?
- What procedures, tests, and treatments are part of the study?
- Do participants cover any costs to take part in the study?

- Do participants receive payment for taking part in the study?
- What are the potential risks of the study?
- What are the potential benefits of the study?

You can find more questions to ask about clinical trials at healthforallproject.org.

## **Finding a Clinical Trial**

Gather details about your health.

- Clinical trials have their own guidelines to decide who can take part. Researchers call these "**eligibility criteria**".
- Eligibility criteria can be very specific. For example, some studies recruit people with a very specific form of a disease. Others might recruit people who already received a specific treatment. Each study's eligibility criteria are different.
- You can't be in a study if you don't match its **eligibility criteria**. So, it's important to know details about your health.

#### Search for clinical trials.

- National resources
  - o Find clinical trials in Illinois through clinicaltrials.gov
  - o Find clinical trials that the National Cancer Institute supports
- Local resources in Chicago
  - o Find clinical trials at Northwestern Medicine
  - o Find clinical trials at UChicago Medicine
  - o Find clinical trials at Rush University Medical Center

#### Join a registry.

You can join a registry if you want researchers to contact you about clinical trials in the future. To join a registry, you fill out questions about yourself. Then, researchers can contact you if their study seems like a good fit.

- <u>ResearchMatch is a free registry the National Institutes of Health</u> <u>supports</u>.
- You can find a list of registries for specific medical issues on the National Institute of Health websites.

## Making a decision about clinical trials

Take a closer look at trials that interest you.

- Look at studies that might interest you to see if you qualify.
  - o Do you meet the **eligibility criteria**?
  - Does the study's main goal match your main goal for your health?
  - o Are you able to get to the study location?
  - o Does your schedule match the study's schedule?
- Contact the researchers or talk with your doctor if the study sounds like it might be a good fit.

#### Ask questions and talk with your health care provider.

- If a clinical trial interests you, you can reach out to the research team on your own. You can ask questions about the study. You can find out if you do not meet the **eligibility criteria**.
- If a clinical trial interests you, you can also ask your health care provider to reach out to the research team for you. They can

ask important questions about the risks and benefits of the study.

- If you signed up for a registry, researchers might reach out to you about a study. You can respond and ask for more information. You can also ask your health care provider to talk to the research team about their trial.
- Remember: only you and your health care providers can make the best decision about a clinical trial. Seek help from a medical professional for any medical issues or questions.

# The risks and benefits of taking part in a clinical trial in general

Each study is different, but there are some risks and benefits to taking part in a clinical trial in general.

#### Benefits of taking part in a clinical trial:

- You might be able to try a new and improved treatment sooner than other people.
- You might receive extra attention to your health, medical care, and safety.
- The trial will help researchers learn more about health and disease. You will help people with illnesses in the future.

#### Risks of taking part in a clinical trial:

- The new treatment might not work better than current treatments.
- Even if a trial treatment works for some people, it might not work for you.

- You might need to spend more time at doctor visits as part of the study.
- Health insurance might not cover all of the patient care costs.

### Notes on this document

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We offer information to help people learn more about clinical trials. We do not mean this document to be a complete guide. We also do not mean to provide any medical advice in this document. Seek help from a medical professional for any medical questions.

The Health for All team made this document with information from three sources. The first is <u>the</u> <u>National Cancer Institute's page</u>, "Deciding to Take Part in a Clinical Trial". The second is <u>the</u> <u>National Cancer Institute's page</u>, "Steps to Find a Clinical Trial". The third is the <u>National Institute</u> <u>of Health's page</u>, "<u>NIH Clinical Research Trials and You: The Basics</u>". We gathered the information from these sites on May 23, 2018 to create this document. We last updated this document on May 24, 2018.You can find the full details on these sources below.

#### Sources

- National Institutes of Health. "The Basics". *NIH.gov* National Institutes of Health, last reviewed 27 October, 2017. Web. Accessed May 23, 2018. [https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics]
- National Cancer Institute. "Deciding to Take Part in a Clinical Trial". *Cancer.gov* National Cancer Institute, last reviewed 22 June, 2016. Web. Accessed May 23, 2018. [https://www.cancer.gov/about-cancer/treatment/clinical-trials/taking-part]
- National Cancer Institute. "Steps to Find a Clinical Trial". *Cancer.gov* National Cancer Institute, last reviewed 23 June, 2016. Web. Accessed May 23, 2018. [https://www.cancer.gov/aboutcancer/treatment/clinical-trials/search/trial-guide]