Should I participate in a clinical trial?

How to make an informed decision about whether or not to join a clinical trial

How can you find more information?
Visit CISCRP’s Education Center for videos, brochures, frequently asked questions and other information about clinical trials.
ciscrp.org/education-center
Visit the AGA GI Patient Center for more information about IBD, Crohn’s disease and ulcerative colitis at patient.gastro.org.

What should you do next?
Get organized. Keep your questions, answers and anything else that you learn in one place. This can help you feel more prepared to make an informed decision. You can use a notebook, computer or smartphone to keep track of what you learn.

Find out more. If you think of additional questions or other things you are not sure of, follow up with a medical professional, or research on your own to find the answers.

Make a list of pros and cons. Once you have asked all your questions and have all the information you need, you can use your list of pros and cons to help you understand how participating might affect you. This can help you make an informed decision about participating in clinical research.

Remember that being in a clinical trial is optional. If you join a trial, you can stop participating at any time for any reason. The staff at the trial site will help you do this safely.

Questions to ask family, friends and others you trust
Talk to family, friends, counselors and other people you trust. Talking to people with different views and information can also help.
- Can you attend doctor visits with me to help make sure I understand everything?
- Can you take notes for me during doctor visits?
- Can you help me organize the information I get?
- Would you be able to watch my kids, pets or house while I go to appointments?
- Would you be able to give me a ride if I need it?
- What do you think about me participating in a clinical trial?
- What do you think about clinical trials in general?

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What to expect in an IBD clinical trial

Inflammatory bowel disease, or IBD, is a medical condition where a person has chronic inflammation in their digestive tract. The two most common types of IBD are Crohn’s disease and ulcerative colitis (UC). Before you join a clinical trial, you and the trial staff will discuss your health and decide if participating in the trial is right for you. When you begin a clinical trial, the trial staff will provide you with a schedule of your visits and what to expect at each one. Some or all the following events can occur during a visit to the study site: overall health check, receiving the trial treatment or placebo, blood testing, other procedures to look at your digestive tract.

Questions to ask yourself

Spend time thinking about why you want to participate. Gather as much information as you need to make a decision that you feel good about. There is no right or wrong choice.

- Why do I want to participate?
- Why don’t I want to participate?
- Does participating fit with my values, beliefs and preferences?
- What would I like to get out of participating?
- What amount of risk am I willing to take?
- Do I have enough time to participate?
- Are there things that I would have to give up to participate? If so, am I willing to do that?
- Would I need to arrange for child care or for the care of another family member if I participate?

Questions to ask a health care professional

Talking with a doctor, nurse or other health care professional about participating in a clinical trial can help you understand the risks and benefits to your health and condition.

It’s important to talk to the team doing a trial, as well as health care professionals who are not part of the trial team. They might have different perspectives to help answer your questions.

- What are the possible risks of participating?
- What are the possible benefits of participating?
- Do the possible benefits outweigh the risks?
- How would the risks and benefits of a trial treatment compare with my current treatment?
- How might participating affect my daily life?
- Would I have to pay for any part of a clinical trial? Will my insurance cover these costs?
- What are the current treatment options for my condition?
- Are there any clinical trials that would be a good option for treatment?
- Can I get the materials in a language I want? Can I get a translator?
- Will you be part of my care team if I participate in a clinical trial?