

Talking to your care team about participating in a clinical trial

Having a list of questions can help make sure all your concerns are discussed.

Print out this worksheet to prompt questions and take notes at your doctor visit.

Questions on the purpose and design of the clinical trial

- What is the purpose of the trial?
- Why do the researchers believe that the treatment being studied may be better than the one being used now? Why might it not be better?
- How long will I be in the trial?
- How is this gene therapy administered?
- Who is eligible to participate? Do you think I am eligible? Do you think my child is eligible?
- Would we need to do any tests to know for sure whether I can participate?
- How will I know if the treatment is working?
- How will I be told about the trial's results?
- Who can I speak with about questions I have during and after the trial?
- Who will oversee my care?

Questions about risks and benefits

- What are the possible side effects or risks of the new treatment? What are the chances they will occur?
- What are the possible benefits? What are the chances they will occur?
- How do the possible risks and benefits of the study drug compare with those of standard treatment?
- Can I decide to leave the trial at any point if I want to?

Questions about costs

- Will I have to pay for any of the treatments or tests?
- What costs will my health insurance cover?
- Who can help answer questions from my insurance company?

Questions about daily life

- How often will I have to go to the hospital or clinic?
- Will I have to stay in the hospital during the clinical trial?
If so, how often and for how long?
- Will I have to travel long distances? Who will pay for travel?
- What follow-up care is involved after treatment (such as testing or doctor visits)?
- Will I be required to do any additional activities at home (such as keeping a diary of my day)?

My questions

My notes

Please note: This document is not meant to provide medical advice. The questions here are not a complete list—they are suggestions to help you get started. When speaking with an HCP, decide on the priorities that matter most to you.

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