Questions to Ask the Research Team

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Key Messages:

- It is important to learn as much as possible about a clinical trial before participating. Talking with your doctor and the research team can help you understand what to expect from the clinical trial.
- Consider asking questions specific to the clinical trial being recommended, including what will be required of you to participate and what costs may be associated with the clinical trial.

Before deciding to participate in a clinical trial [2], you should know as much as possible about the study. It is important for you to feel comfortable asking questions, and the staff should answer them in a way that you can easily understand.

Think of your questions before the appointment, and bring along a way to keep track of the answers you receive. For example, you may want to write down the questions you want to ask and the responses you get on a notepad, ask a friend or relative to come with you for support and to hear the responses to your questions, bring a tape recorder so you can replay the discussion after you get home, or make note of them on your phone [3].

General questions about clinical trials

- What is a clinical trial?
- Why are you recommending a clinical trial?
- What clinical trials are appropriate for me?
- What is ?informed consent [4]??
- Where can I learn more about clinical trials?

Questions about a specific clinical trial

- What is the purpose of this clinical trial?
- Why is this specific approach being studied?
- Why does the research team think the treatment, drug, or medical device will work?
- What are the eligibility criteria to enroll in this study, and am I eligible for this clinical trial? If not, can you recommend other options?
- Why are you recommending this clinical trial for me?
- What other treatment options are available to me, including other clinical trials?
- Who or what organization is sponsoring the clinical trial?
- Who has reviewed and approved this clinical trial?
- Does this clinical trial include the use of a placebo [5] (also called a ?sugar pill?)?

Questions about your participation in a specific clinical trial

- Where is the clinical trial taking place (sometimes called the study site)?
- How often will I have to go to the study site?
- How long will the clinical trial last?
- What are my responsibilities during the clinical trial?
- What kinds of treatments, tests, scans, and other procedures will I have during the clinical trial? How often?
- Will they hurt? If so, for how long?
- What is a biospecimen (tissue sample), and what types are needed for this trial?
- What will be done with the tissue samples? Do I need to donate these in order to participate in the study?
- What tests will be done on the tissue sample?
- What is a biomarker? Will these be tested for in the clinical trial?
- How will the tests and procedures needed in this study compare with tests and procedures I would need to have outside of this study?
- Will I be able to take my regular medications during the clinical trial?
- What medications, procedures, or treatments must I avoid while in the clinical trial?
- Will I have to be in the hospital during the clinical trial?
- Who will know that I am participating in a clinical trial?
- Can I talk to other people in this clinical trial?

- Will I be able to find out the results of the clinical trial? When?
- Will the study researchers work with my doctor while I am in the clinical trial?
- Who will be coordinating my overall health care?
- Who do I contact if I experience side effects or other problems during the clinical trial?
- Who will provide my medical care after the clinical trial ends?

Questions about risks and benefits of a specific clinical trial

- What are the possible advantages of participating in this clinical trial?
- What are the possible risks of participating in this clinical trial?
- How do the possible risks and benefits of this clinical trial compare with the standard treatments for me? How do they compare with other clinical trials open to me?
- What are the possible short-term side effects of both the approved treatments and those being tested in this clinical trial? How can they be managed?
- What are the long-term side effects and how can they be managed?
- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- What happens if my health gets worse during the clinical trial?

Questions related to the cost of a clinical trial

- What costs can I expect if I choose to participate in this clinical trial?
- What are the charges likely to be?
- How do these costs compare to the costs of my other treatment options?
- Is my insurance likely to cover my expenses from this clinical trial? How can I find this out beforehand?
- If I'm worried about managing the costs related to my cancer care [6], who can help me with these concerns?

More Information

Questions to Ask the Doctor [7]

Clinical Trials [8]

Additional Resources

National Cancer Institute: Participating in a Clinical Trial: Questions to Ask Your Doctor [9]

National Cancer Institute: What are Biospecimens and Biorepositories [10]

Links:
[1] http://www.cancer.net/about-us
[2] http://www.cancer.net/node/24877
[3] http://www.cancer.net/node/25555
[4] http://www.cancer.net/node/24386
[5] http://www.cancer.net/node/24390
[6] http://www.cancer.net/node/24865
[7] http://www.cancer.net/all-about-cancer/newly-diagnosed/questions-ask-doctor
[8] http://www.cancer.net/node/24863
[9] http://www.cancer.gov/clinicaltrials/learning/questions-to-ask-about-participating
[10] http://biospecimens.cancer.gov/patientcorner/default.asp