

## **What to consider when joining a clinical trial**

The decision to join a clinical trial is personal and you should weigh the benefits and risks of participating as well as the time commitment required. This section will cover the questions you should ask the research team.

### **Questions to ask when considering a specific trial.**

Clinical trials that test potential drugs and therapies in people with cystic fibrosis are a major part of CF research. They take place at CF centers throughout Australia and enrol people with CF of all ages.

When you are considering whether to join a clinical trial please feel free to ask as many questions as you need. To learn more before the clinical trial begins, you will meet with the study's CF doctor or research coordinator, a team member on staff chosen by the principal investigator to assist in conducting the clinical trial.

A type of research — also called interventional research — that follows certain government guidelines for testing drugs on people. Researchers observe how the drug affects the body under highly controlled conditions and whether the treatment is helpful.

### **Here are some tips to help you prepare.**

Remember, it's best to write down your questions ahead of time and bring them to the meeting. And to reiterate another positive piece of advice, bring a family member or friend to help you feel more comfortable when talking with the CF doctor or research coordinator. They may ask other questions that will help you as you decide – even questions that may not have occurred to you.

Part of the “informed consent” process is gaining a complete understanding of what's ahead, so if you don't comprehend something, don't hesitate to ask! The research team expects that you will have questions for them, so as mentioned elsewhere don't worry about bothering them or asking a “stupid” question. If you are not sure what to ask, here are some suggestions:

What is the purpose of the clinical trial?

Why do researchers think that this particular CF drug or treatment might work?

Who is paying for and supporting the study?

Who has reviewed and approved the study?

Who will be in charge of my care?

Will the trial benefit me or others?

How long will the study last?

What will my responsibilities be if I participate?

What kinds of tests will be involved?

Do I need to stop any of my current CF medications?

How do the possible risks, side effects and benefits compare with my current treatment?

Can I talk to other people who are participating in the study?



Will I be compensated for my participation in the clinical trial and/or travel expenses?

What is the time commitment for me?

Will results of the clinical trial be given to me and, if so, when?

Whom should I communicate with during the trial: the research team, my CF care team or both?