Common Myths & Facts About Clinical Trials

Clinical trials are very important to cancer care. Trials are how we discover new and better treatments, ways to prevent side effects, and improve survival rates. A small percentage of adult cancer patients participate in a clinical trial. There are several myths that contribute to this poor rate of participation by adults. So, let's look at the facts…

Childhood cancer survival is a true clinical trial success story. Cure rates for all childhood cancers were less than 10% in the 1950s, 58% in the mid-70s, to over 80% currently. Experts attribute this to the fact that over 60% of kids with cancer are treated on a clinical trial. Much of what we have learned about cancer survivorship (even in adults) is a result of the great follow-up studies in childhood survivors.

Myth #1: I'll be treated like a guinea pig.

Much the opposite- most clinical trial participants report they were fully informed of the risks and benefits, felt they were treated with respect and dignity, had a positive experience, and would recommend a trial to others. Many participants feel they receive extra attention and have more people watching them and to ask for help, such as nurses or study coordinators.

Myth #2: I'll have lots of extra costs that my insurance won't cover.

Federal law requires insurance companies to cover routine (standard) costs – things you would need regardless of the trial (i.e. regular blood and radiology tests). If the study sponsor requires extra testing, this is not required to be covered but is often covered by the study sponsor. For example, if the pharmaceutical company is concerned about liver damage caused by the study medication, they may request extra blood tests or scans. These do not have to be covered by insurance, but will typically be paid for by the pharmaceutical company or study sponsor.

Medicare has been covering study costs since 2000. The study nurse/coordinator should review any out-of-pocket costs with you.

Myth #3: I could get a placebo.

Placebo (sugar pill or something that has no effect on the cancer) is very rarely used in cancer clinical trials. The only instance where this happens is when there is no other treatment available, so a study may compare a new medication to a placebo. This would be clearly stated in the consent form that you must review and sign before starting a trial. So, you would never be in a study and not know it included a placebo.

Myth #4: I am too old to be in a trial.

About 25% of trial participants are over age 65, but 63% of cancer patients are over 65. The population continues to age and that 63% will continue to rise. We need to study older people to know how to best treat this growing group.

Myth #5: Clinical trials are last-ditch efforts.

Not true at all! There are studies in every stage of cancer and even studies for cancer prevention. Clinical trials can allow access to therapies that are up and coming and not available otherwise.

Myth #6: Once I enroll, I am locked into the trial.

You are in control. If you decide you do not want to participate in the trial anymore, you can withdraw at any time.

Myth #7: I have to go to a big university center to be in a trial.

Many smaller cancer centers offer clinical trials. In some cases, if a particular trial is only available at a big center, you can continue to see your local oncology team for regular care and visit the study center just as needed for the trial.

One thing to keep in mind is your insurance provider network. If your insurance does not allow for out-of-network providers, they do not have to pay for clinical trial care at an out-of-network provider. Talk with someone at your insurance carrier about coverage when looking into other providers and cancer centers.

You can use the OncoLink Clinical Trials Matching Service to find studies in your area relevant to your case. Resources for More Information: Clinical Trials provides more links for more information about clinical trials.
