

Frequently asked questions and answers

Are there any trials out there that could help me/my family member?

The find a trial section of our website lists sarcoma clinical trials recruiting in the UK. As sarcoma is a less common form of cancer with many distinct subtypes, there are only a small number of trials open at one time. We aim to feature all trials available for people with sarcoma on this site. In addition, there may be phase 1 trials recruiting that accept people with sarcoma. For more information on the availability of these trials talk to your sarcoma team.

How safe are clinical trials?

A clinical trial must be approved by an ethics committee before recruiting patients. A committee look to see whether the trial is safe and decide whether it can go ahead or not. They will make sure a trial is planned correctly and the researchers are qualified to carry it out. They will also want to see that the benefits of any trial outweigh any potential side effects. A committee can stop a trial at any time if they think participants are at risk. You should be told about the advantages and disadvantages of taking part in a trial before you enter into it. If you have any concerns about your safety speak to your research nurse or clinical nurse specialist.

Can I take part in a trial in a different part of the UK to where I live?

Sometimes there may be no trials running in your area however it is possible to take part in studies happening in different parts of the UK. If you see a trial taking place outside your area that you think you may be eligible for, do discuss it with your clinical team who may be able to refer you.

What if there isn't a trial for my type of sarcoma?

Even if there are no trials recruiting for your type of sarcoma you may still be eligible to enter phase 1 trials. These trials may recruit from a wide group of people including healthy people and people with different types of cancer. Ask your sarcoma team about the availability of phase 1 trials.

Why are there age restrictions in certain trials?

Researchers use eligibility criteria, including age restrictions, to make sure particular groups of people are as similar as possible. This helps to make sure that the results of the trial are due to the conditions within the trial and not other factors like age, stage of cancer or general health.

Trials for adults will have a wide age range, usually recruiting people who are aged 18 years or older. If there is an upper age limit it may be due to the treatment itself. Some treatments may use high doses or drugs that older adults would find difficult to tolerate. Some trials do look specifically at treatments for people over the age of 65 or 70. There are also trials looking at treatments suitable for children and teenagers.

How do I get in touch with other sarcoma patients who have been on trials?

You can get in touch with other people affected sarcoma by attending a support group or joining a group online. See our website or contact our support line for further details.

Where can I find updates on a trial?

When you sign up for a trial you can ask the research team to keep you updated on the results when the trial is over. If you have taken part in a trial you can contact a member of the research team for updates. If you have difficulty contacting them, get in touch with our support line who can signpost you. Our support line can also provide general information about current and closed trials.

If I go on a trial, how likely is the treatment to work?

Being accepted onto a trial does not guarantee you will access a new treatment. You might be in the group who gets the standard treatment or the group who gets the new treatment. You may also receive a placebo. As clinical trials are about finding answers, no one can know for sure what the outcome of trials will be. The standard treatment may prove to be better than or just as good as the treatment being tested. The new treatment may show to have unexpected side effects.

Your research team can talk through any concerns you may have and help you decide whether taking part is right for you.

Can I stop the trial at any time?

Yes, you can. You will need to talk this through with your sarcoma team beforehand to ensure you stop any treatment safely. After you have left the trial you may be referred back into standard treatment if this is appropriate for you.

How do I access trials in other countries? Can I take part in trials abroad?

It is difficult to access clinical trials abroad. Many studies will not take patients from overseas and accessing treatments this way can be very expensive. For your own safety always check the regulations of the trials as they may not be regulated as strictly as they are in the UK. Be aware that if you do decide to take part in a trial abroad, you do so at your own risk. It is advisable to let your sarcoma team know if you intend to have any additional treatment elsewhere.