

Questions to ask about clinical trials

This information is about questions you might like to ask your medical team if you are thinking about taking part in a clinical trial. It includes a list of questions you might like to ask your medical team, as well as some common questions that we have addressed. We have separate information **about clinical trials** that you might also find helpful.

If you'd like to find a clinical trial that might be suitable for you, you can search for one on our **TrialsLink database**. Our **helpline team** are here to support you if you feel a listening ear would be helpful.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

What questions should I ask about clinical trials?

If you are interested in taking part in a clinical trial, you should be given time to ask any questions you might have. It might be helpful to note down your questions to take with you when you see your consultant or nurse. You also might choose to take someone with you to appointments for support, and to help remember all the points you want to ask about, as well as the information you are given.

Health professionals are used to answering questions, and trials can be difficult to understand. Ask any questions you might have and don't hesitate to ask your medical team to explain something in a simpler way.

We list some questions here that you might like to ask.

Questions about the background of the trial

- What are the aims of the trial?
- What is known about the trial treatment?
- What are the possible advantages and disadvantages of taking part in the trial?
- What treatment will I have if I don't take part in the trial?
- How do you know the trial is safe?
- What tests or checks do the trials go through before being tested on humans?
- Will the trial take longer than standard treatment?
- Can I sign the consent form as soon as I receive the information?

Questions about what happens during the trial

- What happens during the trial?
- What will happen if I change my mind about taking part?
- Will I have more tests than I would in routine care? If so, why?
- Will I have to answer questions about how I am feeling? If so, how many? How often?
- How will the trial affect my day-to-day life?
- Is there anything I should or shouldn't do while I am taking part in the trial?
- Can I take my usual medications?
- Will my travel expenses be paid?
- Who will be responsible for my care?
- What will happen if my lymphoma gets worse while I am in the trial?

Questions about your treatment if you are on a clinical trial

- If I'm treated as part of a trial, will I be able to choose which treatment I have?
- If I'm treated as part of a trial, will my doctor be able to choose which treatment I have?
- Will I know what treatment I am having if I take part in the trial?

- If I was in remission before the trial and I relapse, will I be able to revert to conventional treatment?
- Does the trial use placebos?
- What are the possible side effects of the trial treatment?
- Can I have standard treatment at the same time as taking part in a clinical trial?
- Where will I have treatment?
- If the trial treatment isn't at a local hospital, can I have the pre-trial tests done locally?
- Will I have to stay in hospital during the trial?
- How often will I have treatment?
- How many hospital visits will be involved?

Questions about what might happen after the trial

- What treatment can I have if I leave before the end of the trial?
- If I benefit from the treatment, can I carry on with it after the trial ends?
- When will the trial results be published?
- How can I find out the trial results?
- How long will the follow-up period be?
- What will follow-up involve?
- Will the trial affect my options if I need further treatment? If so, how?

What should I consider before taking part in a clinical trial?

Deciding whether or not to take part in a clinical trial can involve a great deal of thought. You might find it helpful to think through some key questions to help you in reaching a decision. Remember that you can ask your medical team any questions about clinical trials.

- Do I understand what is involved in taking part in the trial?
- Do I understand the potential advantages and disadvantages of taking part?
- Do I understand that I might not benefit from the trial?
- Have I had an opportunity to ask questions?
- Have I got all the information I'd like to help me make my decision?
- Do I feel I will be able to ask the trial team questions?
- If the trial is **randomised**, am I happy that my doctor and I cannot decide which treatment I have?
- If the trial is **blinded**, am I comfortable that I will not know what treatment I am receiving?

- Are there any practical implications to consider, such as travel and an increased number of visits to hospital? How will I manage them?
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My child would like to take part in a clinical trial. What do I need to know?

Some trials are available for children under the age of 16 to take part in. You might find our information about [lymphoma in children](#) helpful – we include information about giving consent for children to receive treatment. Here, we list some questions you might like to ask your child’s medical team before they take part in a trial.

- Does my child need parental/legal guardian consent to take part?
 - Will I have access to my child’s notes and information throughout the trial?
 - Will the trial help my child get better?
 - Can my child stop taking part if either of us change our minds about them taking part?
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Where can I find out more about clinical trials?

If you have further questions and would like to find out more about clinical trials, you might find our other resources helpful:

- information [about clinical trials](#)
 - searching for a trial that might be suitable for you on our [Lymphoma TrialsLink](#)
 - information about [drug development, approval and funding](#)
 - [videos about clinical trials](#)
 - [personal stories](#) of people who have taken part in a clinical trial
 - information about [your medical team](#).
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Clinical trials terminology

Here, we explain some of the common terms you might hear in relation to clinical trials.

What does ‘phase’ mean?

Treatment trials are organised in [phases](#). The phase of a trial reflects how much is known about a particular treatment. Scientists learn more about a treatment as it goes through the different phases, [1 through to 4](#).

What is a placebo?

A **placebo** is a dummy treatment – it doesn't have any active medication in it. It is used to make sure that the results of a trial aren't affected by whether or not participants know they are having active treatment.

If you need treatment for lymphoma, you will not have placebo treatment on its own. You might have a placebo **as well as** active treatment. You won't know if you are having the placebo or another active treatment.

What is 'measurable disease'?

One of the eligibility criterion for most trials is that your lymphoma is 'measurable'. 'Measurable disease' means your lymphoma can be seen by the tests or scans used in the clinical trial, which allows the trial team to measure any changes in your lymphoma. The criteria of 'measurable disease' varies from trial to trial depending on the type of lymphoma being studied and the tests used.

Most people who need treatment for lymphoma have measurable disease.

What are eligibility criteria?

All clinical trials have strict **eligibility criteria**. The criteria are in place to ensure that people taking part are safe, and that the results of different treatment groups can be compared reliably. You might have tests to confirm that you are eligible to enter a trial.

Eligibility criteria are made up of inclusion criteria and exclusion criteria.

- Inclusion criteria set out who can take part in the trial.
- Exclusion criteria set out who cannot take part in the trial.

What is a protocol?

Every trial has a document that gives a detailed description of the trial.

The protocol provides information about:

- why the research is being done
- who can take part
- how many people are needed for the trial
- the treatments and tests involved
- how people taking part will be monitored
- when the trial will end.

Questions about finding a clinical trial

Here, we answer commonly asked questions about finding a clinical trial.

How do I find a clinical trial that might be suitable for me?

Your medical team might ask you if you would consider taking part in a clinical trial. Equally, you could ask your medical team whether there is a clinical trial suitable for you. You can also search for trials yourself. There are several [places you can find information about trials](#) that might be suitable for you.

Some of the information you find might be very detailed and difficult to understand. If you find a trial that you might be eligible for, discuss it with your medical team. They can check the [eligibility criteria](#) and find out whether you may be suitable.

Can I take part in a trial that isn't running at my local hospital?

You might find out about a trial that is not available at your local hospital. If you would consider having treatment at a different hospital, you could ask your medical team about being referred.

If you are referred to another hospital, your medical team will need to share information with staff members there. Think about the practicalities of being treated at another hospital, particularly travel and accommodation, including for friends or relatives who might stay with you or visit you. Some trials will help with practical arrangements for your travel and accommodation, and some might reimburse you for these costs, but the trial team will be able to give you more information about this.

What happens if there isn't a trial suitable for me?

There is not always a suitable trial for everyone. Only a small number of people with lymphoma take part in a trial for their treatment. There are a number of reasons for this:

- There are only a small number of trials running at one time.
- Trials have strict eligibility criteria. This is to make sure that participants are safe, and that the results of different treatment groups can be compared reliably.
- The location of the trial might not be suitable for you.

If there isn't a suitable trial open initially for you to take part in, it's worth checking again at a later date as new trials open frequently. Your medical team can also talk to you about your options if there's not a trial open that is suitable for you.

Questions about the practicalities of taking part in a clinical trial

Here, we answer commonly asked questions about the practicalities of taking part in a clinical trial.

Will I be paid for taking part in a clinical trial for lymphoma?

No – if you take part in a clinical trial, you won't be paid for it. However, some trials might reimburse you for expenses, such as for travel, accommodation or refreshments. Ask your trial team about this. You don't have to pay to take part in a clinical trial.

Can I take part in a trial even if the standard treatment options are available to me?

Yes – clinical trials are not only for people who have no more standard treatments available to them.

Talk to your medical team if you are interested in taking part in a clinical trial. You could ask them if there is a trial that might be suitable for you.

Will I be covered by insurance?

Clinical trials must have insurance to cover the people taking part. Ask your study team for more information about this. If you have or need to take out any personal insurance, for example travel insurance, life insurance, income protection or health insurance, you will usually need to tell the insurance company that you are being treated as part of a clinical trial. It could affect what the insurance company will cover.

Questions about what happens during a clinical trial

Here, we answer commonly asked questions about what happens during a clinical trial.

Who will look after me during the trial?

A trial team will look after you and your care during the trial.

- **Study investigator:** the study investigator is usually a consultant at the hospital. They oversee your care as part of the trial.
- **Research nurses or clinical nurse specialists:** these nurses are dedicated to the care and support of people participating in the trial. You can discuss any worries or questions you might have with the nurses.

If you start to feel unwell during the trial, contact your trial team and they will look after you.

Will my information be confidential?

Personal and medical information about you remains confidential.

If you are taking part in a clinical trial that is running at a different hospital to your local one, your medical team will need to share information with staff members there.

The sponsor of the trial (for example a pharmaceutical company) and the authorities that regulate the trial can look at your medical notes, but they are also bound by confidentiality agreements. Information about you that is collected and recorded as part of the trial has a code reference attached to it instead of your name. Your information won't be taken from your hospital without being made anonymous.

Can I choose my treatment?

In most cases you can't choose your treatment. The treatment is set out in the trial protocol. You are given information about the different treatments in the trial before you enter.

In most cases you are told what treatment you are having. Occasionally a trial is '**blinded**', which means you won't know what treatment you are having in the trial, or '**double-blinded**', which means neither you or your doctor know what treatment you are having.

Can I stop taking part in a clinical trial even if the trial has already started?

Yes – you have the right to withdraw from a trial at any point. If you would like to withdraw from the trial, you can do so at any point and you don't need to give a reason. However, it can be helpful for the trial team to know a bit about your decision, so that they gather as much information about the treatment as possible.

What should I do if I have concerns about my treatment during a trial?

You should be given contact details for people you can speak to if you are unhappy about your care during the trial. If you don't have these contact details, ask your trial team for them.

Questions about after the clinical trial

Here, we answer commonly asked questions about happens after a clinical trial.

What happens to my samples?

Tissue samples from your biopsy and blood samples are often stored for use as part of a trial or as part of a biobank (collection of cancer samples) for future research. This does not happen without your knowledge. Some trials only need samples for research and do not involve treatment.

In some trials, you can opt out of having your samples stored. For the trials that don't allow you to opt out of having your samples stored, this will be made clear before you start the trial.

Do I receive follow-up?

For most trials, there is a period of follow-up. However, not all trials have this follow-up period. You will be asked if you consent to the follow-up period. You can withdraw your consent at this point for any reason.

The duration of follow-up can vary from a few months to a few of years.

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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