

Talk Lung Cancer...

Lung cancer and clinical trials: A handbook for patients

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Johnson&Johnson

Overview

This handbook provides information for lung cancer patients about clinical trials. This includes:

- What they are
- How to take part in one if you're eligible
- How they may help people with lung cancer

You will also find a notes section at the end of the handbook. This is for you to record any important information or questions you would like to ask your healthcare team after reading the handbook.



What are clinical trials?

What?

A clinical trial is a type of research that involves testing medicines to evaluate their impact on human health.[1]

Why?

Clinical trials are vital in helping researchers and healthcare professionals better understand how to treat illnesses like lung cancer.[2] They provide a structured way to assess how new treatments work, whether they have manageable side effects, and how they compare to existing treatment options.[3]

How?

People volunteer to take part in clinical trials. The trials need to be approved before they can start, and are then carefully designed, reviewed and completed.[1] The information gained from a clinical trial is then used to determine if a treatment works, whether the benefits outweigh the risks, and whether it can be made available for people who need it.[2]

Clinical trial phases [1,2]

When you sign up for a lung cancer clinical trial, you may notice that it is in a certain phase. The four phases are:

- **Phase 1:** This involves testing a drug for the first time in a small group of patients, to establish the right dosage range and identify side effects.

- **Phase 2:** If the drug meets set criteria in phase 1, it is then tested in a larger group to monitor for any adverse effects.

- **Phase 3:** Medicines that pass phases 1 and 2 are conducted on much larger groups, often across different countries, and are compared against an existing treatment.

- **Phase 4:** This phase is not required for every lung cancer therapy. It involves continuing to study the use of the medicine in practice as a way of monitoring it in the real world setting, often in a wider population and over a period of continued use.



Deciding whether to take part in a clinical trial



For some people with lung cancer, a clinical trial may provide an opportunity to access a new treatment that is only available in a research setting. This new treatment may have the potential to be more effective or have fewer side effects than an alternative treatment.[4]

This said, there are no guarantees it will work, and you may experience unwanted side effects. It's therefore important to understand the potential pros and cons before you sign up.

Potential benefits[4]	Considerations[4]
The study treatment may help to shrink, reduce or make your lung cancer more manageable.	There is a chance that the treatment isn't effective and/or causes unexpected or more severe side effects.
You may have access to more regular, thorough consultations with healthcare professionals, as well as more blood tests and scans.	Attending frequent appointments may cost you money – for instance, travel costs such as car parking or public transport fares (though these may be reimbursed).
You could help to improve lung cancer treatment for patients in the future.	The process could be time-consuming and inconvenient, so it's important to consider how your work and personal life may be impacted.

It's helpful to speak to your healthcare team, and discuss the process with your loved ones, before making the decision to participate in a clinical trial.

The process

1 Finding a trial

If you're interested in joining a clinical trial, your first point of contact should always be your healthcare team. Your oncologist can tell you if they know of any trials that would be suitable for you. Patient support groups, such as Roy Castle Lung Cancer Foundation and Cancer Research UK may also be able to provide you with useful information about relevant trials, while the Be Part of Research website allows you to sign up for trials and contact research teams directly.

2 Eligility criteria[5]

Researchers call the 'entry requirements' of a clinical trial 'eligibility criteria'. These are put in place to ensure people participating are as similar as possible and have appropriate characteristics to take part. This is so that if one group of patients sees better results than the other, the researchers can be sure it was due to the difference in treatment and not other factors.

Why is diversity important in clinical trials?[6]

Clinical trials should represent a broad spectrum of people from different backgrounds, age groups and ethnicities. This is to increase the chance of new lung cancer treatments being effective for the majority of people with the condition, and to reduce inequalities by ensuring underserved groups aren't excluded or misrepresented.

What if I can't find a clinical trial that's right for me?

Even if there are no clinical trials available to you currently, there is every chance some may arise in the future. Consult with your healthcare team to see if there's an upcoming lung cancer clinical trial that's right for you.



3 Informed consent[7]

If you meet the eligibility criteria, researchers have a legal obligation to explain to you what the trial involves before you agree to take part. This should include things like:

- What the goal of the trial is
- What the likely risks and side effects are
- How often you will have to attend follow-up appointments
- If a hospital stay is required.

If you agree to proceed, you'll give your 'informed consent', which means signing a statement to say you have been told, and understand, what taking part in the trial means. You can ask as many questions as you like if you don't understand anything, and remember that you can always say no to joining the trial if you don't want to.

You can withdraw from a trial at any time, without giving a reason, and it won't affect your ongoing care or treatment in any way.

4 Groups[2]

When you take part in a clinical trial, you're often assigned to one of two groups – sometimes referred to as 'arms':

- **Control group:** These patients receive a treatment that already exists and is approved to treat your type of lung cancer.
- **Treatment, or 'experimental', group:** These patients are given the new treatment being tested.



Most trials with two groups are 'randomised', meaning you're randomly assigned a group using a computer.



Sometimes a study is 'blinded', meaning that you are not told which group you are in, and the researchers may not know either until after the trial. This is to prevent accidental bias.

Because phase 3 lung cancer trials use the current standard of care in the control group, ***you will always be receiving treatment for your lung cancer***, regardless of whether you are in the control group or treatment group.[8]

How are trials regulated?[2]

Before a clinical trial can begin, a government agency called the Medicines and Healthcare products Regulatory Agency (MHRA) needs to review and authorise it, as well as inspect the trial sites.

All medical research involving people in the UK also has to be approved by an independent research ethics committee.

5 Results and follow-up [2,9]

When the trial ends, researchers publish the results and make them available to anyone who took part and wanted to know the findings. You can ask for the results to be explained to you if there are any parts you don't understand.

After your treatment has finished, there may come a follow-up period. During this time, you will be regularly monitored to assess various aspects of your health. This takes place across follow-up appointments in which the trial staff will track the progress of participants. The follow-up period can range from a few months to 10 years or more, depending on the type of lung cancer treatment the trial focuses on.

Advice when taking part in a clinical trial

Ask questions: You should never be afraid to ask questions and get the clarification you need; remember your clinical trial team is there to help you. If there's any part of the process you'd like to discuss, or you have any concerns you would like to share, don't be deterred from starting the conversation yourself.

Track your progress: Before and during a clinical trial, you will be asked many questions about how you are feeling, whether you have encountered any symptoms or what your thoughts are about each step of the process. It can be difficult to remember each and every detail, so it's advisable to keep a diary and journal to chart your progress and log anything that would be useful to share with the clinical trial team.

Lean on family, friends and loved ones: Being part of a clinical trial can be a complex and sometimes worrying experience, but it doesn't need to be one that you undertake alone. Try to open up to people close to you and don't be afraid to ask them for support if you need it.

Live your life: Taking part in a clinical trial is a big decision and should be given plenty of consideration. When weighing up your options, it's important to prioritise your life outside of the trial as well as your participation.



Questions to ask your clinical trials team

It can be helpful to prepare a list of questions you'd like to ask the team running the trial before your appointments, as it's easy to forget them when the time comes. Here are some possible questions that might be useful to ask:

- Who is my point of contact for any questions I have throughout the trial?
- Is the study blinded and will I know if I am getting the study treatment?
- What phase is the trial in? (e.g. phase 1, 2, 3 or 4?)
- What are the expected side effects of the study treatment?
- What benefit might I get from participating in this clinical trial?
- What additional tests will I need to have and how often will I need to have them?
- What happens if my health gets worse during the clinical trial?
- How will the clinical trial affect my everyday life?
- What costs can I be expected to pay, and can I be reimbursed for them?
- Can I continue taking other treatments?
- Who will be in charge of my care while I am in the study?
- What is the role of my usual oncology team?
- What happens once the clinical trial ends?

Notes

References

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For more information and resources on lung cancer, visit the Talk Lung Cancer hub.

The Talk Lung Cancer campaign has been developed by Johnson & Johnson Innovative Medicine, with input from the following Patient Advocacy Groups and healthcare professionals.

AEACaP

a|case italia

GAMIAN-EUROPE

FairLife LUNG CANCER CARE

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