



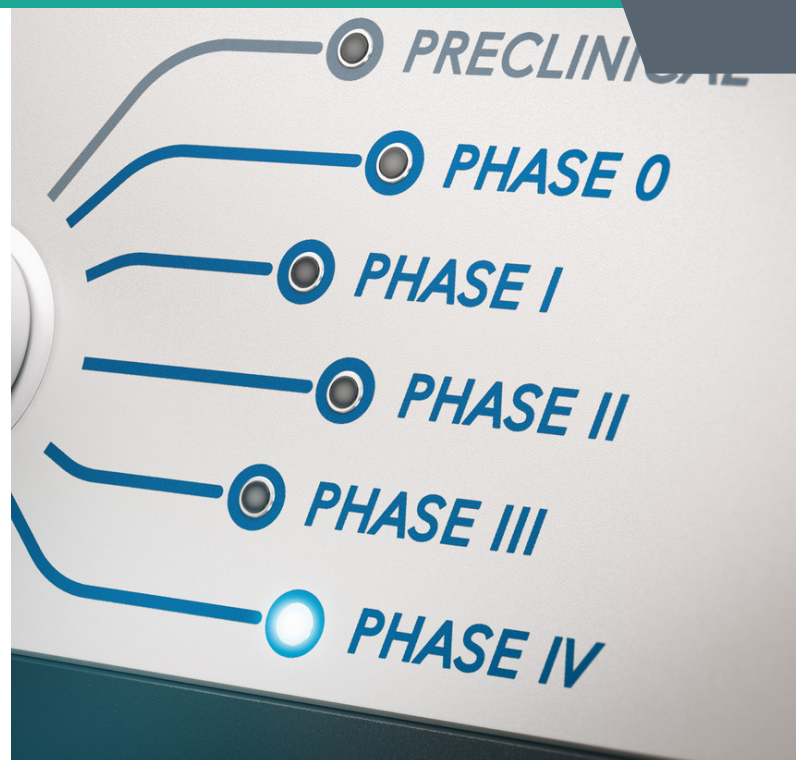
NEUROENDOCRINE CANCER GUIDE

RESEARCH CLINICAL TRIALS

2023



www.neuroendocrinecancer.org.uk



Clinical trials are used to find out if new treatments and techniques are safer and more effective than the ones that already exist or discovering if existing treatments can be used in different ways. Without trials we really cannot make progress.

You may be offered the choice to take part in a clinical trial as part of your treatment. Before you decide if a clinical trial is right for you think about the pros and cons, ask questions and find out what it involves.

In this guide we cover topics such as;

- How Clinical Trials are Run
- Join a Clinical Trial
- Finding a Clinical Trial
- How to use Clinical Trials databases
- Clinical trials FAQs.



Find out about how Clinical Trials are arranged in the UK.



How Clinical Trials are Run

All studies, looking at new treatments, or new uses for existing treatments, are designed differently depending on what is being researched – most now will include monitoring impact on quality of life – not just cancer response or side-effects.

Increasing patients are being included in clinical trial design:

- What to study?
- How?
- What is important to check for? Patient Reported Outcomes (also known as PROMS) and Patient Reported Experiences (also known as PREMS).

However, there are also strict regulations, that need to be followed, to ensure that all stages or 'phases' of a clinical trial can be run safely – for more information about these regulations and rules click [here](#).

Clinical Trials are tested in various phases:



Phase 1

Involves a relatively small number of people – usually healthy volunteers, but some are run with people affected by a particular condition or disease.



Phase 2

Is used to find out whether a drug works, whether it's safe and what the side effects are – this usually includes a few more people than are involved at Phase 1.



Phases 3 & 4

Involve larger numbers of people and are designed to assess how the treatment works, compared with existing treatments, while continuing to assess side effects and risks.

Each study has its own specific checklist for who can take part – this is called an eligibility criteria. You can find out more information about whether a trial is suitable for you by checking this criteria, speaking with your specialist team and / or the research (Clinical Trial) team.



Join a Clinical Trial

If you are searching for trials, it can help to first pull together as much information about your particular neuroendocrine cancer – as this may help you to narrow down your search and find a trial that is suitable for you.

Trials will always have a list of eligibility or inclusion/exclusion criteria.

This is a list of characteristics that all patients must have to be accepted onto the study. Types of eligibility criteria can include age, and current health status but may also specify disease-specific criteria. For example:

- The type and primary site of neuroendocrine cancer
- If it is a functioning or a non-functioning neuroendocrine cancer
- The grade of neuroendocrine tumour
- If the tumour is well-differentiated or poorly differentiated
- Any available genetic or genomic information for example specific biomarkers or receptor.

Some trials may look at one particular type or site of Neuroendocrine Cancer, while others may include a range of types and /or other cancers.

If you are unsure about your specific diagnosis speak to your care team or GP, or [contact us](#) for advice on how and where to obtain this information.

Talk To Your Care Team

If you find a trial, you think you may eligible for you can discuss it with your specialist team.

Your doctor can refer you to trials right for you:

- They will also be able to contact the team running the trial and find out more information about it.
- They will be able to review the information about the trial – alongside all of the things they know about you, your current health and earlier treatments – to see if the trial is suitable for you.

Being under a specialist neuroendocrine team, or having access to that team, ensures that you have access to experts – who will not only have knowledge and experience about your particular cancer and care pathway but also information about or direct involvement in specific Neuroendocrine Cancer research – so will be able to answer questions you may have about clinical trials.



Finding a Clinical Trial

Current Clinical Trials Recruiting in the UK

There are a number of Clinical Trial databases available – some easier to navigate than others!

There are also professional societies and charities, such as Neuroendocrine Cancer UK, that may supply information on trials currently being run in the UK.

One of the largest Clinical Trials database is [ClinicalTrials.gov](https://clinicaltrials.gov): this is a database of privately and publicly funded clinical studies conducted around the world.

For the UK – there is the [National Institute of Health Research](https://www.nihr.ac.uk).

NIHR | National Institute for
Health and Care Research



How to use Clinical Trials databases

Other terms such as an NCT number, drug name, investigator name

Status ⓘ

☐ Recruiting and not yet recruiting studies

☒ All studies

Condition or disease ⓘ (For example: breast cancer)

Other terms ⓘ (For example: NCT number, drug name, investigator name)

Country ⓘ

Search [Advanced Search](#)

ClinicalTrials.gov Database

- In the Status Box – choose “Recruiting and not yet recruiting studies” for all current and due to start trials.
- In Condition or disease – type Neuroendocrine*
- In Other Terms – if you know the name of the trial / drug / trial doctor – add this information here.
- In Country – choose UK – or leave blank if looking for trials anywhere globally.

NIHR Database

In the first search box – it says Keyword – type Neuroendocrine*

In second box – it says location or city – you can either leave this blank for all UK results or type in your postcode if you are only want local results.

I'm looking for research about

Be Part of Research

I'm looking for research about

Keyword e.g. cancer, drug name Location e.g. city, postcode **Search for study** or **View conditions**

Filters **Reset**

Recruiting ⓘ

Health Condition

Age Range

Gender

Updated Within

Study Status

Show Results

All Studies

3788 studies found

Sort by

[The effect of exercise and the immune system on muscle wasting in chronic kidney disease](#)

Recruiting

Open to: All Genders

Age: Adult

Cities/Towns

Neuroendocrine* If you can't find any studies using “Neuroendocrine” as your search term – you can try expanding your search using “OR” to link terms: e.g., Neuroendocrine Tumour “OR” Carcinoma “OR” neoplasm “OR” Cancer.

Filters **Reset**

Recruiting ⓘ

Health Condition

Age Range

Gender

Updated Within

Study Status

Show Results

To filter results to just find current trials – use the Filters box (dark blue box left hand side of screen) – and choose study status from the list

You will have 4 options:

- Recruiting – means trial is open and available to join.
- Completed – means trial has completed
- Not recruiting – means trial may be suspended
- Stopped – means the trial has been stopped and will not re-open

Choose Recruiting for list of all open trials

Then click Show Results.

How to use Clinical Trials databases

You may find, especially on [ClinicalTrials.gov](https://clinicaltrials.gov), you are then presented with a very large list of trials – which you can then whittle down by using page tabs and filters:

In the filters section – left hand side of screen – you can choose to select your own filter:

- status – e.g., is trial open for recruitment or not
- by eligibility criteria – age, sex, “healthy” volunteers
- study type – clinical trial, observational, registry etc.
-

Or use can use the tabs – above the filters box: List / By Topic / on Map / Search Details. If you select map – you can choose a specific country e.g., UK.

N.B. if you choose Search Details – it will tell you the Terms and Synonyms the database used to answer your query – it will also supply a list of Related Terms that you may find useful to refine your search.

Once you have your list – you can then scroll through it to find a trial that might be suitable for you. Click on a trial heading to find out more information:

- The listing should confirm the name of the trial – and the study number (usually a NCT number)
- It should include a description of the trial, its aims, what type of trial and phase, start and end date, inclusion/exclusion (eligibility criteria) and links to any published data
- And there should also be a Point of Contact name, phone number and / or email

To learn more about the study, you or your doctor may contact the study research staff using the point of contact information provided.

If this is a formally listed trial please refer to it by its study number : usually a NCT number, for example: ARTISAN study (Therasphere Selective Internal Radiation Therapy (SIRT) as Treatment for Neuroendocrine Tumours With Liver Mets) the NCT no is NCT04362436

If uncertain how to do this or you have a question about clinical trials and how to find more information – you can [contact us](#).

The screenshot shows the 'Filters' section on the left and a table of results on the right. The filters section includes buttons for 'Apply' and 'Clear', and a list of filter categories: Status, Eligibility Criteria, Study Type, Study Results, Study Phase, Funder Type, and Study Documents. The results table shows 4 rows of data, with columns for Row, Saved, and Status.

Row	Saved	Status
1	<input type="checkbox"/>	Completed
2	<input type="checkbox"/>	Recruiting
3	<input type="checkbox"/>	Completed
4	<input type="checkbox"/>	Active, recruiting



FAQs & Archive

Before committing to take part in a trial it is important to think very carefully about what the trial will mean to your lifestyle.

What are the advantages?

- You might be able to have newer and more effective treatments that aren't available outside the trial.
- You will be helping to improve future cancer treatment for others.
- You may feel you're doing something positive about your health and taking an active role in your treatment and recovery.

What are the disadvantages?

- You may have more frequent testing as well as treatment, which might be inconvenient. This can go on for a long time. Some people also find this makes them worry more about their cancer.
- You might not know in advance about all the possible side effects – the researchers themselves might not know them all yet.
- If the trial is randomised, you won't get a choice about which treatment you have.
- If the trial is blinded, you won't know which treatment you are getting.
- The new treatment may turn out to be no better than the existing treatment.
- There is the risk that the new treatment may not help you, even if it helps others.

Are clinical trials safe?

In short yes, although you might still experience side effects from the treatments that you receive on the trial. The running of clinical trials in the UK is strictly regulated – to ensure physical and mental health safety – and also that ethical standards and professional practice standards are maintained throughout your clinical trial experience.

Ethics committees must approve any trial to decide if it is safe, planned correctly and the researchers are qualified to carry it out. If you decide to take part in a trial, you should be told about the specific advantages and disadvantages of the trial. You should also be given a research nurse or clinical nurse specialist who you can contact any concerns.

Can I stop the trial at any time?

Yes, you can. You can leave the trial at any time without giving a reason. But if you're happy to give a reason, it could help the research team design better trials in the future. If you leave the trial, you will still be offered the standard treatments for your stage of cancer. Health professionals won't treat you differently because you've left a trial.



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

No one can know for sure what the outcome of trials will be. Often the new treatment is tested against the standard treatment (or rarely a placebo) depending on which group you are allocated to. So being on a trial does not guarantee you will access a new treatment.

The standard treatment may prove to be better than or just as good as the treatment being tested or 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.

The underlying goal of the trial is to improve care – whilst maintaining your safety at all times. If during the trial, it becomes obvious that one treatment is much better than the other – the trial may be halted, or all participants may be offered the better treatment for the rest of the time of the trial.

What is placebo?

Some trials compare a new treatment with an inactive drug or treatment called a placebo. You may have heard it being called a “sugar pill”. Placebos are used to rule out patient bias in trials. Many of us can feel better if we believe we have taken something to make us feel better. Even if we’ve only taken a tablet made of sugar. This is called the placebo effect.

A placebo-controlled trial compares a new treatment with a placebo. The two groups of patients then can’t be biased, because they won’t know if they are getting the placebo or the new treatment – for example:

- Group A – placebo
- Group B – new treatment

If you are considering taking part in a clinical trial, ask your team whether it involves the use of a placebo and the likelihood of receiving the drug being studied or a placebo. Also, ask whether there will be an opportunity to receive the study drug at any point in the trial.

Please note that many clinical trials now offer you either best standard care +/- new treatment – for example:

- Group A – best current treatment
- Group B – new treatment

OR

- Group B – best current treatment + new treatment

If, however best current treatment would be surveillance only – then a placebo may be used to minimise bias.



Tissue and blood sample storage / biobanking

Storing tissue and blood samples for use in research is called biobanking. You might be asked if a blood sample or a biopsy of your tumour can be stored in this way. Sometimes the health and well-being of volunteer participants might be followed up with surveys, but often you will only be asked to give a sample.

Biobanks aim to improve the prevention, diagnosis and treatment of a wide range of serious illnesses, including neuroendocrine cancer. It allows scientists to better study the cells to understand how our genes interact with our lifestyle and environment to cause disease. It may also supply new ways of treating diseases or spotting them earlier.

Drug repurposing – giving drugs a second chance

To re-purpose is to “adapt for use in a different purpose”.

New treatments for neuroendocrine cancer can be difficult to discover or develop, so it is important to be aware of all the different ways that therapies might become available in the future. Repurposing means looking at existing drugs and therapies to see if they could be new treatments for cancer. Significant savings can be made in time and money because typically, the safety, efficacy, and toxicity of an existing drug have already been extensively studied. One example of successful repurposing is thalidomide, previously used for morning sickness, now used to target multiple myelomas (another group of rare cancers).

Repurposing medicines in the [NHS in England](#).

Read more: The Redo Project [here](#) and Findacure [here](#).

What are the main areas of Neuroendocrine Cancer research in the UK?

At any one time, there are many studies underway in the different fields of healthcare around the UK. Some of the main studies in laboratories are focusing on better understanding the genetic and immune landscape of neuroendocrine cancer cells.

Looking at current treatments in new ways and evaluating whether there is a difference in outcome depending on the sequence treatments are given in, is another area of study. There are also some trials in imaging looking at new tracers to further improve the images in PET scans (nuclear medicine initiatives). Information on current and published trials is available [here](#).

For further information on Research – visit the NIHR website [here](#).

