Frequently Asked Questions (FAQs) for the EJS ACT-PD trial

[Why does it take so long to recruit people to clinical trials?]

About the trial

What is EJS ACT-PD? How is it different from other clinical trials?

The best way of knowing if new treatments work is by running a clinical research trial. This allows researchers to understand whether a drug or other treatment is having a benefit. Clinical trials usually compare two groups of people (the trial participants):

- one group who gets the trial medication (with or without their usual care, depending on the trial)
- one group who gets their usual care and sometimes a 'placebo' (a fake treatment that looks like the trial medication but doesn't do anything. This is also called a dummy drug).

EJS ACT-PD is a multi-arm, multi-stage (MAMS) trial. This means that researchers can test multiple different treatments against one placebo group. In EJS ACT-PD, the trial will start with three groups (or arms):

- One group that gets the trial medication telmisartan (with their usual care)
- One group that gets the trial medication terazosin (with their usual care)
- One group that gets the placebo (plus usual care).

This trial design also allows the research team to add new treatments in new treatment groups (arms) whilst the trial is ongoing. As the trial progresses, the team plans to add future arms testing more research treatments.

How were the trial treatments chosen?

The treatments were chosen after carefully looking at all the available evidence that has been published about them. People with Parkinson's and care partners were involved in the discussions and advised on what would be acceptable to participants.

The trial treatments have been 'repurposed' for Parkinson's. This means that they are used to treat other conditions, but there is some evidence to show they could also work to slow down Parkinson's progression. We also already understand their safety and possible side effects. In the trial, the team will check if they are effective and how safe they are when taken by people with Parkinson's over a long period of time.

When does EJS ACT-PD expect to complete recruitment?

The trial team aims to recruit 1600 people with Parkinson's in the first instance, and they expect to have finished recruitment about 4 years after the trial starts. But all participants will need to take the trial treatments for up to 3 years to check what effect they are having compared to the placebo.

How have people with Parkinson's been included in the design of EJS ACT-PD?

People with Parkinson's and their carers and loved ones have been involved in all parts of designing the trial as part of the Patient and Public Inclusion and Engagement (PPIE) Working Group.

The PPIE working group have helped:

- make the trial as easy as possible for people to take part in
- make sure that people who take part in the trial have a positive experience
- include participant feedback to improve the design of the trial
- provide results that are meaningful for people with Parkinson's.

EJS ACT-PD also has a Community Advisory Panel (CAP). The CAP includes patient and public members from a range of different ethnicities, locations, and health conditions, including Parkinson's. This is important, as Parkinson's can affect people differently based on their age, gender, and ethnicity. Everyone must be represented in the research trial to make sure treatments work for as many people as possible.

Taking part in the trial

Registering for the trial

Where will the EJS ACT-PD trial take place?

The EJS ACT-PD trial will be taking place at over 40 sites across England, Wales, Scotland and Northern Ireland. You can find a full list of trial sites on the EJS ACT-PD website.

The team is working with local sites to train and prepare staff at all local sites. Some sites will be ready quickly, while others will take more time. They hope to have all sites open and ready to recruit participants by mid 2026.

Why will it take until mid 2026 for all sites to open?

The timeline for opening a new site can vary. There are multiple reasons why, including:

- Administrative requirements - sites need to create contracts and site-specific documents, which can take time.
- Trial staff availability
- Site capacity – many sites run multiple trials at once, and so they may want to finish one trial before launching a new one.

How do I register my interest to take part?

If you decide you would like to take part, you should complete the registration of interest form. You can find the link to the form on the trial website.

Once you have completed the registration of interest form, you will receive a confirmation email. This will include information on whether or not you are eligible to take part.

Who can I contact if I have questions about taking part in the trial?

You can contact uclh.ejs.actpd.enquiries@nhs.net.

You can also find out more about the trial on the EJS ACT-PD website https://www.ejsactpd.com/

Once your local trial site is open, you'll receive contact details for your local research team and will be able to ask them further questions.

You can also visit the Parkinson's UK website or visit the Cure Parkinson's website for more information and support about the condition.

Eligibility criteria

Who is eligible to take part in the EJS ACT-PD trial?

The EJS ACT-PD trial is looking for people with Parkinson's who:

- were diagnosed aged 30 or over
- have been taking dopamine medication to treat their Parkinson's for at least 2 months before starting the trial
- can commit to taking trial medication once a day for up to 3 years

You **won't** be able to take part if you have:

- certain Parkinson's gene mutations (PRKN, PINK1, DJ1)
- low blood pressure (checked by the research team)
- had advanced Parkinson's treatments (e.g. DBS)
- a diagnosis of dementia, or significant cognitive impairment (checked by the research team)
- or you are breastfeeding, pregnant, or plan to become pregnant while part of the trial

Once you have completed the registration of interest form, you'll be notified on-screen immediately after submitting if you may not be eligible. You will also receive a confirmation email. This will include information on whether or not you may be eligible to take part.

Can I take part if I don't have Parkinson's?

If you have been diagnosed with a Parkinson's-like condition, unfortunately, you are not eligible to take part in the trial.

The trial is also recruiting partners of people with Parkinson's who take part, as part of their 'partner sub-study'. Partners will be asked to complete online questionnaires about their quality of life. Partners will **not** be asked to take trial medication. However, partners can only take part in this sub-study if the person with Parkinson's also consents to their involvement.

What if I am not eligible for any treatment in the EJS ACT-PD trial?

The screening appointment will include some tests to check if you are able to take part in the trial. These tests will also check if it's safe for you to take all of the research treatments, or only some of them. If it's not safe for you to take any of the research treatments, then you will not be able to take part in the trial.

However, you may still be able to take part in the trial in the future:

- Some screening tests can be repeated if the first test results suggest you are not able to take part. This is known as re-screening. If the re-screening result shows you are now able to take part, you will be able to continue in the trial.
- You may be ineligible now, but could become eligible in the future. For example, you may have taken one of the trial treatments recently and would need to wait 6 months before you can take part in the trial.
- As the EJS ACT-PD trial progresses, more treatments could be added in future testing groups. These treatments could have different eligibility rules, which means you may be able to take part in the trial in the future.

You can also find many other opportunities to take part in research by searching the Parkinson's UK Take Part Hub or the Cure Parkinson's Get involved with research page.

I've heard that the trial has started, but I haven't been invited to participate, despite meeting all the eligibility criteria. When will I hear?

The team is working with local sites to train and prepare staff. Some sites will be ready quickly, while others will take more time.

The team hopes that all sites will be open and ready by mid 2026. This is the biggest trial for Parkinson's that has ever been run in the UK, so recruitment will take some time. The team aims to complete recruitment in the next 4 years.

If you have registered for the trial, you will receive an alert to let you know when your chosen local site is available. You'll then be invited for an initial screening appointment if your answers suggest that you may be able to take part.

If you haven't heard, likely, your local trial site isn't open yet, or your local site is working through its list of potential participants. Local sites have a limited number of slots for appointments each month.

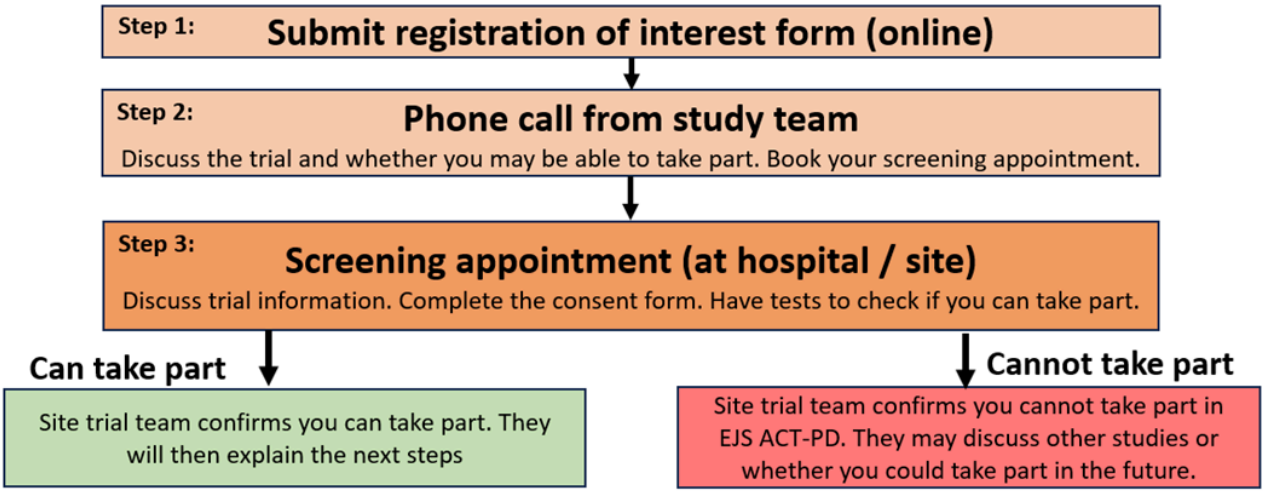
I meet the criteria and would like to take part in EJS ACT-PD, but I do not live in the UK. Can I take part?
Unfortunately no. The EJS ACT-PD trial is a multi-centre trial that will take place across approximately 40 NHS trial sites in the UK.

Taking part

What happens after I register my interest?

After you've submitted the registration of interest form, you will receive a notification to let you know whether or not you may be eligible to take part in the trial.

If your answers suggest that you may be able to take part, and when your local site is ready, you will be contacted by a member of the research team to discuss the trial. This is called a pre-screening call, and the team will ask you some questions to see if you are suitable for the trial. If the research team thinks you might be able to take part, they will invite you to visit your local trial site for a screening appointment.



Step 1: Submit registration of interest form (online)

Step 2: Phone call from study team

Discuss the trial and whether you may be able to take part. Book your screening appointment.

Step 3: Screening appointment (at hospital / site)

Discuss trial information. Complete the consent form. Have tests to check if you can take part.

Can take part

Site trial team confirms you can take part. They will then explain the next steps

Cannot take part

Site trial team confirms you cannot take part in EJS ACT-PD. They may discuss other studies or whether you could take part in the future.

What happens at a screening appointment?

When you attend the screening appointment, a member of the research team will discuss the trial with you again. You can ask them any questions you have about the trial. If you are still happy to take part, you will be asked to sign the consent form.

Once the consent form has been signed, you will be asked to complete the screening tests to check if it's safe for you to take part in the trial. These tests will include a safety blood sample of 10ml (or about 2 teaspoons).

The screening tests will show whether it's safe for you to take part in the trial, and whether any treatments are being tested that would not be safe for you to take. If the tests show that none of the treatments would be safe for you to take, you will not be able to take part in the trial.

At your screening appointment, the trial team will book a phone call to let you know if you are eligible. They will also advise on the next steps and book a 'baseline' appointment with you for between 1 and 4 weeks later.

What does the trial involve?

- You will be randomly allocated to take either one of the trial treatments or a placebo (dummy drug). Neither you nor the local research team will know which one you have been allocated. You will have an equal chance of being allocated to any of the groups that the tests show you can take part in.

- You will take the trial treatment (1 capsule per day) for a maximum of 36 months (3 years).
- You will take the trial treatment in addition to your usual Parkinson's medication.
- You will need to complete 10 trial appointments, plus 3 additional phone calls with the research team.
- **Your first appointment must take place at the hospital or trial site**. The remaining 9 appointments can take place from home (online or by telephone) if you prefer.
- At the end of the trial, once analysis is complete, your research team will contact you to let you know what trial group you were in and what medication you were taking.

What are the sub-studies of the trial? Do I have to take part in these?

The EJS ACT-PD trial also includes substudies that will be offered to participants as part of the trial. These will be important in contributing to the understanding of the trial treatments' effectiveness.

At all sites, you will be offered:

- Digital measures sub-study - Use of a simple waist-worn sensor device to measure how you move
- Partner sub-study - For partners of people with Parkinson's who take part in the main trial. This will help the trial to understand the impact of providing support for a person with Parkinson's
- Genetics sub-study - Analysis of your genetic information, in collaboration with another research trial called PD Frontline. Find out more about PD Frontline on the Parkinson's UK Take Part Hub.

At some sites, you might also be offered:

- Biosamples sub-study - Providing additional blood and/or cerebrospinal fluid samples to look for biological things that could be measured in Parkinson's

Your site research team will ask you if you would like to take part in available substudies at your screening appointment. These substudies are optional. It will not affect your participation in the main trial if you do not want to take part in the substudy.

You should read the appropriate information sheets and consent forms for all sub studies before your screening appointment. These will be provided by your local trial site and can be found on the trial website. You will have the opportunity to ask any questions at the screening appointment.

Can I change my mind about taking part?

Yes, you can change your mind about taking part at any point after signing the consent form, and this will not affect your usual care. You don't need to give a reason, but your trial team can first advise you about any concerns you may have.

If you decide to stop taking your trial medication, you will be asked if you would be willing to continue with the trial appointments. This is important to monitor your safety and to help us ensure that the results of the trial are reliable, but it is entirely optional.

What happens if the treatment I am taking ends early?

EJS ACT-PD will start by testing 2 different treatments. At points during the trial, the team will assess whether the treatment is having an impact on symptoms of Parkinson's, and whether it's safe to take over a long period. At this point, they may decide to stop a treatment early if it doesn't look promising.

If your trial treatment arm stops early, you will be told by the research team. You will be asked to take any of your remaining trial medications to your local pharmacy who will get rid of them safely.

If your trial treatment stops early but you would still like to continue taking part in the trial, you may be able to be allocated to a new trial group. You will need to wait for 6 weeks to make sure there are no problems with stopping your first trial medication. You will then repeat the consent and safety testing process to see if you can still take part in the trial. If you can still take part, you will be randomly allocated again to either a treatment arm or a placebo.

Will I be able to keep taking the trial medication after the trial ends?

At the end of the trial, participants will not be able to receive any more treatment from the research team. This is because the trial medication is not yet licensed to be prescribed to people with Parkinson's. If the results show that a trial treatment is effective, the EJS ACT-PD team will work hard with the NHS and regulators to make the trial medication available to people with Parkinson's as soon as possible. However, there are lots of processes and approvals needed before this can happen.

Can I take the trial medication outside of the trial?

It's very important that no one tries to get or take the trial medication outside of the trial. This medication is not yet approved for Parkinson's and needs to be carefully monitored while being taken. Clinical trials provide a safe environment for new medications to be tested, as the research team will carry out safety checks and monitor any side effects. Taking the trial medication without the research team's oversight could be dangerous.

What support is there during the trial?

If you have any questions or concerns during the trial, you should contact your local research team, who will be able to help. You do not have to wait until your next appointment to contact the research team.

All participants will also be given a participant card which includes emergency contact details, including for out of hours contact if there is a trial-related emergency.

After the trial

What support is there for participants after the trial?

You will have a follow-up appointment with their research team 2 months after you have stopped taking the treatment, to check how you are feeling. After this, there will be no further trial appointments.

The research team may contact your GP if there is any medical follow-up that needs to be completed after the trial medication stops. For example, if while you're on the trial the team notices a change in your blood pressure, they will notify your GP, who can make sure this is monitored.

You will continue under the care of your usual healthcare team whilst taking part in, and after, the trial.

You can also choose to continue to receive updates from the EJS ACT-PD research team as the trial progresses.

Will I have access to my individual trial data?

You will not be able to see individual trial results or assessment scores from the EJS ACT-PD trial or sub-studies. This is because:

- Seeing the results might change how people answer questions, which could affect the trial results.
- If the results are not explained properly, they could be misunderstood or cause confusion.

Can I provide feedback on my experience?

Participant feedback is really important. There will be two ways for participants to give the research team feedback:

- There will be an online feedback form where you can provide anonymous feedback on your experience of taking part in the trial.
- Questionnaires will be used at the start, middle, and end of your time taking part in the trial. These questionnaires will ask questions about your experience of taking part in the trial and any sub studies.

All feedback will be carefully reviewed to help improve the trial, and the team will share how feedback has been used in trial update emails.

Who should I speak to if I have concerns about the trial?

If you have any concerns before or during your time taking part in the EJS ACT-PD trial, you should discuss these with your site research team. The normal NHS complaints mechanisms are also available to you if you wish to complain or raise concerns about any aspect of the way you have been approached or treated by members of staff in relation to taking part in EJS ACT-PD. This information can be found on the trial Participant Information Sheet, the NHS website, or from your site research team.

Staying up-to-date

How do I keep updated if I can't take part?

Once you have completed the registration of interest form, if you are eligible to take part, the EJS ACT-PD trial will send you email updates on trial progress approximately every 2 months.

Parkinson's UK and Cure Parkinson's are committed to keeping the wider community up to date as the EJS ACT-PD trial progresses. Sign up to the Parkinson's UK Research Support Network or to the Cure Parkinson's E-Newsletter for regular updates about research news and opportunities.

Why does it take so long to recruit people to clinical trials?

It can take a long time to recruit people to take part in clinical trials. It's estimated that fewer than 1 in 10 people with Parkinson's have taken part in a clinical trial. There are many reasons why it might be hard to join a trial, such as:

- Not having the time to attend appointments or complete assessments
- Not knowing about the trials they could take part in
- Feeling worried or unsure about taking part.

The EJS ACT-PD trial is trying to make it easier for people to join. Some of the ways they're doing this include:

- Letting participants take part mostly from home if they want to
- Creating a communications plan to let people with Parkinson's know the trial is happening
- Working closely with people with Parkinson's to design a trial that is helpful and meaningful to people with Parkinson's
- Using one pharmacy to handle the trial medication, so that site teams don't have to
- Providing extra staff in some locations to help sites run the trial.