

EJS ACT-PD – The Next Generation of Clinical Trials for Parkinson's

A call for people with Parkinson's and their carers/partners to contribute

Help us develop an exciting new trial for Parkinson's by joining EJS ACT-PD as part of the wider network of patient and carer representatives.

EJS ACT-PD is a 3-year project to design a new type of trial for neuroprotective treatments in Parkinson's – treatments that may slow Parkinson's progression. Currently, individual treatments are tested in a series of clinical trial phases, with each phase set up separately. This results in a very time consuming and inefficient process. We would like to improve on this by testing several treatments at the same time, in different groups of patients, and by linking the phases together, so that patients in the study can move from one phase to the next without a delay in between. This type of trial is called multi-arm multi-stage (MAMS), and is already used successfully in other diseases, like prostate cancer, COVID-19 and multiple sclerosis. You can read more about:

The EJS ACT-PD project here: www.ejsactpd.com

MAMS trials here: <https://www.journalofparkinsonsdisease.com/new-trial-platform-could-accelerate-finding-cure-parkinsons-disease>

The EJS ACT-PD project is funded by the Edmond J. Safra Foundation and led by Prof. Tom Foltynie (University College London) and Dr Camille Carroll (University of Plymouth). We aim to create a MAMS trial by bringing together national and international Parkinson's experts, and importantly people with Parkinson's (PwP) and their carers/partners. Our Patient and Public Inclusion and Engagement (PPIE) Working Group contribute vital input to the project's discussions and decisions.

Occasionally, there are topics that the group would like to receive further input on, to understand a wider perspective from the Parkinson's community. We are therefore looking for people with an interest in research to form a wider patient and carer / partner network for the EJS ACT-PD project. Members of this network would agree to be contacted by the EJS ACT-PD team with requests for input when they arise. The range of input requested from members will vary, but may include being asked to complete online surveys, to vote on different decisions or being invited to take part in focus groups or discussions. Network members would be under no obligation to respond to every request but would agree to their contact details being stored and used for this purpose. The topics in question would be related to the discussions within EJS ACT-PD's Working Groups, which have been set-up to help design the trial:

- 1) Devising and implementing a sustainable **Treatment Selection** strategy
- 2) Developing a feasible **Trial Design**
- 3) Selecting appropriate **Outcome Measures**
- 4) Building the necessary **Infrastructure** for delivery
- 5) Devising a sustainable **Funding** model
- 6) Developing a **Communication** and engagement strategy

Network members would provide a crucial additional input to help present the critical viewpoint of people living with Parkinson's and their care partners.

We are looking for individuals who:

- Are passionate about improving Parkinson's research
- Are willing to contribute as and when needed, in a variety of different ways
- Are willing to link other interested individuals to the EJS ACT-PD network where possible

EJS ACT-PD will retain the wider network's contact details for the purposes of the EJS ACT-PD project only. All personal information will be stored securely within the UCL or University of Plymouth's password protected servers, and only approved members of the EJS ACT-PD team will have access to them.

If you would be interested in joining the EJS ACT-PD wider network of people with Parkinson's / carers and partners, please complete and return the short application form at the end of this document.

Applications should be sent to the EJS ACT-PD team at: ejs-act-pd@ucl.ac.uk. If you have any questions or need any further information, please feel free to contact the team.

Kind regards,

Georgia Mills
Project Manager, EJS ACT-PD

Dr Kevin McFarthing,
PPIE Working Group Chair

Title		Name		Surname	
Gender			Ethnicity		
e-mail			County		
Do you have Parkinson's or are you a carer/partner?					
When were you/the person you care for/partner diagnosed with Parkinson's?					
At what age were you diagnosed with Parkinson's?					